



SERGIPE 2018: BREAST HEALTHCARE ASSESSMENT

An Assessment of Breast Cancer
Early Detection, Diagnosis and
Treatment in Sergipe, Brazil

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AN ASSESSMENT OF BREAST CANCER EARLY DETECTION, DIAGNOSIS AND TREATMENT IN SERGIPE, BRAZIL

A report prepared by the Breast Health Global Initiative for Susan G. Komen® in support of the Breast Cancer Initiative 2.5 campaign.



Breast Health Global Initiative



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Executive Summary

Background: In 1990, the objectives set forth in the Brazilian Constitution of 1988 were consolidated to create the publicly funded health system Sistema Único de Saúde [SUS]. Since then, investments in the health system and guaranteed access to universal healthcare have translated into lower rates of communicable diseases and maternal and infant mortality rates. Like other upper-middle income countries, Brazil is experiencing an epidemiological transition where incidence and mortality rates from non-communicable diseases including breast cancer, have been steadily increasing. In 2004, the government of Brazil issued a Consensus Statement — Controle do Câncer de Mama: Documento de Consenso—for the management of breast cancer. While mortality rates have stabilized or decreased in some regions of Brazil since then, an increase in breast cancer mortality was observed in the Northeastern region: the state of Sergipe had the highest breast-cancer mortality rate, corresponding an annual percentage increase of 4.2%.

In collaboration with the State Secretary of Health of Sergipe and the Municipal Secretary of Health of Aracaju, Susan G. Komen partnered with the Breast Health Global Initiative— member of the Breast Cancer Initiative [BCI] 2.5, a global campaign to reduce disparities in breast cancer outcomes — at the Fred Hutchinson Cancer Research Center, to conduct a baseline assessment of breast healthcare in Aracaju, the municipal capital of the state of Sergipe, Brazil. The assessment sought to:

- Review existing breast healthcare capacity;
- Identify the relative strengths and weaknesses of the health system; and
- Prioritize actionable items to advance breast cancer care in Aracaju.

Methods: In April–July 2017, a baseline assessment of breast cancer healthcare in services Aracaju was conducted through data collection and interviews. Healthcare providers were interviewed at the primary, secondary, and tertiary levels of the publicly funded SUS healthcare clinics and hospitals, and at private clinics and laboratories, which provide pathology and diagnostic services to SUS patients. Breast cancer patients and

survivors were interviewed about their experiences related to health service delivery in the public and private sectors. The tools and strategies used for the assessment were developed and adapted to local needs by BCI2.5 and Susan G. Komen. The data informed a resource-appropriate phased implementation plan to improve breast cancer early detection, diagnosis and treatment in Sergipe.

Key findings: SUS provides free healthcare for all women in Sergipe, including breast health. Prevention, epidemiological surveillance, treatment, information, education and research activities are led by Brazil's Instituto Nacional de Cancer [INCA]—the National Cancer Institute—which has published a Consensus Statement on the management of breast cancer. The assessment found a number of assets in the community for breast cancer control: clinicians throughout the system are committed to delivering and improving breast cancer care in Sergipe; public-private partnerships provide pathology and imaging services to SUS patients to supplement services at public institutions; three tertiary care facilities provide appropriate loco-regional and systemic therapies for treatment.

However, many key challenges also impede availability and access to care. These challenges result in unclear and inefficient clinical pathways for women with breast health concerns and create significant delays in detection, diagnosis, and treatment. As a result, the relatively high proportion of late stage disease reported at tertiary facilities is a cause for concern, with approximately 60% of women diagnosed at advanced stages [III or IV]. While treatment is free for all women, there is evidence that financial barriers and interruptions to drug supply hinders access to systematic treatment.; radiation therapy is only available in one of the tertiary level facilities surveyed in this assessment; and faulty equipment and low overall capacity causes significant delays in radiotherapy treatment. These results are in alignment with the review by the federal government, which found that only 37.5% of patients referred for radiotherapy received appropriate treatment.

SUMMARY OF RECOMMENDATIONS

Successful breast cancer control demands integrating early detection programs with accurate diagnosis and timely, accessible, and effective treatments. Addressing any of these components in isolation will not improve breast cancer outcomes.

Based on the findings of this situation analysis, key recommendations include:

- Effective breast cancer triage at lower levels of the healthcare system with CBE can provide a significant opportunity to reduce delays in the diagnostic process if CBE it is used systematically as recommended by the Consensus Statement, is performed by trained providers for women with breast health concerns, and followed by systematic referral where necessary to a secondary level facility within the SUS for ultrasound evaluation.
- A review of processes underlying delays in referrals could highlight operational and system-specific barriers and provide opportunities for process improvement.
- Providers in primary level facilities should be trained on the signs and symptoms of breast cancer, training on CBE and support in establishing and implementing referral protocols to higher levels of care.
- While expensive, investment in new radiotherapy units will be offset by increased and timely treatment completion rates, higher patient throughput, and less overall cost in ongoing repairs.
- An assessment of the underlying causes of chemotherapy shortages could help to identify key areas to target to address this problem, help streamline service delivery, and reduce burden on patients and on the healthcare facilities via increasing rates successful completion of treatment, shortened wait times, and improvements in participant throughput.

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BACKGROUND

BRAZIL: HEALTH SYSTEM

Brazil, an upper middle-income country, encompasses a total area of 8,514,876 km² in South America and consists of 27 states in five geographical macro-regions: the South, Southeast, Midwest, North, and Northeast. Brazil is the only country in the world with a population of more than 100 million people to have a constitutional right to health on a universal, comprehensive, and equitable basis. In 1990, the objectives set forth in the Brazilian Constitution of 1988 were consolidated to create the publicly funded health system *Sistema Único de Saúde* (SUS, Unified Healthcare System), ensuring free healthcare to all individuals [The Government of Brazil 2010].

The Constitution also makes provision for the establishment of public private partnerships to supplement public healthcare. Approximately 75% of the population accesses healthcare solely through SUS, while the remaining 25% of the population purchases private health insurance via voluntary and non-compulsory health plans and insurance [Pan American Health Organization 2008].

Investments in the health system and guaranteed access to universal healthcare have translated into lower rates of communicable diseases and maternal and infant mortality rates over the past three decades. [Chalkidou et al. 2014] In contrast, like other countries experiencing epidemiological transition, Brazil's incidence and mortality rates of non-communicable diseases have been steadily increasing, and cancer is now the second leading cause of death after cardiovascular disease. In response, the Brazilian government has issued a series of consensus statements and policy recommendations on breast cancer early diagnosis and treatment [Instituto Nacional de Câncer 2004].

BRAZIL: BREAST CANCER AND BREAST HEALTHCARE

Brazil, like most of Latin America, is experiencing an increase in breast cancer incidence [Ferlay et al. 2013]. After non-melanoma-skin cancer, breast cancer is the most common cancer and the primary cause of cancer-related death in Brazil among women, [Instituto Nacional de Câncer 2016; Kluthcovsky et al. 2014] with an age adjusted incidence and mortality rate of 56.2/100,000 and 14.3/100,000 respectively. Publicly funded [SUS] cancer care is provided via 276 state or regional referral centers across Brazil that are responsible for providing diagnosis, staging, and treatment [Lee et al. 2012].

In 2004, the government of Brazil issued a Consensus Statement—Controle do Câncer de Mama: Documento de Consenso—for the management of breast cancer [Instituto Nacional de Câncer 2004]. The document makes a series of recommendations on early detection and diagnosis, treatment, and palliative care, and describes strategies to implement these recommendations within the SUS system. A brief summary of early diagnosis recommendations made in the Consensus Statement follows.

- Annual screening via clinical breast examination (CBE) in all women >40 years. CBE is an integral part of women's healthcare and should be performed at all clinical consultations regardless of age.
- CBE is recommended as a fundamental procedure for the diagnosis of cancer and should be performed as a part of physical and gynecological examinations.
- Annual mammographic screening of women between the ages of 50–69 with a maximum interval of 2 years between examinations. The Ministry of Health- INCA website [2016] subsequently recommends biennial mammography for women aged 50–69 [Instituto Nacional de Câncer 2016].
- Annual mammography for women >35 years at elevated risk for breast cancer.
- Ultrasound is recommended as the method of choice for the assessment of palpable lesions in women <35 years, and should also complement mammography in certain situations, for example, in women with denser breast tissue, suspicions of cysts or breast parenchyma among others.
- Suspicious lesions can be evaluated using fine needle aspiration (FNA), core needle biopsy or surgical biopsy.
 - FNA was recommended in the consensus statement because of its suitability for use in an out-patient setting, its ease of use, and low cost.
- Diagnosis should encompass
 - Diagnostic Cytopathology—benign, malignant, atypia.
 - Histopathology—margin determination, immunohistochemistry.
 - TNM Classification of Malignant Tumors (TNM) staging [UICC 2002].

The Consensus Statement also made the following recommendations to aid in the integration of these guidelines into SUS:

- Educate both healthcare professionals and the public about the importance of CBE.

- Encourage the use of, and teach BSE, while emphasizing that this does not replace CBE performed by a trained health professional.
- Introduce mammographic screening with a guarantee of diagnosis, timely treatment, and follow-up of women with breast disorders.
- Introduce technical and operational standards for breast healthcare across the health network.
- Introduce quality control metrics for mammography.
- Develop a policy of training health professionals at all levels of breast healthcare management, including during their training.
- Perform economic evaluation studies aimed at incorporating new technologies for breast cancer treatment into the SUS.
- Utilize TNM staging of breast neoplasms in reporting cases to the hospital-based and population based cancer registries.

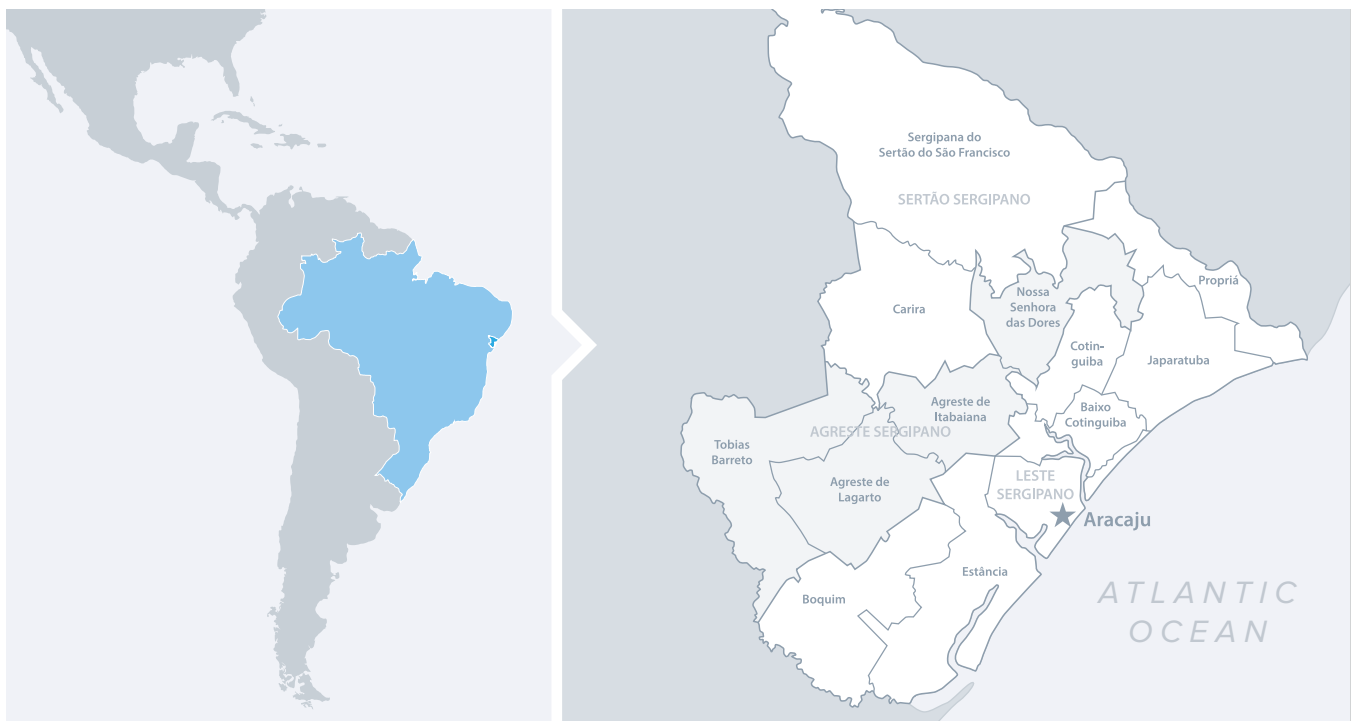
SERGIPE: BREAST CANCER AND BREAST HEALTHCARE

The State of Sergipe is located in the Northeastern coastal region of Brazil. The municipal capital is Aracaju, which has a population of 650,106, representing approximately 33% of the state population. The Brazilian Institute of Geography and Statistics considers the population of Sergipe to be predominately urban [73.4%] [Instituto Brasileiro de Geografia e Estatística 2016].

Aracaju has a network of 14 public and private hospitals, and 2122 beds [331 per 100,000 inhabitants]. The city has two universities with medical schools. For cancer diagnosis and treatment, there are two radiation therapy clinics, two public chemotherapy clinics, several ultrasound and radiology clinics, and six clinical pathology laboratories [International Association of Cancer Registries 2017].

Many of these facilities contribute to the Cancer Registry of Aracaju, which was established in 1998. Data are actively collected from sources that include a university hospital, two general hospitals, six anatomical pathology laboratories, an oncology clinic, two chemotherapy clinics, and four general health systems [APAC, SISMAE E SIM]. Information about deaths is retrieved from the Mortality Information System of the Ministry of Health [International Association of Cancer Registries 2017].

A study from 2012 examined changes in trends in breast cancer mortality in different states in Brazil. While the authors reported a stabilization, or decrease in breast cancer mortality rates in several states, an increase in mortality was observed in the Northeastern region: +2.1% between 1980-2000 and +5.3% from 2000 – 2009. In this region, Sergipe had the highest breast-cancer mortality rate [12.5/100,000], corresponding to an annual percentage increase of 4.2%, [Freitas-Junior et al. 2012], and an age-adjusted incidence rate of 58.89/100,000 [Instituto Nacional de Câncer 2013].



Currently, there is no organized breast-screening program in Sergipe, and most screening is opportunistic [Freitas-Junior et al. 2016a]. A review of opportunistic mammography screening coverage using data from *Departamento de Informática do SUS* in 2013, reported an estimated national coverage of mammography screening via the SUS of 24.8% [range 12.0%-31.3%]. In Sergipe, percent coverage was 19.2% [Freitas-Junior et al. 2016a] which is substantially lower than that recommended by the WHO. Additionally, more than 20% of mammography facilities in the northern and northeastern areas of Brazil are reported to be non-functional [Lee et al. 2012].

In comparison, the Southeast region of Brazil has seen decreases in mortality rates resulting from improved access to mammography and screening programs [Freitas-Junior et al. 2012]. One study of 248 women diagnosed with breast cancer in a hospital in the state of São Paulo, reported that 39.8% were symptomatic at diagnosis. Ninety-five women had been enrolled in a hospital-based mammographic screening program, however, 30.5% were symptomatic at diagnosis, i.e., when they attended for a screening mammogram [Silva et al. 2013]. The paper also reported that CBE was regularly performed by 88.9% of gynecologists in the private and 40.7% in the public health systems.

Prior studies in Aracaju also point to barriers related to navigation, and recognize the lack of adherence to clinical breast examination protocols as a contributing factor to delays in detection of breast cancer. From 2011–2012, a study examining barriers to breast healthcare interviewed 58 women with breast cancer, attending an outpatient oncology clinic in Aracaju. Thirty-eight [63.8%] women reported experiencing at least one barrier to care, of which the majority [65%] was attributed to healthcare organization; less frequent barriers included geographical, sociocultural, and economic barriers. Organizational deficits were

consistently cited as the principal barriers experienced during both the diagnostic and treatment periods. On average, women spent 6.5 months navigating the diagnostic pathway [Goncalves et al. 2014].

Additionally, a small study of 44 women diagnosed with breast cancer who were attending an outpatient chemotherapy clinic at the Onco Hematos Cirurgia Clinic, reported that breast cancer was self-detected by 38.6% of women; via deliberate breast self-examination [38.6%], accidental palpation [38.6%], pain [9%], mammography [6.8%] and 2.27% by CBE. Eighty-one point nine percent of women were diagnosed at advanced stage (IIB, III, IIIA, IIIB, or IV) with 70.44% experiencing either distant or regional lymph node metastasis. The authors suggested that lack of adherence to consensus guidelines—i.e., CBE performed regularly by healthcare providers, combined with lack of access to screening technologies, contributed to late stage diagnosis [Pereira et al. 2011].

The opportunistic screening mammography rate ranged from 12.0% in the northern region to 31.3% in the southern region. When stratified by state, coverage was lowest in the state of Pará and highest in the state of Santa Catarina [7.5% and 35.7%, respectively] [Freitas-Junior et al. 2016b]. In Sergipe coverage [19.2%] was lower than the regional average [22.1%], suggesting that there is still much to be done to improve early detection, diagnosis and treatment, especially among the population with low socioeconomic status served by SUS.

Data from Sergipe also shows severe limitations in the state's capacity to treat the disease. A review of oncology services in Brazil by the Federal Government identified significant delays or indeed the absence of treatment availability for cancer patients in Sergipe. Among cancer patients referred for post-diagnostic care, 37.5% received recommended radiotherapy, 97.0% received chemotherapy, and 27.5% received surgical treatment [Tribunal de Contas da União 2011].

GOALS

In collaboration with the State Secretary of Health of Sergipe and the Municipal Secretary of Health of Aracaju, Susan G. Komen partnered with the Breast Health Global Initiative at the Fred Hutchinson Cancer Research Center—part of the Breast Cancer Initiative [BCI] 2.5, a global campaign to reduce disparities in breast cancer outcomes—to conduct a baseline assessment of breast healthcare in

Aracaju the municipal capital of the state of Sergipe, Brazil. The assessment sought to:

- Review existing breast healthcare capacity;
- Identify the relative strengths and weaknesses of the health system; and
- Prioritize actionable items to advance breast cancer care in Sergipe.

METHODOLOGY

Planning Phase [January–March 2017].

Representatives from Komen and BHGI mapped the goals of the report, developed a list of target institutions in Aracaju, and a protocol for data acquisition. A representative of *MR Assessoria e Consultoria em Saude e Educacao*, working directly with Susan G. Komen (hereon, ‘study personnel’) was trained in the use of four different data collection tools (questionnaires, see Appendix II).

