Caribbean Civil Society Regional Preparatory Meeting

In preparation for the Global NCD Alliance Forum

MEETING REPORT

Healthy Caribbean Coalition
September 2015

Expanded report with full annexes

HEALTHY CARIBBEAN COALITION

NCD Alliance
PUTTING NON-COMMUNICABLE DISEASES ON THE GLOBAL AGENDA


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Healthy Caribbean Coalition
Caribbean Civil Society
Regional Preparatory Meeting

In preparation for the
Global NCD Alliance Forum

Convened by:
The Healthy Caribbean Coalition on June 6th, 2015 at the Courtyard by Marriott, Bridgetown Barbados

The meeting was supported by the NCD Alliance as part of the Expanding Access to Care, Supporting Global, Regional and Country level NCD Action Programme in partnership with Medtronic Philanthropy


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1 MESSAGE FROM THE EXECUTIVE DIRECTOR

The Healthy Caribbean Coalition (HCC) is pleased to be participating in the Global NCD Alliance Forum: *'NCD Advocacy and Accountability in the Post 2015 Era'*, in Sharjah, UAE on November 13-15, 2015. The Global Forum represents a significant occasion for the Caribbean to share civil society experiences and learn from the experiences of our regional and national NCD alliance counterparts from across the globe in the Global North and the Global South. The challenges and priorities of Caribbean CSOs outlined in this report are not unique to our region and this unprecedented coming together of the global NCD civil society community provides a singular opportunity to establish relationships, develop networks and initiate a global dialogue which will allow for collective sharing and problem solving as we move forward into the post 2015 development era. The 2030 agenda clearly sets out seventeen ambitious sustainable development goals and importantly a health goal, which will require tremendous multisectoral collaboration and coordination to facilitate effective prioritisation and resource sharing for far-reaching measurable impact. Civil society is poised to make a extraordinary contribution to this global effort, but a great deal of work must be done to ensure that the collective community, with a focus on LMICs, has the capacity to meaningfully contribute to a whole of society effort. The development and strengthening of national and regional alliances and the establishment of strong inter-alliance networks under the leadership of the NCD Alliance will be one the major factors influencing the role that civil society plays in this global NCD agenda. The Sharjah meeting is a major step forward in this process.

Maisha Hutton, Executive Director, HCC

2 ACKNOWLEDGEMENTS

The Healthy Caribbean Coalition (HCC) would like to thank to the following:

- The NCD Alliance
- Medtronic Philanthropy
- Meeting Rapporteur Mrs. Paula Trotter
- The Meeting Attendees
- The Board of Directors & Volunteers of the Healthy Caribbean Coalition
- Sagicor Life Inc. Barbados

Special thanks are extended to Dr. Cary Adams, Chair of the NCD Alliance and our Patron, Sir George Alleyne for their unwavering support of the HCC and our vision and their invaluable contribution to this meeting.

This meeting was supported by the NCD Alliance as part of the Expanding Access to Care, Supporting Global, Regional and Country level NCD Action Programme in partnership with Medtronic Philanthropy.

3 ACRONYMS & ABBREVIATIONS

ABDA	Antigua and Barbuda Diabetes Association
BDA	Bahamas Diabetes Association
BDF	Barbados Diabetes Foundation
CARICOM	Caribbean Community
CARPHA	Caribbean Public Health Agency
CCH	Caribbean Cooperation in Health
CCS	Caribbean Cardiac Society
CSB	Cancer Society of the Bahamas
CSO	Civil Society Organisation
CSS	Cancer Support Services
DAB	Diabetes Association of Barbados
DAJ	Diabetes Association of Jamaica
DATT	Diabetes Association of Trinidad & Tobago
DCS	Dominica Cancer Society
FCTC	Framework Convention on Tobacco Control
HCC	Healthy Caribbean Coalition
HCP	Health Care Providers
HFJ	Heart Foundation of Jamaica
HLM	High Level Meeting
HSFB	Heart and Stroke Foundation of Barbados
JCTC	Jamaica Coalition for Tobacco Control
LMICs	Low and Middle Income Countries
MDGs	Millennium Development Goals
NCD	Non communicable disease
NCDA	NCD Alliance
NGO	Non Governmental Organisation
PAHO	Pan American Health Organisation
PHC	Primary Health Care
RSR	Regional Status Report
SDGs	Sustainable Development Goals
SLDHA	St. Lucia Diabetes & Hypertension Association
UN	United Nations
UWI	University of the West Indies
WHO	World Health Organisation

4 INTRODUCTION

On November 13-15, 2015, the NCD Alliance (NCDA) will convene the Global NCD Alliance Forum. The Forum will be the first of its kind, bringing together representatives from national and regional NCD alliances from across the world to build a sense of community, share experiences and good practice, support organizational strengthening, stimulate collaboration, identify network-wide priorities and facilitate advocacy planning.

The Forum will be organized under the banner theme of "NCD Advocacy and Accountability in the Post-2015 Era" and will focus on three key areas: Organisational development; Advocacy and accountability – driving change and demanding action; and Twinning – collaborations for success.

In preparation for the Forum, the NCD Alliance conducted a comprehensive participatory needs assessment of civil society NCD alliances aimed at creating a knowledge base and an impetus for civil society strengthening initiatives in the field of NCDs. The findings of the needs assessments will inform the forum capacity building content as well as the NCD Alliance's future strategy and work with the regional/national NCD Alliance network.

Regional civil society preparatory meetings were held to inform the NCD Alliance needs assessment. As one of only four regional NCD alliances globally, and a longstanding partner of the NCD Alliance, the HCC will be representing Caribbean civil society at the Forum. In preparation for the meeting, and with the support of the NCDA, the HCC hosted the Caribbean Regional Preparatory meeting in Barbados on June 6th, 2015.

This report summarizes the proceedings of the Caribbean Regional Preparatory Meeting.

5 ABOUT THE HEALTHY CARIBBEAN COALITION

The Healthy Caribbean Coalition (HCC) was formed in 2008. It is a regional network of non-governmental and civil society organizations from across the Caribbean Region with a remit to address non-communicable diseases (NCDs). The formation of the HCC was catalysed as a result of the Heads of Government Summit of Caribbean Leaders on NCDs, 2007, at which there was a call for engagement of a wide cross section of society in the response to NCDs.

The organization serves over 60 Caribbean-based health NGOs and over 65 not-for-profit organizations and in excess of 250 individuals across the Caribbean and globally. Members include nongovernmental health organizations, professional health and other associations, faith based organizations, neighbourhood organisations, cooperatives charities, unions, social movements and special interest groups.

The mission of the HCC is to harness the power of civil society, in collaboration with government, private sector, academia, and international partners in the development and implementation of plans for the prevention and better control of chronic diseases. The 2012-2016 HCC Strategic Plan focuses on four key strategic areas: 1. Advocacy by empowered Caribbean people with a view to bringing about positive health changes; 2. Enhanced Communication about NCDs to build public awareness; 3. Capacity Building in and among health NGOs in the Region to make them more fit to contribute to the "whole of society" response to NCDs; 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. 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.

HEALTHY CARIBBEAN COALITION

"a civil society alliance for combating chronic diseases"

6 BACKGROUND

Civil society has a central role to play in the achievement of a whole of society response to NCD prevention, treatment and control. However significant capacity building is needed in various areas including advocacy, monitoring and evaluation and ensuring accountability at all levels. When 'fit for purpose', the contributions of civil society are vast and varied. The central aim of the HCC is to add value to the work of civil society organisations in the Caribbean as they seek to achieve their organisational goals and objectives within the wider NCD response. The HCC has worked closely with the NCD Alliance since 2013 to strengthen the capacity for evidence informed NCD advocacy led by the civil society community in the region. In September 2013, the Healthy Caribbean Coalition (HCC) was awarded a grant under the NCD Alliance / Medtronic Philanthropy programme "Strengthening Health Systems, Supporting NCD Action". This programme is aimed at strengthening national and regional civil society NCD advocacy efforts in Brazil, South Africa and key Caribbean Community Countries (CARICOM) to raise demand and advocate to governments to strengthen health systems through an integrated approach to action on NCDs. HCC is currently in its third year of funding under this programme. To date key accomplishments under this grant include: 1. '*A Civil Society Regional Status Report: Responses to NCDs in the Caribbean Community*' report developed using a National/Regional NCD Civil Society Benchmarking Tool; a regional NCD Multi Stakeholder Meeting held in November 2013 aimed at building multisectoral partnerships for a coordinated NCD response; establishment of an HCC Advocacy Technical Working Group; development and implementation of an regional HCC NCD Advocacy Plan; Regional multi-stakeholder meeting on Health Systems Strengthening resulting in a 'CSO Statement of Commitment for HSS - Health Systems Strengthening Improvements' signed by over 40 Caribbean CSOs; production of an NCD Commissions Assessment Report and production of a Joint CARPHA/HCC Brief on trade policy and nutrition; and a report launched in September 2015 entitled: '*A Civil Society Report on National NCD Commissions in the Caribbean: Towards a More Effective Multisectoral Response to NCDs*'.

The NCD Alliance unites over 2,000 civil society organisations from 170 countries through a vision of a future free from preventable suffering and death caused by NCDs. The NCDA functions as a convener of the NCD civil society community, providing thought leadership on global policy, setting priorities for the global NCD response, and mobilising civil society action at national and regional levels. The NCD Alliance is committed to supporting and strengthening the network of regional and national NCD Alliances to maintain momentum on NCDs at national, regional and global levels and building upon programmes such as the "Strengthening Health Systems, Supporting NCD Action" described above.

The November 2015 Global NCD Alliance Forum aims to bring together representatives from a growing network of over 25 national NCD alliances and 4 regional NCD alliances. These alliances are providing important platforms to advocate for improved coverage of NCD interventions, patient empowerment and stronger health systems within their countries. In many instances these CSOs are leading the whole of society approach, working in partnership with governments and in some cases the private sector to drive a multisectoral, multifaceted, coordinated national responses to NCDs. The

forum will provide a timely opportunity to convene NCD civil society following the UN Summit for the Adoption of the Post-2015 Development Agenda which took place on 25-27 September 2015.

The forum will focus on three key areas:

- Organisational development. What do civil society organisations and their NCD alliances need to function optimally and enable effective and sustainable NCD advocacy efforts?
- Advocacy and accountability – driving change and demanding action. What are concrete examples, challenges, best practices and opportunities in advocating for accountability; NCDs as a priority issue; National NCD plans/targets and multisectoral mechanisms?
- Twinning – collaborations for success. How can collaborations between alliances maximize their advocacy impact?

Regional civil society preparatory meetings were planned to inform the Sharjah Forum. As one of only four regional NCD alliances globally, and a longstanding partner of the NCD Alliance, the HCC hosted the Caribbean Regional Preparatory meeting in Barbados on June 6th, 2015.

7 MEETING OBJECTIVES AND EXPECTED OUTPUTS

The aim of the meeting was to gain consensus from Caribbean civil society around regional NCD advocacy priorities, in preparation for the Global NCD Alliance Forum: "NCD Advocacy and Accountability in the Post-2015 Era" to be held in November 2015.

The **objectives** of the meeting were:

- To share experiences, challenges, lessons learnt and best practices.
- To strengthen the regional NCD advocacy capacity:
    - To map out NCD advocacy activities per country.
    - To define NCD advocacy priorities for the region and develop common objectives for national/regional action.
    - To stimulate regional collaboration in advocacy.
- To explore, nurture and support incipient national alliances in the Caribbean.
- To explore the experiences, lessons learned and way forward of civil society actors as conveners of multisectoral partnerships for NCD prevention and control.

The **expected outputs** were:

- A Profile of civil society experiences, challenges, lessons learnt and best practices.
- A Map of NCD advocacy activities across the region including a SWOT analysis.
- Guidance on mechanisms for civil society to lead on multisectoral partnerships.

8 THE PARTICIPANTS

The ½ day meeting brought together health and non-health civil society stakeholders to discuss priorities in civil society led NCD programming in the Caribbean.

Participants at the meeting included: Chair of the NCD Alliance, Dr. Cary Adams; Patron of the HCC, Sir George Alleyne; HCC President, Sir Trevor Hassell; representatives of fifteen civil society organisations from eight Caribbean countries; representatives of national NCD Commissions; and other NCD thought leaders from the region.

The full participant list can be found in Annex I of this report.

9 SESSION SUMMARIES

The meeting programme is found in Annex II. It included presentations, and working group discussions across three key areas: Profiling Caribbean Civil Society: Capacity and Contribution to the NCD Agenda; Mapping Caribbean Civil Society NCD Advocacy; and Civil Society and Multisectoral Partnerships. The proceedings are summarized below in the body of the report. Full text accounts of the opening and closing remarks are shown in Annex III. The outputs from the group discussions are provided in Annex IV.

9.1 OPENING REMARKS AND INTRODUCTIONS

Dr. Victor Coombs, Member of HCC Board of Directors

Dr. Victor Coombs, Director, Healthy Caribbean Coalition (HCC) and Chair of the first session of the meeting opened the proceedings by welcoming all present. He acknowledged the presence of Sir Trevor Hassell, President, HCC; Dr. Carey Adams, Chief Executive Officer of the Union for International Cancer Control (UICC) and Chair of the NCD Alliance (NCDA); and representatives of Caribbean civil society organizations. Dr. Coombs outlined the goal, objectives and outcomes of the meeting. He informed participants that HCC has been invited to attend the NCDA Global Forum and their views and inputs were being sought in the preparation of a Caribbean regional perspective for discussion at the forum. Areas to be considered included organizational development, advocacy and accountability and twinning. This was followed by participant introductions.

