HCC Advocacy, Accountability, Conflict of Interest Workshop
February 17-18th, 2017 Antigua

Overview of national, regional and international NCD reporting systems

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NCD reporting systems

NCD surveillance and reporting in order to monitor mortality, morbidity and risk factors

Aim:

• Identify NCD reporting to various stakeholders

• Identify gaps in NCD data collection, collation and analysis;
National NCD reporting
National CMO reports

• In most countries, Chief Medical Officer reports due annually by law.
• Several countries not up to date
RISK FACTOR SURVEYS
### STEPS or equivalent Risk Factor Surveys in CARICOM states

<table>
<thead>
<tr>
<th>Country</th>
<th>Year of Data Collection</th>
<th>Country</th>
<th>Year of Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anguilla</td>
<td>...</td>
<td>Guyana</td>
<td>2017</td>
</tr>
<tr>
<td>Antigua &amp; Barbuda</td>
<td>...</td>
<td>Haiti</td>
<td>...</td>
</tr>
<tr>
<td>Barbados</td>
<td>2007, 2012</td>
<td>Montserrat</td>
<td>...</td>
</tr>
<tr>
<td>Belize</td>
<td>2010</td>
<td>St. Kitts</td>
<td>2008</td>
</tr>
<tr>
<td>Bermuda</td>
<td>2011, 2014</td>
<td>St. Lucia</td>
<td>2012</td>
</tr>
<tr>
<td>British Virgin Islands</td>
<td>2009</td>
<td>St. Vincent &amp; Grenadines</td>
<td>2014</td>
</tr>
<tr>
<td>Cayman Islands</td>
<td>2012</td>
<td>Suriname</td>
<td>2001</td>
</tr>
<tr>
<td>Dominica</td>
<td>2008</td>
<td>Trinidad &amp; Tobago</td>
<td>2011</td>
</tr>
<tr>
<td>Grenada</td>
<td>2009</td>
<td>Turks &amp; Caicos</td>
<td>...</td>
</tr>
</tbody>
</table>
Prevalence (%) of Specified Disease Conditions by Ten Year Age Bands, Jamaica Healthy Lifestyle II 2008

- Diabetes Mellitus
- Hypertension
- High Total Cholesterol
Awareness, treatment and control for diabetes, hypertension and high cholesterol from Jamaica Healthy Lifestyle Survey 2008
Global Youth Tobacco Survey, Global School Health Surveys in CARICOM states

<table>
<thead>
<tr>
<th>Country</th>
<th>Year of Data Collection GSHS/GYTS</th>
<th>Country</th>
<th>Year of Data Collection GSHS/GYTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antigua &amp; Barbuda</td>
<td>2000, 2004, 2009</td>
<td>Haiti</td>
<td>...</td>
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<tr>
<td></td>
<td></td>
<td>Grenadines</td>
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<tr>
<td>Grenada</td>
<td>2000, 2004, 2008, 2009</td>
<td>Turks &amp; Caicos</td>
<td>...</td>
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Caribbean Unity in Health
LOVE THAT BODY
DISEASE SURVEILLANCE
The Barbados National Registry for Chronic Non-communicable Disease (BNR)

Comprises three national surveillance systems

• Stroke (July 2008)
• Heart (AMI) (July 2009)
• Cancer (end 2009)
Surveillance

Providing information for action through ongoing data collection, collation, analysis and dissemination of results

• Passive (case reports, physician notification)
  – simple, cheap, ?unreliable

• Active ("hot pursuit")
  – more timely but uses more resources

On behalf of the Ministry of Health
Potential use of BNR data

Clinical outcome, care/treatment
- Baseline data for assessment of future trend
  - use of diagnostic tools, survival, disability
- Evaluation of interventions
  - new/complex therapies, prevention
- Access to/utilisation of health services
  - private vs public, rehabilitation services
Cancer Surveillance

