CAPACITY AND INFORMATION NEEDS ASSESSMENT

OF HEALTHY CARIBBEAN COALITION CIVIL SOCIETY ORGANISATION MEMBERS WORKING IN THE PREVENTION AND CONTROL OF NON-COMMUNICABLE DISEASES

HEALTHY CARIBBEAN COALITION

NCD Alliance

Medtronic FOUNDATION

UK HEALTH PREVENTION FIRST FORUM

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Capacity and Information Needs Assessment of HCC Member CSOs Working in the Prevention and Control of NCDs

Part I

Capacity Assessment of HCC Member CSOs Working in the Prevention and Control of NCDs

Part II

Information Needs Assessment of HCC Member CSOs Working in the Prevention and Control of NCDs

July 2016

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FOREWORD

The HCC is pleased to make available this "Report of a Capacity and Information Needs Assessment of Healthy Caribbean Coalition Civil Society Organisation Members Working in the Prevention and Control of Non-communicable Diseases" which is provided in two parts. Part 1 of the Report was produced by Dr. Beverley Barnett, Public Health Consultant, and Part 2 by Ms. Emma Hughes, Senior Information Officer at the UK Health Forum. The Report is based on an analysis of a comprehensive and detailed online survey of member organisations of the Healthy Caribbean Coalition (HCC) followed by a workshop of members of the HCC at which the draft survey findings were discussed.

The Report provides a detailed assessment of the capacity needs of HCC CSO members working in health with a focus on NCDs, and highlights areas for capacity development, collaboration, and resource mobilisation. Capacity building of health and non-health member organisations of the HCC is a cross cutting strategic priority area as we seek to strengthen member organisations. Part 2 of the report identifies the public health NCD information needs and priorities of civil society organisations in the Caribbean.

The HCC will use the findings of the Report and our understanding of the regional needs to: build capacity among the Caribbean civil society organisations based on identified capacity and information needs making them fit for purpose and better positioned to contribute to the multisectoral approach to NCD prevention and control; strengthen CSO health information systems to inform better decision making around service delivery and advocacy efforts; create tools to enable CSOs to better play the role of watchdog - holding governments and other stakeholder accountable to NCD-related commitments; support enhanced timely and comprehensive communication in which information and best practices are shared between member organisations of the region, and experiences and major NCD developments globally made available to NGOs of the region; and develop strategies to address the growing sustainability challenges experienced by CSOs across the region.

The Report is intended primarily for the HCC and its members but is of value in informing wider stakeholders of the needs of civil society organisations in the Caribbean as they seek to contribute to prevention and control of NCDs. The lessons learned and recommendations emerging from this report will inform our HCC 2017-2021 Strategic Plan to ensure that the strategic framework guiding HCC's activities over

the next four years is aligned with the priorities of our member organisations. Working together, leveraging our unique strengths as civil society and drawing on the competencies of our public and private sector partners, collectively we will develop solutions to enable more effective communication, networking, collaboration, monitoring, service delivery, advocacy and resource mobilisation.

As the HCC, within the next 2 years celebrates its 10 year anniversary, the Report will be a tool for use by the organisation's health and non-health civil society members to assist CARICOM countries in contributing to the attainment of the national and regional NCD targets as well as WHO NCD Global Targets and the Sustainable development Goals.
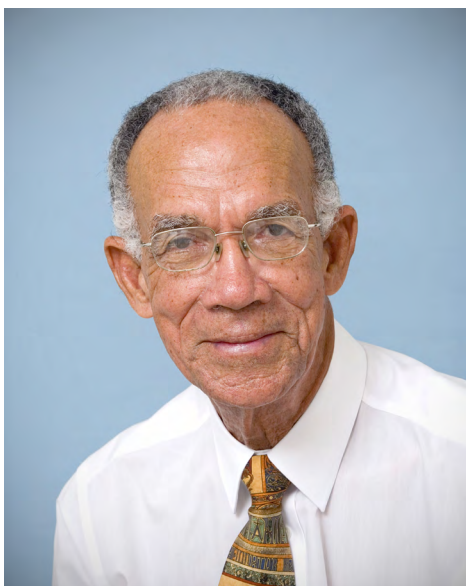
Sir Trevor Hassell
HCC President

Maisha Hutton
HCC Executive Director

ACKNOWLEDGEMENTS

The Healthy Caribbean Coalition (HCC) expresses its gratitude to all HCC civil society organisation (CSO) members working in the prevention and control of non-communicable diseases for their participation in this assessment. The time and effort that the CSO respondents spent in completing the electronic survey, despite its length and technical difficulties, are much appreciated. The Coalition also appreciates the CSOs' feedback on the draft of this report, which facilitated its finalization.

Thanks must also be given to the NCD Alliance, Medtronic Philanthropy, and the United Kingdom Health Forum (UKHF), for their financial contributions in support of the assessment; HCC also thanks Ms. Emma Hughes and Ms. Helena Korjonen of the UKHF for their technical contributions.

The UK Health Forum[1] is a charitable alliance of professional and public interest organisations working to reduce the risk of avoidable non-communicable diseases by developing evidence-based public health policy and supporting its implementation through advocacy, modelling and information provision.

The Research and Information Services team at the UK Health Forum UKHF facilitates and researches the exchange and dissemination of information to all in the non-communicable disease (NCD) prevention area to support the UKHF vision of a healthy society

Finally, HCC acknowledges the contributions and hard work of its Board of Directors; the President, Sir Trevor Hassell; Executive Director, Mrs. Maisha Hutton; Information Technology Officer, Mr. Ian Pitts, and Public Health Consultant, Dr. D. Beverley Barnett, in the conceptualization, implementation, and reporting of the assessment.

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[1] More about the UK Health Forum can be found on their website http://www.ukhealthforum.org.uk/

LIST OF ACRONYMS

ATG	Antigua and Barbuda		MDGs	Millennium Development Goals
BHS	The Bahamas			
BoD	Board of Directors		MoH	Ministry of Health
BRB	Barbados		M&E	Monitoring and evaluation
BLZ	Belize		NCD	Non-communicable diseases
BMU	Bermuda		NCDA	NCD Alliance
CARICOM	Caribbean Community		NGO	Non-governmental Organisation
CARPHA	Caribbean Public Health Agency		NHPSP	National health policy, strategy or plan
CCH	Caribbean Cooperation in Health		ODA	Official Development Assistance
CoI	Conflict of interest			
CoPS	Communities of Practice		PAHO	Pan American Health Organization
CSO	Civil Society Organisation			
CYM	Cayman Islands		POSD	Port of Spain Declaration
DMA	Dominica		S&RH	Sexual and reproductive health
FB	Facebook			
GRD	Grenada		SDoH	Social determinants of health
GUY	Guyana		SM	Survey Monkey
HCC	Healthy Caribbean Coalition		SXM	Sint Maarten
HINARI	HINARI Access to Research for Health Program		SUR	Suriname
			SDGs	Sustainable Development Goals
HPV	Human Papilloma Virus			
HR	Human resources		TTO	Trinidad and Tobago
HTI	Haiti		UKHF	United Kingdom Health Forum
IDF	International Diabetes Federation			
			UN	United Nations
INA	Information Needs Assessment		UNESCOUN	Educational, Scientific, and Cultural Organisation
JAM	Jamaica		UVI	Ultra-violet Index (radiation)
LCA	Saint Lucia		UWI	University of the West Indies
LGBT	Lesbian, Gay, Bisexual and Transgender		WHA	World Health Assembly
			WHO	World Health Organisation

Part I

Capacity Assessment of HCC Member CSOs Working in the Prevention and Control of NCDs

Dr. D. Beverley Barnett

1. LIST OF CHARTS AND TABLES

2. EXECUTIVE SUMMARY

Background

Non-communicable diseases (NCDs) are the major causes of death and illness in the Caribbean, as in many other regions of the world. Actions in non-health sectors, including – but not limited to – trade, education, agriculture, and social services, have significant influence on NCDs and their major risk factors of tobacco use, harmful use of alcohol, unhealthy diet, and physical inactivity. The importance of partnerships that include health and non-health sectors, civil society, and the private sector in addressing the social determinants of health is increasingly recognised, and a multisectoral, health-in-all-policies approach to NCD prevention and control is essential.

The Healthy Caribbean Coalition (HCC) was established in 2008 to harness the civil society response and contribution to NCD prevention and control in the Caribbean, and is the only umbrella organisation for civil society organisations (CSOs) doing such work. In March and April 2016, the HCC conducted an online capacity and information needs assessment among 48 of its CSO members active in NCD prevention and control. The final response rate was 79%, based on 38 completed responses.

The survey, supported by the NCD Alliance, Medtronic Philanthropy, and the United Kingdom Health Forum, obtained demographic, organisational, and contextual information about the CSOs, as well as the strategic frameworks that guide their actions, their governance, services offered, management capacity and structure, funding, and patient engagement. Their successes, challenges, partnerships, and areas for development – including information and communication – were explored, as were issues related to their collaboration with HCC. The findings of the assessment will inform the development of the HCC Strategic Plan 2017-2021.

This report - Part I of the capacity and information needs assessment - details the findings of the capacity assessment; Part II of the report provides the results of the information needs assessment.

Key Findings

CSOs prioritize advocacy, health education, and services; policy development and "watchdog" function lagging
Major CSO functions involve advocacy, communication, and service delivery. Though CSOs use email and social media – mainly Facebook – to communicate with their constituents, they continue to use more traditional electronic media, such radio and television; the need to pay for electronic media use is an important consideration for effective communication by CSOs that are often resource-constrained. Less than half of the CSOs indicated their involvement in policy development and monitoring the NCD-related commitments of governments, and less than a fifth monitored industries with conflicts of interest.

Overall satisfactory governance and internal accountability mechanisms
The CSOs' size and complexity varies, but most have satisfactory governance arrangements through Boards of Directors, and accountability mechanisms through the production of reports.

Patient engagement limited in the governance of CSOs
However, their constituents, including patients, often do not participate in decision-making.

Strategic planning integrates national NCD plans and policies more than international frameworks
Strategic and operational plans – where they exist – take into consideration national health policies, strategies, and plans. However, many do not consider international NCD agreements and frameworks to a significant degree.

CSOs addressing mental health and neurological disorders significantly underrepresented
The survey showed the expected focus on specific NCDs, such as diabetes, cardiovascular disease, and cancer, in line with the main NCD causes of death in the CSOs' countries of location. Relatively few CSOs address issues related to mental health and neurological disorders, which, though causing fewer deaths, are responsible for significant illness and

loss of productivity in the region.

Some vulnerable populations insufficiently targeted by CSOs
The main target for CSO actions is the general public. Though the majority of CSOs state that they target or work with vulnerable groups, these groups are mainly those with limited access to services due to low socio-economic status. Fewer CSOs specifically target groups such as women, children, indigenous people, and people of non-heterosexual orientation.

Resource mobilisation ongoing challenge for sustainability
CSOs indicate resource gaps - financial and human – and request assistance in resource mobilisation and capacity strengthening regarding their traditional functions.

Keen awareness of possible conflict of interest
Despite their funding challenges, no CSOs indicate acceptance of funds from the tobacco industry, and all are aware of conflict of interest (CoI) and ethical issues in their dealings with the private sector, even if they do not have a written CoI policy or Code of Ethics. Some CSOs that are affiliated with international bodies use the relevant policies and code of those bodies to guide their actions.

Coalition building for information- and resource-sharing a priority
A major theme in the findings is the CSOs' need for greater information-sharing and collaboration among themselves – many request that more conferences be held, and that their successes and stories be shared. They indicate the need for capacity strengthening in public education/campaign planning; communication and social media; strategic alliances and partnerships; advocacy; and resource mobilisation, among other areas.

Conclusion
Despite their challenges, the dedication and commitment of the CSOs involved in the survey is evident and they are able to identify successes regarding their institutional development, service provision, partnerships, capacity development, and resource mobilisation, and in their advocacy, health promotion and communication for health. Some have been recognised nationally and internationally. Notwithstanding, the

recommendations for CSOs address, among other issues, improvements in their strategic planning, including the development and use of a monitoring and evaluation framework; development and implementation of a communications strategy; ensuring that service provision reflects advances in clinical care; greater involvement of patients/clients in governance structures; and greater outreach to vulnerable groups.

The CSOs assessed HCC's performance in the Coalition's main strategic areas of advocacy, communication, capacity building, and mHealth/eHealth. Advocacy and communication are favourably rated; capacity building less so; and mHealth/eHealth received the least favourable rating. CSOs made several suggestions for HCC's primary areas of focus, among them advocacy, policy development, building partnerships, and capacity development, resource mobilisation and international representation. Recommendations for HCC point to its role as broker, facilitator, convenor, and monitor, rather than implementer, with focus on advocacy, communication, collaboration with international agencies, contribution to knowledge- and information-sharing among CSOs, capacity building, and sustainability.

Through partnerships among themselves and with governments, other members of civil society, and international agencies – including the UN, particularly in the context of the Sustainable Development Goals and other international frameworks for health and development – HCC and its CSO members can contribute significantly to NCD prevention and control in the Caribbean.

3. INTRODUCTION

In February 2016, the Healthy Caribbean Coalition (HCC)[2], a registered, not-for-profit Caribbean regional network and alliance undertook a detailed capacity and information needs assessment of its civil society organisation (CSO)[3] members working in the prevention and control of non-communicable diseases (NCDs). The HCC is based in Bridgetown, Barbados, and its membership comprises more than 60 Caribbean-based health non-governmental organisations (NGOs), over 65 non-health, non-governmental organisations (NGOs), and in excess of 350 individual members in the Caribbean and across the globe.

The Coalition's objectives are driven by the four strategic priority areas in its 2012-2016 Strategic Plan. The objectives are to:

- Contribute to and participate in all aspects of **advocacy** as a tool for influencing positive change around NCDs through the mobilisation of Caribbean people and the creation of a mass movement aimed at responding to the NCDs.
- Develop effective methods of **communication** for and among members of the Coalition and the people of the Region.
- Build **capacity** among health NGOs and civil society in the Region.
- Contribute to NCD public education campaigns and programmes using novel approaches including **mHealth and eHealth**.

The organisation has not undertaken a formal and structured assessment of its membership until now. Supported by a grant from the NCD Alliance (NCDA)[4]/Medtronic Philanthropy[5] for the capacity assessment and a grant from the United Kingdom Health Forum (UKHF)[6] for the information needs assessment, the HCC developed and disseminated an electronic survey to its CSO members working exclusively on NCDs.

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2   For more information on the HCC, visit http://healthycaribbean.org/

3   For the purposes of this assessment, the World Health Organisation's (WHO's) definition of civil society organisation is used: "Civil society is seen as a social sphere separate from both the state and the market. The increasingly accepted understanding of the term civil society organisations is that of non-state, not-for-profit, voluntary organisations formed by people in that social sphere". WHO. Available at http://www.who.int/trade/glossary/story006/en/, accessed 18 February 2016.

4   The mission of the NCD Alliance is to combat the NCD epidemic by putting health at the centre of all policies. Founded in 2009, we are a unique civil society network uniting 2,000 civil society organisations in more than 170 countries. For more information, visit https://ncdalliance.org/

5   Medtronic Philanthropy aims at expanding access to chronic disease care for the underserved, worldwide.
        For more information, visit http://www.medtronic.com/foundation/who-we-are/index.html

6   The UK Health Forum (UKHF) is a charitable alliance of professional and public interest organisations working to reduce the risk of avoidable non-communicable diseases by developing evidence-based public health policy and supporting its implementation through advocacy and information provision. For more information, visit: www.ukhealthforum.org.uk

The capacity assessment captured demographic and organisational information; main areas of work and frameworks for action; governance; services offered and degree of influence; management capacity and structure; funding and financial issues; level of patient engagement[7]; successes and challenges; partnerships; areas for development; and issues related to collaboration with the HCC.

The information needs assessment targeted individuals working in the CSOs, and captured their demands for, and uses of, various types of information, as well as their access to information and related information technology.

This document summarizes the results of the capacity needs assessment, and offers recommendations for HCC CSO members and for strengthening the HCC's strategic actions towards the achievement of its objectives.

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7   The assessment used the Centre for Advancing Health's 2010 Engagement Behaviour Framework (EBF) in framing questions related to patient engagement. Information on the EBF is at http://www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf, accessed 18 February 2016.

4. BACKGROUND

As embodied in the vision of the 2007 Declaration of Port of Spain: Uniting to Stop the Epidemic of Chronic NCDs[8] by the Heads of Government of the Caribbean Community (CARICOM), the HCC collaborates with regional and international leaders to promote and enable civil society's contribution to the prevention and control of non-communicable diseases (NCDs) in the Caribbean.

In an effort to strengthen its contributions to NCD prevention and control in the Caribbean, the HCC determined that a capacity and information needs assessment of its CSO members working with NCDs would not only add value to the civil society sector by highlighting areas for capacity development, collaboration, and resource mobilisation, but would also allow the HCC strategic planning process for 2017 to 2021 to align with the priorities of its member organisations.

The goal of the assessment was to understand the capacity, development, and activities of CSO HCC members working with NCDs, seeking to capture the issues and factors needed to advance their institutional development and their work, for the achievement of their objectives.

The 10 objectives of the assessment were to:

1. Create a robust database of HCC CSO members working in NCDs
2. Assess basic organisational capacity of the CSOs within this grouping
3. Better understand the primary programing activities of these members
4. Determine their advocacy capacity and priorities
5. Better understand the challenges and needs faced by these CSOs
6. Identify successes in CSO-led prevention and control of NCDs
7. Determine the information and information-related needs of the CSOs
8. Better understand how HCC can add value to its members
9. Map patient support CSOs in the Caribbean with a view to informing expanded activities in the area of patient engagement
10. Inform the upcoming HCC 2017-2021 Strategic Plan

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8   CARICOM. Available at http://www.caricom.org/jsp/communications/meetings_statements/declaration_port_of_spain_chronic_ncds.jsp, accessed 18 February 2016.

The achievement of these objectives would facilitate CSOs' and HCC's contribution to the multisectoral, health-in-all-policies, social determinants of health[9] approaches that are essential for effective, equitable, and sustainable NCD prevention and control in the Caribbean.

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9   The social determinants of health are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and system shaping the conditions of daily life. More information on the SDoH is available at http://www.who.int/social_determinants/en/, accessed 16 April 2016.

5. METHODOLOGY

5.1 The survey

A questionnaire containing the following three complementary components was developed and pilot-tested.

- **Part I**, Demographic, organisational, and contextual information.
- **Part II**, Strategic frameworks, governance, services offered and degree of influence, management capacity and structure, funding and financial issues, patient engagement, successes and challenges, partnerships, areas for development, and issues relating to collaboration with HCC.
- **Part III**, Information needs of individuals working with the CSO.

Every effort was made to provide options for checking responses and to minimise open-ended questions, so as to make the survey more user-friendly, especially in light of its length. The survey instrument is in **Appendices 1 & 2**.

Survey Monkey (SM) was the electronic platform used, and the survey link was sent to 48 CSOs in mid-March 2016, with guidelines for its completion; the deadline for submission was 31 March 2016. Each CSO was asked to designate one person, the head of the CSO or a designated survey lead, to complete Parts I, II, and III, and send Part III to as many individuals working in the CSO as possible for completion. Some survey leads opted not to complete Part III, but forwarded the link to others for completion of that section.

In an effort to maximize the number of respondents, both the HCC President and Executive Director sent numerous email reminders to the CSOs, and the initial deadline for response was extended to 7 April 2016. In addition, telephone contact was made with some respondents to facilitate their responses and their completion of skipped questions. The full survey (Parts I, II and III) and Part III only were closed on 11 April and 18 April, respectively, to facilitate preliminary analysis of the results in preparation for an HCC strategic planning meeting on 22 April 2016. Parts I and II of the survey were subsequently re-opened for a week, to facilitate a response by a specific CSO that had difficulties with submission of the survey due to technical difficulties, despite several attempts.

After deletion of incomplete and duplicate entries for Parts I and II, of the 48 CSOs invited to participate, 38 CSOs in 15 countries completed Parts I and II, for an excellent response rate of 79 percent. **These 38 responses form the basis of this analysis and report of the capacity needs assessment**. The analysis examined question summaries, charts, and individual CSO responses and comments in SM, as well as hard copies of completed Parts I and II, and summary tables of the entries by CSO and country. Skipped questions and other omissions are not detailed, to facilitate presentation of the results.

5.2 Limitations and lessons learned

Limitations in the survey methodology include:

- Some respondents experienced technical difficulties in completing and submitting the survey, with loss of entered data and duplicate entries.
- There may have been challenges with the interpretation of "staff" in Question 52 as paid personnel. Where the CSOs in question operated only with volunteers, this interpretation may have led to omission of, or inaccurate responses to, questions related to CSO personnel.
- Omission of several questions, despite the categorisation of those entries as "complete" and their inclusion in the SM analysis.
- Unwarranted guidance of "tick all that apply" for specific questions, as this led to selection of multiple options and a blurring of responses, as in the categorisation of the CSOs, where CSOs selected up to 5 options (Question 11).
- Failure of SM to accommodate indented "sub-options" under a particular option. This meant that all the possible responses were presented at the same level, artificially increasing the options available, such as the listing of risk factors under "prevention of risk factors" in Question 22 and similar questions.
- Late receipt of the link for completion of Part III, and uncertainty about the relevance of Part III to some of the respondents' work.
- Categorization of the survey as too long, and its completion over several days or weeks, rather than within the desired much shorter time frame. This may have compromised the completeness and accuracy of the responses.

Among the **lessons learned** are the following:

- Intense follow up is required to achieve a high response rate, even against the background of significant commitment of the participating CSOs.
- Shorter, more targeted questionnaires are more likely to prompt more complete and accurate responses, with follow-up qualitative or quantitative surveys to probe and obtain more details on issues raised
- Clear definitions of terminology, such as "staff" are important for accuracy, and requesting absolute numbers, rather than ratios, facilitates more consistent and accurate responses for some items, as in determining the gender profile of the CSOs' Boards of Directors. There was also some uncertainty regarding CSOs' membership in the NCD Alliance, which was termed the "Global NCD Alliance" in the survey to differentiate it from national NCD alliances. One CSO noted that since HCC is a member of the NCD Alliance, CSOs might be regarded as being members through HCC's status, and pointed out that the NCD Alliance website lists several Caribbean CSOs under 'federation association members' by virtue of their membership in NCD-related international NGOs.
- Assumptions regarding the respondents' information technology capacity, and their familiarity and comfort with online surveys, may not hold true.
- It is worthwhile exploring more than one online survey platform for comparison regarding appropriate "fit" for the particular needs of the survey.
- The significant synergies among the CSOs' priorities, expressed needs, and recommendations will facilitate resource mobilisation; capacity building; information sharing and communication; partnerships; and other strategic actions by the CSOs themselves, HCC, national and international partners, and other stakeholders.

6. KEY FINDINGS

6.1 Profile of NCD CSOs in the Caribbean

6.1.1 Demography and organisational context

Responses were received from 15 countries: Antigua and Barbuda (1); The Bahamas (2); Barbados (9); Belize (2); Bermuda (2); Cayman Islands (1); Dominica (2); Grenada (2); Guyana (1); Haiti (2); Jamaica (6); Saint Lucia (1); Sint Maarten (2); Suriname (1); and Trinidad and Tobago (4). **Table 1** summarizes the CSOs in each country that completed Parts I and II of the survey; Barbados had the largest percentages of responses (24%), followed by Jamaica (16%) and Trinidad and Tobago (11%).

Table 1: Completed entries in Survey Monkey by country and CSO

Country	Civil Society Organisation
ATG	Antigua & Barbuda Diabetes Association
BHS	Cancer Society of The Bahamas
	Sir Victor Sassoon (Bahamas) Heart Foundation
BRB	Barbados Alzheimer's Association
	Barbados Association of Palliative Care
	Barbados Cancer Society
	Barbados Diabetes Association
	Barbados Family Planning Association
	Cancer Support Services
	Diabetes Association of Barbados
	Heart & Stroke Foundation of Barbados
	Eastern Caribbean Conference of Seventh Day Adventists
BMU	Bermuda Cancer and Health Care
	Bermuda Diabetes Association
BLZ	Belize Cancer Society
	Belize Diabetes Association
CYM	Cayman Islands Cancer Society
DMA	Dominica Cancer Society
	Dominica Diabetes Association
GRD	Grenada Cancer Society

Country	Civil Society Organisation
	Grenada Heart Foundation
GUY	Cancer Institute of Guyana
HTI	Fondation Haitienne de Diabete et de Maladies Cardiovasculaires
	Group de Support Contre le Cancer
JAM	Caribbean Cardiac Society
	Diabetes Association of Jamaica
	Heart Foundation of Jamaica
	Jamaica Cancer Society
	Jamaica Coalition for Tobacco Control
	Jamaican Committee on Non-communicable Diseases
LCA	St. Lucia Diabetes & Hypertension Association
SXM	Positive Foundation
	Sint Maarten Cancer Foundation
SUR	Pro Health/Health Development Institute
TTO	Alzheimer's Association of Trinidad & Tobago
	Diabetes Association of Trinidad & Tobago
	Heartbeat International of Trinidad & Tobago
	Trinidad & Tobago Cancer Society

- Lead respondents comprise a variety of professional categories, including executive directors; chief executive officers; presidents; educators; programme coordinators; and administrators.
- Females comprise 76% (29) of the lead respondents; 69% (25) of the lead respondents involved other persons in responding to the questionnaire, an indication of teamwork in providing the responses and/or division of labour in the functions of the CSO.
- All except one of the CSOs are registered; several put themselves into multiple categories. Most are registered NGOs (47%), followed by not-for-profits (42%) and charities (37%). Eighteen percent (7) categorise themselves as legal entities and 11% (4) as registered CSOs; however, two do not know how their CSO is categorised, and one not-for-profit is also characterized as a Friendly Society. **See Chart 1.**

Chart 1. Categorisation of CSOs (Q.11)
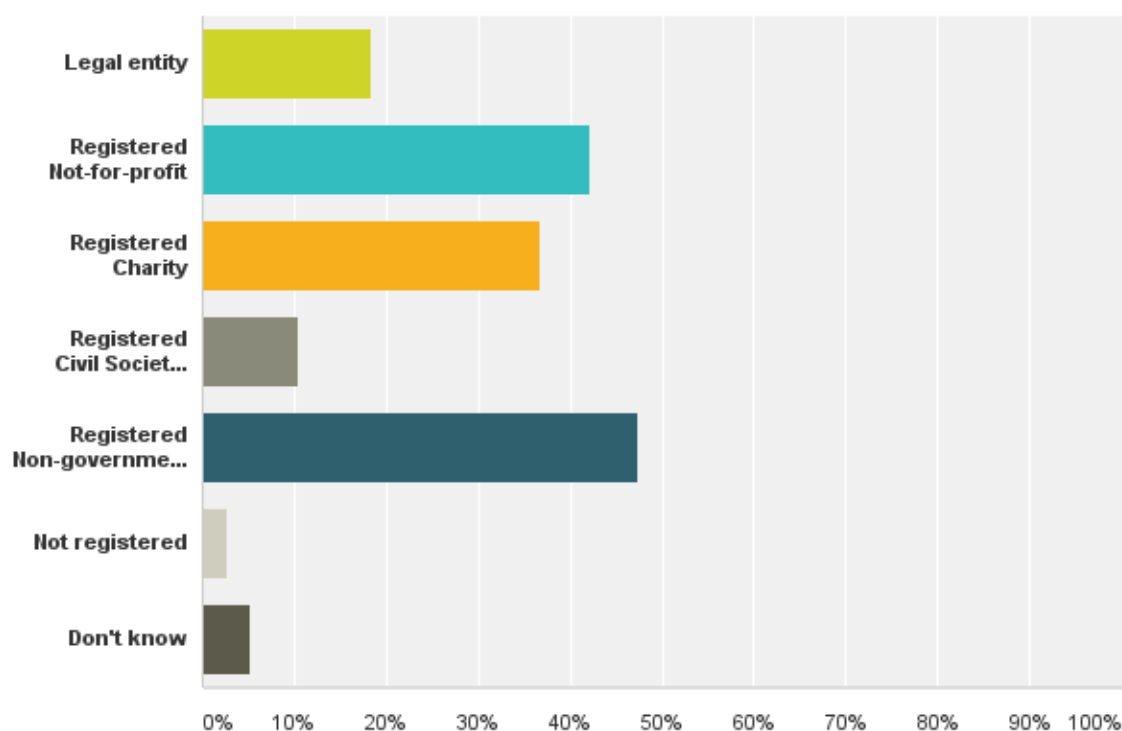
Discussion points

The variety in the respondents' professional categories may signify confidence in delegation of authority by the heads of the CSOs, which can increase efficiency in CSO functioning.

The preponderance of women respondents may suggest that strategies to obtain greater involvement of males in CSOs will be useful, especially given the high prevalence in the Caribbean of sex-related NCDs such as prostate cancer.

Legal standing and registration afford greater legitimacy and accountability to CSOs, including in dealing with governmental and development partner stakeholders.

6.1.2 CSOs' primary constituents

- Ninety-five percent of the CSOs list the general public among their primary constituents/target groups/beneficiaries; 76% list health professionals, while other health care providers, journalists/media practitioners, people with cancer, and people with diabetes are listed by 51% of CSOs. See **Chart 2**. Constituents with other specific disorders are also listed, in addition to researchers (22%) and other (24%), the latter category including the families of people with cancer; governmental bodies; people who need sexual and reproductive health services; and, in the case of one CSO, underprivileged groups, with a strong focus on women.
- Approximately 74% of CSOs state that they specifically target or work with vulnerable groups, mainly those with limited access to services due to socio-economic status. Some CSOs mention work with older persons, persons with disabilities, indigent citizens, in- and out-of-school youth, rural communities, and socially disadvantaged groups, such as those with low literacy, low socio-economic status, and co-morbidities. One CSO mentions men who have sex with men, sex workers, and the LGBT community; another focuses on persons living within the interior of the country, who have limited access to information and health care.
- Examples of CSOs' services to vulnerable groups include offering 100 free mammograms annually to persons who cannot afford them or the uninsured, and establishment of an Equal Access Fund to enable persons without, or with insufficient, health insurance to access services.

