

A Quantitative and Qualitative Assessment of Cancer Services and Needs at the Four Public Oncology Centers within the Botswana Health System



**UNIVERSITY
of
BOTSWANA**



Republic of Botswana
Ministry of Health



RUTGERS
Global Health Institute

30 MAY 2022

Acknowledgments

The Botswana-Rutgers Partnership for Health would like to acknowledge the managers, department heads, and oncology staff at the four cancer centers: Princess Marina Hospital, Sekgoma Memorial Hospital, Nyangabgwe Referral Hospital, and Letsholathebe II Memorial Hospital. We also thank the Bamalete Lutheran Hospital, where the assessment pilot was conducted.

The assessment team offers special thanks to all focus group discussion participants and members of the public who offered their time to contribute to this assessment.

We also extend thanks to the management of the non-governmental organizations that participated in this assessment, namely the Cancer Association of Botswana, Journey of Hope, and the Francistown Women's Institute.

Additionally, we would like to express our gratitude to Elane Gutterman for her valuable contribution and constructive suggestions in the writing and finalizing of the report. Her willingness to offer her time so generously is greatly appreciated. We also acknowledge Vibha Mittal for her excellent work on the graphics for the report.

We gratefully acknowledge the following contributors:

1. Oncology nurses who assisted in organizing focus group discussions:
 - Princess Marina Hospital: Tumisang Segadimo, Keaobaka Kebuang, Bontshwanetse Baaitse
 - Sekgoma Memorial Hospital: Chaikhwa Lobatse
 - Nyangabgwe Referral Hospital: Irene Kablay
 - Letsholathebe II Memorial Hospital: Thembani Kenalemang
 - Bamalete Lutheran Hospital: Neo Matula, facilitator of the pilot of focus group discussions and surveys among health care workers and patients
2. Non-governmental organizations that participated in the Cancer Resources Survey:
 - Cancer Association of Botswana: Boitumelo Ndebele, Motlagomang Gare
 - Journey of Hope: Onica Lekuntwane
 - Francistown Women's Institute: Samba Nyirenda
3. Botswelero Clinic staff who provided a venue for focus group discussions and participated in the surveys:
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This work was supported by the Botswana Ministry of Health, the Office of the Chancellor at Rutgers Biomedical and Health Sciences, and a grant from Bristol Myers Squibb.

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List of Abbreviations

ART	antiretroviral therapy
BNCR	Botswana National Cancer Registry
BRPH	Botswana-Rutgers Partnership for Health
CAB	Cancer Association of Botswana
CAM	cancer awareness measure
CMS	Central Medical Stores
CT	computer tomography
EML	Essential Medicines List
EMR	electronic medical record
FGD	focus group discussion
FNA	fine needle aspiration
FWA	Federal Wide Assurance number
FWI	Francistown Women's Institute
GPH	Gaborone Private Hospital
HDR	high dose rate
HIC	high-income country
HRDC	Health Research and Development Committee
IDCC	infectious disease care clinic
IPMS	integrated patient management system
IRB	Institutional Review Board
JoH	Journey of Hope
LMICs	low- and middle-income countries
RA	research assistant
MoH	Ministry of Health
NEML	National Essential Medicines List
NCD	non-communicable disease
NGO	non-governmental organization
NHL	National Health Laboratory
NRH	Nyangabgwe Referral Hospital
PALM	pathology and laboratory medicine
PMH	Princess Marina Hospital
PSA	prostate-specific antigen
SA	South Africa
SOP	standard operating procedure
SSA	sub-Saharan Africa
TAT	turnaround time
VIA	visual inspection with acetic acid
VMA	vanillylmandelic acid
WHO	World Health Organization

Summary and Recommendations

This **Quantitative and Qualitative Assessment of Cancer Services and Needs at the Four Public Oncology Centers within the Botswana Public Health System** identified critical challenges in the provision of cancer services. Below are summaries of these challenges and broad recommendations for each:

1. The four public oncology centers have the capacity to offer cancer treatment services, although ***essential cancer treatment modalities and surgery are not currently available at all cancer centers***. While chemotherapy is available at three of the facilities, it is not available at Sekgoma Memorial Hospital. Cancer patients from Sekgoma are referred to the Nyangagbgwe Referral Hospital (NRH). Surgery is available where there is a resident surgeon at the facility. At the time of this assessment, Letsholathebe did not have a surgeon. Radiation therapy is not available at any of the four cancer centers. Cancer patients requiring this treatment are referred to the Gaborone Private Hospital (GPH).

Recommendations: Ensure timely access to (though not necessarily provision of) essential cancer surgery and treatment modalities at all public oncology centers.

2. ***Most cancers are diagnosed at advanced stages***. While Botswana has a Cervical Cancer Screening Program, this is currently the only formal screening program. Health care workers described not knowing how to identify cancer and care for cancer patients, contributing to their low index of suspicion. Focus group discussions (FGDs) among patients, caregivers, survivors, and the general population show that there is a need for more community education. Poor referral networks and practices, as well as poor documentation and unreliable electronic medical records (EMRs), worsen patient delays.

Recommendations: Implement measures to maximize earlier diagnosis of cancer types that can be detected at earlier stages (e.g., breast, prostate, colon).

3. There are ***persistent delays from patient presentation to cancer diagnosis***. The assessment showed that, on average, patient delay ranged from two to six months. Factors that contribute to delay in diagnosis include low rates of cancer detection (low index of suspicion) by health care workers, inefficient referral practices, and inadequate mechanisms to help patients move through the system.

Recommendations: Increase efficiency of referral practices and add mechanisms (e.g., patient advocacy or help centers and patient navigators) to assist patients.

4. ***Turnaround times (TATs) for pathology results are lengthy and unreliable***. Arguably one of the biggest challenges in Botswana is the small number of trained pathologists in the country. A

large proportion of pathology procedures are undertaken at the National Health Laboratory (NHL) branches in Gaborone and Francistown, and molecular testing is performed only in South Africa (SA).

Recommendations: Expand laboratory capacity and improve TATs through training, digital options, and investments in pathology diagnostic capacity and information systems.

5. Most oncology care in Botswana is performed by non-oncology specialists and other health care staff. The country has *serious staff shortages in oncology, with many insufficiently trained personnel* who “learn on the job.” Most oncologists are foreign nationals (usually recruited from Cuba and China) who practice in the country for a specified period of time. These specialists are often not promptly replaced on the expiry of their contracts. Additionally, the shortage in staff contributes to delays in patients receiving care.

Recommendations: Increase training opportunities and outsourcing of radiation facilities and strengthen specialist care to improve cancer diagnosis and management. Use audit tools to identify and address inefficient laboratory processes.

6. Health care workers recommended that *cancer be prioritized by policy makers with a focus on prevention* (strong health education and promotion, screening, and early detection). There was a reported need to ensure cancer screening was part of routine health care consultations, similar to other non-communicable diseases (NCDs). Health education on cancer was of interest across a broad range of groups, including patients, caregivers, general population, and health care providers.

Recommendations: Strengthen the capacity of health care workers across all cadres for cancer prevention. Cancer prevention, screening, early detection, and outreach programs should be considered, along with timely and comprehensive care of patients who are diagnosed through earlier detection.

7. Across the four cancer centers, there are *varying provisions of palliative care*. Palliative care should start after cancer diagnosis and be available to all cancer patients, regardless of stage. Provision of this service should be complemented by hospice and home-based care capabilities.

Recommendations: Integrate palliative care into all phases of cancer management.

8. FGDs among cancer patients and health care workers showed that *there is inadequate psychological and social support for cancer patients and for the staff treating them*. Patients reported a lack of support in their respective facilities and noted particular challenges with treatment and care for patients with advanced cancer. This includes assistance with transport fare

to facilities and food supplies, stronger home-based care support, and professional family counseling provision to patients and caregivers.

Recommendations: Add training and services to better meet psychological and social support needs. Cancer support groups should be encouraged, supported, and facilitated. Patient navigators, social workers, and psychologists should be included as part of multidisciplinary (interprofessional) cancer care teams at each site. Support structures for health care workers are needed to address the emotional and psychological impact of caring for cancer patients.

9. The assessment highlighted numerous *deficient organizational procedures at the public oncology centers* that impede the provision of quality cancer care. The high staff turnover further diminishes consistency of care. Currently, the Ministry of Health (MoH) has released cancer management guidelines for cervical, breast, colon, and head and neck cancers, although instruction for health care workers is required to ensure implementation.

Recommendations: Strengthen standardization of care according to guidelines and care protocols with documentation and add the subsequent training for health care workers to implement such standardized care.

10. There is *minimal data collection at the public oncology centers to inform planning*. The use of the electronic medical record appears to be unreliable and, in addition, comprehensive information, such as diagnosis, stage, comorbid conditions, and demographics, are often not captured. These vital information fields should also be easily retrievable in aggregate form. Reporting to the Botswana National Cancer Registry (BNCR) is not uniform across all cancer centers, and what data is contained in the registry is of poor quality.

Recommendations: Develop well-functioning, user-friendly information systems. Develop a standard of practice to submit data to the BNCR at district hospitals.

11. While the country has had considerable success in changing HIV infection from a fatal disease to a chronic condition, there is *insufficient public awareness of cancer as a treatable disease*. Botswana should build on the success of its HIV/AIDS programs.

Recommendations: Raise awareness of cancer treatment and resources in the public and among health care workers and amplify survivor stories to offer hope.

12. The country needs a strategy to *decrease smoking as a modifiable risk factor for cancer and other chronic diseases*. Health care workers expressed an interest in training on how to approach and educate the general public on the risks of smoking and toward smoking cessation.

Recommendations: Combine public health initiatives to reduce smoking with expanded tobacco control regulations and fiscal policies.

1. Introduction

Cancers account for 7 percent of all deaths in Botswana. As an upper-middle income country, Botswana is undergoing an epidemiologic transition, facing the dual burden of infectious diseases and rising NCDs. Rapid urbanization and rising lifestyle-related risk factors (such as tobacco use, alcohol use, physical inactivity, and obesity) are coupled with one of the highest HIV prevalence rates globally. In addition, as the HIV-infected population has aged, cancer has become increasingly common. Many patients present with advanced disease, and cancer mortality is almost 63 percent. Cancer screening is uncommon in the public sector; however, efforts to improve access are underway, especially for cervical screening.

One of the key challenges for cancer care in Botswana is the lack of human resources, such as trained specialists in many fields, such as pathology, clinical oncology, radiology, surgical subspecialties, and medical physicists and engineers. In addition to challenges with human resources, there are often medication stock outs, delayed access to cancer diagnosis, and delayed treatment initiation, due to both patient beliefs and health care delivery system barriers.

There are currently four hospitals in the public health system in Botswana designated for oncology service provision by the MoH, each of which has distinct population catchments. These include the Letsholathebe II Memorial Hospital, NRH, Princess Marina Hospital (PMH), and Sekgoma Memorial Hospital, and, which currently have the capacity to provide cancer services to varying degrees. To decentralize cancer services and improve population access, there is a need to evaluate the current and future needs at these centers, for example, across diagnosis, staging, and chemotherapy infusion as well as supportive care.

This study was, therefore, designed to evaluate the current state of cancer services in the public health system in Botswana and to understand the strengths, weaknesses, and needs regarding the provision of cancer services in the country. Additionally, the aim was to identify the broader gaps in the health care system that impede the provision of quality cancer services. This assessment was completed at the country's four hospital centers designated for oncology services. A mixed-methods approach was used to capture a broad spectrum of perspectives, including those of patients, caregivers, and cancer survivors as well as health care providers and facility management, ensuring engagement of a wide range of stakeholders involved in cancer prevention and care.

This report presents the findings of the needs assessment to help inform the MoH and other stakeholders of the status of cancer care in Botswana. It is hoped that the findings and recommendations will help develop comprehensive models of service delivery and enable stronger health system pathways to address cancer in Botswana now and into the future.

2. Background

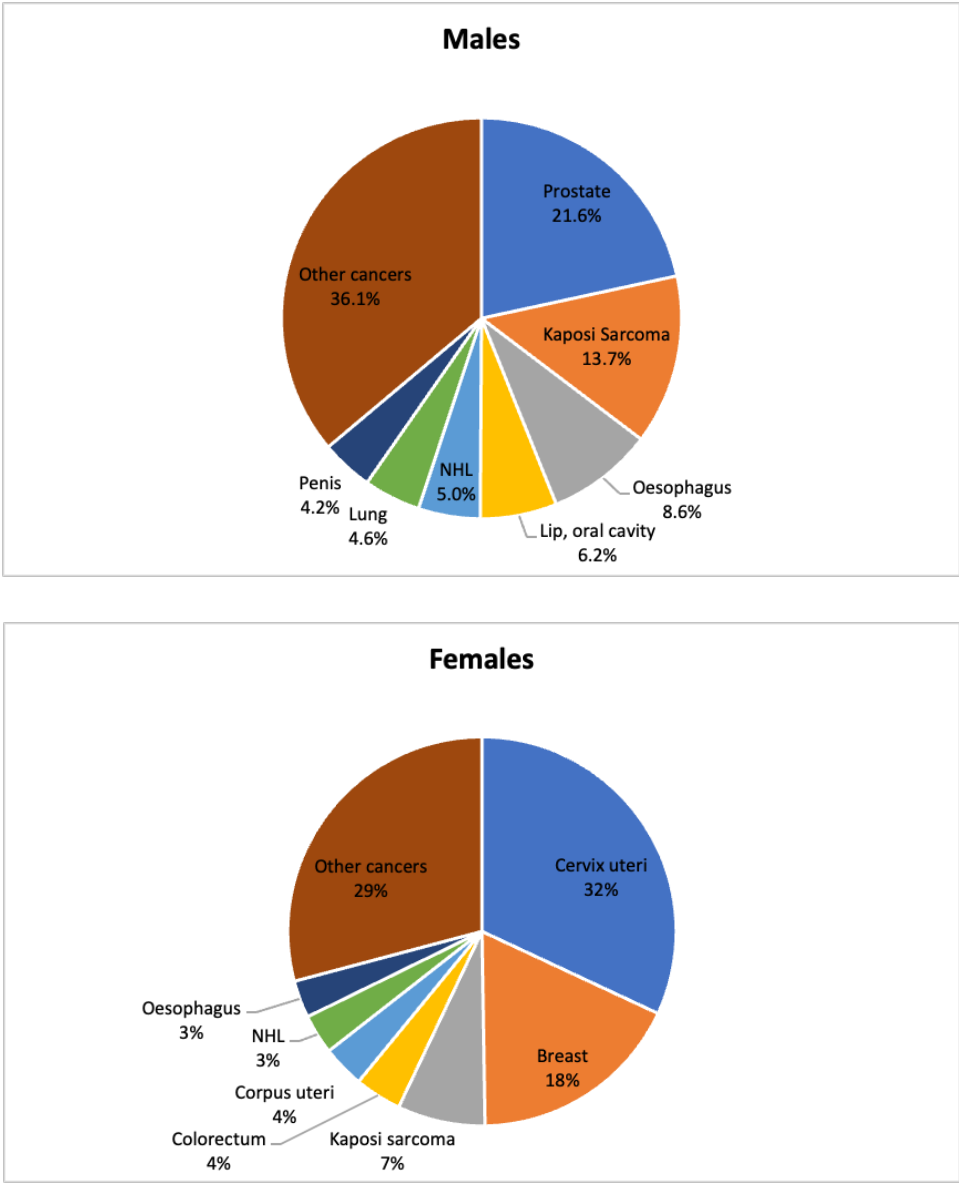
2.1 Burden of NCDs, including Cancer

NCDs are now a leading cause of death globally. In 2016, NCDs accounted for 41 million deaths (71 percent) of all 57 million deaths worldwide.¹ The World Health Organization (WHO) estimates that the greatest NCD burden is within low- and middle-income countries (LMICs), where 78 percent of all NCD deaths and 85 percent of premature deaths occur.¹ The four leading groups of NCDs are cardiovascular disease, cancer, chronic respiratory disease, and diabetes.¹ Cancer has become an increasing problem in sub-Saharan Africa (SSA), where patients are often diagnosed at an advanced stage. According to the Cancer Atlas², in 2018 there were an estimated 752,000 new cancer cases and 506,000 deaths in SSA.²

Botswana is undergoing an epidemiologic transition, facing the double burden of infectious diseases and NCDs because of urbanization, unhealthy lifestyle behaviors (such as tobacco use, alcohol, physical inactivity, and obesity), and one of the highest HIV prevalence rates globally. The 2014 Botswana STEPS survey shows that 30.6 percent of adults are overweight or obese, 18.3 percent smoke, 18.5 percent binge drink, and 95 percent do not eat adequate amounts of fruit and vegetables.³ The four major NCDs, which account for 82 percent of NCD-related deaths in Botswana, are cardiovascular disease, cancer, chronic respiratory disease, and diabetes. Many individuals who have NCDs in Botswana are either undiagnosed or are not aware of their chronic condition. For example, 70 percent of cancers reported in Botswana with staging information are diagnosed at advanced stages, which limits the impact of treatment and the prospects of survival.³

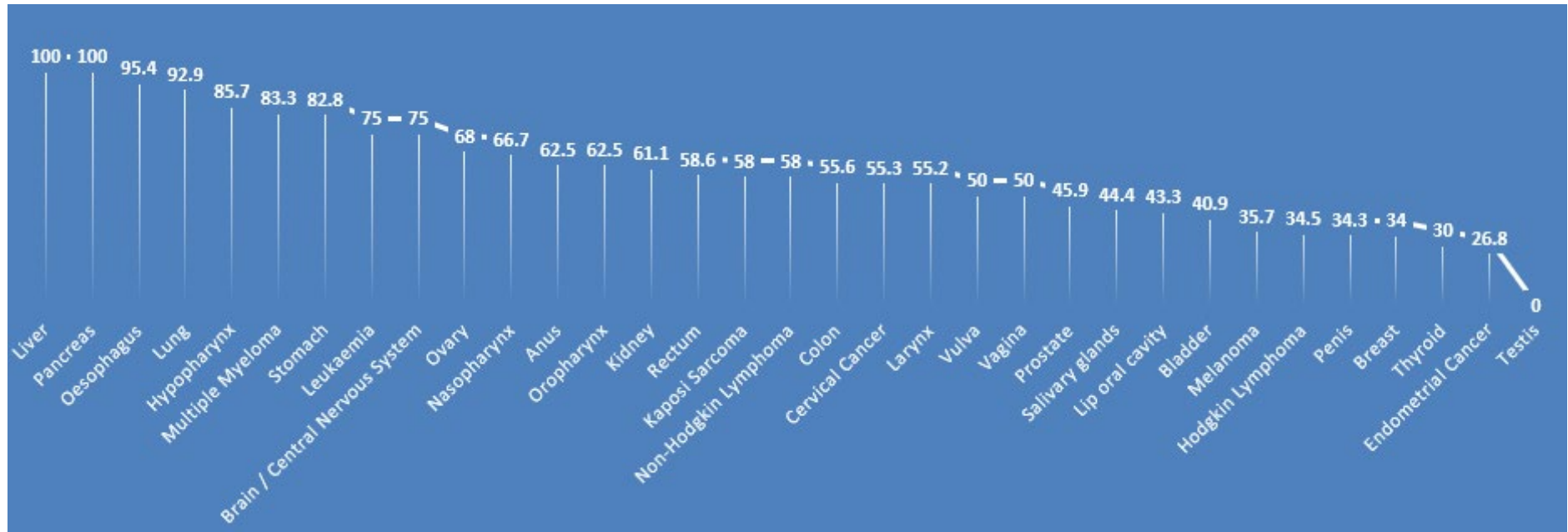
In 2020, a total of 2,010 new cancer cases were reported in Botswana, with a total of 1,112 deaths (Figure 1).⁴ In men, the three most common cancers were prostate, Kaposi sarcoma, and oesophageal cancer. In women, the three most common malignancies were cervix uteri, breast, and Kaposi sarcoma.⁴ According to Chandrakanth,⁵ both cancer incidence and mortality are expected to increase.

Figure 1. Estimated Number of New Cancer Cases in 2020, Botswana, Males and Females



For both sexes combined, the most common cancers in Botswana were cervix uteri (18.6 percent), breast (10.4 percent), and Kaposi sarcoma (10 percent).⁴ Cancer types linked to the highest proportions of cancer deaths were cervix (15.6 percent), Kaposi sarcoma (13.2 percent), esophagus (9.8 percent), breast (6.4 percent), and liver and non-Hodgkin’s lymphoma (5.6 percent).⁶

Figure 2. Mortality to Incidence (%) for Cancers in Botswana



Source: World Health Organization GLOBOCAN 2020

The proportion of deaths linked to a specific cancer type is a function of both incidence and case mortality (Figure 2). In women, after cervical cancer, breast cancer is the second highest cancer type for proportion of cancer deaths. Overall, cancers of the liver, pancreas, and esophagus are the most lethal by case mortality.

2.2 Challenges for Cancer Services Delivery in Botswana's Health System

Botswana aims for a multipronged approach to cancer prevention and control, which involves primary, secondary, and tertiary prevention, which is integrated with the national NCD program. Specialized oncologic services are available in variable supply through referral to the four public oncology centers (PMH, NRH, Sekgoma Memorial Hospital, and Letsholathebe II Memorial Hospital), as well as two private hospitals (GPH and Bokamoso Private Hospital). Ideally, cancer management is overseen by multidisciplinary (interprofessional) teams, which often include a radiologist, a pathologist, a surgeon, a medical and radiation oncologist, specialist nurses, physiotherapists, and social workers. In addition, health care systems should have well-defined, patient-centered referral systems with linkages to secondary care. These multidisciplinary (interprofessional) teams and referral systems require strengthening in SSA countries to enhance cancer care.⁷

Diagnosis (including pathology-based diagnosis) and treatment (including chemotherapy, surgery, and radiotherapy) are available to all Botswana citizens for free through the public health care system. Supportive and palliative care is an integral part of cancer management, which includes other professional services like social work, psychology, occupational health, and hospice and home-based care programs.⁸

A key challenge for cancer care in Botswana is the lack of human resources, such as trained specialists in fields such as pathology, clinical oncology, radiology, and surgical subspecialties as well as medical physicists and engineers.⁹ There is a high (two to four yearly) turnover of specialists seconded by development partner countries. Oncology care in Botswana is primarily provided by non-oncology specialists. There are no formal courses in oncology in either undergraduate or graduate health professions education (such as medical, nursing, or pharmacy); therefore, new graduates learn on-the-job knowledge and skills.

In addition, studies have shown that, at both government and private hospitals, there are shortages in chemotherapy and other antineoplastic drugs, which cause interruption in the administration of multidrug regimens, and there are stock outs of drugs that manage the complications of therapy, like antiemetics, antibiotics, narcotics, and growth factors.⁹ Martei et al¹⁰ found that Botswana has a high alignment (80.5 percent) of its National Essential Medicines List (NEML) with the WHO Essential Medicines List (EML) published in 2015, which subsequently increased to 85.4 percent in June 2016. This is higher than other countries in the African region (median 34.1 percent) and other high-income countries (HICs) (median 73.2 percent), which demonstrates Botswana's commitment to health care and increasing access to quality medicines. However, despite the agreement between the Botswana NEML and the WHO EML, the study found that significant stock outs occurred for chemotherapy drugs for the most commonly diagnosed cancers in Botswana, including cervical, breast, prostate, and colorectal cancer. The median duration of stock outs was about one month, with impacts on many chemotherapy regimens that are dosed every 14 or 21 days, with patients most likely receiving suboptimal treatment due to delays in therapy, caused by missed doses or reduced efficacy or more expensive chemotherapy

drugs.¹⁰ One of the reasons for stock outs is a lack of accurate chemotherapy forecasting and a lack of standardized treatment guidelines for specific cancers, which causes the inability to predict the demand, because oncologists may have varying treatment practices.¹⁰ Additionally, the projected cost for chemotherapy treatment for the 10 most common cancers in the public health care sector of Botswana is estimated at 2.3 million USD.¹¹ Approximately 66 percent of the budget is allocated to buying rituximab and trastuzumab alone, which is used by 10 percent of the cancer population.¹¹

Other barriers to accessing quality cancer care include long-distance travel to referral hospitals for patients living in rural areas.⁹ Chabner et al¹² highlighted cancer care barriers: overcrowded and understaffed hospitals; unreliable health record systems (e.g., patients traveling with their own medical records, which lack comprehensive information for health care workers to provide continuity of care); drug shortages due to an inefficient system of ordering drugs through the Central Medical Stores (CMS); the public health care sector's provision of cancer medication that is limited to generic cytotoxic drugs, with more expensive medication being used only for targeted purposes in the private health care sector; and palliative care services being suboptimal due to a shortage of pain medications and antiemetics.¹² Livingston et al¹³ add that palliative care for cancer patients in Botswana is suboptimal: oral morphine and codeine are the most commonly used drugs if they are available in the hospital pharmacy, while stronger drugs (antiemetics) are generally unavailable because they are expensive.¹³ The generic metoclopramide is used, but the supply is inefficient.¹³

In most countries in SSA, there are not enough pathology services available, and those that exist are of suboptimal quality. Many countries except South Africa and Botswana have one pathologist per 500,000 residents.¹⁴ Pathology services do not have adequate funding, with national health care budgets allocating less than 15 percent of what was agreed upon by heads of state of countries in the African Union in 2001.¹⁵ Inadequate health funding has resulted in inadequate human and material resources for pathology services, which results in insufficient knowledge and inefficient health care practices. TAT for small biopsies is three to seven days; large surgery, seven to 30 days; fine needle aspiration (FNA), one to seven days; gynecologic services/pap smears, three to 28 days; and diagnostic procedures, seven days.¹⁶

Radiation therapy is available only at GPH. Even though radiation is provided only in the private sector, the Botswana government has made this service available for all citizens by covering the costs of treatment for close to 90 percent of those who lack adequate private health insurance/medical aid. A single linear accelerator and a high dose rate (HDR) brachytherapy device are housed at GPH.⁹ The International Atomic Energy Agency (IAEA) recommends four to eight linear accelerators for a population of 2 million like Botswana, which is more than what is currently available in the country.⁹ The issues highlighted illustrate that Botswana, similar to other countries in the SSA region, now requires a coordinated and comprehensive cancer control strategy. Cancer care services are not geographically distributed within reach of populations, which leads to overburdening certain sites.¹⁷

This has led to the MoH designating four public oncology centers that require capacity building across the nation, to decentralize cancer services and improve access in the capital and regional sites.

2.3 Purpose of Study

The purpose of the study was to conduct a comprehensive cancer care needs assessment in Botswana, involving hospital staff, health care providers, cancer patients and survivors, caregivers, the general population, and local entities that provide cancer care support activities to assess the current state of cancer care. The aim was to identify gaps in the health care delivery system for providing quality cancer care. Interviews were conducted across four public oncology centers: PMH in Gaborone, NRH in Francistown, Letsholathebe II Memorial Hospital in Maun, and Sekgoma Memorial Hospital in Serowe. Health facility managers, cancer patients and survivors, caregivers, health care workers, and the general population were engaged through surveys and focus groups to assess their perceptions, attitudes about health and cancer, experiences with cancer diagnosis and treatment, and perceived needs related to preventive and cancer services. The overall goals were to identify the current levels of service availability as well as inefficiencies in the health care delivery system and to create avenues to improve the provision of cancer care services and support systems in Botswana.

2.4 Study Objectives

The study was intended to conduct a comprehensive cancer care and prevention needs assessment at the four public oncology centers in the public health system to understand the strengths, weaknesses, opportunities, and needs in Botswana.

Primary Objectives

1. Assess the capacity and capability of the health care delivery system to provide quality cancer care and prevention services across the continuum at the four oncology referral centers in Botswana, including PMH, NRH, Letsholathebe II Memorial Hospital, and Sekgoma Memorial Hospital.
2. Specifically evaluate the knowledge, attitudes, and practices among the referral center health care workforce as well as training/mentoring needs.
3. Understand cancer patients' and survivors' perspectives of their cancer journey and survivorship.

Secondary Objectives

1. Assess health care providers' knowledge, attitudes, and practices around cancer care, treatment modalities, and prevention and training needs.
2. Evaluate knowledge, attitudes, and practices toward cancer among cancer patients, caregivers, and the general population.

3. Assess the number and types of community-based organizations and services provided.

2.5 Study Setting

Botswana's public health system, complemented by privately run health facilities, provides universal health care to all citizens and residents. The system is delivered through a decentralized model with primary health care being the pillar of the service delivery system.

The country has 27 geographically distributed hospitals that form a three-tiered system overseen by the MoH:

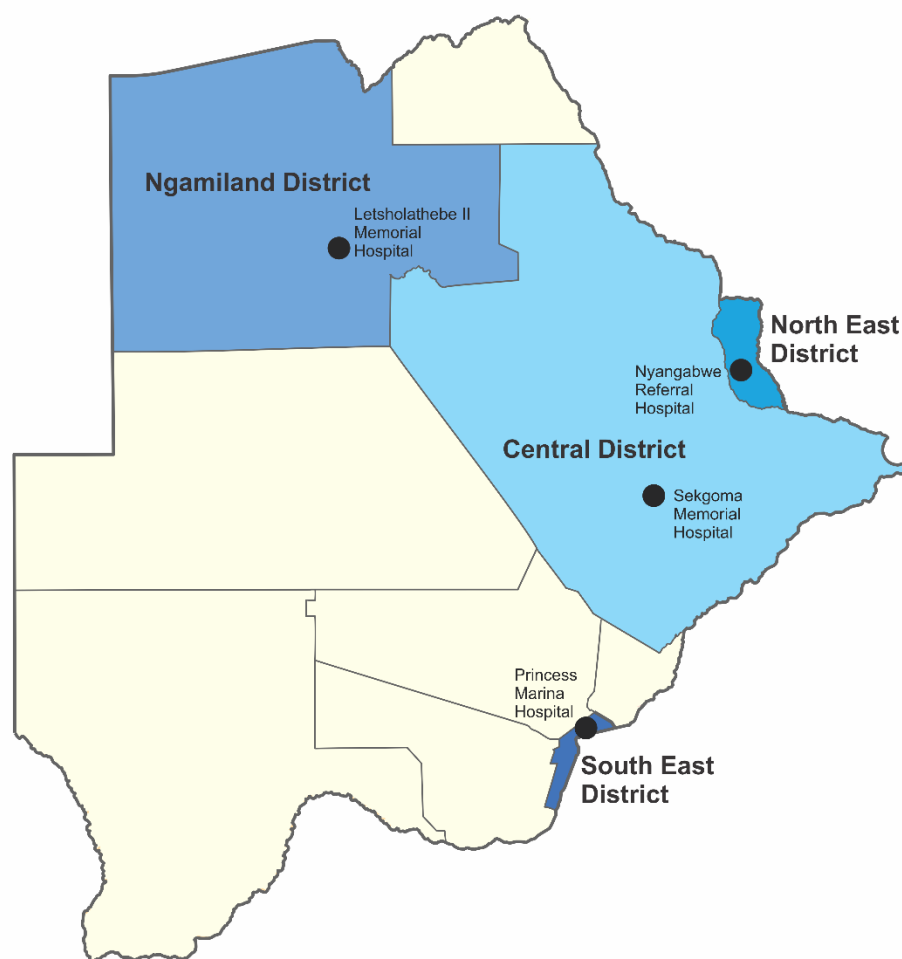
- i. The first tier includes 16 hospitals located in rural areas. Each of these hospitals has between 20 and 70 beds, and each hospital serves a maximum of 10,000 people.
- ii. The second tier is made up of seven district hospitals located in larger villages and cities. Each of these facilities has between 71 and 250 beds.
- iii. The third tier contains three specialized, referral-based hospitals with a bed density of approximately 1.8 beds per 100 people. One of these facilities is a psychiatric hospital.

Table 1. Types of Health Care Facilities in Botswana

Facility Type	Number
Referral hospitals	3
District hospitals	6
Primary hospitals	16
Health clinics with maternity	104
Health clinics without maternity	173
Health posts	338
Mobile posts	844
Private hospitals	6
Private medical clinics	167

Botswana currently has four public hospitals that are designated to provide cancer treatment and care. These facilities offer cancer treatment services of varying degrees and are shown in the map in Figure 3.

Figure 3. Designated Public Oncology Centers in Botswana



Descriptions of the four designated public oncology centers are as follows (also see Table 2):

- PMH in Gaborone is situated in the South-East District of Botswana. According to the Statistics Botswana 2011 *Population and Housing Census*,¹⁸ the district has 85,014 residents.

PMH serves the southern region of the country, catering to patients referred from two districts and eight primary hospitals. The hospital has a dedicated oncology department and a laboratory, although the facility does refer some of its pathology services to the NHL in Francistown.

- Sekgoma Memorial Hospital is a district hospital located in the Central District. According to the Statistics Botswana *Serowe/Palapye Subdistrict Population and Housing Census* of 2011,¹⁹ the total population of the subdistrict is 180,500. The hospital receives referrals from one district and two primary hospitals in the central region.

Situated approximately 300 kilometers from Gaborone, Sekgoma is the largest hospital in the district. The hospital has a single oncologist who is supported by staff members. Although there is a functioning laboratory department, pathology services are referred either to NRH or NHL.

- NRH is located in Francistown, the second-largest city in the North-East District of Botswana. According to the Statistics Botswana 2011 *North-East District Population and Housing Census*,²⁰ the population of the district is 60,264.

The hospital is located approximately 400 kilometers from Gaborone. It is the second of Botswana's three referral hospitals, serving one district and seven primary hospitals. The facility has an oncology department but refers some of its pathology services to the NHL.

