Assessment of Barriers Contributing to Presentation of Breast Cancer Patients in Jamaica

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SURG 560

MASTER OF GLOBAL SURGICAL CARE
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This project fulfills the Master of Global Surgical Care (MGSC) requirements for SURG 560 at the UBC Branch for International Surgical Care (BISC).
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SURG 560 Final Report

This report is a summary of the project “Assessment of Barriers Contributing to Presentation of Breast Cancer Patients in Jamaica” conducted Feb 2020 – Mar 2020. Study overview, initiation, and conduct are described, along with observed cultural context and its interplay with the project. Immediate impact of the study and opinions on any future research engagements are also summarized.

Background

This project sought to reveal factors that delay breast cancer patient presentation in Jamaica. This patient population is known to present at advanced stages, but little is known about what causes this (1–3). The study used studies in similar populations as a basis for protocol development appropriate for the target population.

The study was developed in partnership with Dr. Dingle Spence (local PI), Dr. Steven Smith, and Dr. Brittany Bromfield. Dr. Spence is a Jamaican oncologist whose work focusses on palliative care. She is staff at the Hope Institute cancer centre as well as Kingston Public Hospital. Drs. Smith and Bromfield are general practitioners working as research assistants for Dr. Spence.

Project proposals and ethics applications were submitted in January 2020. On-site study activities were conducted between Feb 2020 and March 2020.

Study Overview

This study was a prospective, cross-sectional survey of Jamaican breast cancer patients and oncologists to characterize breast cancer disease perspectives and potential barriers delaying presentation.

Breast cancer patients answered sets of questions regarding disease understanding, attitude towards the public health system, attitudes towards mammograms, and potential deterrents to accessing care. Patient demographics and disease histology are included to further contextualize the dataset.

Active oncologists treating breast patients were asked questions to frame their perspective on this patient population, their opinions on patient attitudes towards care and assumptions of patient barriers at play. They were also given questions to gauge patient attitudes/deterrents on mammograms.

Data collection commenced on 2 Mar 2020 and ended on 19 Mar 2020.

Protocol details and questionnaires are found in Appendix A

Medical Environment in Jamaica

Jamaican Medical System

Jamaica has a two-tiered medical system consisting of public and private facilities. The private system includes hospitals and independent imaging facilities for patients willing to pay out of pocket for quicker access to healthcare. The public system is funded by the Jamaican government and is free to its citizens.
**Kingston Public Hospital**

Kingston Public Hospital (KPH) is the primary public hospital of Jamaica located in the nation’s capital. It offers comprehensive cancer care services including chemotherapy and radiation therapy. Patients from neighbouring regions are often referred to KPH for cancer treatment and follow up.

KPH operates entirely through paper documentation and does not have an electronic infrastructure to support hospital workflow. Patients arriving for an appointment report to health records and present an appointment card. This triggers delivery of their medical chart to the respective clinic. Patients will then proceed to wait until called. The nurses running each clinic confirms appointments and reviews charts to ensure relevant reports are available for physician review.

This workflow appears consistent for outpatient appointments. We observed this in both outpatient surgical and radiation therapy clinics, and even chemotherapy units. The lack of an electronic medical system significantly hampers hospital speed and efficiency. Clinics are heavily reliant on timely delivery of charts to function and are crippled otherwise.

The study was presented at a monthly tumour board meeting. The KPH staff showed engagement and supported the project enthusiastically, providing feedback on methods to best recruit.

**Spanish Town Hospital**

Spanish Town Hospital (STH) is approximately 20Km west of Kingston, located in St. Catherine’s parish. The population in this region consists of those in lower socioeconomic classes relative to the rest of the country – an important group for this study. The study was presented to physicians and staff at STH rounds and was well received. However, we discovered that breast cancer patients only receive surgical treatment at STH; patients are then referred to KPH for further management and follow up. Since patient recruitment at KPH would include patients from STH, and given other logistical challenges at STH, it was removed as a site for patient recruitment.

Despite an inability to capture our patient subjects at SPH, we disseminated physician questionnaires for their perspective. Unfortunately, we were unsuccessful in recruiting any physicians at this site even after multiple follow up requests to collect data.

**Hope Institute**

The Hope Institute is a cancer centre that aims to provide comprehensive care with a focus on palliative services. The clinic operates in conjunction with KPH as well as regional and international groups. Hope Institute is an active member of the Caribbean Palliative Care Association, advocating for the development of palliative care in the region. It is also a member of the Jamaica Cancer & Research Institute (JACCRI), along side the University of the West Indies and Harvard Massachusetts General Hospital. JACCRI aims to improve access to quality cancer care and welcomes engagement with all sectors towards that goal.
Study Conduct

Ethics and Regulatory

Ethics applications were filed with the University of British Columbia Research Ethics Board (UBCREB), the Jamaican Ministry of Health and Wellness (JMHW), as well as the South East Health Authority (SERHA). Applications were filed in January 2020. UBCREB approval was obtained same month, SERHA approval was granted at the end of February 2020. JMHW did not provide a final response after correspondence and application revisions.

The JMHW requested several rounds of revisions to the application, with a final proposal submitted 17 Mar 2020. The team did not receive a final response, but we were advised by hospital staff that SERHA approval was sufficient to initiate the study. We consistently followed up with the JMHW on the issue throughout conduct, and well after the study.

Study regulatory documents were created in accordance with ICH-GCP guidelines (4). Documents containing patient personal information (eg. Consent, screening/enrolment log) are stored at the Hope Institute; all other files were brought back to Canada for analysis and manuscript preparation.

Patient Data collection

Patients were recruited from surgical and radiation therapy clinic visits, as well as the chemotherapy unit. Our team reviewed charts arriving to these respective clinics and screened for eligible patients. Patients meeting study entry criteria were then approached by a member of the team and introduced to the study. Informed consent was obtained for patients that agreed to participate. Patients that decline or were then determined ineligible at time of interview were marked on the screening log.

After informed consent, the study team member would go through all questions with the participant and mark answers.

We experienced a high level of interest in the study, eager to contribute to efforts that could lead to improvements to the healthcare system. Many patients even felt flattered at the offer to participate.

