A CIVIL SOCIETY REGIONAL STATUS REPORT

RESPONSES TO NCDS IN THE CARIBBEAN COMMUNITY

HEALTHY CARIBBEAN COALITION

March 2014

HEALTHY CARIBBEAN COALITION
"a civil society alliance for combating chronic diseases"

For more information please contact the HCC:
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The NCD Alliance
Putting non-communicable diseases on the global agenda

The NCD Alliance was founded by:

International Diabetes Federation

UICC global cancer control

International Union Against Tuberculosis and Lung Disease
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TABLE OF CONTENTS

TABLE OF CONTENTS

1. FOREWORD

The Healthy Caribbean Coalition (HCC) in association with the NCD Alliance and Medtronic Philanthropy is happy to make this regional NCD Status Report available to policy-makers, civil society and the private sector. The report aims to provide a detailed assessment of progress made in tackling NCDs in the Caribbean as viewed by civil society, and includes a call to action in those areas in which gaps have been detected and about which the HCC will encourage and assist civil society organsation (CSO) led advocacy.

The report is unique in many respects not the least of which is that it represents the first occasion, as far as is known, that CSOs in the Caribbean have come together to produce an in-depth and comprehensive assessment of NCDs as viewed through the lens of civil society. This is an important step in the development of a process and culture that seeks to lead to strong advocacy efforts by the people of the region for improvements in all aspects of health. It is an occasion for celebration by HCC and civil society as we reaffirm our commitment to continue to support the NCD response at organisational, national, regional and global levels in the sixth year of the formation of the HCC - a Caribbean NCD Alliance.

The NCDs are well recognised to be a major threat to health and a serious potential impediment to growth and development of Caribbean people. A concerted approach is needed in an effort to halt the potential of NCDs to reverse all the development gains made in the Caribbean since independence. It is for this reason that the Caribbean has strongly supported and contributed to many global initiatives, including the United Nations High Level Meeting, 2011, and the subsequent WHO Global Action Plan, 2013-2020 and the global NCD Targets, and is keen for NCDs to be included in the Millennium Development Goals, post 2015.

The need for a multi-sector approach and response to NCDs has been well recognised and underpins the response to NCDs at all levels. The challenge is to continue to recognise the need for such a response, assist all sectors of society in the appreciation of the role that they can play in the response, build capacity of sectors to respond, establish mechanisms to allow them to contribute to the response and wherever possible generate resources to facilitate such efforts.

Many persons have contributed to this report including the leadership, staff, members, volunteers and Manager of the HCC, and members of the advisory Technical Working Group established as a direct result of this initiative, however the report would not have been possible without the significant roles played in its production by our UWI collaborators Professor Nigel Unwin, Dr. Alafia Samuels and Ms. Lisa Bishop, from the Public Health Group, Cave Hill Campus, University of the West Indies to whom we say a big "thank you".

An important aspect of the production of the Regional Status Report was an online interview of several stakeholders including representatives of civil society, regional public health institutions and government. A tremendous amount of information and many different perspectives were provided and distilled for this report. However a significant amount of additional information could not be included in this report. Comments and questions on the content of this report are welcome, and should be directed to the HCC.

Finally, this report provides a resource that forms the basis for action by several sectors of the society and is intended to contribute to more comprehensive assessments, undertaken by governments and/or regional health institutions, of the response to NCDs. The Caribbean Region is poised for change. Civil society in the region has become over the past 6 years more "fit for purpose" to contribute to that change, even as we advocate for "The Caribbean: a Healthy Lifestyle and Wellness Region".

Professor Sir Trevor Hassell
President of the Healthy Caribbean Coalition
– A Caribbean NCD Alliance

2. ACKNOWLEDGEMENTS

The Healthy Caribbean Coalition would like to thank the University of the West Indies technical team who collaborated with the HCC in the preparation of this report. The team are made up of Professor Nigel Unwin, Dr. Alafia Samuels and Ms. Lisa Bishop (Public Health Group, Faculty of Medical Sciences, University of the West Indies, Cave Hill).

Our sincere gratitude to those who completed the questionnaires. A detailed list of respondents can be found in Appendix 1 of this report.

We also acknowledge the following:

- Medtronic Philanthropy
- The NCD Alliance Team
  - Cristina Parsons-Perez, Katie Dain, Ariella Rojhani
  - The NCDA Expert Review Committee
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    1. South African NCD Alliance
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- Caribbean Public Health Agency (CARPHA) for their support of the November 2013 Multi-Stakeholder meeting and their ongoing support of the HCC.
- PAHO/WHO for their support of the November 2013 Multi-Stakeholder meeting and their ongoing partnership of the HCC as an NGO in official relations with PAHO.
- CARICOM Secretariat.
- Our member organisations throughout the Caribbean and in particular those health NGOs that contributed in any way to this report.

Finally, we are extremely grateful for the contribution of The Healthy Caribbean Coalition (HCC) Advocacy Technical Working Group (Appendix 1) for their commitment to NCD Advocacy nationally in their respective countries and throughout the region. We thank them for agreeing to share their expertise, and we value the tremendous input they have provided throughout this process and towards the finalisation of this report.

President, Manager, Board of Directors and Staff of the HCC

3. GLOSSARY OF ABBREVIATIONS

C4PI	Caribbean Civil Society Cervical Cancer Prevention Initaitive
CARICOM	Caribbean Community
CARPHA	Caribbean Public Health Agency
CDAP	Chronic Disease Assistance Programme
CDRC	Chronic Disease Research Centre
CNFI	Caribbean Food and Nutrition Centre (now part of CARPHA)
CSO	Civil Society Organisation
CWD	Caribbean Wellness Day
FCTC	Framework Convention on Tobacco Control
GSHS	Global School-based Student Health Survey
GYTS	Global Youth Tobacco Survey
HCC	Healthy Caribbean Coalition
NCD	Non-communicable Disease
NCDA	Non-communicable Disease Alliance
NGO	Non-governmental Organization
NHF	National Health Fund
NNCDC	National Non-communicable Disease Commission
PAHO	Pan American Health Organization
SIDS	Small Island Developing States
STEPS	The World Health Organization Stepwise Approach to NCD surveillance
TMRI	Tropical Medicine Research Institute
TWG	Technical Working Group
UKOT	United Kingdom Overseas Territory
UNHLM	United Nations High Level Meeting
UWI	University of the West Indies
WHO	World Health Organization

4. EXECUTIVE SUMMARY

INTRODUCTION AND BACKGROUND

NCDs are the predominant health problem in CARICOM countries and cause substantially more deaths and disability than infectious diseases. Not only are mortality rates high, but CARICOM countries have approximately double the rate of premature deaths compared to richer countries. Additionally, high rates of the biological risk factors exist, especially obesity, diabetes and hypertension driven in turn by behaviours arising out of environmental and social conditions.

This report seeks to understand and assess the Caribbean response to non-communicable diseases (NCDs), from a civil society perspective. It highlights best practices and identifies areas for further action. It provides an evidence-based platform, from which civil society can monitor progress as well as complement regional and national NCD policies and programmes.

The work for this project was completed within a few weeks and within a relatively small budget thus precluding the active examination of all CARICOM countries. NCD responses were examined in 9 carefully chosen CARICOM countries. These countries were chosen to have a range of socio-economic conditions, to include at least one mainland country, to include at least one United Kingdom Overseas Territory, to represent the range of population sizes within CARICOM, and to have a full range of National policy responses to the 2007 CARICOM Heads of Government Port of Spain Declaration on NCDs. Additionally, data on NCDs in the 20 CARICOM countries were abstracted from readily available data sources to provide a narrative description of the prevalence of their risk factors, their contribution to the burden of disease, their social and economic burden and their social determinants. The restriction of the survey to about half of the CARICOM countries is a limitation of this study, especially since neither Guyana, CARICOM's only lower middle income country nor Haiti, CARICOM's only low income country and its most populous at 10 million, were included. This report however, provides a valuable snapshot of regional action on NCDs and makes recommendations that may resonate for other CARICOM nations that haven't been studied at this time.
'Responses to NCDs in the Caribbean Community – A Civil Society Regional Status Report" represents the first ever civil society assessment of the NCD response in the region and seeks to provide the base for continued multisectoral action and improvements. Heads of Government of CARICOM in a demonstration of significant leadership, regionally and internationally, recognised the need for a multisectoral approach to NCDs in the Declaration of Port of Spain: Uniting to Stop the Epidemic of Chronic Diseases, 2007. Many initiatives have been undertaken in the region since the declaration by several sectors; much more however needs to be done by all sectors to achieve a slowing of the epidemic of NCDs including ongoing and comprehensive assessments of the regional response. This report represents a major contribution by civil society in the Caribbean to such efforts.

MAIN REPORT FINDINGS

The NCD response, regionally and nationally, is overall a satisfactory response, led by regional public health institutions (PAHO/WHO, CARPHA), CARICOM Secretariat, National Governments and their Ministries of Health, with the support of the University of the West Indies, and in-country health non-governmental organisations and the recently formed civil society NCD Alliance, the HCC. The response may be characterised as being strong on statements of support, agreements and policy positions but less so with respect to implementation, monitoring and evaluation. The Region has played a significant role globally in advancing the response to NCDs.

Governments of the Region have theoretically accepted the concept of a 'whole of Government' response, but for the most part have not put this into practice and NCDs have not been inserted into national development plans in the majority of CARICOM countries. Fledgling multi-sectoral activity has been embraced by quite a few CARICOM countries, led by NCD Commissions in the larger CARICOM countries where these have been established. In other CARICOM countries, particularly those with small populations, the multi-sector approach to NCDs has mostly been in the form of NCD meetings. However, in all CARICOM countries Caribbean Wellness Day has contributed to wide stakeholder involvement in the NCD response. The 'whole of society's' response at the Regional level in CARICOM is led by the regional NCD Alliance HCC, but remains weak with HCC, having no official relations with the major regional public health institutions, CARICOM Secretariat or the Political leadership of the Region.

Civil Society, especially health NGOs, play a major role in the Caribbean especially in provision of services, provision of financial support, outreach and education and consider these to be important advocacy efforts. They are less engaged in advanced advocacy efforts such as in the drafting and enactment of national legislation and policies.

Almost all CARICOM countries have ratified the Framework Convention on Tobacco Control (FCTC) but few have implemented the provisions of the Treaty, with for example only four of them enacting legislation banning smoking in public places, very few having programmes in place for treatment of tobacco dependency and only very few having enacted legislation against tobacco company sponsorship and advertising of tobacco products. There are no national policies against advertising of unhealthy foods to children, none against the harmful use of alcohol and national population salt reduction initiatives in only a single country. Community based physical activity is encouraged and supported, and some countries have put specific policies in place to this end.

Fairly robust health systems provide services for NCDs in most CARICOM countries, with the majority providing medications for NCDs at highly subsidised cost at point of delivery. Some gaps identified in health systems included lack of equipment for management of certain lung conditions, absence of some drugs such as tamoxifen for breast cancer treatment, lack of well-established rehabilitative services, inadequate uptake of guidelines, many of which are outdated, lack of accountability in delivery of health services, and absence of widespread use of the chronic care delivery model.

RECOMMENDATIONS FOR ACTION

Based on the foregoing it is recommended that the following actions be taken by CARICOM countries at national level and collectively at the regional level:

- Address risk factors and social determinants of health (such as policies on food - put this somewhere in the sentence or delete), in particular: banning the marketing of energy dense, high salt foods and sugar sweetened beverages to children; promoting reduction in consumption of salt and sugar sweetened beverages (including fruit juices); banning the use/sale of trans-fats; regional standards for clear, consistent, food labelling; policy on physical activity: development, implementation and monitoring of national strategies on the promotion of physical activity and policy on reduction in harm from alcohol.
- Strengthen health systems and improve access to effective health care by ensuring the active dissemination and monitoring of the use of up to date regionally derived evidence based guidelines for the treatment and management of NCDs, including a framework for standardising the treatment of hypertension using available core medication. The chronic care model should be applied in the provision of primary health care services for NCDs in all countries, and there should be advocacy for all residents within CARICOM countries/territories to have access to basic defined packages of NCD care irrespective of their ability to pay.
- Build a truly 'all of society approach', with health in all policies, with NCDs fully addressed within national development plans, and opportunities sought for a multi-stakeholder approach to the response to NCDs by engaging all major groups of the society such as faith-based organisations, groups of retired persons, women's groups, and workers' representatives.

Meeting this, or a similarly ambitious, agenda for NCD action across the CARICOM countries and territories will require national capacity building, regional leadership and a multistakeholder response. From a civil society perspective, HCC is commited to undertaking a regional leadership role, to building the capacity among its member organisations and to holding, together with other CSOs, policy makers to account as part of the traditional civil society "watch dog" role.

5. INTRODUCTION

This project, the completion of a Regional Status Report from the perspective of Civil Society, is part of the work of the NCD Alliance's programme, 'Strengthening Health Systems, Supporting NCD Action' which aims to support and strengthen civil society NCD advocacy efforts in Brazil, South Africa and the Caribbean Community (CARICOM). The Healthy Caribbean Coalition (HCC) is the "National Implementing Partner" for the Caribbean in the implementation of this project funded by Medtronic Philanthropy. The guidance document for the development of this report is the 'Non Communicable Diseases: Join the Fight. An Online Advocay Toolkit' avaibable on the NCD Alliance website at the following link:

http://ncdalliance.org/sites/default/files/rfiles/NCD%20Toolkit%20FINAL.pdf.

6. WHO WE ARE - THE HEALTHY CARIBBEAN COALITION

The Healthy Caribbean Coalition (HCC) is a regional NCD network, formed in 2008 and registered as a not-for-profit company. The HCC was formed as part of the civil society response to the 2007 Declaration of Heads of Government of CARICOM on Non-Communicable Diseases (NCDs) [1]. Membership of the HCC presently consists of more than 50 Caribbean-based health NGOs and over 55 not-for-profit organizations with in excess of 200 individual and organisational members based in the Caribbean and across the globe. The mission of the HCC is to harness the power of civil society, in collaboration with government, private enterprise, academia, and international partners, in the development and implementation of plans and interventions for the promotion of wellness, and the prevention and management of NCDs among Caribbean people. The vision is a reduction in premature death and disability from NCDs among people in the Caribbean.

In December 2012 the HCC finalized: 'A Civil Society Strategic Plan of Action for countries of the Caribbean Community 2012-16', with the following strategic objectives: (1) contribute and participate in all aspects of advocacy as a tool for influencing positive change around NCDs through mobilisation of Caribbean people and the creation of a mass movement aimed at responding to NCDs; (2) develop effective methods of communication for and among members of the Coalition and the people of the Region; (3) build capacity among health NGOs and civil society in the Region; and (4) promote eHealth and mHealth to contribute to NCD public education campaigns and programmes.

The strategic priority area of advocacy is one of the most important available to HCC as it seeks to carry out its mission. The HCC has been a leading advocate for NCDs in the region playing a vital role in linking civil society, the private sector and government, to create environments for effective dialogue and collective action.

7. GLOBAL COMMITMENTS TO ACTION ON NCDS

A global commitment to action on NCDs occurred with the hosting of the United Nations High Level Meeting (UNHLM) on NCDs, 2011, at the conclusion of which a sixty five point Political Declaration was issued which noted that NCDs present a challenge of epidemic proportions, along with its socio-economic and developmental impacts[2]. The Declaration recognised that NCDs can be largely prevented and controlled through collective and multi-sectoral action by all Member States and other relevant stakeholders and it advanced that prevention must be the cornerstone of the global response to NCDs. The key provisions of the UNHLM are to reduce risk factors and create health promoting environments, strengthen national policies and health systems, foster international cooperation, including collaborative partnerships, and research and development.

Government Commitments to action on NCDs within the Caribbean preceded the UNHLM. In September 2007 the Caribbean Community (CARICOM) Heads of Government Summit on NCDs was held. The Port of Spain Declaration that arose out of this summit [1] contains 27 commitments to action by National Governments and Regional organizations [3]. Examples of these commitments include the establishment of National NCD Commissions, risk factor reduction, including the implementation of the Framework Convention on Tobacco Control, surveillance, improved quality of care for people living with NCDs and an annual Caribbean Wellness Day to commemorate the NCD Summit, raise awareness and advocate for action on NCDs.

The UNHLM was followed by several major UN agreements and reports citing NCDs as a development priority for countries. These include the UN Secretary-General's report "A Life of Dignity for All"[4], and Rio+20 which in its outcome resolution acknowledged NCDs as "one of the major challenges for sustainable development in the twenty-first century"[5].

At the Sixty-fifth World Health Assembly (WHA), May 2012, a decision was taken to adopt a global target of a 25% reduction in premature mortality from NCDs by 2025. The WHA also expressed strong support for additional work aimed at reaching consensus on targets, and noted the wide support expressed by member states and other stakeholders around global voluntary targets. A voluntary Global Monitoring Framework (GMF) on NCDs, including nine targets and 25 indicators, was adopted at the World Health Assembly in 2013[6]. These had been developed through a process initiated by the UN Political Declaration. This Global Monitoring Framework (GMF) is one of three critical parts of the Global NCD Framework (the GMF, the Global Action Plan for NCDs 2013-2020, and a global coordinating mechanism for NCDs)[7] expected to inform NCD actions globally, regionally and nationally over the next decade.

"I would therefore wish to see Caribbean civil society organizations bring forcibly to the attention of the public and the government the gaps between the commitments to the prevention and control of NCDs and the execution of them."

Sir George Alleyne
Patron, HCC

8. THE STATUS OF THE NCD EPIDEMIC WITHIN THE CARIBBEAN COMMUNITY (CARICOM)

The countries and territories of CARICOM (with the exception of Haiti) have undergone, or in the case of Guyana is undergoing, a demographic and epidemiological transition[8, 9]. This means that NCDs are now the predominant health problems in these countries/territories, causing substantially more deaths and disability than infectious diseases. In low-income Haiti, World Health Organization figures for 2008 indicated a death rate from all NCDs in men and women of 797 and 594 respectively per 100,000 population per year[10]. The only other CARICOM member with higher rates in men was Trinidad and Tobago, with a rate of 896 per 100,000 per year (in women 506). These figures are 'age-adjusted' to account for differences in population age structures between the countries. Thus, Haiti suffers a double burden of both high infectious disease and NCD mortality.

Rates of death from NCDs in men in CARICOM countries other than Haiti and Trinidad and Tobago are estimated to be lowest in Jamaica (498 per 100,000 per year) and highest in Grenada (722) and Guyana (735); the equivalent figures in women are 479 in Jamaica, 441 in Grenada and 602 in Guyana[10]. By contrast, mortality from NCDs is lower in the USA for both men (458) and women (325) than in all CARICOM member states; and lower again in Canada (387 in men, 265 in women).

