

Caribbean Civil Society Cervical Cancer Advocacy Handbook and Planning Tool

A practical tool for the design & implementation of community based cervical cancer advocacy initiatives

Healthy Caribbean Coalition
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Foreword

The Healthy Caribbean Coalition (HCC) is pleased to make available the Caribbean Civil Society Cervical Cancer Advocacy Handbook and Planning Tool, A practical tool for the design & implementation of community based cervical cancer advocacy initiatives. This tool is aimed at Caribbean Civil Society Organisations (CSOs), and represents a significant resource with respect to NCD related advocacy in the Caribbean.

The HCC was established in 2008 as a regional alliance of health NGOs, other civil society organizations, and the private sector. It aims to contribute to the response to the epidemic of the NCDs, and their risk factors and complications. The HCC seeks to harness the power of civil society, in partnership with government, private enterprise, academia, and international partners to prevent and better manage chronic diseases through the promotion of healthy lifestyles, enabling and supportive environments among empowered people.

This Handbook is specific objective 1: To build the capacity of civil society to advocate for changes in cervical cancer related policy and programmes, one of the key outputs of the 'HCC Cervical Cancer Advocacy Plan for Caribbean Civil Society: Creating a Civil Society Movement for Cervical Cancer in the Caribbean'. It however goes much further in that it builds advocacy capacity which can be applied across all NCDs. The goals and objectives of the tool are aligned with the HCC Strategic Plan 2012 -2016 and reflect all four of the strategic areas of that plan: Advocacy; Enhancing Communication; Capacity Building; and Promoting mHealth and eHealth.

This resource was developed with the full consultation of twenty one Cancer CSOs from across 16 Caribbean countries. The Handbook was piloted at a historic Cervical Cancer Advocacy Capacity Building Workshop for Caribbean Cancer Societies and Foundations held in March 2013 in St. Maarten, and finalised in the months following the workshop.

Special thanks to the HCC team and all of the Cancer CSOs who contributed to the development of this valuable tool for Caribbean organisations engaged in the fight against NCDs.

The HCC is committed to strengthening the capacity of CSOs to effectively address NCDs through a variety of channels. Increasingly Caribbean CSOs will begin to recognise the critical role that advocacy can play in complementing their existing activities and catalysing positive changes in NCD policies and programmes nationally and regionally. The HCC is proud to introduce this handbook, a first step in supporting NCD NGOs in the development of evidence-informed NCD advocacy initiatives.

Professor Trevor A. Hassell President Healthy Caribbean Coalition.

Introduction

Every year, approximately 2,300 women in the Caribbean die unnecessarily from cervical cancer. The Caribbean is among the top four highest sub-regions in the world with respect to incidence of cervical cancer¹ and has the highest burden of HPV in the Americas. Cervical cancer is the second leading cause of death among Caribbean women⁷. Cervical cancer mortality rates in Latin America and the Caribbean are several magnitudes higher than countries such as the USA⁷.

Caribbean civil society organisations (CSOs) are on the front lines of cervical cancer prevention, control and treatment service provision. In the Caribbean we have the resources to avert these unnecessary deaths. There are no excuses - no woman should be dying of this preventable disease.

Civil society has the power to make significant change by demanding drastically improved services and driving increased health-seeking behaviours. Advocacy is one of the central tools at the disposal of civil society however many NGOs are largely focussed on service delivery to fill critical gaps, or as a means of income generation thus resulting in advocacy activities being relegated to "the back burner". There is an increasing need for Caribbean health NGOs to place greater emphasis on generating public awareness and action, creating champions for social change, and driving public health policy. In response to this demand, NGOs have called for tools to support the strengthening of their advocacy agendas and actions. This handbook is a first step. Although the handbook speaks largely to cervical cancer advocacy; the principles can be translated seamlessly to other NCD disease areas.

Let's ACT Now!

Background

The Healthy Caribbean Coalition (HCC) was founded in October 2008 as a loose alliance and network for the purpose of combating chronic diseases, their risk factors and conditions. The mission of the HCC is to harness the power of civil society, in collaboration with government, private enterprise, academia, and international partners, in the development and implementation of plans for the prevention and management of chronic diseases. This will be achieved through the promotion of healthy lifestyles, reduction of the determinants of chronic disease, creation of enabling and supportive environments, better management of chronic diseases, and empowerment of people. The HCC "Civil Society Strategic Plan of Action for Prevention and Control of NCDs for Countries of the Caribbean Community, 2012 -2016" focuses on four key strategic areas: 1. Building Capacity in and among health NGOs in the Region to make them more fit to contribute to the "whole of society" response to NCDs; 2. Advocacy by empowered Caribbean people with a view to bringing about positive health changes; 3. Enhanced Communication about NCDs to build public awareness around the problems and what can be done to slow the epidemic; and 4. Promotion of mHealth and eHealth in NCD prevention and management. These priority areas reflect that the HCC is a regional alliance with the expressed purpose of adding value to civil society in the Caribbean, and empowering people, specifically in the response to NCDs. It further reflects the HCC's mandate to encourage and foster the execution of NCD projects and programmes in-country, undertaken and led by local civil society organizations.

Against the background of an epidemic of chronic non-communicable diseases, the HCC works closely with regional and international leaders in NCD prevention to leverage the power of civil society by strengthening and supporting our membership in the implementation of programmes aimed at reducing the morbidity and mortality associated with NCDs. The Pan American Health Organisation (PAHO) is a key partner of the HCC working on civil society engagement and mobilization around NCD prevention. One of PAHO's priority areas is prevention and control of Women's Cancers, including cervical cancer. This workshop contributes directly to points two (Intensify information, education and counseling) and seven (Advocate for equitable access and affordable comprehensive cervical cancer prevention) in the seven-point action plan of The PAHO Regional Strategy And Plan Of Action For Cervical Cancer Prevention And Control In Latin America And The Caribbean⁷. The strategy illustrates [a] technical report reviewed and endorsed by the Directing Council of the Pan American Health Organization at their 2008 meeting, as well as the Resolution passed by the Directing Council. The Directing Council examined [a] technical report comprised of epidemiological information, scientific evidence on the most appropriate technologies for cervical cancer prevention and control, as well as a 7-point action plan. Consequently, the Directing Council issued a Resolution urging Member States and the Director to actively support the implementation of this Regional Strategy⁷. As one of the NGOs in Official Relations with this regional organization, the HCC has committed to work collaboratively to implement Caribbean programmes which increase awareness and build advocacy around cervical cancer prevention, treatment and support. The HCC participated in the February 2013 PAHO Regional Planning Meeting: 'Women's Cancer Initiative: A joint commitment to save lives' in order to share plans around the HCC Cervical Cancer Advocacy and Education Initiative and explore possible partnerships for implementation.

As part of the American Cancer Society, Global 'Meet the Targets' Programme, the Healthy Caribbean Coalition was awarded a \$12,000.00USD grant to implement a Caribbean cervical cancer awareness/advocacy campaign, which partly finances the cost of this workshop. Through this project, with support from additional regional and international partners, the HCC will impact positively on cervical cancer morbidity and mortality in the region by creating a strengthened civil society, armed with the skills and tools to lobby for changes in cervical cancer policies and programmes. By developing user-friendly tools to strengthen capacity around advocacy, NGOs and other civil society actors, working at the front lines of cervical cancer programming will be better equipped to roll out effective interventions.

The HCC is well placed to implement this initiative given the critical role of civil society in the prevention and treatment of cervical cancer. In the Cervical Cancer Action's Brief 'Coalition Building: A Cornerstone of National Advocacy, Policymaking and Effective Cervical Cancer Prevention Programs' it is noted that 'Cervical cancer is particular among diseases in its relevance to a broad base of stakeholders - cancer advocates, vaccine program managers, individuals fighting for increased gender equity, health rights advocates, women's health advocates, physicians, infectious disease experts and many more. Experience around the world is showing that successful coalition building across disciplines and professions is key to accelerating access to cervical cancer prevention and control resources.' The Healthy Caribbean Coalition is acutely aware of the collective weight of civil society and further recognizes the need to develop innovative partnerships to build public awareness, increase political will, and drive successful advocacy around the need to prioritise the health of women and girls.

Cervical Cancer in the Caribbean

Every year, over 500,000 women develop cervical cancer⁹. Cervical cancer is the second most common cancer among women in the developing world, and the largest cancer killer among women in most developing countries. Every year, approximately 275,000 women die from the disease, about 88% of whom live in developing countries with 159,800 deaths in Asia, 53,000 in Africa, and 31,700 in Latin America and the Caribbean⁶. The Caribbean is among the top four highest sub-regions in the world with respect to incidence of cervical cancer and the highest burden of HPV infection in the Americas. Cervical cancer is the second leading cause of death among Caribbean women. Cervical cancer mortality rates in Latin America and the Caribbean are several magnitudes higher than countries such as the USA. The vast majority of cervical cancer deaths are unnecessary. Ninety-five percent of cervical cancer cases are preventable, and if diagnosed early, cervical cancer is effectively treatable.