Chart 2. CSOs' primary constituents/target groups/beneficiaries (Q.24)
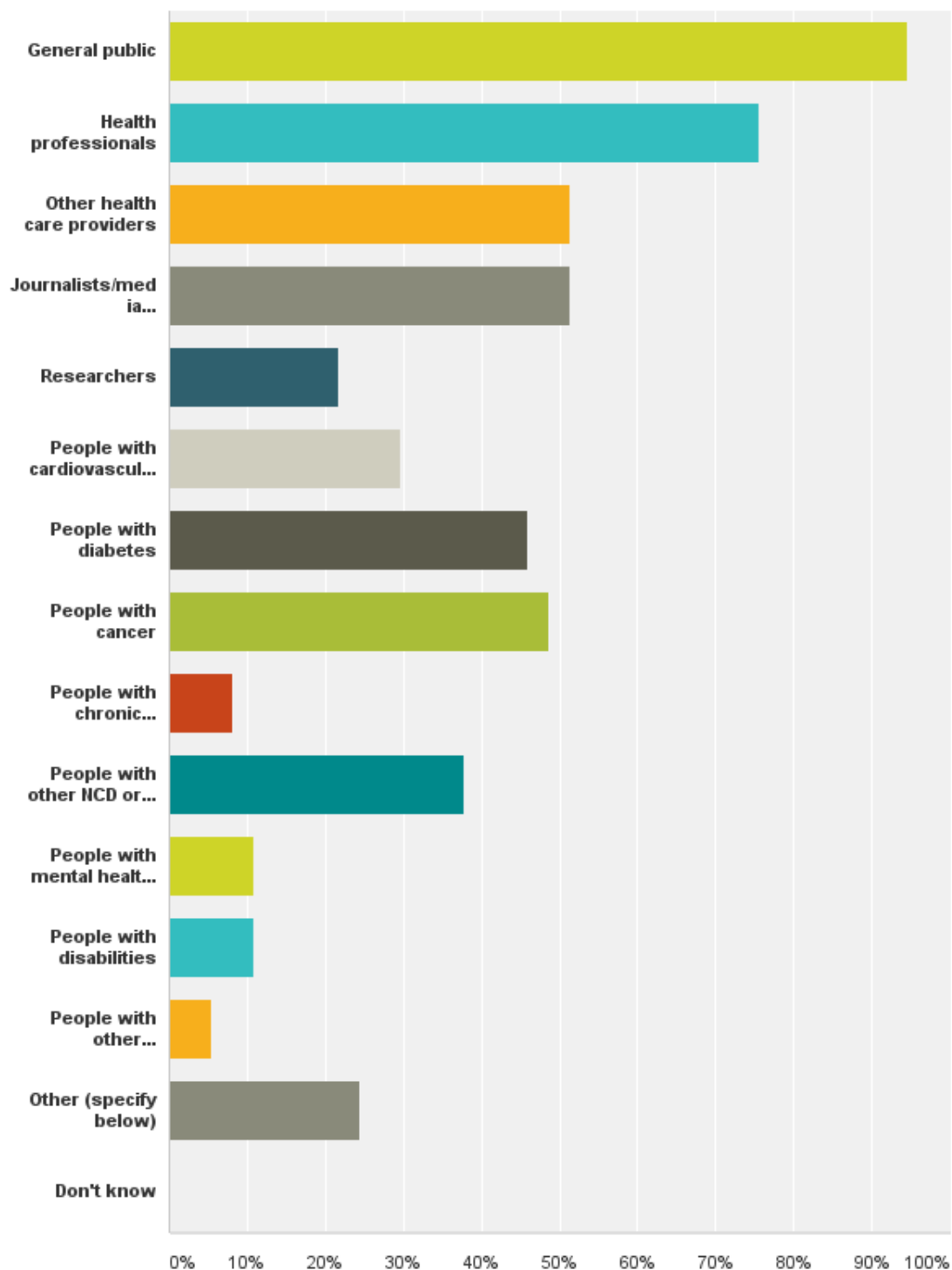
6.1.3 Communications

- Seventy-eight percent (29) of the CSOs have a website and 87% (33) have a presence on social media. The most common social media platform is Facebook (97%), followed by Twitter (35%); 3-6 of the CSOs use Instagram, YouTube, WhatsApp, and LinkedIn. As indicated in **Chart 3**, websites and social media – particularly Facebook – are common vehicles through which CSOs communicate their work, followed by reports and conferences.

- English is the official language in 92% of the countries in which the CSOs are located; French and Dutch are the other official languages. Forty-seven percent of CSOs indicate that there are other languages commonly spoken in their respective countries, among them Spanish, Portuguese, Creole, Garifuna, Maya Ketchi and Maya Mopan in BLZ; French dialect, Kweyol (Creole) in DMA, HTI, and LCA; Spanish Hindi in TTO; and Papiamento in SXM.

Chart 3. CSOs' mechanisms for communicating their work (Q.19)
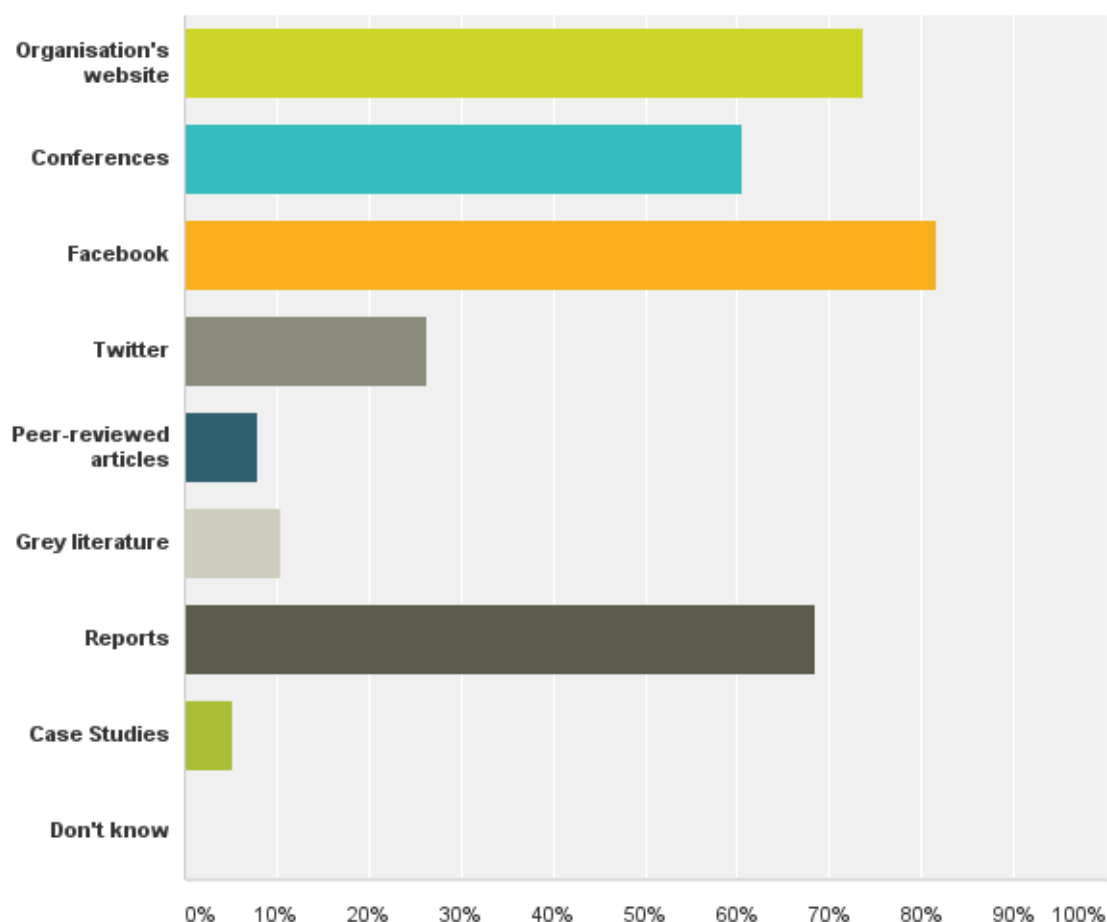
- However, the CSOs' indication of the mechanisms that they use to communicate with their constituents/target groups show that radio and television are still favoured media, as demonstrated in **Chart 4**. Approximately 92% of CSOs use radio; 90%, e-mail; 79%, newspapers; 74%, television; 71%, brochures; and 74%, social media. Fifty-three percent use the internet, for example blogs, and only 32% use newsletters. Smaller percentages of CSOs use telephone, text messaging, annual meetings, lectures, and church services and meetings.

Chart 4. CSOs' mechanisms for communicating with their constituents/target groups (Q.60)

Mechanism	Percentage
Email	~90%
Internet (e.g. blogs)	~52%
Brochures	~71%
Social media	~74%
Newspapers	~82%
Newsletters	~31%
Radio	~93%
Television	~74%
Don't know	0%
Other (please specify)	~16%
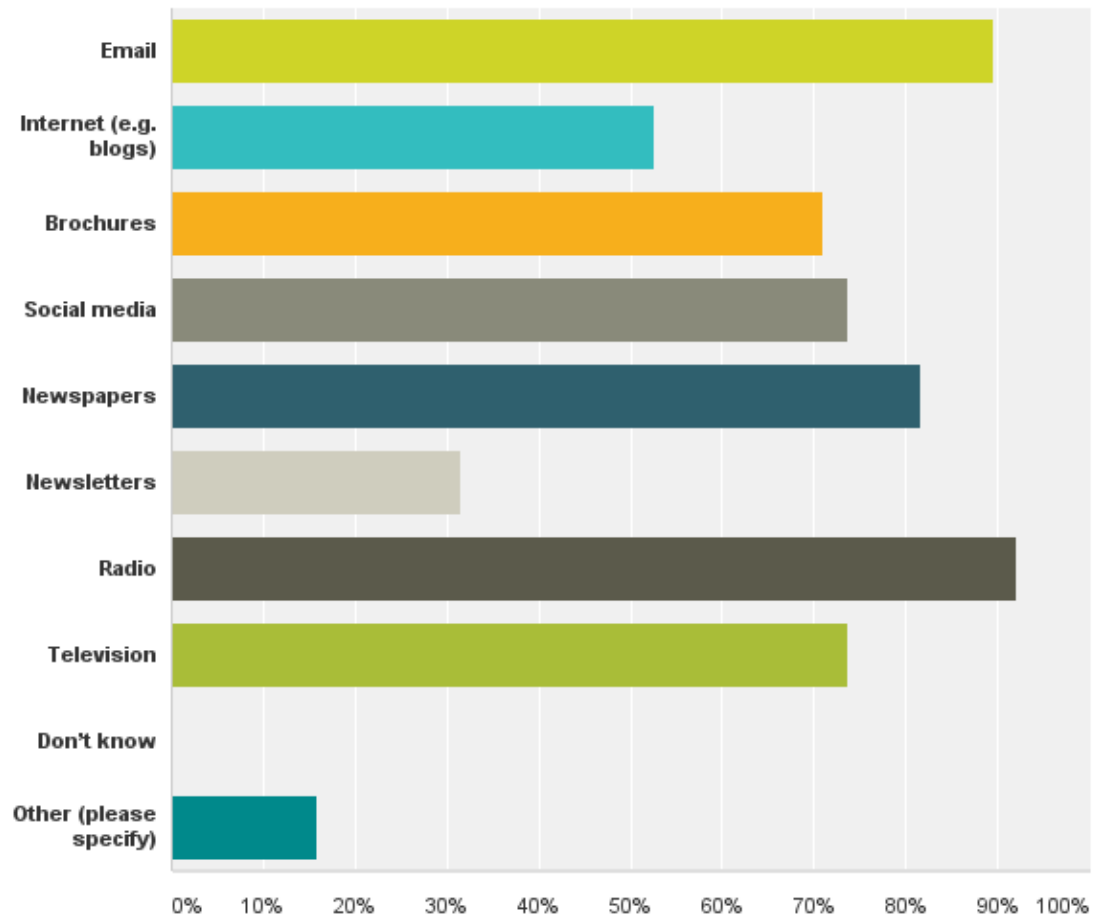
- Thirty-two percent of CSOs indicate that they communicate their work to their main target groups, beneficiaries, or audiences monthly. However, a larger percentage, about 37%, do not communicate daily, weekly, or monthly, but on special occasions such as Caribbean Wellness Day, World Health Day and other international "health days", weeks, or months. Though Facebook may be used almost daily, some CSOs report to various groups annually, biannually, or "as necessary". **See Chart 5**.

Chart 5. Frequency of CSOs' communication to their target audiences (Q.20)
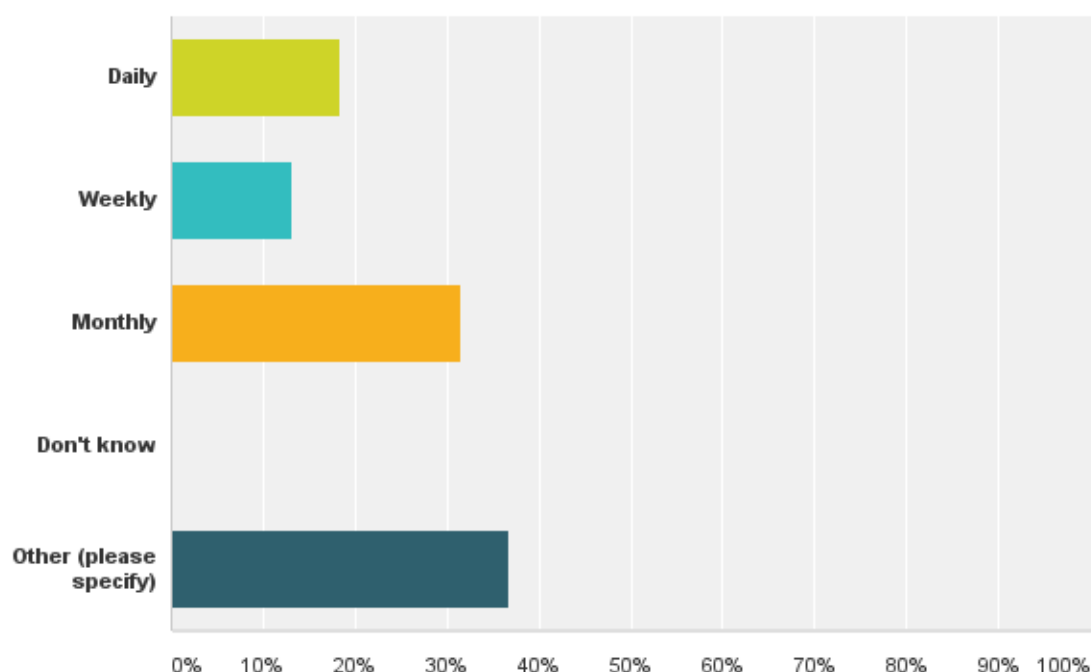
- CSOs report that packaged communication materials produced by other organisations are useful and convenient – 53% indicate that they use such materials sometimes, 32% use them frequently, and 16% use them most of the time. No CSO selected the "never" option. See **Chart 6**.

Chart 6. CSOs' use of external communication materials (Q.21)
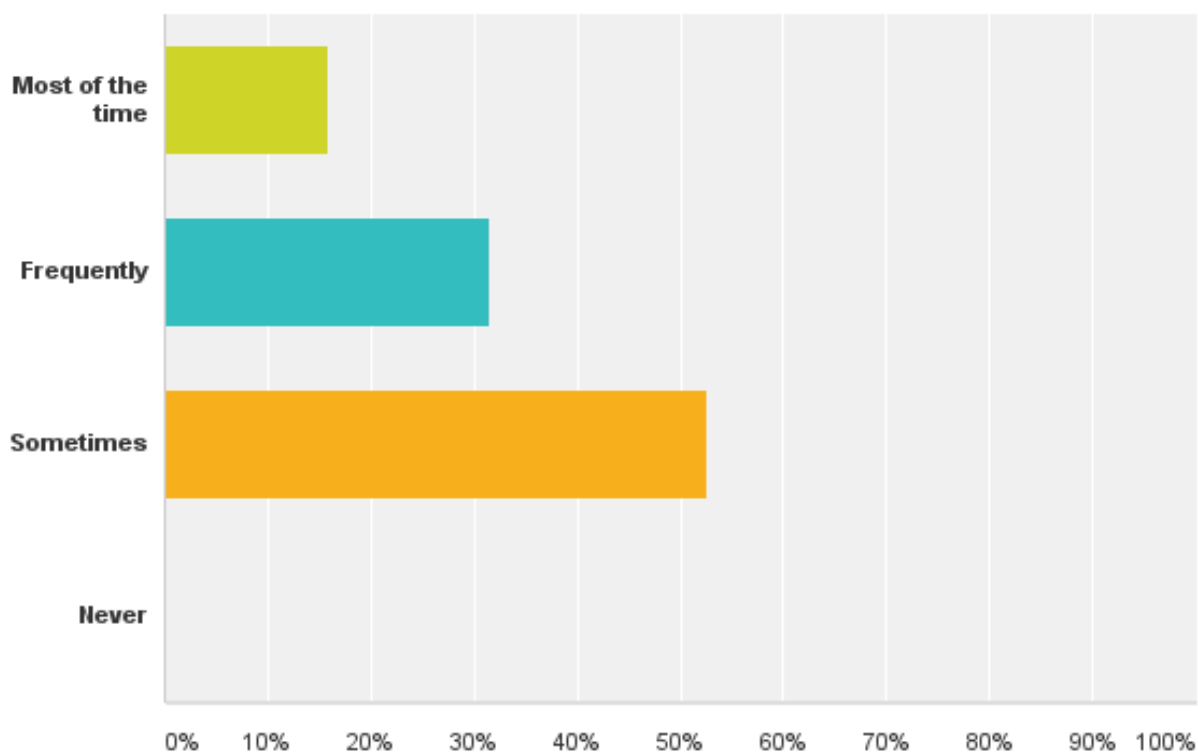
Discussion points

The language differences in countries point to the need for health promotion and communication strategies tailored to vulnerable populations, including indigenous people, who often have health indicators that are below national averages.

While all CSOs should take advantage of the internet and social media, which are cost-effective methods of reaching large audiences, traditional media such as radio and television remain important. Both newer and older media can reach wide audiences, and electronic mail, messaging, and social media and can enable audience segmentation and the dissemination of tailored messages. The cost of disseminating messages by radio and television at "prime time" to ensure maximum exposure may be a barrier to regular, effective communication.

Regular, timely communications with key stakeholders is essential for the promotion, credibility and accountability of any organisation, and CSOs are taking advantage of both old and new media to communicate with their constituents. However, they should ensure that not only are communications sent, but that they are received – is the target audience listening to the radio or watching television at the time the message is communicated? In many cases, it can be expensive to broadcast messages during "prime time". Does a majority of the audience have access to the internet and social media? In particular, some vulnerable groups may not have such access, or may have it intermittently. Answers to these and other questions are important for effective communication.

CSOs with limited capacity to produce their own communication materials can often adopt or adapt materials produced by agencies such as PAHO or WHO. The materials are usually available on the Organisations' websites for download or through PAHO/WHO country offices to be freely used, as long as the source is acknowledged. It behooves CSOs to remain aware of "world days" and materials available through these sources that can be used in a cost-effective manner; agencies such as PAHO/WHO also have a responsibility to promote the materials not only to their governmental counterparts, but also to CSOs working in relevant areas.

6.1.4 Main areas of work and national NCD epidemiological profiles

- As demonstrated in **Chart 7**, the majority of CSOs (71%) indicate their main area of work as prevention and control of NCD risk factors, with most focusing on unhealthy diet, followed by physical inactivity, tobacco use, and harmful use of alcohol. Approximately 47% of CSOs focus on cancer; 47% on cardiovascular diseases, including hypertension; and 42% on diabetes. Only approximately 18% focus on mental health and neurological disorders, while 11% each focus on chronic respiratory diseases, including bronchial asthma, and disabilities.

Chart 7. Main areas of work of CSOs (Q.22)
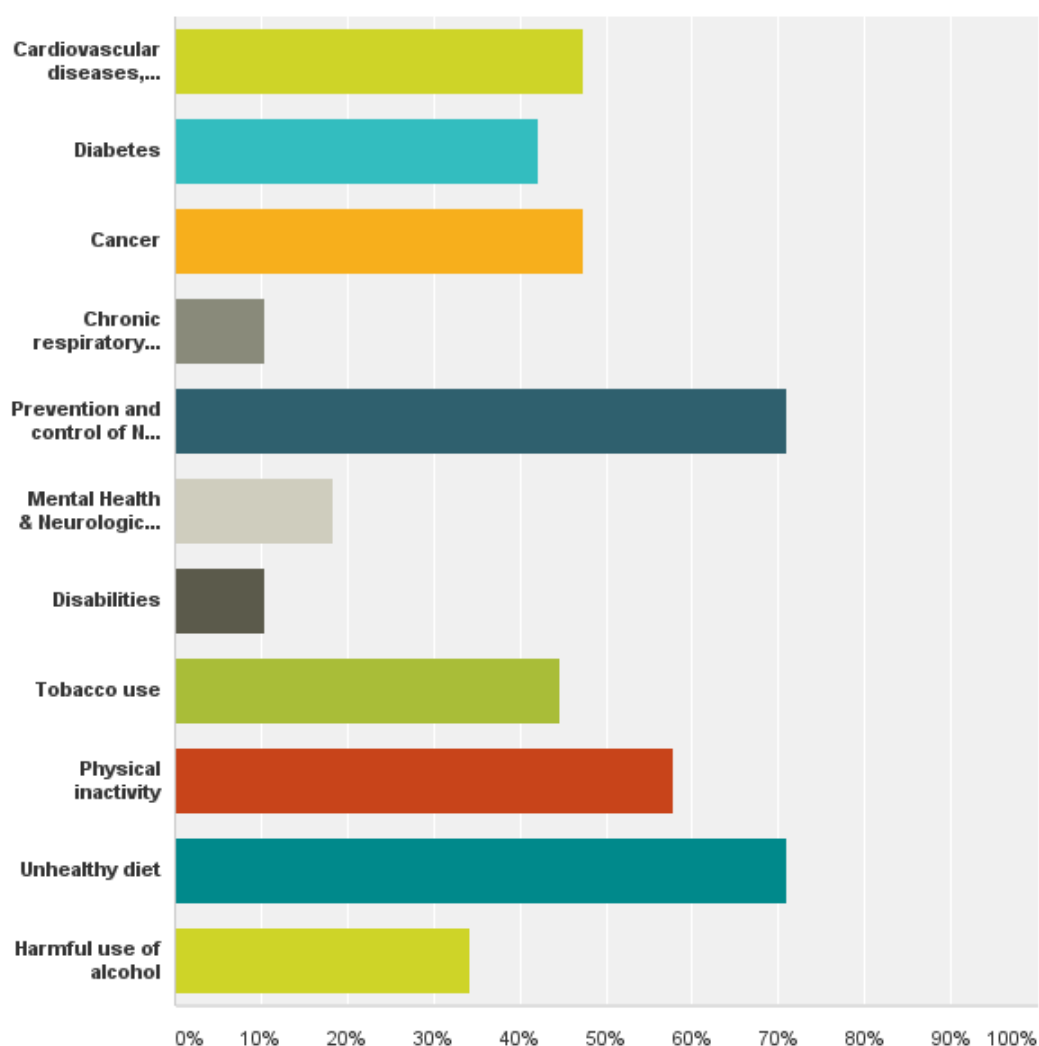
- **Chart 8** shows the CSOs' responses in identifying the top five NCD issues in their countries of location. All CSOs list cardiovascular diseases, including hypertension; 97% list diabetes, 94%, cancer, and 47% list prevention and control of NCD risk factors, with 39% highlighting unhealthy diet. Harmful use of alcohol, tobacco use, and physical inactivity are listed by 23%, 21%, and 13% of respondents, respectively, while 37% name chronic respiratory diseases, including bronchial asthma, and 13% name mental health and neurological disorders. No respondents list disabilities.

- Except for disabilities, the epidemiological situation in the Caribbean mirrors the areas of work of the CSOs. For the period 2000-2008, the top 3 leading causes of death in the Caribbean were cerebrovascular diseases (stroke), diabetes, and ischaemic heart disease[10]. Other cardiovascular diseases and hypertensive heart disease ranked 4th and 5th; among men, prostate cancer ranked 6th to 8th, and among women, breast cancer was the 7th leading cause of death. NCDs are now linked to 7 out of 10 deaths in the Caribbean, which exceeds the global average of nearly 60 percent. A 2014 WHO report on suicide prevention noted that in 2012 the highest rates of suicide were in Guyana, Suriname, and Trinidad and Tobago, with a higher incidence among males than among females[11].

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[10]   Caribbean Public Health Agency (CARPHA). Health situation in the Caribbean. Port of Spain, Trinidad and Tobago: CARPHA, 2013.

[11]   WHO. Preventing suicide: a global perspective (Annex 1). Geneva: WHO, 2014. Available at http://www.who.int/mental_health/suicide-prevention/world report_2014/en/, accessed 16 April 2016.

Chart 8. Main NCD issues in CSOs' countries of location (Q.23)
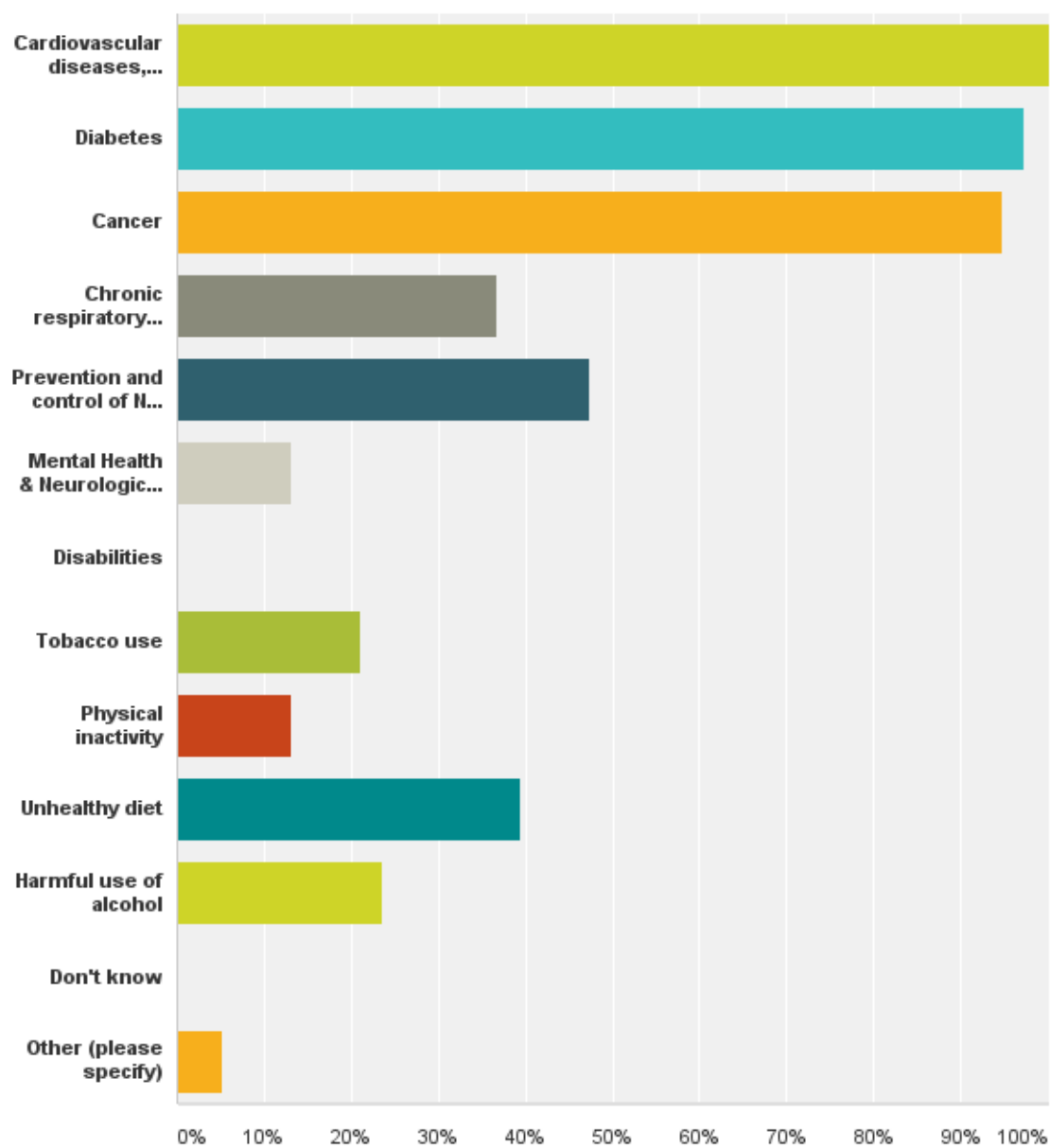
The main areas of work of the CSOs reflect well the level of attention paid to NCDs such as cardiovascular diseases, diabetes, and cancer, given their impact on morbidity and mortality. **However, mental health and neurological disorders, chronic respiratory diseases, and disabilities, though not as prominent among the causes of death in the Caribbean, cause significant illness and loss of productivity, and warrant increased attention by both governmental and civil society organisations, as well as by other stakeholders in health**.

The epidemiological profile highlights the need for increased advocacy for, and attention to, prevention and control of NCD risk factors; mental health; complications of NCDs and mental disorders that may lead to disabilities; health promotion and communication for behaviour change; strengthened health systems that are people-centered; multisectoral action to address the SDoH, with a focus on the most vulnerable populations; and greater participation of civil society, in addition to other key stakeholders in health.

6.1.5 Strategic framework for action on NCDs

Regarding strategic frameworks that guide their actions:

- Approximately 76% of the CSOs are guided by the national health policy, strategy or plan; 53% by the CARICOM POSD on NCDs; 45% by the WHO Global Action Plan on NCDs; 29% by the CARICOM Regional NCD Plan of Action[12]; and 26% by the United Nations (UN) Sustainable Development Goals (SDGs). Not many CSOs (18%) are guided by the CARICOM Caribbean Cooperation in Health Phase III (CCH III), a finding consistent with a March 2016 evaluation of CCH that indicated gaps in the promotion, awareness, and use of the CARICOM initiative[13]. **See Chart 9**.

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12   Strategic Plan of Action for the Prevention and Control of Non-communicable Diseases for Countries of the Caribbean Community, 2011-2015. Available at http://www.archive.healthycaribbean.org/publications/strategic-plan-of-action.html, accessed 15 June 2016.
13   CARICOM, CARPHA, and PAHO. Caribbean Cooperation in Health (CCH III) Evaluation Results and Recommendations for the Way Forward with CCH IV. Bridgetown: PAHO, 2016

- Five CSOs indicate their alignment with the frameworks of international associations of which they are members, in addition to national and regional NCD plans.

