



# A CIVIL SOCIETY BENCHMARK REPORT

## RESPONSES TO NCDS IN EAST AFRICA

**THE EAST AFRICA  
NCD ALLIANCE INITIATIVE**

**June 2014**

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This study was undertaken by the East African NCD Alliance Post-2015 Initiative, a loose coalition of civil society organisations (CSOs) working to tackle the challenge of NCDs in the East Africa region.

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## List of Acronyms

CNCD-Africa	Consortium for NCD Prevention and Control in sub-Saharan Africa
CSOs	Civil Society Organisations
DANIDA	Danish International Development Agency
DMIC	Diabetes Management and Information Centre
DNCDA	Danish NCD Alliance
EAC	East Africa Community
KAPTLD	Kenya Association for prevention of Tuberculosis and Lung Diseases
KCS	Kenya Cardiac Society
KDA	Kenya Diabetes Association
KESHO	Kenya Society for Haemato-Oncology
MoH	Ministry of Health
MP	Member of Parliament
NCDAK	Non Communicable Disease Alliance, Kenya
NCDs	Non-communicable Diseases
NDP	National Development Plan
PLWNCD	People living with non-communicable diseases
TANCDAA	Tanzania Non Communicable Disease Alliance
UN	United Nations
UNCDA	Uganda Non Communicable Disease Alliance
ZNCDA	Zanzibar Non Communicable Disease Alliance



East Africa NCD Alliance Post-2015 Initiative, Planning Meeting, February 2014.

## EXECUTIVE SUMMARY

Non-communicable diseases (NCDs) — such as cancer, cardiovascular disease, chronic respiratory diseases, and diabetes — are a major challenge to health and development in the 21st century. They are the leading cause of death and disability worldwide, exacting a heavy and growing toll on the physical health and economic security of all countries, particularly low- and middle-income countries (LMICs). Driven in large part by exposure to four common modifiable risk factors — tobacco use, physical inactivity, unhealthy diet, and the harmful use of alcohol — these conditions perpetuate and entrench poverty within households and communities, and increase inequalities within and between countries.

NCDs represent a significant challenge for East Africa, and sub-Saharan Africa more broadly. While the NCD epidemic is increasing worldwide, the largest relative increase in NCD deaths globally in the next decade is expected to occur in Africa, where NCDs are projected to become the leading cause of death by 2030. In East Africa, the linkages between NCDs, communicable diseases and maternal and newborn health are clear, as is the need for integrated approaches to prevention, diagnosis, treatment, care and education. These diseases are undermining sustainable human development in the region, and threatening achievement of the Millennium Development Goals (MDGs).

In response to the challenge of NCDs in East Africa, a loose coalition of civil society organisations (CSOs) formed the East African NCD Alliance Post-2015 Initiative. This initiative is led by the NCD alliances of Uganda, Tanzania, Zanzibar, Kenya, and Rwanda, in partnership with the Danish NCD Alliance, the global NCD Alliance, and three universities (University of Southern California Institute for Global Health, Office of Global Health, Department of Internal Medicine, Yale University and Center for Global Health, Aarhus University). The Initiative aims to promote regional cooperation between the East Africa NCD alliances, as well as providing a coordinated platform for advocacy on NCDs in health and development agendas. It is funded by the DANIDA Civil Society Fund.

As part of the initiative, the coalition conducted a benchmark survey of policy progress on NCDs in the East Africa Community. The survey focused on four East African countries — Rwanda, Uganda, Kenya and Tanzania (including the island peninsular of Zanzibar), and was coordinated by the NCD alliances in the region. This report presents the main findings of this survey, providing an evidence-based snapshot of the NCD response in East Africa from a civil society perspective and highlighting gaps and good practices. These findings have been used to inform the development of an East Africa Civil Society NCD Charter, a crucial advocacy tool for the region which will be leveraged in relevant global policy processes on NCDs, most notably the UN High-Level Review on NCDs on 10–11 July 2014 and the ongoing global discussions to define the post-2015 development agenda.