- Letsholathebe II Memorial Hospital is located in the North-West District, formerly the Ngamiland District. According to the Statistics Botswana 2011 *Ngami East Subdistrict Population and Housing Census*,²¹ the total population of the subdistrict is 59,421.

The facility is located in Maun, the fifth-largest town in the country, approximately 1,000 kilometers from Gaborone. The facility has one oncologist; nurses from several departments assist with cancer care. Letsholathebe also has a laboratory, although it refers its pathology to NRH. The facility covers two primary hospitals.

Table 2. Characteristics of the Four Designated Public Oncology Centers

	PMH	Sekgoma	NRH	Letsholathebe
Region	Southern	Central	North-East	North-West
Population (2011)	85,014	180,500	60,264	59,421
No. of Beds	530	176	550	320
Hospital Type	Referral	District	Referral	District
No. of Referring Hospitals	10	3	8	2

3. Methodology

3.1 Study Design

This was a multisite, cross-sectional mixed-method study using qualitative and quantitative methods. Surveys and FGDs were used to gather data from the four hospitals designated as public oncology centers, to understand experiences, perceptions, knowledge, attitudes, and practices among facility management, health care providers, cancer patients, cancer survivors, caregivers, and the general public. This mixed-method approach was selected to enable the quantitative survey data on gaps in specific cancer services to be augmented by a wide range of qualitative perceptions and views on cancer services in Botswana.

The survey administration and FGDs took place from September 2020 to April 2021. The surveys were first piloted in Ramotswa at the Bamalete Lutheran Hospital prior to administration at the needs assessment sites. This assessment used measures that were adapted for Botswana, with permission, from the report of the Comprehensive Cancer Needs Assessment in the Central Virginia Health District.²² These measures are presented in the Appendices.

3.2 Study Population

All participants in both the surveys and FGDs were adults (age 18 or older) who provided informed consent. Sociodemographic characteristics such as age, sex, marital status, education, income, HIV status, chronic comorbidities, occupation, and other risk factors were collected for focus groups and in the quantitative part of this study.

Inclusion Criteria

- a. Health care providers at primary and tertiary levels, including physicians, nurses, pharmacy personnel, laboratory personnel, and social workers
- b. Cancer survivors (age 18 or older)
- c. Cancer patients (age 18 or older)
- d. Caregivers to cancer patients and survivors (age 18 or older)
- e. General population adults (age 18 or older)

Exclusion Criteria

- a. Unable to provide informed consent
- b. Under age 18

Sample Size

Quantitative

One of the primary objectives of this study is to evaluate health facility service capacity and knowledge, attitudes, and practices of oncology center health care workers to determine their training and mentoring needs. At the time of this assessment, there were a total of 56 health care personnel who worked with cancer patients at the four centers. The assessment team aimed to interview all staff members, and, therefore, no sample size computation was required. A total of 47 health care workers participated in the quantitative surveys. Nine health care personnel did not participate because they were unavailable at the time of the surveys. In addition, 30 respondents were recruited for the Knowledge, Attitudes, and Practices Survey.

Qualitative

The study sample size has been informed by literature, and, therefore, each focus group consisted of between six and 12 individuals. In all catchment areas, except for PMH, five FGDs were conducted. In the PMH area, a total of four FGDs took place. For this assessment, a total of 19 FGDs were conducted, with a total of 146 participants. All participants were age 18 or older, with 117 females and 29 males as shown in Table 1.

3.3 Participant Recruitment

Patients, Survivors, and Caregivers (FGDs): Research assistants (RAs) identified a “focal person” at the oncology department of each center to assist with identifying potential FGD participants. The focal person was a designated nurse who worked in some capacity with cancer patients. At PMH, the focal person was an oncology nurse, whereas at the other three sites, the focal persons were nurses (principal or general) who worked in oncology. The focal person introduced the assessment to potential participants, noting their contact details. A list of potential participant names was shared with the RAs, who invited them to participate in the FGDs.

General Population (FGDs): In Gaborone and Francistown, RAs sent a letter to the *kgotla* (traditional meeting place). Social workers were assigned to assist the assessment team and undertook participant recruitment. In Serowe and Maun, focal persons liaised with nurses at nearby clinics, who were able to recruit individuals to participate in the FGDs.

Health Care Workers: Health care workers were recruited for participation in both FGDs and clinician questionnaires.

- **FGDs:** In Serowe and Maun, the focal person identified colleagues to participate. In Francistown, the nursing director (matron) assisted the assessment team with recruitment. No

health care worker FGD took place in Gaborone; because most research in the country takes place at PMH in Gaborone, these health care workers declined participation in the FGD part of this study, possibly due to research fatigue; however, they did complete questionnaires.

- **Surveys:** The assessment team met with the management of each facility, who identified staff meeting the criteria for participation in the surveys. The surveys were undertaken at all four cancer centers.

Table 3. Composition and Number of Health Care Facility Survey Respondents

	PMH	Sekgoma	NRH	Letsholathebe	TOTAL
Oncology Staff (Oncologists)	3	1	2	1	7
Oncology Staff (Physicians)	2	0	1	0	3
Oncology Staff (Nurses)	11	1	1	3	16
Hospital Management	2	1	3	1	7
Head of Department	2	N/A	N/A	N/A	2
Palliative Care	2	N/A	2	N/A	4
Laboratory	2	1	N/A	N/A	3
Pharmacy	1	0	0	0	1
Auxiliaries	2	0	0	2	4
TOTAL	26	5	9	7	47

Table 4. Composition and Number of Respondents to Knowledge, Attitudes, and Practices Survey

	PMH	Sekgoma	NRH	Letsholathebe	TOTAL
Family Medicine	2	0	0	0	2
Internal Medicine	0	2	0	0	2
Gynecology	1	0	0	1	2
Surgery	0	1	1	0	2
General Practitioner	0	0	0	1	1
Nursing	4	3	9	2	18
Radiography*	0	0	0	1	1
Dermatology	1	0	0	1	2
TOTAL	8	6	10	6	30

**Includes one radiology technician*

Table 5. Composition and Number of Focus Group Discussion Participants

	PMH	Sekgoma	NRH	Letsholathebe	TOTAL
Patients	9	7	8	9	33
Survivors	5	8	6	7	26
Caregivers	6	7	9	8	30
General Population	8	8	8	11	35
Health care workers	0	8	6	11	25
TOTAL	28	38	37	46	149

3.4 Data Collection Methods

Trained assessment personnel conducted the interviews in accordance with the protocol and Institutional Review Board (IRB) approved standard operating procedures (SOPs). Following the pilot study conducted in Ramotswa at the Bamalete Lutheran Hospital, the interview guides were updated. Data collection then commenced at the four cancer care sites. Individuals who met the inclusion criteria and provided informed consent were then invited to participate in the surveys and FGDs. After completing

the informed consent process, participants were interviewed for one to two hours at a convenient location.

Surveys

In-person surveys were administered to oncology staff (oncologists, physicians, nurses), hospital management, and department heads, as well as personnel who work in palliative care, the laboratory, and the pharmacy. These surveys were administered to one respondent at a time, with responses being entered onto the study tablet (a portable device used to collect survey data) in real time. When health care workers were not able to take the survey at the appointed time, or when the interview had to be paused for the respondent to attend to their duties as a health care worker, RAs started and completed the survey over the phone.

Confirmation of Service Availability

There were discrepancies in responses regarding provision of services and staffing numbers because some health care personnel were temporary or overseas doctors. The study team, therefore, also performed an assessment of service availability according to the following method. Prior to the start of the confirmation of service availability assessment, a focal person at each center was identified by RAs. These focal persons were nurses who work with oncology patients. Due to their work with cancer patients, these focal persons were knowledgeable about all oncology operations at their particular facilities and, therefore, provided a reliable source in confirming the availability of cancer services, diagnostics, and surgeries for the needs assessment.

To validate the responses of the health care workers who participated in the surveys, an RA confirmed service availability with the identified focal person at each site. The study results show the responses from health care workers, and a table illustrating “study confirmed” results. These tables labeled as “study confirmed” therefore illustrate responses as confirmed by study focal persons at the respective sites and are not responses of the health care workers who participated in the surveys.

FGDs

Health care providers at primary and tertiary levels, including physicians, nurses, pharmacy personnel, laboratory personnel, and social workers, participated in FGDs that were conducted in the four oncology sites, which means the staff at these hospitals were eligible to participate in focus groups.

For patient FGDs, purposive sampling was used, with the following inclusion criteria: 18 years of age or older, patient currently undergoing treatment for cancer, cancer survivor, main caregiver for a cancer patient at home, health care worker working as a service provider for cancer patients in the selected facility, and members of the general population with no cancer diagnosis. The FGD participants are

shown in Table 2. Some health care workers who completed the surveys also participated in the FGDs, although no member of hospital management took part in the FGDs.

The interviews were tape recorded in Setswana or English, depending on the preference of the participants. FGDs were recorded, transcribed verbatim, translated, and analyzed for main themes and cross-cutting ideas. Following transcription, any information that could identify the participant (by name or location) was removed, and information was saved with a participant number. The transcribed text from the FGDs was reviewed and compared so that the main topics that were discussed could be identified. Anything that was said during these discussions has been kept confidential.

3.5 Data Management and Analysis

Quantitative Analysis

Data was captured in REDCap and was downloaded as CSV files and then exported to SPSS v27 for analysis. The data was analyzed by surveys:

- i. Knowledge, Attitudes, and Practices Survey
- ii. Health Care Facility Questionnaire
- iii. Laboratory Survey Data

The majority of the questions were categorical, so frequencies were utilized to describe the data. Some questions required continuous responses, hence the mean (standard deviations) and median (interquartile range) were used to describe the data.

For Likert scale variables/items, the means and standard deviations are presented. For some questions, the means were ranked from smallest to largest, representing the most common and least common, respectively. One example is the question that asked health care workers to rank the most common cancers that are diagnosed in patients each year.

For continuous variables such as demographic data, “the average reported time to cancer diagnosis across all providers,” and “the longest and shortest times,” the mean (standard deviation), median (interquartile range), minimum, and maximum are presented.

For the health care facility and laboratory surveys, data required categorical questions such as yes/no answers, and so frequencies and percentages were utilized for analysis.

Qualitative Analysis

Data was tape-recorded during all FGDs. Data was then transcribed verbatim and translated by trained transcribers and translators who were not part of the assessment team. A workshop on coding was then held for the coders for this data, composed of all members of the assessment team as well as three graduate students doing their master's dissertations using qualitative methods, to enhance the quality of the workshop. The coding workshop covered types of qualitative data analysis, defining coding, coding strategies, coding as a team, and coding steps using ATLAS.ti 9 software, and it included a half-day practicum on coding. A code book was developed during the workshop using four transcripts coded by different coders. This code book was then tested using four more transcripts from different FGDs. Once this code book was agreed upon by the research team, four coders independently coded the remaining transcripts using ATLAS.ti 9. The coders had previously received training on ATLAS.ti 9. The coded documents were then merged on ATLAS.ti 9 and code groups formed from coded transcripts by the four coders. Framework analysis of the transcripts then followed to develop themes and subthemes. The framework approach using study objectives, a flexible tool for qualitative approaches that aims to generate themes in multidisciplinary (interprofessional) health research, was employed to systematically analyze the transcripts.

The assessment team created themes and subthemes for cancer survivors and caregivers about their experiences with cancer diagnosis, treatment, follow-up care, and cancer research. In addition, themes and subthemes were created for the general population about their knowledge and awareness of cancer prevention, cancer screening, and research. We also created themes for health care providers regarding knowledge gaps about cancer care and prevention. ATLAS.ti 9 software was used to perform qualitative data analysis on the FGD transcriptions. Results of the qualitative analysis are reported according to the recommendations set out in the standards for reporting qualitative research.²³

3.6 Ethical Considerations

The protocol and all associated documents were reviewed and approved by the University of Botswana IRB, the Health Research and Development Committee (HRDC) in Botswana, and Rutgers IRB. Informed consent was administered during the interviews. Patients were assured of confidentiality and privacy. They were also made aware that participation was voluntary and that they could withdraw consent at any time with no adverse consequences to their access to service provision. Results are presented in aggregated form with no identifying information that can be traced to the participants.

4. Study Findings

4.1 Findings from Health Care Facility Assessment

4.1.1 Medical Staffing

The assessment team conducted interviews with individuals in staff management and hospital administration, such as clinical managers, hospital matrons, and medical officers. The questions focused on current and required staffing numbers. Respondents were asked to provide numbers for nurses, physicians, pharmacists, health education assistants, and social workers. In addition, questions also explored recruitment practices.

The assessment team distinguished between specialists (oncologists) and physicians (non-oncologists) at each of the four public oncology centers. Hospital management were asked how many oncologists were employed at their facilities. As shown in Table 6, the study reports higher numbers than those reported by management. The table is study confirmed.

The current recruitment process involves facilities requesting or recommending additional oncologists to the MoH. The number of requested staff sent to the individual facilities is ultimately determined by the MoH. This is a time-consuming process that has occasionally resulted in qualified candidates being recruited to other facilities, frequently to the private sector.

Table 6. Study Confirmed Total Number of Oncology Staff at the Public Oncology Centers at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Oncologists	3	1	2	1
Physicians	3	2	2	3
Nurses	16	5	6	5
TOTAL	22	8	10	9

4.1.2 Cancer Treatment Services

Oncology staff at each center were asked about the availability of various cancer treatment services.

Table 7. Study Confirmed Availability of Cancer Treatment Services at the Four Public Oncology Centers at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Intravenous Chemotherapy				
Inpatient	✓	x	✓	✓
Outpatient	✓	x	✓	✓
Radiation Therapy				
Inpatient	x	x	x	x
Outpatient	x	x	x	x
Palliative Care				
Inpatient	✓	✓	✓	✓
Outpatient	✓	✓	✓	✓

Chemotherapy

For the purposes of this assessment, the oncology staff comprised oncologists, physicians, oncology nurses, medical officers, and nurses (principal and general).

Respondents from PMH, NRH, and Letsholathebe stated that chemotherapy was provided at their facilities. According to Sekgoma respondents, chemotherapy was not available at the facility due to lack of resources such as a laminar flow machine, and patients requiring this treatment were referred to NRH, approximately 200 kilometers away.

Oncology staff who stated that chemotherapy was provided at their facility were then asked about the capacity of their facility to accommodate cancer patients who needed chemotherapy. Table 8 shows the mean reported capacity for cancer patients to receive chemotherapy by cancer centers.

Table 8. Number of Patients Accommodated for Chemotherapy by Facility

	PMH	Sekgoma	NRH	Letsholathebe
Reported Facility Capacity – Number of Chemotherapy Patients Accommodated	35	N/A	17	4

Radiation Therapy

Radiation therapy is not available in any of Botswana's public health facilities. The country's only radiation machine is located at the GPH. Cancer patients who are prescribed radiation therapy as part of their treatment are referred to the GPH at no cost, regardless of their location in the country.

Palliative Care

For the purposes of this assessment, palliative care was defined as an active and total (holistic) approach to caring for individuals dealing with life-threatening illness.²⁴ The holistic approach recognizes the patient as an individual with unique physical, psychological, social, spiritual, and cultural gifts and needs.

Oncology staff were questioned about palliative care services available to both inpatients and outpatients. The majority of respondents at the four centers indicated that inpatient palliative care was available, and all respondents stated that outpatient palliative care services were available.

Care for Cancer Patients with Comorbidities

Oncology staff do not provide chronic disease management care to cancer patients with comorbidities; however, the services are available in facility medical departments. Staff at PMH noted that, upon discharge, patients are referred to the relevant outpatient clinic, such as the diabetes clinic, for follow-up. According to their responses, care for these patients is inconsistent and is fragmented across the four centers.

4.1.3 Cancer Screening Services

Oncology staff were questioned about the availability of screening and diagnostic services for specific cancers.

The 2016 National Cervical Cancer Screening Program¹⁵ is the only existing cancer screening program in Botswana. This program has integrated cervical cancer screening and management into routine clinical services for both HIV-positive women (beginning at age 25) and HIV-negative women (starting

at age 35). Women with HIV are routinely seen for treatment and care at facility infectious disease care clinics (IDCCs).

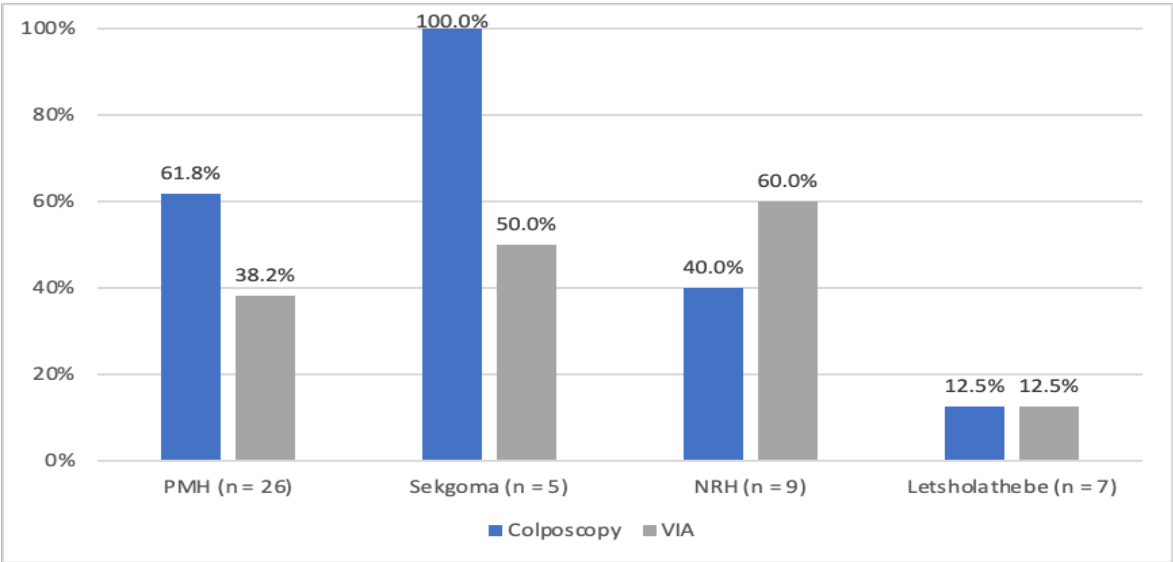
Currently, the public sector has no screening programs for any other types of cancer.

Cervical Cancer Screening

Pap smears are available in both clinics and hospitals. Patients who receive positive results are referred to the designated cancer hospital.

All respondents from Sekgoma, NRH, and Letsholathebe noted that gynecology care is available to patients. Pap smears are widely performed at PMH, including the clinic setting. These responses are encouraging given the adoption of the cervical cancer screening program, which has integrated screening and management into routine primary care clinical services. Figure 4 illustrates oncology staff responses to questions about the availability of the colposcopy and visual inspection with acetic acid (VIA).

Figure 4. Oncology Staff Indicating “Yes” to Availability of Cervical Screening Modalities



Respondents who answered that none of the above-mentioned screening services were provided were asked where patients are referred to for any of these services. According to PMH staff, patients are referred to the private sector. Staff from Sekgoma and Letsholathebe noted that patients are referred to NRH.

Table 9. Study Confirmed Availability of Cervical Cancer Screening Services at the Four Public Oncology Centers at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Gynecology Care	✓	✓	✓	✓
Colposcopy	✓	✓	✓	✓
Pap Smear	✓	✓	✓	✓
Vanillylmandelic Acid	✓	x	✓	✓
VIA	✓	✓	✓	✓

4.1.4 Diagnostic Services

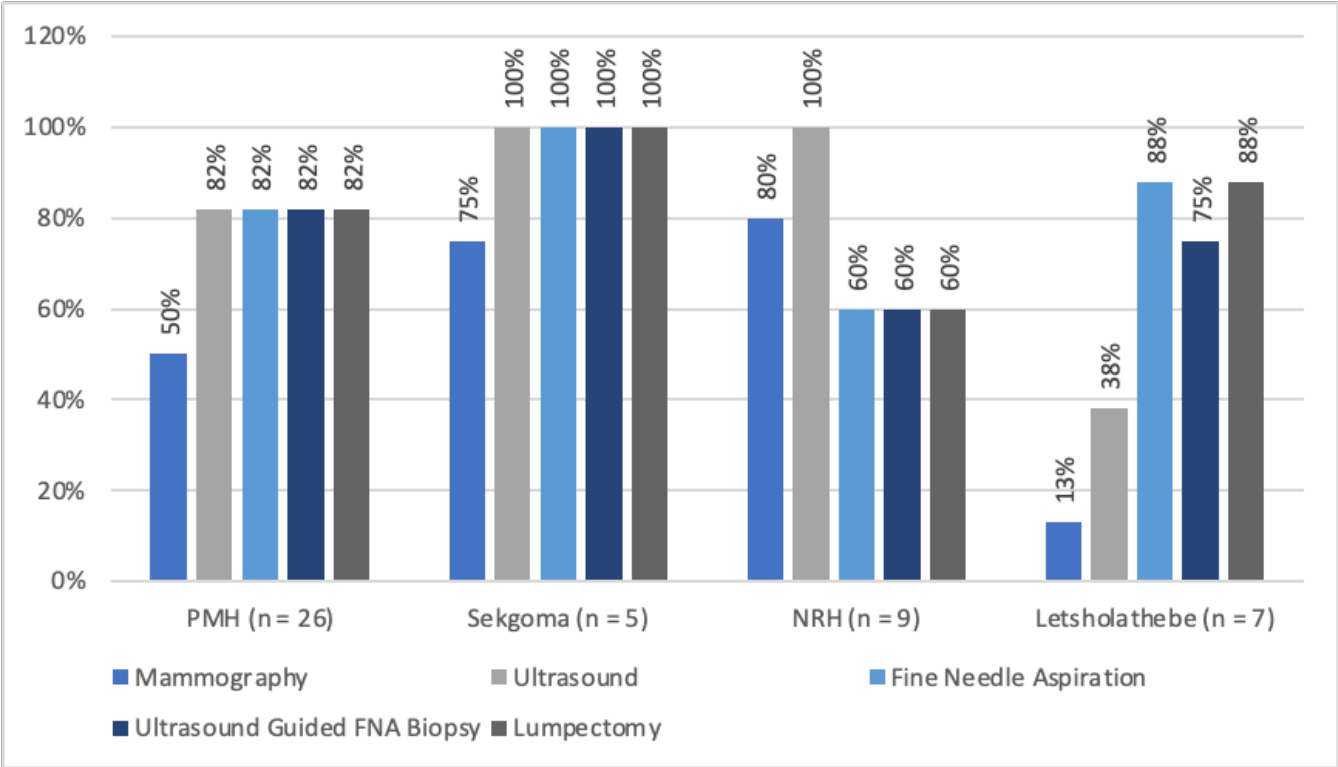
The oncology staff were questioned about the availability of certain diagnostic services.

Breast Cancer Diagnostic Services

Providers indicated that mammography services are limited in Botswana's public health care system. These are primarily available in PMH and NRH. All four public oncology centers reported having breast ultrasound services and ultrasound guided FNA services.

The majority of respondents at PMH and NRH indicated that film mammography was available, whereas only 25 percent of respondents at Sekgoma and Letsholathebe stated the same. Most of the respondents at PMH and NRH indicated that diagnostic mammography is available (Figure 5).

Figure 5. Oncology Staff Indicating “Yes” to Availability of Diagnostic Mammography



Most respondents at PMH, Sekgoma, and NRH confirmed the availability of breast ultrasound. Respondents at the centers stated that FNA and ultrasound guided FNA were available.

Oncology staff who noted the provision of FNA diagnostics were asked a follow-up question about who performed the procedure. Table 10 displays the responses.

Table 10. Oncology Staff Responses to Personnel Who Perform the Fine-Needle Aspiration Procedure

Cancer Center	Personnel Who Perform FNA Procedure
PMH	Surgeons, physicians, NHL
Sekgoma	Surgeons
NRH	Surgeons
Letsholathebe	Oncologists, laboratory technician

When asked about lumpectomy, most respondents at the centers stated that the procedure was available.

Summary of Breast Cancer Diagnostic Services Across the Four Centers

In Botswana, mammography services are solely for diagnostic purposes, and not for screening.

Table 11. Study Confirmed Availability of Breast Cancer Diagnostic Services at the Time of Assessment

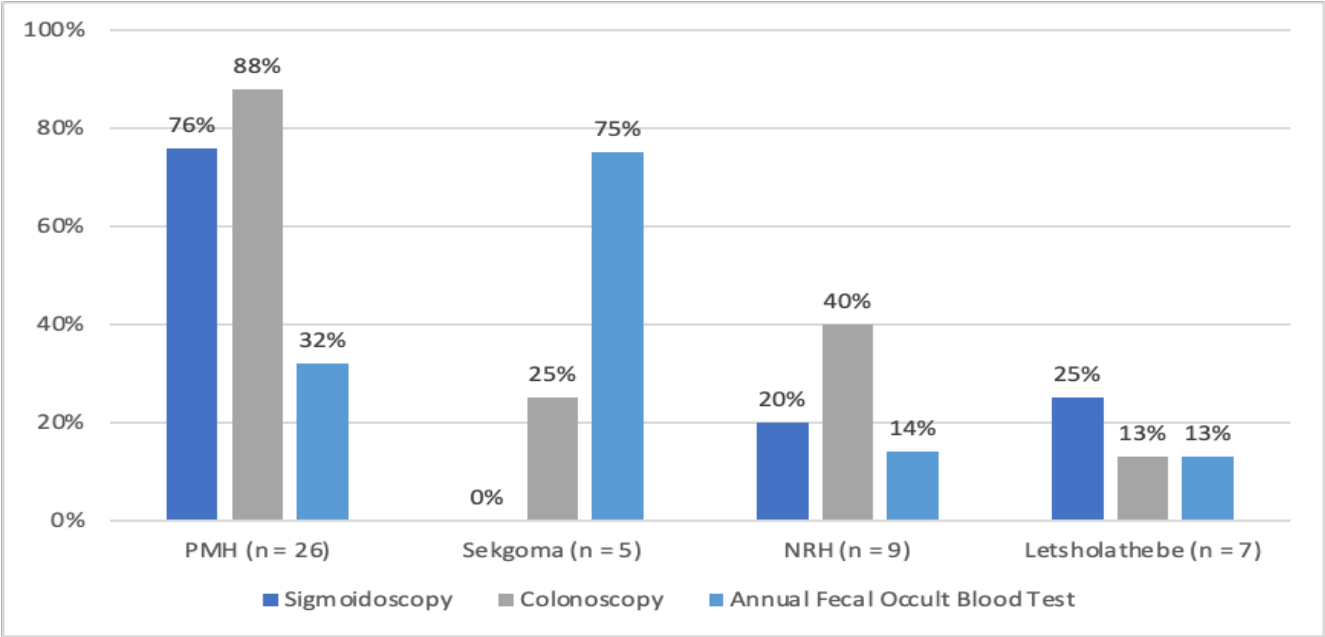
	PMH	Sekgoma	NRH	Letsholathebe
Diagnostic Mammography	✓	x	✓	x
Breast Ultrasound	✓	x	✓	x
FNA	✓	✓	✓	✓
Ultrasound-Guided FNA Biopsy	✓	x	✓	x
Lumpectomy	✓	✓	✓	x

Colorectal Cancer Diagnostics

Respondents were questioned on a wide range of colorectal cancer diagnostic services.

The invasive colonoscopy procedure was reported to be primarily available at PMH, with limited availability at the other three cancer centers. Figure 6 shows participant responses to other procedures. Except for PMH, respondents from all centers verified that these colorectal diagnostic services are unavailable, or they were unaware of their availability.

Figure 6. Oncology Staff Indicating “Yes” to Availability of Colorectal Cancer Diagnostics



Letsholathebe does not provide any of the above-mentioned colorectal diagnostic services, according to a general nurse working in oncology at the facility. The nurse noted that patients are referred to NRH for colorectal cancer diagnostics. They also indicated that the time it takes to receive a report from the diagnostic center is determined by when the patient arrives at the facility. The longest period to receive the report was two months.

Table 12. Study Confirmed Availability of Colorectal Cancer Diagnostic Services at the Time of Assessment

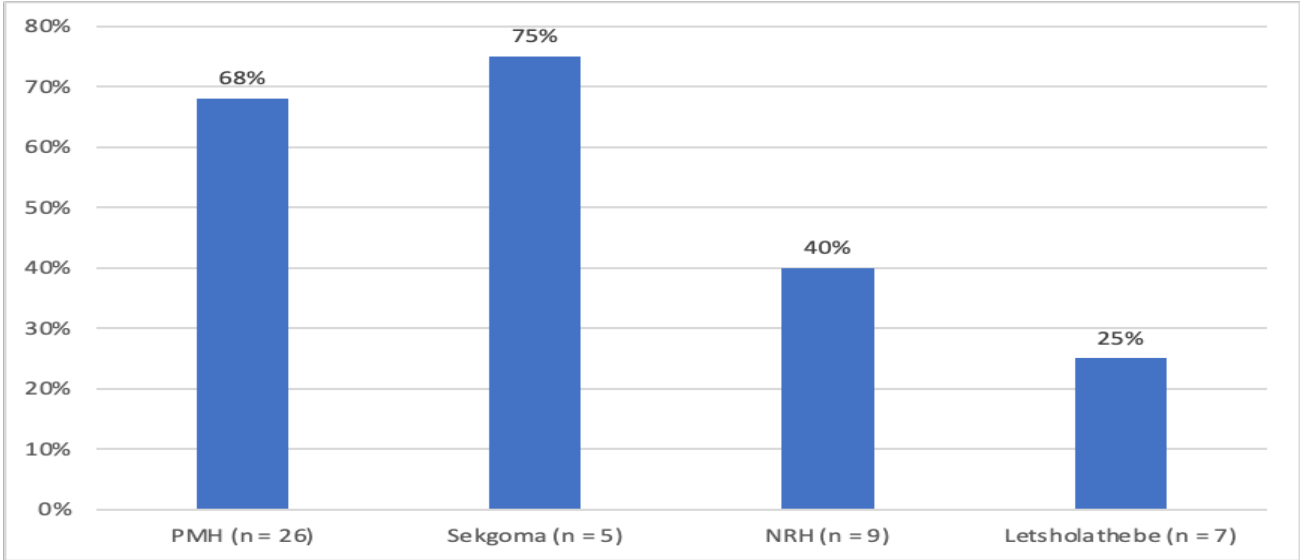
	PMH	Sekgoma	NRH	Letsholathebe
Sigmoidoscopy	✓	x	✓	x
Colonoscopy (Invasive)	✓	x	✓	x
Fecal Occult Blood Test Annually	✓	✓	✓	✓

Prostate Cancer Diagnostics

Respondents were questioned about the availability of prostate cancer diagnostic services. All respondents from Sekgoma and NRH stated that prostate-specific antigen (PSA) testing was available at their facility. At PMH, 94.1 percent stated the service was provided; at Letsholathebe, 12.5

percent answered that the service was available, and 50 percent said they did not know. Figure 7 shows responses when asked about the availability of the digital rectal exam (DRE).

Figure 7. Oncology Staff Indicating “Yes” to Availability of Digital Rectal Exam



When asked about the transrectal biopsy, 41.2 percent of respondents from PMH noted that the service was available. At Sekgoma, NRH, and Letsholathebe, none of the respondents answered in the affirmative. Overall, 33.3 percent of respondents across all centers answered no, and 39.2 percent did not know if the screening was provided.

Table 13. Study Confirmed Availability of Prostate Cancer Diagnostic Services at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
PSA	✓	x	✓	x
Digital Rectal Exam	✓	✓	✓	✓
Transrectal Ultrasound-Guided Biopsy	✓	x	✓	x
Prostate MRI	x	x	x	x
Total Bone Body Scan	x	x	x	x

All sites collect blood samples for PSA and send them to the NHL in Gaborone or Francistown.

Average Time to Diagnose Cancer

Oncology staff were queried on the length of time it takes on average from patient presentation to cancer diagnosis. Table 14 displays the average time to cancer diagnosis by facility. Sekgoma and Letsholathebe district hospitals have a longer time to diagnose cancer than the referral hospitals.

Table 14. Average Time from Patient Presentation to Diagnosis

Cancer Center	Time to Cancer Diagnosis
PMH	2 – 6 months
Sekgoma	3 – 6 months
NRH	1 – 5 months
Letsholathebe	3 – 6 months
Overall Mean Waiting Time	2 – 6 months

4.1.5 Cancer-Related Surgical Services

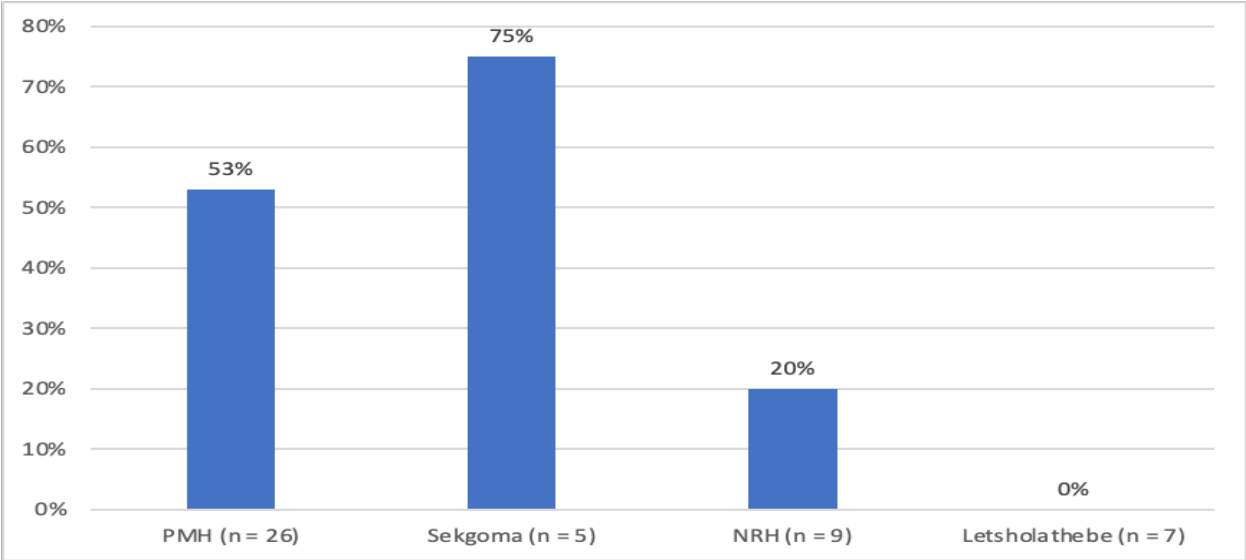
Oncology staff were questioned about the availability of select cancer-related surgeries.