Compared to Canada, therefore, age adjusted death rates from NCDs in men range from 29% higher in the CARICOM country with the lowest rate (Jamaica), to 131% higher in the country with the highest rate (Trinidad and Tobago). In women, the age adjusted death rate from NCDs in CARICOM is lowest in Barbados (363 per 100,000 per year), which is 37% higher than in Canada, while in Guyana, the CARICOM country with the highest rate in women, it is 127% higher. Compared with North America as a whole, diabetes mortality is 800% higher in Trinidad and Tobago, and cardiovascular disease mortality is 75% higher [11]. Cervical cancer mortality rates are 7 times higher in Latin America and the Caribbean than in North America[12].
Not only are mortality rates from NCDs high in all CARICOM members compared to richer countries, a much higher proportion of deaths are premature. In Canada, for example, roughly 1 in 8 NCD deaths in men and 1 in 10 in women occur before the age of 60 years. By contrast, in the Caribbean the proportion of NCD deaths occurring before the age of 60 years ranges from approximately roughly 1 in 5 (e.g. Barbados) to greater than 1 in 3 (e.g. Bahamas and Guyana)[10].

Underlying the high NCD mortality rates in the Caribbean are high rates of biological risk factors (especially obesity, diabetes and hypertension), driven in turn by behaviours shaped by prevailing environmental and social conditions (e.g. poverty, education, gender relations, urbanisation, and globalisation)[13]. Obesity rates in women range from 30% in Dominica to 52% in St. Kitts and Nevis, and among men, from 15% in Jamaica to 38% in St. Kitts and Nevis. Excessive alcohol use causes much morbidity and mortality [14-16].

The WHO estimates that across the region roughly one in three to one in two adults are affected by hypertension [10]. Recent estimates of diabetes prevalence from the International Diabetes Federation suggest that region wide 1 in 10 adults are affected[17], but substantially higher figures are found in some countries. For example, a recent survey from Trinidad and Tobago estimated that around 1 in 5 adults had diabetes[14]. Unsurprisingly, where studies have been done, high rates of complications from diabetes have been found. For example, diabetes-related lower extremity amputations in Barbados are among the highest globally [18]. The only major NCD risk factor on which the Caribbean is relatively better off compared to most other parts of the world is tobacco smoking. Daily tobacco use ranges from 6 – 29% among males, and 1 – 7% among females in the Caribbean Community (CARICOM) countries and territories [19].

Globally the macroeconomic impact of NCDs is known to be considerable [20], and this is undoubtedly the case within the Caribbean, although local data on this issue are relatively scarce. Estimates prepared for 4 CARICOM countries in 2007 of the economic burden of diabetes and hypertension suggested that they jointly account for between 1.4% to 8% of gross domestic product [21].

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

THE STUDY

New data collection was undertaken to document national and regional responses to NCDs within the CARICOM countries. The detailed study protocol that was developed for this work is in Appendix 3. This work was carried out under a very tight time frame, with planning for data collection beginning in the last week of October 2013, and data collection needing to be completed and summarized before November 22nd 2013 for presentation and discussion at a regional multi-stakeholder meeting, as part of the agreement between HCC and the NCD Alliance. This timeframe inevitably meant that aspects of original protocol were modified as data collection began. It also meant that it was not possible to collect data from all the CARICOM countries and territories, and that a subset of these needed to be purposively chosen (described below).

The research questions that guided the work that follows are given below, followed by a summary of the methods.

RESEARCH QUESTIONS

1. What are the current policy responses to NCDs of Governments and Regional Bodies (where applicable) and how do they compare to the indicators in the NCD Benchmarking Tool ; and to the commitments from the 2007 Port of Spain Declaration?
2. How are Civil Society Organisations currently involved in the regional and national response to NCDs, including service provision, advocacy and contribution to Government policy?
3. What has been the role and contribution of Regional Bodies in the Caribbean in advancing the NCD agenda at a regional level, and in providing support for countries in their NCD response?
4. What actions are required to fill the gaps that exist in the current response to NCDs, and in particular how can the role of Civil Society be enhanced to promote those actions?

[1] Note the tool was developed by the NCD Alliance in consultation with an advisory committee consisting of the National Implementing Partners and global NCD M&E Experts. The tool that this is aligned with reflects the six objectives of the Global Action Plan 2013-2020 and commitments in the UN Political Declaration on NCD Prevention and Control, 2011.

METHODS

Geographical Scope

CARICOM is made of up 15 member states and 5 associate members, of which 6 are United Kingdom Overseas Territories (UKOTs). Twelve of the states gained their independence from the United Kingdom between 1962 (Jamaica and Trinidad & Tobago) and 1983 (St Kitts & Nevis), Suriname gained its independence from the Netherlands in 1975, and Haiti from France in 1804. The total population for CARICOM is around 17 million, with Haiti having a population of 10 million, and only Trinidad & Tobago and Jamaica having populations over 1 million.

Given the time and resources available for this work a pragmatic decision was taken to examine the current status of the NCD response in 9 countries/territories. Care was taken to ensure that the 9 countries of the report represent the broad variety of countries and territories found within CARICOM. The criteria that were used for choosing the countries and territories were:

1. The countries/territories should include a range of socio-economic conditions that exist in the CARICOM
2. There should be at least one mainland country
3. The range of population sizes that exist in CARICOM should be covered, from over 1 million in the largest countries to less than 100,000 in the smallest
4. The range of National policy responses to the Port of Spain Declaration on NCDs, from those that have evidence of implementing most of the commitments to those that have implemented the fewest (these data are available from annual monitoring)
5. At least one United Kingdom Overseas Territory
6. Finally, a highly pragmatic consideration, given the time frame, is that members of the study team were able to readily identify at least one individual within the Ministry of Health, and one within Civil Society whom they could approach directly. Haiti, the only low-income country within the whole of the Americas and containing more than half of CARICOM's 17 million population, was not included. Another notable omission is Guyana, the only low middle-income country (all others are high-middle or high income).

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

The following nine countries/territories were chosen for the main study: Belize, Barbados, Bermuda, Cayman Islands, Dominica, Jamaica, St Kitts and Nevis, St Vincent and the Grenadines, and Trinidad and Tobago. In addition, it was decided as the study began that an important area to examine in more detail is the functioning of National NCD Commissions (NNCDCs), a key part of the national inter-sectoral response to NCDs. Chairs of commissions that were known to be functioning were approached after consultation with the President of the HCC. The five countries included in this sub-study were Barbados, Belize, Grenada (thus in addition to those in the main study), Jamaica and Trinidad and Tobago.

Table 1 (Appendix 2, Table 1) illustrates that while it cannot be claimed that the countries selected are a representative sample in a statistical sense, they do capture most of the variety of population size and wealth within CARICOM.

Choice of Regional Bodies

It was decided to interview a key informant from each of the main Regional Bodies with some responsibility for NCD policy and programming, including the Port of Spain Declaration. Key informants were interviewed from the following bodies: CARICOM Secretariat, CARPHA, PAHO/WHO, HCC and the University of the West Indies.

Data Collection

Details of data collection and analysis are given in Appendix 2. In brief, seven complementary questionnaires to be self-administered online (through 'Survey Monkey'[22]) were constructed. All the questionnaires contained common core items, plus items specific to each category of respondent. There were 7 questionnaires in all, one each of the following categories:

Ministry of Health within Government
1. CSO
2. NCD Commission
3. Regional Organisations
   a. CARICOM
   b. PAHO
   c. CARPHA
   d. HCC
   e. UWI (note that an additional questionnaire was not developed for UWI).

The content of the questionnaires was based on:
1. The items in the NCD Benchmarking Tool
2. The 27 commitments in the 2007 Port of Spain Declaration
3. A review of the most recent (2013) World Health Organization questionnaire to assess national NCD capacity

(www.who.int/chp/ncd_capacity/CCS_2013 Questionnaire).

4. The questionnaire for Civil Society Organizations included information about the organization, including size and details of its activities.

It was the intention within each of the 9 chosen countries and territories to obtain a response from at least the NCD focal point within the Ministry of Health (MoH), and a Director/CEO/President of at least one prominent health related CSO. As will be seen, this was not always possible, while in other countries it was possible to gain responses from multiple CSOs.

Copies of the questionnaires for MoHs, CSOs, NNCDCs, and Regional Organisations (PAHO as an example) are provided in a supplementary appendix, and available on request from the authors.

It had been the intention to undertake a formal content analysis of all relevant policy documents. While policy documents were requested from all MoHs, and searched for online, a full content analysis of those that were received was beyond the scope of the time and resources available.

The Benchmarking Tool

The Benchmarking Tool can be found in Appendix 6. To facilitate the assessment of specific items in this Regional Status Report, the NCDA provided the following guidance for scoring of the Benchmarking Tool.

- Where indicators are looking to quantifiably measure a certain element, you are encouraged to add a footnote to the tool, specifying which indicator the number corresponds to.

Dr. Tomo Kanda,
Chronic Diseases Advisor, PAHO

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

- In most cases, indicators seek to be measured according to 'yes/no' or 'present/absent'. The benchmarking tool uses a traffic light color-coding system where for each indicator yes/present corresponds to green and no/absent to red. When a number of indicators are being considered, green corresponds to a positive response on all indicators; yellow to a positive response on half or more of the indicators, and red when there is a positive response for less than half of the indicators.

Utilising this guidance the colour coding system for Tables 5, 6 and 7, which is based on information provided by Government respondents, is as follows:

Red	Absent / No or Little progress
Yellow	In the Development Stages / Moderate Progress
Green	Present /Good Progress
	No response given

The assumption was made that Government informants would be better suited to account for specific status of NCD response within their country, as such their questionnaire focused on the absence/presence and operational status of specific aspects of NCD response. Where possible an attempt to quantify response status was made, as in Benchmarking area 4.4 where the proportion of drugs or services available is indicated.

Though it was assumed that our Civil Society informants would have varying degrees of specific knowledge about their country's NCD Response, it was recognised that their perspective was invaluable to bring our view of the regional NCD response to a higher resolution. To address this we solicited their perceptions regarding the National NCD Responses through 'Likert scale' questions and these are captured in Table 10 and 11. The colour coding for which is as follows:

Red	Less than Adequate Access
Yellow	Adequate Access
Light Green	Good Access
Green	Excellent Access
	No response given

Key Considerations in the Interpretation of the Findings

This Regional Status Report (RSR) is based on 9 of the 20 countries and territories that are part of CARICOM. As previously stated, due to time and other resource constraints under which this work was undertaken, countries and territories were selected based on personal contacts. This resulted in the more advanced and proactive CARICOM members being included in the assessment The findings of this status report represent what is being achieved in the better performing more developed CARICOM countries. The status of the response to NCDs in the less well developed CARICOM countries would be expected to be less favourable.

The second consideration is that it is well known that the size of a country or territory is a key determinant of its capacity to respond to a whole range of issues. All the independent countries within CARICOM are members of the United Nations Conference on Small Island Developing States (SIDS) [24]. They share characteristics of small size, geographical isolation, vulnerabilities to climate change and rising sea levels, and to natural and environmental disasters[24]. These characteristics, particularly small size and geographical isolation, are relevant to their responses to NCDs and other health issues. Over half the CARICOM countries have populations of less than 250,000 and this fact alone limits their resources, both human and financial, to respond to the prevention and treatment of NCDs with the depth and expertise expected in larger countries of similar per capita wealth. Regional (international) institutions have, therefore, a particularly important role to play in helping to provide technical and practical support to these small, geographically isolated, countries.

In compiling this report it was necessary to summarise a considerable body of data provided by the respondents. Inevitably the need to summarise data results in a loss of detail, some of which may be of interest to readers. In addition, it is acknowledged, that had there been more time and resources available, complementary approaches to data collection, such as in-depth interviews and document analyses, could have helped to verify and elucidate the data here presented. The authors have done their best within the time and resources available to present an accurate picture at the time the study was done, and comments and questions on any aspects of this report are welcomed. Despite these potential shortcomings, it is believed that 'in the round' an accurate account is given that significantly advances knowledge and understanding of the responses to NCDs within the Caribbean, and provides a basis for action.

THE FINDINGS

The findings from regional organisations are presented first, followed by responses from national MoHs, CSOs, and finally findings based on responses from the 5 Chairpersons of NNCDCs who were interviewed.

Regional Organisations Responses and Findings

Raise priority of NCDs through international cooperation and advocacy

All five regional organizations described activities that can be considered to contribute to raising awareness about, and the priority given to, NCDs (Appendix 2, Table 2). However, only CARPHA stated that it had a budget specifically devoted to NCDs, and for a population of approximately 17 million people (the CARICOM population) this was a modest 300,000 USD. Within the region, HCC has been particularly active in using electronic and social media to disseminate messages on NCDs, including its 'get the message' campaign in the run up to the 2011 UNHLM. The HCC has held several multi-stakeholder NCD capacity building workshops. During the time of the study the HCC was engaged in a comprehensive regional CSO Cervical Cancer Advocacy Initiative which was initiated with the hosting of a workshop for Cancer CSOs of the region. The cervical cancer initiative includes, for the first time in the Caribbean, the use of an electronic petition to promote cervical cancer screening (this was ongoing at the time of this work).

Strengthen national capacity, multisectoral action and partnerships for NCDs

CARICOM has the key role in promoting and facilitating intergovernmental multi-sectoral action within the region. CARICOM's Regional Organization for Standards and Quality (CROSQ) was, for example, the vehicle through which region wide standards for tobacco labelling were agreed. It was noted that it will need to have an equally important role in agreeing to region wide approaches to food labelling.

The importance of building partnerships for multi-sectoral action was noted by all respondents. However, region-wide fora through which such partnerships can be nurtured are currently limited. PAHO stated that it had inaugurated such a forum which had met once, in the year 2012. HCC noted that it supports the building of links between its CSO membership, governments and the private sector. CARPHA's annual scientific meeting tends to include, in addition to academic and health service researchers, a number of CSO and private sector interests.

Reduce NCD risk factors and social determinants

In terms of reducing risk factors and social determinants, both CARPHA and PAHO have roles in providing technical support to national governments within the region. PAHO, for example, noted the role it is playing in providing support to governments on the implementation of the Framework Convention on Tobacco Control. Both CARPHA and PAHO stated that they intend to give greater priority over the coming year to supporting CARICOM and its governments on approaches to regulating marketing of foods to children.

Strengthen and reorient health systems to address NCDs

CARPHA and PAHO have both been active in initiatives to improve the quality of primary health care for chronic diseases, including through the production of treatment guidelines for diabetes, hypertension and asthma. As will be seen in the following section on National responses, it was noted that these guidelines are now outdated (being produced over 7 years ago) and that their impact on health care practice has not been properly evaluated but is likely to be minimal because of limited attention to their dissemination and implementation. One major health care area that has not been addressed at all is the content and quality of secondary care (hospital services) for NCDs.

Promote national capacity for research and development on NCDs

The University of the West Indies (UWI), as the government sponsored regional university, has an important role to

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

play in helping to build national capacities for research and development. UWI research activities have made significant contributions to knowledge on the burden of NCDs in the Caribbean. Work undertaken by groups in the Tropical Medicine Research Institute (TMRI) is particularly noteworthy, with large epidemiological studies being led from the Epidemiology Research Unit in Jamaica, and the Chronic Disease Research Centre in Barbados. Recent work of the latter, for example, includes the establishment of population based registries for stroke, myocardial infarction and cancer.

CARPHA is also active in the area of research and development, not least through organising the annual regional health research meeting.

Monitor and evaluate progress on NCDs
Within the region CARPHA has a key role in strengthening monitoring and evaluation, which it undertakes through conducting training workshops for staff of Ministries of Health and through collaborating on evaluation projects. Both PAHO and UWI also undertake relevant projects in monitoring and evaluating the impact of interventions, whether at a policy level or within individual health facilities.

National Responses and Findings

Responses were received from the Ministries of Health in 8 out of the 9 countries/territories approached, and from at least one Civil Society Organisation in 8 out the 9 countries/territories. Appendix 1 indicates respondents from countries/territories. There was no MoH response from the Cayman Islands, and no CSO response from St Vincent and the Grenadines.

Responses from the Ministries of Health

As far as possible the responses received from the eight Ministries of Health were summarised by completing the NCD Alliance benchmarking score card (appendix 2, tables 5 through 9). In the specific instance of the Cayman Islands it was possible to complete parts of the scorecard using information obtained previously as part of monitoring of the commitments from the Port of Spain Declaration [3] and from responses provided by the CSO from the Cayman Islands.

In addition to investigating the items in the NCD Alliance benchmarking score card, MOH respondents were asked to rate the level of support received by the MoH from selected regional organisations (appendix 2, figure 1). Examples of these types of support include assistance in building technical capacity, funding for specific risk reduction programmes, and the provision of regional treatment guidelines. Most respondents reported 'adequate' or better levels of support from regional organisations.

Raise Priority of NCDs, Strengthen National Capacity (Appendix 2, Table 5)

In three out of the eight respondents, Barbados, Dominica and Trinidad and Tobago, NCDs were addressed at least to some extent in the National Development Plans, as well as in Ministry of Health plans. A further two countries/territories (Bermuda, Jamaica) had operational NCD plans, the elements of which were said to reside in various documents. The other five countries (Belize, Cayman, Dominica, St Kitts and Nevis, St Vincent and the Grenadines), countries that, with the exception of Belize, have populations under 100,000, stated they were in the process of developing their NCD plans. Bermuda was the only territory with a population below 250 000 to have a plan, and perhaps not co-incidentally has the highest per capita gross national incomes in the region.

Only Barbados had an NCD line item budget, while NCD prevention, control and treatment was funded in the other countries through general Ministry of Health budgets.

A 'Whole of Government and Whole of Society approach', in which the Government's response to NCDs includes activities in Ministries beyond the Ministry of Health, was reported by all respondents. However, the data collected suggest that both intra-governmental and multi-sectoral activity could be much stronger. For example, even in those countries that stated they had operational NCD plans it was noted by respondents that both intra-government and inter-sectoral links were weak. One interpretation of these responses is that the importance of a 'Whole of Government and whole of society approach' is recognised in all countries/territories but progress to date in implementing this has been at best limited.

Almost all countries had convened National NCD consultations and reported that they included CSOs in these consultations. The key mechanism for promoting multi-sectorality - the National NCD Commissions (NNCDCs) - existed in 6 out of

"The call to the CARICOM Secretariat for recognition of the HCC has been seminal and certainly has the potential of reforming the Caribbean community's view of the role of civil society and NCDs."

Dr. Rudolph Cummings,
Program Manager, Health Sector Development, CARICOM Secretariat

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

the 9 countries/territories, and were reported as being under development in St. Kitts and Nevis and St. Vincent and the Grenadines. All NNCDCs were reported to include some degree of CSO participation. However, only respondents from 3 countries (Barbados, Bermuda, and Jamaica) stated that their commissions were currently fully functional.