Virtually all cases of cervical cancer (99%) are linked to genital infection with HPV, which is the most common viral infection of the reproductive tract. Young women are disproportionally burdened with this sexually transmitted infection with the peak incidence of HPV infection occurring between the ages of 16 to 20 years, soon after the onset of sexual activity. Although the infection is usually resolved spontaneously, precancerous lesions may follow which in turn may gradually progress to cervical cancer over a period of 20-30 years. There is considerable socioeconomic impact of this disease related to the loss of these women who are often mothers and grandmothers acting as primary caregivers and major income earners for their families. There are an estimated 35,322 deaths in the Americas from cervical cancer, representing an economic loss of approximately US\$ 3.3 billion per year⁷.

Why this Handbook?

This Handbook is based on the WHO Handbook: 'STOP The Global Epidemic of Chronic Disease: A Practical Guide to Successful Advocacy' and other resources listed in the resource section ¹³.

The HCC and its members recognise health advocacy as a critical skills gap in the Caribbean; in particular advocacy around cervical cancer prevention, treatment and control. This Handbook is a first step towards addressing this need.

The purpose of the Handbook is:

- To provide a simple, user-friendly tool to support a greater understanding and appreciation of cervical cancer advocacy
- To support civil society in the design, implementation and monitoring of basic Advocacy Action Plans
- To support advocacy action across other NCD areas

This Handbook is NOT:

 An exhaustive theoretical guide to Advocacy. There are many useful, well written user-friendly advocacy guides which can be referred to for the purposes of further building your advocacy knowledge.

How do you use this Handbook?

This is an innovative online tool which accommodates evolving CSO realities and priorities around NCD advocacy. Building on HCC's commitment to eHealth, this handbook is a live document, which can be updated to include emerging models of best practice thereby supporting regional sharing of lessons learned, and crossfertilisation. HCC members will be encouraged to share their advocacy experiences, which will periodically be updated in the 'Advocacy in Action' section, thus ensuring the continuing relevance and applicability of this tool.

What is Advocacy?

What is Advocacy?

There are many definitions of advocacy. Advocacy can be a challenging concept for many. Below you will find various definitions or perspectives on advocacy, meant to provide a comprehensive appreciation for the term.

- Advocacy is ultimately about changing minds and driving social change
- Advocacy aims to change an existing situation that is unfavorable to a group of people by applying sufficient pressure on those who control the situation to change the status quo
- Advocacy is the effort to influence people, primarily policy-makers/ decision-makers, to create change, which catalyses the development comprehensive policies and effective programme implementation
- Advocacy in public health plays a role in educating the public, swaying public opinion or influencing policy-makers.
- Advocacy is about empowering people at the grass roots in affected communities to demand their basic human right to access comprehensive health care.
- Advocacy aims to place cervical cancer control high on the political agenda, foster
 political will, increase financial and other resources on a sustainable basis, and
 holding authorities accountable.
- Advocacy aims to convince community opinion leaders of the need for action
- Advocacy occurs along a continuum

What is social mobilization?

Social mobilization is a broad-scale movement that brings together all feasible and practical intersectoral social allies. Its main purpose is to raise people's awareness of, and demand for, cancer prevention and control, to assist in the delivery of resources and services, and to strengthen community participation for sustainability and self-reliance. It involves all relevant segments of society: decision- and policymakers, opinion leaders, bureaucrats and technocrats, professional groups, religious associations, commerce and industry, communities and individuals (UNICEF, 1993)¹². Social mobilisation can be a pre-cursor to public interest advocacy driven by large groups of individuals with a common interest in changing policy or legislation.

Advocacy in Action

Advocacy can be a powerful tool in the fight against cervical cancer. At each stage along the continuum of care from primary prevention, to secondary prevention and tertiary prevention there are examples of civil society action driving policy change.

Primary Prevention: The HPV Vaccine: Making the case for protecting young girls

Despite the knowledge that cervical cancer is caused by sexually-acquired infection

- with Human papillomavirus (HPV) and there are two widely available vaccines
 against HPV licensed in most countries which prevent over 95% of HPV infections
 caused by HPV types 16 and 18, many countries in the Caribbean have been slow
 to invest in HPV vaccination programmes. This is for a variety of reasons including
 variations in the serotype and public perceptions, all of which must be considered
 with developing strong evidence informed advocacy initiatives.
- Civil society can lead national educational campaigns calling for citizens to demand introduction of the HPV vaccine by increasing awareness about cervical cancer and its prevention.
- Culturally tailored messages using innovative delivery mechanisms including mHealth & eHealth can be developed to educate communities, parents, teachers, adolescents and other stakeholders about the HPV vaccine, HPV infection and cervical cancer and the availability of services.
- In particular, sensitive messages are needed to clarify the reasons for targeting young girls. In the absence of this type of communication, rumours and misinformation can significantly undermine programmes.
- Men, including fathers and boys must be included in target audience. Men are of often the primary decision makers in families and thus their buy-in is also essential. Boys must also understand why young girls are the recipients of the vaccine.
- Parents can be involved by providing cervical cancer information to older women and mothers of the girls being offered the vaccine.
- Informed consent for HPV vaccination can be another communication opportunity to educate parents and girls about adolescent health issues or cervical cancer screening.

CASE STUDY HPV Vaccine in Trinidad & Tobago, 2013

The Trinidad & Tobago Ministry of Health took a decision to introduce HPV Vaccine to Trinidad and Tobago in its fight against cervical cancer. Gardasil was selected partially because of its protection against genital warts.

The (EPI) Expanded Programme for Immunization unit of the Ministry of Health held a series of stakeholders meetings to sensitize the public about the vaccine.

Not all invited stakeholders attended the meetings. Notable absences were the Catholic School Board and a prominent Hindu organization.

The HPV Vaccine programme started in schools across the country. There was uproar in the Catholic schools. The Catholic School Board objected, stating it was not informed of the activity and did not give its approval for the vaccinations to take place in its schools. Additional information was requested.

This catalysed a national debate with pros and cons expressed in the media. TV, radio and print media covered the debate intensively. As a result of the national dialogue, the programme was halted in all schools and transferred to Health Centres.

The Ministry of Health then met with the Catholic School Board and other key stakeholders who had missed the initial sensitization meetings. After two weeks of sharing of information the programme resumed in schools with the caveat that written permission must be obtained from parents.

The Ministry of Health Trinidad and Tobago provides the vaccine free of charge. Both vaccines are also available in the private sector.

Lessons to learn

- Ensure that all stakeholders are appropriately engaged prior to starting any programme.
- Education and sensitization should last at least six (6) months with the widest possible involvement of the population.
- All branches of the media should be involved in the sensitization, education, promotion and advertisement.
- Local research should precede introduction of the HPV Vaccination to document the common serotypes in that given population.
- A multi-disclipinary team of gynaecologist/ oncologist/ public health physicians/ nurses and communication specialists should be developed.
- The choice of the vaccine Gardasil versus Cervarix is important and should be explored fully (with strong consideration given to the efficacy, duration of protection and cost) as this may cause conflict in the medical community, and confusion among the public.

Case study provided by Dr Victor Coombs, HCC Director; Chairman, Partners Forum/NCD Commission

Secondary Prevention: Increasing Screening Coverage; developing policies; strengthening health systems; and creating social demand

- Early detection and treatment of precancerous lesions can prevent the majority of cervical cancers however achieving high screening rates continues to be a challenge in many countries in the Caribbean
- Policy makers in Ministries of Health can be targeted to develop national policies and guidelines for cervical cancer screening/ National Cervical Cancer Prevention and Control strategic plans
- Civil society can lead national educational campaigns calling for citizens to demand improved mechanisms of follow up in settings where coverage rates are high but health systems cannot support timely follow up.
- Creative community based Behaviour Change Communication campaigns can be
 developed to educate women and men about the importance of having Pap
 Smears. Tailored messages using innovative delivery mechanisms including
 mHealth & eHealth should directly address the key barriers to uptake which exist in
 the communities such as fear of examination, fear of diagnosis and ignorance of
 treatment options.

CASE STUDY Caribbean Cervical Cancer Electronic Petition, 2013

The Healthy Caribbean Coalition (HCC) and Caribbean Cancer NGOs are using an eHealth platform to build public awareness and create social advocacy movements from the grass-roots which drive improved cervical cancer policies and programmes and simultaneously increase demand and uptake of these services.

