

COMMUNITY ENGAGED APPROACH TO CANCER CONTROL POLICY IN ABIA STATE -  
NIGERIA: A MIXED-METHODS ACTION RESEARCH PROJECT

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By

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## ABSTRACT

### **Background**

Cancers are becoming increasingly common in Nigeria and other developing countries. The most common cancers in the country are those affecting the breast, cervix, and prostate. Beyond the National Cancer Control Plan, most States in Nigeria do not have State cancer control policies which is unlike the situation in Canada and other developed countries. Using the multiple perspective analysis framework, this research sought to explore the perspectives of patients diagnosed with cancer, healthcare providers and health policymakers regarding cancer policy in Abia State.

### **Methods**

A concurrent mixed methods action research design was used. Sampling included individuals aged  $\geq 18$  years who were diagnosed with breast or cervical cancer, provided cancer treatment or made health policy in the State. This study was conducted in collaboration with the Abia Cancer Control Group (ACCG), a community-based coalition of non-governmental organizations, clinicians, and government parastatals. Survey data were collected at the same time as the interviews which occurred following ethical approvals from the University of Saskatchewan's Behavioural Research Ethics Board and Abia State's Ministry of Health Human Research Ethics Committee.

### **Results/Findings**

Survey participants were 29 patients who had been diagnosed with cancer, 50 health care providers and 33 policymakers (n=112), with an average age of 45 ( $\pm 11$ ) years. Challenges identified by  $\geq 60\%$  of participants were: lack of local data regarding cancers (95.2%, 79/83); lack of treatment pathways (92.8%, 77/83); absence of support groups for patients (88.0%, 73/83); low public awareness (75.9%, 63/83); and limited availability of treatment options (62.6%, 52/83). Some themes that evolved from the qualitative data were: low cancer awareness; delays in cancer treatment; and, financial burden on patients. The top three priority areas for a new cancer control policy were: cancer prevention (83%, 93/112); State cancer legislation (80%, 86/112); and multi-agency partnerships (79%, 88/112). Most participants (80%, 90/112) recommended that health insurance should fund  $\geq 16\%$  of cancer control activities, although policymakers were more likely

to make quarterly insurance contributions than patients (7 out of 10 vs. 5 out of 10). Data from participants that agreed to be interviewed (n=24) were grouped into the following themes: Experiences (e.g. challenges regarding cancer prevention, awareness of early detection, delays in cancer service, and cost of services) and Expectations (e.g. priority rating for cancer control, funding structure, and framework for a future cancer control policy). ACCG provided contextual evidence of the usefulness of these findings by organizing community-driven cancer control projects locally linked to advocacy, training of clinicians, patient navigation and support, as well as developing a centralized cancer reporting system.

### **Conclusion**

Cancer control was an important issue for all populations. Inadequate early detection services with a background of >3-month diagnostic delay characterized cancer control in Abia State. Future cancer control policy should emphasize: cancer prevention; the creation of local clinical pathways; and, a blended model for financing cancer control activities. Collaboration with community groups such as ACCG will be critical to the successful development and implementation of a cancer control policy in Abia State.

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## DEDICATION

To my parents, Mr. Ngozi Eguzo and Mrs. Ugochi Eguzo, who made significant investments into my upbringing and education. Your efforts have not been in vain.

To my benefactor, Mrs. Marjorie M. Bash of blessed memory; thank you for providing such strong support in my life at a very critical time. Your memory lives on!

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And to the cancer patients who have given me the privilege to serve them and learn from them. I pray for God's guidance such that we can use this study to serve you better and other cancer patients in Abia State and Nigeria in general.

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LIST OF ABBREVIATIONS

ACCG	Abia Cancer Control Group
AIDS	Acquired Immunodeficiency Syndrome
ASCO	American Society of Clinical Oncology
CCP	Cancer Control Policy
FGD	Focus Group Discussions
GPO	General practitioner in oncology
HIV	Human immunodeficiency virus
LGAs	Local Government Areas
LMIC	Low and middle-income countries
MPA	Multiple perspectives analysis
NCCP	National Cancer Control Plan
RAC	Research Advisory Committee
USD	United States Dollar
WHO	World Health Organization

## CHAPTER 1: GENERAL INTRODUCTION

According to the Global Cancer Incidence, Mortality and Prevalence (GLOBOCAN) 2020 report, there were about 19 million new cancer cases and almost 10 million cancer-related deaths, excluding non-melanoma skin cancers.<sup>1</sup> Countries in Sub-Saharan Africa, including Nigeria, have witnessed the highest rise in cancer incidence and mortality. More than 77% of Nigerian women diagnosed with breast cancer presented with advanced disease (i.e.  $\geq$ Stage 3).<sup>2</sup> This scenario reflects the weak health system in the low and middle-income countries (LMIC).<sup>1,2</sup>

The rise in the incidence and prevalence of cancer in developing countries is largely attributed to the epidemiologic transition from communicable diseases to chronic diseases due to increased life expectancy and the prevalence of risk factors.<sup>2,3</sup> Up to one-third of cancers in the LMIC can be prevented by reducing risk factors including tobacco use, alcohol consumption, infectious agents, and environmental pollution, as well as by the implementation of resource-stratified early detection guidelines.<sup>1,4-6</sup> In 2008, it was estimated that 50% of all new cancer cases and 66% of all cancer-related deaths occurred in LMIC.<sup>7</sup> By 2040, these figures were projected to reach 64% and 95%, respectively.<sup>1,7</sup> The ineffectiveness of the health system to deal with the worsening burden of cancer is further compounded by long wait times to access treatment,<sup>8</sup> as well as the high cost of both diagnostics and treatment services.<sup>9</sup>

Despite the rising burden of cancer, many countries in sub-Saharan Africa, including Nigeria, do not have organized national cancer control systems.<sup>3,4,10</sup> Amid other competing health priorities, especially malnutrition and infectious diseases (e.g. HIV and Tuberculosis), most LMIC are unable to allocate adequate resources to cancer control.<sup>3</sup> The United Nations estimates that LMIC which bear over 80% of the global burden related to cancer have less than 5% of global health spending on cancer control. Such health inequity is complicated by lack of political will, the stigma associated with cancers, and poverty; thus, resulting in limited access to the continuum of cancer control.<sup>3</sup> As in other countries, common cancers in Nigeria are breast, cervical, prostate, and colorectal.<sup>11,12</sup>

Just as Nigeria does not have an operational National Cancer Control Program, most states in Nigeria (including Abia State) lack state-level cancer control programs that are supported by

policy.<sup>13</sup> Considering the growing public health importance of cancer amidst other issues (such as infectious diseases), it is important to understand the local context in the Nigerian States and to use such understanding to propose policy frameworks as well as to develop local programs for cancer control, especially as it affects population health. Many stakeholders (cancer patients, healthcare providers, and policymakers) in Abia State have anecdotally expressed their frustration with the current system, which is characterized by low public awareness, a disorganized approach to cancer control, and poor patient outcomes. There is local interest in developing a new approach to cancer control in Abia State. Love et al.<sup>14</sup> suggested that practitioner-led, community-engaged research would use local knowledge to build effective, cancer control strategies within specific nations/health systems. This research strived to do three things:

1. Understand the nuanced perspectives of different stakeholders (patients, healthcare providers, and policymakers) who are impacted by cancer on how to improve cancer control locally,
2. Describe the impact of pilot community-driven cancer control initiatives that were based on the findings from this research and implemented by local stakeholders, and
3. Propose an organized, government-backed policy framework that would lead to an overall improvement in cancer control in Abia State with emphasis on early detection and treatment.

These three aims of this research as outlined above are similar to the community-driven approach used in the evolution of cancer control in Europe, where groups of healthcare providers (i.e. stakeholders) created the momentum that led to organized cancer care in European countries<sup>15</sup>. It also mirrors the approach to addressing maternal mortality in Nigeria, where local communities and individual states create contextual initiatives to address the issue.<sup>16</sup>

### **1.1. Motivation for Research**

The Researcher has practiced medicine in Abia State and different parts of Nigeria since 2007, as a family physician and general practitioner in oncology (GPO). This has given the Researcher a significant understanding of the challenges of cancer control locally. One has shared the anguish of patients whose cancers could have been better managed if detected early; the Researcher has experienced the frustration of physicians who are unable to provide adequate care because of the lack of a framework for early detection and treatment of cancer. The Researcher has also interacted

widely with health policymakers who bemoan the absence of organized cancer control programs that are supported by a policy. This inspired the Researcher's interest to work with local stakeholders to further understand the issues related to cancer control and to propose improvements to the local system for cancer control based on the perspectives of stakeholders in the State.

This study was innovative as it used a mixed methods action research methodology to explore multiple perspectives and collaboratively applied those perspectives in implementing several community-driven projects to improve cancer control in a setting that lacked policy or organized programs. Previous research studies had either focused on describing cancer epidemiology or highlighting challenges affecting cancer control; none have attempted to collaboratively explore the nuanced perspectives of local stakeholders to develop functional, community-funded/driven cancer control initiatives, and to propose a state-level cancer control policy framework in Nigeria. This is the first research project in Nigeria or West Africa that has used this approach, like how the European cancer control initiatives evolved.<sup>15</sup> The methods, findings, and local impact created through this research could be a model for other jurisdictions that are dealing with less-than-optimal cancer control systems. The model could potentially be used for other health-related issues, as it would provide avenues through which international partnerships could be developed to improve cancer care in Nigeria.<sup>6</sup>

## **1.2. Research Objectives**

Primary objective

- To explore and elucidate the perspectives of multiple stakeholders (i.e. patients, healthcare providers, and policymakers) regarding cancer control in Abia State, Nigeria.

Secondary objective

- To propose a framework for improving cancer control in Abia State, especially related to prevention and early detection

## **1.3. Research Questions**

The questions to be answered by this research are:

1. What are the perspectives (experiences and expectations) of cancer patients, health care providers (HCP), and health policymakers (HPM) in Abia State as it relates to the continuum of cancer control, especially on early detection?

2. In what ways can the perspectives explored be used to inform the development of a patient-centered cancer control framework for Abia State?

#### 1.4. Overview of Cancer Control Policy

The World Health Organization indicates that a National Cancer Control Program is a public health program designed to reduce the number of cancer cases and deaths and improve the quality of life of individuals/patients diagnosed with cancer. This is done by implementing systematic, equitable, and evidence-informed policy on the continuum of cancer control (prevention, early detection, diagnosis, treatment, and palliation) using available resources.<sup>17</sup> These cancer control activities should be based on the best scientific evidence available.<sup>18</sup> Figure 1-1 shows the Cancer Control Continuum.<sup>19</sup>

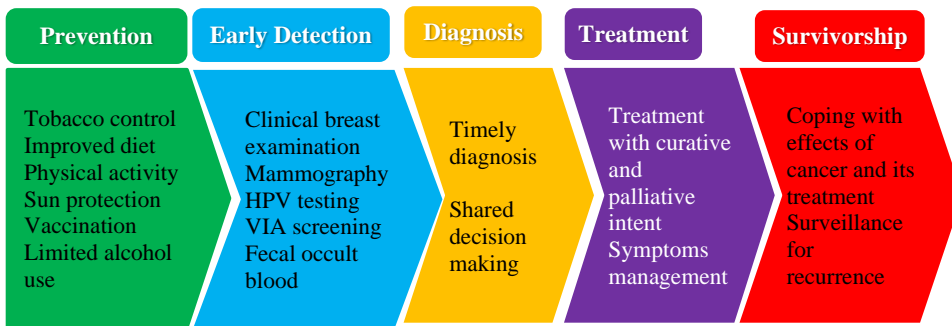


Figure 1- 1 The cancer control continuum

Cancer control is often supported by policy, also known as a Cancer Control Plan. These policies can be made at national or sub-national levels (e.g. States), and their implementation results in Cancer Control Programs. When policies are based on frameworks that are informed by best available evidence, in consideration of the local resources and with the participation of relevant stakeholders, they have a stronger chance of being successfully and sustainably implemented.<sup>20, 21</sup> Policymaking is a role that is undertaken by government at different levels, while community members can participate in the process by proposing and advocating for policies that might be relevant to their society, based on their perspectives. No matter what resource constraints are faced by the country or state, a well-conceived and well-implemented cancer control program reduces the burden from cancer and improves services for individuals/patients diagnosed with cancer and their families.<sup>17</sup> The process of collaborating with local stakeholders to develop this research,

collate local perspectives about cancer control, implement small-scale interventions, and propose a local cancer control policy framework based on the local perspectives are described in the following Chapters.

### 1.5. Dissertation Structure

This is a manuscript-style dissertation with one published peer-reviewed journal article and two manuscripts (that have been published as abstracts) included. It is divided into seven chapters.

The General Introduction (Chapter 1) described the need for the research. It also positioned the researcher/author within the research, as a member of the community affected by cancer control in Abia State. Chapter 2 is a literature review that has been published in a peer-reviewed journal and reflects the current situation regarding cancer control in Nigeria. It also compared the processes of developing cancer control policy in Nigeria with those of three other African countries. Figure 1- 2 provides an overview of the dissertation structure.

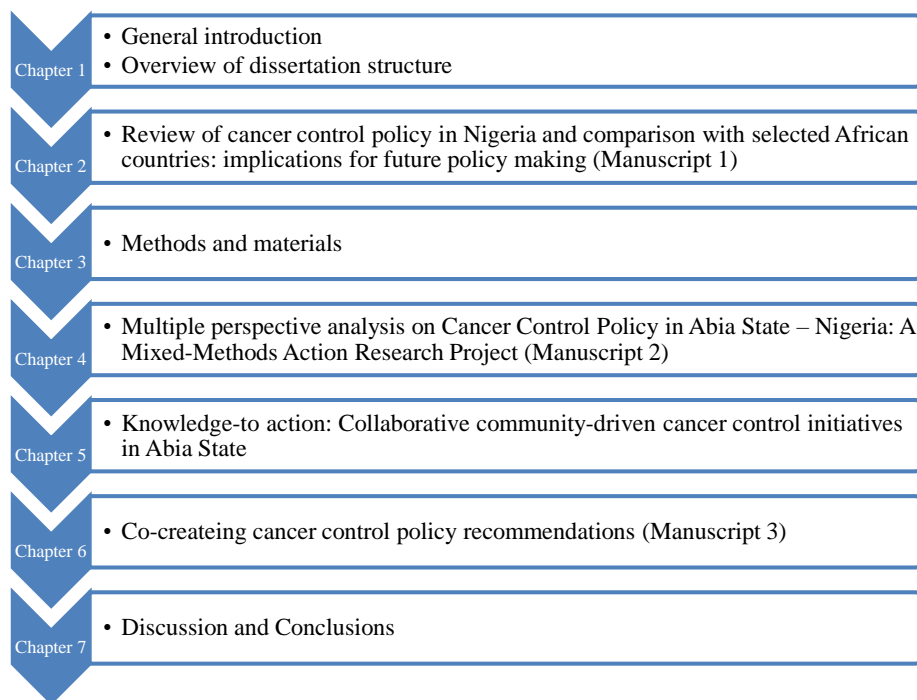


Figure 1- 2 Dissertation Structure



Chapter 3 describes the research methodology. It begins with an introduction to mixed methods action research methodology and its use in cancer control research. This overview was critical as different aspects of the Dissertation (especially the manuscripts) have smaller ‘Methods’ sections. It also describes the study setting and the process of developing the materials used in this research through the Abia Cancer Control Group (ACCG). It also includes the results/findings from the pilot study that was conducted in Akwa Ibom State, Nigeria.

Chapter 4 is a manuscript that focuses on the results/findings from the mixed methods action research data collection undertaken in Abia State, Nigeria. Chapter 5 describes efforts by the community based ACCG to collaboratively implement pilot cancer control initiatives based on the findings from this research project and utilizing community resources. Chapter 6 is a manuscript that includes ACCG’s recommendations on how to structure the Abia Cancer Control Framework, based on the results/findings from this research, reflections from the community-driven pilot cancer control initiatives, and global resource-stratified guidelines. Chapter 7 is a general discussion on the implications of this research. This chapter offers a critical analysis of the entire research project and a conclusion to the work.

There are six Appendices attached at the end. Appendix A is a copy of the surveys that were sent to the different groups of participants (patients, providers, and policymakers). Appendices B – D are copies of the letters received from journals, permitting the use of the copyrighted article and abstracts in this dissertation. Appendices E and F show copies of the Application for Approval of Research Protocol submitted to and subsequently approved by the University of Saskatchewan’s Behavioral Research Ethics Board, Abia State Human Research Ethics Committee, and operational approval from the Medial Women’s Association of Nigeria (Akwa Ibom State Chapter) respectively. Copies of the Certificates of Approval are also included.

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## CHAPTER 2: LITERATURE REVIEW (Peer -Reviewed Journal Article)

### Review of Cancer Control Policy in Nigeria: Implications for Future Research <sup>a</sup>**Manuscript Information**

Prior to exploring multiple perspectives on cancer control policy in Abia State, it was necessary to explore the literature on cancer control policy in Nigeria and other African countries. This review was undertaken in 2019, and the manuscript was submitted to *Ibom Medical Journal* on July 3, 2019. This journal is a peer-reviewed, open-access, online journal and the manuscript was accepted on August 29, 2019, with minor revisions after the first review. The article was published online on January 2, 2020.

As the first author, the Researcher planned, created, reviewed, edited, and submitted the article. The co-authors were the members of the Research Advisory Committee (RAC), as per the Faculty-Student Agreement of the College of Graduate and Postdoctoral Studies at the University of Saskatchewan. The entire Research Advisory Committee reviewed drafts of the manuscript and provided feedback for consideration and approved the final version. The journal has provided a copyright release for the article to be included in this thesis (see Appendix I).<sup>a</sup>

#### 2.1 Abstract

**Background:** A cancer control program is a public health initiative designed to reduce the number of cancer cases and deaths, as well as improve the quality of life of individuals/patients diagnosed with cancer. Despite the rising burden of cancer in Nigeria and the launch of the most recent national cancer control policy in 2018, many Nigerian states do not have robust state cancer control policies and programs. This article reviews policies regarding cancers in Nigeria, with an emphasis on breast and cervical cancers. It focuses on the availability of policy, the process of policy development, its scope, and the implementation of the cancer policy. It uses a comparison of cancer control policy in Nigeria with those of other sub-Saharan African countries to make a case for a new community-engaged approach for developing a framework for cancer control policy in Abia State.

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**Methods:** A structured literature search was done using relevant subject headings and keywords search. Boolean operators 'and'/'or' were used to refine the search. Databases used for the search were Pubmed/Medline, Embase, PsychInfo, Cinahl, Global Health and ERIC. The search included articles published between 2008 and 2018. Data was also collected from the International Cancer Control Plan portal as well as focused Google searches.

**Results and Discussion:** The literature search yielded 306 abstracts, with 112 of them excluded as duplicates. Of the 194 abstracts retrieved, twenty-nine were included in this review. The 2018 Nigerian national cancer control policy showed significant improvement over the 2008 version, in terms of scope and policy development process. The Nigerian policy lacked specific guidelines for breast cancer compared with the Ghanaian policy. Ghana allocated 12% of its total cancer control budget to research compared to 0.4% in Nigeria. The South African Breast Cancer policy was developed using more findings from local research and had the most encompassing, multiple perspectives approach. There was no previous research on the use of multiple perspectives analysis approach to propose cancer policy in Nigeria. Also, there had been no published community-led effort to organize cancer control at the state level.

**Conclusion:** The review shows the content, process, pearls, and pitfalls of cancer control policy in Nigeria and three other African countries. As more Nigerian states are working towards developing state cancer control policies, it is important to address the shortfalls identified in the current national cancer control policy, especially regarding the use of multiple perspectives analysis. There is a need for involving multiple stakeholders to develop a more sustainable cancer control policy that will be grounded in the experiences and expectations of the local community.

**Keywords:** cancer; health policy; Nigeria; public health; global health

## **2.2 Introduction**

Cancer control, which refers to actions taken with the intent of reducing the burden of cancers in a community or nation, is often supported by policies that are often known as cancer control plans. Cancer control policies, like any other health policy, can be made at national or sub-national levels (e.g. states). The implementation of such plans at any level results in cancer control programs.

When policies developed around frameworks that are informed by best evidence, in consideration of the local context and with the participation of all relevant stakeholders, such policies have stronger chance of being successfully and sustainably implemented.<sup>1-4</sup> Common cancer control activities often involve different areas of the continuum of cancer care including advocacy, prevention and early detection, as well as treatment and palliative care.

Despite the well-documented increase in cancer-related morbidity and mortality in Nigeria,<sup>1-4</sup> the country does not have a robust national cancer control program, beyond the cancer control policy document. Similarly, most states in Nigeria, including Abia State, do not have state cancer control policies nor programs.<sup>2,4</sup> The absence of an effective cancer control program that is supported by a robust policy adversely affects patient outcomes.<sup>5-7</sup> This paper reviews the policymaking process and scope of cancer policies in Nigeria, with emphasis on breast and cervical cancers. It focuses on the availability of policy, process of policy development (e.g. stakeholders involved), its scope and the implementation of the cancer policy. The paper compares cancer control policy in Nigeria with those of other sub-Saharan African countries. It is expected that the findings from this review will form the background for research that is aimed at developing an evidence-informed cancer control framework for Abia State in Nigeria. Such findings will also be useful in developing a pilot cancer control program in resource-limited settings such as Abia State.

In order to understand the challenges regarding cancer control policy in Nigeria, specifically related to breast and cervical cancers, it is important to explore the historical approach to this policy issue and to ascertain the extent of the problem.

### **2.3 Methods**

A structured search of the literature was undertaken using the following strategy: subject headings and keywords search using “[Nigeria.mp. or NIGERIA/; breast cancer.mp. or breast neoplasms/; cervical cancer.mp. or uterine cervical neoplasms/; cancer/neoplasms; (control or policy or framework or plan).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms].

Boolean operators 'and/'or' were used to refine the search. Databases used for the search were Pubmed/Medline, Embase, PsychInfo, Cinahl, Global Health and ERIC. The search included articles published between 2008 and 2018. Data was also collected from the International Cancer Control Plan portal, a web-based repository of national cancer control plans. In addition, an internet (Google) search was conducted to find evidence of state cancer control plans. Sources within professional networks were also consulted for updates on cancer control plans in various Nigerian states.

### **2.3.1 Eligibility Criteria**

The eligibility criteria for studies in this review were (1) studies that focused on cancer policy in Nigeria; and, (2) studies that focused on policy regarding breast and cervical cancers. Studies were excluded from this review if they were focused on: epidemiology; clinical medicine (e.g. case reports/case series), laboratory medicine (e.g. molecular/biochemistry/metabolism/drug development/drug evaluation or bio-receptors); and, public awareness programs about various cancers.

### **2.4 Results**

The literature search yielded 306 abstracts, with 112 of them excluded as duplicates. Of the 194 abstracts retrieved, only 29 were included in this review. The remaining were excluded for the following reasons: no full text (15); epidemiology (20); clinical medicine (62); awareness programs (40); extraneous to the cancers of interest (15); and, not focused on Nigeria (13). None of the full text articles reviewed were empirical research conducted regarding cancer policy in Nigeria (i.e. qualitative or quantitative studies that involved data collection). Most of them were review articles or commentaries. Figure 2-1 shows the prism chart for the review.

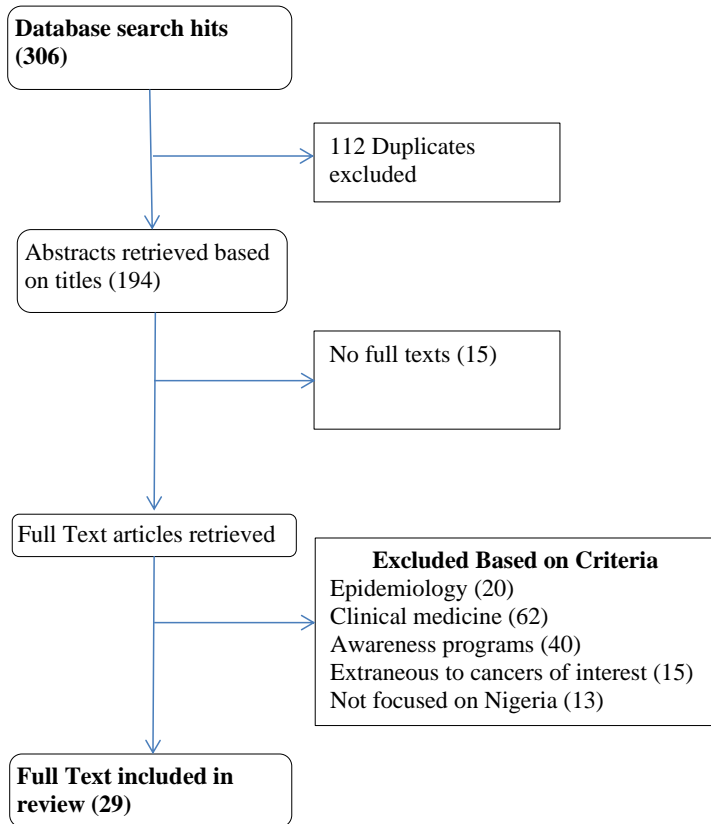


Figure 2- 1 Prism chart for literature review

## 2.5 Discussion

### 2.5.1 Overview of cancer control policy in Nigeria

In 2008, Nigeria launched its first National Cancer Control Plan (NCCP). The overall goal of this policy document was to collaboratively reduce cancer-related mortality and morbidity in the country.<sup>8</sup> It recognized the challenges of cancer control in Nigeria to include ‘underreporting, lack of appropriate diagnosis, limited access to care, deficiencies in technology, manpower, and physical infrastructure, as well as the quality of cancer data systems’. With ten key goals ranging from improving public awareness to better palliative care, this plan outlined basic steps the nation



must take to improve cancer control. It also sought to address key gaps, namely, material resources, financial resources, services, and manpower.

The plan emphasized the following cancers: breast; cervical; colorectal; lung; prostate; skin, as well as leukemia. Some of the strategies outlined to address the gaps were: Increasing public awareness about cancers (e.g. dangers of cigarette smoking); integrating cancer prevention into primary health care (e.g. HPV vaccination); and developing training programs on multidisciplinary cancer management. The plan was not specific on approaches for early detection of any of the common cancers, including breast and cervical cancers.

Although this policy document was developed under the leadership of the Federal Ministry of Health with support from academics and clinicians, there was no evidence of the involvement of individuals/patients that had been diagnosed with cancer, their families, or policymakers at other levels of government in developing this plan.<sup>8</sup> It also did not address the key issues of funding for cancer control; access to cancer care; the surveillance of cancer survivors; and, integration into other health programs. Previous research on this issue showed that effective cancer control policy in Nigeria should be horizontally integrated with other services, make robust provisions for funding, and be multi-sectoral.<sup>9,10</sup> The 2008 National Cancer Control Plan, unfortunately, did not receive much publicity as it was largely not implemented.<sup>11</sup>

In 2018, the Federal Ministry of Health developed a new National Cancer Control Plan (NCCP). This time there was input from a wider variety of stakeholders at the national level, including federal policymakers, academics, clinicians, patient advocates, cancer survivors, and international agencies. The new plan recognized some shortfalls in the implementation of the 2008 plan, such as the integration of vaccination against human papillomavirus (HPV) into primary health care and better mobilization of palliative care resources.<sup>5</sup> The goal of this policy document was to reduce the incidence and prevalence of cancers in Nigeria at the national level. This is a more encompassing vision when compared to the focus on morbidity and mortality in the 2008 Policy. It also focused on the continuum of cancer control, from prevention to palliation with an additional section on data management.

Although this plan involved more stakeholders at the Federal level, it did not receive any input from the State Governments, which provide the bulk of healthcare in Nigeria. The plan also provided a picture of the financial costs related to cancer control in Nigeria, with 75% of the budget expected to come from governments. It did not address the specific role of health insurance in funding cancer control. Although this national document recognized the role of various stakeholders, it did not speak to the role of some traditional institutions (e.g. town unions, churches, and market organizations) in improving cancer control. The 2018 NCCP also mentioned traditional rulers but did not elaborate on their potential role as community leaders. Thus, new research was needed to explore approaches to engage these important stakeholders, especially in their communities. This document could prove to be the major steppingstone that will mobilize political will for cancer control in Nigeria, something that has dogged similar proposals in the past.<sup>9, 10, 11</sup> The plan would have cost more than three-hundred million (\$300,000,000) United States dollars to implement between 2018 and 2022, with 62% of the funds allocated to prevention and 0.4% budgeted for data management/research. Seventy-five percent of the funds were expected to come from the Federal and State government.