Chart 9. Frameworks that guide CSOs' work (Q.32)
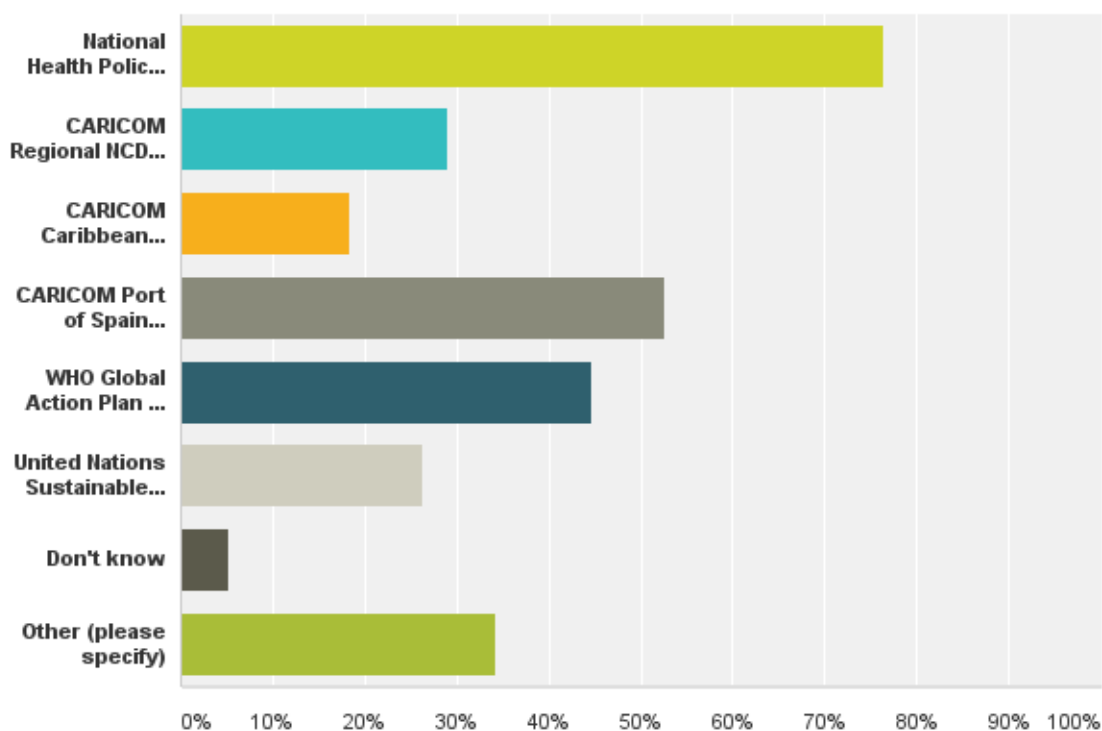
- Approximately 76% of CSOs consider SDoH in their planning, programming and implementation; 65% take account of gender and equity; 57% consider human rights; and 11% take none of these factors into consideration.

Discussion points

In order to contribute to the achievement of national and international health development goals, it is critical for CSOs to explicitly align their activities with relevant NCD frameworks to the extent possible. Not only will such alignment facilitate support from national authorities, but it will also facilitate resource mobilisation from international development partners that are increasingly working to address national and internationally agreed health goals. However, national health policies, strategies, or plans (NHPSP) must first be formulated to address national health priorities as well as the international agreements to which the countries have committed.

The SDGs, approved in September 2015, have replaced the Millennium Development Goals (MDGs) as the global development framework to 2030, and all UN Member States have committed to working toward their achievement[14]. SDG 3, the health goal – though many other SDGs are related to health – specifically mentions NCDs.

There is increasing realisation of the impact that actions in non-health sectors can have on health, and Caribbean countries, in common with other developing and developed countries, are placing emphasis on equity and cross-cutting themes such as human rights, gender, and the SDoH, to ensure that "no one is left behind" as they advance their national development. The SDGs are explicit on these issues, and CSOs, which tend to focus on community work and addressing the needs of the vulnerable, are well-placed to be strong advocates and practitioners for equity in health. There are some vulnerable groups, however, that may continue to be discriminated against and left behind, given the norms and culture in many Caribbean countries, including groups with non-heterosexual orientation.

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14   Information on the SDGs is at https://sustainabledevelopment.un.org/post2015/transformingourworld/publication. Accessed 17 April 2016

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In their own strategic planning:

- Approximately 70% of CSOs have a vision statement and 94% have a mission statement, but only 46% have a strategic plan with goals and/or objectives, time frames, and concrete indicators or measures; 53% have an operational plan that guides day-to-day activities.
- Though approximately 66% of CSOs indicate that they do not have a monitoring and evaluation (M&E) framework to assess their functioning and activities, approximately 92% prepare periodic reports on their activities and achievements, with 67% indicating that the reports are linked to the strategic and/or operational plan. Some CSOs state that M&E take place through the Board, a Committee, Secretariat and Administrative Director, or international affiliates, or are done for some projects. One CSO asks service users to provide feedback and another holds evaluation meetings to review operations.
- Eighty-nine percent of CSOs share their reports, mainly with the Board of Directors (BoD) (94%), but also with the MoH (39%), constituents/target groups (39%), and the general public (33%). Reports are also shared with local and overseas partners, head offices, international associations to which the CSOs belong, grantors, staff, and "all key stakeholders locally, regionally, and internationally".
- Approximately 69% of CSOs have shared beliefs and values, or a Code of Ethics, to guide the Organisation's behaviour and support its purpose. However, 29% respond negatively, and one CSO does not know if such shared values or a Code of Ethics exist. Of those who respond positively, several state that these issues are reflected in their constitution, staff and other manuals, or other organisational documents. One CSO indicates that it is guided by the ethics and values of the international association to which it belongs, and a faith-based CSO points to the Holy Scriptures, as well as a church manual, that provide relevant guidance. A few CSOs indicate that a Code of Ethics is in development.
- With regard to their top 5 priorities for the next 5 years, 79% of CSOs indicate prevention and control of NCD risk factors, with 63% targeting unhealthy diet, 42% physical inactivity, 34% tobacco use, and 18% harmful use of alcohol. Forty-seven percent include cancer, 45% cardiovascular diseases including hypertension, and 40% diabetes; only approximately 8% include mental health and neurological

disorders, and 5% include chronic respiratory diseases, including bronchial asthma. One CSO mentions building organisational capacity for recognition as a centre of excellence; another aims to offer radiation therapy and medical outreach for cancer, and yet another will provide the country's first radiation treatment facility at its Centre. See **Chart 10.**

Chart 10. CSOs' top priorities for the next 5 years (2017-2021) (Q.37)
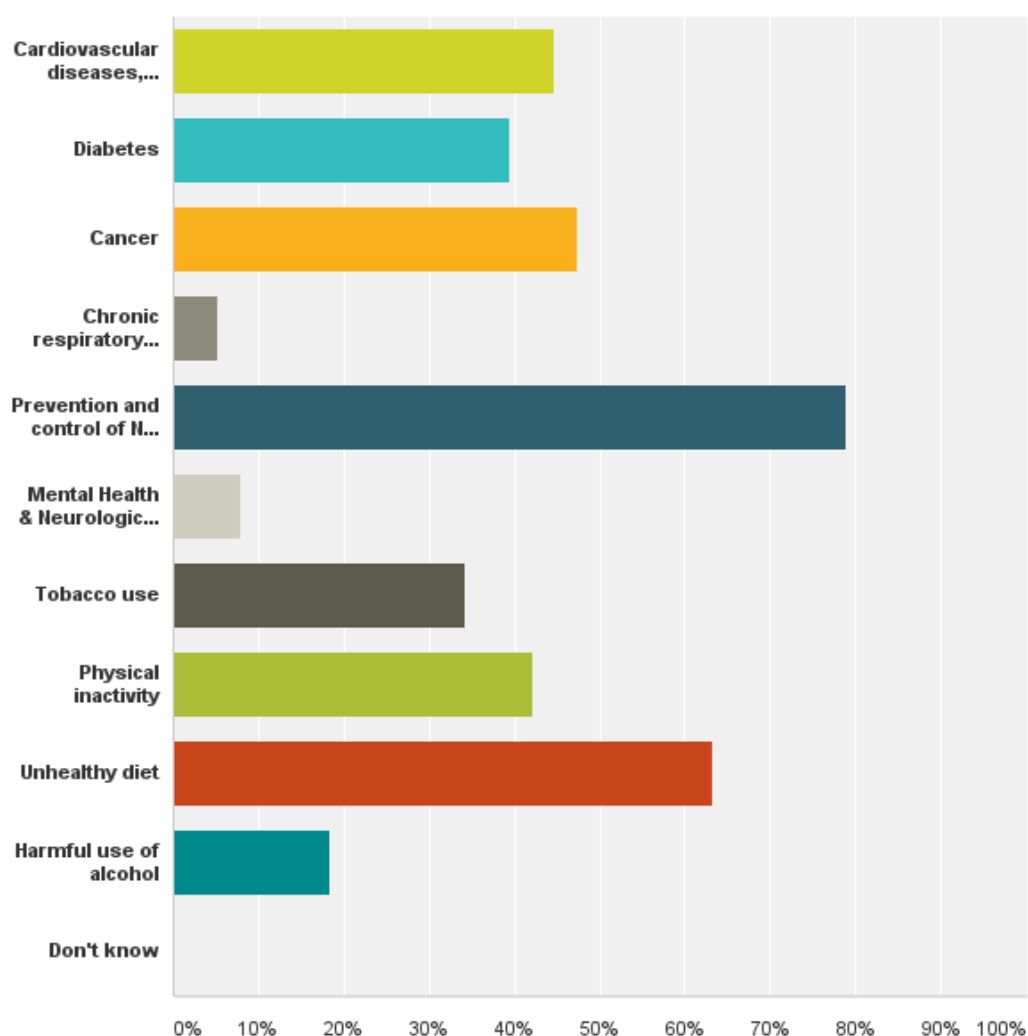
Discussion points

The saying that "what gets measured gets done" might not be applicable in all cases, but having a basic strategic plan that indicates what is to be done, how it will be done, and means of determining and measuring that it has been done, is important. Such a plan enables monitoring and accountability, which are critical issues, even more so where there are limited resources, funds that must be accounted for, and pressure to "produce or perish" within a changing environment. The formulation of agreed objectives and indicators, buttressed by an operational plan that outlines deliverables and time frames for their production, can enable efficient and effective actions by CSOs. In addition, an M&E framework based on the strategic or operational plan facilitates the development and sharing of reports on achievements, challenges, lessons learned, and resources expended. Such reports speak to the CSO's transparency and willingness to be a learning and knowledge-sharing organisation, and enables stronger partnerships and horizontal cooperation.

Given that CSO personnel, including volunteers, are often diverse and may be from various cultures and backgrounds, it is important that there be a unifying Code of Conduct, Code of Ethics, or other written expression of the beliefs, values, and expected behaviour that the CSO espouses, to facilitate its efficient and effective functioning.

While the top 5 priorities for the next 5 years continue to be aligned with the major causes of death in the region, significant causes of morbidity, such as mental and neurological disorders, and chronic respiratory diseases, including bronchial asthma, seem to be on the "back burner", perhaps a reflection of the relative inattention of public health authorities and development partners to these issues, and associated limited resources. However, there are opportunities for bringing these conditions to the fore – one CSO indicated that it will include mental health issues in addressing its main priority of diabetes, as recommended in the 2015 Diabetes Care Protocols of the American Diabetes Association.

6.1.6 Governance

- Approximately 78% of CSOs have by-laws to provide a framework for their operations and management, and 92% have a BoD, with the number of members varying from 3 to 30, the latter being a multi-country organisation. Women are well-represented on the Boards.
- In approximately 46% of the CSOs, the Board meets monthly; 26% meet quarterly, 6% meet annually, and 9% have ad hoc Board meetings, while other CSOs have 2-monthly meetings. Minutes of the BoD meetings are prepared and disseminated by 94% of CSOs.
- The BoD includes a person with NCDs in approximately 76% of CSOs, and a health professional in approximately 91%, but only approximately 50% of CSOs indicated that their constituents/target groups participate in their decision-making process. This takes place via meetings – quarterly, annual general, or special meetings; through membership on the BoD, committees, or technical working groups; and through participation in programmes, where constituents can make suggestions regarding, for example, educational or fund-raising activities.
- **Chart 11** demonstrates that in 88% of CSOs the BoD includes a medical doctor and in 44%, a nurse. Other categories of health professionals on the Boards include dietitian/nutritionist, pharmacist, radiographer, health promotion specialist, and medical technologist. One CSO reports having a public health specialist on the BoD, while another has 4 oncologic surgeons on the Board.

Chart 11. Categories of health professionals on CSOs' Boards of Directors (Q45)
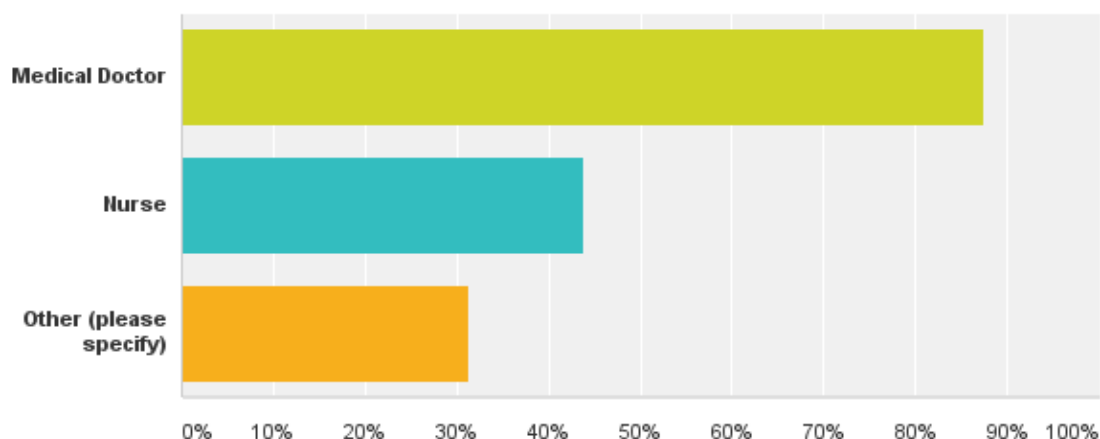
- Most CSOs describe mechanisms for follow-up of BoD decisions, including:
  - Follow-up by persons or units dedicated to the task: Coordinator, President, Secretary, Local Compliance Director, International Compliance Department, Committee or specific Board member;
  - Identification and dissemination of Action Points, Checklists, and Matters Arising from the Minutes of BoD meetings;
  - Management meetings and dissemination of action plans to relevant persons;
  - Preparation of Board Reports by Department Heads, with specific sections for performance review, key issues affecting performance, and future plans and strategies; and
  - Emails and telephone contact.
- Although approximately 14% of CSOs state that they have no other governance elements, 60% have a Management Committee/Team; 23%, an Advisory Committee; 20%, a Technical Working Group; and 11%, an Advisory Board. Other governance structures listed include committees dealing with specific topics such as fund-raising, finance, financial aid, medical assistance, education, training, membership, outreach, and science; volunteer network; and private sector partners. See **Chart 12**.

Chart 12. CSOs' governance elements, other than Board of Directors (Q47)
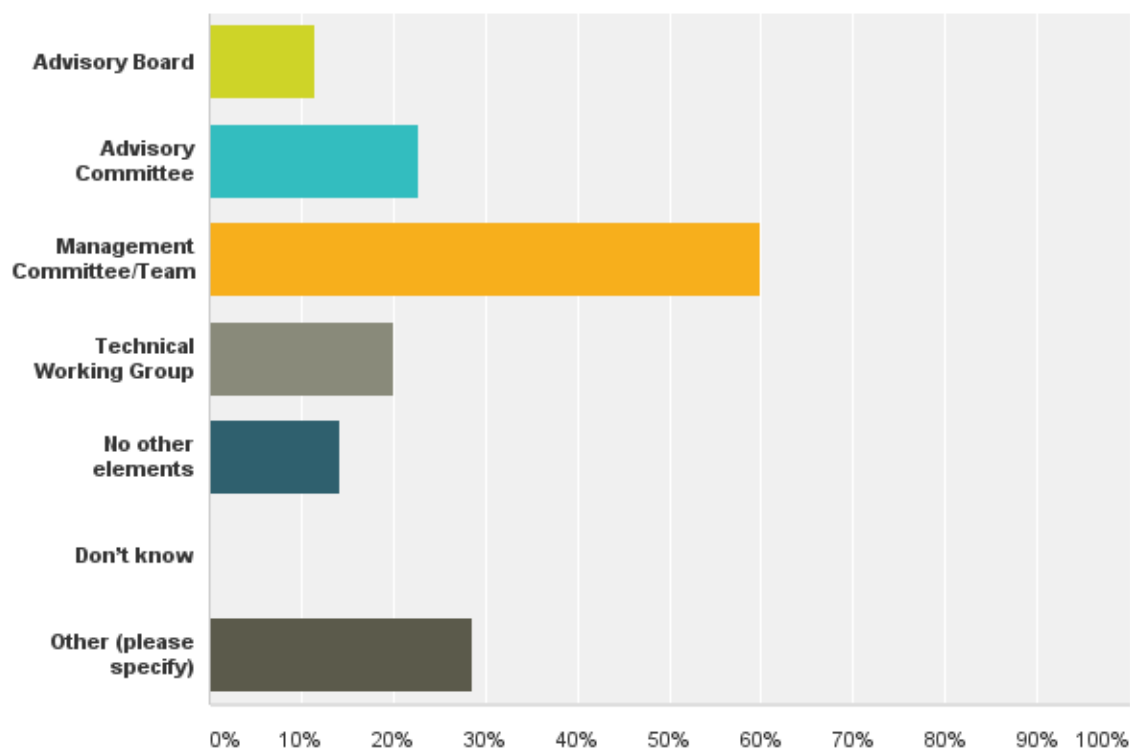
Discussion point

The finding that medical doctors, including specialists, are represented on BoDs, given the medical/clinical themes of the CSOs, is not unexpected. However, NCDs demand a multi-pronged approach, and the focus – current and planned – of most CSOs on prevention and control of NCD risk factors, demands that patients/clients and other types and categories of professionals, both health and non-health, be included; they bring valuable perspectives to the decision-making process.

6.1.7 Primary roles and functions

- As demonstrated in **Chart 13**, the most common primary roles/functions of CSOs are public education/information dissemination (approximately 87% of CSOs); advocacy (87%); screening (71%); counselling/psychological or emotional support/ mental health services (66%); and influencing or participating in official NCD mechanisms/bodies/committees (63%), and provision of patient services (55%).
- Fifty-eight percent of CSOs support global action on NCDs, 53% support the NCD work of international and/or intergovernmental organisations, and 45% are involved in policy development. Though CSOs are often cast as "watchdogs" of government, only 42% monitored the NCD-related commitments of governments, and even fewer (16%) were involved in monitoring industries with conflicts of interest.
- Medical litigation is not a strong feature of the Caribbean environment, so it is not surprising that only two CSOs listed litigation among their primary roles and functions.

Chart 13. CSOs' primary roles/functions (Q.51)

Role/Function	Percentage
Provision of patient...	~56%
Screening	~71%
Diagnosis, including...	~31%
Treatment	~29%
Rehabilitation	~13%
Counselling/psychological...	~66%
Palliative care, includ...	~18%
Public education/in...	~87%
Research	~29%
Advocacy	~87%
Policy development	~45%
Stakeholder capacity...	~34%
Litigation	~5%
Coordinating civil societ...	~21%
Building national or...	~40%
Monitoring NCD-related...	~43%
Monitoring industries w...	~16%
Supporting global actio...	~58%
Influencing or participatin...	~63%
Supporting NCD work of...	~53%
Other (please specify)	~11%

Discussion point

CSOs are playing traditional roles, and their roles and functions obviously depend on their capacity and resources. Those that are relatively well-resourced, with built capacity, might be well-placed to expand their functions for greater involvement in policy development; in monitoring governments' commitments and actions for NCD prevention and control; and in determining possible negative impact of non-health sector polices and interventions, and private sector actions, on NCDs. **A more in-depth determination of selected CSOs' contribution to policy development and the efficacy of their "watchdog" function is warranted**.

Often CSOs prefer to remain "outside" of the governmental efforts, in order to maintain their independence and integrity, and some may prefer not to comment on private sector activities, given that the sector may be a source of funding. However, there are mechanisms whereby CSOs can collaborate with government and other partners to contribute to public health efforts without compromising their values.

The SDGs call for greater involvement of civil society and this new development framework presents opportunities that CSOs should take advantage of; alliances with "neutral" parties such as UN agencies may be useful. Current efforts to formulate CCH IV, led by the CARICOM Secretariat in collaboration with CARICOM Member States, PAHO/WHO, and the UWI (Cave Hill), offer opportunities for CSO involvement at national and regional levels; the HCC has already been identified as a valued partner in the effort.

6.1.8 Human resources

- Analysis of the staffing of the CSOs was complicated by varying interpretations of the word "staff" and wide variations in the number of part-time paid staff and ad hoc volunteers, according to events and activities. Some CSOs interpret staff as meaning paid personnel only, excluding volunteers; one respondent notes zero staff, with the notation "we are all volunteers", indicating that there are 12 ad hoc volunteers. Notwithstanding, total staff range from 1 to 174, the latter related to a multicountry faith-based organisation; full-time paid staff, 0-55; full-time volunteer staff 0-15; part-time paid staff 0-14; part-time volunteer staff 0-150, with responses that include "many" and "varies"; and ad hoc volunteers "several", with responses such as "hundreds for various events/activities" and "entire membership".

- Notwithstanding the above, approximately 68% of CSOs have a management team, with varying management experience. Some members of the team come with management experience; some learned on the job; some have no experience; and some "need updating". In one CSO, the Executive Committee acts as the management team.

- In recruiting personnel, 57% each of CSOs rely on job advertisement and personal recommendation/word of mouth; 29% on internships; 14% on an employment agency, and 6% on a job centre/employment office. Other mechanisms include volunteers joining through public relations, the work of the CSO with communities and individuals, and job seekers contacting the CSO. **See Chart 14**.

- Only 24% of CSOs have a human resources (HR) plan; 14% indicate that such a plan is not applicable to them. Similar findings obtain with regard to staff succession planning, with only 24% carrying out such planning and 14% indicating "not applicable". However, 64% of the CSOs carry out staff training/capacity development/team building, though 18% deem such training not applicable. Forty-seven percent of CSOs carry out formal performance evaluation of staff, and 18% indicate that it is not applicable. Most of the CSOs who respond positively carry out annual performance evaluations, though two do so 6-monthly and one quarterly; two indicate that informal, rather than formal, evaluations are done.

Chart 14. CSOs' methods for recruiting personnel (Q54)
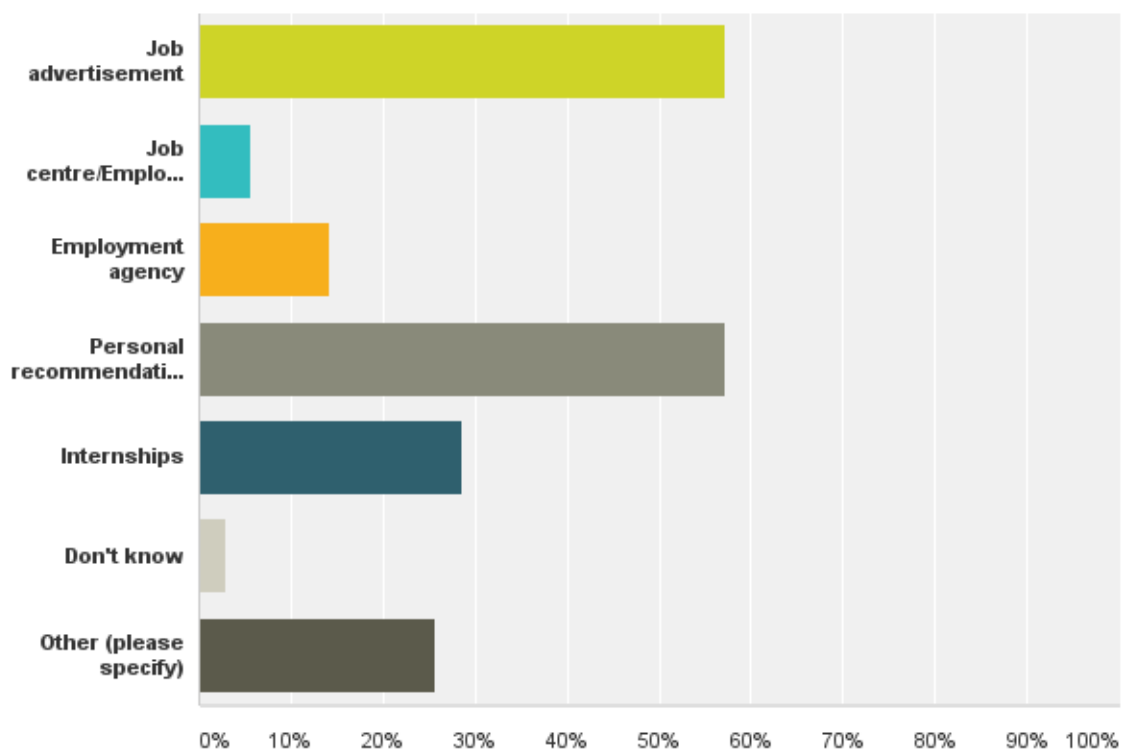
- In their internal communications with personnel, 89% of CSOs use e-mail; 66% hold regular team meetings; 60% hold ad hoc meetings; 17% use an internal newsletter; and 14% use an intranet. Other methods of communication include telephone, text messaging, memoranda, bulletins, and one-on-one meetings.

Discussion points

While it is evident that volunteers play a major role in CSOs, the human resources of the CSOs will need to be re-determined, with clear definitions for each of the category options. It is important that there be a full-time person or team to provide uninterrupted critical functions, assisted by others – full-time, part-time or ad hoc - depending on the size and desired functions of the organisation.

As in many other organisations, sometimes persons from technical and other backgrounds, without management experience, are asked to manage CSOs. This may be inevitable, but CSOs should seize opportunities to ensure that the members of the management team receive training in how to manage.

Notwithstanding the preponderance of volunteers in many CSOs, HR management remains a key aspect of organisational functioning. An HR plan that is aligned with the strategic or operational plan is important for decisions regarding who will perform the functions needed for the implementation of the respective plans; how the persons will be recruited; whether they need to be full- or part-time; and the source of financial or other resources to support their efficient functioning. The HR plan need not be a complex document, but given the need for the CSOs' sustainability, contingent measures and succession planning should also be considered, as well as capacity building to enable performance improvement and/or career advancement for at least the full-time staff of the CSO.

6.1.9 Infrastructure

- Eighty-two percent of CSOs have dedicated office space; 29% own the space, 36% rent, and 36% have other arrangements, which include space provided free of charge by the government, church, a trust or other entity.
- The 18% of CSOs that do not have dedicated office space/building have varying arrangements: administrative work and meetings at the respondent's home ("my dining room table is often the meeting place to discuss next steps or decision

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making"); shared office space and staff; and space made available by the government for meetings.

> **Discussion point**
> While recognising and commending the dedication and commitment of CSO personnel, who, in the absence of owned, rented, or offered space, advocate with partners or provide their homes to ensure CSO functioning, a more permanent infrastructure is desirable for sustainability.

6.1.10 Funding and finances

- Approximately 50% of the CSOs have an accounting policy and procedures manual; two CSOs indicate "not applicable" in response to this question. Seventy-six percent use accounting software and 58% have a dedicated accounts clerk. For the 34% without an accounts clerk, the functions are performed by the treasurer, a director, an office administrator, an administrative assistant (supervised by an accountant) or the vice president (using QuickBooks). Sixty-two percent of the CSOs have a dedicated financial manager/accountant; for the approximately 35% without, the functions are performed by the treasurer, the vice-president, a director, an administrative officer, or an officer who works with auditors.
- Ninety percent of the CSOs produce financial reports, and 88% have annual audits of the reports.
- Sixty-four percent of the CSOs develop a budget linked to the strategic or operational plan; for some of the 28% that do not develop a budget with such links, the budget is activity-based, linked to projects, based on the previous year's budget or "ad hoc". Three CSOs indicate that this item is not applicable to them; one CSO indicates that the 2017-2020 strategic plan is being developed, another notes "no budget made available" (an organisation currently characterised as "defunct", but for which there are revitalisation plans), and a fourth notes "not in detail".
- The highest ranked primary source of funding for the CSOs is service delivery,

followed by fee-for-service arrangements, government subvention, donations (from individuals and corporate entities), grants/official development assistance (ODA), and constituent/target group subscriptions or fees. **See Chart 15**.

Chart 15. CSOs' primary sources of funding (Q.71)
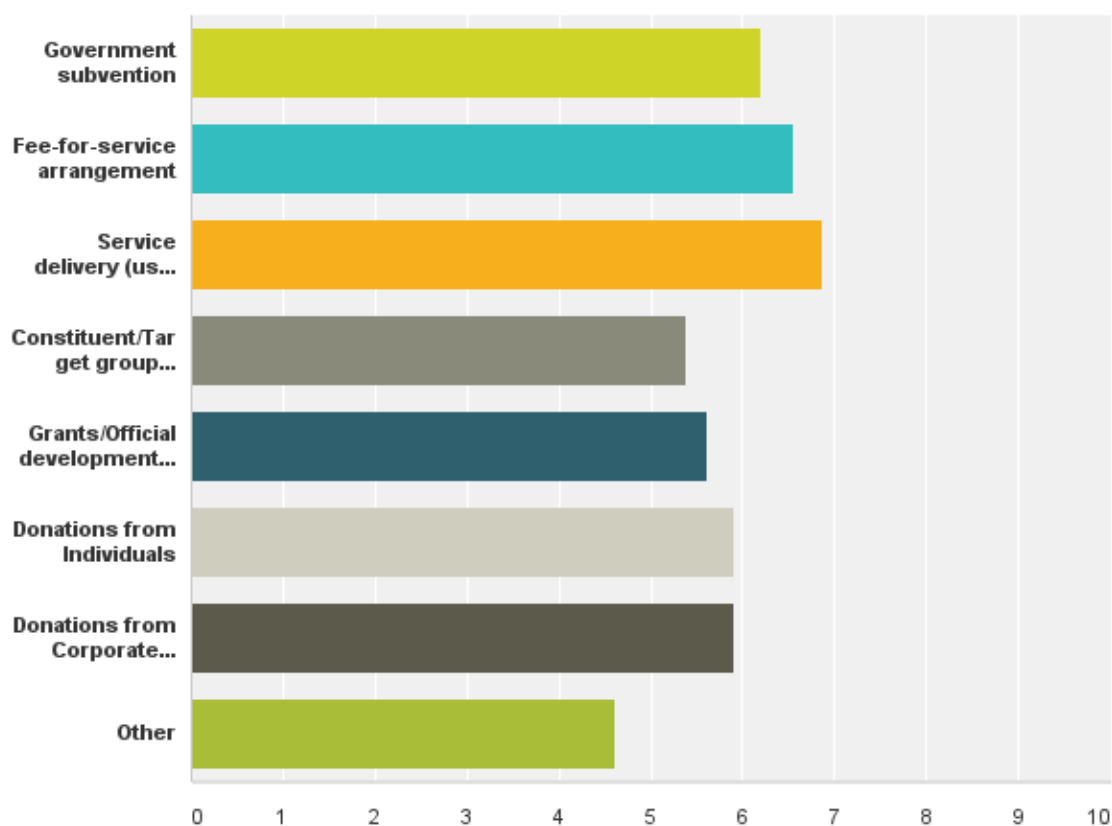
- Though not the highest ranked, non-government funders contribute significantly to CSOs, and, as **Chart 16** shows, 78% of CSOs identified <u>individuals</u> as the main type of such funders, followed by the private sector (76%), philanthropic foundations (41%), international NGOs/CSOs (30%), and UN agencies and international financing institutions (11% each). One CSO listed the HCC-Australian High Commission's Direct Aid Program (DAP) as a source of funding; another cited student organisations as a source of non-government funds, and two cited fundraising activities.