9.2 THE NCD ALLIANCE AND THE GLOBAL NCD ALLIANCE FORUM: THE REGIONAL PREPARATORY MEETING – OBJECTIVES AND EXPECTED OUTCOMES

Dr. Cary Adams, Chair, NCD Alliance

Dr. Adams began by giving a brief overview of the composition and role of the NCDA which was founded in 2009. He indicated that the growing network NCD alliances around the world reflected an obvious demand for people to be organized at national and regional levels and the NCDA has had to respond to this demand by changing the way in which it has operated throughout the last 5 years. Further change is expected with the expiration of the current business plan at the end of this year. He emphasized that, in developing the new plan, the NCDA is seeking and listening to the opinions of many people in order to identify what should be the organization's role in order to maximize its impact over the next three years.

Dr. Adams then reviewed developments in the global political response to NCDs and the NCDA's role beginning with the 2011 Political Declaration to address NCDs globally and subsequent developments culminating in the endorsement in 2013, of the Global Action Plan for the Prevention and Control of NCDs, 2013- 2020. Dr. Adams noted that with this 'refreshed' action plan providing a

clear roadmap for the attainment of global targets, the NCDA would be better organized to put pressure on governments and hold them accountable to their commitments. He added that a global coalition mechanism has been put in place to review progress in implementation of the action plan and the NCDA intends to focus its attention on the monitoring of agreed targets, and will also be following up on the policy responses to NCDs in the post-2015 development agenda.

Dr. Adams noted that while there were many developments at the global level, the Secretary General of the UN, in his 2014 report, stated that national progress was insufficient and highly uneven and that continued efforts at national level were essential for achieving a world free of the burden of NCDs. Dr. Adams urged participants to step up advocacy efforts locally in holding governments accountable to commitments, and observed that the global initiatives served to place civil society in a better position to achieve greater gains at national and regional levels.

In commenting on the growing network of national and regional NCD alliances, all of which were active, Dr. Adams predicted the emergence of 60 - 70 different NCD-type alliances in the next 2-3 years. He observed that there was no rulebook or "one size fits all" model for these alliances. Contrasting views could lead to difficulties in the early stages but these could be resolved by focusing on common areas of concern or interest. He added that Ministers of Health seemed to appreciate this type of collaboration and were also required to promote this type of engagement for NCDs.

In the final part of his presentation, Dr. Adams discussed the Global NCD Alliance Forum to be held in Sharjah, United Arab Emirates from November 13-15, 2015. Invitees included representatives from regional and national NCD alliances and coalitions, WHO and other NCD partners and stakeholders. The objectives and theme of the Global Forum, the key questions to be discussed and the provisional workshop programme were then outlined. Dr. Adams referred to two activities currently being conducted by the NCDA: a situational analysis of the national and regional NCD alliances which will provide feedback on priority needs and the type of support required from the NCDA in moving forward; and, regional preparatory meetings for the Global NCD Forum. He pointed out that the situational analysis and needs assessment for the Caribbean will begin at this regional preparatory meeting convened by the HCC which will also include the mapping of regional advocacy activities.

Comments

Sir George Alleyne inquired whether Dr. Adams wished to comment on the possibility of formalising the affiliation of the NCD alliances with the NCDA. In response, Dr. Adams explained that the NCDA had no formal relationship now with any of the national or regional NCD alliances. As part of the plans for the next three years, NCDA will be exploring mechanisms to formalize these relationships. This was needed to protect the NCDA brand but would also allow the NCDA to enter into more official relationships with the alliances which will facilitate information sharing and the development of more meaningful working partnerships. However he noted that although the NCDA was considering a more formal

structure, the degree of formalization remains uncertain. A type of accreditation scheme was being considered which would indicate that a particular organization or grouping is recognized as being affiliated to the NCDA. Sir Trevor commented that the formalization of relationships between the NCDA and the NCD alliances was important. He explained that HCC has been using the NCDA logo with the approval of the organistaion. The formalization of the relationship with NCDA would be helpful in simplifying issues relating to the use of NCDA brand.

9.3 HCC: SUPPORTING CIVIL SOCIETY LED NCD ADVOCACY AND ACTION

Mrs. Hutton, Executive Director HCC

Mrs. Hutton reiterated earlier statements that the meeting represented the first stage of a consultative process for determining NCD advocacy priorities for the region in preparation for the Global NCD Alliance Forum. She noted that fifteen health NGOs were represented at the meeting, but contact will also be made with the other health NGOs as well as non-health NGOs which form part of the HCC coalition to obtain their views on advocacy priorities and needs in preparation for the Forum. Mrs. Hutton asked participants, in their deliberation on advocacy priorities, to think about ways in which the HCC as a regional alliance could be more effective in engaging its membership and serving their needs. She then highlighted some of the key achievements under the HCC/NCD Alliance/Medtronic Philanthropy Grant project, which has helped to strengthen advocacy in the region, and also mentioned continuing efforts in health systems strengthening and capacity building around advocacy issues related to childhood obesity.

9.4 CIVIL SOCIETY ORGANISATIONS – EXPERIENCES, CHALLENGES, LESSONS LEARNT & BEST PRACTICES

Participants were invited to make brief presentations highlighting some key challenges and future priorities for their respective organizations. Many of the organizations were involved in service delivery and priorities were mainly aimed at addressing existing constraints affecting quality of care and access to services. Areas identified included: issues of financing and sustainability of operations; the upgrading of facilities; staffing and training needs; and, resources for supporting and sustaining volunteer efforts to allow greater outreach as well as the delivery of a wider range of specialist services. The urgency in mobilizing technical and financial support for addressing weaknesses in surveillance and monitoring was repeatedly stressed. Training in advocacy tools, methods and approaches for improving levels of engagement in advocacy efforts was also among priorities identified. Another area of concern was the limited effectiveness of public awareness and educational programmes on NCD prevention and the need for garnering resources for strengthening educational interventions. Some of the salient points arising from the presentations are summarized below.

Issues of financing and sustainability

The presentation by the representative of the St. Lucia Diabetic and Hypertension Association generated much discussion. The Association has adopted a more business-like approach to financing its operations and it was suggested that this approach could be a model for other NGOs in the region. The organization has applied for a loan from St. Lucia Development Bank to extend its operations and increase its staff complement and has asked the government to be a guarantor for the loan to get the project off the ground. It was still awaiting the response from government. The bank has indicated its willingness to approve the loan and advised that because of the viability of the project the loan could be repaid in two years. It is expected that significant savings will accrue after just two years of project implementation.

Sir Trevor thought this was an interesting approach and pointed out that NGOs often did not function in this way. Dr. Adams commented that the according to the details presented, the proposal provided an extraordinary return on investment which would also be attractive to a personal investor and this type of approach would be helpful for others to consider. He agreed that this novel approach would require a change of mindset on the part of NGOs. A participant observed that as registered charities, they may not be able to pay dividends to personal investors. All confirmed that their organizations (except Jamaica Coalition for Tobacco Control which is subsumed under the Jamaica Heart Foundation) were legal entities and some indicated that their organizations could borrow money. Dr. Coombs advised that there are no ethical challenges associated with NGOs generating surplus funds which are then channelled back into the organisation to support their operations. He pointed to the difference between earning income and earning profit and explained that profits on investments which are then used as dividends may not be allowed but profits on project activities that are reinvested into the organization's general consolidated fund was acceptable. The importance of having a cycle of revenue generation for sustainability was stressed. The option of borrowing against assets was also mentioned. There was a request from a participant for the St. Lucia Association to share a copy of its charter or governance structure for review by other NGOs represented at the meeting. This discussion highlighted the need for strengthening the basic and more sophisticated financial capacity of civil society.

Civil Society Organizations' involvement in service delivery

[Following the presentation by the Diabetes Association of Barbados], Sir Trevor observed that, in many countries in the world, NGOs were providing significant amount of service delivery, filling gaps in services not provided by governments. He noted that this core of activities was sometimes identified as a form of advocacy because it signalled NGO involvement in the provision of essential services.

Interventions in the health insurance sector

The representative from the Diabetes Foundation of Barbados observed that although modern NCD protocols called for a multidisciplinary approach to management, many specialist services were not covered by health insurance plans. She indicated that the Foundation had initiated discussions with Guardian Life and Sagicor regarding the need to sensitize underwriters about NCD management protocols and the savings to the companies if clients were encouraged to seek the recommended type of care. Mrs. Hutton pointed out that the issue of insurance coverage in NCD care had been raised repeatedly by organizations across the region and this was a possible area where the HCC could provide a platform to facilitate sharing of experiences, communication with the insurance sector and problem-solving. Dr. Adams added that because of the importance of this issue, particularly in relation to cancer and the cost of cancer treatment, it should also be addressed globally.

Volunteerism, Fundraising

[Following presentation by The Cancer Society of the Bahamas – CSB], Mrs. Hutton commended the Cancer Society's ability to mobilize a large core of committed volunteers and their significant successes in fundraising. In response, the CSB representative remarked on the generosity of their donors and also referred to the reputation of the organization which was recognized for its honesty and openness.

Data collection and analysis

There was collective consensus around challenges related to data collection and analysis. While some organisations shared that they did have databases many lacked the resources (human and financial) for data collection and analysis and thus were unable to monitor and evaluate the impact of their work. Many of the organizations were involved in service delivery; however comparatively little had data on coverage. This has implications at the level of the NGO and nationally leading to gaps in data on service coverage and the national achievement of targets. There was consensus that assistance should be provided in data collection and analysis because information on coverage would be useful in advocacy efforts with governments. Mrs. Hutton supported this view and added that HCC, in cervical cancer training, had emphasized the importance of data collection and how the data could be used to inform the Ministry of Health about the cancer societies' contributions towards the achievement of targets for cervical cancer screening. However, she noted that the organizations lacked the personnel and funds for data collection and analysis. The need for capacity building in Information technology was also touched on.

Country-to-country Support

Following presentation by the Dominica Cancer Society] It was pointed out that the Dominica Cancer Society had been engaged in two critically important areas: advocacy efforts at national and regional level for the establishment of cancer registries; and access .

connecting with other cancer societies (through a platform supported by HCC) to facilitate access to reduced cost cancer treatment and care in Guyana. The representative from Dominica explained that because of the absence of advanced cancer treatment in Dominica, and the difficulties in accessing treatment services in Barbados, the Society had to find an alternative site. Contact was made with a number of countries during the March 2013 cancer society advocacy meeting and the Cancer Institute of Guyana offered the most favourable package in terms of cost.

Increasing Youth participation

The representative of Youth4NCDs, HCC, reminded participants of the importance of youth participation in NCD prevention and control efforts. He commented on the lack of participation of HCC members in Youth4NCDs although its activities were mentioned in the Weekly News Round Up. A call was made for participation from all HCC members to engage youth leaders in their countries so that a collective Caribbean youth voice could be nurtured and impact could be felt regionally and internationally. Sir Trevor supported this call and urged participants to read the Round Up to keep abreast of developments in the region and elsewhere.

Support from Government

[Following presentation by The Bahamas Diabetes Association], Sir Trevor highlighted the issue of subventions from governments and questioned whether the acceptance of this assistance would compromise civil society's ability to hold the government accountable. He asked Sir George if he could speak to this issue in his closing comments. Taken from closing comments: Sir George: Once there is mutual respect on the part of both partners, the acceptance of a government subvention should not prevent a civil society organizations from holding the government accountable.

Provision of Palliative Care Services

[Following presentation by Barbados Cancer Support Services], the need to strengthen palliative care services in the region was emphasized. It was suggested that NGOs like the Cancer Support Services had the potential to develop and strengthen these services. Sir George further underscored this in his closing remarks.

Collaboration among agencies at national level

Many of the participants spoke about the need to acquire or refurbish buildings as a base for the organization's operations. Dr. Coombs suggested that a possible solution would be for all the NGOs to come together and rent or acquire one building which would be called the NCD House. Each organization could pay rent to cover maintenance expenses. Sir Trevor thought this was a useful suggestion because individual ownership of buildings sometimes proved to be a significant challenge. This approach would possibly lay the groundwork for the formation of national NCD alliances.

9.4.1 Profile of Caribbean Civil Society – Health NGOs

Across the 20 CARICOM Countries HCC has in excess of 65 health NGO members. There are NCD disease-specific organsiations in most islands with the civil society landscape dominated largely by diabetes and cancer NGOs and to a lesser extent heart and stroke associations. Well-established, high-functioning NGOs are generally found in the territories with larger populations. In contrast civil society in smaller countries (population) tend to be less developed with weaker organisational structures.

The snapshot of Caribbean health NGOs below, is based on the experiences and perspectives of the participating health organisations and the experiences of the HCC.

Governance & Management

- There is significant variation in the size and structure of Caribbean CSOs
- Larger well-established CSOs are formally registered entities and have strong governance and management systems in place.
- Smaller organisations are less likely to be formally registered and they tend to be loose alliances of individuals brought together around a collective vision. Many have weak or absent governance structures and poor overall management systems.
- Many do not have strategic plans guiding the goals, objectives and activities of the organisation (and used as benchmarking for reporting).
- Many do not generate periodic performance reports.
- Most do not have formal membership structures and associated dues.