Passive reporting registries
- Guyana
- Trinidad & Tobago

Hospital-based registers
- Bahamas, Belize, Bermuda, Cayman Islands and Suriname
- Jamaica cancer registry covers only Kingston & St. Andrew, not the whole island, and is based on laboratory reports only
Regional NCD reporting
2007 CARICOM Heads of Government NCD Summit Declaration
POS Evaluation Grid annually 2008 - 2015

<table>
<thead>
<tr>
<th>NCD Progress Indicator</th>
<th>COMMITMENT</th>
<th>TOBACCO</th>
<th>NUTRITION</th>
<th>PHYSICAL ACTIVITY</th>
<th>EDUCATION / PROMOTION</th>
<th>SURVEILLANCE</th>
<th>TREATMENT</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1.14 NCD Plan</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 NCD budget</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 NCD Summit convened</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Multi-sectoral NCD Commission appointed and functional</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
</tr>
<tr>
<td>3 FCTC ratified</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Tobacco taxes &gt;50% sale price</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
</tr>
<tr>
<td>3 Smoke Free indoor public places</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>3 Advertising, promotion &amp; sponsorship bans</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>7 Multi-sector Food &amp; Nutrition plan implemented</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
</tr>
<tr>
<td>7 Trans fat free food supply</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>7 Policy &amp; standards promoting healthy eating in schools implemented</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
<td>±</td>
</tr>
<tr>
<td>8 Trade agreements utilized to meet national food security &amp; health goals</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>9 Mandatory labeling of packaged foods for nutrition content</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>6 Mandatory PA in all grades in schools</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>10 Mandatory provision for PA in new housing developments</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>10 Ongoing, mass Physical Activity or New public PA spaces</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>12 NCD Communications plan</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>15 CWD multi-sectoral, multi-focal celebrations</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>10 ≥50% of public and private institutions with physical activity and healthy eating programmes</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>12 ≥30 days media broadcasts on NCD control/yr (risk factors and treatment)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>11, 13 Surveillance: - STEPS or equivalent survey</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>11, 14 Minimum Data Set reporting</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>11, 14 Global Youth Tobacco Survey</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>11, 14 Global School Health Survey</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>5 Chronic Care Model / NCD treatment protocols in ≥50% PHC facilities</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>5 QOC CVD or diabetes demonstration project</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Legend: √ In place ± In process/partial X Not in place * Not applicable □ No information Changed since last year
The Evaluation of the 2007 CARICOM Port of Spain NCD Summit Declaration
Goal of the formal evaluation

• To evaluate, seven years on,
  – Learn lessons that will support and accelerate its further implementation
  – Inform the attainment of the UNHLM NCD commitments

• April 2014 - March 2016 – research
• April 2016 – March 2017 – dissemination
Research Partners

• UWI
  – Chronic Disease Research Centre
  – Public Health Group, Cave Hill
  – Department of Community Health and Psychiatry, Mona
  – HEU, Centre for Health Economics, St. Augustine
  – Institute of International Relations, St. Augustine

• G8 Research Group, University of Toronto
• Healthy Caribbean Coalition
• Caribbean Public Health Agency
• Pan American Health Organization
• CARICOM
• Canadian International Development Research Centre (funders)
EVIDENCE BRIEFS

The Evaluation of the 2007 CARICOM Heads of Government Port of Spain NCD Summit Declaration
International NCD reporting
21 NCD Reports requested from countries

<table>
<thead>
<tr>
<th>Frequency of Reporting</th>
<th>Reports</th>
<th>Surveys with sampling frame</th>
</tr>
</thead>
</table>
| **Annually**           | 1. POS grid (UWI) – August  
2. Mortality data (CARPHA to PAHO)  
3. CCH 4 (Caribbean Cooperation in Health)  |                                                                                                                                              |
2. WHO FCTC Parties Progress Report – April 2016  
3. WHO global Information system on alcohol and health (GISAH) – Dec 2017  
4. WHO Mental Health Atlas - ? date due  
| **3 yearly**           | 9. WHO Country capacity survey – July 2018  
10. PAHO Risk Factor regulatory capacity monitoring tool – Dec 2018  
14. PAHO - Add CKD treatment, Treated ESRD, Social protection, Strategic fund for drugs, Seatbelts  
15. PAHO Health Analysis Unit – Services & Coverage  |
| **5 yearly**           | 16. WHO Global Information System on Resources for the Prevention and Treatment of Substance Use Disorders every 4 years – 2018  
17. PAHO Coverage of micronutrient supplementation programs - 2020  | 18. STEPS NCD risk surveyor equivalent  
19. GYTS (Global Youth Tobacco Survey), GSHS (Global School Health Survey),  
20. GATS (Global Adult Tobacco Survey)  
or include core GATS key policy questions add to STEPS  
21. Nutritional indicators (anthropometric, anemia, vitamin A, yodo, breastfeeding) – no fixed date  |
NCD reporting requirements