Physician Data Collection

Physicians at KPH were eager to participate and we did not encounter issues recruiting them. All physician participants completed their questionnaires independently without assistance from the study team.

Results

74 patients and 13 physicians were enrolled and completed study procedures. Majority of patients reside in the Kingston, St. Catherine, and St. Andrew parishes – all regions neighbouring KPH (Figure 1). Income and education data were collected (Figure 2 and Figure 3). The two lowest income brackets (<10,000 JMD and 10,000 < 50,000 JMD monthly) contained the bulk of participants. All participants identified as Christian and deemed spirituality to be significantly important in life (Figure 4).

Participants showed a high level of trust in western medicine. Across all 12 questions that posed a potential barrier, no factor stood out as a common deterrent (Figure 6). All 12 questions received a majority response.
disagreeing with the stated barrier. Finances, fear of unwanted results, and fear of medical tests scored the highest in terms of impact that may deter patients, but these sentiments were not shared by even half the entire group.

Similar results were found with respect to mammograms (Figure 7). Pain from the procedure, distance between home and a mammogram location, nor misconceptions were considered factors preventing mammogram uptake. Only cost of a mammogram received a majority agreement that it impacted ability to access the service.

Responses received from physicians were mixed and suggest some incongruency with patient perspectives (Figure 8). The responses suggest physicians agree negative results, testing, wait times, and finances were the primary deterrents, contrasting the patient responses. However, both groups were in alignment with respect to confidence and trust in the medical system and physicians. Physician responses to mammogram questions were consistent with patient responses (Figure 9).

**Study Limitations**

As with any study, this one was also subject to limitations. The patient sample is biased towards capturing patients that already seek western healthcare practises. Those that believe in other spiritual healing practises may not eventually seek western care, leaving this group completely unaccounted in the results. The sample is also heavily skewed towards Jamaicans living near, or in neighbouring regions of Kingston. Jamaicans living with breast cancer living in distant parishes that are unable to travel to KPH are undoubtedly excluded from this sample as well.

Questionnaire construction is another potential limitation. The results did not identify any of the proposed barrier as a significant deterrent. An open-ended field was included in the questionnaire allowing patients to provide an example of a barrier not already listed. However, only 19 participants provided a response and the majority already fell into the listed categories.

Patient privacy is a pillar of healthcare and is no different in clinical research. Where possible, participants were consented and interviewed in any available spots that afforded a level of privacy. This was managed well in the outpatient clinics but was not achievable in the chemotherapy unit. The layout of this unit is one large room with chemotherapy chairs placed along the walls side by side. Patients were discouraged from leaving the room by staff after checking in, nor were any private spaces available in the vicinity. Given the sensitive nature of these questions, it is possible that the lack of privacy could have influenced the responses given by this group.

**COVID-19**

Jamaica confirmed its first COVID-19 case on 10 Mar 2020, and immediately the Jamaican government mobilized to address the virus. Consequently, KPH postponed or canceled non-essential activities including outpatient clinics. At this point we ceased data collection and shifted towards data analysis with the last patient recruited on 19 Mar 2020.

**Cultural and Environmental Considerations**

**Reaction to Findings**

The study team found the results surprising, expecting answers consistent with previous studies. The physician data also supports a disconnect between patient experiences and physician perspectives.
Patients place a significant amount of trust in their physicians, agreeing to undergo procedures without question. Health literacy is low, and patients are at diminished capacity to self-advocate. They may have bloodwork collected or have a diagnostic scan without understanding what purpose the procedure serves and why it is being done. They also face long wait times and little support for navigating the healthcare system. Nonetheless, patients still stressed importance of care, and demonstrated adherence to prescribed care plans.

The predominance and significance of Christianity amongst participants may explain some of the results. Spirituality could have a positive influence towards health seeking behaviour. As an example, some participants viewed the western healthcare system as the agent by which God was acting. Engagement in the system would therefore be in line with their faith. Prayer was often mentioned as a source of hope and comfort. Hope that their disease would be cured with diligent prayer, comfort in their relationship and trust in God.

Brain Drain

Jamaica is no different from other LMICs regarding brain drain. In conversation with my study colleagues, it is often the goal for medical students in Jamaica to seek American residency placements and remaining there to practise. Some do decide to return to Jamaica, as evidenced by the numerous attending physicians at KPH having done so.

The phenomenon is also seen within the Jamaica two-tiered system. All KPH attendings run their own practice, dividing their time between private and public domains. This is done understandably, as private practise is the primary source of income for physicians in Jamaica. However, this does cause a decrease in services for the Jamaican public.

Immediate Impact

The results of the study were disseminated to the KPH oncologists, and the consensus was that the system is failing the patients. Despite study limitations, it is reasonable that delayed presentation may not be a consequence of patient-centered barriers, but perhaps by the healthcare system itself. The findings spurred the creation of a working group at KPH to review the current state of the oncology service to patients.

Diagnosis and management of breast cancer requires a plethora of appointments with various medical specialties. A slow, under-resourced system extends the total amount of time a patient spends from initial presentation to diagnosis, and eventually treatment. Investigation into the time spent by patients between each node of care could yield service gaps that are directly impacting patient outcomes. The study team agreed that future studies would include: 1) a retrospective chart review of time between diagnosis to treatment and overall treatment duration and 2) a prospective study interviewing newly diagnosed breast cancer patients about their time from symptom presentation to diagnosis.

Future Direction

There is an appetite for clinical research activity in the oncology community in Jamaica. From experience, retrospective, or minimal risk studies are best suited in Jamaica’s public system. These types of studies require relatively low demands in financial resources and can be conducted with small study teams. The various cancer types alone provide ample opportunity for gathering epidemiological data. Further, the low complexity of these studies makes them
ideal projects for Jamaican medical students or junior physicians seeking specialization. This approach benefits the medical system and adds value to medical trainees.

In high income countries, industry funded clinical trials provide access to therapies for patients that have exhausted all standard care options, and benefits institutions as a source of revenue. As the research is driven by industry to generate profit, this type of research is heavily regulated and resource intensive. The Jamaican public system is not currently equipped to handle many of these industry studies, but it is not totally precluded from engaging this industry.