Letsholathebe did not have a surgeon on site at the time of this assessment.

General Surgery On-Site

Respondents were asked if they had on-site access to oncology surgery. Figure 8 shows that the majority of respondents from PMH and Sekgoma confirmed there was access, whereas the majority from NRH and Letsholathebe verified there was no access to oncology surgery.

Figure 8. Oncology Staff Indicating “Yes” to Having Access to Oncology Surgery On-Site



Staff who stated that they had access to oncology surgery were asked to list the types of oncology surgeries available. Surgeons from PMH and Sekgoma were interviewed on the types of surgery available. They are gastroenterology, colostomy, debulking, mastectomy, amputation, hysterectomy, and lymph node removal. PMH and NRH were the only sites that had active surgical theaters when the research was taking place. Sekgoma had a surgeon, but the theater was not operational at the time, so instead they referred to NRH. Letsholathebe did not have a surgeon.

Respondents who answered that they did not have access to oncology surgery were asked what course of action they take for a patient who requires surgery. At Letsholathebe, respondents stated that patients are referred to NRH.

Respondents were then asked about the types of cancer-related surgeries performed at their respective facilities. The question covered female cancer-related surgeries, gastrointestinal surgeries, and surgeries for other select cancers.

Breast and Gynecological Surgery

For breast segmental or complete mastectomy, all respondents from Sekgoma, 92.1 percent from PMH, and 60 percent from NRH noted that these surgeries were performed at their facility. The majority of respondents at Letsholathebe stated that the surgery was not performed. Letsholathebe refers patients to NRH for these surgeries.

Figure 9 shows the responses by center for breast reconstruction, complete mastectomy, hysterectomy/oophorectomy, and ovarian debulking.

Figure 9. Oncology Staff Indicating “Yes” to Availability of Breast and Gynecological Surgery

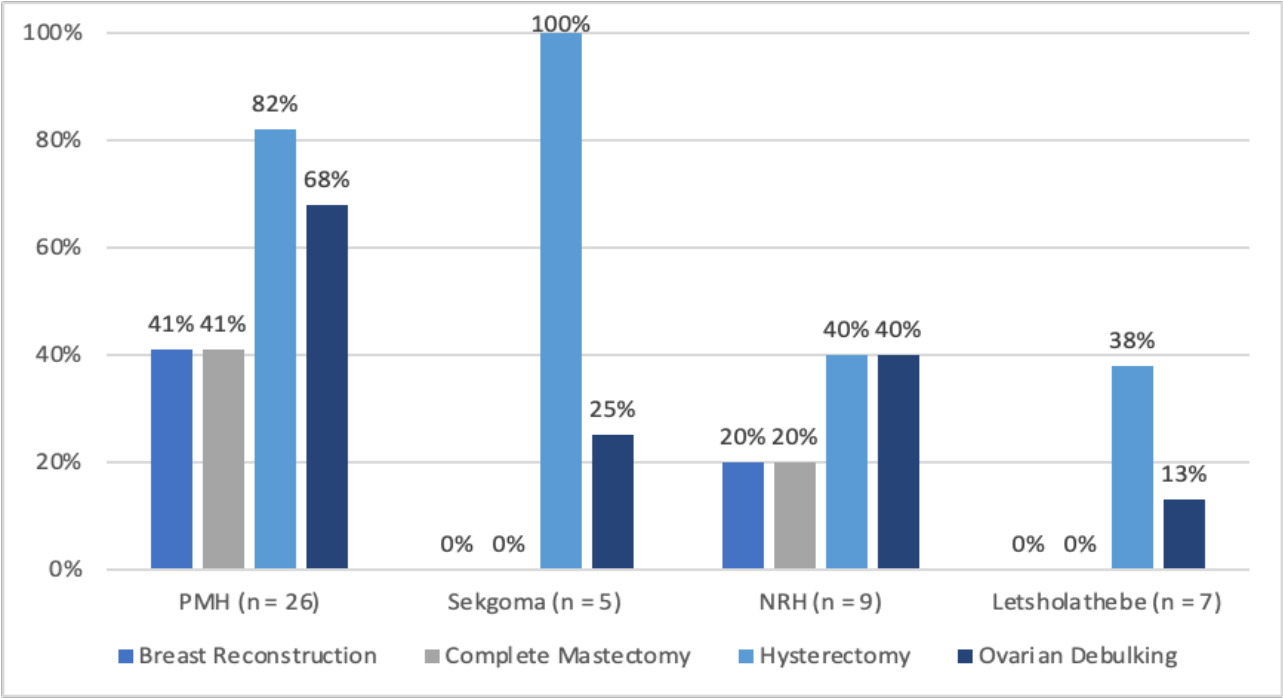


Table 15. Study Confirmed Availability of Breast and Gynecologic Surgeries at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Breast Reconstruction	x	x	x	x
Complete Mastectomy	✓	✓	✓	x
Hysterectomy / Oophorectomy	✓	x	x	x
Ovarian Debulking	✓	x	✓	✓

Gastrointestinal Surgeries

The assessment team sought to determine if gastrointestinal resections of the upper and lower tracts, liver, and pancreas were performed at the cancer centers. Figure 10 illustrates the responses to these questions. PMH oncology staff confirmed that 82 percent of all procedures are available. However, other staff responses indicate that availability is not uniform. All respondents from Sekgoma answered in the affirmative.

Figure 10. Oncology Staff Indicating “Yes” to Availability of Gastrointestinal Surgeries

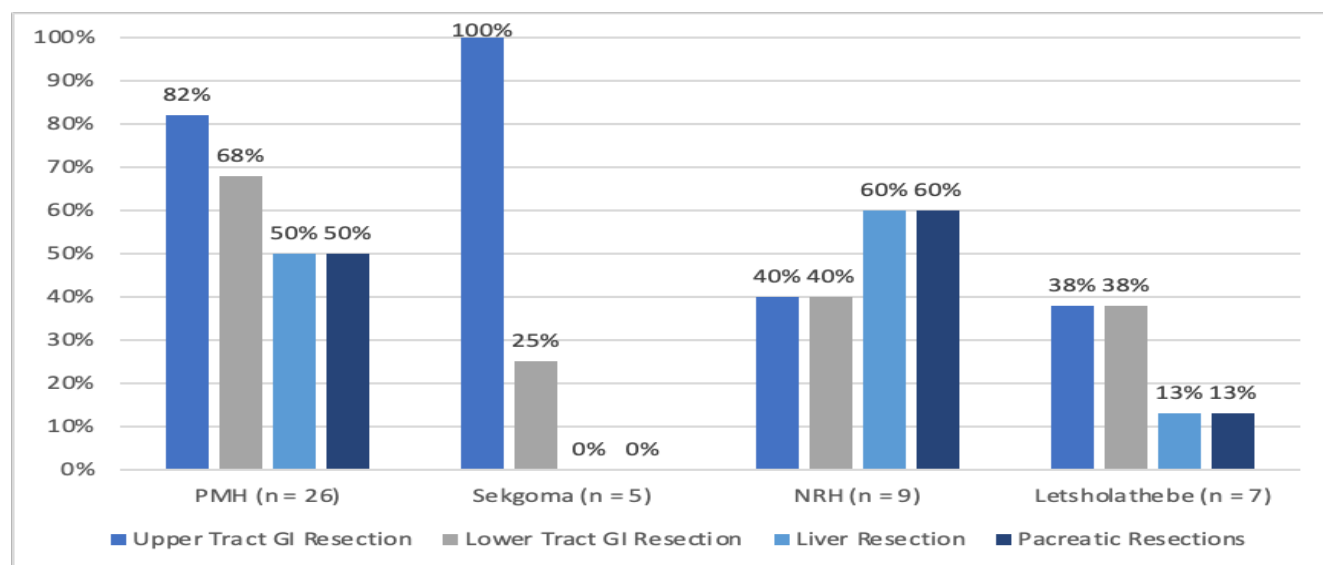


Table 16. Study Confirmed Availability of Gastrointestinal Resections at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Upper Tract Resection	✓	✓	✓	x
Lower Tract Resection	✓	x	✓	x
Liver Resection	✓	x	✓	x
Pancreatic Resection	✓	x	✓	x

Select Cancer Surgeries

Neurosurgery is available only at PMH and NRH. Personnel at Sekgoma and Letsholathebe indicated limited or no availability of brain surgery; lung surgery; and ear, nose, and throat surgery.

According to all respondents at Sekgoma, 40 percent at NRH, and 75 percent at Letsholathebe, prostatectomy is not performed at those facilities. However, 60 percent of respondents at NRH, 18.2 percent at PMH, and 25 percent at Letsholathebe did not know if the procedure is carried out at their respective facilities. The PMH was the only facility where 57.6 percent respondents believed the procedure was available.

Following these questions, respondents were asked if there were any other cancers that were not listed for which surgeries are performed at their facilities. Respondents from PMH mentioned the laparotomy, while those from NRH noted soft tumor and thyroid surgeries.

Table 17. Study Confirmed Availability of Select Surgeries at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Prostatectomy	✓	x	✓	x
Brain	x	x	x	x
Lung	✓	x	✓	x
Ear, Nose, and Throat	✓	x	✓	x

4.1.6 Palliative Care and Patient Navigation Services

A total of nine palliative care personnel were interviewed to gather information on palliative care, hospice services, and support and educational programs. In Botswana, hospices are facilities that provide palliative care. These facilities can be day hospices or inpatient wards run by nurses.

Respondents were first asked about inpatient hospice services and whether they were provided by a facility or a private organization. The majority of respondents across the four centers stated that inpatient hospice services were not available.

Palliative Care Program

When asked if their facilities had a palliative care program, 77.8 percent (seven out of nine) of all centers answered in the affirmative. One respondent at Letsholathebe noted that a program was “coming soon.”

Those who stated there was a palliative care program were asked about the composition of the palliative care team. Table 18 notes the responses.

Table 18. Composition of the Facility Palliative Care Team, as Reported by Palliative Care Staff

	PMH	NRH
Composition of Palliative Care Team	Medical doctor, nurse	Chaplain, medical doctor, nurse, nurse practitioner, social worker, registered dietician

The same respondents were probed on the characteristics of their palliative care program. Table 19 shows their responses.

Table 19. Palliative Care Staff Responses to the Characteristics of the Palliative Care Program

Cancer Center	PMH	NRH
Consultation Service	✓	✓
In-Patient Beds	x	x
Outpatient Clinic	✓	✓

Table 20. Study Confirmed Availability of Palliative Care Services at the Time of Assessment

	PMH	Sekgoma	NRH	Letsholathebe
Palliative Care Program	✓	x	x	x
Cancer Patient Navigators	x	x	x	x
Cancer Prevention and Educational Programs	x	✓	x	x

4.1.7 Laboratory Services

A common challenge identified among hospital staff, health care workers, and all other FGD participants was the length of time it takes to receive pathology results from diagnostic centers.

To understand pathology and laboratory medicine (PALM) services, the assessment team interviewed six laboratory personnel from PMH, NHL, Sekgoma, and Letsholathebe. Respondents from NHL were interviewed at PMH. These facilities have functioning laboratories, although capabilities differ among the facilities.

Laboratory personnel were asked if their facility offers genetic counseling for cancer risk. All respondents answered no. Genetic testing is not offered at these four centers.

Personnel

Laboratory personnel were questioned on the level of training of their personnel on the following procedures:

- i. Simple biopsies
- ii. Core needle biopsies
- iii. Punch biopsies
- iv. Simple excisions
- v. Complex excisions
- vi. Internal organ surgery
- vii. Major surgery

Respondents from PMH rated the skill sets of their personnel as being advanced in all procedures, and those at Sekgoma rated them intermediate in all procedures.

Laboratory Practices

Respondents were questioned about laboratory practices. The preparation of slides, special stains, and immunohistology are not performed on-site, but are referred to the NHL in either Gaborone or Francistown. Molecular testing is referred to South African laboratories.

Pathology

- All respondents from PMH and Sekgoma said that there was no mechanism or pathway to acquire reagents for pathology, nor were there programs to obtain anatomic pathology diagnosis using remote services.
- Laboratory personnel at PMH and Sekgoma reported that their pathology reports are electronic and that pathology results are in the Integrated Patient Management System (IPMS), which is an electronic medical record all public hospitals in Botswana. They also stated that pathological (historic, published, or current) data for the geographic area in which they operate is available. All laboratories are connected to the IPMS.
- Respondents were asked if reported pathology results are sent to the BNCR. Respondents from PMH answered in the affirmative, while those at Sekgoma noted that their results are not sent to the BNCR. Results are reported on IPMS; where the system is not functional, paper records are utilized and then manually entered into the system.

Communication Infrastructure

- Both facilities stated that there is a national identification number for patients that is shared across institutions, as well as a referral network from clinics and/or hospitals.

- All respondents reported that their anatomical laboratories had existing communication infrastructure. Respondents were not aware of the current speed or bandwidth of the internet service at the anatomical laboratory.

Support/Assistance Required

- Respondents were asked what support mechanisms or assistance they required. Those from Sekgoma stated that they would like assistance with pathology in terms of resources and more trained personnel to avoid having to refer to the NHL.
- Respondents from PMH and NHL noted that pathology samples are not given the urgency they deserve, as well as the following needs:
 - i. More pathologists
 - ii. Better equipment
 - iii. Regular supply of reagents
 - iv. An on-site histology and cytology laboratory
 - v. Staff dedicated to pathology samples
 - vi. Training on new techniques

4.2 Findings from Health Care Worker Surveys

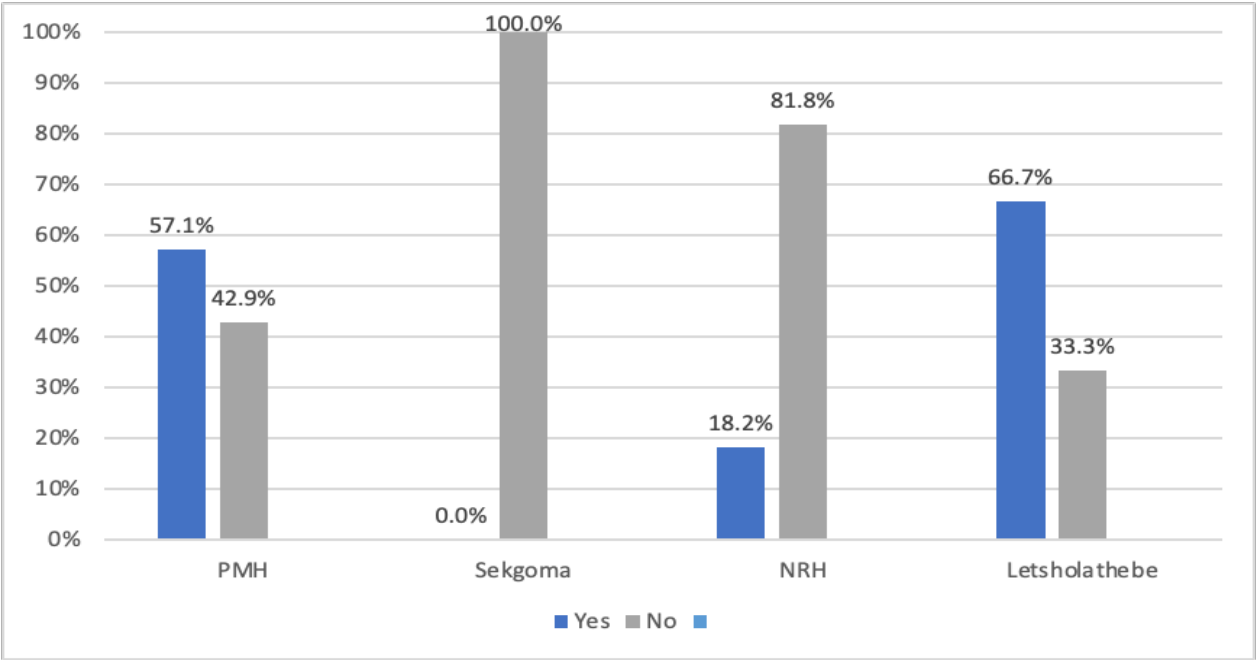
4.2.1 Knowledge, Attitudes, and Practices of Health Care Workers

The population for these surveys were health care personnel who did not work exclusively in the oncology ward nor solely with oncology patients.

A survey was administered to a total of 12 physicians and 18 nurses to enable the study team to assess their knowledge, attitudes, and practices regarding cancer screening, diagnosis, and care, as well as research and clinical trials.

Health care personnel were asked if they were aware of the cancer screening guidelines, as shown in Figure 11. Personnel at Sekgoma and NRH had the highest number of respondents expressing a lack of awareness.

Figure 11. Percentage of Health Care Workers Reporting Their Awareness of Cancer Screening Guidelines



No specific screening guidelines were referred to in the query. That is, the question did not address whether awareness of cancer screening guidelines was related to national guidelines, in-house guidelines, or other types of screening guidelines.

Those reporting knowledge of guidelines were asked about challenges experienced in implementing screening recommendations. In response to the questions, PMH personnel noted delays in the procurement of screening tools, a staff shortage, and poor patient knowledge. Those from Letsholathebe mentioned the weakness of the primary health system, the length of time it takes to receive test results, and a lack of information about numbers of patients tested. One respondent from NRH mentioned the difficulties associated with missing and pending results.

Health care workers were asked their opinion on factors that prevent patients from receiving recommended cancer screening. Respondents from all centers stated that patient fear of diagnosis was one of the top three reasons. PMH and NRH are the only facilities that listed financial constraints as one of the top three reasons. At Sekgoma and Letsholathebe, lack of screening facilities was the number one reason. Sekgoma was the only facility that cited a lack of insurance as one of the top reasons.

Health care workers were further requested to rank on a scale of 1 to 8 (1 being the most common), what they reported to be the most common cancers diagnosed each year at their facilities. Table 21 highlights the similarities in perception across all centers.

Table 21. Health Care Workers’ Perceptions of the Most Commonly Diagnosed Cancers Each Year at Their Facilities

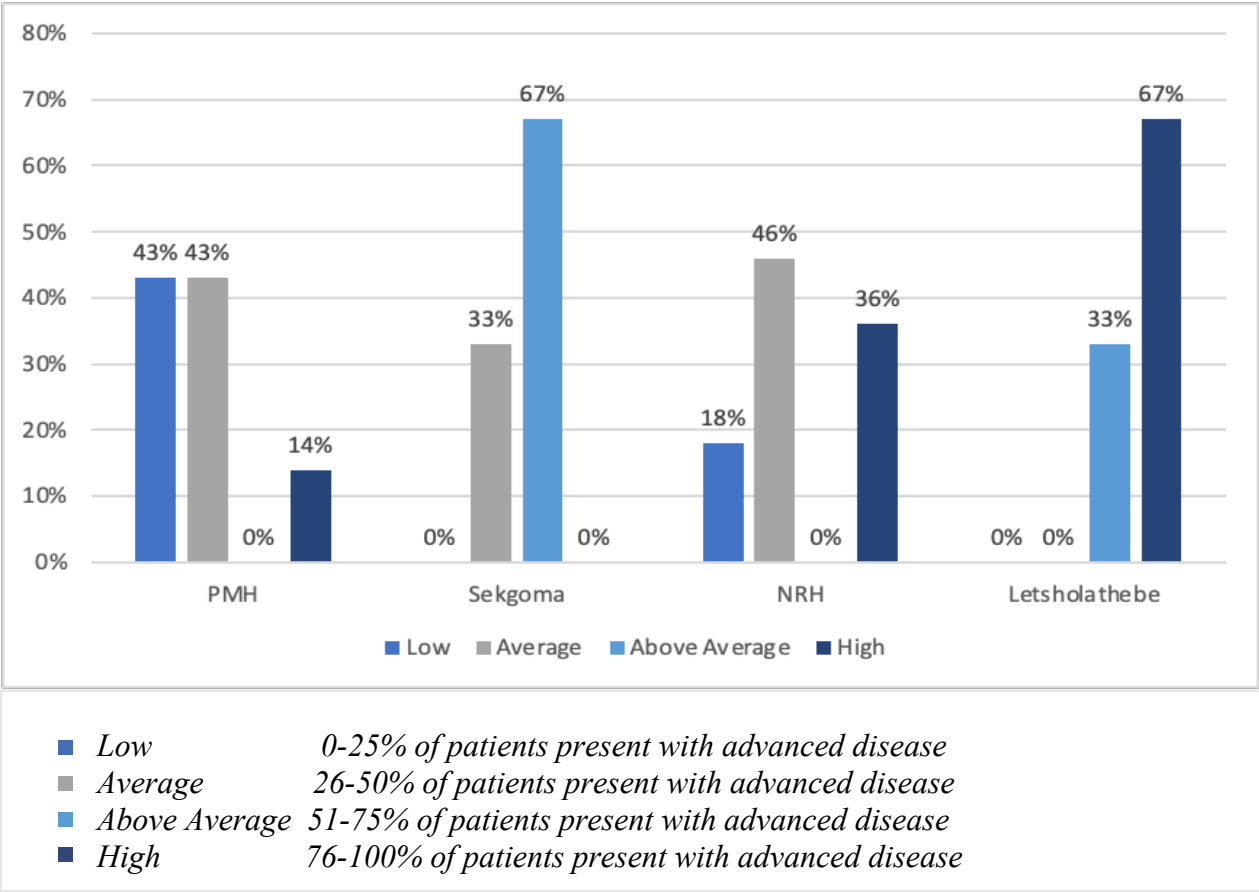
Rank	PMH	Sekgoma	NRH	Letsholathebe
1	Cervical	Breast	Breast	Cervical
2	Breast	Cervical	Lung	Breast
3	Prostate	Kaposi sarcoma	Cervical	Kaposi sarcoma
4	Lung	Prostate	Kaposi sarcoma	Lung
5	Kaposi sarcoma	Lung	Hematologic	Prostate
6	Hematologic	Hematologic	Prostate	Melanoma
7	Colorectal	Colorectal	Melanoma	Hematologic
8	Melanoma	Melanoma	Colorectal	Colorectal

Breast cancer was the first or second most common cancer among the top three cancers at every facility. The top five cancers at PMH, Sekgoma, and Letsholathebe were cervical, Kaposi sarcoma, breast, lung, and prostate. The NRH was different from these facilities in that it listed hematologic cancer in its top five.

Respondents were then requested to name any other commonly diagnosed cancer. Those from PMH mentioned leukemia and ovarian cancer. Respondents from NRH stated leukemia, while ovarian and uterine cancers were mentioned by Letsholathebe respondents.

Health care workers were asked to estimate the proportion of total patients with cancer that present with advanced disease across all cancers (Figure 12). Respondents at PMH and NRH reported seeing lower numbers (up to 50 percent of patients) than those at Sekgoma and Letsholathebe, who expressed that larger proportions of their patients presented with advanced disease.

Figure 12. Health Care Workers’ Perceptions of Percentage of Patients Who Present with Advanced Disease



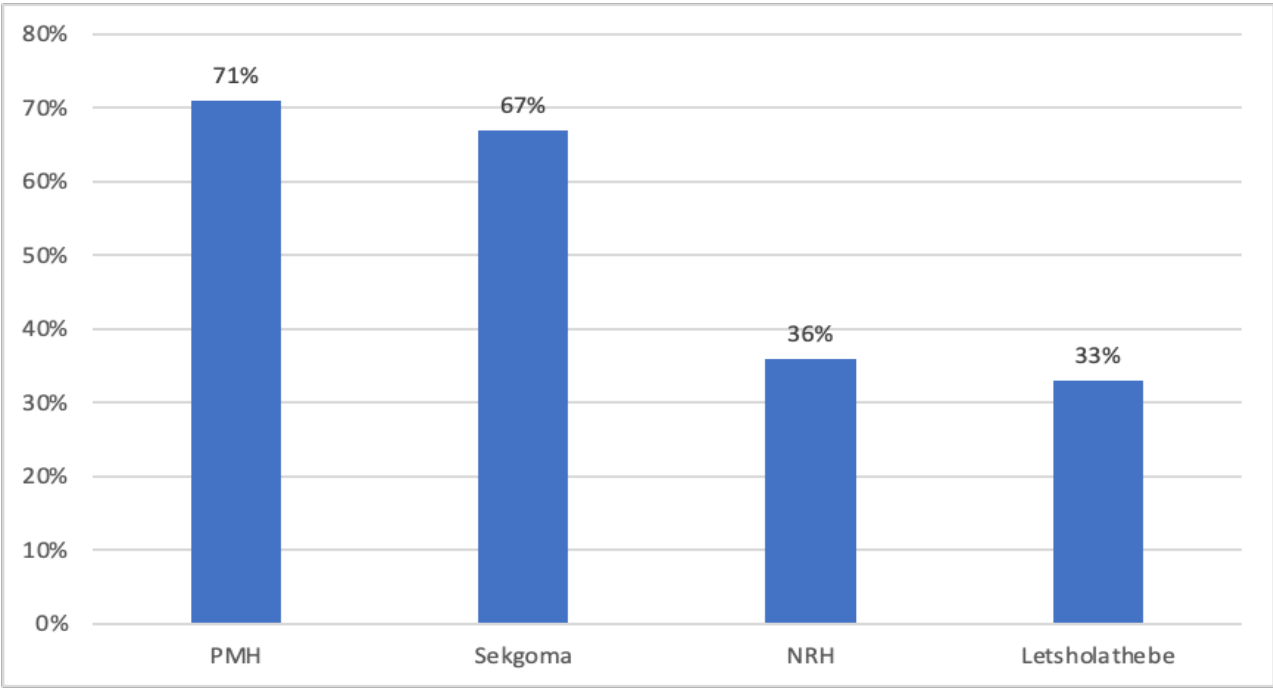
Respondents were requested to select post-cancer topics for which they would like to receive further information. Table 22 shows overall responses from all centers.

Table 22. Health Care Workers' Interest in Cancer Management Topics

Rank	PMH	Sekgoma	NRH	Letsholathebe
1	Pain management	Pain management	Long-term cancer effects: monitoring and palliation	Pain management
2	Long-term cancer effects: monitoring and palliation	Surveillance of cancer recurrence: monitoring and palliation	Surveillance of cancer recurrence: monitoring and palliation	Surveillance of cancer recurrence: monitoring and palliation
3	Surveillance of cancer recurrence	Long-term cancer effects: monitoring and palliation	Pain management	Long-term cancer effects: monitoring and palliation
4	Genetic counseling for family members	End-of-life care and planning	End-of-life care and planning	End-of-life care and planning
5	Wellness and prevention of cancer recurrence	Genetic counseling for family members	Genetic counseling for family members	Genetic counseling for family members
6	End-of-life care and planning	Wellness and prevention of cancer recurrence	Wellness and prevention of cancer recurrence	Wellness and prevention of cancer recurrence

Health care workers were asked if they report all cancer diagnoses and stages to the BNCR. Responses illustrate that this could be practiced at PMH and Sekgoma, but not at NRH and Letsholathebe (Figure 13).

Figure 13. Health Care Workers’ Responses to Reporting of Diagnosis and Stage to a Cancer Registry



Health care workers were asked to list the barriers to cancer diagnosis for individuals suspected to have cancer. Table 23 shows their responses.

Laboratory deficiencies or diagnostic delays were cited as barriers to diagnosis by respondents at every facility.

One oncologist at PMH provided a detailed response to the facilities’ shortcomings. This response included necessary training for oncologists and nurses as well as education and awareness for the general public. Importantly, they also stated that facilities require more scans, such as MRI, as well as radiotherapy machines, and that chemotherapy and mammography machines must be operational and well maintained.

Additionally, this oncologist stated that the IPMS is not being used for patient records outside of pathology and labs, and that the link between IPMS and the Patient Information Management System (medical record that manages the patient information) is not functional. It was suggested that facilities consider referring patients to local hospitals for biopsies and that staging should be undertaken locally.

Table 23. Health Care Workers' Perceptions of Barriers to Cancer Diagnosis

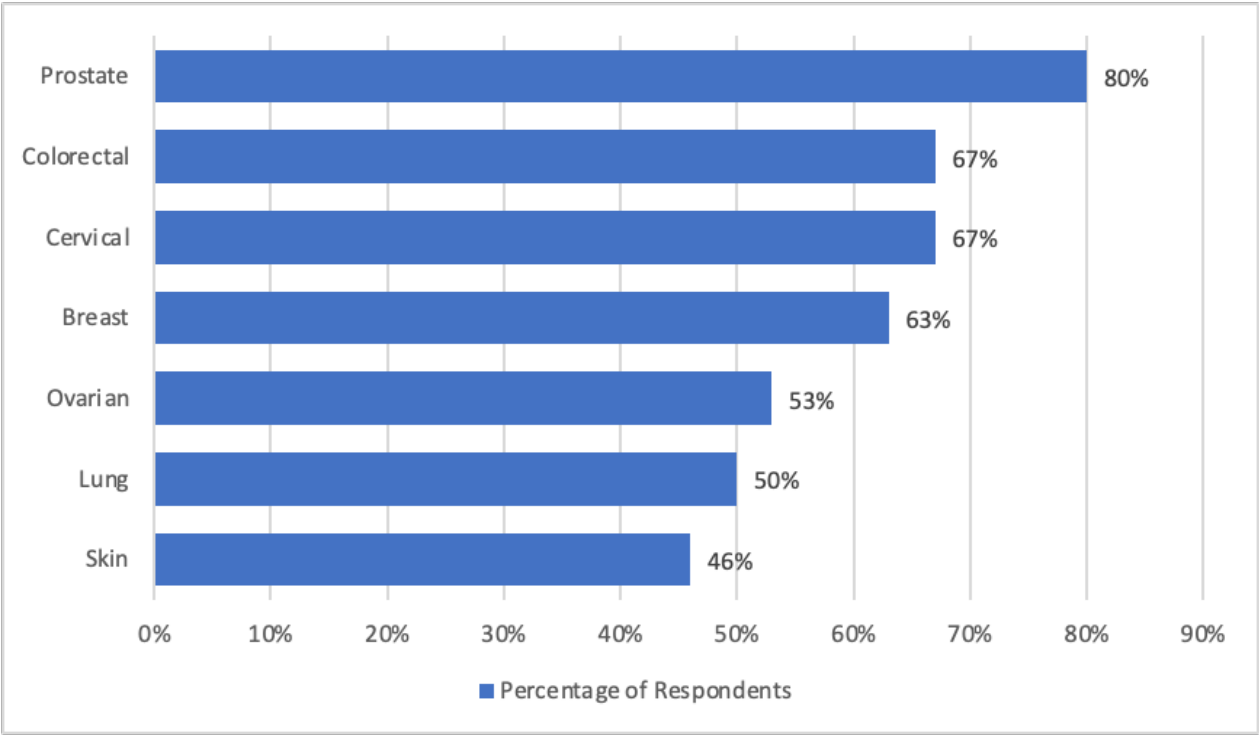
Cancer Center	Reported Barriers to Cancer Diagnosis
PMH	<ul style="list-style-type: none"> ▪ Financial constraints ▪ Lack of insurance (medical aid) ▪ Lack of knowledge ▪ Traditional views ▪ Patient fear ▪ Superstitions ▪ Transport to health facility ▪ Poor access to institutions that provide screening ▪ Distance to the facility ▪ Poor access to biopsy procedures ▪ Lack of laboratories for testing ▪ Lack of mammogram ▪ Length of time to receive results (pathology process) ▪ Delays in procurement of screening tools
Sekgoma	<ul style="list-style-type: none"> ▪ Length of time to receive confirmation of diagnosis ▪ Lack of screening facilities ▪ Patient fear of outcome
NRH	<ul style="list-style-type: none"> ▪ Lack of personnel to perform tests ▪ Long pathology process ▪ Length of time to receive results ▪ Length of time to secure bookings ▪ Long waiting list ▪ Shortage of diagnostic modalities ▪ Health system failure
Letsholathebe	<ul style="list-style-type: none"> ▪ Lack of machinery ▪ Laboratory referral to NRH ▪ Lack of specialists ▪ Lack of diagnostic modalities ▪ Stigma ▪ Use of alternative medicine ▪ Poor access to care ▪ Limited resources for reporting ▪ Too large of a catchment area

4.2.2 Health Care Workers' Knowledge Gaps

Health care workers were asked if they would like to receive further information on signs and symptoms of cancer. The majority of general health care workers at every cancer center answered in the affirmative.

Respondents were asked to choose cancers for which they wanted information on screening or updated screening recommendations. Health care workers at Sekgoma, NRH, and Letsholathebe all had common areas of interest, mentioning prostate, lung, and colorectal cancers. Respondents from PMH showed a particular interest in breast, ovarian, and cervical cancers. Figure 14 shows the overall responses from all centers.