Chart 16. Non-government funders of CSOs (Q.72)
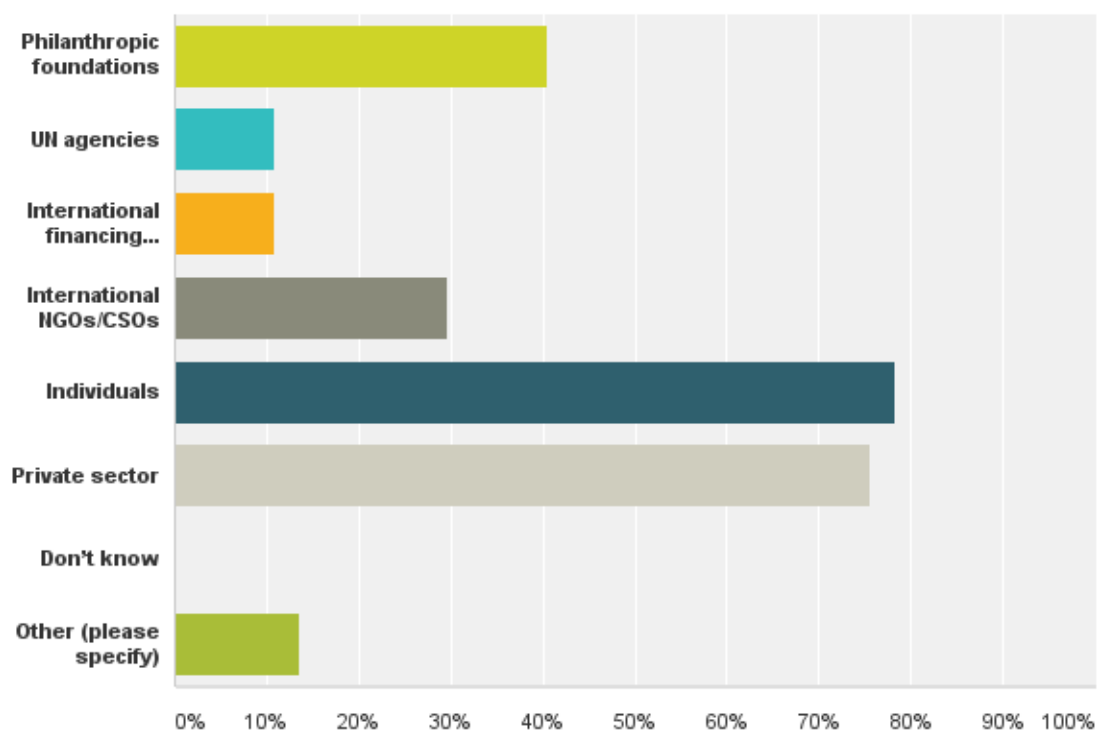
- In response to a specific question on funding from private sector enterprises, 71% of CSOs indicate that they receive such funding, while 29% state that they do not. Probed about those private sector enterprises that provide them with resources, 39% each names the food and pharmaceutical industries; 29%, health insurance providers, and 18% soft drink/soda companies. Two CSOs indicate that they receive funds from the alcohol industry, but none indicate the tobacco industry as a source of funds.

- Other private sector funding is provided by a variety of enterprises, including manufacturing and distribution, financial (banks), telecommunication, medical/ health diagnostic, food retail, travel and leisure, accounting, automobile, and advertising.

- In response to a question on consideration of conflict of interest (CoI) in their submissions for, or acceptance of, funding, 66% of CSOs indicate that it is a consideration, but only 33% have a CoI policy. Nonetheless, some CSOs note that they do not request sponsorship from makers of products that are considered high risk for NCDs or are associated with negative effects on health, or from organisations that do not share their values. One CSO states that though there is no formal policy, "the usual red flags are checked".

- Sixty-six percent of CSOs indicate that there is no single entity that provides a third or more of their total annual funding, confirming the diverse funding sources noted above. However, of the 34% who admit to having such funding support, 31% identify the funding entity as government; 30%, philanthropic foundation, and 23%, private sector. One CSO identifies tithes and offerings from membership as the funding type, and one operates a pharmacy that serves people with diabetes.

- A large majority (84%) of CSOs state that they undertake fundraising activities, most of which are special events (90%), followed by cause- or theme-related marketing (52%) and legacies (26%). Examples of special events include concerts, lunches, rides, walks, runs, dinners, dances, and balls; sale of meals, T-shirts, and Medic Alert bracelets; annual raffles; gospel concerts; and movie nights.

- Despite all the sources funding noted above, 57% of CSOs describe their current funding situation as inadequate to meet current plans; 35% describe it as adequate for current activities, but nothing in the pipeline for future plans; and 8% describe themselves as having a solid base of funders, providing for both current and future plans.

Discussion points

For transparency and accountability, concepts that are increasingly important in both resource allocation and mobilisation, it is essential that CSOs not only report on their project and programme achievements, but also on how financial resources were used, through the production of accurate financial reports, ideally audited annually.

There is scope for CSOs to improve their share of grant, technical cooperation, and ODA funds, with strengthened strategic approaches within national and international health frameworks, greater knowledge of traditional and non-traditional development partner interests and procedures, and strengthened grant proposal capacity.

Overall, CSOs appear to be careful regarding CoI in their dealings with the private sector (and other entities). However, a CoI policy, like a Code of Ethics or Code of Conduct, helps to set the tone, values, norms, and standards of the organisation, and should be developed and disseminated among CSO personnel and key stakeholders. There can be no justification for accepting funding from, for example, the tobacco industry, where the product is detrimental to health in any amount.

CSOs have many lessons to share regarding efficient and effective resource mobilisation for their sustainability; alliances and mentoring among the CSOs themselves are important knowledge-sharing mechanisms.

6.1.11 Patient engagement

- The CSOs engage with patients in many ways, as summarised in **Chart 17**. Consistent with the functions identified previously, approximately 78% of CSOs help patients to advocate for/promote health; 70% play a role in patients' communication with health care professionals and in their quest for health knowledge; 68% help patients to find safe, appropriate, and decent health care; 60% assist in accessing psychological support/counselling/mental health services; and 57% help patients make good treatment decisions and participate in support groups. Just under half (46%) of CSOs help patients get preventive health care, and 38% help with organising patients' health care and participation in their own treatment.
- Smaller percentages of CSOs assist patients with paying for their health care (38%), organising logistics for their care and wellbeing (30%), and with planning for end-of-life, if appropriate (21%); only 5% of CSOs helped patients to access legal services.
- Some CSOs list other aspects of patient engagement including: training of caregivers; "helping the patient in any way we can", including conducting research on medications and making information on side-effects available; making referrals, seeking feedback, and measuring client satisfaction; and determining clients' (not patients') pressing needs, planning with them to manage in the immediate, short, and longer term.

Chart 17. CSOs' actions in engaging with patients (Q.82)
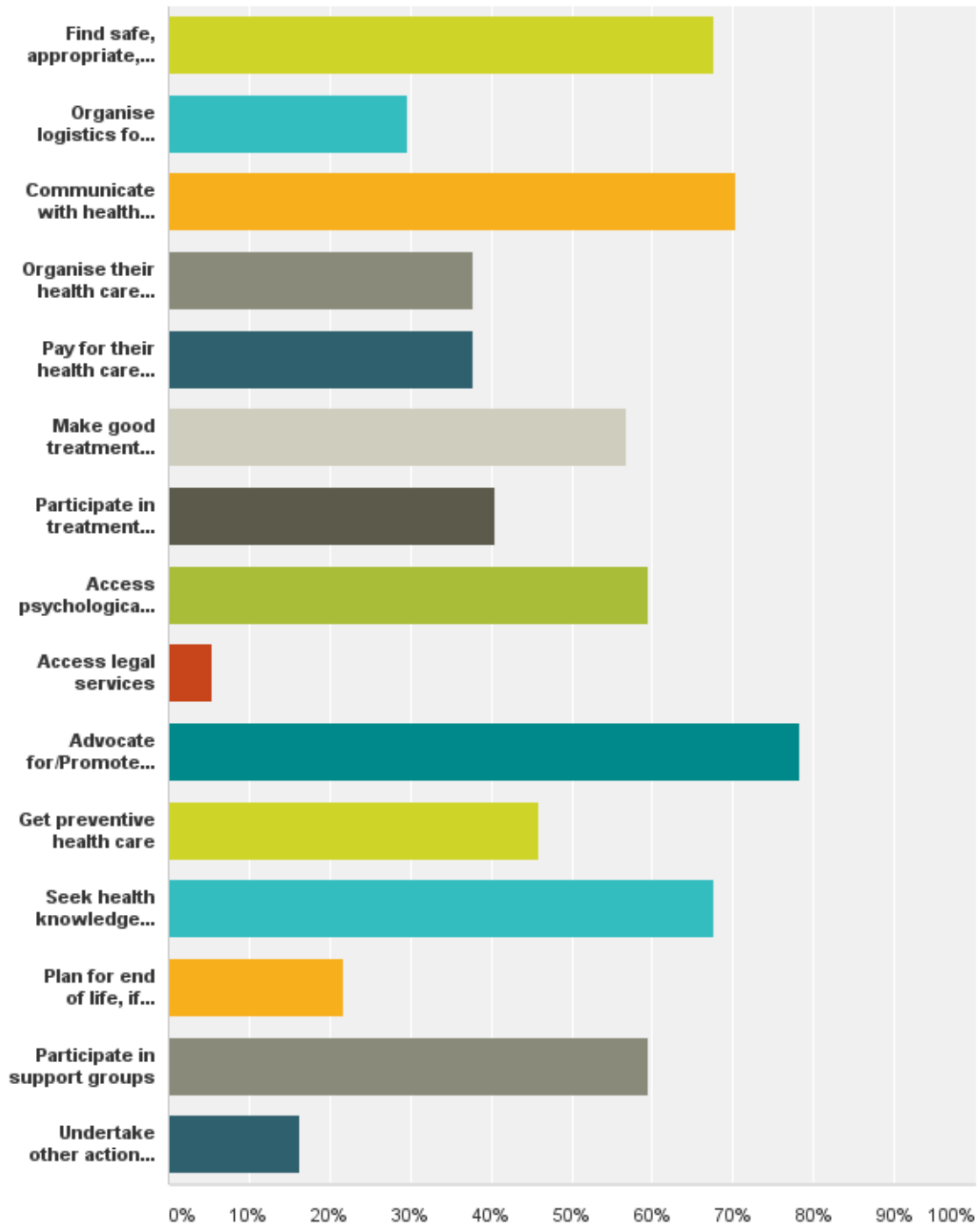
- The level of patient involvement in various aspects of the CSOs' governance and operations varies considerably. As indicated in **Chart 18,** the vast majority of CSOs (89%) encourage patients to share their stories in the media; 87% involve them in public education initiatives; 83% involve them in peer support programmes, and 83% engage them as advocates at community or other levels. Though patients are well-represented among volunteers in 64% of CSOs, only 40% involve them in programme and policy development; only 33% have patients represented on the BoD, and only 29% involve them in the strategic planning process. Some CSOs indicate patient involvement in fund raising, project planning, outreach programmes and testimonies, while one CSO states that patients are involved in "all major activities" conducted by the CSO.

Chart 18. Level of patient involvement in CSOs' governance and operations (Q.83)

| | Yes | No | Not applicable |
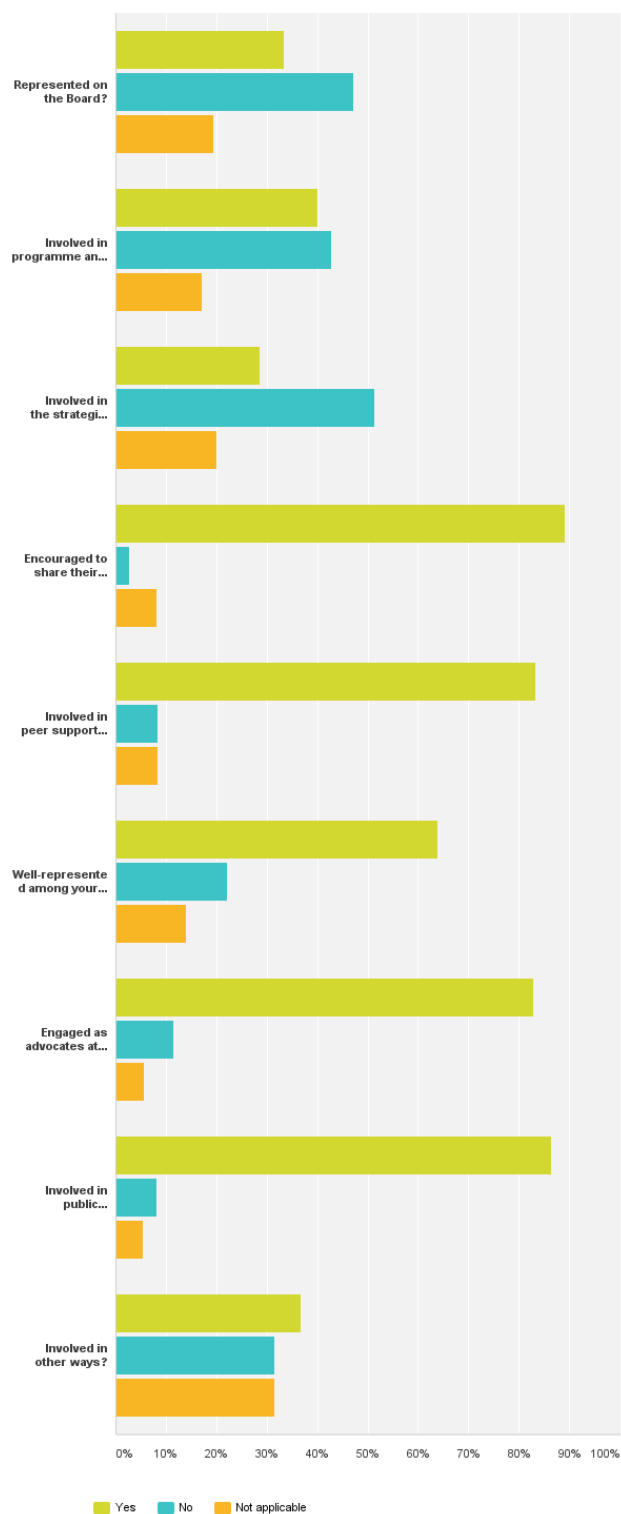
Discussion points

In keeping with strategic planning principles and interventions that address and satisfy the needs of the main beneficiaries of the initiatives, programmes, and projects, the CSOs' constituents, including patients/clients, should be involved in all aspects of the CSOs' operations, to the extent feasible. The insistence on the use of the term "client" instead of "patient" by one CSO is noted, as "client" is a wider term that covers family members, with whom the CSO may have to engage when they seek information or services on behalf of the of the person with the disorder. Patients/clients can offer valuable perspectives on what activities to undertake, and how best to implement them.

Relatively few CSOs address planning for end-of-life, if appropriate; however, CSOs have a role to play in advocacy for survivorship and palliative care, engaging patients/clients as powerful advocates for stronger health systems that include relevant programmes.

As noted in section 9.1.15 below, only 32% of CSOs selected "models for patient engagement" as an area for their development and/or capacity strengthening; this may not be a priority for most CSOs at this time, but should be seen as an area for growth.

6.1.12 Successes and contributing factors

- CSOs have had many successes over the past 5 years, in areas related to institutional development; service provision; partnerships; capacity development; resource mobilisation; strategic planning and programming; and advocacy, health promotion, and communication for health. Some CSOs have gained national and international recognition for the quality of their work, and have formed critical partnerships with Ministries of Health, becoming key players in national health systems. Selected CSO successes are summarized in **Table 2**.

Table 2. Summary of selected CSO successes over the past 5 years

Categories	Examples
Institutional development	Registration as a CSO
	Membership in international hospice association
	Development of own website and Facebook page
	Resuscitation of the national Diabetes Association
	Pioneering work to establish two branches in sister island
	Staff training in clinical and administrative areas
	Establishment of branches of the Association in three other districts in the country
	Formation of a Cervical Cancer Committee with support from the MoH
	Accreditation of the CSO's cardiac rehabilitation programme
	Establishment of a Youth Arm of the CSO
Service provision	Palliative/hospice care in the home
	Prevention and early detection of cancer, emphasising primary health care
	Country-wide screening programmes, usually free of charge to the users
	Purchase of HPV vaccines and implementation of a national HPV vaccination programme targeting girls in public schools
	Charity voucher programme for cancer screening tests
	Largest civil society provider of Pap smears in the country
	Integration of mental health into S&RH service delivery model, with no-fee referrals to in-house psychologists and social workers
	Camp for young people with diabetes
	Foot clinic
	Digital mammography services
	Equipment for colonoscopy, urology, and a new gynaecological oncology suite to the public tertiary care institution
	Monthly medical clinic held at the Association
	First holistic diabetes care facility in the Caribbean
	Monitors, testing supplies, insulin, and syringes for persons living with diabetes

Categories	Examples
	Free cervical cancer screening, treatment of various types of early stage cancers, and procurement of the services of a full-time consultant oncologist
	Networking with Oncology 21 for patient treatment
	Formation of support group for women with cancer
	Diabetes-related services, including kidney dialysis and digital retinal screening
	Heart surgery for over 70 children
	Formation of cancer survivor groups
	Medical assistance programme
	Extension of outreach activities into rural areas
Partnerships	Collaboration with a counterpart CSO (in another Caribbean country) to convene the latter's national conference
	Partnerships with local, regional, and international organisations, including NGOs/CSOs for diabetes prevention and control
	Pharmaceutical service advocacy, especially for tobacco control
	Working with academia in health promotion
	Strengthening of relationships with PAHO and the MoH
	Building partnership and collaboration with the HCC
	Collaboration with national and international entities in the implementation of the SunSmart programme
	Collaboration with partners for community outreach in cancer prevention and control
Capacity development	Foot care training for health professionals and non-health personnel
	Emergency cardiac care training programmes for lay persons and health professionals
	Yearly seminars in collaboration with the National Committee on Ageing
	Programmes for caregivers and patients living with Alzheimer's Disease
	Quarterly train-the-trainer workshops on health promotion/ communication, with different partners each time
	Training of volunteers in health promoting strategies

Categories	Examples
	Staging of conferences for medical professionals locally and internationally
	Psychosocial training for cancer management
Resource mobilisation	Fundraising for programme addressing cancer in children
	Raising over 1 million USD for the country's first Radiation Treatment Centre (which will be operated by the CSO)
Strategic planning and programming	Implementation of a Community Action project for blood pressure control, leading the "buddy initiative" pilot
	Development of a National Strategic Plan for NCDs
	Implementation of a School and Adolescent Mothers Programme
	Enabling inclusion of NCDs as indicators in the National Health Census Training of Health Care Professionals
	Passage of national tobacco legislation
	Implementation of the SunSmart programme, in partnership with the Americas Cup Youth sailing programme and St Baldrick's*, including presentations in schools and purchase of the country's first radiometer for daily readings of the UVI
Advocacy, health promotion, and communication for health	Creating greater awareness among the population
	Advocacy for tobacco control
	Promotion of national cancer registries
	Local and regional (Caribbean) engagement to raise cancer awareness
	Inclusion of schools in health promotion programmes
	Participation in World Alzheimer's' Month
	Week of activities for World Diabetes Day, including a Walk for Diabetes with Healthy Breakfast
	Country-wide community-based awareness-raising programmes
	Advocacy resulting in the establishment of two major cancer centres of excellence and access to expensive life-saving drugs by vulnerable cancer patients
	Persistence with prostate awareness programs

* St. Baldrick's Foundation is a "volunteer-powered charity committed to funding the most promising research to find cures for childhood cancers and give survivors long, healthy lives". For more information, visit http://www.stbaldricks.org/. Accessed 18 April 2016.

Categories	Examples
	Establishment of a cooking school at a church, and involvement of schools in in health-promoting activities
	Successful advocacy for nutrition labelling in a fast food restaurant and food labels on milk cartons
	Establishment of the national Red Dress campaign for heart health awareness
Recognition	Official national recognition of the CSO
	Appointment of CSO official as First Vice President of the IDF
	Award given to CSO official for work in the field of diabetes at the Dubai Convention
	Recognition by the public and MoH that the CSO is a key player in cancer control and treatment, and NCD prevention and control

In considering the main factors contributing to their successes/achievements, the CSOs included the following:

- Human resources: Commitment, dedication, engagement, and confidentiality of CSO personnel – volunteers, doctors, nurses, administrators, health coordinator; professional leadership and expertise; acquisition of office staff; genuine interest in helping patients and improving their quality of life, and understanding the needs; full team believing in programmes; hard work and persistence
- Management systems: Supportive and engaged BoD, good management team; interdepartmental collaboration
- Advocacy and outreach: Strategic and deliberate advocacy; outreach programs and community activities, creating goodwill; holistic approach to clients, focus on adolescent health
- Recognition: CSO's good reputation, in terms of services and accountability; recognition of quality work, with acknowledgement, support and investment from the public
- Partnerships: Inclusion by, and collaboration with, the MoH and PAHO; great working relationship with the MoH and strong technical support from international partners; networking and linkages, including with other NGOs, government departments, and international agencies; regular presence in, and strong collaboration with, the

media
- Resource mobilisation: Increased funding; fundraising; excellent support from the Bloomberg Philanthropies for tobacco control; excellent support from the HCC to attend meetings on NCDs and provide evidence-based materials

Discussion points

The successes identified provide a basis for strengthening information sharing among CSOs, enabling documentation of good practices, and fostering cooperation among the CSOs.

An overriding theme emerging from the success factors identified is the manner in which all categories of CSO personnel conduct themselves, demonstrating their commitment to the well-being of their clients and the quality of their work. Resources – financial, human, and infrastructural – are necessary, but not sufficient; the spirit of service allows successes even where there are limited resources, enabling teamwork, partnerships, and resource mobilisation to get the job done

6.1.13 Challenges

As **Chart 19** demonstrates, an overwhelming majority (90%) of CSOs identify funding as their main challenge, followed – at a distance – by human resources (63%), infrastructure (50%), strategic planning (45%), technical capacity (45%), and monitoring and evaluation/ accountability (42%). Fewer CSOs face challenges in governance (34%), management (26%), partnerships (26%), external communication (24%), and internal communication (13%).

Chart 19. CSOs main challenges (Q.86)

Challenge	
Governance	~34%
Human resources	~63%
Technical capacity	~44%
Funding	~90%
Infrastructure	~50%
Strategic planning	~45%
Management	~27%
Internal Communication	~13%
External Communication	~24%
Monitoring and evaluation/a...	~42%
Partnerships	~27%
Don't know	~2%
Other (please specify)	~13%
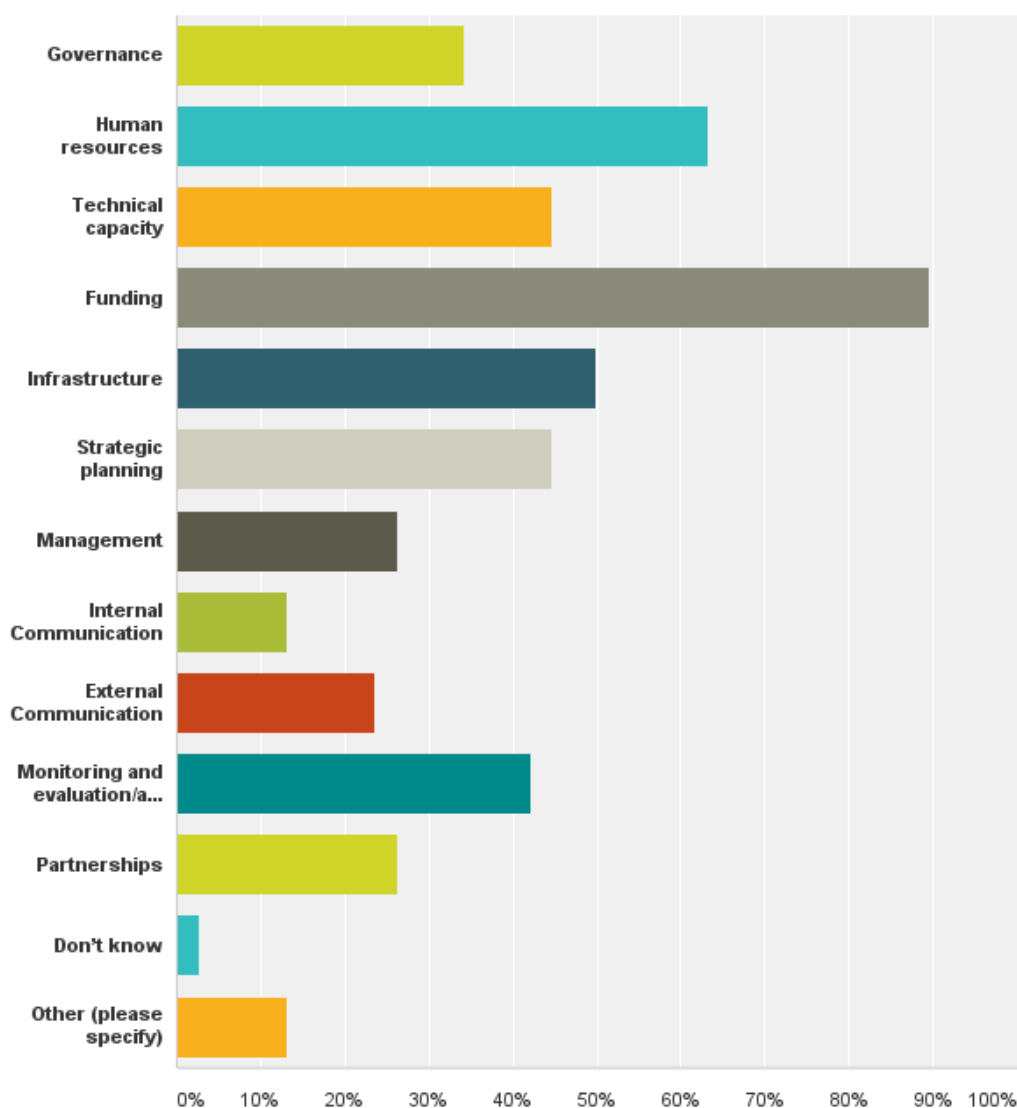
Discussion point

Resource mobilisation remains a top priority for CSOs' institutional development, capacity strengthening, and effective functioning, in addition to a strategic approach to planning, programming, and human resources management, as discussed in sections above.

6.1.14 Partnerships

- Seventy-two percent of CSOs indicate that there is a National NCD Commission or National Wellness Commission in their country of location (3 CSOs do not know if one is present). One CSO comments that the Commission is not functioning, and another states that there is an NCD strategic planning group that should evolve into a commission. Twenty-two CSOs comment further on whether they are members of an existing Commission – 13 are, and 9 are not. One of the latter indicates that it has never been invited, another, with S&RH as its main area of work, notes that "there is a lack of awareness of the scale of our work in NCD".

- Only 20% of CSOs (7) indicate that there is a National NCD Alliance in their country of location; 49% (17) indicate that such a coalition does not exist in the country and 31% (11) do not know. Of the 28 CSOs without a National NCD Alliance in their countries ("no" and "don't know" responses), 72% think that such an entity would be of value, and all but one indicate that they would join it; that one CSO responds "maybe, provided it is engaged for positive action".

- Only 9% (3) of CSOs state that they are members of the global NCD Alliance[15]; 68% are not, and 24% don't know.

- None of the CSOs has any formal or informal affiliation with the tobacco or alcohol industry; 4 (11%) are affiliated with the food industry, which provides sponsorship for events. One CSO notes that the alcohol industry may be present depending on the type of fundraising event, but there is no formal agreement.

- In identifying their main partners in NCD prevention and control - **see Chart 20 – 92%** of CSOs name the MoH, followed by other CSOs/NGOs (49%), the private sector (46%) and PAHO/WHO (43%). Thirty-eight percent named the national NCD focal point; 30%, other government ministries; 27%, academia; 16%, other UN or intergovernmental organisation; 11%, CARPHA; and 5% other CARICOM institution. Some respondents name international CSOs, CSOs in other Caribbean countries, and HCC; one CSO indicates that the partners are "too many to list".

- Only three CSOs are members of the global NCD Alliance; 68% are not, and 24% don't know.

- Seventeen CSOs indicate that they have a formal, signed agreement with various

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[15]   Information on the NCD Alliance is at https://ncdalliance.org/, accessed 18 April 2016

partners, the latter including MoHs; a health services authority; national commissions and committees (addressing issues such as mental health and ageing); other CSOs, national and international; academia (UWI, McGill University); PAHO/WHO; and international professional associations.

Chart 20. CSOs' main partners in NCD prevention and control (Q.90)
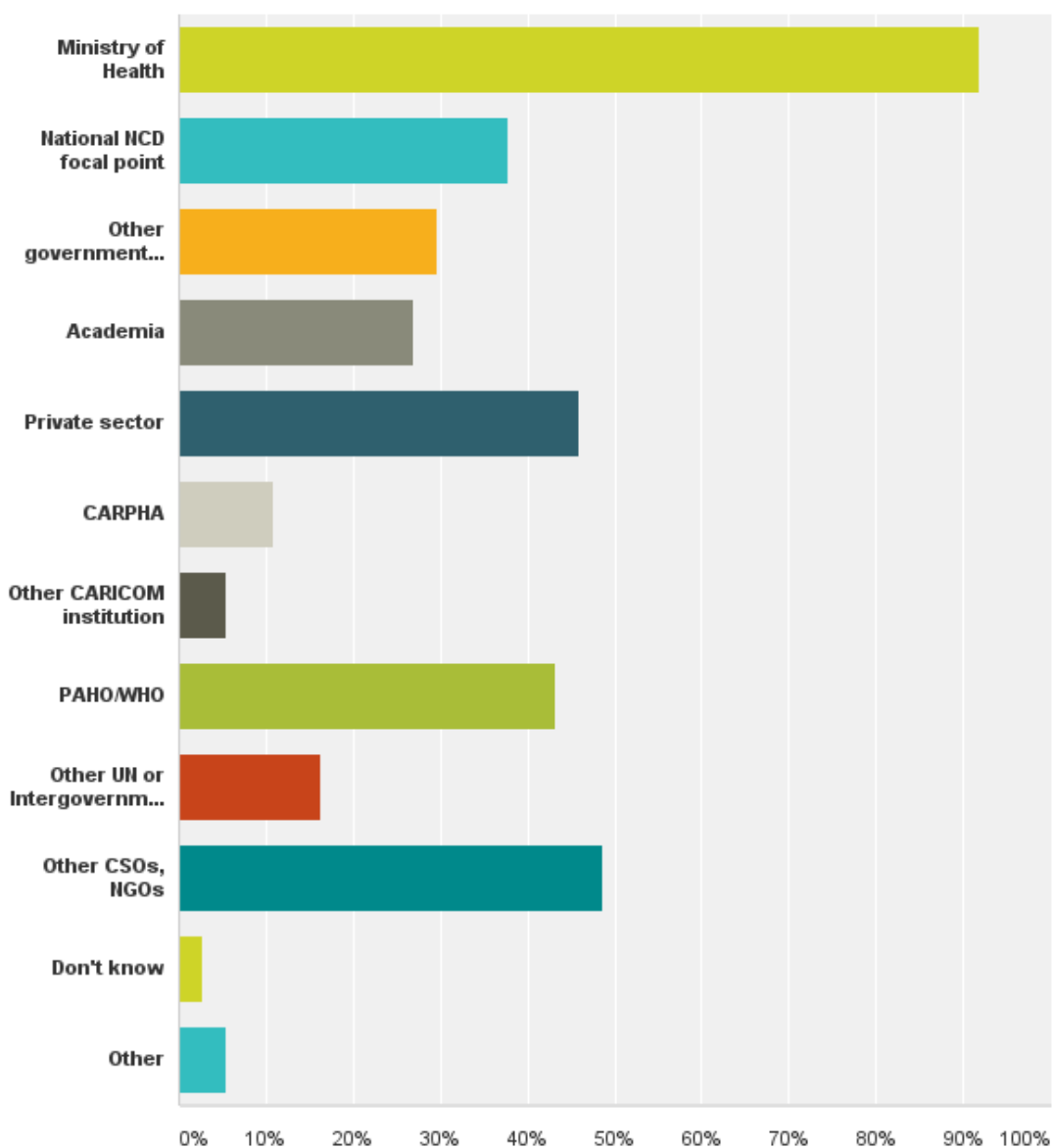
Discussion points

CSOs' advocacy and visibility, through promotion and dissemination of their work to wide audiences, is critical for enabling their involvement in governmental and other entities dealing with NCD prevention and control.

