Women’s Cancer Initiative of the Pan American Forum for Action on NCDs (PAFNCD)

Report of the First Meeting of Public-Private Sector Partners
5-7 February, 2013
PAHO office, Washington D.C.
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I. BACKGROUND

The Pan American Health organization convened a small group of its Member States and partner organizations for a meeting on women’s cancers, as part of the Pan American Forum for Action on NCDs (PAFNCDs). The meeting took place at the PAHO headquarter office in Washington, DC on February 5-7, 2013, with over 90 participants from governments, international organizations, non-governmental organizations and the private sector.

The purpose of this first meeting of the Women’s Cancer Initiative (WCI) was to jointly create an operational work plan that will mobilize communities and stakeholders, build capacity, scale up access to HPV vaccination, breast and cervical cancer screening, diagnosis, treatment, and palliative care, and expand operational research.

Many organizations have been working for several years to address women’s cancers, including the Pan American Health Organization (PAHO), World Health Organization, International Agency for Research on Cancer, Union for International Cancer Control together with Ministries of Health in the Americas; international and national non-governmental organizations, professional associations, and private sector companies. Several coalitions have already been created, including the Alliance for Cervical Cancer Prevention, the Breast Health Global Initiative, and the network of Cancer Institutes of the Americas (RINC). Thus, the time is ripe to create this platform for public-private partnerships that will catalyze and synergize all organizational efforts around the common goal of reducing morbidity and mortality from breast and cervical cancer.

The objectives of the first WCI meeting were as follows:

1. To exchange information about current breast and cervical cancer prevention and control initiatives in the Americas, and identify the gaps and needs for policy, programs and services, and research.

2. To discuss ideas and proposals for advancing breast and cervical cancer prevention and control in the Americas through four main areas of work: a) communications and social mobilization; b) capacity building for providers and program managers; c) access to services
and program strengthening, including guidelines and cancer registration; and d) operational research.

3. To jointly develop a workplan for breast and cervical cancer prevention and control, including specific objectives, activities and expected results which PAHO, Member States and partner organizations can execute together through the PAF Women’s Cancer Initiative.

4. To jointly identify opportunities to mobilize the additional necessary resources to make the implementation of the plan possible.

This report summarizes the presentations and discussions which took place during the meeting. Prior to the meeting, participants provided a summary of their work in the area of women’s cancers and an initial mapping of the various activities in the Region was prepared. To obtain results of this mapping exercise, more information about the initiative and to access the presentations made during the meeting, please visit the Women’s Cancer Initiative on the PAFNCD website: http://new.paho.org/panamericanforum/?p=948

II HIGHLIGHTS FROM THE FIRST MEETING OF THE WOMEN’S CANCER INITIATIVE

Opening session

Dr. Carissa Etienne, having taken office as Director of the Pan American Health Organization on February 1, 2013, opened the meeting reaffirming her commitment to non-communicable diseases and cancer as a priority for the organization. She noted PAHO’s convening power and catalytic role, as well as honest brokering role, which will continue to be amplified, as well as continuing to build new alliances and relationships across sectors to create a strong multi-sector response to the NCD problem in the Americas. Noting the tremendous burden and suffering caused by breast and cervical cancer in the Region, Dr. Etienne expressed the unique position of PAHO to mobilize high-level political support for women’s cancers, and the intention to do so through advocacy and through PAHO’s normative role and building country capacity for cancer prevention and control.

Dr. Julie Torode, of the Union for International Cancer Control joined Dr. Etienne to provide welcoming remarks on behalf of civil society organizations. She noted the alignment of goals of the UICC with that of this Women’s Cancer Initiative, and commented that the UICC’s priorities
are to: improve access to cancer medications; scale up palliative care services; support national cancer control plans and strengthening cancer registries; and to country specific projects which build civil society capacity for cancer control.

Dr. Luiz Santini, Director of the Brazil National Cancer Institute and Director of the South American network of National Cancer Institutes (RINC) provided welcoming remarks on behalf of the governments. He highlighted the leadership role of Brazil in instituting comprehensive breast and cervical cancer programs in their public health system, as well as the lead role of Brazil in creating the network of cancer institutes to foster south-south collaboration. He noted the opportunity that this multi-stakeholder Women’s Cancer Initiative creates for the RINC network to synergize actions around women’s cancers.

Dr. Andrew Rudman, from the Pharmaceutical Research and Manufacturers of America (PhRMA) provided welcoming remarks on behalf of the private sector partners. He pledged pharma’s support to this multi-stakeholder initiative, and noted that many of their member companies are currently engaged in public-private partnerships including the Pink Ribbon Red Ribbon initiative.