Meanwhile, the 2018 NCCP recognized the roles of states in implementing the plan and for developing their state-level cancer control plans.<sup>5</sup> This made it imperative for each state to propose its policy framework that would enable each state to meet the goals outlined in the 2018 NCCP. The state implementation framework should therefore be tailored to the realities of the state and should be built upon the perspectives of local stakeholders. Considering the aforementioned, it is important to review the current scenario regarding the efforts of various state governments in developing local cancer control implementation frameworks.

There are thirty-six states in Nigeria, and each has been requested to develop a state-specific cancer control policy.<sup>5</sup> In May 2017, the Lagos State government approved the law establishing the Institute for Cancer and Disease Control.<sup>12</sup> This was initiated as a Private Member's Bill which passed through the House Committee on Health. Ondo State is working on a comprehensive cancer control bill that will include a state cancer center, while Enugu State is exploring ways to adapt the current national cancer control plan into their local context. In Enugu, the effort is led by the State Ministry of Health, supported by academics and patient advocates. Oyo State also adapted

the national cancer control policy, using almost the same content. The momentum to create cancer control policies at the state level, where they exist, is driven by governments, although none of these efforts have resulted in organized, sustainable cancer control programs in those states. There is no current effort to create a government-led cancer control policy in Abia State. It is hypothesized that community-driven efforts at cancer control will lead to the creation of sustainable cancer control programs and a State Cancer Control Framework. The first step in creating a community-driven approach to cancer control would involve exploring the perspectives of local stakeholders and working with them to develop a program and policy that best suits the community. None of the current initiatives for cancer control in Nigeria have used this approach.

Apart from formal cancer control plans, other policy thrusts that impact cancer control in Nigeria include the national tobacco control policy. The first national tobacco control policy was introduced in 1951, with the policy focused on licensing and regulation, but not limiting exposure to this known carcinogen. In 1990, the national tobacco control decree was passed by a military government but converted to an Act in 2000 by a democratic government.<sup>13</sup> The most recent tobacco control policy (National Tobacco Control Act, 2015) in Nigeria was passed and signed into law in May 2015. This evolved from concerted actions from civil society organizations, the Federal Ministry of Health, the National Assembly, and the Federal Executive Council.

## **2.5.2 Comparison of the context and content of Nigeria cancer control plan with other African countries**

### **1. Ghana**

The National Strategy for Cancer Control in Ghana was launched in 2011, with projections for the years 2012-2016.<sup>14</sup> It was developed by a technical team comprised of Expert Clinicians. This is different from the process of developing the 2018 cancer control plan in Nigeria, which had greater involvement of patient advocates and non-clinicians. Under the leadership of the National Cancer Control Steering Committee, nine technical working groups (TWG) developed the specific aspects of the plan. Each of the TWGs focused on specific cancers, while one TWG was responsible for the final format of the policy document (editorial). Thus, in comparison with the Nigerian plan, the Ghana NCCP provided more detailed information about strategies and objectives for specific diseases, such as breast and cervical cancers. It also has a clearer description of the guidelines

related to the prevention for each cancer type, unlike the Nigeria 2018 Plan. For instance, the Ghana Plan promoted the use of breast self-examination and clinical breast examination for the early diagnosis of breast cancer.

Unlike the Nigerian 2018 NCCP, the Ghana National Cancer Control Plan did not outline the roles for different stakeholders (e.g. traditional rulers). However, it outlined implementation strategies at different levels of the healthcare system (e.g. national cancer treatment centers and district hospitals). It also emphasized surveillance by making cancer a notifiable disease. Forty-six million US dollars was required to implement the Ghana plan, with about 23% allocated to early detection, 17% earmarked for prevention, and 12% budgeted for cancer registry/research. Most of the funds were expected to be raised from government allocations. The plan also advocated for the inclusion of cancer medicines in the national health insurance coverage.

## **2. Kenya**

In June 2017, the Kenya Ministry of Health published its National Cancer Control Plan.<sup>15</sup> It was built on the gains of the previous version of their cancer control plan (2011-2016). It also included findings from the imPACT study, which sought to assess the status of Kenya's capacities for the implementation and delivery of cancer control plans and activities.<sup>16</sup> The overarching goal of the 2017 NCCP was to reduce cancer incidence, morbidity, mortality as well as improve the survival rate from cancer in Kenya. It sought to accomplish these objectives/goals through access to population-based primary prevention, early detection, quality diagnostics, treatment, and palliative care. Kenya has made tremendous progress in the implementation of its national cancer control plan in the last several years.<sup>9</sup>

Unlike the Ghanaian NCCP<sup>14</sup> but like the Nigerian NCCP,<sup>5</sup> the Kenyan NCCP did not contain a specific framework for various cancers. Rather, it had a more detailed action plan for different stakeholders. Although the policy described committee consultation meetings, it was not clear what each committee contributed to the final policy document. This was unlike the approach that was used in the Nigerian NCCP.<sup>5</sup>

### 3. *South Africa*

Cancer control policy documents in South Africa date back to 1999 with the publication of the National cancer control program baseline document.<sup>17</sup> Since then, the country has published a series of guidelines for different cancers for use by healthcare providers. The Strategic Plan for the Prevention and Control of Non-Communicable Diseases is a key document that outlined its overall strategy to manage non-communicable diseases.<sup>17</sup> Regarding cancers, this policy document recognized the importance of controlling risk factors such as tobacco, alcohol, and human papillomavirus.<sup>17</sup> It also targeted screening every woman with a history of sexually transmitted diseases for cervical cancer at five-yearly intervals.

Although South Africa did not have a current national cancer control plan, it published the Breast Cancer Control Policy in 2017. This sought to “(i) reduce breast cancer morbidity and mortality by promoting breast healthcare awareness and access to early breast cancer detection and, diagnosis, appropriate treatment and palliative care; and (ii) serve to streamline the overall breast care service outlines”.<sup>18</sup> The breast cancer control policy outlined eight key policy areas with actions aligned to them. The areas include 1.) Prevention and early detection, screening, and genetic assessment; 2.) Timely access to care; 3.) Assessment, diagnosis, and staging; 4.) Treatment of breast cancer; 5.) Palliative care in breast cancer; 6.) Follow-up and surveillance in breast cancer; 7.) Data, monitoring, and research; and, 8.) Community outreach and engagement.<sup>18</sup>

The process of policy development in South Africa was slightly different from those of the other countries reviewed. Matsoso, et. Al<sup>17</sup> described the collaborative, multisectoral approach involved in developing the Strategic Plan for the Prevention and Control of Non-Communicable Diseases. A summit was hosted in 2011 by the Minister of Health where cancer healthcare providers, survivors, government representatives, non-profit organizations, academics, and other experts made contributions to the document. The policy document also included findings from relevant research done within the country.<sup>17</sup> The South African policy, however, was not community-driven, and it has not led to a sustainable cancer control program in South Africa. The development of the breast cancer control policy in South Africa also followed a similar approach. That policy document acknowledges the importance of multiple perspectives in policy development, although it did not describe the procedure for analyzing and merging those perspectives.<sup>18</sup> Currently, efforts

are being made to develop a robust national cancer prevention and control plan. As part of the policy development process, the Cancer Association of South Africa (CANSA) submitted its contribution to the draft policy document.<sup>19</sup> Their contribution echoes the need to include multiple perspectives in policy development, as each perspective adds unique pieces to the final policy document. The South African approach, when applied in Nigerian State could lead to a sustainable cancer control framework locally, although there has been no research done to explore how this might work.

## **2.6 Analysis of the process of policymaking for cancer control in Nigeria**

It is important to consider the process through which cancer policies have been developed and implemented in Nigeria. Both cancer control plans (2008 and 2018) were developed through sub-committees that focused on different aspects of the policy.<sup>5</sup> For instance, the team of experts which drafted the 2018 NCCP was broken down into seven priority areas of action: (1) prevention; (2) diagnosis and treatment; (3) supply chain management (logistics); (4) hospice and palliative care; (5) advocacy and social mobilization; (6) data management and research; and, (7) governance and finance.<sup>5</sup> The members of each of the sub-groups were drawn from health-related disciplines.<sup>5, 11</sup>. There is no evidence that either of these cancer control plans (2008 and 2018) received input from other sectors of the economy which may be impacted by the activities proposed in the policy such as the Ministries of Finance, Education, or Women's Affairs.

Effective health policy making often requires multidisciplinary and multi-sectoral collaboration.<sup>4</sup>  
<sup>20</sup> The lack of such collaboration had disastrous effects on previous attempts to pass the Tobacco Control Act in Nigeria<sup>13</sup> as some ministries felt 'left out' of the process of policy development. However, the input from other relevant Ministries in the government was not evident in the 2018 NCCP. In addition, there was no evidence that stakeholders such as traditional rulers, state governments, and religious organizations had been engaged in the development of the policy. This lack of engagement often leads to difficulties in policy implementation. Future efforts to build on the national cancer control plan must therefore be more inclusive. For instance, states seeking to develop local cancer control plans should involve more stakeholders, such as individuals/patients that had been diagnosed with cancer, traditional rulers, religious leaders, and the leadership of other government ministries. This would make the policy more locally relevant. Community-led

approaches to policy development are also known to be more sustainable as the people feel a greater sense of ownership.<sup>20</sup>

Meanwhile, the evidence for some of the projections of the 2018 NCCP was not clear. For instance, Goal 1B in the Plan, (i.e. make screening services and early detection of cancer available for all Nigerians), aimed at achieving 50% coverage of screening for the eligible population by 2022 but does not provide any current data on the trends of cancer screening in Nigeria. Although it proposed to conduct a baseline survey to effectively monitor this policy target, the projection could have been better contextualized if more individual/patients' perspectives had been included. This would have given a more realistic statistical picture of the pattern of utilization of screening services for those diagnosed with cancer. Thus, states seeking to develop local cancer control frameworks would make their policy more context-specific by including local data related to cancer screening.

### **2.7 The pattern of cancer diagnosis in Nigeria and policy implications**

One key improvement of the 2018 NCCP over the previous policy was the emphasis on data management and research. Although the plan recognized the absence of comprehensive local data on cancer incidence and prevalence, it placed emphasis on strengthening cancer registration for improved policymaking.<sup>5</sup> The most common cancers in Nigeria include breast, cervical, prostate, liver and colorectal.<sup>21, 22</sup> The 2018 NCCP promotes screening for common cancers whereas not all of them would yield mortality reductions with screening programs, e.g. liver cancer. It will be important for state cancer control plans to be more specific about pathways for screening, based on local evidence, perhaps like the Ghana Plan.<sup>14</sup> While the science around early cancer detection is evolving, most established screening programs globally focus on breast, cervical and colorectal. Among the cancers that can be detected early through screening, breast cancer has however been reported to cause the greatest mortality in Nigeria followed by cervical cancer.<sup>23</sup> Most people diagnosed with cancer in Nigeria generally present late and as a result have advanced disease.<sup>24-26</sup> The high incidence of breast and cervical cancers makes them diseases of public health importance, and thus deserve more attention.<sup>27, 28</sup> It is also important to recognize the aggressive screening for slow-growing cancers (e.g. prostate) can result in greater morbidity and poorer patient outcomes in some populations.<sup>29</sup>

The 2018 NCCP set a target of having 90% HPV vaccination coverage by 2022; that would be achieved through integration into the current national immunization schedule.<sup>5</sup> However, immunization has become a divisive issue in Nigerian society based on religious and cultural beliefs. Ophori et al<sup>30</sup> described regional variations in immunization coverage in Nigeria, with the northern region reporting lower vaccine acceptance. Any future cancer control policy by the states should engage the community leaders more effectively so that the targets (e.g. HPV vaccination coverage) can be co-created and be made more locally relevant. This is one area where multiple stakeholders could help improve the co-creating, co-implementation, and co-evaluation of the cancer control policy.

## **2.8 Experience of cancer control in Nigeria and policy implications**

Cancer places an enormous financial burden on patients and their families due to the cost of treatment and loss of income.<sup>27,31</sup> The economic burden of cancer treatment affects adherence with therapy. Up to 66% of cancer patients do not complete their chemotherapy due to poverty.<sup>32</sup> According to Nuhu et al,<sup>25</sup> up to 33% of cancer patients in Nigeria reported having a poor quality of life, with males faring worse than females. Although the 2018 NCCP proposed increased funding by the government for cancer services, it did not sufficiently address the issue of cost.<sup>9</sup> The role of health insurance and other financial actors in improving access to screening, treatment, and survivorship services was not clear. Perhaps this is due to the lack of representation by the National Health Insurance Scheme on the team of experts who developed the plan. There is limited data on the cost of cancer services in Nigeria and how this might be improved. Such information will provide better situational analysis. Such could be achieved by involving more individuals/patients, families, and frontline health care providers in the development of cancer control policy. States looking to adopt the present NCCP need to further explore the role of health insurance organizations and how to mobilize financial resources for sustainable state-wide cancer control.

Nigerian health care professionals (HCPs) have limited knowledge about cancer care,<sup>33,34</sup> and the need to improve cancer-related education among HCP in Nigeria is recognized.<sup>35</sup> The national cancer control plan also acknowledged the dearth of clinicians who provide cancer services.<sup>5</sup> It proposed to increase the number of skilled providers by 15% annually. This target would be most



applicable at the health institutions which are funded by the federal government (e.g. Federal Medical Centers), due to the structure of the Nigerian health system where different levels of government fund different health institutions. Thus, States that seek to create a cancer control policy would need to make provisions for improving the competence of their local health workforce. Eguzo et al<sup>33,34</sup> have demonstrated that continuing professional development courses are effective means of creating a community of HCPs with added competence in cancer control.

### **2.9 The case for a new approach to cancer policy development in Nigeria**

From the foregoing, it is evident that more work needs to be done on developing cancer control policies in Nigeria, especially at the State level. The 2018 NCCP provided a good first step and identified some challenges to its implementation. Some of these include but are not limited to low political will among policy makers; public awareness; engagement of stakeholders; availability of suitably-trained healthcare providers; and, others. However, the NCCP did not sufficiently address how state governments might address these, as the plan focused largely on the role of the Federal Government. Evidence also suggests that practitioner-led, community-engaged research which uses local knowledge to build effective cancer control strategies within specific health systems would be most effective.<sup>36</sup> This community-driven approach was pivotal to improving cancer control in Europe.<sup>37</sup>

In order to sufficiently address the policy issue of cancer control at the state level, further research needs to be done to include the perspectives of multiple stakeholders. Multiple perspective analysis (MPA) is a method of gaining a deeper understanding of policy issues and their potential solutions by systematically exploring multiple perspectives (personal, organizational, and technical) to the issue being addressed.<sup>38</sup> The technical perspective focuses on functional aspects of the system being analyzed (e.g. what screening methods to use); the organizational perspective dwells on the structural and procedural aspects (e.g. who will be responsible for the policy implementation); while the personal perspective focuses on outcomes (e.g. ease of access to treatment by patients).<sup>39</sup> Linstone<sup>40</sup> specifically developed this approach “to help the systems practitioner bridge the gap between analysis and action, between model and real-world”. Each perspective has separate underlying assumptions and is essential to understanding complex technical systems that are meant to interact with a group of people. Originally proposed by Linstone,<sup>40</sup> multiple perspectives

analysis approach has been used to develop sustainable water policy in Australia<sup>41</sup> as well as in describing physicians and patients' roles in point-of-care health decisions.<sup>42</sup> In Uganda, the multiple perspectives approach was used by Ssengooba et al<sup>43</sup> to inform HIV policy.

Key perspectives required to build on the proposals outlined in the 2018 NCCP must include individuals/patients (personal), healthcare providers (technical) and policymakers (organizational), at the State level. These perspectives represent different interests regarding the issue of cancer control policy and need to be considered jointly in order to find a balance. Concerning the development of a cancer control policy, analysis of these three perspectives will provide local knowledge, understanding, and evidence on local realities related to the issue (cancer control). This will potentially lead to the development of more nuanced adaptations of the national cancer control plan in Nigeria, which would then be re-framed and co-created with communities to meet the needs of the people being served before implementation at the state level.

None of the cancer control plans reviewed adopted the MPA approach, and there has been no previous research conducted in Nigeria on how to use an MPA to propose a state cancer control framework or create pilot cancer control programs based on data generated by local MPA research. By using this approach, future research might successfully mobilize local political will as policymakers would be engaged in the process. Low political will had been identified as a challenge to effective cancer control in Nigeria by the 2018 NCCP.<sup>5</sup> Using the community-driven MPA could potentially develop a more patient-centered policy as the individuals/patients diagnosed with cancer would be involved in co-creating the framework. This approach would also better engage other relevant stakeholders (e.g. health insurance, community leaders, relevant government ministries) in policymaking. The engagement of several stakeholders in formulating local health policy through research has been shown to lead to more local ownership and subsequently to more sustainable implementation. A multiple perspective analysis could improve the scenario of cancer control policy in Abia State and other resource-limited settings sustainably.

## **2.10 Conclusion**

This review analyzed the process and outcome of cancer control policies in Nigeria between 2008 and 2018. The government-led efforts at policymaking have not resulted in robust cancer control programs, especially at The State level. There is a need to adopt a community-driven multiple

perspectives approach in exploring the perspectives of community stakeholders, proposing local cancer control frameworks, and in developing cancer control programs. If this approach is used to organize cancer control in states without cancer control programs, such as Abia State, it could lead to more sustainable improvements in cancer advocacy, early detection, treatment, and patient outcomes. There is a need to generate evidence that would potentially demonstrate the benefits and impact of community-driven action to improve cancer control in resource-limited settings, such as Abia State.

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### 3.1 Study Design

This study was undertaken using a mixed methods action research (MMAR) design. MMAR involves collecting both quantitative and qualitative data in the same research study.<sup>1</sup> This is a form of inclusive inquiry where research is done by or with the insiders of an organization or community, and not to or on them.<sup>1</sup> Macdonald et al<sup>2</sup> defined it as “a participatory and consensual approach towards investigating problems and developing plans to deal with them”. It is a cyclical process of reflection, inquiry, and informed action which generates knowledge and enables problem-solving by direct engagement of stakeholders in the research.<sup>2</sup>

According to Ivankova<sup>1</sup>, pragmatism is the philosophical foundation of mixed methods research, as this justifies the combination of both qualitative and quantitative approaches within one study. This emphasizes that what has practical and functional value is ultimately important and valid. It takes the epistemological position that there are many ways of knowing, which include both qualitative and quantitative ways. This (pragmatic) approach transcends the either/or argument between qualitative and quantitative methods and posits that truth is ‘what works best for understanding a particular problem/research question.’<sup>3,4</sup> Thus, pragmatism presents a very practical and applied research philosophy, which is what the questions asked in this study sought to accomplish (see Section 1.3). This worldview aligns perfectly with the multiple perspectives analysis approach to structuring policy problems, such as the one used in this project.

Several researchers have used this methodology to study cancer control issues in other parts of the world. Randall et al<sup>5</sup> reported a partnership between CrossWorks, a faith-based community organization with academics from North Carolina Breast Cancer Screening Program to plan and implement a program to promote breast cancer screening in North Carolina, USA. In 2006, Sinding et al<sup>6</sup> studied the experience of lesbians (n=26) diagnosed with cancer, to demonstrate the support they received from lesbian communities in Ontario, Canada. They used mixed methods (surveys followed by focus group discussions [FGD]). Ma et al<sup>7</sup> described a community project involving interviews with leaders of Asian communities in the Delaware Valley region of the USA (n=52), which formed a coalition to improve tobacco and cancer control. They further sampled 1,374 individual members of these communities through a facilitator-administered survey. Kangawa-

Singer et al<sup>8</sup> also conducted a mixed-methods study to explore breast and cervical cancer control among Southeast Asian women, living in California – USA. The successes reported by other investigators in using this methodology to address cancer control in various locations support the use of MMAR in the proposed research in Abia State, Nigeria.<sup>8-11</sup>

The low scientific rigor of mixed methods action research has been identified as a limitation. Several studies have highlighted concerns with the precision of estimates from MMAR (e.g sample size<sup>2,5</sup>) and generalizability and comparability of findings from MMAR with other studies conducted using the positivist paradigm which tends to dominate science.<sup>8,12</sup> Mitchell et al<sup>12</sup> identified the challenge of obtaining ethics approval from different communities, that have different structures for conducting research.

Meanwhile, evidence suggests that practitioner-led, community-engaged research, which uses local knowledge to build cancer control strategies within specific health systems, is most effective, especially in terms of achieving sustainable impacts.<sup>14</sup> The literature on community-engaged research regarding cervical cancer in Sub-Saharan Africa (SSA) shows that working with community groups, including members of the community in research efforts, and creating an enabling environment for collaborative implementation of projects, improves cancer control.<sup>15</sup> However, there are no studies that have addressed the optimal approach for using community-engaged research to structure cancer control policies at the State level, or to pilot a community-driven cancer control program based on the perspectives of multiple stakeholders in Sub-Saharan Africa.

Multiple perspective analysis (MPA) is a method of gaining a deeper understanding of policy issues and their potential solutions by systematically exploring multiple perspectives (personal, organizational, and technical) to the issue being addressed.<sup>16</sup> The technical perspectives focus on functional aspects of the system being analyzed (e.g. what screening methods to use); the organizational perspectives dwell on the structural and procedural aspects (e.g. who will be responsible for what on the policy); while the personal perspectives focus on outcomes (e.g. ease of access to treatment by patients).<sup>17</sup> Linstone<sup>18</sup> specifically developed this approach “to help the systems practitioner bridge the gap between analysis and action, between model and real-world”.



Each perspective has separate underlying assumptions and is essential to understanding the complex technical systems that are meant to interact with a group of people. The MPA approach has been used to develop sustainable water policy in Australia<sup>19</sup>; as well as in describing physicians' and patients' roles in point-of-care health decision-making regarding HIV policy in Uganda.<sup>20</sup>

By using mixed methods action research methodology with multiple perspectives analysis, it was expected that this research would effectively explore the perspectives of all relevant stakeholders and propose a cancer control framework that can be implemented and sustained over time. The quantitative strand would provide data regarding the breadth of perspectives (e.g. access to early detection) while the qualitative would help explain the qualitative findings (e.g. how access to early detection affects cancer diagnosis). The engagement of several stakeholders in formulating local health policy through research has been shown to lead to more local ownership and subsequently to more sustainable implementation.<sup>21</sup> For instance, this research would make it easier to mobilize political will locally as policymakers would be engaged in the process. Low political will was identified as a challenge to effective cancer control in Nigeria by the 2018 National Cancer Control Plan.<sup>22</sup> Working collaboratively with the Abia Cancer Control Group, a community-based coalition of governmental and non-governmental organizations, this research could develop an innovative, patient-centered cancer control framework for Abia State based on the lived experiences and expectations of local stakeholders. Thus, mixed methods action research methodology was well suited for this research which was to explore how the multiple perspectives of local stakeholders could be analyzed and applied in the development of a cancer control framework in the setting of Abia State.

In choosing this approach for this research project, considerations were given for timing (temporal relationship between the quantitative and qualitative), the priority to be given to each strand, and how they would be 'mixed'. Onwegbuzie et al<sup>3,4</sup> outlined various approaches to conducting mixed methods research. In summary, data for both strands could be collected concurrently or sequentially; findings from one strand could have more priority; data analyses could be combined or separated. For this study, a concurrent data collection approach was used with both strands given equal priority and findings were combined during the interpretation of both quantitative and

qualitative results/findings. It was anticipated that the results from the quantitative strand would provide the breadth of perspectives while the qualitative strand would provide depth to those perspectives. Combining both results and findings would provide triangulation (correspondence of results from each method) while increasing the credibility and applicability of the outcomes of the study.

### 3.2 Study Setting and Sampling

#### 3.2.1 Population

The study population was drawn from Abia State in Nigeria. As shown in Figure Abia State is located in southeastern Nigeria (5°25'0.01" N 7°30'0.00" E), with an estimated population of four million spread across 17 Local Government Areas (LGAs).<sup>24</sup>

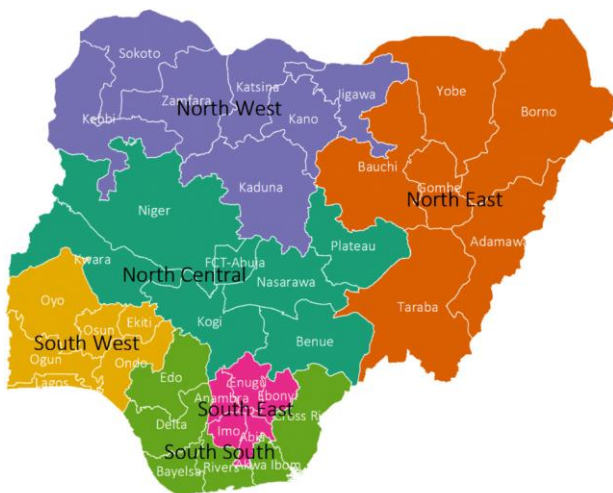


Figure 3- 1 Political map showing the states in Nigeria<sup>24</sup>

Like most Nigerian states, Abia lacks a state-level cancer control policy; this is unlike the scenario for maternal health where the state drives policy development and implementation.<sup>25</sup> This project undertook data collection using questionnaires and in-depth key informant interviews. Follow-up focus group discussions were used by the ACCG to facilitate the interpretation of the findings and the development of local cancer control initiatives before the development of a set of recommendations for cancer control policy.

The populations of interest (research participants) were as follows:

- **Patients:** individuals diagnosed with breast or cervical cancers within the last 5 years and patients currently receiving cancer treatment at various health institutions in Abia State. Key informants for this group were selected from cancer survivors because they would have experienced various aspects of cancer care in the state.
- **Providers:** Physicians and nurses currently serving in Abia State. Key informants for this group were selected from those who worked in facilities known to provide cancer services (especially breast and cervical cancers) because they would have the most experience regarding cancer control in the state.
- **Health Policymakers in Abia State,** including senior personnel in the Ministry of Health, legislators, and local government primary health care directors. Key informants for this group were selected from senior personnel at the Ministry of Health since they were expected to be most conversant with existing policies.

Some potential participants were already known to the Researcher, who practiced as a Family Physician/General Practitioner in Oncology in Abia State. The community-based Abia Cancer Control Group (ACCG) was set up, with participants drawn from known members of each category of participants (patients, providers, policymakers, and academic researchers). Led by a local nongovernmental organization and working collaboratively with the researcher, the ACCG was involved in the research design co-creation; participant recruitment; data interpretation; knowledge translation; design and implementation of the pilot cancer control initiatives; development of the proposed cancer control framework; and report writing.

### 3.3 Sample Size

There were no data about access to cancer screening in Abia State. However, previous studies have shown that 75% to 92% of Nigerian women have not accessed cervical cancer screening.<sup>23,25</sup> This rate of utilization for cervical cancer screening could also apply to breast cancer screening as both services are provided during the same clinical visit in Nigeria and other developing countries.<sup>26,27</sup> For the quantitative arm of this project, a minimum sample size of 73 participants was required to understand the lived experiences of cancer screening at a 95% confidence level and a 10% error margin, with the assumption that 75% of the participants would report no access to cancer

screening. This value was estimated using an online calculator (<https://bit.ly/3jZ55br>) that employed Cochran's formula,

$$n = \frac{z^2(p)(1-p)}{e^2}$$

Where: Z = value from standard normal distribution corresponding to desired confidence level (Z=1.96 for 95% CI); P is the expected true proportion (75%); and e is the desired precision (half desired CI width; 5%).

Considering the three subgroups in the study (i.e. patients, providers, and policymakers) about 30 participants would be required in each group to ensure normal distribution (i.e. access to early detection) according to the central limits theorem.<sup>28</sup> For the qualitative component, previous research<sup>29,30</sup> recommended that a minimum sample size of 12-20 interviews (i.e. four participants from each of the three groups) would be required to reach data saturation, the point at which new data no longer contributes new findings due to the repetition of themes and comments by participants.

