





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

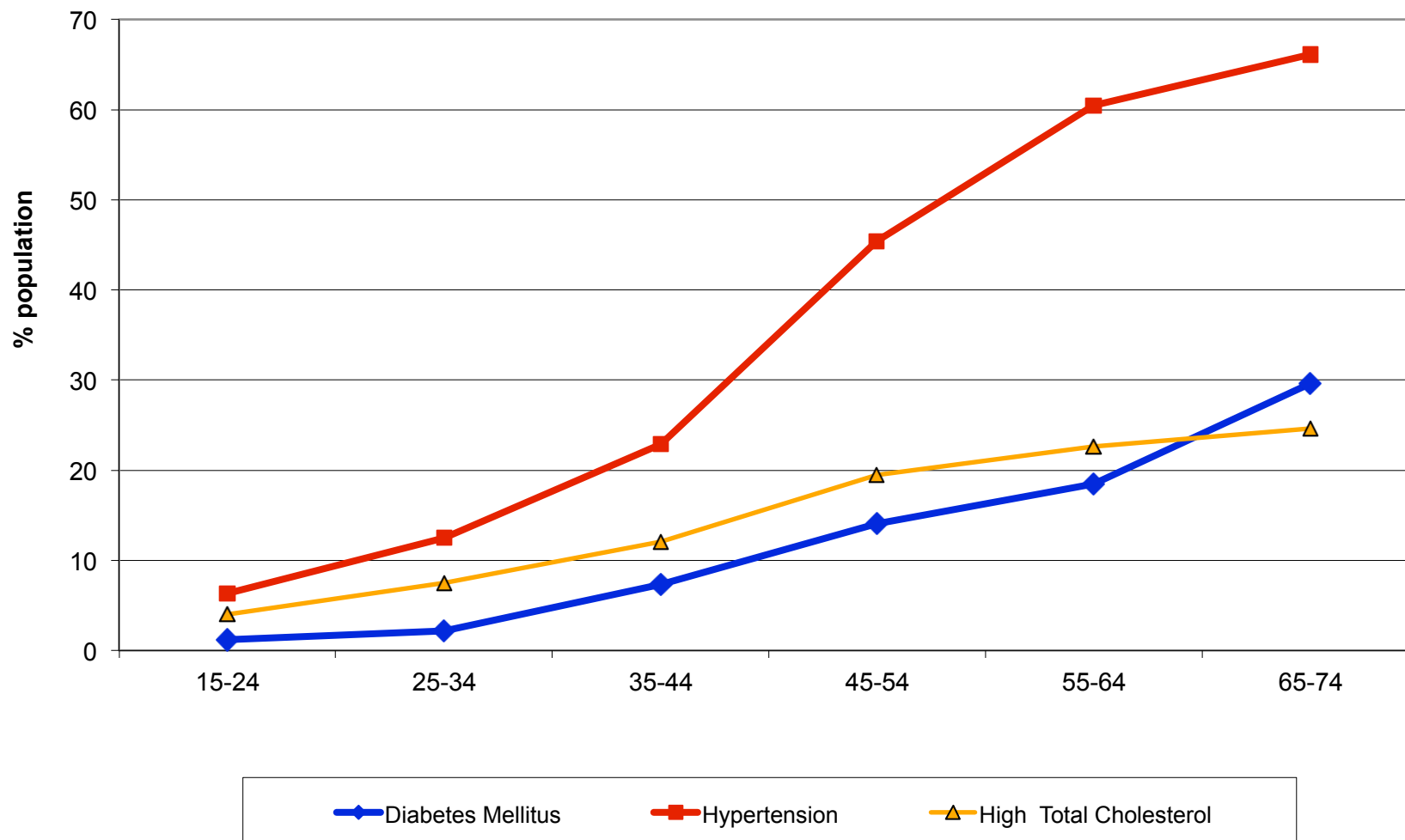
RISK FACTOR SURVEYS



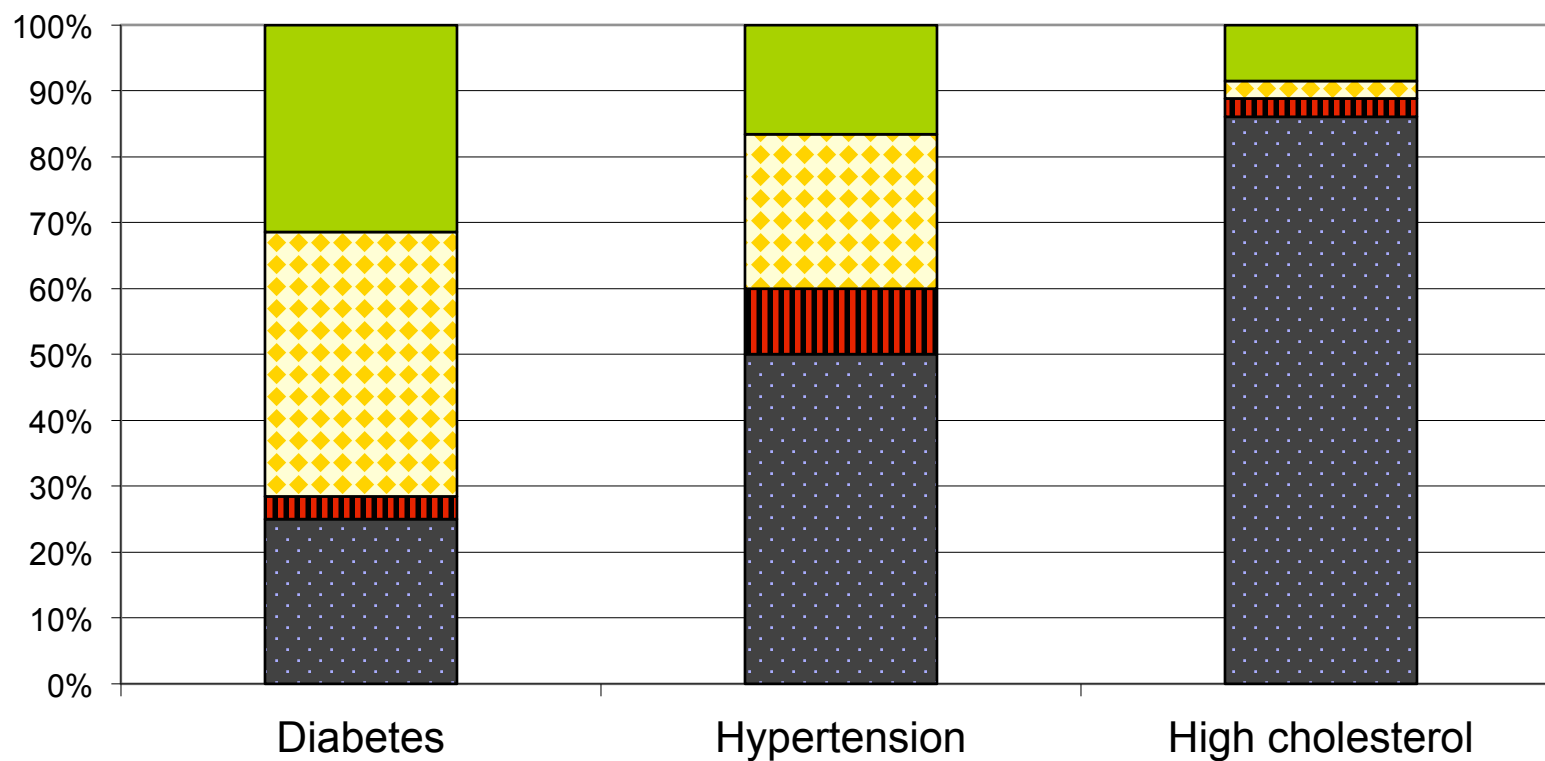
STEPS or equivalent Risk Factor Surveys in CARICOM states

Country	Year of Data Collection		Country	Year of Data Collection
Anguilla	...		Guyana	2017
Antigua & Barbuda	...		Haiti	...
Bahamas	2005, 2011		Jamaica	2000, 2008
Barbados	2007, 2012		Montserrat	...
Belize	2010		St. Kitts	2008
Bermuda	2011, 2014		St. Lucia	2012
British Virgin Islands	2009		St. Vincent & Grenadines	2014
Cayman Islands	2012		Suriname	2001
Dominica	2008		Trinidad & Tobago	2011
Grenada	2009		Turks & Caicos	...