Session I: PAFNCD Women’s Cancer Initiative

Dr. Irene Klinger introduced the concepts and ideas, as well as the achievements over the past year of the Pan American Forum for Action on NCDs (PAFNCD). Since it was launched at the time of the UN High Level Meeting on NCDs in September 2011, the PAFNCD has convened public and private sector partners at its first Forum meeting in Brazilia 2012, and then subsequently convened specific meetings with Forum partners on physical activity, salt reduction, and now this one on women’s cancers. The role of the PAFNCD is to bring the multi-
sector approach to help countries implement the NCD political mandates, commitment and policies which the governments have established.

Ms. Silvana Luciani provided an overview of the burden of cervical and breast cancer, noting the inequities associated with the over 400,000 women newly diagnosed each year and approximately 130,000 women dying each year in the Americas. She highlighted the advances being made by governments in HPV vaccination, screening, treatment, and palliative care; as well as the technical support which PAHO has been providing to Member States in these areas. She then introduced the Women’s Cancer Initiative framework, which will work across four main areas: communications and advocacy; building capacity; increasing access to services and strengthening programs; and operational research.

Session II: Building on Global and Regional Initiatives for Women’s Cancers

The World Health Organization’s work in women’s cancer was presented by Dr. Islene Araujo, from the perspectives of a healthy lifecourse approach. She urged participants to consider an integrated approach to women’s cancer, rather than vertical programmatic approach; and one that strengthens the health system response for women’s cancers, while intervening early in the lifestage; as well as addressing gender equality, social inclusion and cultural beliefs/barriers. She reaffirmed WHO’s commitments to partnering on the topic of women’s cancers, and noted the forthcoming special issue of the WHO Bulletin on this topic.

The Harvard Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries was presented by Dr. Felicia Knaul. She described the equity imperative for cancer and called attention to the urgent need to close the cancer divide through innovative delivery design, access to medicines and treatment, and innovative financing schemes. She provided the example of Mexico of integrating breast and cervical cancer interventions into their anti-poverty scheme and integrating financial protection for cancer into health coverage. She also noted that machismo and stigma are the societal cancers which must also be beaten.

International initiatives of the Susan G Komen for the Cure were described by Ms. British Robinson who noted the clarion call to act as a community for women’s cancers. She highlighted Komen’s core competencies and examples of their 20 years of international work, including the Pink Ribbon Red Ribbon initiative. She announced Komen’s new global breast cancer program, which aims to save 2.5 million women’s lives by 2025, through earlier detection, increased access to treatment and palliative care, and supportive care.
Mr. Walter Zoss, serving as the secretariat for the South American network of Cancer Institutes (RINC) gave an overview of this network’s history which began in 2007 at the time of the International Cancer Control Congress in Brazil, and its evolution to a network of countries working together in the priority areas of: cervical cancer, tobacco control, biobanks, quality assurance for mammography. The RINC cervical cancer group has already developed a proposal and will begin to implement joint activities soon in the following areas: HPV vaccination, HPV testing, examining barriers to follow up care, screen and treat approaches, and health information systems.

A new cervical cancer project for Latin America and the Caribbean, developed jointly by the US Department of Health and Human Services including CDC and NCI, the American Cancer Society and PAHO, was presented by Dr. Marcus Plescia and Dr. Cristina Parsons-Perez. The project aims to create at least 4 training centers in the region which would serve as resource centers for clinical and programmatic aspects of cervical cancer; create a social movement for cervical cancer; strengthen screening and HPV vaccination; and undertake operational research. This cervical cancer project serves as a starting point for the Women’s Cancer Initiative, and additional partners were invited to participate in the project.

Session III: Mapping Regional Initiatives on Women’s Cancers

In this session, all participants attending the meeting were provided an opportunity to inform about their current priorities and work in the region of the Americas on women’s cancers. NGO partners, governments, international organizations, and private sector partners spoke of a variety of initiatives, allowing participants to familiarize with each other’s work and identify possible connections. For a summary of each organization’s initiatives, please refer to the results of the mapping exercise available on the PAFNCD website.
Session IV: Communications and Advocacy

The issue of engaging women’s groups for social mobilization in the Americas was presented by Dr. Cristina Parsons Perez, from the perspectives of the American Cancer Society’s work to build NGO capacity in Latin America over the past 15 years. She noted the importance of a robust NGO movement to drive a policy agenda for cancer and break the social stigma and silence on cancer. Ms Bertha Aquilar provided a tangible example of social engagement and advocacy for women’s cancers, through the work of her Mexican NGO CIMAB, as well as the network of NGOs, ULACAM, which she is coordinating. She stressed the importance of empowering women with information, supporting survivors and supporting women to demand their rights to timely diagnosis and treatment services.

