Caribbean Civil Society Regional Preparatory Meeting

In preparation for the Global NCD Alliance Forum

MEETING REPORT

Healthy Caribbean Coalition
September 2015

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[1], 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

[1] Available in the expanded report

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[2] - 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

[2] Available in the expanded report

	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.

11.4ANNEX IV: OUTPUTS FROM WORKING GROUP SESSIONS

11.4.1 Table 1: Profiling Caribbean Civil Society

11.4.2 Table 2: Organisational Advocacy Priorities

Available in the expanded meeting report[3]

11.5ANNEX 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
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%

[3] The expanded report contains all annexes

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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