# Women's Cancers in the English Caribbean:

A regional multi-sector discussion to define feasible strategies to improve the effectiveness of breast and cervical cancer programs

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**University of Miami**
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*Participants of the Women's Cancers in the English Caribbean meeting at the University of Miami, May 12, 2016.*

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## Overview of the meeting

In the English Caribbean, breast and cervical cancer are the leading cancers among women, with more than 16,000 women diagnosed and more than 6,000 dying from these diseases each year. Bahamas and Barbados have the highest incidence rates of breast and cervical cancer, of over 100/100,000 women. If the status quo is maintained, breast and cervical cancer incidence in the Caribbean is expected to increase by almost 40% by 2030.

Through the PAHO Plan of Action for the Prevention and Control of Noncommunicable Diseases (NCDs) in the Americas 2013-2019, Ministries of Health have recognized the need to improve the situation for women's cancer and other NCDs. Among the commitments, is to increase breast cancer screening to at least 50% coverage in women ages 50-69 years and to increase cervical cancer screening to at least 70% in women aged 30-49 years, while ensuring effective and timely cancer treatment and palliative care. Because of the challenges associated with cancer prevention and control, very few countries in the English Caribbean have reached the screening coverage indicators and face numerous challenges to improve cancer treatment and palliative care services.

Collaboration among governments, civil society and academia, including international cooperation and South-South collaboration can accelerate the number of countries that achieve a high screening coverage, and improve access and quality of their breast and cervical cancer programs to improve outcomes for women.

To support the coordination of country-specific and a regional response to achieve these goals, PAHO, with the support of the PAHO Foundation and together with the University of Miami cohosted a two-day forum on women's cancer in the Caribbean. The convening assembled 27 professionals from 14 countries in the English Caribbean, including representatives from Ministries of Health, civil society and academia, to identify potential areas of collaboration to support the improved effectiveness of women's cancer programs in the Caribbean. Also in attendance were 26 health professionals, technical experts and academics from 13 international health-related NGOs, government agencies, universities and research centers in the United States, Canada and Mexico.

**Countries represented:**

- Antigua and Barbuda
- Bahamas
- Barbados
- Belize
- Curacao
- Dominica
- Grenada
- Guyana
- Jamaica
- Puerto Rico
- Saint Lucia
- Suriname
- Trinidad and Tobago

**Partner organizations represented:**

- American Cancer Society
- International Gynecologic Cancer Society
- Pan American Health Organization (PAHO)
- PAHO Foundation
- Susan G. Komen Foundation
- ULACAM

- Tómatelo al Pecho
- University of Miami
- University of Washington/Fred Hutchinson Cancer Centre
- USA Centers for Disease Control
- USA National Cancer Institute

A complete list of meeting participants, as well as detailed agendas, can be found in the Appendices, beginning on page 38.

**PURPOSE**

The two-day convening included presentations from technical experts, academics, and representatives from government, and civil society. Participants engaged in group discussions and in breakout working groups, oriented to fulfilling the following:

- review of currently available knowledge, evidence and scientific gaps on breast and cervical cancer prevention, screening, early detection, treatment and palliative care; and
- sharing successful experiences and challenges in implementing breast and cervical cancer programs in the Caribbean; and
- identifying opportunities to improve financing, access, quality and utilization of women's cancer services.

**OUTCOMES:**

1. **Exchange of knowledge:** participates shared information about the status of breast and cervical cancer programs in their country, reviewed the scientific evidence for screening and early detection, and the difficulties and needs to improve outcomes.
2. **Deeper understanding of challenges and opportunities:** Through group discussion and working group meetings, participants articulated the specific challenges to establishing and/or advancing comprehensive women's cancers programs in their country, as well as the barriers and enabling factors which could potentially improve programs and services.
3. **Draft country action plans:** representatives from country Ministries of Health, worked together with representatives from academia and NGOs in their country, as well as with partner organizations to develop country specific action plans to advance appropriate and culturally sensitive women's cancer programs and services in their country.
4. **Opportunities for collaboration:** Country representatives, meeting hosts and partner organizations identified areas for potential international collaboration to improve women's cancers initiatives in the English Caribbean, including:
    a. Publishing a series of articles on the unique needs, challenges and opportunities to address women's cancers in the English Caribbean, to raise awareness of the needs within the global health community.
    b. Developing guidelines for comprehensive cancer care specific to the resources and needs of Caribbean countries.
    c. Supporting countries to implement their country action plan.
    d. Advocating and promoting the available resources to improve cancer care, such as the PAHO Revolving Fund and Strategic Fund, which provide low cost vaccinations and access to essential medicines; the University of Miami Gynecology Fellowship program; and a variety of assessment and data tools.)
    e. Conducting research to determine the best practices for addressing women's cancers concerns specific to English Caribbean countries.

5. **Expanded network:** Participants built new relationships with peers in their own countries and counterparts in the regional and international community to increase collaboration and engagement of governments, civil society and international organizations.

The main points shared and discussed during the plenary presentations and working groups are summarized in the following document, followed by the conclusions and next steps discussed to improve and expand the prevention, detection and treatment of breast and cervical cancers in the English Caribbean.

## Day 1 content and presentation summaries

### Welcome and opening remarks

*Dr. Felicia Knaul, University of Miami; Ms. Silvana Luciani, PAHO; Dr. Ben Anderson, BCI2.5 and University of Washington/Fred Hutchinson Cancer Centre; Dr. Steve Neymar, Sylvester Comprehensive Cancer Center, University of Miami*

In their opening remarks, speakers expressed their shared concern, commitment and collective desire to collaborate with the 14 countries representing the English Caribbean on efforts to improve comprehensive women's cancer care in the region. Speakers emphasized a mandate to improve health and, ultimately, prevent cancer, through international and intra-regional collaboration to identify challenges, barriers and possible solutions for developing evidence-based, region-appropriate and culturally sensitive approaches to effectively and sustainably increase access to and utilization of programs to prevent, detect and treat cancer.

Ms. Silvana Luciani set context by providing an overview of the purpose and goals of the meeting. In addition to the tangible desired outcome of the meeting – the drafting of country-based action plans to strengthen women's cancer programs – speakers also expressed their hopes that lasting partnerships for the improvement of public health would be cultivated during the two-day forum.

Dr. Felicia Knaul and Dr. Steve Neymar underlined how this convening aligns with the mission and intention of the University Miami to become a hemispheric university, partnering with the Latin American and Caribbean region to create and share knowledge, leverage expertise and jointly invest in the health and well-being of the Americas. It was noted that, as a culturally diverse community with strong Latin America and Caribbean influences, Miami has an intrinsic sensitivity to the cultural issues that may impact that utilization of cancer care programs in the region. This makes University of Miami uniquely qualified to support participating countries in designing appropriate and effective solutions.

### Keynote address: strengthening health systems: women's cancers in the English Caribbean

*Dr. Julio Frenk, President, University of Miami*

Dr. Julio Frenk opened the two-day meeting on Women's Cancers in the English Caribbean with a presentation highlighting the new world health order, common misconceptions related to health systems, ways to begin rethinking health systems and a diagonal approach to addressing women's cancers in the English Caribbean.

The study of the hemisphere is a critical aspect of the University of Miami, which was founded in 1925 with a vision of becoming a Pan-American university. Dr. Frenk shared his deep connection with PAHO and with the foundation, as well as with the countries of the English Caribbean, forged in part during his six years as Mexico's Secretary of

Health. He spoke of the University's desire and commitment to strengthen its relationship with the Caribbean as a gateway to the region, in adherence to the founding vision of the University and also to his own passion for global health, particularly matters of women's health.

Dr. Frenk discussed a framework for women's cancer care in the English Caribbean, from the perspective that all cancer care happens within a healthcare system. He covered four topics related to the development of a clear conceptual framework about health systems and why they are important.

**The new world health order**

We are living through special times in which rapid change is more the norm than the exception. Since 2000, there have been major changes in healthcare. The defining reason for these changes is the growing importance of health on the global agenda. Health has increasingly been seen as both intrinsically important and fundamental to larger pressing global issues such as economic concerns, security issues and democratic governance.

A second aspect of the new world health order is the expansion in funding over the last several decades. The Development Assistance for Health (DAH) grew from US $5.6 billion in 1990 to US $38 billion in 2013 (IHME, 2015). No other area of International Development Assistance has grown as rapidly as health. Although initially this rapid growth was driven by the AIDS pandemic, of which the Caribbean was one of the epicenters, it has expanded to encompass other global health issues. In parallel to that, low- and middle-income countries (LMICs) have been expanding their domestic investments in health, growing their health-related expenditures from US $128 billion to US $760 billion in 2013. Although this is significantly less than the nearly US $3 trillion the United States invests in health, it does indicate an increase in the understanding among governments of developing countries that health is imperative to achieving economic growth, security, political stability and the protection of human rights.

The expansion in funding explains the growing pluralism among organizations operating at global scale. Before the 1990's there were only a handful of organizations working in global health: PAHO, WHO, UNICEF, to name a few. There are currently approximately 72 entities, alliances and hybrid organization that are active in addressing global health, including private sector companies, civil society and universities.

This growing pluralism is occurring in the context of major power shifts in the global theater: from the bi-polar world of the Cold War to the uni-polar world following the collapse of the former Soviet Union to the now multi-polar world with multiple centers of geopolitical power distributed among formal national states as well as emerging non-nation states.

This is accompanied by an unprecedented health transition, mostly marked by the rise in noncommunicable diseases (NCDs), among which cancer is a major component. In response to this transition, and the increasing prevalence of chronic disease, complex health systems have emerged. Currently, health systems are the largest sector in the US economy (18% of GDP), and absorb 10% of the global economy, employing millions of health professionals.

**Common misconceptions**
Dr. Frenk described several common misconceptions around health systems that present possible barriers to the development of robust and effective systems.

1. **The health systems as a "black box"** into which you funnel resources and then by some vague and mysterious process "something" happens on the other side.
2. **The health system as a black hole** into which you put a lot of resources but nothing comes out.
3. **The health system as a laundry list or building block**. Health systems are not merely a collection of items such as human resources, technology and funding; the power and functionality of a health system comes from understanding how these components connect and the relationship among the components.