Figure 14. Health Care Workers’ Screening Areas of Interest across All Public Oncology Centers

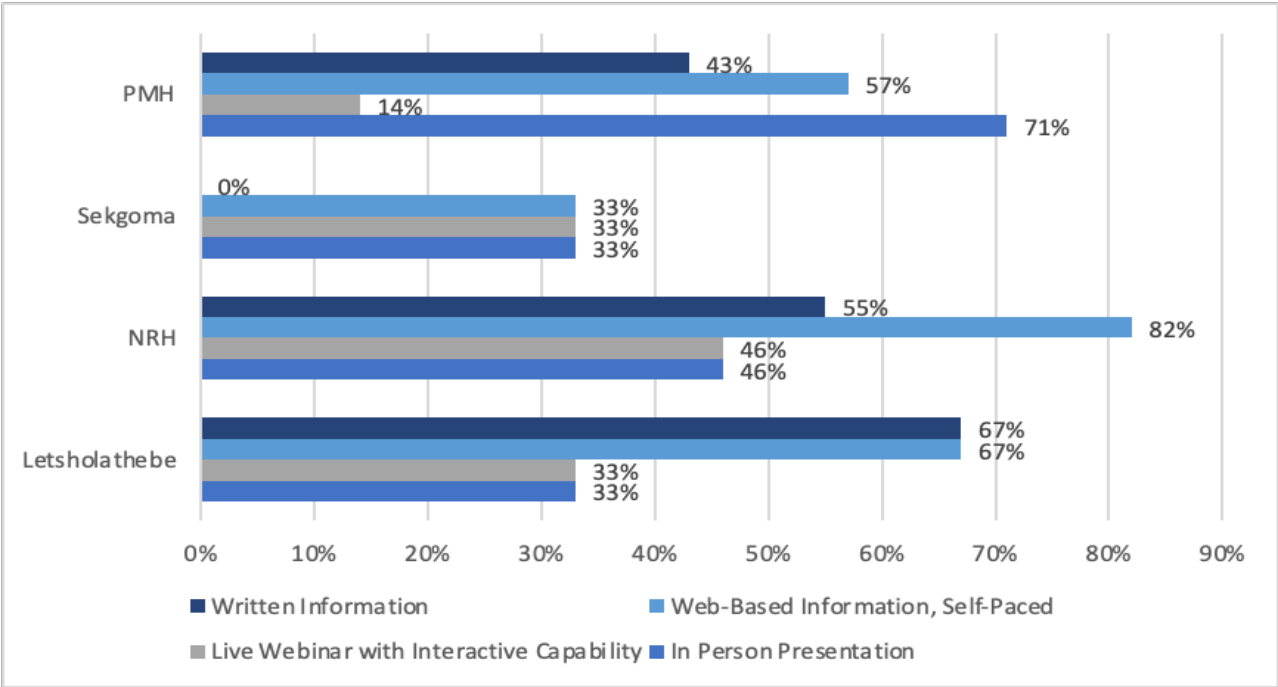


**Percentage is calculated based on the total number of responses out of the total number of health care workers (n = 30) who completed this survey, stratified by type of document from oncology team.*

Health care workers were then asked about their preferred method of receiving additional information about cancer. As shown in Figure 15, centers were almost similar in their preferences.

Written and web-based information were preferred by health care workers at NRH and Letsholathebe. At PMH, the popular choice was in-person presentation, followed by web-based information.

Figure 15. Health Care Workers’ Preferred Methods of Receiving Further Information on Signs and Symptoms of Cancer



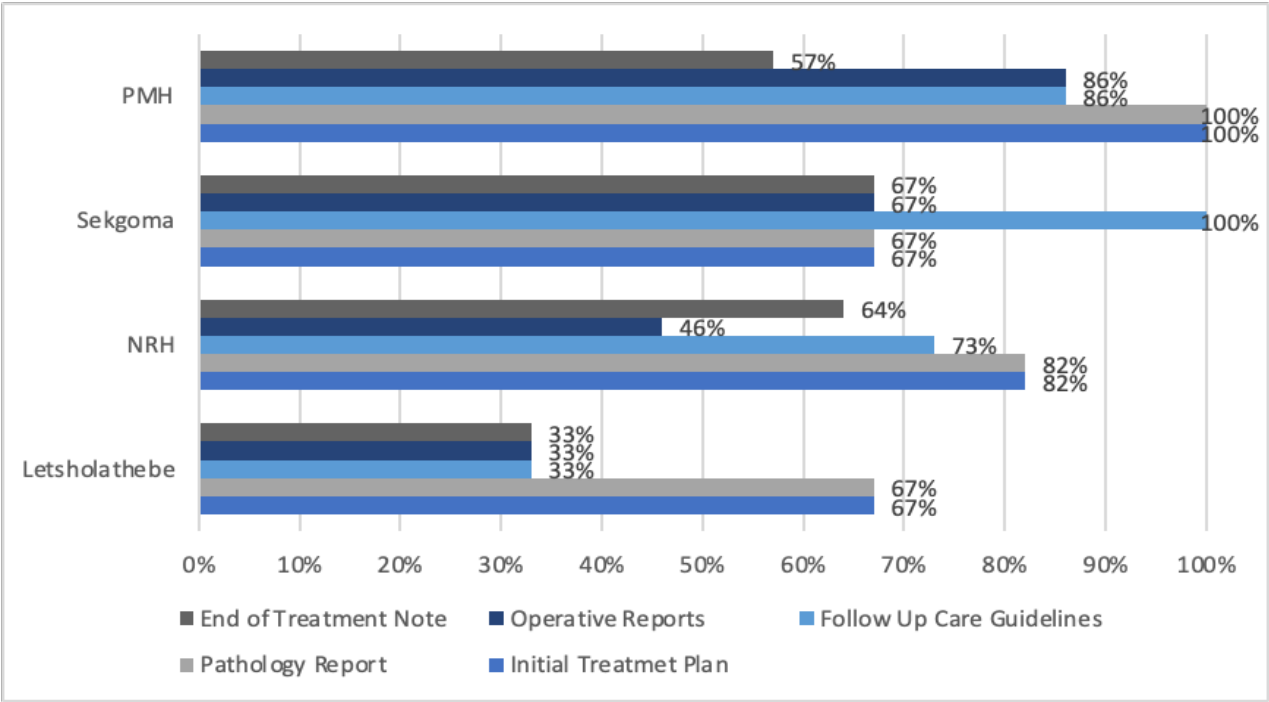
**Percentage is calculated based on the total number of responses out of the total number of health care workers (n = 30) who completed this survey, stratified by type of document from oncology team.*

When asked where they would be most likely to refer newly diagnosed patients for oncology surgery, overall, general health care workers preferred referral to a local surgeon, followed by the referral hospital surgeon.

There are no oncology surgeons in the public sector. Any patient requiring cancer-related surgery is referred to a local surgeon. If the surgeon is unable to perform the surgery, the patient is referred to one of the two referral hospitals. Only surgeons in the referral hospitals are authorized to refer a patient out of the country for a surgical procedure that cannot be performed locally.

Health care workers were asked what they viewed as the most important information that they could receive from the facility oncology team. Across all centers, the initial treatment plan and pathology report scored high (Figure 16). Sekgoma was the only facility that emphasized the importance of follow-up care guidelines.

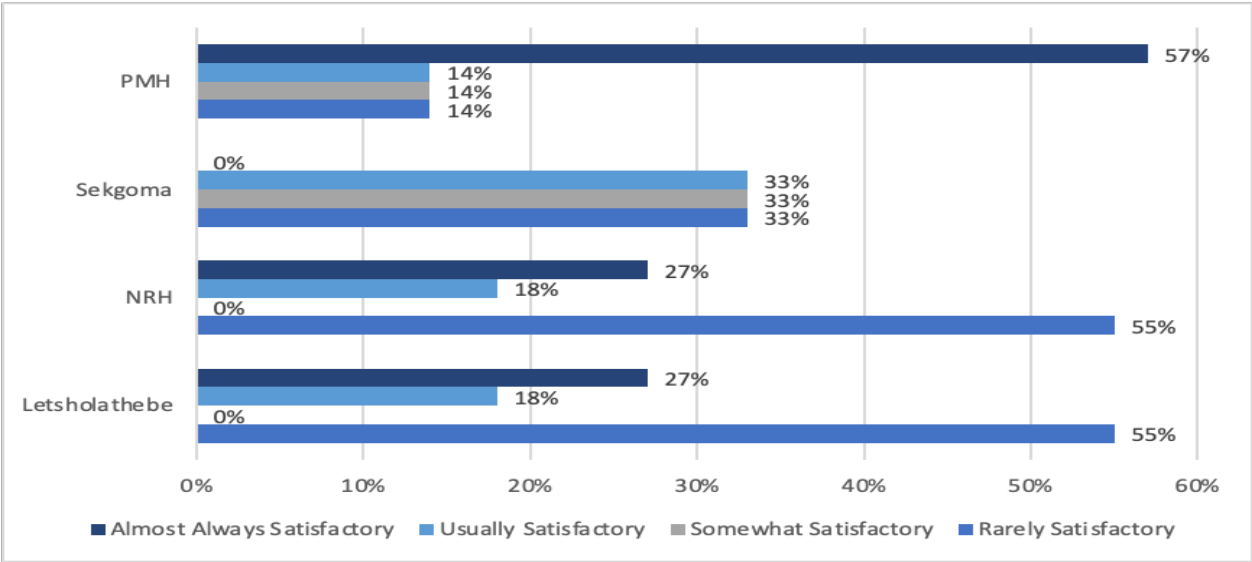
Figure 16. Health Care Workers’ Responses to the Most Useful Information from the Oncology Team



**Percentage is calculated based on the total number of responses out of the total number of health care workers (n = 30) who completed this survey, stratified by type of document from oncology team.*

Respondents were asked about the quality of communication between themselves and the oncology team. Figure 17 shows that respondents at NRH and Letsholathebe stated that communication was rarely satisfactory, in contrast to those at PMH, who noted that communication was almost always satisfactory.

Figure 17. Percentage of Time Satisfactory Communication Occurs between Health Care Workers and Oncology Team

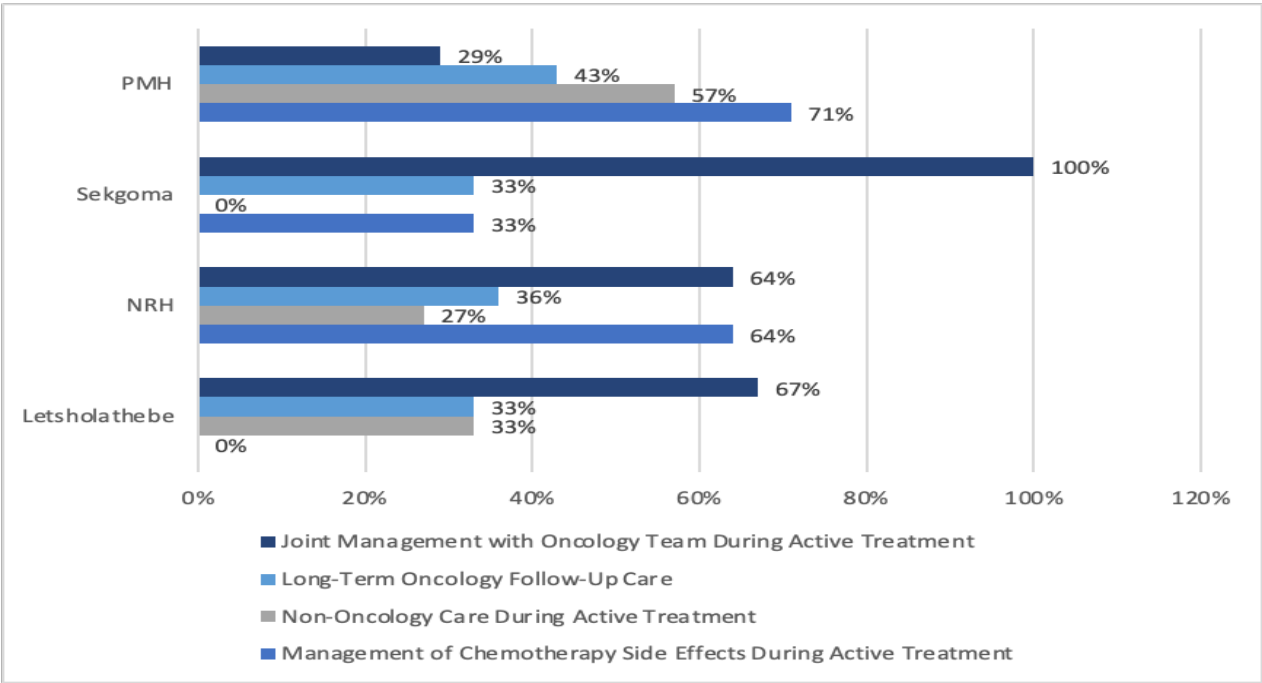


**Percentage is calculated based on the total number of responses out of the total number of health care workers (n = 30) who completed this survey, stratified by type of document from oncology team.*

Health care workers were asked to describe how communication could be improved. PMH respondents believed that if proper lines of communication were established, and health care workers were adequately trained, workflows would be more seamless. An important point raised by those at PMH and Sekgoma was the provider-to-provider language barrier between local and contract oncologists from other countries, describing this barrier as a “disturbance.” In addition, a respondent at Sekgoma remarked that the service and treatment gaps are difficult for patients as they transfer to different facilities for care. Respondents at Letsholathebe believed there should be methods for escalating or triaging urgent cases as well as mechanisms for coordinating follow-up with patients, and that treatment guidelines should be known by all. PMH and NRH had oncologists from China; Sekgoma and Letsholathebe had oncologists from Cuba.

Health care workers were asked about the different types of care they could provide to cancer patients, in order to assess these health care workers’ level of comfort in providing care. Respondents from Sekgoma, NRH, and Letsholathebe all expressed comfort with providing joint management care with the oncology team (Figure 18), as opposed to those at PMH, who preferred the management of chemotherapy or radiation side effects. Across all centers, respondents did not show confidence in oncology follow-up care.

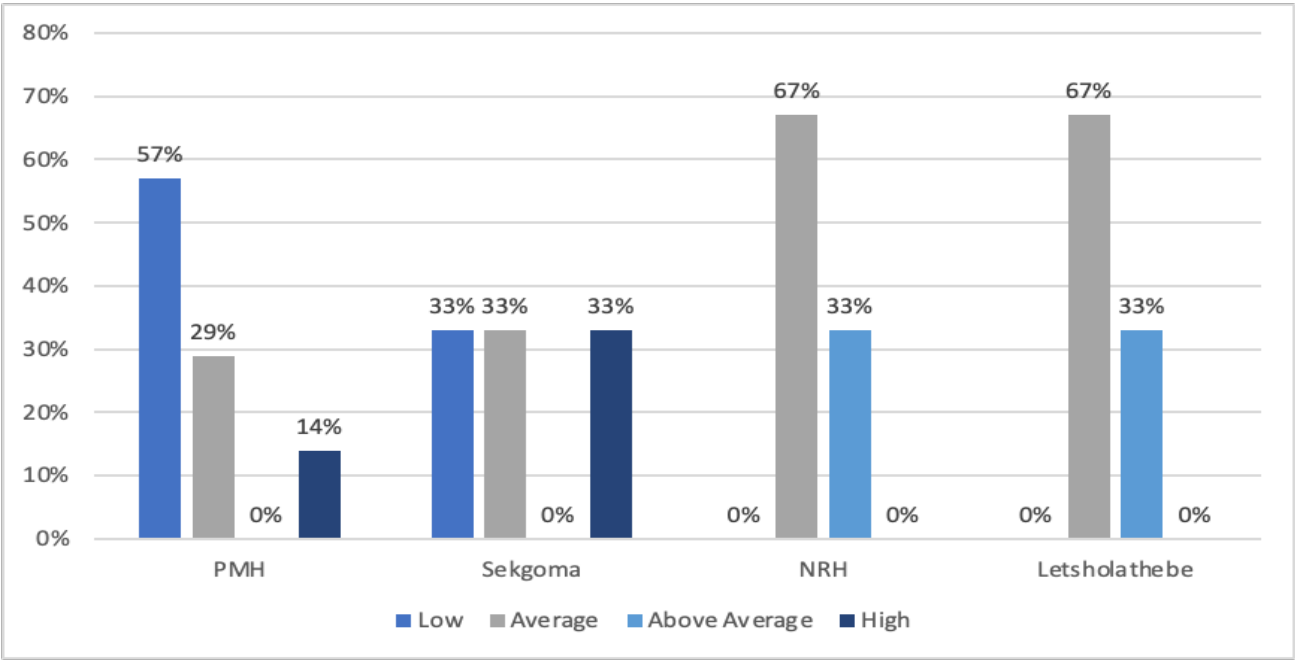
Figure 18. Health Care Workers’ Comfort Levels in Caring for Oncology Patients



**Percentage is calculated based on the total number of responses out of the total number of health care workers (n = 30) who completed this survey, stratified by type of document from oncology team.*

Respondents were requested to estimate the proportion of cancers they see that are related to tobacco use, shown in Figure 19.

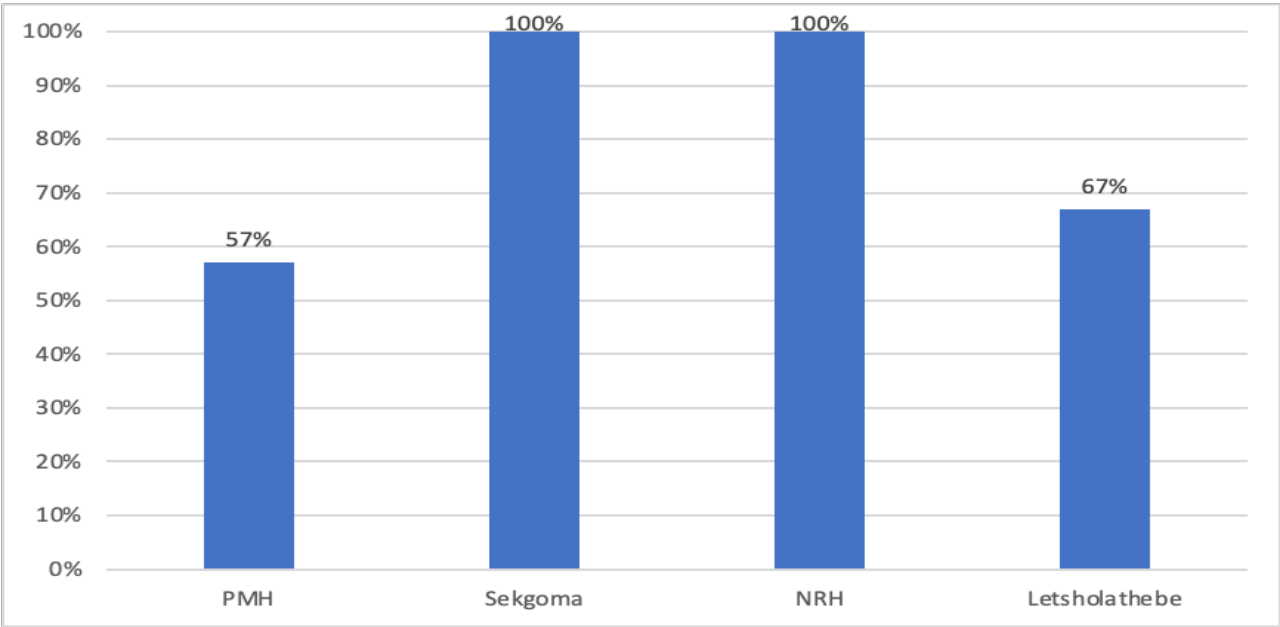
Figure 19. Proportion of Cancers Health Care Workers Reported to Be Related to Tobacco Use



- Low 0-25% of patients present with advanced disease
- Average 26-50% of patients present with advanced disease
- Above Average 51-75% of patients present with advanced disease
- High 76-100% of patients present with advanced disease

Health care workers were asked to determine if it is routine to ask patients about their tobacco use. All respondents from Sekgoma and NRH reported questioning patients, while a much smaller number at PMH and Letsholathebe reported doing so (Figure 20).

Figure 20. Proportion of Health Care Workers Questioning Patients on Tobacco Use



Those who replied that they did not ask patients this question were asked why. One respondent from PMH stated that patients do not want to talk about their use of tobacco, while another stated that this question has never been asked and is being overlooked.

These health care workers were further asked if they advise patients to stop using tobacco, to which they responded that patients do not want to be lectured on what they already know.

Health care workers were asked if they would be interested in receiving information about tobacco treatment. Every respondent from PMH and NRH expressed interest, whereas only 66.7 percent from both Sekgoma and Letsholathebe answered yes.

4.3 Findings from Patient, Caregiver, Cancer Survivor, and Health Care Worker Focus Groups

4.3.1 Experiences with Cancer Diagnosis

Patient and Caregiver Experiences

Patients and survivors were able to describe their journey through the health system following diagnosis of cancer. The subthemes identified in this section included i) presenting symptoms, ii) reactions to presenting symptoms, iii) types of cancers reported by participants, iv) reactions to cancer diagnosis, and v) disclosure of cancer diagnosis.

- **Presenting Symptoms**

Patients reported a variety of symptoms that they first noticed. Symptoms involved the different organ systems, including fractures, abdominal pain, swallowing difficulties, bladder dysfunction, vaginal symptoms, lumps, and skin sores. Sometimes they were specific to known cancers such as perianal warts, vaginal bleeding, or breast lump. The timing of symptoms also varied with symptoms, at times presenting early as though it were nothing serious:

He had a tiny sore, which was on his neck [3:50 ¶ 137 in Francistown caregivers, English]

Other times, symptoms suggested a late-stage presentation of the cancer as observed by health care workers:

By the time it comes to the hospital, you find that it has different lumps, it is already at an advanced stage... So, it is just, more like palliative care [20:23 ¶ 7 in Serowe health care workers]

- **Reactions to Presenting Symptoms**

Reactions to the symptoms varied depending on the individual and how they interpreted the meaning of the symptoms. If symptoms were perceived as not immediately life threatening, then a patient would wait and observe without sharing the information with anyone initially:

I took it lightly and just kept quiet without telling anyone anything and saying let me observe it. Like every day from March to April, I would feel a lump... [1:2 ¶ 12 in Nyangabgwe patients]

However, if a patient interpreted symptoms to be a sign of something serious, they would react with concern, think about steps to take regarding the symptoms, and even share their findings with a family member:

I then woke up and told my daughter that I felt that I had a lump on this side, so she said, “Now what do you think?” “Mm I could not even sleep, I am going to see a doctor.” We have a private doctor in Tati Siding [1:59 ¶ 52 in Nyangabgwe patients]

Sometimes patients presented with late symptoms because health care workers missed the diagnosis over time, despite recurrent presentations at health facilities by patients:

You would find that there is a problem that somebody would be going there. We sometimes have a problem when we are at palliative care: a person would be at an advanced stage but when looking in the records, he would be having like 15... years going to the clinic, going to the clinic, the poor person complaining [16:47 ¶ 120 in Francistown health care workers]

- **Types of Cancers Reported by Participants**

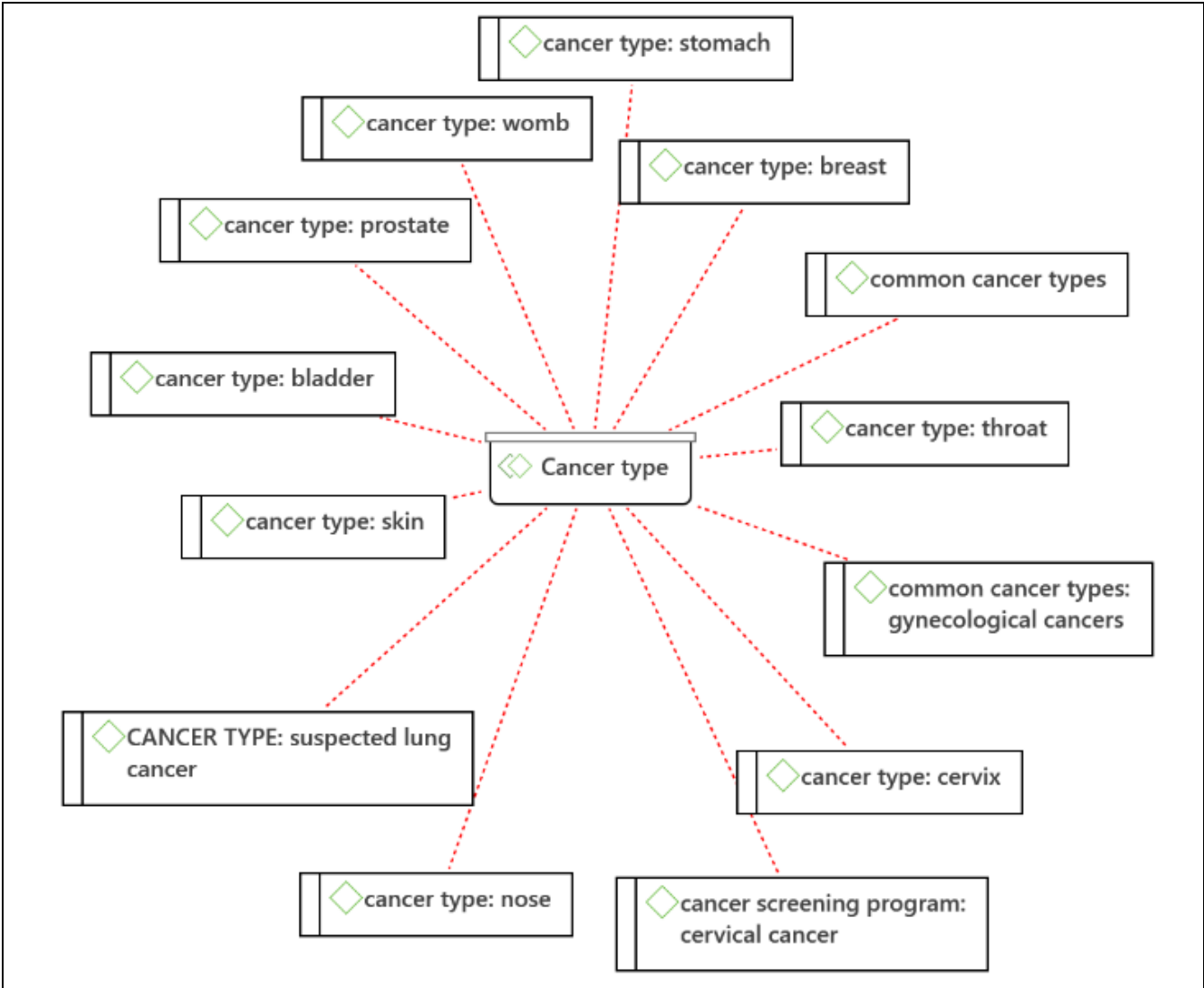
The evidence from both patients and survivors showed that patients were diagnosed with different types of cancers. Some were the common types, such as breast and cervical cancer, while others were less common, such as nasal cancer. Cancers reported by patients were predominantly gynecological, especially cancers of the cervix and breast. Health care workers’ perceptions of the common cancers that patients were diagnosed with did not significantly differ from those of the patients, except with addition of Kaposi sarcoma and the lymphomas:

The most types we have in Botswana or that we are registering it will be... we have more Kaposi sarcoma, breast cancer... cervical cancer [18:1 ¶ 12 in Maun health care workers (final)]

We also have prostate cancer, lung cancer, as well as a... non-Hodgkin’s and Hodgkin’s (lymphoma) [18:2 ¶ 15 in Maun health care workers (final)]

Figure 21 shows the types of cancers reported by patients in this study.

Figure 21. Cancer Types Identified by Patients and Health Care Workers



• **Reactions to Cancer Diagnosis**

When patients were told of their cancer diagnosis, they reacted in different ways, ranging from shock, confusion, and denial to fear, crying, and feeling emotionally drained, and from immediate acceptance to late acceptance. Some patients’ thoughts were focused on pragmatic issues such as the stage of cancer and its implications, the support that they would need, and thoughts about death.

Shock and confusion were predominant reactions for patients immediately upon receiving the diagnosis, as exemplified by one patient who walked from one place to the other without even realizing it:

You know when I left, after he told me that I have cancer of the womb, I don't know how I left this place; I left the car and only to snap out of the moment when I was in the middle of Main Mall, seated on the ground, calling my daughter who was in school [4:58 ¶ 45 in FGD PMH 01]

The initial shock and confusion would eventually be followed by acceptance by most participants. Quite often the journey to acceptance of a cancer diagnosis was not straightforward and could even be delayed because of a patient's denial. The denial stage could last until late in the diagnosis period, when the cancer had already spread. Caregivers witnessed this emotional reaction of their loved one to the diagnosis:

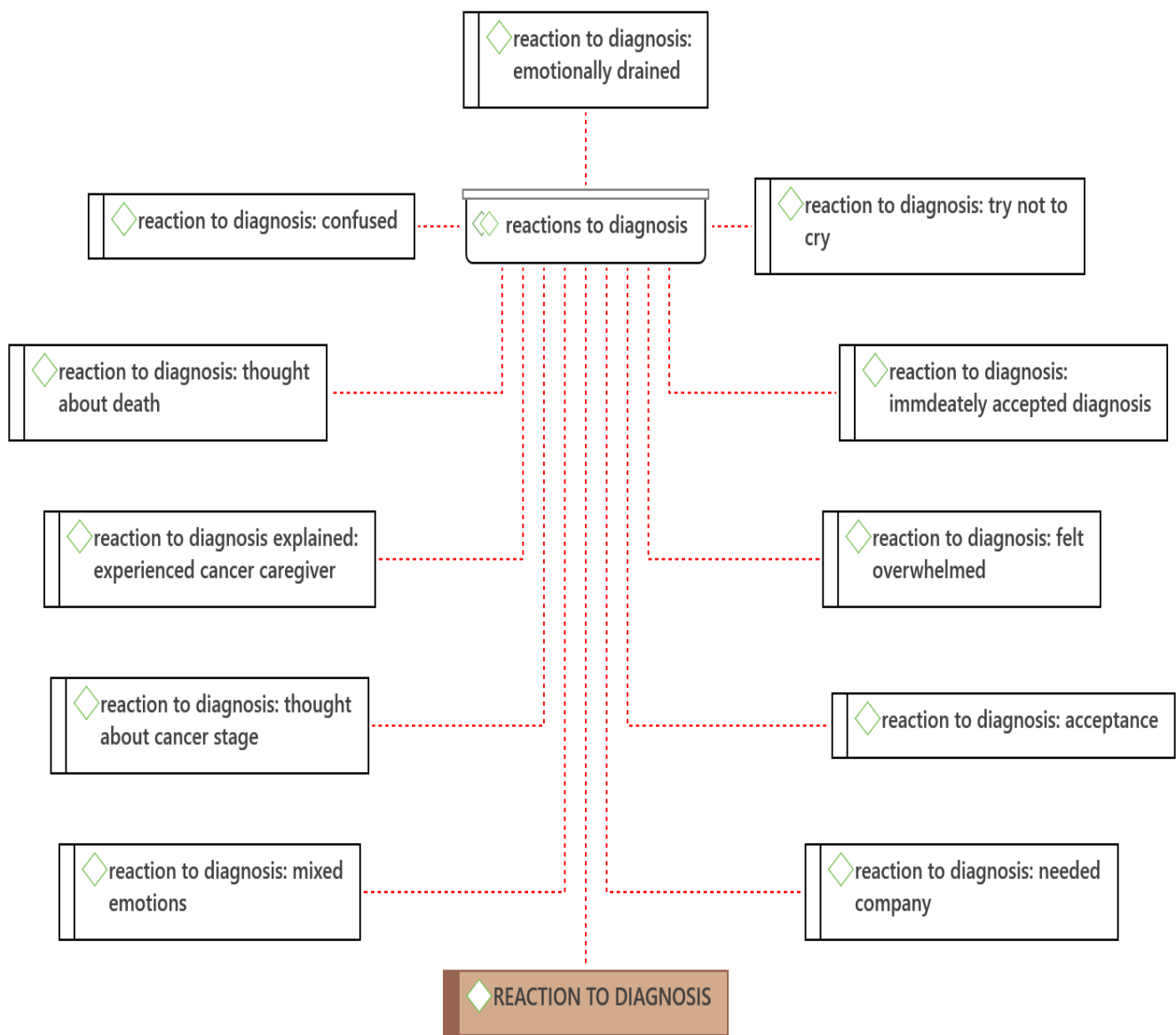
That's when now she realized that this thing is indeed cancer and has really spread [3:42 ¶ 121 in Francistown caregivers]

Reactions of family members to their loved ones' cancer diagnosis were generally like those of the patients. These reactions were predominantly emotional, especially crying, praying, confusion, denial, and lack of acceptance. One patient captured these reactions when they witnessed their family members exhibiting denial, confusion, and lack of acceptance:

That's when I said my eldest siblings' children; I took them one by one in the family and told them, and they were all in denial, like they were not accepting, you know, they were in a confused state [1:73 ¶ 54 in Nyangabgwe patients]

Family reactions to a family member's cancer diagnosis were influenced by factors such as their relationship with the patient, where they were at the time the patient received the diagnosis, and their own inner strength. Some family members would eventually become caregivers for the patient.