Staffing & Volunteers

- Inadequate Staffing. Most do not have more than one full time paid staff and many smaller NGOs operate with only volunteer staff.
- Larger well-established NGOs tend to have more full time staff with defined roles and responsibilities including financial management.

Financing

- Predominantly small under-resourced operations.
- Primary funding sources are fees for services, community events and private sector donation.
- Many of the smaller organisations receive subventions from governments or perceive that they should.
- Some receive funding from governments based on services provided.

Partnerships

- Very little interaction between the disease specific health NGOs either within countries or within the region
- Limited partnerships with the public sector with the exception of some organisations which have 'fee for service' arrangement or a receive government subventions.

- Limited sustained partnerships with the private sector with the exception of the larger organisations.
- Limited partnership with academia (formal or otherwise).
- Limited partnership with global NCD organisations with the exception of some of the NGOs which have strong linkages with 'parent' international organisations such as the IDF, UICC or WHF.

Primary Activities

- Community education and health promotion.
- Early diagnosis (screening).
- Service delivery.

Research, Monitoring & Evaluation

- Little or no research (linked to the limited partnerships with academia), monitoring and evaluation capacity.

Advocacy and Accountability

- Very few are involved in traditional advocacy.
- Very few play a watchdog role holding governments, private sector and other civil society organisations accountable.

The purpose of the session was to gather information on individual members of the HCC in order to prepare the profile of the HCC in preparation for the NCDA Global Forum in November 2015. The information being requested included the organization's experiences, challenges, successes, lessons learned and future priorities in relation to six areas: capacity needs; advocacy; risk factor reduction; systems and NCD service delivery; surveillance, monitoring and accountability; and, patient engagement. Participants used worksheets for each organization represented at the meeting. The outputs from the breakout session are listed, by organization, in Annex 4, Table 1.

9.5 HOW CAN CIVIL SOCIETY BETTER ENGAGE EACH OTHER? EXPLORING THE FORMATION OF NATIONAL NCD ALLIANCES

Sir Trevor Hassell, President HCC

Sir Trevor Hassell provided introductory remarks to open the discussion. He stated that the topics being discussed must be placed within the context of the proposed Sustainable Development Goals (SDGS) which are expected to shape the world post-2015. UN member states are expected to agree to the draft set of the seventeen SDGS at a Summit in September and the goals should become applicable in January 2016. He also referred to the nine voluntary global NCD targets for 2025 around which much of the ongoing discussions are centred and which should also help to frame strategies for engagement and alliance building.

Sir Trevor also reminded participants of the membership categories of the HCC, the organization's emphasis on inclusiveness and its continuing efforts to find ways of strengthening the coalition to

make it more effective and sustainable. Underlying these efforts is the recognition that civil society must be well positioned and developed to play its role as a major contributor to the NCD response for prevention and control. In this connection, he stressed, there was also need to determine what structures should be put in place to make the coalition more effective at a national level. One consideration was the development of national NCD alliances (for which the HCC has unsuccessfully advocated since its formation in 2008). He raised the issue of whether non-health civil society organizations should be included in the alliances. Sir Trevor observed that the non-health NGOs have participated in HCC meetings and have a vital role to play in a whole of society approach. He emphasized that the idea of the formation of these alliances was a proposal for discussion. He further explained that the HCC approach to date has been to help build capacity and add value to organizations within countries through project implementation. In addition to assisting with project execution, HCC also assisted with - more importantly - financial management, accountability and reporting.

Comments/Questions

Structure of the national NCD alliances in the NCDA network

Dr. Adams indicated that there was no defined structure or template to follow. The underlying components of the current national and regional NCD alliances were representation by the four key NCD organisations (cancer, lung, heart, diabetes) - largely because most of the global dialogue in last five years had been about these diseases. He noted a distinction between smaller 'associations' versus larger more established 'societies'. In any country, there may be many cancer societies, heart associations etc. but it was generally the national societies that tended unite under the umbrella of a national NCD alliance. Methods of operation varied from country to country: some had formal MOUs, and others did not; and some had a small secretariat based in one of the organizations e.g. the role of UICC as fiscal agent for the NCDA. Most of them elected a chair, a leader of the group, but the way in which this was done was varied between countries. The majority of the alliances focused attention on the nine NCD targets and worked collectively on the priority issues which were of benefit to all. They may include palliative care, insurance coverage, and availability of data and registries. Thus they prepared an agenda which was very simple, of value to all, on which they could collectively engage primarily for advocacy. There were also examples where alliance members pooled resources on specific projects in order to achieve greater impact. Dr. Adams cited a few occasions when a Minister of Health approached leading organizations in a country requesting they unite as an NCD alliance in order to arrive at a unified civil society view or response on a particular issue. He reiterated that there was no model structure to follow. Feedback from the alliances indicates they are confident in the value and impact of their work. For the most part, they have stayed together and keep growing. They were aware of the benefits of working together but remained respectful of their differences and specific interests. He stressed that having a shared agenda has been central in keeping the alliances together.

NCD Commissions vs. NCD Alliances

NCD commissions are instruments of government and are composed of government, civil society, and the private sector. NCD alliances are civil society organizations. The primary focus of the NCD Commission is to drive the NCD agenda forward within the context of national and global targets. Dr. Adams was concerned about the ability of civil society to arrive at a common position within the context of the Commission. He suggested that a common position reached through a NCD alliance could then be discussed as the civil society contribution in the Commission. The success of this model, however, depended on the strength of the Commissions and the level of cooperation among the NGOs.

Formation of national NCD alliances in the Caribbean

The representative of the Jamaica Coalition for Tobacco Control (JCTC) thought that the proposal of a national NCD alliance had some merit and observed that the Diabetes Association was already a part of the JCTC so the organization was close to being a national alliance. She suggested that training in management and health leadership will be needed. There was also need to flag mental health as a special area for attention. The representative of the Diabetes Foundation of Barbados indicated that she fully supported the proposal. She mentioned that the Foundation had prepared a proposal for the rationalization of health and wellness promotion. The objective was to arrive at a cost-effective mechanism to rationalize resources applied to health and wellness promotion for effective coordination of messages, approaches and resources. The proposal included a section on monitoring and evaluation, which was an essential aspect of the work of the Diabetes Foundation. She indicated that she was willing to share and discuss the draft document with HCC to advance the discussion.

Dr. Sealy emphasized the importance of a strong, coordinated NGO network. She gave the example of the network of women's NGOs in Trinidad and Tobago, which was so well established that government consistently consulted with them on women's affairs. She insisted that the recognition of a strong alliance was possible with or without a Commission and the advantage was that it was a coordinated mechanism that could serve many purposes including advocacy.

Further discussion focused on the need for capacity building in promoting the establishment of NCD alliances. The participant from the Heart and Stroke Foundation of Barbados (HSFB) called for an assessment of the capacity needs of civil society organizations before an alliance is formed or as the first task to be undertaken by the grouping. The delegate of the Bahamas Diabetes Association also emphasized the need for training and referred to a PAHO-sponsored training programme for NGOS that was conducted a few years ago and which he found very useful. He suggested that assistance should be sought from PAHO if the expertise was not available within the HCC.

Sir Trevor informed participants that HCC has received support from the NCDA to undertake capacity assessments of member organizations. He mentioned that, some indication of the funding needs of member organizations - especially of the health member organizations would be included in the assessments. Dr. Adams advised that it would be useful to NCDA if the funding proposal were framed in the following way: the size of problem in this country is Z; the work we do affects X % of the problem; if we had A, B, C inputs, in the next X years, we could address up to X % of the problem. For example, if a screening program is planned and the target is 4000 individuals, and the current coverage is 500, then with X and Y inputs, it would be possible to reach the target in a year and it would cost X dollars. Sir Trevor assured him that this approach would be followed. The representative of The Cancer Society of the Bahamas agreed with the approach suggested by Dr. Adams. He added that a similar approach was used to advocate for an additional mammogram machine for one of the Family Islands. Although the proposal showed the savings to be made by acquiring the machine than flying women into Nassau and back for the service, the Cancer Society Board did not approve the proposal because it included a fee for the screening, and the Society has always provided services free of cost. He pointed out that this was an example of some of the constraints to expanding services and which NGOs needed help in resolving.

9.6 MAPPING CARIBBEAN CIVIL SOCIETY NCD ADVOCACY: THE ROLE FOR ADVOCACY AMONG CIVIL SOCIETY IN THE CARIBBEAN – REALITIES, EVIDENCE, EXPERIENCES AND THE FUTURE

In discussing civil society's role for advocacy in the region, some of the specific advocacy activities carried out by the HCC were shared. The establishment of a technical working group to guide HCC on priority areas for NCD advocacy action and outlined advocacy efforts carried out in collaboration with HCC member organizations. The latter included initiatives in the areas of cervical cancer prevention, tobacco control and health systems strengthening. HCC's engagement at the global level in discussions addressing issues of food and nutrition was also mentioned. The challenges and realities in conducting advocacy work were explored including: lack of skills, time and resources, and insufficient appreciation of the benefits of advocacy against a background of competing priorities. In moving the NCD advocacy agenda forward, evidence was needed and key gaps were identified in the 2014 '*A Civil Society Regional Status Report: Responses to NCDs in the Caribbean Community*' HCC/NCDA report. Many advocacy tools were available; and priorities would be discussed in the working group session as part of this meeting.


SHAWN HERCULES

9.7 CONSENSUS ON CSO PRIORITY ACTIONS

Organisations were asked to list and present their organisational NCD advocacy activities and priorities across key areas using a matrix. The group then arrived at a consensus on priority advocacy activities listed below. The information gathered would inform a mapping of regional and national advocacy activities and priorities. The outputs from the breakout session are listed, by organization, in Annex 4 - Table 2.

Recommended CSO Priority Actions

Action	Comment
Strengthening organisational capacity of Caribbean CSOs	In order to make Caribbean civil society organisations more 'fit for purpose', investments must be made into building the organisational capacity with an emphasis on: governance; financial management; information management; partnership/ alliance building; media and communications; and advocacy.
Promotion of mhealth	The Caribbean has a high penetration of smart phones and is thus fertile territory for the implementation of population based mhealth interventions building upon lessons learned from small-scale regional and larger scale global interventions.
Strengthening Advocacy	• Strengthening advocacy capacity (including policy literacy and communication) among CSOs (and within various groups including patient/ survivor groups and young people) using innovative strategies such social media. • Tobacco legislation (implementation and enforcement of FCTC) • Taxation on high sugar products (implementation and enforcement) • Product reformulation • Package Labelling • Childhood obesity including marketing of unhealthy foods to children and school policies around nutrition and physical activity • Expanded insurance coverage (challenges vary across territories) • Improved palliative care • Health Systems Strengthening (Caribbean Civil Society Organisations Statement of Commitment on HSS) • Population salt reduction/ Improved management of hypertension • Comprehensive Alcohol Policy • Cervical cancer screening (including provision of VIA) and HPV vaccination • Comprehensive Workplace wellness programmes
Formation of National NCD Alliances	The significant interest on the establishment and strengthening of National NCD Commissions (NNCDCs) presents a unique opportunity to advocate for the formation of national NCD alliances united around the four common risk factors. HCC has been pushing this agenda in the Caribbean for many years with little success but within the past year at least three territories have indicated an interest to establish national NCD alliances which would feed into the regional NCD alliance the HCC. Models such as the JCTC in Jamaica could

	be used to guide the process. The national NCD alliances would also be the ideal CSO representative body on the NNCDCs. This is an urgent priority for the HCC.
Increasing Collaboration between civil society organisations	There is a need to collaborate and coordinate civil society led programmes at a national level to avoid duplication, share resources and maximise impact. The formation of National NCD Alliances would provide a mechanism for increased partnerships among national NCD CSOs (including health and non health NGOs) *see above *Formation of National NCD Alliance*.
Increasing Leadership Capacity	There is a need to cultivate health leadership capacity as a very specific skill set for civil society; especially within the context of high-level advocacy.
Strengthening Strategic Partnerships with the public and private sector for prevention and control of NCDs.	CSOs currently relate to governments and private sector largely around funding for specific activities. There is a need for civil society to develop the skills to more effectively partner with governments and the private sector in the prevention and control of NCDs. CSOs need to make stronger cases for working with governments as valued collaborators in planning and implementation of national NCD programmes. Private sector partnerships for prevention represent and important and largely untapped arena with significant potential for mutual gain and far reaching impact on behaviours through the workforce and in the community; however CSOs must be equipped to navigate these relationships with a full awareness of conflict of interest issues.
Increasing Data Management & Research Capacity	Many CSOs collect significant amounts of data in the course of their routine activities whether within the context of community outreach, screening, treatment services etc. This data is often important for national surveillance systems and at an organisational level, to feed into decision-making around programming and resource allocation. The skillsets and resources needed for data collection, data entry, analysis and report generation often do not exist within these organisations. There is a need to develop the capacity of CSOs to use their own data more efficiently (to inform programming and advocacy priorities) and to ensure accurate data is being fed into national surveillance systems. Partnerships with academia and academic research units in particular, can strengthen the capacity of CSOs to better manage and use the information they generate in their daily operations. Increasingly there is an important role, as community gatekeepers, for civil society to be engaged in the setting, development and implementation of national and regional research agendas.
Prepare and maintain a database of active NCD CSOs in the Caribbean region.	There is a need for a comprehensive assessment Caribbean NCD civil society organisations to develop profiles and capture key information around needs, and current and planned activities. This information should be housed in an online, updated, database of active NCD CSOs in the Caribbean region.