Answers received from both MoH and CSO respondents indicated that governments in the region are in general willing to work with CSOs in several areas of their national response to NCDs. These relationships between MoHs and CSOs include MoHs providing financial support to CSOs for the provision of treatment and counselling services. An example of such an arrangement is the fee for service contract that exists between the Heart and Stroke Foundation of Barbados and their government to provide cardiovascular and stroke rehabilitation services. Other major activities of CSOs included Health Promotion, Advocacy and participating in the development of NCD policies.

Reduce risk factors and social determinants (Appendix 2, Table 6)

While there was clear evidence of activities across the region to raise awareness and strengthen national capacity, there were major gaps in the reported existence of strategies to reduce NCD risk factors. Strategies around nutrition, reduction in alcohol related harm and promotion of physical activity were poorly developed or absent in most countries/territories. Particularly noteworthy is the fact that no country/territory was able to report good progress on regulatory controls around marketing of unhealthy foods to children, and none had regulatory controls to reduce salt consumption. On the latter point, however, Barbados did report voluntary pledges from local food producers to reduce salt in food and had initiated a limited salt reduction programme.

There was some progress seen in the implementation of elements of the Framework Convention on Tobacco Control. All countries/territories surveyed are signatories to and have ratified the Framework Convention on Tobacco Control; however implementation of the provisions of the Convention has been very slow. Most of this progress has occurred in the last three years, which for some countries has been nearly ten years after ratification. In addition, there are some aspects of the FCTC that have not been addressed by any country within the sample, most obviously the provision of guidelines for the treatment of tobacco dependence.

Strengthen and re-orientate health systems (Appendix 2, Tables 7&8)

This section aims to assess the level of response of healthcare systems to the needs of persons living with NCDs. In addition, as described in the methods section above, the WHO survey for Assessing National Capacity for the Prevention and Control of Non-communicable Diseases was used to augment the Benchmarking tool indicators. The drugs and services about which specific enquiry was made are those lists of World Health Organization Essential Drugs and Services (Table 8).

Of the 6 countries/territories that answered the questions on WHO essential NCD drugs, all stated that they provide the majority of these drugs free of charge at the point of delivery to patients in financial need.

The majority of drugs on the WHO essential drugs list were available in all countries (Table 7). However, availability was limited for the breast cancer drug Tamoxifen, and for medications for Chronic Respiratory Conditions. Overall, it can be concluded that there is a deficit regionally in provision of care for Chronic Respiratory Conditions, which in most countries represented a lack of equipment or functioning equipment (for spirometry in particular). In addition, there are no smoking cessation therapy programmes provided as part of Government or national insurance health schemes. All smoking cessation programmes in the region were reported to be offered by the private sector and by CSOs.

Another significant gap was that no country was able to report good progress on implementing treatment guidelines for NCDs. Regional guidelines have been developed for the treatment of hypertension, diabetes and asthma in primary health care. However, these guidelines have not been updated for over 6 years (although it is known that updates of the hypertension and diabetes guidelines are in progress). In addition, implementation and uptake of guidelines was reported to be less than adequate, with guidelines being disseminated to varying degrees but with little follow up to support their use in practice and no evaluation of impact. Systems of delivery of medication for patients with hypertension were considered to be sub-optimal in most countries. This was also noted by CSO informants.

Finally, it is noted that out of 7 countries, only two reported that there was good progress on strengthening services for palliative and rehabilitative care.

Provision of NCD Services as Reported by CSO Respondents (Appendix 2, Table 10)

CSOs indicated that treatment guidelines were not well adhered to including by CSOs, nor was adherence to guidelines, where they did exist, being adequately monitored. As CSOs in the region are heavily involved in service provision the questionnaire attempted to solicit the level of oversight applied to service provision by CSOs. A few CSOs reported being required to submit annual reports to their government and/or a parent organisation.

Most CSO respondents indicated that facilities available for the care and management of Chronic Respiratory Conditions are adequate. This is in contradiction to the view expressed by Government respondents. The responses from CSO and Government respondents were similar concerning the adequacy of facilities for persons with Diabetes and Cancer. Half of our sample expressed the view that provision for palliative care in their country was inadequate (Table 11). It is noteworthy that in two of the countries where care was reported by the CSO respondents to be inadequate the Ministry of Health respondent indicated that there was good progress on strengthening these services (Table 8). An optimistic interpretation of this is that in these two countries the inadequacies have been recognised by the Ministry and are in the process of being addressed. Further work would be required to know if this interpretation is correct.

A limitation of this work is that a thorough investigation into levels or quality of care provided in primary care and in secondary care was not possible. The responses indicate where further investigation should be directed to better understand shortcomings in NCD health care provision and how to overcome them.

Promote national capacity for research and development and monitor and evaluate progress

As noted in the section on regional institutions, significant work is undertaken by the University of the West Indies, especially through TMRI and its Epidemiology Research Unit and the Chronic Disease Research Centre, in the promotion and execution of research, together with development of teaching programmes.

Only three Countries indicated any items on their National Research Agenda, but all reported surveys on the prevalence of risk factors for NCDs (Appendix 2, Table 9).

A thorough literature search conducted as part of a systematic review on the social determinants of diabetes, its risk factors (including smoking, obesity, diet and physical inactivity) identified 45 publications on the topic of NCDs over the past 5 years from among the 9 countries surveyed. The vast majority of these publications, however, are from three countries: Barbados, Jamaica and Trinidad and Tobago.

Finally, all countries stated that they have national NCD targets and indicators with monitoring mechanisms in place. However, the adequacy of the targets and indicators, and the monitoring mechanisms were not explored in detail.

POS evaluation as a monitoring mechanism

In 2008, a one-page colour-coded grid was designed, implemented and endorsed by the CARICOM heads of government and ministers of health to monitor the implementation of the POS NCD Summit Declaration in the 20 CARICOM member states (Appendix 3). The grid is updated annually by the NCD focal point, validated by the Chief Medical Officer and presented to the Ministers of Health and Heads of Government. It summarises country self-reports on compliance with the POS Declaration, including Commitments (NCD plan, budget, Summit, Inter-sectoral Commission), Tobacco (FCTC ratified, taxes, Smoke Free indoor spaces, advertising), Nutrition (plans, trans fat, trade, labelling), Physical Activity (in schools, housing developments, communities), Promotion (communications plan, Caribbean Wellness Day, workplaces, media), Surveillance (STEPS, GYTS, GSHS) and Treatment (Chronic care model, quality of care projects). The grid was revised from 21 to 26 indicators in 2010.

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

The grid was used by the HCC in 2010 to summarize response to the POS Declaration and was the basis for a more formal evaluation commissioned by PAHO in 2011[3]. A paper describing this evaluation process has recently been accepted for publication [23].

Responses from Civil Society Organizations

Responses were received from 11 National CSOs in 8 of the participating countries. Details of the responding organisations are given in Appendix 2, Table 15. The majority of the CSO respondents were from Health NGOs. In addition to providing data on their own CSO, respondents were also requested to provide information on ways that any other national CSOs contributed to the prevention or treatment of NCDs.

Activities of Civil Society Organizations

A great breadth of activity, including provision of services, assisting ministries in research, training, contribution to national policy formulation, and health promotion was reported as contributions of CSOs to the national NCD response within the past 2 years (Tables 12 & 13).

Mandates and priorities of CSOs

Mandates and stated priorities of the responding CSOs were seen as increasing national access to NCD screening, monitoring and various aspects of treatment.

Each of the CSO respondents stated that providing financial and/or psycho-social support to persons living with NCDs was a major priority for their organisation. Sometimes that included direct practical and financial support, as with the Cayman Island Cancer Society which provides 'financial assistance for treatment and living support to people with cancer' and vouchers for breast, cervical and prostate cancer screening.

CSOs respondents also stated that health promotion and advocacy activities, aimed at the prevention of NCDs, were priorities for their organizations. Their reported activities included media campaigns, physical activity events (e.g. fund raising walks/runs), health fairs and public lectures.

CSO Respondents' Views on What Constitutes 'Advocacy'

When asked what fell under the heading of 'advocacy' most respondents indicated that it meant raising awareness of:

1. The burden of NCDs and the steps that individuals can take to avoid them;
2. The impact of NCDs upon the lives of those living with NCDs, and what can be done to reduce that impact.

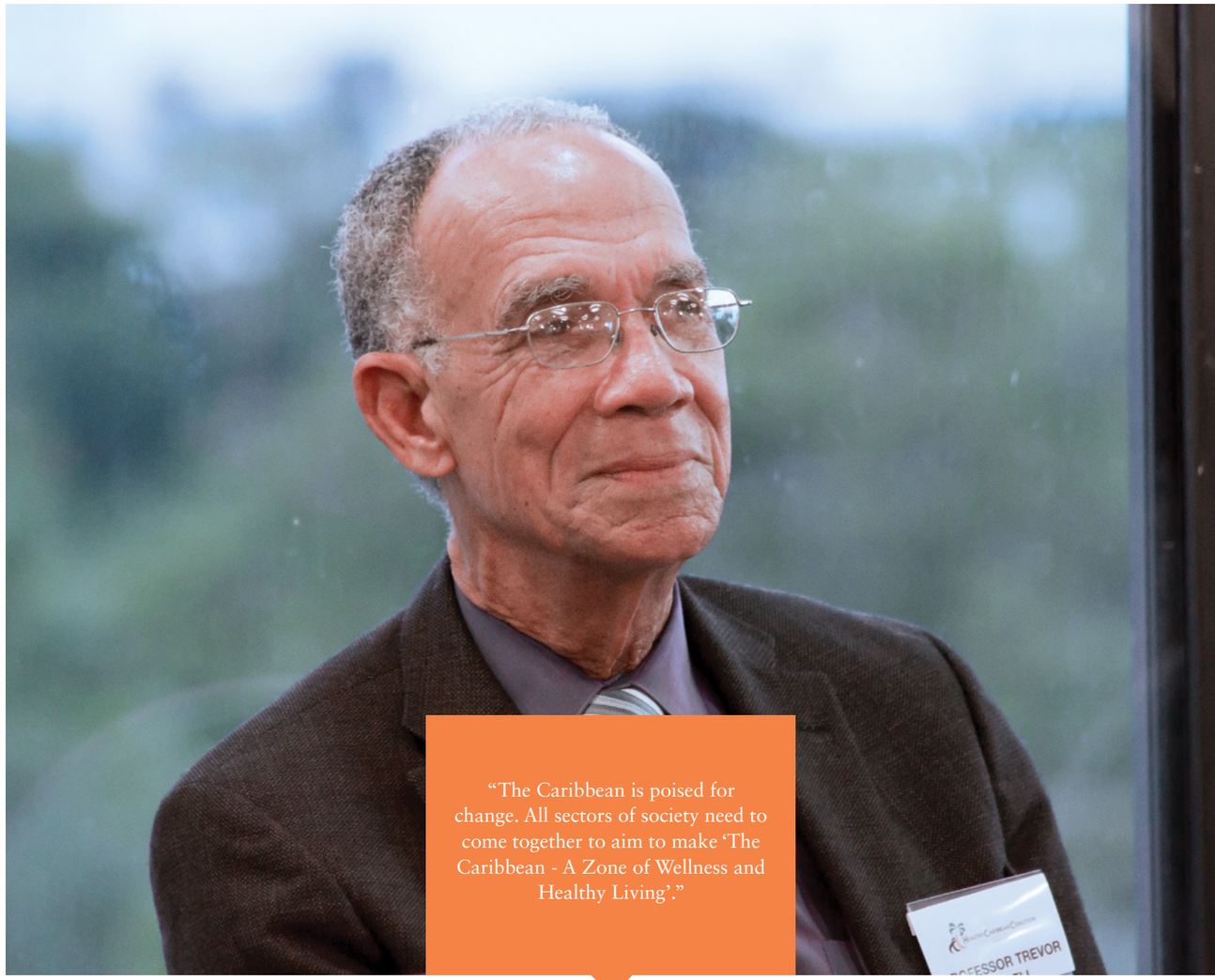
Less commonly reported was 'advocacy' as lobbying. For example, The Cayman Islands Cancer Society and Jamaica Coalition for Tobacco Control have lobbied their governments for an HPV Vaccination programme and Tobacco Legislation respectively, while the Belize Cancer Society has lobbied for the establishment of a cancer registry. Many CSOs in the region also reported contributing to NCD policy development as a key part of their 'advocacy role'.

Examples of advocacy provided included awareness raising, provision of services, providing financial assistance, working with the ministry of health on drafting policy, building partnerships with the private sector, and organising medical education sessions.

Challenges Reported by Government and CSO Respondents

A significant barrier to the NCD response was reported to be the sub-optimal coordination of efforts. Government respondents spoke of weak intra-government links, and though universally recognized as a key goal, there has been much difficulty 'extending the response beyond the MOH'. Both Government and CSO respondents suggested that their NCD prevention and control activities would be much improved by greater communication, collaboration and coordination.

Both CSO and Government respondents reported that their activities were hampered by limited financial resources. Indeed, while most of the countries have operational NCD plans funded through MOH financial allocations, only Barbados had a dedicated, though modest budget earmarked for NCDs. Jamaica has established the National Health Fund (NHF) with tobacco taxes, which supports subsidies for NCD drugs and health promotion activities. Trinidad and Tobago has established the Chronic Disease Assistance Programme



Professor Sir Trevor Hassell
President, HCC

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

(CDAP) to provide many chronic disease drugs free of cost. Other challenges reported included a lack of human resources, training opportunities and equipment, all compounded by the reality of competing for scarce resources with other health programmes, such as HIV.

Some CSO respondents also referred to the challenges of Governments implementing measures to reduce the consumption of alcohol and tobacco when such measures might be seen to threaten powerful economic interests, and additionally might be unpopular because they may be seen to threaten employment opportunities. These might be some of the reasons that several CSO respondents reported feeling that there was ultimately a lack of political will to take the action required to prevent and control NCDs.

Successes Reported by Government and CSO Respondents

The major successes identified by Government respondents focused on the development of National NCD policy, and much of that work was related to elements of the FCTC. Tobacco represented a significant area of work for CSOs as well. CSOs in Jamaica, Cayman Islands and Barbados highlighted their lobbying activities for Smoke – Free public enclosed spaces as major successes. CSOs also noted the establishment of smoking cessation programmes like 'Fresh Start' of the Jamaica Cancer Society among their recent successful ventures.

Another reported success was the Jamaica National Cervical Cancer screening programme, which has been credited with reducing age specific Cervical Cancer Incidence Rates by 31% between the periods of 1993-1997 to 2003-2007 in the parishes of Kingston and St. Andrew, Jamaica.

In Dominica, a 'rest stop' to accommodate rural patients accessing chemotherapy and other procedures in Roseau was established jointly by the Dominica Diabetes Association and the Dominica Cancer Society. Often these treatments require patients from rural areas to overnight or to remain in town for the entire day. This facility highlighted how partnerships and collaboration could help alleviate some challenges experienced due to limited resources. Their initiative was then further supported by an annual subvention from the Government for the up keep and maintenance of the building.

National NCD Commissions

As described in the methods section above, it was decided as part of documenting the national responses to NCDs, to examine in detail the role of National NCD Commissions (NNCDCs). The chairpersons of the NNCDC in five countries, known to have active commissions were approached, and all completed an online questionnaire.

Genesis of multi-sectoral NCD Commissions in the Caribbean

In 2004, the Ministry of Health in Barbados documented their "Strategy for the Prevention and Control of Chronic Non-Communicable Diseases" which included the creation of a Multi-sectoral NCD Commission, Senior Medical Officer of Health for NCDs and a Health Promotion Unit with three staff. The Barbados National Commission on Chronic Non-Communicable Diseases (NCCNCD) first met in March 2007. Prof Sir Trevor Hassell has been its chair since its inception.

In September 2007, CARICOM Heads of Government issued the "Port of Spain Declaration: Uniting to Stop the Epidemic of NCDs" which states "we strongly encourage the establishment of National Commissions on NCDs or analogous bodies to plan and coordinate the comprehensive prevention and control of chronic NCDs"

Support for establishing commissions has been provided including Guidelines and Model Terms of References published in the CARICOM Regional NCD Plan 2011-2015.

Implementation of this mandate

To date, establishing Commissions has been associated with country population size. With the exception of Haiti, 6/7 (85%) countries with populations >250,000 have established NCD Commissions, compared to 3/12 (25%) among the smaller countries with <250,000 population.

Inter-sectoral Membership of NCD Commissions

POS NCD Summit Declaration recognizing the multi-factorial causation of NCDs and their risk factors, specified the need for multiple sectors to respond, both "whole of government" (intra-sectoral) and "whole of society" (inter-sectoral). The NCD Commissions are designed to be the engine of this collaboration.

Membership of the 5 Commissions surveyed reflects multi-sectoriality with 4/5 Commissions having representatives from Ministries of Education and Agriculture (government); Faith-based Organizations, Health CSOs and Trade Unions (civil society) and 3/5 Commissions including private health sector, manufacturers and the media (private sector). All Commissions include Ministry of Health professional and technical staff as ex-officio members.

Resources to support NCD Commissions

Human Resources: Technical or professional Ministry of Health staff support is available to 4/5 Commissions surveyed, but 3 Commissions have no dedicated technical staff. Technical staff assigned to support Commissions report to both the Ministry of Health and the NCD Commission, with their functions in the NCD Commission not well defined. Indeed, in several instances, the Commissions seem unclear about their own roles, relationships and function.

Three of the Commissions have a strategic plan and 2 have a budget. Funding was reported to be sourced from PAHO in some instances, and from the private sector for specific projects. Most Commissions produce annual or more frequent reports, though some reports are recorded minutes of meetings of Commissions, with no reflective analysis.

Relationships with HIV/AIDS and Mental Health, the other two main chronic diseases are ad hoc at best, and absent in most cases.

Examples of Success Stories

Smokefree legislation has been enacted in 4/5 countries. STEPS NCD risk factor surveys or equivalent were reported to have been conducted in all 5 countries, and enhanced awareness of harmful effects of high salt intake and establishment of National Registry for stroke, heart attacks and cancer in Barbados.

In February 2014 the Declaration of Bridgetown: Faith-Based Organisations of Barbados Uniting to Prevent and Control NCDs (Appendix 5) was adopted by acclamation by sixty-two representatives of twenty-six (26) Faith-based organisations (FBOs) from across Barbados at a Consultation held by the Nationla NCD Commission and the Healthy Caribbean Coalition. The NCD Commission and the HCC will make the Declaration known to the Political leadership in other CARICOM countries in support of advocating for a more meaningful multi-sector response to NCDs by FBOs in Barbados and the Caribbean.

Some successes reported were process measures without any impact on population health status, e.g. workshops with food and beverage manufacturers, smooth transitions from one political administration to another and access to Ministry of Health Executives.