The voice of patients and advocating for cancer patients was presented by Dr. Eva Maria Ruiz, from the perspective of the experiences in Peru in her NGO, Esperantra. There are many health system barriers which prevent women from receiving adequate care, that NGO involvement to support patients and coordination of their care is so instrumental to improving outcomes. She also noted that patient groups are an important constituency to help shape health policy.

The Healthy Caribbean Coalition (HCC), a grassroots civil society movement for NCDs in the Caribbean, was presented by Ms. Maisha Hutton. HCC is initiating a Caribbean wide cancer NGO network to collectively advocate for better cervical cancer screening services, and provide support and linkages between communities and health services.

In the discussion on this topic, the participants noted the importance of empowering women to make their own decisions about their health, involving men in communications and advocacy initiatives, as well as women’s groups and linking to the broader women’s health agenda. Several innovative community based communication activities were mentioned, including Grounds for Health’s work with coffee cooperatives, Jamaica Ministry of Health engaging taxi drivers as health educators, and Mexico’s campaign “Favor de tocar”.

Session V: Primary Prevention

What is known and the gaps in knowledge about breast cancer prevention was presented by Dr. Isabelle Romieu from the International Agency for Research on Cancer. The evidence was emphasized on nutrition and links to breast cancer, particularly high intake of sugar, low intake of fiber and folates, high intake of ultra-processed foods and trans-fatty acids, vitamin D deficiency, obesity and alcohol. This calls for the need for more evidence based prevention.
strategies, which will benefit not only breast cancer but NCD risk reduction overall. The recommendations are: to eat mainly foods of plant origin, maintain a healthy body weight into adulthood, moderate intake of alcohol, limit consumption of energy dense foods and engage regularly in physical activity. To better understand the breast cancer risk factors in the Latin American population, and distribution of phenotypes and genetic characteristics, IARC is beginning a new multi-centre study called PRECAMA, in pre-menopausal women in the region.

Dr. Andrea Vicari from PAHO’s immunization program provided a status report on HPV vaccination in the region. Ten countries in the Americas include HPV vaccines in their publicly funded, national immunization programs, an illustration that it is feasible to create sustainable HPV vaccine programs in the region. The barriers for more rapid introduction are that these vaccines are still perceived as being unaffordable and too expensive, and the perceptions of uncertainty around effectiveness, safety, and duration of protection. Dr. Vicari noted that a regional framework for HPV vaccine monitoring and evaluation is currently in development, and will include short, medium and long term indicators of vaccine coverage, HPV typing and prevalence of HPV, pre-cancer and invasive cervical cancer. How this will be carried out will depend on the country, and available resources, but will involve sentinel surveillance, population based surveys, and cancer registration.

In the discussion on this topic, participants emphasized the need for more and accurate messages to adolescent girls about lifestyle and risk reduction for both breast and cervical cancer, as well as about HPV vaccines. The research priorities in this area were also noted and included: testing 2 dose vs 3 dose of HPV vaccines, cultural factors associated with screening and HPV vaccine coverage.
Session VI: Screening, Early Detection and Treatment

Dr. Ben Anderson presented on breast cancer guidelines and the experiences of the Breast Health Global Initiative (BHGI). He noted that an estimated 18% of breast cancers are preventable, and that downstaging the disease and providing early treatment in low and middle income countries need to be the priorities. The BHGI guidelines are a tool which offer evidence based guidance on health system strengthening for breast health. He noted how the tool has been used in Colombia, which illustrated how educating health providers in the guidelines led to earlier stage diagnosis; and in Peru, where a community based education and primary health care approach were being tested.

The new WHO cervical cancer control guidelines were presented by Dr. Nathalie Broutet, and they will be issued formally later this year. The guideline will include recommendations on HPV vaccines, HPV testing and VIA screening, as well as the traditional cytology screening, and include algorithms to aid clinical decision making. The guideline was developed using the WHO GRADE approach for guideline development which involves an extensive review of the literature along with expert input.