**Rethinking health systems**
Dr. Frenk challenged meeting participants to think differently about health systems. He introduced five questions that are essential to understanding health systems. These questions were based on the conceptual framework for assessing performance, which was created prior to the 2000 WHO report that produced the first ranking of global health systems. (Murray CJL, Frenk J., 2000)

1. **What is a health system? (Boundaries, actions, relationships*):*** In this framework, Dr. Frenk proposed a broader definition of health systems to include any entity or anyone whose primary intent is to improve health. He articulated a shift in thinking from lists of health care components to focusing on the relationships between these components. Health systems are also not only institutions, they include the population itself, as well: patients with needs, consumers with expectations, financiers, citizens with rights, and co-producers of health through care seeking, therapeutic compliance and behaviors.
2. **What are health systems for? (Goals):** Although the defining goal of a health system is health improvement, goals should also encompass the equitable distribution of health improvement, the improvement of health without creating disparity, responsiveness to legitimate expectations of the population, treating people with respect to individual rights and human dignity, fair financing and achieving effective coverage.
3. **What is the architecture of a health system? (Function)**: Historically, the architecture of health systems focused on the delivery of services. Dr. Frenk identified a shift from thinking in terms of service provision only to financing, resource generation, and stewardship.
4. **How good is a health system? (Performance)**
5. **How can we relate health system architecture to performance? (the science of health systems)**

**Health systems and women's cancers: the diagonal approach**
In conclusion, Dr. Frenk discussed the relationship of health systems to women's cancers and shared a vision for the use of a "diagonal approach" to cancer care. In the past, public health has been divided between the vertical approach of focusing on specific diseases and the horizontal approach of strengthening health systems without a clear sense of priorities, resulting in a health system that caters to the majority. The diagonal approach provides an alternative whereby explicit intervention priorities are used to drive improvements into the health system.

The diagonal approach is a synthesis between the vertical and horizontal approaches to health systems improvement. Priorities in the diagonal approach must comprise all components of the double burden of disease: the unfinished agenda (i.e., cervical cancer), as well as emerging challenges (i.e., breast cancer)**.**

The "diagonal approach" takes specified priorities to achieve improvements in the most pressing aspects of health systems: sustainable funding, human resources, logistics, information systems, long-term planning of healthcare facilities, quality assurance, and the idea of integrated health systems.

Dr. Frenk concluded with a quote from Amartya Sen (Co-Chair, UN Commission on Human Security) expressing the opportunity that accompanies the major transformations of this age:

> *We live in a world that is not only full of dangers and threats, but also one where the nature of the adversities is better understood, the scientific advances are more firm, and economic and social assets that can encounter these menaces are more extensive. Not only do we have more problems to face, we also have more opportunities to deal with them. (Amartya Sen, International Symposium on Human Security Tokyo, July 28, 2000)*

# 1. Session 1: overview of women's cancers and integrating services into health systems

## *1.1. Closing divides: health system responses to the challenge of breast and cervical cancer (Dr. Felicia, Knaul, Director, Miami Institute for the Americas, University of Miami)*

Dr. Felicia Knaul shared evidence-based perspectives on approaches to closing the cancer divide, establishing this as an equity imperative, particularly in the Latin America and Caribbean regions. She emphasized the need for a duality in response, with evidence based advocacy informing advocacy-inspired evidence, resulting in action impacting patients, projects, programs and policies.

Dr. Knaul's presentation introduced the thesis that, if not addressed, breast and cervical cancers will become like "neglected tropical diseases" that have the highest mortality rates among poor women low- and middle- income countries (LMICs). Already, this is a trend that can be observed in data illustrating the incidence and mortality rates of cervical cancer in Latin America, the Caribbean and other developing countries.

Expanding cancer care and control in LMICs is dependent on shifting powerful misconceptions that equitable cancer care is unnecessary, unaffordable, impossible and inappropriate, to the certainty that it should be done and can be done by exploring innovative delivery; access to medicine, vaccines and technicians; innovative financing, both domestically and globally; evidence-based decision-making; and strong stewardship and leadership.

Breast and cervical cancers are the most prevalent cancers impacting adult women globally and in the Caribbean, and are among the leading causes of death in the Caribbean. While cancer impacts women across all socio-economic and geographic barriers, it is increasingly poor women in LMICs who suffer the most. Dr. Knaul outlined five facets related to this trend: 1) exposure to risk, 2) preventable cancers caused by infections, 3) treatable cancer death and disability, 4) stigma and discrimination associated with cancer and 5) cancer treatment, and the incurring of what is, ultimately, avoidable pain and suffering by women diagnosed with breast or cervical cancer.

The costs of inaction with regards to closing the cancer divide emphasize the financial imperative. One-third to one-half of cancer deaths are "avoidable". This equates to 2.4 to 3.7 million deaths, of which 80% are in LMICs. Prevention and treatment to reduce these mortality rates offer a potential world savings of US $130 to US $940 billion. Costs to close the cancer divide may be less than many assume: all but 3 of 29 LMIC priority cancer chemo and hormonal agents are off-patent, pain medication and vaccinations are becoming more affordable and available, and innovative approaches to delivery and financing are allowing for aggregated purchasing and stabilized procurement.

Not only is closing the cancer divide necessary and affordable, it is also appropriate. Women and mothers in LIMCs face many risks throughout their life cycles, from mortality in childbirth, to breast and cervical cancers to high incidences of diabetes. Closing the cancer divide requires a diagonal approach to harness synergies that provide opportunities to tackle disease-specific priorities while addressing systemic gaps and optimizing available resources. The diagonal approach promotes prevention and healthy lifestyles, reduces stigma for women's cancers, harnesses existing financing and delivery platforms and orients towards achieving universal health coverage (UHC). A truly effective UHC response to cancer must integrate interventions across the continuum of disease, from prevention to palliative care, as well as address each health system function (stewardship, financing, delivery, and resource generation).

Dr. Knaul demonstrated how closing the cancer divide is possible by sharing an example of the diagonal approach Mexico is taking to strengthen early detection, survivorship and palliative care. Over the last few years Mexico has expanded the financial coverage for cancers, including them in the national catastrophic illness fund. Mexico is also including early detection of breast cancer into its anti-poverty program and investing in training primary care promoters, nurses and doctors in methods of early detection.

In conclusion, Dr. Knaul presented findings and recommendations for evidence-based policy regarding the importance of integrating survivorship care into UHC and each health system function, educating policy-makers about long-term care and quality of life issues, and investing in capacity building for health care providers and promoters at the primary level.

### *1.2. Breast and cervical cancer in the caribbean and PAHO/WHO recommendations (Ms. Silvana Luciani, PAHO)*

Ms. Luciani shared with participants an overview of the situation related to breast and cervical cancers in the Caribbean and presented related recommendations from PAHO/WHO.

Ms. Luciani discussed the prevalence of women's cancers in the Caribbean, as well as the unique challenges these countries face in implementing comprehensives cancer programs. Breast cancer and cervical cancers are the leading causes of death for women in the Caribbean. The ratio of incidence to mortality is also higher in the Caribbean countries than in the United States and Canada; this is reflective of a tendency in the Caribbean towards late detection, lack of access to care, cultural barriers to utilizing available care and other factors.

Since 2005, a series of political commitments have been made by the World Health Assembly, CARICOM, the United Nations, Pan American Health Organization (PAHO) and countries in the region to rally resources to help reduce cancer and NCD-related mortality. These commitments included resolutions to strengthen cancer prevention and control, initiate a global monitoring framework, promote universal health access and coverage and enhance palliative care. Ms. Luciani reminded participants that these commitments represent opportunities to remind their respective governments that they have an obligation to take action.

PAHO/WHO has developed recommendations for comprehensive cancer programs, which Ms. Luciani shared with meeting participants. PAHO promotes a comprehensive approach to cancer that includes the community (primary prevention), primary health care (screening and early detection), and secondary and tertiary health care (diagnosis, treatment, and palliative care). The coordinated interaction between these components comprises an organized program, incorporating financing, training, cancer registry and quality assurance. Although this approach represents the ideal scenario, Ms. Luciani acknowledged that specific interventions would need to be customized based on the unique needs and available resources of each country.

Ms. Luciani presented the preliminary results of a survey conducted by PAHO in 2015 to understand the capacity and current state of cancer care systems in the Caribbean. The survey highlighted strengths and gaps in each of the countries' existing systems. One of the challenges in many countries is access to opioids and vaccinations. Ms. Luciani shared information about PAHO's Revolving Fund and Strategic Fund programs, which provide low cost vaccinations and access to essential medicines to participating countries in the Region.

With regards to cervical cancer prevention and control, WHO has several recommendations, which Ms. Luciani discussed. These recommendations include a comprehensive approach to cervical cancer care, the inclusion of the HPV vaccine in national immunization programs (if cervical cancer prevention is a priority and HPV vaccination is feasible); and screening regularly for cervical

cancer in women aged 30-59 using a HPV DNA test, cytology or VIA. Specific recommendations for effective screening methods were shared, introducing variations to the preferred methods in resource constrained settings.

PAHO/WHO recommends the development and implementation of comprehensive breast cancer programs that are 1) based on the health system's resource level; 2) financially sustainable; and 3) focus on the priority of early detection linked to timely treatment. PAHO/WHO encourages population-based screening, the utilization of clinical, imaging and pathology modes of diagnosis; treatment approaches that include surgery, radiotherapy, chemotherapy, endocrine/biological therapy (where these options exist) and palliative care to address pain and symptom relief, as well as psychological and spiritual support for cancer patients.

In conclusion, Ms. Luciani cited challenges to improving breast and cervical cancer programs in the Caribbean, including competing public health priorities, limited awareness and demand for services from the public, adoption of new strategies, and financial implications of improving care. However, she reminded participants that there are also great opportunities as well, in the political commitments made to address NCDs, through community mobilization opportunities and international cooperation to respond to the challenges facing the region.

### *1.3. Breast cancer: services and resources needed for improve outcomes (Dr. Ben Anderson, Fred Hutchinson Cancer Centre, University of Washington)*

Dr. Anderson presented global breast cancer incidence and mortality trends, noting that breast cancer is the most common cancer among women, with the 12.7 million cases in 2008 predicted to rise to 22.2 million by 2030. Dr. Anderson also discussed the process of adapting cancer control strategies to resource-constrained health systems. He shared resources derived from BHGI global summits and the NCCN's resource-stratified guidelines, which provide a framework for prioritizing early detection, diagnosis and treatment strategies.

The most financially efficient cancer control tactics were discussed, with the cost barriers to implementation in poorer countries noted. Peru's current breast care model was examined to encourage strategies that go beyond early detection, diagnosis, and treatment to include survivors who will advocate and help organize to create awareness.

Dr. Anderson concluded his presentation with an introduction to the Breast Cancer Initiative 2.5 (BCI2.5): a global campaign to reduce disparities in breast cancer outcomes for 2.5 million women by 2025. The initiative has created educational and assessment tools that facilitate baseline assessments to determine next steps for program building based on a resource-stratified framework.