The Hope Institute has leveraged its partnerships to attract more research activity. With the emergence of the legal marijuana industry, Hope Institute has been considered as a study site. It has engaged in talks with sponsors to research marijuana in the palliative setting, with support from Harvard through JACCRI. With ongoing support from international institutions, research capacity can be built within the Jamaican public healthcare system, ultimately towards improving patient outcomes.

**Personal Comments**

This experience was an absolute privilege. The Jamaican community proved incredibly welcoming and were incredibly encouraging of the study team’s work. This sentiment was expressed by the patients, the nurses, physicians, and even the taxi drivers I had come to rely upon. I am incredibly thankful for the healthcare staff that took time during their workday to guide and support the project.

Jamaica is known as a tourist destination thanks to its climate. The northern and western parishes contain the resorts that house travellers, as well as the residences of Jamaica’s wealthiest. In Kingston and its neighbouring parishes, the wealth divide is much more apparent. The neighbourhood across the street from KPH is a collection of metal sheets used as doors and walls of a crumbling building. However, within a ten-minute drive you will find large, fenced-off homes with multiple vehicles parked in front. Whereas the wealthier Jamaicans are afforded the best care through the private system, the rest must endure a severely resource-limited public system.

Jamaica’s status as an LMIC has ties to its history as a British colony. Slaves were brought into Jamaica to produce cotton, tobacco, and sugarcane. It was not until 1962 that Jamaica gained full independence. I was afforded the time to visit cultural heritage sites to learn more about the nation’s history. I observed the remnants of colonialism still permeate Jamaican society. The school system is modeled after the British, with students dressed in traditional uniforms. The healthcare system is no different. Nurses still use the dress, apron, and cap seen in traditional uniforms, and head nurses are referred to as “sisters”.

Overall, I found this experience to be invaluable. Working in a low-resource setting allows a full appreciation of the principles of patient-centered care. Historical and cultural context are a necessity to understand a patient’s perspective and goals of care. My interactions with these patients taught me how these contexts influence the relationship between patient and care provider – knowledge which I now apply with patients I work with in Canada.
Citations


**Figures**

**Figure 1:** Patient reported Parish of residency.

**Figure 2:** Patient reported monthly income in Jamaican Dollars. 10,000 JMD $\approx$ 90 CAD, 50,000 JMD $\approx$ 450 CAD, 100,000 JMD $\approx$ 900 CAD
Figure 3: Participant reported highest level of education. College/University classes and any type of formal training (e.g., Job specific certifications) qualified as post-secondary education.

Figure 4: Participant reported importance of spirituality in life, with "extremely important" being the highest level. No participants reported a level lower than "somewhat important" and those categories are omitted from this figure.
Figure 5: Responses to questions probing understanding of breast cancer

Breast Cancer Questions Part 1

- Could bewitchment/witchcraft/evil spirits/obeah increase any woman’s chances of getting breast cancer?
  - Yes: 8
  - No: 45
  - Don’t know: 21

- Before seeing a doctor, did you try self-medication, for example get some ointment to apply from the local supermarket?
  - Yes: 8
  - No: 62
  - Don’t know: 13

- When you noticed a change in your breast or breasts, did you tell someone close to you?
  - Yes: 58
  - No: 16
  - Don’t know: 5

- Before seeing a doctor, did you visit a herbalist or obeah man/madda?
  - Yes: 73
  - No: 19
  - Don’t know: 8

Figure 5: Responses to questions probing understanding of breast cancer
Figure 6: Participant responses to questions regarding barriers to accessing medical care
**Figure 7: Patient attitudes towards mammograms**

- **I would find it difficult to go for a mammogram because it is painful**
  - Strongly Agree: 4
  - Agree: 21
  - Neutral: 3
  - Disagree: 39
  - Strongly Disagree: 9
  - Did not answer: 2

- **I would find it difficult to go for a mammogram because of the cost**
  - Strongly Agree: 3
  - Agree: 38
  - Neutral: 27
  - Disagree: 2
  - Did not answer: 2

- **I would find it difficult to go for a mammogram because it is too far away**
  - Strongly Agree: 1
  - Agree: 15
  - Neutral: 47
  - Disagree: 9
  - Did not answer: 2

- **I would find it difficult to go for a mammogram because it is embarrassing**
  - Strongly Agree: 4
  - Agree: 54
  - Neutral: 34
  - Disagree: 2
  - Did not answer: 2

- **I don’t see the need for a mammogram**
  - Strongly Agree: 2
  - Agree: 7
  - Neutral: 3
  - Disagree: 50
  - Did not answer: 10
Figure 8: Physician perspectives of barriers to accessing care

<table>
<thead>
<tr>
<th>Perception</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Did Not Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients find it difficult to go for medical help because they are worried about negative results.</td>
<td>2</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because they are worried about what tests they might have to do.</td>
<td>1</td>
<td>7</td>
<td>1</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because they are too busy or have other things to worry about.</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because it takes too long to be seen at the clinic/health centre.</td>
<td>3</td>
<td>9</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because they have no money for transport or the clinic/health centre charges.</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because they would not feel confident about discussing symptoms or would have difficulty talking about how they feel.</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because of distrust in the medical system.</td>
<td>8</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients find it difficult to go for medical help because they feel embarrassed.</td>
<td>3</td>
<td>2</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I discuss the cost of treatment with my patients</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>You consider the cost of treatment options when offering them to your patients</td>
<td>2</td>
<td>7</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>It is uncomfortable or embarrassing to discuss medical costs with patients</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economic status of patients affects patient decisions regarding treatment choice</td>
<td>2</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Economic status of patients affects patient treatment compliance</td>
<td>4</td>
<td>6</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
**Figure 9: Physician perspectives on patient attitudes towards mammograms**

<table>
<thead>
<tr>
<th>Reason for Difficulty</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Did Not Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Painful</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too far away</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Embarrassing</td>
<td>3</td>
<td>8</td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>No need</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Appendix A – SERHA Approved Application

1. **Title:** Assessment of Barriers Contributing to Presentation of Breast Cancer Patients in Jamaica. A cross-sectional survey study of patient delay in breast cancer diagnosis and its associated factors from patient and oncologist perspectives.