Figure 22. Patients’ Reactions to Cancer Diagnosis



• **Disclosure of Cancer Diagnosis**

Patients also started to think about whom they would disclose the diagnosis to, and how and when that would happen. While some patients were able to identify whom they would disclose to, other patients felt alone with no one to talk to:

I didn’t know what to say and to who? You know what bothers me is that I don’t have a mother, I don’t have an aunt; I have no one [1:67 ¶ 52 in Nyangabgwe patients]

Immediate family members were often the first people that patients thought about, especially patients' children. Additionally, those patients who thought about the possibility of dying also thought about the impact of the diagnosis on their dependents, such as the orphaned children that they take care of. Disclosure, however, seemed to mainly occur without delay, irrespective of the patient's circumstances except on a few occasions when the patient preferred to wait for completion of their investigations first:

We will wait for the pending results, and when they arrive, that's when we would inform our children that I have been diagnosed. Let's not tell them that I have been diagnosed before we know the complete results, and then later after receiving the results [1:12 ¶ 12 in Nyangabgwe patients]

Sometimes the disclosure of the diagnosis was not done for fear of how others in the community where the patient lived would react:

Mhhh, I got scared that if I could tell those in the village, more so that they know this disease as killer disease... I then told my child because he works in the hospital, so I thought, let me just tell him [1:50 ¶ 48 in Nyangabgwe patients]

Knowing that the person being disclosed to would react positively seemed to encourage the disclosure process.

• Perspectives from Survivors

Survivors shared the main methods that they used to cope with the diagnosis of cancer and its treatment effects. Two main themes came out, which were diagnosis acceptance and faith-based coping mechanisms. Self-acceptance was described as an important part of coping with the illness by survivors. They explained that lack of acceptance could result in other medical conditions, such as heart attack:

R2: I mean that thing if you are not the kind of person who has accepted your situation you can even be killed by heart (attack)

Additionally, being accepted by others, especially close family members, played an important role in helping the patient cope with the illness, particularly when the acceptance of the patient was combined with counseling support for both patient and family:

R2: A thorough one, thorough counseling. Also the people you live with should accept you (your situation), treating you accordingly hmmm so that you could also see that I am not alone here (Maun)

Survivors also described the activities that they engaged in as part of their faith, which helped them cope with the illness and treatment side effects. These included going to church to listen to the word of God for encouragement. This helped with self-acceptance:

R3: You know, just to go to church . . . Just the word being preached, you accept your situation, I really had accepted my situation (Maun)

Prayer and surrendering all to a higher power was another way of coping with the diagnosis and treatment side effects that survivors used:

R4: But when I took the drip, I couldn't feel the much talked about pain because I had already surrendered that all I want is to... I had prayed the whole night that my God at least let me be given treatment, so I was given the drip then I went back home (Maun)

R5: I am also a prayerful person so that day I didn't sleep; I spent the whole night in prayer and the whole day the next day [Francistown]

Despite the diagnosis of cancer, the treatment side effects, and other challenges that come with the diagnosis, Maun survivors and caregivers also gave an optimistic view of the fact that things can get better with treatment. A survivor described the feeling of being alive again after their treatment, where they were now able to engage in some daily activities of living including walking:

I stayed (at home) but still in pain. However, when I got back for the second time, I know felt that the pain was no more, I felt alive and was able to walk on my own [Maun survivor]

One caregiver shared the same experience of their patient, who had lost a lot of weight due to the illness, also coming alive with treatment:

R5: Then we signed right there. However, when they administered medication, I then saw lots of improvement... like it seemed those things were awakening her (making her to feel better) [caregiver Maun]

- **Health Care Provider Experiences**

Health care workers described varying experiences, depending on where they work, when it comes to issues around cancer care. The experiences ranged from lamenting the inadequacy of services provided due to lack of knowledge to frustration and emotional burden that they felt due to caring for the cancer patients. The emotional burden was especially felt when caring for patients with late-stage cancer.

- **Health Care Worker Knowledge Gaps**

Health care workers identified their own knowledge gaps that affected the quality of service that they provided to patients. An example of this was described by a health care worker who observed their lack of knowledge in diagnosing cancer in a patient who presented repeatedly to their health facility:

Our clients, they visit the clinics, sometimes you don't even know if it's cancer. The patient would be coming back saying, "I have a wound that doesn't heal for years," and that patient would be coming back every day, "What do we do?" We give Betadine, "go and dress," we dress. We don't even know if it's cancer [18:22 ¶ 55 in Maun health care workers]

This knowledge gap demonstrated by health care workers was also observed by members of the public:

What a person is coming with mainly (complaining about), it's just a person (health professional) would just come and only pick what he understands [17:57 ¶ 55 in Francistown general population (English)]

Specific training needs were identified by the health care workers that could improve the quality of care they give to patients. These included general training on cancer care and management as well as on morphine use and work ethic within the cancer care process.

- **Experiences of Health Care Workers: Effects on Mental Health**

Health care workers also identified the mental health effects that caring for cancer patients had on them. These effects were a prominent theme among health care workers in Francistown, especially when attending to patients with late-stage cancer. They alluded to their need for emotional support to address this:

We need counseling; how many patients die? ... you know we do palliative care; we call the relatives and the patients [18:93 ¶ 184 in Maun health care workers]

Health care workers made several observations that contributed to their experiencing mental health effects of caring for cancer patients. These included late presentation to facilities by patients, effects of advanced cancer on these patients, effects of caring for patients with advanced cancer on health care workers, and some dilemmas that health care workers faced when treating late-stage cancer.

Health care workers in different parts of the country made the same observation that patients presented late to care:

I think most of them they come now when the cancer is now at an advanced stage [20:19 ¶ 7 in Serowe health care workers]

Signs... like when cancer now it's showing signs, he would be experiencing some discharges, bleeding and whatnot, like when now the disease has gone out of control [16:49 ¶ 122 in Francistown health care workers]

This was not helped by the long process followed to investigate a patient presenting with cancer. It was felt that the long process may even contribute to the late diagnosis:

Usually isn't it they have to confirm that "now you are a cancer patient." That's when they go, and the whole process that they measure that "this is a cancer patient" is very long. To the extent that most of the patients who are admitted are in the terminal stage. They are in the advanced stage [20:139 ¶ 81 in Serowe health care workers]

Health system factors were also observed to contribute to late presentations, including equipment breakdown or unavailability of necessary equipment as well as missed diagnoses:

And right there what is the treatment of choice? It's radiation, yes, and there is only one radiation machine in the whole country at GPH. You promised this patient that "now you are on stage three, and stage three with treatment you could get better, we are booking you for radiation." Poor person he leaves and didn't take anything; he would stay for 10 to 11 months because the machine is down, waiting to be called in for radiation. By the time he comes back to you, it is in stage four, you see? [16:144 ¶ 312 in Francistown health care workers]

You will find that a person who is said to be advanced has years coming for consultation; going to the hospital this whole time and at the end you hear that they have cancer and it's even advanced; there is no help [20:64 ¶ 28 in Serowe health care workers]

The late diagnosis was observed to affect patients' psychological well-being, including leading to depression:

Let me add on that, like they are saying about the issue, that it's depressing even for the patients [16:151 ¶ 329 in Francistown health care workers]

The late-stage presentation was found to contribute to poor psychological health for health care providers. This was compounded by other factors, primarily breaking bad news and the pain that bad news causes for patients:

You won't know where to start or what to leave out, like even you, as a health worker, you have to provide support and you would find that you won't know that... it's weighing on you now

because you would find that, like I have already said, you break those news [16:140 ¶ 308 in Francistown health care workers]

High mortality of patients being cared for was also an important contributor to the emotional burden that health care workers faced:

I know that cancer patients come and go, die. You can have like three deaths in a week, so it's really depressing not only for the family but for us nurses as well [16:132 ¶ 296 in Francistown health care workers]

Other concerns that health care workers had included unavailability of hospice care for patients and the merits of feeding patients with late-stage cancer. Health care workers faced dilemmas about why they were doing it, whether it was causing harm to patients and a feeling that they had to follow doctors' orders:

It's painful, I don't know how to express it, even to us as health workers it's really painful, like if you hear me saying it's really painful [16:146 ¶ 318 in Francistown health care workers]

- **Experiences with Cancer Referral Pathways**

Cancer care requires a multidisciplinary (interprofessional) approach. Health professions in cancer care include physicians, surgeons, oncologists, psychologists, dieticians, and home-based community care workers. Patients experienced challenges with the referral systems among professionals and cancer sites for several reasons. These included communication among these health care teams and access to the health care teams, especially home-based care and dieticians for nutritional requirements. This inadequate access was experienced by patients, caregivers, general population, and health care workers:

Services reach us really late, to an extent that you may have been diagnosed with a disease but because of your lack, you end up just eating anything that is within your reach, even if you could have been given instruction of what to eat [17:24 ¶ 208 in Francistown general population]

I am a dietician. We also have a problem of late referral. Yes, we refer very late while now they are very sick yes, I think there should be a system in place like when they diagnose them. Finally... we are bringing them when they are already wasted, and we also have a problem when it comes to nutritional support on how we are supposed to support them [18:72 ¶ 129 in Maun health workers]

Francistown health care workers observed that even if a patient is referred, this implies that patients are supposed to transport themselves rather than be transported by government vehicles to another hospital, even though some of the patients don't have the resources to go there. Additionally, even

when patients were referred, sometimes there was a perception that health care workers were not talking to each other:

We have to rectify that situation. Like I take it that their communication and working together to study the papers could help to see that “no our patient is for this and that” so we if we could all work together, we could do this to treat this patient so now mm mmm I am only focusing on my own and that one is also focusing on his own [3:213 ¶ 323 Francistown caregivers]

Challenges accessing the home-based care team were particularly felt by patients and their caregivers, as were lack of referral to a dietician for patients requiring dietary assessment, nasogastric tube, food basket, or supplements. Lack of referral, therefore, left patients and relatives worried about how this is likely to affect the patients:

Where they were saying there are certain supplements which when taking cancer treatment, they can affect your treatment like in a negative way... So, I asked him “so is what I’m taking now okay?” So, he started to say “aah I don’t know” [4:187 ¶ 335–339 in FGD PMH]

Challenges accessing home-based care were predominantly linked to the COVID-19 pandemic:

They said they won’t be able to come at home due to COVID [3:149 ¶ 180 in Francistown caregivers]

4.3.2 Knowledge of Cancer

- **Causes of Cancer**

Beliefs about what causes cancer were explored among patients, survivors, caregivers, and the general community. Three main subthemes emerged from the various FGDs: tobacco use, food production, and diet-related beliefs.

- **Tobacco Use**

Smoking appeared to feature as a familiar cause of cancer within the different communities:

There are things that could make us end up having cancer like throat cancer, as mentioned, it goes hand-in-hand with smoking [8:12 ¶ 94 in Maun general population (English)]

Was saying cancer is also caused by... there is one which is caused by smoking tobacco [17:12 ¶ 89 in Francistown general population (English)]

- **Accelerated Food Production**

Using methods that accelerated the rate of food production and consumption was a major concern as a contribution toward cancer. Accelerated production of chickens and use of fertilizers to grow fruits such as oranges were mentioned as contributors to cancer causation:

Let me say maybe these fried - chips are hot then you put them into a plastic, yes, they say there are chemicals (reaction) there that takes place which would... R2: That comes from the plastic R3: Yes, it would cause cancer right there [917:36 ¶ 250–252 in Francistown general population (English)]

We don't know how dangerous those chemicals they use are. Sometimes you will find a fully grown orange or apple this big and you wonder what made this apple or orange to grow this big [8:25 ¶ 261 in Maun general population (English)]

Participants also associated eating fatty foods, uncooked spices, and consuming so-called “doggy” alcohol, a homemade brew, with cancer.

- **Traditional Practices**

There were some traditional practices that were also believed to be cancer causing, especially in Maun. These included drinking some traditional herbal remedies and some local sexual practices in causing cancer of the cervix:

We women we have our way of doing things trying to do Setswana techniques ... That thing can end up causing cancer of the cervix [8:14 ¶ 100–102 in Maun general population (English)]

- **Perceptions of Cancer**

Participants had an opportunity to share their views on what cancer means to them. Three subthemes came out of this discussion: i) fear of cancer, ii) cancer and stigma, and iii) feeling that cancer as a disease was not prioritized by policy makers.

- **Fear of Cancer**

Conversations with the general population helped explain some of the reactions to possible symptoms of cancer. There was a lot of fear of cancer, which could lead to either delayed health-seeking behaviors or lead a patient to seek behaviors quickly:

The lung cancer, they are kinds of things that I am scared of [17:19 ¶ 114 in Francistown general population (English)]

Over and above general fears about cancer, there are also fears toward cancer screening, cancer treatments, disfiguring effects of cancer treatments such as amputation, perceived stigma from the diagnosis itself, treatment results such as infertility, as well as shame of being diagnosed with cancer, especially cervical cancer and death due to the cancer:

Even myself I am scared of it; I am scared to test [17:56 ¶ 541 in Francistown general population (English)]

You see, the main thing is I have experienced cancer; cancer would amputate fingers, nose got cut and they will say “this person is suffering from cancer” [8:66 ¶ 722 in Maun general population (English)]

The fear seemed to be fueled by perceptions of what cancer can do to the individual’s physical health. Some members of the general public believed that everyone has cancer, and it is just a matter of finding it:

Yes, but cancer on its own is there. Because if an old woman like me, if could go to the hospital when they examine me, they will see it. They have never told me that I have cancer because these English diseases have a way of hiding themselves [8:42 ¶ 593 in Maun general population (English)]

- **Cancer and Stigma**

There was stigma associated with cancer, which seemed to emanate from changes in physical appearance observed among cancer patients:

We always see such people who are suffering from this cancer ... R4: It’s just that eish really ... they would be looking not good [17:20 ¶ 116–118 in Francistown general population (English)]

Then my breast gets removed and I get to live with just one, now people are not used to me having only one breast [17:22 ¶ 122 in Francistown general population (English)]

- **Cancer Not Prioritized**

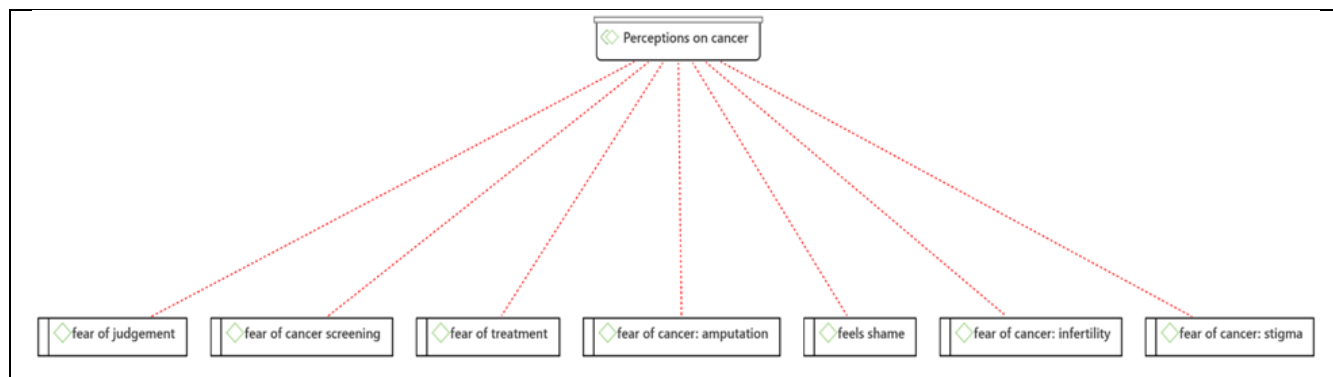
There was a sense among health care workers that cancer care is not prioritized by policy makers in the country, and that because policy makers do not seem to be affected by cancer, they would even shift funds earmarked for cancer to other unimportant programs:

Looks like it doesn’t really kill them so much, so that’s why they would get funds that I directed towards a... financing a program and they give it to some... some unimportant program [18:135 ¶ 429 in Maun health care workers]

Over and above that, focus was perceived to be on treatment of cancer rather than on cancer prevention:

They are putting money trying to cure things but they are not putting money in trying to prevent, isn't it? [18:141 ¶ 444 in Maun health care workers]

Figure 23. Perceptions of Cancer



Cancer Screening

Cancer screening was viewed from different perspectives. Health care workers talked about it from the perspective of availability of screening services, while patients discussed it from the effect the screening has on them. The type of screening tests could at times be a prohibitive factor toward screening from a layperson perspective:

The way I hear it hai (hey) most men may shy away from it because when you get there, they said something like you remove your pants and put it there. Then you bend and fingers are inserted in your anus... [17:55 ¶ 529–531 in Francistown general population (English)]

Additionally, the time intervals between screening and receipt of results influenced the degree of public engagement with screening processes:

After testing to go and wait until you come again, you are going to come for revisit after a year or two so that issue is what is making cancer (cases) to be high...So now this one for the cervix we really check it, but these years set in between (appointments), those facilitate the increase in these diseases [8:50 ¶ 626 in Maun general population (English)]

The general population was noted to be slow to go for screening tests, and they acknowledge that as well:

To tell the truth, most of us we don't test. I remember when I went to the hospital to test for some these common diseases, and it was in 2018 [8:64 ¶ 693 in Maun general population (English)]

The reception from health care workers when patients wanted to test for cancer also influences uptake of screening services for cancer by the patients:

I went there at Donga clinic but aah I didn't get any help, and they asked me if I had cancer, "why do you say you want to test?" I ended up owaiiii (oh well) ... I tried to give reasons saying "no I was just checking." I came back not tested [17:54 ¶ 527 in Francistown general population (English)]

Suggestion for cancer-screening initiatives by the general members of the public included outreach services to hard-to-reach settlement areas. Participants suggested that outreach services should combine screening for cancer with that for other common chronic diseases such as diabetes, and this should be done on a regular basis:

I would ask health workers that such deadly diseases like cancer... If they could go into these settlements where people are gathered and have us checked right there [8:51 ¶ 648–650 in Maun general population (English)]

If they came this month, the other three months others would come, they test for sugar, test for cancer, the one for the cervix [8:70 ¶ 778 in Maun general population (English)]

Cancer Prevention

This was explored in detail with patients and health care workers as well as the general population. Four subthemes emerged under this section: i) prevention through physical activity, ii) prevention through health education, iii) prevention through testing for cancer, and iv) barriers to cancer prevention.

- **Prevention through Physical Activity**

Physical activity was also described as a measure to prevent development of cancer, including within the Maun community, who talked about traditional ways of exercising (ploughing, cutting trees, and rearing cattle), while in Bontleng, the community mostly discussed going to the gym as a preventive measure.

- **Prevention through Health Education**

Health education was considered a key issue when it comes to cancer prevention and was considered important by health care workers and patients:

Mostly the treatment that works the most is health education [20:57 ¶ 24 in Serowe health care workers]

The need for health education was also emphasized by the general population, who recognized a desire in understanding what an individual needs to do to get checked for cancer and assistance with understanding the meaning of some of the cancer symptoms:

I take it that if the elders could also be taught emm... it might help [5:42 ¶ 53 in Bontleng community]

These cancers which... this one that makes a person's leg amputated; that is what we don't understand ... that for you to see if you have that cancer,

do you then have to be checked in your legs... to see if I have cancer, my leg is going to be amputated or it comes in what form? [8:115 ¶ 575 in Maun general population]

According to health care workers, health education should be extended to the general population as well, so that they make sense of symptoms that they see or experience:

Lots of education reaching people, it's just by ensuring that people receive lots of education [16:54 ¶ 128 in Francistown health care workers]

In addition, there was an expectation on policy makers to prioritize cancer prevention rather than cure:

They are putting money trying to cure things, but they are not putting money in trying to prevent, isn't it? [18:21 ¶ 444 in Maun health workers]

What prevention of cancer through health education might look like was suggested, such as empowering health care workers to diagnose, treat, and detect cancer early:

The first thing is to give and empower health care workers to be able to diagnose the cancer and detect cancer symptoms early Awareness [16:43 ¶ 116 in Francistown health care workers]

So, there's a need for more empowerment of the health care workers because if I am not empowered, we will continue to wing it... later the illness will be detected when it is far when it is already too much [20:83 ¶ 33 in Serowe health care workers]

Why health care worker training and empowerment are needed and the benefits of empowering health care workers was shared:

Like also for us we realized that the Under 5 card was modified so that from birth up to 5 years, those children will be screened for Retinoblastoma. Then we trained the health workers and health care assistants so that by the time every child goes for child weighing or child welfare, they are also screened for cancer [20:70 ¶ 31 in Serowe health care workers]

Health care worker capacity building was a dominant theme under prevention. The capacitation needs to be comprehensive and integrated with other health care programs while taking into consideration the needs of the patients. Screening for symptoms needs to be prioritized and done well by health care professionals. Additionally, screening should be extended to specific patient age groups as they attend for routine health care at the facilities:

A lot of education and integration and inclusive comprehensive assessment. I don't know why we should exclude screenings for cancers. Or asking common... common, you know, questions like if it's a woman: "You have a lump? You have history of a lump?" or if it's a child, you look at the, you know, the structure of the eye. If it's an HIV patient, you ask: "How is your CD4 count?" "So, if you see any growth don't hesitate to come to the facility." We need to intensify because all cancers they normally lead to death. [20:73 ¶ 31 in Serowe health care workers]

Another way of preventing cancer was suggested to include leveraging existing initiatives that have been successful in raising awareness of specific cancers through different media platforms:

A lot has been done for breast cancer right now – I think we should investigate other conditions and also find media platforms. Like for us, I look for media platforms where – because everybody is not an eye specialist. So that we tell them and sensitize them that, "You know these are the symptoms of cancer" [20:75 ¶ 31 in Serowe health care workers]

Overall, when it comes to what should be done at the policy and facility levels, suggestions point to health education for both health care workers and the public as an important intervention. Suggestions on how this can be done were also provided.

- **Prevention through Cancer Testing**

Prevention of cancer through testing was a strong theme among the different groups, especially health care workers. There was a strong suggestion to make testing for cancer a part of routine health care consultation like other NCDs such as hypertension and reproductive health:

Making it routine just like when a person comes to check BP, like as long as you go to the hospital to be checked for cancer and all sorts of things [16:41 ¶ 114 in Francistown health care workers]

Whenever you see a patient, like you offer (routine HIV test) RHT like the insert... why can't we screen the patients? I don't know why we should exclude screenings for cancers [20:72 ¶ 31 in Serowe health care workers]

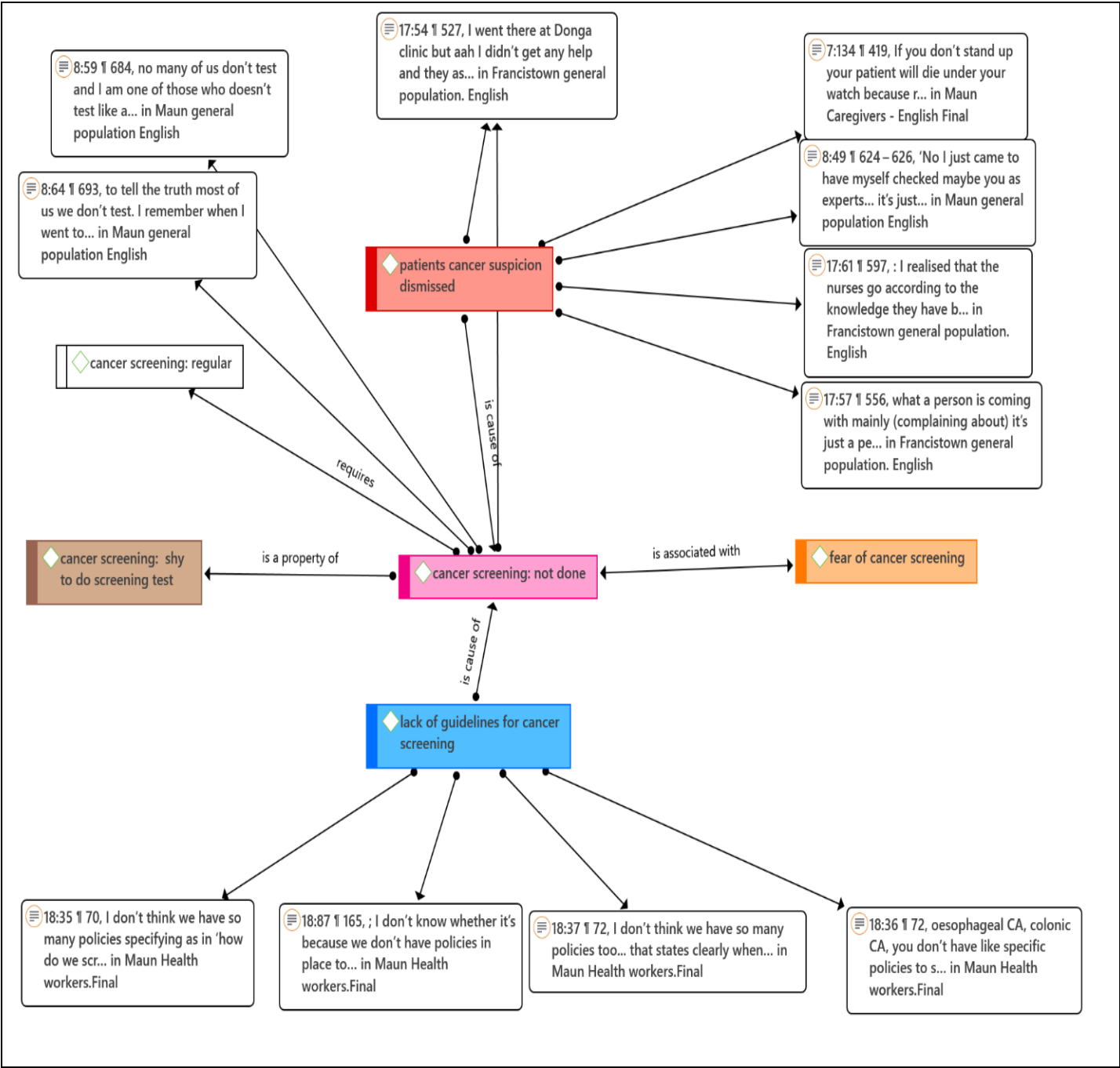
I tested more frequently even when he was still alive, I was the kind of person who screens for cancer a lot. Even today I still have myself checked, even just last year I checked [8:154 ¶ 680 in Maun general population]

Health care workers seemed to strongly support mandatory testing for cancer, especially among specific at-risk populations, such as women:

We are still seeing high numbers of women coming in advanced stage but still we have clinics which are said to be offering pap smear, and this means they are less used unless and until we do something which forces women that "you... you are going to do it" [16:39 ¶ 113 in Francistown health care workers]

The issues around screening were complex. FGD participants explained their observations on screening. Participants were aware of some screening programs, especially for breast, cervical, and prostate cancers. There was, however, some confusion about screening for the uncommon cancers, such as cancer of the colon. The confusion was borne out of a perception that there were no clear policies on screening for various cancers. Participants were amenable to screening for cancers but were dissuaded by several factors: fear of cancer; discomfort with the test, particularly the digital rectal exam required for prostate cancer screening; and health care worker attitudes that were perceived to be less receptive when patients request to be screened for cancer. Participants' experiences with cancer screening are summarized in Figure 24.

Figure 24. Participants’ Experiences with Screening for Cancer



- **Participants' Ideas on Cancer Prevention**

Patients suggested dietary improvements at the community level, including making use of available dietary resources such as wild fruits and avoiding spicy diets, chili sauces, and mayonnaise, which were considered as a new phenomenon:

Apart from eating vegetables, they were the kind of people who went into the bush a lot; they would go into the bush to get wild fruits such as wild grapes and even wild vegetables like pigweed (thepe in Setswana), yes [5:76 ¶ 124 in Bontleng community]

Other lifestyle activities were also recognized by some as ways to prevent cancer, such as smoking cessation (especially among men), reducing high-sugar diets, and eating high-fiber foods:

I would like to encourage men who are smoking to stop smoking because you might end up having it [8:26 ¶ 78 in Maun general population]

Food with roughage that can help you not to have cancer; they can actually help you against many diseases [5:72 ¶ 114 in Bontleng community]

Patients also shared their views on cancer screening, which seemed to echo those of health care workers and advanced arguments for access to screening services to prevent cancer in the community, especially in hard-to-reach areas:

What I would ask would be... to ask health workers that such deadly diseases like cancer... If they could go into these settlements where people are gathered and have us checked right there [8:143 ¶ 648–650 in Maun general population]

These suggestions led to exploration of factors that prevent people from engaging with cancer prevention measures.

- **Barriers to Cancer Prevention**

- i. **Unavailable Skilled Personnel**

Unavailability and appropriate use of skilled personnel trained in cancer were recognized as challenges to provisions of cancer services, including cancer prevention. Even when a trained person is available, they sometimes get transferred to other duties and not the oncology-related duties they were trained for. This leads to the loss of the few skilled personnel and results in disadvantages for the patients who benefitted from their services, as shared by Serowe participants:

For example, we used to have one oncology nurse at surgical, and she trained for some few months outside the country then she became an oncology nurse but later... She knew issues of oncology; she was trained as an oncology nurse – it was more of a field of specialty. But later she was just... “Oh, you’re a surgical nurse, you’re no longer an oncology nurse.” And then this issue of now it being said that “You are a surgical nurse; you will start to work on only surgical things only, you no longer focus on oncology now.” And then she decided: Okay, since my qualification of oncology is not recognized, let me go somewhere. And then there was no oncology nurse who was addressing those oncology cases or oncology issues, maybe, in the absence of the oncologist. [20:79 ¶ 33 in Serowe health care workers]

Unavailability of trained health care personnel can affect service provision, including screening for cancer. Those not trained may not think of screening patients for cancer despite recurrent presentations to health facilities. And this can lead to the cancer being caught only when it is in an advanced stage:

I have this and being given drugs... he would be given doxycycline and would go (back); it’s just that that person would go until he shows the signs... like when cancer now it’s showing signs, he would be experiencing some discharges, bleeding and whatnot like when now the disease has gone out of control. [16:48 ¶ 122 in Francistown health care workers]

ii. Health Care Workers’ Attitudes

On the other hand, health care workers’ attitudes toward patients who present at health facilities requesting to be checked for cancer were found to be prohibitive by patients. Patients at times felt discouraged, and their requests were questioned by health care workers when they came to ask to be screened for cancer so that it can be caught early:

“How did you see that you have cancer?” “No, I just came to have myself checked maybe you as experts...” “I don’t know if it would show” ... “No go back home you will come when you have felt something inside” and he won’t even look at you! (...examine you) [8:139 ¶ 626 in Maun general population]

Sometimes health care workers’ attitudes seemed to contradict the health promotion messages that encourage people to come and test for cancer. When patients come, they are turned away:

When there is disease outbreak, they will say come to the hospital when you have symptoms, do you see that issue? It is the one that kills us (put us in danger) and make the disease spread and even this cancer cases are going to be too many because of this issue. Sometimes when you come to the hospital and say you came to test for breast cancer “what did you feel in your breasts” [8:137 ¶ 622 in Maun general population]

iii. Patients' Fear of Cancer Testing

Patients also talked candidly about their fear of testing for cancer, sometimes even when they had symptoms:

We are afraid to test [4:31 ¶ 37 in FGD PMH 01]

And back in 1998, I felt lumps in my breasts whenever I touched them, and I just dismissed it [8:133 ¶ 619 in Maun general population]

The fear of testing can be due to factors around the testing procedures themselves. These can cause fear of testing due to pain and discomfort envisaged:

What is the problem that is causing us not to check ourselves... Aah those devices are painful [8:159 ¶ 687 – 688 in Maun general population]

iv. Unavailable Testing Services

Some health care workers expressed opinions that focusing on specific cancer services, like screening for cervical and breast cancer, may lead to focus on those cancers at the expense of other cancers. Therefore, while it is important to educate people about those cancers, other cancers should also be included because they are important:

Like we are capitalizing on breast cancer and cervical cancer, but other cancers also claim life [20:74 ¶ 31 in Serowe health care workers]

4.3.3 Participants' Cancer Information Needs

- **Biomedical Aspects of Cancer**

Under this theme, patients expressed varying views on their information needs. While some patients felt that they had been given all the information they needed, others wanted additional information. Patients and caregivers wanted information on what cancer is; signs and symptoms; types of cancer to be aware of; treatment side effects, especially chemotherapy side effects; and investigations, disease progression, and prognosis.

Francistown caregivers had the most discussions about their experiences with information provided by health care workers when they are “breaking bad news” to the patients. The caregivers seemed to experience a more compassionate approach from health care workers during breaking bad news

than PMH or Nyangabgwe patients. However, caregivers still felt that there was some information that health care providers did not share with them. There was a sense of secrecy felt by caregivers when it comes to communication from health care workers.