Key considerations for Advocacy in the Caribbean context

There is a considerable variation in the understanding and value placed upon advocacy in the Caribbean CSO setting. Advocacy is time-intensive and requires special skills and it competes directly with income-generating activities such as service delivery and fundraising which are critical for the financial sustainability of most organisations. In addition to this, the watchdog role of CSO in the region is very much in its infancy and hence the idea of holding governments, private sector, and the civil society community (including one's own organisations) to account - is one which is novel and requires ongoing sensitisation. Furthermore, there are significant data gaps which hamper targeted advocacy efforts. In particular cost data is largely absent; many of CSOs site this as a challenge as the financial impact of recommended policies and programmes is the most influential in driving change within governments.

Resources for Caribbean CSO led-NCD Advocacy

There are several resources available for Caribbean CSO led-advocacy including WHO global tools, PAHO and CARPHA regional tools and more home-grown resources targeting civil society can be accessed through the HCC website and the HCC weekly roundup. The websites and facebook pages of civil society organisations throughout the region are also valued resources. Additional resources and evidence to drive advocacy are in the table below.

Evidence	• 2014 HCC/ NCD Alliance report: *A Civil Society Regional Status Report: Responses to NCDs in the Caribbean Community* includes an advocacy call to action to guide evidence informed advocacy in the Caribbean http://www.healthycaribbean.org/projects/documents/HCC-NCDA-RSR-FINAL-MARCH-2014.pdf . • University of the West Indies (Tropical Medicine Research Institute (TMRI)/ and Chronic Disease Research Centre (CDRC))
Technical Resources (toolkits)	• NCD Alliance NCDs in the Post 2015 Development Agenda http://ncdalliance.org/sites/default/files/rfiles/NCDA_AdvocacyToolkit_EN_0.pdf • International Diabetes Federation Advocacy Toolkit http://www.idf.org/sites/default/files/attachments/IDF_Advocacy-Toolkit-EN.pdf • Union for International Cancer Control Advocacy Toolkit http://www.uicc.org/advocacy-toolkit • World Heart Federation Advocacy Toolkit http://www.world-heart-federation.org/what-we-do/global-advocacy/advocacy-toolkit • HCC Cervical Cancer Advocacy Toolkits http://www.healthycaribbean.org/publications/hcc-and-sagicor-advocacy-handbooks.html • HCC Jamaica Tobacco Advocacy Toolkit (to be released)
Capacity Building Opportunities	• HCC 2013 Workshop on Cervical Cancer Advocacy Capacity Building for Caribbean Cancer Societies • Mentoring through the HCC Advocacy Technical Working Group
Technical & Financial Assistance	The NCD Alliance/ Medtronic Philanthropy Grant 'Strengthening Health Systems, Supporting NCD Action' provides resources for building of advocacy capacity among CSO members of the Healthy Caribbean Coalition.

9.8 CIVIL SOCIETY AS CONVENERS OF MULTISECTORAL PARTNERSHIPS AROUND NCDS

The importance and benefits of building and sustaining multisectoral partnerships for strong coordinated whole of society response to NCDs was discussed. The potential contributions of the three actors in the state – government; civil society; private sector – to the development of productive and meaningful partnerships were outlined and discussed with a focus on the increasingly important role of civil society as a leader in creating neutral spaces for multisectoral collaboration.

Examples of civil society leading on multisectoral action around specific projects were highlighted including the work of the HCC at the regional level through the hosting of multiple multistakeholder meetings including the engaging the private sector around NCDs and bringing together regional NCD Commissions to discuss models and recommendations for strengthening the commissions; the Caribbean Civil Society Cervical Cancer Prevention Initiative which was led by civil society and brought together public and private sector around increasing access to vulnerable women to cervical cancer education, screening and referral and expanding HPV vaccination programmes; grass roots civil society led research related to breastfeeding and childhood obesity; and the Jamaica Coalition for Tobacco Control (JCTC) internationally recognised work in bringing together key partners in the public sector around tobacco legislation. There was consensus on the need for cultivating health leadership capacity as a very specific skill set for civil society; especially within the context of high-level advocacy requiring engagement with senior policy makers and decision makers in the private and public sectors.

9.9 CLOSING COMMENTS

Sir George Alleyne, Patron, HCC

Sir George shared some of his reflections on the proceedings of the meeting as well as those of the meetings conducted on the previous two days. He observed that initially much of the discussion centred on service delivery but was pleased that attention was also given to other aspects of the role of civil society organizations, particularly relating to the issues of advocacy and accountability. He explained that accountability did not imply conflict and strongly emphasized that one did not have to be in confrontation with governments in order to hold them accountable for the commitments they made. He also stressed it was not only governments that should be accountable but that civil society organizations should be themselves accountable for the commitments that that they made and should also hold their partners accountable. The issue of government subventions for NGOs was raised and Sir George commented that once there was mutual respect on the part of both partners, the acceptance of a government subvention should not prevent a civil society organizations from holding the government accountable.

Sir George highlighted the importance of capacity building and noted the different forms discussed at the meetings particularly the need for training in leadership development and communication. In relation to the latter, the increased use of social media and the channelling of messages through popular music and song, for example, calypso and rap. A call was made for the development of an

epistemic community in support of NCD action; knowledge-sharing through effective communication strategies would be important in this regard.

On the issue of advocacy for policy change, Sir George made three salient points: the need to identify and target the appropriate people who were in a position to influence policy development and change, and to recognize that politicians were not the only policy makers; secondly, collective advocacy action by the disease-specific associations at national level should be based on a declared commitment to jointly address the main NCD risk factors; and thirdly, that all sectors of society were responsible for the achievement of the nine globally agreed NCD targets, not only governments. He also pointed to the need to include the provision of palliative care among priorities and observed that thousands of people in the Caribbean die in pain needlessly because of the lack of drugs which were affordable. In closing, Sir George strongly urged participants to take concrete actions towards the formation of NCD alliances in their respective countries.

10 CONCLUSIONS & RECOMMENDATIONS

The meeting was a valuable opportunity for civil society organisations to review and share experiences, and to highlight challenges and achievements, while identifying future priorities for NCD action. Many of the civil society organizations reported significant contributions to NCD prevention and control particularly in the area of service delivery and their priorities were mainly aimed at addressing existing constraints affecting quality of care; access to services and to a lesser extent, advocacy. They were urged to step up advocacy efforts and give increased attention to accountability for NCDs at the national level. It was recognized that capacity building and the mobilization of resources would be required for ensuring effective and sustainable NCD advocacy efforts. The formation of NCD alliances at the national level to promote more coordinated advocacy action focused on the common NCD risk factors was strongly recommended. A detailed list of recommended priority CSO actions is found in section 8.7.

11 ANNEXES

11.1 ANNEX I: LIST OF PARTICIPANTS

TITLE	FIRST NAME	SURNAME	POSITION	NAME OF ORGANIZATION
Dr.	Cary	Adams	CEO/ Chair	The Union for International Cancer Control/ NCD Alliance
Sir	George	Alleyne	Director Emeritus/ Patron	PAHO/ Healthy Caribbean Coalition
Mrs.	Kathleen	Baptiste	President	Dominica Cancer Society
Dr	Homer	Bloomfield	Board Member	Cancer Society of the Bahamas
Mrs.	Stacia	Brewster	Administrator	Diabetes Association of Barbados
Mr	George	Eugene	President	St. Lucia Diabetes & Hypertension Association
Sir	Trevor	Hassell	President, Chair	Healthy Caribbean Coalition/ NCD Commission, Barbados
Mr.	Shawn	Hercules	HCC Youth4NCDs Lead	Healthy Caribbean Coalition
Mrs.	Maisha	Hutton	Executive Director	Healthy Caribbean Coalition
Ms.	Juanita	James	President	Antigua and Barbuda Diabetes Association
Mrs.	Kathy-Ann	Kelly-Springer	President	Cancer Support Services
Mrs.	Lurline	Less	Chairman/ Past Member	Diabetes Association of Jamaica / Jamaica National NCD Committee
Mrs.	Barbara	McGaw	Project Manager - Tobacco Control	The Heart Foundation of Jamaica/ Jamaica Coalition for Tobacco Control
Mrs.	Noreen	Merritt	President	Diabetes Association of Barbados
Dr.	Mortimer	Moxey	Board Member/ Director	Bahamas Diabetes Association/ Healthy Caribbean Coalition
Mrs	Gina	Pitts	Chief Executive Officer	Heart & Stroke Foundation of Barbados
Mrs.	Zobida	Rabgirsingh	IPP Immediate Past President; Current chairperson of Princes TownBranch DATT	Diabetes Association of Trinidad & Tobago
Mrs.	Beverly	Reddock	Director	Lions Club of Kingstown SVG
Dr.	Karen	Sealey	Independent International Health Consultant, Former PAHO Senior Adviser	INDEPENDENT
Mrs.	Norma	Springer	Programme Coordinator	Barbados Diabetes Foundation
Mrs.	Paula	Trotter	Rapporteur	Healthy Caribbean Coalition (HCC)

11.2ANNEX II: MEETING AGENDA

MEETING PROGRAMME I JUNE 6, 2015 I COURTYARD MARRIOTT, BARBADOS		
TIME	ACTIVITY	SPEAKER
8.15am – 8.30 am	REGISTRATION	
8.30am – 8.35 am	Official Welcome and Opening Remarks & Introductions	Dr. Victor Coombs HCC Director
8.35am – 8.55 am	The NCD Alliance and the Global NCD Alliance Forum The Regional Preparatory Meeting – Objectives and Expected Outcomes	Dr. Cary Adams NCD Alliance
8.55am – 9.00 am	HCC: Supporting CSO led NCD Advocacy and Action	Maisha Hutton - HCC
	Profiling Caribbean Civil Society: Capacity and Contribution to the NCD Agenda *Moderators: Sir Trevor Hassell/Mrs. Maisha Hutton*	
9.00 am – 9.20 am	Civil Society Organisations – Experiences, Challenges, Lessons Learnt & Best Practices ORGANISATIONAL BREAKOUT SESSION Capacity/ Advocacy / Reduction of risk factors/ Systems and delivery of NCD services/ Surveillance, monitoring and *accountability/ Patient engagement*	
9.20 am – 9.40 am	Organisational Experiences - CSO PRESENTATIONS	
9.40 am – 9.55 am	Consensus on key challenges, successes, lessons learnt and best practices for Caribbean Civil Society DISCUSSION	
9.55 am – 10.15 am	How Can Civil Society Better Engage Each Other? Strategies for Engagement. Exploring the Formation of National Alliances of Health NGOs in the Caribbean DISCUSSION	
10.15 am – 10.30 am	HEALTH BREAK	
	Mapping Caribbean Civil Society NCD Advocacy *Moderators: Dr. Victor Coombs/Dr. Mortimer Moxey*	
10.30 am – 10.40 am	The role for advocacy among civil society in the Caribbean – realities, evidence, experiences and the future. *- Caribbean Civil Society Organisations Statement of Commitment on HSS* PRESENTATION	
10.40 am – 11.10 am	Mapping of National and Regional NCD Advocacy Activities and Priorities COUNTRY GROUP BREAKOUT SESSION	
11.10 am – 11.30 am	NCD Advocacy Activities and Priorities GROUP PRESENTATIONS	
11.30 am – 12.00 pm	Consensus on national and regional NCD Advocacy Activities and Priorities and Resources Required DISCUSSION	
	Civil Society and Multisectoral Partnerships	
12.00 pm – 12.30 pm	Civil society as Conveners of multisectoral partnerships around NCDs – challenges, successes, lessons learnt and the way forward Working with governments/ private sector/ academia PRESENTATION & DISCUSSIONS	Mrs. Maisha Hutton/ Sir Trevor Hassell
12.30 pm – 12.45pm	Closing comments	Sir George Alleyne, NCD Alliance
12.45pm – 1.00pm	Evaluation & Wrap up	Mrs. Maisha Hutton/ Sir Trevor Hassell
1.00 pm – 2.00 pm	LUNCH	
2.00 pm	WORKSHOP CLOSES	

11.3 ANNEX III: FULL TEXT ACCOUNTS OF OPENING AND CLOSING REMARKS

Opening Remarks: Dr. Victor Coombs

Good morning. Sir Trevor, Dr. Carey Adams and distinguished members of civil society in Trinidad and Tobago. I wish to welcome you on behalf of the HCC and we will just share with you a few remarks on the objectives of the morning's program. So the goal of the meeting is to gain consensus from Caribbean civil society around regional NCD advocacy priorities, in preparation for the Global NCD Alliance Forum: "NCD Advocacy and Accountability in the Post-2015 Era" to be held in November 2015.