2. **Protocol version date:** 25-Feb-2020

3. **Investigators**
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4. **Sites of Research**

We will recruit participants from the Kingston Public Hospital and Spanish Town Hospital. Participants will complete questionnaires at their respective hospitals’ outpatient surgical clinics.

5. **Number of Subjects:** 93 patients and 20 physicians will be recruited to the study.

6. **Study duration:** 3 months

7. **Project Summary:**

Early detection of breast cancer is crucial to improving survival and quality of life outcomes. Screening through breast evaluation and mammograms can identify early stage breast cancers and other breast abnormalities. This facilitates localized, less intensive treatment relative to regimens for late stage diseases involving regional or distant metastases. Effective screening programs require adequate resources to reach the public at a primary level for referral to secondary and tertiary facilities for further screening and management. However, despite the availability of resources; patient-centric obstacles can prevent access to care. Jamaican breast cancer patients typically present at advanced stages with palpable tumours and nodal involvement despite a modest ability to detect and treat early stages. Patient-centric obstacles are common in low and middle-income countries (LMICs) and current literature examining these obstacles in Jamaica are similar. Lack of education, cultural considerations, distrust in the western model of medicine, and financial constraints result in delayed access to care. To date, there is no study that specifically studies patient and physician reported perceptions that contribute to delayed presentation.

This study is a cross-sectional, survey-based study of biopsy proven breast cancer patients, and active oncologists at surgical outpatient clinics at the Kingston Public Hospital and Spanish Town Hospital. The survey will probe patient perspectives of their disease, and reveal factors contributing to delayed presentation. The survey will also elicit oncologist perspectives on factors delaying patient presentation.

Prior to commencing this study, ethical approval will be ensured through the Jamaican Ministry of Health and Wellness. Patients’ confidentiality will be maintained through the study period and beyond. The de-identified datasheet will be stored in a locked cupboard in the principal investigator’s office and destroyed by shredding after 5 years. The risk to the patients in this study will be minimal. This study is being submitted in partial fulfilment of the requirements for the Masters in Global Surgical Care at the University of British Columbia, Vancouver, Canada.
1. Project Proposal

1.1. Rationale for proposed study
Detection of breast cancer at early stages results in improved disease outcomes. Mammography and adjunctive clinical breast examination are standard methods to screen for breast cancer.

The cancer control framework in Jamaica is still developing. The country lacks a coordinated breast cancer screening program, but has some means to provide this service to the population through primary care physicians and some mammogram units (1). Existing studies report that the majority of breast cancer patients present at stage T2+, often as invasive carcinoma with regional node involvement.

Presentation is defined as the time from patient symptom recognition to first medical appointment. A 3 month or more gap between patient recognition and appointment is considered delayed presentation. There is a negative correlation of disease outcome and time to presentation (2).

Delayed presentation is not unusual in limited resources settings. Such a phenomenon is seen across the region of Sub-Saharan Africa, and many studies have investigated patient reported factors contributing to delay (3,4). Lack of education, prevalence of myths, mistrust in western medicine, and fear of treatment are commonly reported factors delaying presentation.

Similar reasons are found in the Jamaican context, but these studies have been general in scope, or focus on particular factors. There is mistrust of health professionals resulting in a perspective that physician consultations are futile. Spiritual beliefs regarding cancer drive patients to seek alternative treatment in the form of bush doctors or spiritual healers (5). Symbolic reasons (i.e. breasts as a representation of women’s sexuality) deter access to care (6). Fear of procedures involved deter patients as well. A 2009 study investigated the sociocultural deterrents to mammographic screening for those eligible, and showed that of women having their first mammogram, the main reasons deterring them were that they “did not need it”, “no one sent me” and “fear of the procedure” (7). Hard costs can also contribute to delayed presentation. While mammograms are available, the procedures are not free, as patients must pay out-of-pocket. Reports on cost of mammograms affecting screening uptake Jamaica vary and warrants further investigation (8,9).

To date, there has been no Jamaican study focusing solely on delayed presentation of breast cancer through patient and oncologist reports.

1.2. Significance and innovation of this study
This study will provide a landscape of the barriers resulting in delayed breast cancer presentation in Jamaica. Results of this study can be used to guide public health policy and allocation of resources to reduce time to patient symptom recognition and access to medical care. Successful reduction in delays can translate into improved patient outcomes.
2. Objectives

2.1. Primary Objectives
   1. To identify patient-centric factors that prevent earlier presentation of breast cancer
   2. To understand patient knowledge and beliefs about breast cancer
   3. To identify oncologist perspectives of delayed presentation of breast cancer

2.2. Secondary Objectives
   2.2.1.1. To determine the age distribution of these patients
   2.2.1.2. To determine the clinicopathological features of the patients surveyed

3. Patient Selection
We anticipate enrolling 93 patients, and 21 oncologists over a two-month period to the study. Descriptive statistics will be used to report patient responses to identify trends.

3.1. Inclusion criteria – Patient Group
   • Participants equal to or greater than 18 years of age
   • Have biopsy proven breast cancer

3.2. Exclusion Criteria – Patient Group
   • Inability to understand or unable to provide written informed consent
   • Inability or unwillingness to participate in the surveys

3.3. Inclusion criteria – Oncologist Group
   • Active oncology staff that treat breast cancer at the Kingston Hospital and Spanish Town Hospital

3.4. Exclusion Criteria – Oncologist Group
   • Oncologists that do not treat breast cancer
   • Unwillingness to participate in the surveys

4. Study Design
This is a cross-sectional survey study to elucidate the deterrents to presentation of patients with biopsy proven breast cancer from a patient and physician perspective. Two surveys will be administered, one for patients and one for oncologists. The patient questionnaires will capture patient demographics, socioeconomic information, patient attitudes and knowledge towards disease and western medicine, and other health-seeking behaviours. The oncologist questionnaire will ask their opinions on patient barriers.