### *1.4. Cervical cancer: evidence based approaches (Dr. Erin Kobetz, University of Miami)*

Dr. Kobetz began her presentation by exploring the global distribution of cervical cancer in 2008, and reviewing regional cervical cancer screening practices across the world. She then focused in on trends in cervical cancer incidence and mortality in Latin America, and barriers to cancer screening and treatment in the region. Barriers include limited resources and awareness, the lack of centralized national programs and infrastructure and cultural factors.

Dr. Kobetz discussed cancer control strategies in the face of these barriers. She presented the PAHO ProVac Initiative for HPV vaccine education, policy creation and affordable access. She also reviewed the SUCCESS Project: a community health worker-delivered HPV self-sampling program, which has been particularly effective among Haitian and Hispanic women in both Miami and Haiti. Dr. Kobetz noted that the program might also be implemented in Caribbean countries, given its success.

The presentation concluded with an overview of the HPV Rapid Assay – a paper-based HPV detection tool that is now in development and the subject of a research study of the University of Miami. Since it does not require laboratory infrastructure, the test can be delivered by paraprofessionals, and could dramatically increase cervical cancer screening in rural and resource-limited Caribbean areas.

### *1.5. Palliative care: how to expand access in the Caribbean (Dr. Dingle Spence, Hope Institute, Jamaica)*

Dr. Spence began her presentation with a basic overview of what palliative care entails, and the global need for palliative care initiatives. She introduced the first-ever global resolution on palliative care, which was adopted unanimously at the World Health Assembly in May 2014. The resolution addresses the need to make palliative care an integral component of global health systems and to develop evidence-based palliative tools and guidelines.

Dr. Spence reviewed the steps that WHO is taking in response to the resolution to develop tools and evidence-based models for member states. The WHO public health model was examined through the categories of: drug availability, policy and implementation.

Regarding drug availability, it was noted that 93% of the world's morphine is used by 7% of the world's countries. The presentation included an overview of regional morphine availability, and explained the Global Opioid Policy Initiative (GOPI) – which aims to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East.

In closing, Dr. Spence detailed strategies for expanding access to palliative care. Strategies discussed included education and training with basic, intermediate and specialist tracks; improvements in research and quality of care; and the creation of palliative care models specific to LMICs.

### *1.6. Remarks from conversation catalysts (Dr. Gilberto Lopes, Johns Hopkins University; Dr. Judith Hurley, Sylvester Comprehensive Cancer Center, University of Miami; and Dr. Ramon Figueroa, Ministry of Health, Belize)*

Following the opening presentations on women's cancers and integrating services into health systems, four "conversation catalysts" shared their reactions and observations to provoke discussion among the participants.

**Dr. Gilberto Lopes** shared his perspective that when doing anything to address cancer the starting point is to have a cancer control plan. He noted that many countries have cancer plans, but they may not be reviewed regularly, updated or widely known. He emphasized the importance of collecting the information that is available, thoroughly understanding it and making it readily available to those who are key actors in the execution of a countrywide cancer plan.

**Dr. Judith Hurley** spoke to some of the particulars related to cancer prevention and control in the Latin America and Caribbean region, narrowing the focus from a global perspective. Dr. Hurley cited some of the specific challenges faced by countries in LAC including the lack of cancer registries and the lack of information about breast cancer in the Caribbean. She referenced the health and developmental changes occurring among girls and women throughout the Caribbean and the implications of these changes on views of and approaches to breast cancer and cervical cancer detection, prevention and treatment. Currently, 86% of cancer cases in the Caribbean are self-detected, predominantly at late stages (3 and 4). Yet, in many places self-examination is culturally unacceptable. Countries have challenges in implementing other types of screening as well – estrogen receptor (ER) testing is temperature dependent, mammography is not always feasible, pap smears are cumbersome. The geographically and culturally specific challenges faced by the region require recommended responses and treatment guidelines that are equally specific to a Caribbean women's cancers initiative. Dr. Hurley's concluding recommendations emphasized: the importance of early detection with screenings beginning at younger ages; the critical need for tumor registries; the need to shift cultural perspective regarding the acceptability of self-examination and self-done pap smears; the development of less expensive and temperature insensitive tests for ER; widespread HPV vaccination; piloting programs for treatment alternatives and training other health care providers in breast cancer care.

**Dr. Ramon Figueroa** reflected on his experiences as the Chief Medical Officer in Belize and shared the challenges of implementing improved cancer care and prevention programs within limited resource settings. He shared his perspective that access to information is not the problem – health providers know what needs to be done. Advocating for health transformation in the face of competing political, economic, or social priorities is the greater challenge. Dr. Figueroa spoke to the significant financial challenges facing small, fragile island economies often dependent on tourism, and the difficulty in elevating the importance of investing in the health system when there are other pressing financial needs. He raised the question with the group of how to develop leadership and stewardship capacity within each of their respective countries, citing a need for this not only in the Ministries of Health, but also across all levels

of government to understand the importance of health investment as an economic need. Other key issues he referenced included accountability to following through on plans and commitments and fundraising to sustain implementation. He concluded his remarks with a call to action to consider the individual person as part of the health system and to involve them in how professionals organize and deliver health care.

## Tracing the literary heritage of women's cancer in Latin America and the Caribbean (*Dr. Donette Francis, University of Miami)*

Dr. Donette Francis, a professor in the Department of English at the University of Miami, explored the portrayal of breast and cervical cancers in the literature of Latin America and the Caribbean. Her insights and observations were primarily based on: Audre Lorde's *The Cancer Journal* (1980), Junot Diaz's *The Brief Wondrous Life of Oscar Wao* (2007), Elizabeth Nunez's *Anna Novels* (2009, 2011) and Edward Baugh's *It Was the Singing* (2000). Through these works we see multi-generational examples of the few male and female writers who have been breaking the silence and giving voice to women living and dying with breast cancer. Dr. Francis observed that, notably, there were nearly no literary narratives illustrating the experience of cervical cancer in the Caribbean, and those that she did come across contained only obscure references to vague and unnamed health conditions.

Dr. Francis's literature review highlighted several poignant themes in the perception and portrayal of women's cancers in the Caribbean, underlining the cultural mores that limit discussion of women's health and bodies. Frequently in the literary portrayals, the issue of breast cancer received attention only at the moment of discovery and was then not referred to again. This hints at a cultural overtone where breast cancer is overshadowed with silence and shame. Dr. Donette raised questions as to what this means in terms of perception towards women's bodies and health, and the passing along of intergenerational knowledge. Would developing a more open attitude towards discussing women's health and more positive body talk empower the next generation to take a different approach to their own health and wellness? Would this encourage women to feel more comfortable engaging in preventative measures and seeking treatment earlier when needed?

Dr. Francis concluded by stating that this occasion to explore the portrayal of women's cancer in Caribbean literature was revealing and surprising in terms of how few direct references there actually were, particularly to cervical cancer. She shared her newfound commitment to making sure cancer and women's bodily health issues are not overlooked in her teaching and criticism of these books and encouraged participants to continue to engage in these thoughtful inter-disciplinary dialogues as we find ways to "discuss the most silent of silences."

### Participant reactions

Following Dr. Francis's presentation, participants had the opportunity to share their reactions, which are summarized below:

- The depiction of women's cancers shared in Dr. Francis's presentation reminded participants, many of whom are physicians, of personal experience they have had with delivering cancer diagnosis to patients and their families. They found this a touching reminder of the very human element that must be considered in cancer care, and the implications of a cancer diagnosis on patients, their families, their livelihood and their self-image.
- Participants responded to the quote from *The Cancer Journal* that described a women's reaction to cancer as coming from a whole pattern of her life, which is part of the design of who she is and how she has lived. This gave participants insights into why different women respond in such different ways to cancer.
- The depiction of how the children of cancer patients are impacted, and in some cases defined, by a cancer diagnosis reminded participants that the suffering and stress caused by cancer impacts not only the patient.
- Participants were struck by the void of material discussing or alluding to cervical cancer.
- It was noted that faith and religion plays a significant role in how a Caribbean woman chooses to respond to breast and/or cervical cancer. Many times when women are diagnosed they choose to pray for healing rather than go to a doctor. Frequently, by the time they do decide to seek treatment the disease is too advanced.
- Participants with knowledge of cancer treatment in other parts of the world noted that the situations described are not isolated to the Caribbean, citing similarities in West Africa and other developing countries.

## Discussion summary: *session 1 - overview of women's cancers and integrating services in to health systems*

Participants discussed themes that emerged over the course of the morning. This discussion is summarized below:

- **Stewardship:** There is a need for improved stewardship of financial resources, evaluation capacities at the Ministries of Health, guidelines for screening and national protocols for breast and cervical cancers care.
- **Access to medication:** Many countries have been experiencing difficulty in accessing basic pain medication and vaccines, yet there are resources available that some were not aware of and/or have not been taking advantage of, such as PAHO's Revolving Fund and Strategic Fund. In addition to access, guidance on the appropriate administration of medication and logistical support to ensure the delivery of quality medication may also be needed.
- **Primary health care and prevention:** There is a need to improve methods of screening for women's cancers so they are being detected earlier, rather than waiting until a patient needs treatment for stage 3 and 4 cancer.
- **Affordability and financing:** Implementing comprehensive cancer care, including increased screening and diagnostics, will require financial investment. Many countries in the Caribbean are operating with limited financial and human resources. How do representatives from these countries convince policy makers to invest money in terms of prevention and treatment? If it is less expensive for a woman to survive cancer, how can they use this information to generate increased funding and

a high priority status for women's cancers programs on their respective national agendas?

- **Taking a diagonal approach:** It was noted that while in some instances different components of the health system are working collaboratively, there are many opportunities to improve how community, primary, secondary and tertiary health systems work together to address health issues in a truly diagonal manner.
- **A call to commitment:** One participant observed that there is a need for higher levels of commitment among the key actors in the various elements of the represented health systems. It was noted that while each country is challenged by limited resources, health care professionals need to be more committed to achieve their goals in the face of these challenges.

## 2. Session 2: country experiences on improving women's cancers: government perspectives

### *2.1. Bahamas (Dr. Raleigh Butler, Ministry of Health, Bahamas)*

Dr. Raleigh Butler's presentation began with an overview of gynecological malignancies and breast cancer trends from 2000-2014. Incidence rates for cervical cancer have slightly decreased while uterine cancer incidence has increased; ovarian cancer, vaginal cancer and vulvar cancer have remained stable; and breast cancer incidence has also seen a slight increase.

In the Bahamas, cervical cancer screening rates are under 10%, despite access to 110 clinics and free pap smears. The average patient is 48, with 48% of patients under the age of 50. 75% of cervical cancer cases are diagnosed at stage 3, with 50% of patients projected die in less than 18 months. Dr. Butler highlighted the significant economic burden of the projected mortality rate, even with the development of a palliative care system.