Data Collection [April–July 2017].

The data was collected by study personnel using four different data collection tools, administered during in-person interviews with healthcare providers, breast cancer patients and survivors.

BCI2.5 Breast Healthcare Assessment Questionnaire surveys breast healthcare facilities at the primary, secondary, and tertiary level. A representative of Komen travelled to 18 health facilities in Aracajú, the municipal capital of the state of Sergipe, Brazil, and administered the questionnaire to health facility staff. Table 1 lists the public and private facilities surveyed during the data acquisition phase. The assessment questionnaire is designed to capture existing service capacity, identify the relative strengths and weaknesses of the health system, and highlight the gaps, priority areas, and potential actionable recommendations for building capacity within the breast healthcare system.

Provider’s perceptions of breast healthcare questionnaire offers insight on the views of healthcare providers acting in the healthcare system. Thirty-eight healthcare providers completed a brief survey and/or provided comments only on their perceived barriers to breast healthcare.

Referral Process Evaluation Questionnaire assesses the referral process across different levels of the health system for women seeking breast healthcare, in particular the patient experiences with breast cancer screening, referral, and treatment. Study staff interviewed twenty-two women who attending public and private healthcare facilities in Aracajú. Women were randomly selected from waiting areas in clinics and hospitals, and asked if they would consent to be interviewed by study staff; no identifying information was collected. Eight women also provided a summary of their healthcare history, which varied from accessing yearly mammograms via out-of-pocket payments at a private facility, to breast cancer surgery and chemotherapy at a tertiary-level institution.

Breast Cancer Survivor Questionnaire. This questionnaire asks a series of in-depth questions about women’s perceptions of breast cancer detection, diagnostic and treatment processes within the SUS breast healthcare system prior to and after a diagnosis of breast cancer. The questionnaire was administered by study personnel to three breast-cancer survivors who are part of the Sergipe NGO *Mulheres de Peito*.

Data synthesis and analysis [April–Sept. 2017].

Questionnaire data were entered into REDCap, an electronic data capture platform hosted at the Fred Hutchinson Cancer Research Center.

Information was reviewed and synthesized by BCI2.5 to provide an overview of breast healthcare early diagnosis and treatment capacity. Results for individual facilities are presented in Appendix I.

Table 1: Health facilities assessed in Aracajú

SUS	
Primary level	Unidade Básica de Saúde Adel Nunes
	Unidade de Saúde Antonio Alves
	Unidade de Saúde Manoel de Souza Pereira
	Unidade Básica de Saúde Maria Do Céu
	Unidade de Saúde Joaldo Barbosa
Secondary Level	Unidade Saúde da Família Dona Sinhazinha
	Centro de Atenção Integral A Saúde da Mulher-CAISM
	Cemar-Centro de Especialidades Médicas de Aracaju
Tertiary Level	Hospital de Cirurgia
	Hospital Universitário Universidade Federal de Sergipe
	Hospital de Urgência de Sergipe Governador João Alves Filho [HUSE]
Private	
Pathology laboratories	Laboratório de Anatomia Patológica E Citopatologia Ltda
	Laboratório de Patologia Cirúrgica E Citologia Ltda
	LAPMA- Laboratório de Anatomia Patológica
Imaging centers	Hospital Do Rim de Sergipe
	CLIMAGEM
	Clínica Santa Anna
IMAMA [also provides pathology services]	

KEY FINDINGS

I. Assessment of the Breast Healthcare System in Sergipe

Staff members of both public and private facilities were surveyed to capture the existing service capacity, identify the relative strengths and weaknesses of the health system in relation to breast health, and highlight the gaps and potential actionable recommendations needed. Table 2 provides a summary of breast healthcare services

identified in Sergipe, across primary, secondary, and tertiary level SUS-facilities, and in private clinics. Tables 3a-c provide a breakdown of early detection, diagnostic and treatment services by facility at each level. Tables 4a-d present data on early detection and diagnostic services at private facilities under contract to the SUS.

Table 2: Current Distribution of Breast Health Services via SUS

Service	Primary	Secondary	Tertiary	Private	Comments
Clinical Breast Examination [CBE]	✓	✓	✓	✓	While it is theoretically available, it is not systematically performed; low awareness of breast cancer symptoms among patients may prevent its routine use at primary levels
Ultrasound Imaging	✗	✓ [Limited]	✓	✗	U/S imaging is generally unavailable. Patients are referred to private facilities under contract to the SUS upon request from primary care providers, via PPI. In private facilities, it is restricted to patients with private insurance. Could be made more widely available at secondary level facilities. U/S-guided FNA and sampling not usually performed: only one of three tertiary level facilities surveyed performed U/S guided tissue sampling. See also Clinicians Perspectives
Mammography Imaging	✗	✓ CAISM	✗	✓	Mammography imaging is generally unavailable outside of reference centers. Patients are referred for mammograms to private facilities under contract to the SUS upon request from primary care providers, via PPI. BI-RDS used consistently. Digital mammography available. Referral for mammographic screening is opportunistic [See also Clinicians Perspectives]
Pathology	✗	✓ [Limited]	✓	✓	Pathology services available via both private and SUS laboratories at tertiary and some secondary levels. Services provision appears appropriate, and both quality assurance and standard protocols are in place.
Surgery	✗	✗	✓	✓	
Chemotherapy	✗	✗	✓	✓	Available at two of three tertiary level facilities surveyed
Radiation therapy	✗	✗	✓	✓	Available at two of three tertiary level facilities surveyed
Palliative care	✗	✗	✓	✓	Available at two of three tertiary level facilities surveyed



Table 3a: Overview of service provision at primary-level SUS-funded health facilities

	Unidade Basica de Saúde Adel Nunes	Unidade de Saúde Antonio Alves	Unidade de Saúde Manoel de Souza Pereira	Unidade Basica de Saúde Maria Do Céu	Unidade de Saúde Joaldo Barbosa	Unidade Saúde da Família Dona Sinhazinha
Detection and diagnosis (imaging & workup)						
CBE	✓	✓	✓	Data unavailable	Data unavailable	Data unavailable
Diagnostic mammography	✗ Outsourced to private facilities.	✗	✗	✗	✗	✗
Ultrasound	✗	✗	✗	✗	✗	✗
Tissue sampling	✗	✗	✗	✗	✗	✗
Pathology	✗	✗	✗	✗	✗	✗
Treatment						
Surgery	✗	✗	✗	✗	✗	✗
Radiation therapy	✗	✗	✗	✗	✗	✗
Systemic treatment	✗	✗	✗	✗	✗	✗
Palliative care						
	✗	✗	✗	✗	✗	✗
Further Comments						
Unidade Basica de Saúde Adel Nunes Doctors rarely perform CBE or mammography referrals; usually performed by nurses.						
Unidade de Saúde Manoel de Souza Pereira Family health program unit—23 community health workers & a 4-member multi-disciplinary team						
Unidade de Saúde Joaldo Barbosa Follow-up for imaging and/or further treatment is done by CHW who visits the patient's house to remind them to return to the health service for further tests or treatment						
Unidade Saúde da Família Dona Sinhazinha Is a reference center for 5 health centers in the region (pop. 116,000). Barriers to care: lack of resources and materials; bureaucratic issues						

Table 3b: Overview of service provision at secondary-level SUS-funded health facilities

	Centro de Atencao Integral a Saude da Mulher-CAISM	Cemar-Centro de Especialidades Médicas de Aracaju
Detection and diagnosis (imaging & workup)		
CBE	✓	✓
Diagnostic mammography	✓ Non-functional at time of assessment	✗ Referral to a private imaging center
Ultrasound	✓	✗
Tissue sampling	✓	✗
Pathology	✗ Outsourced to a private laboratory	✗ Outsourced to a private laboratory
Treatment		
Surgery	✗	✗
Radiation therapy	✗	✗
Systemic treatment	✗	✗
Palliative care		
	✗	✗

Table 3c: Overview of service provision at tertiary-level SUS-funded health facilities

	Hospital de Cirurgia*	Hospital Universitário Universidade Federal de Sergipe	Hospital de Urgência de Sergipe [HUSE]
Detection and diagnosis (imaging & workup)			
CBE	✗	✓	✗
Diagnostic mammography	✗	✓	Non-functional at time of assessment
Ultrasound	✗	Non-functional at time of assessment	✓
Tissue sampling	✗	Not currently image guided	Ultrasound guided
Pathology	✗ Provided by partner laboratory. Report available 1-4 weeks post biopsy.	✓ Report available 1-4 weeks post biopsy. ER measured at private facility	✗
Treatment			
Surgery	✓ Total Mastectomy SLN biopsy (radiotracer, blue dye), breast conserving & reconstruction surgery	✓ Mastectomy SLN biopsy (radiotracer, blue dye), breast conserving & reconstruction surgery	✓ Mastectomy SLN biopsy (radiotracer) breast conserving & reconstruction surgery
Radiation therapy	✓ LINAC, fully functional	✗	✓ LINAC, fully functional
Systemic treatment	✓ All WHO-recommended systemic therapies are available. Some financial barriers reported.	✗	✓ All WHO-recommended systemic therapies are available.
Palliative care			
	✓	✗	✓

*Receives referrals for treatment from other SUS hospitals

**Respondent insufficiently familiar with this topic to respond to questions



Tables 4a-4d refer to detection and diagnostic technologies available to SUS patients referred to private facilities.

Table 4a: Detection and diagnostic technologies available to SUS patients at private facilities

	Hospital do Rim de Sergipe	Climagen	Clínica Santa Anna	IMAMA
Mammography machine	✓	✓	✓	✓
Functional and currently operating	✓	✓	✓	✓
Are the majority digital mammography machines	✓	✓	✓	✓
If no, do you have sufficient film to meet your needs for the majority of the time?	N/A	✗*	N/A	✗*
Current service contract to maintain the mammography machines?	Don't know	✓	✓	✓
Number of Mammography machines	✗*	1	2	1
Ultrasound machine[s] suitable for breast imaging [linear with >7 MHz transducer]	✗	✗	✗	✗
Are they functional and currently operating?	N/A	N/A	N/A	N/A
Is Ultrasound used to guide biopsies or FNAs?				
The institution has sufficient paper to print out images for either medical records or to give to patients				
Number of ultrasound machines				
MRI with dedicated breast coil	✗	✗	✗	✗
CT scanner to stage breast cancer patients	✗	✗	✗	✗
PET scanner to stage breast cancer patients	✗	✗	✗	✗

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Table 4b: Early detection methods available to SUS patients at private facilities

	Hospital do Rim de Sergipe	Climagen	Clínica Santa Anna	IMAMA
The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	✗	✓	✗	✓
The institution offers opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]	✗	✓	✗	✓
The institution offers mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]	✓	✓	✗	✓
Mammographic screening is free to women if their health insurance doesn't cover it	✗	✗	✗	✗
CBE is offered to women without breast symptoms at screening clinics	✗	✗	✗	✓
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	✓	✗	✗	-
The institution encourages/teaches BSE	Don't know	✓	✓	✓

Table 4c: Methods to evaluate symptomatic disease available to SUS patients at private facilities

	Hospital do Rim de Sergipe	Climagen	Clínica Santa Anna	IMAMA
Evaluation of women with palpable breast lumps using CBE	×	×	×	✓
Evaluation of women with palpable breast lumps using ultrasound	×	×	×	✓
Utilization of ultrasound-guided FNA	×	×	×	✓
Utilization of core needle biopsies	×	×	×	✓
Diagnostic mammography for women with palpable breast lumps	×	✓	×	✓

Table 4d: Diagnostic services available to SUS patients at private facilities

	Hospital do Rim de Sergipe	Climagen	Clínica Santa Anna	IMAMA
Medical history & physical examination	×	✓	×	✓
Clinical Breast Exam	×	×	×	✓
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	×	×	×	✓
Sentinel lymph node [SLN] biopsy with blue dye	×	×	×	✓
Image guided breast sampling	×	×	×	✓
Preoperative needle localization under mammography and/or Ultrasound guidance	×	×	×	✓
SLN biopsy using radiotracer	×	×	×	✓
Diagnostic breast ultrasound	×	✓	×	✓
Plain chest & skeletal radiography	×	✓	— *	✓
Liver Ultrasound	×	✓	×	✓
Blood chemistry profile	×	✓	✓	×
Complete Blood Count	×	✓	✓	×
Diagnostic mammography	×	✓	✓	✓
Specimen radiography	×	✓	×	✓
Bone scan	×	×	×	×
CT scan	N/A	N/A	N/A	N/A
PET scan	N/A	N/A	N/A	N/A
Breast MRI	N/A	N/A	N/A	×
BRCA 1/2 testing	×	×	×	✓
Mammographic double reading	×	×	×	×

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STRENGTHS

The main strength of the healthcare system is that SUS provides free healthcare for all women in Sergipe, including breast health. Prevention, epidemiological surveillance, treatment, information, education, and research activities are led by Brazil's Instituto Nacional de Câncer (INCA)—the National Cancer Institute—a technical branch of the Federal Government located in Rio de Janeiro, under the direct administration of the Ministry of Health, the Institute delivers cancer care within the Integrated Public Health System (SUS). INCA has published a Consensus Statement on the management of breast cancer (Instituto Nacional de Câncer 2004).

Early diagnosis

The survey also indicated that there appears to be a wide range of educational materials available through SUS.

There is a process in place to address gaps in public health service provision by partnering with private screening centers for mammography provision.

With regard to pathology services, while some SUS-funded facilities have in-house pathology labs, the majority of breast-cancer pathology requirements are met by private laboratories, as part of a public-private partnership. Pathology services meet the 2004 Consensus statement recommendations: both ER and PR testing

appears to be routinely available, either in-house or more usually at a private facility. TNM staging is carried out as recommended by the 2004 consensus statement (Table 5). As expected, the only facility that provides FNA analysis, (IMAMA) also has a detection/diagnostic unit.

One secondary level facility and the two tertiary level facilities that were assessed, have hospital based cancer registries, which contribute high-quality regional data to the Cancer Registry of Aracaju, (International Association of Cancer Registries 2017) which has been officially integrated into the Brazilian National Cancer Institute (INCA). These in turn contribute to the CI5: Cancer Incidence in Five Continents (<http://ci5.iarc.fr/Default.aspx>).

Treatment

The three tertiary care facilities—Hospital de Cirurgia, the Hospital Universitário Universidade Federal de Sergipe, and Hospital de Urgencia de Sergipe (HUSE)—provide appropriate loco-regional and systemic therapies for treatment.

According to survey results, there appears to be appropriate service provision at higher levels with tertiary hospitals providing in-house surgery, radiotherapy, and chemotherapy. All WHO-recommended systemic therapies for the treatment of breast cancer appear to be available at the tertiary level.

Table 5: Overview of pathology services provided to SUS patients by private facilities in Aracaju*

	Laboratório de Patologia Cirúrgica E Citologia Ltda (No. 1)	Lapma- Laboratório de Anatomia Patológica	Laboratório de Anatomia Patológica E Citopatologia Ltda (No. 2)	IMAMA
Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	✓	✓	✓	✓
Determination and reporting of TNM stage	✓	✓	✓	✓
Estrogen receptor (ER) status by immunohistochemistry (IHC)	✓	✓	✓	✓
Determination of margin status	✓	-	✓	✓
Determination of ductal carcinoma in situ (DCIS) content	✓	✓	✓	✓
Measurement of HER-2/neu overexpression or gene amplification	— **	✓	✓	✓
Progesterone receptor (PR) status by IHC	✓	✓	✓	✓
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	✓	✓	✓	✓
Pathology double reading	— *	✓	✓	— *
Gene profiling tests	✓	— *	— *	— *
Fine Needle Aspirates (FNA)	— *	— *	— *	✓

* Pathology services are provided by the Hospital Universitário da Universidade Federal de Sergipe as part of the SUS-funded healthcare system.

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WEAKNESSES

Public-private partnerships, while useful in providing key services such as pathology to the public health services, they add an extra layer of complexity to the patient pathway through the early diagnosis system, which may contribute to the late stage disease observed at the tertiary care facilities. For example, breast imaging—either for diagnostic or more rarely for screening purposes—is exclusively provided by private imaging centers, which may cause delays as patients wait for referrals to private facilities. The scope of service provision at these centers varies considerably [see Tables 4a-d]. Comments collected during administration of the questionnaire also raised concerns about the stability of the interface between public and private facilities [see *‘Breast cancer detection and diagnosis in Sergipe: the clinician’s perspective’*]. According to one provider, *‘During a recent strike of health professionals, payments from the SUS were not made in a timely fashion to the private facilities and reports were subsequently delayed’*.

There is some evidence that the institutions at the primary level could be better integrated into the breast healthcare system. For example, none of the primary level care facilities could approximate the final stage distribution of patients who were referred for further care, which indicates that the primary care does not receive feedback from specialized care.

Early diagnosis

Early detection and diagnosis strategies such as CBE and ultrasound, can be a low-cost and effective part of the early diagnosis toolkit, and should be encouraged for women with breast health concerns or symptoms [Instituto Nacional de Câncer 2004]. However, there was little evidence of routine and systematic use of CBE at primary level facilities, and ultrasound appear to be either underutilized, or entirely absent in the majority of SUS-funded facilities. Unfortunately, the procedure is not

provided by the private network accredited services, as the SUS does not cover the costs at a sufficient level for it to be profitable.

The relatively high proportion of late stage and metastatic disease reported at tertiary facilities is a cause for concern and may reflect delays during the patient referral pathway [Table 6]. This contrasts with the higher proportion of early stage diagnoses at private facilities], and at the secondary level facility from SUS, Centro de Atenção Integral da Saúde da Mulher-CAISM. This facility is equipped with ultrasound, and the capacity to biopsy suspected tumors, leading to diagnoses at earlier stages.

Treatment

Palliative care is centralized at the tertiary level.

Radiation therapy is available in only one of the tertiary level facilities surveyed in this assessment. This supports the results of the review by the federal government that found that only 37.5% of patients referred for radiotherapy received appropriate treatment.[Tribunal de Contas da União 2011].

From data derived from comments from clinicians made in the *BCI2.5 Breast Healthcare Assessment* questionnaire, there are some indications that financial barriers may sometimes occur that hinder access to systematic treatment:

- Patients have to pay for chemotherapy at the institution if they don’t have health insurance.
- Chemotherapy drugs are in short supply at the institution.
- Patients have to buy the drugs from outside sources.
- Patients don’t start treatment because of the cost.
- Patients don’t complete their treatment because of the cost.