The CCCEP is the first Caribbean-wide electronic petition and the first health specific petition conducted across the Caribbean by the people of the Region. Caribbean people are being asked to stand up and take action by signing the petition which requests Heads of Government of Caribbean Countries to 'Increase Caribbean women's access to affordable Cervical Cancer screening'. The goal of the petition supports the internationally and regionally agreed goal of 80% coverage in cervical cancer screening by 2025 and the WHO Best Buy Interventions in particular for cancer: Screening and treatment of pre-cancerous lesions to prevent cervical cancer. It is also supportive of the recently launched Declaration for Universal Access to Cervical Cancer Prevention issued by leading women's health, cancer and business organizations, including PATH, the International Planned Parenthood Federation and the International Union Against Cancer global at the Global Forum on Cervical Cancer at the Women Deliver 2013 conference in Kuala Lumpur, Malaysia.

The petition has been supported at the highest levels in our region and signed by: PM of St. Kitts & Nevis and CARICOM Lead Head of Government for Health, HIV and Human Resources, the Right Hon. Dr. Denzil Douglas; the Most Hon. Portia Simpson-Miller PM of Jamaica; the Minister of Public Health, Social Development and Labour Hon. Cornelius de Weever of St. Maarten; The Hon. Minister of Health of Dominica Mr. Julius Timothy; and Mrs. Kim Simplis Barrow, Wife of the Belize PM, Special Envoy for Women and Children and a cancer survivor. The CCCEP also has the endorsement of a major regional religious body - the Anglican Church.

The petition is being promoted through social media, traditional media and mobile platforms. The process empowers Caribbean people with the knowledge and the power to be equal partners in shaping health programming and policy particularly within the context of NCDs. The HCC hopes that this project will serve as a platform for increasing regional advocacy efforts.

After four months, the CCCEP has 6000+ signatures. The CCCEP has a target of 50,000 signatures. At the end of the CCCEP, the signatures will be presented to Heads of State of CARICOM. HCC is currently exploring a mechanism for regional and national recognition of e-advocacy.

Tertiary Prevention: Providing first line care in resource limited settings; the Urgent Need for Palliative Care

- They key challenges faced in treatment of cervical cancer is insufficient national capacity to provide surgery and/or radiotherapy and chemotherapy or existing services are not accessible and affordable to the majority of affected women.
- NGOs can exert pressure on Ministries of Health to establish and maintain an
 appropriate treatment referral network to enable timely access and continuity of
 care and ensure systems are in place to increase treatment compliance. These
 would be reflected in a comprehensive National Cervical Cancer Policy.
- Civil society can initiate public awareness campaigns around the urgent need for
 palliative care policies and programmes including access to opiods for women with
 advanced cervical cancer. Telling 'stories' with powerful messages found in
 personal testimonials and photo essays is often one of the most effective tools in
 engaging audiences and highlighting need. Messages can then call the public to
 action through signing of petitions; writing letters to local representatives; and
 demanding policymakers to establish national palliative care policies and
 programmes.

Developing Your Advocacy Action Plan - Your Action Plan Matrix

Creating your advocacy action plan is a simple task and follows essentially the same steps you would use in the development of any standard project workplan. These steps are summarised below

- STEP 1: Defining the Situation: What are the priority issues around cervical cancer advocacy in your community/ country?
- STEP 2a/2b: Goal Identification and Objective Setting: What is the advocacy goal of your plan in order to address the priority issues? What are the objectives you will set to achieve your goal and address the priority issues?
- STEP 3: Audience Identification: Who is your target audience? You may have multiple audiences.
- STEP 4: Key Message Development: What do you want to say to your audience? What is the call to action?
- STEP 5: Activity Identification: What activities are required to achieve each of your objectives? Activities are linked to specific objectives.
- STEP 6: Identification of Responsible Persons: Who within your organisation will lead on implementation of each activity in your plan
- STEP 7: Partner Identification: Who are the key stakeholders you will be working with to implement your plan?
- STEP 8: Establishing Timelines: How long will each activity take to implement? Be realistic when determining length of time for implementation considering other tasks which the responsible individual may be [accountable for]
- STEP 9: Determination of Costs: What is your plan's budget? What is the source of funds? Are the funds confirmed or will they need to be sourced? You should at this stage be sticking to activities for which you have confirmed funds or expect to obtain funds readily (ie. government, local donor etc.)
- STEP 10: Development of Monitoring and Evaluation Plan: How is your advocacy initiative working? Are you achieving your objectives? Are some minor or major changes required? You must monitor and evaluate the implementation of your plan.

Each of the points above corresponds to a step in the 10 steps to creating your plan.

The next 10 sections will take you through this 10 – step process. You can use the spaces provided to complete your responses. You will also find useful examples to assist in this process. Once you have gone through the 10 steps you can transfer your responses to the planning matrix below.

Caribbean Civil	Society Ad	vocacy Action	Plan			
Date	mm/dd/yyyy					
Organisation		isation name, (Country			
Organisation	r an organ	ioation name, c	J G G I I I I J			
Representative	Full organ	isation represe	ntative nam	e. Position w	rithin organisation	n .
Plan Title				,	······································	
Defining the	List X prio	rity problems y	our plan wil	l be focussin	ig on	
Situation	1.	<i>y</i> 1	ı			
	2.					
STEP 1	3.					
Duration of	Time in we	eeks/ months				
Plan						
*link STEP 8						
Total Cost of	\$ Local Cu	urrency				
Plan						
*link STEP 9						
Goal	То					
STEP 2a	_					
Objectives	То					
STEP 2b						
Target						
Audience(s) STEP 3						
Key Messages						
STEP 4						
Objectives	Activities	Responsible	Partners	Timelines	Cost (local	M&E
	7 (011711100	Persons	T artifold	(days/	currency) &	Indicators/
		(within org)		months)	Source of	Notes
		- 3/			Funds	
STEP 2b	STEP 5	STEP 6	STEP 7	STEP 8	STEP 9	STEP 10
1. To						

Step 1: Defining the Situation

Your advocacy plan must be EVIDENCE-INFORMED.

Your advocacy plan must meet the PRIORITY ADVOCACY NEEDS in your country.

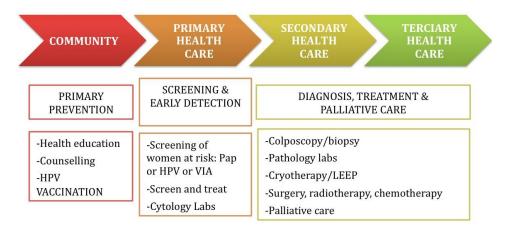
A basic understanding of what is happening in your country around cervical cancer is essential in order to develop an advocacy plan which responds to identified gaps and needs.

In order to develop and appropriate advocacy response, we must adequately define the problem: What is the cervical cancer situation in your country. You must have a good idea of the **burden of disease** in your country. What is the annual incidence of cancer? This is the number of new cases during a one-year period. What is the annual prevalence? This is the number of cases during a certain time period. What is the annual mortality? This is number of deaths during a certain time period.

Once we understand the local epidemiology we must then understand what services are in place to address the problem. The figure below illustrates the gold standard of care for cervical cancer prevention, treatment and palliative care.

COMPREHENSIVE CERVICAL CANCER PROGRAMS:

THE OPPORTUNITY



ORGANIZED PROGRAM

Information system/Call-recall/Monitoring-Evaluation

Cervical cancer will be treated in public health care system, in the private care system and through non-governmental organisations such as local Cancer Societies and support services. In Annex of this document you will find two (2) surveys and a simple checklist which can assist you in collecting this information. The first survey is a PAHO/HCC Cervical Cancer Situational Analysis which largely captures the public and private

sector health systems response to the disease. The second survey is an HCC NGO assessment tool which captures the NGO response to cervical cancer. The checklist is from the WHO Guidance Note: Comprehensive cervical cancer prevention and control: a healthier future for girls and women. It allows one to quickly assess your country cervical cancer programme. These tools can be used in concert to paint a comprehensive picture of activities around cervical cancer prevention, control and treatment in your country.

Have a look at the examples below which may also apply to your community or country.

Example 1: Low coverage for PAP Tests

Example 2: Insufficient national data; No National Cancer Registry

Now list the top three (3) challenges related to cervical cancer that your organisation would like to address.

1.

2.

STEP 2a: What is the Goal of your Plan?

In order to design your cervical cancer advocacy programme you must identify an overarching goal and a series of objectives to achieve that goal. The goal and the objectives must represent the priority areas based a number of factors; the cervical cancer situation in your country (ie. country context); the financial and human resources realities; your organisational mandates; your organisational skill sets (ie. the unique strengths of your organisation).

Let us first develop the Goal. Your Goal must address the challenges identified in STEP

1. What broad impact would you like your programme to have?

Your Goal must be consistent with the mission and values of your NGO and the resource realities of your NGO.

Your Goal can be very broad and non-specific.

Example 1: Improved Pap Smear Coverage

Example 2: Improved Cervical Cancer related information systems	
Now write down the Goal for your advocacy plan:	

STEP 2b: What are the Objectives of your Plan?

Development of your objectives is critical.