Caribbean Wellness Day (CWD) has been a success in many CARICOM countries, acting as a catalyst for national NCD awareness using innovative strategies to increase public consciousness of NCDs.

Challenges

There were concerns with defining the relationship with the Ministry of Health, and challenges in getting political support for an "all of Government" response to the NCD epidemic. One Chair of a Commission was of the view that the Commission of which he/she was Chairperson aimed to be too ambitious in its reach of initiatives and numbers of beneficiaries. Most Chairs of Commissions considered that NCD Commissions were not sufficiently action oriented, with an inability to guarantee implementation of recommendations. Human and financial resource gaps hampered their programmes.

All Commission Chairs expressed concern about defining and operationalizing the needed multi-sectoral response. There were difficulties tracking activities by other agencies, communicating with and involvement of other stakeholders and how to make NCDs an issue beyond health.

Comments from CSOs and Government surveys on the NCD Commissions agreed with the above comments to a large extent. Additional points made were that 2 Commissions were no longer functional and had not yet been re-appointed. There was often a long delay in reconstituting NCD Commissions with changes in political leadership. A suggestion made to address this issue was the appointment of Commissions by the Head of State for a fixed period of time under conditions that allowed it to continue to function through changes in political administrations. CSOs suggested newsletters from the

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

Commissions to enhance communications with those CSOs not appointed to or represented on NCD Commissions, and promote advocacy efforts of CSOs and promote CSO role in NCD programmes in the community.

Options for multi-sectorality in small countries struggling with NCD Commissions

Only one quarter of the smaller countries (populations <250,000) have NCD commissions. However there have been some multi-sectoral responses and activities in countries without commissions, as indicated in the national responses reported by respondents in St Kitts & Nevis, St Vincent & Grenadines, Dominica and the Cayman Islands. NCD meetings and celebration of Caribbean Wellness Day are the two consistent forms of multi-sectoral engagement occurring in these four countries.

NCD meetings were all multi-sectoral with representation from Health CSOs, other CSOs, Government agencies and private sector (all of Society). Dominica excelled in the number of organizations involved, while the Cayman meeting was a private entrepreneurs meeting, to which the Ministry of Health asked to be invited. There was no clear indication of what activities resulted from these meetings to reduce the prevalence of NCDs or their risk factors.

Caribbean Wellness Day

Multi-sectoral participation in planning, funding and participation in Caribbean Wellness Day (CWD) was evident in all countries. However, the representative from Cayman had been in office less than 3 years, and was unable to report on prior or current arrangements for CWD.

Most countries in CARICOM have celebrated CWD most of the 6 years (2008 – 2013). These celebrations have taken place with equal frequency in islands with populations <250,000 (most of which do not have an NCD Commission) as in those with populations >250,000. Activities around CWD have involved a wider cross section of CSOs and private sector organizations than have routine NCD meetings (Appendix 1), and have been focused around activities to reduce NCD risk factors, and in urging countries to "Make every day Wellness Day".

CWD has been institutionalized in most countries through political will and leadership and technical supports. Most NCD commissions have had no direct involvement, but have supported the celebrations.

Branding of CWD has been multi-media in scope. The slogan for CWD is "Love That Body" with countries encouraged to append their own slogans to that regional stem (e.g. Love That Body, Portions Count"). Fact Sheets to mobilize schools, faith-based organizations, workplaces and the private health sector; Public Service Announcement, jingles, the creation of a new poster each year and a website www.paho.org/CWD09 have all been used to promote CWD. In the early years, there were monthly teleconferences with CWD focal points in each country to support their mobilization of civil society and the private sector, and to share initiatives and problem solving.

In 2011, with support from Pepsico, a Regional NCD newspaper supplement was published on Sunday, Sept 25th 2011 entitled KILLER NON COMMUNICABLE DISEASES – CARICOM LEADS GLOBAL ACTIONS. The cover photo was of the Scotiabank Women Against Breast Cancer 5K Walk/Run in Port of Spain in September 2011. It is acknowledged that accepting support from a transnational food corporation, and in particular one that is a major promoter of sugar sweetened beverage consumption, is not without controversy. It provides a case study on where the balance lies between promoting public health and commercial interests that are damaging to public health.

Several countries have implemented ongoing mass physical activity programmes as a result of CWD. The most successful and enduring of these has been in Diego Martin in Trinidad & Tobago which is the Caribbean's 1st Ciclovia/"Streets for Wellness" / "Keep Moving Family Fitness Sundays" started on the 1st Caribbean Wellness Day Sept 13th 2008, and continued every Sunday, 6am to 9am, with prohibiting of vehicular traffic on 2 km of the Diego Martin Highway to allow the community to use the highway to walk, ride, skate, and engage in Physical Activity classes. Community members enthusiastically support the impact of these events on community cohesion, which bring upper middle class and lower socio-economic communities together in pursuit of enhancing their own physical and mental fitness. The POS NCD Summit Declaration encourages this type of community based mass physical activity.

"The Jamaican Cancer Society strongly believes that CSOs have the power to influence and bring about change through advocacy, partnering with media, adopting innovative strategies to access hard to reach communities, and identifying champions for the NCD cause."

Yulit Gordon,
Executive Director, JCS

9. NATIONAL AND REGIONAL RESPONSES TO NCDS

The "Keep Moving Family Fitness Sundays" is sponsored from within the community by an insurance company and the owner of a cycle shop. It receives a wide range of financial and technical support including provision of electricity services, police and ambulance services and receives inputs from Ministries of Health and Sports. The Impact of the Ciclovia on the Physical Activity of Diego Martin residents has been the subject of a study by Dr Samantha Mohan in her 2011 MPH research project, which demonstrated that knowledge of the Ciclovia and having ever participated were positively associated with self- reported achievement of the recommended amount of physical activity per week.

10. CHALLENGES AND GAPS – A CIVIL SOCIETY PERSPECTIVE

GAPS IN REGIONAL RESPONSES

Regional organisations have a key role to play in improving responses at the national level. There are obvious successes that are wholly or partly attributable to the activities of regional organisations, including: the Port of Spain Declaration: Uniting to Stop the Epidemic of Chronic Diseases; ratification of the FCTC by all but one Caribbean country, improved labelling of tobacco products, and risk factor surveillance. However, there are also obvious gaps. These include:

- Lack of regional initiatives on the labelling and marketing of food to children, and lack of regional initiatives on physical activity, and on alcohol.
- Current lack of up to date regional evidence based guidelines for the management for chronic diseases in primary health care and in hospitals, and poor access to palliative care.
- Little evidence of mechanisms to involve Civil Society in regional bodies or their policy development with respect to NCDs.
- No clearly established forum for nurturing the development of region wide multi-sectoral partnerships with respect to NCDs.

GAPS IN NATIONAL RESPONSES

There were obvious gaps in national responses across all six major headings of the NCD Alliance benchmarking tool.

While there was much evidence of a response to NCDs at a government level in all countries, there was little evidence that NCDs are really being taken into account in national development plans, with only 2 out of 8 responses indicating that they were explicitly mentioned in such plans. In addition, Barbados is the only country to have a specific budgetary allocation for its response to NCDs.

Major gaps were reported in actions to reduce risk factors and social determinants. The best progress was reported on tobacco control, although even here there remain some clear gaps. All independent CARICOM countries, with the exception of Haiti, have ratified the Framework Convention on Tobacco Control (FCTC). However, 4 countries reported that they have no legislation banning tobacco advertising; and not one of the 9 countries/territories had guidelines in place for treating tobacco dependency.

Nutrition was the area where least progress was reported. No countries/territories had policies in place on marketing of foods to children, none reported the existence of a national strategy on nutrition, and none reported the existence of national policies on salt reduction. Physical activity appeared a little better, with 2 out of 8 respondents reporting the existence of a national strategy, and 2 out of 7 respondents reporting 'good progress' on national measures to reduce alcohol related harm.

The scorecard on strengthening and reorienting health systems revealed major gaps across most countries/territories. All scored poorly on the use of national evidence based guidelines. In addition, reported access to essential NCD services was suboptimal in national health care or insurance schemes in all countries apart from Barbados. Three out the 7 respondents reported major deficiencies, suggesting that those with NCDs who are poorly insured or on low incomes may face real difficulties in accessing basic care. In addition, 5 out of 7 countries reported poor or suboptimal initiatives to strengthen services for palliative care and rehabilitation. This impression of poor access to palliative care was reinforced by responses from the CSOs, who stated in four countries that availability was inadequate.

Finally, only three countries reported recent research and monitoring and evaluation activities. In addition, only in the larger countries (Jamaica, Trinidad & Tobago and Barbados), each of which has a campus of the University of the West Indies is there evidence of consistent research output on NCDs.

National NCD Commissions (NNCDCS)

The establishment of NNCDCs was one of the commitments in the 2007 Port of Spain Declaration. One of the key roles of each commission is to provide the vehicle for multi-sectorality in the national response to NCDs, including government ministries other than health, civil society and the private sector. While all the responding countries had established an NNCDC, 5 out of 8 described its functioning as suboptimal. In the sub study on NNCDCs only 3 out of the 5 contacted had a strategic plan, and only 2 out of 5 a specific budget. It was noted too that of the smaller countries only 3 out of 12 had actually established an NNCDC.

10. CHALLENGES AND GAPS – A CIVIL SOCIETY PERSPECTIVE

CHALLENGES FROM THE PERSPECTIVES OF CSOs

This study demonstrated that Civil Society Organisations are playing major roles in the national and regional responses to the NCD epidemic. Their activities are broad, from service delivery, the provision of facilities and equipment, public outreach and education initiatives, through to advocacy for action by governments. Commonly reported challenges included, weak governance and management structures, inadequate capacity, scarcity of resources (human and financial) and lack of training, particularly with regard to service delivery. It is noteworthy, for example, that no CSO reported using evidence based guidelines.

It was apparent in all settings, with the exception of Jamaica, that health NCD CSOs tended largely to work in isolation. However, respondents acknowledged that CSOs could benefit from greater interaction and cooperation. Potential benefits include learning from each other, such as on how to organise their services, collaborating on the provision of services, and becoming more effective advocates for government change by speaking with a louder, unified, voice.

In Jamaica, the Council for Voluntary Social Services acts as a 'non-profit' umbrella organisation, designed to facilitate 'mutual support and joint action', and provide a single representative body to liaise with government. Exploration of how well this umbrella organisation serves the interests of its members, and what lessons may be drawn for other parts of the Caribbean would be worthwhile but was beyond the scope of this project.

Finally, it is important to note that the CSOs included in this study were health CSOs e.g. diabetes, CVD and cancer organisations. Noting the need for multi-sectoral action, other types of CSOs clearly have much to contribute in responding to NCDs. These include trade unions, faith based groups, organisations representing retired persons, youth organisations and so on. An important challenge therefore, but one that was only lightly touched on in this study, is how to involve the range and diversity of CSOs in building a more effective response to NCDs.

"We in the Caribbean do well in developing policies and strategic plans but we are very unimpressive in migrating from plan to programme…more attention needs to be paid to a kind of implementation science."

Dr. Omowale Amuleru-Marshali, Chair, NCD Commission, Professor & Director, Community Health and Outreach, Office of the Provost, St. George's University

11. CALL TO ACTION

The overriding goal for this work was to provide an assessment of the gaps that currently exist in the response to NCDs and in how the roles of Civil Society, particularly the role of 'advocacy', can be enhanced to help fill those gaps as presented in a 'Call to Action'.

As part of the process of completing the work for this report two presentations were given at the multi-stakeholder meeting, held in Trinidad on November the 22nd 2013, ' "Strengthening Health Systems, Supporting NCD Action" – Advocating for Policies and Action'[25]. This meeting was organised by the Healthy Caribbean Coalition, and sponsored by the NCD Alliance with support of Medtronic Philanthropy. It was attended by over 60 delegates from 14 Caribbean countries/territories. There were representatives from health CSOs, government, private sector, trade unions, women's groups, the media, international organisations, service clubs, faith based organisations and medical associations. The report is available on the "Strengthening Health Systems, Supporting NCD Action:Advocating for Policies and Action" meeting page on our HCC website at the following link: http://www.healthycaribbean.org/ncda-multistakeholder-meeting-2013/index.html.

At this meeting an interim Regional Status Report and the results of investigating the activities of five NNCDCs were presented.. Feedback on these presentations was encouraged both within the time allocated for them and in the ensuing panel discussions.

In response to this NCD Alliance supported project the HCC established a Civil Society Advocacy Technical Working Group (TWG) with the objective of representing the NCD advocacy related interests of Caribbean CSOs within the context of the project and in the longer term in support of the HCC 2012-2016 Strategic Plan which identifies Advocacy as one of the organisations' four strategic priorities. The TWG, representing a broad cross section of NCD disease focused CSOs, academia and medical associations, reviewed this report in great detail and contributed significantly to the identification of evidence-based priority areas to inform the 'Call to Action'. What follows in this section is based on the authors' interpretation of the findings in this report, which is shaped by the comprehensive stakeholder consultations that took place at the November meeting and in the months following.

There are three broad categories that encompass the 'Call to Action'. These are structures for engagement, advocating for action and holding governments and regional organisations to account.

STRUCTURES FOR ENGAGEMENT

Here we refer to two broad and interrelated areas of engagement. One is the engagement between CSOs themselves, and the other between CSOs and national and regional policy makers.

Engagement Between CSOs

CSOs could be more effective as providers and advocates through greater collaboration. This is especially relevant given the small size of the majority of CARICOM members, and the associated scarcity of human and financial resources. National fora, similar to the Jamaican Council for Voluntary Social Services, should be convened that provide a vehicle for engaging with each other and with government.

At present most CSOs involved in the response to NCDs have specific health mandates. Yet, as is clear, be it from the Port of Spain Declaration[1] or the outcomes of the UN HLM [6], the response to NCDs needs to involve the whole of society. Other CSOs must also be involved, including Faith Based Organizations, Associations of Retired Persons, Parent Teacher Associations, Trade Unions, Women's organizations, Service clubs, Consumer organizations, Sports and Fitness clubs and so on. All such organisations should be included in national Civil Society fora whose goals are to promote and support an all of society approach to NCD prevention and control. These fora should provide the vehicles for effective partnerships between the civil society, government and the private sector.

The Healthy Caribbean Coalition which has focussed significantly in the area of collaboration among civil society organisations and other sectors of the society (government and private sector) since it was formed could continue to lead in this process in several ways. One is through maintaining an up-to-date register of all (as far as possible) civil society organisations within the CARICOM members. A second would be through active promotion of national coalitions or fora of civil society organisations which might include not only promotion of the concept but also continuing to host further regional workshops to provide guidance on how to establish such national fora.

Engagement Between CSOs, National Governments and Regional Bodies

There is one obvious national forum for improved engagement between government and CSOs, and indeed between these two and the private sector, and that is the National NCD Commissions. However, as this report has shown, a functioning NNCDC does not exist in many countries. This is especially the case in the smaller countries and territories, where human and financial resources are under severe strain to meet the different roles demanded of government. Creative solutions need to be found, making the best use of scarce human resources. Possibilities include broadening the remit of commissions to include other chronic conditions, such as HIV and mental health, thus saving on the time commitments of individuals who might be asked to contribute to all these areas. Another possibility would be to merge the structures, and bring together the individuals who contribute to Caribbean Wellness Day. The underlying denominator to these suggestions is finding ways within countries/territories of (1) promoting an all of society approach and (2) avoiding excessive demands on the individuals with the connections and expertise to contribute.

Engagement between Civil Society and regional organisations is currently ad hoc. However, it was encouraging to hear that CARPHA is keen to appoint a civil society representative to its board. HCC could monitor progress on this, and how civil society is actually engaged. There is need for additional regional fora to those held by the HCC that brings together intergovernmental regional bodies, regional civil society and the private sector. The establishment of a regular (e.g. annual) multi-stakeholders meeting should be a priority.

ADVOCATING FOR ACTION

The gap analysis has identified several major areas where current policy and action is deficient. This provides a clear agenda for CSO advocacy, to lobby national governments, seeking their urgent attention. Exactly how this is done will vary between countries/territories, dependent to a large extent on the existing structures for engagement discussed above.

The authors wish to highlight the following gaps that CSOs across the region could be encouraged, coordinated by the HCC, to pay particular attention to:

Addressing risk factors and determinants

- Policy on food, in particular: banning the marketing of energy dense, high salt, foods and sugar sweetened beverages to children; promoting reduction in salt and sugar sweetened beverages (including fruit juices); banning the use/sale of trans fats; regional standards for clear, consistent, food labelling;
- Policy on physical activity: development, implementation and monitoring of national strategies on the promotion of physical activity;
- Policy on reduction in harm from alcohol: development, implementation and monitoring of national strategies on the reduction in harm from alcohol.

Addressing access to effective health care and health systems strengthening

- Advocating for active dissemination of up to date regionally derived evidence based guidelines for the treatment and management of NCDs. Active dissemination is emphasised because without proactive measures to encourage the use of guidelines they are known to have little impact.
- Advocating that all residents within CARICOM countries/territories have access to basic defined packages of NCD care irrespective of their ability to pay.
- Application of the chronic care model in the provision of primary health care services in countries.
- Development and implementation of a framework for standardising the treatment of hypertension using available core medications.
- Advocating for adequate provision of palliative and rehabilitative care.

11. CALL TO ACTION

Building a truly all of society approach, with health in all policies

- An ultimate goal, indicating a truly all of society response, is to see the response to NCDs fully addressed within national development plans.
- Seek opportunities for a multi-stakeholder approach to the response to NCDs by engaging major groups of the society such as Faith-based organisations, groups of retired persons, women's groups, and the workers representatives.

Meeting this or a similar agenda for CSO advocacy across the CARICOM countries and territories will require regional leadership. HCC is ideally placed to undertake this role, and could work on developing a regional advocacy toolkit built around the above issues. A good starting point for this would be the NCD Alliance toolkit.

CSOS as Actors, More than Advocates

The main rationale of this report, as requested by the NCD Alliance, was to help inform areas on which civil society should be advocating to improve the response to NCDs. However, it is important to acknowledge that within the Caribbean CSOs are also major providers of services, and that the concept of 'advocacy' is broad, being seen as much more than 'arguing and/or acting in support of a particular cause, policy, group of people etc'[26]. It is worth noting therefore the potential roles, in addition to advocacy, of CSOs in filling some of the gaps identified:

- Patient education on self-management and screening – this is a role than many CSOs already see themselves as providing, some with support from, and using materials from, outside bodies, such as the International Diabetes Federation. It is at least worth reviewing the need for the development of bespoke, evidence based, regional materials to support patient education for common NCDs;
- Ensuring that all CSO staff delivering care follow evidence based, ideally newly developed regional, guidelines and that they carry out audits of care and quality improvement measures;
- Delivering services not currently provided by governments or through insurance schemes. Obvious possibilities include smoking cessation services and support for problem drinkers and their families;
- Taking direct action (rather than through government policy) on certain issues. One example could be monitoring the accessibility, choices and quality of prepared (fast) foods, and lobbying directly the manufacturers and vendors of such foods.