Prevalence (%) of Specified Disease Conditions by Ten Year Age Bands, Jamaica Healthy Lifestyle II 2008



Awareness, treatment and control for diabetes, hypertension and high cholesterol from Jamaica Healthy Lifestyle Survey 2008



■ unaware

■ Aware, not treated

■ Aware, treated, not controlled

■ Aware, treated, controlled

Global Youth Tobacco Survey, Global School Health Surveys in CARICOM states

Country	Year of Data Collection GSHS/GYTS	Country	Year of Data Collection GSHS/GYTS
Anguilla	2009	Guyana	2000, 2004, 2010
Antigua & Barbuda	2000, 2004, 2009	Haiti	...
Bahamas	2000, 2004, 2009, 2013	Jamaica	2000, 2006, 2010
Barbados	2002, 2007, 2011	Montserrat	2000, 2008
Belize	2002, 2008, 2011	St. Kitts	2002, 2010, 2011
Bermuda	2006, 2011, 2012, 2013	St. Lucia	2000, 2007, 2011
British Virgin Islands	2001, 2009	St. Vincent & Grenadines	2002, 2007, 2011
Cayman Islands	2007, 2012	Suriname	2000, 2004, 2009
Dominica	2000, 2004, 2009	Trinidad & Tobago	2000, 2007, 2011
Grenada	2000, 2004, 2008, 2009	Turks & Caicos	...

DISEASE SURVEILLANCE



The Barbados National Registry for 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

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





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2007 CARICOM Heads of Government NCD Summit Declaration



POS Evaluation Grid annually 2008 - 2015

NCD Progress Indicator Status / Capacity by Country in Implementing CARICOM POS NCD
Summit Declaration Updated: September 2014; September 2015

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	±	±	√	√	√	√	√	√	√	√	√	√	√	±	√	√	√	√	√	±
4 NCD budget	X	±	√	√	X	X	X	±	√	√	√	√	√	X	±	√	√	√	√	±
2 NCD Summit convened	X	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	X
2 Multi-sectoral NCD Commission appointed and functional	±	±	√	√	±	√	√	X	±	√	√	X	√	X	±	√	±	±	√	X
TOBACCO																				
3 FCTC ratified	*	√	√	√	√	*	*	√	√	√	√	√	√	√	√	√	√	√	√	*
3 Tobacco taxes >50% sale price	√	X	±	√	X	±	X	√	√	√	√	√	X	X	±	±	X	√	X	±
3 Smoke Free indoor public places	X	√	±	√	±	√	√	√	±	√	√	√	X	√	X	±	±	X	√	±
3 Advertising, promotion & sponsorship bans	X	X	±	X	X	√	√	√	X	X	±	X	±	X	X	±	X	√	√	±
NUTRITION																				
7 Multi-sector Food & Nutrition plan implemented	±	√	√	√	±	±	√	X	√	√	√	X	√	√	±	±	√	X	±	±
7 Trans fat free food supply	X	X	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	±	±
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
PHYSICAL ACTIVITY																				
6 Mandatory PA in all grades in schools	√	√	√	√	√	±	±	√	√	√	±	X	±	X	±	±	X	X	√	√
10 Mandatory provision for PA in new housing developments	X	±	√	√	√	±	±	X	X	X	±	X	±	±	±	±	X	X	X	X
10 Ongoing, mass Physical Activity or New public PA spaces	X	√	√	√	√	±	±	√	√	√	√	X	√	±	±	±	√	√	√	X
EDUCATION / PROMOTION																				
12 NCD Communications plan	X	X	±	√	X	√	√	±	±	√	√	X	±	X	±	X	±	±	√	√
15 CWD multi-sectoral, multi-focal celebrations	√	√	√	√	√	√	√	√	√	√	√	√	±	√	√	√	√	√	√	√
10 ≥50% of public and private institutions with physical activity and healthy eating programmes	±	±	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
- Global School Health Survey	√	√	√	√	√	X	√	√	√	√	√	X	√	±	±	√	√	√	√	X
TREATMENT																				
5 Chronic Care Model / NCD treatment protocols in ≥ 50% PHC facilities	X	√	√	±	±	±	±	±	±	±	±	X	√	±	±	√	±	±	√	X
5 QOC CVD or diabetes demonstration project	±	√	√	√	±	±	±	√	X	√	√	±	√	X	X	√	±	√	√	X
	ANG	ANT	BAH	BAR	BEL	BER	BVI	CAY	DOM	GRE	GUY	HAI	JAM	MON	SKN	STL	SVG	SUR	TRT	TCI