Table 6: Stage distribution at diagnosis among women attending tertiary level hospitals in Aracajú

Level	Health Facility	Percentage			
		DCIS	Early Stage [I/II]	Locally Advanced [III]	Stage IV
SUS-funded; Tertiary level*	Hospital de Cirurgia	-	20	60	20
	Hospital Universitário da Universidade Federal de Sergipe	20	20	40	20
SUS-funded; Secondary level	Centro de Atenção Integral da Saúde da Mulher-CAISM	10	70	15	5
Private Imaging Facility	CLIMAGEN	60	48	10	2

*One of three tertiary level facilities surveyed did not report on cancer stage distribution

OPPORTUNITIES FOR IMPROVEMENT

Early detection and diagnosis

Effective breast cancer triage at lower levels of the healthcare system can be developed by supporting systematic use of CBE as recommended by the Consensus Statement [Instituto Nacional de Câncer 2004]. CBE performed by trained providers for women with breast health concerns, followed by systematic referral where necessary to a secondary level facility within the SUS for ultrasound, can provide a significant opportunity to reduce delays in the diagnostic process.

Providers in primary level facilities can benefit from education on signs and symptoms of breast cancer, training on CBE and support in developing referral protocols to higher levels of care. Strengthening provider education and developing process improvements to enable appropriate and timely referrals to secondary level facilities will help build an effective primary level component of the early detection and diagnostic pathway.

Providing reports to primary care facilities on their patients' diagnoses and treatment should be considered, which might help to emphasize their role as a key component in the early diagnosis pathway. Continual feedback about patients' diagnoses can provide evidence about how and why healthcare providers at this level should modify their early diagnostic practices.

Ultrasound is a more fundamental diagnostic tool than mammography, [Shyyan et al. 2008] and its utility as a low-cost, flexible tool for breast cancer diagnostic triage at lower levels of the healthcare system makes it a suitable tool for secondary-level facilities [Instituto Nacional de Câncer 2004]. The government does not, and as of October 2017, has no plans to reimburse private healthcare facilities as part of the public-private partnership service provision for ultrasound for SUS-patients, due to the cost. In the absence of private facility service provision, increased training and investment in ultrasound units at the secondary level could be considered. Initial investments could be offset by decreased reliance on private facilities for diagnostic mammography, which appear to add significant delay and complexity to the patient pathway.

Once diagnostic ultrasound is established at the secondary level, ultrasound-guided FNA could be considered, by utilizing private facilities for cytopathology services, or on some cases, in-house facilities.

Treatment

As discussed above and supported by data from patient experiences, faulty equipment, and low overall capacity causes significant delays in radiotherapy treatment. While expensive, investment in new radiotherapy units will be offset by increased and timely treatment completion rates, higher patient throughput, and less overall cost in ongoing repairs.

It may be appropriate at a later point to decentralize some palliative care services through establishing a home-based care model, reducing patient burden by reducing travel time and expense.

The following quotes are from healthcare providers and facility administrators, made during the data acquisition phase

'During a recent strike of health professionals, payments from the SUS were not made in a timely fashion to the private facilities, who did not then provide the reports' *Provider, Tertiary level.*

'Unfortunately, this Hospital is an Urgent Care Unit that is overloaded with cancer cases. In Aracaju, there should be a Cancer Hospital. We do not have the infrastructure to record of the cases [we see] in a systematic way. There is no statistical study at the hospital, and all medical records are paper-based. There are long queues for most of the procedures offered.' *Provider, Tertiary level.*

'The failure to correctly fill in the forms that must be submitted by professionals who carry out the collection of the samples which are then shipped for analysis, is one of the biggest problems we face during the diagnostic process.' *Pathologist, Private facility.*

'We provide ultrasonography and magnetic resonance for the private sector, but for the public sector, only mammography' *Radiologist, Private facility.*

'We provide both mammography and ultrasonography services but only mammography is contracted by the public service. There are no medical consultations before mammography at this service. The results of mammography are referred to applicants by the patients' *Radiologist, Private facility.*

'The demand of the public sector and the private sector are equivalent. They have the ultrasonography service, but not for the public system' *Manager, Private facility.*

II. Breast cancer detection, diagnosis, and treatment in Sergipe: the referral process

Women attending health facilities were surveyed using the referral process questionnaire with the goal of offering insight on the steps and actions required to detect, diagnose, and treat the disease. Twenty-two women responded to the questionnaire, of these 10 had had a diagnosis of breast cancer. Women were attending four different health facilities for a variety of reasons presented in Table 7.

Ten of the 22 women had received a diagnosis of breast cancer, and had attended 2-3 physicians at different facilities. Three women with a diagnosis of breast cancer cited financial concerns that delayed treatment, and four women said that financial barriers prevented them from accessing treatment and/or diagnostic tests. Of the 10 women diagnosed with cancer, five said that they had never had a breast examination, and seven said that they were aware of information about signs and symptoms of breast cancer.

Seven of the 22 women who completed the survey also provided additional comments about their experience. These women attended both public and private facilities for a variety of reasons including waiting for screening mammography, consultations to schedule diagnostic tests, and to receive their prescribed chemotherapy. Many of the women interviewed said they had to pay for the ultrasound examinations because of the extensive delays in the SUS-system, which can take up to a year. Health professionals confirmed these delays, citing the small number of professionals trained to perform breast ultrasound in the public sector, as well as by the scarcity of equipment available. The procedure is not provided by the private network accredited services, as the SUS does not cover the costs at a sufficient level for it to be profitable.

Table 7: Summary of referral times for diagnosis and/or treatment for twenty-two women attending public and private facilities in Aracaju, Sergipe.

Facility	Reasons for attending center	Mean Age [range]	Mean time from first visit to doctor for diagnosis and having surgery	Mean time from referral for chemotherapy and starting treatment	Time from referral for radiotherapy and starting treatment
CEMAR	Diagnosis [N=3] Screening [N=1]	58.8 [52-68]	N/A	N/A	N/A
CAISM	Diagnosis [N=5] Screening [N=1]	45.8 [26-66]	N/A	N/A	N/A
HOSPITAL UNIVERSITÁRIO	Diagnosis [N=1] Surgery [N=3] Concerns re symptoms [N=1]	46.6 [29-75]	9.5 months [range 2-24]	10 months [range 8-12]	N/A
HUSE	Chemotherapy [N=6] Radiotherapy [N=1]	53.6 [39-69]	10.7 months [range 1-24]	5.2 months [range 1-12]	8 months

Additional comments from seven women who completed the Referral Process Questionnaire

A 46-year-old patient from Aracaju experienced pain in her arm, and noticed the presence of a lump in her breast. She attended a primary care facility, and was referred for a mammogram in February 2015. Her doctor said that it was negative. Uncomfortable with the presence of the lump, she consulted another doctor in the private network, and received an ultrasound in July 2016. She was immediately referred to the University Hospital for treatment. In August 2016, she started chemotherapy at HUSE, and in May 2017 had surgery, 10 months after the referral of the doctor who performed the ultrasound. She is currently awaiting a vacancy for further rounds of chemotherapy at HUSE.

A 28-year-old patient noticed breast lumps at 19. She consulted a doctor as soon as she noticed the changes, but due to lack of continuity of care, delays in scheduling her diagnostic tests, and her second pregnancy, she did not receive a diagnosis. In November 2016, she underwent further tests and received the results in March 2017. She was referred for a consultation in June 2017, when she completed this questionnaire.

A 66-year-old woman says she pays for annual mammograms, due to delays in scheduling them via the SUS.

A 56-year-old resident of Ubaúba underwent an ultrasound in the private network. She has been waiting for over 6 months for a referral to a mammologist at CAISM. The patient cited cost of transport and accommodations when travelling as a barrier to accessing care.

A 36-year-old patient visited a gynecologist in her city [Itabaiana] after finding lumps in her breasts. Due to her age, the doctor refused her initial request for a mammogram. She insisted that the doctor perform a CBE; he subsequently referred her for a mammogram. She paid for a private consultation with a mastologist in Aracaju, who requested an ultrasound where more nodules were detected. The patient also paid for a breast biopsy in the private network. She has been referred for surgery, and is waiting for the procedure to be scheduled. The patient reports a lack of confidence in doctors.

A 56-year old patient underwent a biopsy in August 2014, and began radiotherapy in October. Her breast

swelled, the tumor burst and she was hospitalized for 75 days. She reported that there were 300 people in line for radiotherapy at HUSE. She contacted the Public Prosecutor's Office, which determined that the State should pay for her treatment in the private network. Her radiotherapy was carried out at the CHAMA hospital in Arapiraca. She is currently struggling to access her prescribed chemotherapy at HUSE, and is experiencing significant financial hardship to pay for food and travel.

Another patient [age unknown] sought medical care because of her symptoms [painful breasts], and was referred for a mammogram. Her doctor said that there were no suspicious findings on the mammogram. Her symptoms continued, and she had a follow-up appointment with the same doctor, who referred her for another mammogram. She was seen by a second doctor, who immediately recommended a biopsy. She paid for the biopsy and diagnostic procedures herself. After her diagnosis of cancer, she had surgery at a private hospital, and is currently undergoing treatment at HUSE.



III. Breast cancer detection and diagnosis in Sergipe: the clinician's perspective.

Thirty-five healthcare providers from primary care level facilities [19 Doctors [11 specialists in family health/general medicine; 3, obstetrics/gynecology; 4, other] and 19 nurses [9 specialists in family/community and public health; 8 unspecified/other; 2 obstetrics/gynecology]] completed a brief survey [Tables 8a-8c] and provided feedback about their perspectives of breast healthcare, in response to open ended questions on the referral system, and early detection practices. A reviewer from the State Secretary of Health of Sergipe provided additional comments.

Fifteen of the thirty-five primary-level respondents provided information of the percentage of women attending their clinics who receive CBE as part of their routine healthcare [Table 8d]. Three oncologists from tertiary level facilities were also asked for their comments on the breast healthcare system. Direct quotes from providers are in italics.

The majority of clinicians perceived that CBE's role was 'very important' in the early diagnosis of breast cancer. The majority stated that they performed CBE either 'always' [17.1%] or 'frequently' [65.7%; Table 8b]. However only 14.3% of clinicians said that they were 'very confident' in their ability to perform CBE correctly [Table 8c]. Of the fifteen respondents who provided this information, only 26.6% of their respective clinics were providing routine CBE over 80% or women attending their clinics for non-breast related healthcare [Table 8d].

Table 8a: Primary care clinicians' perception of the importance of CBE

How important is the Breast Exam for the early diagnosis of breast cancer?	N (%)
Very important	26 [74.3%]
Moderately important	7 [20.0%]
Not important	2 [5.7%]
Total	35

Table 8b: Frequency of CBE utilization among primary care clinicians

How often do you use CBE to assess women's breast health in your professional practice?	N (%)
Always	6 [17.1%]
Frequently	23 [65.7%]
Sometimes	5 [14.3%]
Rarely	1 [2.9%]
Total	35

Table 8c: Primary care clinicians' confidence in their performance of CBE

How much confidence do you place in your ability to perform CBE correctly?	N (%)
Very Confident	5 [14.3%]
Moderately Confident	17 [48.6%]
A small level of confidence	11 [31.4%]
Not confident	2 [5.7%]
Total	35

Table 8d: Percentage of women who receive routine CBE at primary care clinics.

% of women attending primary level clinics who receive CBE as part of their routine healthcare	Number of clinics (%)
10	1 [6.7%]
15	1 [6.7%]
20	1 [6.7%]
30	1 [6.7%]
40	3 [20%]
50	4 [40%]
80	2 [13.3%]
100	2 [13.3%]
Total	15

STRENGTHS

The majority of clinicians were aware of the importance of CBE in the early diagnosis of breast cancer. Several respondents commented that CBE was always performed when women attended clinics for cervical cancer screening, and a relatively high percentage of clinicians said that they 'always' or 'frequently' performed CBE. One family health provider stated that he taught all of his adult female patients how to perform a breast self-examination.

WEAKNESSES

Providers at the primary level spoke about barriers that they experience with performing CBE. One public health nurse stated *'The area [that we cover] is much bigger than the team's capacity. There is a lot of demand, but we just "put out the fire"'*. A doctor commented *'Due to a large workload we don't have time to perform it [CBE] routinely, generally it's done in a directive way for patients who have breast complaints'*. Another doctor at the primary care level stated that *'It really has not been a priority at the*

consultations, but it is necessary to change this.'

The clinical breast exam is an important low-cost resource that supports early detection efforts, especially for more aggressive cancers [Provencher et al. 2016]. Only 14.3% of clinicians were 'very confident' in their ability to perform CBE, suggesting that primary level providers could benefit from training in CBE. Similarly, only 26.6% of clinics appear to provide routine CBE at rates in excess of 80% of their patients [Table 8d].

Providers at both the primary- and tertiary levels spoke of their concerns with the referral system: one doctor stated that *'The time that it takes to schedule the referrals compromises the validity of the examinations'* [Doctor, primary level]. *'Patients experience significant delays [>6 months] during the diagnostic /investigative period'* [Oncologist].

All of the doctors and nurses at the primary level spoke of a lack of feedback about the final diagnoses/outcomes of women who were referred on from their care. The only reports that they receive are from their patients, if or when they return for other primary-level consultations.

Three oncologists all commented on the lack of ultrasound machines. Despite having clinicians trained in the technique, the SUS has *'insufficient ultrasound devices'*; *'In Sergipe we have only one SUS clinic which performs ultrasound-guided FNA so it is difficult to schedule that procedure.'* One clinician noted that *'We don't have a breast care center [within the SUS] with to perform early diagnostic procedures and examinations such as vacuum-assisted breast biopsy, core needle biopsy and US guided FNA.'*

Approximately 60-85% of women are symptomatic [breast lumps, pain] at time of diagnoses. Clinicians at the tertiary level attributed this to delays in the diagnostic process, and lack of training in CBE at the primary care level. Screen detected cancers *'are rare'*, and account for approximately 15% of breast cancer diagnoses. *'Mammography is opportunistic'* [Oncologist].

However, a comment from a Dr. Luiz Henrique Gebrim, Medical Director of Perola Byington Hospital in Sao Paulo, suggests that while ultrasound is a necessary component of early diagnosis, acquisition of equipment should only be considered *'when there is [a need] for daily utilization of at least 12 hours and generation of more than 60 examinations per day'*.

OPPORTUNITIES FOR IMPROVEMENT

As discussed under *'Breast cancer detection, diagnosis, and treatment in Sergipe: the referral process'*, a review of processes underlying delays in referrals could highlight operational and system-specific barriers and provide opportunities for process improvement.

As stated above, feedback about patients' diagnoses can provide evidence about how and why healthcare providers at the primary level should modify their early diagnostic practices.

Providers in primary level facilities can benefit from education on signs and symptoms of breast cancer, training on CBE and support in developing referral protocols to higher levels of care. Strengthening provider education and developing process improvements to enable appropriate and timely referrals to secondary level facilities, will help build an effective primary level component of the early detection and diagnostic pathway.

Effective breast cancer triage at lower levels of the healthcare system can be developed by supporting systematic use of CBE as recommended by the Consensus Statement. As outlined under *'strengths'* above, women attending cervical cancer screening always received a CBE – standardizing this process or integrating CBE with other public health interventions—such as maternal and child health—might represent opportunities to expand provision of CBE among women without breast health concerns or symptoms [Instituto Nacional de Câncer 2004].

Dr. Gebrim [Professor Livre-Docente da Disciplina de Mastologia da UNIFESP] also commented on the necessity of optimizing *'the use of equipment and doctors by [hospital] managers, including monitoring the quality of the service provided [for example, the number of biopsies performed in benign cases, [and the number of patients] lost due to lack of referral]. It is worth noting the need for doctors and processes to be evaluated periodically by the managers [to ensure] quality of services.'*

IV. Breast cancer detection and diagnosis in Sergipe: the patient's perspective

In addition to data collected from 22 women on their experiences of the referral system, three breast-cancer survivors responded to an in-depth semi-qualitative questionnaire about their experiences of breast healthcare from initial symptoms to receipt of treatment.

While educational materials appear to be widely available, it is unclear how effective they are in reaching their target audience. Reports cited lack of awareness of risk factors and the importance of seeking timely care among women with breast cancer [Gonçalves et al. 2014]. The three breast cancer survivors interviewed for this study spoke of their own lack of knowledge and the importance of disseminating education about the importance of seeking timely care.

A number of patients interviewed spoke about a lack of trust in doctors [see above – *Breast cancer detection, diagnosis, and treatment in Sergipe: the referral process*]. The comments appear to reflect a lack of training, understanding, and/or education among healthcare providers who in some cases were dismissive of women's symptoms and concerns. One woman reported having to persuade her doctor to perform a clinical breast examination; another reported failure to refer for appropriate diagnostic tests, resulting in out-of-pocket expenses for care at a private facility.

Women also discussed the issue of long wait times for referral for diagnostic imaging and for treatment. The referral system appears to be unclear, especially when women must access diagnostic and imaging services via private hospitals. While the small numbers of breast cancer survivors who completed in-depth questions about their experiences of care make it impossible to draw more than very general conclusions from their stories, it is clear that many women experienced significant delays at various points during their patient pathway [see below – *Women's stories of breast cancer detection, diagnosis, and treatment in Sergipe*].

Early Detection & Diagnosis

Many of the women interviewed about their experiences of the referral process spoke of paying out-of-pocket for ultrasound examinations at private facilities because of the extensive delays in the SUS-system, which can take up to a year to schedule [see *Breast cancer detection, diagnosis, and treatment in Sergipe: the referral process*]. Health professionals confirmed these delays, citing

the small number of professionals who are trained to perform breast ultrasound in the public sector, as well as the scarcity of equipment available in the network.

Treatment

While the numbers of breast cancer survivors interviewed are too small to draw firm conclusions, all three women highlighted their dissatisfaction with their experience of radiotherapy treatment, citing long waiting times, and interruptions in therapy due to equipment failure. Short interviews during assessment of the referral process also highlighted significant delays in accessing care, including a queue of 300 women waiting for radiotherapy services.

A number of women interviewed also reported interruptions in chemotherapy treatment due to drug shortages [see *Breast cancer detection, diagnosis, and treatment in Sergipe: the patient's perspective* and *Breast cancer detection, diagnosis, and treatment in Sergipe: the referral process*].



OPPORTUNITIES FOR IMPROVEMENT

Assessing reach and effectiveness of current breast health awareness among target populations in Sergipe may highlight areas for improving educational interventions. These may include novel delivery of health messages on topics such as signs and symptoms of breast cancer, and the importance of seeking timely care.

Providing education and training to healthcare providers at all levels of care about breast cancer signs and symptoms, and referral for appropriate diagnostic tests will strengthen the referral system and reduce patient delays.