HOLDING POLICY MAKERS TO ACCOUNT – THE WATCHDOG ROLE

A key potential role of CSOs is to hold the policy makers to account. Thought should be given as to how this can be supported at a national level and at a regional level. Indeed integral to any advocacy tool kit and training programme must be guidance on how to monitor progress. The NCD Alliance scorecard, based as it is on the WHO Global Action Plan [27], provides one important tool. However, responses to such a tool are typically based on policy statements, whether from policy makers verbally or the contents of policy documents. This may be a poor indication of what has actually been done i.e. what has been implemented, and to what degree. National CSOs, and the Caribbean NCD Alliance, the HCC, with their local knowledge and connections, are in a position to get beneath 'stated policy' and help monitor 'implemented policy' i.e. what has actually changed. Tools to help do this should be developed as part of the advocacy tool kit.

"I hope that in producing this report we have made an important contribution to the NCD response in the Caribbean."

Professor Nigel Unwin,
Professor Public Health, UWI

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13. APPENDICES

APPENDIX 1: ACKNOWLEDGEMENTS

With Much Thanks we would like to acknowledge our key informants, without whom this project would not have been possible.

National Respondents

Country	Government	Civil Society
Barbados	**Dr. Kenneth George** Senior Medical Officer Non Communicable Diseases Ministry of Health	**Gina Pitts** Chief Executive Officer Heart & Stroke Foundation of Barbados
Belize	**Dr. Marvin Manzanero** Internist Epidemiology Unit HIV and NCD focal Point Ministry of Health	**Laura Tucker Longsworth MSN, RN** President Belize Cancer Society
Bermuda	**Dr. Virloy Lewin** Health Promotion Officer Department of Health	**Debbie Jones** Board Member Bermuda Diabetes Association
Cayman Islands	**Not Applicable**	**Dr. Sook Lee Yin** Medical Director Cayman Islands Cancer Society & Cayman Heart Fund
Dominica	**Antheila James** Coordinator Health Promotion (Ag) Ministry of Health	**Allison Samuel** Board Member Dominica Cancer Society
Jamaica	**Dr. Tamu Davidson** Director Disease Prevention and Control Ministry of Health	**Barbara McGaw** Heart Foundation of Jamaica **Yulit Gordon** Executive Director Jamaica Cancer Society **Winsome Wilkins** Chief Executive Officer Council for Voluntary Social Services
Trinidad & Tobago	**Yvonne Lewis** Director Health Promotion MOH	**Nicole Jordan-Coombs** General Manager Trinidad & Tobago Cancer Society
St. Kitts & Nevis	**Petrinella Edwards** NCD Programme Coordinator/ Acting Director Community Health Ministry of Health	**Board Member** Reach for Recovery Breast Cancer Support
St. Vincent & The Grenadines	**Dr. Simone Keizer-Beache** Chief Medical Officer Ministry of Health, Wellness and the Environment	**Not Applicable**

NCD Commission Respondents

Barbados	Prof. Sir Trevor Hassell
Belize	Dr. Marvin Manzanero
Grenada	Dr. Omowale Amuleru-Marshall
Jamaica	Prof. Rosemarie Wright-Pascoe
Trinidad & Tobago	Dr. Victor Coombs

Regional Respondents

PAHO/WHO	**Dr. Branka Legetic** Regional Advisor & Unit Chief a.i. Noncommunicable Diseases and Disabilities Department of Noncommuncable Diseases and Mental Health
	Dr. Tomo Kanda NCD Advisor, Barbados and the Eastern Caribbean Countries
CARPHA	**Dr. C. James Hospedales** Executive Director
University of the West Indies	**Prof. Nigel Unwin** Professor of Public Health and Epidemiology Dr. T. Alafia Samuels Senior Lecturer, Public Health and Epidemiology UWI - Cave Hill Campus
Healthy Caribbean Coalition	**Prof. Sir Trevor Hassell** President

13. APPENDICES

Members of the HCC Civil Society Advocacy Technical Working Group

Name	Organisation	Position
Anthony Castillo	Belize Diabetes Association	President
Barbara McGaw	Jamaica Coalition for Tobacco Control	Project Officer
Debbie Chen	Heart Foundation of Jamaica	Executive Director
Gina Pitts	Heart & Stroke Foundation of Barbados	Chief Executive Officer
Laura Tucker Longsworth	Belize Cancer Society	President
Dr Martin Didier	Caribbean Cardiac Society	President
Nicole Jordan	Trinidad & Tobago Cancer Society	General Manager
Prof. Rainford Wilks	Epidemiology Research Unit, Tropical Medicine Research Institute, UWI	Director
Simone McConnie	Barbados Diabetes Foundation	Chief Operating Officer
Sook Lee Yin	Cayman Islands Cancer Society	Medical Director
Sir Trevor Hassell / Maisha Hutton	HCC	President / Manager
Vinna Royer / Tina Alexander	Dominica Cancer Society	Former President / Director
Yulit Gordon	Jamaica Cancer Society	Executive Director

APPENDIX 2: RESULTS TABLES AND FIGURES

Table 1: Caricom Countries and Territories by Population Size and World Bank Income Group, and Indicating those Chosen for this Study (HCC RSR)

		Population ['000]	Population category	HCC RSR	Sample by population category
Haiti		10,300	>5mill		0/1
Jamaica		2,741	1-5 mil	Yes	
Trinidad & Tobago		1,341		Yes	2/2
Guyana		754	250-999,000		
Suriname		525			
Bahamas		343			
Belize		312		Yes	
Barbados		286		Yes	2/5
Saint Lucia		161	<250,000		
Grenada		108		Yes[1]	
Saint Vincent & Grenadines		104		Yes	
Antigua & Barbuda		87			
Dominica		73		Yes	
*Bermuda		68		Yes	
*Cayman Islands		50		Yes	
Saint Kitts & Nevis		50		Yes	
*Turks & Caicos Islands		43			
*British Virgin Islands		25			
*Anguilla		15			
*Montserrat		5			5/12
TOTAL		17,084			9

World Bank income category: red = low income; orange = low middle income; yellow = high middle income; green = high income.
*UK Overseas Territory
1Only included the National NCD Commission sub-study

Table 2: Summary of the Main Reported Activities of Regional Organisations Against the Headings of the NCD Alliance Benchmarking Tool

Main reported activities		
1. Raise priority of NCDs through international cooperation and advocacy	CARICOM	'Partially operational NCD plan'; supported annual regional meeting of NCD focal points 2010 and 2011; a current priority is to complete STEPS surveys on all members (this through CARPHA).
	CARPHA	Active NCD plan, with goals and targets. No regional communication plan, but this will be a core activity of CARPHA. Current dedicated NCD budget of 300,000USD. Planned to convene a donors meeting
	HCC	Strategic plan includes communication to raise awareness – examples include social media campaigns (e.g. 'get the message' in 2011, and a cervical cancer e-petition) and organisation of regional meetings with CSOs
	PAHO	Has strategic plan, and multiple activities within the region, including NCD focal points meeting in 2011
	UWI	Awareness raising through education programmes, including Masters in Public Health and the Doctorate in Public Health, and through dissemination of relevant research.
2. Strengthen national capacity, multisectoral action and partnerships for NCDs	CARICOM	Has a key role in intergovernmental multi-sectoral action, such as through the CARICOM Regional Organisation for Standards and Quality (CROSQ). In addition to the health desk, other relevant desks include human development, sport, international trade, foreign and community relations.
	CARPHA	Key role is to provide support to countries on Surveillance and on Monitoring & Evaluation.
	HCC	Supports member CSOs in advocacy activities, and in building links with government and the private sector
	PAHO	Has inaugurated an NCD multi-sectoral forum. Only one Regional Meeting so far, in 2012
	UWI	Capacity building through education programmes (as indicated above), and multisectoral action through partnership in projects (including this one)
3. Reduce NCD risk factors and social determinants	CARICOM	Common regional standards have been agreed for the labelling of tobacco products, with support to countries to implement them; food labelling is on the agenda of CROSQ; no regional policies on marketing of foods to children. Support for and promotion of Caribbean Wellness Day
	CARPHA	Plans to address marketing of foods to children in 2014/5 work program. Major advocacy role in reducing exposure to tobacco. Other major plans going forward will arise out of the evaluation of the 2007 Port of Spain Declaration.
	HCC	Through social media campaigns and lobbying and supporting member organisations in their work in this area.
	PAHO	Supports countries in the development and implementation policies to reduce NCD risk, including the implementation of the Framework Convention on Tobacco Control, development of policy on reduction of harmful use of alcohol, implementation of cost-effective interventions and recently development of regulations on marketing to children. Task Force for childhood obesity prevention and control established in HQ and currently a Regional and Sub Regional Road map for combatting childhood obesity is under development.
	UWI	Largely through activities indicated for #1&#2 above.
4. Strengthen and reorient health systems to address NCDs	CARICOM	Role largely delivered through CARPHA. Regional pharmaceutical policy (not specific to NCDs) adopted in 2011. Regional NCD plan 2011 – 2015 acts as a reference for national plans. Revised PHC and Chronic Care policies produced for countries to adapt and adopt.
	CARPHA	Responsible for primary health care treatment guidelines on diabetes, hypertension and asthma. Diabetes and hypertension guidelines are in the process of being updated. No plans for guidelines that include secondary care
	HCC	Through social media campaigns and lobbying and equipping CSO membership with information to guide advocacy in this area.
	PAHO	Technical support provided for integration of Chronic Care Model into primary health care settings and implementation of Quality of Care for patients with chronic diseases particularly diabetes achieved 100% in English Speaking Caribbean countries
	UWI	Through educational activities (as listed in #2) and ad hoc contribution to relevant projects, such as drafting treatment guidelines

13. APPENDICES

Main reported activities		
5. Promote national capacity for research and development on NCDs	CARICOM	Role largely delivered through CARPHA
	CARPHA	A major role of CARPHA, and includes organisation of an annual regional scientific meeting
	HCC	Working in partnership with regional research institutions to ensure community based research approaches including CSOs and disseminating research through wide regional electronic network.
	PAHO	Capacity training provided for NGOs to develop grant proposal for external grant/ funds. Supported the Member States to collaborate with academic institute for research for effective policy development.
	UWI	Through training of personnel, as indicated above
6. Monitor and evaluate progress on NCDs	CARICOM	Role largely delivered through CARPHA
	CARPHA	A major role of CARPHA, includes running training workshops to strengthen M&E activities; planned major contribution to evaluation of the Port of Spain Declaration
	HCC	Support CSOs in advocating to governments to be accountable to NCD commitments; encouraging CSOs engaged in service delivery to feed service delivery data into national data collection systems; and supporting of related initiatives such as development of cancer registries.
	PAHO	Provided tools for monitoring and evaluation for the Member States. Initiated a research project to carry out evaluation for NCD policy in the Caribbean making a case for Caribbean policy dialogue.
	UWI	Through NCD related research undertaken within TMRI, particularly the Epidemiology Research Unit and the Chronic Disease Research Centre. In addition, through specific projects undertaken by staff and graduate students, often in collaboration with others (e.g. CARPHA and HCC) such as auditing quality of care for NCDs and success of NCD policy implementation

Table 3: Major Achievements and Challenges Reported by the Regional Organizations

	Achievements	Challenges
CARICOM		
	• 2007 Port of Spain Declaration on NCDs • The establishment of CARPHA • Agreement on tobacco labelling through COTEDa	• Lack of dedicated funding for NCDs • Low number of staff devoted to health • Region wide coordination of activities
CARPHA		
	• Surveillance – e.g. STEPS surveys • Awareness raising on childhood obesity	• Limited resources • Engaging CARICOM policy mechanisms • Organization of newly formed agency
HCC		
	• Get the message campaign (2011), • Electronic / social media platforms, • Practical expression to 'whole of society approach' • Caribbean Civil Society Cervical Cancer Advocacy Initiative	• Demonstrating value to disease specific CSOs of broader approach • True engagement by policy makers with CSOs at both national and regional levels
PAHO		
	• Supporting the development within countries of NCD policy and multi-sectoral action plans, including the implementation of the FCTC, obesity control, Health Information Systems • Support for development of alcohol policy and implementation of cost-effective intervention on reduction for harmful use of alcohol • Capacity building for NGOs and civil society to combat NCD prevention and control	• Gaps between political commitment and actual implementation • Difficulty in prioritization due to limited resources in country • Natural disasters which change priority and influence on actual implementation
UWI		
	• Established training for public health at Mona and Cave Hill – MPH, DrPH and PhD programmes	• Relatively low capacity compared to training needs • Difficulty of accessing funds for research

[a]Council for Trade and Economic Development.
NB – questions on achievements and challenges not completed for PAHO

13. APPENDICES

Figure 1: Ministry of Health Perceptions of Support from Regional Organisations

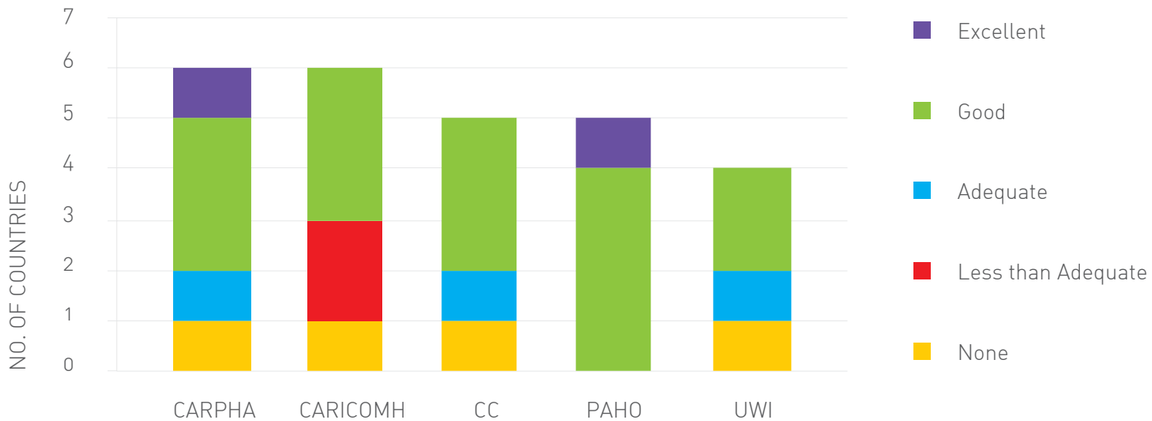

Table 4: Example of Support from Regional Organisations Reported by Ministries of Health

Regional Organisation	Examples of Support from Regional Organisations
CARPHA	Training for the STEPS Survey methodology, Monitoring and Evaluation Training Support through then CFNI for training on National dietary guidelines and development of food and nutrition policy. Development of Young Child Health Records, Trans - Fats in Foods Survey, Anaemia Study, National Food and Nutrition Policy, School Health and Nutrition Policy, Training of district staff on management of obesity, training of Community Health Aids, NCD management Guidelines for clinical care e.g diabetes and hypertension.
CARICOM	COHSOD led meetings Caribbean Wellness Day Support with initiative towards reducing Tobacco use. Providing a road map and plan for a Regional NCD Response Assistance with Capacity Building.
HCC	Cancer advocacy Training on NCDs at regional level Caribbean Wellness Day Support for National representation at meetings and information sharing Text messaging campaigns
PAHO	Technical support, funding of programmes Capacity building, NCD policy and plan development, NCD programme support, CWD, Assistance with Tobacco control Development of a guideline for management of Diabetes and hypertension, STEPS survey funding
UWI	Capacity building, Caribbean Health Leadership Advancing the research agenda with respect to obesity, diabetes and cancer

13. APPENDICES

Table 5: Summary of Reported Progress Against the NCDA Scorecard Sections #1 & #2 - Raise Priority of NCDs, Strengthen National Capacity

Benchmark Indicator		Country / Territory								
		BAR	BEL	BER	CAY	DOM	JAM	SKN	SVG	T&T
1.1	Inclusion of NCDs in current national development plan									
	Presence of National NCD Planning									
1.2	Government inclusion of NCDs in Official Development Assistance (ODA) Framework									
1.3	Operational national NCD alliance/coalition/network of CSOs that engages People Living with NCDs (PLWNCDs)									
1.4	Government -led, supported or endorsed national NCD conference /summit/meeting held in the last 2 years with active participation of CSOs									
1.5	Government-led or endorsed public media campaign on NCD awareness or NCD prevention, partnering with CSOs and held in the last 2 years									
2.1	Operational National NCD Plan (number of key elements outlined below): If score less than 4, please refer to 2.2									
2.1 a)	National NCD Plan with a 'whole of government' approach ie with areas for action beyond the health sector									
2.1 b)	Functional national multisectoral NCD commission/mechanism (incl. CSOs, People Living with NCDs and private sector)									
2.1 c)	National budgetary allocation for NCDs (treatment, prevention + health promotion, surveillance, monitoring/evaluation, human resources)									
2.1 d)	CSOs and PLWNCDSs engaged in National NCD Plan development									
2.2	Number of subnational jurisdictions (state, district, etc.) with an operational NCD plan that meets the full criteria outlined above	Not applicable to these small states								
2.3	Number of operational NCD Public-private partnerships supporting elements of National NCD Plan	Highlighted in CSO contributions provided below								
2.4	National Government partnerships with CSOs on NCD initiatives									

[a]NB All Ministries do of course expend resources on NCD care, this item was interpreted as referring to earmarked or ring fenced funds for NCDs

Key

Red	No or Little Progress
Yellow	Moderate Progress
Green	Good Progress
Grey	Not Assessed
	Not Available

13. APPENDICES

Table 6: Summary of Reported Progress Against the NCDA Scorecard Sections #3 - Reduce NCD Risk Factors and Social Determinants

	Benchmark Indicator	Country / Territory								
		BAR	BEL	BER	CAY	DOM	JAM	SKN	SVG	T&T
3.1	(m)POWER policies/interventions in existence:									
	Existence of recent nationally representative information on youth and adult prevalence of tobacco use[a]	2007	2008			2009	2010	2010	2011	2011
	National Legislation banning smoking in health-care in all indoor public places including workplaces, restaurants and bars[b]									
	Existence of national guidelines for the treatment of tobacco dependence									
	Legislation mandating visible and clear health warnings covering at least half of principal pack areas									
	Legislation banning tobacco advertising, promotion and sponsorship OR Legislation comprehensively banning all forms of direct tobacco marketing in all forms of media and advertising									
	Tobacco taxation policy of between 2/3 and ¾ of retail price									
3.2	National strategies on the major NCD risk factors:									
3.2 a)	Tobacco									
3.2 b)	Alcohol									
3.2 c)	Nutrition									
3.2 d)	Physical Activity									
3.3	Increased taxes on alcohol in last 5 years									
3.4	National policies and regulatory controls on marketing to children of foods high in fats, trans fatty acids, free sugars or salt									
3.5c	National action on salt reduction									
	National policies/regulatory controls on salt reduction									
	Number of voluntary company pledges to salt reduction	3								
3.6	Physical education in schools with resources and incentives									