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)

www.onecaribbeanhealth.org



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

Frequency of Reporting	Reports	Surveys with sampling frame
Annually	<ol style="list-style-type: none"> 1. POS grid (UWI) – August 2. Mortality data (CARPHA to PAHO) 3. CCH 4 (Caribbean Cooperation in Health) 	
2 yearly	<ol style="list-style-type: none"> 1. WHO Global Report on the Tobacco Epidemic/monitor implementation of six tobacco control policies/ interventions – Dec 2016 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 5. PAHO Report on Plan of Action for the Prevention of Obesity in Children and Adolescents 	
3 yearly	<ol style="list-style-type: none"> 9. WHO Country capacity survey – July 2018 10. PAHO Risk Factor regulatory capacity monitoring tool – Dec 2018 11. WHO Global Status Report on Road Safety – multi-sectoral – January 2018 12. PAHO/WHO Global Monitoring Framework (GMF) - May 	<ol style="list-style-type: none"> 13. Nutrition Survey 14. PAHO - Add CKD treatment, Treated ESRD, Social protection, Strategic fund for drugs, Seatbelts 15. PAHO Health Analysis Unit – Services & Coverage
5 yearly	<ol style="list-style-type: none"> 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 	<ol style="list-style-type: none"> 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

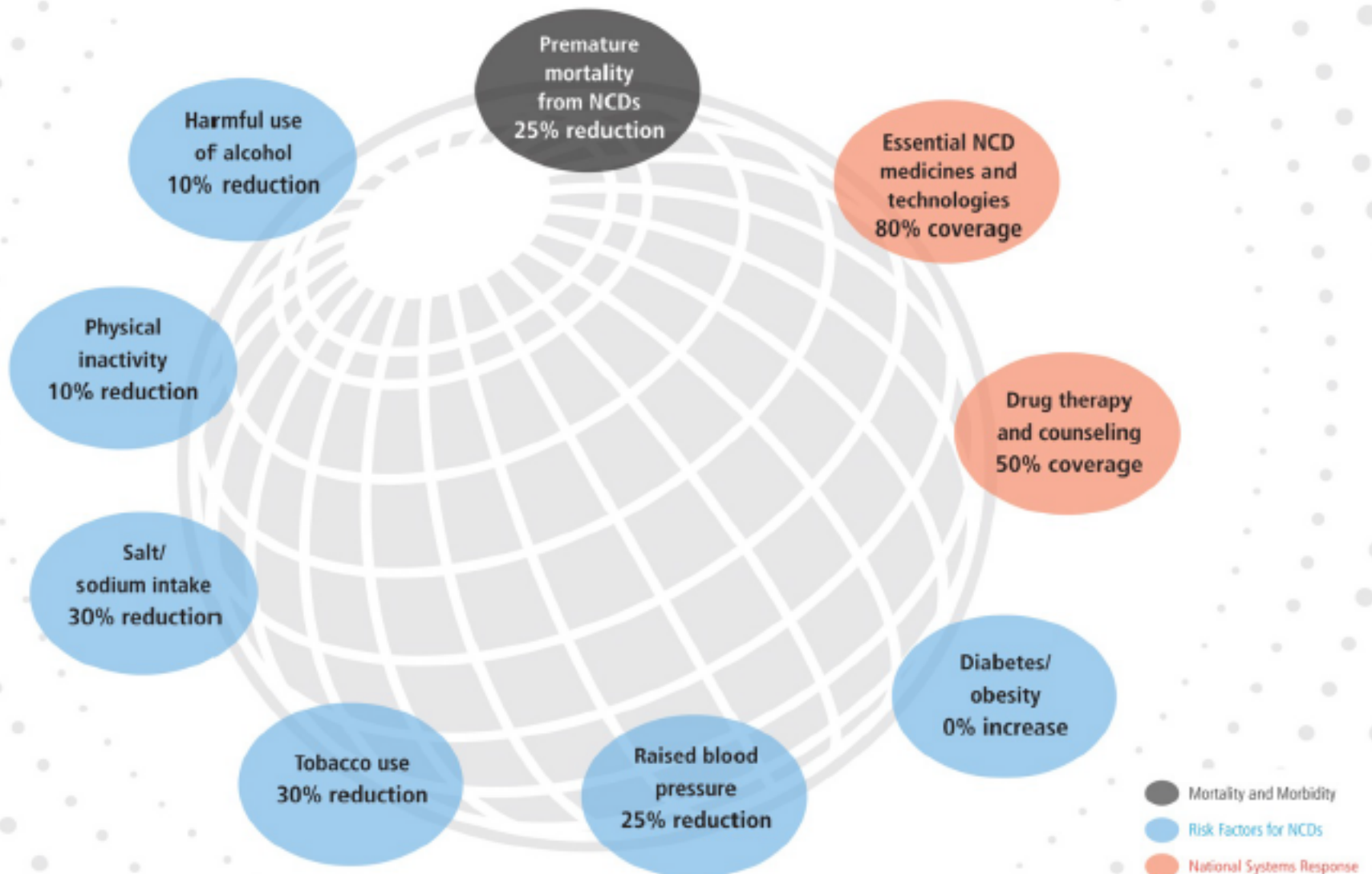
- Some data not available or available from non-health agencies.
 - Age, sex, ethnicity stratified census data
 - Police for injuries data
 - Ministries of Trade, Finance, Agriculture for food and taxation data
- Data are not always shared with regional organisations.
- Other UN and international agencies may have relevant data e.g. ECLAC, UNICEF and others.