Patient disease characteristics from medical reports will also be captured where available.

Potential participants from the patient group will be identified at time of appointment at one of the two listed healthcare centres. A member of the study team will introduce the study and provide a consent form for consideration.

Oncologists from the Kingston Public Hospital and Spanish Town Hospital will be sent a paper or electronic questionnaire depending on their preference.
5. Patient Registration
   5.1. Participant Recruitment and Consent
Recruitment of patients will be done during days which each respective hospital has scheduled surgical outpatient cancer clinics. Patients will be identified for recruitment at these clinics by a member of the clinic staff. Potential participants in the patient group will be introduced to the study by the clinic staff and their consent to participate in the study will be requested. Once consented, a member of the study team will then explain the study to potential participants. Patients that provide written consent will be registered through assignment of a study number and proceed to fill out the questionnaires.

Recruitment of physicians will be done by identifying the appropriate eligible physicians based on staff lists at each hospital. The study will be presented to both hospitals during staff meetings and department heads will assist with identifying physicians eligible to participate. Potential participants in the oncologist group will be contacted through email to seek consent to participate. Information about the study will be sent by a study staff member. Physicians that provide consent will then proceed to fill out questionnaires.

6. Statistical Analysis
   6.1. Data Collection and Analysis
After ethical approval, potential participants will be identified for consent. A study number will be assigned to each patient, no identifying information will be recorded from the docket. Study staff will interview patients in clinic and fill out the survey simultaneously. Completed surveys will be stored in patient study files.

Patient medical records/dockets will be available at time of appointment in clinic. Disease data collected will include: Sex, age, staging (TNM), and pathological characteristics (cancer subtype, ER/PR status and other biomarkers).

All de-identified data will be captured using a data collection sheet (appendix 1) and transferred to a Microsoft Excel spreadsheet. The data will only be accessed by all the collaborators listed above.

Data from participants will be collected over February 2020 and March 2020 inclusive. Data analysis will take place in April 2020 onwards.

Descriptive and chi-squared tests will be performed to determine statistical significance between the studied variables. Logistic regression will be used to find associations between the studied variables and delayed presentation. A P-value of <0.05 will be considered significant for all tests. Statistical analyses will be conducted using SPSS software version 23 (IBM Corporation, Armonk, NY, USA).

   6.2. Sample Size
   6.2.1. Patient Sample Size
National breast cancer prevalence in Jamaica is not available. Additionally, patient caseload data is not collected at the Kingston Public Hospital and Spanish Town Hospital. A retrospective analysis of breast cancer cases between 2006 and 2007 at the University Hospital of the West Indies found 121 malignant cases (10).
Based on this aforementioned study, our calculated minimum sample size for this study is 93 with a 5% margin of error, 95% confidence interval, and 50% response distribution. The following equation is used to calculate the sample size:

$$n = \frac{N \times X}{X + N - 1}$$

$$X = \frac{Z_{\alpha/2}^2 \times p \times (1 - p)}{MOE^2}$$

Where N is population, $Z_{\alpha/2}$ is the critical value of the Normal distribution at $\alpha/2$ (1.96 for a confidence level of 95%), $p$ is the sample proportion, and MOE is the margin of error.

After assessment of the study population from clinical records, the sample size will be determined proportionately for each facility.

### 6.2.2. Physician Sample Size

Despite the lack of public records of active oncology staff at the Kingston Public Hospital and Spanish Town Hospital, the oncologist study population of 21 was estimated from consultants who attended monthly multidisciplinary team meetings/tumour board. As such, the minimum sample size was calculated to be 20 with a 95% confidence interval, 5% margin of error and 50% response distribution. The same formula used for patient sample size is used to determine physician sample size.

### 7. Risks and discomforts

This is a minimal risk study to participants. There may be minor discomforts associated with certain questions. Participants do not need to answer any question they are not comfortable answering.

#### 7.1. Benefit to Participants and the Community

While there is no immediate benefit to study participants, the data obtained from the study can prove useful in directing interventions in the community to improve outcomes for future breast cancer patients.

#### 7.2. Participant Confidentiality

Personal identifying information of patients will not be disclosed or published in this study. All participants will be assigned a study number. A log, matching patient identifiers to study number, will be kept securely and only accessible by study team members.

Oncologist personal information will not be collected as part of the study. Participating oncologists will be assigned a study number. A log, matching oncologist identifiers to study number, will be kept securely and only accessible by study team members.

### 8. Limitations

We anticipate certain limitations that will impact the integrity of the study. There is possibility that patients are reluctant to participate in the survey. Patients may also decline to fully answer all questions in the questionnaire resulting in gaps in data. Patient health literacy may also impact the ability of patients to answer all questions. Proportion of enrollments between the two sites may also influence the generalizability of the data collected.
Patient medical information is accessed solely in paper format. Any missing pages or delayed reports in patient chart/dockets will impact data gathered as part of the sampling.

Due to a lack of epidemiological data, our sample size calculation is a limiting factor and generalizability of results should be considered cautiously.

The lack of public records of active oncology staff at the study sites will also be a limitation in the generalizability of data from this group.

9. Reporting
Results of the study will be submitted as a report for the Master’s students degree requirements as well as a journal article for publication.