### **3.3.1 Participant Recruitment Strategy**

A purposive sampling method was used for participant recruitment. Working collaboratively with the Abia Cancer Control Group, participants were recruited from health institutions, community events, and government offices within Abia State of Nigeria. This research study was advertised at locations where potential participants could be invited to participate. Social media posts, email, and bulk text messaging were adopted and used by the institutions in Abia State to reach their clients, staff, and associates, to advertise the research. The researcher did not have direct contact with the potential participants as their email addresses or phone numbers were not made public. Interested individuals were required to contact the researcher using the information provided in the advertisements. The multi-modal advertisements outlined the purpose of the study as well as details on what participation would involve.

Participants were also recruited in hospitals/clinics providing cancer services, with the cooperation of the leadership of such facilities. Physicians and nurses were also recruited in the manner described above. Policymakers were recruited directly from the Ministry of Health, Ministry of

Education, and other agencies involved in health policy making (e.g. Abia State House of Assembly). Providers and policymakers were also recruited at community events, such as Continuing Medical Education. All potential participants had an opportunity to read and/or listen to a description of the study, including the informed consent. Only people who provided written consent were included in the data collection. Individuals who did not provide consent were excluded from the study.

The concurrent mixed methods approach was used for data collection, where quantitative and qualitative data were collected at the same time before data analysis. This meant that a subset of the survey participants also participated in the interviews. Quantitative data were collected using questionnaires, while semi-structured key informant interviews yielded the qualitative data.

### **3.3.2 Study Instrument**

A literature search involving the databases Medline, EBSCOhost, ERIC, Global Health, and CINAHL, did not reveal any validated survey that had been used to explore multiple stakeholder perspectives on cancer control in a developing country. Thus, a new instrument was developed for this study through a review of closely related studies. Some of the questions in the survey and the in-depth interview were adapted from a previously validated questionnaire developed by Jedrzejewski et al.,<sup>31</sup> which was used to compare expectations on cancer control between people in the United Kingdom and Poland. Questions were also adapted from the WHO cancer control self-assessment questionnaire.<sup>32</sup> The questions evaluate the experiences of each individual regarding cancer awareness, prevention, and treatment, as well as their expectations on a new cancer control plan. The interview questions were adapted from the questionnaires. Research partners in Abia State and Akwa Ibom State helped review and revise the study instrument. The draft instruments were pilot tested in Akwa Ibom State, Nigeria, as described in the following section.

### **3.4 Ethical Considerations**

Before commencing this research, a Certificate of Approval for the pilot project was obtained from the University of Saskatchewan's Behavioral Research Ethics Board (BEH 16-44; February 11, 2016; Appendix 1); as well as operational approval from the Akwa Ibom State Chapter of Medical

Women's Association (May 5, 2016; Appendix 2). The University of Saskatchewan's Certificate of Approval was amended through an addendum (September 19, 2017) to include a new study site (Abia State). The Abia State Human Research Ethics Committee approved the study on April 19, 2018. A second amendment was submitted and approved by the University of Saskatchewan's Behavioural REB to include several new categories of participants who would be involved in knowledge translation/dissemination. At the University of Saskatchewan, the ethics approval was renewed annually, per university protocol.

The privacy of participants was ensured as data was stored in a secure, electronic cabinet that was provided by the University of Saskatchewan. Only participants who provided informed consent were recruited into the study. Their identity was protected through the use of alternate identifiers (pseudonyms) for qualitative data and the use of aggregated data for reporting quantitative data. Participants were informed of their right to withdraw from the study at any point without consequences until all the data were aggregated and de-identified for analysis.

### **3.5 Pilot Study**

#### **3.5.1 Pilot Study Design**

The researcher conducted a pilot study to test the research method in partnership with the Medical Women's Association of Nigeria, Akwa Ibom State Branch. Akwa Ibom State was chosen for this pilot study because it is similar to Abia State culturally, economically, and socially.

The objectives of the pilot study were as follows:

1. To test the utility of the research design in obtaining reliable data on the perspectives of the proposed stakeholders regarding cancer control.
2. To evaluate the utility of the research design in proposing a cancer control framework and to inform the development of an evidence-informed cancer control program.
3. To gain insights into the issue of cancer control from local stakeholders

#### **3.5.2 Pilot Study Sampling**

At least three (3) individuals from each category of participants were required for the pilot study; this represented 10% of the estimated sample size per group for the larger study (n=73) to be conducted in Abia State. A purposive sample of participants were recruited at the Cancer Control

in Primary Care (CCPC) course and institutions in Akwa Ibom State. The CCPC course attracted individuals from the population of interest; making it a great opportunity to test the research instruments/design. Participants in the pilot study included cancer survivors, healthcare providers, and health policymakers who attended the three-day event. The pilot study was advertised to the audience through posters and oral announcements. Interested participants were requested to provide their opinion on the study instrument using in-depth interviews and by completing the relevant interviewer-administered questionnaires. In partnership with the conference organizers, potential participants for this pilot study were identified. These individuals were approached by members of the research team and invited to participate in the study. Interested persons were provided a summary of the study (see Appendix A) and a Consent Form (hand-delivered). Data were collected only from individuals who provided written consent.

The design of the pilot study followed the mixed methods action research methodology, as described earlier. The interviews were conducted by nursing students and were all audio-recorded. An orientation was provided to the students regarding the ethical conduct of research, especially confidentiality. At the end of each day of interviews, the researcher conducted a debrief with the students to better understand the perspectives of each participant.

### **3.5.3 Pilot Study Instrument**

An amended version of the previously validated questionnaire developed by Jedrzejewski et al.<sup>31</sup> was used to evaluate the patients' perspectives. An amended version of the WHO Cancer Control Self-Assessment Questionnaire was used to evaluate the perspectives of providers and health policymakers.<sup>32</sup> Thus separate, but similar questionnaires were developed to explore the perspectives of patients, providers, and policymakers. Qualitative data was collected using key informant interviews. The open-ended interview questions were framed around the themes in the questionnaires, which included experiences (e.g. cancer awareness) and expectations (e.g. expectations (e.g. prevention).

### **3.5.4 Pilot Study Data Analysis**

Quantitative data were analyzed using descriptive statistics, and categorical data were analyzed using Chi-square. The main outcome variables were perspectives on the challenges to cancer prevention, training of clinicians, and ranking of cancer as a disease of public health importance.

Quantitative data analysis was conducted using SPSS V.25, while qualitative data were analyzed using NVivo V.11. For the qualitative component, the recorded interviews were transcribed verbatim, and the content was deductively coded into themes that were developed a priori to match the structure of the questionnaire. Data analysis intended to understand if the questions were clear, the duration of time it took to complete the surveys, general feedback on the research design, and some insight into the perspectives of local stakeholders regarding cancer control.

### 3.5.5 Pilot Study Results

As seen below, a total of twenty-eight individuals completed the surveys (each survey had the same content but were targeted for each specific group). Three patients, eleven healthcare providers and three policymakers participated in the interviews. All patients had been diagnosed with breast cancer. The demographics of the participants in the Pilot Study are summarized in Table 3- 1.

*Table 3- 1 Demographics of participants in the Pilot Study*

<b>Attribute</b>	<b>Patients n=3 (%)</b>	<b>Providers n=14 (%)</b>	<b>Policymakers n=11 (%)</b>
<b>Sex</b>			
Female	3 (100)	7 (50.0)	4 (36.4)
Male	0 (0)	7 (50.0)	7 (63.6)
<b>Age (Years)</b>			
Mean=48 ( $\pm$ 10)			
30-39	0 (0)	4 (28.6)	0 (0)
40-49	1 (33.3)	2 (14.3)	2 (18.2)
$\geq$ 50	2 (67.7)	8 (57.7)	9 (81.8)
<b>Profession</b>			
Physician		11 (78.6)	5 (45.5)
Nurse		3 (21.4)	6 (54.5)
Other	3 (100)	0 (0)	0 (0)



Seventy-three percent (16/22) of participants ranked cancer as a very important public health priority, with a median ranking of 9 (1QR: 7-10, on an 11-point scale). Belief systems (especially regarding witchcraft) and low political will were identified as barriers to cancer control. Most participants expected a new policy to focus on: creating awareness, integrating screening with other services, and improved access to treatment. Seventy-nine percent (22/28) agreed that patients, providers, and policymakers, should be involved in developing the policy. About 90% of providers (12/14) recommended the training of healthcare providers on cancer early detection and management, while 79% of all participants suggested that the State Assembly should pass legislation related to cancer control.

Themes from the qualitative analysis undertaken with all groups of participants (i.e. patients, providers, and policymakers) were grouped into experiences and expectations. Figure 3- 2 shows the concept map for the qualitative analysis.

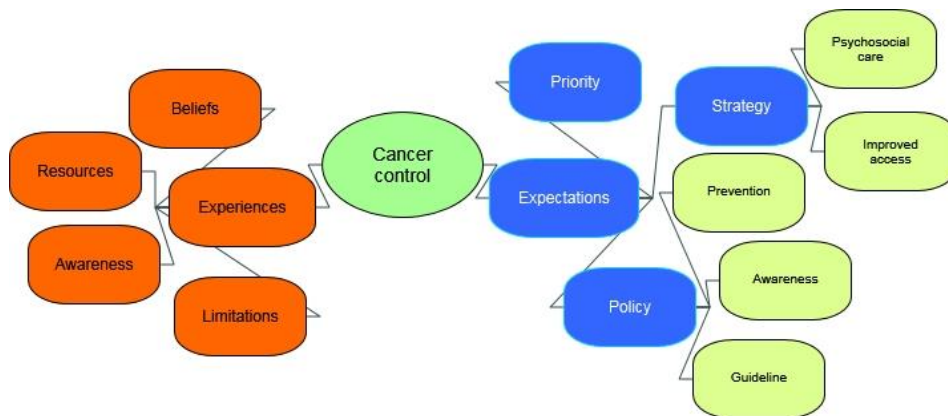


Figure 3- 2 Concept map from qualitative analysis

Some comments from the qualitative analysis: *“It’s a public health problem because it has caused a lot of mortality which affects families”* (**provider**); *“Patients should be involved in developing policy... since they know what they passed through during the sickness”* (**patient**).

Feedback from the Pilot Study was as follows:

- A. **The number of questions:** Most participants (75%, 21/28) thought there were too many questions on the survey, and that research could get the same feedback with fewer but focused questions. This survey instrument had 47 survey questions. There were no concerns regarding the number of Key Informant Interview questions.
- B. **Appreciation for time spent:** Although people were willing to participate in the research, many felt that they should be given some compensation/appreciation for the time invested. Some of the interviews lasted over 20 minutes. Patients diagnosed with cancer were interested in receiving compensation in the form of a treatment subsidy/drugs. Some providers suggested that telephone airtime (pre-paid cards) would be an acceptable appreciation.
- C. **Clarity of questions:** Concerns were raised regarding the clarity of questions. For instance, 'what is the sex of the individual answering this survey', was considered confusing. They suggested replacing the sentence with the single word 'sex'.
- D. **Data collection strategy:** Participants felt comfortable completing the survey and were interested in helping to recruit other potential participants. Working with local partners, such as the organizers of the CCPC course was viewed as a good approach to participant recruitment.

### 3.5.6 Pilot Study Discussion

The pilot study was conducted with a sample size (n=28) that was sufficient to provide useful insight into the proposed research, as this was more than 10% of the estimated sample size for the larger study (n=73). The pilot study demonstrated that mixed methods action research methodology was an appropriate design to effectively research cancer control policy in Abia State. It was observed that combining both quantitative and qualitative data provided good insight into the various perspectives regarding cancer control. The insights provided by the small sample of patients, providers, and policymakers highlighted the importance of the issue to the participants.

Working collaboratively, members of the Abia Cancer Control Group (ACCG) and the Researcher reviewed the data from the pilot study and considered its implications for the larger

study. The reflective feedback was used to revise the study instruments. The questionnaires and interview instruments were honed until the group leadership (n=5) were satisfied with the revisions. Data from the pilot study showed a strong interest from providers regarding education on cancer control. This prompted ACCG to explore avenues for improving the cancer-related competence of providers in Abia State. Details of the implementation of such innovative actions are described in Chapter 5. Research partners in Akwa Ibom State also used the data from the pilot study to inform local action regarding cancer advocacy, early detection, coordination of the care of cancer patients, and the training of healthcare providers locally. This illustrates the completion of one of the cycles of mixed methods action research, which included planning, acting, developing, and reflecting.<sup>34</sup>

### **3.6 Limitations of Mixed Methods Action Research Methodology**

Mixed methods action research methodology has some limitations. Time constraint is one of such limitations. The process of stakeholder and participants engagement, as well as relationship building, is time-consuming.<sup>33, 34</sup> The time involvement also includes the management of group dynamics, such as interpersonal tensions.<sup>33</sup> The methodology thrives on strong collaboration among different groups, such as the researchers, funders, participants, etc. This need for collaboration can be a limitation in terms of differences around role definition, research outcomes expectations, and the research process.<sup>33, 34</sup> The participatory process might lead to the creation of other research questions or interests, which might distract from the original question.<sup>34</sup>

### **3.7 Conclusions**

It became clear through the pilot study that the research questions were important to the different groups of community stakeholders, and that some revisions to the research instruments used for each of the groups were necessary. The pilot study provided evidence that the use of a mixed methods action research methodology would be appropriate to answer the research questions in Abia State. The results/findings have been used to initiate community-driven action that were aimed at improving cancer control locally. Chapter Four describes how the expanded MMAR study was conducted in Abia State, as well as its results/findings.

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**CHAPTER 4: MULTIPLE PERSPECTIVES ANALYSIS ON CANCER CONTROL POLICY IN ABIA STATE – NIGERIA: A MIXED-METHODS ACTION RESEARCH PROJECT (Manuscript 2)<sup>b</sup>**

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#### 4.1 Manuscript Information

Following the pilot study described in Chapter 3, the Researcher conducted research in Abia State to explore the perspectives of cancer patients, healthcare providers, and health policymakers regarding cancer control in the state. This chapter describes the process and results/findings from that study. The abstract from this manuscript was presented at the 2020 Annual Meeting of the American Society of Clinical Oncology (ASCO) on March 27, 2020, and was published in the Journal of Clinical Oncology.

The Researcher was the lead author of the article. The co-authors were the Supervisor, members of the Research Advisory Committee (RAC), as well as members of the Abia Cancer Control Group (ACCG). All members of the Research Advisory Committee reviewed draft versions of the manuscript and provided feedback for consideration and approved the final version.

#### 4.2 Abstract

**Background:** Despite the rising burden of cancers in Nigeria and beyond the National Cancer Control Plan, most States in the country do not have State cancer control policies. Using the multiple perspectives analysis framework, this research sought to explore the perspectives of patients diagnosed with cancer, healthcare providers and, health policymakers regarding cancer policy in Abia State. Its focus was to understand the utilization of early detection services and to identify potential components of a future state cancer control framework.

**Methods:** The project used a concurrent mixed methods action research (MMAR) design. The sample included individuals aged above 18 years who were diagnosed with cancer, provided cancer treatment, or made health policy in Abia State, Nigeria. Data were collected using

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<sup>b</sup> The full citation for the abstract from this chapter is: Eguzo K, Ekanem U, Oluoha C, Nnah K, Olatunbosun O, Muller A, Walker V, Mpofu C, Ramsden VR. Using multiple perspective analysis to propose state cancer control policy in Abia State, Nigeria. J Clin Oncol 2020 38:15\_suppl, e14132-e14132.

questionnaires and key informant interviews. Data analysis involved descriptive statistics, chi-square tests, non-parametric tests, and deductive thematic analysis. The study was approved by the Human Research Ethics Committee at Abia State Ministry of Health and the Behavioral Research Ethics Board at the University of Saskatchewan.

**Results:** Twenty-nine patients, 50 providers and 33 policymakers (n=112) participated in the research. Participants were mostly females (71.4%, 80/112) with an average age of 45 ( $\pm$ 11) years. Most participants (75.0%, 84/112) acknowledged the absence of early detection programs in Abia State. The interval between presentation and diagnosis was three months or longer. Common themes from the qualitative analysis showed low cancer awareness, delays in cancer treatment, the financial burden of cancer on patients, as well as priority areas for the cancer control framework. The top three areas of emphasis for a new cancer control policy were public awareness of cancer and early detection (83%, 93/112), State cancer legislation (80%, 86/112), and multiagency partnerships (79%, 88/112).

**Conclusion:** Cancer control was an important issue for all populations. There was poor access to and utilization of early detection services, where they existed. Future cancer control policy should emphasize cancer awareness, early detection, innovative funding, and the creation of local Cancer Management Pathways. A state-level, patient-centered cancer control framework is needed in Abia State, which builds upon the perspectives of local stakeholders. These perspectives could be useful in developing local cancer control programs.

### 4.3 Introduction

Nigeria is experiencing an increase in cancer incidence, prevalence, morbidity, and mortality.<sup>1</sup> As has been described in the preceding sections, this change in cancer statistics is attributed to several factors including a rise in cigarette smoking, alcohol abuse, physical inactivity, obesity, and changing dietary patterns.<sup>1-3</sup> The absence of state cancer control policies beyond the 2018 National Cancer Control Plan<sup>4</sup> has been reported. The adverse effects of the lack of organized cancer control on patient outcomes have also been documented.<sup>5,6</sup> Health policies made at the state level for maternal health and HIV/AIDS have often led to greater local ownership in Nigeria.<sup>7,8</sup> When policies are informed by best evidence, in consideration of the local context and with the



participation of all relevant stakeholders, including patients, there is a greater chance of successful implementation and sustainability.<sup>9,10</sup> Patient engagement is an important strategy in developing policies that reflect the insights, needs, and priorities of those most affected.<sup>11</sup> It is recommended that patients and communities should be included as collaborators in research that influences health policy.<sup>11, 12</sup>

This research sought to evaluate the cancer-related perspectives of local stakeholders (patients, healthcare providers, and policymakers) with emphasis on early detection, as a springboard for co-creating a community-driven cancer control initiative. It also sought to propose an organized, government-backed policy framework that would lead to an overall improvement in cancer control in Abia State, considering the scenario that was identified in Chapters 1 and 2. The research questions were as follows:

1. What are the perspectives (experiences and expectations) of cancer patients, health care providers (HCP), and health policymakers (HPM) in Abia State as it relates to the continuum of cancer control, especially on early detection?
2. In what ways can the perspectives explored be used to inform the development of a patient-centered, cancer control framework for Abia State?

## **4.4 Methods**

### **4.4.1 Study Design**

This concurrent mixed methods action research (MMAR) design used a multiple perspectives analysis approach by collecting quantitative and qualitative data simultaneously.<sup>13,14</sup> MMAR involves collaboratively conducting research with those affected by the issue being studied and often leads to informed action which generates knowledge and thus enables problem-solving through the authentic engagement of stakeholders.<sup>15,16</sup> The rationale for choosing a mixed-methods design has been described in Section 3.1. This methodology has been successfully used for studying cancer care disparities in other parts of the world, characterized by health inequity and poorer cancer-related outcomes (similar to Abia State).<sup>17-19</sup>

#### **4.4.2 Study Setting and Sampling**

#### **4.4.3 Study Population**

As described in Section 3.2, the participants were comprised of patients, healthcare providers, and health policymakers from Abia State in Nigeria. Abia State is in southeastern Nigeria (5°25'0.01" N 7°30'0.00" E), with an estimated population of four million spread across 17 Local Government Areas (LGAs).<sup>20</sup> Patients eligible for this project were individuals aged 18 years of age or older, who had been diagnosed with breast or cervical cancer within the preceding five years from 2018. Eligible health care providers were physicians and nurses providing direct healthcare to patients diagnosed with cancer. Eligible policymakers were Directors of Health and Traditional Rulers from all the 17 Local Government Areas, as well as people working with various Government Ministries, Departments, and Agencies whose services and/or policies had an impact on health. Members of Abia Cancer Control Group (ACCG), comprised of representatives from the study population, were involved in drafting/reviewing the research proposal, developing/reviewing the adapted research instruments, and facilitating knowledge translation.

#### **4.4.4 Sample Size**

Previous studies have shown that the between 75% and 92% of women in Nigeria have not accessed cervical cancer screening.<sup>21,22</sup> For the quantitative component of this project, a minimum sample size of 73 participants was required to understand lived experiences regarding uptake of cancer screening at a 95% confidence level and a 10% margin of error, with the assumption that 75% of the participants would report no access to cancer screening. For the qualitative component, previous research<sup>23,24</sup> recommended a minimum sample size of 12 interviews (i.e. four participants from each of the three groups) to reach data saturation, the point at which new data no longer contributed new findings due to the repetition of themes and comments by participants.

#### **4.4.5 Data Collection**

Quantitative data was collected using questionnaires adapted from those reported in the literature,<sup>25,26</sup> as there had been no similar study conducted in Africa before this research. The questionnaires were tested for validation in a pilot study in Akwa Ibom State, Nigeria (see Section 3.4) and were organized into three themes: experience of cancer prevention and early detection, challenges regarding cancer control, and expectations on cancer control policy. Three separate but similar questionnaires were developed for the patients, providers, and policymakers to explore their

perspectives. Qualitative data was collected using key informant interviews. The open-ended interview questions were structured to align with the themes of the questionnaires. See Appendices F, G, and H.

The study was advertised through relevant institutions (e.g. hospitals and government ministries). A purposive sample of interested individuals completed an online/paper questionnaire, using the information provided on the advertisements. Consecutive consenting individuals were enrolled in the study until no new participants expressed interest in each of the three groups. After completing the self-administered questionnaire, and before data analysis, some interested participants volunteered to provide more data through in-depth key informant interviews. The interviews were discontinued after data saturation was reached, the point at which new data appears not to contribute new findings due to the repetition of themes and comments by participants. Pre-paid telephone cards were provided to participants who completed the interviews as appreciation for their time.

#### **4.4.6 Ethical Consideration**

Prior to commencing this research, a Certificate of Approval was obtained from the University of Saskatchewan's Behavioral Research Ethics Board (BEH 16-44) and Abia State Human Research Ethics Board (April 19, 2018). Although study participants were not anonymous due to the nature of the interviews, their data was kept confidential using alternate identifiers. Details of the ethical considerations for this project were provided in Section 3.3.

#### **4.4.7 Data Analysis**

Descriptive statistics were used to summarize frequencies, as well as to show the similarities and differences among the three groups of participants. T-tests, Chi-square tests, and non-parametric tests were used to analyze relevant data types. For the qualitative component, the recorded interviews were transcribed verbatim. Coding of interview text was done using a codebook that was developed to mirror the themes of the questionnaires. Related codes were further categorized into themes using a deductive analysis approach. The qualitative themes were predetermined using the structure of the survey, which were broadly categorized into Experiences and Expectations. The experiences were sub-categorized into challenges regarding cancer prevention, awareness of early detection, delays in cancer services, and cost of services. The expectations were sub-

categorized into priority rating for cancer control, funding structure, and a framework for a future cancer control policy. Data analysis occurred concurrently, such that data collected through one arm (quantitative) was not completely analyzed and published prior to analyzing the other (qualitative) arm. Coding and data analysis were done by the lead author alone (as this was part of a doctoral thesis), while other authors reviewed the results. This level of analysis (descriptive statistics with thematic analysis) was appropriate to answer the research questions and to achieve the goal of this study, that is, to propose an evidence-informed cancer control policy.<sup>27</sup> Member-checking was employed to increase the level of scientific rigor. This was achieved by sharing the de-identified data analysis with some of the study participants and members of the ACCG to ensure accuracy.

**4.5 Results/Findings**

**4.5.1 Quantitative Data**

A total of 112 individuals (29 patients, 50 providers, and 33 policymakers) participated in the research project. The participants were mostly females (71.4%, 80/112) with an average age of 45 (±11) years, and the healthcare providers saw an average of 41 patients per week. Most of the patients (55%, 16/29) earned less than 36,000 Naira (equivalent to USD 100) monthly and had breast cancer (69%, 20/29). The demographics of the participants are outlined in Table 4- 1 Demographic characteristics of survey participants.

*Table 4- 1 Demographic characteristics of survey participants*

<b>Attribute</b>	<b>All N=112 (%)</b>	<b>Patients, n=29 (%)</b>	<b>Providers, n=50 (%)</b>	<b>Policymakers, n=33 (%)</b>
Proportion of total		25.9%	55.4%	29.5%
Average age (SD)	44.9 (11.4)	49.4	43	44
Average no. of years in service or practice (SD)			14.5 (2.1)	7.9 (7.9)
<b>Sex</b>				
Female	80 (71.4)	29 (100)	34 (68.0)	18 (54.5)
Male	32 (28.6)		16 (28.0)	15 (45.5)
Profession or Designation			Doctors=16 Nurses=31 Others=3	Commissioner=2 Director= 11 Traditional Ruler=1 Others=19
<b>Location of practice or treatment</b>				

Public Hospital		8 (27.6)	23 (46.0)	
Missionary Hospital		14 (48.3)	13 (26.0)	
Private Hospital		7 (24.1)	14 (28.0)	
Previous training on cancer management or policy			Yes: 30 (60) No: 20 (40)	Yes: 13 (39.4) No: 20 (60.6)

#### 4.5.2 Cancer Prevention and Early Detection

Most participants (75.0%, 84/112) reported that cancer prevention and early detection services were not available locally. Where such services existed, they were provided through churches (7.1%, 8/112), non-governmental organizations (6.3%, 7/112), and community groups such as women's organizations (6.3%, 7/112). Participants indicated that 5.3% (6/112) of all prevention services were provided by healthcare institutions. Providers and policymakers (n=83) were asked to share further insights regarding challenges with providing cancer services in Abia State. Issues identified as challenges by at least 60% of participants from both groups (i.e.  $n \geq 50$ ) were: lack of funds for early detection (62.6%); limited availability of treatment options (62.6%); low public awareness (75.9%); absence of support groups for patients (88.0%); lack of treatment guidelines/pathways (92.8%); and lack of local data regarding cancers (95.2%). More policymakers than providers considered the lack of local data to be a challenge (63.6% vs 38.0%,  $p=0.03$ ).

Only 20.5% of participants (15/73) agreed that the time interval between the first presentation to a health facility and definitive diagnosis (i.e. diagnostic interval) was within one month, while 79.5% thought that the interval was longer than one month (patients – 90.9%; providers – 65.2%; policymakers – 56.6%). Perspectives varied regarding the causes of the delay, although lack of funds was the most common (Table 4-2). Fewer patients (7%) than providers (68%) or policymakers (76%) attributed the diagnostic delays to distance from treatment facilities.

Table 4- 2 Pattern of diagnostic delay

Attribute	All N=112 (%)	Patients n=29 (%)	Providers n=50 (%)	Policymakers n=33 (%)
<b>Diagnostic interval</b>				
<1 month	10 (8.9)	1 (3.4)	8 (16.0)	1 (3)
1 – 3 months	22 (19.6)	10 (34.5)	7 (14.0)	5 (15.1)
>3 months	38 (33.9)	13 (44.9)	16 (32.0)	9 (27.3)

Not sure	42 (37.5)	5 (17.2)	19 (38.0)	18 (54.6)
<b>Causes of the diagnostic delays</b>				
Lack of funds	82 (96.5)	10 (34.5)	43 (82.7)	29 (87.9)
Diagnostic tests	57 (95.0)	9 (31.0)	27 (51.9)	21 (63.6)
Patients seeking other solutions	73 (96.1)	10 (34.5)	39 (78.0)	25 (75.6)
Distance to a treatment facility	61 (95.3)	2 (6.9)	34 (68.0)	25 (75.6)
Non-functioning hospitals	60 (95.2)	5 (17.2)	31 (62.0)	24 (72.7)

### 4.5.3 Cost of Cancer Treatment and Perspectives on Future Funding

Typically, a breast cancer patient who requires all three treatment modalities (six cycles of chemotherapy, radical surgery, curative radiation) would spend about N652,000 (USD 1,449) - N231,000 (USD 513) on chemotherapy, N164,000 (USD 365) on radiation therapy, and N257,000 (USD 572) on surgery. Out-of-pocket expenses accounted for most of the costs for cancer treatment (66%-94%), and only policymakers (24.2%, 8/33) thought that health insurance contributed to payment for cancer treatment. Perspectives on the average contributions from different sources of funding for cancer treatment are shown in Figure 4- 1.