The identification by most CSOs of the MoH as a main partner is important, as this partnership facilitates the CSOs' alignment with NHPSP and their contribution to national health development, and can be an entry point to advocate for multisectoral action in support of NCD prevention and control. However, the disparity between CSOs reporting partnerships with the MoH (>90%) and with the National NCD Focal Points who are in the MoH (<40%) highlights the need to review the relationship and its mechanisms to facilitate strengthening.

The greater proportion of CSOs reporting relationships with PAHO/WHO, compared with regional institutions such as CARICOM and CARPHA, indicates that the international health organisation has largely succeeded in engaging and involving civil society in its technical cooperation. The finding may indicate gaps in regional institutions' engagement with CSOs at country level and/or with the HCC as the lead regional agency for civil society collaboration in NCDs, on behalf of national CSOs.

There is also scope for strengthening partnerships with academia. HCC has a role to play in the development of formal partnerships with this sector to support regional and country-level civil society collaboration in research for health.

Membership in wide and diverse networks enables CSOs to better consider and address the SDoH and other international health frameworks, enables knowledge exchanges and learning, and facilitates resource mobilisation – financial and technical. However, CSOs' participation in such networks must be strategic and managed, in order to enable actions in advancing their mission, purpose, and objectives, rather than divert their attention.

The lack of affiliation of the CSOs with the tobacco industry is commendable, and there is evident caution in establishing ties with the alcohol and food industries, given their significant contribution to NCD risk factors. CSOs must continue to be alert to CoI when dealing with these industries so as not to undermine their own credibility and values, notwithstanding the industries' willingness to provide much-needed resources; CoI policies would provide useful frameworks to guide potentially sensitive private sector partnerships.

6.1.15 Areas for development and/or capacity strengthening

- **Chart 21** demonstrates that the areas selected by most CSOs for development and/or capacity strengthening are awareness/public education campaign planning and implementation (71%), communication and social media (71%); training (71%); forming strategic alliances and partnerships (68%); advocacy and related strategies (63%); grant proposal writing and resource mobilisation (61%); and research capacity for policy analysis and development (53%).
- Half of the CSOs select areas such as running an efficient, effective CSO (50%), while just under half select strategic planning and management (47%); and best practices to reduce exposure to NCD risk factors (45%). Even fewer CSOs selected greater awareness of knowledge of national, subregional, regional, and global NCD frameworks (40%); NCD monitoring and accountability tools (37%); good governance and organisation building (37%); multisectoral engagement and partnerships (34%); examples of NCD prevention and control best practices (32%); models for patient engagement (32%); and better access to information on advancements in treatment and care (24%).

Chart 21. CSOs' areas for development/capacity strengthening (Q.94)
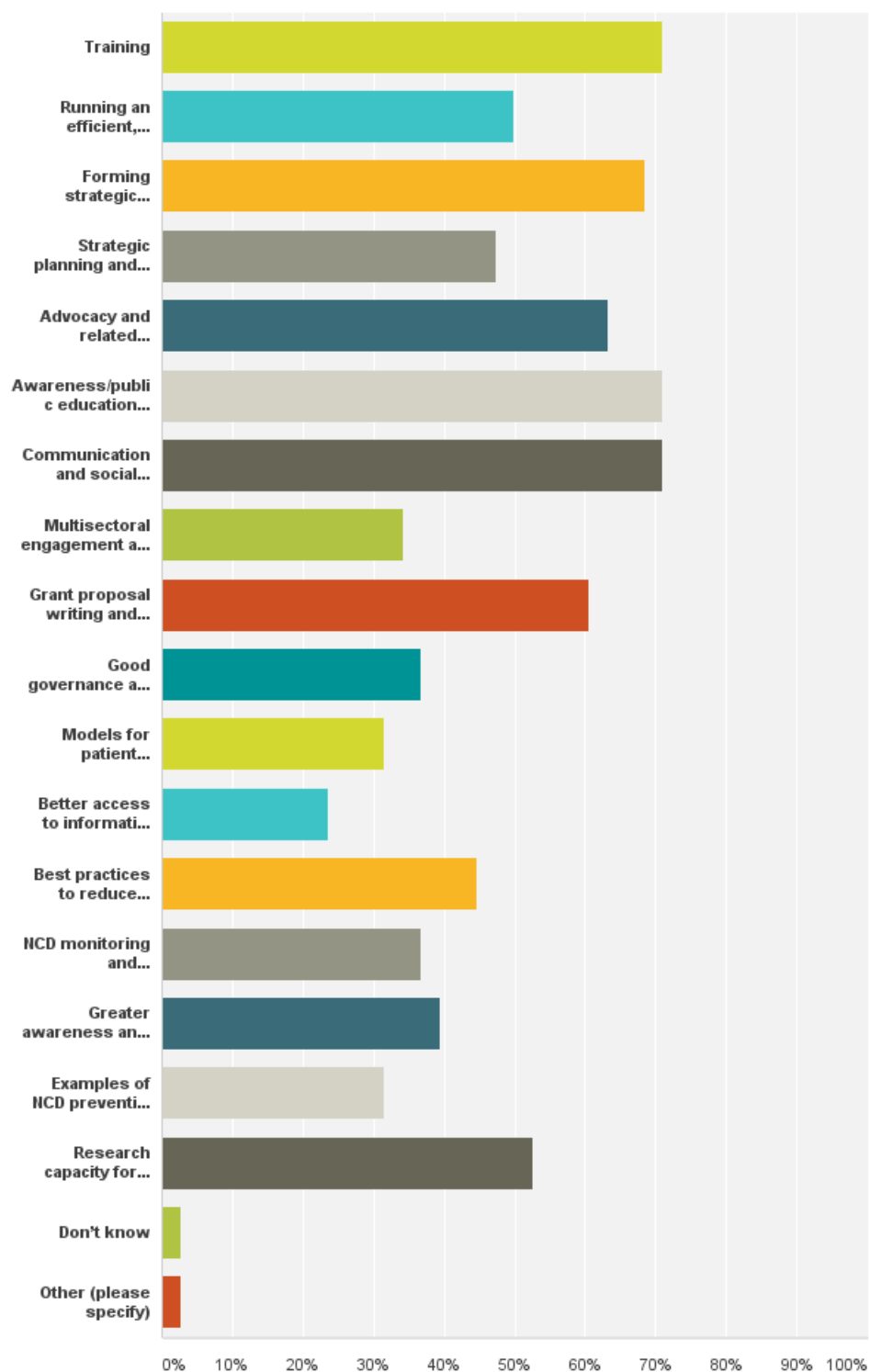
> **Discussion points**
>
> Most CSOs wish training to improve their functioning in their traditional areas of work - public education, communication, and advocacy, even as they recognise the need for enhanced capacity in policy analysis and development, developing partnerships, and undertaking resource mobilisation.
>
> Consistent with findings noted previously, most CSOs seem fairly satisfied with their governance and management structures, as well as their awareness of NCD frameworks, good practices, and strategic planning. They also seem less interested in strengthening capacity in patient engagement and learning of advances in treatment and care; this might indicate the willingness of most CSOs to leave advanced clinical care to the public and private sectors, and to focus on what they do best using national, rather than international, frameworks for action.
>
> However, to enable partnerships, alliances, and networking to advance their mission, it will be critical for CSOs to look outward as well as inward, sharing experiences, learning lessons and mobilising resources as appropriate, without compromising their values and norms.

6.1.16 HCC collaboration, communication, and performance

Collaboration

- Of 38 CSOs, 90% (34) are members of the HCC and 8% (3) characterise themselves as non-members. However, two of the three are, in fact, HCC members; the third, a national, government-led, multi-stakeholder committee with CSO representation, was invited to participate in the assessment because of its range of membership and its key role in shaping the country's response to NCDs. One CSO responds "don't know" to the question of membership in the HCC.
- Eighty-nine percent of CSOs indicate that they have benefitted from HCC membership. As demonstrated in **Chart 22**, most (94%) through receipt of the

weekly electronic publication "HCC Roundup", followed by attendance at regional meetings (73%), capacity building (46%) and receipt of sub-grants for special projects (36%).

- Other benefits listed include linkages to the international NCD movement; recognition by international agencies such as the NCDA, American Cancer Society, WHO, and UNESCO; sub-grants; and physical visits from HCC, with guidance and support for decision-making.

Chart 22. Areas in which HCC membership benefits CSOs (Q.97)
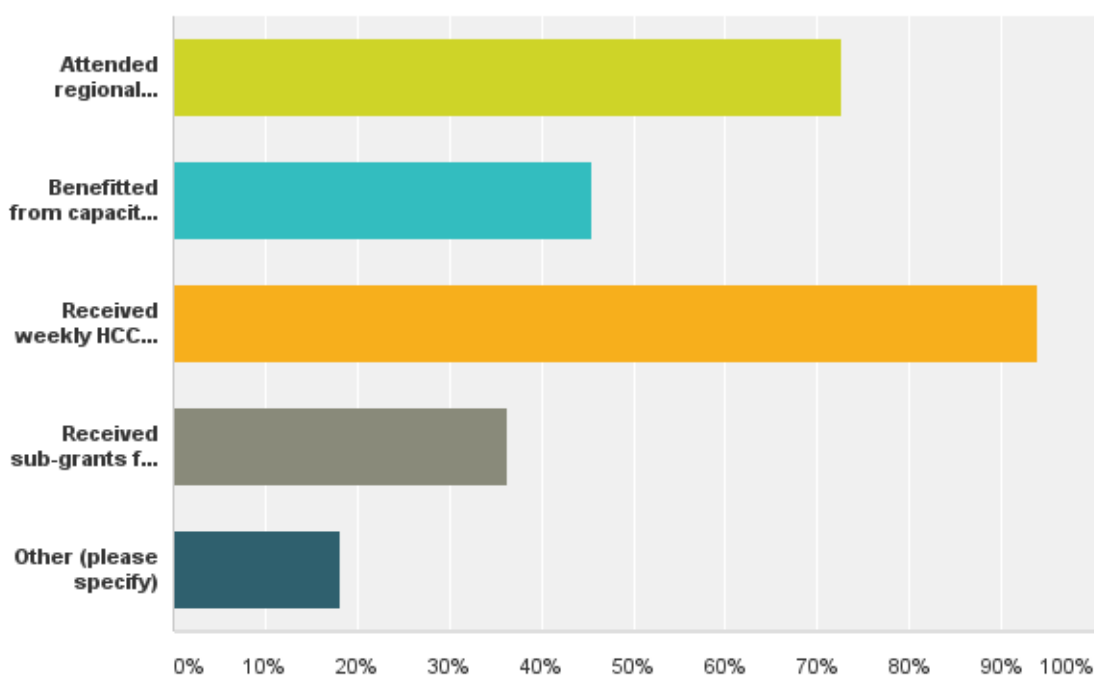
- Asked to state the main ways in which HCC can assist their development and capacity strengthening, 66% of CSOs select training; 63%, providing funding; 61%, sharing information/good practices/tools; 58% each, establishing partnerships and resource mobilisation; 45%, strengthening the CSO's online presence; 42% monitoring and evaluation; and 40%, strategic planning. **See Chart 23**. One CSO indicates "assistance in kind".

Chart 23. Main ways in which HCC can assist CSOs' development (Q.98)
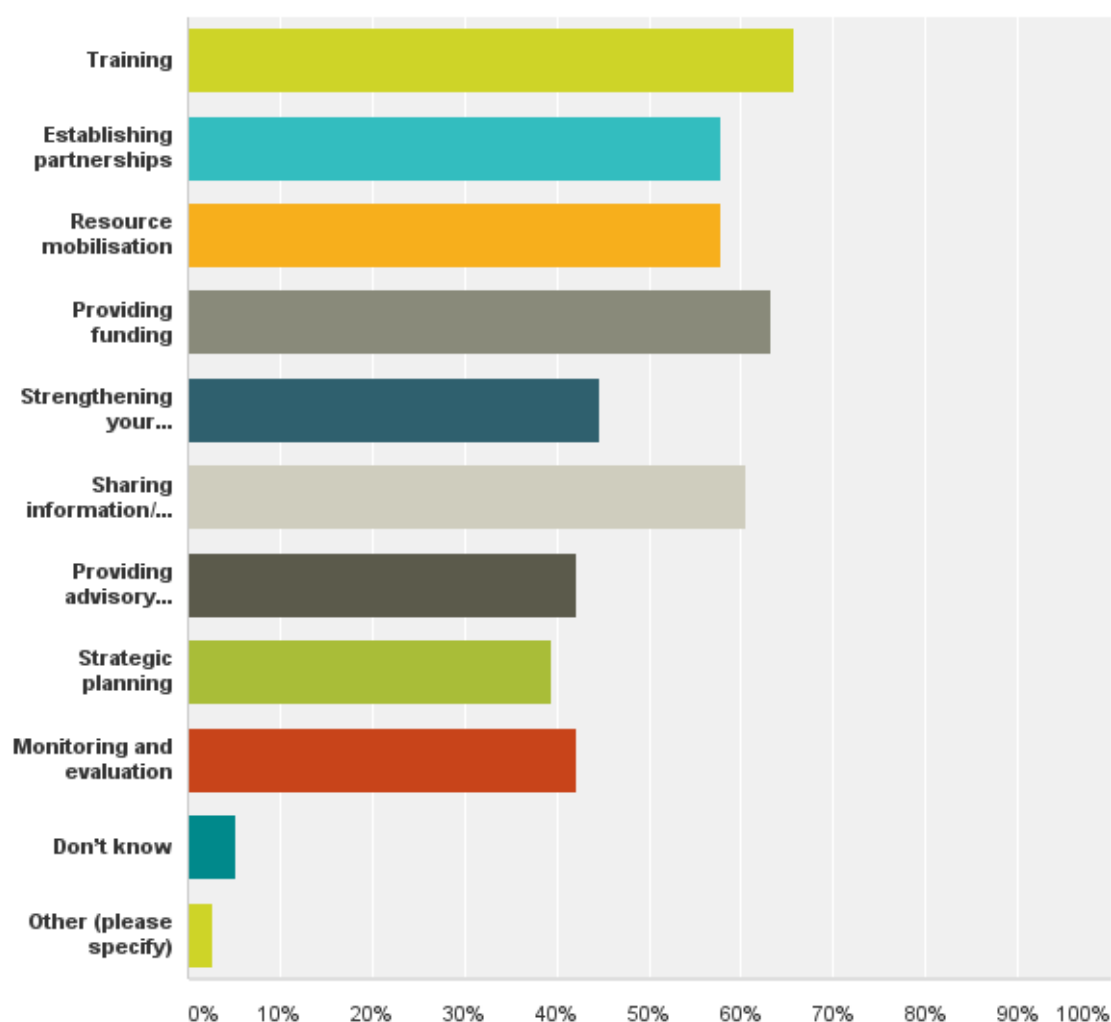
- The CSOs' suggestions for HCC's primary areas of focus, demonstrated in **Chart 24,** complement the suggestions for HCC's assistance, in some areas. Eighty-six percent of CSOs state that HCC should focus on advocacy; 74%, policy development (political level); 69%, building partnerships; 66%, capacity building; and 63% each, resource mobilisation, international representation, and communication. Strategic planning was selected by 40% of CSOs; monitoring and evaluation by 37%; and mHealth/eHealth by 34%. One CSO suggested that HCC focus on "assisting organisations by sharing best practices, resources, and creating a conference".

Chart 24. CSOs' suggestions for HCC's primary areas of focus (Q.117)
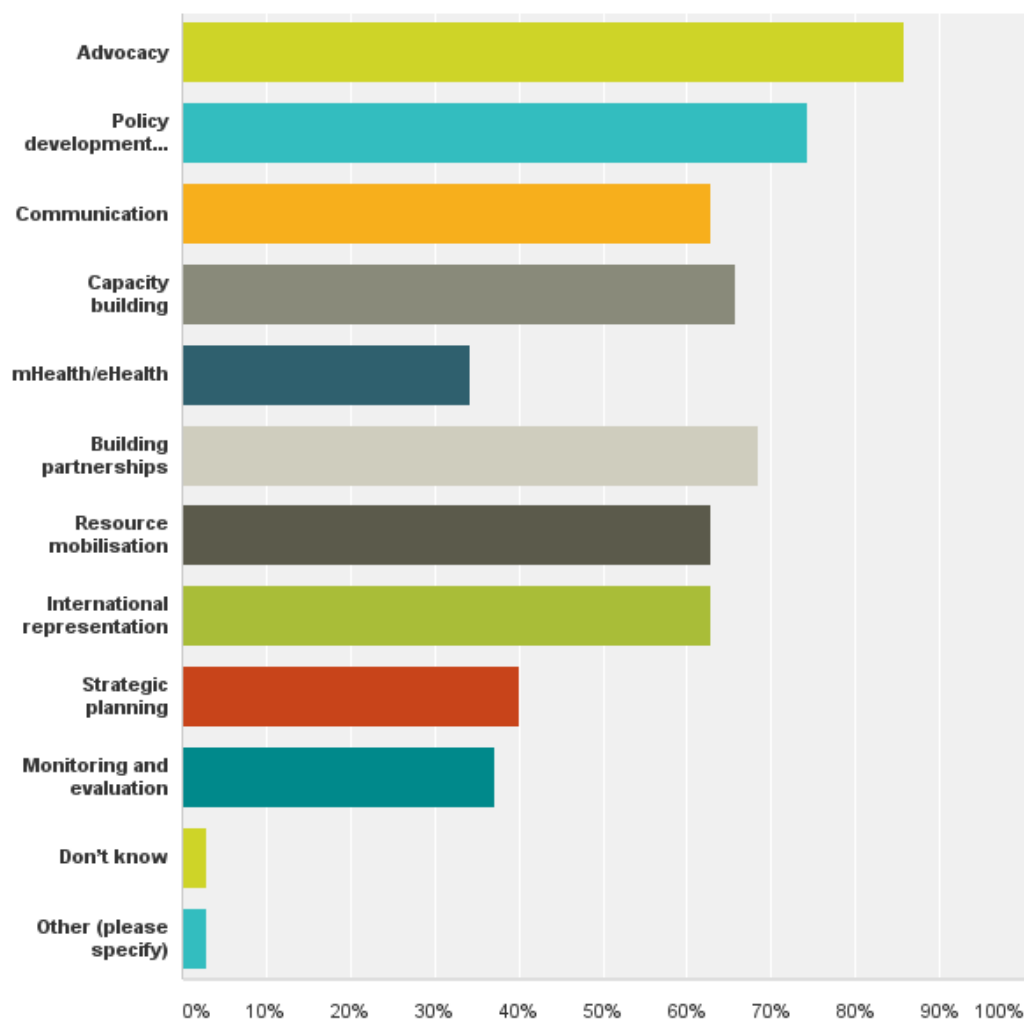
- Further validation of these themes is seen in CSOs' listing of ways in which HCC can better serve their organisations. The responses include:

  - Institutional and capacity development: Technical assistance to address governance and administration issues; increased organisational capacity and sustainability; capacity building, training, staff development; provision of advice on how to become an effective advocate for the NCD cause
  - Improving communication and information sharing: More communication; communication strategy; development of resources in French; knowledge exchange and sharing of good practices; education
  - Partnerships: Stimulating collaboration and new partnerships that would enhance access to treatment options in the region; strategic alliances, conferencing, participation in subregional workshops, and networking; advocacy for linkages between NCD planners and providers of services in other areas, such as sexual and reproductive health, and adolescent health
  - Resource mobilisation: Funding, information on funding sources, and access to grant funding opportunities
  - Strategic planning and programming: Policy development, service development, data collection

Communication

- Eighty-nine percent of CSOs indicate that they have visited the HCC website, and 84% find it useful and informative; the remaining 16% don't know. One CSO notes the "enormous amount of information on the website" and that "it is not always clear how to get to desired information", while another asks for "more templates and examples".
- Ninety-two percent of CSOs indicate that they receive the weekly **HCC Roundup**, and all find it informative. Though 81% of CSOs (30) find the Roundup information useful in their work, two do not find the information useful for their work, and five don't know.
- Fifty-six percent of CSOs have submitted information for inclusion in the Roundup, 36% have not, and 8% don't know. Asked how HCC can make it easier for CSOs

to contribute to the Roundup, some CSOs note that it is already easy to submit content, but one suggests that HCC issue invitations for submissions, especially where a CSO is thought to be doing something well or different. Another suggests that articles on specific topics be requested, and there is also a suggestion that there be a more operationally-focused section.

- Some CSOs express their satisfaction with the content of the Roundup, but others make suggestions for improvement: feature exchanges of information and sharing of best practices with others engaged in similar work; include more articles on NCDs; encourage CSOs to make a commitment to submit regular contributions; and focus on real-life stories.
- On the issue of social media:
  - Sixty percent of CSOs have "liked" the HCC Facebook (FB) page, 32% have not, and 8% don't know; 65% find HCC's FB posts useful, while 35% don't know. One CSO suggests that there be more information on global agreements; salt, sugar, and tobacco initiatives; and best practices.
  - Fourteen percent of CSOs follow HCC on Twitter, 75% do not, and 11% don't know. Therefore, only 23% find HCC's tweets useful and informative; 7% do not, and 71% don't know.
  - Sixty-six percent of CSOs don't know if HCC should be on any other social media; 20% say yes, and 14% say no. One respondent admits to seldom using social media, hence not being in a position to advise; however, the respondent notes that many people regularly communicate by WhatsApp, for example. Two CSOs suggest that HCC have a presence on Instagram, one CSO suggests LinkedIn, and another notes that "if we want to get the word out, then we should make use of every aspect of social media".

Performance

- With respect to HCC's performance in its key strategic areas of advocacy, communication, capacity building, and mHealth/eHealth, 94% and 92% of CSOs, respectively, find communication and advocacy to be either very satisfactory or satisfactory. For capacity building and mHealth/eHealth, 73% and 61% of CSOs, respectively, rate HCC's performance as very satisfactory or satisfactory, with 24%

and 36% of CSOs, respectively, responding "don't know"; only one CSO rates them as unsatisfactory. **See Chart 25**.

Chart 25. CSOs' rating of HCC's performance in four strategic areas (Q.99)

Very satisfactory   Satisfactory   Unsatisfactory   Don't know
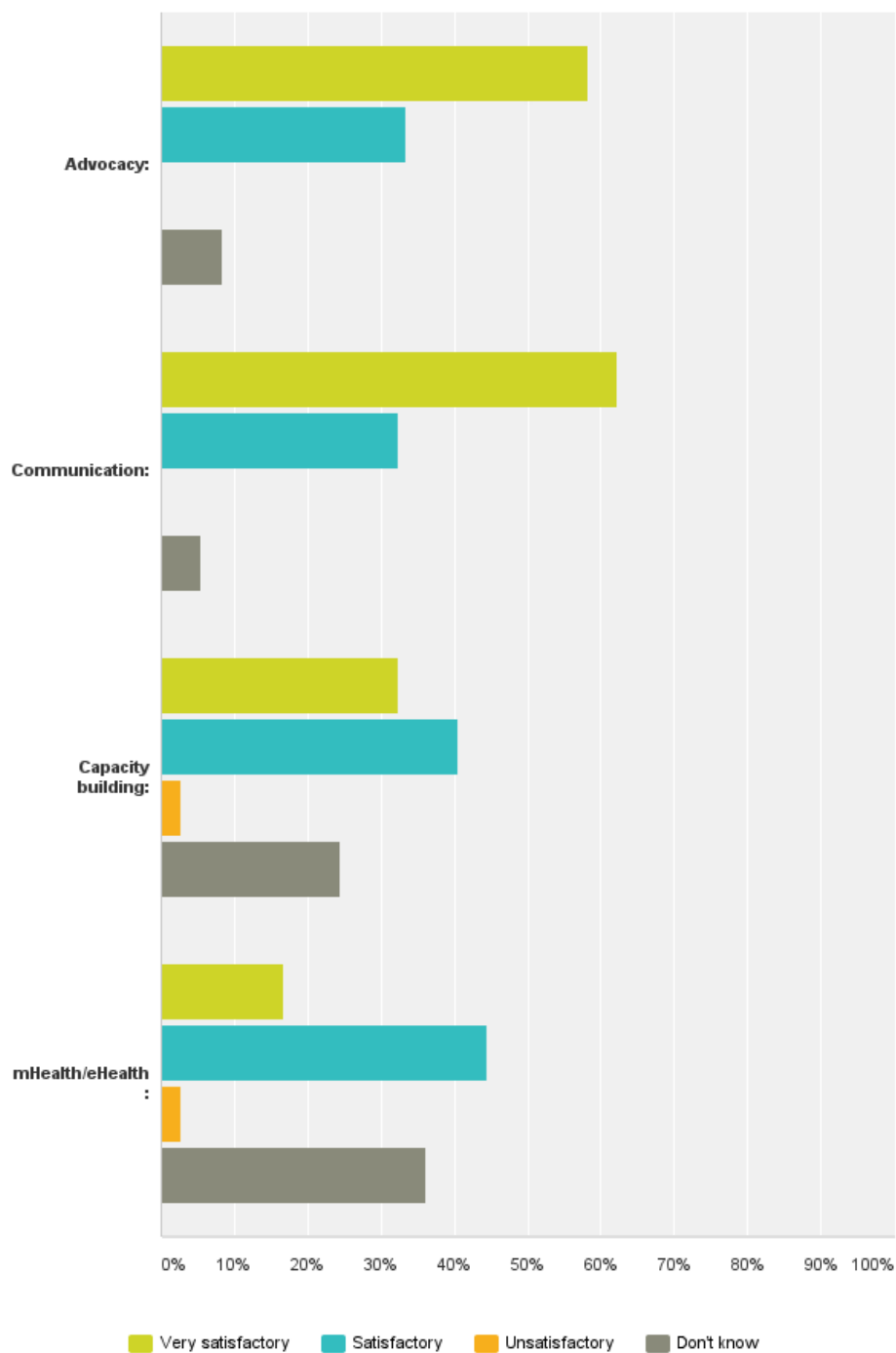
- In rating HCC's performance in fostering a whole-of-society, whole-of-government approach to NCDs, 38% of CSOs deem it very satisfactory; 51%, satisfactory; and 11%, don't know. There is no unsatisfactory rating. One CSO proposes the creation of a civil society alliance, another the creation of NCD alliances, and a third simply states "more societal and less governmental".
- Thirty percent of CSOs rate HCC's performance in improving their understanding of, and activities in, advocacy for NCDs as very satisfactory, while 60% rate it as satisfactory; 5% don't know, and 5% found the question not applicable. In their comments, two CSOs express appreciation for HCC's support in grant development and writing; one proposes training at the grass roots level and making information available outside of having to search for it on the internet; another proposes segmenting its constituents; and yet another suggests the creation of an NCD alliance.
- HCC's contribution to improving CSOs' contribution to policy development for NCDs is rated as very satisfactory by 22% of CSOs; satisfactory by 51%; and unsatisfactory by 3% (one CSO). Four CSOs indicate that they don't know, and 5 CSOs see this item as not applicable. One CSO suggests that training be provided at the local association level.
- CSOs also have suggestions on how HCC can exert greater influence on NCD prevention and control at global, regional (Caribbean), and national levels. The suggestions are summarized in **Table 3**. One CSO finds it "difficult to say", as the HCC is "doing a great job already".

Table 3. CSOs' suggestions for HCC's greater influence at national, regional, and global levels

National	Regional	Global
Convene face-to-face meetings of CSOs	Convene face-to-face meetings of CSOs	Advocate for palliative care to be included in addressing the SDGs
Engage more stakeholders	Assist in collection and exchange of information	Assist in collection and exchange of information
Share experiences	Make linkages between the NCD agenda and S&RH – many women's S&RH programs should improve the quality of NCD screening and treatment, as S&RH is an entry point for many women and girls to health services	Ensure ongoing exposure
Hold more frequent meetings	Share experiences	Convene annual symposium
Advocate	Increase dialogue/initiatives	Advocate
Strengthen partnerships with NCD Commissions	Hold more frequent meetings	Provide statistics
Create NCD alliance	Advocate	
Hold local workshops for CSOs	Learn from the HIV/AIDS campaign and consolidate health and wellness messaging under its umbrella. This would allow for a structured, escalating, and long-term programme to identify the barriers to lifestyle change in order to develop and deliver intervention programmes	
Fund community level programmes	Increase visibility in CARICOM meetings	
	Provide statistics	
	Strengthen role by increasing membership across the region	

Discussion points

The suggestions for HCC's contribution to CSOs' institutional and capacity development, and its primary areas of focus are in line with HCC's mission "To harness the power of civil society, in collaboration with government, private enterprise, academia, and international partners, as appropriate, in the development and implementation of plans for the prevention and management of chronic diseases among Caribbean people". The themes provide valuable input for the development of the Coalition's strategic plan 2017-2021. With the imperative for greater civil society involvement, partnerships, networking, and horizontal cooperation in development work, HCC can enhance its role as an intermediary, enabler, facilitator, and broker, addressing its members' needs and helping them to achieve their goals, while simultaneously fulfilling its own mission.

HCC's weekly Roundup and presence on the web and social media are of value to the CSOs. However, there appears to be scope for a review of the communication products, perhaps with re-tooling and streamlining of the content. Greater sharing of CSO experiences and real-life stories, in addition to information on international events and frameworks, may find greater traction with HCC members, as they see a greater reflection of themselves and their work.

The findings suggest a need for HCC's strengthened action in the areas of capacity building and mHealth/eHealth, wider targeting of CSOs for relevant activities, and/ or improved dissemination of information on actions taken.

HCC has a strong role to play in enabling CSOs' advocacy, and their contribution to multisectoral action and policy development for NCDs. There are several frameworks that will facilitate such action, among them CCH IV, SDoH, Health in All Policies (HiAP), the UN HLM Declaration and WHO Global Plan of Action, and the SDGs; these can provide impetus for HCC and CSOs alike.