Patient delays and the referral pathway should be reviewed—see above. The patient pathway—defined as the patient’s path through the healthcare system beginning with identification of a breast health issue and ending with its resolution—should be reviewed to eliminate redundancies or steps that contribute to significant delay in receiving a timely diagnosis.

In response to the interruptions to the supply of chemotherapy affecting patients’ ability to complete treatment, an investigation of underlying causes could help to identify key areas to target to address this problem. This understanding can also help streamline service delivery and reduce burdens on patients and on the healthcare facilities via increasing rates successful completion of treatment, shortened wait times, and improvements in participant throughput.

Timely treatment of breast cancer has the potential to reduce the risk of the cancer spreading and increases chances for survival. As previously discussed, in Sergipe there is an opportunity to improve radiotherapy capacity so that women can receive timely treatment.

WOMEN’S STORIES OF BREAST CANCER DETECTION, DIAGNOSIS, AND TREATMENT IN SERGIPE.

Three breast cancer survivors—Alícia, Bianca, and Cláudia [not their real names] residents of Aracaju and who are part of the Sergipe NGO *Mulheres de Peito* responded to a series of questions about their experiences in the SUS breast healthcare system prior to and after a diagnosis of breast cancer. They provided a description of the care they received from initial presentation of symptoms to completion of treatment in publically funded facilities. While this limited sample is not representative of all patient experiences it does shed light on general challenges and barriers faced by patients. All three women rated aspects of their care on a scale of 1 to 10, where 10 was the best score.

Alícia’s story

Alícia’s breasts had not been examined by a physician or nurse as part of her regular medical care before she was diagnosed with breast cancer. Her cancer was asymptomatic, and was detected via screening mammography. As core biopsies were not performed at the SUS-facility, she was referred for a biopsy to a private institution for a biopsy—she waited 8 months for an appointment. Alícia rated the referral process as poor [1 out of a possible score of 10]. While she felt that the process itself was clear, there were significant delays in obtaining a diagnostic evaluation, and scheduling the surgery. She specifically commented on the excessive levels of bureaucracy at each step, which further delayed her access to care. Alícia reported that both the surgical and chemotherapy services were good, and that she initiated and completed her indicated treatment. In contrast, she characterized radiotherapy services as ‘*awful*’—she waited for 6 months to begin treatment. The radiotherapy was scheduled to be completed within 6 weeks of initiation; however, it took 3 months to complete due to LINAC service outages. Alícia relied exclusively on care through SUS-facilities, which she rated as average [5/10], but it took 22 months from receiving a suspicious finding on a mammogram to completing her care.

Bianca’s story

Bianca said that her breasts were regularly examined by a physician or nurse as part of the regular medical care prior to being diagnosed with breast cancer. Her cancer was self-detected, and she saw a gynecologist who referred her for a biopsy with a mastologist within 15 days. She received a formal diagnosis within 2 months of her biopsy. Bianca rated the referral process as good [7/10] and said that the diagnostic process was clear. She initiated treatment within 2 months after the diagnosis. She did not require radiotherapy.

Bianca received all of her breast cancer care at SUS-facilities. While she was happy with the surgery that she received at the University Hospital, she said that while she successfully completed her indicated treatment, her experience of chemotherapy was ‘*awful, problematic and interrupted due to lack of chemo medication*’. She rated her overall experience as average [5/10]. When asked about what she could do to improve aspects of the healthcare system as related to breast cancer, Bianca commented: “*I think breast cancer is not given its rightful importance. There should be more campaigns, more education in health and the healthcare system must be improved. There is a lack of medications and there isn’t a reference hospital for cancer.*”

Cláudia's story

While Cláudia's breasts were examined by a physician or nurse as part of her regular medical exam prior to being diagnosed with breast cancer, her cancer was self-detected, via breast self-examination. She did not think it important as it was painless and she had just stopped breast-feeding. She waited 4 months and only sought medical care after seeing a TV documentary about breast cancer, in which a doctor encouraged women with symptoms of breast cancer to speak to their doctors.

Cláudia did not have a health plan but was aware of delays in getting appointments with a mastologist in the SUS-system. As a result, she paid out-of-pocket to see a doctor at a private clinic. She was seen the same day, and while the doctor said that while it was unlikely that she had cancer given the lack of family history of breast cancer, he referred her for a mammogram at a private facility. The mammogram was negative, but as she had subsequently developed another palpable lump near her armpit, the doctor performed an FNA. As Cláudia felt that she was unlikely to have cancer, she waited another month to get the results. The FNA results suggested a malignancy, and she was referred to HUSE for a biopsy. While she felt that while the diagnostic process was clear, she described the referral process 'terrible' rating it 3/10 and identified the lack of patient support as a problem. Once she had sought care, she waited for up to 2 months between the biopsy and receipt of a diagnosis, and a further 2 months before beginning treatment.

Cláudia rated her overall experiences of the care she received in the public facility [biopsy, surgery, and first round of chemotherapy and radiotherapy] as 'okay' [6/10]. She said that there were delays receiving the biopsy results, lack of availability of chemotherapy drugs for the second phase of her chemotherapy, and serious problems with receiving the indicated radiotherapy as the LINAC kept breaking down. As a result of her experience in the SUS-facility, she attended a private facility for the second round of chemotherapy: she rated the service as 'wonderful' [10/10]. Cláudia spoke about her frustrations with delays in receiving treatment and problems accessing breast care services. *"I began to suffer with the neglect in the second phase of chemotherapy when medication was no longer available. I began chemo treatment in a private clinic, because I had already surpassed my health plan's grace period for this type of treatment. Then I went back to suffering from radiation therapy where the device broke down frequently interrupting my treatment."* She added, *"I faced great difficulties to start and finish the treatment [radiotherapy] because in the State of Sergipe there are only 2 devices, one that does the 2D treatment with approximately 37 years of use and the other that does the 3D treatment that has about 17 years of use. These appliances break down frequently which totally disrupted my treatment."*



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Suggested Citation

Sergipe 2018. Breast Healthcare Assessment. An Assessment of Breast Cancer Early Detection, Diagnosis, and Treatment in the State of Sergipe, Brazil

Catherine Duggan, Maísa Real Tavares Porto, Tauane Araújo Cruz, Cristiani Ludmila Mendes Sousa Borges, Anna Cabanes, Breast Health Global Initiative [BHGI] and Susan G. Komen. 2018.

Funding Support

Susan G. Komen & the Pfizer Foundation

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Acknowledgments

We would like to acknowledge the support and coordination provided by the State Secretary of Health of the State of Sergipe and the Municipal Secretary of Health of Aracaju. Special thanks to all of the healthcare professionals, cancer survivors and advocates who responded to the questionnaires and who contributed their time during the on-site visits. We also want to recognize important contributions from the following collaborating organizations:

Centro de Especialidades Médica de Aracaju [CEMAR]

Fundação Beneficência Hospital de Cirurgia

Hospital do Câncer de Barretos

Hospital Pérola Byington

Hospital Universitário da Universidade Federal de Sergipe [HU-UFS]

Hospital de Urgência de Sergipe [HUSE]

Instituto Oncoguia

Mulheres de Peito

Photo Credits: Tauane Araújo Cruz & Mulheres de Peito

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APPENDIX I: Health facilities assessed

Unidade Basica de Saúde Adel Nunes, Aracaju

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable*
Pathology	Unavailable
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

*women are referred to other centers for mammography

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as Primary Care facility—
- It receives government funding
- The main healthcare payment methods for patients are via public health insurance
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- As this is a primary care facility the stage distribution at diagnosis is unknown

Number of women attending the facility per week for breast health concerns/cancer care?	Don't know
Number of new cases of breast cancer seen monthly?	Don't know
The percentage of women with suspicious findings who do not return after their initial consultation	Don't know

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes

Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	7
Cancer registry	0

Medical records are maintained as follows

Paper-based patient medical records	No
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	No
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	No
The institution utilizes a unified medical record number for each patient that is used throughout the institution	No
There is a unified medical record/patient ID number used across different health facilities	No

There is no hospital-based cancer registry at this institution.

Unidade de Saúde Antonio Alves, Aracaju

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Unavailable
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a primary care facility
- It receives government funding
- The main healthcare payment method for patients is via Government/public insurance [free for all patients]
- The percentage of women attending with symptomatic cancer is unknown at this institution.
- As a primary level hospital the stage distribution at diagnosis is unknown
- Number of women attending the facility per week for breast health concerns/cancer care—unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Don't know
Cancer registry	None

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes

The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

There is no hospital-based cancer registry at this institution.

Unidade de Saúde Manoel de Souza Pereira, Aracaju

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Unavailable
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a primary care facility
- It receives government funding
- The main healthcare payment methods for patients is Government/public insurance [free for all patients]
- The estimated distribution of cancer stage among the breast cancer patients is unknown at this institution, nor the percentage of women attending with symptomatic cancer

Number of women attending the facility per week for breast health concerns/cancer care	Don't know
Number of new cases of breast cancer seen monthly	Don't know
The percentage of women with suspicious findings who do not return after their initial consultation	Don't know

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	2
Cancer registry	None

Medical records are maintained as follows

Paper-based patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	No
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	No
The institution utilizes a unified medical record number for each patient that is used throughout the institution	No
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome. There is no hospital-based cancer registry.

Unidade Basica de Saúde Maria do Céu, Aracaju

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Insufficiently familiar
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a Provincial or Secondary-level hospital—highly differentiated by function with five to ten clinical specialties
- It receives government funding
- The main healthcare payment method for patients Government/public insurance (free for all patients)
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- As this institution is a secondary level hospital and refers women to higher level institutions for diagnosis, stage distribution at diagnosis is unknown
- It was unknown how many women attend the facility per week for breast health concerns/cancer care

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Unknown
As a secondary level institution, there is no hospital-based cancer registry	-

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- As this institution is a secondary level hospital and refers women to higher level institutions for diagnosis, stage distribution at diagnosis is unknown
- It was unknown how many women attend the facility per week for breast health concerns/cancer care

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

Unidade Basica de Saúde Joaldo Barbosa, Aracaju

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Insufficiently familiar
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a Provincial or Secondary-level hospital—highly differentiated by function with five to ten clinical specialties
- It receives government funding
- The main healthcare payment method for patients Government/public insurance (free for all patients)

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Unknown
As a secondary level institution, there is no hospital-based cancer registry	-

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

Unidade Saúde da Família Dona Sinhazinha, Aracajú

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Insufficiently familiar
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a Provincial or Secondary-level hospital—highly differentiated by function with five to ten clinical specialties
- It receives government funding
- The main healthcare payment method for patients is via Government/public insurance (free for all patients)
- The percentage of women attending with symptomatic cancer is unknown at this institution.
- As a secondary level hospital the stage distribution at diagnosis is unknown
- Number of women attending the facility per week for breast health concerns/cancer care—unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Unknown
Cancer registry	Unknown

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry, which contributes data to a population-based national cancer registry. The following data are collected:

Personal identification (Name, age, sex, registration number, contact information)	Yes
Demographic (address ethnicity)	Yes
Tumor data (Incidence date, basis of diagnosis Topography [site] Morphology [histology], Behavior, Source of information)	Don't know
The tumor and its investigations (Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site[s] of distant metastases; Multiple primaries; Laterality)	Don't know
Treatment (Initial treatment)	Don't know
Follow-up (Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death)	Don't know

Centro de Atenção Integral A Saúde da Mulher-CAISM, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis (imaging & workup)	Complete
Pathology	Unavailable*
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

*services provided by a partner institution

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as an imaging center
- It is a publically/government funded institution, and partners with Américas Amigas to improve breast healthcare services
- The main healthcare payment methods for patients are
- Government/public insurance (free for all patients)
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- The majority of women are diagnosed at Stages I-II

Estimated distribution of cancer stage among the breast cancer patients

DCIS (Stage 0)	10
Early stage (Stage I or II)	70
Locally advanced (stage III)	15
Metastatic (Stage IV)	5
Number of women attending the facility per week for breast health concerns/cancer care?	
266	
Number of new cases of breast cancer seen monthly?	10
The percentage of women with suspicious findings who do not return after their initial consultation	5

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes

Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	1
Cancer registry	Unknown

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	No
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry, which contributes data to a population-based national cancer registry. The following data are collected:

Personal identification (Name, age, sex, registration number, contact information)	Yes
Demographic (address ethnicity)	Yes
Tumor data (Incidence date, basis of diagnosis Topography [site] Morphology [histology]. Behavior, Source of information)	Yes

The tumor and its investigations [Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site(s) of distant metastases; Multiple primaries; Laterality]	Yes
Treatment [Initial treatment]	Yes
Follow-up [Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death]	Yes

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

This section was completed by a nurse.

Staffing levels

Radiologist	Part-time	3
Radiographer or radiology technologist	Part-time	4
Sonographer	Part-time	2

BI-RADS is used to report results for the following modalities. Breast imaging is reported as:

Mammography	Yes
Ultrasound	Yes

Available detection and diagnostic technologies

Mammography machine	Yes
Functional and currently operating	No
Are the majority digital mammography machines	No
If no, do you have sufficient film to meet your needs for the majority of the time?	Yes
If no, do you have sufficient film to meet your needs for the majority of the time?	Yes
Current service contract to maintain the mammography machines?	Yes
Number of Mammography machines	2
Ultrasound machine(s) suitable for breast imaging (linear with >7 MHz transducer)	Yes
Are they functional and currently operating?	Yes
Is Ultrasound used to guide biopsies or FNAs?	Yes
The institution has sufficient paper to print out images for either medical records or to give to patients	Yes
Number of ultrasound machines	2
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	Yes
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The institution offers opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]	Yes
The institution offers mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]	Yes
Mammographic screening is free to women if their health insurance doesn't cover it	Yes
CBE is offered to women without breast symptoms at screening clinics	No
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	Yes
The institution encourages/teaches BSE	Yes

Palpable disease—early detection

Evaluation of women with palpable breast lumps using CBE	Yes
Evaluation of women with palpable breast lumps using ultrasound	Yes
Utilization of ultrasound-guided FNA	Yes
Utilization of core needle biopsies	Yes
Diagnostic mammography for women with palpable breast lumps	Yes

Available methods of breast cancer diagnosis

Medical history & physical examination	Yes
Clinical Breast Exam	Yes
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	Yes
Sentinel lymph node [SLN] biopsy with blue dye	No
Image guided breast sampling	Don't Know
Preoperative needle localization under mammography and/ or Ultrasound guidance	No
SLN biopsy using radiotracer	No
Diagnostic breast ultrasound	Yes
Plain chest & skeletal radiography	No
Liver Ultrasound	Yes
Blood chemistry profile	No
Complete Blood Count	No
Diagnostic mammography	Yes
Specimen radiography	No
Bone scan	No
CT scan	N/A
PET scan	N/A
Breast MRI	N/A
BRCA 1/2 testing	No
Mammographic double reading	No

4. PATHOLOGY

While there are no pathology services at this institution, the services are provided by a partner laboratory. Biopsies are routinely sent to laboratories that are either private, or that are a part of the health service (not in institution), and the pathology report is sent to the breast health providers. Pathology costs are covered by the institution.

CEMAR-Centro de Especialidades Médicas de Aracaju, Aracajú

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Available—some services outsourced
Pathology	Unavailable
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a Provincial or Secondary-level hospital—highly differentiated by function with five to ten clinical specialties, including internal medicine, obstetrics-gynecology, pediatrics and general surgery
- It is a publically/government funded institution,
- The main healthcare payment methods for patients are
- Government/public insurance (free for all patients)
- Between 50% and 75% of women who attend the institution for breast health concerns have symptoms of breast cancer

Stage distribution at diagnosis is unknown

Number of women attending the facility per week for breast health concerns/cancer care?	100
Number of new cases of breast cancer seen monthly?	6
The percentage of women with suspicious findings who do not return after their initial consultation	0

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	5
Cancer registry	0

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Medical records held/maintained by patients?	No
Is it the responsibility of the patient to bring their records to medical appointments?	No
Does your institution have a system for following patients after a diagnosis of metastatic breast cancer?	No
Does your institution maintain contact with patients by telephone, mail or other methods to inform them of results?	No
Does your institution maintain contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment?	Yes
Does your institution send information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment?	Yes
Does your institution utilize a unified medical record number for each patient that is used throughout the institution?	Yes
Is there a unified medical record/patient ID number used across different health facilities in your country?	No

Information collected on cancer incidence and outcome

There is no hospital-based cancer registry.

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

It is unknown what reporting system is used for imaging technologies.

Staffing levels

Radiologist	Part-time	3
Radiographer or a radiology technologist	-	0
Sonographer	Part-time	1

Available detection and diagnostic technologies

Mammography machine[s]	No
Ultrasound machine[s] suitable for breast imaging (linear with >7 MHz transducer)	Don't know
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	No
The institution offers opportunistic mammographic screening of women without breast symptoms (i.e. mammography is offered to women when they attend the institution for unrelated reasons)	No
The institution offers mammographic screening of women without breast symptoms at a screening clinic (i.e., women can attend for breast screening, but it is not part of a systematic screening program)	No
Mammographic screening is free to women if their health insurance doesn't cover it	No
CBE is offered to women without breast symptoms at screening clinics	No
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	Don't know
The institution encourages/teaches BSE	Yes

Palpable disease—early detection

Evaluation of women with palpable breast lumps using CBE	Yes
Evaluation of women with palpable breast lumps using ultrasound	Yes
Utilization of ultrasound-guided FNA	No
Utilization of core needle biopsies	No
diagnostic mammography for women with palpable breast lumps	No

Available methods of breast cancer diagnosis

Medical history & physical examination	Yes
Clinical Breast Exam	Yes

Ultrasound-guided FNAB of sonographically suspicious axillary nodes	No
Sentinel lymph node [SLN] biopsy with blue dye	Yes
Image guided breast sampling	No
Preoperative needle localization under mammography and/or Ultrasound guidance	No
SLN biopsy using radiotracer	No
Diagnostic breast ultrasound	Yes
Plain chest & skeletal radiography	No
Liver Ultrasound	Yes
Blood chemistry profile	Yes
Complete Blood Count	Yes
Diagnostic mammography	No
Specimen radiography	No
Bone scan	No
CT scan	-
PET scan	-
Breast MRI	-
BRCA 1/2 testing	No
Mammographic double reading	No

4. PATHOLOGY

This section was completed by a nurse.

Specimens are sent to another institution within the health system and to private laboratories, at no cost to the patient. The institution receives a copy of the pathology report.

Hospital de Cirurgia, Aracajú

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Unavailable
Surgery therapy	Available
Radiation therapy	Available
Systemic treatment	Available
Palliative care	Available

1. INSTITUTION: OVERVIEW

Five individuals contributed to the report.