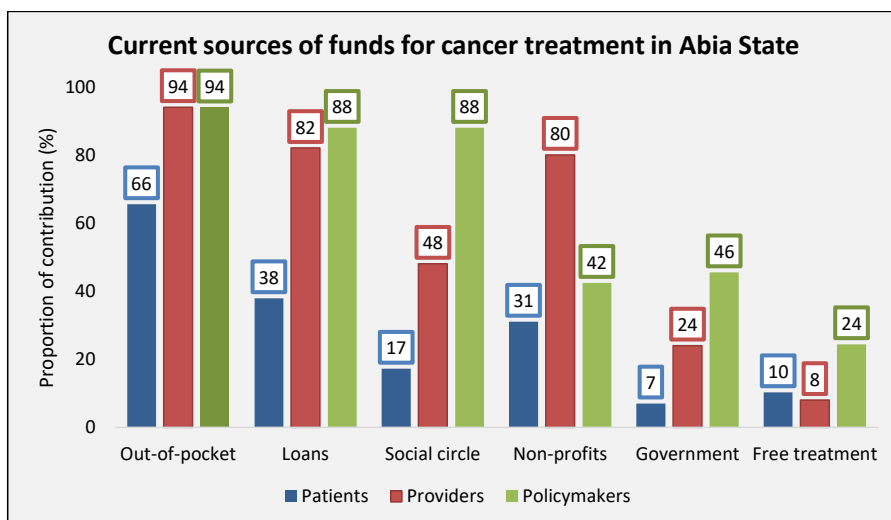


Figure 4- 1 Perspectives on contributions of different sources of funds for cancer treatment

Participants recommend the following as median proportion of contributions by potential funding sources, including government (50%, IQR 28-80%), health insurance (50%, IQR 28-

80%), patients (40% IQR 20-100%), and ‘other sources’ (10% IQR 1-20%). A Likert scale that ranked likelihood to contribute to health insurance showed that the typical participant was moderately willing (6 out of 10) to contribute N5, 000 (i.e. USD 13.9) to health insurance every quarter. Policymakers were most likely (7 out of 10, Average = N6,600), while patients were least likely (5 out of 10, Average = N1,700) to make quarterly contributions. Most policymakers thought that patients should bear at least 80% of the cost of cancer services, while patients preferred to contribute about 10% of the cost. The differences in perspectives on what proportion of cost should be borne by each stakeholder (e.g. patients and health insurance) regarding funding cancer control are shown in Figure 4- 2.

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**Framework for Future Cancer Control Policy**

Overall, misinformation or incorrect beliefs about cancer (aggregated 55%; patients 26.2%, providers 50.8%, policymakers 23.0%), lack of local data (aggregated 61%; patients 17.6%, providers 52.9%, policymakers 29.4%), lack of funds to finance a policy (aggregated 63%; patients 25.4%, providers 52.1%, policymakers 22.5%), and the government’s unwillingness to make cancer a public health priority (aggregated 64%; patients 20.8%, providers 56.9%, policymakers 22.2%) were identified as common reasons for the lack of a Cancer Control Policy in Abia State. All the participants agreed that Abia State needed a Cancer Control Policy, with each group of participants rating cancer 9 out of 10 as a public health priority.

The top three areas of emphasis for the proposed Abia State Cancer Control Policy were cancer prevention/early detection (83%, 93/112), (Abia State or The State-national) State cancer legislation (80%, 86/112) and multiagency partnerships (79%, 88/112). The distribution of the perspectives of different groups regarding focus areas for the proposed Cancer Control Policy are shown in Table 4- 3.

*Table 4- 3 Distribution of participants' perspective regarding focus areas for future cancer control policy.*

<b>Attribute</b>	<b>All N=112 (%)</b>	<b>Patients n=29 (%)</b>	<b>Providers n=50 (%)</b>	<b>Policymakers n=33 (%)</b>
Focus on local cancer data/research	83 (74.1)	18 (62.1)	35 (70.0)	30 (90.9)

Create local cancer fund	83 (74.1)	19 (65.5)	38 (76.0)	26 (78.8)
Build cancer center	84 (75.0)	17 (58.6)	36 (72.0)	31 (93.9)
Build capacity of providers	86 (76.8)	16 (55.2)	39 (78.0)	31 (93.9)
Create multi-agency partnerships	88 (78.6)	19 (65.5)	38 (76.0)	31 (93.9)
Pass Abia Cancer legislation	89 (79.5)	21 (72.4)	39 (78.0)	29 (87.8)
Emphasize prevention	93 (83.0)	19 (65.5)	43 (86.0)	31 (93.9)

#### 4.5.4 Qualitative Data

A total of 24 individuals (patients=9, providers=6, and policymakers=9) participated in the key informant interviews. Most of the patients (33.3%, 3/9) had been diagnosed with breast cancer. The demographic characteristics of the interview participants were as outlined in Table 4- 4.

Table 4- 4 Demographic characteristics of interview participants.

Attribute	All N=24 (%)	Patients n=9 (%)	Providers n=6 (%)	Policymakers n=9 (%)
Proportion of total		36.0%	24.0%	36.0%
<b>Age group (years)</b>				
30-40	3 (12.5)	1 (11.1)	1 (16.7)	1 (11.2)
40-50	14 (58.3)	8 (88.9)	2 (33.3)	4 (44.4)
50-60	4 (16.7)		2 (33.3)	2 (22.2)
>60	3 (12.5)		1 (16.7)	2 (22.2)
<b>Sex</b>				
Female	16 (66.7)	9 (100)	4 (66.7)	3 (33.3)
Male	8 (33.3)		2 (33.3)	6 (66.7)
Profession or Designation			Doctors=2 Nurses=4	Commissioner=2 Director= 2 Traditional Ruler=1 Others=4

As described on Page 48, the themes were broadly categorized into Experiences and Expectations, and the Sub-themes were categorized as follows:

##### Experiences

- Low awareness of prevention
- Delays in cancer treatment
- Challenges in providing cancer control services
- The high financial burden of cancer treatment

##### Expectations



- Funding structure
- Prioritizing cancer control
- Framework for Abia Cancer Control Policy
  - a. Guidelines and pathways
  - b. Leadership
  - c. Stakeholder roles
  - d. Focus on cancer prevention

For each theme, representative verbatim quotes were used to share the perspectives of participants. The interviews continued until saturation was reached. For instance, after interviewing eight (8) patients, the data collected from the ninth patient did not yield any new information. This confirmed that there was no need to interview additional patients, and hence, saturation was achieved. A concept map showing the relationship between the themes is shown in Figure 4- 3.

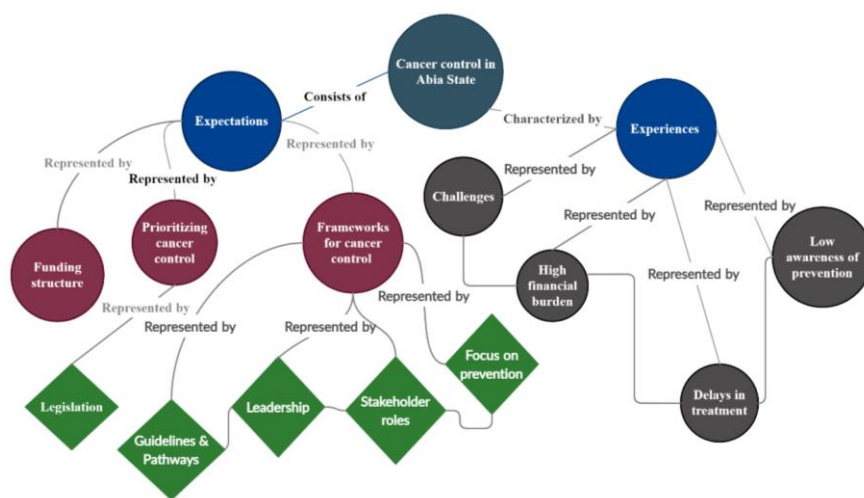


Figure 4- 3 Distribution of participants' perspective regarding focus areas for future cancer control policy.

**Main Theme: Experiences**

This broad theme describes the current scenario of cancer control in Abia State.

**Sub-theme: Low awareness of preventive services**

The following quotes are regarding the availability of early detection services, and awareness about them.

*"I heard about screening previously. But I did not know that this thing will happen to me..."* **Patient**

*"This is largely influenced by their religious beliefs. They will say let me go to the church; my pastor will 'preach me out of it'... They should also be made to know that early treatment is the best way to go after detection."* **Provider**

*"...But they may not know if it is cancer, because not everyone knows about cancer."* **Policymaker**

**Sub-theme: Delays in cancer treatment**

Participants shared experiences that characterized delays related to cancer treatment in Abia State.

Some of those delays are captured by these quotes:

*"The hospital hid the diagnosis. They did not tell us what the diagnosis was... Six months later, the problem started."* **Patient**

*"Some of our clinicians do not understand the need for timely action regarding cancers. And would delay patients unnecessarily."* **Policymaker**

**Sub-theme: Other challenges in providing cancer control services**

*"Also, the secretive aspect of our culture. Again, fear. Some of them say 'instead of going there and they discover something that will cost me my sleep, let me keep quiet'."* **Provider**

*"People often prefer to seek spiritual and traditional help first."* **Policymaker**

**Sub-theme: High financial burden of cancer treatment**

The issue of financial cost featured prominently among participants, as shown in these quotes:

*"My disease developed to that extent because there was no money to take me to the hospital for test."* **Patient**

*"The greatest challenge is that patients do not have the funds to complete their treatment."* **Provider**

### **Main theme: Expectations**

Participants shared perspectives regarding a future cancer control policy. The following quotes describe this theme and its sub-themes.

#### **Sub-theme: Funding structure**

The following quotes illustrate participants' perspectives on how to fund a future cancer control policy.

*"If you tell them the importance of health insurance, some people will buy the idea. That way we can reduce the costs ..."* **Patient**

*"...But let it just be a free-will donation. Like special Sunday offering in church."* **Patient**

*"We have community 'meetings' where people make periodic contributions in order to save money. The cancer control policy might be able to leverage such contributory mechanisms to raise money to finance the plan."* **Policymaker**

#### **Sub-theme: Prioritizing Cancer Control**

Participants reported their desire to have a State which prioritizes cancer control backed by legislation and local data.

*"...And if it is passed into law, the state will have a reason to fund cancer control. That way it is more likely for the cancer control policy to be successfully implemented."* **Policymaker**

*"Abia should have a law setting up the cancer control program. This law will help people know that the government backs the project on cancer screening."* **Policymaker**

*"One thing I'd like to include in the policy is to make cancer a reportable disease in the State."* **Policymaker**

#### **Sub-theme: Framework of cancer control policy**

Participants shared insights regarding the framework for a potential State cancer control policy. The comments were summarized using the nodes (headings) below.

#### **Guidelines/pathway:**

*"It will also create opportunity for early 2-way referrals."* **Provider**

*"Many communities do not know about the services available in the local medical facilities."* **Policymaker**

## **Leadership**

*“It will be better for the government to organize it. Because coming together with the private will bring in discrimination that might lead to delay of treatment and lives will be at stake” **Patient***

*“In order to ensure sustainability, this plan should be led by the non-governmental organizations, with government as partners. This will help us move faster and farther” **Policymaker***

## **Stakeholder roles**

Comments coded as ‘Stakeholder roles’ describe the potential contributions from each stakeholder.

*“They [providers] should assist the government in educating the general public ...”  
**Patient***

*“By involving Cancer survivors will make people believe that cancer is real.” **Patient***

*“Church leaders; they are really believed in this country.” **Provider***

*“Ndi-Eze have the powers to control those things in different ways. We can use our vigilante groups to enforce laws.” **Policymaker***

## Focus on Prevention

*“The plan should start with education, to enlighten people about it.” Patient*

*“I think the policy should focus more on prevention, including immunization against HPV and cigarette smoking.” Policymaker*

## 4.6 Discussion

This research sought to explore the perspectives of patients diagnosed with cancer, healthcare providers, and health policymakers regarding a Cancer Control Policy in Abia State. In this study, more patients (93%) and policymakers (81%) than providers (64%) reported the lack of early detection programs as a challenge in providing cancer control services in the State. The differences in perception of the utilization of early detection services among the groups of participants could mean that although such services were available in the State, they were not promoted adequately within the community. The proportion of patients who did not access cancer screening before their diagnosis in Abia State was comparable to the 75-92% that was reported in previous Nigerian studies.<sup>21,22,28,29</sup> In places where advocacy or early detection services were available, these were largely provided through churches (7.1%) and community organizations (6.3%). This scenario underscores the need to include these stakeholders (churches and community organizations) in the development and implementation of an Abia Cancer Control Framework. The role of the churches in cancer advocacy within Abia State has also been documented.<sup>30</sup>

Unfortunately, cancer treatment in Abia State was characterized by significant delays. At least 34% of patients had to wait longer than three months between their initial presentation and definitive diagnosis (i.e. diagnostic interval). The fact that up to 38% of research participants were ‘not sure’ about the diagnostic interval underscores the need for an organized cancer data system in Abia State. Lack of funds and patients seeking other solutions (e.g. spiritual) were among the most common reasons for the delay. This might be the reason why 83% of participants (93/112) suggested that the proposed cancer control policy should emphasize advocacy and early detection.

The story from a patient highlights the reality of the challenge of awareness:

*“First, I consulted one of my sisters who runs a chemist shop. She was treating me but there was no improvement. Then I asked other people, they said it was a disease that can be cured only through traditional medicine.”*

Funding for cancer control was addressed by the 2018 National Cancer Control Plan (NCCP), with suggestions that the government should pay up to 75% of the cost.<sup>4</sup> However, this study showed that out-of-pocket expenses by the patients contributed to 60-94% of the funding for cancer treatment, although patients would like to pay no more than 10% of the costs. Considering that 55% of the patients sampled made N36, 000 (about USD 100) or less monthly, it would take at least 18 months' income for such patients to complete all three cancer treatment modalities, namely chemotherapy, surgery, and radiotherapy. Policymakers would like the government's share of the cost to be about 24%, and not the 75% in the 2018 NCCP.<sup>4</sup> A major task for a future cancer control framework should be to explore different methods of funding cancer control activities in the State. This paper is the first to report on the cancer-related financial burden in a Nigerian state from multiple perspectives. Previous research focused on a single facility.<sup>31</sup> This research could help provide a better context for the roles of health insurance and other funding sources, beyond what was suggested in the 2018 NCCP.<sup>4</sup> Organized crowdfunding was also suggested as a way of funding cancer control in the State, and 74% of participants (83/112) agree on the need to establish an Abia Cancer Fund. Such will be a novelty in Nigeria, where a statewide fund is designated for cancer control. At least 79% of participants would like the State House of Assembly to pass a law regarding cancer control.

*“Abia should have a law setting up the Cancer Control Program. This law will help people know that the government backs the project on cancer screening. Consider immunization, people feel free to come for immunization because they know that the law requires it.”* **Policymaker**

This research was innovative in many ways. Its use of the MMAR design provided a unique structure from which to collect rich data from various perspectives (patients, health care providers and policymakers) as previous research on cancer control in Nigeria had been largely quantitative. Also, to our knowledge, this was the first empirical study that explored the context for feasible cancer control in a Nigerian state before the development of a local policy framework. Although many researchers have highlighted the importance of organized cancer control in developing countries, none of them have studied the local context through which such a system could be deployed in Nigeria.<sup>5, 32-34</sup> Similarly, by seeking the perspectives of local stakeholders who were directly impacted by cancers (i.e. patients, providers, and policymakers) this study created a strong example of a bottom-top-approach in public policy development. Policies that were developed

with strong input from the frontline (i.e. bottom-top approach) have been reported to have stronger potential for sustainable implementation, even though this approach is not commonly applied in Nigeria.<sup>10</sup> Also, this project underscored the need for greater engagement of policymakers by providers, especially considering the divergent views regarding the reality of cancer prevention in Abia State. This need has also been reported in the literature.<sup>35,36</sup>

Meanwhile, this project has limitations due to its design, which was context-specific. The use of community engaged mixed methods action research makes it difficult to translate the findings beyond the setting of Abia State (i.e. areas with cancer disparities and having poorly organized cancer control systems) but the approach could be used elsewhere. However, the study met the elements of rigor required for mixed methods studies, including transferability, confirmability, credibility, etc. Although this paper focused on the experience of patients diagnosed with cancer, it did not consider other objective outcomes such as quality of life or patient satisfaction. Those are important metrics that could be used to monitor the quality of cancer services that are delivered in and by the State.

#### **4.7 Conclusion**

Cancer control is an important issue for the people of Abia State. Most patients, providers, and policymakers confirmed poor access and utilization of early detection services as obstacles. Treatment services are inadequate with a background of more than a three-month diagnostic delay. Future cancer control policies should emphasize cancer awareness, early detection, and the creation of a local Cancer Management Pathway. Such a policy should harness the influence of churches and community organizations as such institutions are presently leading efforts to improve cancer control locally. A state-level, patient-centered Cancer Control Framework is needed in Abia State, one that builds upon the perspectives of local stakeholders.<sup>37</sup> Future research might evaluate the implementation of community-driven cancer control initiatives in a resource-limited setting.

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## CHAPTER 5: KNOWLEDGE-TO-ACTION: USING THE INTEGRATED KNOWLEDGE TRANSLATION APPROACH FOR COMMUNITY-DRIVEN CANCER CONTROL INITIATIVES IN ABIA STATE (BRIDGING CHAPTER)

Commented [RV3]: Chapter 5.

### 5.1 Introduction

Improving disparities in cancer control, including inadequate access to early detection, suboptimal approaches to treatment, or limited competence of healthcare providers requires the collaborative use of government-led and community-driven interventions.<sup>1</sup> Engaging community stakeholders such as community-based organizations (CBOs), healthcare providers, community leaders, or policymakers in developing and implementing interventions aimed at improving cancer control are successful in different parts of the world.<sup>1,2</sup> Community-based organizations with interests in developing policies and initiatives to reduce cancer burden and improve cancer control are crucial for identifying community needs, creating interventions, evaluating outcomes, and advocating for more government involvement.<sup>1,3</sup> The dearth of government-driven efforts to improve cancer control in Abia State and other parts of Nigeria has been documented,<sup>4</sup> and there is limited evidence on the use of integrated knowledge translation approach to promote community-driven efforts on cancer control.

Having worked closely with community partners (i.e. Abia Cancer Control Group) in the design and implementation of this research, it became important to apply the findings from this study to improve detection and treatment locally. This chapter addresses the research objective: “*to propose a framework for improving cancer control in Abia State, especially related to prevention and early diagnosis*” It describes how integrated knowledge translation strategies were applied throughout this research and demonstrates the impact of such strategies. This chapter might be useful for other researchers who might be seeking guidance on how to bridge the knowledge to action gaps when working with multiple stakeholders.

### 5.2 Overview of Integrated knowledge translation (iKT)

According to the Canadian Institutes of Health Research (CIHR), knowledge translation (KT) is “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health

services and products and strengthen the health care system.”<sup>5</sup> Integrated knowledge translation (iKT) is an approach to research whereby academics collaborate with knowledge users from study conception (e.g. research design) through interpreting results to applying the findings in the users’ context and disseminating the findings.<sup>6,7</sup> Typically, knowledge users include individuals or organizations that can apply research findings toward their practice or to inform policy decisions. They have the familiarity of the local context which is critical in adapting research evidence to the local setting. Effective KT needs the strong involvement of knowledge users throughout the research process, including research design, data collection, knowledge creation, implementation of findings, dissemination of results, as well as outcome evaluation.<sup>7</sup> This approach has been recognized to increase the relevance, applicability, and impact of research results, as it reduced the gap between research and its application in real life (i.e. ‘know-do’ gap).<sup>8</sup>

Although no previous study has used the iKT approach in cancer control in Nigeria, it was thought that the approach would be useful in addressing the low political will that had been identified as a major limitation toward improving cancer control in the country.<sup>4</sup> This approach will also bridge the research-to-policy gap that has resulted in the limited use of evidence-informed-policies in Nigeria.<sup>9</sup>

In developing effective knowledge translation<sup>5</sup>, academics need to consider the following aspects:

- The goal of KT: what is the target for knowledge translation? For instance, the goal might be to inform/change practices
- The audience of KT: to whom should the knowledge be translated? The sample audience would be policymakers, legislators, or clinicians.
- Strategies for KT, speak to the mix of approaches that will be used for knowledge diffusion (e.g. conference presentations), dissemination (e.g. briefing notes), and application (e.g. create interventions).
- Team expertise for KT ensures that effective KT would require a diverse group of experts such as researchers, community leaders, and web developers.
- Resources for KT, including financial costs for workshops or interventions.

The next section provides a detailed description regarding the use of iKT related to this study as well as their impact.

### 5.3 Approach to Integrated Knowledge Translation

In this study, the Researcher collaborated with the Abia Cancer Control Group (ACCG) in formulating the research questions and designing the study. The strong engagement of a diverse group of stakeholders from the beginning, including policymakers, was thought to be critical for ensuring the use of the research results/findings. The stakeholders within the ACCG included the Nigerian Medical Association (Abia State Branch), National Association of Nigerian Nurses and Midwives (Abia State Chapter), Abia State Primary Health Care Development Agency, Health Development Initiative, Nigerian Christian Hospital, Initiative for Public Health Advancement and Research, as well as several higher education institutions in Abia State.

Throughout this study, the researcher used diverse methods to engage with ACCG in the process of knowledge translation. The goals of the sustained knowledge translation were to inform/change attitudes, practices, technology, and behaviors among the stakeholders and within the larger community. The audience of the knowledge translation were largely members of ACCG, which comprised clinicians, nongovernmental organizations, policymakers, and media practitioners. Some of the clinicians had also been cancer patients at different times, and so provided useful feedback from a patients' perspective. The iKT strategies used in the knowledge translation included the following.

- **Periodic virtual meetings**, especially using WhatsApp®: this social media platform was integral in sharing ideas and designing projects with the ACCG. The use of WhatsApp was affected by unpredictable internet connectivity.
- **Phone conversations**: the Researcher maintained robust phone contact with key members of the ACCG. This strategy helped to address some of the challenges of using WhatsApp. Phone conversations also facilitated in-depth discussions, often beyond the scope of group conversations on WhatsApp.
- **Briefing notes** were used to keep top policymakers abreast of the research, its findings, and potential implications. Considering that this research spanned two administrations in

Abia State, briefing notes were helpful to bring new policymakers (e.g. Commissioners of Health) up to speed regarding the study.

- **Workshops:** ACCG made presentations to groups of stakeholders (e.g. Association of General Private Nursing Practitioners and Pharmacists Society of Nigeria) regarding the research, its findings, and implications for practice locally. The workshops provided opportunities for more stakeholders to make inputs on the future direction of cancer control in Abia State.
- **In-person meetings:** the Researcher made frequent trips to Nigeria to hold in-person meetings with key stakeholders in ACCG and senior policymakers, including the Executive Governor of Abia State. Such meetings increased the buy-ins of stakeholders, especially to ensure the engagement of new government personnel.
- **Conference presentations:** The leadership of ACCG made several presentations about the ongoing efforts to improve cancer control in Abia State. Through the presentations at National and international cancer conferences, ACCG generated interest in its approach to community-driven cancer control. In recognition of the pivotal role of the Researcher on cancer control in Abia State, he was presented the Young Leader Award by the Union for International Cancer Control (2017).<sup>10</sup> The Researcher was also invited as a Keynote Speaker during the 2018 Uppsala Health Summit to share perspectives on cancer control in Nigeria.

The various knowledge translation strategies resulted in different interventions that were informed by the results from both the pilot study and the main study. These interventions focused on different aspects of the cancer control continuum that was described in Section 1.4 (i.e. Figure 1-1). The next section describes those interventions and their impact.

#### **5.4 Impact of Knowledge Translation on Cancer Control in Abia State**

After the completion of the pilot study, the Researcher reviewed its findings with ACCG to develop the final research instrument for the main study. Some of the findings from the pilot study, as described in Section 3.4.5, highlighted the need to raise public awareness about cancers and to train clinicians on cancer prevention, including early detection. Similarly, the findings from the main study (Section 4.11) revealed the need to emphasize cancer advocacy, provision of early

detection services, development of local treatment guidelines, education of clinicians, exploring of blended model for funding cancer control programs, as well as the use of multi-agency partnerships.

## **5.5 Cancer Prevention/Advocacy**

### **5.5.1 We Can, I Can Conquer Cervical Cancer**

ACCG used funding from the International Papillomavirus Society to promote cervical cancer awareness among community women and secondary schools in Abia State (2018). The Researcher facilitated the project design and its implementation. ACCG used a combination of essay competitions, radio shows, Facebook Live®, and in-person presentations to reach more than 4,300 individuals. The essay competition entries from secondary school students showed their interest in knowing more about cervical cancer.<sup>11</sup> This project also provided further insights into the breadth of interventions that could improve cancer prevention as it led to increased awareness about risk factors.

### **5.5.2 Cancer Control in My Community Project**

In the lead-up to the 2021 Breast Cancer Awareness Month, ACCG collaborated with partners to host the Cancer Control in My Community project. This featured essay competitions and art contests from secondary schools in Abia and Akwa Ibom States. Cancer awareness events were also hosted in churches and community events in both states. More than 65 essay entries were received from ten (10) schools in both states. This project had strong leadership of cancer survivors as they sought to reduce misinformation about cancers in the community and to combat stigma. Feedback from participants showed increasing interest in the public regarding cancer advocacy. Using funds raised within the communities, the project organizers awarded prizes to students and schools that participated in the project.

## **5.6 Cancer Early Detection**

Based on evidence that about 75% of cancer patients in Abia State did not access early detection services,<sup>12</sup> ACCG implemented several early detection programs.



### **5.6.1 Community-Driven Cancer Early Detection Initiatives**

Since the onset of knowledge translation from this project, ACCG had created programs that expanded access to early detection services in Abia State through collaboration with churches,<sup>13</sup> community organizations,<sup>11</sup> and health institutions in the State. Working with the Methodist Hospital (Uzuakoli), Nigerian Christian Hospital (Nlagu), Marjorie Bash College of Health Sciences and Technology (Aba), and several private hospitals, ACCG has initiated regular clinical screening for breast and cervical cancers in the state. The researcher worked with ACCG and the Nigerian Medical Association to develop a unified requisition form that is being used to report cancer screening.

Also, Project Screen 1,000<sup>11</sup> had provided cancer screening to more than 1,300 women who were clinically examined for breast and cervical cancers. This project used social media marketing, including Facebook adverts, while screening services were provided mostly by nurses. It provided access to people in 76% (13/17) of the Local Government Areas in Abia State. To date, this was the most robust cancer early detection project in the State, and it was ongoing at the time of this report.

### **5.7 Diagnosis and Treatment**

ACCG determined that it was important to introduce a cancer clinical pathway and patient navigation program to facilitate access to diagnosis and treatment. A patient navigation program (PNP) is a systematic approach to guiding patients through the complexities of health care systems and removing the barriers to access to health care services.<sup>14</sup> The use of clinical pathways to streamline the diagnosis and management of cancers based on resource-stratified clinical guidelines was one of the recommendations from local research in Abia State.<sup>12</sup> Since 2020, the Abia Clinical Pathway and Patient Navigation Project created pathways for breast and cervical cancers. The pathways were supported by a robust online electronic medical record that was developed by ACCG, with support from the Researcher.<sup>15</sup> They have helped navigate the 1,300 people who had undergone cancer early detection in the State.

## **5.8 Survivorship**

Providing ongoing support to people diagnosed with cancers was identified by ACCG as a priority service. This stemmed from the fact that many cancer management guidelines recognized survivorship as an important piece in the cancer control continuum. As part of the Clinical Pathway and Patient Navigation Project,<sup>15</sup> ACCG worked with the Researcher to develop a support group for cancer patients in Abia State. Led by nurses, the Abia Cancer Support Group provided customized Get-well-soon greeting cards to patients, alongside a cash token. Through their monthly meetings, the support group has helped to improve the experience of people who had recently completed cancer treatment or were undergoing treatment. Due to the COVID-19 pandemic, ACCG adopted a hybrid meeting format for the support group, using Google Meet®. This innovation enabled cancer survivors to access the services of volunteer patient counselors locally and internationally, while making it possible for patients who were admitted to different hospitals to join the meetings.