The presentation noted current initiatives in the Bahamas, including a Spanish government-donated colposcopy clinic, the introduction of the HPV vaccine into the Bahamas's public health system, and free breast exams and pap smears provided by the Cancer Society.

Dr. Butler also shared data from the Bahamas Breast Cancer Initiative Foundation from 2011-2014. The Bahamas has the highest incidence of BRCA mutations in the world, with 13-17% of Bahamian women carrying the BRCA1 or BRCA2 mutation.

The presentation ended with an examination of regional barriers to treatment including cultural, economic and infrastructural barriers, and a discussion of opportunities for healthcare initiatives to overcome those barriers in the form of community involvement, preventative vaccines, palliative care and universal health care.

### *2.2. Barbados (Dr. Heather Armstrong, Ministry of Health, Barbados)*

Dr. Armstrong provided background information on women's cancer in Barbados including behavioral risk factors in Barbadian females over 15, and cancer in Barbados. Of 226 cancer deaths in 2008, 20% were women's cancer. The 5-year survival rate in Barbados for women diagnosed in 2008 with cervical and uterine cancer is 51%, and the breast cancer 5-year survival rate is 47.4%.

Barbados' current strategic plan for cancer prevention, screening, diagnosis, treatment and palliative care was detailed in the presentation. Highlights included the Gynecological Cancer and Diagnostic Unit at the Queen Elizabeth Hospital: a therapeutic center that also provides screening and referral for treatment.

Dr. Armstrong outlined challenges and opportunities for growth in the Barbados Cancer Program. Financial challenges and technical challenges were examined, as well as cultural barriers in Barbadian women such as fears of a cancer diagnosis, the mammogram machine, and stigmatization. Opportunities for growth and overcoming barriers include multi-sector responses to risk factors, surveillance support from CARPHA, raised awareness through media partnerships, and the development and implementation of a national cancer plan in Barbados.

### *2.3. Puerto Rico (Dr. Guillermo Tortolero-Luna, University of Puerto Rico, Comprehensive Cancer Center, Puerto Rico)*

Dr. Tortolero-Luna began by addressing the burden of cancer in Puerto Rico, which is the leading cause of death in the country – accounting for approximately 25% of all deaths. For breast cancer specifically, an average of 2,048 women were diagnosed every year between 2009 and 2013, with an average of 424 women dying from breast cancer in the same time period. An average of 248 women each year was diagnosed with invasive cervix uteri cancer between 2009 and 2013, and 56 women died each year.

Cancer treatment challenges in Puerto Rico include its relatively high national debt and low median annual income, with 45% of Puerto Ricans living below poverty level. The Puerto Rican government's health plan is also a challenge area, as is the exodus of healthcare professionals from Puerto Rico at an average rate of 1 per day. On the other hand, Puerto Rico has a low percentage of uninsured citizens (7.6%), access to federal funding and a large network of federally qualified health centers (FQHC) – all of which provide opportunities for progress.

Dr. Tortolero-Luna closed his presentation with an overview of Puerto Rico's Comprehensive Control Program and 2015-2020 plan, highlighting HPV vaccination, breast cancer, and cervical cancer initiatives.

### *2.4. Trinidad and Tobago (Dr. Dylan Narinesingh, National Radiotherapy Center, Trinidad and Tobago)*

Dr. Narinesingh opened with an overview of Trinidad and Tobago's population demographics and cancer treatment statistics. Noncommunicable diseases (NCDs) account for 60% of deaths in the country, with cancers ranked #2. The government spent $15 million (USD) on chemotherapy drugs from 2014-2015.

Turning the focus to cervical cancer: it ranks as the 2nd most frequent cancer among Trinidadian women between 15 and 44 years of age. Current mortality estimates indicate that every year 125 women are diagnosed with cervical cancer, and 93 die from the disease. Trinidad and Tobago's current cancer resources for women include two gynecology clinics and colposcopy services offered at all major public hospitals.

The costs of cervical cancer treatment tactics were also explained – including palliation, chemo and radiation therapy, and surgery. Dr. Narinesingh presented treatment practices for the HPV vaccine, as well as a study on the low awareness among Trinidadian women of the association between HPV and cervical cancer.

Breast cancer data and treatment details were also detailed, including an in-depth look at mammography knowledge and attitudes in patients. Having access to a physician who recommended mammography was found to be the strongest predictor of breast cancer screening.

Dr. Narinesingh discussed palliative care in Trinidad and Tobago, citing morphine shortages as the largest current challenge. The presentation concluded with a push to enlist NGOs in helping the public sector create and implement policies. Dr. Narinesingh shared the women's health initiatives of the Trinidad and Tobago Cancer Society – the NGO providing the biggest impact on screening in Trinidad and Tobago.

Trinidad and Tobago will hold a National Symposium on Breast and Cervical Screening in June of 2016.

## Discussion summary: *session 2 - country experiences on improving women's cancers: government perspectives*

At the conclusion of the four country presentations, participants shared their reactions:

- Cancer plans must be comprehensive and culturally relevant
- The political dynamics of each country must be considered. Governments change every four or five years and often, each time, health care providers seeking to implement changes in the health system must "start fresh" each election cycle. Additionally, participants commented on the challenges of working with Ministers of Health who are often focused on getting re-elected.
- The statistics are disturbing and there is urgency in understanding what is being done that is working and what is not working that the outcomes continue to fall below the desired levels.
- The cost of healthcare treatment is only one aspect of the financial barriers to care. For example, Jamaica offers free health care, yet, although people can now see a physician for free, they may still be unable to afford the cost of the trip of travelling to the doctor's office.
- In many countries, delays in the health care system contribute to poor outcomes. In some cases, a patient may receive a diagnosis early enough to be treatable, but delays caused by the health system prevent that treatment from taking place in a timely manner and the patient may go from curable to incurable waiting to take the next step.
- Countries are in need of sustainable funding (versus sporadic influxes of money) to support consistent cancer programs, awareness campaigns and other interventions related to the detection prevention and treatment of cancers.
- Along with improved of screening methods comes higher incidences of breast and cervical cancers. Health systems must have the capacity to respond to these increases in potential patients.
- In the smaller, less resourced countries there are very basic needs to address; needs that health representatives are well aware of but lack the funding or the expertise to address.
    - Lack of oncology specialists
    - Lack of basic infrastructure for cancer screening
    - Lack of HPV testing and HPV vaccination
    - Lack of sufficient numbers of medical professionals to support sustainable, efficient health care systems at the country level
- Other themes related to barriers in improving cancer care and outcomes:
    - Limited access to pain medication and other drugs resulting in shortages
    - The differences between private care, in which treatment may be available but is very expensive, and public care, where resources are much more constrained
    - Patient incompliance with treatments
    - Lack of adequate palliative care, barriers to opioid access, and lack of survivorship programs

## 3. Session 3: civil society experiences in improving women's cancer in the Caribbean

### *3.1. Susan G. Komen Foundation (Dr. Anna Cabanes)*

Dr. Cabanes reviewed Susan G. Komen Foundation's mission and strategic priorities in the areas of research, community health, and global partnerships. The Foundation's goal is to contribute to reducing premature mortality from breast cancer through early detection strategies and access to treatment.

In the Bahamas, breast cancer incidence and mortality rates are among the highest in the world, and are the highest in the Americas. The rate of prevalence of the BRCA1 and 2 gene mutations is also the highest in the Bahamas. Dr. Cabanes detailed the Foundation's strategy in the region to assess evidence and critical needs, engage stakeholders, address critical needs with multi-sector partnerships, align national cancer plans to national needs, and support the implementation of sustainable initiatives.

The Foundation's partnership with the Bahamian government and the Sunshine Insurance Marathon have helped fund genetic studies, train breast health educators, develop and distribute educational materials, and provide treatment equipment, decreasing the treatment discomfort for underserved women.
Looking forward, Susan G. Komen Foundation hopes to build global and local alliances to provide direction to breast cancer research, policy and care. Dr. Cabanes emphasized the Foundation's desire to work collaboratively to achieve common goals.

### *3.2. Health Caribbean Coalition (Ms. Maisha Hutton)*

Ms. Hutton began with background on the Healthy Caribbean Coalition (HCC) – which arose out of the 2007 Heads of Government CARICOM Summit on noncommunicable diseases. Its mission is to harness the power of civil society, in collaboration with multi-sector partners. Its members include 60+ Caribbean-based NGOs, 65+ nonprofit organizations, and 250+ individual and organizational members around the globe.

The HCC's four strategic areas are building capacity, strengthening advocacy, promoting health, and enhancing communication. Its Cervical Cancer Advocacy Initiative aims to create a civil society-led cervical cancer advocacy movement. One of the results of this initiative was the creation of the Caribbean Cancer Alliance of 20 Caribbean cancer societies, which met in February of 2016.

The Caribbean Civil Society Cervical Cancer Prevention Initiative (C4PI) will build partnerships with governments to meet education and screening targets, support treatment of uninsured women, and increase access to the HPV vaccine. The HCC's work in palliative care and survivorship focuses on mechanisms for greater patient engagement, and will create a survivorship plan for the region through the Cancer Survivors in Action's first regional conference in October 2016.

Ms. Hutton closed her remarks by reiterating the importance of international dialogue and collaboration in improving cancer outcomes.

### *3.3. Belize Cancer Society (Ms. Laura Tucker-Longsworth)*

Ms. Tucker-Longsworth began with a brief overview of the Belize Cancer Society (BCS), which was founded in 1996 with a mission to advocate, educate, provide evidence-based guidance, and to promote awareness, prevention, and treatment of cancer through partnerships with public and private sectors.

One of the BCS's key partners is the Ministry of Health. The partnership has led to the establishment of a National Cervical Cancer Committee, and facilitates requests from BCS for the development of a comprehensive cancer program and the sourcing of funds for pediatric cancer treatment in Mexico. BCS has also partnered with the Healthy Caribbean Coalition to achieve advocacy objectives, and has partnered with the Belize Family Life Association to work on cervical cancer control.

Ms. Tucker-Longsworth also detailed an initiative to add HPV vaccines to the national schedule for girls between 9-13 years, and the Belize Cancer Center Dangriga – which allows patients to receive chemotherapy regardless of their ability to pay.

Ms. Tucker-Longsworth closed her presentation with a quote from Sun Tsu, an Ancient Chinese Military Strategist: "Strategy without tactics is the slowest route to victory; tactics without strategy is the noise before defeat."