[a]Global Youth Tobacco Survey, [b]Response supplement with Port of Spain monitoring grid

Key

Red	No or Little Progress
Yellow	Moderate Progress
Green	Good Progress
Grey	Not Assessed
	Not Available

13. APPENDICES

Table 7: Summary of Reported Progress Against the NCDA Scorecard Sections #4 - Strengthen and Re-Orientate Health Systems

	Benchmark Indicator	Country / Territory								
		BAR	BEL	BER	CAY	DOM	JAM	SKN	SVG	T&T
4.1	Evidence based national guidelines on individual NCDs:									
	Cancer									
	Cardiovascular disease									
	Chronic Respiratory Diseases									
	Diabetes									
	Mental Health									
	Tobacco Dependence									
	Alcohol Dependence									
4.2	Government initiatives strengthening the capacity of primary health care for NCDs:									
	NCD health promotion and prevention									
	Screening and early detection									
	Treatment and referral									
	Rehabilitation and palliative care									
4.3	Number of NCD medicines in country essential medicine list made available free of charge to patients with limited resources	16/16	14/16			12/16	16/16	11/16	16/16	
4.4	*NCD-related services and treatments are covered by health insurance system									
4.4 a)	Cancer Screening Services	8/8	4/8	7/8		7/8	6/8	7/8	6/8	
4.4 b)	Diabetes	6/7	2/7	3/7		5/7	4/7	7/7	4/7	
4.4 c)	CVD	6/6	1/6	6/6		6/6	6/6	6/6	5/6	
4.4 d)	Chronic Respiratory Diseases	3/3	1/3	1/3		3/3	1/3	3/3	1/3	
4.4 e)	Related NCD Treatments	4/5	1/5	1/5		3/5	5/5	3/5	2/5	
4.5	Operational NCD Surveillance system:									
	Areas included in national health reporting system									
	Cause-specific mortality related to NCDs									
	Population-based NCD mortality data									
	Population-based morbidity data									

Key

Red	No or Little Progress
Yellow	Moderate Progress
Green	Good Progress
Grey	Not Assessed
	Not Available

*See Table 8a: Lists of World Health Organization NCD Essential Drugs and Services and Table 8b: Additional NCD Services on WHO Essential List

13. APPENDICES

Table 8A: Lists of World Health Organization NCD Essential Drugs and Services

	Essential Medicines List for NCDs	NCD-related services and treatments
Cancer	Tamoxifen Oral morphine	Cervical cytology VIA (Visual Inspection with Acetic acid) Breast cancer screening by palpation Mammogram Prostate cancer screening by digital exam Prostate canc er screening by PSA Faecal occult blood test Colonoscopy
Diabetes	Insulin Metformin Glibenclamide	Blood glucose measurement Oral glucose tolerance test HbA1c test Urine microalbuminuria Dilated fundus examination Foot vibration perception by tuning fork Foot vascular status by doppler
Cardiovascular Diseases	Aspirin (81 or 100 mg) Thiazide Diuretics ACE Inhibitors CC Blockers Beta Blockers Statins	Electrocardiogram Blood pressure measurement Total cholesterol measurement HDL cholesterol measurement LDL cholesterol measurement Triglycerides measurement
Chronic Respiratory Diseases	Salbutamol Prednisolone tab Steroid inhaler Hydrocortisone injection Ipratropium bromide	Peak flow measurement Spirometry Nebulization

Table 8b: Additional NCD Services on WHO Essential List

Related NCD Services	Retinal photocoagulation Renal dialysis Renal transplantation Radiotherapy Chemotherapy

Table 9: Survey Activities Reported as Part of the National Research Agenda

Barbados	Dominica	St Vincent and the Grenadines
1. Alcohol Abuse 2. Salt Intake 3. Child Obesity 4. Diabetic Foot 5. Physical Activity	1. STEPwise approach to surveillance (STEPS) 2. Global Youth Tobacco Survey (GYTS) 3. Obesity 4. Salt in Bread	1. STEPwise approach to surveillance (STEPS)

13. APPENDICES

Table 10: Activities of National Governments According to The CSO Respondents

Indicator		Country / Territory								
		BAR	BEL	BER	CAY	DOM	JAM	SKN	SVG	T&T
4.1: Evidence based national guidelines on individual NCDs										
Utilisation of Guidelines										
	Public Health Facilities									
	Private Health Facilities									
	Civil Service Organisations									
Government oversight of your CSO										
4.4: NCD-related services and treatments are covered by health insurance system (public health system)										
Availability of tests and procedures										
Cancer	Cervical cytology									
	VIA (Visual Inspection with Acetic acid)									
	Breast cancer screening by palpation									
	Mammogram									
	Prostate cancer screening by digital exam									
	Prostate cancer screening by PSA									
	Faecal occult blood test									
	Colonoscopy									
Diabetes	Blood glucose measurement									
	Oral glucose tolerance test									
	HbA1c test									
	Urine microalbuminuria									
	Dilated fundus examination									
	Foot vibration perception by tuning fork									
	Foot vascular status by doppler									
CVD	Electrocardiogram									
	Blood pressure measurement									
	Total cholesterol measurement									
	HDL cholesterol measurement									
	LDL cholesterol measurement									
	Triglycerides measurement									
Chronic Respiratory Conditions	Peak flow measurement									
	Spirometry									
	Nebulization									

Key

Red: Less than Adequate; Yellow: Adequate; Lt Green: Good; Green: Excellent; Not Available

Table 11: Views on Palliative Care

Benchmark Indicator		Country / Territory								
		BAR	BEL	BER	CAY	DOM	JAM	SKN	SVG	T&T
Palliative Care	Availability									
	CSO Provision	no	yes	yes	yes		yes	yes		yes

(See Table 9 for colour code)

13. APPENDICES

Table 12: Types of Activity Reported by CSOs by Country/Territory

Country	Types of Activity	Activities Reported
Barbados	Advocacy	Heart and Stroke Foundation of Barbados (HSFB) participates in tobacco cessation advocacy Asthma and Diabetes Societies lobbied for drugs to be on the formulary.
	Counselling	The HSFB, the Diabetes Groups and the asthma association, as well as church groups provide counselling and referral services.
	Health Promotion	HSFB and other local CSOs hold or participate routinely at community health fairs and Seminars, TV and radio messages
	NCD policy	Contributing to the development Ministry of Health Strategic Plan 2013-2017
	Surveillance	Assists with surveillance through links with Barbados National Registry for CNCD's
Belize	Advocacy	Was threaded throughout all activities. Australian Commission Direct Aid Program funded (AUS DAP) / HCC managed Civil Society Cervical Cancer Prevention Initiative (C4PI) - development of materials and promotion of CCCEP and supporting the development of an HPV National Policy.
	Counselling	BCS provides nutrition consults for children with cancer, counselling, and have a vibrant cancer support group in Belize City.
	Health promotion	Cancer awareness education conducted in the private and public sectors, churches, and select communities.
		Development of a case management system to guide persons to available services in country for diagnosis and treatment in and out of country. BSC also provide the interpretation of results and follow up.
		We participate in established campaigns by the Ministry of Health which includes tobacco control and wellness day activities.
		The Society observes World Cancer Day with an established theme which guides our education campaigns throughout the year. In the month of May, cancer awareness activities are executed for one month.
		AUS DAP HCC National Cancer Health Symposium.
	Research	Belize Cancer Society In collaboration with the Ministry of Health and US counterpart conducted a study on 496 women to determine genotype of HPV
	Treatment	BSC collaborates with Belize Cancer Center in Dangriga which is a private non-profit facility which provides chemotherapy regardless of the ability of persons to pay.
		Belize Cancer Center has located a site in Guatemala who provides Radiation services for an excellent fee, since the service is not available in Belize.
	Counselling	AUS DAP HCC screening of 700+ disadvantaged women in rural communities.
Bermuda	Counselling	Provide cancer patients free access to licensed registered grief and mental health counsellors
	Health promotion	Bermuda Diabetes Association in collaboration with other CSOs and the Ministry of Health produce a calendar with health promotion messages.
		Bermuda Diabetes Association also collaborates with Ministry of Health and other CSOs with the Healthy Schools Programme.
	Research	Bermuda Diabetes Association assisted the Ministry with STEPS NCD risk factor survey
Cayman Islands	Advocacy	Cayman Islands Cancer Society lobbies for Smoking Laws and establishment of Cancer Registry
		Cayman Heart Fund monitors adherence to the Food Standard Policy in schools.
		Cayman Island Cancer Society lobbied to drug companies to lower their price of the quadrivalent HPV vaccine
	Counselling	Provide cancer patients free access to licensed registered grief and mental health counsellor
	Health promotion	Mass Media messages, Free public health fairs and "Lunch and Learn" presentations. Health promotion events in schools, including providing healthy eating brochures for students, to doctors, hospitals, schools and parents. Also holds Health Fairs.
		the Cayman Heart Fund through its Children's Health Task force aim to promote healthy lifestyle in early childhood by educating the parents, care givers and teachers.
		Promote women's heart care through Expos and The 'Red Dress' events.
	NCD policy	Contributed to the development of the National Health Policy and Strategic Plan for the Cayman Islands 2012-2017
	Research	Cayman Islands Cancer society has done some BRCA gene testing
		Cayman Heart Fund assists with research at the St. Matthew's University School of Medicine on heart disease.
	Surveillance	Cayman Island Cancer Society provide salary for National Cancer Registrar
	Training	Provide resources to health care providers for various cancer diagnosis and treatment areas.
		Train smoking cessation facilitators
		Provide CPR/BLS and AED orientations
	Treatment	Cayman Island Cancer Society funded a 4 chair chemo unit as a gift to the public hospital
		Cayman Heart Fund in conjunction with St. Matthew's University, School of Medicine provide free cardiac risk screenings to the public several times per year.
		Cayman Heart Fund assists with funding patients' care overseas.
	Other	Helping schools, hospitals and individuals with financial and other assistance.
		Cayman Island Cancer Society provides medical equipment for home care, wigs for Chemotherapy patients, and prosthetic supplies for women who have had mastectomies.

13. APPENDICES

Country	Types of Activity	Activities Reported
Dominica	Advocacy Health promotion Research Surveillance Training Treatment Other	Various print, audio media, social media including special collaborations with Seventh Day Adventist Church. Annual Cancer Walk used to help erode 'taboo' surrounding being a person affected by cancer. Australian Commission Direct Aid Program funded (AUS DAP) / HCC managed Civil Society Cervical Cancer Prevention Initiative (C4PI) - development of materials and promotion of CCCEP.
		Education sessions, public service announcements/posters serving as cues to action. To increase access, Breast & Prostrate cancer screening clinics are organised in collaboration with Health Districts and Ross University School of Medicine.
		Collaborated with Ross University School of Medicine and the University of Toronto.
		Diabetes Association and Cancer Society collect data on trainings and screenings done
		Foot care trainings; AUS DAP HCC training with MOH of outreach workers for cervical cancer.
		Through collaborations with external tertiary health institutions facilitates access to advanced treatments for Dominica's cancer clients needing such services. Collaboration with Cancer Advisory Board yielded the construction of an Oncology clinic, to be opened in 2014. Cancer Society in collaborated with the Central Medical Stores and a NGO: Espwa Dominique (Dominica's Hope), established a financial partnership (similar to a revolving fund) which allows for the purchase of chemotherapy in bulk which reduces cost and increases clients' access. Collaborating with the Cancer Institute of Guyana to access radiation for breast cancer and cervical cancer patients. AUS DAP HCC vouchers for cervical cancer related treatment.
		Development of Wellness Centre for both the Cancer Society and the Dominica Diabetes Association clients from rural areas to use as "rest - stop" when accessing treatment in urban centre. Youth arm aimed at engaging youth around NCD issues using cultural activities to raise awareness eg. Carnival band.
Jamaica	Advocacy	A member of the Jamaica Coalition for Tobacco Control, JCS lobby for the Government to pass legislation for tobacco free public spaces Tobacco cessation programmes for adults and teenagers. Lobby with Government agency, to have cancer drugs placed under the National Health Fund so as to make them accessible and affordable to all cancer patients. Australian Commission Direct Aid Program funded (AUS DAP) / HCC managed Civil Society Cervical Cancer Prevention Initiative (C4PI) - JCS promotion of CCCEP.

Country	Types of Activity	Activities Reported
Jamaica Con't	Health promotion	The HFJ is very involved in general advocacy in terms of tobacco control issues. As a member of the Jamaica Coalition for Tobacco Control, HFJ worked closely with the Government to pass the Public Health Tobacco Control Regulations. HFJ offer some tobacco cessation counselling for smokers.
		JCS in partnership with the Ministry of Health, the Department of Medicine, the Jamaica Urological Association, offers free public health education to the following: • Faith based institutions • The Ministry of Education • Service Groups • Community groups • Corporate organisations JCS in partnership with the Department of Medicine, UHWI, offers members of the medical fraternity, CME Credits, by staging quarterly medical symposiums. JCS offers cancer screening through its fixed and mobile clinics. Participate in health fairs hosted by government and corporate bodies. Regular contributor to local newspapers, radio and television health programmes. Stage annual breast cancer walk and luncheon, relay for life awareness event. HFJ participate routinely in community health fairs and seminars, and have a regular presence in radio outside broadcasts and health related TV programmes. HFJ has an island wide screening program for heart disease.
	Research	JCS contributes 1% of its gross annual revenue raised from its Relay for Life event to the American Cancer Society to aid in cancer research.
	Counselling	JCS has an established counselling and support network of highly trained counsellors that provide this service free of charge to cancer patients and their families.
	Treatment	JCS has an established cancer treatment fund from which it offers financial support to indigent cancer patients. AUS DAP HCC JCS screening of 500 disadvantaged women in rural communities. HFJ offers services to its patients at reduced cost. The HFJ has hypertension, renal, diabetic, cardiac and nutritional clinics. Services also include echocardiogram and stress treadmill testing.
	NCD Policy	JCS sits on the National Committee for NCD Control and Prevention and has an input in the decision making process. HFJ sits on the National Committee for NCD Control and Prevention and has been part of the team that helped to complete the National Strategic and Action plan for the Prevention and Control Non-Communicable Diseases, approved by Cabinet.

13. APPENDICES

Country	Types of Activity	Activities Reported
St. Kitts and Nevis	Advocacy	Reach for Recovery Breast Cancer Support (RRBCS) lobbied for breast health day to be endorsed by Minister of Health 2013
	Health promotion	RRBCS provides educational sessions in various settings
		Established a breast examination and education centre (The Pink Zone) in October 2012 and 2013
	NCD policy	RRBCS participated in national summit for NCD and national consultation for NCD Policy and Strategic Plan

Table 13: Reported Contributions of Civil Society Organizations to the National NCD Response within the Past 2 Years

Role	BAR		BEL		BER		CAY		DOM		JAM		SKN		SVG		T&T	
Research	✓	X	X	✓	X	✓		✓	✓	✓	✓	✓	X	X	X			X
Advocacy	✓	✓	✓	✓	X	✓		✓	✓	✓	✓	✓	✓	✓	X		✓	X
NCD policy	✓	✓	✓	✓	X	X		✓	X	✓	✓	✓	✓	✓	X		✓	X
Surveillance	X	✓	X	X	X	✓		✓	✓	✓	✓	✓	X	X	X		X	X
Treatment	✓	✓	X	✓	✓	X		✓	✓	✓	✓	✓	✓	✓	✓		✓	X
Counselling	✓	✓	X	✓	✓	✓		✓	✓	✓	✓	✓	✓	X	✓		✓	X
Training	✓	✓	X	✓	✓	X		✓	✓	✓	✓	✓	✓	X	X		✓	X
Health Promotion	✓	✓	X	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	X		✓	X
Other																		

Key

Reported by Government | Reported by CSOs | Not Available

✓ Yes Contribution | X No Contribution

Table 14: Examples of Activities Reported by CSO Respondents as 'Advocacy' (Using Their Own Words)

CSO	Responses to: Please list all of the advocacy related activities of your organization in the past 2 years
Barbados Heart & Stroke Foundation	Salt awareness campaign Red dress initiative to highlight the numbers of women with heart disease Tobacco ban in the workplace and enclosed spaces Whole grain initiative with Purity Bakeries 'Get the message' campaign
Belize Cancer Society	Obtain specialist services for patients within the public health system: access, cost effective care etc. Telephone triage is conducted, case management of diagnosed patients with follow up, ensuring that results are returned to patients in a timely fashion. Cancer Centre facilitates communication with the Oncologist and the treatment center. (NOTE: The Oncologist lives and works in the US and visits every six weeks to see patients). Lobbying for cancer registry leading to the production of a draft cancer control plan. BCS sits on the NCD Commission and participated in meetings to discuss the NCD strategic and action plans.
Bermuda Diabetes Assoc.	Obesity symposium with overseas speakers addressing the obesity epidemic Special event at a public venue with key speakers on the obesity epidemic Round table discussions with Government on the chronic disease problem in Bermuda Making a call for dedicated centre for chronic disease, both management and prevention
Cayman Island Heart Fund	Provided financial assistance for persons to go abroad to receive treatment for heart conditions that could not be done on island. Donated EKG machines, treadmill, ACLS training mannequins & equipment to the local government hospital & their Cardiac Rehab Program. Provide FREE cardiac risk screenings several times per year to the general public. Donated 10 AEDs to government schools in the Cayman Islands. Changed the Food Standard Policy in the government schools to ensure that the cafeterias serve healthy lunches. Provide medical symposia for local medical professionals on island.
Dominica Diabetes Assoc.	The Society approached government to provide a Wellness Centre for both the Cancer Society and the Dominica Diabetes Association. This allows the public access to information and provides a "rest-stop" for clients accessing chemotherapy and other procedures that require them to overnight or to remain in town for the entire day. (Especially those who are from the rural areas). The government did respond positively and provided an annual subvention for the upkeep and maintenance of the building.