10. Declaration of Conformity with Guidelines
This statement is to confirm that all principles enunciated in Ministry of Health’s Guidelines for the Conduct of Research on Human Subjects have been complied with.
11. References


Registration Worksheet


Registration Worksheet

Patient Study Number #: ______________________________

Registration Date: ___-____-____

dd-Mmm-yyyy

Gender:  ☐ Female  ☐ Male

Date of first diagnosis: ___-____-____

dd-Mmm-yyyy

TNM Stage: _____________ Grade: ________________

Breast cancer histology:

☐ Invasive ductal carcinoma  ☐ Invasive lobular carcinoma  ☐ Medullary carcinoma

☐ Mucinous (colloid) carcinoma  ☐ Tubular carcinoma  ☐ Papillary carcinoma

☐ Metaplastic breast cancer  ☐ Phylloides tumours  ☐ Mammary Paget disease

☐ Inflammatory breast cancer  ☐ Other: _____________

Biomarker Status:  ER: ☐ Positive ☐ Negative ☐ Unknown

PR: ☐ Positive ☐ Negative ☐ Unknown
HER2: ☐ Positive ☐ Negative ☐ Unknown

____________________  ______________________________  ___________________
Completed By            Signature                        Date (dd-Mmm-yyyy)
Questionnaires

Patient Questionnaire


1. How old are you?  
2. What is your Parish or Town?  
3. What is your current marital status?  
   - Married  
   - Living together with a partner  
   - Single  
   - Separated/Divorced  
   - Widowed  
   - Prefer not to answer  
4. What best describes your living arrangements?  
   - At your own home  
   - Nursing Home  
   - Other (specify)  
5. Do you live alone?  
6. What is the location of your residence?  
   - Rural (country)  
   - Urban (city)  
7. What is your highest level of education?  
   - No schooling  
   - Primary/Preparatory School  
   - Did not complete secondary school or high school  
   - Completed secondary or high school  
   - Had some post-secondary education (e.g. University, college, community college, technical college, trade school etc...)  
   - University degree (e.g. BA, BSc)  
   - Graduate degree (e.g. Master's, PhD, MD)  
8. Are you employed?  
9. If no, what is your source of income?
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. What is your monthly income?</td>
<td></td>
</tr>
<tr>
<td>11. How important is spirituality or religion in your life?</td>
<td>Extremely important</td>
</tr>
<tr>
<td></td>
<td>Very important</td>
</tr>
<tr>
<td></td>
<td>Somewhat important</td>
</tr>
<tr>
<td></td>
<td>Not very important</td>
</tr>
<tr>
<td></td>
<td>Not at all important</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td>12. Do you identify with a formal religious group or practice?</td>
<td>Christian</td>
</tr>
<tr>
<td></td>
<td>Muslim</td>
</tr>
<tr>
<td></td>
<td>Buddhist</td>
</tr>
<tr>
<td></td>
<td>Jewish</td>
</tr>
<tr>
<td></td>
<td>Hindu</td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
</tr>
<tr>
<td>13. Do you identify as:</td>
<td>Black</td>
</tr>
<tr>
<td></td>
<td>White</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
</tr>
<tr>
<td></td>
<td>Asian</td>
</tr>
<tr>
<td></td>
<td>Other:</td>
</tr>
</tbody>
</table>

The following questions ask about breast cancer in general

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Could bewitchment/witchcraft/evil spirits/obeah increase any woman’s chances of getting breast cancer?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td>15. Before seeing a doctor, did you try self-medication, for example get some ointment to apply from the local supermarket?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td>16. When you noticed a change in your breast or breasts, did you tell someone close to you?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>17. Before seeing a doctor, did you visit a herbalist or obeah man/madda?</td>
<td>Yes, No, Don’t know</td>
</tr>
<tr>
<td>18. If yes, how long did it take you visit a herbalist or obeah man/madda after noticing the problem?</td>
<td>&lt;1 week, Between 1 week and 1 month, Between 1 month and 3 months, 3 months or more</td>
</tr>
<tr>
<td>19. After you noticed a change in your breast or breasts, did you visit the pharmacy or other health care centre before seeing a doctor?</td>
<td>Yes, No, Don’t know</td>
</tr>
<tr>
<td>20. If yes, how long did it take you to visit a pharmacy or other health care centre before seeing a doctor?</td>
<td>&lt;1 week, Between 1 week and 1 month, Between 1 month and 3 months, 3 months or more</td>
</tr>
<tr>
<td>21. After you noticed a change in your breast or breasts, is there anything else you did before seeing a doctor? (please specify):</td>
<td></td>
</tr>
</tbody>
</table>

The following questions ask about reasons that might make it difficult to go to see a doctor

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. I would find it difficult to go for medical help because I would be worried about wasting the nurse/clinical officer/doctor’s time.</td>
<td>Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree</td>
</tr>
<tr>
<td>23. I would find it difficult to go for medical help because I would be worried about what the nurse/clinical officer/doctor might find wrong.</td>
<td>Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree</td>
</tr>
<tr>
<td>24. I would find it difficult to go for medical help because I would be worried about what tests the nurse/clinical officer/doctor might do.</td>
<td>Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree</td>
</tr>
<tr>
<td>25. I would find it difficult to go for medical help because I am too busy or have other things to worry about.</td>
<td>Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree</td>
</tr>
<tr>
<td>26. I would find it difficult to go for medical help because it takes too long to be seen at the clinic/health centre.</td>
<td>Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree</td>
</tr>
<tr>
<td>Question</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>----------</td>
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</tr>
<tr>
<td>27. I would find it difficult to go for medical help because I have no money for transport or the clinic/health centre charges.</td>
<td></td>
</tr>
<tr>
<td>28. I would find it difficult to go for medical help because I would not feel confident about talking about my symptoms or would have difficulty talking about how I feel.</td>
<td></td>
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<tr>
<td>29. I would find it difficult to go for medical help because I have had a bad experience in the clinic/health centre in the past.</td>
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<tr>
<td>30. I would find it difficult to go for medical help because I would feel embarrassed.</td>
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<tr>
<td>31. I would find it difficult to go for medical help without a family member or friend going with me</td>
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<tr>
<td>32. I would find it difficult to go for medical help because the nurse/clinical officer/doctor would not understand my language or culture.</td>
<td></td>
</tr>
<tr>
<td>33. I would find it difficult to go for medical help because I think that ‘if I have a disease like cancer there is no use for the nurse/clinical officer/doctor and I will die anyway’.</td>
<td></td>
</tr>
<tr>
<td>34. Are there any other reasons you can think of that would make it difficult for you to see a doctor?</td>
<td></td>
</tr>
</tbody>
</table>

The following questions ask about reasons that might make it difficult to go get a mammogram

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>35. I would find it difficult to go for a mammogram because it is painful</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>36. I would find it difficult to go for a mammogram because of the cost</td>
<td></td>
<td></td>
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<tr>
<td>37. I would find it difficult to go for a mammogram because it is too far away</td>
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<tr>
<td>38. I would find it difficult to go for a mammogram because it is embarrassing</td>
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</tbody>
</table>
### Oncologist Questionnaire