What are you trying to achieve with this plan? What are the objectives you need to achieve to attain your goal? What are the outcomes you need to achieve in order to achieve the desired impact at goal level?

Your objectives should be SMART: Specific, Measurable, Achievable, Realistic & Timebound.

Example 1: To increase the demand for Pap Smears from X to X in six months (by September 2013)

Example 2: To Develop a National Cancer Registry by March 2014

Now write down two objectives to meet the overall Goal of your plan:

Objective 1:		
Objective 2:		

STEP 3: Who are your Target Audiences?

In order for advocacy to be successful it must lead to change. Therefore we must direct our advocacy campaigns to those who have the authority to make decisions and those who influence the decision-makers. There will generally be 2 audiences:

- Decision-Makers. Primary Audience.
- Influencers. Secondary Audience.

The identification of your target audience is one of the most critical elements in the development of your advocacy plan. Whom do you need to target in order to achieve your objectives? What will motivate and influence them?

Below are examples of Target Audiences taken from the WHO Handbook: 'STOP The Global Epidemic of Chronic Disease: A Practical Guide to Successful Advocacy' 13. Perhaps you can think of others in your communities/ countries.

Potential decision-makers

Decision-makers on chronic disease are likely to be broadly grouped as follows:

- Government (ministries and parliament). For example:
- presidents and prime ministers.
- health ministers and their deputies.
- budgetary decision-makers (for example, cabinet, ministries of finance and planning).
- ministers of related sectors and their deputies (for example ministers of education, transport and/or agriculture)
- Donors/funding agencies for low-middle income countries.
- Private sector employers, for example national and local businesses and business associations and multinationals.
- Community leaders.
- Implementing NGOs.

Potential influencers

The individuals and groups who may be able to influence the decision-makers, and who may become partners in your campaign, could include:

- Civil society: formal and informal organizations and groups; NGOs; faith-based groups.
- Opinion leaders: community and business leaders, authors, activists, religious leaders, the media.
- Entertainment and sports personalities.
- Teachers, professors and researchers.

- Consumer groups: for example patient organizations, disease support groups or groups of concerned family members.
- Health-care professionals.

Note: Annex 3 lists Potential messengers for specific audiences.

Who is **YOUR ORGANISATION** trying to reach through your advocacy campaign? This could be one audience or multiple audiences.

Example 1: Women ages 30-65 years, Service providers, Policy makers

Example 2: High level Policy makers in the Ministry of Health

Now list your Target Audience(s):

STEP 4: Developing Key Messages to Influence Your Audience

Key messages are central elements of successful advocacy campaigns. Key messages underscore what you want to achieve.

Your advocacy messages should include calls to action.

They are short, simple and concise. Your audience or target group must 'connect' to your messages so ensure the language is appropriate and the benefits of your message are clearly understood. Annex 3 provides examples of Advocacy and communication messaging for different target audiences.

Example 1: *Is it your year for a Pap Smear?*(http://www.healthinfonet.ecu.edu.au/key-resources/promotion-resources?lid=17068)

Don't just sit there (http://www.advertising.nsw.gov.au/campaigns/dont-just-sit-there)

Example 2: Cancer Registry Now: Better Information = Better Programmes

Now write down some key messages for each of your objectives:

Objective 1:

Objective 2:

STEP 5: Defining your Activities

What are the types of activities needed to achieve each of your objectives?

Example 1: a. Assess cervical cancer related KAPB through small focus groups; b. Design and awareness and advocacy campaign for women which includes messaging around the importance of having pap smears disseminated through basic posters, community forums, and Facebook and an e-petition; c. Meet with service providers to ensure providers have resources to meet increased demand; d. Implement multi-faceted awareness campaign including e-petition aimed at demanding improved service provision ie. training of providers; adequate supplies; and e. Measure the increase in demand/ uptake of services.

Example 2: a. Determine Cancer Registry resource needs (technical, financial and human); b. Identify Key policymakers; c. write letters to policymakers; and d. develop e-petition for policy makers

STEP 6: Identifying Responsible Individuals

Central to the success of your plan is the identification and agreement of organisational roles and responsibilities around each activity.

In doing this, one must ensure that the responsible individual has the capacity to execute the task. Capacity refers to ability or skill and the time to effectively undertake the task.

Note that responsible individuals may also include individuals designated to deliver your key messages. Annex 4 provides examples of Potential Messengers for Specific Audiences.

Example 1: a. Local Research Group Partner. Assess cervical cancer related KAPB through small focus groups; b. Public Relations Officer. Design and awareness and advocacy campaign for women which includes messaging around the importance of having pap smears disseminated through basic posters, community forums, and Facebook; c. President: Meet with service providers to ensure providers have resources to meet increased demand; d. President/ Public Relations Officer: Implement multi-faceted awareness campaign including e-petition aimed at demanding improved service provision ie. training of providers; adequate supplies; and e. Local Research Group Partner: Measure the increase in demand/ uptake of services.

Example 2: a. *President:* Determine Cancer Registry resource needs (technical, financial and human); b. *President*: Identify Key policymakers; c. *Public Relations Officer*: write letters to policymakers; d. *Social Media Volunteer*: Develop e-petition for policy makers.

Now list responsible individuals within your organization for each of the activities identified in STEP 4:

Objective 1:			
Responsible Individuals:			
a			
b			
C			
d			

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Objective 2:	
Responsible Individuals:	
a	
b	
C	
d	

STEP 7: Who are your Partners?

Identify the partners you will be working with in your community to execute each of the activities in the plan.

Your partners are those individuals or organisations who will assist you in the implementation of your plan. These can be past or existing partners with whom you have successfully collaborated, or stakeholders you have never worked with. You can undertake a stakeholder mapping which allows you to assess pivotal actors in your community and how they will impact your project. This process will guide you in the comprehensive identification of partners to support your organisation as you engage in your advocacy initiative. When identifying your partners, ask yourself the following questions. What organisations have shared interests and the resources (human, financial etc.) to strengthen your initiative? What organisations/ entities have an interest in the successful implementation of your plan? Who will be impacted by your plan positively or negatively? What groups can benefit? Are there any key gatekeepers or decision makers you need to 'get on board'? Who can assist you in spreading your message?

Examples of key partners are:

- Other Health NGOs
- Research NGOs/ Academia
- Other Civil Society actors ie. women's groups
- Ministry of Health
- Health Service Providers
- Local Media
- Key decision makers and gatekeepers
- Faith-based organisations
- Trade unions
- Service Clubs

Now list potential partners for each of the activities identified in STEP 5:

Objective 1:		
Potential Partners:		
a	 · · · · · · · · · · · · · · · · · · ·	
b	 	
C		
d.		

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Objective 2:	
Potential Partners:	
a	
D	
o	
d	

Step 8: What are your timelines?

What is the duration of your plan? When will each activity start? When will each activity end? Think about the timeframe needed for each activity. Ensure there are no conflicts with other major obligations within your organisation or major community activities.

Example 1: a. 2 weeks: Assess cervical cancer related KAPB through small focus groups; b. 2 weeks: Design and awareness and advocacy campaign for women which includes messaging around the importance of having pap smears disseminated through basic posters, community forums, and facebook; c. 1 week: Meet with service providers to ensure providers have resources to meet increased demand; d. 4-6 weeks: Implement multi-faceted awareness campaign including e-petition aimed at demanding improved service provision ie. training of providers; adequate supplies; and e. 2 weeks: Measure the increase in demand/ uptake of services.

Example 2: a. 2 weeks: Determine Cancer Registry resource needs (technical, financial and human); b. 1 week: Identify Key policymakers; c. 1 week: write letters to policymakers; d. 1 week: Develop e-petition for policy makers.

Objective 1:	
Timeline:	
a	
b	
C	
d	
Objective 2:	
Timeline:	
a	
b	
C	
d	

Now list the timeline for each of the activities identified in STEP 4:

STEP 9: What are the Costs?

How much is this plan going to cost? What is the total budget? Does your organisation have the financial resources to implement this plan? You should list the estimated costs associated with each activity; an appropriate breakdown, and the source of funds.

Your plan should be achievable within the parameters of your current resource pool. If you are confident that your organisation can secure funds from outside sources please indicate this in your plan.

Example 1: a. \$100.00. Assess cervical cancer related KAPB through small focus groups; b: \$0.00: Design and awareness and advocacy campaign for women which includes messaging around the importance of having pap smears disseminated through basic posters, community forums, and Facebook; c. \$0.00: Meet with service providers to ensure providers have resources to meet increased demand; d. \$1000.00: Implement multi-faceted awareness campaign including e-petition aimed at demanding improved service provision ie. training of providers; adequate supplies; and e. \$500.00: Measure the increase in demand/uptake of services.