## **5.9 Cross-cutting Issues**

### **5.9.1 Funding**

Low funding was identified as one of the challenges for detection and treatment through this research. ACCG explored different sources to finance the initiatives that were described above. They secured funding from non-governmental sources to provide advocacy and the clinical pathway project.<sup>16</sup> Community members have also contributed funds to support early detection. Some of the funding for Project Screen 1000<sup>11</sup> were provided by people with Nigerian heritage (i.e. Nigeria Diaspora) living in the United States. With the donation of a cryotherapy machine by a Canadian physician, ACCG partnered with local hospitals to reduce the out-of-pocket cost of early treatment of precancerous lesions in the cervix using the screen-and-treat model.<sup>17</sup> Through this initiative, patients in Abia State paid only N1,500 (equivalent to USD 4) for the early detection (and possible treatment) of cervical cancer.

### **5.9.2 Online Cancer Reporting System**

The Abia cancer reporting system that was developed to support screening and patient navigation is a strong example of the impact of knowledge translation that strengthens local capacity. Working

with a local university and the Researcher, ACCG customized an open-source electronic medical record that was hosted online to facilitate reporting of suspected cancer cases that were identified during community early detection programs. This system sends email alerts to Patient Navigators to follow-up patients with suspicious screening results. It also helps Navigators to identify and reduce barriers that would impact patients' early diagnosis and treatment. The design of the system was based on evidence found in the literature that 53.5% of people in Abia State waited longer than one month between their initial presentation and final cancer diagnosis and that there was a need to develop a system for collecting data regarding cancers in Abia State.<sup>12</sup> Since this system was launched in late 2019, other states in Nigeria have expressed interest in adopting it.

### **5.9.3 Training of Healthcare Providers**

Based on the findings from the pilot study (Section 3.4.5) which highlighted the need to train clinicians, ACCG used the traditional, in-person model of continuing medical education to deploy the cancer control in primary care course with support from the American Society of Clinical Oncology.<sup>18</sup> This resulted in the training of 120 physicians and nurses from different parts of the state. Using an innovative blended learning approach, with technical guidance from the Researcher, ACCG has also trained more than 400 individuals, especially physicians, nurses, and students in healthcare professions on breast cancer management and the development of clinical pathways. A peer-reviewed publication on the feedback from participants in one of these educational interventions<sup>19</sup> confirmed the importance of locally driven continuing education on the sustainability of an organized, state-wide approach to cancer control. To promote ongoing learning, ACCG has provided periodic hospital-based training mostly at missionary hospitals with large numbers of cancer patients. These short courses have created a pool of clinicians that provide cancer-related services within the State.

### **5.10 Conclusion and Policy Implications**

These innovative activities that were developed based on evidence from the pilot and main studies, illustrate the 'reflecting' phase of the 'Planning-Acting-Observing-Reflecting cycle in mixed-methods action research methodology.<sup>20</sup> They have demonstrated the feasibility of improving cancer control in Abia State using different strategies, thus validating the perspectives of local stakeholders, as reported in Chapters 3 and 4. Through the initiatives, ACCG has harnessed the

influence of local institutions such as town unions and religious organizations in the effort to improve cancer control locally. Evidence shows that religious institutions have powerful influences in Nigeria<sup>21</sup>, but such influences were not harnessed in the 2018 National Cancer Control Plan.<sup>4</sup> Such community linkages would be important in the implementation and sustainability of future state cancer control framework. Also, funding of cancer control was one of the major challenges that were identified in Chapter 4. The innovative funding approach adopted by ACCG in these initiatives, including community donations and support from Nigerian citizens in the diaspora, provide insights on the feasibility of funding a future cancer control program using support from a variety of sources. Although the 2018 National Cancer Control Plan largely considered funding from patients and government sources, ACCG through its community-driven initiatives has demonstrated the feasibility of mobilizing funds from non-traditional sources, including the diaspora community.

Meanwhile, ACCG has increased the interest of the public and the clinical community regarding cancer control through these initiatives. This may have prepared the ground for the acceptability of a future cancer control policy framework in the state. The use of iKT in this project may lead to a more sustainable cancer control initiative in Abia State, as previous researchers in Nigeria who used the approach reported greater sustainability for a health insurance policy.<sup>9</sup> Thus, it became necessary to propose a policy framework upon which the Government of Abia State can build a future cancer control plan. The description of iKT in this chapter hopefully provided some insights to future researchers on how to use this approach to promote evidence-informed policy development, especially within resource-limited settings such as Abia State. The next chapter highlights the policy recommendations that were based on the findings from this research, reflections from implementing the community-driven initiatives, and context-relevant guidelines from international organizations.

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## **CHAPTER 6: CO-CREATING CANCER CONTROL POLICY IN ABIA STATE: A POLICY BRIEF (Manuscript 3)<sup>c</sup>**

### **6.1. Manuscript Information**

Based on the findings of the study and practical experience from the community-driven cancer control initiatives, a Policy Brief was developed to summarize the research findings and to propose a cancer control policy framework. The brief also considered current practices in the developing world, which emphasize breast health awareness (e.g. breast self-examination), periodic clinical breast examination as well as breast imaging (e.g. mammography and breast ultrasound). It is targeted at policymakers in Abia State.

The lead author on the Brief was the Researcher, the co-authors were the Supervisor, members of the Research Advisory Committee (RAC), as well as members of the Abia Cancer Control Group (ACCG). All members of the entire Research Advisory Committee reviewed draft versions of the Brief and provided feedback for consideration and approved the final version, which was developed using the IDRC Framework for policy briefs.<sup>1</sup>

### **6.2. Executive Summary**

The burden of cancer in Nigeria is rising but most states in the country do not have a State Cancer Control Plan, beyond the National Cancer Control Plan/Frameworks. This lack of a State-level Plan contributes to a scenario where most patients present at hospitals with advanced disease, which results in poorer outcomes and a greater financial burden.

Using the multiple perspectives analysis framework, this research sought to explore the perspectives of patients diagnosed with cancer, healthcare providers and health policymakers about how to co-create a State-level Cancer Control Policy Framework in Abia State. Data from 112 participants (29 cancer patients, 50 providers and 33 policymakers) demonstrated that there were local gaps in advocacy, early detection, timely access to treatment, use of clinical guidelines, as well as the financial aspects of management and treatment of cancers in the State. Practical

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experience from the Abia Cancer Control Group (ACCG) which developed several cancer control initiatives in the State based on the findings from this research demonstrated the feasibility for creating and sustaining cancer advocacy, early detection, patient navigation, and training of healthcare providers using a community-engagement approach.

It was recommended that Abia State Government should develop a State-level Cancer Control Policy Framework that would focus on public awareness about prevention, create early detection programs that were supported by patient navigation, and leverage multi-agency partnerships for sustainability. Such a policy would build on these evidence-informed initiatives which were developed with ACCG based on results/findings from this research.

### **6.3. Introduction**

Mitigating cancer refers to actions taken with the intent of reducing the burden of cancer in a community or nation which in this case are most commonly related to early detection and treatment. However, it can be broadened to involve implementing systematic, equitable, and evidence-informed policy about the continuum of cancer control (prevention, early detection, diagnosis, treatment, and palliation) using available resources.<sup>2,3</sup> All cancer control activities need to be based on the best scientific evidence while considering available resources and other competing public health priorities.<sup>4</sup> Cancer control is often supported by policy, also known as a Cancer Control Plan which outlines details of how activities would be implemented in a particular jurisdiction. These policies, like any other health policy, can be made at National or sub-national levels (e.g. States and Local Government Areas). The implementation of such a plan results in a cancer control program.

A cancer control program is a public health program designed to reduce the number of cases and deaths from cancer, and improve the quality of life for individuals/patients diagnosed with cancer.<sup>2</sup> When policies are informed by best evidence, grounded in the local context and with the participation of all relevant stakeholders, such policies have a stronger chance of being successfully implemented and sustained.<sup>5,6</sup> Taking into account the resource constraints faced by the country or state, a well-conceived and well-implemented cancer control program has the potential to reduce the burden from cancer and improves services for individuals/patients

diagnosed with cancer and their families.<sup>3</sup> This policy brief was created to provide a framework that would be used to develop a Cancer Control Policy in Abia State, Nigeria. It was built upon the results/findings of this research project which explored the perspectives of cancer patients, healthcare providers, and health policymakers regarding cancer control in the state.<sup>7</sup> The research was conducted by a team involving Nigerian and Canadian researchers. The recommendations are also grounded in the experiences of the Abia Cancer Control Group (ACCG) which created several small-scale initiatives to demonstrate the feasibility of implementing the research findings.<sup>8,9</sup>

#### **6.4. Approach and Results**

A total of 112 participants (29 patients, 50 providers, and 33 policymakers) participated in the research project. Data were collected using a combination of surveys and interviews. Most participants (75.0%, 84/112) reported that cancer prevention and early detection services were not locally available. Where such services existed, they were provided through churches (7.1%, 8/112), non-governmental organizations (6.3%, 7/112), community groups e.g. women's organizations; (6.3%, 7/112), and hospitals (5.3%, 6/112). Issues that were identified as challenges by at least 60% of participants were: lack of local data regarding cancers (95.2%, 79/83); lack of treatment pathways (92.8%, 77/83); absence of support groups for patients (88.0%, 73/83); low public awareness (75.9%, 63/83); and limited availability of treatment options (62.6%, 52/83).

Funding was a great concern. Typically, a breast cancer patient who required all three treatment modalities (six cycles of chemotherapy, radical surgery, curative radiation) would spend about N231,000 - N652,000 (\$513-1,449 USD) on chemotherapy, N164,000 (\$365 USD) on radiation therapy, and N257,000 (\$572 USD) on surgery. About 60 - 94% of all costs had to be paid 'out-of-pocket' by the patients. Figure 6- 1 shows the current situation of funding for cancer services, as perceived by different stakeholders. A Likert scale which ranked likelihood to contribute to

health insurance showed that the typical participant was moderately willing (6 out of 10) to contribute N5,000 (i.e. \$13.9 USD) to health insurance every quarter.

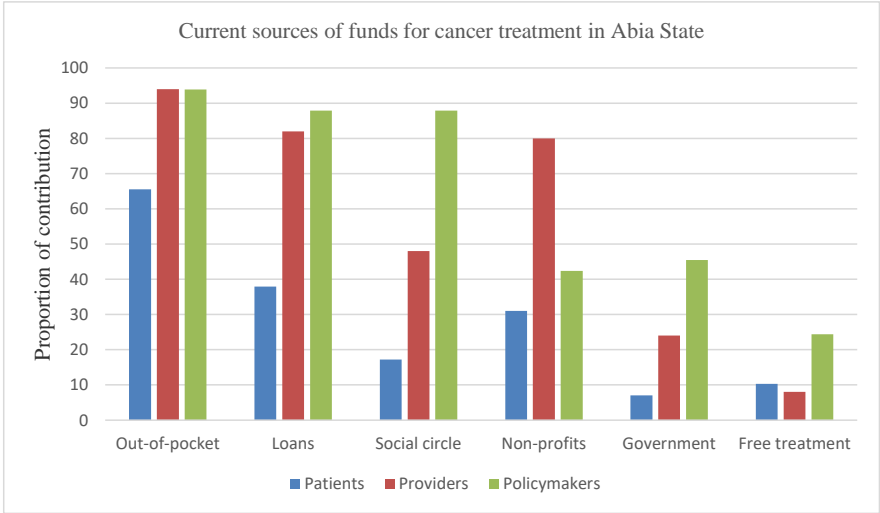


Figure 6- 1 Situation of funding for cancer treatment in Abia State

The participants were asked to rank their perspectives on how to improve cancer control in Abia State. Implementation of early detection programs was top priority to most (83.0%, 93/112) of the participants. Table 6-1 summarizes these perspectives by participant groups.

Table 6- 1 Perspectives of research participants on cancer control policy in Abia State

Attribute	All N=112 (%)	Patients, n=29 (%)	Providers, n=50 (%)	Policymakers, n=33 (%)
Emphasize prevention/early detection	93 (83.0)	19 (65.5)	43 (86.0)	31 (93.9)
Pass Abia Cancer legislation	89 (79.5)	21 (72.4)	39 (78.0)	29 (87.8)
Create multi-agency partnerships	88 (78.6)	19 (65.5)	38 (76.0)	31 (93.9)
Build capacity of providers	86 (76.8)	16 (55.2)	39 (78.0)	31 (93.9)
Build a Cancer Center	84 (75.0)	17 (58.6)	36 (72.0)	31 (93.9)
Focus on local cancer data/research	83 (74.1)	18 (62.1)	35 (70.0)	30 (90.9)
Create a Local Cancer Fund	83 (74.1)	19 (65.5)	38 (76.0)	26 (78.8)

## **6.5. Summary**

The research showed that there was a strong need for an organized cancer control plan in Abia State. Many people who were diagnosed with cancer started treatment very late and were often limited by funding. The absence of local cancer control guidelines in Abia State affected the ability of healthcare providers to provide early detection, timely diagnosis, and appropriate treatment. All the participants agreed on the importance of having a Cancer Control Policy (CCP) in the State, and 83% of them suggested that the Policy should emphasize cancer prevention and early detection.

## **6.6. Policy Implications and Recommendations**

The results/findings from this study identified that there was a need to develop and implement a CCP in Abia State. It would help to improve patient outcomes and make the local health system more efficient and effective. Such a policy would be effective if it addressed all the domains of cancer control e.g., prevention, early detection, etc.

The following recommendations have been proposed as a framework that would guide the development of Abia State Cancer Control Policy. They were based on the data from this research,<sup>6</sup> contextual experience from ACCG,<sup>8,9</sup> as well as best practices from a review of resource-stratified global guidelines on cancer control planning.<sup>10-12</sup>

### **6.6.1 Prevention**

- Increased physical activity and obesity reduction through monthly voluntary jogging (just like monthly environmental sanitation). Use of the media (e.g. Facebook and Radio) to promote physical activity would help. This could reduce one of the risk factors for breast and other cancers.
- Encourage HPV vaccination using at least one dose for children above nine years following National Guidelines. Vaccination would greatly reduce the chances that a woman would have cervical cancer. It would also reduce the cases of other HPV-linked head and neck cancers.
- Encourage immunization against Hepatitis B virus (HBV) following National Guidelines. Hepatitis B virus causes liver cancers, which can be prevented through immunization.

- Ban smoking indoors and in public spaces, including restaurants. Cigarette smoking has been linked to many cancers. The government would save lives and money through this ban. It would also be necessary to ban the advertisement of cigarettes in Abia State with fines levied on broadcasters and to empower traditional rulers to encourage compliance with regulations on cigarette smoking within their jurisdictions.
- Reward organizations and communities that promote smoke-free spaces as a way of preventing cancers that are linked to cigarette smoking locally.

#### **6.6.2 Early Detection & Screening**

- Promote periodic breast health awareness (e.g., breast self-examination) using traditional, electronic, and social media. This could increase public awareness about breast and other cancers. Although a mammogram is the global gold standard for breast cancer screening, this recommendation considered the resource constraints that are prevalent in Abia State, including limited access to mammography.
- Promote annual clinical breast examination by a trained health provider for women aged 30 years or older, based on existing guidelines. This could improve the early detection of cancers.
- Collaboration with churches and community groups should be used to increase the uptake of early detection services.
- Consider an annual mammogram and/or breast ultrasound as an adjunct to clinical breast examination, beginning at age 40 or sooner in women with a family history of breast cancer.
- Promote cervical cancer screening using HPV testing, visual inspection methods, as well as cryotherapy for treatment of early lesions for women aged 25 to 65 years.
- Encourage timeliness in diagnosis using patient navigation services, such as the one initiated by the ACCG.

#### **6.6.3 Treatment and Survivorship**

- Expand the adoption of the evidence-based clinical pathways that were developed by ACCG using widely accepted guidelines for the management of common cancers

(especially breast and cervical cancers) to enhance resource optimization. This would ensure that patients always get the best care possible within the available resources.

- Encourage the establishment of treatment services (including radiotherapy), especially through partnerships involving private and public providers. Such would improve access and save on the foreign exchange that is used for treatment abroad.
- Enhance access to medicines required for the control of pain and other symptoms (e.g. morphine), because pain management is an essential aspect of cancer treatment.
- Scale up the current Cancer Patients Navigation Program to cover the entire State, and set up additional support groups as needed. These will help to prevent patients from being lost to follow-up.

#### **6.6.4 Governance and Finance**

- Pass an Executive Bill/Law that sets up a Cancer Agency in Abia State, as a collaboration between government and non-governmental organizations, such as the ACCG. The Cancer Agency would require competent leadership with a focus on the patients. Such an organization would provide oversight for cancer control activities in the State.
- Set up a mechanism for the monitoring and evaluation of cancer control activities in Abia State, as a tool for guiding the implementation of the policy.
- Provide funds for the early detection and treatment of cancers, using a blend of public, insurance schemes and private financing. This would require the establishment of an Abia Cancer Fund, administered by the proposed Cancer Agency, to assist with reducing the financial burden on patients/individuals and families. This would help to sustain cancer control activities in the State.

#### **6.6.5 Health Workforce, Research and Health Information**

- Expand the availability of training opportunities for healthcare professions to improve their cancer management-related skills. Such training could be delivered through the blended learning approach to include specialized/short courses, using a collaboration that would involve local and international educational institutions.

- Make cancer diagnosis a reportable disease such that healthcare professionals would provide ongoing data regarding all cancer screening and diagnoses in Abia state. The electronic medical record (EMR) system that was developed by ACCG could be adopted and expanded for this purpose. This would ensure care coordination, patient monitoring, and evaluation. In addition, it would be necessary to establish a statewide cancer registry to be managed by the State Cancer Agency. These would greatly enhance the work of patient navigators who would follow up cancer patients.
- Promote and coordinate local cancer research through the Agency, using funds from governmental, non-governmental, the diaspora, and private organizations. This would have the potential to establish Abia State as a hub for research regarding cancer control in resource-limited settings.

#### **6.7. Next Steps**

Although there are ongoing efforts by a local consortium involving governmental agencies and non-governmental organizations in Abia State to improve cancer control, the next step would be to consolidate these efforts through an Executive Bill. Such a Bill when passed by the State House of Assembly and supported by budgetary allocations would facilitate and support cancer control in Abia State. Periodic stakeholder meetings to review progress and develop short-term targets would help to ensure that the recommendations that were made in the Policy Brief were implemented and subsequently evaluated. It would also be important to use the data which would be generated to explore cancer patient outcomes, as a measure of the success of the Cancer Control Policy after its implementation.

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## CHAPTER 7: DISCUSSION AND CONCLUSIONS

### 7.1 Introduction

A literature review revealed that there was a paucity of studies about Cancer Control Policy in Nigeria.<sup>1</sup> The 2018 Nigerian National Cancer Control Plans (NCCP)<sup>2</sup> was not developed through community engagement. Similarly, many of the cancer control policies reviewed from other countries did not use the multiple perspective analysis approach.<sup>2,3</sup> This gap could explain the limited adoption and implementation of the Nigerian NCCP by the 36 Nigerian states. Considering the diversity of Nigerian society and differences in the experiences of people who may have been impacted by cancer (i.e. patients, providers, and policymakers), it became imperative to consider the nuanced perspectives of stakeholders regarding cancer control. Hence, this research sought to explore the perspectives of relevant stakeholders and how perspectives from all of the stakeholders could be used to propose a sustainable, community-oriented Cancer Control Policy in Abia, one of the 36 states in Nigeria.

### 7.2 Methodology and findings

The mixed-methods action research methodology (MMAR) has been demonstrated to be appropriate for research questions such as those explored in this research. By collecting data using surveys and key informant interviews, the data collected allowed for robust exploration of the breadth and depth of issues regarding Cancer Control Policy in Abia State, Nigeria. Various elements of scientific rigor in MMAR for the qualitative arm (i.e. credibility, reliability, trustworthiness, and transferability) and the quantitative arm (i.e. validity, reliability, replicability, and generalizability)<sup>4-6</sup> were espoused within the study. Confirmability was ensured through the linking of the results/findings to the research context, its data, as well as the analysis of the data. The qualitative data achieved saturation, i.e. the point at which new data no longer contributed new findings due to the repetition of themes and comments by participants. Data were presented in a credible way using direct quotes from the participants; as well as a concept map of themes that is linked to the data. Sufficient description was provided regarding the research design and conduct such that subsequent researchers could utilize the processes undertaken in the study (i.e. transferability and replicability). Validity and reliability were ensured through the pilot testing of questionnaires in a setting like Abia State. Generalizability may be possible given that the sample (n=112) was 50% higher than the minimum size required (n=73) to answer the research question.

This research also demonstrated the value of action research methodology.<sup>4,5</sup> It was designed by individuals who were directly impacted by the issue, e.g. clinicians and community members. Although the study was researcher-led, community members through the ACCG contributed to the implementation of the project. The engagement of the community in this research was evident through the integrated knowledge translation approach which led to the implementation of several community-driven initiatives to improve cancer control at the local level.<sup>7-9</sup> The transformation that resulted from the results/findings of this study included the implementation of early detection programs in collaboration with community-based organizations, the development of local clinical pathways, as well as the set up of the first statewide electronic medical record system for reporting cancers in Nigeria. Such effective implementation of research findings by community partners demonstrated the uniqueness of the project in proffering feasible and sustainable solutions to health and health policy considerations such as a Cancer Control Policy. This study demonstrated the cycles of an action research project, which involved planning, acting, observing, and reflecting.<sup>4,5</sup>

### **7.3 Implications for Cancer Control in Abia State and Nigeria in General**

From the pilot study to the research project, this thesis demonstrated that developing a locally relevant cancer control policy was important to people in Nigeria. Despite the rising number of cancer cases, there was a gap in access and utilization of early detection services, as shown by the results/findings of this study. This might explain the high proportion of patients that presented with advanced cancers in different parts of Nigeria, including Abia State.<sup>1</sup> Previous research, however, did not explore the contextual factors that contributed to the negative experience of cancer patients in accessing care, such as the impact of strike action that resulted in closure of hospitals or the financial burden that cancer placed on patients in Nigeria. This study was the first to explore the breadth and depth of issues surrounding CCP in Abia State, Nigeria with the goal of proposing a sustainable framework for addressing cancer across the continuum.

The use of multiple perspectives analysis with strong engagement by community members has proven to be innovative in extending the impact of the study. The ACCG has applied the results/findings from this study in the co-creation of several community-driven initiatives<sup>7-9</sup> that have significantly changed the scenario of cancer control in different parts of the State. These

initiatives have prepared the ground for potential public acceptance and ongoing engagement with any CCP that may be implemented by the State government. It is safe to say that this study has had an impact in Abia State. It is clear, from this study that a multiple perspectives analysis was an effective approach to studying issues around CCP and to propose local policy frameworks due to the embedded engagement of stakeholders such as patients/individuals diagnosed with cancer, healthcare providers, and policymakers.

#### **7.4 Proposed Cancer Control Framework**

Health policy frameworks can become more sustainable if they are informed by local data and experiences within the context where they will be implemented.<sup>10,11</sup> The CCP framework that was proposed in this study was grounded on the experiences and expectations of local stakeholders. The framework was also informed by experiences that evolved from implementing some of the research results/findings from this study in the community as well as recommendations from resource-stratified international guidelines on cancer control.<sup>12-14</sup> This addressed the research objective of ‘how to propose a cancer policy framework using the perspectives of local stakeholders.’ No previous health policy developed in Abia State or Nigeria adopted this innovative approach which has led to a robust framework which addresses all elements of the continuum of cancer control. By implementing some aspects of this proposed framework through community-driven initiatives<sup>15,16</sup>, it has been shown that larger-scale implementation by the government would have the potential to yield a remarkable transformation of cancer control in Abia State.

#### **7.5 Strengths and Limitations**

A key strength of this project is the high level of community engagement. The strong participation of ACCG from the design of this study to implementation of findings was very critical in achieving the ongoing impact that was created through the study. As with any research project, there were limitations to this project. The use of a mixed-methods action research design in this project was highly contextualized to Abia State, where participants were recruited from a diverse background (e.g. public and private healthcare institutions as well as government agencies). This might limit the generalizability of the research findings beyond Abia to other settings in the developing world, where the delivery of healthcare or the process of making health policies might be different.

However, the methods and findings are transferable to states or communities that are similar to Abia State, Nigeria; areas that were characterized as having cancer disparities, but with a strong local network of people who might be interested in improving the local system. For instance, other Nigerian States looking to apply this approach might need to identify and build on an existing network of stakeholders (like ACCG), to successfully apply it. The findings from the study could have been different if a sequential mixed-methods approach was used (instead of concurrent), where the findings from one approach (e.g. qualitative) would be used to design the other approach (e.g. quantitative). For instance, if in-depth interviews were conducted and analyzed before the development of a survey, the focus of the research might have been narrower. It would also have added value if focus group discussions were used to gain wide-ranging input from a larger number of patients, providers, and policymakers. This study did not include patient outcomes, in terms of mortality or quality of life. Such data/tools would help to support the case for an improved Cancer Control Policy.

#### **7.6 Future Directions**

In addition to the recommendations contained in the Policy Brief, it will be important for significant investment to be made in the training of healthcare providers (e.g. primary care doctors and nurses) to provide essential cancer-related services, especially where there are no oncologists.<sup>14</sup> There is increasing evidence that such investments would lead to better access and improved patient outcomes.<sup>13-15</sup> New research could evaluate the impact of increased training on different healthcare professionals related to the uptake of early detection services, as well as the diagnostic interval.

Similarly, future research would need to evaluate the implementation of the policy recommendations that evolved from the results/findings from this study. It will also be important to use the data which would be generated from the proposed Abia Cancer Agency to explore patient outcomes, as a measure of the success of the CCP after its implementation. An economic analysis would also be necessary to shed more light on the financial aspects of cancer control in Abia State.

## 7.7 Conclusions and Recommendations

This research sought to understand the perspectives of core stakeholders regarding cancer control in Abia State and how such perspectives might be used to propose a state cancer control policy framework. It has shown that although participants had nuanced experiences regarding cancer control, they had common expectations of having a state cancer control policy which emphasized early detection, the use of clinical pathways, and one that reduced the financial burden on patients. Through integrated knowledge translation, the study also demonstrated the feasibility and potential sustainability of developing a state cancer control policy based on the lived experiences and expectations of local patients, providers, and policymakers.

It is recommended that the Government of Abia State partner with stakeholders, including the ACCG to develop a broad policy that would be built around the proposed cancer control framework. Such a policy would strengthen the work that is ongoing in Abia State. According to a research participant:

*“...And if it is passed into law, the state will have a reason to fund cancer control. That way it is more likely for the cancer control policy to be successfully implemented.” **Policymaker.***

These statements highlighted the importance of having a CCP in Abia State. The time has come to dispel the prevailing notion that cancer control is not feasible in the developing world.<sup>17</sup> This research has demonstrated that when patients/individuals diagnosed with cancer, healthcare providers, and health policymakers work together, it is possible to develop a cancer policy that can meet the needs of the community, when implemented.

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APPENDIX A Ethics Application

For administrative use only	
File Number:	Date received:



### Application for Behavioural Research Ethics Review

**Evaluating Applications**

The matters of greatest concern to the Behavioural Research Ethics Board (Beh-REB) are the issues of informed consent of participants, voluntary participation, protection of individual privacy (confidentiality and anonymity), and safeguarding participants from any harmful results due to participation or non-participation in the proposed investigation or research project. Our evaluation of an application is based on the degree to which each of these concerns are satisfied; when filling out the application, researchers are urged to consider these points, and to explain to the Beh-REB the steps they will take to address the concerns. Researchers are also urged to consult the [Tri-Council Policy Statement 2](#) for more information and guidance.

The Beh-REB acknowledges the variety of paradigms and methodologies currently available to researchers, and that each of these paradigms entails its own particular ethical issues. Thus, there may be more than one way to address an ethical issue. Researchers should feel free to suggest alternative approaches or to explain why a particular requirement is not appropriate in the context of a given project.