- In final general comments, CSOs express gratitude for, and appreciation of, HCC's support and contributions, including in enabling project funding and CSO networking. One CSO sees the HCC as the "main driver for monitoring and evaluation of the Port of Spain Declaration and building alliances", while another opines that "HCC is well-placed to provide the development thrust needed for NGOs throughout the region". The HCC is thought to be doing a "great job" and is offered "best wishes for continued success". One CSO "looks forward to working together in the future", though another notes that "not all HCC members are developing at the same pace", and suggests a mentoring initiative, where the lesser developed members are twinned with the more developed ones. The overall sentiment is captured in the comment from a CSO that "we are happy and excited to be a part of HCC"

7. RECOMMENDATIONS

7.1 Recommendations for Civil Society Organisations

The findings from the CSO assessment support the following recommendations for capacity strengthening among Caribbean Health CSOs working in NCD prevention and control:

- *Governance and strategic management*
  - Ensure registration and legal status in the country of location.
  - Articulate a vision and mission, and develop a strategic plan with agreed objectives and indicators of their achievement, as well as an operational plan that includes human resources and indicative budget, to guide day-to-day activities, resource allocation/mobilisation, and transparency and accountability. The budget figures should be realistic, and should cover operating, implementation, and M&E costs.
  - Ensure that the strategic plan addresses national NCD policies, strategies or plans, and takes into consideration the SDoH, international NCD frameworks such as the POSD, CCH, PAHO and WHO NCD Action Plans, and the SDGs, especially SDG 3.
  - Develop a Code of Ethics for the operations of the CSO, and a Conflict of Interest policy that includes guidance for collaboration with the private sector and other key stakeholders. The WHO Framework for Engagement with Non-State Actors that was approved at the World Health Assembly (WHA) in May 2016[16] offers useful advice for the CoI policy.
  - Strengthen functions related to NCD policy development and the monitoring of government and private sector actions that impact NCDs and their risk factors.
  - Develop an HR plan for the efficient and effective implementation of the strategic and operational plans, outlining HR needs as well as mechanisms to recruit or source, manage, and retain the various categories of personnel needed.
  - Review the composition of the Boards of Directors and other governance and strategic planning structures, and ensure the inclusion of patients/clients, as well as a greater proportion of non-clinical health professionals, including

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[16]   The WHA Resolution and Framework are available at http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_R10-en.pdf, accessed 16 June 2016.

those knowledgeable in public health policy, communication for behaviour change, health system management, and partnerships, including for resource mobilisation.

- Explore options for permanent infrastructure for the CSO, through negotiations with government or other entity for dedicated physical space – rented, owned, subsidized or rent-free – to provide a permanent secretariat.

- *Capacity building and resource mobilisation*
  - Forge links and a mentoring arrangement with more developed CSOs, such as those with built capacity in management and resource mobilisation, to assist in institutional and capacity development.
  - Approach and collaborate with government agencies; intergovernmental agencies, including UN agencies, funds, and programs, and regional institutions; and the private sector, which may offer management courses, sometimes at little or no cost.
  - Improve skills and competencies in grant and project proposal development; CSOs with a solid base of funders, able to address both current and future plans, should share their experiences and expertise with others in less favourable situations.

- *Programming and service provision*
  - Keep updated regarding the major NCD and health priorities in the countries of location and the wider Caribbean, and determine if there are strategic contributions that CSOs can make to their prevention and control.
  - Consider how best to include causes of significant illness, such as mental and neurological disorders, and chronic respiratory diseases, including asthma, in the scope of work, perhaps as co-morbidities in addressing the main priorities.
  - For those involved in service provision, keep abreast of approaches to, and developments and advances in, the management of persons with disorders that are being addressed, so as to contribute to the health system's provision of quality care.

- *Communication*
  - Determine the most efficient and effective methods of getting messages to the desired audiences; develop a communication strategy linked to the strategic plan, with clearly defined audiences and definition of the types and mechanisms of communication best suited for effective advocacy, health communication, and health promotion.
  - Include the production of materials in non-official languages where appropriate, to target vulnerable groups whose primary language may not be the official one.
  - Allocate and/or mobilise resources for efficient implementation of the communication strategy, and monitor and evaluate the reach and impact of the messages.

- *Advocacy*
  - Advocate for, and contribute to, the formulation and/or update of NHPSP and the development of national SDG targets.
  - Highlight issues related to the relatively underserved areas of survivorship and palliative care, including patients/clients as advocates.

- *Partnerships*
  - Strengthen the relationship with the HCC, including through periodic and frequent submissions for the HCC weekly Roundup that reflect the type of content most useful to CSOs.
  - Ensure active engagement on the National NCD Commission (or equivalent) where they exist.
  - Seek out partnerships with the local Ministry of Health, in particular the National NCD Focal Point.
  - Seek out partnerships with local academic institutions.
  - Continue working with PAHO/WHO, and, where possible CARPHA and CARICOM.
  - Consider reaching "beyond the comfort zone" and/or forming alliances to strengthen the focus on vulnerable, discriminated-against, and excluded groups, in order to foster inclusion and reduce inequity.

- Expand partnerships with the private sector to support workplace wellness programmes and to advocate for greater private sector action and accountability in leveraging CSOs' core strengths to influence NCD prevention and control.

- *Accountability*
  - Ensure that there is an M&E framework to allow accountability, with regular development and dissemination of reports aligned with the strategic and operational plans – including audited financial reports – to constituents and other key stakeholders, highlighting successes, lessons learned, and challenges.

- *Patient engagement*
  - Review various models for patient engagement and consider the pros and cons of undertaking and/or expanding patient engagement functions.
  - Actively recruit patients for the Board of Directors and other governance structures.

7.2 Recommendations for the HCC

- *Governance and strategic management*
  - Review the Coalition's vision and mission to reflect its role as the premier regional civil society umbrella organisation in the Caribbean for NCD prevention and control, with wide and diverse membership, contacts, and partnerships that encompass national governments, regional entities, and international development partners.
  - Formulate the Strategic Plan 2017-2021 to address the expressed needs of HCC members and to contribute to Caribbean regional objectives in NCD prevention and control, through strengthened roles as advocate, broker, facilitator, convenor, and monitor.
  - Develop annual operational plans for the implementation of the Strategic Plan, identifying the outputs, deliverables, and resources (indicative budget and human resources) needed for the achievement of the respective outcomes.
  - Enhance HCC's work to enable CSOs' institutional development; capacity strengthening; strategic planning and programming; partnerships; advocacy,

health promotion and communication; information and knowledge exchange; horizontal cooperation; and resource mobilisation. HCC's actions in these areas can be enabled by – among other strategies – the Coalition's:

- Advocacy and networking, including with entities such as the NCD Alliance
- Representation and participation in regional and other international fora, the latter including the WHO's World Health Assembly, and communication of outcomes and possible benefits to CSOs
- Vigorous promotion of international NCD prevention and control frameworks that can be adapted to national and regional contexts
- Compilation of a database of development partners with interest in collaborating with developing countries for NCD prevention and control
- Continued dissemination of information on capacity development and funding opportunities
- Development and dissemination of a compendium of CSOs' achievements, successes, and good practices to facilitate information and knowledge sharing, and horizontal cooperation among its members, entities in the wider Caribbean, and in other regions.

- **Consider inclusion of strategic priorities and outcomes in the HCC Strategic Plan 2017-2021 around the themes of:**
  - Strengthening the institutional development and capacity of CSOs to contribute to NCD prevention and control through advocacy, partnerships resource mobilisation, horizontal cooperation, service provision, and patient engagement where appropriate
  - Communicating effectively for NCD prevention and control, including audience segmentation, and the appropriate use of print, electronic, and social media
  - Fostering resource mobilisation, partnerships, horizontal cooperation, and exchanges of information, knowledge, and experiences related to NCD prevention and control
  - Enhancing strategic and equitable approaches to NCD prevention and control, including planning, programming, and monitoring and evaluation of programmes and interventions
  - Enhancing HCC's functioning, sustainability, partnerships – at national, regional, and international levels – and overview of civil society's contribution to NCD prevention and control in the Caribbean

- *Accountability*
  - Ensure that the Strategic Plan includes a monitoring and evaluation framework and that resources are allocated for related activities.
  - Conduct a formal assessment of the use and impact of the Coalition's communication products, including the HCC Roundup. The assessment should determine number of hits daily/weekly/monthly, and satisfaction with frequency of publication, layout and content, and include interviews with CSOs and other key audiences to determine what specifically they like about the publication and what content is useful to them in their work. Interviews should include the relatively few CSOs who indicate that the Roundup is not useful for their work, and strategies should be developed to pique CSOs' interest and obtain content from them, perhaps using external resources to assist those CSOs with limited capacity. These actions should be included in the communications strategy that must be an integral part or complement of the HCC strategic plan.

- *Capacity building and resource mobilisation*
  - Explore options for sustainable sources of funding and human resources, and relevant capacity building, to support HCC's technical and administrative functions, given its critical roles in strengthening CSOs' work for NCD prevention and control in the Caribbean. Options may include contributions from Caribbean governments and the establishment of a Fund financed through taxes aimed at reducing risk factors, such as tobacco taxes.

- *Advocacy*
  - Disseminate and use the CSO capacity assessment report as an advocacy and resource mobilisation tool, since it identifies the stated needs of the CSOs for institutional and capacity development, and summarises their recommendations on how the HCC can better serve their needs.
  - Continue and strengthen advocacy for, and information-sharing on, NCD prevention and control in the Caribbean, especially targeting relevant regional and international entities and fora.

- *Research*
  - Consider additional qualitative surveys to probe some of the issues revealed, or not completely addressed, in the capacity assessment, such as the legal status of CSOs, their human resources, their management systems, their contributions to policy development, and their roles in monitoring government and private sector commitments and actions that affect NCDs.

8. CONCLUSION

The survey highlighted important issues related to HCC CSO members working in the prevention and control of NCDs. They are doing an excellent job in serving the needs of their constituents, in most cases with limited resources, and have achieved successes and many good practices. Notwithstanding, they have many needs, prominent among them adequacy of resources and more opportunities to meet, share information and experiences, and collaborate. There is scope for more strategic approaches, greater rigour and transparency in their operations, and greater success in their partnerships and resource mobilisation efforts. Stronger alignment with national health policies, strategies and plans, and with international frameworks for health such as the Caribbean Cooperation in Health, regional and global NCD plans, and the Sustainable Development Goals, will enhance strategic approaches, facilitate partnerships, and strengthen CSOs' contribution to national and regional health development.

Continued capacity building in the CSOs, including in management and resource mobilisation skills; enhanced partnerships and multisectoral collaboration; greater attention to health promotion and communication for equity; improved human resource management; greater transparency and accountability; and strategic sharing of information and expertise among the organisations themselves will all contribute significantly to the CSOs' efficient and effective functioning.

Facilitated by the HCC, the CSOs need to be proactive in forging links with each other, the UN, and other international agencies that may provide technical cooperation as well as financial resources. In turn, also in collaboration with the HCC, these agencies should be proactive in building CSOs' capacity to participate effectively in the multisectoral partnerships that are essential for NCD prevention and control.

CSOs underscore their deep appreciation of the HCC and its support, notwithstanding their suggestions for its improved functioning. As an umbrella organisation with a unique overview of its members, the Coalition is already recognised and valued nationally, regionally, and globally, especially for its communication platforms and advocacy. The HCC is therefore well-placed to facilitate and contribute to improvement in the functioning of its members, playing the strategic roles of enabler, facilitator, contributor, and broker, as it seeks to strengthen its own strategic approaches. The development, implementation, monitoring, and

evaluation of the HCC Strategic Plan 2017-2021 will respond to the expressed needs of the Coalition's members and international NCD frameworks, ensuring that the HCC will continue to be a valued partner in, and contributor to, the prevention and control of non-communicable diseases in the Caribbean.

Part II
Information Needs Assessment of HCC Member CSOs Working in the Prevention and Control of NCDs

1. LIST OF FIGURES AND TABLES

2. EXECUTIVE SUMMARY

The objectives of the information needs assessment (INA) were: to gain an understanding of information needs of civil society organisation (CSO) members working in non-communicable diseases (NCDs) in the Caribbean; and to explore information use, information needs, barriers to information and information literacy skills as well as their use of online networks, such as Communities of Practice.

An online survey was created and disseminated to CSOs. The survey was open from March – April 2016 gathering both qualitative and quantitative data. Results were analysed in Microsoft Excel.

There were 90 respondents to the survey. The results showed that respondents worked in a variety of topic areas and therefore required a variety of information to use for different aspects of their role. There were common barriers to information such as cost of registration/participation, cost of travel and cost of subscriptions.

Respondents collaborate with others both in their country, within the Caribbean and outside of the Caribbean.

CSO members working in NCDs look for and need all kinds of information and apply it in a variety of ways from keeping up-to-date to teaching and training. The results have similarities to findings of previous research undertaken by UK Health Forum, but highlight previously undetected barriers to information such as cost of travel and registration/participation fees. We recommend further research to gain a better understanding of these barriers and how they impact of the work of individuals. HCC should explore ways a Community of Practice would be established as a facilitator to information sharing and linking with colleagues who are geographically distant. Consideration should also be given to making information literacy training available.

3. INTRODUCTION

The Healthy Caribbean Coalition (HCC) has not previously undertaken a detailed, structured assessment of this kind. Supported by a grant from the UK Health Forum, an electronic survey was developed and disseminated to its CSO members working on NCDs.

This document summarises the findings of the information needs assessment (Part III of the survey). The results of the capacity assessment can be found in Part 1 of the survey report, available on the HCC website.

This research aims to:
- Support the provision of public health NCDs information for CSOs in the Caribbean
- Explore information and eHealth literacy skills amongst the NCDs focussed CSOs workforce
- Explore how evidence is used within CSOs
- Understand what unique information challenges exist in the region and what barriers there may be to accessing and utilising information
- Highlighting opportunities and solutions for sharing of information and improving collaboration between countries and organisations.

Objectives of this research:
- Collaborate with the HCC to undertake an information needs assessment of CSOs in the Caribbean
- Use a survey method to gather qualitative and quantitative data
- The survey will explore:
- Sources of information used
- Types of resources used
- Barriers to accessing information
- Systems and tools used to source information
- Skills in retrieval and critical appraisal of information
- The role of evidence in decision-making and supporting work

4. BACKGROUND

Information provision and access to the latest best evidence is becoming increasingly important in public health decision-making.

Universal access to information was a prerequisite to the Millennium Development Goals and current Sustainable Development Goals. *'Information need' has been defined as "the motivation people think and feel to seek information"*(1)

Previous research undertaken by the UK Health Forum (UKHF) into information needs of the public health workforce in the UK (2, 3) found that there was a lack of public health evidence, lack of organisational access to information and lack of time to search for and read information.

There has been little research around the information needs of the Caribbean population, but what research there is (4-7) suggests that there is limited access to the internet or a computer at work and that information sharing is limited. There is also a problem of accessing indigenous material (8). Our literature search found no papers focussing on the information needs of public health professionals in the Caribbean and therefore this research should start to build an understanding of the information needs of this community.

5. METHODOLOGY

The survey was built using questions previously used in information needs assessments undertaken by the UKHF. These questions were modified and added to by HCC to ensure the questions fit their requirements.

Once the questions were finalised, the questions were put into Survey Monkey and became part III of a three part survey that was also a capacity assessment of the CSOs of the Caribbean.

The survey was pilot tested. Once finalised, the survey was disseminated to 48 identified CSOs with a request that as many members of staff as possible complete the information needs assessment (part 3) of the survey.

The survey had a qualifying question at the beginning: 'Which survey have you been asked to complete? Parts 1 to 3 or Part 3 only.'

The survey was open for 4 weeks through March and April 2016. The initial deadline was 31st March but this was extended to 18th April to allow people more time to complete the survey. Several email reminders were sent by the HCC President and Executive Director during this period. Once the survey closed, the results data were exported into Microsoft Excel for analysis.

6. RESULTS

Ninety respondents completed the information needs assessment part of the survey. Due to the nature of dissemination we were unable to calculate a response rate. As respondents were able to skip questions it is not necessarily the case that 90 respondents answered all questions in the information needs assessment.

Tables and charts will be presented with a short narrative to highlight interesting results. Where relevant, responses will be described with n= or % of responses.

Number of responses by country

Table 1 (below) shows the number of responses by country. As the table shows, we had significantly higher responses from some countries compared to others and therefore we have not broken down any results by country as it was decided that to do so would be an unfair comparison.

Table 1. Number of respondents per country

Country	No. of responses
Antigua & Barbuda	4
Bahamas	4
Barbados	26
Belize	6
Bermuda	3
Cayman Islands	1
Dominica	10
Grenada	3
Guyana	1
Haiti	6
Jamaica	10
St. Lucia	3
St. Maarten	2
Suriname	1
Trinidad & Tobago	10

What topics do you work with?

Figure 1 displays the topics CSOs of the Caribbean work with. Respondents were able to select as many topics as applied. All topics had a least one response with no one topic significantly standing out, suggesting that respondents work on several topics. The most common was 'Prevention and control of NCD risk factors' (n=50) and least common 'Disabilities' (n=9). See Appendix 3 for list of topics respondents gave under 'Other'.

Figure 1. Topics CSOs work with (n=)

Tobacco use, 25
Cardiovascular diseases, 36
Unhealthy diet, 48
Diabetes, 42
Physical inactivity, 39
Cancer, 42
Disabilities, 9
Harmful use of alcohol, 18
Mental Health & Neurological Disorders, 10
Chronic respiratory diseases, 11
Other (please specify), 10
Prevention and control of NCD risk factors, 50
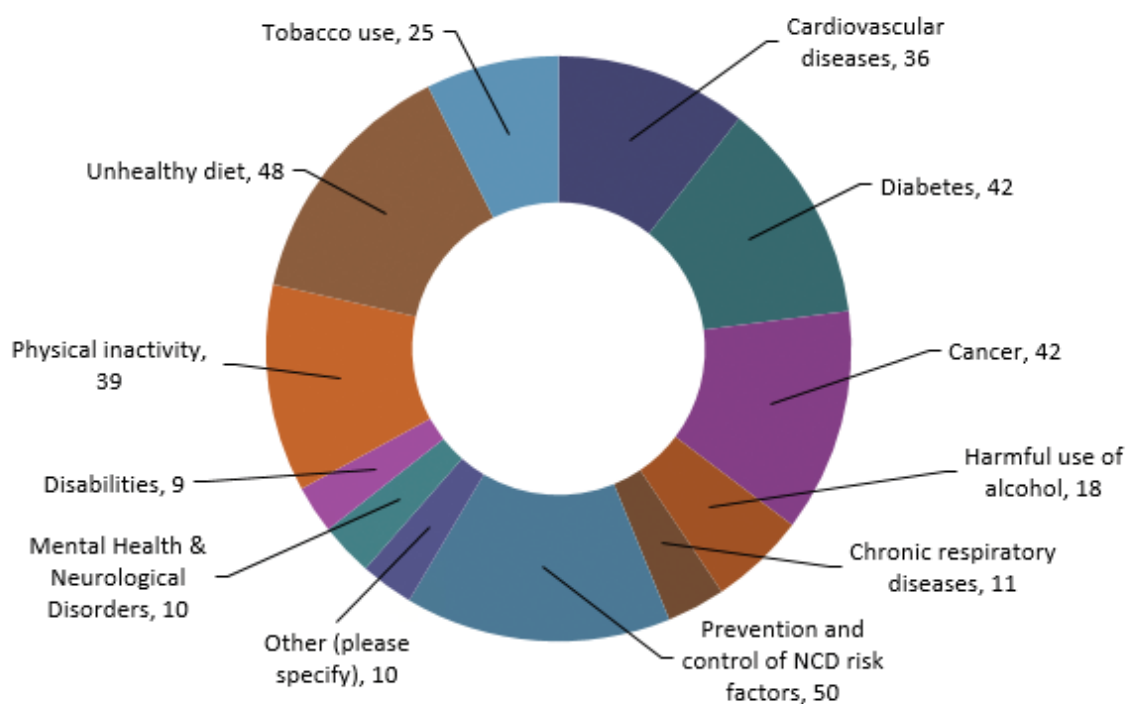
Many respondents engaged with the public as part of their role (80%, n=70). Patients (67%, n=58) and policy makers (53%, n=46) were also common (Figure 2). As respondents were allowed to select as many as applied, these results suggest that respondents engage with a variety of people as part of their role. Other people respondents said they engage with include board members, health professionals, partners and clients.

Figure 2. With whom do you have direct contact or engage in your role in your organisation?
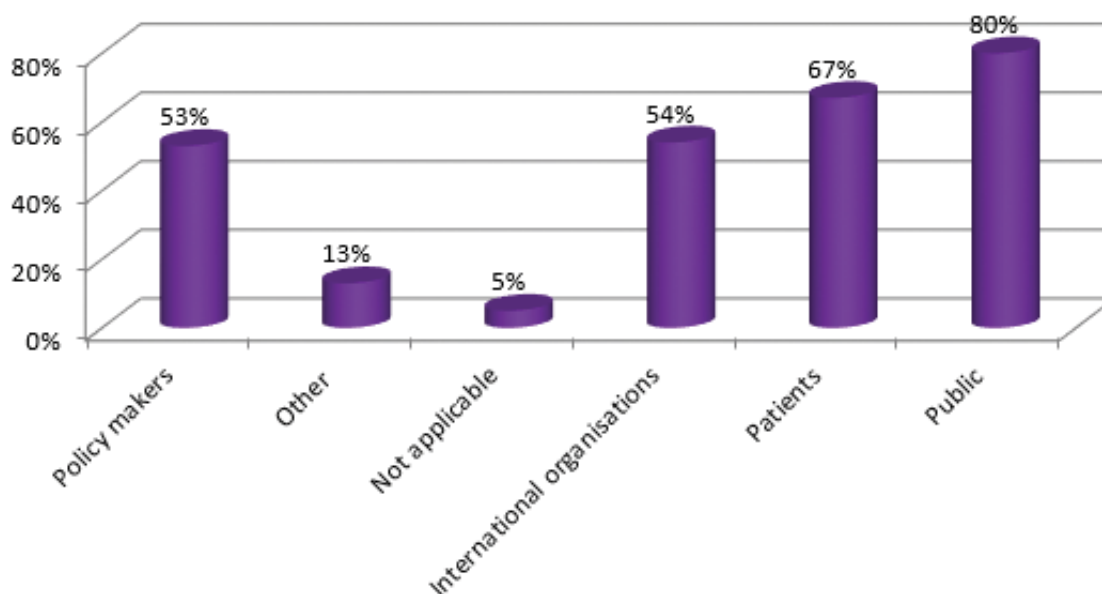
Information seeking

Figure 3 displays the factors that determine when respondents seek information rated by frequency. Organisational need/demand and personal learning were common factors. Disaster/critical need was the least common factor.

Figure 3. Frequent factors that determine when you seek information
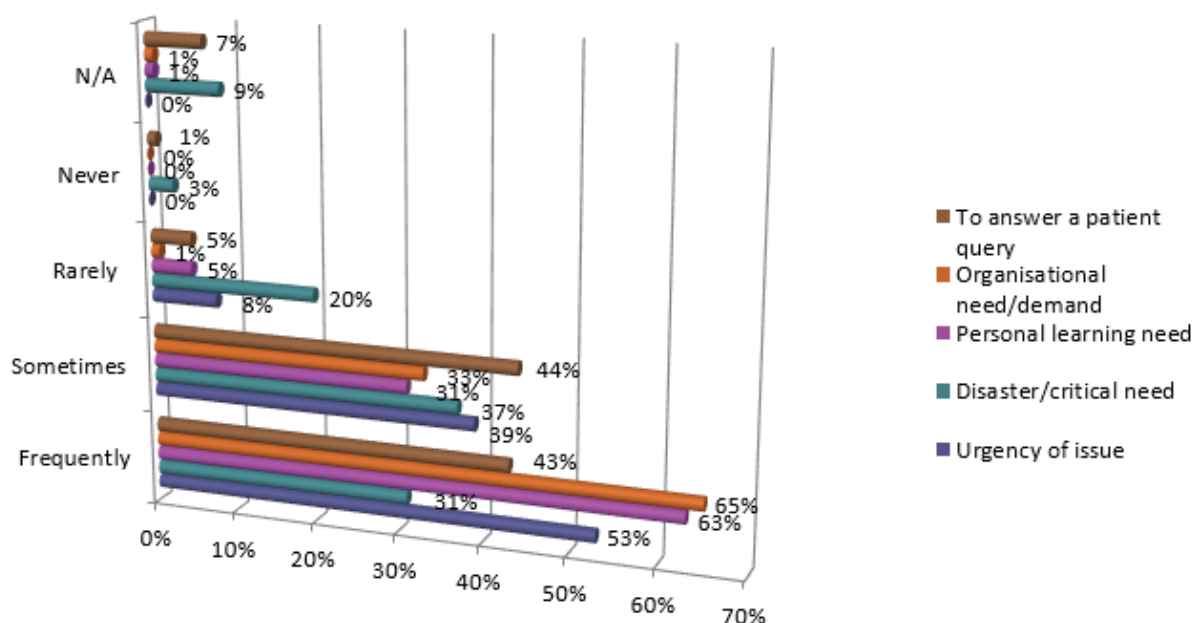
When faced with the need to access information you first…

Respondents were asked to indicate what their first action usually is when looking for information. Responses are shown in table 2. The majority of respondents started by searching the web. When asked to specify other first actions, responses included medical professionals and that it depends on the information that is required.

Table 2. When faced with the need to access information you first

Ask a colleague	28%
Ask your organisation's information professional/librarian	7%
Other (please specify)	3%
Search the web	62%

Almost half of respondents (47%, n=41) do not have access to an information specialist in their organisation. 38% (n=33) reported that they did and 15% (n=13) were unsure.

Figure 4. How many hours of your working week (40 hours) do you spend looking for information/evidence (not on the internet) and on the internet?
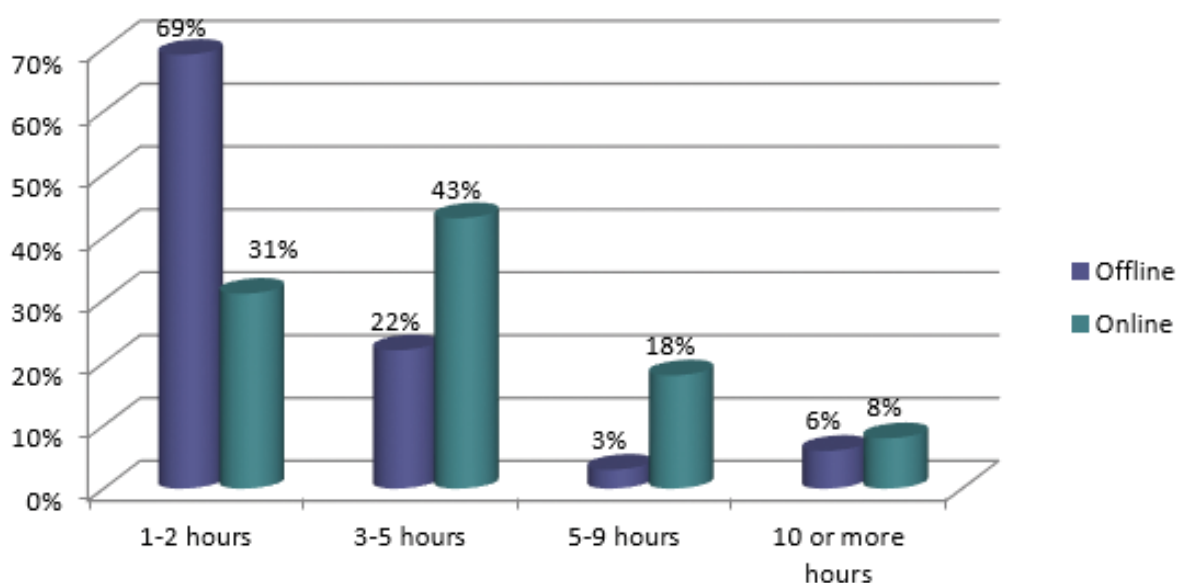
More time at work appears to be spent searching online for information than offline. 43% (n=36) of respondents spend 3-5 hours searching for information online compared to 22% (n=18) of respondents spending 3-5 hours searching for information offline. 18% (n=15) reported spending over 5 hours searching for information online compared to 3% (n=2) spending the same amount of time searching offline.

When asked 'Do you have your own devices with internet access?' 90 respondents owned at least one of the devices listed in Table 3 and 100% of them used their devices to search for information.

Table 3. Do you have your own devices with internet access?

Desktop computer	59%
Other	2%
Tablet	59%
Laptop computer	83%
Mobile phone	81%

Information use

This part of the survey looked at what respondents use the information they access for. Respondents reported a variety of uses for the information that they search for and access. The most commons uses for information were keeping up to date (n=75, 83%), personal development (n=70, 76%) and teaching/training (n=61, 66%). Least common was grant proposals/bid writing (34%, n=31). However, therefore was no use of information that was significantly less than the others suggesting that respondents use information for several different aspects of their role. Other uses for information respondents listed under 'Other' include responding to media, preparing financial reports and assisting patients (Appendix 5). Figure 5 displays the full results.

93% of respondents described their work as evidence-based.

Figure 5. What do you use information for?
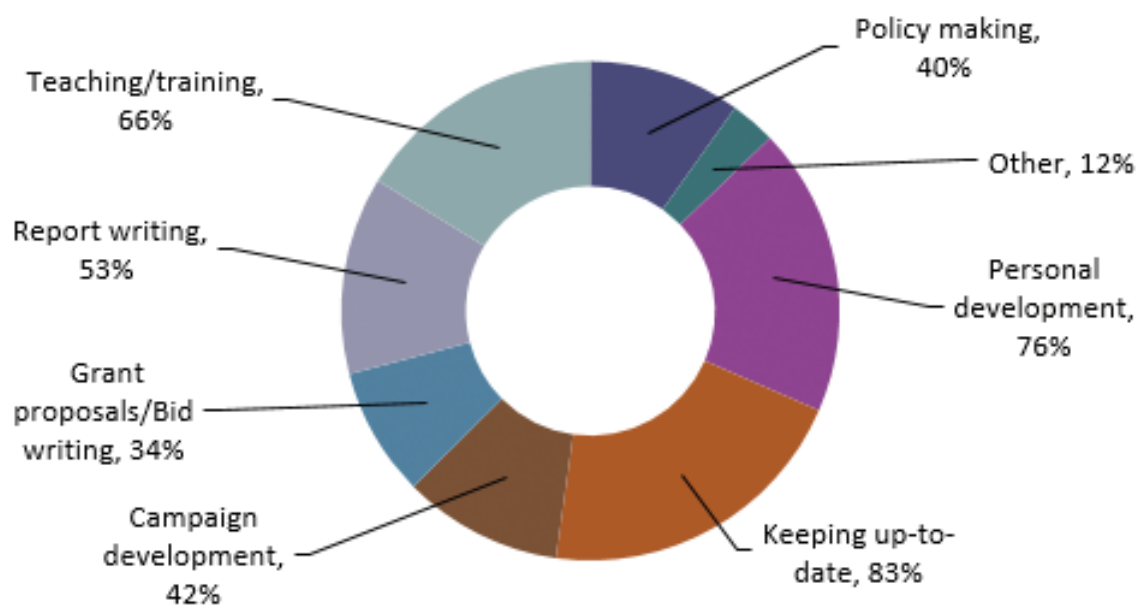
Resources types

What types of information do you consult most?

A high percentage of respondents (78%, n=70) consulted guidelines the most followed by data (70%, n=63) and peer-review literature (57%, n=51). Other types of information consulted ranked much lower with grey literature being the least commonly consulted by respondents (20%, n=18). Other types of resources some respondents specified included financial information and journals (Appendix 4).