The objectives of the meeting are:

- To share experiences, challenges, lessons learnt and best practices.
- To stimulate a multisectoral approach to NCD prevention and control by fostering collaborations between civil society and other key NCD stakeholders in the region.
- To explore, nurture and support incipient national alliances in the Caribbean.
- To strengthen the regional NCD advocacy capacity:
    - To map out NCD advocacy activities per country
    - To define NCD advocacy priorities for the region and develop common objectives for national/regional action.
    - To stimulate regional collaboration in advocacy

The expected outputs and outcomes are:

- A Profile of civil society experiences, challenges, lessons learnt and best practices.
- A Map of NCD advocacy activities across the region including a SWOT analysis.
- Guidance on mechanisms for civil society to lead on multisectoral partnerships.

The NCD Alliance and the Global NCD Alliance Forum: The Regional Preparatory Meeting – Objectives and Expected Outcomes will be the topic of the next speaker. There will be a meeting in November of the Global NCD Alliance Forum and HCC has been invited to that meeting and we wish to get your views and your input into what is the regional response in order to participate at that meeting. We expect to look at areas such as organizational development, advocacy and accountability and possibly twinning. Before I introduce the next speaker, however, I would like each participant to just stand and state your name and the organization that you represent so we can get a feel for each other's background. Thank you very much.

So I will introduce Dr. Carey, Adams who is the Chief Executive Officer (CEO) of the Union for International Cancer Control and Chair of NCD Alliance. He has a plethora of academic qualifications as well as a depth and breadth of experiential learning both in the financial sector and the NGO sector. So without further ado I will invite Dr. Carey Adams to address us. Please give him a warm welcome.


VICTOR COOMBS

Closing Remarks: Sir George Alleyne

For me it has been a very rich two and half days and once again I have to thank you all for making it so enjoyable. I have a just a couple of comments to make, things I reflected on today, yesterday and the day before. The first thing I will mention is - today I heard a lot initially about the role of civil society in providing services and it is quite understandable that the individual disease-specific organizations would focus on services. I was so pleased to hear Maisha talk about the other things that they expect the civil society organizations to do. So then I need to hear more on the aspects of advocacy and accountability. You were very eloquent about what should happen in terms of the advocacy. Accountability, in the sense of having persons, organizations accountable for their commitments does not imply conflict. You can have governments account for what they have done or to what they have committed without entering into conflictual arrangements with governments. One does not have to be in a conflicting mode with government in order for one to point out that they should be accountable for the commitments that they made.

Secondly, it is not only governments that should be accountable. We should be ourselves accountable for the commitments that we make and our other partners should be accountable for the commitments we make. Therefore if we take the thesis that within a commission there are at least three entities, government, public to private sector, we should be accountable within that arrangement for the commitments we made. So accountability does not only imply holding governments speak to the fire. It means holding ourselves and other partners accountable for the commitments we make. This is a very important point and it turns on the first, not to see government as some agent out there who is dumping on us and we have to be always in a confrontational mode with governments. That is not the idea. The idea is that one can make the population understand that governments made commitments without being confrontational. I want to make that point crystal clear. We should not think ourselves as soldiers against the government. That is not the idea. It does not work well. It does not work well. I repeat ad nauseam that if we have civil society, government and the private sector as part of this commission, there is nothing inherent in that arrangement in us as civil society ensuring that there is accountability of all three partners. There is no conflict in that, with civil society having these other roles which I will come on to. So that is the first point I want to make. So services are absolutely crucial and that underpins a lot of what I was hearing. I was again pleased to hear Maisha refer to the other aspects of the roles of civil society.

The second point I would make is – the question was asked: does a subvention from government stop you as a civil society from discharging the function of holding the various parts of the association accountable? No, it does not. If there is mutual respect on the part of both sets of partners, the fact of a subvention from government does not stop the organization from holding government and its other partners accountable. I think, and experience has shown that, once there is that respect, it does not stop that from happening.

The other point I wish to make is in relationship to capacity building. I was so pleased to hear the references to the various forms of capacity building. I was pleased to hear the discussion on the need

for leadership and need for training in leadership. There is the old saying, 'Leaders are born and not made'. That is nonsense… even if leaders are born; they make better leaders if they are trained. There is always within the organizations room for this training. I always think a lot of the training takes place almost by osmosis, and the very fact that member participate in these meeting is their form of training. We learn from one other and we create one another in these collective endeavours.

The other point I was very pleased to note in terms of capacity building is a capacity for communication. I think one of your young people mentioned the issue of the social media, even Obama now tweets, and the need for tweeting. I don't because I am incompetent but my granddaughter does. And the need for you, young people to be able to tweet. Another form of communication which I think is even more important in our part of the world is in song, our calypsonians and our rappers. I don't think I heard in any of the calypsos last year any mention of the NCDs. The point I am making is that this is a medium that I think we could cultivate. Why I am saying this? One of the things that the NCD community has to do is to create what we call an epistemic community, create a community of people who are knowledgeable about and interested in what we do. That is what the HIV community did beautifully. Create an epistemic community, create groups of people who are knowledgeable about and interested about any one of the disease patterns or any one of risk factors. That is critical for us - to create these epistemic communities in the Caribbean, groups of people who are knowledgeable about and speak about the NCDs.

I was pleased to hear Maisha say we need to influence policy makers and influence policy but one of the things we have to realize is that policy makers come in different shapes and forms. Not only politicians are policy makers. As a friend of mine used to say Baptist preachers are probably more effective policy makers than many politicians because they have more captive audiences and more readily believed than politicians.

You mentioned the advocacy tool kit for influencing policy. It is really very good and I encourage everyone to take a look at it. But Carey said it yesterday, I repeated it and I am going to repeat it today. If one is going to talk to the things for which one should advocate and if you are going to have the diabetes, cancer, heart, lung and stroke associations coming together to advocate. There are these nine targets. Just of interest, an article recently in the Economist, was giving the UN hell about the number of targets. They said that Moses came down from the mount with only 10 and no good set of targets should exceed 10. I am not so sure about that. But the idea is and I think this is really critical as we advocate collectively, even although you are a diabetes association, even although you are a cancer association, you can say, we as a society, that we are committed to the nine targets to address these four risk factors. This can be the lingua franca of all of us regardless of the association to which we belong. This can be our lingua franca. The other point in that context, I would make, is do not only think that it is government's responsibility for these targets. These are targets, which as countries, we all are in a sense responsible for, not only governments.

The penultimate point that I would make -it has not been discussed much a lot here. But I would hope in our discussions on the NCDs, we remember what the 2011/14 UN document spoke to. It did not

only speak only to promotion, prevention, rehabilitation but also spoke to palliative care. We sometimes forget palliative care in our discussions on the kind of things in which we should be interested. The issue of palliative care is the probably the most egregious manifestation of inequality in health; 15% of the world's population use 95% of the world's morphine. In Jamaica, if look at average use compared to the rest of the region as a whole, Jamaica has 2 mg use per head, while the region as a whole has 30 mg use of morphine [per head]. Thousands of people in Caribbean die in pain needlessly for things that cost pennies. We will talk more about that next week in Jamaica - what associations can do so that opiates become more readily available.

My last point I am going to make is in response to the comment that Lurlene made when she referred to the point that I made yesterday –"*Make no little plans. They have no magic to stir men's blood.*" What Burnham was referring to is not the elaboration of grand plans, but that the success of grand plans often depend on the attention you pay to the little things below. It is not that we must make grand plans and forget the nuts and bolts that have to be done. The grand plans are going to depend on whether the little nuts and bolts actually get screwed together. I feel passionately about Caribbean and these grand plans and feel passionately about what the Caribbean can do to achieve these grand plans but that does not mean we should not contend with the nuts and bolts which should be put in place.

This is really my last point. One of the things I hope you will go away from here thinking about is the excellent work by the individual associations. But it would gladden my heart if some of you went back and I could hear that in some countries there were really NCD alliances. It would really gladden my heart to hear that in various countries, you could get together the cardiac society, the diabetes association, the cancer society and I could hear that there is an NCD Alliance in Trinidad and Tobago and there is an NCD alliance in The Bahamas etc. That would really gladden my heart. I would count that as a major outcome of meeting, if there is commitment that at national level we could see the formation of these NCD alliances. They would be in no way inimical to the work of the HCC. I really hope we can see at national level we could see the formation of NCD alliances. And when next Trevor brings us together we can hear not only presentations of individual associations but we can hear presentations on common approaches that the individual disease specific entities are taking as an alliance for NCDs. That would really gladden my heart. Thank you all very much.

11.4 ANNEX IV: OUTPUTS FROM WORKING GROUP SESSIONS

11.4.1 Table 1: Profiling Caribbean Civil Society

Caribbean Civil Society Regional Preparatory Meeting, June 6 2015, Barbados

TABLE 1: BREAK-OUT SESSION 1: PROFILING CARIBBEAN CIVIL SOCIETY

Antigua and Barbuda Diabetic Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Lack of appropriate space to house Headquarters and Meeting Place. • No paid staff. • Funding mainly through membership fees; limited fund-raising activities and occasional donations.	• Renovating building leased from government. • Sustaining volunteerism. • Limited funds. • Increasing membership.	• Leasing of building from government. • Collaboration with Ministry of Health and University School of Nursing in programme implementation. • Core group of dedicated volunteers. • Availability of space in churches, hospital and Ministry of Health for conducting outreach.	• Costs for some programme activities can be met through collaborations. • Student volunteers can assist with programme implementation.	• Obtaining a subvention from government to help in covering basic operating costs. • Renovation of leased building to house headquarters. • Increasing fund-raising activities including targeting the private sector. • Engaging and training student volunteers from the Universities. • Strengthening partnerships locally and regionally.
2. Advocacy				
• Securing free blood glucose meters and test strips for persons on insulin. • Obtaining an increase in number of test strips through the Medical Benefits Scheme.	• A long process in achieving results. • Volunteers' unwillingness to use electronic media.	• Adults on insulin are now entitled to 50 test strips per month and children, up to 100 strips, based on recommendation of the doctor. • Free media time for educational programmes.	• Be patient and persevere. • Work with allies and lobby at every opportunity.	• Ensure all children with diabetes receive free glucometers and test strips whether on insulin or not. • Training in advocacy. • Lobbying government to obtain a subvention and assistance in renovating the leased building. • Improving communication with different target groups.
3. Reduction of Risk Factors				
• Promotion of healthy	• Sustaining programmes	• Ongoing screening for	• Importance of program	• Structured interventions

Antigua and Barbuda Diabetic Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
eating and regular physical activity in varied settings including schools, community and workplaces.	because of the lack of adequate funding and personnel. • Evaluation of programmes to assess impact.	risk factors. • Education/health promotion in schools, workplaces and communities.	monitoring and evaluation. • Collaborations with partners improve programme implementation and monitoring.	in schools and workplaces. • Increased use of mass media.
4. Systems and Delivery of NCD Services				
• Training/Education programmes to improve self-management. • Provision of free glucometers (and sometimes test strips) and lancets to persons who are not eligible to receive these items from government.	• Lack of headquarters or appropriate space where services can be provided on an ongoing basis.	• Convening annual workshops for persons living with diabetes and their families. • Programmes which bring children and parents together for education and support.	• Some services can be delivered despite lack of headquarters.	• Training/capacity building for members of the Association. • Continue education programmes and provision of basic services when renovation of building is completed.
5. Surveillance, Monitoring and Accountability				
• Lack of data on incidence and prevalence of diabetes and on risk factors.	• Data collection and management including risk factor surveillance.	• Collection of data on children with diabetes from hospital dietitian and paediatricans. • Collection of data on amputations from hospital. • Collation of findings from screening programmes conducted in schools, workplaces and communities. • Annual reports of the Association and audited accounts.	• Working with partners to encourage and promote data collection, collation and analysis and use of the data.	• Continue to promote accurate and timely data collection and management. • Training and support to improve data management and surveillance.
6. Patient Engagement				
• Monthly meetings of the Association. • Strengthening peer				

Antigua and Barbuda Diabetic Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
support especially for children with diabetes. • Provision of opportunities for affected persons to share experiences.				

Cancer Society of The Bahamas				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Cancer Society formed in 1976. • Services include: Screening for breast, cervix and prostate cancer (>20years). • Six paid members at Cancer Centre. • Eleven branches of the society in The Family Islands.	• Geography of The Bahamas – multiple small islands. • Lack of medical facilities and personnel in the Family Islands. • Limited funding for services. • Dealing with cultural beliefs and myths. • Data collection and analysis	• The Cancer Society is nationally recognized. • Establishment of Cancer Caring Centre in Nassau. • Establishment of patient support system in Nassau. • Introduction of mammogram screening programme in 2 Family Islands. • Formation of 11 self-funded branches of the Society in The Family Islands. • Fundraising.		• Improved facilities in The Family Islands. • Expansion of the Cancer Caring Centre. • Obtaining funding from government to support service delivery and programmes. • Increased focus on advocacy and alliance-building.
2. Advocacy				
• Limited experiences in advocacy activities. • Obtained mammogram machine for 2 Islands. • Advocated for the introduction of HPV vaccination for children	• The need for stronger advocacy skills and methods. •	• Establishment of hospital-based cancer registry. • Introduction of mammogram screening programme in 2 Family Islands. • Introduction of HPV vaccination for children (9 -12 years; males and females)	• Slow pace of government bureaucracy. • The importance of advocacy in achieving objectives.	• Strengthening of advocacy skills and methods.
3. Reduction of Risk Factors				
• Basic screening programmes (on-going)	• Levels of obesity. • Early onset of breast cancer. • Alcohol consumption patterns. • Smoking rates among teens. • Presence of 2 cigarette	• Increased public awareness of cancer prevention messages. • Continuation of breast and cervical cancer screening programmes but limited increase in uptake.	• Patient privacy issues. • The urgent need to extend services/to do more.	• Island Branches to make greater inroads in the following areas: o Recruiting volunteers o Increased funding and support for programmes.