The hospital is secretive. You would just die like that while they know what is killing you and you won't know about it [7:20 ¶ 133 in Maun caregivers]

- **Information on Treatment Effects and Nutrition**

PMH patients emphasized their need to be counseled on treatment and its side effects as well as to receive education on nutrition. Caregivers indicated their need to have things explained to them, especially what to expect when caring for a cancer patient. This was a strong need, especially among caregivers who needed information about the condition and treatment:

The medical personnel, they are supposed to inform us that if your patient is a cervical cancer patient or breast cancer patient or... you will see such and such symptoms instead of us seeing symptoms that we don't even know if they are for cancer or what [3:320 ¶ 228 in Francistown caregivers]

They didn't explain anything to us... that when this happens it's because of this. They didn't explain anything. So, we are in the dark [3:282 ¶ 242 in Francistown caregivers]

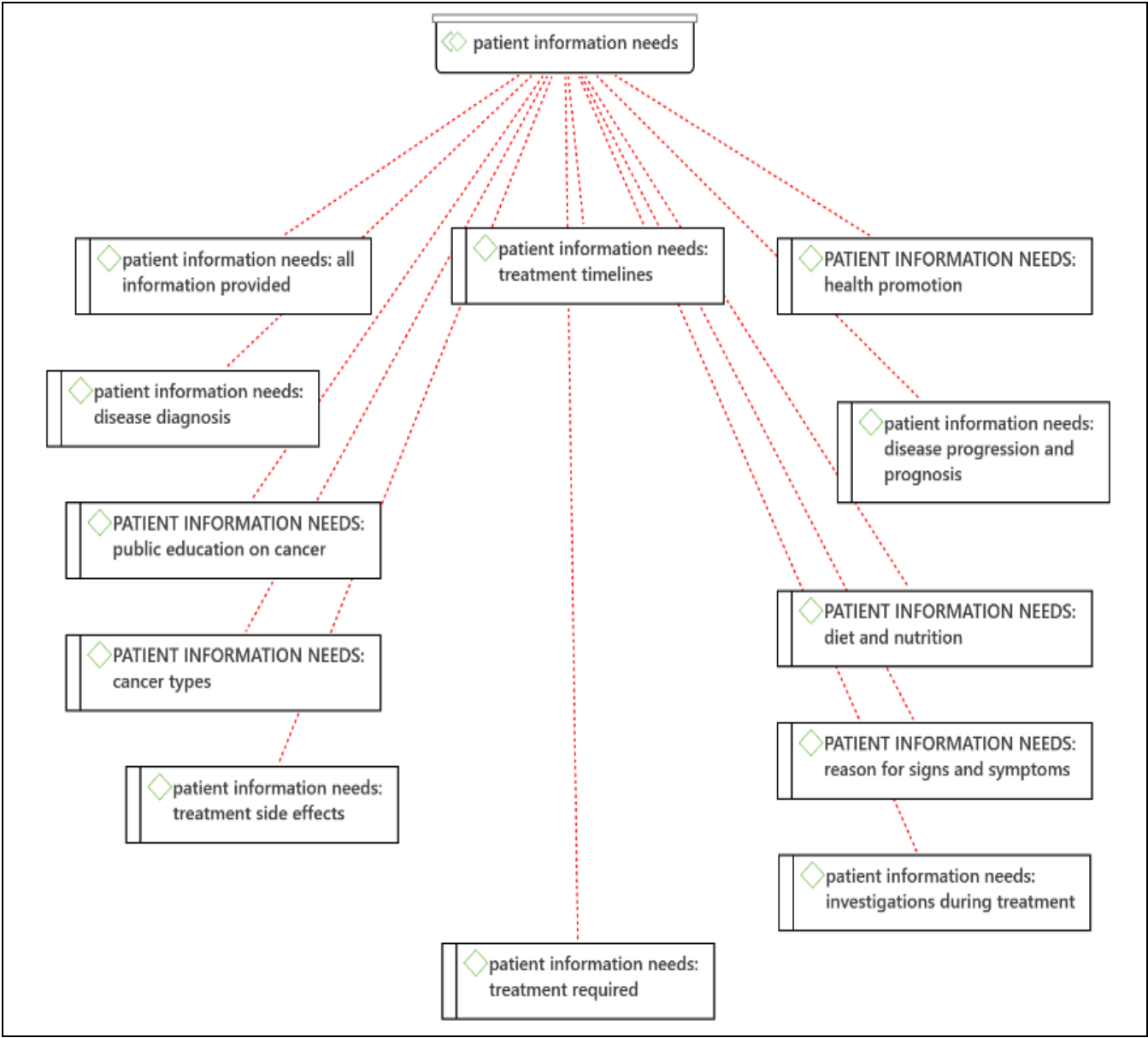
- **Shared Knowledge and Experiences**

Sharing of experiences among caregivers was also felt to be a need. This would enable them to better understand the condition:

It should gather us together so that we may be able to share ideas, to share knowledge and experiences [7:57 ¶ 457 in Maun caregivers]

A summary of information needs as described by participants is provided in Figure 25.

Figure 25. Participants’ Information Needs



4.3.4 Access to Cancer Management

- Access to Care and Treatment**

Difficulties with access to treatment was a significant theme across all the focus groups. Participants shared their challenges with access to cancer treatment. Two major challenges identified were the unavailability of medicines and access to those who can provide treatment, especially doctors. Several barriers to treatment and care were also identified.

- **Access to Medicines**

Both patients and health care workers described their experiences with this issue. From a health care worker's perspective, poor access was mainly because of unavailability of drugs and the lack of timely delivery by pharmacies. Sometimes the drugs were unavailable because of communication between pharmacies and health care workers or because of unavailability from CMS. Drugs required for treating cancer were often unavailable either because of price and being unaffordable to patients, such as tamoxifen and Herceptin, or simple stock outs from pharmacies.

From a patient's perspective, drug availability challenges were due to cost and the pharmacy not making them available on time. A strong feeling of poor access due to long queues and waiting times at pharmacies was identified by patients. At times, medications were to be couriered to patients, but delays were experienced by the couriers themselves while delivering medication to the patients.

- **Access to Specialists**

An important factor lamented by participants was the unavailability of relevant specialists to treat their cancer, which was deemed to contribute to disease progression and deaths:

Next time when you come, “no come on such and such a date, the doctor is not around,” while the disease continues to grow, and cancer spreads quickly [7:38 ¶ 421 in Maun caregivers]

These specialists included not only oncologists, but also other specialists such as neurologists, nephrologists, and surgeons. Patients could experience serious negative outcomes, including death, as a result of specialists' unavailability, as observed by health care workers:

We don't have a neurologist, we don't have a nephrologist, we don't have a surgeon, but someone is not passing urine; we end up losing a lot of patients due to that gap... yes [18:28 ¶ 159 in Maun health care workers]

- **Health Care Workers' Attitudes**

Patients and caregivers at times perceived health care workers' approach to reported symptoms as prohibitive to accessing treatment. Patients and caregivers perceived that symptoms of concern were often not taken seriously and not explained. As a result of this attitude, patients and caregivers believed that HCWs did not prescribe further interventions or treatments. This leaves patients and relatives distressed:

Instead of seeing someone vomiting blood, because we don't know if it's something that is supposed to be there or what, and when you ask a doctor, he too would not give you an answer

as to why the person is vomiting blood; they would ignore the issue which means to them it's okay, but to us it is not okay [3:173 ¶ 228 in Francistown caregivers]

Communication from health care workers to patients was a dominant theme. Patients felt that health care workers did not take time to explain or provide relevant information to help them understand what was happening. Sometimes patients would even be ignored, despite having asked about symptoms on more than one occasion:

Two weeks before I started chemo, my arm started becoming very painful to an extent that at times even painkillers were not helping. So, the first time when the doctor had come to assess me and prescribe for me on what to take, I talked about the issue; he didn't say anything. I came to take the first cycle of chemo and I even talked about it, but nothing! I also mentioned it when I came for the third cycle, that was when now he started examining me [190 ¶ 352 in FGD PMH]

This poor communication happened even at times when patients perceived doctors were not too busy to explain things to patients:

Especially regarding the fracture... I mean, you would find a doctor just talking to his phone, from there he would look at you and say, "what is it?" then he would just write down hmmm [3:161 ¶ 212 in Francistown caregivers]

- **Patient-Related Factors**

Patients sometimes delayed accessing treatments for various reasons. These reasons included treatment refusal, advice from a traditional health practitioner who doubted the diagnosis of cancer, or being made aware of traditional herbs that are renowned for curing cancer such as *monnamontsho* (Blackman):

Even when they are awaiting treatment, some of them will say, "So, I went to a traditional doctor who advised me not to go for chemo. I have been referred to go for chemo in Francistown, for example, but I met a traditional doctor who said: "This is not cancer, it's something else" [20:108 ¶ 45 in Serowe health care workers]

Religious beliefs of caregivers and patients also played a critical role in delaying access to treatment. Patients and caregivers' beliefs appeared to be fueled by trusting that religious healers were able to heal cancer, compared to conventional medical practitioners, which the caregivers and patients believed would save the government from wasting money on chemotherapy:

These funds for chemotherapy and all these should be used... more so that a patient is recommended to be transported six times in a month, so maybe if they could transport people to TB Joshua (a prophet in Nigeria) because it seems like these people who go to TB Joshua are

getting healed from cancer... they get healed so maybe they could be coming to take our patients this side for healing instead of... chemotherapy, from what I gather one cycle costs a lot of money because is not doing anything because wounds come out but with Joshua maybe it's better because when they have transported him here so that he could throw us that water, as we touch it we would feel the fire and fall then sickness... all the wounds would heal like I saw them healing [3:162 ¶ 212 in Francistown caregivers]

Shared experiences from other patients also influenced whether newly diagnosed patients would continue with chemotherapy. This happened when patients met each other at the health facility:

As we are seated, there are people who hold discussions on how chemo is treating them “heee it would make you go insane, yes you are going to die, it can’t be cured” like saying all kinds of things... bad things about people with cancer, so if it’s your first time to take treatment and you hear all these, you might end up not coming at all, that’s how it is [1:168 ¶ 211 in Nyangabgwe patients (210209_001)]

- **Alternative Cancer Therapies**

Alternative therapies toward cancer diagnosis and management were also suggested to help with cancer treatment. Some patients consulted alternative medicine practitioners, while some caregivers were aware and believed that traditional healers and some religious leaders could treat cancer:

I then I met a Chinese doctor, and he asked to check if it’s not cancer. “I want to check cancer and...” he said something to do with environment... allergy but he did not cut the skin (biopsy) because there were fluids coming out, he drained that fluid [1:39 ¶ 46 in Nyangabgwe patients (210209) (English)]

If they could transport Joshua (TB) because it seems like these people who go to Joshua are getting healed from cancer, I even had a thought that if they could allow the traditional doctors [3:70 ¶ 212 in Francistown caregivers]

4.3.5 Health System Challenges

- **Poor Communication within Referral System**

Delays in treatment access were also due to poor communication among health care workers, especially if patients required referral to other specialists. Delays in treatment were also noted because of delays in referrals to home-based care or, if referred, delayed visits to patients at home by the home-based care teams:

Services reach us really late, to an extent that you may have been diagnosed with a disease, but because of your lack, you end up just eating anything that is within your reach even if you could have been given instruction of what to eat [17:13 ¶ 208 in Francistown general population]

- **Equipment Unavailability**

Caregivers felt that equipment unavailability contributed significantly to delays in accessing treatment, and that equipment unavailability seemed to occur on more than one occasion:

When we get there, or they will tell us same story that ... that issue that “our machines are not yet okay” and they just let us go there when they know that their machines are not okay and we are using money (to get there) [3:178 ¶ 238 in Francistown caregivers]

The main equipment seemed to be the computer tomography (CT)scanners, and this was corroborated in conversations with health care workers:

Booking CT scans also... We have issues of CT scan not working [20:97 ¶ 39 in Serowe health care workers]

You refer him for CT (scan) to other institutions, meaning that it takes time [16:70 ¶ 158 in Francistown health care workers]

Barriers to treatment were extensively discussed, focusing on the lack of communication between health care workers and patients, health care workers’ attitudes, and information needs not satisfied. Language barrier was another factor that patients identified:

You would find that like a doctor who is here today, seeing he is Chinese, who seem not to even understand English, or he may understand but we don’t know what is happening; because there is no clear communication of what is happening, so we know what is happening [4:185 ¶ 331 in FGD PMH 01]

- **Delays in Diagnosis Due to Delayed Test Results**

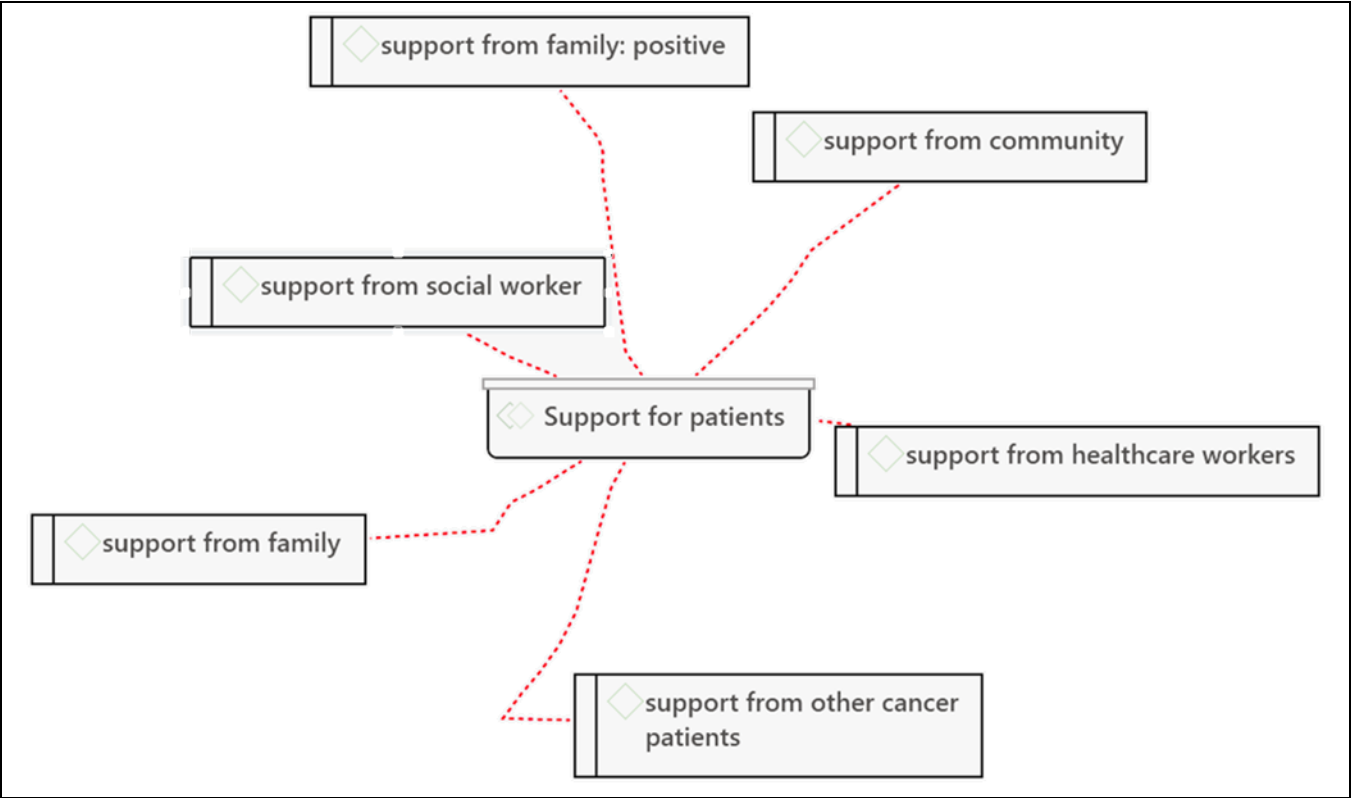
Both Bontleng community members and Serowe patients expressed their discontent with the pap smear results taking a long time. The delays are partly due to the shortage of health care workers, so patients' appointments are rescheduled to a later date, but mostly secondary to the delay of the pap smear results.

4.3.6 Support Systems

- **Patients and Survivors**

Support came from family members, health care providers, social workers, and other members of the community, including volunteers and individuals from faith-based organizations. While support came from various sources, health care workers and family support were the most cited sources of support. Support for patients and caregivers came from different sources, as shown in Figure 26 below.

Figure 26. Support Structures for Patients



- **Support from Health Care Providers**

One of the prominent themes discussed is the support from health care workers, especially by Nyangabgwe patients. PMH and Serowe patients also described supportive health care workers. Both Nyangabgwe and Serowe patients mentioned the existence of cancer support groups, while PMH patients did not have support groups and expressed a wish that there would be an arrangement for provision of psychosocial support within the community.

Support from health care workers was received very well and appreciated by patients. The support came in various forms, predominantly that of being shown love and care, being talked to nicely, being called by their names, and going the extra mile for the patients:

I am asking for your support, they didn't even say corona, that... we would wear gloves then lift her up from the car, the six or eight of us, and that is love [3:221 ¶ 347 Francistown – Caregivers]

I am a surgeon; I have done my part, but anything that you need... if they become difficult just call me [4:87 ¶ 98 in FGD PMH 01]

- **Support from Family Members and Community**

The family support was from the patients' children, partners, or siblings. The support was usually positive, such as words of encouragement from the family:

After the news were broken to me that I have the sickness, my younger siblings, we are 10, let me say we are nine now because the other one passed away, they sat down and said to me "our sister don't take the route our brother took, just do the chemo and all the treatments. God is with you; do everything that the doctors say you should do [4:154 ¶ 254 in FGD PMH 01]

And other volunteers used to come here and the people from the church; they come here you see; And prayed for him... [3:311 ¶ 104 in Francistown caregivers]

Families of cancer patients also needed support to cope with the suffering they saw their family members going through. Some families would even avoid visiting patients in the hospital because it is a difficult situation for them to witness:

Even the family we had allowed them to just come and visit him... they were afraid of him, there were times when they were not afraid of him though so now when he reached stage four... there they were already... sometimes like during visiting hours they would not come now, they just left him there without visiting him; they didn't want to see him because now he wasn't really okay. It wasn't easy for them and the family [16:130 ¶ 293 in Francistown health care workers]

- **Caregivers Perspectives about Quality of Care**

Caregivers shared their experiences and perspectives on the quality of care provided to patients at the facilities. Several perceptions and expectations were noted, including teamwork, communication from health care workers, and emotional support.

While team composition has been a recurring theme in this research, the focus this time was on perceived benefits of having a team made up of local doctors who can speak the same language as patients and caregivers. There was a perception that Botswanan doctors would empathize more. In

addition, there were mixed feelings regarding the support that patients get from doctors. Some caregivers reported that some doctors did a great job giving them hope and a caring attitude and that some even used humor to help the patients relax. Others, however, barely examined patients and, at times, ordered tests considered inappropriate, such as repeat COVID-19 testing.

It appears that caregivers also expected health care providers to coordinate home-based care, including waste management and collection. Overall sentiments expressed were that the quality of care was inadequate.

Cancer patient navigators were not discussed as a specific topic during the FGDs. It was clear, however, from the survivor FGDs that some survivors managed to receive timely care because they got help from someone who understood the health system and how it works:

I cried so bad after this diagnosis because I was told the result and immediately told to be admitted. There was somebody I know who worked in the hospital, and I told her that I was given results that I have cancer, and it is still difficult for me. She advised me to come the next day to see Ms. L [20:15 ¶ 63 in Serowe cancer survivors]

This someone could be a family friend or relative who is a health care worker. Sometimes there were health care workers who were not known to patients who would go an extra mile to help them navigate the system:

You see there is a senior lady that side, she was the one who then helped us immediately [7 ¶ 12 in Maun caregivers (English) (Final)]

4.4 Findings Regarding Cancer Resources

- **Cancer Community Resources**

Botswana has few cancer-related community resources specifically for cancer patients and their families. The ones that do exist are concentrated in Gaborone. The assessment team identified three registered NGOs that offer cancer-related services:

- i. Cancer Association of Botswana (CAB)
- ii. Journey of Hope (JoH)
- iii. Francistown Women's Institute (FWI)

Management personnel of these organizations were invited to complete a face-to-face survey. The results of these surveys are shown in Table 24.

Table 24. Cancer Resources Survey Results

		CAB	JoH	FWI
Organization Information				
Organization Category	National Nonprofit	x		x
	Local Nonprofit		x	
	Other	x		
Cancer Resources				
Primary Service Population of the Organization	Cancer Patients			x
	Cancer Survivors	x		x
	Caregivers / Family Members	x		x
	Other		x	
Type of Cancer Related Services Provided	Written Information on Cancer	x		x
	Information on Cancer / Support Services	x		x
	Management of Cancer Support Groups			
	Social Support for Cancer Control / Care	x		x
	Psychosocial Support	x		
	Navigational Services			
	Transportation			x
	Other	x	x	x
Number of Cancer Patients Seen Annually		> 150	> 150	51 - 100
Advertising for the Organization	Local Media		x	
	Organization Website			
	Online	x	x	x
	Pamphlets Describing Services		x	
	Word of Mouth	x	x	x
	Other	x		
Organizational Needs	Financial Support	x	x	x
	Human Resources			x
	Access to Experts for Consultation			x
	Physical Space / Facilities	x		
	Collaborators		x	x
	Volunteers			x
	Other	x		x

Challenges		-Resources for traveling -Transport -Financial	-Reaching the largest number of people beyond the annual “Big Journey”	-Number of members -Not advertising ourselves well -Input from consultants
Goals for the Next Five Years		-To reach out to four main areas of cancer -Form cancer support groups in all districts of Botswana	-Awareness -Encouraging people to get checked	-To reach more people living with cancer -Empower and help health care workers
Partners Organizations		-PMH -Baylor Clinic -Humana -Marathon and Associates -Book Binder Law	-CAB -All stakeholders who deal with NCDs	-Red Cross Simulations Center -The Blind Center -Curves Gym
Interested in Collaboration		Yes	Yes	Yes

- Human Resources

Both in Serowe and Francistown, health care workers identified the problem of shortage of health care workers, especially specialists: pathologists in Francistown and gynecologists and surgeons in Serowe. In both districts, health care workers pointed out the importance of screening for cancers as a preventive measure. In contrast with the Francistown health care workers, Serowe health care workers mentioned the inadequacy of the referral system (prolonged delays, lack of knowledge by a referring health care worker) as a barrier to cancer diagnosis. Serowe health care workers put great emphasis on managing cancer by a multidisciplinary (interprofessional) team consisting of an oncologist, a psychologist, a social worker, a dietician, and others. They also singled out the Serowe Cancer Support Group as the one that motivates cancer patients, while Francistown health care workers extensively focused on pain management and lack of resources for health care workers as challenges in cancer patients’ management.

- **Infrastructure and Commodities**

Gaps in the required infrastructure for treating cancer were identified and revolved around drugs stock outs, access and availability, facility setup, equipment availability, patient transportation, and long-distance travel to access treatment at various cancer centers. These are summarized in Figure 27.

The diagram is a conceptual map centered on 'CANCER RESOURCE CHALLENGES'. It branches out into several categories of challenges, each supported by participant quotes:

- lack of resources: in rural areas**
 - Quote: "18:101 1 246, everything is based in Gaborone and nothing in Maun; not based in Nga... in Maun Health workers.Final"
- lack of resources: medication**
 - Quote: "17:65 1 622, There is also this thing of giving (prescribing) someone pills saying... in Francistown general population. English"
 - Quote: "18:124 1 357, of late what we face, there is emmm there is no morphine syrup in phar... in Maun Health workers.Final"
 - Quote: "18:61 1 115, that is where the country is lacking in terms of pills, in terms of bi... in Maun Health workers.Final"
 - Quote: "18:112 1 286, regrastine will be there this month and then the other three months we... in Maun Health workers.Final"
 - Quote: "18:111 1 278 – 280, , we also have some challenges with supply chain I: Mmm R1: Sometimes... in Maun Health workers.Final"
- barriers to treatment: long distance travel**
 - Quote: "18:101 1 246, everything is based in Gaborone and nothing in Maun; not based in Nga... in Maun Health workers.Final"
- lack of resources: medical utensils**
 - Quote: "18:101 1 246, everything is based in Gaborone and nothing in Maun; not based in Nga... in Maun Health workers.Final"
- lack of resources: dietician**
 - Quote: "18:101 1 246, everything is based in Gaborone and nothing in Maun; not based in Nga... in Maun Health workers.Final"
- barriers to treatment: long queues**
 - Quote: "18:101 1 246, everything is based in Gaborone and nothing in Maun; not based in Nga... in Maun Health workers.Final"
- healthcare worker: doctor not available**
 - Quote: "7:98 1 249, we heard they told us its just that doctor wasn't in in Maun Caregivers - English Final"
 - Quote: "7:137 1 421, Next time when you come 'no come on such and such a date the doctor is... in Maun Caregivers - English Final"
 - Quote: "18:82 1 159, we don't have a Neurologist, we don't have a Nephrologist, we don't ha... in Maun Health workers.Final"
- long waiting period to doctor appointment**
 - Quote: "18:49 1 100, we don't have a surgeon here in Maun Health workers.Final"

Relationships between nodes are indicated by arrows with labels: 'is cause of', 'includes', 'is associated with', and 'is a property of'.

5. Summary of Identified Gaps in Cancer Care

Knowledge of Cancer

Cancer knowledge gaps were a major theme in the FGDs. The general population in Maun had very little knowledge about cancer compared to those living in Francistown. Both populations seemed inquisitive about cancer diagnosis, treatment, and management. The communities' knowledge gaps span the causes, symptoms, and treatment of cancer. The knowledge gaps were also identified among health care providers.

Cancer Prevention and Management

Health worker attitudes emerged as a barrier to prevention and early detection of cancers, as patients felt belittled when they visited health facilities for cancer screening. Patients also highlighted that their facilities lacked cancer screening outreach services. Other patients feared testing procedures and, hence, avoided screening. Poor access to cancer drugs, associated with stock outs, long queues and waiting times at pharmacies, and high costs to patients, contributed to weak treatment and management for cancer patients. Patient and caregiver factors such as treatment refusal, negative advice from a traditional health practitioner, religious beliefs, and negative shared experiences from other patients were also identified as cancer management influencers.

From the health care workers' perspectives, while there were very few oncologists in the system, most cadres, such as general doctors, nurses, pharmacists, and radiographers, were reported to lack basic training in cancer care. Poor cancer patient management was also attributed to shortages of other supporting specialists, such as neurologists, nephrologists, and surgeons.

Barriers to Diagnosis and Treatment

Lack of communication among health care workers as well as between health care workers and patients, particularly when patients required referral to other specialists, appeared to be an important hindrance to cancer diagnosis and treatment. This was said to be compounded by a shortage of skilled health care workers who specialized in cancer (nurses, doctors, and others), a shortage of cancer medications, a general lack of CT scanners across sites, and long laboratory results TATs due to scarcity of pathology laboratories. Caregivers and patients also lamented transport costs to attend treatment and diagnostic centers.

Barriers to Improved Health

The main identified gaps relate to health care workers giving support to patient and their caregivers, including social workers and home-based care service providers. Participants generally reported

minimal nutritional support for cancer patients as well as the absence of counseling services for cancer patients and caregivers.

Quality of Health Services Provision

The capacity and capabilities of health care workers and the health care system to provide quality cancer care services are inadequate. This includes poor health worker-patient communication, weak palliative care and home-based care systems, and poor hygiene and care in health facilities as factors that contributed to poor quality of health provision.

6. Strengths and Limitations

Strengths

This needs assessment addresses all four designated public oncology centers in Botswana and, therefore, has a national scope. In contrast, with a few exceptions²⁵, most published studies address cancer care at PMH or GPH.^{26,27,28,29,30,31}

This inquiry encompasses multiple perspectives of cancer care. Study participants ranged from administrative and clinical staff at the four designated hospitals (from both oncology and other medical/surgical services) to cancer patients and survivors, caregivers, and members of the general community. Interviews were also conducted with management personnel from community-based organizations serving cancer patients.

By incorporating both quantitative and qualitative approaches, we gathered quantifiable and contextual aspects of cancer care. An unanticipated finding was the psychological difficulties expressed by both oncology and non-oncology staff during focus groups with regard to their treating cancer patients at advanced stages of disease.

This study will inform the policy priorities of the MoH as it moves from a broad NCD strategy, which includes cancer, to a detailed, national cancer-specific plan.

Limitations

Assessments of the provision of cancer care at each hospital were based on staff reports and perceptions. The study did not include medical record review to confirm descriptions. After there is consensus on essential elements for cancer care, future studies can use medical record review to document the provision of care, especially for specific types of cancer.³²

Furthermore, the availability of procedures (e.g., oncology surgery) and treatments (e.g., chemotherapy and radiation) was only addressed with respect to presence or absence. Accordingly, quality of care issues (e.g., conformity to standardized guidelines for care or capacity to promote completion of a multi-visit treatment course, characteristic of radiation or chemotherapy) were beyond the scope of this study.

For oncology staff surveys, small sample sizes by hospital constrained the robustness of comparisons between hospitals. Sample sizes were limited by restricted staff numbers, as well as limited availability of an overstretched staff during interview times. Non-participation of staff was not systematically reported. In addition, at times, staff were impacted by COVID-19 pandemic-related lockdowns, which resulted in some surveys being conducted via telephone.

Findings from a number of survey questions were contradictory, apparently because question intent was not clear to respondents, and the assessment team excluded these findings from the analysis. The survey questions were adapted from a HIC with different resources and challenges. These questions were piloted with medical staff and patients from a primary hospital with no oncology service (Bamalete Lutheran Hospital in Ramotswa). Inability to pilot the study with staff focused on cancer care was an inherent problem that could not be rectified for this study.

7. Discussion and Recommendations

Essential Cancer Surgery and Treatment Not Available at the Public Oncology Centers

Several essential cancer services are unavailable at one or more designated public oncology centers, particularly those outside PMH (Table 6). All patients can access radiation therapy at GPH at government cost, irrespective of which cancer hospital is providing their treatment. However, none of the four public oncology centers has on-site access to radiation therapy. Efstathiou et al.⁹ indicate that temporary housing is provided for radiation therapy patients who travel long distances.

With respect to intravenous chemotherapy, it is available at three of the public oncology centers; at Sekgoma, patients are referred to NRH. However, the extent to which availability matched need was unclear. Oral cancer agents were seemingly available at PMH, NRH, and Letsholathebe, while it is unclear whether these drugs are prescribed at Sekgoma. In addition, stock outs for cancer drugs described by health care workers in our surveys have been identified in published work as an obstacle for treatment.¹⁰ Martei¹⁰ indicates that standardized treatment guidelines tailored to specific cancers are a critical step to increase the accuracy of forecasting. Cancer surgery also varied by hospital, with most surgeries available at PMH and fewer surgical types available at Sekgoma and NRH. Letsholathebe does only limited gynecological surgery (Tables 14–16).

Although WHO recognizes that centralized cancer services can maximize quality, it also underscores the need to promote geographical accessibility.³³ The provision of pediatric cancer care, which was not separately addressed by the needs assessment, also requires focused attention, due to specialized care needs. Currently, pediatric cancer care is centralized at PMH, although health workers at 50 percent of government hospitals were provided training on how to recognize and refer children with cancer to this service.³⁴

Recommended Strategies

Ensure timely access to (though not necessarily provision of) essential cancer surgery and treatment at all public oncology centers.

- a. Expand capacity for radiation therapy, especially outside Gaborone.
- b. Increase access to radiation therapy, especially outside Gaborone, through full provision of transportation, lodging, and food to patients who must travel for this treatment.
- c. Initiate provision of intravenous (IV) chemotherapy at Sekgoma through addition of necessary equipment (laminar flow cabinet) and trained staff.
- d. Ensure access to oral cancer agents at the four public oncology centers, as well as subsequent provision of these medications at primary and district hospitals closer to patients' homes.

- e. Improve forecasting for cancer drugs to reduce stock outs, which requires standardized treatment guidelines for specific cancers, particularly the most common cancers.
- f. Review cancer surgery needs by type across the four public oncology centers to determine needs, maximize current capacity, ensure standard protocols, and optimize equitable access regardless of region.
- g. Separately address pediatric cancer needs and optimize geographical access.

Most Cancers Are Diagnosed at Advanced Stages

About 70 percent of cancers are diagnosed at an advanced stage,³ which leads to limited options for treatment and high mortality. Although the MoH has established programs for cervical cancer screening, cervical cancer continues to be the most common cancer, and cervical cancer screening is far less than optimal. Screening for other types of cancer, such as breast, prostate, and colon, is not available in public health facilities.

While WHO strongly endorses cervical cancer screening with further evaluation, it does not automatically recommend other cancer screening for asymptomatic persons. On the other hand, it advises maximizing early diagnosis as an effective public health goal, which requires “awareness of symptoms, rapid clinical and pathological diagnosis, and referral to an appropriate treating facility” (see Section 4.1.3, *Cancer Screening Services*).³³

In Botswana, the establishment of a network of cervical cancer screening efforts and focused efforts to expand the network to 80 percent coverage of women within designated ages is consistent with WHO recommended priorities. By 2023, the MoH plans to introduce breast cancer screening using clinical breast exams for women 40 and older within the primary care system.³

There is widespread recognition that the general population needs to be educated about the warning signs of cancer. In addition, women within designated ages need encouragement to follow the schedule of cervical cancer screening. At the same time, health care workers need to be more informed about available cancer screening, warning signs, and procedures for early detection. While diagnostic mammography and breast ultrasound are available at PMH and NRH, they are not available at Sekgoma and Letsholathebe (Table 10).

Recommended Strategies

Implement measures to maximize earlier diagnosis of cancer types that can be detected at earlier stages.

- a. Formulate strategies to educate the general population about the warning signs of cancer and when to seek medical help. Messages to the public need to dispel myths, address stigma, and counter hopelessness about cancer.

- b. Optimize participation of age-designated women in current screening for cervical cancer and ensure timely referrals and treatment for women requiring further evaluation or treatment.
- c. Educate health care workers on available cancer screening, warning signs of cancer, procedures for early diagnosis, and best practices for referrals.
- d. Incorporate questions about signs and symptoms of cancer into routine primary and ambulatory care, similar to other NCDs.
- e. Ensure adequate technology for early diagnosis of breast (Table 10), cervical (Table 8), and colorectal (Table 11) cancers with widespread gaps identified in Sekgoma.
- f. Review the adequacy of early diagnosis of prostate cancer, as broad provision of relevant assessments across the four public oncology centers was vague (Table 12).
- g. Consider stepwise inclusion of clinical breast exams within routine primary and ambulatory care when there is adequate access to follow-up through mammograms and ultrasounds.
- h. Educate traditional doctors on cancer signs and symptoms, and collaborate with them to ensure they promptly refer patients to the health care facilities.