**\*\*All text boxes will expand once <Enter> is selected or the cursor moves to the next section.\*\***

PART 1: IDENTIFICATION			
1.1	<b>Project Title</b> <a href="#">GN 1.1</a> Exploring the experiences and expectations related to cancer control with patients, health care providers (physicians and nurses), and policy makers in Akwa Ibom State – Nigeria		
1.2	<b>Principal Investigator</b> <a href="#">GN 1.2</a> Full Name: Dr. Vivian R Ramsden Mailing Address: Department of Academic Family Medicine University of Saskatchewan West Winds Primary Health Centre 3311 Fairlight Drive Saskatoon, SK S7M3Y5 Email: viv.ramsden@usask.ca Phone: 306-655-4214 NSID number (U of S faculty only): vrr124		
1.3	<b>University/Institutional Affiliation of Principal Investigator</b> <a href="#">GN 1.3</a> Position: Professor & Director Department: Academic Family Medicine, College of Medicine Division: Research		
1.4	If this is a student/graduate/resident project, please provide the following information: <a href="#">GN 1.4</a> a) Student Name(s) and Student ID or NSID (s): Dr. Kelechi Eguzo (kne201) b) Supervisor Name: Dr. Vivian Ramsden		
1.5	<b>Project Personnel (include graduates/post graduates/residents):</b> <a href="#">GN 1.5</a> <table border="1" style="float: right;"> <tr> <td>Add Personnel</td> <td>Remove Last</td> </tr> </table> Full Name: Dr. Kelechi Eguzo Full Name: _____ Project Position/Role: Student Project Position/Role: _____ University/Institutional Affiliation: University of Saskatchewan University/Institutional Affiliation: _____ Email: kelechi.eguzo@usask.ca Email: _____ Phone: 306-766-0395 Phone: _____	Add Personnel	Remove Last
Add Personnel	Remove Last		

3.1	<p>1. To evaluate the methods to be used in the development of an evidence-informed, cancer control program in Akwa Ibom State – Nigeria, with an emphasis on prevention.</p> <p>2. To evaluate the data collected using the research instruments for the development of a framework for improving cancer control in Akwa Ibom State.</p> <p>At the end of the pilot project, we will have gained a better understanding of what worked and what did not (methods and instruments) in gathering evidence about the cancer-related experiences and expectations of patients, health care providers and health policy makers in Akwa Ibom State. This will be very helpful in carrying out the main study in Abia State. Also, findings from this study could be used by MWAN and Akwa Ibom State government to facilitate improvements in cancer control within that jurisdiction.</p> <p><b>References</b></p> <ol style="list-style-type: none"> <li>Farmer P, Knaul FM, Shulman LN, Alleyne G, Armstrong L, Atun R, et al. Expansion of cancer care and control in countries of low and middle income: a call to action. <i>Lancet</i>. 2010 Oct 2;376(9747):1186-93.</li> <li>Eguzo K, Camazine B. Beyond limitations: practical strategies for improving cancer care in Nigeria. <i>Asian Pac J Cancer Prev</i>. 2013;14(5):3363-8.</li> <li>Adenipekun AA, Elumelu-Kupoluyi TN, Omoyeni NE, Soyannwo OA. Knowledge and experience of cancer patients receiving chemotherapy in a teaching hospital in Nigeria. <i>Internet J Pain Symptom Control Palliat Care</i>. 2012;9(1):3.</li> <li>Love RR. Global cancer research initiative. <i>Cancer Manag Res</i>. 2010;2:105-9.</li> <li>Kreling BA, Canar J, Catipon E, Goodman M, Pallesen N, Pomeroy J, et al. Latin American Cancer Research Coalition: community primary care/academic partnership model for cancer control. <i>Cancer</i>. 2006;107(8 Suppl.):2015-22.</li> <li>Abdulla R, Quinn G, Gwede C, Ealey J, Vadaparampl S, Lee JH, et al. Strategies toward improving the uptake of colorectal cancer screening among under-served communities: providers' perspectives. <i>Cancer Epidemiol Biomarkers Prev</i>. 2011;20 (10 Meeting Abstracts).</li> </ol>												
3.2	<p><b>Provide a description of research design and methods to be used:</b> <a href="#">GN 3.2</a></p> <p>This mixed-methods, action research project will undertake data collection through in-depth interviews, surveys and a follow-up discussion group to facilitate the interpretation of the findings prior to the development of a Framework for Cancer Control. Individuals who are participants at the CCPC Conference will be invited to participate and at least six individuals from each category in the populations of interest will be identified on a first-come basis or if a large number of individuals are interested in participating then they will be randomly selected so that everyone has an equal opportunity to participate. The populations of interest are: patients/patient advocates; health care professionals - physicians; health care professionals - nurses; as well as, health policy makers (Directors/Deputy Directors in the Ministry of Health, Department of Primary Health Care, Public Health and Legislators in the State House of Assembly).</p> <p>All potential participants (Registered Delegates of the CCPC Conference) will be invited to participate in this pilot project via an Letter of Invitation (see Appendix 1.). The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, the elements of a Consent Form (see Appendix 2.). Using a semi-structured questionnaire and a demographic survey (see Appendices 3. and 4.), members of the research team will collect data that will explore the experiences and expectations of the participants regarding cancer control in Akwa Ibom State. Each interview and group discussion will be audio recorded on a digital device.</p> <p>The interviews and group discussion will be transcribed and analyzed inductively through immersion/crystallization from which common themes will evolve. Survey data will be entered into SPSS v.22 and analyzed using descriptive statistics and Chi-square, as fits the data. Results from the quantitative data will describe the populations engaged in the Pilot Project and the qualitative findings will illuminate the experiences and expectations identified by the various populations.</p>												
3.3	<p>Provide details regarding the duration and location of data collection event(s): <a href="#">GN 3.3</a></p> <p>Individual interviews and the group discussions will involve no more than 60 minutes of the participant's time. All data collection will be conducted at the venue of the CCPC conference organized by MWAN in Uyo and held February 17- 19, 2016.</p> <table border="0"> <tr> <td><input checked="" type="checkbox"/> Questionnaire</td> <td><input type="checkbox"/> Participant Observation</td> </tr> <tr> <td><input checked="" type="checkbox"/> Individual Interviews</td> <td><input type="checkbox"/> Focus Groups</td> </tr> <tr> <td><input checked="" type="checkbox"/> Group Interview</td> <td><input type="checkbox"/> Non-invasive physical measurements</td> </tr> <tr> <td><input checked="" type="checkbox"/> Video/audio recording</td> <td><input type="checkbox"/> Secondary use of data or analysis of existing data</td> </tr> <tr> <td><input type="checkbox"/> Home Visits</td> <td><input type="checkbox"/> Ethnography</td> </tr> <tr> <td><input type="checkbox"/> Other: _____</td> <td></td> </tr> </table>	<input checked="" type="checkbox"/> Questionnaire	<input type="checkbox"/> Participant Observation	<input checked="" type="checkbox"/> Individual Interviews	<input type="checkbox"/> Focus Groups	<input checked="" type="checkbox"/> Group Interview	<input type="checkbox"/> Non-invasive physical measurements	<input checked="" type="checkbox"/> Video/audio recording	<input type="checkbox"/> Secondary use of data or analysis of existing data	<input type="checkbox"/> Home Visits	<input type="checkbox"/> Ethnography	<input type="checkbox"/> Other: _____	
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<input type="checkbox"/> Other: _____													

<b>PART 4: PROJECT DETAILS</b>	
4.1	<p><b>4.1.1 Will you have any internet-based interaction with participants?</b> <a href="#">GN 4.1</a></p> <p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p>

4.2	4.2.1 Will your research involve Aboriginal Peoples including First Nations, Inuit and Métis peoples? <a href="#">GN 4.2</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.3	4.3.1 Will the project involve community-based participatory research? <a href="#">GN 4.3</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.4	Will deception of any kind be necessary in this project? <a href="#">GN 4.4</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.5	Indicate how the participants will be debriefed following their participation (if applicable), and describe how the information on the results of the research will be made available to participants once the study has ended. Debriefing is particularly important if deception has been used. <a href="#">GN 4.5</a> Debriefing is not necessary for this project. Results/findings from this research endeavour will be made available to the participants following analysis and reflection. When completed, Dr. Eguzo will circulate the information to the CCPC and through the networks of MWAN-AKS.
4.6	Will participants be compensated? <a href="#">GN 4.6</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.7	4.7.1 Will participants be anonymous in the data gathering phase of the study? (Anonymous means that no link can be established between the participant and the research - no one including the researcher knows who has participated in the research): <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No 4.7.2 Will the confidentiality of participants and their data be protected? (Confidentiality means that no link can be established between the collected information and the participant's identity) <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No 4.7.3 If yes, are there any limits to confidentiality: <input checked="" type="checkbox"/> Limits due to the nature of group activities (e.g. focus groups): the researcher cannot guarantee confidentiality <input checked="" type="checkbox"/> Limits due to context: individual participants could be identified because of the nature or size of the sample or because of their relationship with the researcher. <input checked="" type="checkbox"/> Limits due to selection: procedures for recruiting or selecting participants may compromise the confidentiality of participants (e.g. participants are referred to the study by a person outside the research team) <input type="checkbox"/> Other:

PART 5: ESTIMATION OF RISKS AND BENEFITS	
5.1	5.1.1 Do you consider this project to be: <a href="#">GN 5.1</a> <input checked="" type="checkbox"/> Minimal Risk <input type="checkbox"/> Above Minimal Risk 5.1.2 Indicate if the participants might experience any of the following: Risk of psychological or emotional harm or discomfort (e.g. trauma, anxiety, stress) None known. Legal repercussions for participating in the study(e.g. possibility of being sued, charged with criminal activity, disclosure of past or future criminal activities, etc.) None known. Social repercussions (e.g. ostracized, being negatively judged by peers or employer, fired from your job) None known. Risk of physical harm or discomfort (e.g. falling, muscle pain, tiredness, weakness, nausea) None known. 5.1.3 Describe how the risk will be managed (including an explanation as to why an alternative approached could not be used). If appropriate, identify any resources, e.g. physician or counselor, to which participants can be referred. <a href="#">GN 5.1.3</a> N/A 5.1.4 If above minimal risk, what are the likely benefits of the research to the researcher, participant, the research community and society that would justify asking participants to participate? <a href="#">GN 5.1.4</a> N/A

<b>PART 6: PARTICIPANT RECRUITMENT</b>	
6.1	<p><b>Describe the participants and the criteria for their inclusion or exclusion. Indicate the number of participants and a brief rationale for the intended number of participants: <a href="#">GN 6.1</a></b></p> <p>The populations of interest are: patients/patient advocates; health care professionals - physicians; health care professionals - nurses; as well as, health policy makers (Directors/Deputy Directors in the Ministry of Health, Department of Primary Health Care, Public Health and Legislators in the State House of Assembly). Individuals who are participants at the CCPC Conference will be invited to participate and at least six individuals from each category in the populations of interest will be identified on a first-come basis or if a large number of individuals are interested in participating then they will be randomly selected so that everyone has an equal opportunity to participate.</p>
6.2	<p><b>6.2.1 Provide a detailed description of the method of recruitment. <a href="#">GN 6.2</a></b></p> <p>Individuals who are participants at the CCPC Conference will be invited to participate and at least six individuals from each category in the populations of interest will be identified on a first-come basis or if a large number of individuals are interested in participating then they will be randomly selected so that everyone has an equal opportunity to participate. All potential participants (Registered Delegates of the CCPC Conference) will be invited to participate in this pilot project via an Letter of Invitation (see Appendix 1.). The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, the elements of a Consent Form (see Appendix 2.). Using a semi-structured questionnaire and a demographic survey (see Appendices 3. and 4.), members of the research team will collect data that will explore the experiences and expectations of the participants regarding cancer control in Akwa Ibom State. Each interview and group discussion will be audio recorded on a digital device.</p> <p><b>6.2.2 How will prospective participants be identified?</b></p> <p>Individuals who are participants at the CCPC Conference will be invited to participate and at least six individuals from each category in the populations of interest will be identified on a first-come basis or if a large number of individuals are interested in participating then they will be randomly selected so that everyone has an equal opportunity to participate. All potential participants (Registered Delegates of the CCPC Conference) will be invited to participate in this pilot project via an Letter of Invitation (see Appendix 1.). The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, the elements of a Consent Form (see Appendix 2.).</p> <p><b>6.2.3 Who will contact prospective participants? Describe the source of the contact information, how they will be contacted and as applicable, who originally collected the contact information. Ensure any letters of initial contact or other recruitment materials are attached, e.g. advertisements, flyers, telephone script, etc.</b></p> <p>Prospective participants will be contacted by Dr. Eguzo through the organizers of the CCPC conference.</p>
6.3	<p><b>In cases where the research involves special or vulnerable populations, distinct cultural groups, or in cases where the research is above minimal risk, the researcher should describe their experience or training in working with the population. If none of these criteria apply, this section may be omitted. <a href="#">GN 6.3</a></b></p>
6.4	<p><b>Where relevant, please explain any relationship (pre-existing, current or expected to have) between the researcher(s) and the researched (e.g. instructor-student, manager-employee, co-workers, family members/intimate relationships, etc). Please pay special attention to relationships in which there may be a power differential. Describe any safeguards and procedures to prevent possible undue influence, coercion or inducement. <a href="#">GN 6.4</a></b></p> <p>Some of the participants may be former colleagues of Dr. Eguzo. No power differentials or conflicts of interest are expected.</p>

<b>PART 7: CONSENT PROCESS</b>	
	<p><b>Describe the process that will be used to obtain informed consent. Please note that it is the content of the consent, not the format that is important. If the research involves collection of personally identifiable information from a research participant or extraction of personally identifiable information from an existing database, please describe how consent from the individuals or authorization from the data custodian will be obtained. If there will be no written consent, please provide a rationale for oral or implied consent (e.g., cultural appropriateness, online questionnaire, etc.) and explain how consent will be recorded.</b></p>
7.1	<p><b>7.1.1 Describe the consent process. <a href="#">GN 7.1</a></b></p> <p>Individuals who are participants at the CCPC Conference will be invited to participate and at least six individuals from each category in the populations of interest will be identified on a first-come basis or if a large number of individuals are interested in participating then they will be randomly selected so that everyone has an equal opportunity to participate. All potential participants (Registered Delegates of the CCPC Conference) will be invited to participate in this pilot project via an Letter of Invitation (see Appendix 1.). The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, the elements of a Consent Form (see Appendix 2.). All questions will be answered and a Consent Form signed prior to the in-depth interview being commenced.</p> <p><b>7.1.2 Who will ask for consent?</b></p>

1.6	<b>Primary Contact Person for Correspondence (if different than Section 1.2) <a href="#">GN 1.6</a></b> Full Name: _____ Mailing Address: _____ Email: _____ Phone: _____
1.7	Research Site(s) where project will be carried out: Uyo, Akwa Ibom State - Nigeria during the Cancer Control in Primary Care (CCPC) Program organized by Medical Women's Association of Nigeria, Akwa Ibom State Branch, February 17-19, 2016
1.8	1.8.1 Proposed Project Period: <a href="#">GN 1.8</a> From (MM/DD/YY) ASAP To (MM/DD/YY) 06/30/16
1.9	1.9.1 Has this project applied for and/or received ethical approval from any other Research Ethics Board? Will you be seeking REB approval through the Sask. ethics harmonization process? <a href="#">GN 1.9</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No 1.9.2 Please be advised that approvals may need to be sought if you are collecting data from schools, within health regions and may be required from other organizations, agencies, or community groups. Will you be contacting potential participants or collecting data from any such organizations? <a href="#">GN 1.9.2</a> <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No If yes selected then open: Specify where, provide details and submit a copy of the certificate or letter of approval (when obtained). Please provide justification if you do not plan to seek approval. Medical Women's Association of Nigeria - Akwa Ibom State Branch
1.10	1.10.1 Status of Funds: <a href="#">GN 1.10</a> <input type="checkbox"/> Awarded <input type="checkbox"/> Pending <input checked="" type="checkbox"/> Unfunded

## PART 2: CONFLICT OF INTEREST

2.1	2.1.1 Is there any real, potential or perceived conflict of interest (any personal or financial interest in the conduct or outcome of this project)? <a href="#">GN 2.1</a> None 2.1.2 Will any of the researcher(s), members of the research team and/or their immediate family members: <ul style="list-style-type: none"> <li>- Receive personal benefits in connection with this project over and above the direct costs of conducting the project, such as remuneration or employment?</li> <li>- Receive significant payments of other sorts from the sponsor such as grants, compensation in the form of equipment or supplies or retainers for ongoing consultation and honoraria?</li> <li>- Have a non-financial relationship with a sponsor (such as unpaid consultant, board membership, advisor or other non-financial interest)?</li> <li>- Have any direct involvement with the sponsor such as stock ownership, stock options or board membership.</li> <li>- Hold patents, trademarks, copyrights, licensing agreements or intellectual property rights linked in any way to this project or the sponsor?</li> <li>- Have any other relationship, financial or non-financial, that if not disclosed, could be construed as a conflict of interest?</li> </ul> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
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## PART 3: BRIEF OVERVIEW OF RESEARCH PROJECT

	<b>Briefly describe the project, its objectives and potential significance (250-500 words): <a href="#">GN 3.1</a></b> Cancer is an emerging global health problem in low- and middle-income countries, including Nigeria.(1) Despite this rising burden, Nigeria does not have an organized national cancer control system.(2) The absence of an organized cancer control program has adversely affected patient outcomes in Nigeria.(2,3) Evidence suggests that practitioner-facilitated, community-engaged research would use local knowledge to build effective, horizontal cancer control strategies within specific nations/ health systems.(4) Action research has been successfully used to improve cancer disparities in other parts of the world.(5,6) We are planning a mixed-methods, action research study to assist with improving cancer disparities in Abia State of Nigeria.  This project will begin by conducting a pilot project of the research instruments that will be used for the research study described above. Akwa Ibom State was chosen for this pilot project because it is similar to Abia State culturally, economically and socially. The CCPC Course will bring together a number of individuals from the three populations of interest who will be at the Course talking about cancer control; thus, providing a wonderful environment for the pilot project. The objectives for the pilot project are:
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7.1.3	<b>Where, and under what circumstances will consent be obtained?</b> Consent will be obtained in person immediately prior to the commencement of the in-depth interview.
7.1.4	<b>Describe any situation in which the renewal of consent for this research might be appropriate and how this would take place (e.g. longitudinal studies, multiple data collection events, etc.).</b> N/A
7.2	<b>If any or all of the participants are children and/or are not competent to consent, describe the process by which capacity/competency will be assessed, the proposed alternate source of consent - including any permission/information letter to be provided to the person(s) providing the alternate consent - as well as the assent process for participants.</b> <a href="#">GN 7.2</a> N/A
7.3	<b>Describe your plans for providing project results to the participant?</b> <a href="#">GN 7.3</a> Findings from this research will be made available to the participants by Dr. Eguzo, and will also be shared through the networks of MWAN-AKS.
7.4	<b>How and when are participants informed of the right to withdraw? What procedures will be followed for participants who wish to withdraw at any point during the study?</b> <a href="#">GN 7.4</a> Participants would be informed about the right to withdraw from the research in both the Letter of Invitation and the Consent Form. Participants will be able to withdraw from the in-depth interview at any time until the data has been aggregated after which who said what can not be identified. Individuals wishing to withdraw should contact Dr. Eguzo via e-mail/phone or through the organizers of the CCPC Conference.

#### **PART 8: DATA SECURITY AND STORAGE**

Indicate the procedures you plan to implement to safeguard and store the data. Identify the person who will be assuming responsibility for data storage (University regulations require the researcher or the supervisor, in the case of student research, to securely store the data at the University of Saskatchewan for a minimum of five years upon the completion of the study - ([Procedures for Stewardship of Research Records at the University of Saskatchewan 2010.](#))

8.1	<b>Who will conduct the data collection?</b> <a href="#">GN 8.1</a> Dr. Eguzo and members of the research team engaged in data collection.
8.2	<b>Who will have access to the original data of the study?</b> <a href="#">GN 8.2</a> All members of the research team will have access to the original data.
8.3	<b>How will confidentiality of original data be maintained as well as preserving or destroying data after the research is completed. For all data (e.g. paper records, audio or visual recordings, electronic recordings), indicate the:</b> <a href="#">GN 8.3</a> <b>8.3.1 Person responsible for data storage:</b> Dr. Vivian R Ramsden will be responsible for storing the data in an appropriately secure location within the Department of Academic Family Medicine, University of Saskatchewan. <b>8.3.2 Data security during transportation from collection site:</b> Audio recordings will be electronically stored on a password-protected digital device and uploaded to PAWS as soon as possible. De-identified paper surveys will be copied and scanned into PAWS as soon as possible; and, the original data will be transported in a locked bag. <b>8.3.3 Means and location of storage (e.g. a locked filing cabinet, password protected computer files, encryption):</b> Data will be stored in an appropriately secure location in the Department of Academic Family Medicine, University of Saskatchewan and the de-identified data backed up in Cabinet on PAWS. <b>8.3.4 Time duration of storage (Must be &gt; 5 Years):</b> The data will be appropriately stored for a minimum of 5 years. <b>8.3.5 Final disposition (archive, shredding, electronic file deletion):</b> When the data is no longer required, it will be appropriately destroyed and/or destroyed beyond recovery.
8.4	<b>Indicate how the data collected is intended to be used (thesis, journal articles, conference presentation, media, etc).</b> <a href="#">GN 8.4</a> The results/findings from this Pilot Project will be used to further develop the PhD Research Project being undertaken by Dr. Kelechi Eguzo and as such may be included in the Dissertation. The results/findings will be shared with the leadership of MWAN and Akwa Ibom State Ministry of Health. Findings may also be presented at appropriate conferences or published in appropriate peer-reviewed journals.

#### **PART 9: Declaration by Principal Investigator (or Supervisor for student projects)**

**Project Title**

Exploring the experiences and expectations related to cancer control with patients, health care providers (physicians and nurses), and policy makers in Akwa Ibom State – Nigeria

- I confirm that the information provided in this application is complete and correct.
- I accept responsibility for the ethical conduct of this project and for the protection of the rights and welfare of the human participants who are directly or indirectly involved in this project.
- I will comply with all policies and guidelines of the University and Health Region/affiliated institutions where this project will be conducted, as well as with all applicable federal and provincial laws regarding the protection of human participants in research.
- I will ensure that project personnel are qualified, appropriately trained and will adhere to the provisions of the REB-approved application.
- I certify that any significant changes to the project, including the proposed method, consent process or recruitment procedures, will be reported to the Research Ethics Board for consideration in advance of its implementation.
- I certify that a status report will be submitted to the Research Ethics Board for consideration within one month of the current expiry date each year the project remains open, and upon project completion.
- If personal health information is requested, I assure that it is the minimum necessary to meet the research objective and will not be reused or disclosed to any parties other than those described in the REB-approved application, except as required by law.
- I confirm that adequate resources to protect participants (i.e., personnel, funding, time, equipment and space) are in place.
- I understand that if the contract or grant related to this research project is being reviewed by the University or Health Region, a copy of the ethics application inclusive of the consent document(s), may be forwarded to the person responsible for the review of the contract or grant.
- I understand that if the project involves Health Region resources or facilities, a copy of the ethics application may be forwarded to the Health Region research coordinator to facilitate operational approval.

\_\_\_\_\_  
Signature of Principal Investigator and/or Supervisor

\_\_\_\_\_  
Printed Name of Principal Investigator and/or Supervisor

\_\_\_\_\_  
Date (MM/DD/YY)

\_\_\_\_\_  
Signature of Student Investigator

\_\_\_\_\_  
Printed Name of Student Investigator

\_\_\_\_\_  
Date (MM/DD/YY)

**Department Head (UoFS and RQHR only) :** The signature/approval of the Department/Administrative Unit acknowledges that he/ she is aware of and supports the research activity described in the proposal.

\_\_\_\_\_  
Signature of Department Head

\_\_\_\_\_  
Printed Name of Department Head

\_\_\_\_\_  
Date (MM/DD/YY)

**Project Title**

Exploring the experiences and expectations related to cancer control with patients, health care providers (physicians and nurses), and policy makers in Akwa Ibom State – Nigeria

- I confirm that the information provided in this application is complete and correct.
- I accept responsibility for the ethical conduct of this project and for the protection of the rights and welfare of the human participants who are directly or indirectly involved in this project.
- I will comply with all policies and guidelines of the University and Health Region/affiliated institutions where this project will be conducted, as well as with all applicable federal and provincial laws regarding the protection of human participants in research.
- I will ensure that project personnel are qualified, appropriately trained and will adhere to the provisions of the REB-approved application.
- I certify that any significant changes to the project, including the proposed method, consent process or recruitment procedures, will be reported to the Research Ethics Board for consideration in advance of its implementation.
- I certify that a status report will be submitted to the Research Ethics Board for consideration within one month of the current expiry date each year the project remains open, and upon project completion.
- If personal health information is requested, I assure that it is the minimum necessary to meet the research objective and will not be reused or disclosed to any parties other than those described in the REB-approved application, except as required by law.
- I confirm that adequate resources to protect participants (i.e., personnel, funding, time, equipment and space) are in place.
- I understand that if the contract or grant related to this research project is being reviewed by the University or Health Region, a copy of the ethics application inclusive of the consent document(s), may be forwarded to the person responsible for the review of the contract or grant.
- I understand that if the project involves Health Region resources or facilities, a copy of the ethics application may be forwarded to the Health Region research coordinator to facilitate operational approval.

\_\_\_\_\_  
Signature of Principal Investigator and/or Supervisor

\_\_\_\_\_  
Printed Name of Principal Investigator and/or Supervisor

\_\_\_\_\_  
Date (MM/DD/YY)

\_\_\_\_\_  
Signature of Student Investigator

\_\_\_\_\_  
Printed Name of Student Investigator

\_\_\_\_\_  
Date (MM/DD/YY)

**Department Head (UoFS and RQHR only)** : The signature/approval of the Department/Administrative Unit acknowledges that he/she is aware of and supports the research activity described in the proposal.

\_\_\_\_\_  
Signature of Department Head

\_\_\_\_\_  
Printed Name of Department Head

\_\_\_\_\_  
Date (MM/DD/YY)



**SECTION 10: APPENDICES [GN 10](#)**

Document	Included?	Description
Recruit Material(s)	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
Letter (s) of Initial Contact	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	This is the cover letter that will introduce the study.L
Consent Form(s)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	
Assent Form(s)	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
Research Tool(s) (e.g. Questionnaires, focus group guides, interview scripts, etc.)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	
Transcript Release Form(s)	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
RQHR Operational/Departmental Approval Form	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
Other (please specify): Approval Letter from MWAN	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	Letter from MWAN expressing approval for the research study to be conducted during the CCPC conference

## APPENDIX B Ethics Addendum

### PROTOCOL AMENDMENT/ADDENDUM I

**NAME OF THE STUDY:** Exploring the experiences and expectations related to cancer control with patients, health care providers and policy makers in Akwa Ibom State – Nigeria

**STUDY NUMBER:** BEH 16 – 44  
**DATE OF THE AMENDMENT:** September 18, 2017  
**FUNDING SOURCE:** Unfunded  
**INVESTIGATORS:** Drs. Kelechi Eguzo, Vivian R Ramsden

#### I. Purpose

The purpose of this Protocol Amendment/Addendum is to include, a new study site; new study partners; and, amendments of the study protocol and data collection tools.

#### II. Amended Protocol Revisions

##### A. Additional Study Site

- Abia State of Nigeria

##### B. Additional Study Partners

- Abia State Primary Health Care Development Agency; Abia State - Ministry of Health; and, individuals/community partners who comprise the Community Advisory Group (CAG)

##### C. Application - Amendment of Study Protocol

###### Section 1.9.2

We have obtained letters of support from Abia State Ministry of Health. (See attached)

###### Section 3.2: Provide a description of research design and methods to be used. GN 3.2

This concurrent mixed-methods and action research project will undertake data collection through surveys, in-depth, key informant interviews, and a follow-up discussion group to facilitate the interpretation of the findings prior to the development of a framework/plan for cancer control. The populations of interest (potential research participants) include: 1) individuals who have completed active cancer treatment within the last five years (cancer survivors), patients who are currently receiving cancer treatment at various health institutions in Abia State. Key informants will be selected from this group until saturation is reached because they will have experienced various aspects of cancer control in the state. 2) Physicians and nurses who are currently serving in Abia State. Key informants (equal numbers of physicians and nurses) will be selected from facilities known to provide cancer services until saturation is reached because they would have the most experience providing cancer control in the state. 3) Health policymakers in Abia State, including but not limited to senior personnel in the Ministry of Health, legislators and directors of primary health care in the various local government areas. Key informants will be selected from senior personnel at the Ministry of Health and other relevant institutions (e.g. state legislators) until saturation is reached because they would be most conversant with existing policies.