Cancer Society of The Bahamas				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
	manufacturers in country.			
4. Systems and Delivery of NCD Services				
• Free screening programmes • Provision of patient support/accommodation services.	• Geography of The Bahamas – multiple small islands. • Inadequate funds	• National recognition of the services offered by the Society. • Introduction of HPV		• Building of alliances • Obtaining additional funding. • Improved facilities and access in The Family Islands
• Fund raising	• Recruiting volunteers to assist with service delivery and programme implementation.	Vaccination country-wide.		
5. Surveillance, Monitoring and Accountability				
• Limited surveillance • Good accountability by the Cancer Society	• Recruiting volunteers to assist with data collection and analysis. • Funding constraints.			• Establishment of national Cancer Registry.
6. Patient Engagement				
• Provision of patient support/accommodation services.	• Slow response of patients to information and treatment. • Late presentation for diagnosis, care and treatment. • Patients' cultural beliefs and myths.			

The Bahamas Diabetes Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Present rental space will not be available so Association has to find a new base for operations. • Funding for Association provided by Bahamas government, Atlantic Medical Insurance Company and membership fees.	• Finding appropriate space for the provision of services. • Lack of administrative and professional staff, and office equipment. • The need to increase membership. • Lack of total commitment of some Board members. • Outreach to the other islands in the archipelago.	• Obtained a promise of land from Bahamas government. • The interest and passion of new, younger persons who were recently elected to the Executive Board. • Likely collaboration with the Ministry of Health in training diabetes educators. • The Ministry of Health appreciates the need for NGO action and collaboration.	• Training in NGO management, accountability and transparency is critical.	• Identifying and obtaining a building which will serve as the Association's Headquarters; the building will be well equipped and have a cadre of trained staff. • Training of diabetes educators. • Training in best practices for administering an NGO/health NGO. • Establishment of foundation for fundraising.
2. Advocacy				
• Frequent meetings with: o Chief Medical Officer (CMO) o Deputy CMO o Chronic Disease Coordinator o Governor General of The Bahamas				• Collaboration with Cancer Society of Bahamas and other CSO partners.
3. Reduction of Risk Factors				
• Participation in educational programmes for reduction of risk factors.	• Smoking rates; alcohol consumption patterns; high levels of elevated blood pressure; obesity and physical inactivity	• Screening and education programmes • Collaboration with Atlantic Medical in annual fundraising fun run/walk.		
4. Systems and Delivery of NCD Services				
• Screening programmes • Provision of glucometers and test strips.				• Provision of ophthalmology services

The Bahamas Diabetes Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
• Education via the mass media and a newsletter. • Individual counselling and group/community education. • Sees referrals from clinics of Dept. of Public Health and the Ministry of Health.				
5. Surveillance, Monitoring and Accountability				
• No Epidemiologist on staff. • Very little external monitoring carried out. • Internal monitoring carried out to some extent.				
6. Patient Engagement				
• Availability of foot care services. • Many opportunities for screening exist e.g. at workplaces; health fairs.	• Inadequate numbers of trained educators. • The lack of adequate equipment for screening.	• High public demand for diabetes screening.		

Barbados Cancer Support Services				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Founded in 1996. Cancer Support Services currently offers several ongoing services.	• Ageing membership. • The need to initiate and sustain successful collaborations.	• Increased visibility of services • Structured organization with board of directors and general membership. • Building relationships.	• Branding is important in promoting services.	• Owning a building to serve as Headquarters.
2. Advocacy				
•	• Time constraints	• Clients' willingness to speak out and share stories about their journey with cancer.		
3. Reduction of Risk Factors				
		• Information sharing • Counselling • Medical conference • Public lectures		
4. Systems and Delivery of NCD Services				
• Provision of sustainable support to cancer patients. • Annual School Grants for those children whose parent have been diagnosed with cancer or have died, and families are in need of financial assistance.	• The lack of training opportunities.	• Adopted WDC12 approach. • Home visits. • Educational activities in schools and communities.	• Social welfare training had significant impact on quality of services.	• Building partnerships.
• Regular visits to Ward C12 at QEH; • Grief counselling; welfare funds; and assisting with nursing care to patients who choose to remain at home.				
5. Surveillance, Monitoring and Accountability				
• Preparation of audited financial statements		• Documentation of services		

Barbados Cancer Support Services				
		• Establishment of a website; use of social media		
6. Patient Engagement				
• Organization of educational activities.	• Work commitments of clients affect attendance.	• Encourage social interactions		

Dominica Cancer Society				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Society has 3 branches including youth arm. • Operate in rental premises; subvention provided by government. • Dedicated volunteers: hospital support group, house management and secretarial services. • Annual fund raising activities.	• Lack of administrative support. • Staffing – volunteers and support team members require further training. • Limited resources to sustain services. • Inadequate staffing • Need to meet operational costs of rented building •	• Receives a subvention (EC$30,000) from Government, shared with Diabetic Association. • Collaborative efforts with Ministry of Health including the Oncology Dept. at Princess Margaret Hospital, private diagnostic institutions and other NGOs. • Received a grant from the Australian Government through the HCC, which allowed the DCS to provide training of HCWs and community workers, video and print media on Cervical Cancer and Colposcopy vouchers to indigent women. • Training of health workers and community leaders re advocacy for Cervical Cancer screening.	• The benefits to be derived from collaboration and networking. • The effectiveness of planning with others and not for others. • The importance of having dedicated and motivated volunteers who are united and share a common vision. • The relevance of effective program planning based on identified needs and monitoring and evaluation of implemented activities with a view to improving on identified deficiencies. • The involvement of senior students from secondary schools to assist with programme planning and implementation..	• Purchase of a building as permanent base for operations. • Continuous training of volunteers and support group members and the general membership. • Continuous recruitment of members • Recruitment of full-time employees.
2. Advocacy				
• Fully engaged in advocacy efforts throughout the island through: • Workshops • Training sessions • Awareness-raising/targeted	• Cost of using communication media (audio and video PSAs). • Cost of treatment. • Minimal access to funding agencies to assist members with treatment	• Establishment of funding protocol. • Established partnerships with Ministry of Health and other collaborating agencies. • Financial support from	• Resources (human and financial) are critical to advocacy efforts. • Sustaining multi-sectoral collaborations are key to advancing advocacy. • Effective advocacy	• Continued advocacy efforts to influence: o Policy making as regards cancer prevention and management (diagnostics and

Dominica Cancer Society				
campaigns • To advocate for decreased cost of cancer diagnostic procedures and surgical interventions as regards public versus private physicians. • Advocacy on behalf of clients for assistance from government, private health facilities and regional and international health institutions for meeting treatment costs. • Influenced government policy on cancer prevention, and management (diagnostics and treatment).	cost. • Need for national health insurance scheme. • Slow response of public to awareness-raising.	NGOs and corporate Dominica. • An indication that government is considering the Society's suggestions re a proposed national health insurance scheme.	depends on continuous support from key stakeholders and from evaluating activities from a "public" standpoint.	treatment) o Plans for proposed national health insurance scheme o Reduction in cost of cancer treatment. • Improve advocacy skills among the Youth Arm
3. Reduction of Risk Factors				
• Implementation of education programs on (i) the non-modifiable and modifiable risk factors for cancers and (ii) cancer prevention, early intervention practices. • Development and dissemination of educational material in print media. • Preparation and airing of educational public service announcements (PSAs) and on Social Media.	• The need for greater collaboration in addressing common risk factors. • Resources for sustaining programmes. • The cost of developing and disseminating health education and infomercials in the media (audio and video). • Lack of research capacity on cancer risk factors and identifying these risk factors in the environment and otherwise.	• Successful outreach programs in all health districts in the island. • Use of media as a marketing tool.	• There is need for continued efforts at awareness raising re risk factors for cancer. • Community buy-in yields more fruit (participation with resulting behavior change over time) • Peer advocacy is more effective depending on the target group.	• Advocate for public health policies on risk reduction • Extend outreach to different target groups. • Greater use of media for promoting educational messages.
4. Systems and Delivery of NCD Services				

Dominica Cancer Society				
• Provision of Oncology services by Ross University on a voluntary basis. • Provision of Oncology services by Ross University Consultants, and by visiting specialists under the Technical Assistance Cooperation or on a voluntary basis.	• The absence of a local Oncologist on permanent staff of main hospital is the major challenge to timely and effective management and referral of clients. • Limited and costly diagnostic services. • Limited availability of drugs for cancer treatment (Cytotoxic drugs are not ordered in bulk and stored as other drugs so they have to be sourced on demand which delays management). • Limited capacity for provision of palliative care including availability of drug regimens for late stage cancers) • Limited training opportunities for nurses in cancer care and treatment and palliation.	• Established supportive relationships with the Central Medical Stores which facilitates ordering of drugs. • The appointment of a liaison officer from the DCS with the PMH to assist with clients' referrals (local and overseas). • The establishment of outpatient unit at main hospital and regular clinics. • The provision of chemotherapy services at main hospital. • Good working relationships with private diagnostic services.	• Acceptance of the members of the DCS as support for clients accessing chemotherapy • Improved attitudes of health care personnel but training required to build capacity in Oncology services and especially palliation resulting in improved care.	• Recruitment of a local Oncologist to be assigned to main hospital. • Identifying/conducting training for the staff of the Oncology Unit • Obtaining/providing scholarships for local medical doctor to pursue post-graduate studies in Oncology and related fields. • Formalizing working relationships with external diagnostic and cancer care/management centres.
5. Surveillance, Monitoring and Accountability				
• Annual reports on lab-diagnosed cancers • Limited data collection and data analysis on cancer incidence and management/treatment. • Non-formal relationships for accessing data from private diagnostic centres	• Limited technical support for establishment of national cancer registry.	• Implementation of screening programmes (breast and prostate cancer; BRAC). • Collation of data from screening programmes and submission to Ministry of Health.	• The ethical considerations related to conducting screening programmes and the impact on local public health system.	• Advocate for Government to provide training opportunities/obtain scholarship/s for staff training in the establishment and maintenance of national cancer registry and use of the data to influence policy and program

Dominica Cancer Society				
				development.
6. Patient Engagement				
• Education of patients and provision of social support to encourage disclosure and open discussion about their conditions. • Partially trained health navigators • Provision of care services including accommodation for patients/family members during period of chemotherapy treatment. • Payment of airfares for patients travelling to Guyana for radiation treatment; also help to defray treatment costs.	• Limited funds for educational activities. • Patient delay due to fear resulting in late diagnosis and treatment. • Limited volunteers for Hospital Support Team	• Generation of funds to assist patients to meet costs of tests and treatment. • Organization of annual Walk for Cancer Care - main fund raising activity. • An increase in Society's membership. • Support group activities have contributed to members' increased knowledge and engagement on matters of personal health. • Introduction of 'after chemotherapy' care services.	• Openness/disclosure on the part of the leadership of the Society has led to increased awareness on part of members and general public.	• Advocacy for a Caribbean treatment centre where costs for patients would be subsidized. • Mobilization of resources for increasing quality and impact of educational programmes.

HCC: Youth4NCDs (Y4NCDs)				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Structured forum for Y4NCDs. • Funding for regional link up between advocates.	• Gaining participation from National NCD Commissions, CSOs and NGOs to make youth interested.	• To date, there is participation in Belize, Trinidad and Barbados. • Recording of video giving information about Y4NCDs and how prevalence of risk factors can be reduced. • Meeting with Seun Adebiyi from ACS (Youth Advocate). • Conference call with advocates in Belize, Trinidad and Barbados.	• Listen to what others have to say about the Forum and what they want to get out of it to get 'buy in".	• Organizing another conference call in June. • Planning a meet-up session in one of the islands to gain participation and familiarity among members. • Y4NCDs members are active in their communities.
2. Advocacy				
		• Completed a video encouraging advocacy among young people in the Caribbean which gained some attention regionally.		
3. Reduction of Risk Factors				
4. Systems and Delivery of NCD Services				
5. Surveillance, Monitoring and Accountability				
6. Patient Engagement				

Diabetes Association of Jamaica				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Self-sustainable diabetes association in operation for 20+ years. • Employs 7 full-time and 20 part-time staff. • Services include: screening; education; medical care; kidney dialysis. • Have one mobile unit for outreach activities.	• Inadequate resources for staff training and public education programmes. • Inability of patients to pay minimal fees for services. • Lack of technical support for data collection and analysis. • Limited administrative support including basic office equipment and supplies. • Operating in tight economic space.	• Recruitment of volunteers. • Retention of group of dedicated staff. • Conducted island-wide screening and education with National Health Fund (NHF) and other community based organizations. • Conducting Life for a child (LFAC) programme supporting 280 children.	• The importance of patient compliance. • The need to structure activities around the needs of communities.	• Strengthening of primary health care system to support patients at community level. • Organization of more mobile clinics to extend outreach to communities (need additional mobile unit).
2. Advocacy				
• Member organization of national NCD Committee. • Organization and participation in World Diabetes Day activities. • Promotion of diabetes prevention and care in public spaces e.g. in supermarkets.	• Cost of media support. • Inadequate funds to sustain advocacy efforts.			
3. Reduction of Risk Factors				
• Conducting of in house and outreach activities including talks, screening, education and follow-up services	• Limited funding for screening and education. • The need for additional volunteers. • The lack of visual teaching (local) materials. • Unable to analyze data to identify gaps.	• Successful interactions with personnel in schools, workplaces and communities.	• The availability of dedicated staff is critical to program implementation. • The high cost of transportation borne by patients in accessing care and medication.	• More training for staff. • Giving scholarships to children with diabetes to assist them with completing their education.
4. Systems and Delivery of NCD Services				
• Island-wide screening and	• Need for more mobile	• Screening and education	• Ensure system in place	• The circulation of