- The institution is described as a Tertiary-level hospital—highly specialized staff and technical equipment. Clinical services are highly differentiated by function; might have teaching activities...
- It receives a mix of government and private funding

- It partners with a variety of organizations including National Universities/educational or research institutions (Universidade Tiradentes, Estácio de Sá, Universidade Federal de Sergipe) and cancer support and advocacy groups (AMO, ACASE, Legião Feminina) to improve breast healthcare services
- The main healthcare payment methods for patients are
- Government/public insurance (free for all patients)
- Private Insurance (patients or their employers purchase private health insurance)
- Between 75% -90% of women who attend the institution for breast health concerns have symptoms of breast cancer
- The majority of women are diagnosed at Stages I-III

Estimated distribution of cancer stage among the breast cancer patients

DCIS (Stage 0)	-
Early stage (Stage I or II)	20
Locally advanced (stage III)	60
Metastatic (Stage IV)	20
Number of women attending the facility per week for breast health concerns/cancer care?	25
Number of new cases of breast cancer seen monthly?	4
The percentage of women with suspicious findings who do not return after their initial consultation	Don't know

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	2
Cancer registry	Don't know

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
Is it the responsibility of the patient to bring their records to medical appointments?	No
Does your institution have a system for following patients after a diagnosis of metastatic breast cancer?	Don't know
Does your institution maintain contact with patients by telephone, mail or other methods to inform them of results?	No
Does your institution maintain contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment?	Yes
Does your institution send information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment?	Yes
Does your institution utilize a unified medical record number for each patient that is used throughout the institution?	No
Is there a unified medical record/patient ID number used across different health facilities in your country?	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry which contributes data to both a population-based regional and national cancer registry. The following data are collected:

Personal identification (Name, age, sex, registration number, contact information)	Yes
Demographic (address ethnicity)	Yes
Tumor data (Incidence date, basis of diagnosis Topography [site] Morphology [histology], Behavior, Source of information)	Don't know
The tumor and its investigations (Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site[s] of distant metastases; Multiple primaries; Laterality)	Don't know
Treatment (Initial treatment)	Don't know
Follow-up (Date of last contact; Status at last contact [alive, dead, emigrated, unknown]; Date of death; Cause of death; Place of death)	Don't know

4. PATHOLOGY

This section was completed by a nurse.

Pathology services are provided by a partner laboratory that is part of the health service (not in institution), and the pathology report is sent to the breast health providers. Pathology costs are covered by government/public health insurance.

- Surgical biopsy and mastectomy samples are used to obtain initial tissue diagnoses
- Pathology reports are usually available between 1-4 weeks from biopsy
- It is unclear what pathology tests are carried out

5. SURGICAL THERAPY

This section was completed by a member of the surgical team.

Procedures performed at this institution

Early stage cancer	
Modified radical mastectomy	Yes
Breast conserving surgery	Yes
Sentinel lymph node (SLN) biopsy with blue dye	Yes
Sentinel lymph node biopsy using radiotracer	Yes
Breast reconstruction surgery	Yes
Locally advanced cancer	
Modified radical mastectomy	Yes
Breast conserving surgery	Yes
Sentinel lymph node biopsy using radiotracer	Yes
Breast reconstruction surgery	Yes
Metastatic OR recurrent cancer	
Total mastectomy for ipsilateral breast tumor recurrence after breast conserving surgery	Yes

6. RADIATION THERAPY

This section was completed by a radiation oncologist.

It is unclear how many radiation oncologists are at the institution.

Radiotherapy sources

Linear accelerator (LINAC)	Yes
If yes, what year was it purchased?	1984
If yes, approximately how many months of the year is it functioning?	12
Is there a machine that delivers HDR brachytherapy at your institution	No

Planning

Medical physicist	Yes
Dosimetrist	No
Physician	Yes

Treatments are available to women with breast cancer

Stage I	
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	Yes
Stage II	
Post-mastectomy irradiation of chest wall and regional nodes for high-risk cases	Yes
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	Yes
Locally advanced	
Post-mastectomy irradiation of chest wall and regional nodes	Yes
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	Yes
Metastatic or recurrent	
Palliative radiation therapy	Yes

7. SYSTEMIC TREATMENT

This section was completed by a nurse.

There are six medical oncologists at the institution.

Number of women who are treated with chemotherapy at your institution each month	200
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Available systemic therapies

Doxorubicin	Yes
Cyclophosphamide	Yes
Paclitaxel	Yes
Docetaxel	Yes
Methotrexate	Yes
5-fluorouracil	Yes
Trastuzumab	Yes
Carboplatin	Yes
Capecitabine	Yes
Vinorelbine	Yes
Gemcitabine	Yes
Tamoxifen	Yes
Anastrozole (or other Aromatase inhibitor—Letrozole and/or Exemestane)	Yes

Chemotherapy access and cost

Patients have to pay for chemotherapy at the institution if they don't have health insurance	Sometimes
Chemotherapy drugs are in short supply at the institution	Sometimes
Patients have to buy the drugs from outside sources	Sometimes
Patients don't start treatment because of the cost	Sometimes
Patients don't complete their treatment because of the cost	Sometimes
Tamoxifen is prescribed to all women as the majority do not have information on ER status	Sometimes
Chemotherapy drugs are prepared in a functioning containment hood	Yes, always

8. PALLIATIVE CARE

This section was completed by a surgeon.

Pain management options available for breast cancer patients

NSAIDS	Yes
Opioids—morphine (oral or parenteral),	Yes
Co-analgesics e.g. steroids	Yes
Fentanyl patch	No
Non-morphine opioids [e.g. methadone]	Yes
Management of pain-related physical symptoms	Yes
Complementary and alternative medicine [CAM] and non-drug pain management	Yes
Radiotherapy [single and multi-fraction]	Yes
Physical and Occupational therapy for functional limitations or pain management	Yes
Pain screening	Yes
Pain care plan	Yes
Opioid pumps	No
Consultation with specialist in pain therapy	Yes
Surgery [cord compression, fracture, obstruction]	Yes
Locoregional anesthesia, spinal analgesia	Yes
Home based care for patients requiring palliation	No
Approximately how many women receive palliative care at your institution each month?	200

Major impediments to the availability of opioids such as morphine for pain relief

Shortages of opioids result in inadequate availability to patients.	No, never
Physicians are reluctant to prescribe opioids	No, never
Patients are reluctant to take opioids.	No, never
Opioid products are not available in needed dosage forms and dosages.	No, never
Laws or regulations restrict the amounts of opioids which can be prescribed.	No, never

It is difficult for patients to obtain opioids for use at home.	No, never
Patients often cannot afford opioids	No, never
Pain in cancer patients is not treated adequately	No, never
Healthcare professionals do not have adequate educational opportunities to learn about the use of opioids in pain management.	No, never
For severe pain, strict control of morphine results in the prescribing of weaker, less controlled, analgesics	Sometimes

Psychosocial and Spiritual support for cancer patients

Patient and family education [treatment-related]	Yes
Peer support by trained volunteers	Yes
Spiritual support: community- or religious-based	Yes
Patient and family support groups	Yes
Psychosocial support by health professionals	Yes
Screening and referrals for depression/distress by mental health specialist	No
Patient and family education [survivorship]	Yes
Peer support by trained breast cancer survivors	Yes
Emotional, social support by health professionals	Yes
Psychosocial counseling by mental health specialist	Yes

Hospital Universitário Universidade Federal de Sergipe, Aracajú

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis [imaging & workup]	Available
Pathology	Available
Surgery therapy	Available
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

Two individuals contributed to the report.

- The institution is described as a Tertiary-level hospital—highly specialized staff and technical equipment. Clinical services are highly differentiated by function; might have teaching activities
- It is a publically/government funded institution,
- The main healthcare payment methods for patients are

[in order of importance]

- Government/public insurance [free for all patients]
- Patient/Family pays some of the cost [less than 50%]
- Less than 50% who attend the institution for breast health concerns have symptoms of breast cancer
- The majority of women are diagnosed at Stages I-III

Estimated distribution of cancer stage among the breast cancer patients

DCIS [Stage 0]	20
Early stage [Stage I or II]	20
Locally advanced [stage III]	40
Metastatic [Stage IV]	20

Number of women attending the facility per week for breast health concerns/cancer care?	500
Number of new cases of breast cancer seen monthly?	10
The percentage of women with suspicious findings who do not return after their initial consultation	0

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Don't Know
Cancer registry	Don't Know

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
Is it the responsibility of the patient to bring their records to medical appointments?	No

Does your institution have a system for following patients after a diagnosis of metastatic breast cancer?	No
Does your institution maintain contact with patients by telephone, mail or other methods to inform them of results?	No
Does your institution maintain contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment?	Yes
Does your institution send information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment?	Yes
Does your institution utilize a unified medical record number for each patient that is used throughout the institution?	Yes
Is there a unified medical record/patient ID number used across different health facilities in your country?	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry, which contributes data to a population-based regional and national cancer registry. The following data are collected:

Personal identification [Name, age, sex, registration number, contact information]	Yes
Demographic [address ethnicity]	Yes
Tumor data [Incidence date, basis of diagnosis Topography [site] Morphology [histology], Behavior, Source of information]	Yes
The tumor and its investigations [Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site(s) of distant metastases; Multiple primaries; Laterality]	Don't know
Treatment [Initial treatment]	Don't know
Follow-up [Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death]	Don't know

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

A radiologist completed this section.

- It was unclear what image-based reporting system [e.g. BI-RADs] is used
- The institution uses an electronic system for storing images from ultrasounds or other technologies [SERVIDOR]

Staffing levels [all part-time]

Radiologist	10
Radiographer or a radiology technologist	27
Sonographer	3

Available detection and diagnostic technologies

Mammography machine	Yes
Are they functional and currently operating?	Yes
Are the majority digital mammography machines?	Yes
Does your institution have a service contract to maintain the mammography machines?	Yes
If you have Mammography machines, how many units do you have?	1
Ultrasound machine(s) suitable for breast imaging [linear with >7 MHz transducer]	Yes
Are they functional and currently operating?	No
Is Ultrasound used to guide biopsies or FNAs?	Yes
Do you have sufficient paper to print out images for either medical records or to give to patients?	Yes
If you have suitable ultrasound machines, how many units do you have?	4
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	Non-operational
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

Performance of mammography of women without breast symptoms as part of a population-based mammographic screening program	Yes
Availability of opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]	Yes
Availability of mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]?	Yes
Availability of free mammographic screening if health insurance doesn't cover it	Yes
CBE offered to women without breast symptoms at screening clinics	Yes
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	Yes
BSE is taught and encouraged	Yes
Palpable disease—early detection	
Evaluation of women with palpable breast lumps using CBE	Yes
Evaluation of women with palpable breast lumps using ultrasound	Yes
Ultrasound-guided FNA of women with breast lumps [either symptomatic or screen-detected]	Yes
Core needle biopsies of women with breast lumps [either symptomatic or screen-detected]	No
Diagnostic mammography of women with breast lumps	Yes

Methods of breast cancer diagnosis

Medical history & physical examination	Yes
Clinical Breast Exam	Yes
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	Yes
Sentinel lymph node [SLN] biopsy with blue dye	Yes
Image guided breast sampling	No
Preoperative needle localization under mammography and/or Ultrasound guidance	No
SLN biopsy using radiotracer	No
Diagnostic breast ultrasound	Yes
Plain chest & skeletal radiography	Yes
Liver Ultrasound	Yes
Blood chemistry profile	Yes
Complete Blood Count	Yes
Diagnostic mammography	Yes
Specimen radiography	Yes
Bone scan	Yes
CT scan	No
PET scan	No
Breast MRI	No
BRCA 1/2 testing	No
Mammographic double reading	No

4. PATHOLOGY

This section was completed by a pathologist.

- There are four pathologists and six technicians at this institution
- The institution has a standard process or protocol for fixing tissue, but does not have quality assurance measures in place to ensure standard protocols are being followed
- Pathology review occurs in house, and also makes use of a partner laboratory that is also part of the health system
- The center provides pathology service both for its own patients as acts as a referral service center for other institutions.
- Costs of the pathology report [appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade] is covered by Government/Public health insurance
- HER2/neu testing is covered via out of pocket payments/private insurance
- Pathology reports are usually available between 1-4 weeks from biopsy

Pathology tests/reporting available

Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	Yes
Determination and reporting of TNM stage	Yes
Estrogen receptor (ER) status by immunohistochemistry (IHC)	No
Determination of margin status	Yes
Determination of ductal carcinoma in situ (DCIS) content	Yes
Measurement of HER-2/neu overexpression or gene amplification	No
Progesterone receptor (PR) status by IHC	No
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	No
Pathology double reading	Yes
Gene profiling tests	No
Fine Needle Aspirates (FNA)	Yes
If FNA processing is performed at your institution, are they interpreted by staff trained in cytopathology?	Yes

Methods used to obtain initial tissue diagnoses among breast cancer patients

Fine needle aspiration [cytology]	Yes
Core needle tissue biopsy [histology]	No
Surgical biopsy	Yes
Mastectomy	Yes

5. SURGICAL THERAPY

This section was completed by a surgeon.

Procedures performed at this institution

Early stage cancer	
Modified radical mastectomy	Yes
Breast conserving surgery	Yes
Sentinel lymph node (SLN) biopsy with blue dye	No
Sentinel lymph node biopsy using radiotracer	No
Breast reconstruction surgery	Yes
Locally advanced cancer	
Modified radical mastectomy	Yes
Breast conserving surgery	Yes
Sentinel lymph node biopsy using radiotracer	No
Breast reconstruction surgery	Yes
Metastatic OR recurrent cancer	
Total mastectomy for ipsilateral breast tumor recurrence after breast conserving surgery	Yes

Hospital de Urgência de Sergipe Governador João Alves Filho (HUSE), Aracaju

Sections Completed

Overview	Complete
Patient data, records & tracking	Complete
Detection and diagnosis [imaging & workup]	Available
Pathology	Unavailable
Surgery therapy	Available
Radiation therapy	Available
Systemic treatment	Available
Palliative care	Available

1. INSTITUTION: OVERVIEW

Two individuals contributed to the report.

- The institution is described as a Cancer care/breast care facility- specialized in cancer or breast cancer diagnosis and treatment
- It is a publically/government funded institution,
- The main healthcare payment methods for patients Government/public insurance [free for all patients]
- The proportion of women who attend the institution for breast health concerns have symptoms of breast cancer was unknown
- The stage distribution of cancers in women attending this facility was also unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	No
Signs and symptoms of breast cancer	No
Information about how to practice breast self-examination	No
The importance of breast cancer early detection	No
Outreach/education encouraging CBE for age groups at high risk	No
Diagnosing breast cancer	No
Treatment of Breast Cancer	Yes
Importance of screening mammography	No
Information about where to access breast healthcare	No
Information about breast cancer advocate networks	No
Information about where to access breast cancer support groups	No
Information about access to financial resources to pay for diagnosis or treatment, for example	No

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	1
Cancer registry	0

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	No
Are medical records held/maintained by patients?	No
Is it the responsibility of the patient to bring their records to medical appointments?	No
Does your institution have a system for following patients after a diagnosis of metastatic breast cancer?	No
Does your institution maintain contact with patients by telephone, mail or other methods to inform them of results?	Yes
Does your institution maintain contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment?	Yes
Does your institution send information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment?	Yes
Does your institution utilize a unified medical record number for each patient that is used throughout the institution?	Yes
Is there a unified medical record/patient ID number used across different health facilities in your country?	Yes

Information collected on cancer incidence and outcome

There is no hospital-based cancer registry at this facility.

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

BI-RADs is used for reporting ultrasound and mammography.

Staffing levels (all part-time)

Radiologist	5
Radiographer or a radiology technologist	15
Sonographer	2

Detection and diagnostic technologies

Mammography machine	Yes
Are they functional and currently operating?	No
Are the majority digital mammography machines?	Yes
Does your institution have a service contract to maintain the mammography machines?	No
Ultrasound machine(s) suitable for breast imaging [linear with >7 MHz transducer]	Yes
Are they functional and currently operating?	Yes
Is Ultrasound used to guide biopsies or FNAs?	Yes

Do you have sufficient paper to print out images for either medical records or to give to patients?	Yes
If you have suitable ultrasound machines, how many units do you have?	1
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

Performance of mammography of women without breast symptoms as part of a population-based mammographic screening program	No
Availability of opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]	No
Availability of mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]?	No
Availability of free mammographic screening if health insurance doesn't cover it	No
CBE offered to women without breast symptoms at screening clinics	No
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	No
BSE is taught and encouraged	No
Palpable disease—early detection	
Evaluation of women with palpable breast lumps using CBE	Yes
Evaluation of women with palpable breast lumps using ultrasound	Yes
Ultrasound-guided FNA of women with breast lumps [either symptomatic or screen-detected]	Yes
Core needle biopsies of women with breast lumps [either symptomatic or screen-detected]	Yes
Diagnostic mammography of women with breast lumps	Yes

Methods of breast cancer diagnosis

Medical history & physical examination	Yes
Clinical Breast Exam	Yes
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	Yes
Sentinel lymph node [SLN] biopsy with blue dye	Yes
Image guided breast sampling	Yes
Preoperative needle localization under mammography and/or Ultrasound guidance	Yes
SLN biopsy using radiotracer	Don't Know
Diagnostic breast ultrasound	
Plain chest & skeletal radiography	Yes
Liver Ultrasound	Yes
Blood chemistry profile	Yes
Complete Blood Count	Yes

Diagnostic mammography	Yes
Specimen radiography	Don't Know
Bone scan	No
BRCA 1/2 testing	No
Mammographic double reading	No

4. PATHOLOGY

- There are no pathology services at this institution
- Biopsies are sent to partner laboratories for pathology, and reports are sent back to this institution
- Pathology reports are usually available between 1-4 weeks from biopsy

5. SURGICAL THERAPY

This section was completed by member of the surgical team.

Procedures performed at this institution

Early stage cancer	
Modified radical mastectomy	Yes
Breast conserving surgery	Yes
Sentinel lymph node [SLN] biopsy with blue dye	No
Sentinel lymph node biopsy using radiotracer	Yes
Breast reconstruction surgery	Yes
Locally advanced cancer	
Modified radical mastectomy	Yes
Breast conserving surgery	Yes
Sentinel lymph node biopsy using radiotracer	Yes
Breast reconstruction surgery	Yes
Metastatic OR recurrent cancer	
Total mastectomy for ipsilateral breast tumor recurrence after breast conserving surgery	Yes

6. RADIATION THERAPY

This section was completed by a health professional who works in the field of radiation oncology.