A minimum of six individuals meeting the criteria for key informants in each of the three categories listed above will be identified and invited to participate in key informant interviews. If a large number of individuals are interested in participating in the interviews then they will be randomly selected so that everyone has an equal opportunity to participate. Some potential key informants are already known to Dr. Kelechi Eguzo, who has practiced as a General Practitioner in Oncology in Abia State. Interviews will continue until data saturation has been attained (i.e. when there is enough information to replicate the study or when no new information is obtained from the interviews).

In addition, Dr. Eguzo will undertake surveys of individuals within each category, to achieve the desired sample size. According to Onwuegbuzie et al (1), a sample size of at least 51 individuals per group is sufficient to answer the research questions, where a nested sample of at least six participants per group will be involved in interviews. This sample size represents those needed to detect a medium, one-tailed statistically significant relationship or difference with 0.80 power at 5% level of significance. The quantitative arm of this study will help in data triangulation and be complementary; thus, enhancing the quality of the study. (2) This design will ensure the credibility, transferability and dependability of the findings from this research. (2) Please note that individuals selected to be invited for a key informant interview will be nested within each of the populations identified (i.e. patients, providers or policymakers).

All potential participants will be invited to participate in this research via a Letter of Invitation (see Appendix A) and recruitment advertisement (Appendix B). The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, elements of the Consent Form (see Appendix C). Key informant interviews will follow a semi-structured format (See respective data collection tools for each population). Each interview will be audio recorded on a digital device. Interviews might be conducted in person or via telephone based on what is convenient for the participant. Surveys with interview questions for each group are included in Appendix. The survey will be disseminated using both paper and electronic formats. This is to enhance the response from the targeted participants, as some individuals might prefer one format over the other.

The interviews and group discussion will be transcribed and analysed deductively through immersion/crystallization from which common themes will evolve. Qualitative data analysis software, such as NVivo v.11, will be used for qualitative data analysis. Survey data will be entered into SPSS v.24 and analysed using descriptive statistics, T-tests and Chi-square, as fits the data. Results from the quantitative data will describe the most common experiences and expectations of the study sample, while the rich qualitative findings will illuminate these experiences and expectations identified by each group.

Following the analysis of both qualitative and quantitative data, findings/results will be returned to the Community Advisory Group (CAG) for interpretation. The CAG will be comprised of individuals from each of the populations of interest and who have expressed interest in this research project. Discussions at the meetings of this group will suggest how to use the findings/results from this research project to develop a cancer control framework. Consensus on the final framework will follow the Delphic approach. These discussions will be audio recorded.

#### Section 4.1

##### 4.1.1 Will you have any internet-based interaction with participants?

Yes

##### 4.1.2 If you are using a third party research tool, website survey software, how will you ensure the security of data gathered at that site?

This will be done through Fluid Survey on-line software available through the University of Saskatchewan. Should Fluid Survey not be available at the time, another secure, online survey website will be used. De-identified data will be housed in Cabinet on PAWS at the University of Saskatchewan.

##### 4.1.3 Describe how permission to use any third party owned site(s) will be obtained, if applicable

The Fluid Survey on-line software is available to Graduate Students of the University of

Saskatchewan.

4.1.4 How will you protect the privacy and confidentiality of participants who may be identified by email addresses, IP addresses, and other identifying information that may be captured by the system during your interactions with these participants?

The online survey will be open to potential participants who are associated with the partner organizations (e.g. Abia State Primary Health Care Development Agency, Nigerian Christian Hospital, Marjorie Bash Foundation, etc); however, e-mail and IP addresses will not be captured, or retained. The partner organizations may send out the invitation with the link to the survey a maximum three times. Dr. Eguzo will not have direct contact with the potential participants (in terms of their email addresses or phone numbers). After the survey is completed, the CAG will develop a Summary that will be circulated to the partner organizations who will in turn distribute it through their networks.

4.1.5 Will the project involve deception?

No.

4.2 Will your research involve Aboriginal Peoples including First Nations, Inuit and Métis peoples?

This research project will not involve Aboriginal peoples.

Section 4.3 Will the project involve community-based participatory research?

Yes. This project will involve community-based participatory research.

4.3.2 Please outline the plans to obtain community engagement for this project

This project will be undertaken by Dr. Eguzo (supervised by Dr. Ramsden) supported by the Abia State Ministry of Health (ABMOH), Abia State Primary Health Care Development Agency (ABSPHCDA), and other organizations in Abia State (e.g. Nigerian Christian Hospital and the Marjorie Bash Foundation). The agencies were engaged in the conceptualization and design of this study. Dr. Eguzo has been involved in various face-to-face, phone and email conversations with the leadership of ABPHCDA and other organizations regarding this project. Representatives of the study population based in Abia (patient advocates, health providers and policymakers) have also provided input into the design. ABSPHCDA, as well as, the Abia State Ministry of Health have provided letters of support for the project.

As part of their commitment to this project, Abia State Primary Health Care Development Agency and other community partners (e.g. Marjorie Bash Foundation) may provide resources to facilitate data collection and knowledge translation. This could include, but not limited to, office space and a vehicle.

4.3.3 Describe the organizational structure and community processes required to obtain approval

ABPHCDA is overseen by a Board of Governors, but led by an Executive Secretary (Dr. Chukwuemeka Oluoha) while the Abia State Ministry of Health (ABMOH) is headed by the Commissioner for Health. Letters of support for the project were obtained from ABPHCDA and ABMOH after the project was conceptualized.

4.3.4 Will a research agreement between the researcher and community be prepared?

A research agreement is not required, as the letters of support are sufficient.

4.3.5 Will community representatives have the opportunity to participate in the interpretation of the data

ABMOH, ABPHCDA and other community partners have been involved in the conceptualization and design of this study. They have also provided input into the revisions of the study instruments following the Pilot Project in Akwa Ibom State in 2016. The partner organizations and members of the Community Advisory Group (CAG) will also be involved in the interpretation of findings/results. At the completion of data analysis, Dr. Eguzo will convene a meeting of the group where the findings/results will be discussed, prior to the Final Report being written. The final results will be shared with the populations of interest in Abia State through ABSPHCDA, ABMOH, members of the CAG; as well as, hospitals where patients and providers were invited to participate and professional organizations.

**Section 4.5** Indicate how the participants will be debriefed following their participation (if applicable)  
Debriefing is not necessary for this project. Findings/results from this research endeavour will be made available to the participants following analysis and reflection. When completed, Dr. Eguzo will circulate the findings to the participants as described in 4.3.5 above.

**Section 4.6** Will participants be compensated?

Participants in the research, especially individuals who participate in key informant interviews, may be compensated for their transportation cost to the interview venue. If the interviews are conducted over lunch hour, they will be provided with lunch. Individuals who contact Dr. Eguzo by phone and had to travel to join the study will have their expenses (travel and communication) reimbursed, using pre-paid phone cards, or other locally acceptable methods (such as mobile money).

Individuals who complete the survey will be compensated with 500 Naira pre-paid (\$2 CDN) phone cards (popularly called Recharge Cards or Virtual Top-Ups in Nigeria) to pay for data costs of completing the survey, especially the online version. Individuals who would like to receive this recharge card will be required to provide their phone numbers and/or email address on a separate piece of paper (or will be redirected to a separate website where this information will be collected). This is to ensure that there will be no link between their survey response and their contact information (phone numbers and email address).

**Section 6.1** Describe the participants and the criteria for their inclusion or exclusion.

The populations of interest will include: 1) individuals who have completed active cancer treatment within the last five years (cancer survivors); as well as, patients who are currently receiving cancer treatment at various health institutions in Abia State. Key informants will be selected from this group until saturation is reached because they will have experienced various aspects of cancer control in the state. 2) Physicians and nurses who are currently serving in Abia State. Key informants (equal numbers of physicians and nurses) will be selected from facilities known to provide cancer services until saturation is reached because they would have the most experience providing cancer control in the state. 3) Health policymakers in Abia State, including but not limited to senior personnel in the Ministry of Health, legislators and directors of primary health care in the various local government areas, and other relevant government institutions. Key informants will be selected from senior personnel at the Ministry of Health and other relevant institutions until saturation is reached because they would be most conversant with existing policies.

**Section 6.2**

**6.2.1** Provide a detailed description of the method of recruitment

Participants will be recruited from health institutions, community events and offices within Abia State, Nigeria. This research study will be advertised at locations where potential participants could be recruited using a recruitment advertisement (Appendix B). In addition, other

communication channels used by these institutions in Abia State to reach their clients, staff and associates (e.g. social media posts, email and bulk text messaging) will be adopted to share information about the research project. Dr. Eguzo will not have direct contact with the potential participants (in terms of their email addresses or phone numbers). Interested individuals will be invited to contact Dr. Eguzo using the information provided on the advertisement.

Participants will also be recruited directly (in person) from hospital/clinics that are known to offer cancer services, or at other locations within the state. Dr. Eguzo will approach the patients directly at the facilities where they receive care, with the permission from the leadership of these facilities. Physicians and nurses will be recruited in a similar manner. Policymakers will be recruited directly from the Ministry of Health and other agencies and institutions that are involved in health policy making (e.g. Abia State House of Assembly). In addition, Dr. Eguzo will recruit providers and policymakers at community events, such as a venue for Continuing Medical Education events.

All potential participants will be invited to participate in this research via a Letter of Invitation (see Appendix A) and recruitment advertisement (Appendix B). The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, elements of the Consent Form (see Appendix C). Key informant interviews will follow a semi-structured format (See Appendix D). Each interview will be audio recorded on a digital device. Interviews might be conducted in person or via telephone based on what is convenient for the participant. Data collection tools for each group are included in the appendix. The survey will be disseminated using both paper and electronic formats. This is to enhance the response from the targeted participants, as some individuals might prefer one format over the other. For instance, some individuals may find it more convenient to access the survey on their mobile device.

#### 6.2.2 How will prospective participants be identified?

Participants will be recruited from health institutions, community events and offices within Abia State of Nigeria. This research study will be advertised at locations where potential participants could be recruited using a recruitment advertisement (Appendix B). In addition, other communication channels used by these institutions in Abia State to reach their clients, staff and associates (e.g. social media posts, email and bulk text messaging) will share information about the research project. Dr. Eguzo will not have direct contact with the potential participants (in terms of their email addresses or phone numbers). Interested individuals will be required to contact Dr. Eguzo using the information provided on the advertisement.

Participants will also be recruited directly (in person) from hospital/clinics that are known to offer cancer services, or at other locations within the state. Dr. Eguzo will approach the patients directly at the facilities where they receive care, with the permission from the leadership of these facilities. Physicians and nurses will be recruited in a similar manner. Policymakers will be recruited directly from the Ministry of Health and other agencies that are involved in health policy making (e.g. Abia State House of Assembly). In addition, Dr. Eguzo will recruit providers and policymakers at community events, such as a venue for Continuing Medical Education events. Providers and policymakers may also volunteer themselves by contacting Dr. Eguzo in response to the advertisement (Appendix B) about the research.

#### 6.2.3 Who will contact prospective participants?

Prospective participants will be contacted primarily by Dr. Eguzo. The contact information of prospective participants (i.e. clinic days at hospitals; organogram of Ministry of Health; date/venues of Continuing Medical Education events) is largely public knowledge. Dr. Eguzo has practiced in Abia State and is familiar with this information already. Stakeholders in the research

(i.e. Abia State Ministry of Health and Abia State Primary Health Care Development Agency) ~~may be approached~~ to provide updated information regarding the clinics/offices where potential participants might be recruited. The leadership of professional associations (such as Abia State Chapter of Nigerian Medical Association, where Dr. Eguzo is a member) ~~may be approached~~ to share the advertisement about the research with their members through their usual communication channels. Dr. Eguzo will not have direct contact with the potential participants (in terms of their email addresses or phone numbers). Interested individuals may contact Dr. Eguzo about participating in the research study in response to the advertisement (Appendix B).

## **Section 7.1**

### **7.1.1 Describe the consent process.**

The consent process will begin at recruitment. All potential participants ~~will be invited~~ to participate in this research via a Letter of Invitation (see Appendix A) and Recruitment advertisement (Appendix B), as previously described. The Letter of Invitation will contain an overview of the study, the names and contact information for the research team; and, the elements of a Consent Form (see Appendix C). Key informants interview will follow a semi-structured format. Each interview will be audio recorded on a digital device. The survey ~~will be disseminated~~ using both paper and electronic formats. This is to enhance the response from the targeted participants, as some individuals might prefer one format ~~over~~ the other. For instance, some individuals may find it more convenient to access the survey on their mobile device.

Every potential participant ~~will be invited~~ to sign the Consent Form prior to the commencement of data collection. The Cover Letter for the survey will also provide the contact information for Dr. Eguzo and the Research Ethics Office at the University of Saskatchewan should the participants have any questions or concerns.

### **7.1.2 Who will ask for consent?**

Dr. Eguzo will ask for consent.

### **7.1.3 Where, and under what circumstances will consent be obtained?**

Consent ~~will be obtained~~ in person immediately prior to the commencement of data collection. Individuals who participate in the survey electronically will be required to provide implied consent prior to commencing the survey. Individuals who participate in a key informant interview will be required to provide consent that includes the opportunity for the interview to be audio-recorded. Interviews may be conducted in person or by ~~telephone~~ (oral consent will be obtained) based on the preference of the participant.

### **Section 7.3 Describe your plans for providing project results to the participant?**

At the completion of data analysis, Dr. Eguzo will convene a meeting of the Community Advisory Group (CAG) where the findings/results ~~will be discussed~~ and interpreted prior to the Final Report being written. The final findings/results will shared with the community in Abia State through: ABSPHCDA; members of the CAG; hospitals where patients and providers ~~were recruited~~; as well as, professional organizations.

In order to engage the community in Abia State, Dr. Eguzo and the community partners involved in this research will create a social media (e.g. Facebook) page to publicize the research protocol, provide updates and share findings/results. This will foster further interaction between Dr. Eguzo, the community partners and the wider community regarding the cancer control.

### **Section 7.4 How and when are participants informed of the right to withdraw?**

Participants ~~would be informed~~ about the right to withdraw from the research in both the Letter

of Invitation and the Consent Form. Participants will be able to withdraw from the research at any time until the data has been aggregated after which who said what cannot be identified. Individuals wishing to withdraw should contact Dr. Eguzo via e-mail/phone until June 30, 2018 after which it will not be possible to withdraw.

**Section 8.1 Who will conduct the data collection?**

Dr. Eguzo will conduct the data collection.

**Section 8.2 Who will have access to the original data of the study?**

Drs. Eguzo and Ramsden will have access to the original data.

**Section 8.4 Indicate how the data collected is intended to be used**

The findings/results from this study will be used for a PhD Dissertation by Dr. Kelechi Eguzo. The findings/results will be shared with the leadership of Abia State Ministry of Health, Abia State Primary Health Care Development Agency and other community partners. Findings/results may also be presented at appropriate conferences or published in appropriate peer-reviewed journals.

Updated references

1. Onwuegbuzie AJ, Collins KM. A typology of mixed methods sampling designs in social science research. Qual Rep. 2007;12(2):281-316. Available from <http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=1638&context=tqr>
2. Fusch PI, Ness LR. Are we there yet? Data saturation in qualitative research. Qual Rep. 2015;20(9):1408-16. Available from <http://tqr.nova.edu/wp-content/uploads/2015/09/fusch1.pdf>





## Behavioural Amendment

For Internal Use Only

UnivRS Internal ID:

Date Received: [Click here to enter a date.](#)

### Key Information

UnivRS Internal Project ID# or old Ethics ID# (Beh-xx-xxx): \* BEH 16 – 44

PI Name: \* Vivian R Ramsden

Title: \* Exploring the experiences and expectations related to cancer control with patients, health care providers and policy makers in Akwa Ibom State – Nigeria

Current status of this project: \* Recruitment is open; data collection involving participants is ongoing

Summarize and provide rationale for proposed revision(s): \* The purpose of this revision is to include new category of participants who would be involved in knowledge translation. They will be important in helping disseminate the findings of the research in Abia State but will not be involved in data collection. These categories include:

**Religious leaders (e.g. pastors)**

**Community leaders (e.g. leaders of market organizations, autonomous communities)**

**Patient advocates (e.g. leadership of non-profits working on cancer awareness)**

**Members of the media (e.g. journalists working in Abia State)**

The leadership of such organizations will be identified through public records and will be invited to review the final framework that will be developed from this research. They might also be requested to help share the findings from this project with their members or within their networks, to help increase the chances of implementing the outcome of the research.

Indicate how participants will be notified of proposed revisions: \* No current participants

If other, specify:

### Change to Sponsor(s) and Agency(ies)

Sponsor(s)	
Add / Remove:	Sponsor:
<input type="text"/>	<input type="text"/>

Agency(ies)	
Add / Remove:	Agency:
<input type="text"/>	<input type="text"/>



Project Application(s) Directly Associated with the Fund(s) Supporting this Project  
 Specify the **UnivRS** Internal ID# (for pending grants or contracts):

Project(s) Directly Associated with the Fund(s) Supporting this Project  
 Specify the **UnivRS** Internal ID# (for awarded grants or contracts):

**Change to Location(s) Where Research Activities are Conducted**

Add / Remove:	Building or Organization:	Country:
<input type="text"/>	<input type="text"/>	<input type="text"/>

**Change to Project Personnel**

**Principal Investigator**

New PI Name:	NSID:	Email:	Phone:	Organization (Department):
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Sub-Investigator(s)**

Add Remove:	Name:	NSID:	Email:	Phone:	Organization (Department):
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Student(s)**

Add Remove:	Name:	NSID:	Email:	Phone:	Organization (Department):
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Primary Contact**

Add Remove:	Name:	NSID:	Email:	Phone:	Organization (Department):
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Secondary Contact**

Add Remove:	Name:	NSID:	Email:	Phone:	Organization (Department):
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Declaration by Principal Investigator**

By submitting this amendment form, the Principal Investigator confirms that he/she is responsible for the scientific and ethical conduct of this project and agrees to conduct this project in compliance



with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014), the Personal Health Information Protection Act (HIPA) and other relevant laws, regulations or guidelines.

Date the form was completed: 2018-07-30  
Name of person who completed the form: Dr. Kelechi Eguzo

If form submitted on behalf of the PI:

Dr. Kelechi Eguzo is authorized to prepare and submit this form on behalf of the Principal Investigator

Authorized person contact information:

Email: [Kelechi.eguzo@usask.ca](mailto:Kelechi.eguzo@usask.ca)

Phone: 306-715-4428

#### DOCUMENT(S)

Provide a list of documents that are being submitted along with this amendment: **None**

APPENDIX C Ethics Certificate (University of Saskatchewan)



Behavioural Research Ethics  
**Certificate of Approval**

<b>PRINCIPAL INVESTIGATOR</b> Vivian Ramsden	<b>DEPARTMENT</b> Family Medicine	<b>BEH#</b> 16-44
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED</b> Nigeria		
<b>STUDENT RESEARCHER(S)</b> Kelechi Eguzo		
<b>FUNDER(S)</b> UNFUNDED	<b>SPONSOR(S)</b> UNFUNDED	
<b>TITLE</b> Exploring the Experiences and Expectations Related to Cancer Control with Patients, Health Care Providers (Physicians and Nurses), and Policy Makers in Akwa Ibom State - Nigeria		
<b>ORIGINAL REVIEW DATE</b> 04-Feb-2016	<b>APPROVAL ON</b> 08-Feb-2016	<b>APPROVAL OF:</b> Application for Behavioural Research Ethics Review Recruitment Poster Participant Consent Form Surveys [3] - Patients - Health Care Providers - Policy Makers
		<b>EXPIRY DATE</b> 07-Feb-2017

Full Board Meeting  Delegated Review

**CERTIFICATION**  
The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

**ONGOING REVIEW REQUIREMENTS**  
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: <http://research.usask.ca/for-researchers/ethics/index.php>

Patricia Simonson, Designate  
University of Saskatchewan  
Behavioural Research Ethics Board

Please send all correspondence to:  
Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1602-110 Gymnasium Place  
Saskatoon SK S7N 4J8  
Telephone: (306) 966-2975 Fax: (306) 966-2059



Behavioural Research Ethics Board (Beh-REB)

**Certificate of Approval  
Study Amendment**

PRINCIPAL INVESTIGATOR Vivian Ramsden	DEPARTMENT Family Medicine	Beh # 16-44
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INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT: Nigeria

STUDENT RESEARCHER(S): Kelechi Eguzo

FUNDER(S): UNFUNDED

SPONSOR(S): UNFUNDED

TITLE: Exploring the Experiences and Expectations Related to Cancer Control with Patients, Health Care Providers (Physicians and Nurses), and Policy Makers in Akwa Ibom State - Nigeria

APPROVAL OF Protocol Amendment/Addendum I Recruitment Poster Consent Form - Survey Participant Consent Form - Interview/Discussion Group Key Informant in-depth interview questions Providers Key Informant in-depth interview questions Providers Survey Questions Health Policymakers Survey Acknowledgement of: Letter of Support - Abia State Government of Nigeria Ministry of Health Letter of Support - Government of Abia State of Nigeria	APPROVED ON 05-Oct-2017	CURRENT EXPIRY DATE 18-Jan-2018
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Full Board Meeting

Delegated Review

**CERTIFICATION**

The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

**ONGOING REVIEW REQUIREMENTS**


In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: <http://research.usask.ca/for-researchers/ethics/index.php>

Patricia Simonson, Ethicist  
University of Saskatchewan  
Behavioural Research Ethics Board

Please send all correspondence to:

Research Services and Ethics Office  
University of Saskatchewan  
Room 223 Thorvaldson Building  
110 Science Place  
Saskatoon SK Canada S7N 4J8

APPENDIX D Operational Approval (Akwa Ibom State/Medical Women's Association)



**MEDICAL WOMEN'S ASSOCIATION OF NIGERIA**  
AKWA IBOM STATE BRANCH  
**MOTTO: MATRIS AMINO CURANT**  
*"Heal with the Love of a Mother"*  
c/o Medical Women's Association of Nigeria Secretariat, 172 Atiku Abubakar Way  
(Same Building with Christian Pilgrims Board), Ground Floor, Uyo, Akwa Ibom State  
E-Mail: mwanaks@yahoo.com

17th January, 2016.

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Dr. Kelechi Eguzo  
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University of Saskatchewan  
Regina, SK, Canada

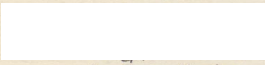
Dear Dr. Eguzo,

**LETTER OF APPROVAL TO CONDUCT RESEARCH ON CANCER CONTROL IN AKWA IBOM STATE**

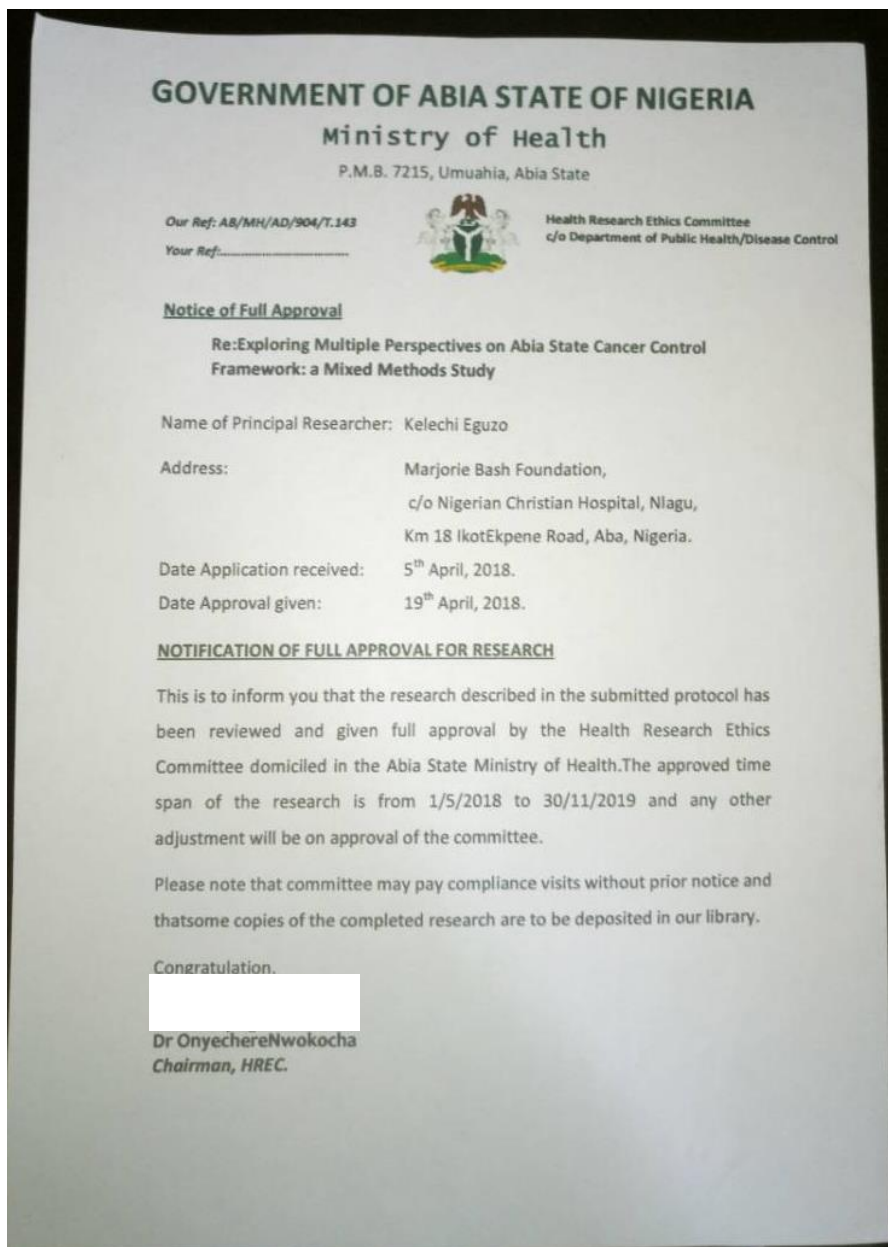
On behalf of the leadership of the Medical Women's Association of Nigeria (MWAN), Akwa Ibom State branch, I write to express our approval for the proposed research on cancer control in Akwa Ibom State during our Cancer Control in Primary Care Course.

It is our understanding that you will be working with some members of our organization to explore the perspectives of health care professionals, policy makers and patients' advocates who will be attending the CCPC workshop on February 17 - 19, 2016 in Uyo. Your research plans are in line with the vision of MWAN to improve the lives of people living in Nigeria.

Please keep us informed about the progress of your research. Good luck!

Regards,  
  
Dr. Emem Abraham

APPENDIX E Ethics Certificate (Abia State Ministry of Health)



## APPENDIX F Data Collection Tool (Patients)

### Exploring patients' experiences and expectations regarding cancer control in Abia State

Participant ID #:

#### Key Informant in-depth interview questions

1. Please tell me about yourself (scope: name, age, occupation, etc.)
2. Tell me a bit about your history and your perception of the disease? (scope: brief history of the disease, their perception about origin, etc.)
3. How did you find out that it was cancer?
4. After you found that that you had cancer, what happened next?
5. What were the difficulties you faced in receiving treatment?
6. What were you expecting to happen regarding your treatment (scope: did you have adequate information about the disease, time taken before treatment started, cost associated with the treatment, etc.)
7. In many parts of the world, governments have cancer control plans. This describes how the government/state would create awareness, prevent cancers, provide treatment and generally handle the issues surrounding cancer (just like we have for HIV/AIDS). If we had such a system in Abia State, how do you think it would have helped your cancer experience?
8. It has been recommended that multiple stakeholders who are impacted by cancer (cancer patients, health care providers, health policymakers, etc.) should come together to develop cancer control plans for their areas. As a patient, how do you think that we should go about this in Abia State?
9. What is most important to you that should be in any cancer control plan?
10. What do you think is preventing us from having an effective cancer control plan in Abia State?
11. How do you think we can overcome the problems, challenges, barriers you have identified above?
12. Given your experience with this disease, would you be interested in promoting cancer awareness in your community?
13. Do you think there would be any value in having a support group for cancer patients/survivors in the state, just like the case with HIV/AIDS?
14. How do you think a partnership between the government (public) and non-governmental/private organizations would help improve cancer control in Abia State?
15. From your experience, how would you like cancer services (screening, diagnosis, treatment) to be funded? (who should pay for it)
16. What is your opinion on creating an insurance scheme where the public and government contribute to help pay for cancer and other health services?
17. Is there anything else you would like to tell me about your experience or what you expect regarding cancer control, as a patient/survivor?



