A Civil Society Regional Status Report: Responses to NCDs in the Caribbean Community

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University of the West Indies
Cave Hill
A Huge Thank You to All the Participants

**Civil Society Organisations**
- Barbados Diabetes Foundation
- Belize Cancer Society
- Bermuda Diabetes Association
- Cayman Heart Fund
- Cayman Islands Cancer Society
- Council of Voluntary Social Services
- Dominica Cancer Society Inc.
- Heart & Stroke Foundation of Barbados
- Heart Foundation of Jamaica
- Reach for Recovery Breast Cancer Support
- The Trinidad & Tobago Cancer Society

**Ministry of Health in:**
- Barbados
- Belize
- Bermuda
- Dominica
- Jamaica
- St Kitts and Nevis
- St. Vincent and the Grenadines
- Trinidad and Tobago

**Regional Organisations**
- CARICOM
- CARPHA
- Healthy Caribbean Coalition
- PAHO
- UWI
Background

• **Strengthening Health Systems, Supporting NCD Action** (NCD Alliance)
  • Strengthen civil society advocacy
  • Brazil, South Africa, Caribbean Community (CARICOM)
  • National/Regional Status Reports to inform a call for action

• **CARICOM Regional Status Report**
  • Led by HCC, with Public Health, UWI, Cave Hill
  • Designed to inform a ‘call for action’
  • 2nd October to January 15th 2014
What did we want to find out?

1. National Governments’ policy responses
2. Regional Organisations’ NCD response, including support to individual countries
3. Involvement of Civil Society Organisations
4. Gaps in current response and the implications for call for action and for civil society advocacy
Detailed data collection guided by:

- Policy responses
  - Items from the NCD Alliance benchmarking tool
  - Any additional items related to POS Declaration

- NCD CSOs
  - Range of activities
  - Meaning of ‘advocacy’

- Illustrative examples
  - Achievements
  - Challenges
Major headings of the NCD Alliance benchmarking tool

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

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

# 3: Reduce NCD risk factors and social determinants

# 4: Strengthen and reorient health systems to address NCDs

# 5: Promote national capacity for research and development on NCDs

# 6: Monitor and evaluate progress on NCDs
Choice of study participants

- Regional Organizations
  - CARICOM, CARPHA, HCC, PAHO, UWI

- Choice of countries
  - Purposive sample
  - Capture the breadth of population sizes, economic conditions
  - Personal contacts (given the tight time frame)
    - Government
    - Civil Society Organisations
<table>
<thead>
<tr>
<th>Country</th>
<th>Population ['000]</th>
<th>Population category</th>
<th>HCC RSR</th>
<th>Sample by population category</th>
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<tbody>
<tr>
<td>Haiti</td>
<td>9,993</td>
<td>&gt;5mill</td>
<td></td>
<td>0/1</td>
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<tr>
<td>Jamaica</td>
<td>2,741</td>
<td>1-5 mil</td>
<td>Yes</td>
<td></td>
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<tr>
<td>Trinidad &amp; Tobago</td>
<td>1,341</td>
<td></td>
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<td>2/2</td>
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<td>Guyana</td>
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<td>250-999,000</td>
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<td>Suriname</td>
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<tr>
<td>Bahamas</td>
<td>343</td>
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<td></td>
<td></td>
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<tr>
<td>Belize</td>
<td>312</td>
<td></td>
<td>Yes</td>
<td>2/5</td>
</tr>
<tr>
<td>Barbados</td>
<td>286</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Saint Lucia</td>
<td>161</td>
<td>&lt;250,000</td>
<td></td>
<td></td>
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<tr>
<td>Grenada</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saint Vincent &amp; Grenadines</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Antigua &amp; Barbuda</td>
<td>87</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Dominica</td>
<td>73</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Bermuda</td>
<td>68</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>*Cayman Islands</td>
<td>50</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Saint Kitts &amp; Nevis</td>
<td>50</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>*Turks &amp; Caicos Islands</td>
<td>43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*British Virgin Islands</td>
<td>25</td>
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<td></td>
<td></td>
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<tr>
<td>*Anguilla</td>
<td>15</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>*Montserrat</td>
<td>5</td>
<td></td>
<td></td>
<td>5/12</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>17,084</td>
<td></td>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>

*World Bank income category: red = low income; orange = low middle income; yellow = high middle income; green = high income. *UK Overseas Territory
Data collection

- Self completion questionnaire
  - Survey monkey
  - 31\textsuperscript{st} October to 10\textsuperscript{th} November
  - Follow up phone/Skype interviews as necessary

- Identification and review of policy documents
  - (Not discussed here)
Preliminary Results

Regional Organisations
NCD Response - examples

- CARICOM
  - Regional NCD plan ‘partially operational’, no dedicated budget
  - Key role in multi-sectoral intergovernmental action e.g. CROSQ and food labeling

- CARPHA
  - Specific NCD plan, 300,000 USD Budget
  - Major roles in surveillance and M&E