It is unclear how many radiation oncologists are at the institution.

Radiotherapy sources

Linear accelerator [LINAC]	Yes
If yes, what year was it purchased?	2002
If yes, approximately how many months of the year is it functioning?	12
Is there a machine that delivers HDR brachytherapy at your institution	Yes

Planning

Medical physicist	Yes
Dosimetrist	No
Physician	Yes

Treatments available to women with breast cancer

Stage I	
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	Yes
Stage II	
Post-mastectomy irradiation of chest wall and regional nodes for high-risk cases	Yes
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	Yes
Locally advanced	
Post-mastectomy irradiation of chest wall and regional nodes	Yes
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	Yes
Metastatic or recurrent	
Palliative radiation therapy	Yes

7. SYSTEMIC TREATMENT

This section was completed by a nurse.

- There are three medical oncologists at the institution
- The respondent wasn't aware of the total number of women are treated with chemotherapy each month at this institution

Available systemic therapies

Doxorubicin	Yes
Cyclophosphamide	Yes
Paclitaxel	Yes
Docetaxel	Yes
Methotrexate	Yes
5-fluorouracil	Yes
Trastuzumab	Yes
Carboplatin	Yes
Capecitabine	Yes
Vinorelbine	Yes
Gemcitabine	Yes
Tamoxifen	Yes
Anastrozole [or other Aromatase inhibitor—Letrozole and/or Exemestane]	Yes

Chemotherapy access and cost

Patients have to pay for chemotherapy at the institution if they don't have health insurance	No, never
Chemotherapy drugs are in short supply at the institution	Sometimes
Patients have to buy the drugs from outside sources	Don't know
Patients don't start treatment because of the cost	No, never
Patients don't complete their treatment because of the cost	No, never
Tamoxifen is prescribed to all women as the majority do not have information on ER status	Don't know
Chemotherapy drugs are prepared in a functioning containment hood	Yes, always

8. PALLIATIVE CARE

Pain management options available for breast cancer patients

NSAIDS	Yes
Opioids—morphine (oral or parenteral),	Yes
Co-analgesics e.g. steroids	Yes
Fentanyl patch	No
Non-morphine opioids [e.g. methadone]	Yes
Management of pain-related physical symptoms	Yes
Complementary and alternative medicine (CAM) and non-drug pain management	No
Radiotherapy [single and multi-fraction]	-
Physical and Occupational therapy for functional limitations or pain management	Yes
Pain screening	Yes
Pain care plan	Yes
Opioid pumps	Don't know
Consultation with specialist in pain therapy	Yes
Surgery [cord compression, fracture, obstruction]	Yes
Locoregional anesthesia, spinal analgesia	Yes
Home based care for patients requiring palliation	No

Major impediments to the availability of opioids such as morphine for pain relief

Shortages of opioids result in inadequate availability to patients.	Sometimes
Physicians are reluctant to prescribe opioids	Don't know
Patients are reluctant to take opioids.	Sometimes
Opioid products are not available in needed dosage forms and dosages.	Sometimes
Laws or regulations restrict the amounts of opioids which can be prescribed.	No, never
It is difficult for patients to obtain opioids for use at home.	No, never
Patients often cannot afford opioids	Yes, always

Pain in cancer patients is not treated adequately	Sometimes
Healthcare professionals do not have adequate educational opportunities to learn about the use of opioids in pain management.	Sometimes
For severe pain, strict control of morphine results in the prescribing of weaker, less controlled, analgesics	Yes, always

Psychosocial and Spiritual support for cancer patients

Patient and family education [treatment-related]	Yes
Peer support by trained volunteers	Yes
Spiritual support: community- or religious-based	Yes
Patient and family support groups	Yes
Psychosocial support by health professionals	Yes
Screening and referrals for depression/distress by mental health specialist	yes
Patient and family education [survivorship]	Yes
Peer support by trained breast cancer survivors	No
Emotional, social support by health professionals	Yes
Psychosocial counseling by mental health specialist	Yes

Laboratório de Patologia Cirúrgica E Citologia Ltda, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis [imaging & workup]	Unavailable
Pathology	Complete
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as pathology lab
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are
- Government/public insurance [free for all patients]
- Employer funded health insurance
- Private Insurance [patients or their employers purchase private health insurance]

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Unknown
Cancer registry	Unknown

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	No
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	No
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is no hospital-based cancer registry.

3. PATHOLOGY

This section was completed by an administrator.

- There are four pathologists and 10 pathology technicians at this institution
- The institution has a standard process or protocol for fixing tissue
- There are quality assurance measures in place to ensure standard protocols are being followed
- Pathology review occurs in house, and also makes use in country partnerships at pathology labs that are part of the health service
- On average pathology reports are provided within 1 week post-biopsy
- Government/public health insurance covers
 - The costs of Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade
 - ER testing
- HER2/neu testing is covered via out of pocket payments/private insurance

Pathology tests/reporting available

Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	Yes
Determination and reporting of TNM stage	Yes
Estrogen receptor [ER] status by immunohistochemistry [IHC]*	Yes
Determination of margin status	Yes
Determination of ductal carcinoma in situ [DCIS] content	Yes
Measurement of HER-2/neu overexpression or gene amplification	No
Progesterone receptor [PR] status by IHC	Yes
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	Yes
Pathology double reading	Don't know
Gene profiling tests	Yes
Fine Needle Aspirates [FNA]	No

Methods used to obtain initial tissue diagnoses among breast cancer patients

Fine needle aspiration [cytology]	No
Core needle tissue biopsy [histology]	No
Surgical biopsy	No
Mastectomy	No

Who receives copies of the pathology report?

Patient only—it is their responsibility to share the report with their breast health provider	Yes
My institution prepares the pathology report and it is sent to the referring institution or referring provider outside of my institution	Yes
The breast health provider at my institution	Yes

LAPMA—Laboratório de Anatomia Patológica, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis [imaging & workup]	Unavailable
Pathology	Complete
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as a Pathology laboratory—
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are [in order of frequency]
- Private Insurance [patients or their employers purchase private health insurance]
- Employer funded health insurance
- Government/public insurance [free for all patients]
- Patient/Family pays 100% of the cost [out-of-pocket expenses]
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- Stage distribution at diagnosis is unknown

Number of women attending the facility per week for breast health concerns/cancer care?	Unknown
Number of new cases of breast cancer seen monthly?	Unknown
The percentage of women with suspicious findings who do not return after their initial consultation	Unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Unknown
Cancer registry	None

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is no hospital-based cancer registry.

3. PATHOLOGY

This section was completed by an administrator.

- The institution has a standard process or protocol for fixing tissue
- There are 4 pathologists and 15 pathology technicians on staff
- There are quality assurance measures in place to ensure standard protocols are being followed
- Pathology review occurs in house, and also makes use of international services, and in-country partner private laboratories
- On average pathology reports are provided between within 1 week post- biopsy
- It is unknown what methods are used to obtain initial tissue diagnoses among breast cancer patients
- Government/public health insurance covers
 - The costs of a Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade
 - HER2/neu testing is covered via out of pocket payments/private insurance
 - No information on coverage of ER testing costs

Pathology tests/reporting available

Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	Yes
Determination and reporting of TNM stage	Yes
Estrogen receptor (ER) status by immunohistochemistry (IHC)*	Yes
Determination of margin status	No
Determination of ductal carcinoma in situ (DCIS) content	Yes
Measurement of HER-2/neu overexpression or gene amplification	Yes
Progesterone receptor (PR) status by IHC	Yes
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	Yes
Pathology double reading	Yes
Gene profiling tests	No
Fine Needle Aspirates (FNA)	No

Copies of the pathology report are sent to the following

Patient only—it is their responsibility to share the report with their breast health provider	Yes
The institution prepares the pathology report and it is sent to the referring institution or referring provider	Yes

Laboratório de Anatomia Patológica E Citopatologia Ltda (No. 2), Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis (imaging & workup)	Unavailable
Pathology	Complete
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is a specialized pathology laboratory that receives biopsy specimens from referring hospitals
- It receives a combination of government and private funding

- The main healthcare payment methods for patients are
 - Government/public insurance (free for all patients)
 - Employer funded health insurance
 - Private Insurance (patients or their employers purchase private health insurance)
- The institution has a standard process or protocol for fixing tissue
- It is unclear if there are quality assurance measures in place to ensure standard protocols are being followed
- Pathology review occurs in house, and also makes use of private partner laboratories
- On average pathology reports are provided between 1 and 4 weeks post- biopsy
- The pathology report is sent to the referring institution or referring provider
- Government/public health insurance covers the costs of
 - Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade,
 - ER testing
 - HER2/neu testing

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	2
Cancer registry	2

Medical records are maintained as follows

Paper-based patient medical records	No
Electronic patient medical records	Yes
Are medical records held/maintained by patients?	No
Is it the responsibility of the patient to bring their records to medical appointments?	No
Does your institution have a system for following patients after a diagnosis of metastatic breast cancer?	No
Does your institution maintain contact with patients by telephone, mail or other methods to inform them of results?	No
Does your institution maintain contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment?	No
Does your institution send information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment?	No
Does your institution utilize a unified medical record number for each patient that is used throughout the institution?	Yes
Is there a unified medical record/patient ID number used across different health facilities in your country?	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry, which contributes data to a population-based national and regional cancer registry. The following data are collected:

Personal identification [Name, age, sex, registration number, contact information]	Yes
Demographic [address ethnicity]	Yes
Tumor data [Incidence date, basis of diagnosis Topography [site] Morphology [histology], Behavior, Source of information]	Yes
The tumor and its investigations [Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site(s) of distant metastases; Multiple primaries; Laterality]	Yes
Treatment [Initial treatment]	N/A
Follow-up [Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death]	N/A

3. PATHOLOGY

There are three pathologists at this institution, and two technicians.

Pathology tests/reporting available

Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	Yes
Determination and reporting of TNM stage	Yes
Estrogen receptor [ER] status by immunohistochemistry [IHC]*	Yes
Determination of margin status	Yes
Determination of ductal carcinoma in situ [DCIS] content	Yes
Measurement of HER-2/neu overexpression or gene amplification	Yes
Progesterone receptor [PR] status by IHC	Yes
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	Yes
Pathology double reading	Yes
Gene profiling tests	No
Fine Needle Aspirates [FNA]	No

IMAMA, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis [imaging & workup]	Complete*
Pathology	Complete
Surgery therapy	Unavailable

Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

* See under *Private Facilities, Imaging*

1. INSTITUTION: OVERVIEW

Note: IMAMA also provides imaging services—see under ‘Private facilities, imaging’.

One individual contributed to the report.

- The institution is described as an imaging center-
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are [in order of frequency]
 - Private Insurance [patients or their employers purchase private health insurance]
 - Government/public insurance [free for all patients]
 - Employer funded health insurance
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- Stage distribution at diagnosis is unknown

Number of women attending the facility per week for breast health concerns/cancer care?	Unknown
Number of new cases of breast cancer seen monthly?	Unknown
The percentage of women with suspicious findings who do not return after their initial consultation	Unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	1
Cancer registry	None

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	No
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is no hospital-based cancer registry.

3. PATHOLOGY

This section was completed by a medical oncologist.

- Number of pathology technicians and pathologists at this institution—unknown
- The institution has a standard process or protocol for fixing tissue
- There are quality assurance measures in place to ensure standard protocols are being followed
- Pathology review occurs in house, and also makes use of publically funded (i.e. part of the health service) and private pathology labs.
- On average pathology reports are provided within 1 week post-biopsy
- A variety of tissue samples are used to obtain initial tissue diagnoses, including FNA, core needle tissue biopsy, surgical biopsy and mastectomy samples

- Government/public health insurance covers
 - the costs of Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade
- ER testing
- HER2/neu testing

Pathology tests/reporting available

Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	Yes
Determination and reporting of TNM stage	Yes
Estrogen receptor (ER) status by immunohistochemistry (IHC)*	Yes
Determination of margin status	Yes
Determination of ductal carcinoma in situ (DCIS) content	Yes
Measurement of HER-2/neu overexpression or gene amplification	Yes
Progesterone receptor (PR) status by IHC	Yes
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	Yes
Pathology double reading	No
Gene profiling tests	No
Fine Needle Aspirates (FNA)	Yes
If FNA processing is performed at your institution, are they interpreted by staff trained in cytopathology?	Yes

Methods used to obtain initial tissue diagnoses among breast cancer patients

Fine needle aspiration (cytology)	Yes
Core needle tissue biopsy (histology)	Yes
Surgical biopsy	Yes
Mastectomy	Yes

Copies of the pathology report are sent to the following:

Patient only—it is their responsibility to share the report with their breast health provider	Yes
The institution prepares the pathology report and it is sent to the referring institution or referring provider	Yes
The breast health provider at the institution	N/A

Hospital do Rim de Sergipe, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis (imaging & workup)	Complete
Pathology	Unavailable
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

Two individuals contributed to the report.

- The institution is described as an Imaging center
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are [in order of importance]
 - Government/public insurance [free for all patients]
 - Employer funded health insurance
 - Private Insurance [patients or their employers purchase private health insurance]
- The estimated distribution of cancer stage among the breast cancer patients is unknown at this institution, as is the percentage of women attending with symptomatic cancer

Number of women attending the facility per week for breast health concerns/cancer care?	40
Number of new cases of breast cancer seen monthly?	Unknown
The percentage of women with suspicious findings who do not return after their initial consultation	Unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes

Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Unknown
Cancer registry	1

Medical records are maintained as follows

Paper-based patient medical records	No
Electronic patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	Yes
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry, which contributes data to a population-based national cancer registry. The following data are collected:

Personal identification [Name, age, sex, registration number, contact information]	Yes
Demographic [address ethnicity]	Yes
Tumor data [Incidence date, basis of diagnosis Topography (site) Morphology (histology), Behavior, Source of information]	Yes
The tumor and its investigations [Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site[s] of distant metastases; Multiple primaries; Laterality]	Yes
Treatment [Initial treatment]	No
Follow-up [Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death]	No

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

Completed by an administrator.

Staffing levels

Radiologist	Part-time	2
Radiographer or a radiology technologist	Part-time	2
Sonographer	Part-time	1

- BI-RADS is used to report results from Mammography
- The institution has a picture and communication archiving systems [PACS] for digital images [Carestream]

Reporting modality used

BI-RADS [Breast Imaging reporting and data system] for Mammography	No data provided
BI-RADS [Breast Imaging reporting and data system] for Ultrasound	
BI-RADS [Breast Imaging reporting and data system] for MRI	
Other [specify]:	

Available detection and diagnostic technologies

Mammography machine	Yes
Functional and currently operating	Yes
Are the majority digital mammography machines	Yes
If no, do you have sufficient film to meet your needs for the majority of the time?	N/A
If no, do you have sufficient film to meet your needs for the majority of the time?	N/A
Current service contract to maintain the mammography machines?	Don't know
Number of Mammography machines	Blank
Ultrasound machine[s] suitable for breast imaging [linear with >7 MHz transducer]	No
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	No
The institution offers opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]	No
The institution offers mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]	Yes

Mammographic screening is free to women if their health insurance doesn't cover it	No
CBE is offered to women without breast symptoms at screening clinics	No
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	Yes
The institution encourages/teaches BSE	Don't know

Palpable disease—early detection

Evaluation of women with palpable breast lumps using CBE	No
Evaluation of women with palpable breast lumps using ultrasound	No
Utilization of ultrasound-guided FNA	No
Utilization of core needle biopsies	No
Diagnostic mammography for women with palpable breast lumps	No

Available methods of breast cancer diagnosis

Medical history & physical examination	No
Clinical Breast Exam	No
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	No
Sentinel lymph node [SLN] biopsy with blue dye	No
Image guided breast sampling	No
Preoperative needle localization under mammography and/or Ultrasound guidance	No
SLN biopsy using radiotracer	No
Diagnostic breast ultrasound	No
Plain chest & skeletal radiography	No
Liver Ultrasound	No
Blood chemistry profile	No
Complete Blood Count	No
Diagnostic mammography	No
Specimen radiography	No
Bone scan	No
BRCA 1/2 testing	No
Mammographic double reading	No

Climagem, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis (imaging & workup)	Complete
Pathology	Unavailable
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

1. INSTITUTION: OVERVIEW

One individual contributed to the report.

- The institution is described as an imaging center
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are (in order of frequency)
 - Government/public insurance (free for all patients)
 - Private Insurance (patients or their employers purchase private health insurance)
 - Patient/Family pays 100% of the cost (out-of-pocket expenses)
 - Employer funded health insurance
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer

Estimated distribution of cancer stage among the breast cancer patients

DCIS (Stage 0)	60
Early stage (Stage I or II)	48
Locally advanced (stage III)	10
Metastatic (Stage IV)	2

Number of women attending the facility per week for breast health concerns/cancer care?	75
Number of new cases of breast cancer seen monthly?	Don't know
The percentage of women with suspicious findings who do not return after their initial consultation	Don't know

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	No
Signs and symptoms of breast cancer	No
Information about how to practice breast self-examination	No
The importance of breast cancer early detection	No

Outreach/education encouraging CBE for age groups at high risk	No
Diagnosing breast cancer	No
Treatment of Breast Cancer	No
Importance of screening mammography	No
Information about where to access breast healthcare	No
Information about breast cancer advocate networks	No
Information about where to access breast cancer support groups	No
Information about access to financial resources to pay for diagnosis or treatment, for example	No

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	Don't know
Cancer registry	None

Medical records are maintained as follows

Paper-based patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No
The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	No
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	No
The institution utilizes a unified medical record number for each patient that is used throughout the institution	No
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is a hospital-based cancer registry, which contributes data to a population-based national cancer registry. The following data are collected:

Personal identification (Name, age, sex, registration number, contact information)	Yes
Demographic (address ethnicity)	Yes
Tumor data (Incidence date, basis of diagnosis Topography (site) Morphology (histology), Behavior, Source of information)	Yes
The tumor and its investigations (Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site[s] of distant metastases; Multiple primaries; Laterality)	No

Treatment (Initial treatment)	No
Follow-up (Date of last contact; Status at last contact [alive, dead, emigrated, unknown]; Date of death; Cause of death; Place of death)	No

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

Staffing levels

Radiologist	Part-time	2
Radiographer or a radiology technologist	Part-time	3
Sonographer	Part-time	2

- BI-RADS is used to report results from Ultrasound and Mammography
- The institution has a picture and communication archiving systems (PACS) for digital images

Available detection and diagnostic technologies

Mammography machine	Yes
Functional and currently operating	Yes
Are the majority digital mammography machines	Yes
If no, do you have sufficient film to meet your needs for the majority of the time?	[No entry]
If no, do you have sufficient film to meet your needs for the majority of the time?	[No entry]
Current service contract to maintain the mammography machines?	Yes
Number of Mammography machines	1
Ultrasound machine[s] suitable for breast imaging (linear with >7 MHz transducer)	No
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	Yes
The institution offers opportunistic mammographic screening of women without breast symptoms (i.e. mammography is offered to women when they attend the institution for unrelated reasons)	Yes
The institution offers mammographic screening of women without breast symptoms at a screening clinic (i.e., women can attend for breast screening, but it is not part of a systematic screening program)	Yes
Mammographic screening is free to women if their health insurance doesn't cover it	No
CBE is offered to women without breast symptoms at screening clinics	No
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	No

The institution encourages/teaches BSE	Yes
--	-----

Palpable disease—early detection

Evaluation of women with palpable breast lumps using CBE	No
Evaluation of women with palpable breast lumps using ultrasound	No
Utilization of ultrasound-guided FNA	No
Utilization of core needle biopsies	No
diagnostic mammography for women with palpable breast lumps	Yes

Available methods of breast cancer diagnosis

Medical history & physical examination	Yes
Clinical Breast Exam	No
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	No
Sentinel lymph node (SLN) biopsy with blue dye	No
Image guided breast sampling	No
Preoperative needle localization under mammography and/or Ultrasound guidance	No
SLN biopsy using radiotracer	No
Diagnostic breast ultrasound	Yes
Plain chest & skeletal radiography	Yes
Liver Ultrasound	Yes
Blood chemistry profile	Yes
Complete Blood Count	Yes
Diagnostic mammography	Yes
Specimen radiography	Yes
Bone scan	No
BRCA 1/2 testing	No
Mammographic double reading	No

Clínica Santa Anna, Aracajú

Sections Completed

Overview	Complete
Patient data, records & tracking	Insufficiently familiar
Detection and diagnosis (imaging & workup)	Complete
Pathology	Unavailable; biopsies are not taken
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

They provide ultrasonography and magnetic resonance for the private sector, but for the public sector, only mammography.