Persistent Delays from Patient Presentation to Cancer Diagnosis

There are persistent delays from the time a patient presents to health care providers with suspicious cancer signs or symptoms until a cancer diagnosis is received. Overall, the average delay ranged from two to six months. Minimum times tended to be shorter at NRH and PMH (one to two months, respectively) and at least three months at Sekgoma and Letsholathebe (Table 13).

WHO emphasizes the importance of coordination of care and strengthening “care pathways”.³³ Botswana’s NCD strategic plan is similarly focused on improving these health system paths.²³

Recommended Strategies

Increase efficiency of referral practices and add mechanisms to assist patients.

- a. Set up uniform procedures for referrals with follow-up and tracking to ensure that patients get timely appointments and follow through.
- b. Train medical doctors in primary and district hospitals on performance of true-cut biopsies and FNA, as well as how to stage cancers.
- c. Initiate patient advocacy (help) centers that patients can contact if they are not getting services.
- d. Establish a system of patient navigators to support cancer patients through their care journey.

Lengthy and Unreliable TATs for Pathology Results

Inadequate resources for pathology are a particular obstacle. A large proportion of pathology procedures at both PMH and Sekgoma are sent to Francistown or NHL. **4.1.7 Laboratory Services** In addition,

molecular testing for patients from PMH, Sekgoma, and Letsholathebe is performed in South Africa (see section 4.1.7, *Laboratory Practices*). The lack of on-site capacity most likely accounts for median time of about four weeks (ranging from two to 274 days) for receipt of pathology reports in a study conducted in medical records from 2012 to 2014 at PMH.³¹ Health care workers at the four designated public oncology centers identified pathology TATs as a problem (Table 22).

Recommended Strategies

Expand laboratory capacity and improve tracking and speed.

- a. Expand laboratory capacity to increase on-site performance of pathology tests.
- b. Increase speed of reporting results; develop tracking systems to reduce misplaced tests and extended, unnecessary delays.
- c. Increase pathology training to increase the number of pathologists in the country, and have staff dedicated specifically to managing pathology samples.
- d. Upskill existing pathologists on new basic techniques, such as immunohistochemistry.
- e. Consider ways to use telepathology to augment capacity of pathology services.
- f. Equip laboratories with up-to-date equipment and ensure that they undergo regular maintenance.
- g. Ensure that there is a steady supply of reagents at all laboratories.

Staff Shortages in Oncology with Many Insufficiently Trained Personnel

There are variable numbers of physicians staffing oncology services across designated public oncology centers (Table 5). Parallel staff shortages have been described in nursing, pharmacies, laboratories, and palliative care within hospitals. Reliance on oncologists from other countries, including non-English speaking physicians, contributes to cultural misunderstandings and communication difficulties. Patients describe long waits and queues. Both long- and short-term strategies are needed to increase the numbers of formally credentialed oncology staff and to increase the training of current personnel.

Recommended Strategies

Increase training opportunities.

- a. Provide training to current health workers in oncology to increase their proficiency and build in supports to provide oversight.
- b. Develop a comprehensive curriculum of workshops and incentivize completion of multiple skill-relevant workshops. Offer locally recognized certificates.
- c. Establish cancer committees to review cases and augment learning.
- d. Host oncology and palliative care grand rounds in a safe and collaborative environment for health care workers to share their experiences, dilemmas, concerns, and fears related to patient-

centered care within the facility and to offer health care professionals an opportunity to learn approaches for the care of cancer patients as an interprofessional team.

- e. Facilitate interprofessional patient rounds with all team members participating in the care of the cancer patient.
- f. Streamline hiring strategies to recruit specialty talent and identify and resolve obstacles that inhibit strategic hiring.
- g. Review academic programs at Botswana universities, colleges, and technical schools to increase the numbers of credentialed and well-trained staff for oncology needs and services.
- h. Maximize resources for training using telemedicine and telementoring through collaboration with external universities.

Policy Makers Should Focus on Cancer Prevention Interventions

Health care workers' held strong perceptions that cancer should be prioritized by policy makers with a focus on prevention including health education and promotion, screening, health worker training, and legislation. There was a strong suggestion to make cancer screening part of routine health care consultations similar to that which is in place for other common NCDs. Health education on cancer was a strong theme across patients, caregivers, general population, and health care providers.

Recommended Strategies

- a. Strengthen capacity of health care workers across the spectrum of cancer management, including screening, early detection, and management of the cancer patient.
- b. Develop capacity for cancer prevention and early detection within primary care, health posts, HIV clinics, and traditional healers, ensuring knowledge among all frontline health workers.
- c. Consider cancer screening outreach programs to augment facility-provided care, including health education and outreach campaigns with specific linkages to screening and treatment services.
- d. Focus public health campaigns on ensuring that health education and promotion interventions, such as healthy lifestyle education and tobacco cessation, are accessible.

Varying Provision of Palliative Care across Designated Cancer Centers

There is uneven provision of palliative care across the four public oncology centers. Palliative care, as defined by WHO, aims to improve quality of life among those facing physical, psychological, and social suffering associated with life-threatening illness, including cancer.³⁵ In a country where most cancers are diagnosed at advanced stages, the availability of palliative services at all public oncology centers is especially acute. Furthermore, evaluation of patients' palliative care needs should start after cancer diagnosis and not be limited to cancer patients in their terminal phase. While PMH offers palliative care

as a consultation service and an outpatient clinic (Table 18), there appears to be an absence of organized palliative care services at the other three public oncology centers (Table 17). The provision of palliative care to cancer patients must also be augmented by organizations that offer hospice and in-home care.³⁶ Krakauer et al.³⁷ identify cervical cancer patients as a group particularly prone to high levels of physical suffering (i.e., pain, vaginal bleeding and discharge, urinary catheterization, adult diapers) and social hardship (i.e., spousal abandonment, isolation, and extreme poverty).

The MoH strategic plan also prioritizes an upgrading of palliative care, particularly in relation to pain management and referral to home-based services.³

Recommended Strategies

Integrate palliative care into all phases of cancer management.

- a. Expand provision of palliative care services beyond PMH, i.e., to the three public oncology centers outside Gaborone.
- b. Educate health workers on a broad definition of palliative care needs among cancer patients.
- c. Ensure adequate forecasting of drugs for pain relief.
- d. Ensure adequate staffing and capacity of hospice and in-home care, particularly outside Gaborone.
- e. Train health care workers at the public oncology centers to make more timely referrals to community organizations providing hospice, in-home, and community care.
- f. Train health care workers at the public oncology centers on best ways to educate patients and families on the role of systemic therapy, including chemotherapy for palliative purposes and medications to reduce chemotherapy side effects.

Recommended Strategies

Add training and services to better meet needs for psychological and social support.

- a. Increase awareness of need for patients and caregivers to obtain access to psychosocial support.
- b. Provide training to oncology staff and health workers on optimal ways to communicate diagnoses of cancer and to engage with patient to plan for treatment.
- c. Establish counseling services and support groups to promote well-being and treatment completion as well as coping among cancer survivors.
- d. Prepare written materials to help patients understand their diagnosis, and prepare separate materials to help them understand treatments.
- e. Customize social support to individual patient needs, including travel costs and food supplies.
- f. Establish psychological support for oncology staff.

Deficient Organizational Procedures at Public Oncology Centers

There are multiple organizational and procedural factors that impede the provision of good cancer care. Standardized guidelines are especially critical when oncology staff vary in their level of specialty oncology training, come from different countries, and when staff turnover is frequent.

According to the MoH strategic plan, evidence-based and resource-sensitive treatment guidelines will be introduced for major cancers.³ The MoH has released guidelines for cervical, breast, colon, and head and neck cancers. Health care workers need to be educated on implementation.

Apart from PMH, there appear to be communication issues, particularly linked to English language facility, between the oncology team and other health care providers (Figure 18).

Recommended Strategies

Strengthen standardization of care, documentation, and data-based oversight.

- a. Facilitate standardized guidelines for all aspects of cancer care and guidelines for specific cancer types.
- b. Review EMR to ensure systematic capture of relevant information for diagnosis, treatment, and ongoing surveillance.
- c. Monitor quality of care and adherence to guidelines by cancer type, as reflected by comprehensive documentation in EMR.
- d. Improve team-based health care team communication.

Minimal Data Collection at the Four Public Oncology Centers to Inform Planning

Digital data is not yet uniformly collected at each hospital to support assessment of the annual flow of inpatients and outpatients by diagnosis; stage; comorbid conditions; and demographics, including age category, sex, and residence. Such information is necessary to make informed decisions about allocation of resources for staffing, supplies, technology, and infrastructure. Although the existence of the BNCR is a positive resource for Botswana, the provision of patient data from the public oncology centers to the BNCR is incomplete, and there appears to be no procedure for cross-validation (Figure 13).

WHO views robust information systems as a critical element in the planning and ongoing build-up of effective cancer services.³³

Recommended Strategies

Develop well-functioning, user-friendly information systems.

- a. Equip the public oncology centers to generate summary lists of cancer patients with relevant details for planning and reporting.
- b. Pool and analyze data on cancer patients across hospitals so that decisions about allocation of resources can be informed by data.
- c. Ensure provision of cancer data to BCNR at timely intervals
- d. Increase capacity for BCNR to register all new cases of cancer going forward.
- e. Ensure all cancers are a mandatory notifiable disease after confirmed diagnosis, including pathology.
- f. Mandate the recording of cancer deaths to BNCR.
- g. Address insufficient public awareness of cancer as a treatable disease.

As a result of inadequate public education, cancer patients are not informed about interventions for cancer and their efficacy, particularly patients diagnosed in early stages. The country has had considerable success in changing HIV infection from a fatal disease to a chronic condition. The country should build on the success of the HIV program.

Recommended Strategies

Raise awareness of cancer treatment and resources; amplify survivor stories to offer hope.

- a. Create public education programs that clarify the signs and symptoms of cancer and emphasize the importance of visiting the health care facility for these signs or symptoms, as well as for other abnormalities.
- b. Undertake public education programs to eliminate common cancer-related misconceptions, particularly in rural areas.
- c. Devise innovative strategies to educate the public about potential for success in treatment of cancer.

Decrease Smoking as a Modifiable Risk Factor for Cancer and Other Chronic Diseases

Smoking rates among men and women, ages 15 to 69, in Botswana are estimated at 31.4 percent and 4.9 percent, respectively,³⁸ linked to a continuing burden of avoidable disease in Botswana, including cancer, particularly among men. While health workers highlighted the need to educate the public about the health risks of smoking, they also wanted training on how to discuss this problem with their patients and motivate patients who were smokers toward cessation (see Section 4.2.2, *Health Care Workers' Knowledge Gaps*). Although this involvement is an effective strategy to reduce smoking, it is essential to note that WHO recommends that smoking cessation be one of six strategies adopted to reduce smoking-attributable deaths (SADS).³⁹ A recent study modeled the following distribution for the estimated 22 million SADS prevented in 88 countries that fully implemented at least one strategy: increased cigarette taxes (7 million), followed by comprehensive smoke-free laws (5.4 million), large

graphic health warnings (4.1 million), comprehensive marketing bans (3.8 million), and comprehensive cessation interventions (1.5 million).⁴⁰

Following evidence-based research, WHO endorses approaches to primary prevention of cancer that combine legislation, regulation, and fiscal policies, along with public health messaging campaigns.³³ Tobacco control is a particularly effective focus for primary prevention of cancer.

The MoH strategic plan highlights the progress Botswana has made in the regulation of smoking and tobacco (e.g., banning tobacco advertising, promotion, and sponsorship; 30 percent taxes on cigarettes; partial prohibitions on smoking in public places), while noting gaps (e.g., package warnings, more comprehensive bans on indoor smoking in public spaces, higher taxes on smoking products). The strategic plan also addresses expanding smoking cessation services.³

Recommended Strategies

Combine public health initiatives to reduce smoking with expanded tobacco control regulations and fiscal policies.

- a. Educate the public on the dangers of smoking and secondhand smoke.
- b. Train health care workers on how to discuss smoking and effective smoking cessation with their patients.
- c. Establish smoking cessation programs that includes a Quitline (telephone call-in support service), nicotine replacement therapy, and related patient education resources.
- d. Explore the feasibility of adding other MPOWER strategies to more broadly reduce the access and appeal of smoking, particularly among youth.

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9. Appendices

A: Health Care Providers and Facilities

1. To assess the health care facility, equipment, infrastructure, and workforce, a Health Care Facility Questionnaire (**Appendix A**) was developed for oncology staff, hospital management, dietitians, heads of department, palliative care staff, and laboratory personnel.
2. To evaluate knowledge, attitudes, and practices among the cancer facility workforce, and to understand their training and mentoring needs, a Primary Physician/Nurse Survey (**Appendix B**) was developed and administered to general practitioners and nurses (both principal and general) in family medicine, dermatology, pharmacy, social work, gynecology, and other practices.
3. An FGD guide (**Appendix F**) was used to conduct discussions with health care workers (nurses, medical officers, general practitioners) from different departments (including oncology, surgery, and outpatient) to ascertain their knowledge, attitudes, and practices about cancer care and prevention.

B: General Population Perspectives

Questions relating to cancer in the community, lifestyle factors, tobacco use, environmental factors, and cancer research formed the basis of the general population FGD (**Appendix C**). The study aimed to determine levels of knowledge on cancer risks and which, if any, misconceptions may be widespread.

C: Cancer-Related and Social Resources for the Community

To assess the number and types of community-based organizations and services provided, registered NGOs that offer cancer-related and social services were identified. These services included psychosocial support, transportation, and cancer awareness as well as provision of information on cancer and support resources. Management of these entities were requested to provide information by way of a Cancer Resources Survey (**Appendix D**). The survey sought to gather information on the organization's mission, source of funds, services offered, areas of need, challenges, and other topics.

D: Perspectives of Cancer Patients, Survivors, and Caregivers

FGD guides were developed for cancer patients (**Appendix E**), cancer survivors (**Appendix I**), and caregivers (**Appendix J**). The objectives of these discussions were to understand these populations' perspectives on their experiences with cancer. Discussions were centered around experiences with cancer diagnosis, treatment, and side effects; the availability of resources; experiences after completion of treatment; available psychosocial support; lifestyle factors; and cancer research.

Appendix A: Health Care Facility Questionnaire

Oncology Staff

Provider First and Last Name
Position in the Health Care Facility
Organization
Person Interviewing
Interview Date (MM/DD/YY)

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at (Insert organization name _____) will contribute to our understanding and will ultimately lead to improved cancer services and programs in Botswana. Your responses will be kept completely confidential and your name will not be included in any report created from this effort.

Facility

1. First, do you have a cancer registry at your facility? Yes ☐ No ☐
 - a. If yes, what is the name of the Registrar? _____
 - b. If no, is the registry maintained by another medical center/facility? Yes ☐ No ☐
 - c. If yes, what is the name of that facility? _____
 - d. What is the name of the Registrar of that facility? _____
 - e. What do you use to record cancer diagnosis?
 - f. Is it routine protocol to document the patients' HIV status in the registry?
Yes ☐ No ☐ Unknown ☐
 - g. Do you currently have the capacity to notify cancer diagnoses and stage to the Botswana National Cancer Registry? Yes ☐ No ☐
 - h. If not, what assistance do you require to enable notifications to the National Registry?
2. Does the facility have a cancer committee? Yes ☐ No ☐ Unknown ☐
 - a. If no, please indicate which staff members would be interested in forming a cancer committee.
 - b. What support would be required to form a cancer committee at your facility?
3. Please list all physicians who treat oncology patients you have on staff and their specializations. You may also list oncologists who come temporarily, noting how long they stay in the facility/country.
4. Are services for the following items provided by the physicians at this facility?
 - a. Intravenous Chemotherapy
 - Inpatient Yes ☐ No ☐
 - Outpatient Yes ☐ No ☐
 - i. If NO to Inpatient, where are patients sent for chemotherapy?
 - ii. If NO to Outpatient, where are patients sent for chemotherapy?

b. Radiation Therapy

Inpatient Yes ☐ No ☐

Outpatient Yes ☐ No ☐

i. If NO to Inpatient, where are patients sent for radiation therapy?

ii. If NO to Outpatient, where are patients sent for radiation therapy?

c. Palliative Care

Inpatient Yes ☐ No ☐

Outpatient Yes ☐ No ☐

i. If NO to Inpatient, where are patients sent palliative care?

ii. If NO to Outpatient, where are patients sent for palliative care?

The next few questions are about cancer screenings and diagnostic procedures offered at your facility.

Screening and Diagnosis

5. For breast cancer, do you offer:

- | | |
|---|---|
| a. Mammography screening | |
| i. Film | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| ii. Digital | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| b. Diagnostic mammography | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| c. Breast ultrasound | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| d. Breast MRI | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| e. Breast Biopsy (radiology guided) | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| f. Breast Biopsy (ultrasound guided FNA biopsy) | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| g. Fine Needle Aspiration (FNA) | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| h. Biopsy (Lumpectomy) | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |

6. Does your facility offer:

- | | |
|----------------------------------|---|
| a. Gynecology care | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| b. Colposcopy | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| c. Pap smear | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| d. VMA (Vanillylmandelic Acid) | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| e. Visual Inspection with Acetic | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| f. Acid | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |
| g. Liquid-based Cytology | Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> |

IF RESPONDENT ANSWERED “NO” TO #5

7. Where are patients referred for gynecology care, colposcopy, pap smear, VMA, visual inspection with acetic acid, or liquid based cytology?

8. For Colorectal Cancer, do you offer:

- | | | | |
|---|------------------------------|-----------------------------|----------------------------------|
| a. Sigmoidoscopy | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| b. Colonoscopy (invasive) | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| c. CT Colonography - Virtual Colonoscopy (non-invasive) | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| d. Fecal Occult Blood Test Annually | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |

IF RESPONDENT ANSWERED “NO” TO ALL COLORECTAL CANCER SCREENING/DIAGNOSTIC MODALITIES:

9. Where are patients referred for colorectal cancer diagnostics?

10. How long do you wait to receive a report from the diagnostic center?

11. For prostate cancer, do you offer

- | | | | |
|---|------------------------------|-----------------------------|----------------------------------|
| a. PSA (Prostate-specific antigen) testing | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| b. DRE (Digital rectal exam) screening | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| c. Trans-rectal ultrasound guided prostate biopsies | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| d. Prostate MRI | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |
| e. Total body Bone scan | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |

IF RESPONDENT ANSWERED “NO” TO ALL PROSTATE CANCER SCREENING/DIAGNOSTIC MODALITIES:

12. Where are patients referred for prostate cancer diagnostics?

13. How long do you wait to receive a report from the diagnostic center?

14. How many days does it take on average from patient presentation to cancer diagnosis? If there are delays, why?

15. When you refer for pathology, where do you send the patient, and how long on average does it take to receive a result?

16. What type of **cancer-related surgeries** are performed at this facility?

- a. Breast segmental/complete mastectomy Yes ☐ No ☐ Unknown ☐
- If YES to mastectomy, do you perform sentinel nodes sampling? Yes ☐ No ☐
- b. Breast Reconstruction Yes ☐ No ☐ Unknown ☐
- c. Complete mastectomy with axillary lymph node dissection Yes ☐ No ☐ Unknown ☐
- d. Gynecologic (hysterectomy/oophorectomy) Yes ☐ No ☐ Unknown ☐
- e. Gynecologic (ovarian debulking) Yes ☐ No ☐ Unknown ☐
- f. Gastrointestinal (resection)
- i. upper tract Yes ☐ No ☐ Unknown ☐
 - ii. lower tract Yes ☐ No ☐ Unknown ☐
 - iii. liver Yes ☐ No ☐ Unknown ☐
 - iv. pancreas Yes ☐ No ☐ Unknown ☐
- g. Lung Yes ☐ No ☐ Unknown ☐
- h. Prostatectomy Yes ☐ No ☐ Unknown ☐
- i. Ears, Nose, Throat Yes ☐ No ☐ Unknown ☐
- j. Brain Yes ☐ No ☐ Unknown ☐
- k. Other (please specify):
17. Do you have access to oncology surgery? Yes ☐ No ☐ Unknown ☐
- a. If yes, which ones?
- b. If no, what do you do?
18. Does the facility have interventional radiology? Yes ☐ No ☐ Unknown ☐
19. Is there option for image guided biopsy? Yes ☐ No ☐ Unknown ☐
20. For chemotherapy:
- a. How many patients can the facility accommodate?
 - b. How many patients can be treated in a day?
 - c. Do you have a process for obtaining oral chemotherapy and targeted therapy?
 - d. Do you have a process for obtaining oral supportive care medication?
21. Does your facility offer routine screening of colon cancer YES or NO (Hereditary Nonpolyposis Colorectal Cancer)?
- If Yes, which cancers do you screen?

Patient Follow-up

22. Do you have a system to recall patients for regular cancer screenings? For example, annual mammograms, repeat mammography and 2 yearly pap smears.

a. If not, what assistance do you require to create a patient recall system?

23. Do you have a program to review patients at regular intervals to provide ongoing and continuity of care for chronic diseases including cardiovascular disease, diabetes?

24. If not, would a patient registration system with your health facility assist? What other assistance do you require to provide continuity of care?

Appendix A: Health Care Facility Questionnaire

Hospital Management

Provider First and Last Name
Position in the Health Care Facility?
Organization
Person Interviewing?
Interview Date (MM/DD/YY)

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at (Insert organization name _____) will contribute to our understanding and will ultimately lead to improved cancer services and programs in Botswana. Your responses will be kept completely confidential and your name will not be included in any report created from this effort.

1. Are you currently trying to recruit doctors who treat oncology patients to practice at this facility? Yes ☐ No ☐

2. Are you currently trying to recruit nurses who treat oncology patients at this facility?

Yes ☐ No ☐

i. If not, how do you get a nurse / doctor who treats oncology patients recruited to your facility?

ii. How long does it take?

iii. Which specializations in oncology are needed?

3. Please help us understand the cancer care workforce in your health facility:

a. Please state how many of the following staff that assist with cancer care and prevention you have in your facility **at present**, and estimate how many might be **needed** in each cadre:

CADRE	Number <i>at present</i>	Number <i>needed</i>
Nurses		
Physicians		
Pharmacists		
Pharmacy Technicians		
Health Education Assistants / Healthcare Auxiliaries		
Social Workers		
Others (Please specify)		

4. Could you provide us with annual or related reports of the number and types of cancer that are treated at your facility? Yes ☐ No ☐

5. If not, what support could help you to provide these reports?

Appendix A: Health Care Facility Questionnaire

Head of Department

Provider First and Last Name
Position in the Health Care Facility?
Organization
Person Interviewing?
Interview Date (MM/DD/YY)

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at (Insert organization name _____) will contribute to our understanding and will ultimately lead to improved cancer services and programs in Botswana. Your responses will be kept completely confidential and your name will not be included in any report created from this effort.

Clinical Trials

The next few questions are about research related issues.

1. Does the facility have a Federal Wide Assurance number (FWA) required to perform federally sponsored clinical trials? Yes ☐ No ☐ Unknown ☐
2. Does the facility use an Institutional Review Board (IRB)? Yes ☐ No ☐ Unknown ☐
 - a. If yes, what is the name of the IRB?
 - b. Is the IRB hosted at your facility or at a partner hospital? This facility ☐ Partner Hospital ☐
Name: _____
3. Do you have a cancer clinical trials program? Yes ☐ No ☐ Unknown ☐
 - a. If yes, can you provide us with the clinical trials menu? Yes ☐ No ☐ Unknown ☐
 - b. If yes, with whom are you affiliated?
 - c. If no, would like to start a clinical trials program? Yes ☐ No ☐ Unknown ☐

Appendix A: Health Care Facility Questionnaire

Palliative Care

Provider First and Last Name
Position in the Health Care Facility?
Organization
Person Interviewing?
Interview Date (MM/DD/YY)

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at (Insert organization name _____) will contribute to our understanding and will ultimately lead to improved cancer services and programs in Botswana. Your responses will be kept completely confidential and your name will not be included in any report created from this effort.

Hospice and Palliative Care Services

1. What Hospice Services are offered to patients?
 - a. Inpatient hospice
 - i. Facility supported Yes ☐ No ☐ Unknown ☐
 - ii. Private organization Yes ☐ No ☐ Unknown ☐
2. Do you have a Palliative Care program? Yes ☐ No ☐ Coming soon ☐
 - b. If yes,
 - i. What is the composition of the palliative care team?:
 1. Care Coordinator
 2. Chaplain
 3. Medical Doctor
 4. Nurse
 5. Nurse Practitioner
 6. Registered Dietician
 7. Social Worker
 8. Other, please specify
 - ii. What are the characteristics of your program?
 - ☐ consult service (providing recommendation to the attending service to treat palliative needs)
 - ☐ In-patient beds (a palliative care unit in the hospital)
 - ☐ Out-patient clinic (clinic specific to palliation of symptoms)

Support and Educational Programs

3. Do you have a cancer patient navigator (PN) at this facility? Yes ☐ No ☐ Unknown ☐

a. If yes,

i. How many PNs do you have?

ii. For which cancer types?

iii. Credentials

☐ Lay person

☐ Nurse

☐ Social Worker

☐ Other, please specify

b. If no, would you like to start PN services?

Yes ☐ No ☐

4. Do you host patient and family cancer support groups at this facility?

Yes ☐ No ☐ Unknown ☐

a. If yes, please list all support groups:

b. If no, would you like to start a support group?

Yes ☐ No ☐

5. What cancer site would you like to start a support group for?

☐ Brain Cancer

☐ Breast Cancer

☐ Cervical Cancer

☐ Prostate Cancer

☐ Lung Cancer

☐ Kaposi Sarcoma

☐ Testicular Cancer

☐ Other, please specify

6. Do you host or hold cancer prevention education programs for your local community?

Yes ☐ No ☐ Unknown ☐

c. If yes, please list names of each program

Key Leader Interview (Dikgosi, Politicians, District Commissioners)

7. What are the most pressing healthcare deficiencies (personnel, level of training, healthcare facilities and services offered) related to:

b. The risk reduction of cancer in your community

c. The detection/diagnosis of cancer in your community

d. The treatment of cancer

e. Post-treatment and survivorship care

- f. Palliative/hospice care
8. What are the most pressing needs of primary care physicians in your community related to:
- a. Continuing education related to cancer & cancer survivorship
 - b. Patient cancer diagnosis
 - c. Patient referral for cancer treatment and communication pre & post treatment
 - d. Post-treatment and survivorship care of oncology patients
 - e. Palliative/hospice care related to cancer patients?
9. Would you be willing to be the Key Leader for cancer related care and prevention programs in your facility with appropriate support and mentoring programs?

Appendix A: Health Care Facility Questionnaire

Laboratory

Provider First and Last Name

Position in the Health Care Facility?

Organization

Person Interviewing?

Interview Date (MM/DD/YY)

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at (Insert organization name _____) will contribute to our understanding and will ultimately lead to improved cancer services and programs in Botswana. Your responses will be kept completely confidential and your name will not be included in any report created from this effort.

1. Do you work in the laboratory / Are you a laboratory technician?

☐ Yes

☐ No

2. Do you offer genetic counselling for cancer risk?

☐ Yes

☐ No

☐ Don't Know

(a) If yes, is the counselling offered

☐ At your facility

☐ Referred out for counselling

(i) Who provides the counselling (RN, MP, GC, etc.)?

3. In the last 12 months, has your healthcare centre facilitated genetic testing for cancer risk?

☐ Yes

☐ No

☐ Don't Know

(a) If yes, which genetic tests?

☐ BRCA ½

☐ Other tumor markers (please specify)

4. Please outline the following processes:

(a) Process for preparing pathology slides

(b) Process for sending out specimens when needed

5. What immunohistochemistry and special stains are available on site?

6. Where are the additional immunohistochemistry and special stains performed if they are not available on site?

7. What molecular testing is available on site?

8. What additional molecular testing is performed , if they are not yet available on site?

9. Is there any equipment that has not been maintained, is unavailable or not being used, that would assist the laboratory with cancer management?

☐ Yes

☐ No

☐ Don't Know

Specific Questions Regarding Pathology Services

1. Are there any surgical / pathological data available for the area (historic, published or current)?

☐ Yes

☐ No

☐ Don't Know

2. How does a patient access biopsy or surgical services at this site?

3. Is there a referral network from clinics and / or district hospitals?

☐ Yes

☐ No

☐ Don't Know

4. What is the minimum and maximum travel time expected for patients from their village to a site to have a biopsy performed?

5. If patients presented **today** with a mass on their neck or face, how long would you estimate it takes for them to have a pathological diagnosis of the lesion and begin treatment?

6. Are there cytology (fine needle aspirate, fine needle biopsy) services available for patients at any level of healthcare?

☐ Yes

☐ No

☐ Don't Know

7. What level of training do healthcare workers in the area have in performing the following:

	Introductory	Intermediate	Advanced
(a) simple biopsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Core needle biopsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Punch biopsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Simple excisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Complex excisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(f) Internal organ surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(g) Major surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Is formalin fixative (10%) commonly available in clinics for healthcare workers to collect tissue samples? ☐ Yes ☐ No ☐ Don't Know

9. Are tools and instruments available for healthcare workers to collect tissue samples (sterile blades, alcohol, suture, etc.)? ☐ Yes ☐ No ☐ Don't Know

10. Is there currently a functional anatomic pathology laboratory in the proposed site? [This question is limited to the two referral hospitals] ☐ Yes ☐ No ☐ Don't Know

11. Are there one or more anatomic pathologists currently located in this site?

12. Are there any active programmes in the country to obtain anatomic pathology diagnosis using remote services (that is, sending tissue samples to another city, another country, or using telepathology in the proposed site)? ☐ Yes ☐ No ☐ Don't Know

13. Is there a mechanism / pathway to get reagents and supplies for pathology to the proposed site? ☐ Yes ☐ No ☐ Don't Know

14. If there are currently anatomic pathology reports generated, in what format are they (electronic, paper, oral, report)?

16. How and where are pathology results reported?

17. If an anatomic pathology result is reported, is the data sent to the Cancer Registry?

☐ Yes ☐ No ☐ Don't Know

18. Does the anatomical laboratory have any existing communication infrastructure such as cell phones, **wired** Internet access, wireless Internet access, cellular data access, landline telephones, email access?

☐ Yes ☐ No ☐ Don't Know

19. What is the current speed / bandwidth of the Internet service at the anatomical laboratory?

(a) What kind of medical records do patients currently have?

☐ Electronic ☐ Paper ☐ Piecemeal

20. Is there a national identification number for patients that is shared across institutions?

☐ Yes ☐ No ☐ Don't Know

Appendix B: Cancer Needs Assessment Primary Physician/ Primary Care Nurse/Healthcare Personnel Survey

Thank you for participating in this survey. As an important physician within your community, your contribution is vital to our effort to gather information about cancer care. The information we gather will be published in a Cancer Needs Assessment that will be publicly available, and will be used to direct efforts to address the cancer care needs of this community. The Cancer Care and Prevention Needs Assessment is being sponsored by the Botswana-Rutgers Partnership for Health. The information you provide will be kept confidential.

Please, indicate the primary district health management team that you practice in: _____

Indicate your primary care practice

- ☐ Family Medicine ☐ Internal Medicine ☐ Nurse ☐ Dermatology
☐ Obstetrics/Gynecology ☐ Surgeon ☐ Urology ☐ Other, please specify

I. SCREENING

- Are you aware of the recommended guidelines for cancer screening in Botswana? ☐ Yes ☐ No
- If yes, what challenges do you find to implement the screening recommendations in your practice? Please specify.
- What are the most common cancers that are diagnosed in your patients each year (number in order)?
 ___ Breast ___ Cervical ___ Colorectal ___ Hematologic ___ Kaposi Sarcoma
 ___ Lung ___ Melanoma ___ Prostate ___ Other, please specify
- How many of these patients would you estimate present at initial consult with advanced stage disease?
☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100% ☐ Don't Know
- What percentage of your age/risk-appropriate female patients would you estimate have cancer screenings for the following cancers according to recommended guidelines?

a. Breast	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
b. Cervical (Pap Smear)	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
c. Colorectal	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
d. Kaposi Sarcoma	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
- What percentage of your age/risk-appropriate male patients would you estimate have cancer screenings for the following cancer according to recommended guidelines?

a. Colorectal	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
b. Prostate	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
c. Kaposi Sarcoma	<input type="checkbox"/> 0-25%	<input type="checkbox"/> 26-50%	<input type="checkbox"/> 51-75%	<input type="checkbox"/> 76-100%
- Do you screen your patients for other cancers? (Please, select yes or no for cancers listed below):

a. Lung	<input type="checkbox"/> Yes	<input type="checkbox"/> No
b. Ovarian	<input type="checkbox"/> Yes	<input type="checkbox"/> No
c. Skin	<input type="checkbox"/> Yes	<input type="checkbox"/> No
- What do you feel are the most common reasons your patients choose not to have recommended cancer screenings (check all that apply)?