Example 2: a. \$0.00: Determine Cancer Registry resource needs (technical, financial and human); b. \$0.00: Identify Key policymakers; c. \$20.00 [paper costs]: write letters to policymakers; d. 1 \$100.00 [social media consultant]: Develop e-petition for policy makers... etc

Now list the cost for each of the activities identified in STEP 4:	
Objective 1:	
Budget:	
a	
)	
>	
4	

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Objective 2:	
Budget:	
a	
b	
C	
d.	

STEP 10: Developing your Monitoring & Evaluation Plan

You must monitor and evaluate the implementation of your plan. You will need to develop a basic M&E Plan based on your project objectives and activities. This allows you to assess efficacy in real-time and reprogramme where necessary to ensure you are on track to achieving your plan objectives and goal. An evaluation at the end of your plan allows you to determine how effective your plan was and measure achievement against agreed milestones/ targets. Your final evaluation report should answer questions such as: Was the goal achieved? Were the objectives achieved as defined by the indicators and targets? What were the key challenges and successes? What were the lessons learnt? What are the recommendations for future programmes?

Your M&E plan is vital to the success of your project as it allows you to:

- 1. Track the progress of your sub projects
- 2. Re-programme where necessary
- 3. Demonstrate success to possible sponsors

You will develop a set of SMART indicators for each of your objectives (this measures project outcomes) and for each of the activities (this measures project outputs). You will then need to set targets/ milestones for each indicator. Ideally you should have a project logframe which clearly illustrates your goal, objectives, activities; the indicators at each level; sources of verification; and risks and assumptions. The HCC will assist you in developing your respective logframes.

For the purposes of this exercise we will only be identifying indicators for each of your objectives and for each of your activities. M&E is a critical element of any programme implementation and development of a logframe is a central component in the M&E process. This is beyond the scope of this handbook, however HCC can provide technical assistance in this area if required. Try to develop your project logframe using the sample logframe in the Annexes of this Handbook as a guide.

Example 1:

Objective 1 Indicator: The number of women receiving pap smears at baseline and at after the campaign is implemented at 6 months.

Activity a. Indicator. 1 KAPB implemented through 2 focus groups at baseline. Results of KAPB reported and used to inform campaign design by week 2.

Etc.

Example 2:

Objective 2 Indicator: National Cancer Registry developed by March 2014.

Activity a. Indicator: Cancer Registry resource needs (technical, financial and human) identified and documented by week 2.

Etc

Now develop indicators both objectives and for each of the activities identified in
STEP 4:
Objective 1:
Activities:
a
b
C
d
Objective 2:
Activities:
a
b
C
d

Sample Advocacy Plan

The matrix below provides a sample advocacy plan for a fictitious community however the country situation is based on the reality in many Caribbean countries.

Caribbean Civil Society Advocacy Action Plan							
Date	March 2013						
Organisation	The Healthy Caribbean Coalition /The Caribbean Cancer Alliance (CCA)						
Organisation Representative							
Plan Title	The Healthy Caribbean Coalition /The Caribbean Cancer Alliance (CCA)						
Defining the Situation	1. Approximately 2300 Caribbean women die of cervical cancer annually, 95% preventable						
STEP 1	2. Studies have shown that up to 50% of women who die of Cervical Cancer have never had a Pap Smear						
	3. In some Caribbean Territories Pap smear coverage is less than 20%						
	4. Turnaround of Pap smear results can take up to 1 year in some Caribbean countries						
	1. *Additional supporting data found in PAHO/HCC Ca Cx Situational Analysis (March 2013)						
Duration of Plan	6 months – 1 Year						
*link STEP 8							
Total Cost of Plan	Objective 1: ~ \$50USD						
*link STEP 9							
Goal STEP 2a	To obtain 50,000 electronic signatures from Caribbean people in support of increased access to cervical cancer screening						
Objectives STEP 2b	1. To create a first of its kind electronic petition which allows Caribbean people to easily voice their support for improved cervical cancer screening services.						
	2. To Develop a website which supports the CCCEP.						
	3. To develop a Public Service Announcement in support of the CCCEP and air across the Caribbean.						
	4. To develop CCCEP flyers which can be tailored at country level for use in community outreach						
	5. To gain high-level support for the CCCEP						

Target C Audience(s) STEP 3		Carib	Caribbean Heads of Government						
] , 3		Cervical Cancer now. woman should die of cervical cancer.							
Objectives	Acti	vities	Responsible Persons (within org)	Partners	Timelines (days/ months)	Cost (local currency) & Source of Funds	M&E Indicators\ Notes		
STEP 2b	STE	P 5	STEP 6	STEP 7	STEP 8	STEP 9	STEP 10		
1. To create a first of its kind electronic petition which allows Caribbean people to easily voice their support for improved cervical cancer screening services. 2. To Develop a websiteetc	Ider peti plat Tes	port ntify tion form t form	IT coordinator, HCC Manager, HCC Directors, Volunteers & CCA to review and approve the platform	National and regional stakeholders with shared vision and websites to place CCCEP link; the Media to promote the CCCEP; etc.	1 month	No cost for IT Coordinator HCC staff ~\$50 USD for purchase of domain name for CCCEP	CCCEP platform live and functioning well (ie. allowing signatures and capturing key data)		

Implementing Your Plan

Now that you have developed your plan, it is time to put it into action.

This may not be as simple as it sounds.

The successful implementation of your plan depends exclusively on the development of a SMART plan. Let us revisit what SMART stands for:

S – specific

M – measurable

A – achievable

R – realistic

T - time bound

The 'A' and the 'R' are most critical elements to successful roll out of your advocacy plan. When you developed the Goal and Objectives of your plan you were asked to ensure they were consistent with the resource realities of your organisation. These realities refer to all aspects of human and financial resources and partner buy-in.

Some of your organisations consist of one individual volunteer driven by passion but unfortunately unable to commit 100% to the organisation... Whereas some of your organisations are much larger with many full time staff and access to a wide committed volunteer pool.

So ask yourself ... What is your full time staff complement? If you rely heavily on volunteers - how much time can they commit? What are your competing priorities ... and associated timelines? Ensure there are no scheduling conflicts. Do you have the buy-in of key stakeholders, key decision makers and gatekeepers? Are you over committing partners? Are your expectations of your staff, yourself, your collaborators real or ambitious?

SET YOUR ORGANISATION UP FOR SUCCESS!

Make your plan achievable and realistic. When you succeed, you will attract the attention of individuals and organisations who are interested in funding you to implement even 'bigger and better' programmes.

Now let's get on with it and implement our cervical cancer advocacy action plans!

Critical Advocacy Partner: Engaging Media Interest

"If you don't exist in the media, for all practical purposes, you don't exist"

Daniel Schorr, commentator, National Public Radio

Media coverage is one of the best ways to gain the attention of decision-makers. Working with the media is a powerful, credible, cost-effective way of communicating messages to a large target audience. The media is a vital element of successful community education and advocacy. It can raise awareness, inform, persuade and motivate the public and through thoughtful, compelling 'stories'.

"Too often, communications is still treated as an add-on or an optional extra. Yet in today's work it is absolutely indispensable."

March Malloch Brown, previous Deputy Director-General, United Nations

How can you work with the media to support your advocacy initiative and shine a spotlight on your cause?

- Advertising: expensive but can reach large numbers of people and your messages can be controlled.
- Media relations and publicity: this includes media events; news/ press releases; press conferences; and interviews (messages are harder to control)
- Comment and opinion pieces: Editorials which can be challenging to secure, and letters to editors.
- Education through entertainment: this involves the placement of education
 messages in the entertainment media in order to promote changes in knowledge,
 attitudes, beliefs and behaviours. This method has been used successfully to
 promote social and health issues through television and radio (in soap operas, for
 example), music, comic books and novels.
- Social Media: The use of facebook, twitter to bring attention to an issue.

ANNEXES

Annex 1: Instruments for Defining Country Situations

Annex 2: M&E: Sample Logframe

Annex 3: Advocacy and communication messaging for

different target audiences

Annex 4: Potential Messengers for Specific Audiences

Annex 1: Instruments for Defining Country Situations

MAPPING OF CERVICAL CANCER CSO ADVOCACY EFFORTS

CERVICAL CANCER PREVENTION AND CONTROL CSO REPSONSE

The following questionnaire has been designed to collect basic information about your organization and its work to strengthen cervical cancer prevention, control and treatment advocacy efforts in the Caribbean. This information will be extremely valuable to map current work in the Region and identify possible linkages with HCC Cervical Cancer Advocacy Initiative.

Additionally, it will be a very useful input to guide discussions during the meeting sessions and the working groups.

•	Name of your organization:
•	Contact details of the person responsible of completing this questionnaire:
•	Name: Position: Email: Website: Facebook: Twitter: Date:

What is the mission of your organization?
Please describe all of the primary services provided by your organization.
List the NGOs and other civil society actors in your country working in cervical cancer prevention, control and treatment?
Does your NGO provide cervical cancer related services? Yes No if No skip to Q13
What are the areas of work in which your organization is currently involved for cervical cancer prevention, control and treatment?