1. INSTITUTION: OVERVIEW

Two individuals contributed to the report.

- The institution is described as a Imaging center—A facility with imaging and sometimes biopsy equipment used for the detection and diagnosis of breast cancer.
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are
 - Government/public insurance [free for all patients]
 - Employer funded health insurance
 - Private Insurance [patients or their employers purchase private health insurance]
 - Patient/Family pays 100% of the cost [out-of-pocket expenses]

It is unknown what the Estimated distribution of cancer stage among the breast cancer patients is at this institution, nor the percentage of women attending with symptomatic cancer.

Number of women attending the facility per week for breast health concerns/cancer care?	Unknown
Number of new cases of breast cancer seen monthly?	Unknown
The percentage of women with suspicious findings who do not return after their initial consultation	Unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	No
Signs and symptoms of breast cancer	No
Information about how to practice breast self-examination	No
The importance of breast cancer early detection	No
Outreach/education encouraging CBE for age groups at high risk	No
Diagnosing breast cancer	No
Treatment of Breast Cancer	No
Importance of screening mammography	No
Information about where to access breast healthcare	No
Information about breast cancer advocate networks	No
Information about where to access breast cancer support groups	No
Information about access to financial resources to pay for diagnosis or treatment, for example	No

2. PATIENT DATA, RECORDS & TRACKING

While these services are available at the institution, the respondent felt that they were insufficiently familiar with them to respond to this section.

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

Filled out by an administrator.

Staffing levels

Radiologist	Part-time	3
Radiographer or radiology technologist	Part-time	5
Sonographer	Part-time	2

- BI-RADS is used to report results from Mammography
- The institution has a picture and communication archiving systems [PACS] for digital images

Available detection and diagnostic technologies

Mammography machine	Yes
Functional and currently operating	Yes
Are the majority digital mammography machines	Yes
If no, do you have sufficient film to meet your needs for the majority of the time?	N/A
Current service contract to maintain the mammography machines?	Yes
Number of Mammography machines	2
Ultrasound machine[s] suitable for breast imaging [linear with > 7 MHz transducer]	No
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	No
The institution offers opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]	No
The institution offers mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]	No
Mammographic screening is free to women if their health insurance doesn't cover it	No
CBE is offered to women without breast symptoms at screening clinics	No
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	No
The institution encourages/teaches BSE	Yes

Palpable disease—early detection

Evaluation of women with palpable breast lumps using CBE	No
Evaluation of women with palpable breast lumps using ultrasound	No

Utilization of ultrasound-guided FNA	No
Utilization of core needle biopsies	No
diagnostic mammography for women with palpable breast lumps	No

Available methods of breast cancer diagnosis

Medical history & physical examination	No
Clinical Breast Exam	No
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	No
Sentinel lymph node [SLN] biopsy with blue dye	No
Image guided breast sampling	No
Preoperative needle localization under mammography and/or Ultrasound guidance	No
SLN biopsy using radiotracer	No
Diagnostic breast ultrasound	No
Plain chest & skeletal radiography	Unknown
Liver Ultrasound	No
Blood chemistry profile	Yes
Complete Blood Count	Yes
Diagnostic mammography	Yes
Specimen radiography	No
Bone scan	No
BRCA 1/2 testing	No
Mammographic double reading	No

IMAMA, Aracajú

Sections Completed

Overview	Complete
Patient data, records and tracking	Complete
Detection and diagnosis [imaging & workup]	Complete*
Pathology	Complete
Surgery therapy	Unavailable
Radiation therapy	Unavailable
Systemic treatment	Unavailable
Palliative care	Unavailable

* See under *Private Facilities, Pathology*

1. INSTITUTION: OVERVIEW

Note: IMAMA also provides pathology services—see under ‘Private facilities, pathology’.

One individual contributed to the report.

- The institution is described as an imaging center-
- It receives a mix of private and government funding
- The main healthcare payment methods for patients are

(in order of frequency)

- Private Insurance [patients or their employers purchase private health insurance]
- Government/public insurance [free for all patients]
- Employer funded health insurance
- Less than 50% of women who attend the institution for breast health concerns have symptoms of breast cancer
- Stage distribution at diagnosis is unknown

Number of women attending the facility per week for breast health concerns/cancer care?	Unknown
Number of new cases of breast cancer seen monthly?	Unknown
The percentage of women with suspicious findings who do not return after their initial consultation	Unknown

The institution provides the following information to women

Promotion of awareness of breast cancer risk factors	Yes
Signs and symptoms of breast cancer	Yes
Information about how to practice breast self-examination	Yes
The importance of breast cancer early detection	Yes
Outreach/education encouraging CBE for age groups at high risk	Yes
Diagnosing breast cancer	Yes
Treatment of Breast Cancer	Yes
Importance of screening mammography	Yes
Information about where to access breast healthcare	Yes
Information about breast cancer advocate networks	Yes
Information about where to access breast cancer support groups	Yes
Information about access to financial resources to pay for diagnosis or treatment, for example	Yes

2. PATIENT DATA, RECORDS & TRACKING

Staffing levels

Medical records	1
Cancer registry	None

Medical records are maintained as follows

Paper-based patient medical records	Yes
Electronic patient medical records	Yes
Are medical records held/maintained by patients?	No
It is the responsibility of the patient to bring their records to medical appointments	No
The institution has a system for following patients after a diagnosis of metastatic breast cancer	No
The institution maintains contact with patients by telephone, mail or other methods to inform them of results	No

The institution maintains contact with patients by telephone, mail or other methods to schedule diagnostic examinations or treatment	Yes
The institution sends information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment	Yes
The institution utilizes a unified medical record number for each patient that is used throughout the institution	No
There is a unified medical record/patient ID number used across different health facilities	No

Information collected on cancer incidence and outcome

There is no hospital-based cancer registry

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

Completed by a medical oncologist.

Staffing levels

Radiologist	Part-time	1
Radiographer or a radiology technologist	Part-time	2
Sonographer	Part-time	3

- BI-RADS is used to report results from Ultrasound and Mammography
- The institution has a picture and communication archiving systems (PACS) for digital images (Carestream)

Available detection and diagnostic technologies

Mammography machine	Yes
Functional and currently operating	Yes
Are the majority digital mammography machines	Yes
Current service contract to maintain the mammography machines?	Yes
Number of Mammography machines	1
Ultrasound machine(s) suitable for breast imaging (linear with >7 MHz transducer)	No
MRI with dedicated breast coil	No
CT scanner to stage breast cancer patients	No
PET scanner to stage breast cancer patients	No

Non-palpable disease—early detection

The institution performs mammography of women without breast symptoms as part of a population-based mammographic screening program	Yes
The institution offers opportunistic mammographic screening of women without breast symptoms (i.e. mammography is offered to women when they attend the institution for unrelated reasons)	Yes

The institution offers mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]	Yes
Mammographic screening is free to women if their health insurance doesn't cover it	No
CBE is offered to women without breast symptoms at screening clinics	Yes
Healthcare providers routinely perform CBE on women as part of their general care for early detection purposes	-
The institution encourages/teaches BSE	Yes

Palpable disease—early detection

Evaluation of women with palpable breast lumps using CBE	Yes
Evaluation of women with palpable breast lumps using ultrasound	Yes
Utilization of ultrasound-guided FNA	Yes
Utilization of core needle biopsies	Yes
Diagnostic mammography for women with palpable breast lumps	Yes

Available methods of breast cancer diagnosis

Medical history & physical examination	Yes
Clinical Breast Exam	Yes
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	Yes
Sentinel lymph node (SLN) biopsy with blue dye	Yes
Image guided breast sampling	Yes
Preoperative needle localization under mammography and/or Ultrasound guidance	Yes
SLN biopsy using radiotracer	Yes
Diagnostic breast ultrasound	Yes
Plain chest & skeletal radiography	Yes
Liver Ultrasound	Yes
Blood chemistry profile	No
Complete Blood Count	No
Diagnostic mammography	Yes
Specimen radiography	Yes
Bone scan	No
BRCA 1/2 testing	No
Mammographic double reading	Yes

Appendix II: Breast Cancer Initiative 2.5 (BCI2.5)

Breast Healthcare Assessment Questionnaire

Thank you for agreeing to take part in this survey of breast health services at your institution. It should take approximately 30 minutes to complete.

No personal data are being collected, and responses are anonymous.

The survey asks a variety of questions on breast cancer early detection programs, diagnostic procedures and treatment that may be available at your institution. The data will be used to develop an overview of breast health services that are available to women in your region.

You may answer the survey either as part of a group effort; i.e. where individuals with different roles in your institution answer different sections of the survey, or acting as the sole representative from your institution.

Sections of the survey may ask questions on topics that you are unfamiliar with, if so, we encourage you to skip these sections. Completed questionnaires can be emailed to info@bci25.org

Again, thank you for contributing to this effort

Institution: _____

City: _____

Country: _____

Date: __/__/____ [dd/mm/yyyy]

How many individuals contributed to the completion of this survey? _____

1. INSTITUTION: OVERVIEW

1.1 What best describes your facility? [please select only one option]

	Select one
Primary care facility —provides primary healthcare to patients who come to the facility with any undiagnosed symptom, or health concern. The services provided at the primary care facility do not have distinct specialties.	<input type="checkbox"/>
Provincial or Secondary-level hospital —highly differentiated by function with five to ten clinical specialties, including internal medicine, obstetrics, gynecology, pediatrics and general surgery.	<input type="checkbox"/>
Tertiary-level hospital —highly specialized staff and technical equipment. Clinical services are highly differentiated by function; might have teaching activities.	<input type="checkbox"/>
Cancer care/breast care facility —specialized in cancer or breast cancer diagnosis and treatment.	<input type="checkbox"/>
Imaging center —A facility with imaging and sometimes biopsy equipment used for the detection and diagnosis of breast cancer.	<input type="checkbox"/>
Pathology laboratory —A specialized facility for processing and diagnosing breast biopsy samples	<input type="checkbox"/>
Palliative care facility —provides medical care that focuses on reducing the severity of disease symptoms, rather than a cure or reverse progression of the disease itself. The goal is to prevent and relieve suffering and to improve quality of life for cancer patients.	<input type="checkbox"/>

1.2 What is the main source of funding for your institution?

	Select one
Public—Government funded	<input type="checkbox"/>
Private [for profit]—No government funding	<input type="checkbox"/>

	Select one
Mixed—government and private funding	<input type="checkbox"/>
Not-for-profit	<input type="checkbox"/>
Mission/faith-based	<input type="checkbox"/>
Foreign aid	<input type="checkbox"/>
Other (specify):	<input type="checkbox"/>

1.3 Please select from the following list any partnerships that your institution has to improve the delivery of breast healthcare

	Select all that apply	List partners where appropriate
Cancer support/advocacy groups	<input type="checkbox"/>	
Religious groups	<input type="checkbox"/>	
National Foundations/organizations	<input type="checkbox"/>	
National Universities/educational or research institutions	<input type="checkbox"/>	
Other domestic health institutions	<input type="checkbox"/>	
Industry	<input type="checkbox"/>	
Foreign governments	<input type="checkbox"/>	
Foreign (non-National) Universities/educational or research institutions	<input type="checkbox"/>	
International organizations	<input type="checkbox"/>	
Other (specify):	<input type="checkbox"/>	

1.4 How do the majority of patients pay for breast-health services at your institution? Please rank in order of importance. [If you select more than one answer, please rank your answers in the order of frequency with 1 being the most frequent, 2 being the second most frequent, etc.]

Rank in order of importance	Rank
Government/public insurance (free for all patients)	<input type="checkbox"/>
Employer funded health insurance	<input type="checkbox"/>
Private Insurance (patients or their employer purchase private health insurance)	<input type="checkbox"/>
Patient/Family pays 100% of the cost (out of pocket expense)	<input type="checkbox"/>
Patient/Family pays the majority of the cost (more than 50%)	<input type="checkbox"/>
Patient/Family pays some of the cost (less than 50%)	<input type="checkbox"/>
Institution provides service free of charge	<input type="checkbox"/>

1.5

	No	Yes	Don't know
Do women present with palpable lumps at your facility?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have clinicians at your facility who have been trained to evaluate breast lumps?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are clinicians trained in clinical breast examinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do women receive CBE as part of their routine healthcare- i.e. opportunistic screening?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have organized screening programs based on clinical breast examinations (CBE)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1.6 Which percentage best describes women who attend your institution for breast health concerns who have symptoms of breast cancer?

Symptoms might include palpable lumps with or without palpable nodes, or other visible signs and symptoms of breast cancer.

	Select one	Don't know
Less than 50% of women (<50%)	<input type="checkbox"/>	<input type="checkbox"/>
Between 50% and 75% of women (>50%—<75%)	<input type="checkbox"/>	
Between 75% and 90% of women (>75%– 90%)	<input type="checkbox"/>	
More than 90% of women (>90%)	<input type="checkbox"/>	

1.7 What is the estimated distribution of cancer stage among the breast cancer patients in your facility?

	Percentage	Don't know
DCIS [Stage 0]	____ %	<input type="checkbox"/>
Early stage [Stage I or II]	____ %	
Locally advanced [stage III]	____ %	
Metastatic [Stage IV]	____ %	

1.8

	Freq./Percent	Don't know
How many women attend your facility per week for breast health concerns/cancer care?	____ %	<input type="checkbox"/>
How many new cases of breast cancer does your institution see monthly?	____ %	<input type="checkbox"/>
What percentage of women with suspicious findings do not return after their initial consultation?	____ %	<input type="checkbox"/>

1.9 Does your institution either alone, or in partnership with other organizations, provide any information to women on the following topics? This information can be printed [leaflets, posters], media-based [television, radio] or through local or regional outreach and educational programs.

If your institution utilizes national or regional resources for this purpose, please select 'yes'.

	No	Yes	Don't know
Promotion of awareness of breast cancer risk factors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Signs and symptoms of breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about how to practice breast self-examination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The importance of breast cancer early detection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outreach/education encouraging CBE for age groups at high risk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diagnosing breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment of Breast Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Importance of screening mammography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about where to access breast healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about breast cancer advocate networks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about where to access breast cancer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about access to financial resources to pay for diagnosis or treatment, for example	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. PATIENT DATA, RECORDS AND TRACKING

2.1 Please select the most appropriate response from the following 2 questions:

I don't know enough about either medical records or cancer registration **at my institution** to respond accurately to these questions. [skip to section 3]

These services are available **at my institution** and i am sufficiently familiar with them to respond to these questions with reasonable accuracy. [Please complete all questions in this section]

2.2 Approximately how many staff work in the following departments?

	Number	The institution doesn't have this department	Don't know
Medical records	-----	<input type="checkbox"/>	<input type="checkbox"/>
Cancer registry	-----	<input type="checkbox"/>	<input type="checkbox"/>

Please answer the following regarding the status and maintenance of medical records	No	Yes	Don't know
Are <u>paper-based</u> patient medical records maintained by your institution?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are <u>electronic</u> patient medical records maintained by your institution?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are medical records held/maintained by patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is it the responsibility of the <u>patient</u> to bring their records to medical appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution have a system for following patients after a diagnosis of metastatic breast cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution maintain contact with patients by telephone, mail or other methods to inform them of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution maintain contact with patients by telephone, mail or other methods to <u>schedule</u> diagnostic examinations or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution send information about patients to other providers outside of your institution—for example if patients are referred to another hospital for treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution utilize a unified medical record number for each patient that is used throughout the institution?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is there a unified medical record/patient ID number used across different health facilities in your country?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.3 Please indicate if your institutions records information about cancer incidence and outcome

	No	Yes	Don't know
Is there a hospital-based cancer registry in your institution?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If no, please go to section 3			
If yes , does it contribute data to a population -based regional cancer registry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes , does it contribute data to a population-based national cancer registry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes , which of the following data do you collect?			
Personal identification (Name, age, sex, registration number, contact information)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Demographic (address ethnicity)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tumor data (Incidence date, basis of diagnosis Topography [site] Morphology [histology], Behavior, Source of information)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The tumor and its investigations (Certainty of diagnosis; Method of first detection; Clinical extent of disease before treatment; Surgical-cum-pathological extent of disease before treatment; TNM system; Site[s] of distant metastases; Multiple primaries; Laterality)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment (Initial treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Follow-up (Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. DETECTION AND DIAGNOSIS (IMAGING & WORKUP)

3.1 Please select the most appropriate response from the following 3 questions:

There are no detection or diagnostic services available at my institution [skip to section 4]

These services are available, but i don't know enough about either breast cancer detection and diagnosis **at my institution** to respond accurately to these questions [skip to section 4]

These services are available **at my institution** and i am sufficiently familiar with them to respond to these questions with reasonable accuracy [Please complete all questions in this section]

3.2 What is your role?

	Yes	No
Are you a radiologist	<input type="checkbox"/>	<input type="checkbox"/>
Are you a radiographer or a radiology technologist	<input type="checkbox"/>	<input type="checkbox"/>
Are you a sonographer	<input type="checkbox"/>	<input type="checkbox"/>

3.3 If no, what is your primary role at the institution?

	Select all that apply
Policy	<input type="checkbox"/>
Administrative	<input type="checkbox"/>
Finance	<input type="checkbox"/>
Pathology	<input type="checkbox"/>
Surgery	<input type="checkbox"/>
Radiation Oncology	<input type="checkbox"/>
Medical oncology	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>
Medical records/ Cancer registry	<input type="checkbox"/>
Other [Specify]	<input type="checkbox"/>

3.4 How many staff work in the radiology department, and are they full- or part-time?

	None	Number	Part-time	Full-time	Don't know
Radiologist	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiographer or a radiology technologist	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sonographer	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.5 How is breast imaging reported in your institution for the following modalities

	Yes	No	Don't know
BI-RADS [Breast Imaging reporting and data system] for Mammography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BI-RADS [Breast Imaging reporting and data system] for Ultrasound	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BI-RADS [Breast Imaging reporting and data system] for MRI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No	Don't know
Other [specify]: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.6 Which of the following detection and diagnostic technologies do you have and use?