**Assessment of Barriers Contributing to Presentation of Breast Cancer Patients in Jamaica. A survey study of patient delay in breast cancer diagnosis and its associated factors from patient and oncologist perspectives.**

1. What type of oncologist are you?  
   - Surgical Oncologist
   - Radiation Oncologist
   - Medical Oncologist
   - Other: _____________

2. Where is your primary practise?  
   - Kingston Regional Hospital
   - Spanish Town Hospital
   - Other: _____________

3. How many years have you practised oncology?  
   Number of years: _____________

The following questions ask about reasons that might make it difficult for patients to go to see a doctor:

<table>
<thead>
<tr>
<th>1. Patients find it difficult to go for medical help because they are be worried about what negative results.</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>2. Patients find it difficult to go for medical help because they are be worried about what tests they might have to do.</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>3. Patients find it difficult to go for medical help because they are too busy or have other things to worry about.</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
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<td>---</td>
<td>---</td>
</tr>
<tr>
<td>4.</td>
<td>Patients find it difficult to go for medical help because it takes too long to be seen at the clinic/health centre.</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>5.</td>
<td>Patients find it difficult to go for medical help because they have no money for transport or the clinic/health centre charges.</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>6.</td>
<td>Patients find it difficult to go for medical help because they would not feel confident about symptoms or would have difficulty talking about how they feel.</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>7.</td>
<td>Patients find it difficult to go for medical help because of distrust in the medical system.</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>8.</td>
<td>Patients find it difficult to go for medical help because they feel embarrassed.</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>9.</td>
<td>Are there any other reasons you can think of that make it difficult for patients to see a doctor?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I discuss the cost of treatment with my patients</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>11.</td>
<td>You consider the cost of treatment options when offering them to your patients</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>12.</td>
<td>It is uncomfortable or embarrassing to discuss medical costs with patients</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>13.</td>
<td>Economic status of patients affects patient decisions regarding treatment choice</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>14.</td>
<td>Economic status of patients affects patient treatment compliance</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
</tbody>
</table>

The following questions ask about reasons that might make it difficult to go get a mammogram

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Patients find it difficult to go for a mammogram because it is painful</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
</tbody>
</table>
2. Patients find it difficult to go for a mammogram because of the cost

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

3. Patients find it difficult to go for a mammogram because it is too far away

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

4. Patients find it difficult to go for a mammogram because it is embarrassing

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

5. Patients don’t see the need for a mammogram

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

6. Are there any other reasons you can think of that would make it difficult for patients to go for a mammogram?
Consent Forms

Participant Information and Consent Form


Principal Investigators:

Principal Investigator

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Co-Investigator

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Co-Investigator

Steven Smith, MD
Clinical Research Associate at the Jamaica Cancer Care and Research Institute (JACCRI)
1. Invitation

Many people in Jamaica with breast cancer go to see a doctor when their breast cancer has moved past an early stage and we wish to know why. The purpose of this study is to see if there are common reasons among breast cancer patients that are causing them to delay looking for help from a doctor.

You are being invited to take part in this research study about patient factors that may delay them from seeking medical help for breast cancer. You have been invited because you are over 18 years of age, can understand English, and you have a diagnosis of breast cancer. In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. Please take your time to read this information sheet and make your decision.

2. Your participation is voluntary

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which you are entitled or are presently receiving. If you wish
to participate in this study, you will be asked to sign this form. You may withdraw from this study at any time without giving reasons.

If you volunteer to participate in this study, you will fill out the questionnaire for the study and give permission to the study staff to collect medical data about your breast cancer. There is no cost to your participation.

3. **Who is conducting this study?**

This study is being done as part of a Master’s program at the University of British Columbia in Vancouver, Canada, with support from the Jamaica Cancer Care and Research Institute and Princess Margaret Cancer Centre Global Cancer Program.

4. **What are the possible benefits, harms and discomforts?**

This study might not provide direct benefit to you through participation in this study, but the results from the study might be able to help other breast cancer patients in the future by finding areas of improvement in the community to make it easier to find medical help.

There will be minimal risk to you. The interview topic may cause mild emotional distress for some patients. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.

5. **How will my taking part in this study be kept confidential?**

Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the study staff, and Research Ethics Boards for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you, so that your identity will be kept confidential. Information that contains your identity will remain only with the study staff.
Disclosure of Race/Ethnicity

Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals because these characteristics may influence how people respond to different planning tools. Providing information on your race or ethnic origin is voluntary.

6. Who do I contact if I have questions about the study during my participation?

If you have any questions or want further information about this study before or during participation, you can contact Lorenz Yeung, Dr. Steven Smith, or Dr. Brittany Bromfield and the information listed above.

7. Signatures

My signature on this consent form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I understand I will receive a copy of this consent form for my records

I consent to participate in this study and have received a copy of this consent.
Obtaining Consent

If the participant is being represented by a legally authorized representative

Witness Signature (Not affiliated with study)
Participant Information and Consent Form – Oncologists


Principal Investigators:

Principal Investigator
Dingle Spence, MD
Hope Institute Hospital
7 Golding Avenue
Kingston 7, Jamaica WI
Email: dinglespence@gmail.com; P: 876-317-8652

Co-Investigator
Lorenz Yeung, CCRP
Masters Student in Global Surgical Care
The University of British Columbia, Vancouver, BC, Canada
Email: Lorenz.Yeung@gmail.com; P: 866-876-1764/604-417-0417

Co-Investigator
Steven Smith, MD
Clinical Research Associate at the Jamaica Cancer Care and Research Institute (JACCRI)
The University of the West Indies, Mona Kingston 7, Jamaica, W.I.
8. Invitation

The purpose of this study is to see if there are common reasons among breast cancer patients and what oncologists view that are causing them to delay looking for help from a doctor.

You have been invited because you are an active oncologist that treats breast cancer at the Kingston Regional Hospital or Spanish Town Hospital in Jamaica. In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. Please take your time to read this information sheet and make your decision.