Communications and social mobilization (education) Please specify:
Advocacy Please specify:
Operational research Please specify:
Training and capacity building Please specify:
☐ Strengthening programs and improving access to services. Please specify:
Service Delivery. Please specify:
Other; please specify:
Do you have the following skill sets in your organisation?
Communication Officer Part-time Full-time Advocacy Officer Part-time Full-time Full-time Full-time Full-time Part-time Full-time Officer Part-time Full-time Full-time Officer Part-time Full-time Officer Part-time Full-time Officer Part-time Full-time Full-time Officer Part-time Offic
How do implement your work for cervical cancer prevention, control & treatment?
Directly With Ministries of Health With local NGOs With local private sector groups Funding other partners directly Other; please specify:
 Has your organisation undertaken any activities through which you tried to influence specific decisions, policies or practices related to cervical cancer? Yes No if Yes please specify.

 What further type of change would you like to work towards in the context of cervical cancer in your country?
How can your organization contribute to the HCC Cervical Cancer Initiative?
• Expertise in:
 Communications and advocacy Social Media Research, Training and capacity building Improving access and strengthening programs Other; please specify:
 Human resources Financial resources Other; please specify:
What are your expectations for the Cervical Cancer Advocacy Workshop for Caribbean Cancer Societies and Foundations?

PAHO/HCC SITUATION ANALYSIS

CERVICAL CANCER PREVENTION AND CONTROL NATIONAL RESPONSE

COUNTRY:

Contact information for the person completing the survey.

Name :	
Position:	
Organization:	
Address:	
E-mail:	
Telephone number:	
Date of survey:	

•	DEMOGRAPHIC DATA						
1.1	1.1 Total number of women aged 25-64 years in the population by 5 year age groupings:						
	• 25-29 yrs:	• 35-39	yrs:	• 45-49	yrs:		
	• 30-34 yrs:	• 40-44	1 yrs:	• 50-54	l yrs:		
	• 55-59 yrs:	• 60-64	1 yrs:				
1.2	Total number of girls aged 9-12	2 in the pop	ulation:	'			
	• 9 yrs:		• 11 yrs:				
	• 10 yrs:		• 12 yrs:				
1.3	Percentage of girls that comple	ete primary s	school education				
Note.	Please indicate the source and year for	the data provid	ded above:				
		BURDEN C	F DISEASE				
1.4	Incidence of Cervical Cancer						
1.5	Mortality associated with Cervical Cancer						
1.6	Number of cases per year						
1.7	Number of deaths per year						
1.8	Has any HPV infection prevalence study been done in your country? If so what were findings, Please provide reference:						
Note: Please indicate the source and year for the data provided above:							
•	CERVICAL CANCER PREVE	NTION ANI	O CONTROL POL	ICIES AND I	PROC	GRAM	S
2.1	Does your country have a p control?	oolicy for ce	ervical cancer pre	vention and		Yes □	No
2.2	Does your country have a program?	cervical ca	ancer prevention	and control	□ No	Yes	
2.3	Is there a cervical cancer prev	ention and c	control program mai	nager?	□ No	Yes	
2.4	Is there a work plan to imple control program?	ement the c	ervical cancer pre	vention and	□ No	Yes	
2.5	Is there an identifiable budge and control?	et allocated	to cervical cancer	prevention	□ No	Yes	

•	CERVICAL CANCER PREVENTION AND CONTROL POLICIES AND PROGRAMS						
2.6	Are there clinical guidelines or protocols for cervical cancer prevention Yes and control?						
2.7	Is there a referral and who require:	contra-referral system for wo)Hen	of precancerous lesions of invasive cancer are			
Pleas	se attach a copy of the policy,	program and work plan if available.					
•	PRIMARY PREVENTI	ON: HPV VACCINATION					
3.1	Is HPV vaccination included in your country's national immunization program? Yes No If YES, please specify:						
	Year started:Target sex and aVaccination sett	age group: ing and tactic (e.g. schools	s, clinics):				
3.2	Are there any agencies or NGOs carrying out HPV vaccination demonstration projects in your country? If YES, please specify:						
	 Year started: Target sex and age group: Vaccination setting and tactic (e.g. schools, clinics): 						
3.3	If HPV vaccination is nare there plans to do s	ot included in your national ir o in the near future?	mmunization progr	am,			
If <u>YE</u>	<u>S</u> , please indicate the next ste,	os identified for HPV vaccine introduc	ction:				
•	SECONDARY PREVE OF PRECANCEROUS	INTION: CERVICAL CANCE S LESIONS	ER SCREENING /	AND TREATMENT			
•	CERVICAL CANCER SCREENING						
		Рар	Visual Inspection with Acetic Acid (VIA)	HPV DNA testing			
•	Which screening tests are recommended in your country's policy?						

CERVICAL CANCER	PREVENTION AND CONT	ROL POLICIES AND) PROGRAMS			
 Which screening tests are available in your primary care services? 	Public sector ☐ Private sector ☐	Public sector ☐ Private sector ☐	Public sector Private sector			
 What is the target population? (Age groups, high risk groups) 						
 What is the recommended interval for cervical cancer screening? 						
 What is the screening coverage? 						
If you have provided information about screening coverage, please explain how this parameter is defined and estimated:						
 What is the coverage target for your country's cervical cancer prevention and control program? 						
What percentage of women with precancerous lesions receive complete follow up and treatment?	Data not available					
If you have provided follow up data, please explain how this parameter is defined and estimated:						
Do women pay for screening tests?	□Full payment □ Partial payment □Free	□Full payment □ Partial payment □ Free	□Full payment □ Partial payment □ Free			
Is your country consider recommendations?	dering a policy change in s	screening	• Yes No			

CERVICAL CANCER PREVENTION AND CONTROL POLICIES AND PROGRAMS					
 If <u>YES</u>, please specify which strategies a 	are under consideration:				
 Are there any ONGOING social mobilization and educational programs to promote cervical cancer screening in your country? 					
Public sector: Yes No	Private sector: ☐ Yes ☐ No				
If <u>YES</u> , please name of Ministries/Agencies/C	Organizations involved:				

SECONDARY PREVENTION: CERVICAL CANCER SCREENING AND TREATMENT OF PRECANCEROUS LESIONS						
TREATMENT OF PF		JS LESIONS				
Are colposcopy ser	vices available	e? If <u>YES, ple</u>	ease	e indicate their co	st.	
Public sector: Ye	Public sector: ☐ Yes ☐ No Private sector: ☐ Yes ☐ No					
If possible, determing		r of	Pι	ublic sector		
colposcopes availa	ble:		Pr	ivate sector		
 Are the following tre country? If <u>YES</u>, ple services and their of 	ase indicate ti				•	
Treatment	Ava	ailability		Cost for	patients	
Cryotherapy	Public sector	☐ Yes No		□Full payment □ P	'artial payment □Free	
	Private sector	☐ Yes No		☐Full payment ☐ P	'artial payment □Free	
• LEEP	Public sector	☐ Yes No		☐Full payment ☐ P	artial payment Free	
	Private sector	☐ Yes No		☐Full payment ☐ P	artial payment Free	
 Cold Knife conization 	Public sector	☐ Yes No		☐Full payment ☐ P	artial payment Free	
COMERCION	Private sector	☐ Yes No		□Full payment □ P	artial payment Free	
 VIA followed by cryotherapy in a 	Public sector	☐ Yes No		☐Full payment ☐ P	artial payment □Free	
single visit	Private sector	☐ Yes No		□Full payment □ P	'artial payment □Free	
CYTOLOGY LABOR	RATORIES					
 How many cytology 	labs are there	e in your cou	ntry'	? Public sector: Private sector:	:	
	 What was the total number of cervical smears processed in the past year? Public sector: Private sector: 					
 How are cervical smears transported from the government clinic to the cytology lab? 						
 Is there an information system at the government cytology labs? ☐ Yes ☐ No 						
If <u>YES</u> , does it includ	de results from the	e private sector	?	☐ Yes ☐	No	