- Healthy Caribbean Coalition
  - Strategic plan used to seek funds
  - Major roles in coordinating regional civil society responses, including regional social media advocacy campaigns

- PAHO
  - Broad range of technical support to governments
  - NCD multi-sectoral partners forum, met once so far

- UWI
  - Policy relevant research
  - Regional employer, wellness for staff and students
Involvement of Civil Society

- **CARICOM**
  - No CSO representation in governance
  - No established mechanism for CSO consultation
- **CARPHA**
  - Advocating for CSO rep to be on Executive Board
  - CSOs participate in CARPHA scientific meeting
  - No established regional partners forum
- **PAHO**
  - Mechanism for (international) CSOs in relationship with PAHO
  - CSOs regular participants at regional meetings
- **UWI**
  - Contribution to work of regional and national CSOs
Achievements and challenges - examples

- **CARICOM**
  - **A:** CARPHA inauguration, tobacco labelling standard (COTED), regional pharmaceutical policy (COHSOD)
  - **C:** Funding, staffing, coordinating activities

- **CARPHA**
  - **A:** Strengthening surveillance, nutrition policy, raising awareness on childhood obesity
  - **C:** Limited resources, engaging CARICOM policy mechanisms, reorganisation
Achievements and challenges - examples

• HCC
  • A: Get the message campaign (2011), electronic/social media platforms, practical expression to ‘whole of society approach’
  • C: Demonstrating value to disease specific CSOs of broader approach and HCC, true engagement by policy makers with CSOs

• PAHO

• UWI
  • A: Training for Public Health – MPH, DrPH, PhD, policy relevant research, health and wellness
  • C: Sourcing funding for research, relatively low capacity against training/research needs
Preliminary Results

National Responses – Benchmarking Tool and Government Perspectives
# Preliminary Results

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

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<table>
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<tr>
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</tr>
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<tbody>
<tr>
<td><strong>1.1</strong></td>
<td>Inclusion of NCDs in current National Development Plan</td>
<td><strong>Good</strong></td>
</tr>
<tr>
<td></td>
<td>NCDs included in the national health sector plan</td>
<td>6 / 9</td>
</tr>
<tr>
<td><strong>1.3</strong></td>
<td>Government led, supported or endorsed national NCD conference / summit/meeting held in the last 2 years with active participation of CSOs</td>
<td>7 / 9</td>
</tr>
</tbody>
</table>

## #2: Strengthen national capacity, multisectoral action & partnerships for NCDs

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<tbody>
<tr>
<td><strong>2.1</strong></td>
<td>Operational National NCD Plan</td>
<td><strong>Good</strong></td>
</tr>
<tr>
<td></td>
<td>Under development</td>
<td>6 / 9</td>
</tr>
<tr>
<td><strong>2.4</strong></td>
<td>National Government partnerships with CSOs on NCD initiatives</td>
<td>8 / 9</td>
</tr>
</tbody>
</table>

## #3: Reduce NCD risk factors and social determinants

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>3.2</strong></td>
<td>National strategies on the major NCD risk factors (out of total listed below)</td>
<td><strong>Fair</strong></td>
</tr>
<tr>
<td></td>
<td>Tobacco</td>
<td>8 / 9</td>
</tr>
<tr>
<td></td>
<td>Harmful use of alcohol</td>
<td>7 / 9</td>
</tr>
<tr>
<td></td>
<td>Unhealthy diet</td>
<td>8 / 9</td>
</tr>
<tr>
<td></td>
<td>Physical activity</td>
<td>7 / 9</td>
</tr>
<tr>
<td><strong>3.3</strong></td>
<td>Increased taxes on alcohol in last 5 years</td>
<td>3 / 9</td>
</tr>
<tr>
<td><strong>3.4</strong></td>
<td>National policies and regulatory controls on marketing to children of foods high in fats, trans fatty acids, free sugars or salt. (operational)</td>
<td>0 / 9</td>
</tr>
</tbody>
</table>
## Preliminary Results

### # 4: Strengthen and reorient health systems to address NCDs

<table>
<thead>
<tr>
<th></th>
<th>Evidence based national guidelines on individual NCDs (out of total listed below)</th>
<th>Fair</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td><strong>Cancer</strong></td>
<td>1 / 9</td>
</tr>
<tr>
<td></td>
<td><strong>Cardiovascular disease</strong></td>
<td>2 / 9</td>
</tr>
<tr>
<td></td>
<td><strong>Chronic respiratory diseases</strong></td>
<td>3 / 9</td>
</tr>
<tr>
<td></td>
<td><strong>Diabetes</strong></td>
<td>5 / 9</td>
</tr>
<tr>
<td></td>
<td><strong>Mental health</strong></td>
<td>3 / 9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Number of NCD medicines included in the country essential medicines list (EML) made available at low cost to patients with limited resources</th>
<th>Generally 5 of 9 countries were able to provide at free or low cost the 17 NCD medicines identified by WHO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.3</td>
<td><strong>NCD-related services and treatments are covered by health insurance system.</strong> (&gt;90%) of patients with NCDs in your country access the care at either no cost (e.g. through government provision) or a cost they can afford (e.g. through health insurance)</td>
<td>5 / 9</td>
</tr>
</tbody>
</table>
## Preliminary Results