Table 4. What types of information do you consult most?

Guidelines	78%
Data	70%
Other	8%
Peer-reviewed literature	57%
Grey literature	20%
Case studies	40%

What is your preferred format for research information?

Forty nine percent (n=42) of respondents preferred research information format to be in a written paper, 35% (n=30) preferred an oral presentation and 10% (n=9) a poster presentation (figure 6). When asked to specify, people also reported that all forms are preferred and one respondent said that it did not matter what format information was in (Appendix 7).

Information access

Respondents access information through a variety of sources. Internet search engines (94%, n=85), websites of health agencies/institutions (81%, n=73) and face-to-face seminars (67%, n=60) were most common. Physical libraries were the least common source to access information (22%, n=20). See Appendix 6 for other ways respondents reported that they accessed information.

Figure 6. How do you access information that you need?
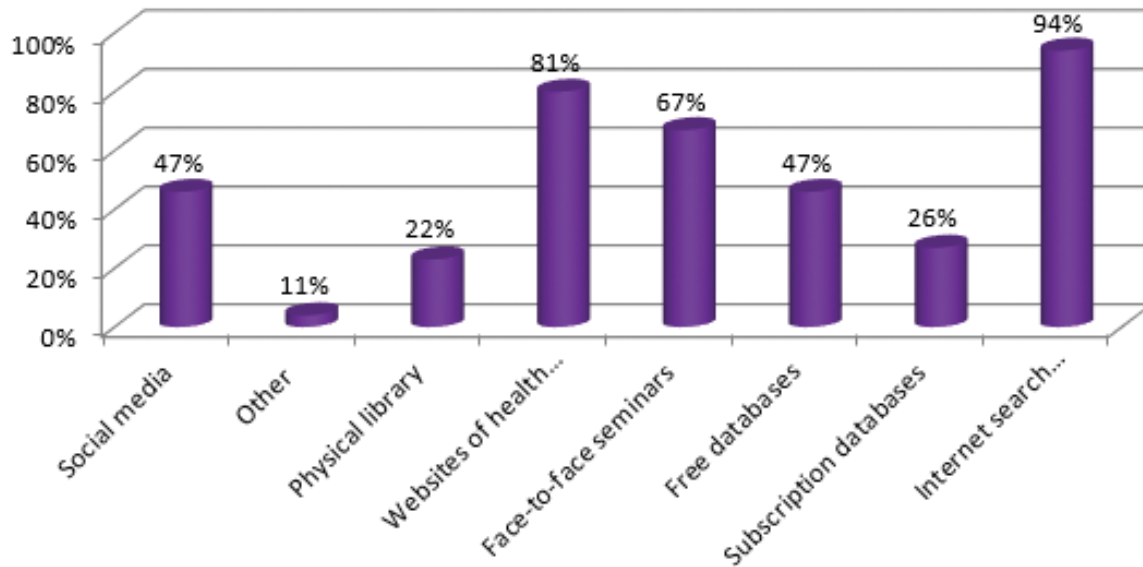
What are your preferred sources for information?

Figure 7. What are your preferred sources for information?

The word cloud in figure 7 displays respondents preferred sources for information. This was a free text response. The bigger the word, the more frequent the occurrence of it in the responses.

When asked what libraries respondents had access to 68% (n=50) stated that they had access to International organisations, 49% (n=36) to Universities, 32% (n=23) to public/local library, 31% (n=23) Government institutions. Other libraries respondents listed included journal websites, HIV portal and HINARI.

Barriers to information

Respondents reported a number of barriers when trying to access information (figure 8). Registration/participation fees (51%, n=46), cost of subscription (48%, n=43), cost of travel (42%, n=38) and lack of time (41%, n=37) were the most common barriers. Internet access was the least common barrier although it was still experienced by a number of people (n=16, 18%).

Figure 8. What barriers do you experience in accessing the information?
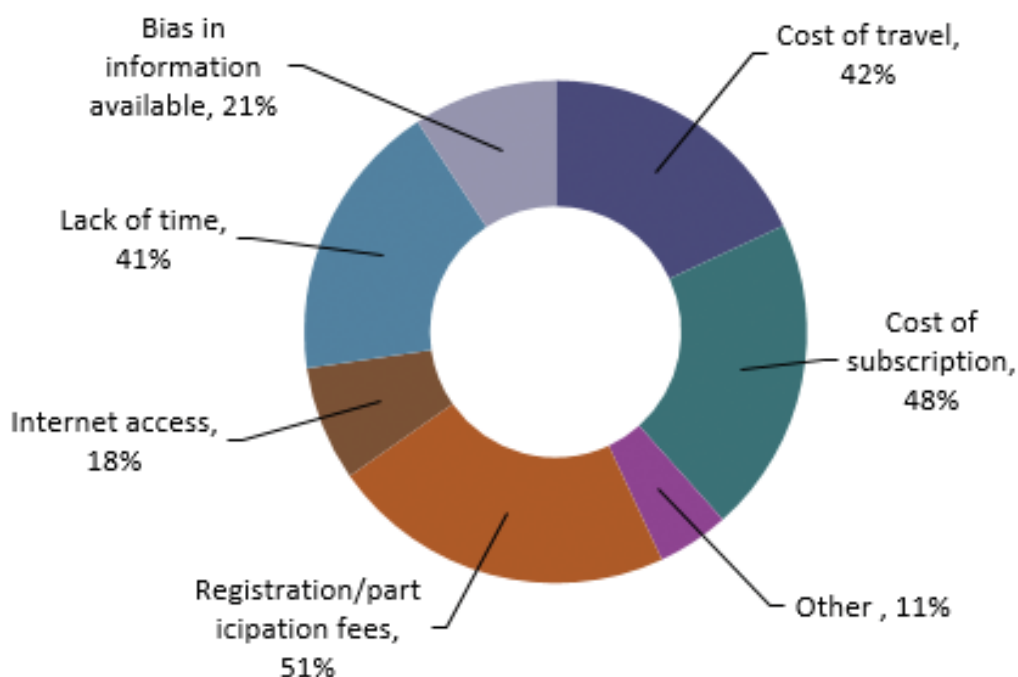
Other barriers to information that respondents specified included determining authenticity of information, too much information and unavailable information (See Appendix 8).

Respondents were asked if they felt isolated in their work. Eighty one percent (n=73) of respondents said they did not feel isolated.   When asked if information on the health situation in their country was readily available, 52% (n=47) said No and 48% (n=43) said Yes.

For those that answered 'yes', the information was mainly available on the internet (84%, n=36) and in print (74%, n= 32). Other ways respondents said information was available to them included discussions, public service announcements and meetings with colleagues.

Eighty six percent (n=76) felt they were able to access information from other countries to use in their local setting whilst 14% (n=12) did not.

Ninety three percent (n=81) of respondents do not experience any language barriers when accessing information. Some of those that do experience language barriers reported that information is sometimes not available in Spanish or English.

What one information resource could you not live without?

This question was a free-text response. Frequently occurring answers included the internet, Google, online databases and contact with peers. See Appendix 9 for full list of results.

What information resources would make your life easier?

This question was free-text response. The internet appeared frequently as well as access to social media and up to date information. Figure 9 shows a word cloud of the results. The larger the word, the more frequent the occurrence of it in the results. See the full list of responses in Appendix 10.

Figure 9. What information resources would make your life easier?

Do you collaborate extensively with individuals?

Of the 68 people who responded to this question, 96% (n=65) of respondents collaborated extensively with individuals in their country. There is also collaboration with individuals in the Caribbean (59%, n=40) and with individuals outside of the Caribbean (59%, n=40).

The respondents were asked how collaboration could be improved, email contact (70%, n=61), regular online meetings (57%, n=50) and regular face-to-face meetings (49%, n=43) were the main suggestions. Conferences, workshops and lectures were other suggested ways to improve collaboration (Appendix 11). See figure 10 for full breakdown.

Figure 10. How could collaboration/information sharing be improved?
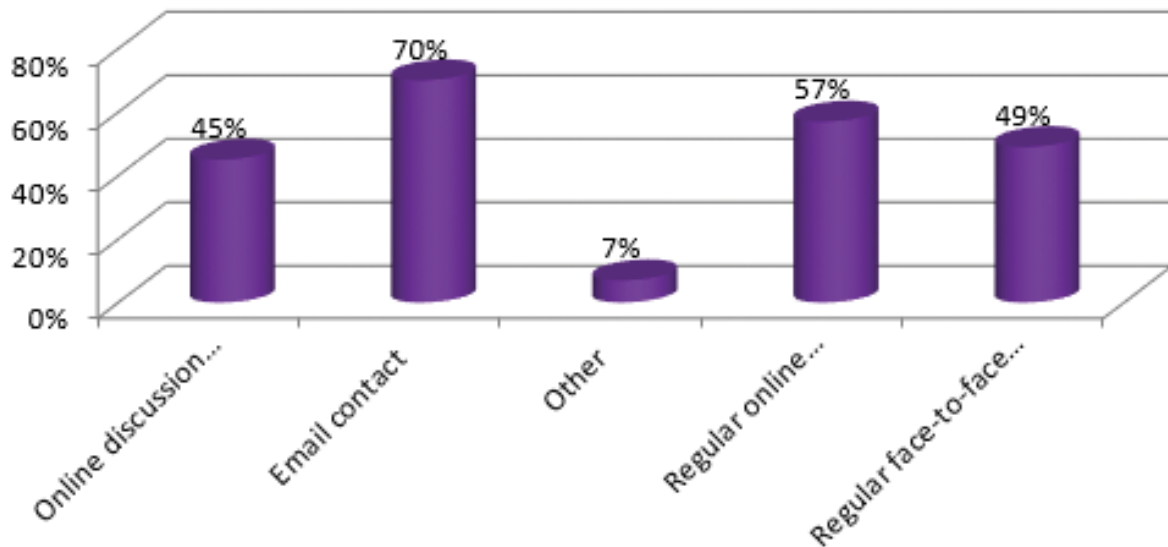
Communities of Practice

Respondents were asked if they were a member of any Communities of Practice (CoP). Forty percent (n=35) of respondents had never heard of CoPs, 45% (n=39) reported that they were not a member of any and 15% (n=13) were a member of at least one CoP. CoPs that respondents were members of included Facebook, Twitter, Global Health Delivery Online and Inroads.

When asked what their main reason for joining a CoP would be, the biggest reason was to keep up to date (76%, n=58) followed by sharing information (72% n=55). See figure 11 for full results.

Figure 11. If you are not already a member of a CoP or network, what would be your main reason for joining?
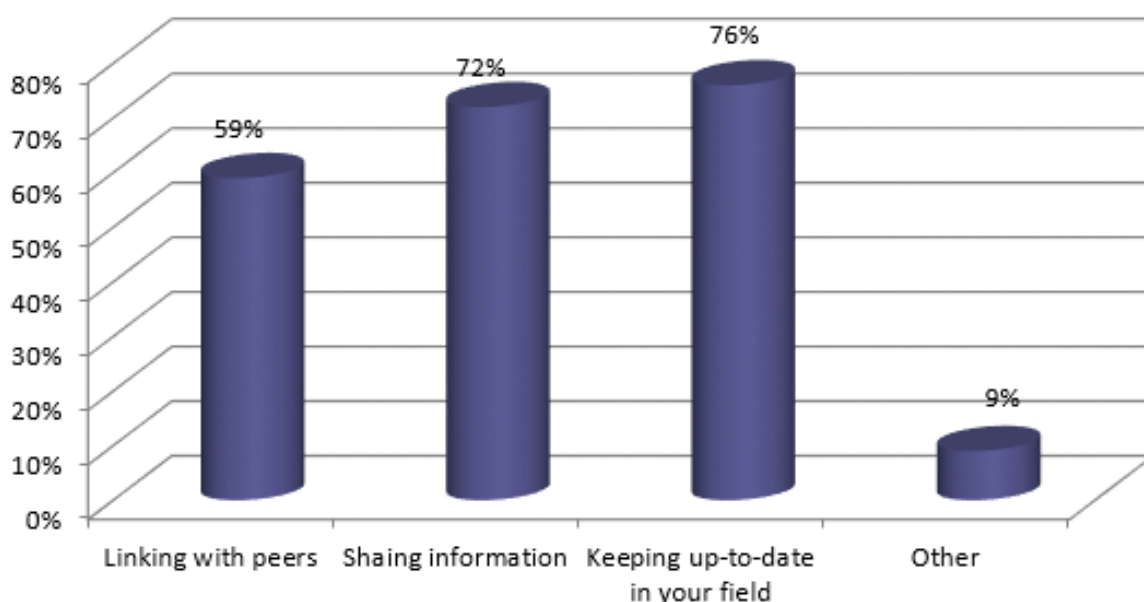
Other responses included marketing and sharing case studies. Others said they were already a member of a CoP and one respondent suggested that a CoP could be used for fundraising and staff training. Please see Appendix 12 to read other response left

Information skills

People are confident in information searching, with no respondents reporting a lack of confidence in this skill. Slightly less confidence was found in critical appraisal and managing references. Respondents appeared to be less confident in computer hardware, software and mobile devices.

Table 5. From an information perspective, please rate your confidence levels in the following areas

	Very confident	Somewhat confident	Neutral	Somewhat unconfident	Very unconfident
Information searching	56%	36%	8%	0%	0%
Critical appraisal	32%	48%	17%	2%	0%
Managing references	32%	45%	21%	2%	0%
Computer hardware	28%	33%	27%	10%	1%
Computer software	23%	40%	27%	9%	1%
Mobile device	33%	43%	21%	3%	0%

Respondents were asked what their preferred learning methods were (Figure 12). Discussion (n=57, 64%), face-to-face (n=49, 55%) and self-directed (n=47, 53%) were the most common choices. Online (n=29, 33%) and problem solving (n=31, 35%) were the least popular. It is not understood from the results whether discussion and face-to-face learning would be preferred teacher-led or with peers.

Figure 12. What are your preferred learning methods?
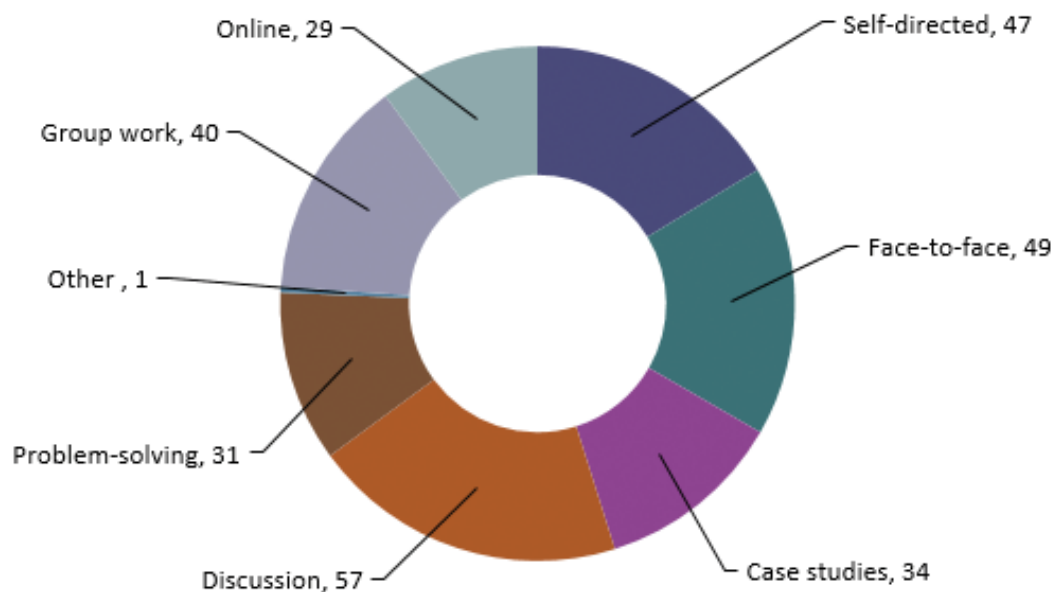
General comments

At the end of the survey, people were able to leave any general comments about the survey. Below are some example comments. Please see Appendix 14 to read other comments left.

"Through increased training and sharing of CSO best practices, NGO's within the Caribbean will be able to continuously increase their knowledge base and build their capacity to address the rising issues of NCDs as a collaborative CSO body."

"Information sharing is an important aspect of gaining confidence in your field, therefore this must be full endorsed and encouraged."

7. DISCUSSION

In this section we cover the main findings of the results. There has been little research around the information needs of the CSOs working on NCDs in the Caribbean region but previous research has suggested that there are barriers to access information as well as limited information sharing. The findings of this information needs assessment highlight how individuals in this community search for information, types of information required to information work and barriers to accessing information. .

The findings show that there is no average worker in CSOs of Caribbean region. The spread of the use of information and types of information required highlights the variety of work undertaken by this community. Further research to develop information behaviour profiles of individuals in different roles could help to support and develop information provision in NCDs.

It is clear from the results that information is mainly sought for and accessed online. Having internet access and use of online resources is important to CSOs and therefore appeared frequently as a resource that they could not live without. More people spent time searching for information online compared to offline. Lack of Internet access was a barrier to information for some and improving access was listed as a resource that would make respondents' lives easier. This was similar to findings of previous research in the Caribbean (8). Further research should be considered to understand the problem of limited internet access, whether it is a country-wide problem, work problem or problems with internet access from individual homes.

Common barriers to information revolved around finances; cost of travel, cost of registration/participation and subscription fees. Although it is not clear from the results, it is presumed that cost of registration/participation and cost of travel related to attending events, courses, meetings etc. Further research should explore ways to reduce these barriers, such as online meetings, live streaming of conferences and making presentations available online. These could be shared via CoPs. Barriers to information in the form of subscription costs and lack of time match those found in information needs assessments undertaken by the UKHF of public health professionals in the UK (2).

It is not clear why some information is not available to CSO members. Is it because certain research or data has not been gathered before? Has it not been shared or disseminated? Is it behind a paywall?

Are people looking in the wrong sources to find it? Qualitative research using semi-structured interviews or focus groups may provide insight into this.

Respondents were generally confident in their information literacy skills, although they were slightly less confident in critical appraisal and managing references. We are not sure why this is, it could be because they have not received training or it is something they do not do often enough to be confident. Further research could explore whether the provision of additional training could help to support the workforce in developing their information skills. It would also be necessary to analyse whether such training might be best provided through face to face sessions or via e-learning modules and/or online guides or forums such as CoPs. People were least confident with computer hardware and software and mobile devices. Further research should aim to understand what computer hardware and software and mobile devices people felt unconfident with and how it impacts their work, with the possibility that training courses be developed and implemented. Many respondents either don't have or do not know if they have access to an information specialist. Further research could investigate whether those that do not know, do have access but are unaware.

Information specialists may help to overcome barriers to accessing information and provide training in information literacy and IT skills.

Respondents appear to collaborate with others in their country, within the Caribbean and outside of the Caribbean too. The majority of respondents did not report feeling isolated in their work and although suggestions were made on how to improve collaboration, it was not clear whether respondents felt that better collaboration was required or if they were satisfied with the collaboration that they currently had.

It was an almost equal split between people that did not feel health information in their country was readily available and those that did. It could be that the health information required is not gathered, that information is not shared by the organisation that gathered it or that such information is behind a paywall. Further research should seek to answer this.

Very few respondents were already a member of a CoP, 40% of respondents had not heard of CoPs. Previous research has found many benefits to being a member of a CoP including knowledge sharing and sharing of best practice, linking with peers across different professions, institutions and

geographical areas. Virtual CoPs can be an inexpensive way of meeting peers you may not meet in person. They can also be an effective space to disseminate information and evidence. Although it may appear that there is little interaction on a CoP due to little posting, analysis of analytics can often show that there are high levels of logging in and reading activity, suggesting that people are still getting value out of a CoP(9, 10).

CoPs have been most successful when used to support groups that also meet face-to-face(9, 11). This may be because people feel more comfortable interacting in a virtual space where they know the other people or because there are set tasks to do on the CoP. Therefore an organisation, such as the HCC, may be well placed to support and lead the success of a CoP for individuals working in CSOs of the Caribbean. CoP moderators or 'champions' may help to encourage activity on the CoP. Moderators who are well known to the commuting frequently posting and prompting others to participate in discussion should help to make a successful CoP (12).

Keeping up to date would be the main reason for joining a CoP, closely followed by sharing information and liking with peers. This was found in previous research from UKHF investigating the use and value of CoPs(9). Consideration should be given to developing an online CoP to encourage further information sharing and collaboration and HCC would be well placed to develop such a platform.

8. LIMITATIONS

The 90 respondents to this survey are unlikely to be representative of all CSOs members of staff and therefore the results cannot be generalised to the whole community.

We are aware that some respondents experienced technical difficulties when completing the survey which may have prevented some from completing this survey. Further research could use other methods that do not rely on online methods.

As reported in the results section, we had higher numbers of responses in some countries compared to other countries in the Caribbean and therefore country comparisons of the data were not appropriate. It is not clear why there is a difference, but further research should explore differences in information needs by country.

9. RECOMMENDATIONS

This research has started to build a picture of the information needs and behaviour of this community and we have made the following recommendations for developments and further research:

HCC should prioritise increased collaboration and information sharing between organisations and countries. As the umbrella for these CSOs, they are best placed to establish a platform, such as a CoP, for information sharing and networking. This will help the community keep up to date and access the latest information in NCD prevention. UKHF is experienced in developing and evaluating CoPs and could provide assistance.
In their strategic plan 2017-2021, HCC should have a focus on information sharing, sharing of best practice and networking among individuals and CSOs of the coalition.
HCC should continue with research into the information needs of this community to obtain a deeper understanding of issues identified in this assessment. This could take the form further surveys, semi-structured interviews with individuals or focus groups.
Explore ways to make meetings more accessible, perhaps with online resources and video streaming.

Create and/or promote information training opportunities for CSO members, particular in computer software and hardware. This could be face-to-face training or the development of e-learning modules.

Scope out possibilities to provide technical support to assist in accessing information that is currently unavailable.

10. CONCLUSION

This research is the first of its kind to assess the information needs of civil society organization members working in NCDs in the Caribbean. The results mirror findings from previous information needs research in the UK but also highlights previously undetected barriers to information such as internet access, cost of travel and cost of registration/ participation and establishes priorities for information provision.

In their Strategic Plan 2017-2021, HCC should make plans for increasing information provision to assist individuals in accessing relevant and up to date information in NCDs prevention and continue to assess the information needs of this community to build a stronger picture.

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APPENDICES

APPENDIX 1: Introduction/Introductory Email

CAPACITY AND INFORMATION NEEDS ASSESSMENT OF HCC CIVIL SOCIETY
ORGANISATION MEMBERS WORKING IN NON-COMMUNICABLE DISEASES

INTRODUCTION
The Healthy Caribbean Coalition (HCC)[17] is conducting a detailed capacity assessment
of its civil society organisation (CSO) members working in NCDs, complemented by
an assessment of the information needs of individual CSO personnel. The information
needs assessment is supported by a grant from the UK Health Forum (UKHF)[18], while
the capacity assessment is supported by a grant from the NCD Alliance (NCDA)[19]/
Medtronic Philanthropy[20]

The HCC assessment represents an important step in strengthening the capacity,
institutional development, and actions of its CSO members in support of NCD
prevention and control in the Caribbean; the HCC is counting on and anticipating your
full participation.

GUIDELINES FOR COMPLETION
The survey questions are grouped in three complementary parts:
Part I captures demographic, organisational, and contextual information.
Part II captures strategic frameworks; governance; services offered and degree of
influence; management capacity and structure; funding and financial issues; patient
engagement; successes and challenges; partnerships; and areas for development.
Part III captures the information needs of individuals working with the CSO.

Parts I and II aim to collect information from an organizational perspective and should
be completed by one designated representative of the CSO.

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17   The Healthy Caribbean Coalition is a registered, not-for-profit regional network and alliance that works closely with regional and international leaders to promote
and enable civil society's contribution to the prevention and control of non-communicable diseases (NCDs) in the Caribbean. For more information, visit http://healthycaribbe-
an.org/
18   The UK Health Forum (UKHF) is a charitable alliance of professional and public interest organisations working to reduce the risk of avoidable non-communicable
diseases by developing evidence-based public health policy and supporting its implementation through advocacy and information provision. For more information visit: www.
ukhealthforum.org.uk
19   The mission of the NCD Alliance is to combat the NCD epidemic by putting health at the centre of all policies. Founded in 2009, we are a unique civil society
network uniting 2,000 civil society organisations in more than 170 countries. For more information visit https://ncdalliance.org/
20   Medtronic Philanthropy aims at expanding access to chronic disease care for the underserved, worldwide. For more information, visit http://www.medtronic.com/
foundation/who-we-are/index.html

Part III aims to collect individual, personal perspectives and should be completed by as many individual staff members as the CSO deems appropriate.

The three-part survey should be completed electronically using SurveyMonkey at the link provided; Parts 1 and II should take no more than 45 minutes to complete, and Part III should take no more than 15 minutes.

The deadline for submission of the survey is 31 March 2016.

APPENDIX 2: Survey Questions

PART I – DEMOGRAPHIC AND ORGANISATIONAL INFORMATION/CONTEXT

Please select the survey you have been asked to complete:
    Parts I, II, and III – Capacity assessment and information needs/full survey ☐
    Part III – Information needs only ☐

Full name of organisation:

Country of location:

Address of organisation:

Name of person completing Parts I and II of the survey:

Professional category/Title of respondent:

Are you   Male? ☐   Female? ☐   Prefer not to say ☐

Are you responding to this assessment as the official lead for your organisation?
        Yes ☐   No ☐

Were other persons in your organisation involved in this capacity assessment process?
        Yes ☐   No ☐
If Yes, please provide their names and titles:

Please provide your contact information:
        Telephone: Email:

How do you categorise your organisation? (Check all that apply):
        Legal entity ☐
        Registered Not-for-profit ☐

Registered Charity ☐
Registered Civil Society Organisation ☐
Registered Non-governmental Organisation ☐
Not registered ☐
Other ☐   Please specify:
Don't know ☐

If registered:
What is your organisation's registration number?
What is your organisation's date of registration?

If not registered, when was your organisation established? (Please give date)

Does your organisation have a website?
Yes ☐   No ☐   Don't know ☐
If Yes, please state the URL:

Is your organisation on social media?
Yes ☐   No ☐   Don't know ☐

If Yes, please indicate which social media, as below, and state the relevant account name/handle/title:
Facebook   Name:
Twitter   Name:
Instagram   Name:
YouTube   Name:
Other ☐   Please specify and provide account name:

What is the official language of your country of location? (Please check a maximum of two):
English ☐   Spanish ☐
French ☐   Dutch ☐

Are any other languages commonly spoken?

        Yes ☐   No ☐   Don't know ☐

If Yes, please specify:

How does your organisation communicate its work? (Check all that apply)

        Organisation's website ☐

        Facebook ☐

        Twitter ☐

        Conferences ☐

        Peer-reviewed articles☐

        Grey literature ☐

        Reports ☐

        Case studies ☐

        Other ☐   Please specify:

        Don't know ☐

How often is your organisation's work communicated to its main target groups/beneficiaries/audiences?

        Daily ☐

        Weekly ☐

        Monthly ☐

        Other ☐   Please specify:

Don't know ☐

To what extent do you and/or your organisation use communication packages/materials prepared by other organisations/sources? (Check one)

        Most of the time ☐

        Frequently ☐

        Sometimes ☐

        Never ☐

MAIN AREAS OF WORK AND FRAMEWORKS FOR ACTION

What NCDs, conditions, themes, or topics does your organisation work with? (Check all that apply)

- Cardiovascular diseases, including hypertension ☐
- Diabetes ☐
- Cancer ☐
- Chronic respiratory diseases, including bronchial asthma ☐
- Mental health and neurological disorders ☐
- Disabilities ☐
- Prevention and control of NCD risk factors ☐
  - Tobacco use ☐
  - Physical inactivity ☐
  - Unhealthy diet ☐
  - Harmful use of alcohol ☐
- Other ☐   Please specify:
- Not applicable ☐   If this option is selected, please explain:

What are the top five NCD issues in your country of location?

- Cardiovascular diseases, including hypertension ☐
- Diabetes ☐
- Cancer ☐
- Chronic respiratory diseases, including bronchial asthma ☐
- Mental health and neurological disorders ☐
- Disabilities ☐
- Prevention and control of NCD risk factors ☐
  - Tobacco use ☐
  - Physical inactivity ☐
  - Unhealthy diet ☐
  - Harmful use of alcohol ☐
- Other ☐   Please specify:
- Don't know ☐

Who are your <u>primary</u> constituents/target groups/beneficiaries? (Check all that apply)

General public ☐
Health professionals ☐
Other health care providers ☐
Journalists/media practitioners ☐
Researchers ☐
People with cardiovascular diseases, including hypertension ☐
People with diabetes ☐
People with cancer ☐
People with chronic respiratory diseases, including bronchial asthma ☐
People with other NCD or NCD risk factor ☐   Please specify:
People with mental health and neurological disorders ☐
People with disabilities ☐
People with other disease/condition ☐   Please specify:
Other persons/groups ☐   Please specify:
Don't know ☐

Please proceed to Part II of the survey.

PART II – STRATEGIC FRAMEWORK AND MANAGERIAL STRUCTURE

Does your organisation work with or target any vulnerable or disadvantaged groups?

      Yes ☐   No ☐

If Yes, please specify:

Does your organisation consider the following issues in its planning, programming, and implementation? (Check all that apply)

      Gender ☐

      Equity ☐

      Human rights ☐

      Social determinants of health ☐

      None ☐

      Don't know ☐

Does your organisation have a Vision statement[21]?

      Yes ☐   No ☐   Don't know ☐

If Yes, what is the Vision statement?

Does your organisation have a Mission statement[22]?

      Yes ☐   No ☐   Don't know ☐

If Yes, what is the Mission statement?

Does your organisation have a current, written Strategic Plan with goals and/or objectives, time frames, and concrete indicators/measures?

      Yes ☐   No ☐   Don't know ☐

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21   Vision statement reflects clear, specific, and compelling understanding of what the organisation aspires to become or achieve; it is consistently used to set priorities and drive actions. (http://caseygrants.org/resources/org-capacity-assessment/, accessed 25 February 2016.
A one-sentence statement describing the clear and inspirational long-term desired change resulting from the organisation's work (desired end-state). (https://topnonprofits.com/examples/vision-statements/, accessed 25 February 2016).

22   Mission statement is a clear expression of the organisation's reason for existing; it reflects its values and purpose. (http://caseygrants.org/resources/org-capacity-assessment/, accessed 25 February 2016).
A one-sentence statement describing the reason an organization or program exists, and used to help guide decisions about priorities, actions, and responsibilities (what you do). (https://topnonprofits.com/examples/nonprofit-mission-statements/, accessed 25 February 2016).

If Yes, where is the Strategic Plan available?

Does your organisation have an Operational Plan that guides its day-to-day behaviour and activities?

        Yes ☐   No ☐   Don't know ☐

If Yes, where is the Operational Plan available?

Does your organisation have shared beliefs and values, or a Code of Ethics, which guide its behaviour and support its purpose?

        Yes ☐   No ☐   Don't know ☐

If Yes, where is this information available?