9. Your participation is voluntary

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which you are entitled or are presently receiving. If you wish to participate in this study, you will be asked to sign this form. You may withdraw from this study at any time
without giving reasons. If you choose to enter the study and then decide to withdraw at a later time, you have the right to request the withdrawal of your information collected during the study. If you would like to request the withdrawal of your data, please let your study team member know.

10. **Who is conducting this study?**

This study is being done as part of a Master’s program at the University of British Columbia in Vancouver, Canada, with support from the Jamaica Cancer Care and Research Institute and Princess Margaret Cancer Centre Global Cancer Program.

11. **What does the study involve?**

Participants will be given a survey that asks them questions about what they think are specific reasons that cause patients to put off going to the doctor for breast cancer. There is no cost to you participating in this study.

12. **What are the possible harms and discomforts?**

There will be minimal risk to you. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can stop taking part in the study at any time.

13. **What are the potential benefits of participating?**

This study might not provide direct benefit to you through participation in this study, but the results from the study might be able to help other breast cancer patients in the future by finding areas of improvement in the community to make it easier to find medical help.

14. **How will my taking part in this study be kept confidential?**

Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the study staff, and UBC Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent. No information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you, so that your identity will be kept confidential.
contains your identity will remain only with the study staff. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

15. Who do I contact if I have questions about the study during my participation?

If you have any questions or want further information about this study before or during participation, you can contact Lorenz Yeung, Dr. Steven Smith, or Dr. Brittany Bromfield and the contact information listed above.

16. Signatures

My signature on this consent form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I understand I will receive a copy of this consent form for my records

I consent to participate in this study and have received a copy of this consent.

________________________________________________________________________
Participant’s Signature             Printed name               Date
Signature of Person  Printed name  Study Role  Date

Obtaining Consent

If the participant is being represented by a legally authorized representative

Participant’s Representative Signature  Printed name  Date

Witness Signature (Not affiliated with study)

Witness Signature  Printed name  Date
February 25, 2020

Steven Smith
University of the West Indies
Mona Kingston 7

RE: Evaluation of Research Proposal “Assessment of Barriers Contributing to Presentation of Breast Cancer Patients in Jamaica”

The South East Regional Health Authority is pleased to inform you that ethical approval has been granted for you to carry out the above captioned research. Please communicate with the Chief Executive Officer, Senior Medical Officer, the Parish Manager and the Medical Officers of Health at the various institutions prior to commencing your data collection at the facilities.

If you have any further questions, please feel free to contact the Regional Surveillance Unit by email at archresearchproposals@gmail.com or by way of telephone 876-754-3439.

Kindly forward a copy of this study to this office upon completion of the research.

Best wishes for a successful study.

Yours truly

SOUTH EAST REGIONAL HEALTH AUTHORITY

Dr. Sandra Chambers
Regional Technical Director

Cc. Mrs. Kathleen Cooper – Brown – Chief Executive Officer, Kingston Public Hospital
   Dr. Natalie Whyte – Senior Medical Officer, Kingston Public Hospital
   Mr. Dwayne Francis - Chief Executive Officer, Spanish Town Hospital
   Dr. Jacqueline Wright James – Senior Medical Officer, Spanish Town Hospital

Board of Directors: Mr. Wantworth Charles (Chairman), Mr. Maureen Golde (Regional Director), Dr. Curtis Bourne (Regional Technical Director), Mrs. Colleen Wright (Chief Executive Officer (Actg)), Mr. Peter Jarvis, Mr. Andrew Johnson, Ms. Kathy Smith, Mr. Wayne Hunte, Mr. Wilford Brown, Mrs. Lisa Scarce Lewis, Mr. Peter Jarvis, Dr. Karen Webster-Keys
ETHICS CERTIFICATE OF EXPEDITED APPROVAL

**PRINCIPAL INVESTIGATOR:** Brian D. Westerberg  
**INSTITUTION / DEPARTMENT:** UBC/Medicine, Faculty of Surgery  
**UBC CREB NUMBER:** H19-03647

**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:**  
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<th>Institution</th>
<th>Site</th>
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<tbody>
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**Other locations where the research will be conducted:**  
Kingston Public Hospital - Kingston, Jamaica  
Spanish Town Public Hospital - Spanish Town, Jamaica  
Margaret Cancer Centre - Toronto, Canada (Data analysis will take place here if not fully done prior to departure of Jamaica. Course advisor also at this location)

**CO-INVESTIGATOR(S):**  
N/A

**SPONSORING AGENCIES:**  
N/A

**PROJECT TITLE:**  

**THE CURRENT UBC CREB APPROVAL FOR THIS STUDY EXPIRES:** March 9, 2021

The UBC Clinical Research Ethics Board Chair or Associate Chair, has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants approval.

This approval applies to research ethics issues only. The approval does not obligate an institution or any of its departments to proceed with activation of the study. The Principal Investigator for the study is responsible for identifying and ensuring that resource impacts from this study on any institution are properly negotiated, and that other institutional policies are followed. The REB assumes that investigators and the coordinating office of all trials continuously review new information for findings that indicate a change should be made to the protocol, consent documents or conduct of the trial and that such changes will be brought to the attention of the REB in a timely manner.

**DOCUMENTS INCLUDED IN THIS APPROVAL:**  
**APPROVAL DATE:**

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Version</th>
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<td>Protocol</td>
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<td>February 25, 2020</td>
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<td>Consent Forms</td>
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<td>Patient Questionnaire</td>
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### Other Documents:

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### CERTIFICATION:

**In respect of clinical trials:**

1. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the Food and Drug Regulations.
2. The Research Ethics Board carries out its functions in a manner consistent with Good Clinical Practices.
3. This Research Ethics Board has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site. This approval and the views of this Research Ethics Board have been documented in writing.

The documentation included for the above-named project has been reviewed by the UBC CREB, and the research study, as presented in the documentation, was found to be acceptable on ethical grounds for research involving human subjects and was approved by the UBC CREB.

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**Approval of the Clinical Research Ethics Board by:**

Dr. Stephen Hoplion Cann,
Chair