### *3.4. Jamaica Cancer Society (Mrs. Yulit Gordon)*

Mrs. Gordon began with a discussion of Jamaica's national situation regarding breast and cervical cancer. Current challenges include a lack of national screening and public sector mammography machines, cultural stigma surrounding women's cancer, and financial barriers to providing widespread treatment.

Jamaica's current national breast and cervical cancer screening guidelines were detailed, as were its public and private sector partnerships both in the region and globally. Mrs. Gordon also presented the history of cancer advocacy through the partnership of the Jamaica Cancer Society and the Jamaican government.

The 2013-2018 National Strategic Plan for the Prevention and Control of Cancer hopes to reduce preventable morbidity and disability due to cancer in Jamaica by 25% by the year 2025. The plan's strategic objectives were outlined, and opportunities for collaboration in the areas of HPV testing and technical training were highlighted.

Mrs. Gordon concluded underlining the value of Jamaica Cancer Society's media partnerships for distributing cancer campaigns.

## Discussion summary: *session 3 - civil society experiences in improving women's cancer in the Caribbean*

At the conclusion of the four civil society country presentations, participants discussed their reactions:

- Antigua and Barbuda representatives shared that they have a survivorship program in which they educate women who have been diagnosed and provide emotional support to patients and their families throughout the treatment process. Specific support services include patient navigation and treatment compliance.
- The Bahamas has a caring center where families can go to receive treatment and guidance. The center offers counseling and patient navigation.
- In Dominica, when a patient goes to the oncology clinic they get involved in the social aspect of supporting patients, sometimes providing more emotional and financial aid to the patient than the families can. In some cases, the health system in Dominica will pay for rental homes in Guyana, where they send patients to receive radiation therapy.

## Day 1 concluding remarks

### *Dr. Felicia Knaul, Director, Miami Institute for the Americas, University of Miami*

Dr. Felicia Knaul offered concluding remarks to adjourn the first day of the convening on women's cancers in the English Caribbean. She expressed a belief that there is potential, based on all that was discussed during day one, to conduct research on health systems in the Caribbean in order to better understand the strengths, gaps, opportunities and challenges. She further offered the suggestion to work with PAHO and other strategic partners present to author academic articles for publication specifically on cancer prevention and care in the Caribbean. She invited participants to consider whether they would be interested in participating in series of articles or primary research.

## Day 2 content and presentation summaries

### Review of day 1

Before beginning the content and presentations for day two of the women's cancers in the English Caribbean convening, participants were asked to review key takeaways from the first day of the meeting. Highlights from this review are summarized below:

- **The human face of cancer:** The literature review of women's cancers in Caribbean writing reminded participants that there is a very real and powerful human face to cancer and that this is something that should be emphasized in medical training.
- **Funding for health initiatives:** Access to sustainable funding for health initiatives was a theme that emerged in day one. Many countries in the English Caribbean are experiencing economic depression, resulting in decreased availability of funding for health. Governments are struggling to fill the financial gaps that exist. In order for cancer care plans to be implemented they must be seen as a priority among competing priorities. Countries must also consider the total cost of implementing programs, i.e. it is not just the cost of the HPV vaccines or testing, one must also consider the cost of implementing this protocol countrywide.
- **The diagonal approach:** This continued to stand out as a theme as a way to organize and deliver health care; the theory of a diagonal approach as opposed to the horizontal or vertical approach that is traditionally taught in public health.
- **Opportunities for collaboration:** With similar challenges and barriers experienced across the region and among government agencies and civil societies, there seem to be ample opportunities for partnership and collaboration to find shared solutions to common problems.
- **Challenges with organization of health services:** Countries across the region are facing similar challenges with regards to implementing cancer screening and treatment, from testing, to access to care, to the access to medication and palliative care.
- **The need for cancer registries:** Throughout the day, the need for more accurate tracking and monitoring of reported cancer incidences was cited as an important step in improving cancer treatment and prevention.
- **Regional diversity:** Although many countries in the English Caribbean are experiencing similar challenges and barriers, among these countries there is also considerable diversity in terms of access to resources, availability of funding, scope of services provided, and other population-based nuances.
- **Increasing importance of health on the global agenda:** Although population health has increased in importance on the global agenda over the past decade, there is still work to be done within the region to prioritize health as a fundamental influencer of overall economic, political and social stability.

## Diagnostic work-up: how it relates to screening

***Dr. Ben Anderson, Fred Hutchinson Cancer Research, University of Washington***

In response to questions that were raised by participants during the first day of the meeting, Dr. Anderson presented a brief overview of the process of care for breast cancer screening, diagnosis and treatment.

It is early treatment, not just early detection of breast cancer that increases the chances of survival. To illustrate this, Dr. Anderson shared the results from a study conducted in Indonesia in which the use of mammography was compared to clinical breast exams in a population that had never been screened before. 1179 women were screened using both mammography and clinical breast exams. Through the mammography screening, 289 women showed suspicious findings, however only 14 of these turned out to be cancer. Dr. Anderson cautioned that when you begin to conduct breast cancer screening you are going to find more possible cancers, which providers must be prepared to be able to diagnose Clinical breast exams of the same population identified 13 of the 14 cases. As a result of this study, Dr. Anderson suggested that clinical breast exams, rather than mammography screening might be a first step for low-resource countries.

Dr. Anderson concluded his presentation by reviewing the NCCN Guidelines for Breast Cancer Screening and Diagnosis, walking participants through the recommended sequence for systematically identifying a suspicious sample and then taking the appropriate and timely next steps from diagnosis to treatment.

### Summary of reactions

Dr. Anderson's presentation sparked discussion, which is summarized below:

- Health systems must have the infrastructure and the resources in place to manage an increase in volume of cases that will likely result from screening. Failure to provide adequate treatment to women in whom cancer is detected represents a health system failure and an ethical problem.
- There seems to be a gap in country guidelines and protocols for breast cancer and the NCCN guidelines are a resource. These guidelines could be adapted to the realities in each country.
- It is important to select and implement detection methods that are appropriate for each country – based on population needs, cultural preferences, resources and health system capacity.
- Participants discussed the various advantages and disadvantages of using a variety of diagnostic methods, including FNA and other biopsy procedures.
- Participants questioned the effectiveness of administering Tamoxifen in circumstances in which women are diagnosed as ER positive. Dr. Anderson responded that one would anticipate benefit in such a trial in terms of reducing the percentage of future resurgence. Dr. Gilberto Lopes echoed that there are residual benefits to administering Tamoxifen, though they diminish over time. Dr. Judith Hurley commented that even five years out there are still benefits to instituting hormonal therapy, and hormonal therapy can continue to deliver benefits for five to ten years.

## 4. Session 4: international perspectives on cancer care and treatment

### *4.1. Comprehensive cancer centers: minimum requirements and considerations for limited resource settings (Dr. Mary Gospodarowicz, Princess Margaret Hospital, Canada)*

Dr. Gospodarowicz discussed the predicted rise in global cancer cases, and the need for evolving responses tailored to region, development, and country. She recognized the progress that has been made over the last 40 years in women's cancer survival rates, but also noted the large equity gaps between more and less developed regions. Gaps exist in the availability of care, the affordability of care, and awareness. Dr. Gospodarowicz also detailed the purpose and recommendations of the Institute of Medicine report, which focused on issues of quality in health care.

Essential services for cancer were broken down into the categories of diagnostic, surgery, radiotherapy, chemotherapy, and palliative care. Dr. Gospodarowicz highlighted the huge shortages of facilities, equipment and people to provide these services – with many regions having fewer than 30,000 health professionals to treat millions.

Dr. Gospodarowicz explained the idea of a comprehensive cancer system, and the framework for planning and organizing services to support such a system. She detailed the framework while recognizing that implementation will need to be adapted based on each country's cancer burden, existing capacity and resources, government resources, and advocacy opportunities.

**Summary of reactions**
Following Dr. Gospodarowicz presentation the following topics were discussed:

- The availability of radiation services among the participating countries, and alternative approaches implemented in countries where radiation services are not available.
- Participants discussed the value of having a clear structure for approaching the development of a population-based, resource appropriate comprehensive cancer care center. Needs for cancer care are often much more basic: technical training, procurement, procedures, policies and infrastructure.
- Dr. Gospodarowicz shared examples of how Ontario provides radiation therapy to members of the population living at great distance from the established cancer centers. Solutions she highlighted included the use of mobile radio-bunkers, transportation and free housing for patients in need of treatment, the use of Skype, FaceTime and other more secure channels of communication to allow for virtual follow up, tele pathology and tele radio.
- Participants discussed the full scope of what is needed in order to run comprehensive cancer care centers – including the diagnostic equipment, machinery, human resources, management and administration support and a variety of core support services; and how difficult it is to achieve this in small island nations.

- Participants discussed actions being taken in some countries to decentralize clinical oncology services and redistributing resources to hospitals around the country to reduce patient travel.

### *4.2. Caribbean fellowship in gynecology oncology (Dr. Brian Slomovitz, Sylvester Comprehensive Cancer Center, University of Miami)*

Dr. Slomovitz began his talk by discussing efforts to start the Sister Society Gynecology Fellowship, and introducing the first fellows from that program.

Dr. Slomovitz then explained the reasons for the creation of the fellowship program. 85% of cervical cancer deaths occur in lower-middle income countries. Improvements in care from increased screenings will take time, and improved screening will result in more patients who have early-stage cancer and are consequently in need of hysterectomies. The region will need to be prepared to respond to more cases detected and a subsequent increase in patients.

The goal of IGCS is to train regions to address their own needs by creating sustainable partnerships and by training people to treat the needs of the community. IGCS has taken initial steps towards this goal with the creation of the Sister Society and the creation of an inaugural fellowship with the University of Miami and the University of the West Indies.

The fellowship was created to address current challenges surrounding gynecological training – well trained Caribbean staff is not engaged in the training of the next generation of sub-specialists, and trainees who are not properly prepared to practice within limited regional resources often return oversees after training.

The synergy of the University of Miami's mission and the goals of IGCS provide the opportunity to develop a mentored training program that builds on existing relationships between the University of Miami and the University of the West Indies. Dr. Slomovitz detailed the specifics of the fellowship partnership between the two universities, and reiterated its aim to train fellows to be leaders in providing services based on the needs of the Caribbean region, with the resources available to them.