• Multiple (21 and 3 to come) NCD reporting requirements for countries:
  – PAHO/WHO e.g. NCD Global Monitoring Framework from 2011 UNHLM on NCDs;
  – The Sustainable Development Goals;
  – The Caribbean Public Health Agency;
  – The Port of Spain NCD Declaration grid.

• Challenge to respond, especially smallest countries.
Data from Other Sources

• Some data not available or available from non-health agencies.
  – Age, sex, ethnicity stratified census data
  – Police for injuries data
  – Ministries of Trade, Finance, Agriculture for food and taxation data

• Data are not always shared with regional organisations.

• Other UN and international agencies may have relevant data e.g. ECLAC, UNICEF and others.
WHO Global Monitoring of NCDs
Set of 9 voluntary global NCD targets for 2025

- Harmful use of alcohol: 10% reduction
- Physical inactivity: 10% reduction
- Salt/sodium intake: 30% reduction
- Tobacco use: 30% reduction
- Raised blood pressure: 25% reduction
- Premature mortality from NCDs: 25% reduction
- Essential NCD medicines and technologies: 80% coverage
- Drug therapy and counseling: 50% coverage
- Diabetes/obesity: 0% increase

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Global Monitoring Framework

Mortality & Morbidity
- Unconditional probability of dying between ages 30 and 70 years from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases
- Cancer incidence by type of cancer

Risk Factors
- Harmful use of alcohol (3)
- Low fruit and vegetable intake
- Physical inactivity (2)
- Salt intake
- Saturated fat intake
- Tobacco use (2)
- Raised blood glucose/diabetes
- Raised blood pressure
- Overweight and obesity (2)
- Raised total cholesterol

National Systems Response
- Cervical cancer screening
- Drug therapy and counseling
- Essential NCD medicines & technologies
- Hepatitis B vaccine
- Human Papilloma Virus vaccine
- Marketing to children
- Access to palliative care
- Policies to limit saturated fats and virtually eliminate trans fats

Total number of related indicators in brackets

25 Indicators

World Health Organization

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Reporting UN NCD Indicators

• Sources of data for 25 indicators
  – STEPS Risk surveys (8)
  – GYTS, GSHS (3)
  – Special survey (3)
  – Policy review (3)
  – Cancer registry (2)
  – Mortality data (1)
  – No evident source (5)

• CARICOM members data availability:
  – Ranges from 1/25 to 18/25
  – Half the countries can report 12/25 or less
<table>
<thead>
<tr>
<th>MOST DIFFICULT TO REPORT</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Alcohol per capita consumption/yr in males and in females</td>
<td>Production, export and import statistics possible, but tourist consumption will be included. Gender estimates possible from STEPS</td>
</tr>
<tr>
<td>5. Alcohol-related morbidity and mortality in youth and in adults</td>
<td>There is no routine testing for alcohol use</td>
</tr>
<tr>
<td>15. Mean % from saturated fats in males and in females</td>
<td>There is no capacity to estimate saturated fats</td>
</tr>
<tr>
<td>24. Hepatitis B vaccination rates in target populations</td>
<td>There is no defined target population or mechanism to monitor Hep B vaccination</td>
</tr>
<tr>
<td>18. Prop high CVD risk with drugs &amp; counselling</td>
<td>There is no systematic categorization into CVD high risk. There are few electronic records in the private sector</td>
</tr>
<tr>
<td>19. Availability of NCD meds &amp; basic tech in public / private sector</td>
<td>There is limited data from the private sector</td>
</tr>
</tbody>
</table>
Sustainable Development Goal on Health