	No	Yes	Don't Know
Mammography			
Mammography machine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, how many units do you have?	_____		<input type="checkbox"/>
Are they functional and currently operating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are the majority digital mammography machines?			
If no, do you have sufficient film to meet your needs for the majority of the time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution have a service contract to maintain the mammography machines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picture and communication archiving systems (PACS)			
Do you have an electronic system for storing images from ultrasounds or other technologies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, what system is used?	_____		
If no, do you rely on patients to bring images to future medical appointments or store films for future care needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ultrasound			
Ultrasound machine(s) suitable for breast imaging (linear with >7 MHz transducer)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, how many units do you have?	_____		<input type="checkbox"/>
Are they functional and currently operating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is Ultrasound used to guide biopsies or FNAs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have sufficient paper to print out images for either medical records or to give to patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.7 Which of the following detection and diagnostic technologies do you have and use?

	No	Yes	Don't Know
MRI			
MRI with dedicated breast coil	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is it functional and currently operating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution have a service contract to maintain the MRI machine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other			
CT scanner to stage breast cancer patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is it functional and currently operational?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PET scanner to stage breast cancer patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is it functional and currently operational?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.8 Which of the following early detection and diagnostic processes occur at your institution?

	NO	YES	DON'T KNOW
Non-palpable disease—early detection			
Does your institution perform mammography of women without breast symptoms as part of a population-based mammographic screening program?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	NO	YES	DON'T KNOW
Does your institution offer opportunistic mammographic screening of women without breast symptoms [i.e. mammography is offered to women when they attend the institution for unrelated reasons]?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution offer mammographic screening of women without breast symptoms at a screening clinic [i.e., women can attend for breast screening, but it is not part of a systematic screening program]?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is mammographic screening free to women if their health insurance doesn't cover it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is CBE offered to women without breast symptoms at screening clinics?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do healthcare providers routinely perform CBE on women as part of their general care for early detection purposes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your institution encourage or teach BSE?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palpable disease- early detection			
Do you evaluate women who come to your center with palpable breast lumps using CBE ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you evaluate women who come to your center with palpable breast lumps using ultrasound ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do women with breast lumps [either symptomatic or screen-detected] undergo ultrasound-guided FNA ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do women with breast lumps [either symptomatic or screen-detected] undergo core needle biopsies ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do women with palpable lumps receive diagnostic mammography ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.9 Which of the following methods of breast cancer diagnosis are available in your institution?

	NO	YES	DON'T KNOW
Medical history & physical examination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical Breast Exam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ultrasound-guided FNAB of sonographically suspicious axillary nodes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sentinel lymph node [SLN] biopsy with blue dye	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Image guided breast sampling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preoperative needle localization under mammography and/or Ultrasound guidance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SLN biopsy using radiotracer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diagnostic breast ultrasound	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Plain chest & skeletal radiography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Liver Ultrasound	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood chemistry profile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complete Blood Count	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diagnostic mammography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specimen radiography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bone scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CT scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PET scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast MRI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BRCA 1/2 testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mammographic double reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. PATHOLOGY

4.1 Please select the most appropriate response from the following 3 questions

These services are available, but i don't know enough about pathology services **at my institution** to respond accurately to these questions [Please skip to section 5]

This service is available **at my institution** and i am sufficiently familiar with it to respond to these questions with reasonable accuracy [Please complete all questions in this section]

There are no pathology services at my institution [Please respond to the following single table of questions, then skip to section 5]

4.2 If there are no pathology services at your institution please indicate which of the following occurs: [if pathology services are available, please skip to the next table]

	No	Yes	Don't know
All tissue specimens taken at surgery are sent for a pathology report	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, how often does this occur?			
The majority of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>	
Rarely	<input type="checkbox"/>	<input type="checkbox"/>	
Specimens are sent to another institution within the health system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specimens are sent to a private laboratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your institution automatically receives copies of the pathology report	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is the responsibility of the patient to obtain the pathology report.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Who <u>usually</u> pays for the pathology service?			
The institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The patient [health insurance]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The patient [out of pocket]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If your institution does not provide pathology services please skip to section 5, otherwise please complete this section.

4.3 What is your role?

	Yes	No
Are you a pathologist?	<input type="checkbox"/>	<input type="checkbox"/>
Are you a pathology technician?	<input type="checkbox"/>	<input type="checkbox"/>

4.4 If no, what is your main role?

	Select all that apply
Policy	<input type="checkbox"/>
Administrative	<input type="checkbox"/>
Finance	<input type="checkbox"/>
Imaging [Radiology]	<input type="checkbox"/>
Surgery	<input type="checkbox"/>
Radiation Oncology	<input type="checkbox"/>

	Select all that apply
Medical oncology	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>
Medical records/Cancer registry	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>

4.5 How many pathologists are at your institution? _____ Don't Know ☐

4.6 How many pathology technicians are at your institution? _____ Don't Know ☐

4.7 What tests and pathology reporting are performed at your institution?

	No	Yes	Don't know
Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Determination and reporting of TNM stage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Estrogen receptor (ER) status by immunohistochemistry (IHC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Determination of margin status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Determination of ductal carcinoma in situ (DCIS) content	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Measurement of HER-2/neu overexpression or gene amplification	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Progesterone receptor (PR) status by IHC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHC staining of sentinel nodes for cytokeratin to detect micro-metastases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pathology double reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gene profiling tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fine Needle Aspirates (FNA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If FNA processing is performed at your institution, are they interpreted by staff trained in cytopathology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.8 What methods are used to obtain initial tissue diagnoses among breast cancer patients in your facility?

	No	Yes	Don't know
Fine needle aspiration (cytology)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Core needle tissue biopsy (histology)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgical biopsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fixing tissue			
Does your institution have a standard process or protocol for fixing tissue?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, are quality assurance measures in place to ensure standard protocols are being followed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.9 Where are your pathology slides reviewed by a pathologist? (Select all that apply)

	No	Yes	Don't know
At our institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In country—a partner laboratory that is part of the health service (not in institution)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In country partner laboratory (private)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Don't know
Sent Abroad/International Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telepathology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Service not available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other [specify]:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.10 On average, how long does it take to receive a pathology report?

	Select one
Up to one week	<input type="checkbox"/>
Longer than one week but less than one month	<input type="checkbox"/>
Longer than one month but less than 3 months	<input type="checkbox"/>
Longer than 3 months	<input type="checkbox"/>
Don't Know	<input type="checkbox"/>

4.11 Who receives copies of the pathology report?

	Yes	No	Don't know
Patient only—it is their responsibility to share the report with their breast health provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My institution prepares the pathology report and it is sent to the referring institution or referring provider outside of my institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The breast health provider at my institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other [specify]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.12 Who pays for the following services in the majority of cases?

	Government/public health insurance	The hospital provides services free of charge	The patient, via out-of-pocket payments or through private insurance	Don't know
Pathology report containing appropriate diagnostic and prognostic/predictive information to include tumor size, lymph node status, histologic type and tumor grade	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ER status by immunohistochemistry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Measurement of HER-2/neu overexpression or gene amplification	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fine Needle Aspirates [FNA] diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. SURGICAL THERAPY

5.1 Please Select The Most Appropriate Response From The Following 3 Questions

Breast Cancer Surgery Is Not Performed My Institution [Skip To Next Section 6]

These Services Are Available But I Don't Know Enough About Breast Cancer Surgery At My Institution To Respond Accurately To These Questions [Skip To Next Section 6]

This Service Is Available At My Institution And I Am Sufficiently Familiar With It To Respond To These Questions With

Reasonable Accuracy [Please Complete All Questions In This Section]

5.2 What is your role?

	Yes	No
Are you a surgeon?	<input type="checkbox"/>	<input type="checkbox"/>
Are you a member of the surgical team—for example, a nurse or anesthesiologists	<input type="checkbox"/>	<input type="checkbox"/>

5.3 If no, what is your main role at this institution?

	SELECT ALL THAT APPLY
Policy	<input type="checkbox"/>
Administrative	<input type="checkbox"/>
Finance	<input type="checkbox"/>
Imaging [Radiology]	<input type="checkbox"/>
Pathology	<input type="checkbox"/>
Radiation Oncology	<input type="checkbox"/>
Medical oncology	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>
Medical records/Cancer registry	<input type="checkbox"/>
Other [Specify]	<input type="checkbox"/>

5.4 Which of the following procedures are performed at your institution?

	NO	YES	DON'T KNOW
Early stage cancer			
Modified radical mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast conserving surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sentinel lymph node [SLN] biopsy with blue dye	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sentinel lymph node biopsy using radiotracer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast reconstruction surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Locally advanced cancer			
Modified radical mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast conserving surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sentinel lymph node biopsy using radiotracer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast reconstruction surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Metastatic OR recurrent cancer			
Total mastectomy for ipsilateral breast tumor recurrence after breast conserving surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. RADIATION THERAPY

6.1 Please select the most appropriate response from the following 3 questions

Radiotherapy for breast cancer is not available at my institution [Skip to section 7]

These services are available but i don't know enough about radiation therapy at my institution to respond accurately to these questions [Skip to section 7]

These services are available at my institution and i am sufficiently familiar with it to respond to these questions with reasonable accuracy [Please complete all questions in this section]

6.2 What is your role?

	Yes	No
Are you a radiation oncologist?	<input type="checkbox"/>	<input type="checkbox"/>
Are you a medical oncologist?	<input type="checkbox"/>	<input type="checkbox"/>
Do you work in the field of radiation oncology for example as a nurse, dosimetrist or in another role?	<input type="checkbox"/>	<input type="checkbox"/>

6.3 If no, what is your main role at this institution?

	Select all that apply
Policy	<input type="checkbox"/>
Administrative	<input type="checkbox"/>
Finance	<input type="checkbox"/>
Imaging [Radiology]	<input type="checkbox"/>
Pathology	<input type="checkbox"/>
Surgery	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>
Medical records/Cancer registry	<input type="checkbox"/>
Other [Specify]	<input type="checkbox"/>

6.4 How many radiation oncologists are there in your Institution? _____ Don't Know ☐

6.5 Which of the following radiotherapy sources do you have at your institution? [Select all that apply]

	No	Yes	Don't know
Cobalt-60 unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, what year was it purchased?	_____	<input type="checkbox"/>	
If yes, approximately how many months of the year is it functioning/operational?	_____	<input type="checkbox"/>	
Do you have a service contract for the unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Linear accelerator [LINAC]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, what year was it purchased?	_____	<input type="checkbox"/>	
If yes, approximately how many months of the year is it functioning?	_____	<input type="checkbox"/>	
Is there a machine that delivers HDR brachytherapy at your institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, approximately how many months of the year is it functioning	_____	<input type="checkbox"/>	

6.6 If any of the radiotherapy machines are non-functional, please specify why not

Who performs the planning for patients? Select all that apply	No	Yes	Don't know
Medical physicist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Who performs the planning for patients? Select all that apply	No	Yes	Don't know
Dosimetrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.7 Which of the following treatments are available to women with breast cancer at your institution?

	No	Yes	Don't know
Stage I			
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stage II			
Post-mastectomy irradiation of chest wall and regional nodes for high-risk cases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Locally advanced			
Post-mastectomy irradiation of chest wall and regional nodes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast-conserving whole-breast irradiation as part of breast-conserving therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Metastatic or recurrent			
Palliative radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. SYSTEMIC TREATMENT

7.1 Please select the most appropriate response from the following 3 questions

Systemic therapy is not available at my institution [Skip to section 8]

Systemic therapy is available but i don't know enough this service at my institution to respond accurately to these questions [Skip to section 8]

These services are available at my institution and i am sufficiently familiar with it to respond to these questions with reasonable accuracy [Please complete all of the questions in this section]

7.2 What is your role?

	Yes	No
Are you a medical oncologist?	<input type="checkbox"/>	<input type="checkbox"/>
Do you work in the field of medical oncology in another role such as an oncology nurse?	<input type="checkbox"/>	<input type="checkbox"/>

7.3 If no, what is your main role at this institution?

	Select all that apply
Policy	<input type="checkbox"/>
Administrative	<input type="checkbox"/>
Finance	<input type="checkbox"/>
Imaging [Radiology]	<input type="checkbox"/>
Pathology	<input type="checkbox"/>
Radiation Oncology	<input type="checkbox"/>
Surgery	<input type="checkbox"/>
Nurse	<input type="checkbox"/>

	Select all that apply
Pharmacist	<input type="checkbox"/>
Medical records/Cancer registry	<input type="checkbox"/>
Other [Specify]	<input type="checkbox"/>

7.4 Approximately how many women are treated with chemotherapy at your institution each month? _____ Don't Know ☐

7.5 How many medical oncologists are at your institution? [excluding those who specialize exclusively in radiation oncology] _____ Don't Know ☐

7.6 Which of following medicines for breast cancer treatment are available in your institution?

	Available	Not available
Doxorubicin	<input type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide	<input type="checkbox"/>	<input type="checkbox"/>
Paclitaxel	<input type="checkbox"/>	<input type="checkbox"/>
Docetaxel	<input type="checkbox"/>	<input type="checkbox"/>
Methotrexate	<input type="checkbox"/>	<input type="checkbox"/>
5-fluorouracil	<input type="checkbox"/>	<input type="checkbox"/>
Trastuzumab	<input type="checkbox"/>	<input type="checkbox"/>
Carboplatin	<input type="checkbox"/>	<input type="checkbox"/>
Capecitabine	<input type="checkbox"/>	<input type="checkbox"/>
Vinorelbine	<input type="checkbox"/>	<input type="checkbox"/>
Gemcitabine	<input type="checkbox"/>	<input type="checkbox"/>
Tamoxifen	<input type="checkbox"/>	<input type="checkbox"/>
Anastrozole [or other Aromatase inhibitor—Letrozole and/or Exemestane]	<input type="checkbox"/>	<input type="checkbox"/>

7.7 Please indicate, to the best of your knowledge, which of the following occur regularly, sometimes or not at all

	No, Never	Sometimes	Yes, Always	Don't know
Patients have to pay for chemotherapy at the institution if they don't have health insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chemotherapy drugs are in short supply at the institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients have to buy the drugs from outside sources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients don't start treatment because of the cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients don't complete their treatment because of the cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tamoxifen is prescribed to all women as the majority do not have information on ER status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chemotherapy drugs are prepared in a functioning containment hood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. PALLIATIVE CARE

8.1 Please select the most appropriate response from the following 3 questions

Palliative care is not available at my institution [Please skip to the last page of the survey]

Palliative care is available but i don't know enough this service at my institution to respond accurately to these questions [Please skip to the last page of the survey]

These services are available at my institution and i am sufficiently familiar with it to respond to these questions with reasonable accuracy [Please complete all questions in this section]

8.2 What is your role?

	Yes	No
Are you a specialist in palliative care [either a nurse or medical doctor]	<input type="checkbox"/>	<input type="checkbox"/>

8.3 If no, what is your main role at this institution?

	Select all that apply
Policy	<input type="checkbox"/>
Administrative	<input type="checkbox"/>
Finance	<input type="checkbox"/>
Imaging [Radiology]	<input type="checkbox"/>
Pathology	<input type="checkbox"/>
Radiation Oncology	<input type="checkbox"/>
Surgery	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>
Medical records/Cancer registry	<input type="checkbox"/>
Other [Specify]	<input type="checkbox"/>

8.4 Which of the following pain management options are available for breast cancer patients at your institution?

	No	Yes	Don't know
Drug therapy			
NSAIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opioids—morphine [oral or parenteral],	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Co-analgesics e.g. steroids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fentanyl patch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-morphine opioids [e.g. methadone]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Management of pain-related physical symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary and alternative medicine [CAM] and non-drug pain management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiotherapy [single and multi-fraction]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical and Occupational therapy for functional limitations or pain management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain screening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain care plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Don't know
Opioid pumps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consultation with specialist in pain therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgery [cord compression, fracture, obstruction]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Locoregional anesthesia, spinal analgesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home based care for patients requiring palliation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8.5 Approximately how many women receive palliative care at your institution each month? _____ Don't Know ☐

8.6 What are the major impediments to the availability of opioids such as morphine for pain relief at your institution?

	No, Never	Sometimes	Yes, Always	Don't know
Shortages of opioids result in inadequate availability to patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physicians are reluctant to prescribe opioids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients are reluctant to take opioids.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opioid products are not available in needed dosage forms and dosages.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laws or regulations restrict the amounts of opioids which can be prescribed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is difficult for patients to obtain opioids for use at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients often cannot afford opioids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain in cancer patients is not treated adequately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healthcare professionals do not have adequate educational opportunities to learn about the use of opioids in pain management.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For severe pain, strict control of morphine results in the prescribing of weaker, less controlled, analgesics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8.7 Does your institution provide psychosocial and spiritual support for cancer patients during and after treatment?

	No	Yes	Don't know
Patient and family education [treatment-related]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peer support by trained volunteers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual support: community- or religious-based	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient and family support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial support by health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Screening and referrals for depression/distress by mental health specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient and family education [survivorship]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peer support by trained breast cancer survivors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional, social support by health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial counseling by mental health specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

THANK YOU

Thank you for completing this questionnaire.

If you have any additional comments, please write them below.

Version V, June 16, 2017