## 5. Session 5: work group sessions to develop country action plans

Following a series of morning presentations on day two, participants separated into three working groups, based on country size and resource availability. Representatives from partner organizations, international NGOs and academia were distributed among the working groups to provide technical assistance and guidance. The workshop groups were instructed to reflect on ways to improve breast and cervical cancer prevention and control in their individual country and to define what is needed for a successful program. Each working group was further tasked with identifying country specific barriers and possible solutions for establishing and implementing a successful program. Finally, country representatives were charged with developing an initial draft of an action plan to

address the identified barriers and solutions. The agenda for the working group break out session, worksheets, and a complete listing of working group members can be found in the appendix on page 38.

| Working Group | Members |
|---|---|
| **Working Group A** | **Countries:** Antigua and Barbuda, Barbados, Dominica, Grenada, Saint Lucia<br>**Partner organizations**: American Cancer Society, Fred Hutchinson Cancer Center, Johns Hopkins University, PAHO, PAHO Foundation, University of Miami |
| **Working Group B** | **Countries:** Bahamas, Jamaica, Puerto Rico, Trinidad and Tobago<br>**Partner organizations**: Centers for Disease Control and Prevention, National Cancer Institute, Fred Hutchinson Cancer Center, IGCS, PAHO, PAHO Foundation, University of Miami |
| **Working Group C** | **Countries:** Belize, Curacao, Guyana, Suriname<br>**Partner organizations**: Fred Hutchinson Cancer Center, Susan G. Komen Foundation, Tómatelo al Pecho, PAHO, University of Miami |

## Overview of mapping and survey tools

### *Women's global health atlas (Brenda Kostelecky, National Cancer Institute)*

Ms. Kostelecky provided an overview of the Women's Global Health Atlas, a tool to map and trace all actors within a health system. The tool is designed to conduct geo-spatial, stakeholder and, ultimately political and financial mapping of in-country activities on women's cancer care and control in LMICs. It is an open source, web-based, interactive tool and database that will map all sectors of health systems to monitor what services they are providing and how are they providing them. The database will map providers, donors, regulatory bodies, research and training, in both public and private sectors.

### *Global breast health analytics map and assessment tool (Allison Dvaladze, BCI2.5)*

Ms. Dvaladze introduced participants to two tools that are available for their use through BCI2.5's Knowledge Center:

- **Global breast health analytics map (GloBAM):** integrates and visualizes global breast cancer data gathered from national and international sources including GloboCan, Concord, World Bank, among others. This data helps countries assess their needs, identify where bottle necks may exist and design solutions to address barriers.
- **Assessment tool:** developed in alignment with resource-stratified guideline intended to provide organizations with a tool to assess their level of compliance with these guidelines. Multiple people within an organization may complete the tool, which has questions customized for different roles. Upon completion of the assessment tool, a report is generated to help organizations begin to identify their resource gaps

## 6. Session 6: action plan and commitment reports

Following the working group breakout sessions, each country was invited to share highlights from their plans, as well as the immediate actions steps they were committed to taking to advance women's cancer care in their home countries. The main results of the working groups presented in the final plenary session are summarized below.

***Working group A: Antigua and Barbuda, Barbados, Dominica, Grenada, Saint Lucia***

**Summary of emergent themes and next steps identified in working group A:**

- Implement assessment of women's cancer programs and services
- Enhance Cancer Registry
    - Review updated PAHO report on state of registries
    - Support drafting legislation and enforcing existing legislation
    - Technical assistance with regard to database management
    - Advocate for unique patient identifiers (important for the registries)
- Conduct Palliative Care Workshop (Caribbean Palliative Care Association, CARIPALCA and Caribbean Association of Hematologists and Oncologists) and Oncology Workshop (Caribbean Gynecological Cancer Society)
- Identify access to funding sources (e.g., through PAHO Strategic Fund)
- Develop updated and target age appropriate range and modalities for cancer screenings specific to Caribbean countries (COAH and CGCS)
- Improve quality control for ensuring testing accuracy (e.g., avoid exposure to heat)
    - Consider SOP's for specific diagnostics, treatment, screening interventions
- Conduct qualitative research/focus groups on self-exam/early detection experiences
- Reconcile positioning of where existing women's cancer programs fall within different ministry of health organizations: reproductive health (cervical cancer) and chronic NCD (breast cancer)
- Implement HPV updates and dialogue between countries about HPV vaccine experiences (i.e., get MSD* (vaccine manufacturer) involved)
- Conduct needs assessment/individual country status reports on current inventory of services/resources (PAHO publishing spring/summer 2016)
- Pool resources (knowledge, explore systems of purchasing morphine, etc. – pathology, radiation, specialized services)
- Create atlas/directory of all contacts of people/organizations working in the region on women's cancer
    - Develop social network communication strategies to support networking/information sharing/support within the region
- Initiate PAHO-led mentoring: where countries with more resources provide technical assistance to countries with fewer resources for developing cancer plan
- Develop social media outreach strategies to women population encouraging participation in screenings…sharing/disseminating tools and information
- Engage with cancer support services regarding survivorship and survivor support services…identify gaps.

***Working group B: Bahamas, Jamaica, Puerto Rico Trinidad and Tobago***
In addition to country plans, Working Group B identified common areas barriers and areas for improvement:

**Areas for improvement:**

- Cancer registries and data collection
- Dissemination of information across geographic, social and political barriers (e.g. ensuring)
- Communications across and within sectors (e.g. ensuring Ministries of Health communicate information out to health care providers and civil society, improving consistency of communication between civil society and physicians)
- Encouraging the utilization of services by the population
- Infrastructure and resources in the public health system
- Policies and procedures for diagnostic follow-up

**Barriers**

- Insufficient resources to implement and sustain programs
- Government, primary care, private care and civil society operating in silos
- Social and cultural challenges in encouraging utilization of services
- Limited ability to collect and interpret data
- Competing priorities on the funding agenda

**What success looks like**

- Public health systems with the infrastructure and resource capacity to address the population's needs
- Health NGO's focusing on advocacy, education, communication/awareness, patient support, accessibility and survivorship
- Data collection capacity established and maintained in -country

***Country-specific comments and action steps***

| Bahamas | |
|---|---|
| **Cancer Data Collection** | • The Bahamas doesn't have a cancer registry but this won't change policy<br>• Data collection related to how patients flow through the system will provide more information on where delays occur, what the issues are and how to address them |
| **Cancer Screening** | • Capacity to conduct sufficient screening exists but data doesn't reflect satisfying outcomes<br>• Improvements are needed in public awareness of the programs that do exist (this was highlighted as a "big thrust" in the near future)<br>• We need to make sure our medical education system reinforces the importance of screenings in universities and DM training |
| **HPV Vaccination** | • Vaccinations are being implemented but there is a need to |

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| | assess the extent to which vaccines are being administered and whether the system is effective<br>• Conduct a study of whether children are receiving the HPV vaccination and whether it is functioning<br>• There is a need to measure and maintain the quality of the code chain in the in-country distribution of vaccines |
| **Cancer Diagnosis and Treatment** | • Although diagnosis is typically made in "good time" it was noted that delays do occur<br>• The identified solution is to encourage continued dialogue among colleagues to reduce the incidences of delay from diagnosis to treatment<br>• Need to investigate opportunities for acquiring cancer medications (e.g. the PAHO Strategic Fund) |
| **Supportive/ Rehabilitative/ Palliative Care** | • These programs do exist in-country but need to be improved |
| **Immediate Action Steps** | • Improve dialogue between the Ministry of Health and health care workers across sectors<br>• Identify the stakeholders that are addressing various aspects of cancer in the Bahamas<br>• Increase PR and public awareness in terms of existing programs, with the goal of increasing uptake and utilization of services<br>• Assess and address data collection needs and capacity |

| **Jamaica** | |
|---|---|
| **Themes in Barriers** | Representatives from Jamaica distilled the barriers they identified into five thematic areas:<br>• Communications<br>• Education (medical and population)<br>• Finance/funding<br>• Team work<br>• Being proactive instead of reactive |
| **Immediate Action Steps** | |
| **Identify Stakeholders** | • Identify and engage stakeholders that can be leveraged to improve cancer care programs<br>○ Engage ground-level support (personal care assistants) to support public education and distribution of information<br>○ Leverage community leaders |
| **Convene Stakeholders** | • Bring stakeholders to the table from all levels, not just professionals with degrees, include people on the ground and in the field who know more about resources, stewardship and financing<br>• Develop a dedicated timeline and transparent process to encourage groups /individuals to work together and report back on progress |

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| **Conduct SWOT Analysis** | • Representatives identified a need to understand and quantify what they don't have and assess the what they do have |
| **Improve Communication** | • Communication from the Ministry of Health was cited as a barrier<br>• Representative agrees to work to advocate for increased communication from the Ministry of Health so that all partners have a clear sense of the situation and are operating with the same data |
| **Health Promotion** | • Develop a method for integrating health education into the population<br>  ○ For example: as students are transitioning out of the school system they take a class on important health issues. They then can serve as educators and trainers in their respective families and communities<br>• Engage the Ministry of Education in this discussion<br>• Assemble curriculum<br>• Request that physicians who regularly publish articles in newspapers and journals commit to writing one article a month on important health topics<br>• Request that television and radio programs dedicate air time to a promoting awareness of population health issues |
| **Leadership** | • Explore the possibility of establishing a technical leader for women's cancers in-country. This person would be responsible for managing and coordinating all activities related to women's cancers. |

| **Puerto Rico** | |
|---|---|
| **Puerto Rico has a comprehensive cancer care plan for 2015 – 2020, covering the continuum of care.** | |
| **Prevention** | • HPV vaccination has been lagging behind, however Puerto Rico has one of the highest vaccination rates in the United States |
| **Awareness** | • Puerto Rico is using social media and mass meetings to increase awareness within the population<br>• The country is also promoting the use of the registry as a tool to monitor the effectiveness of vaccination |
| **Collaborations** | • The comprehensive care plan calls for collaboration with different groups in the community, including:<br>  ○ FQHC – to implement more organized systems of screening |
| **Education** | • Puerto Rico is investing in educating providers on the importance of HPV vaccination |
| **Early Detection** | • The goal articulated in the country plan is to increase screening rates, particularly for cervical cancer |
| **Treatment** | • The country has fewer initiatives related to treatment.<br>• It is working on educating people about available resources and trying to increase participation in trials |

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| **Survivorship** | • The focus of Puerto Rico's work in survivorship is to increase awareness and utilization of existing resources |

| **Trinidad and Tobago** | |
|---|---|
| **Summary of Discussion** | • Trinidad and Tobago share a commonality with many of the interventions reported on by other country representatives<br>• Trinidad and Tobago considered in its planning the base concerns in order to identify priorities: financial, human resources, logistics, IT, stewardship and leadership<br>• Representatives considered PAHO's framework as well as national government policy, current economic constraints and the country's emphasis on vulnerable populations |
| **Identified Priorities** | • Enhance public education and awareness throughout public health, civil society and private sector, with the goal of fostering understanding that women's cancers are the #1 cancer killers of women<br>• Decrease stigma and misperception associated with screenings<br>• Leverage social media to increase education and awareness among vulnerable populations<br>• Promote advocacy to raise the issue of women's health as a political priority, leading to changes in policy and legislature<br>• Emphasize the review of Trinidad and Tobago's national plan, including the development of protocols for women's cancers management<br>• Enhance cancer registry<br>• Review access to essential medicine (particularly narcotics) and supply chains |