13. APPENDICES

CSO	Responses to: Please list all of the advocacy related activities of your organization in the past 2 years
Dominica Diabetes Assoc.	Collaboration with the Cancer Advisory Board yielded the construction of an Oncology clinic, which is in its final stages and should be opened in 2014. It addresses the limited space and discomfort experienced at the Out-patient Clinic where chemotherapy is currently administered. The Society has collaborated with the Central Medical Stores and a NGO; Espwa Dominique (Dominica's Hope), to establish a financial partnership (similar to a revolving fund) which allows for the purchase of chemotherapy in bulk to thus reduce cost and increase accessibility of medication. Screening clinics (Prostate and Breast) have been organised in collaboration with the Health Districts and the Ross University School of Medicine to increased access to these services. Collaborations with external tertiary health institutions have yielded major advances in accessibility of care for Dominica's cancer clients Education sessions have been organised nationally via churches and schools and radio programs. An annual Cancer Care Walk has yielded much support from Dominicans both locally and in the diaspora and this has allowed many more individuals to come forward and identify themselves as cancer survivors or as being affected by cancer...this is still a 'taboo' subject in some domains.
St. Kitts Reach for Recovery Breast Cancer Support	Established a breast examination and education centre (The Pink Zone) in October 2012 and 2013. Developed partnership with corporate sector (Subway, Life Fitness Centre, St Kitts Bottling Co) to support breast cancer awareness and prevention. Obtained endorsement of Minister of Health to declare October 31, 2013 as Breast Health Day nationally.

Table 15: List of Participating National Civil Society Organisations

Civil Society Organisation	Status & Mandate	Month and Year of Foundation	Number of Staff	Main Sources of Funding
Heart and Stroke Foundation of Barbados	Registered not for Profit Reduce the incidence of Heart Disease and Stroke Nationally	05/04/1985	Salaried Full Time 9 Salaried Part Time 4 Volunteer Part Time 1	Fee for Service with Government Fund Raising
Belize Cancer Society	Registered not for profit	08/08/1996	Salaried Full Time 3	Fund Raising Government Subvention Community Donations
Bermuda Bermuda Diabetes Association (BDA)	Registered Charity Raise awareness of diabetes and promote activities to prevent diabetes and delay complications in those with diabetes	02/12/1979	Salaried Full Time 5 Salaried Part Time 2 Volunteer Full Time 5 Volunteer Part Time 2	Funds from BDA Pharmacy Fund Raising
Cayman Islands Cayman Heart Fund	Registered not for profit Alert, reduce and help prevent the incidences of cardiovascular disease	01/31/2008	Salaried Full Time 1 Volunteer Part Time 5	Fund Raising Regional Organisations Corporate & Private Donations Government Subventions International Organisations
Cayman Island Cancer Society	Registered Charity To increase awareness amongst people of cancer, to counsel & support cancer patients & families.	07/06/1995	Salaried Full Time 2 Volunteer Part Time 5	Fund Raising Corporate Grants Private Donation & Bequests

13. APPENDICES

Civil Society Organisation	Status & Mandate	Month and Year of Foundation	Number of Staff	Main Sources of Funding
Dominica: Cancer Society Inc.	Registered not for Profit To be a supportive entity in alleviating the pain associated with cancer and its complications		Salaried Part Time 1	Fund Raising Government Subvention Corporate Donations
Jamaica: Jamaica Cancer Society	Registered not for profit To eliminate cancer as a major public health issue in Jamaica	12/15/1955	Salaried Full Time 15 Volunteer Part Time 30	Fund Raising Clinical Fees Membership Fees Donations & Memorial
Jamaica: Heart Foundation of Jamaica	Registered not for profit The Foundation is involved in prevention programmes for cardiovascular disease	1971	Total Staff 52	Fundraising Donations Clinical fees
Jamaica: Council of Voluntary Social Services	Registered not for profit Build the capacity of members through training, advocacy, networking and joint action	11/01/1940	Volunteer Full Time 3 Volunteer Part Time 350	Fund Raising International Organisations Government Subvention International Organisations
St Kitts and Nevis: Reach for Recovery Breast Cancer Support	Registered not for profit	07/02/2002	Volunteer Part Time 14	Fund Raising Government Subvention Sponsorship & Donation
Trinidad and Tobago: The Trinidad & Tobago Cancer Society	Registered not for profit	05/19/1970	Salaried Full Time 16 Salaried Part Time 8 Volunteer Part Time 20	Fund Raising Government Subvention Corporate Donations

APPENDIX 3: POS MONITORING GRID 2013

NCD Progress Indicator Status / Capacity by Country in Implementing NCD summit Declaration

Updated September 2011; September 2012; September 2013

POS NCD #	NCD Progress Indicator	ANG	ANT	BAH	BAR	BEL	BER	BVI	CAY	DOM	GRE	GUY	HAI	JAM	MON	SKN	STL	SVG	SUR	TRT	TCI
	COMMITMENT																				
1,14	NCD Plan	±	±	✓	✓	±	✓	✓	✓	✓	✓	✓	X	✓	±	✓	✓	±	✓	✓	X
4	NCD budget	X		✓	✓	X	X	X	✓	±	✓	✓	X	X	X	X	✓	X	✓	✓	X
2	NCD Summit convened	X	✓	✓	✓	X	✓	✓	X	✓	✓	✓	X	✓	✓	✓	✓	X	✓	✓	X
2	Multi-sectoral NCD Commission appointed and functional	±	X	✓	✓	±	✓	✓	X	±	✓	✓	X	✓	X	X	✓	X	±	✓	X
	TOBACCO																				
3	FCTC ratified	*	✓	✓	✓	✓	*	*	✓	✓	✓	✓	X	✓	*	✓	✓	✓	✓	✓	*
3	Tobacco taxes >50% sale price	X	X	±	✓	X		X	±	X	✓	✓	X	✓	X	±	✓	X	✓	X	X
3	Smoke Free indoor public places	X	✓	*	✓	±	✓	✓	✓	±	✓	✓	X	✓	X	*	✓	X	✓	✓	X
3	Advertising, promotion & sponsorship bans	X	X	±	✓	X	✓	✓	✓	X	X	±	X	✓	X	X	X	X	✓	✓	X
	NUTRITION																				
7	Multi-sector Food & Nutrition plan implemented	✓	✓	✓	✓	±	X	✓	X	✓	✓	✓	X	✓	✓	✓	X	✓		±	±
7	Trans fat free food supply	X	X	X	X	X	±	X	X	X	X			±	X	X	X	X	X	±	X
7	Policy & standards promoting healthy eating in schools implemented	±	✓	✓	✓	±	✓	X	✓	±	X	±		✓	±	±	X	±	X	±	X
8	Trade agreements utilized to meet national food security & health goals	X	X	X	X	X	X	X	X	X	X	±		X	X	±	X	X	X	✓	X
9	Mandatory labeling of packaged foods for nutrition content	X	X	X	X	X	±	X	±	±	X	±		X	X	X	X	X	±	X	X
	PHYSICAL ACTIVITY																				
6	Mandatory PA in all grades in schools	✓	✓	✓	✓	✓	±	±	✓	✓	X	±		±	X		X	X	X	✓	✓
10	Mandatory provision for PA in new housing developments	X		✓	✓	✓		*	X	X	X	X		X	±		X	X	X	X	X
10	Ongoing, mass Physical Activity or New public PA spaces	X	✓	✓	✓	✓	✓	X	✓	✓	✓	✓		✓	±	✓	✓	✓	✓	✓	X

✓ In place ± In process/partial X Not in place * Not applicable No information Recent update

13. APPENDICES

Updated September 2011; September 2012; September 2013

POS NCD #	NCD Progress Indicator	ANG	ANT	BAH	BAR	BEL	BER	BVI	CAY	DOM	GRE	GUY	HAI	JAM	MON	SKN	STL	SVG	SUR	TRT	TCI
	EDUCATION / PROMOTION																				
12	NCD Communications plan	X	X	±	±	X	✓	*	✓	±	±	✓	X	±	X	X	X	X	±	✓	X
15	CWD multi-sectoral, multi-focal celebrations	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓	✓
10	≥50% of public and private institutions with physical activity and healthy eating programmes	X	X	X	X	X	±	X	±	X		±			X		±	±	X	±	X
12	≥30 days media broadcasts on NCD control/yr (risk factors and treatment)	X	✓	X	✓	X	✓	X	✓	±		✓		✓	X	±		±	✓	✓	X
	SURVEILLANCE																				
11, 13, 14	Surveillance: - STEPS or equivalent survey	X	X	✓	✓	✓	✓	✓	✓	✓	✓	±	X	✓	±	✓	✓	±	±	✓	±
	- Minimum Data Set reporting	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	±	X	✓	±	±	✓	✓	✓	✓	X
	- Global Youth Tobacco Survey	X	✓	✓	✓	✓	X	✓	±	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	X
	- Global School Health Survey	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	X	✓	±	✓	✓	✓	✓	✓	X
	TREATMENT																				
5	Chronic Care Model / NCD treatment protocols in ≥ 50% PHC facilities	X	✓	✓	±	±	±	±	±	X	✓	±	X	✓	±	±	✓	±	±	✓	X
5	QOC CVD or diabetes demonstration project	±	✓	✓	✓	±	±	±	✓	X	✓	✓	±	✓	X	±	✓	X	✓	✓	X

✓ In place ± In process/partial X Not in place * Not applicable No information Recent update

APPENDIX 4: STUDY PROTOCOL

A Regional Status Report on Responses to Non-Communicable Diseases in the Caribbean Community

RATIONALE

Globally, non-communicable diseases are the leading cause of morbidity and mortality, accounting for 36 million deaths per year, that is two out of three deaths, and account for half of all disability worldwide. If no action is taken deaths from NCDs will increase by 17 per cent in the next decade. The NCD epidemic is exacting a heavy and growing toll on the health of populations, economic security, and already overburdened health systems. NCDs affect all areas of human and economic development and threaten progress towards the achievement of the Millennium Development Goals (MDGs). The burden of NCDs is higher in the Caribbean than in other regions of the Americas; and is twice as high as for communicable diseases and injuries combined.

This project, the completion of a Regional Status Report from the perspective of Civil Society, is part of a larger programme of work lead by the NCD Alliance. The programme, entitled 'Strengthening Health Systems, Supporting NCD Action' aims to support and strengthen civil society NCD advocacy efforts in Brazil, South Africa and the Caribbean Community (CARICOM). It is intended that such efforts will raise demand and advocate governments to strengthen health systems through an integrated approach to action on NCDs. As part of this programme, national (regional where appropriate) level research, analysis and dialogue will highlight success stories and good practice that will be applied to promote further investment, and examples exported to support global advocacy and action in other countries. In the Caribbean, the Healthy Caribbean Coalition (HCC), a member of the World Heart Federation (one of four NCD Alliance federations), will deliver the programme's regional and in-country activities. The HCC has a proven expertise and commitment, and will use this project to promote and develop networks of support for action on NCDs.

The Caribbean Community (CARICOM), which is currently made up of 15 member states and 4 associate members, has been a global champion and advocate for action on NCDs. The 2007 CARICOM Port of Spain (POS) Declaration "Uniting to Stop the Epidemic of Chronic Non-communicable Diseases" was a pioneering commitment to action from all the governments. This was followed by CARICOM's championing, along with many countries, civil society organisations and others, of the United Nations (UN) resolution that led to the UN High Level Meeting (HLM) on NCDS in 2011. Plans are currently underway to evaluate, with support from the Canadian International Development Research Centre (IDRC), the impact to date of the Port of Spain Declaration. The results from this evaluation will be used to accelerate and strengthen its implementation. The evaluation is being led by, on behalf of CARICOM and the Pan American Health Organization, the Public Health Group at Cave Hill Campus, University of the West Indies. This group has a strong track record in studying the epidemiology of NCDs and in evaluating interventions, including policies, to prevent and control them. At the invitation of the Healthy Caribbean Coalition, they are collaborating on the work described here.

This Regional Status Report, which fully complements the evaluation of the Port of Spain Declaration, will help to strengthen the role of civil society in advocating for effective policies and programmes to prevent and control NCDs. The Report will evaluate the current status of National and Regional responses to the prevention and control of NCDs. Because of limited capacity due to small size in many Caribbean countries, the supports from regional organisations are particularly important and relevant. This project will identify gaps in national and regional plans and programmes that must be addressed to ensure progress towards the implementation of regionally and globally agreed commitments and achievement of targets. The results from this evaluation will be used to generate 'calls for action' that enhance the role of civil society in promoting actions to prevent and control NCDs.

13. APPENDICES

AIM AND RESEARCH QUESTIONS

Overall Aim

The overall aim of this work is to develop a Regional NCD Status Report that informs a 'Call to Action' to improve the responses by Governments and Civil Society Organisations to Chronic Non-Communicable Diseases in CARICOM member and associate member states

Research Questions

In order to meet the aim, the following research questions will be addressed.

In CARICOM:

1. What is currently known of the health, social, and economic burden of NCDs, including the status of the WHO NCD targets and indicators?
2. What are the current policy responses to NCDs of Governments and Regional Bodies (where applicable) and how do they compare to the indicators in the NCD Alliance Benchmarking Tool and the commitments from the 2007 Port of Spain Declaration?
3. How are Civil Society Organisations currently involved in the regional and national response to NCDs, including service provision, advocacy and contribution to Government policy?
4. What has been the role and contribution of Regional Bodies in the Caribbean in advancing the NCD agenda at a regional level, and in providing support for countries in their NCD response?
5. What actions are required to fill the gaps that exist in the current response to NCDs, and in particular how can the role of Civil Society be enhanced to promote those actions?

METHODS

Geographical Scope

CARICOM is made of up 15 member states and 4 associate members, of which 5 are United Kingdom Overseas Territories (UKOTs). Twelve of the states gained their independence from the United Kingdom between 1962 (Jamaica and Trinidad & Tobago) and 1983 (St Kitts & Nevis), Suriname gained its independence from the Netherlands in 1975, and Haiti from France in 1804. The total population for CARICOM is around 17 million, with Haiti having a population of 10 million, and only Trinidad & Tobago and Jamaica having populations over 1 million.

The work for this project needs to be completed within a few weeks and within a relatively small budget. It is beyond its scope therefore to attempt data collection from all 20 countries and territories. A pragmatic decision was taken therefore to examine the current status of the NCD response in 9 countries/territories. The criteria for choosing the countries and territories are given below.

Choice of Countries/Territories

The following criteria were considered in choosing the countries and territories for this study.

1. The countries/territories should include a range of socio-economic conditions that exist in the CARICOM
2. There should be at least one mainland country
3. The range of population sizes that exist in CARICOM should be covered, from over 1 million in the largest countries to less than 100,000 in the smallest
4. The range of National policy responses to the Port of Spain Declaration on NCDs, from those that have evidence of implementing most of the commitments to those that have implemented the fewest (these data are available from annual monitoring)
5. At least one United Kingdom Overseas Territory
6. Finally, a highly pragmatic consideration, given the time frame, is that members of the study team were able to readily identify at least one individual within the Ministry of Health, and one within Civil Society whom they could approach directly. This consideration meant unfortunately that Haiti, the most populous country, was not included.

The following nine countries/territories have been chosen for this study: Belize, Barbados, Bermuda, Cayman Islands, Dominica, Jamaica, St Kitts and Nevis, St Vincent and the Grenadines, and Trinidad and Tobago.

Choice of Regional Bodies

It was decided to interview a key informant from each of the main Regional Bodies with some responsibility for implementation, or supporting the implementation, of the Port of Spain Declaration. These Bodies (and the key informants) are:

1. CARICOM Secretariat (Dr Cummings, Health Desk)
2. Caribbean Public Health Agency (Dr Hospedales, Executive Director)
3. Pan American Health Organization (Dr Legetic, Regional Advisor for NCDs)
4. Healthy Caribbean Coalition (Prof Hassell, President)
5. Caribbean Cardiac Society (Dr Martin Didier, Council Member)
6. University of the West Indies (Prof Unwin, Dr Samuels, Ms Bishop – members of the study team, Public Health Group, Cave Hill)

DATA COLLECTION AND ANALYSIS

Burden of NCDs

The aim here is not to provide a comprehensive account, but set the background for the rest of the report. Data on the burden of NCDs therefore will be abstracted from readily available data sources. These include:

- The Pan American Health Organization's 'basic indicators' for health in the Americas
- The Pan American Health Organization's Country Profiles from "Health in the Americas 2012"
- Any reports related to NCDs or their risk factors, that include the Caribbean, produced by the Pan American Health Organization and others within the past 5 years
- World Health Organization's (Geneva) country NCD profiles, where these add relevant additional data to that available from PAHO.

13. APPENDICES

From these sources data will be abstracted to provide a narrative description, with summary tables as appropriate, of the following:

- The prevalence of NCD risk factors listed within the 25 indicators agreed to at the World Health Assembly in 2013. Gaps in the available data for these risk factors will be noted.
- The disease burden from cardiovascular diseases, diabetes, cancers and chronic respiratory diseases. The nature of this description will depend upon the available data but ideally would include morbidity measures (such as prevalence and incidence) and mortality.
- The social and economic burden of the above conditions.
- The social determinants of the above risk factors and disease outcomes.

Regional and National responses and the involvement of Civil Society

Data collection to answer research questions 2, 3 and 4 will be via self-completion questionnaire (with follow up by phone if necessary), and review of NCD policy documents.

Questionnaire responses will be sought from at least two participants from each country/territory: one who is able to speak to the Government response to NCDs and the other who is able to speak to the role of Civil Society. It is expected that in all instances the Government participant will be the 'NCD focal point', the person with designated responsibility for NCDs within the Ministry of Health. This person will be identified with the help of the Chief Medical Officer (who in some cases will also be the NCD focal point).

The participant for Civil Society will represent a prominent Civil Society Organisation (CSO) that is known to be actively involved in responding to NCDs, whether in the provision of services, in advocacy or in other ways. This individual will also be expected to give some information on the activities of other CSOs within that country or territory. Suitable individuals will be identified with the help of both the Healthy Caribbean Coalition (through its membership of this study team) and by asking the Chief Medical Officer within each country/territory for their impression of active CSOs. Participants will be approached from Regional Bodies, as described above.

Finally, documents relevant to the national NCD response will be identified in two ways: firstly by asking each of the participants to identify NCD policy documents; and secondly through an internet search to identify documents online.

Data collection

Six complementary questionnaires have been designed and constructed within 'Survey Monkey'. While requesting the same core information, these questionnaires seek the different perspectives of Governments, CSOs (including the Caribbean Cardiac Society), CARICOM, CARPHA, PAHO and the Healthy Caribbean Coalition respectively. An email will be sent to each participant providing the link to the relevant questionnaire. Reminders will be sent by email, with follow up phone calls if necessary. In addition, once the questionnaire has been 'completed', it will be reviewed by the study team, and if there are missing data, or some of the responses to the open questions are unclear, follow up phone calls will be attempted to complete or clarify responses.

Information from the University of the West Indies will be collated by the study team members and there is not the need for a separate questionnaire on Survey Monkey.