•	Is there an internal quality control system?						
	Public sector: Yes No	Private sector: ☐ Yes ☐	No				
•	Is there an external quality control system?						
	Public sector: Yes No	Private sector: ☐ Yes ☐	No				
•	TREATMENT AND PALLIATIVE CARE						
5.1	Do any of your gynecologists perform radio	cal hysterectomy?					
	Public sector: ☐ Yes ☐ No	Private sector: ☐ Yes ☐ No					
5.2	Describe the availability of chemotherapy in PUBLIC SECTOR:	in your country:					
	PRIVATE SECTOR:						
5.3	Describe the availability of radiotherapy in PUBLIC SECTOR:	your country:					
	PRIVATE SECTOR:						
5.4	Describe the availability of palliative care in PUBLIC SECTOR:	n your country:					
	PRIVATE SECTOR:						
•	MONITORING AND EVALUATION						
6.1	Is evaluation of the cervical cancer performed with a standardized method and If <u>YES</u> , please attached the latest evaluation	d at established time intervals?	☐ Yes ☐ No				
6.2	Is there a cancer registry? If YES, please specify its location, type	of registry (population based or	☐ Yes ☐ No				
	hospital based) and coverage:						
6.3	Is there an information system that allows screening test results?	follow-up of patients with abnormal	☐ Yes ☐ No				
6.4	Does the information system have a unique for all tests?	ue identifier for each woman used	☐ Yes ☐ No				
	If <u>YES</u> , please indicate the nature of the un ID, passport number, social security numb	, ,					

•	HUMAN RESOURCES					
7.1	Please state whether the following	ng categories of staf	f are ava	ailable in your country:		
	Gynecologists	Public sector: Yes	☐ No	Private sector: Yes No		
	Radiotherapists	Public sector: Yes	☐ No	Private sector: Yes No		
	Oncologists	Public sector: Yes	☐ No	Private sector: Yes No		
	Gynecological oncologists	Public sector: Yes	□ No	Private sector: ☐ Yes ☐ No		
	Nurse oncologists	Public sector: Yes	☐ No	Private sector: ☐ Yes ☐ No		
	Medical physicists	Public sector: Yes	☐ No	Private sector: Yes No		
	 Palliative care specialists 	Public sector: Yes	□ No	Private sector: ☐ Yes ☐ No		
	Pathologists	Public sector: Yes	□ No	Private sector: Yes No		
	Cytotechnologists	Public sector: Yes	☐ No	Private sector: Yes No		
7.2	Please indicate the total numbe	r of trained cytology	staff ava	ailable in your country:		
7.3	Is there a continuous education providers?	on system for cervi	cal can	cer service		
7.4	When was the last time in-servi in cervical cancer screening?	ce training was prov	vided for	r health professionals involved		
	Doctors:					
	Nurses:					
	Pathologists:					
	Cytotechnologists:					
•	CIVIL SOCIETY CERVICAL CA	NCER RESPONSE				
8.1	Are there Civil Society Actors is cervical cancer prevention, trea If <u>YES</u> , please list the NGOs being	tment and control?	viding se	ervices related to Yes No		

• (GENERAL EVALUATION OF THE SITUATION	
	After analysis of the different components of the cervical cancer prevention and control program has been completed in the previous sections, you are requested to do a general evaluation of the situation. Complete the following questions by marking one of the 4 options: H: High: M: Moderate; L: Low; U: Unknown VS: Very satisfactory; S: Satisfactory; UN: Unsatisfactory; U: Unknown	
9.1	The burden of cervical cancer in your country is considered to be:	□ H □ M □ L □ U
9.2	The need to improve the health services provided to women is:	□ H □ M □ L □ U
9.3	The need to improve the health services provided to adolescents is:	□ H □ M □ L □ U
9.4	The possibility of receiving external support and collaboration by organizations is:	□ H □ M □ U
9.5	How would you rate the current screening policies:	□ VS □ S □ UN □ U
9.6	The success of the current screening policies is:	□ H □ M □ L □ U
9.7	How would you rate the current adolescent immunization policies?	□ VS □ S □ UN □ U
9.8	The success of the current adolescent immunization policies is:	□ H □ M □ L □ U
9.9	The political interest in improving cancer control is considered to be:	□ H □ M □ L □ U

9.10	The political interest in improving cervical cancer control is considered to be:	☐ H ☐ M ☐ L ☐ U
9.11	The possibility that the government will finance strengthening of the screening services is:	□ H □ M □ L □ U
9.12	The possibility that the government will finance introduction of the HPV vaccine is:	□ H □ M □ L □ U
9.13	The feasibility of strengthening the screening programs in the future is:	☐ H ☐ M ☐ L ☐ U
9.14	The feasibility of introducing HPV vaccination programs in the future is:	□ H □ M □ L □ U
9.15	The current role of civil society in cervical cancer prevention, treatment and control is:	□ VS □ S □ UN □ U
9.16	The importance of civil society in cervical cancer prevention, treatment and control is:	□ H □ M □ L □ U

Annex 2: M&E: Sample Logframe

The Logframe below is taken from the 'HCC Cervical Cancer Advocacy Plan for Caribbean Civil Society Creating a Civil Society Movement for Cervical Cancer in the Caribbean'.

Note that the production of this Handbook is one of the activities under Specific Objective 1 (SO1). The logframe also allows for reporting against targets as done in the LF below as of August 2013.

Summary of Objectives and Activities	Objectively Verifiable Indicators	Means/ Sources of Verification/ STATUS	Assumptions/ Risks
Goal: To Facilitate and mobilize Caribbean civil society around cervical cancer prevention, treatment and support advocacy	No. of policies/programme s developed as a direct result of advocacy funded under this grant		

Specific Objectives:			
SO1. To build the capacity of civil society to advocate for changes in cervical cancer related policy and programmes.	 No. of participating organizations supporting roll out of regional awareness mHealth initiative No. of participating organizations implementing their own cervical cancer advocacy initiative 	Electronic audit of member organizations	NGOs are interested and willing to participate. Funding secured for workshop.
SO2. To increase public awareness and action around cervical cancer prevention, treatment and service gaps/needs.	 Improved cervical cancer awareness among the general public Increased cervical cancer advocacy among general population 	Online survey	Funding secured.

SO3. To increase cervical cancer advocacy at the highest levels of decision-making.	 Increased numbers of policy makers advocating for changes in cervical cancer policy 	Brief Assessment of action by targeted policymakers	Policymakers are receptive to communication.
SO4. To support the creation of a supportive network for women living with cervical cancer.	Improved coping among women living with cervical cancer	 Feedback forms from women participating in online forum 	Funding secured. Survivors willing to self-identify and participate in forum.
SO5. To evaluate the Caribbean Civil Society Cervical Cancer Education and Advocacy Initiative	Evidence-base for scaled up regional civil society advocacy initiatives	Evaluation report	Funding secured.

Expected Outcomes:			
EO1: Strengthened cervical cancer advocacy among targeted HCC members (provided with a "blue print for action": skills and tools)	 1 HCC Advocacy Action Plan ratified 1 Advocacy Handbook completed Proportion of organizations with Advocacy Action Plans developed Proportion of targeted NGOs rolling out elements of their Advocacy Plan's 3 months after workshop completion 	 HCC Regional Action Plan Advocacy Handbook Workshop reports 	NGOs apply skills gained in workshop in their respective settings. HCC has resources (time and funds) to support application of these skills.
EO2: Caribbean people and women in particular empowered through increased awareness and action.	Increased cervical cancer awareness	Online survey findings / some proxy indicator of increased awareness such as signing a petition	Resources for survey available.
EO3: A greater awareness among political leaders about cervical cancer and steps that they might take to address the issue.	Proportion of targeted policymakers indicating commitment to improving cervical cancer service delivery	Email correspon- dence with targeted policymak-ers	Policymakers are receptive to communication.

EO4: A Forum provided that allows people with a cervical cancer to communicate among themselves about their illness.	No. of Testimonials/ feedback forms from users re the utility of the forum	Forum implementation report	Funding secured. Survivors willing to self-identify and participate in forum.
EO5: Evaluation of the initiative completed and documented with recommendation s for regional scale up.	 1 evaluation plan To be defined based on contents of plan (ie. no. of surveys completed; no feedback forums conducted) 	Evaluation Report	Funding secured.