***Working group C: Belize, Curacao, Guyana, Suriname***

Priorities and immediate action steps reported on by countries in Working Group C are summarized below:

| **Belize** | |
|---|---|
| **Cancer plan** | • Belize currently has a cancer plan, although they expressed a need make the plan more operational, possibly through engaging consultative support to operationalize the plan |
| **Stakeholder buy-in** | • One of the immediate actions related to operationalizing the existing plan is to get buy-in from necessary stakeholders |
| **HPV Vaccinations/ Medication** | • Initiate relationship with PAHO revolving fund to begin procuring medicines through PAHO<br>• Assess medication needs, specifically among the cancer centers |
| **Leadership** | • Belize will reactivate its now dormant chronic NCD commission with representatives from different sectors. |

| | |
|---|---|
| | • This group will address, among other things, cross-cutting factors and develop a social marketing plan to look at public awareness and education need |
| **Information systems** | • Reach out to CARFA regarding support for launching a cancer registry in Belize |

| **Curacao** | |
|---|---|
| **Summary of Actions** | • Curacao currently has no national plan but the country does have a multidisciplinary team that meets weekly to discuss coordination of treatment<br>• The country has preventative measures that it conducts within the breast cancer and cervical cancer program<br>In 2017, they will begin administer the HPV vaccine<br>• Belize has a stated of the art oncology department in the hospital<br>• Coordinate awareness generated through TV and PR |

| **Guyana** | |
|---|---|
| **Summary of Priorities** | • Implement national polity and protocols for the country<br>• Organize an oncology ward<br>• Develop a palliative and outpatient center<br>• Implement breast cancer screenings nationally<br>• Utilize PAHO Strategic Fund to procure needed medication |

| **Suriname** | |
|---|---|
| **Summary of Long-Term Priorities** | • Update national cancer control plan<br>• Introduce HPV vaccination<br>• Revive database<br>• Implement pilot program for cervical cancer screenings<br>• Execute a data conference with NCI to discuss protocols for screening |
| **Mid-Term Priorities** | • Conduct an assessment of the health system to identify strengths and gaps<br>• Explore the possibilities of implementing a breast cancer screening program<br>• Explore using ultrasound diagnostics instead of mammography<br>• Develop a draft pan for supportive and rehabilitative care<br>• Update palliative care plan |

## 7. Session 7: identify opportunities for technical cooperation among countries and with international organizations

**Susan G. Komen** detailed the discussion of challenges and opportunities they'd had in their work group. They would like to hear more about regional needs surrounding the training of healthcare professionals, and to share promising practices and initiatives. They are interested in connecting groups across boundaries and understanding regional barriers to quality care. They want to help communicate recommendations to country leadership.

**ACS** gave information on its global program. It is small, but has plans for growth. The program focus areas represent the cancer continuum: prevention, patient support, and treatment. ACS highlighted their capacity to do more formative research on cancer knowledge and awareness and to share information. They noted poor uptake of the HPV vaccine in the U.S., and educational endeavors to improve uptake. The HPV fact sheets they create can then be adapted for other countries.

**Fred Hutchinson Center** detailed BCI2.5, and its goal to continue to make progress by aggregating knowledge about global cancer tactics.
NCI discussed last year's cancer summit and questions on how to move forward to engage other partners, and to make sure that what they have started keeps moving forward.

**ULACAAM** addressed specific opportunities for collaboration – the IGCS fellowship program, continuing research in the Caribbean, assisting the Ministry of the Americas with research – that arose at the Women's Cancer Meeting. They discussed potential results of the meeting, such as a comparative academic publication on palliative care.

## Concluding remarks

***Silvana Luciani, PAHO; Areana Quiñones, PAHO Foundation***

In closing, Silvana Luciani thanked participants for their contributions to a rich two-day meeting and expressed her gratitude to participants for sharing information on their challenges and ideas on how to improve women's cancers in the Caribbean. She remarked that this is an important time to make a difference in the detection, treatment and prevention of breast and cervical cancer in the Caribbean. PAHO is committed to continuing to foster and cultivate this network of country leaders in a more formal and structured manner around a Caribbean Women's Cancer Initiative focused on providing technical assistance in the areas of advocacy, assessments, guidelines and protocols and capacity building. She reminded representatives to bring to the attention of their Ministries of Health the resources PAHO offers through its Strategic Fund and Revolving Fund. Going forward, PAHO will identify themes that focus on the priorities discussed to inform ongoing work with the governments of countries in the English Caribbean. From

PAHO Washington, the organization will be able to through country offices to advance the work initiated during this meeting.

**Areana Quiñones** expressed her thanks on behalf of the Board of Trustees and leadership of PAHO Foundation to Dr. Felicia Knaul of the University of Miami for serving as host, and PAHO and its partners for an educational and energizing meeting. She offered the Foundations' commitment to continuing to support women's cancers initiatives in the Caribbean by bringing to the table nontraditional, private and public sector partners along with chambers of commerce within the region. PAHO Foundation brings new ideas and critical resources to the region to advance women's cancer prevention and care. In addition to supporting PAHO's mission, PAHO Foundation is also an independent 501(c)3 interested in exploring opportunities to engage with other partners in the region to making long-term systemic change

# Appendices

## *Appendix I: meeting agenda*

### Women's Cancers in the English Caribbean:
**A regional multi-sector discussion to define feasible strategies to improve the effectiveness of breast and cervical cancer programs**

**May 11-12, 2016**
**University of Miami, Casa Bacardí**
**1531 Brescia Avenue, Coral Gables, Florida, USA**

**AGENDA**

**BACKGROUND:**

In the English Caribbean, breast and cervical cancer are the leading cancers among women, with more than 16,000 women diagnosed and more than 6,000 women dying from this disease each year. Bahamas and Barbados have the highest incidence rates from breast and cervical cancer, of over 100/100,000 women. If the status quo is maintained, breast and cervical cancer incidence in the Caribbean is expected to increase by almost 40% by 2030.

Through the PAHO Plan of Action for the Prevention and Control of Noncommunicable Diseases (NCDs) in the Americas 2013-2019, Ministries of Health have recognized the need to improve the situation for women's cancer and other NCDs. Among the commitments, is to increase breast cancer screening to at least 50% coverage in women ages 50-69 years and to increase cervical cancer screening to at least 70% in women aged 30-49 years, while ensuring effective and timely cancer treatment and palliative care. Because of the challenges associated with cancer prevention and control, very few countries in the English Caribbean have reached the screening coverage indicators and face numerous challenges to improve cancer treatment and palliative care services.

Collaboration among governments, civil society and academia, including international cooperation and South-South collaboration can accelerate the number of countries that achieve a high screening coverage, and improve access and quality of their breast and cervical cancer programs to improve outcomes for women.

Therefore, PAHO, with the support of the PAHO Foundation and together with the Miami Institute for the Americas and the Sylvester Comprehensive Cancer Center at the University of Miami and the Breast Cancer Initiative 2.5, are cohosting a sub-regional forum to identify potential areas of collaboration to support countries in the Caribbean to improve the effectiveness of women's cancer programs.

1

**PURPOSE:**

1. To present the currently available knowledge, evidence and scientific gaps on breast and cervical cancer prevention, screening, early detection, treatment and palliative care.
2. To discuss strategies, successful experiences and challenges in implementing breast and cervical cancer programs in the Caribbean.
3. To exchange ideas and identify opportunities for evidence-based approaches to improve financing, access, quality and utilization of women's cancer services.
4. To define an operational research agenda for breast and cervical cancer in the region.

**EXPECTED OUTCOMES:**

1. Report on country situation assessment that describes: the breast and cervical cancer situation, program status, health system gaps and barriers, and potential areas for international collaboration to improve women's cancer outcomes.
2. Draft country plans for advancing international cooperation vis-à-vis women's cancer control.
3. Expanded network and increased collaboration and engagement of governments, civil society and international organizations to improve women's cancers in the Caribbean.
4. Report and manuscript describing the proceedings and outcomes of the meeting.

**MEETING SCHEDULE:**

**Wednesday, May 11, 2016**

| | |
|---|---|
| 7:20am | meet in lobby of the Biltmore hotel |
| 7:30am | shuttle transfer from Biltmore hotel to Casa Bacardi for breakfast |
| 8:00am | breakfast and networking at Casa Bacardi |
| 9:00am | meeting begins |
| 6:15pm | meeting ends |
| 6:30pm | transfer from Casa Bacardi to IBIS House for UM dinner reception |
| 7:00pm | dinner reception at IBIS House |

**Thursday, May 12, 2016**

| | |
|---|---|
| 7:20am | meet in lobby of the Biltmore hotel |
| 7:30am | shuttle transfer from Biltmore hotel to Casa Bacardi for breakfast |
| 8:00am | breakfast and networking at Casa Bacardi |
| 9:00am | meeting begins |
| 5:00pm | meeting ends |
| 5:30pm | shuttle transfer from Casa Bacardi to Biltmore hotel |