Diabetes Association of Jamaica				
education using mobile unit. • Trained staff and standardized equipment used in service delivery based on guidelines by Ministry of Health	units and equipment. • Inadequate follow-up support from primary health care system.	programmes. • Community outreach programmes.	for follow up care – primary health care services including availability of drugs.	guidelines on diabetes management to all medical personnel. • Training on diabetes management for health care workers and patients.
Experience	Challenges	Successes	Lessons Learned	• Future Priorities
5. Surveillance, Monitoring and Accountability				
• Collect a lot of data from screening programmes.	• Limited capacity for data analysis and use for identifying gaps and determining future action.	• Feed available data from service delivery into national database.	• Screening to identify persons with diabetes, hypertension and high cholesterol and recommend for treatment.	• Strengthening capacity for identifying and addressing gaps in service delivery and programme development.
6. Patient Engagement				
• Organization of camps for needy children with diabetes. • Training of peer counsellors. • Conducting screening and community education programmes.	• Lack of funds for training and production of local educational materials. • Inability to provide incentive/stipend to volunteers. • Lack of support group for children with diabetes.	• Educational activities in workplaces and schools. • Follow-up with patients using text messages.	• The importance of being able to mobilize resources including funding. • The need for care and follow up of children with diabetes and their parents.	• Increasing public awareness on diabetes prevention and management. • Informing patients, families and communities about standards of diabetes care. • Establishment of patient registry especially for children. • Formation of support group for children and arrange meetings for parents/communities.

Heart Foundation of Jamaica/Jamaica Coalition for Tobacco Control				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Coalition of 9 member organizations. • Office with staff and volunteers. • High level of commitment by coalition members.	• Lack of personnel with technical skills in tobacco control.	• Full cooperation of coalition members and ongoing efforts to change policies.	• Recognition of the important role of the media in increasing awareness and effecting change. • The importance of collaborating with key stakeholders for policy change. • The need for capacity building activities to increase awareness about tobacco control.	• Working towards achieving regional support for tobacco control activities. • Providing inputs (on tobacco control) in Strategic Plan for NCDs in the region.
2. Advocacy				
• Engaged in advocacy efforts for tobacco control.	• The interference of the tobacco industry. • Lack of political will to effect change. • Lack of media and communication plan including the use of social media. • The lack of appropriate mechanism for monitoring of policy implementation.	• Support given to new regulations on tobacco control. • Recent increase in taxes on tobacco.	• The need to have multi-disciplinary support and communication/media plan.	• Full implementation of the WHO Framework Convention for Tobacco Control (FCTC). • Promoting "best practice" from the Jamaica experience to support tobacco control efforts in other countries.
3. Reduction of Risk Factors				
• It is expected that the current tobacco control legislation in Jamaica should reduce tobacco use.	• The lack of research data to assess the impact of the tobacco control legislation – the need to update the GATS and GYTS to measure impact of the legislation.	• Anecdotal evidence of reduced tobacco use and reduced hospital admissions for related respiratory conditions.		
4. Systems and Delivery of NCD Services				

Heart Foundation of Jamaica/Jamaica Coalition for Tobacco Control				
5. Surveillance, Monitoring and Accountability				
• Inadequate monitoring of the impact of the tobacco control legislation.	• The lack of a research component in the tobacco control project.		• Data are needed to measure impact of project and to determine future priorities.	Updating the GATS and GYTS to measure impact of the tobacco legislation.
6. Patient Engagement				

St. Lucia Diabetes and Hypertension Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Operate from one office located in the capital with 2 staff members. • Limitations in capacity for program implementation –staffing; membership; funding.	• Submitted project proposal (US$100, 00.00) to government and the Development Bank; requested government to guarantee the loan from the bank. The bank agreed to approve the loan but no word yet from the government.	• In receipt of $EC 20,000.00 subvention from government. • Self-funding of services and supplies. • Completed training for community leaders.	• The need to adopt a more business-like approach in running the organization.	• Mobilization of resources (US$100, 00.00) for project implementation - which would allow the Association to extend services to additional areas and to recruit about 20 professionals to strengthen service delivery.
2. Advocacy				
• Limited involvement in advocacy activities.	• The need to use the mass media more effectively in promoting educational messages.	• Well established organization and highly regarded by the government, private sector and the public.		• Training to strengthen advocacy skills.
3. Reduction of Risk Factors				
• Insufficient monitoring of risk factors.	• Resource constraints (training needs and funding) affect service delivery and program implementation.			• Training of diabetes educators. • Collation and analysis of data on risk factors.
4. Systems and Delivery of NCD Services				
• Conducting screening and education programs.	• The lack of adequate staff trained in foot care and nutrition and physical activity counselling.			• Mobilization of resources for extending services throughout the island.
5. Surveillance, Monitoring and Accountability				
• Weaknesses in data collection. • Diabetes and hypertension registries exists.	• Development of databases			• Technical support for improving data bases.
6. Patient Engagement				

Diabetes Association of Barbados				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Limitations in capacity for program implementation –staffing; membership; funding.	• Staffing needs – the need to recruit a nurse and nutritionist. • Improved capacity for strategic planning and financial management.	• Recent introduction of different types/categories of membership fees.		
2. Advocacy				
3. Reduction of Risk Factors				
4. Systems and Delivery of NCD Services				
• Implementation of community outreach activities - use of mobile unit for health screening. • Introduction of programme to assist children with diabetes. • Use of social media for education.	• Inadequate staffing for outreach activities – the need for more staff and volunteers. • Some of the children do not access follow up care. • The lack of funds for expanding services e.g. provision of insulin pumps. • Obtaining assistance for updating/maintaining website.	• Increased awareness of person with diabetics of the significance of the Hb A1C test results. • Improved care for children with diabetes. • Recent introduction of Instagram page and active updates on Facebook page.	• The effective targeting of children via social media.	• Increasing coverage of outreach programmes. • Mobilizing additional funding to expand range of services offered to children e.g. provision of insulin pumps; lancets and other items required for daily diabetes management.
5. Surveillance, Monitoring and Accountability				
• Collection of data from records of service delivery.	• The need for assistance in data analysis.			
6. Patient Engagement				
• Association members utilize services offered.	• The need to motivate some members to participate in the group education sessions.		• Programmes should be tailored to suit the needs of members – some have more time than others to participate in educational activities.	• Modify programme to offer an additional shorter option. • Introduce special programme for new members.

St. Vincent and the Grenadines Diabetes Association				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Efforts are ongoing to establish main branch of the Association in Kingstown.	• Obtaining funding to house and equip the Secretariat of the Association. • Recruitment of new members and volunteers. • Motivating members to pay fees.	• Screening for NCDs. • Education programmes on foot care • Organization of health fairs.	• Ability to achieve more by linking with HCC.	• Obtaining funding for meeting operating costs of the Association (US$60,000.00 for 3 years)
2. Advocacy				
• Education programmes on the radio.	• The need to increase NCD advocacy efforts particularly for reduction in the cost of medication.			• Mobilization of resources for extending outreach programmes. • Giving assistance to persons with diabetes by providing test strips.
3. Reduction of Risk Factors				
4. Systems and Delivery of NCD Services				
• Plans to introduce screening for hypertension in isolated communities.	• Funding for sustainability of services. • The need for counsellors. • Reducing the numbers of amputations among persons with diabetes. • Reducing non-compliance with medication.		• Strategies for dealing with persons at different levels for ensuring programme implementation.	• Mobilization of resources for continuity of service delivery. • Collecting data on reasons for amputations to inform programme planning. • Promotion of a buddy system to increase rates of compliance with medication for diabetes and hypertension.
5. Surveillance, Monitoring and Accountability				
• Inadequate surveillance and monitoring.	• Addressing training needs for strengthening surveillance and monitoring.	• Maintenance of proper records.	• Recognition of the need to use recognized accounting system.	
6. Patient Engagement				

St. Vincent and the Grenadines Diabetes Association				

Diabetes Association of Trinidad and Tobago				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Limitations in capacity for program implementation –staffing/training needs; funding.	• Addressing training needs. • Increasing public awareness/education. • Establishment of national diabetes registry. • The office in need of refurbishing.	• Formation of 22 branches. • Screening programmes conducted country-wide. • The use of peer educators.	• The value of peer educators.	• Recruitment of Research Officer. • Upgrading IT equipment in the office. • Technical support and funding for establishment of national diabetes registry.
2. Advocacy				
• Use of mass media (TV, Radio) and social media to increase public awareness.	• Identifying dedicated and committed persons to translate the technical medical knowledge to layman language for use in public education.	• Locally produced series of TV and radio programmes. • Increase in membership of the Association from 3000 to 6000.	• The importance of having effective education programmes which reach the population.	• Funding to make local videos to be used in public education/awareness-raising programmes.
3. Reduction of Risk Factors				
• Conducting diabetes education programs in schools.	• Recruitment and training of volunteers. • Funds for stipends and preparation of learning materials.	• Programmes piloted in schools in 2 counties (517 students). The focus is on nutrition and healthy lifestyles.	• The children wanted to learn more about diabetes and healthy lifestyle changes for families and communities.	• Funding for training of trainers programme and material production.
4. Systems and Delivery of NCD Services				
• Lack of adequate attention to foot care services for persons with diabetes.	• Recruitment of foot care specialist.			• Funds to support employment of foot care specialist.
5. Surveillance, Monitoring and Accountability				
• Collection and collation of data from screening programmes.	• Use of data for improving diabetes care and management.	• In screening programmes, identified persons with diabetes who were unaware they had the condition.	• The importance of continuing screening and education programmes.	• Funds to support more free diabetes screening events and the development of awareness education programmes.
6. Patient Engagement				
• Organization of camps for	• Recruitment and training	• Local camp experience	• The importance of peer	• Organization of annual

Diabetes Association of Trinidad and Tobago				
children with diabetes.	of peer leaders to ensure sustainability. • Increasing parent education and involvement in diabetes care.	has had positive results and helped campers to better manage and control their diabetes.	support and networking for children with diabetes.	camps; training of trainers; workshop for parents.

Partners Forum for CNCDs in Trinidad and Tobago				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
1. Capacity Building				
• Existence of a dedicated Secretariat. • Communication need for media/marketing. • Networking with local and regional NGOs.	• Functions on ad hoc basis; depends on Ministry of health. • Dedicated education funding. • Lack of a common vision.	• Preparation of minutes for meetings usually on time. • Networking with local media (radio, TV, newspapers). • Excellent relationship with HCC.	• Focal point located in Ministry of Health. • Interest exists but people want more information. • Regional organizations e.g. HCC help to lift profile of the Partners Forum.	• Establish and equip separate office for focal point and staff. • Recruit dedicated Public Relations officer. • Creation of databases.
2. Advocacy				
• Each NGO on the Forum does separate advocacy.	• Lack of a unified voice.	• Tobacco legislation enacted. • Improvements in school feeding programme. • More persons are exercising at community level.	• How to be a cooperative rather than a competitive partner with the Ministry of Health. •	• Work towards achieving; one voice; one mission; one vision.
3. Reduction of Risk Factors				
• Workplace Wellness programmes (WWPs) in several companies have contributed to: o Decrease in smoking o Increase in physical activity o Weight reduction o Improved control of blood pressure, blood sugar and cholesterol levels.	• WWPs are satisfactory in the large and medium sized companies but small enterprises need help. • Health sector Treatment Teams are not fully on board with prevention efforts.	• Successful WWPs in: o Petrotrin o Massy Group o Guardian Group o BP TT o Banks • Successful implementation of activities annually in observation of Caribbean Wellness Day.	• How to motivate companies to start WWPs.	• Target small and medium sized companies.
4. Systems and Delivery of NCD Services				
• Government of Trinidad and Tobago recently established a NCD Unit;	• "Not my business" competition has negative fallout among	• The growing recognition by the Ministry of Health that NGOs were better	• Regional bodies like HCC were organized and experienced and	• WHO/UN/PAHO targets and checklists to be more widely used.