The questionnaires have been designed to cover all items within the NCD Alliance Benchmarking Tool and all items relevant to the 2007 Heads of Government Port of Spain Declaration. The questionnaires have drawn heavily on the most recent (2013) World Health Organization questionnaire (www.who.int/chp/ncd_capacity/CCS_2013 Questionnaire) to assess NCD capacity within member states. They have been expanded to inquire about the role of CSOs in the response to NCDs, including service provision, involvement in Government policy formation and/or implementation, awareness raising activities and advocacy. In addition, questions are included on the sources of support for CSOs, including any received from Government. The questionnaire contains open questions that inquire about particular challenges faced in responding to NCDs, lessons learned and examples of success stories. Finally, participants are asked to indicate the adequacy of the support they have received from Regional Bodies, including CARPHA (including CFNI and CAREC), CARICOM, UWI, PAHO, and HCC.

Data collection from policy documents

Available Government and core regional health policy documents, identified by the key informants or by the internet search, will be reviewed to identify 'policy statements' relevant to the prevention and control of NCDs within each country/territory. For the purposes of the status report a 'policy statement' is:

'A written statement made by government of goals, objectives and means in order to create a framework for activity directed at the prevention and control of NCDs'.

Statements will be abstracted based around both the headings of the Port of Spain Declaration, as operationalized in the CARICOM 2011-2015 Strategic Plan on NCDs (available from www.caricom.org) and the Benchmarking Tool of the NCD Alliance.

Given the limited timeframe and resources for this work, the main focus will be on the identification of the most recent national policy documents that incorporate policy statements for the prevention and control of NCDs. Ideally, this would be the most recent 'NCD Strategic Plan' or equivalent, but if such a plan does not exist, then it is likely to be the most recent 'Strategic Health Plan' or equivalent.

Data analysis

The total number of individual participants in this work will be 30 or less (depending on response), divided between Government, CSOs and Regional Bodies. Such numbers do not lend themselves to statistical data analysis, but rather to a descriptive quantitative data analysis. Where appropriate qualitative descriptions, such as examples of good practice, will be given from responses to open questions. The analysis will focus on the following.

The Government response to NCDs within each country

- Data will be presented and organised around the headings of the NCA Alliance Benchmarking Tool
    - Policy statements will be distinguished from reported policy implementation
    - Data will be 'triangulated' by comparing the responses to specific items from the NCD focal point, to those from the CSO key informant, and the extent to which either are corroborated by documentation
- Current strengths and challenges identified by the interviewees in organising a Government response.

The Role of Civil Society Organisations within each country

- A description of the different CSOs in each country/territory involved in responding to NCDs and, where possible, their sources of support
- The roles of different CSOs, noting in particular service provision, providing information/guidance, advocacy, holding government to account, and any role in formulating and implementing Government Policy
- Any differences between the roles of CSOs as reported by the NCD focal point and the CSO key informant will be noted
- Current strengths and challenges identified by the interviewees in the CSO response to NCDs.

13. APPENDICES

The Roles of Other Sectors

- A description of the roles of any other sectors identified by the interviewees, including the private sector, and other sectors of Government – such as education, agriculture, and finance.
- The focus will be on the extent to which they have contributed to meeting commitments within the POS Declaration and indicators in the NCDA Benchmarking tool

The roles of the Regional Bodies

- From the perspectives of the National Governments and Civil Society Organisations – what support have they received from them, did they consider this adequate, and how might they provide more support in the future?
- From the perspectives of the Regional Bodies themselves – have they met relevant commitments from the POS Declaration, and how better might they support National Governments and CSOs?

Gap analysis and preliminary drawing up a 'Call to Action'

The gap analysis for this project will be based on the NCDA Benchmarking Tool. The gap analysis will inform the 'call to action' and will highlight the key strengths and weaknesses in the regional and national NCD responses with a discussion of the successes and challenges and lessons learned. The findings of the gap analysis will be used to develop a series of recommendations or 'calls to action' in the form of a menu of priority NCD advocacy actions with a subset of these reflecting key focus areas for civil society led action. The 'Call to Action' must incorporate the following:

- The main policy, resourcing, service development and implementation "asks" that stem from the assessment of country's progress in NCD control and capacity;
- Analysis of both the regional (Caribbean level) response, and national response. The countries are too small to have subnational (regional/state/municipal) level action points;
- The context of reaching the globally agreed NCD targets for 2025;
- How to improve and increase civil society participation in NCD planning and how civil society can better support policy implementation;
- Articulate follow up to the National Civil Society NCD Status Report.

The 'Call to Action' will be developed through consultation with HCC Directors and the HCC CSO Advocacy Technical Working Group (TWG) prior to the November 22nd meeting. The presentation and ensuing discussion of the draft Regional Status Report at the meeting on November 22nd will also contribute to the 'Call to Action'. The finalisation of the 'Call to Action' is beyond the scope of this project and will be completed by the leadership of the Healthy Caribbean Coalition.

Ethical considerations

Advice was sought from the Chairman (Dr M Campbell) of the Institutional Review Board of the University of the West Indies, Cave Hill, on whether this study required formal ethical approval. He advised that the study did not require ethical approval because all interviewees in the study will participate within their professional capacity. This means that no personal data are being collected only data relevant to each interviewee's professional role on behalf of the organisation they represent.

Even though formal ethical approval was not required, normal good ethical standards in data collection were maintained. Interviewees were informed about how the data they provide will be used, that they are able to withdraw from the study at any time during data collection, and they were asked to indicate their consent to be part the study.

Study team, timeframe and project milestones

As described above, this project is being conducted on behalf of the Healthy Caribbean Coalition (HCC) by Dr Alafia Samuels, Ms Lisa Bishop and Prof Nigel Unwin, of the Public Health Group, Cave Hill Campus, University of the West Indies. In undertaking the project they are working very closely with Prof Trevor Hassell, President HCC, and Ms Maisha Hutton, Manager HCC. These five individuals comprise the 'study team'.

The project began on October 1st 2013. Key milestones and deadlines in this project are given in the table below.

Milestones	Who Responsible	Deadline
Preparation of protocol and questionnaires	All	25th October
Identification of participants	All	25th October
Invitations and questionnaires out to all participants	LB/AS/NU	4th November
Initial collation and analysis of results	LB/AS/NU	14th November
Consideration of initial results, implications for 'Call to Action'	All	15th November
Presentation of draft report to multi-stakeholder meeting	NU	22nd November
Full draft report circulated to study team	NU	23rd December
Feedback on report to NU	LB/AS/TH/MH	9th January
Final report submitted to HCC	NU	15th January

APPENDIX 5:

DECLARATION OF Bridgetown: Faith Based Organisations of Barbados Uniting to Prevent and Control NCDs.

We, the representatives of the Faith Based Organisations (FBOs) of Barbados meeting at Lloyd Erskine Sandiford Centre, Bridgetown, Barbados on 26 February 2014 on the occasion of a FBO non-communicable diseases (NCDs) consultation;

Aware of the scourge of NCDs, and the threat they pose to health and human development in Barbados, the Caribbean and beyond and recognizing that 25% of adult Barbadians have an NCD;

Recalling the first consultation between FBOs and the National Commission for NCDs in 2008, which affirmed the desire of FBOs to commit to tackling the NCDs;

Affirming the Declaration of Port of Spain; Uniting to Stop the Epidemic of NCDs, 2007, in which regional Heads of Government were united in their support for, encouragement of, and commitment to the prevention and control of NCDs and the need to achieve this through a multi-sector action;

Inspired by the principles of religious faith, which mandate the pursuit of a healthy mind in a healthy body;

Fully persuaded that the burden of NCDs can be reduced through education, training, empowerment, creation of an enabling environment by legislation and appropriate policies, and enlisting of our congregations in the science and art of healthy lifestyles;

Declare by acclamation -

- Our full support for initiatives and programs aimed at the prevention, control and better management of NCDs
- Our commitment to establish and further develop Health and Wellness Ministries for the planning and execution of health programs;
- Our commitment to teach the theological and faith based rationale for healthy living so that over and beyond the medical scientific evidence our members will have the motivation which is the foundation for their existence as faith based organizations;
- Our commitment to reach children and youth in our congregations and communities with specially developed age appropriate programs to promote health across the life course to prevent NCDs;
- That we shall develop and implement a variety of programs for educating and training our members in healthy lifestyle practices for prevention of NCDs, to include health lectures, panel discussions, healthy lifestyle workshops, cooking classes, exercise sessions and health fairs, health counselling
- That we will engage in active education of our congregations;
- That we will plan outreach health programs aiming to reach all persons, especially most at risk populations with information on chronic disease prevention and healthy living;
- That we shall strive to promote good nutrition by serving healthy meals at all functions held at our premises;
- That we hereby declare our support to the NCD Commission in its efforts to reduce risk factors associated with chronic diseases and pledge to promote healthy lifestyle activities and further declare to support Caribbean Wellness Day held in September annually and will designate that weekend annually as Health and Temperance OR HEALTHY LIFE STYLE Weekend, for our members in commemoration of this important and decisive consultation;

We resolve to make this Declaration known to the Political leadership in Barbados and other CARICOM countries as we seek to contribute to, and advocate for, multi-sector response to NCDs by FBOs in Barbados and the Caribbean.

APPENDIX 6:

National/Regional NCD Civil Society Benchmarking Tool

INSTRUCTIONS FOR ADVOCATES

- The benchmarking tool provides a core set of indicators intended to allow for comparisons of country/regional capacities and responses. The benchmarking tool intends to be simple and easy to use for civil society advocates. Examples of data sources are listed here (LINK TO DATA SOURCES BELOW).
- Where indicators are looking to quantifiably measure a certain element, you are encouraged to add a footnote to the tool, specifying which indicator the number corresponds to.
- In most cases, indicators seek to be measured according to 'yes/no' or 'present/absent'. The benchmarking tool uses a traffic light color-coding system where for each indicator yes/present corresponds to green and no/absent to red. When a number of indicators are being considered, green corresponds to a positive response on all indicators; yellow to a positive response on half or more of the indicators, and red when there is a positive response for less than half of the indicators.
- You are encouraged to add additional indicators as a way of tailoring the tool to your national circumstances.
- The completion of this benchmarking tool and development of the Nation NCD Civil Society Status Report will indicate the level of progress countries are making on upholding NCD commitments. Based on this, advocacy efforts should focus on strategies that encourage implementation of national or regional NCD commitments and remind governments of their accountability.
- Module 4 provides a set of general indicators to capture a top line view of progress on NCDs and health systems. You may expand areas in this module with indicators that delve further into your country/region capacity for the care of each individual non-communicable disease. For support with this, you and members of your NCD network or alliance are encouraged to reach out to your Federations. The founding NCD Alliance Federations (International Diabetes Federation, the World Heart Federation, the Union for International Cancer Control and the International Union against Tuberculosis and Lung Disease) are involved in ongoing advocacy efforts monitoring progress on these diseases.
- Examples of some disease-specific indicators can be found in the 2013 PAHO country profiles on NCDs (these explore country health services and NCD medicines) and the 2013 PAHO/WHO country profiles on cancer in the Americas; as well as the policy options listed under objective 4 of the WHO Global Action Plan on the Prevention and Control of NCDs (2013-2020).

See following pages for a Sample Benchmarking Tool.

13. APPENDICES

#1: Raise priority of NCDs through international cooperation and advocacy

1.1	Inclusion of NCDs in current National Development Plan	✓
	If yes to 1.1, does the National Development Plan include a goal or target on NCDs?	x
	If no to 1.1, are NCDs included in sub-national/regional development plans?	
	If no to 1.1, are NCDs included in the national health sector plan?	
1.2	(If a high income donor country use this indicator) Inclusion of NCDs in Overseas Development Assistance (If a low/middle income country use this indicator) Government inclusion of NCDs in UN Development Assistance Frameworks (UNDAFs)	✓
1.3	Operational national NCD alliance/coalition/network of CSOs that engages People Living with NCDs (PLWNCDs)	x
1.4	Government led, supported or endorsed national NCD conference /summit/meeting held in the last 2 years with active participation of CSOs	✓
1.5	Government-led or endorsed public media campaign on NCD awareness or NCD prevention, partnering with CSOs and held in the last 2 years	x

2: Strengthen national capacity, multisectoral action and partnerships for NCDs

2.1	Operational National NCD Plan (number of key elements outlined below): If score less than 4, please refer to 2.2	3/4
	National NCD Plan with a 'whole of government' approach ie with areas for action beyond the health sector	✓
	Functional national multisectoral stakeholder NCD commission /mechanism (incl. CSOs, People Living with NCDs and private sector)	x
	National budgetary allocation for NCDs (treatment, prevention + health promotion, surveillance, monitoring/evaluation, human resources)	✓
	CSOs and PLWNCDSs engaged in National NCD Plan development	✓
2.2	Number of subnational jurisdictions (state, district, etc) with an operational NCD plan that meets the full criteria outlined above	2/10
2.3	Number of operational NCD Public-private partnerships supporting elements of National NCD Plan	
2.4	National Government partnerships with CSOs on NCD initiatives	x
	If yes, describe the nature of the partnership and the initiative focus	

3: Reduce NCD risk factors and social determinants

3.1	Number of tobacco (m)POWER policies/interventions in existence:	4/6
	Existence of recent nationally representative information on youth and adult prevalence of tobacco use	✓
	National Legislation banning smoking in health-care and educational facilities and in all indoor public places including workplaces, restaurants and bars	✓
	Existence of national guidelines for the treatment of tobacco dependence	x
	Legislation mandating visible and clear health warnings covering at least half of principal pack areas	✓
	Legislation banning tobacco advertising, promotion and sponsorship OR Legislation comprehensively banning all forms of direct tobacco marketing, covering all forms of media and advertising	✓
	Tobacco taxation policy of between 2/3 and ¾ of retail price	
3.2	National strategies on the major NCD risk factors (out of total listed below)	x
	Tobacco	3/4
	Harmful use of alcohol	✓
	Unhealthy diet	✓
	Physical activity	✓
3.3	Increased taxes on alcohol in last 5 years	x
3.4	National policies and regulatory controls on marketing to children of foods high in fats, trans fatty acids, free sugars or salt	✓
3.5	National action on salt reduction	✓
	National policies/regulatory controls on salt reduction	✓
	Number of voluntary private sector commitments/pledges to salt reduction	2[iii]
3.6	Physical education in schools with resources and incentives	x

13. APPENDICES

4: Strengthen and reorient health systems to address NCDs

4.1	Evidence based national guidelines on individual NCDs (out of total listed below)	1/5
	Cancer – Number of evidence based guidelines for the cancers prioritised in National Cancer Plan	3/3
	Cardiovascular disease	X
	Chronic respiratory diseases	X
	Diabetes	X
	Mental health	X
4.2	Government initiatives strengthening the capacity of primary health care for NCDs :	
	NCD health promotion and prevention (advocates to add own indicators)	
	Screening and early detection (advocates to add own indicators)	
	Treatment and referral (advocates to add own indicators)	
	Rehabilitation and palliative care (advocates to add own indicators)	
4.3	Number of NCD medicines included in the country essential medicines list (EML) made available at low cost to patients with limited resources	
	National EML list updated since last time WHO updated EML? If yes, are NCD medicines included in the update (Annex EML list as resource and highlight NCD meds on the EML)	✓
4.4	NCD-related services and treatments are covered by health insurance system	±[ii]
4.5	Operational NCD Surveillance system (number of elements below):	0/2
	Cause-specific mortality related to NCDs included in national health reporting system	X
	Population-based NCD mortality data and population-based morbidity data included in national health reporting system	X

5: Promote national capacity for research and development on NCDs

5.1	National research agenda for NCDs	X
5.2	Government funding support for national research on NCDs	X
5.3	Number of published articles on NCDs in country in the last 5 years	25[iii]

6: Monitor and evaluate progress on NCDs

6.1	National NCD targets/indicators with monitoring mechanisms in place	✓

EXAMPLES OF DATA SOURCES:

- **Global status report on noncommunicable diseases 2010**. Geneva, World Health Organization, 2011. http://www.who.int/nmh/publications/ncd_report_full_en.pdf
- **Non-communicable diseases country profiles 2011**. Geneva, World Health Organization, 2011. http://whqlibdoc.who.int/publications/2011/9789241502283_eng.pdf
- **Assessing national capacity for the prevention and control of noncommunicable diseases: report of the 2010 global survey.** Geneva, World Health Organization, 2010. http://www.who.int/cancer/publications/national_capacity_prevention_ncds.pdf
- **WHO MPOWER for tobacco control.** http://www.who.int/tobacco/mpower/publications/en/index.html
- **WHO Tobacco Control Country Profiles.** WHO Report on the Global Tobacco Epidemic, Geneva, World Health Organization, 2013.
- http://www.who.int/tobacco/surveillance/policy/country_profile/en/index.html
- **WHO Regional Offices resources. E.g.**
  - PAHO,NCDs: http://www.paho.org/hq/index.php?option=com_content&view=category&layout=blog&id=1199&Itemid=852&lang=en
  - PAHO Country profiles on noncommunicable diseases, 2012 http://www.paho.org/hq/index.php?option=com_docman&task=doc_view&gid=17854&Itemid
  - Cancer in the Americas, Country Profiles 2013, PAHO/WHO http://www.paho.org/hq/index.php?option=com_content&view=category&layout=blog&id=1866&Itemid=3904
  - Strategic Action Plan for the Prevention and Control of NCDs in the Caribbean Community 2011-2015: http://www.caricom.org/jsp/community_organs/health/chronic_non_communicable_diseases/ncds_plan_of_action_2011_2015.pdf
  - WHO AFRO, NCDs: http://www.afro.who.int/en/clusters-a-programmes/dpc/non-communicable-diseases-managementndm/overview.html
- **National government sources/resources. E.g.**
  - Brazil National NCD Plan 2011-2022: http://portalsaude.saude.gov.br/portalsaude/arquivos/pdf/2012/Ago/29/cartilha_ingles_13102011.pdf
  - South Africa Strategic Action Plan for NCDs 2013-2017: http://www.hsrc.ac.za/uploads/pageContent/3893/NCDs%20STRAT%20PLAN%20%20CONTENT%208%20april%20proof.pdf

To determine the total number of published articles on NCDs in your country in the last 5 years, go to http://www.ncbi.nlm.nih.gov/pubmed

Enter the text below in the search box. Replace South Africa from the example below with your country name. As well as the search below for publications on “Non communicable diseases” try replacing “Non communicable diseases” for “chronic diseases” or the acronym “NCDs”

((South Africa[Affiliation]) AND Non communicable diseases) AND (“2008/11/1”[Date - Publication] : “3000”[Date - Publication])

i List public private partnerships
ii Specify why you gave the +/- sign. Eg. NCD treatments and services covered by the health insurance systems cover x, y and z but not 1,2,3.
iii Specify the voluntary commitments
iv This indicator may serve as a proxy measure for research into a country’s own NCD burden, impact and tailored solutions

For more information please contact the HCC at
hcc@healthycaribbean.org or visit our website **www.healthycaribbean.org**