**GOAL 3**  Ensure healthy lives and promote well-being for all at all ages

**GOAL 8**  Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all
SDG 3

Ensure healthy lives and promote well-being for all at all ages

Target 3.4  By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment, and promote mental health and well-being*

NCDs are highly preventable and can be controlled through public policies and regulations, health services, and setting lifestyles conducive to health

Promoting mental health by reforming services and protecting the human rights of people with mental disorders

Well-being is the complete integration of body, mind, and spirit – the realization of everything we do, think, feel, and believe

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Target 3.5 **Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol***

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Harmful use of alcohol occurs in both non-dependent and dependent individuals. The problem requires population-wide policies and targeted interventions.

Implementing an approach to address the gap between treatment and care of persons affected by these disorders.
Target 3.8 Achieve universal health coverage*, including financial risk protection, access to quality essential health-care services, and access to safe, effective, quality, and affordable essential medicines and vaccines for all

Universal access to health and universal health coverage are the Alma-Ata of the 21st century
Identify gaps in NCD data collection, collation and analysis
<table>
<thead>
<tr>
<th>GAPS</th>
<th>RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unique Identifiers</strong> for citizens, thus the risk of double-counting.</td>
<td>Need regional programme for unique identifiers for each citizen</td>
</tr>
<tr>
<td><strong>Data quality</strong> - Lack of standardized data collections formats across agencies and across countries, e.g. different age-groupings</td>
<td>Regional and national cross-agency standardized data collected formats developed and adapted by countries, Ongoing training in data reconciliation, and data cleaning.</td>
</tr>
<tr>
<td>Data validation across agencies</td>
<td></td>
</tr>
<tr>
<td><strong>Mortality data</strong></td>
<td>Ongoing training in death certificates and coding</td>
</tr>
<tr>
<td>Poor certification by physicians and inappropriate coding of deaths</td>
<td>All causes of death: immediate, underlying and contributory documented to facilitate Multiple cause analysis</td>
</tr>
<tr>
<td>underlying cause of death not being reported</td>
<td></td>
</tr>
</tbody>
</table>
## GAPS

- **Morbidity data** - Few national registries for NCDs – heart attacks, stroke, diabetes, hypertension, cancer, asthma
  - Diabetic and hypertensive registers in PHC facilities are rarely consistent and standardized.
  - Data generated rarely collated or analyzed to monitor the health situation.

- **Census data**
  - Sex and 5-year age-group of census data for calculation and standardization of rates are often not shared by the Statistical Depts.
  - Inter-censal estimates are often not available

## RECOMMENDATIONS

- Define a standardized format for data collection in public and private sector
- Build capacity for standardized data collation and reporting and analysis.
- Strengthen country capacity for cancer surveillance through IARC Caribbean Cancer Registry Hub at CARPHA.

- Build capacity at national statistical offices in the respective countries to share sex and age-group census data and to routinely generate annual population estimates distributed by sex and five-year age-groups.
Proposal: National Data Audits

Our exploration of health inequalities in the Caribbean is just beginning.

Greater access to national data sources is needed to help identify subpopulations vulnerable to NCDs.

National data resources are a vital tool in the fight against NCDs.

National data audits document and organise the data resources owned by governments.

An audit can help governments understand and control what data can be shared, with whom, and for what purpose.
Summary

• Too many, overlapping, demands for reporting being made on countries
• Requesting agencies need to collaborate and rationalise reporting demands
• Need for support and capacity building for countries to make full use of the data collected, e.g. social determinants of risk factors using STEPS data
• Regional organisations should continue to enhance training and capacity building in reporting NCD indicators.

DATA

• Greater collaboration between regional and international organisations on monitoring, (e.g. UNICEF - nutrition surveillance; UN Environment Programme on climate change).
• National data audits and sharing across sectors for UN NCD global monitoring and SDGs should be authorised.