| Wednesday May 11, 2016 | |
|---|---|
| 9:00am | **WELCOME AND OPENING REMARKS:** *Representatives from PAHO,UM, and BCI2.5* |
| 9:15am | **KEYNOTE ADDRESS:** *Dr. Julio Frenk, President, University of Miami* |
| 9:45am | Questions and answers |
| 10:00am | COFFEE BREAK |
| 10:15am | **SESSION 1: OVERVIEW OF WOMEN'S CANCERS AND INTEGRATING SERVICES INTO HEALTH SYSTEMS** |
| 10:20am | Closing divides: health system responses to the challenge of breast and cervical cancer. *Dr. Felicia Knaul, University of Miami* |
| 10:40am | Breast and cervical cancer in the Caribbean and PAHO/WHO recommendations. Ms. *Silvana Luciani, PAHO* |
| 10:50am | Discussion |
| 11:15am | Breast cancer: Services and resources needed for improved outcomes. Dr. *Ben Anderson, Fred Hutchinson Cancer Centre* |
| 11:30am | Cervical cancer: evidence based approaches. *Dr. Erin Kobetz, University of Miami* |
| 11:45am | Palliative care: how to expand access in the Caribbean. *Dr. Dingle Spence, Hope Institute, Jamaica* |
| 12:00pm | Remarks from conversation catalysts – *Dr. Judith Hurley, Dr. Gilberto Lopes, and Dr. Ramon Figueroa* |
| 12:30pm | Discussion |
| 1:00pm | LUNCH and Lunchtime speaker: Dr. Donette Francis, University of Miami |
| 2:00pm | Free time |
| 2:30pm | **SESSION 2: COUNTRY EXPERIENCES ON IMPROVING WOMEN'S CANCERS: Government perspectives** Brief introduction of the panel of Ministry of Health representatives who will discuss experiences and challenges in reducing the burden of women's cancers in their country. |
| 2:35pm | **Bahamas** – Dr. Raleigh Butler |
| 2:50pm | **Barbados** – Dr. Heather Armstrong |
| 3:05pm | **Puerto Rico** – Dr. Guillermo Tortolero-Luna |
| 3:20pm | **Trinidad and Tobago** – Dr. Dylan Narinesingh |
| 3:35pm | Discussion: this will be an opportunity for all other government representatives to provide brief remarks |
| 4:00pm | COFFEE BREAK |
| 4:15pm | **SESSION 3: CIVIL SOCIETY EXPERIENCES IN IMPROVING WOMEN'S CANCER IN THE CARIBBEAN** Brief introduction of the panel of civil society representatives who will discuss experiences in mobilizing communities and improving cancer outcomes. |
| 4:20pm | **Susan G. Komen Foundation** – Dr. Anna Cabanes |
| 4:35pm | **Healthy Caribbean Coalition** – Mrs. Maisha Hutton |
| 4:50pm | **Belize Cancer Society** – Mrs. Laura Longsworth |
| 5:05pm | **Jamaica Cancer Society** –Mrs. Yulit Gordon |
| 5:20pm | Discussion: this will be an opportunity for all other civil society representatives to provide brief remarks |

| | |
|---|---|
| **6:00pm** | **Wrap up of Day 1** |
| **6:15pm** | **Adjourn and transfer to Ibis House for dinner reception** |

| **Thursday May 12, 2016** | |
|---|---|
| **9:00am** | **REVIEW of the discussions and results of the first day** |
| **9:10am**<br><br>9:40am<br><br>9:50am | Comprehensive cancer centers: minimum requirements and considerations for limited resource settings.<br>*Dr. Mary Gospodarowicz, Princess Margaret Hospital, Canada*<br><br>Role of the IGCS in global gynecologic cancer prevention and treatment<br>*Dr. Linus Chuang, International Gynecologic Cancer Society*<br><br>Discussion |
| **10:00am** | **SESSION 4: WORK GROUP SESSIONS TO DEVELOP COUNTRY ACTION PLANS:**<br><br>Participants will break out into smaller work groups to discuss a set of questions to define in more depth, the situation, challenges, strategies and country action plans to improve women's cancer programs in the Caribbean. Each group will be composed of a mix of representatives from government, civil society and academia (see attached list of working group composition).<br><br>Coffee provided in the work group rooms |
| **1:00pm** | **LUNCH and brief overview of mapping and other survey tools** |
| **2:00pm** | **SESSION 4 cont'd:** finalize country plans in work groups |
| **3:00pm** | **SESSION 5:** Brief report back from each country on action plans and commitments for next steps. |
| **3:45pm** | **COFFEE BREAK** |
| **4:00pm** | **SESSION 6: IDENTIFY OPPORTUNITIES FOR TECHNICAL COOPERATION AMONG COUNTRIES AND WITH INTERNATIONAL ORGANIZATIONS:**<br>PAHO, U. Miami, Fred Hutch/BCI2.5, Susan G. Komen, and ULACCAM |
| **4.30pm**<br><br>**4:45pm** | **Final agreements: Priorities and recommendations**<br><br>**Conclusions and next steps** |
| **5.00pm** | **Adjourn** |

## *Appendix II: participant, observer, and meeting staff list*

# Women's Cancers in the English Caribbean:

**A regional multi-sector discussion to define feasible strategies to improve the effectiveness of breast and cervical cancer screening programs**

**May 11-12, 2016**
**University of Miami, Casa Bacardi**
**1531 Brescia Avenue, Coral Gables, Florida, USA**
**PARTICIPANTS**

**Antigua & Barbuda**
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Medical Officer of Health
Ministry of Health

Ms. Valarie Williams
NCD Focal Point
Ministry of Health

Ms. Eunetta Bird
President
Breast Friends-Women in Touch

**Bahamas**
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Consultant/Oncologist
Ministry of Health

Dr. Williamson Chea
Vice President
Cancer Society of the Bahamas

**Barbados**
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Senior Medical Officer of Health
Ministry of Health

Dr. Vikash Chatrani
Medical Director
Barbados Cancer Society

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Temporary Lecturer- Public Health
University of West Indies

Ms. Maisha Hutton
Executive Director
Healthy Caribbean Coalition

**Belize**
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Chief Medical Officer of Health
Ministry of Health

Mrs. Laura Longsworth
Executive Director
Belize Cancer Society

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**Dominica**
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Ministry of Health

**Grenada**
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Chief Community Health Nurse,
Ministry of Health

**Guyana**
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Medical Doctor
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Mrs. Yulit Gordon
Executive Director
Jamaica Cancer Society

Dr. Dingle Spence
Senior Medical Officer
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Dr. Aleiya Virgo-Herron
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Dr. Maryam Richards
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St. George West

Dr. Jacqueline Sabga
Executive Director
Trinidad & Tobago Cancer Society

**PARTNER ORGANIZATIONS**

**American Cancer Society**

Ms. Jacqui Drope
Managing Director
Global Cancer Prevention

**Harvard University**

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Research Associate
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**International Gynecologic Cancer Society**

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Chair, Society of Gynecologic Oncology International Committee

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**University of Washington/Fred Hutchinson Cancer Centre**
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Ms. Allison Dvaladze
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Dr. Catherine Duggan
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**USA- Centers for Disease Control**
Dr. Denisse Duran
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**PROFESSIONAL FACILITATORS**
Mr. John Davidoff
Founder and Chief Mission-Driver
Davidoff Mission-Driven Business Strategy

Ms. Lynette Morris
Vice President
Davidoff Mission-Driven Business Strategy

## *Appendix III: working group session agenda and worksheets*

**Women's Cancers in the English Caribbean:**

A regional multi-sector discussion to define feasible strategies to improve the effectiveness of breast and cervical cancer programs

# WORK GROUPS TO DEVELOP COUNTRY ACTION PLANS

| PURPOSE | |
|---|---|
| To jointly develop a plan of action to improve breast and cervical cancer programs in the Caribbean, including capacity building, access to services and program strengthening; and define next steps to begin its implementation. | |
| **WORK GROUP AGENDA** | |
| 10:00:-10:05am | **Introductions and review work group methodology and objectives** |
| 10:05-10:30am | **Group discussion: reflections on improving breast and cervical cancer prevention and control programs in the country**<br>Brief reflections on what is needed for a successful program on cervical and breast cancer prevention and control in the country.<br><br>*Sheet 1* to be used by each participant to record notes |
| 10:30-10:45am | **COFFEE BREAK** |
| 10:45-11:45am | **Group discussion: Barriers and possible solutions to improve breast and cervical cancer programs in the country**<br>1. What are the barriers in your country to establish and implement such a successful program?<br>2. Considering the identified barriers, what are some possible solutions to address each barrier?<br><br>*Sheet 2* to be used by each participant to record their notes |
| 11:45am- 1:00pm | **Action planning:** Each country team prepares a one year plan of action to address the identified barriers and solutions<br>*Sheet 3* to be used by each country team to record their plans |
| 1:00-2:00pm | **LUNCH** |
| 2:00-3:00pm | **Action plan continued:** country representatives discuss their plans for feedback and further input/refinement. Then, identify the immediate next steps to be completed in 1-2 months.<br>*Sheet 3* to be used by each country team to record their plans |
| 3:00pm | **BACK TO PLENARY SESSION:** Report back – reflections from each group and report back on commitments for immediate next steps |

# SHEET 1

## REFLECTION ON WHAT IS NEEDED FOR BREAST AND CERVICAL CANCER PREVENTION AND CONTROL IN THE CARIBBEAN

Briefly discuss and reflect on what is needed for a ’successful’’ program on cervical and breast cancer prevention and control, such as:

- National cancer policy or plan that includes the country’s policy on HPV vaccination, breast and cervical cancer screening/early detection, diagnosis, treatment, palliative care.
- Health system capacity to detect, diagnose, and treat cancer and provide palliative care. This includes adequate primary, secondary, and tertiary health care facilities, referral mechanisms, infrastructure and functioning equipment, supplies, and adequate number of trained health providers.
- Community education, outreach and information for an informed and involved community.
- Organized program, that provides maximal screening coverage of women in the at risk age group (typically 30-49 years for cervical cancer, and 50-69 years for breast cancer) and follow up care to ensure all women receive timely diagnosis and timely treatment.
- Treatment protocols for breast and cervical cancer.
- Quality assurance and quality control procedures to achieve high quality of testing and care.
- Sufficient funding for services and an organized program.
- Cancer registry for monitoring and evaluation and program planning.

Record any notes here:

## SHEET 2

### BARRIERS AND SOLUTIONS

Based on the discussion and reflections on what is needed for a successful breast and cervical cancer program in your country, identify the barriers and possible solutions to improve breast and cervical cancer prevention and control programs in your country.

| | | Barriers | Possible solutions |
|---|---|---|---|
| **HEALTH POLICY AREAS** | **Overall health system issues (eg. infrastructure, providers, funding, etc)** | | |
| | **National cancer plan** | | |
| | Other: | | |
| **SPECIFIC TOPIC AREAS** | **Advocacy, communication and community mobilization** | | |
| | **HPV vaccination** | | |
| | **Cervical cancer screening and precancer treatment** | | |

## SHEET 3

### ACTION PLAN FOR THE COUNTRY TO ADDRESS THE BARRIERS AND SOLUTIONS

1. Identify the actions – note whether they are immediate, medium term or long term- to improve the cervical and breast cancer program in your country.
2. Identify who would/could be responsible for these actions to be completed.
3. Note the type of support, and possible sources of this support, needed to put implement the actions.

| | | Actions | Responsible | Support needed (+possible sources) |
|---|---|---|---|---|
| GENERAL | Overall health system issues (eg. infrastructure, providers, funding, etc) | | | |
| | National cancer plan | | | |
| TOPIC SPECIFIC | Advocacy, communication and community mobilization | | | |
| | HPV vaccination | | | |

## *Appendix IV: links to meeting materials*

A complete list of meeting materials and presentations can be found here.