- ☐ Afraid of being diagnosed with cancer
☐ Lack of screening facilities
 ☐ Apprehension about the test
☐ Too busy
 ☐ Financial constraints
☐ Other, please specify
9. For which of the following cancers would you like information on screening and/or updated screening recommendations (check all that apply)?
- ☐ Breast ☐ Cervical ☐ Colorectal ☐ Ovarian
☐ Lung ☐ Prostate ☐ Skin ☐ Other, please specify
10. Are you interested in further information on cancer signs and symptoms? If so, please provide a list of cancers you would like to learn more about.
11. Please advise in what form would you prefer to receive further cancer information?
- ☐ In person presentation ☐ Live webinar with interactive capability ☐ Web-based information, self-paced
☐ Written information ☐ Other, please specify

II. CANCER DIAGNOSIS AND CARE

1. For patients you suspect with cancer, please describe any barriers to cancer diagnosis that you face in your community?
Please describe the pathology and imaging tests you refer to for cancer diagnosis in your community?
2. On average, how long does it take to confirm a cancer diagnosis after you suspect it? _____
How long before surgical or oncology review? _____
3. After one of your patients is diagnosed with cancer, where you are most likely to refer them for treatment- **Would refer for Surgery to:**
- ☐ Local Surgeon
☐ Referral Hospital Surgeon
☐ Surgeon at a Private Hospital
☐ Surgeon outside of Botswana
☐ Other, please specify
4. After one of your patients is diagnosed with cancer, where you are most likely to refer them for treatment- **Would refer for Medical Oncology to:**
- ☐ Local Medical Oncologist
☐ Referral Public Hospital Oncologist
☐ Oncologist at Private Hospitals
☐ Oncology clinics in Public Hospitals in Botswana
☐ Other, please specify
5. What information coming from the oncology team about your patient is most useful to you? (Check all that apply)
- ☐ Initial treatment plan
☐ End of treatment note
☐ Pathology report
☐ Operative reports
☐ Follow-up care management
☐ Other, please specify
6. How often do you receive satisfactory communication from the oncologist treating your patient?
- ☐ Always ☐ Very Often ☐ Sometimes ☐ Rarely ☐ Never
7. How could communication be improved in your view? Please describe.
8. How often do you see cancer patients whilst they are undertaking their treatment program at referral centers?
- ☐ Weekly ☐ Monthly ☐ Never ☐ Other, please specify

9. What kind of treatment are you comfortable providing after your patient has received a cancer diagnosis (Check all that apply)?
- ☐ Non-oncology care during the time the patient is being treated for cancer
 - ☐ Joint management of care with the oncology team during the time the patient is being treated for cancer
 - ☐ Long-term oncology follow-up care
 - ☐ Management of chemotherapy or radiotherapy side effects or surgical complications
 - ☐ Other, please specify
10. Number the following post-cancer treatment care topics in order of interest to receive further information (1 – most interest; 7 least interest)?
- | | | | | | | | |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Pain Management | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| Surveillance of cancer recurrence | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| Long-term cancer treatment effects: monitoring and palliation | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| End-of-life care and planning | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| Genetic counseling for family members of cancer patients | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| Wellness and prevention of cancer recurrence | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| Oncological Emergencies | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
| Other, please specify | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 | <input type="checkbox"/> 7 |
11. In what form would you prefer to receive further cancer information?
- ☐ In person presentation
 - ☐ Live webinar with interactive capability
 - ☐ Web-based information, self-paced
 - ☐ Written information
 - ☐ Other, please specify
12. Please comment on what you believe to be the most pressing challenges and barriers for the health care workforce in your community in relation to cancer screening and diagnosis.
13. What are the best days to host a virtual or in-person sessions (check all that apply)?
- ☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday ☐ Saturday
14. What are the best times to host a virtual or in-person sessions (check all that apply)?
- ☐ 7am-8am ☐ 12-1pm ☐ 1-2pm ☐ 4pm-5pm ☐ 5pm-6pm ☐ 6pm-7pm
15. Please comment on what you believe to be the most pressing challenges and barriers for the healthcare workforce in your community in relation to providing adequate care of patients after completing cancer treatment.
16. Please provide your view on whether a multi-disciplinary team would assist in overcoming these barriers such as a community-based patient navigator, hospital-based navigator, pharmacist, nurse, social worker, and other relevant partners/ non-government organizations?

III. RESEARCH AND CLINICAL TRIALS

1. Rank your knowledge of cancer clinical trials on a scale of 1 (no knowledge) to 5 (expert).
- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
2. Are you interested in learning more about the development and management of cancer clinical trials? Scale 1 (not interested) to 5 (very interested)
- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
3. How important is it to you to have cancer clinical trials in your area? Scale of 1 (not important) to 5 (very important)
- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
4. Would you like to learn about the cancer clinical trials being offered in your area? Scale of 1 (not interested) to 5 (very interested)
- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
5. Do you report all cancer diagnoses and stage to a cancer registry? ☐ Yes ☐ No or some reported
- a. If yes, which registry?

- b. If no or some reported, what support would assist you?

IV. TOBACCO USE

1. Do you ask patients about tobacco use? ☐ Yes ☐ No
a. If yes, do you keep a record of patients who smoke? ☐ Yes ☐ No
b. If no, what are the reasons?
2. Do you advise patients to stop using tobacco? ☐ Yes ☐ No
a. If no, why?
☐ I don't know
☐ We don't have in-house cessation programs
☐ There are no referral system for smokers
☐ There is no time
☐ Other, please specify
3. Do you offer any tobacco treatment services? ☐ Yes ☐ No
a. If yes, what do you offer (check all that apply)?
☐ Individual or Group Counseling
☐ Nicotine Patch
☐ Nicotine Oral Preparation (Gum, Pastille, Lozenge)
☐ Bupropion
☐ Varenicline
☐ Other, please specify
b. If no, what are the reasons?
4. Would you be interested in receiving training on tobacco treatment? ☐ Yes ☐ No

Appendix C: General Population Focus Group Discussion Guide

INTRODUCTION TO FOCUS GROUP PROCESS AND INFORMED CONSENT [7 MINUTES]

Thank you all for coming today. My name is <<INSERT YOUR NAME>>, and this is <<INSERT ASSISTANT'S NAME>>. Thank you for agreeing to be here. Your opinions are important to us.

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for about two hours or less. During these two hours, I will ask you some questions about your opinions on **cancer prevention, cancer screening, and research**. We want you to draw on your experiences. We do not need to know the details of your medical history. The goal is for you to discuss the questions as a group. The most important information will come from the range of everyone's thoughts and ideas. It is very important that everyone feels free to speak and share, especially if you have a different idea or view from others in the group. There are no "right" or "wrong" answers to the questions.

My role is to help guide the discussion. I may ask specific people about their thoughts or ideas if they have not had a chance to share very much in the discussion. We want to everyone opinions. Again, there are no right or wrong answers. We just want to learn what you think about your community.

Also, you do not have to answer any questions that will make you feel uncomfortable. If we need to move on to another topic, I may ask you to hold your thoughts on that topic for us to come back to. I do not want to keep you longer than the two hours so my job is to make sure that I keep the discussion moving along at a good pace. However, I don't want you to hold back on your thoughts – as I said, if I need to move us along, I will - but please feel free to express yourself!

I would like to go over a couple of ground rules for our discussion as a group, and then would like to ask you what other rules you think we should follow to make our time most productive. First, as facilitators, we will respect the privacy of all group members and keep the content of our talk confidential. By confidential, we mean that it will be kept private. We will be tape recording the discussion, and you may see us taking notes. These steps are needed for us to accurately record what is said today, but we will not include any information that will personally identify you in our notes or recordings. When we review our notes from this meeting, we will be most interested in what the group as a whole has to say. When we write up and report of these focus group discussions, no person will ever be identified by name.

Second, I would ask that we call each other only by first names or the names that you have selected and written on your name tag. Do any of you have other ground rules that you think would be good to allow opportunity for everyone to express themselves freely?

We will be taking a break about half way through our discussion, but if you need to get up before that please do so as quietly as possible. You are free to stop participating in the discussion at any time or even to leave.

Airtime may be provided as a token to call back if any questions or concerns have not been raised.

Does anyone have any questions? [Answer any questions]

WARM-UP [8 minutes]

Before moving on to the main topic of our discussion, I would like to take a few moments for everyone to introduce himself or herself by first name. Please tell us something about your experience in this community/hospital, how long you have lived/work here, etc.

[Turn off tape recorder for this section of the discussion.]

[Moderator: Introduces herself / himself in the format they would like everyone else to use and then goes around the table.]

[Facilitator: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible to document more easily who in the group is speaking when taking notes.]

1. CANCER IN COMMUNITY: GENERAL DISCUSSION [15 minutes]

So, let us get started!

- a. First, I would like you to tell us what you think are the most important illnesses, diseases, or other health conditions in your community. ([List on flip chart](#))
- b. [IF NO ONE COMMENTS ON CANCER]: Is cancer a health problem in your community? How so? ([Review list on flip chart](#))
- c. What do friends, family, or others in your neighborhood say about cancer?
- d. Is developing cancer something that you worry about for yourselves?
- e. What worries you most about getting cancer?
- f. What kinds of cancer are you most worried about?

2. LIFESTYLE FACTORS: [30 minutes total]

Let's talk about the way people live, their habits and lifestyle, and how these affect their health

- a. Describe some behaviors or ways of living (lifestyles) that may have a good effect on a person's health? ([List on flip chart](#))
- b. What are some of the things that people do that may influence their own health in negative ways? ([List on flip chart](#))

[Review the list on flip chart](#)

A. Let's talk a little more about Nutrition:

- a. Describe how what a person eats can affect their health. (PROBES: What illnesses or disease can be affected by what we eat? What foods, or ways of eating, can improve health? What foods or ways of eating can harm health?)
- b. Are there eating habits that can reduce a person's chances of getting cancer?
- c. What foods or eating habits or ways of eating can increase risk for getting cancer?

Summarize their statements about diet, health and cancer. Then ask:

- a. What are some barriers to eating healthy for people in your community?
- b. Where would you go in your community for help to eat a healthier diet? (PROBE: Is there a program that people have access to that teaches them how to eat a healthier diet?)
- c. What are some ways to motivate or make it easier for people in your community to eat healthier? (PROBE: If you were designing a plan or project to help people in your community eat healthier, what would it look like?).

Review points made during nutrition discussion before moving on.

B. Exercise is also (is not) on the list of things that you said can improve health.

I would like to give you a definition of exercise and physical activity for the following discussion:
Physical activity is - "any body movement produced by skeletal muscles that results in energy expenditure above resting level."

Exercise - physical activity that is planned, structured, and repetitive for the purpose of conditioning any part of the body.

- a. How easy is it for people in your community to be physically active? (PROBE: Where do people go to exercise or get physical activity?)
- b. What stops people from being more physically active in your community?
- c. What are some ways to make it easier or motivate people in your community to exercise or be physically active? (PROBE: If you were designing a plan or project to help people in your community be physically active, what would it look like?)

Summarize exercise comments before moving on to weight control.

C. Weight Control: Not being overweight is important to have improved health

Obesity/Overweight definition: abnormal or excessive fat accumulation that presents a risk to health. A person with a BMI of 30 or more is generally considered obese. A person with a BMI equal to or more than 25 is considered overweight.

- a. What are your thoughts on weight in your community?
- d. Are you and/or people in your community concerned about obesity? (PROBE: At the community level, is there concern over obesity as a health problem?)

- e. What do you think about the relationship between being overweight or obese and chances of getting cancer?
- f. What do you think is a “healthy weight” (PROBE: How do you decide if a person has a healthy weight?)
- g. Where would you go in your community for help losing weight? (PROBE: Is there a program that people have access to that helps people lose weight?)
- h. What could be done in your community to help/encourage people to have a healthy weight?

Summarize weight comments before moving on to weight control.

BREAK

Continue LIFESTYLE FACTORS: [15 minutes total]

Welcome back! We are going to keep working on some topics about community health starting with tobacco. If everyone is settled we can get started.

D. TOBACCO

- a. In general, how do people feel about tobacco use. and How much of a problem do you think tobacco use, (smoking tobacco, chewing or dipping tobacco) is in your community? (PROBE: About how many people use tobacco, not very many, a lot, about half...)
- b. Are there any community wide efforts to change the smoking habits of people who live here?
- c. What resources or programs are available in your community to help someone quit using tobacco? How effective do you think they are?
- d. What do you think would be the best ways to get people to stop using tobacco in your community?

E. ENVIRONMENTAL FACTORS

For our discussion, I would like this term to mean anything that exists in the natural surroundings of the neighborhood where you live or in the location where you work that could affect your health.

- a. Do you think there are any environmental factors, or things in the environment of your community that might cause cancer?

3. DISCUSSION OF CANCER SCREENING [15 minutes TOTAL]

Now I would like to talk about your thoughts on tests that can check if a person has cancer.

- a. Do you know of any tests that a person can have done to see if they have cancer? (List on flip chart in columns of screening vs. diagnostic)

Good, I think you have listed most of them. (Identify the cancers and tests that they

have not mentioned – add them to the list)

- b. I would like you to tell me about your thoughts and feeling about each one of these tests, so we will answer the following questions for each one individually: “What are your thoughts and feelings about:
 - a. Breast self-examination
 - b. Pap Smear
 - c. Mammogram
 - d. Colonoscopy
 - e. Fecal Occult Blood Test (FOBT)
 - f. Digital Rectal Prostate Exam
 - g. Prostate Specific Antigen (PSA) Test
- c. Do you know how often you are required to have the above tests which assist us detect cancer at early stages? Are you aware that most common cancers, if caught early through screening tests, can be cured?
- d. Is it easy for people in your community to get these screening tests?
- e. What are some reasons people you know don’t get a cancer test when their doctor tells them they should?
- f. Are you aware of a vaccination to prevent the most common causes of cervical cancer?

4. CANCER RESEARCH SECTION [15 MINUTES]

- a. Can anyone who has participated in a research study or know someone who has, share their experience?

What are your opinions about:
 - b. Information and experiences on cancer research
 - c. Role of clinical trials in cancer management
 - d. Participation in cancer research in your community

Summarize the information that they have provided about cancer screenings and cancer research before moving on to the final wrap-up.

OVERALL PERSPECTIVES AND WRAP UP [5 MINUTES]

- a. What haven’t we discussed about cancer and issues relating to cancer that you think are important to keep in mind?

Do a final summary of the information.

Thank you so very much for helping us with this project. We appreciate your time and candid thoughts on these important subjects.

Appendix D. Cancer Resources Questionnaire

My name is [insert name] and I am the Research Assistant for the Cancer Care and Prevention Needs Assessment project being conducted by the Botswana-Rutgers Partnership for Health.

Thank you for agreeing (I am calling to ask if you would be willing) to answer some questions related to your organization and the cancer-related services that you provide. You will be contributing to the cancer needs assessment for the [insert name] Health District. The purpose of which is to identify the existing resources available to cancer patients and their families, and those that are needed for the Health District. The information gathered will be used to inform relevant private and public organizations to mobilize resources to meet identified needs.

Organization's name: _____

Address: _____

Phone: _____ Fax: _____

Website: _____

Contact person: _____

Best time to contact: _____

Date of meeting/interview: _____

1. What is the resource organization's MISSION statement:

2. Which category best describes your organization:

- ☐ National Non-Profit
- ☐ Local Non-Profit
- ☐ For Profit Service Organization
- ☐ Governmental Organization
- ☐ Municipal Government Organization
- ☐ Donors
- ☐ Other _____

3. What is the major source of funds for your organization?

- ☐ Competitive Grants
- ☐ Government funds
- ☐ Service fees / charges
- ☐ Donations
- ☐ Other _____

(REDCap modification: allow for respondents to select multiple answers)

4. What is the primary service population for your organization (check all that apply):

- ☐ Cancer Patients
- ☐ Cancer survivors
- ☐ Cancer caregivers/family members
- ☐ Other: _____

5. Which of the following services do you provide to cancer patients? (Check all that apply)

- ☐ Provision of written information on cancer
- ☐ Provision of information on cancer care and support resources
- ☐ Management of cancer support groups
- ☐ Social support for cancer control/care
- ☐ Psychosocial support
- ☐ Navigational services
- ☐ Transportation
- ☐ Other: _____

6. How do you advertise your organization and services?
- ☐ Local media organizations
- ☐ Website / Online
- ☐ Distribution of pamphlets describing services
- ☐ Word of mouth
- ☐ Other _____
7. Approximately how many people needing cancer related services do you see annually?
- ☐ < 10
- ☐ 11 - 25
- ☐ 26 – 50
- ☐ 51 – 150
- ☐ > 150
8. What are the areas of need of your organization?
- ☐ Financial support
- ☐ Human resources (skilled employees, volunteers, etc.)
- ☐ Access to experts for consultation
- ☐ Physical space/facilities
- ☐ Collaborators Volunteers
- ☐ Other _____
9. What are the greatest challenges that your organization has in meeting its mission?
- _____
- _____
- _____
- _____
10. What are the goals of your organization for the next 1 – 5 years?
- _____

11. Are there organizations in the community with which you partner? (List)

12. Would you be interested in collaboration?

Appendix E: Cancer Patient Focus Group Discussion Guide

INTRODUCTION TO FOCUS GROUP PROCESS AND INFORMED CONSENT

[7 MINUTES]

[Tape recorder turned on at beginning of remarks, which are to be made by the facilitator]

Thank you all for coming today. My name is <<INSERT YOUR FIRST NAME>>, and this is <<INSERT FACILITATOR'S FIRST NAME>>. Thank you so much for agreeing to be here. Your opinions are very important to us.

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for two hours or less. During this time, I will ask you questions about your experiences with **cancer diagnosis, cancer treatment, follow-up care and cancer research**. We do not need to know the details of your medical history. For our purposes, a cancer patient is defined as anyone who has a confirmed cancer diagnosis, and is currently undergoing treatment for cancer, be it chemotherapy, hormonal therapy, radiotherapy, surgery and/or palliative care. We want you to draw on your experiences as patients, and know that no two patient's experiences are the same.

The goal is for you to discuss the issues as a group. The most important information will come from the range of everyone's experiences, thoughts and ideas. It is very important that everyone feels free to speak and share, especially if you have a different idea or view from others in the group. There are no "right" or "wrong" answers to the questions.

My role is to help guide the discussion. I may ask specific people about their thoughts or ideas if they have not had a chance to share very much in the discussion. If we need to move on to another topic, I may ask you to hold your thoughts on that topic for us to come back to. I do not want to keep you longer than the two hours, so my job is to make sure that I keep the discussion moving along at a good pace. However, I don't want you to hold back on your thoughts – as I said, if I need to move us along, I will - but until then please express yourself!

GROUND RULES

I would like to go over a couple of ground rules for our discussion as a group, and then would like to ask you what other rules you think we should follow to make our time most productive. First, as facilitators, we will respect the privacy of all group members and keep the content of our talk confidential. By confidential, we mean that it will be kept private. We will be tape recording the discussion, and you may see us taking notes. These steps are needed for us to accurately record what is said today, but we will not include any information that will personally identify you in our notes or recordings. When we review our notes from this meeting, we will be most interested in what the group as a whole has to say. When we write up the report of these focus group discussions, no person will ever be identified by name.

Second, I would ask that we call each other only by first names or the names that you have selected and written on your name tag. Also, I would ask that you turn your phones to silent or vibrate, and have them placed out of sight for the duration of the discussion, unless you are expecting a call. I will have my phone out solely for the purpose of keeping track of time. Other than that, do any of you have other ground rules that you think would be good to allow opportunity for everyone to express themselves freely?

We will be taking a break about half way through our discussion, but if you need to get up before that please do so as quietly as possible. You are free to stop participating in the discussion at any time or even to leave.

WARM-UP [10 minutes]

Before moving on to the main topic of our discussion, I would like to take a few moments for everyone to introduce himself or herself. Please tell us your first name, or name you like to be called, something about your experience living in this community and how long you have lived here.

Tape recorder turned OFF here to maintain confidentiality.]

[Moderator: Introduces herself and then goes around the table.]

[Facilitator: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible to document more easily who in the group is speaking when taking notes.]

Tape recorder turned on here:

In today's discussion, we will be discussing various aspects of your cancer experience, including diagnosis, treatment, and aftercare, along with your views on resources, research, and the community. To keep us on schedule, I may ask that you hold a particular thought until a later portion of the discussion.

Experiences with cancer diagnosis and getting cancer information (10 minutes)

I'm going to start by asking you some questions about your experiences being diagnosed with cancer, going through cancer treatment, getting information and support about things related to your cancer. We'll start with when you were first diagnosed, your experiences, reactions thoughts, and then your information needs and how your needs may have changed over time.

1. Cancer diagnosis experiences
2. Cancer information needs

3. Cancer treatment
4. Post cancer treatment
5. Cancer care resources
6. Cancer research

1. Tell us about your experiences with cancer diagnosis (please tell your story)

- a. Type of cancer, How it came to be diagnosed (when, delays)
- b. Your emotional reactions
- c. What you did once you knew the diagnosis
- d. Coping mechanisms they used
- e. What help you got in their community

2. Tell us your experiences with getting cancer information that you needed

- a. Information needs and availability at diagnosis (immediate needs)
- b. Sources of information
- c. Barriers to getting the information
- d. Changes in information needs during the illness (later needs)

3. Describe the journey through your cancer treatment (medical care)

- a. Where care and treatment were received?
- b. Treatment plan (availed, communication)
- c. Type of treatment and its effects including side effects
- d. Treatment delays and interruptions if any
- e. Community support needed
- f. Community support received (financial, personnel, social, occupational)
- g. Experiences navigating the health system during treatment

4. Describe your experiences after you completed cancer treatment

- a. Was there a follow up treatment plan?
- b. Communication during follow up (family, all HCWs and other relevant services)
- c. Team work among treating healthcare professionals
- d. Cancer support (awareness, availability and volunteerism)

5. Looking at your experiences with cancer diagnosis and treatment, what would you say are the RESOURCES needed to support a cancer patient

- a. Help with daily activities of living (what needs, from who)
- b. Work related needs
- c. Availability of support (timeliness, quality)

6. What are your opinions on cancer research?

- a. Information on cancer research
- b. Role of clinical trials in cancer treatment
- c. Participation in research for cancer treatment

7. Wrap up

- a. Additional thoughts
- b. Gaps in community-based cancer support

Appendix F. Healthcare Provider Focus Group Discussion Guide

To describe healthcare provider knowledge, attitudes and practices around cancer care and prevention.

Many patients are treated for cancer in Botswana. We are going to discuss cancer care in Botswana and I would like you to share your thoughts and experiences. All contributions are valuable to us and I am looking forward to learning from you.

Knowledge:

Please tell me about cancer care in Botswana...

Probes

- i. Please tell me about the types of cancers that are common in Botswana.
- ii. Where are the cancer care services available in Botswana?
- iii. What type of cancer care is available at your facility?
- iv. Describe the role of each health profession involved in cancer care at your facility.
- v. What treatment modalities are there in Botswana?
- vi. How can the most common cancers in Botswana be prevented?

Attitudes:

Please share your thoughts about cancer care in Botswana.

Probes:

- i. Please tell me about cancer care in Botswana.
- ii. What do you think of the cancer care offered in Botswana?
- iii. Please tell me about the cancer care received by your patients
Probe: Do you discuss warning signs and symptoms with your patients?
Probe: Do you offer patient / caregiver education related to the cancer?
- iv. Please share your experiences about caring for cancer patients **broad*
Probe: Do you feel you have adequate resources to care for cancer patients?
Probe: What additional resources are needed at your facility to provide optimal care?
- v. What are your thoughts on measures to prevent cancer in Botswana?

Practice:

Tell me how you coordinate care with different specialities at your hospital and the referral hospitals

Probes:

- i. How do you diagnose cancer in the Botswana health system?
- ii. Describe the role of the patient and family involved in the ~~care plan~~ = Decision making process
- iii. Please tell me at what stage most cancer patients are diagnosed.
- iv. What do you do in your facility for cancer patients?
Ask by group: physicians, nurses, pharmacists, pharmacy technicians, etc. – *how each defines their role in cancer care*
- v. Tell me how you manage care for your cancer patients. - specific to physicians
- vi. Tell me how you provide comfort care for your cancer patients.
- vii. Tell me how you prevent deterioration in your cancer patients.

Appendix H: Cancer Awareness Measure Survey

1. There are many warning signs and symptoms of cancer. Please name as many as you can think of:

2. The following may or may not be warning signs for cancer. We are interested in your opinion:

Yes No Don't know

Do you think an unexplained lump or swelling could be a sign of cancer?
Do you think persistent unexplained pain could be a sign of cancer?
Do you think unexplained bleeding could be a sign of cancer?
Do you think a persistent cough or hoarseness could be a sign of cancer?
Do you think a persistent change in bowel or bladder habits could be a sign of cancer?
Do you think persistent difficulty swallowing could be a sign of cancer?
Do you think a change in the appearance of a mole could be a sign of cancer?
Do you think a sore that does not heal could be a sign of cancer?
Do you think unexplained weight loss could be a sign of cancer?

3. If you had a symptom that you thought might be a sign of cancer how soon would you contact your doctor to make an appointment to discuss it?

4. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?

Yes often Yes sometimes No Don't know

I would be too embarrassed
I would be too scared
I would be worried about wasting the doctor's time
My doctor would be difficult to talk to
It would be difficult to make an appointment with my doctor
I would be too busy to make time to go to the doctor
I have too many other things to worry about
It would be difficult for me to arrange transport to the doctor's surgery
I would be worried about what the doctor might find
I wouldn't feel confident talking about my symptom with the doctor
Other (please specify)

5. What things do you think affect a person's chance of developing cancer?

6. These are some of the things that can increase a person's chance of developing cancer. How much do you agree that each of these can increase a person's chance of developing cancer?

Strongly Disagree Not sure Agree Strongly Agree

Smoking any cigarettes at all
Exposure to another person's cigarette smoke
Drinking more than 1 unit of alcohol a day
Eating less than 5 portions of fruit and vegetables a day
Eating red or processed meat once a day or more
Being overweight (BMI over 25)
Getting sunburnt more than once as a child
Being over 70 years old
Having a close relative with cancer
Infection with HPV (Human Papillomavirus)
Doing less than 30 mins of moderate physical activity 5 times a week

7. In the next year, who is most likely to develop cancer?

Someone in their....

20's

30's

40's

50's

60's

70's

80's

Cancer is unrelated to age

8a. What do you think is the **most** common cancer in women?

8b. What do you think is the **second** most common cancer in women?

8c. What do you think is the **third** most common cancer in women?

8d. What do you think is the **most** common cancer in men?

8e. What do you think is the **second** most common cancer in men?

8f. What do you think is the **third** most common cancer in men?

9a. As far as you are aware, is there a breast cancer screening programme?

If yes, at what age are women first invited for breast cancer screening? _____

9b. As far as you are aware, is there a cervical cancer screening programme (smear tests)?

If yes, at what age are women first invited for cervical cancer screening? _____

9c. As far as you are aware, is there a bowel cancer screening programme?

If yes, at what age are people first invited for bowel cancer screening? _____

Appendix I. Cancer Survivor Focus Group Discussion Guide

In today's discussion, we will talk about various aspects of your experience as a cancer survivor: your after care, quality of life after treatment, collaboration between yourself and the facility, your views on resources, psychosocial support, research, gaps in the health care system, and the community.

I'll start by asking you questions about your experiences as a cancer survivor, your treatment and diagnosis, side effects, and after care treatment.

1. EXPERIENCE AS A CANCER SURVIVOR, DIAGNOSIS AND TREATMENT, SIDE EFFECTS, AND AFTERCARE TREATMENT

1. Tell us about your experiences as a cancer survivor. (Take us through your journey as a cancer survivor)

Probes:

- i. The type of cancer you have or had
- ii. The symptoms and signs that you experienced
- iii. How the cancer came to be diagnosed
- iv. The treatment, after treatment, and side effects
- v. When were you first told you have cancer?
- vi. What was your first reaction to hearing this?
- vii. What is your understanding of being called cancer survivor?

2. Did you get adequate information about what your treatment entailed?

Probes:

- i. Name and nature of the treatment
- ii. Side effects
- iii. The duration of the treatment
- iv. Did you receive all the treatment that the doctor planned?

3. Transition from active treatment back to primary care.

Probes:

- i. Doctor-patient relationship: does / did the oncologist relate or communicate well with you?
- ii. Follow up sessions: how often do you go for follow-ups?
- iii. Do / did they refer you to another specialist if you are not well?
- iv. Are you on any medication?

2. AVAILABILITY OF NEEDS AND RESOURCES

4. Looking at your experiences as a cancer survivor, what would you say about cancer care treatment and resources in Botswana? Do you think we have trained and skilled personnel, resources, etc.?

Probes:

- i. Are resources sufficient?
- ii. Where are the gaps?
- iii. What would you tell someone starting treatment?

3. PSYCHOSOCIAL SUPPORT AS A PATIENT – IN THE FAMILY AND IN THE COMMUNITY

5. Cancer survivors experience mental health challenges such as anxiety and depression, which may affect their quality of life. Would you tell us more about mental health difficulties that you encountered.

Probes:

- i. Have you encountered any mental health difficulties, e.g., depression and anxiety?
 - ii. Did you receive any counselling before and after treatment?
 - iii. If yes, where and by whom?
 - iv. Were you happy with services you received?
 - v. If you experienced any mental difficulties, how did you tackle them?
 - vi. What support did you have?
 - vii. Are there any support groups in the community?
6. Would you be interested in raising cancer awareness and supporting others with cancer in your community?
7. What do you think is the biggest gap in your community, in the support for cancer survivors?
- i. Any suggestions for closing the gaps?
8. How does your family play a role in your well being as a cancer survivor?

4. LIFESTYLE FACTORS

Let's talk about how people live, their habits, lifestyle, and how these affect their lives.

9. Do you think exercising played a major role in making you survive cancer?

Probes:

- i. How often do you exercise?
- ii. How long have you been exercising?
- iii. Does your community have a place where you can exercise?
- iv. How does keeping fit play a major role in your health?

Food and Nutrition

10. Do you think what a person eats can contribute to surviving cancer?
- i. Does a balanced meal play an important part in a survivor's life?
 - ii. Do you have access to advice from a professional trained on healthy diets, such as a nutritionist?

5. CANCER RESEARCH

11. Now we are going to talk about cancer research. When you hear the words "cancer research", what comes to mind?

Probes:

- i. How important is it to have cancer research available to people living with cancer?

6. OVERALL PERSPECTIVE AND WRAP UP

We are getting towards the end of our time.

12. I want to ask a few questions to make sure we haven't left anything out.

- i. Are there any other things that haven't come up yet that get in the way of you getting the services and support that you need?
- ii. Are there other barriers that have kept you from getting what you need?
- iii. What do you think is the biggest gap in your community in the programmes, services, or support for cancer survivors?
- iv. What haven't we discussed about cancer and issues relating to cancer survivors that you think are important to keep in mind?

Thank you for your time.

Appendix J: Caregiver Focus Group Discussion Guide

In today's discussion, we will talk about various aspects of your experience as a caregiver, including your needs, support and collaboration between yourself and the facility, aftercare, and your views on resources, research, and the community.

I will start by asking you some questions on your experiences with medical care, and cancer diagnosis and treatment.

1. EXPERIENCES WITH LOCAL RESOURCES, DIAGNOSIS AND TREATMENT OF THE PERSON YOU TAKE CARE OF

1. Tell us about your experience as a caregiver of a cancer patient.
2. I'd like everyone say whether your patient was diagnosed and treated in the community you live in, or whether you travelled outside of your community for their diagnosis and/or treatment.

Probes:

- i. If you do/did travel outside of your community for either diagnosis or treatment, please tell us why.
3. Thinking about the time during which the person you cared for was treated for cancer, were there things that were particularly helpful to you as they went through treatment?
Probes:
 - i. Were there things that made it difficult for them to get treatment?
 - ii. What would have assisted you to continue with the treatment programme as prescribed? For example, more information from your health provider, a support patient navigator or case manager?
4. From your experience, what is lacking in your community that could make the treatment of cancer easier?

5. Let us focus on the experience you had after the person you cared for completed treatment.

- i. Do you think that the facility told you enough about the follow-up care that your patient would need after they completed treatment? Did they provide a written plan for follow-up care?
- ii. Was it clear to you what doctor would follow up on the person you were caring for and how often should they would need to go for for check-ups?
- iii. What support services you were referred to after treatment?
- iv. Would you be interested in raising cancer awareness and supporting others with cancer in your community?

2. LOCAL RESOURCES AND NEEDS

The following questions relate to resources in your local community to support caregivers.

1. How many of you could have benefitted from assistance with your everyday life as a caregiver to a cancer patient, especially during their treatment and recovery? What kind of assistance

would have helped you, whether from the hospital (e.g., training) or from the community (e.g., a support group), or any other assistance you can think of?

2. What kind of help did you get **locally** when taking care of your patient during their diagnosis, treatment, or after the treatment period? From whom?

Probe:

- i. Did you get involved with any cancer support groups, or get help with your bills, transportation, etc.?
3. Was there a time that you needed assistance or information and were unable to get it in your community? What assistance or information was that?
4. Have you heard of any resources from **other** areas, that would have been helpful to you had you had access to them locally?

3. CANCER RESEARCH SECTION

Let's talk about cancer research.

1. When you hear the words, "cancer research" what comes to mind?
2. How important do you think it is to have cancer research available to people with cancer in your community?

4. OVERALL PERSPECTIVE AND WRAP UP

We are getting towards the end of our time. I want to ask a few questions to make sure we haven't left anything out.

1. Are there any other things that haven't come up yet that get in the way of you getting the services and support that you need?
2. Are there any other barriers that have kept you from getting what you need?
3. What do you think is the biggest gap in your community in the programmes, services, or support for cancer caregivers?
4. What haven't we discussed about cancer and issues relating to caregiving that you think are important to keep in mind?

Thank you for your time.