In the discussion on this topic, several countries noted that screening coverage for breast and cervical cancer were very low and that there was a need to understand the reasons and test innovative strategies to increase screening coverage. Other countries, like Colombia, noted that the screening coverage was not their greatest challenge, but the follow up diagnosis and treatment, which also require further investigation to understand the barriers and to test strategies to overcome this. The issue of training primary care providers in health education and screening was also emphasized.

Session VII: Operational Research

The status and plans for operational research in cervical cancer was presented by Dr. Rolando Herrero from the International Agency for Research on Cancer. He noted that HPV testing, in addition to being a more accurate screening test than cytology, offers the advantage of extending the screening intervals and thus optimizing limited resources. The question remains, however, about how best to manage women with HPV positive test results. Thus, IARC is beginning a new multi-centre study, ESTAMPA, to test the various options for triage of HPV positive women in Latin America.
The WHO is currently undertaking cost-effectiveness studies on breast cancer screening in 5 Latin America countries and Dr. Cecilia Sepulveda presented the preliminary results of the studies. These studies have helped build capacity for cost-effectiveness analysis, and have also given countries more local data upon which to base their policy decisions on screening methodology.

In the discussion, it was noted that translating all the research results into changing policies, programs and clinician practice was perhaps the greatest challenge before us. The need to further disseminate results from current breast and cervical cancer studies from this Region was also noted. NIH has funding opportunities for dissemination and implementation research.

Session VIII: Resource Mobilization

A panel on the opportunities which exist to mobilize resources for women’s cancers was presented. From the World Bank, Dr. Fernando Lavadenz noted that more intelligence is still needed on women’s cancers, for example not enough documented experiences on the impact of interventions, few risk factor studies have been done, and data on the local burden of disease is still needed as well as proof of principle that interventions are feasible in low income settings. Then Finance Ministers need to be engaged more broadly on discussions of financing services.

From the perspectives of the Pan American Health and Education Foundation, Eli Brtva offered suggestions to be more donor-centric, to listen to what philanthropists and donors are willing to invest in and to consider corporations, individuals as well as foundations and inspire the donors with innovative ideas and very specific ‘asks’.

Dr. Maria Freire from the Foundation for the National Institutes of Health offered that communications and advocacy are intimately linked to resource mobilization. And that the group should define the human, technical and financial resources needed to solve the problem. The donor landscape is changing and although philanthropy in the USA is very large, it is non-existent outside the USA. She suggested identifying and mapping the potential donors in countries in Latin America and the Caribbean, and identifying women’s groups who have influence, power and decision making authority to engage them in the cause.
Session IX: Towards the Multi-stakeholder Plan of Action for Women’s Cancers in the Americas

The last day of the meeting was used to collectively discuss and begin to develop a joint plan of action for the Women’s Cancer Initiative. Below is a summary of the ideas, according to the four areas of work for the initiative. This is a preliminary list which participants recognized requires further discussion with additional partners, and fleshing out of detailed activities, identification of resources and responsibilities.

COMMUNICATIONS AND ADVOCACY

ADVOCACY:
- Map NGO capacity/needs, policy and advocacy models (regionally and by country).
- Build NGO capacity (informing on value of advocacy, training, etc).
- Empowerment of women’s groups, male involvement (especially for cervical cancer).
- Engagement of 1st ladies, and other powerful/influential decision makers (eg. Female Heads of State).
- Identify and foster champions, survivors, models for advocacy for cervical cancer.

COMMUNICATIONS:
- Assess country communication ability/strategies and share communication strategies/materials, successful communication campaigns.
- Qualitative studies: understanding how people access health information, interpret it, specific to the country/context.
- Define clear and common messages to drive behavioral change, per target audiences and media channels (by country, by disease).
- Use a common/aligned media campaign for all of us in this partnership.
- Media outreach: Traditional: tv, radio, mass media
- Social media: MHealth, e-health, text messages for cxca and brca
- Use patient voice in storytelling.
- Develop an education/curriculum for virtual and in-person courses for health promoters and providers for breast and cervical cancer education.