WHO Global Monitoring of NCDs



Set of 9 voluntary global NCD targets for 2025



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

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



MOST DIFFICULT TO REPORT	COMMENTS
3. Alcohol per capita consumption/yr in males and in females	Production, export and import statistics possible, but tourist consumption will be included. Gender estimates possible from STEPS
5. Alcohol-related morbidity and mortality in youth and in adults	There is no routine testing for alcohol use
15. Mean % from saturated fats in males and in females	There is no capacity to estimate saturated fats
24. Hepatitis B vaccination rates in target populations	There is no defined target population or mechanism to monitor Hep B vaccination
18. Prop high CVD risk with drugs & counselling	There is no systematic categorization into CVD high risk. There are few electronic records in the private sector
19. Availability of NCD meds & basic tech in public / private sector	There is limited data from the private sector

Sustainable Development Goal on Health

GOAL3 Ensure healthy lives and promote well-being for all at all ages

GOAL8 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*

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



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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



GAPS	RECOMMENDATIONS
Unique Identifiers for citizens, thus the risk of double-counting.	Need regional programme for unique identifiers for each citizen
Data quality - Lack of standardized data collections formats across agencies and across countries, e.g. different age-groupings Data validation across agencies	Regional and national cross-agency standardized data collected formats developed and adapted by countries, Ongoing training in data reconciliation, and data cleaning.
Mortality data Poor certification by physicians and inappropriate coding of deaths underlying cause of death not being reported	Ongoing training in death certificates and coding All causes of death: immediate, underlying and contributory documented to facilitate Multiple cause analysis

GAPS	RECOMMENDATIONS
<p>Morbidity data - Few national registries for NCDs – heart attacks, stroke, diabetes, hypertension, cancer, asthma</p> <p>Diabetic and hypertensive registers in PHC facilities are rarely consistent and standardized.</p> <p>Data generated rarely collated or analyzed to monitor the health situation.</p>	<p>Define a standardized format for data collection in public and private sector</p> <p>Build capacity for standardized data collation and reporting and analysis.</p> <p>Strengthen country capacity for cancer surveillance through IARC Caribbean Cancer Registry Hub at CARPHA.</p>
<p>Census data</p> <p>Sex and 5-year age-group of census data for calculation and standardization of rates are often not shared by the Statistical Depts.</p> <p>Inter-censal estimates are often not available</p>	<p>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.</p>

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.