## Survey questions

Participant ID #:

Thinking back to the time BEFORE you were diagnosed with cancer...

1. Were you aware of any programs in your community to help raise awareness about cancer?  
 Yes  No  Not sure
2. If yes, please tell us more about the program \_\_\_\_\_
3. For how long did you notice the symptoms you described above before you went to see a health provider (doctor/nurse)?  
 Less than 1 month  About 3 – 6 months  Greater than 6 months  Can't remember
4. What did not allow you to seek medical care about this sooner?
5. Were you aware of any programs in your community that would help to detect cancers early?  
 Yes  No  Not sure
6. If yes, please what is the name of the program \_\_\_\_\_
7. Did your health provider (doctor or nurse) ever recommend that you should be screened for cancer before the disease developed?  
 Yes  No  Not sure
8. Were you ever screened for cancer before the disease developed?  
 Yes  No  Not sure

Thinking back to the time AFTER you were diagnosed with cancer...

9. How long did it take from the time you were informed that you had cancer until the time treatment was started \_\_\_\_\_
10. What was behind the delay in starting treatment? (please tick all that apply to you)  
 I didn't have money  Tests were being done  Hospitals were not functioning   
 Treatment was not available close to my home  I was seeking other solutions (e.g. spiritual/traditional)   
 Some other reasons (please state) \_\_\_\_\_

Abia State, does not have a Cancer Control Plan. This plan usually describes how the government/state would create awareness, prevent cancers, provide treatment and generally handle the issues surrounding cancer (just like we have for HIV/AIDS).

11. Do you think it is important for the state to develop a State Cancer Control Plan? Yes  No  Not sure
12. If yes, why is this important to you? (please tick all that apply to you)

Will promote cancer awareness/prevention	Will enhance early detection
Will help control things that cause cancers	Will guide the doctors/nurse on how to care for patients
Will help provide data on cancers in the state	Will provide support for cancer patients
Will guide the public on where to go for cancer services	Some other reason (please state)

13. On a scale of 0 – 10, with 10 being the highest, where would you rank cancer among the diseases which deserve urgent attention from the government and the general public? (please circle one number only)

0	1	2	3	4	5	6	7	8	9	10	
Unimportant			Somehow important			Important			Very important		

14. What aspects do you expect a future cancer control plan for Abia State to focus on, especially regarding breast and cervical cancers? (please tick as many as apply to you)

Promote public awareness/advocacy	Control cancer risk factors (e.g. smoking, alcohol)	
Early detection of cancers	Introduce cancer management guidelines	
Organize data collection/cancer registration	Create support group for cancer patients/survivors	
Improve access to treatment services	Train people to provide cancer services	
Some other aspect (please state)	Improve access to immunization against the viruses that cause cancers (e.g. HPV and HBV)	

15. Why do you think there is no cancer plan in the state? (please tick as many as apply to you)

Our people do not believe that cancer is real	Policymakers had have little/no interest in cancers	
Lack of funds to implement a plan	Lack of data about people affected by cancer	
Some other reason (please state)		

16. How do you think we can overcome the barriers in developing and implementing a cancer control plan for the state? (please tick as many as apply to you)

Educate our people on cancers	Make cancer a public health priority	
Develop the manpower to provide cancer services	Do more research about cancers in Abia State	
Persuade policymakers to create a plan	Create a special fund for cancer control	
Some other reason (please state)	Build partnership between government and other groups to promote/fund cancer control	

To what extent do you agree or disagree with the following statements regarding involvement of patients, health care providers (HCPs), health policymakers (HPM) and non-governmental organizations (NGOs) in developing cancer control plan, especially for breast and cervical cancers?

Stakeholder Involvement	Strongly disagree	Disagree	No Opinion	Agree	Strongly agree
17. Cancer patients/survivors should be involved in developing a cancer control plan.					
18. HCPs should be involved in developing a cancer control plan.					
19. Health policy makers, including primary health care, should be involved in developing a cancer control plan.					
20. NGOs should be involved in developing a cancer control plan.					
21. A multi-disciplinary and multi-sectoral committee should be set up to develop a cancer control plan for the State.					
22. The House of Assembly should pass a Bill establishing an Abia Cancer Agency, just like the State HIV/AIDS Control Agency.					
23. Abia State Health Insurance Scheme should pay for the cost of cancer prevention, screening and treatment services in the state.					
24. The government should develop partnership between government and non-governmental/private organizations as a way of implementing the cancer control plan.					

25. Please comment on stakeholder involvement (especially cancer patients/survivors) in developing and implementing policy related to cancer control.

26. Cancer services (screening, diagnosis and treatment) can often be expensive. How do you think we should pay for them?  
 Patients/Family \_\_\_\_\_ (%)    Government \_\_\_\_\_ (%)    Insurance \_\_\_\_\_ (%)    Others \_\_\_\_\_ (%)

27. If an insurance scheme was created to help pay for cancer and other health services, how likely are you to pay money into it? (Please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

28. If an insurance scheme was created to help pay for cancer and other health services, how much can you contribute per quarter (every three months)? N \_\_\_\_\_

29. If an insurance scheme was created to help pay for cancer and other health, how likely are you to encourage your friends and family to pay money into it?

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

30. If a cancer center (radiotherapy and chemotherapy) is established in the state, how likely are you to refer people there? (Please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

31. How much did/does the treatment cost per month, especially the chemotherapy? \_\_\_\_\_

32. How much did/does the treatment cost per month, especially the radiotherapy? \_\_\_\_\_

33. How much did the surgery cost? \_\_\_\_\_

34. How did/do you pay for your treatment? (please select as many as apply)

Personal funds	Donations from family/friends	Health insurance	
Loan from others	Support from NGO	Free treatment	
Support from NGO	Support from government/politician	Other sources	

Demographics

35. What is your age? \_\_\_\_\_
36. Which of the following best describes your marital status? (please select one)
1. Married  2. Separated/divorced  3. Widowed
4. Single/never married
37. Please indicate the highest level of education you have attained
1. No formal Education  2. Primary School  3. Secondary School
4. Post-secondary (university, polytechnic, etc.)
38. What is your present occupation? \_\_\_\_\_
39. Which of these best describes the place where you received most of your cancer care in Nigeria?
- Private Hospital/Clinic  Missionary Hospital  State General Hospital
- Teaching Hospital  Other (Please Specify) \_\_\_\_\_
40. What is your sex? Male  Female  Prefer not to say
41. In what year were you first diagnosed with cancer? \_\_\_\_\_
42. What form of cancer were you diagnosed with? Breast  Cervical  Other (please state) \_\_\_\_\_
43. How long did/has your treatment last(ed)? \_\_\_\_\_
44. How much do you think is your family total monthly income? (Please tick one)
1. <del>N</del>20,000  2. <del>N</del>20,000 – <del>N</del>36,000  3. <del>N</del>36,000 – <del>N</del>69,000
4. <del>N</del>69,000 – <del>N</del>145,000  5. ><del>N</del>145,000
45. Given your experience with cancer, would you like to be involved in raising cancer awareness/advocacy in the community?
- Yes  No  Don't Know
46. Is there anything else you would like to tell me about your experience or what you expect regarding cancer control, as a patient/survivor?

If you would like to participate in a short (10-15 minute) interview to further discuss your experience and expectations, please provide your name and phone number below. We will provide N500 recharge card to appreciate your time.

Thank you

## APPENDIX G Data Collection Tool (Providers)

### Exploring providers' experiences and expectations regarding cancer control in Abia State

#### Providers Key Informant in-depth interview questions

Participant ID #:

1. Please tell me about yourself and your practice (scope: name, age, years in practice, scope of practice, etc.)
2. What is your experience with providing cancer awareness and prevention in your regular practice?
3. Tell me about your experience in managing patients who present with cancers. (scope: financial, family support, uncertainty among healthcare teams, travel to other states, etc.)
4. What are the strengths/good aspects of the current system of managing cancers in the state?
5. What challenges do you face in providing cancer awareness, prevention and treatment in your practice?
6. In what ways would you want the current system of managing cancers to change?
7. In many parts of the world, governments have cancer control plans. This describes how the government/state would create awareness, prevent cancers, provide treatment and generally handle the issues surrounding cancer (just like we have for HIV/AIDS). If we had such a system in Abia State, how would it help in your cancer experience?
8. It has been recommended that multiple stakeholders who are impacted by cancers (cancer patients, health care providers, health policymakers, etc.) should come together to develop cancer control plans for their areas. How do you suggest that we should go about this in Abia State, as a healthcare provider?
9. What is most important to you that should be in any cancer control plan?
10. What do you think could prevent us from having an effective cancer control plan in Abia State?
11. How do you think we can overcome the barriers you have identified above?
12. Given your experience with this disease, would you be interested in promoting cancer control in your community and among your colleagues?
13. What sort of training do you think healthcare providers in Abia State would need regarding cancer control?
14. How do you think a partnership between the government (public) and non-governmental/private organizations would help improve cancer control in Abia State?
15. From your experience, how would you like cancer services (screening, diagnosis, treatment) to be funded? (who should pay for it)
16. What is your opinion on creating an insurance scheme where the public and government contribute to help pay for cancer and other health services?
17. Is there anything else you would like to tell me about your experience or what you expect regarding cancer control, as a healthcare provider?

### Providers Survey Questions

Participant ID #:

Thinking back to your practice with regular/non-cancer patients...

- Are you aware of any programs in your community or hospital that help to raise awareness about cancers?  
Yes  No  Not sure
- If yes, please tell us more about the program \_\_\_\_\_
- Are you aware of any programs in your community or hospital that provide early detection (screening) of cancers?  
Yes  No  Not sure
- If yes, please tell us more about the program \_\_\_\_\_
- How could your practice be more involved in promoting cancer awareness and prevention? (please select all that apply)

Create cancer awareness in hospital/clinic	Provide new screening services	Collaborate with other providers and organizations
Counsel patients on cancer risk factors (e.g. smoking)	Integrate cancer services into other services (e.g. family planning)	Other approaches (please state)

Thinking back to your practice with cancer patients...

- How long (months) does it take, on average, from the time patients are diagnosed with cancer until the time treatment is started \_\_\_\_\_
- What do you think causes this relative time lag between diagnosis and treatment? (please tick all that apply to you)

Patients don't often have money	Tests results take time
Hospitals not functioning sometimes (e.g. strike)	Preferred treatment is not often available close to their home
Patients seek other solutions prior to settling for medical care (e.g. spiritual/traditional)	Some other reason (please state)

- What proportion of your patients would you say receive their treatment as prescribed? (i.e. having surgery on time, completing chemotherapy when due, etc.) (please tick  <25%  25-30%  30-75%  >75%  one)
- What challenges do you face in providing the treatment for patients diagnosed with cancer?

Ignorance among patients (they just don't know)	Influence of cultural and religious beliefs	Non-availability of treatment modalities (e.g. drugs, radiation, etc.)
Lack of an organized local approach to guide me (unlike HIV/AIDS)	Inability of patients to afford existing treatment	I do not have adequate training to manage cancer patients
Other issues (please state)		

- What changes would you expect in the process of providing cancer treatment in the state? (please tick all that apply)

Improve training for healthcare providers	Integrate cancer control activities with other services (e.g. family planning)	Improve availability of treatment modalities (e.g. drugs, radiation, etc.)
Create an organized local approach (like HIV/AIDS)	Improve access to treatment (e.g. through subsidy or health insurance)	Other issues (please state)

Abia State does not have a cancer control plan. This plan usually describes how the government/state would create awareness, prevent cancers, provide treatment and generally handle the issues surrounding cancer (just like we have for HIV/AIDS).

11. Do you think it is important for the State to develop a state cancer control plan?  Yes  No  Don't Know

12. If yes, why is this important to you?

Will promote cancer awareness/prevention	Will enhance early detection	
Will help control things that cause cancers	Will guide the doctors/nurses on how to care for patients	
Will help provide data on cancers in the state	Will provide support for cancer patients	
Will guide the public on where to go for cancer services	Some other reason (please state)	

13. On a scale of 0 – 10, with 10 being the highest, where would you rank cancer among the diseases which deserve urgent attention from the government and the general public? (please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
Unimportant	Somehow important			Important			Very important			

14. What aspects do you expect a future cancer control plan for Abia State to focus on, especially regarding breast and cervical cancers? (please tick as many as apply to you)

Promote public awareness/advocacy	Control cancer risk factors (e.g. smoking, alcohol)	
Early detection of cancers	Introduce cancer management guidelines	
Organize data collection/cancer registration	Create support group for cancer patients/survivors	
Improve access to treatment services	Train people to provide cancer services	
Some other aspect (please state)	Improve access to immunization against the viruses that cause cancers (e.g. HPV and HBV)	

15. Why do you think there is no cancer plan in the state? (please tick as many as apply to you)

Our people do not believe that cancer is real	Policy makers had little/no interest in cancers	
Lack of funds to implement a plan	Lack of data about people affected by cancer	
Some other reason (please state)		

16. How do you think we can overcome the barriers in developing and implementing a cancer control plan for the state? (please tick as many as apply to you)

Educate our people on cancers	Make cancer a public health priority	
Develop the manpower to provide cancer services	Do more research about cancers in Abia State	
Create a special fund for cancer control (prevention, screening, diagnosis, treatment)	Build partnership between government and other groups to promote/fund cancer control	
Persuade policymakers to create a plan	Some other reason (please state)	

To what extent do you agree or disagree with the following statements regarding involvement of patients, health care providers (HCPs), health policymakers (HPM) and non-governmental organizations (NGOs) in developing cancer control plan, especially for breast and cervical cancers?

developing a cancer control plan.					
18. HCPs should be involved in developing a cancer control plan.					
19. Health policy makers, including primary health care, should be involved in developing a cancer control plan.					
20. NGOs should be involved in developing a cancer control plan.					
21. A multi-disciplinary/multi-sectoral committee should be set up to develop a cancer control plan for the State.					
22. The House of Assembly should pass a bill establishing an Abia Cancer Agency, just like the State HIV/AIDS Control Agency.					
23. Abia State Health Insurance Scheme should be involved in paying for the cost of cancer services in the state.					
24. The government should develop partnership between government and non-governmental/private organizations as a way of implementing the cancer control plan.					
25. Please comment on stakeholder involvement in developing/implementing policy related to cancer control.					

26. Cancer services (screening, diagnosis and treatment) can often be expensive. What proportion of the cost do you think each category should contribute? (e.g. Patients/Family 100%)  
 Patients/Family \_\_\_\_\_ (%)    Government \_\_\_\_\_ (%)    Insurance \_\_\_\_\_ (%)    Others \_\_\_\_\_ (%)

27. If an insurance scheme was created to help pay for cancer and other health services, how likely are you to pay money into it? (Please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

28. If an insurance scheme was created to help pay for cancer and other health services, how much can you contribute per quarter (every three months)? N \_\_\_\_\_

29. If an insurance scheme was created to help pay for cancer and other health, how likely are you to encourage your friends and family to pay money into it?

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

30. If a cancer center (radiotherapy and chemotherapy) is established in the state, how likely are you to refer people there? (Please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			



31. How much does cancer chemotherapy treatment cost per month in your facility? \_\_\_\_\_
32. How much do you think patients pay for radiation therapy (within the country)? \_\_\_\_\_
33. How much do you think patients pay for surgery cost (e.g. mastectomy)? \_\_\_\_\_

**G. Demographics**

34. What is your age? (years) \_\_\_\_\_
35. What is your sex?  Male  Female  Prefer not to say
36. What is your profession?  
 Physician  Nurse  Other (please state) \_\_\_\_\_
37. Please specify additional specialization \_\_\_\_\_ (e.g. surgeon, oncology nurse, general practitioner, midwife, etc.)
38. In what year did you finish undergraduate/basic training? \_\_\_\_\_
39. Which of these options best describes the place where you practice primarily? (please select one)
- |   |                        |
|---|------------------------|
| Private Hospital/Clinic                             | Missionary Hospital    |
| Teaching/Specialist Hospital/Federal medical center | State General Hospital |
| Other (please state) _____                          |                        |
40. During a typical week, approximately how many patients would you see in your primary practice location? \_\_\_\_\_
41. Please estimate the number of patients ever diagnosed with breast or cervical cancer you have cared for in the last six months? Breast \_\_\_\_\_ Cervical \_\_\_\_\_
42. Have you received any training or instruction on cancer management and control?  Yes  No  Not sure
43. If yes, how did you receive this training? (please select all that apply)
- |   |                                       |
|---|---------------------------------------|
| Formal course (e.g. Residency/Fellowship) | Seminar/continuing education/Workshop |
| Mentorship by colleagues                  | Self-directed learning (e.g. online)  |
| Some other method (please state) _____    |                                       |
44. If no (or if you would like additional training), how would you like this to be delivered? (please select all that apply)
- |   |                                       |
|---|---------------------------------------|
| Formal course (e.g. Residency/Fellowship) | Seminar/continuing education/Workshop |
| Mentorship by colleagues                  | Self-directed learning (e.g. online)  |
| Some other method (please state) _____    |                                       |
45. Is there anything else you would like to tell me about your experience or what you expect regarding cancer control, as a healthcare provider?

If you would like to participate in a short (10-15 minute) interview to further discuss your experience and expectations, please provide your name and phone number below. We will provide N500 recharge card to appreciate your time.

Thank you

## APPENDIX H Data Collection Tool (Policymakers)

### Exploring policymakers experiences and expectations regarding cancer control in Abia State

Participant ID #:

#### Key Informant in-depth interview questions

1. Please tell me about yourself and your practice (scope: name, age, years in service, portfolio, etc.)
2. What is your experience related to the development of policies related to cancer awareness and prevention in your regular job?
3. Tell me about your experience with people in the community who have been diagnosed with cancers
4. What are the strengths/good aspects of the current system of controlling cancers in the state?
5. What challenges do you face in making policies for cancer awareness, prevention and treatment?
6. In what ways would you want the current system of cancer control to change?
7. In many parts of the world, governments have cancer control plans. This describes how the government/state would create awareness, prevent cancers, provide treatment and generally handle the issues surrounding cancer (just like we have for HIV/AIDS). If we had such a system in Abia State, how would it help in your cancer experience?
8. It has been recommended that multiple stakeholders who are impacted by cancers (cancer patients, health care providers, health policymakers, etc.) should come together to develop cancer control plans for their areas. How do you suggest that we should go about this in Abia State, as a policymaker?
9. What is most important to you that should be in any cancer control plan?
10. What do you think could prevent us from having an effective cancer control plan in Abia State?
11. How do you think we can overcome the barriers you have identified above?
12. Given your position as a policymaker, would you be interested in promoting cancer control in your community and among your colleagues?
13. What sort of training do you think health policymakers in Abia State would need regarding cancer control?
14. How do you think a partnership between the government (public) and non-governmental/private organizations would help improve cancer control in Abia State?
15. From your experience, how would you like cancer services (screening, diagnosis, treatment) to be funded? (who should pay for it)
16. What is your opinion on creating an insurance scheme where the public and government contribute to help pay for cancer and other health services?
17. Is there anything else you would like to tell me about your experience or what you expect regarding cancer control, as a health policymaker?

## Policymakers Survey questions

Participant ID #:

Thinking back to your practice as a policymaker...

1. Are you aware of any programs in your community that help to raise awareness about cancers?

Yes  No  Not sure

2. If yes, please tell us about the program \_\_\_\_\_

3. Are you aware of any programs in your community that provide early detection (screening) of cancers?

Yes  No  Not sure

4. If yes, please tell us more about the program \_\_\_\_\_

5. How could your office be more involved in promoting cancer awareness and prevention? (please select all that apply)

Create cancer awareness in the community	Provide new screening services in hospitals/clinics	Collaborate with other providers and organizations
Promote lifestyle changes for cancer risk factors (e.g. smoking, alcohol)	Integrate cancer services into other services (e.g. family planning)	Other approaches (please state)

6. How long (months) do you think it takes, on average, from the time patients in the state are diagnosed with cancer until the time treatment is started? \_\_\_\_\_

7. Why do you think patients delay starting cancer treatment in the state? (please tick all that apply to you)

They don't have money	Tests results take time
Patients seek other solutions prior to settling for medical care (e.g. spiritual/traditional)	Preferred treatment is not often available close to their home
Hospitals not functioning sometimes (e.g. strike)	Some other reasons (please state)

8. What challenges do you think healthcare providers in the state face in providing the treatment for patients diagnosed with cancer?

Ignorance among patients (they just don't know)	Influence of cultural and religious beliefs	Non-availability of treatment modalities (e.g. drugs, radiation, etc)
Lack of an organized local approach to guide them (unlike HIV/AIDS)	Inability of patients to afford existing treatment	Providers do not have adequate training to manage cancer patients
Other issues (please state)		

9. What changes would you expect in the process of providing cancer treatment in the state?

Improved training for healthcare providers	Integrate cancer control activities with other services (e.g. family planning)	Improve availability of treatment modalities (e.g. drugs, radiation, etc)
Create an organized local approach (like HIV/AIDS)	Improve access to treatment (e.g. through subsidy or health insurance)	Other changes (please state)

Abia State, does not have a cancer control plan. This plan usually describes how the government/state would create awareness, prevent cancers, provide treatment and generally handle the issues surrounding cancer (just like we have for HIV/AIDS).

10. Do you think it is important for the State to develop a state cancer control plan?  Yes  No  Don't Know

11. If yes, why is this important to you?

Will promote cancer awareness/prevention	Will enhance early detection
Will help control things that cause cancers	Will guide the doctors/nurses on how to care for patients
Will help provide data on cancers in the state	Will provide support for cancer patients
Will guide the public on where to go for cancer services	Some other reason (please state)

12. On a scale of 0 – 10, with 10 being the highest, where would you rank cancer among the diseases which deserve urgent attention from the government and the general public? (please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
Unimportant	Somehow important			Important			Very important			

13. Why do you think there is no cancer plan in the state? (please tick as many as apply to you)

Our people do not believe that cancer is real	Policymakers had have little/no interest in cancers
Lack of funds to implement a plan	Lack of data about people affected by cancer
Some other reason (please state)	

14. What aspects do you expect a future cancer control plan for Abia State to focus on, especially regarding breast and cervical cancers? (please tick as many as apply to you)

Promote public awareness/advocacy	Control cancer risk factors (e.g. smoking, alcohol)
Early detection of cancers	Introduce cancer management guidelines
Organize data collection/cancer registration	Create support group for cancer patients/survivors
Improve access to treatment services	Train people to provide cancer services
Some other aspect (please state)	Improve access to immunization against the viruses that cause cancers (e.g. HPV and HBV)

15. Why do you think there is no cancer plan in the state? (please tick as many as apply to you)

Our people do not believe that cancer is real	Policymakers had have little/no interest in cancers
Lack of funds to implement a plan	Lack of data about people affected by cancer
Some other reason (please state)	

16. How do you think we can overcome the barriers in developing and implementing a cancer control plan for the state? (please tick as many as apply to you)

Educate our people on cancers	Make cancer a public health priority
Develop the manpower to provide cancer services	Do more research about cancers in Abia State
Pressure policymakers to create a plan	Build partnership between government and other groups to promote/fund cancer control
Some other reason (please state)	

To what extent do you agree or disagree with the following statements regarding involvement of patients, health care providers (HCPs), health policy maker (HPM) and non-governmental organizations (NGOs) in developing cancer control plan, especially for breast and cervical cancers?

Stakeholder Involvement	Strongly disagree	Disagree	No Opinion	Agree	Strongly agree
17. Cancer patients/survivors should be involved in developing cancer control plan					
18. HCPs should be involved in developing a cancer control plan.					
19. Health policymakers, including primary health care, should be involved in developing a cancer control plan.					
20. NGOs should be involved in developing a cancer control plan.					
21. A multi-disciplinary/multi-sectoral committee should be set up to develop a cancer control plan for the State.					
22. The House of Assembly should pass a Bill establishing an Abia Cancer Agency, just like the State HIV/AIDS Control Agency.					
23. Abia Health Insurance Scheme should pay for the cost of cancer prevention, screening and treatment services in the state.					
24. The government should develop partnership between government and non-governmental/private organizations as a way of implementing the cancer control plan.					
25. Please comment on stakeholder involvement in developing/implementing policy related to cancer control.					

26. Cancer services (screening, diagnosis and treatment) can often be expensive. How do you think we should pay for them?  
 Patients/Family \_\_\_\_\_ (%)    Government \_\_\_\_\_ (%)    Insurance \_\_\_\_\_ (%)    Others \_\_\_\_\_ (%)

27. If an insurance scheme was created to help pay for cancer and other health services, how likely are you to pay money into it? (Please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

28. If an insurance scheme was created to help pay for cancer and other health services, how much can you contribute per quarter (every three months)? N \_\_\_\_\_

29. If an insurance scheme was created to help pay for cancer and other health, how likely are you to encourage your friends and family to pay money into it?

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

30. If a cancer center (radiotherapy and chemotherapy) is established in the state, how likely are you to refer people there? (Please circle one number only)

0	1	2	3	4	5	6	7	8	9	10
No comment	Not likely			Likely			Very likely			

31. How much do you think patients pay for chemotherapy treatment every month in the state? \_\_\_\_\_
32. How much do you think patients pay for radiation therapy (within the country)? \_\_\_\_\_
33. How much do you think patients pay for surgery (e.g. mastectomy to remove the breast)? \_\_\_\_\_

**Demographics**

34. What is your age? (years) \_\_\_\_\_
35. What is your sex?  Male  Female  Prefer not to say
36. In what year did you finish undergraduate/basic training? \_\_\_\_\_
37. What is your profession (e.g. doctor, nurse, accountant, politician, traditional ruler, etc.)? \_\_\_\_\_
38. What is your official designation (e.g. Director, Deputy Director, Legislator, etc.)? \_\_\_\_\_
39. Which ministry/local government area/Community do you work in? \_\_\_\_\_
40. How long have you worked in your current position (years)? \_\_\_\_\_
41. Please estimate how many patients ever diagnosed with breast or cervical cancer you are aware of in the last 6 months?  
Breast \_\_\_\_\_ Cervical \_\_\_\_\_
42. Have you received any formal training or instruction regarding cancer control/policy?  
 Yes  No  Not sure

43. If yes, how did you receive this training? (please select all that apply)
- |   |                                       |
|---|---------------------------------------|
| Formal course (e.g. Residency/Fellowship) | Seminar/continuing education/Workshop |
| Mentorship by colleagues                  | Self-directed learning (e.g. online)  |
| Some other method (please state)          |                                       |

44. If no (or if you would like additional training), how would you like this to be delivered? (please select all that apply)
- |   |                                       |
|---|---------------------------------------|
| Formal course (e.g. Residency/Fellowship) | Seminar/continuing education/Workshop |
| Mentorship by colleagues                  | Self-directed learning (e.g. online)  |
| Some other method (please state)          |                                       |

45. Is there anything else you would like to tell me about your experience or what you expect regarding cancer control, as a health policymaker?

If you would like to participate in a short (10-15 minute) interview to further discuss your experience and expectations, please provide your name and phone number below. We will provide N500 recharge card to appreciate your time.

Thank you

## APPENDIX I Copyright Release Letter (Ibom Medical Journal)

**Ibom Medical Journal** <ibomjournal@yahoo.com>  
to me ▾

Sun, Sep 6, 2:07 AM

Dear Dr. Kelechi Eguzo,

We are currently updating information in our website and copyright policy is one of such information. Part of our Journal's policy include authors can hold copyright of their articles without restriction. And also publishing right without restriction. As soon as the information appears on the website, I do not think that you shall need any separate letter of approval. However I like to suggest and advise that you discuss and get the consent of your co-authors. Please do not hesitate to contact us for any further assistance. Thank you.

Dr. Ekpe, E. E.; MBBS, FWACS, FMCS, FACS  
Associate Professor of Surgery & Consultant Cardiothoracic Surgeon  
Editor,  
Ibom Med J.  
<https://www.ibomedicaljournal.org>

## APPENDIX J Copyright Release Letter (Journal of Clinical Oncology)

Using multiple perspectives analysis to propose state cancer control policy in Abia State, Nigeria.

Author: Kelechi Ngozi Eguzo, Uwemedimbuk Smart Ekanem, Oluoha Chukwuemeka, et al

ASCO Journals

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