Partners Forum for CNCDs in Trinidad and Tobago				
Experiences	Challenges	Successes	Lessons Learned	Future Priorities
staff are being hired. • The Ministry of Health's delivery system is disjointed and in some areas dysfunctional.	different units.	positioned to implement and deliver in several areas. • HCC held a Health Systems Strengthening meeting in Dominica in 2014.	credible to deliver on promises.	
5. Surveillance, Monitoring and Accountability				
• Weaknesses in data collection. • Cancer registry exists but need for more morbidity data not just mortality data.	• Establishment of registries for NCDs. • Improving morbidity and mortality reporting.	• Establishment of cancer registry.		• Establishment of national and regional databases. • Preparation of quarterly reports. • Funds to support staff and IT hardware and software.
6. Patient Engagement				
• Diabetes: • Hypertension: • Cancer: • Obesity: • Chronic Lung illnesses: • Alcohol consumption:	• Too much emphasis on treatment; more preventive efforts needed. • Compliance with reduction in salt use. • Smoking rates. • Growing epidemic in adults and children. • Not very visible since TB has almost been eradicated. • Increasing abuse.	• Free medication. • Free medication. • Conducted salt survey. • Tobacco legislation enacted. • Workshop with Food and Beverage Industries held. • Formation of Thoracic Society. • Legislation enacted.	• Benefits and impact of prevention. • Pap smears; breast exams, fecal occult blood tests. • More weight reduction clinics. • Detecting asthma and COPD. • More fines for drinking under the influence of alcohol.	• Coordinate strategies • Complete salt survey. • Education on Food/screening. • Provision of insurance and workplace benefits for achieving BMI in normal range. • Environmental improvements to support healthy choices. • Extend screening programmes to more workplaces.

11.4.2 Table 2: Organisational Advocacy Priorities

TABLE 2A: ORGANISATIONAL ADVOCACY PRIORITIES

ORGANISATIONAL ADVOCACY PRIORITIES					
Country/CSO	NCDs	Risk factors	Health Systems Strengthening	Patient Engagement	Other
Bahamas Diabetes Association	Diabetes	• Increase public awareness of the common NCD risk factors through education programmes in schools, churches, workplaces and the mass media.	• Conduct meetings with CMO and other senior officials in the Ministry of Health.	• Implement screening programs – prevention of amputations should be a priority. Greater attention to be given to foot care services including education.	
Dominica Cancer Society	Cancer	• Implement public awareness campaign.	• Strengthen service delivery – screening; prevention; treatment. • Improve data collection to determine coverage of services and to inform future planning.		
HCC: Youth4NCD	All major NCDs	• Promote (specifically) healthier diets and increased physical activity.		• Increase collaboration with CSOs/ clinics to identify young people with NCDs in order to provide support.	
Diabetes Association of	Diabetes and hypertension	• Target all four common NCD risk	• Strengthen primary health care systems	• Increase attention to patient	

Jamaica		factors.	to improve NCD prevention and care services. • Training of staff to upgrade capacity for delivering quality NCD care.	education and formation of community support groups.	
Heart Foundation of Jamaica/Jamaica Coalition for Tobacco Control	All major NCDs	• Regional support to Tobacco Control implementation. • Support small and resource-poor countries. • Give technical support to countries in meeting FCTC commitments.			
St. Lucia Diabetes and Hypertension Association	Diabetes and Hypertension	• Focus on: Obesity prevention.	• Improve foot care services -prevention of amputations. • Strengthen dialysis services. • Address issues related to retention and training of health care professionals. • Support the strengthening of data collection systems and NCD surveillance.	• Promote and support the provision of glucometers and test strips.	
St. Vincent and the Grenadines Diabetes Association	Diabetes	• Promote Early Childhood Nutrition. • Promote healthy diet and exercise.	• Increase attention to prevention and reduction of amputations.		

Diabetes Association of Trinidad and Tobago	Diabetes	• Promote healthier lifestyles targeting the four common NCD risk factors.			

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TABLE 2B: ORGANISATIONAL ADVOCACY PRIORITIES

ORGANISATIONAL ADVOCACY PRIORITIES					
Country/CSO	NCDs	Risk factors	Health Systems Strengthening	Patient Engagement	Other
Antigua and Barbuda Diabetes Association "Prevention, Care, Support"	Diabetes: Hypertension	Obesity with special attention to Childhood Obesity • Poverty & vulnerability • Improve access to healthy foods. • Promote the Organisational Food Based Guidelines. • Develop and implement school nutrition policy. • Dietary Salt Reduction	• National Integrated database • Strengthen NCD surveillance systems to include screening for NCD risk factors • Conduct nutritional surveillance of school-aged children. • Establish a survey/research culture • Increase health promotion programmes • Integrated programme with the Ministry of Health	• Education on Diabetes and healthy lifestyles in various settings e.g. schools; workplaces • Encourage Dietary Salt Reduction • Counselling & referral services • Provision of screening supplies	• Improve screening for chronic kidney disease (CKD). • Decrease risk for CKD and demand for haemodialysis. • Educate health care professionals and patients on prevention and control of CKD. • Promote patient referral to the Diabetes Association from community clinics. • Greater use of the media • Strengthen networking with other NGOs, CBOs & FBOs
Cancer Society	Cancer	• Target all four	• Increase public		• Increase

of The Bahamas	Targets: • Increase mammogram access in The Family Islands. • Fifty per cent reduction in incidence of cervical cancer (in 3 -5 years). • Establishment of Cancer society branches in all Family Islands by 2016.	common NCD risk factors. In addition: - • Sexual practices. • Lack of access to screening programmes • Lack of commitment of patients to preventive actions.	awareness of NCD risk factors. • Increase access to screening and treatment programmes.		accommodation facilities at Cancer Centre. • Mobilize financial resources. • Promote formation of support groups. • Access increased media support.
The Bahamas Diabetes Association	Diabetes	• Target all four common NCD risk factors.	• Promote use of the Diabetes Passport and Protocol.	• Increase attention to patient education. • Provision of glucometers and test strips. • Strengthen basic counselling services. • Encourage patient referral to the Diabetic Association from community clinics.	
Barbados Cancer Support Services	Cancer	• Target all four common NCD risk factors.	• Increase public awareness of NCD risk factors. • Strengthen palliative care services. • Strengthen basic counselling services.	• Strengthen patient support systems. • Encourage information sharing.	
Diabetes	Diabetes	• Decrease level of	• Modify local recipes to		

Association of **Barbados**		physical Inactivity and obesity. • Reduce premature mortality from Diabetes.	be prepared in a healthy way. • Encourage self-monitoring of blood glucose levels aimed at improved self-management and reduction in complications and mortality.		
Barbados Diabetes Foundation	Diabetes and comorbidities	• Care protocols not adhered • Inadequate data collection and collation • Adolescent health and wellness • Inadequate attention to the dangerous coalition of diabetes and mental health • Inadequate podiatric care	• Role of Diabetes Specialist Nurse – Nurse Practitioner recognised • 1969 Diabetes as Notifiable Disease legislation reactivated for enforcement • Youth health clinics and wellness fairs supported by legislative reform • Integration of mental health care into NCD care plans • Strengthen Step-by-Step foot care programme at community level	• Food knowledge surveys to support message development and home economics education • Youth Voices – capture the personal stories of children and youth with chronic conditions to understand concerns and coping strategies towards improved institutional response • National conversations about mental health and wellbeing	• Engage the health insurance sector to reexamine coverage vis-à-vis care protocols
Barbados Heart and Stroke Foundation	Cardiovascular – Heart & Stroke	• Target CVD in women and children & youth • Target obesity	• AACVPR accredited cardiac rehabilitation unit post AMI, Stroke and heart surgery • Increase public	• Through Doctor and self-referral systems • Community counseling	• Covers full range of disease process including AHA accredited basic life support classes

		• Target hypertension control • Tobacco control	awareness through community screening • Strengthen policy implantation through advocacy at governmental and corporate level • Address obesity crisis through a variety of physical activity programmes	• Stroke and cardiac patient groups • Public lectures • Integrated fundraising activities with health promotion rooted at the centre of the activity • Annual Go Red for women red Dress event conducted • Observe heart and stroke months with activities for public	• Integrates complimentary therapies into the care of stroke patients
HCC/**Barbados**: Youth4NCDs	Cardiovascular Disease	• Youth (12-19 years) physical inactivity – inability to see activity as relevant to their age group. • Obesity in women – inactivity; poor social and income levels. • Food security – salt, sugar labelling (poor education and reading levels).	• Conduct national screening programme.	• Implement Fat loss programme. • Annual Go Red for Women Event	• Increase access to free spaces to promote physical activity. • Encourage peer support for behavior change. • Implement relevant social communication • Open -----??? Weekends • Conduct high level meetings with policy makers and food manufacturers. • Work with partners/NCD alliances.
Dominica Cancer Society	Cervical cancer (50% of women		• Increase coverage of screening		• Develop/implement national health

	screened)
	Breast cancer
	Prostate Cancer (20% of men screened)
			programmes.
			• Strengthen palliative care services:
			  ○ Training
			  ○ Provide more treatment options.
			• Develop/revise polices for increasing access to cancer treatment.
					insurance scheme.

Diabetes Association of **Jamaica**	Diabetes (Target: Reduction in mortality by 25% by 2025)	• Target all four common NCD risk factors.	• Sensitize policy makers on the need to strengthen primary health care system and to increase the availability of medicines for control of NCDs. • Allocate more resources to patient education and screening. • Promote community education and formation of support groups.	•	
Heart Foundation of Jamaica/**Jamaica** Coalition for Tobacco Control	All major NCDs	• Target: 30% reduction in Tobacco use by 2025. • Implement Tobacco control legislation aligned to the FCTC. • Sensitize policy makers on the need for legislation.			

		• Educate the public on the dangers of tobacco and the need to stop smoking. • Offer cessation services where needed.			
St. Lucia Diabetes and Hypertension Association	Diabetes and Hypertension	• Promote healthy diet and exercise.	• Implement screening and education programmes. • Educate community leaders on NCD risk factors and prevention. • Conduct STEPS survey. • Conduct training on foot care. • Recruit more dietitians. • Provide more dialysis machines.		
St. Vincent and the Grenadines Diabetes Association	Diabetes				
Diabetes Association of Trinidad and Tobago	Diabetes	• Obesity	• Develop policies/programs based on findings of child obesity survey. • Promote and implement National Nutritional guidelines prepared by Trinidad and Tobago Association of		• Extend implementation of Childhood Diabetes Awareness Programme (DEAPS) to all schools.

			Nutritionists and Dietitians. • Continue efforts to improve the national school feeding programme. • Conduct salt survey.		

11.5 ANNEX V: MEETING EVALUATION

Although the objectives of the meeting were largely achieved, the meeting was not without challenges as described below:

1. Duration: The meeting was too short however given our considerable funding restrictions we had no choice but to piggyback on the COMSEC meetings (as per discussions with CP) and make use of the fact that our member CSOs were assembled and could therefore be consulted.
2. Participation: Budget limitations restricted the level of participation for the meeting. The original plan was to overcome this with a virtual connection but this also proved to be quite costly in the end.
3. Working sessions: The working assignments were too complex and lengthy for the short breakout sessions; the matrices should have been simpler and shorter.

Formal Evaluation

Overall the meeting was well reviewed. The participants were asked to complete evaluation forms. The findings of the evaluations are below.

Thirteen participants completed the workshop evaluation. Sixteen participants were asked to complete the evaluation form (excludes HCC core team) with a response rate of 81%.

The findings from the evaluation form are presented below in tabular format.

I. CONTENT

	Excellent	Good	Fair	Poor
1. Covered Useful Material	85%	15%	0%	0%
2. Relevant to My Organisational Needs and Interests	92%	8%	0%	0%
3. Well Organized	83%	15%	0%	0%
4. Presented at the Right Level	85%	15%	0%	0%
5. Sufficient time allocated to discussion sessions	46%	38%	15%	0%
6. Useful Visual Aids and Handouts	69%	23%	8%	0%

II. PRESENTATIONS

	Excellent	Good	Fair	Poor
1. Overall Instructor's/ Speaker's Knowledge	85%	15%	0%	0%
2. Overall Instructor's/ Speaker's Covered material clearly	77%	23%	0%	0%
3. Overall Instructor's/ Speaker's Responded well to questions	85%	15%	3%	0%
4. Overall Instructor's/ Speaker's allowed for adequate participant input	77%	8%	15%	0%
5. The meeting was interactive	85%	8%	8%	0%
6. Well organized	77%	15%	8%	0%
7. Relevance of Discussion Sessions	85%	8%	8%	0%

III. SUMMARY FEEDBACK

1. Do you have any suggestions for how the meeting could have been improved?

    - Invite more civil societies
    - Allow more time to complete activities
    - Reversing the structure of the programme
    - Forms be completed by organisation rather than individuals
    - Best practices could have been shared among related organisations

2. What should HCC do to build on the momentum of this meeting? What are key next steps?

    - Ensure all the associates have remain committed to all of the challenges and achieve their goals
    - Follow up the NCD Alliance in CARICOM countries
    - Continued forum for such sharing and discussion opportunities
    - Support the national dialogues
    - Dr. Samuels' presentation- Identify what the next steps are for the regional NNCD commission
    - Speak vigorously on the strengthening capacity of N.G.O members

3. Do you have any general comments about this experience?

    - It was a great experience
    - Ask the participants prior to these meetings to re their expectations and outcomes expected of the meeting. More clarity needed on next steps.
    - It was a learning experience; provided a wealth of knowledge

11.6 ANNEX VI: MEETING PRESENTATIONS

All presentations are available on the HCC website in pdf format. They can be found at this link: http://www.healthycaribbean.org/meetings-june-2015/june-4/#slides.

11.7 ANNEX VII: MEETING MATERIALS

All meeting materials including the programme, handouts, and photos, are available on the HCC website. They can be found at this link: http://www.healthycaribbean.org/meetings-june-2015/june-4/.

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