Activities:			
SO1.1: Conduct a desk-based situational analysis of civil society advocacy around cervical cancer.	1 Situational Analysis report produced	ReportCOMPLETE	
SO1.2: Create a static database of key regional civil society actors and policy makers.	 1 Database produced in excel 1 Database hosted on HCC website No. of member websites hosting database 	DatabaseCOMPLETE	
SO1.3: Develop a User Friendly Civil Society Handbook for Cervical Cancer Advocacy.	1 Handbook Developed	 Handbook Consultant and graphic artist expenditure COMPLETE 	

SO1.4: Conduct a 'How To Advocate' Workshop.	 1 regional capacity building workshop conducted 1 Advocacy Action costed workplans developed by each participating NGO 	 Workshop expenditure \$3000.00USD Workshop reports COMPLETE 	
SO1.5: Conduct Civil Society Led E-Petition advocating for: e.g. improved access to screening, timely reporting of results, evidence- based treatments, HPV testing and vaccine, palliative care.	No. of NGO/civil society/provider/ academics signatures	Signed PetitionUNDERWAY	
SO1.6: Develop a Caribbean Cancer Network.	No of Cancer Societies signing Network MOP	Signed MOPsUNDERWAY	NGOs willing to sign MOPs
SO1.7 Send out 1 Press Releases to Media Houses in each of target countries.	No. of media reports in target countries	 Press clippings/ links to websites PRESS COVERAGE COLLATED BY COUNTRY 	

SO2.1 Conduct mHealth campaign in selected countries using text messages aiming to reach 500,000 Caribbean people around cervical cancer prevention, treatment, and needs.	 No. of text messages developed covering each theme (prevention, treatment, service/policy needs, calls for action) No. of C'bbean residents across X islands receiving text messages No. of C'bbean residents sending text (SMS) and social media 'signatures' to demand urgent action on cervical cancer 	 Contract with service provider Service provider reports ACTIVITY CANCELLED DUE TO LACK OF FUNDING 	Funding secured.
SO3.1 Create list of 30 leading policymakers using defined selection criteria.	List Created	Selection CriteriaListUNDERWAY	Contacts easily accessible.
SO3.2 Contact 30 leading policy makers via email about cervical cancer on at least 6 occasions in which they are informed of the issue of cervical cancer and the need to take action to prevent and treat the condition.	 No. of policy makers selected No. of emails sent to each policy maker 	EmailsUNDERWAY	

SO4.1 Create an online Forum of ~ 100 women affected by cervical cancer that allows them to "share their stories"	 Online Forum developed No. of members of forum No. of testimonies posted on the forum 	 Forum Website data on forum users Forum data including testimonials INCOMPLETE 	Funding secured. Survivors willing to self-identify and participate in forum.
SO5.1 Conduct an evaluation of the initiative using the logframe as a guiding document for this exercise by evaluating achievement against targets using agreed indicators.	Evaluation Report completed	Evaluation Report with completed logframe	Funding secured.

Annex 3: Advocacy and communication messaging for different target audiences

The following table is reproduced from the United Nations Population Fund (UNFPA). Comprehensive Cervical Cancer Prevention and Control. Programme Guidance for Countries.

Core messages for all target audiences

- Basic information on cervical cancer and HPV infection
- Universality of HPV infection
- Disease burden in the country; prevention strategies and the effectiveness and safety of different interventions
- Emphasis that both vaccination and screening are necessary
- Information on other relevant adolescent health issues such as prevention of HIV and other
- STIs, prevention of pregnancy should be considered as appropriate

Messages for high-level decision-makers

- Disease burden and comparison with other key national health issues
- Benefits of improved cervical cancer prevention programming, including public health benefits and financial benefits (savings in future cancer treatment costs and continuing productivity by adult women)
- Impact of new programs on budgets, health systems, and Millennium Development Goals and other national or global indicators

Messages for managers and health care providers

- Impact on existing services, and benefits of the programme
- Opportunities for using cervical cancer prevention to promote other health services such as adolescent health, and sexual and reproductive health services
- Necessary systems requirements including procurement, reporting, call and recall, and quality control
- Service provision and counseling skills related to cervical cancer (training)

Messages for clients

- Specifics of what services are provided and how they are performed
- Information regarding vaccine dosage and schedules required, and target age
- Schedule for screening, target age and treatment options
- Specifics on where and when services will be offered
- Costs of different services
- Respond to rumors, misinformation, client assumptions

Annex 4: Potential Messengers for Specific Audiences

The following table was adapted from the WHO Handbook: 'STOP The Global Epidemic of Chronic Disease: A Practical Guide to Successful Advocacy'.

Target audience	Messenger
General public - when you want to illustrate the human cost of chronic disease.	An individual who suffers from a chronic disease, or a family member who has lost a relative to a preventable condition.
A minister of finance - when you are arguing that investment in chronic disease prevention and control is not only cost effective but could also provide economic benefits.	A leading international or national economist, or a finance minister from another country, who is able to argue convincingly for the economic benefits of action.
A prime minister considering supporting legislation.	Ministers; current and former aides; political leaders in his or her political party; respected religious and community leaders; leading business people; financial supporters.
General public - when you are seeking to educate and motivate.	Physicians, scientists, academics. Sports figures and celebrities may also be effective messengers for education and motivation.
Physicians – when you are educating about the need for an integrated approach to chronic disease.	Internationally or nationally respected physicians, or physicians who have institutional or economic influence within the medical community. As well as professional contact with their colleagues, such people are often used as expert commentators within the popular or professional media.
Trainee physicians	Medical school professors and lecturers.
Journalists - when you are seeking media coverage of an issue.	Individuals who have personally suffered from chronic disease. If someone from your organization is to be interviewed, it is usually best to have someone who can speak from their own experience - someone who works directly on the issue – as long as (s)he is a good communicator.

References

- CARICOM. Strategic Plan of Action for the Prevention and Control of Chronic Non-Communicable Diseases (NCDs) for Countries of the Caribbean Community (CARICOM) 2011 – 2015. 2011. Accessed November 25, 2012.
- Cervical Cancer Action. Coalition Building: A Cornerstone of National Advocacy, Policymaking and Effective Cervical Cancer Prevention Programs. Available at: http://www.cervicalcanceraction.org/pubs/CCA_national_coalition_building.p df. Accessed November 26. 2012.
- 3. Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. GLOBOCAN 2008, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10. Lyon, France: International Agency for Research on Cancer; 2010. globocan.iarc.fr. Accessed November 25, 2012.
- 4. Healthy Caribbean Coalition. Cervical Cancer Advocacy Plan for Caribbean Civil Society Creating a Civil Society Movement for Cervical Cancer in the Caribbean. 2013.
- 5. J. Sherrisa, T., I. Agurtob, S. Arrossic, I. Dzubad, L. Gaffikine, C. Herdmana, K. Limpaphayomf, S. Lucianib. Advocating for cervical cancer prevention. International Journal of Gynecology and Obstetrics (2005) 89, S46—S54.
- 6. PACT. Strengthening and Measuring Advocacy Capacity of Civil Society Organisations. Best Practice Series. 2005.

 http://www.pactworld.org/galleries/resource-center/strengthening_measuring_adv_capacity_csos.pdf. Accessed February 25. 2013.
- 7. Pan American Health Organization (PAHO) Cervical cancer in the Americas: Regional strategy and plan of action for prevention and control. 2010. Available at: http://www.rho.org/files/PAHO_Regional_Strategy_2010.pdf. Accessed Nov 25, 2012.
- 8. Path. Progress in preventing cervical cancer: Updated evidence on vaccination and screening. Outlook Volume 27, Number 2, April 2010. Available at: http://screening.iarc.fr/doc/RH_outlook_27_2.pdf . Accessed November 25, 2012.
- 9. Progress in Cervical Cancer Prevention: The CCA Report Card. January 2012. Available at: http://www.cervicalcanceraction.org/pubs/CCA_reportcard_low-res.pdf. Accessed November 25, 2012.
- Sundaram, Viji. "Stigma of Cervical Cancer puts Ethnic Women at Risk." New America Media., 18 Nov. 2010. Available at: http://newamericamedia.org/2010/11/stigma-of-cervical-cancer-puts-ethnic-women-at-risk.php. Accessed January 20, 2013.
- 11. United Nations Population Fund (UNFPA). Comprehensive Cervical Cancer Prevention and Control. Programme Guidance for Countries. 2011. Available at: http://www.unfpa.org/webdav/site/global/shared/ENGLISH-%20Cervical%20Cancer%20Guidance.pdf. Accessed November 25, 2012.
- 12. World Health Organisation (WHO). Cancer Control: Knowledge into Action: WHO Guide for Effective Programmes. Policy and Advocacy. 2008.

Available at:

- http://whqlibdoc.who.int/publications/2008/9241547529_eng.pdf. Accessed January 1, 2013.
- 13. World Health Organisation (WHO). STOP The Global Epidemic of Chronic Disease: A Practical Guide to Successful Advocacy. 2006. Available at: http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf. Accessed November 20, 2012.
- 14. World Health Organisation (WHO). WHO Communications Toolkit. 2007. Available at: http://www.who.int/nuvi/advocacy/communications_toolkit.pdf. Accessed January 1, 2013.
- 15. World Health Organisation (WHO). WHO Guidance Note. Comprehensive cervical cancer prevention and control: a healthier future for girls and women. 2013.
 - http://apps.who.int/iris/bitstream/10665/78128/3/9789241505147_eng.pdf. Accessed March 14, 2013.
- 16. World Health Organization (WHO). Strengthening cervical cancer prevention and control. 2010. Available at: http://whqlibdoc.who.int/hq/2010/WHO_RHR_10.13_eng.pdf. Accessed January 13, 2013.

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Dominica Cancer Society

Grenada Cancer Society

Groupe de Support Contre Le Cancer

KeLaHa Projects

Pink Ribbon Foundation Suriname

Positive Foundation

Reach for Recovery

St. Lucia Cancer Society

The Jamaica Cancer Society

The Sint. Maarten Cancer Foundation

Trinidad & Tobago Cancer Society





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