Are your organisation's goals/objectives/activities based on, or aligned with, national, subregional, regional, or global frameworks for health, such as (Check all that apply):

        National Health Policy, Strategy, or Plan ☐
        CARICOM Regional NCD Plan of Action ☐
        CARICOM Caribbean Cooperation in Health ☐
        CARICOM Port of Spain Declaration on NCDs ☐
        WHO Global Action Plan on NCDs ☐
        United Nations Sustainable Development Goals ☐
        Other ☐   Please specify:
        Don't know ☐

Does your organisation prepare periodic reports on its activities and achievements?

        Yes ☐   No ☐   Don't know ☐

If Yes, how often are the reports prepared?

Are the reports linked to the Strategic and/or Operational Plan?

        Yes ☐   No ☐   Don't know ☐

If No, what is the format/basis for their preparation?

Are the reports shared?

  Yes ☐   No ☐   Don't know ☐

If Yes, with whom? (Check all that apply)

  Board of Directors ☐
  Constituents/target groups ☐
  General public ☐
  Ministry of Health ☐
  Other ☐   Please specify:

What are your organisation's top five (5) priorities for the next 5 years?

  Cardiovascular diseases, including hypertension ☐
  Diabetes ☐
  Cancer ☐
  Chronic respiratory diseases, including bronchial asthma ☐
  Mental health and neurological disorders ☐
  Disabilities ☐
  Prevention and control of NCD risk factors ☐
  Tobacco use ☐
  Physical inactivity ☐
  Unhealthy diet ☐
  Harmful use of alcohol ☐
  Other ☐ Please specify:
  Don't know ☐

GOVERNANCE

Does your organisation have a Board of Directors?

  Yes ☐   No ☐   Don't know ☐   Not applicable ☐
  If Yes:

How many Board members are there?

What is the ratio of men to women?

How often does the Board meet?

Is there a person living with an NCD on the Board?
    Yes ☐   No ☐

Is there a health professional on the Board?
    Yes ☐   No ☐

If yes, please indicate the category of health professional:
    Medical doctor ☐
    Nurse ☐
    Other ☐   Please specify:

Are minutes of the Board meetings prepared and disseminated?
    Yes ☐   No ☐   Don't know ☐   Not applicable ☐

What mechanisms are in place to ensure and assess follow-up of decisions made by the Board? Please describe:

What other elements comprise your organisation's governance and undertake decision-making? (Check all that apply)
    Advisory Board ☐
    Advisory Committee ☐
    Management Committee/Team ☐
    Technical Working Group ☐
    Other ☐   Please specify:
    Don't know ☐

Does your organisation have by-laws?

Yes ☐   No ☐   Don't know ☐

Does your organisation have a monitoring and evaluation framework to assess its functioning and its activities?

Yes ☐   No ☐   Don't know ☐

If Yes, please summarise the main monitoring and evaluation actions:

Do your organisation's constituents/target groups participate in the organisation's decision-making process?

Yes ☐   No ☐   Don't know ☐

If Yes, in what way?

SERVICES OFFERED AND DEGREE OF INFLUENCE

What are the primary roles/functions of your organisation? (Check all that apply)

Provision of patient services ☐

Screening ☐

Diagnosis, including laboratory services ☐

Treatment ☐

Rehabilitation ☐

Counselling/psychological support/mental health services/emotional support ☐

Palliative care, including pain relief ☐

Other ☐

Public education/information dissemination ☐

Research ☐

Advocacy ☐

Policy development ☐

Stakeholder capacity building ☐

Litigation ☐

Coordinating civil society action ☐

Building national or local coalitions, strengthening CSO and/or community

networks ☐

Monitoring NCD-related commitments of governments ☐

Monitoring industries with conflicts of interest ☐

Supporting global action on NCDs ☐

Influencing or participating in official NCD mechanisms/bodies/committees ☐

Supporting NCD work of international and/or intergovernmental organisations ☐

Other ☐   Please specify:

MANAGEMENT CAPACITY AND INFRASTRUCTURE

What is your staff complement? Please indicate the categories and numbers as below:

Total number of staff

Number of full-time paid staff

Number of full-time volunteer staff

Number of part-time paid staff

Number of part-time volunteer staff

Number of ad hoc volunteers

Is there a management team?

Yes ☐   No ☐   Don't know ☐

If Yes:

Is the team experienced in managing CSOs?

Yes ☐   No ☐   Don't know ☐

How does your organisation recruit staff? (Check all that apply)

Job advertisement ☐

Job centre/Employment office ☐

Employment agency ☐

Personal recommendation/word of mouth (from friends, colleagues) ☐

Internships ☐

Other ☐   Please specify:

Don't know ☐

Does your organisation have a human resources plan?

Yes ☐　　　No ☐　　　Don't know ☐　　　　Not applicable ☐

Is there staff succession planning?

Yes ☐　　　No ☐　　　Don't know ☐　　　　Not applicable ☐

Does your organisation carry out staff training/capacity development/team building?

Yes ☐　　　No ☐　　　Don't know ☐　　　　Not applicable ☐

Does your organisation carry out formal performance evaluation of staff?

Yes ☐　　　No ☐　　　Don't know ☐　　　　Not applicable ☐

If Yes, how often?

What mechanisms does your organisation use to communicate with staff? (Check all that apply)

　　　Email ☐
　　　Intranet ☐
　　　Regular team meetings ☐   How often?
　　　Ad hoc meetings ☐
　　　Internal newsletter ☐
　　　Other ☐　　　Please specify:
　　　Don't know ☐

What mechanisms does your organisation use to communicate with its constituents/ target groups? (Check all that apply)

　　　Email ☐
　　　Internet (e.g. blogs) ☐
　　　Brochures ☐
　　　Social media ☐
　　　Newspapers ☐
　　　Newsletters ☐
　　　Radio ☐

Television ☐
Other ☐   Please specify:
Don't know ☐

Does your organisation have dedicated office space/building?
        Yes ☐   No ☐

If Yes, does the organisation:
        Own the space/building? ☐
        Rent the space/building? ☐
        Have another arrangement? ☐   Please specify:

If No, how does the organisation function in this regard?

FUNDING AND FINANCIAL ISSUES

Does your organisation have an accounting policy and procedures manual?
        Yes ☐   No ☐   Don't know ☐   Not applicable ☐

Does the organisation use accounting software?
        Yes ☐   No ☐   Don't know ☐   Not applicable ☐

Does the organisation have a dedicated accounts clerk?
        Yes ☐   No ☐   Don't know ☐   Not applicable ☐

If No, which category of staff performs relevant functions?

Does the organisation have a dedicated financial manager/accountant?
        Yes ☐   No ☐

If No, which category of staff performs relevant functions?

Does the organisation produce financial reports?

      Yes ☐   No ☐   Don't know ☐   Not applicable ☐

If Yes, are the reports audited annually?

      Yes ☐   No ☐   Don't know ☐   Not applicable ☐

Does the organisation develop a budget linked to the Strategic and/or Operational Plan?

      Yes ☐   No ☐   Don't know ☐   Not applicable ☐

If No, on what basis is the budget developed?

What are your organisation's primary sources of funding? (Please check all that apply and rank in order of importance):

      Government subvention ☐
      Fee-for-service arrangement) ☐
      Service delivery (user fees) ☐
      Constituent/Target group subscriptions/fees ☐
      Grants/Official Development Assistance ☐
      Donations from: Individuals ☐ Corporate entities ☐
      Other ☐   Please specify:
      Don't know ☐

What are the main types of non-Government funders of your organisation?

      Philanthropic foundations ☐
      UN agencies ☐
      International financing institutions ☐
      International NGOs/CSOs ☐
      Development cooperation from governmental agencies in other countries ☐
      Individuals ☐
      Private sector ☐
      Other ☐   Please specify:
      Don't know ☐

Does your organisation receive funding from private sector enterprises?

Yes ☐   No ☐   Don't know ☐

If Yes, please indicate those from which your organisation receives funds:

      Soft drink/soda companies ☐
      Food industry ☐
      Tobacco industry ☐
      Alcohol industry ☐
      Pharmaceutical industry ☐
      Health insurance providers ☐
      Other ☐   Please specify:
      Don't know ☐

Is there a single entity that provides a third or more of your organisation's total annual funding?

      Yes ☐   No ☐

If Yes, please indicate the type of entity:

      Government ☐
      Philanthropic foundation ☐
      UN agency/organisation ☐
      International financing institution ☐
      International NGO/CSO ☐
      Individual ☐
      Private sector ☐
      Other ☐   Please specify:
      Don't know ☐

In your organisation's submissions for and/or acceptance of funding, is conflict of interest a consideration?

      Yes ☐   No ☐   Don't know ☐

If Yes, does your organisation have a conflict of interest policy?

        Yes ☐   No ☐   Don't know ☐

If there is no conflict of interest policy, how does your organisation manage conflict of interest? Please explain:

Does your organisation undertake fundraising activities?

        Yes ☐   No ☐   Don't know ☐

If Yes, what type of fundraising activities does your organisation commonly undertake?

        Special events ☐   Please give examples:

        Cause- or theme-related marketing ☐

        Legacies ☐

        Other ☐   Please specify:

What is the most appropriate description of your organisation's current funding situation? (Please check <u>one</u>)

        Inadequate to meet current plans ☐

        Adequate for current activities, but nothing in the pipeline for future plans ☐

        Solid base of funders, providing for both current and future plans ☐

PATIENT ENGAGEMENT

In engaging with patients, does your organisation help them to: (Check all that apply)

        Find safe, appropriate, and decent care (health professional or health facility)? ☐

        Organise logistics for their care/well-being, e.g. transportation, personal shopping? ☐

        Communicate with health care professionals (symptoms, explanations, medication)? ☐

        Organise their health care (appointments, medication, accompanying)? ☐

        Pay for their health care (insurance, out-of-pocket, receipts, claims)? ☐

        Make good treatment decisions (evaluation of options)? ☐

        Participate in treatment (awareness of side effects, monitoring of symptoms)? ☐

Access psychological support/counselling/mental health services? ☐

Access legal services? ☐

Advocate for/Promote health (behaviour change, enabling environment)? ☐

Get preventive health care? ☐

Seek health knowledge (information on condition, risks, development of personal health targets)? ☐

Plan for end of life, if appropriate? ☐

Participate in support groups? ☐

Undertake other actions for their health? ☐   Please specify:

To what extent are patients involved in your organisation's governance and operations?

Are patients: (Check all that apply)

Represented on the Board?	Yes ☐	No ☐	Not applicable ☐
Involved in programme and policy development?	Yes ☐	No ☐	
Not applicable ☐			
Involved in the strategic planning process?	Yes ☐	No ☐	
Not applicable ☐			
Encouraged to share their stories in the media?	Yes ☐	No ☐	
Involved in peer support programmes?	Yes ☐	No ☐	
Not applicable ☐			
Well-represented among your organisation's volunteers?	Yes ☐	No ☐	
Engaged as advocates at community or other levels?	Yes ☐	No ☐	
Involved in public education initiatives?	Yes ☐	No ☐	
Involved in other ways?	Yes ☐	No ☐	

If Yes, Please specify:

SUCCESSES

Over the past 5 years, what have been your organisation's five biggest successes/achievements related to NCD prevention and control?

What have been the main factors contributing to these successes/achievements?

CHALLENGES

What are your organisation's main challenges? (Check all that apply)
>   Governance ☐
>   Human resources ☐
>   Technical capacity ☐
>   Funding ☐
>   Infrastructure ☐
>   Strategic planning ☐
>   Management ☐
>   Communication: Internal   ☐   External ☐
>   Monitoring and evaluation/accountability ☐
>   Partnerships ☐
>   Other ☐   Please specify:
>   Don't know ☐

PARTNERSHIPS

Is there a National NCD Commission or National Wellness Commission in your country?
>   Yes ☐   No ☐   Don't know ☐

If Yes, is your organisation a member of the Commission?
>   Yes ☐   No ☐   Don't know ☐

Is there a National NCD Alliance (coalition of NCD NGOs) in your country?
>   Yes ☐   No ☐   Don't know ☐

If Yes, is your organisation a member of the Alliance?
>   Yes ☐   No ☐   Don't know ☐

If there is no National NCD Alliance in your country, do you think such an Alliance would be of value?

        Yes ☐   No ☐   Don't know ☐

Would your organisation join such an Alliance?

        Yes ☐   No ☐   Don't know ☐

Which entities/stakeholders are your organisation's <u>main partners</u> in NCD prevention and control? (Check all that apply)

        Ministry of Health ☐

        National NCD focal point ☐

        Other government ministries ☐

        Academia ☐

        Private sector ☐

        CARPHA ☐

        Other CARICOM institution ☐   Please specify:

        International organisations (e.g. international financing institutions) ☐

        PAHO/WHO ☐

        Other UN or Intergovernmental organisation ☐   Please specify:

        Other CSOs, NGOs ☐

        Other ☐   Please specify:

        Don't know ☐

With which partner(s) does your organisation have a formal, signed agreement, such as a memorandum of understanding, letter of agreement, or similar instrument? (Please list)

Is your organisation a member of the Global NCD Alliance?

        Yes ☐   No ☐   Don't know ☐

Does your organisation have any formal or informal affiliation with any of the following industries (Check all that apply)

Tobacco   Yes ☐   No ☐   Don't know ☐

Alcohol	Yes ☐	No ☐	Don't know ☐
Food	Yes ☐	No ☐	Don't know ☐

If yes to any, please indicate the type of relationship/sponsorship/support:

AREAS FOR DEVELOPMENT AND/OR CAPACITY STRENGTHENING

What are your organisation's major areas for development and/or capacity strengthening? (Check all that apply)

Training ☐:
Running an efficient, effective CSO ☐
Forming strategic alliances and partnerships ☐
Strategic planning and management ☐
Advocacy and related strategies ☐
Awareness/public education campaign planning and implementation ☐
Communication and social media ☐
Multisectoral engagement and partnerships ☐
Grant proposal writing and resource mobilisation ☐
Good governance and organisation building ☐
Models for patient engagement ☐
Better access to information on advancements in treatment and care ☐
Best practices to reduce exposure to NCD risk factors ☐
NCD monitoring and accountability tools ☐
Greater awareness & knowledge of national, subregional, regional, and global NCD   frameworks ☐
Examples of NCD prevention and control best practices ☐
Research capacity for policy analysis and development ☐
Other ☐   Please specify:
Don't know ☐

HEALTHY CARIBBEAN COALITION

Is your organisation a member of the Healthy Caribbean Coalition?
        Yes ☐   No ☐   Don't know ☐

If Yes, since when has it been a member?   Month…   Year…

Has your organisation benefitted from its membership in the HCC?
        Yes ☐   No ☐   Don't know ☐

If Yes, how has the organisation benefitted? (Check all that apply)
        Attended regional meetings ☐
        Benefitted from capacity building ☐
        Received weekly HCC Roundup ☐
        Received sub-grants for special projects ☐
        Other ☐   Please specify:

What are the main ways in which the HCC can assist your organisation's development and capacity strengthening? (Check all that apply)
        Training ☐
        Establishing partnerships ☐
        Resource mobilisation ☐
        Providing funding ☐
        Strengthening your organisation's online presence ☐
        Sharing information/good practices/tools ☐
        Providing advisory services ☐
        Strategic planning ☐
        Monitoring and evaluation ☐
        Other ☐   Please specify:
        Don't know ☐

Please rate HCC's performance in the following key strategic areas:

Advocacy: Very satisfactory ☐ Satisfactory ☐ Unsatisfactory ☐ Don't know ☐

Communication: Very satisfactory ☐ Satisfactory ☐ Unsatisfactory ☐ Don't know ☐

Capacity building: Very satisfactory ☐ Satisfactory ☐ Unsatisfactory ☐ Don't know ☐

mHealth/eHealth: Very satisfactory ☐ Satisfactory ☐ Unsatisfactory ☐ Don't know ☐

Specifically, how can HCC's communication with its members be improved? Please answer the following questions:

Have you visited the HCC website?
Yes ☐ No ☐

Do you think the website is useful and informative?
Yes ☐ No ☐ Don't know ☐

How can the website be improved?

Do you receive the HCC Weekly Roundup?
Yes ☐ No ☐ Don't know ☐

Do you find the Roundup informative?
Yes ☐ No ☐ Don't know ☐

Do you find the information in the Roundup useful in your organisation's work?
Yes ☐ No ☐ Don't know ☐

Has your organisation ever submitted information for inclusion in the Roundup?
Yes ☐ No ☐ Don't know ☐

How can HCC make it easier for your organisation to contribute to the content of the Roundup?

How can the content of the Roundup be improved?

Have you "liked" the HCC Facebook page?
        Yes ☐   No ☐   Don't know ☐

Do you find the HCC Facebook posts useful?
        Yes ☐   No ☐   Don't know ☐

How could HCC improve its posts? Please describe:

Do you follow HCC on Twitter?
        Yes ☐   No ☐   Don't know ☐

Do you find HCC's tweets useful and informative?
        Yes ☐   No ☐   Don't know ☐

How can HCC improve its tweets? Please describe:

Do you think HCC should be on any other social media?
        Yes ☐   No ☐   Don't know ☐

If Yes, which ones?

How would you rate HCC's performance in fostering a whole-of-society, whole-of-government approach to NCDs?
        Very satisfactory ☐   Satisfactory ☐   Unsatisfactory ☐   Don't know ☐

What suggestions do you have for improving HCC's performance in this area?

How would you rate HCC's performance in improving your organisation's understanding of, and activities in, advocacy for NCDs?

        Very satisfactory ☐   Satisfactory ☐   Unsatisfactory ☐   Don't know ☐
        Not applicable ☐

What suggestions do you have for improving HCC's performance in this area?

How would you rate HCC's performance in improving your organisation's contribution to policy development for NCDs?

        Very satisfactory ☐   Satisfactory ☐   Unsatisfactory ☐   Don't know ☐
        Not applicable ☐

What suggestions do you have for improving HCC's performance in this area?

How can HCC exert greater influence on NCD prevention and control at:
Global level?

        Regional level (Caribbean)?
        National level?
        What should be HCC's primary areas of focus? (Check all that apply)
        Advocacy ☐
        Policy development (political level) ☐
        Communication ☐
        Capacity building ☐
        mHealth/eHealth ☐
        Building partnerships ☐
        Resource mobilisation ☐
        International representation ☐
        Strategic planning ☐
        Monitoring and evaluation ☐
        Other ☐   Please specify:
        Don't know ☐

Please list three (3) ways in which HCC can better serve your organisation:

Any final, general comments?

Please proceed to Part III of the survey

PART III – INFORMATION NEEDS

Full name of organisation:

Country of location:

Professional category/Title of respondent:
        Are you   Male? ☐   Female? ☐   Prefer not to say ☐

What topics do you work with? (Check all that apply)
        Cardiovascular diseases, including hypertension ☐
        Diabetes ☐
        Cancer ☐
        Chronic respiratory diseases, including bronchial asthma ☐
        Mental health and neurological disorders ☐
        Disabilities ☐
        Prevention and control of NCD risk factors ☐
        Tobacco use ☐
        Physical inactivity ☐
        Unhealthy diet ☐
        Harmful use of alcohol ☐
        Other ☐   Please specify:

What factors determine when you seek information? (Check all that apply)
        Urgency of an issue:
        Frequently ☐   Sometimes ☐   Rarely ☐
        Never ☐   Not applicable ☐
        Disaster/critical need:
        Frequently ☐   Sometimes ☐   Rarely ☐
        Never ☐   Not applicable ☐
        Personal learning need:
        Frequently ☐   Sometimes ☐   Rarely ☐   Never ☐
        Not applicable ☐

Organisational need/demand: Frequently ☐   Sometimes ☐   Rarely ☐

Never ☐   Not applicable ☐

To answer a patient query:

Frequently ☐   Sometimes ☐   Rarely ☐   Never ☐

Not applicable ☐

Other ☐   Please specify:

What types of information do you consult most? (Check all that apply)

Peer-reviewed literature ☐

Grey literature ☐

Case studies ☐

Data ☐

Guidelines ☐

Other ☐   Please specify:

What do you use information for? (Check all that apply)

Policy making ☐

Teaching/training ☐

Report writing ☐

Grant proposals/Bid writing ☐

Campaign development ☐

Personal development ☐

Keeping up-to-date ☐

Other ☐   Please specify:

How do you access information that you need?

Physical library ☐

Internet search engines ☐

Subscription databases ☐

Free databases ☐

Websites of health agencies/institutions ☐

Face-to-face seminars ☐

Social media ☐

Other ☐   Please specify:

What barriers do you experience in accessing the information?

      Cost of travel ☐

      Cost of subscription ☐

      Registration/participation fees ☐

      Internet access ☐

      Lack of time ☐

      Uncertain where to look for information ☐

      Bias in information available ☐

      Other ☐   Please specify:

T

o which online libraries do you have access?

      University/ies ☐   Please specify:

      Government institution/s ☐   Please specify:

      International organisation/s ☐   Please specify:

      Public/local library/ies ☐   Please specify:

      Other ☐   Please specify:

Which are your preferred information sources, e.g. organisations, websites, universities, or agencies? Please list (maximum of three):

How many hours of your work week (40 hours) do you spend looking for information/evidence (not on the internet)?

      1-2 ☐

      3-5 ☐

      5-9 ☐

      10 or more ☐

How many hours of your work week (40 hours) do you spend <u>on the internet</u> looking for information/evidence?

      1-2 ☐

      3-5 ☐

      5-9 ☐

      10 or more ☐

Is information/evidence on the health situation in your country readily available to you?
  Yes ☐   No ☐

How is that information available to you? (Check all that apply)
  Print ☐
  Internet ☐
  Other ☐   Please specify:

Do you access information from other countries to use in your local setting?
  Yes ☐   No ☐

Do you feel isolated in your work?
  Yes ☐   No ☐

If No, do you collaborate extensively with individuals:
  In your country? ☐
  In the Caribbean? ☐
  Outside the Caribbean? ☐ Please specify:

How could collaboration/information sharing be improved? (Select top two)
  Email contact ☐
  Regular face-to-face meetings ☐
  Regular online meetings (online conferencing/webinars) ☐
  Online discussion groups/community of practice ☐
  Other ☐   Please specify:

Do you use online networks, such as Communities of Practice (CoPs)[23], to share information and collaborate with others?
  Yes ☐   No ☐   Never heard of them ☐

If Yes, please list the networks/CoPs in which you are a member:

---

[23] Online Communities of Practice (CoPs) are tools that enable interaction between peers on an ongoing basis to share topic information and best practices and network. They can also support professional development and help to overcome geographical and professional isolation.

If not already a member of a CoP or network, what would be your main reason for joining? (Check all that apply)

Linking with peers ☐

Sharing information ☐

Keeping up-to-date in your field ☐

Other ☐　　　　　Please specify:

What is your preferred format for research information?

Oral presentation ☐

Poster presentation ☐

Written paper ☐

Other ☐　　　　　Please specify:

Would you describe your work as evidence-based?

Yes ☐　　　　No ☐

If No, what are the main factors that guide your work and relevant decisions? Please describe:

What <u>one</u> information resource could you not live without?

What information resources would make your life easier? Please list (maximum of five):

Do you have your own devices with internet access? (Check all that apply):

Desktop computer ☐

Laptop computer ☐

Mobile phone ☐

Tablet ☐

Other ☐　　　　　Please specify:

Do you use this device/these devices to search for and access information online?

Yes ☐　　　　No ☐

Is there an information specialist/focal point in your organisation?

Yes ☐　　　No ☐　　　Don't know ☐

With whom do you have direct contact or engage in your role in your organisation? (Check all that apply)

Public ☐

Patients ☐

Policymakers ☐

International organisations ☐

Other ☐　　Please specify:

Not applicable ☐

When faced with the need to access information, you <u>first</u>: (Check one)

Ask a colleague ☐

Search the web ☐

Write down the search question and plan what needs to be done to find the information ☐

Ask your organisation's information professional/librarian ☐

Other ☐　　Please specify:

Do you experience language barriers when retrieving/accessing information?

Yes ☐　　　No ☐　　　Please expand on your answer (optional):

From an information perspective, please rate your confidence levels in the following areas:

Information searching:

Very confident ☐　　Somewhat confident ☐　　Neutral ☐　　Somewhat unconfident ☐　　Very unconfident ☐

Critical appraisal of information:

Very confident ☐　　Somewhat confident ☐　　Neutral ☐

Somewhat unconfident ☐　Very unconfident ☐

Managing references:

Very confident ☐　　Somewhat confident ☐　　Neutral ☐

Somewhat unconfident ☐ Very unconfident ☐

Computer hardware:

Very confident ☐ Somewhat confident ☐ Neutral ☐

Somewhat unconfident ☐ Very unconfident ☐

Computer software:

Very confident ☐ Somewhat confident ☐ Neutral ☐

Somewhat unconfident ☐ Very unconfident ☐

Mobile devices:

Very confident ☐ Somewhat confident ☐ Neutral ☐

Somewhat unconfident ☐ Very unconfident ☐

What are your preferred learning methods? (Check no more than three)

Self-directed ☐

Group work ☐

Problem-solving ☐

Discussion ☐

Case studies ☐

Online ☐

Face-to-face ☐

Other ☐ Please specify:

Any final, general comments?

Thank you for taking the time to complete this information needs assessment. Your cooperation and input are much appreciated.

APPENDIX 3: 'Other' topics you work with

Alzheimer's Disease and other dementias

Appropriate use of herbal medicines

Finance related

Lifestyle diseases

No particular topic

Paediatric patients

Palliative Care

Screening and diagnostic services

Skin care products that contain harmful chemical

Spiritual well-being of community.

APPENDIX 4: Other types of information consulted most

Financial

I am mostly involved in the finacial business

Internet search engines

N/A

Professional Journals online literature

scientific journals

APPENDIX 5: Other uses for information

Appropriate patient management

Assistance where possible

Awareness

informing patients

N/A

patient care

Preparation of monthly finanicals

Responding to queries from individuals, the media

to assist clients when they request information

to repackage and share with audiences on facebook page

APPENDIX 6: Other ways to access information needed

Colleagues Members of the public

Data gathered by SDA hospitals and life style centers located mainly in North America

Membership website

N/A

On line training

Other Non- governmental organisations

Pubmed

Reports from Ministry of Health including hospital   Reports from other Ministries/ Departments of Government

Source documentation within the organisation

APPENDIX 7: What is your preferred format for research information?

Abstract

All, as is best suited

E-copy

It does not matter the form of information.

Peer review online jounrals

APPENDIX 8: Other barriers in accessing information

conflicting information

Determining the authenticity of information

I do not have any barriers because I have internet access time is not a barrier because I am retired and any training I subscribe to is affordable at this time.

Information simply not available, or not accessible.

Must seek only from credible sources to avoid bias

N/A

No barriers experienced

none really!

Sometimes, too much information.

APPENDIX 9: Coded What one information resource could you not live without?

Internet	48
Data on current health data in other countries	1
Dictonary/Glossaries	1
Email	1
Google	5
None	2
Search engines	5
John Hopkins information	1
Journal articles	1
Online database	3
Person-to-person	2
Pubmed	1
TV	1
Websites	1

APPENDIX 10: What information resources would make your life easier?

Credible Health literature and reliable internet access

Symposium/Public Forum, Social Media, Access to Medical Library, Access to wide-based cancer related information

A high yield photocopier

access to a research database

access to updated information database

Books, posters, leaflets,

Data, regular presentations, newsletters, knowledge groups

don't know

Effective internet service

faster internet speed more access to health information

Governmental data bases from Barbados that give up-to-date health information

Greater access to research information, face to face intervention,seminars and training sessions, easier access to current information of data

Interactive workshops and networking sessions Knowledge exchange and sharing of good practice Collaboration and new partnerships

Internet

Internet Research Papers Magazines

internet Social media networkinh'

internet service, written

internet, social media, websites

IT staff well trained staff members who can multi-task more people to do more work More colleagues to help me!

Mobile, Internet

more Focus group discussions, ABDA website,

More public service messages on NCDs. More free data based.

N/A

NCCN, WHO, NCI ,Clinical Practice Today from Duke Medicine, Journal of Epidemiology

Open Journal Access Scientific medical information

printed materials, research papers

Printed Presentations Oral presentations

Regular conference calls, journal clubs, case studies, peer reviews

relationship with peers relationship with consultant abstracts of recent research - especially Caribbean

Resource materials Access to updated information

review literature, health publications, up to date country reports, epidemiology reports, international health releases

Search engines

Statistic info / reports / graphic tools / presentations / documentaries

Statistics

Swifter internet access Proven Information (from universities etc.) Testimonials (video or written)

Those available are OK

up to date statistics would enable my job to be a little more efficient

Up-to-Date Access to a better range of journals from my university More reliable internet access at work A course on cardiac rehab

what I currently utilise

APPENDIX 11: Other ways collaboration/information sharing could be improved?

As soon as the TTHF complete its restructuring

Online sometimes provides difficulties.

The information is usually for personal use, and collaboration is not necessary

visits from experts to inform all practitioners through workshops

We would love to have a conference where we could all meet, talk and share information.

Work shops or lectures with significant persons

APPENDIX 12: Other reasons for joining a CoP

Market Caring and Sharing

N/A

No not a member

supervision - case studies

Time and money

Very often, the work of the Barbados Cancer Society is straightforward and hands on with routine problems and solutions, and our small team is fully occupied. Our major problem is fundraising and staff competencies. We are able to manage linking. sharing and keeping up to date, in general with the present range of methods.

We are members of the CoP/Network

APPENDIX 13: Other people you have direct contact or engage with in your role in your organisation

Board
Board members, staff
Church members
Clients, those who need specific cancer-related assistance or advice Funds-raising prospects Medical Fraternity
Doctors
General manager
Health Leader for the Conference
Health Professionals
Local partners and organizations
Other NGOs, private sector, IPPF Member associations globally
Partners

APPENDIX 14: General comments

1. We believe that the sharing of information and experiences on patient care will improve the quality oc care for our Patients 2. The Public should be more informed of the services that are available to them without being afraid of the cost of care. 3. Networking amongst agencies should not be seen as competition, but as services "webbed" to provide protection for care.

I retain information better if it is to do with a real person or case study delivered by a real person, in person or by video link

I wish you success in what you set out to achieve

Information sharing is an important aspect of gaining confidence in your field, therefore this must be full endorsed and encouraged.

NO

no

NO

No

No

No

No!

None

not really, very interesting survey!

Quite introspective

Survey was too long

Thank you for your interest in my opinion. We are truly trying to promote GSCC and to increase and improve the services that we provide. Our Board Members are volunteers.

The CSOB has been an outstanding organisation in the Bahamas, and any additional support/ information resources will be greatly appreciated.

The survey was designed for a professional response and did not cater for organisations with volunteers who may themselves be patients and/or non-professionals (healthcare).

This assessment has alerted me to various aspects of my organisation that requires major strengthening.

Through increased training and sharing of CSO best practices, NGO's within the Caribbean will be able to continuously increase their knowledge base and build their capacity to address the rising issues of NCDs as a collaborative CSO body.

We appreciate all you are doing.

We hope that this survey will be beneficial to all concerned.

HEALTHY CARIBBEAN COALITION

The work of the HCC would not be possible without
core funding from Sagicor Life Inc.

Sagicor

Wise Financial Thinking for Life