CERVICAL CANCER: CAPACITY BUILDING

The proposed cervical cancer project, developed by PAHO, ACS and the US Department of Health and Human Services, including CDC and NCI, was felt by the participants to be a good starting point for joint work. It was noted that the project should support the RINC cervical cancer working group priorities: HPV vaccination, HPV testing, examining barriers and strategies to improve follow up and treatment, screen and treat strategies, and health information system strengthening. Participants also requested that the following topics be included in the workplan for cervical cancer:
• HPV vaccine roll out, M&E, sharing experiences.
• Include all screening tests: VIA, Cytology, HPV testing.
• Knowledge exchange of teams going to country that need assistance, not only having training centres in well resourced countries.
• Capacity building for clinical aspects as well as program management and evaluation.
• Virtual training and q.a./q.c.
• Add stakeholder meetings to disseminate evidence, encourage adoption of new strategies.
• M&E: provide models for info systems, strengthen and use mortality data, provide methodology (including indicators) for standardized approach.
• Emphasize palliative care in this proposal as well the breast cancer activities.
• Roll of communities as partners for capacity building—mobilize communities.
• Case studies: document and disseminate what is being done, what are the challenges, solutions, etc. with regards to cervical cancer screening, diagnosis, treatment, community education, research in the Region.

BREAST CANCER: CAPACITY BUILDING
• Situation assessment/ mapping of breast cancer situation and of health system capacity for screening, diagnosis, treatment, palliative care.
• Guidelines for breast cancer prevention and control.
• Framework for decision making (algorithm) on what strategies to use based on system capacity and breast cancer situation.
• Models of care (eg. symptomatic management, treat and cure what is curable).
• Education and training: of providers, health promoters, technicians, (eg.QA/QC mammography, CBE, community outreach, diagnosis).
• Case studies: document and disseminate what is being done, what are the challenges, solutions, etc. with regards to breast cancer screening, diagnosis, treatment, community education, research.
• Treatment access: Inform and advocate for the use of the PAHO Strategic Fund to procure cancer drugs.
• Examine how to reduce barriers to availability of medicines.
• Review and provide models for health insurance schemes/financing mechanisms to reduce barriers of costs of treatment.

OPERATIONAL RESEARCH
1-Health systems research:
• Needs assessment and asset mapping of screening, diagnosis, treatment services at country level.
• Evaluation to understand barriers and enablers for access to screening, diagnosis, treatment and palliative care.
• Pharmaco-vigilance (post treatment follow up esp. for breast cancer patients).
2-Operational research/implementation studies:
- Support/expand IARC studies in the LAC region: ESTAMPA (triage testing for HPV screening) and PRECAMA studies (case-control study on pre-menopausal breast cancer).
- Evaluate introduction of new screening tests (HPV testing, VIA) in selected countries.
- Evaluate and document HPV vaccination experiences (2 doses vs 3 doses; what works, what doesn’t work; lessons learned from successful experiences)
- Test models of care which integrate services for women’s health in primary care level (eg. blood pressure checks, glucose testing, routine screening, etc)

3-Qualitative research (KAB)
- Studies to better understand women’s attitudes, perception, barriers to access screening and care for breast and cervical cancer.
- Studies with health providers and health promoters to better understand their knowledge, attitudes and behaviors towards breast and cervical cancer.

4- Policy case studies
- Analyze policies and laws which have greatest impact on reducing br/cxca mortality rates (eg. Chile, Brazil)

5- Cost and cost-effectiveness studies
- Provide costing tools to countries to enable them to determine cost of implementing cxca and brca screening and treatment programs.
- Support/expand ProVAC initiative in LAC countries (model and methodology for cost-effectiveness evaluation of HPV vaccine + screening).
- Disseminate results of the WHO Breast Cancer CEA studies which are being conducted in 5 countries.

6- Monitoring and surveillance
- Country ‘report card’ on breast and cervical cancer program performance, using standardized indicators (eg. coverage, follow up, quality testing, etc.)
- Develop standardized questions on screening and include as part of routine population based NCD surveillance.

III CONCLUSIONS AND NEXT STEPS
As this was the first meeting of a new public-private partnership on women’s cancers, there was much energy, enthusiasm and great ideas on how we can create this partnership together. PAHO will take use the information and ideas generated during the meeting to develop the workplan for the Women’s Cancer Initiative, working together with a small Steering Group with representation from governments, NGOs and private sector.
The smaller group will begin to mobilize resources to fund the activities in the workplan. Part of the work plan activities will include country specific demonstration projects, a media and advocacy campaign and trainings of providers. In addition, PAHO is planning a high level advocacy event on women’s cancers, involving the Female Heads of State from Latin America and the Caribbean, to take place at the time of the UN General Assembly in September 2013. An e-community platform is being created, under the Pan American Forum for Action on NCDs, and this will facilitate on-going multi-stakeholder interaction and sharing of experiences with partners involved in the Women’s Cancer Initiative. In the meantime, the PAFNCD monthly newsletter and email communications will serve for ongoing communications with the partners of the Women’s Cancer Initiative.