<table>
<thead>
<tr>
<th>#  5: Promote national capacity for research and development on NCDs</th>
<th>Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 National research agenda for NCDs</td>
<td>Included: STEPS Survey, Obesity Study, Salt intake, Risk factors for the diabetic foot</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th># 6: Monitor and evaluate progress on NCDs</th>
<th>Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1 National NCD targets/indicators with monitoring mechanisms in place</td>
<td>9 / 9</td>
</tr>
</tbody>
</table>
Civil Society – Government Perspective

- According to our sample Governments there were four major areas of response where Civil Society Organisations were involved in
  1. Health promotion
  2. Treatment
  3. Counselling
  4. Advocacy

- These did mirror civil society view of their own activities.
Support received from regional organisations

Please rate the level of programme support your Ministry of Health has received from the following:

- CARPHA
- CARICOM
- HCC
- PAHO
- UWI
- Other (Specify)

Level of support:
- Excellent
- Good
- Adequate
- Less than adequate
- None
Success stories

- Majority of Governments which participated identified progress with developing National NCD policies or plans as a major success thus far.

- That these plans have a whole of government and whole of society approach was also highlighted as a success.

- Jamaica’s National Cervical Cancer screening programme had been attributed to being the major factor in reducing there Cervical Cancer Age Standardised Incidence Rates in Kingston and St. Andrew by 31% between the 1993-1997 period to 2003-2007.
Challenges

- Lack of political will to push the agenda beyond planning to implementation.
  - ‘The disconnect between what was signed on to by the political directorate and what is happening at national level.’
  - ‘No funding to support scaling up or implementation’
  - ‘Poorly developed inter-sectoral partnerships’

- Lack of coordination mechanisms at national level.

- Dealing with competing health priorities
  - Mental Health
  - Emerging and Re-emerging infectious diseases.
Preliminary Results

National Responses - Civil Society Perspectives
Characteristics of CSOs in the Study

• The Civil Society Organisations participating in the study were primarily health non-governmental organisations.

• 73% or 8 of these were registered non for profit organisations while 2 were registered charities 1 simply identified as an NGO.

• All were long standing agencies, the youngest being 13 years in existence the oldest having been established in 1955.
CSO Activities Addressing NCDs

- Main Activities of the Regions Civil Society Organisations
  - Health Promotion
  - Advocacy was highlighted – mostly related to raising national awareness about the disease.
- Delivery of Health Services
  - Screening, Treatment, Counselling
- Fund raising to support all other activities.
CSOs and Advocacy

- Main definition of ‘advocacy’ for CSO in the region is the act of ‘brining awareness’ of living conditions of person living with NCDs and those affected by NCDs, their challenges and what changes could improve their lives.

- Advocacy also encompassed
  - Lobbying and campaigning for specific improvements
  - Providing support to governments to further the NCD agenda
  - Providing support for persons living with NCDs
  - Participating in policy development
Challenges

• Most significant challenge all the CSOs were facing was lack financial and human resources. Specifically highlighted need
  1. Funds for training
  2. Funds to carry out ‘sustained’ health communication

• CSOs are also dealing with the complex issues around the loss of income which might occur by reducing success of tobacco and alcohol industries.
Success stories

- Reported the Seventh Day Adventist Church in Barbados has implemented Complete Health Improvement Programme (CHIP).

- Passing of elements related to FCTC
Success stories

• The Dominica Diabetes Associations and the Dominica Cancer Society worked collaboratively to establish a "rest-stop" for patients accessing chemotherapy and other procedures which requires them to overnight or to remain in town for the entire day. This facility is fulfilling a critical need for persons from the rural areas.

• Further partnership, their government in support will be providing an annual subvention for the upkeep and maintenance of the building.
Some conclusions

- Obvious major gaps in current response
  - Food and nutrition
    - Marketing to children
    - Food labelling
  - Alcohol
  - Implementation of evidence based treatment guidelines
  - Affordable NCD care for all

- Coordinated action by/within Regional Organisations needed
  - Food, FCTC, pharmaceuticals, treatment guidelines
  - Caribbean Wellness Day
Implications for a ‘call for action’ for civil society

• **Advocacy**
  • Nationally: fill policy gaps e.g. food, alcohol, evidence based guidelines, access to care
  • Regionally: Strengthened regional cooperation and institutions to support countries

• **Structures for engagement** with National Governments and Regional Organisations e.g.s
  • National CSO forums
  • Representation on NCD commissions
  • Representation on executive bodies of Regional Organisations

• **‘Watch dog’**
  • ‘Stated policy’ becomes ‘implemented policy’
Thank You