## **The main findings of this report include:**

- While the East Africa region has made strong commitments for action on NCDs and some progress has been achieved, there remain challenges and gaps in implementation;
- NCDs are generally prioritised in national health and development plans, yet this is not translating into sufficient domestic and bilateral resource allocations. This may be in part due to the absence of specific targets and indicators on NCDs in National Development Plans (NDPs), as well as donors not aligning aid with country priorities;
- All countries are at various levels in formulating National NCD Plans, and there are concerted efforts to develop these plans in collaboration with civil society. However only one country — Kenya — has developed and endorsed national NCD targets;
- There is coordinated and well-organised civil society movement for NCDs in East Africa that engage people living with NCDs, including the recently formed NCD alliances in the region. These alliances have been formed through a pioneering twinning initiative with the Danish NCD Alliance;
- There is a strong track record in East Africa of successful collaboration and partnership between civil society and national governments (particularly Ministry of Health) to respond to the NCD challenge, including in advocacy, awareness raising activities, and providing patient support;
- Although policies, strategies, and legislation exist to reduce exposure of the NCD risk factors, implementation remains weak. For example, all East Africa countries have ratified the WHO Framework Convention on Tobacco Control (FCTC), yet implementation has been patchy. Action on nutrition and physical activity stand out as being areas for particular attention and priority;
- One of the major challenges of controlling NCDs in the East Africa region is health systems not designed or oriented towards chronic conditions like NCDs. While governments have embarked on training health personnel in NCD management, and efforts have been made to provide community-based NCD services, limited resources remain a major barrier to strengthening health systems for NCDs;
- There is limited national research for NCDs due to financial and human resource constraints. However, with support from development partners, some countries have initiated NCDs research projects;
- Surveillance and monitoring of NCDs in East Africa has improved, however NCDs are still not sufficiently integrated into national health information and management systems and there is limited capacity of health personnel for surveillance and data collection on NCDs.

# OUR PROFILE — EAST AFRICAN NCD ALLIANCE POST-2015 INITIATIVE

The East African NCD Alliance Post-2015 Initiative is a loose coalition of civil society organisations (CSOs) working to tackle the challenges of NCDs in the East Africa region. The coalition was formed to provide a platform to advocate and lobby national governments to prioritise NCDs in health and development agendas.

## Members of the East African NCD Alliance Post-2015 Initiative:

- **Uganda Non Communicable Disease Alliance (UNCDA):** Member associations are Uganda Heart Foundation, Uganda Cancer Society and Uganda Diabetes Association.
- **Tanzania NCD Alliance (TANCDA):** Member associations are Tanzania Diabetes Association, Tanzania Heart Foundation, Tanzania Cancer Association and Tanzania Association for Respiratory Diseases.
- **Zanzibar NCD Alliance (Z-NCDA):** Association members are Zanzibar Diabetes Association and the Zanzibar Cancer Association.
- **NCD Alliance Kenya (NCDAK):** Alliance members are Kenya Cardiac Society (KCS), Kenyan Heart-National Foundation, Diabetes Management and Information Centre (DMIC), Diabetes Kenya Kenya (formerly Kenya Diabetes Association), Kenya Society for Haemato-Oncology (KESHO), Kenya Association for prevention of Tuberculosis and Lung diseases (KAPTLD), The Neurological Society of Kenya, Rheumatological Society of Kenya and Consortium for NCD Prevention and Control in sub-Saharan Africa (CNCD-Africa) and African Medical Research Foundation.
- **Rwanda NCD Alliance (RNCDA):** While still in early stages of formation, many disease and patient advocacy groups exist such as Rwanda Heart Foundation, Rwanda Diabetes Association, Cardiac Patients' Network, and many others, including those representing cancers, disabilities, oral and eye health.
- **The Danish NCD Alliance (DNCDA):** Consisting of the Danish Cancer Society, Danish Heart Foundation and Danish Diabetes Association, DNCDA aims to contribute to the fight against the global NCD epidemic, by supporting development of NCD organisations in Africa and by taking part in the global campaign for political attention and action to prevent and control NCDs.
- **The NCD Alliance:** The NCD Alliance is a global network of 2000 organisations in 170 countries. The NCD Alliance consists of the World Heart Federation, the International Diabetes Federation, Union for International Cancer Control, The International Union against TB and Lung Disease, Alzheimer's Disease International and Management Sciences for Health.
- **Universities:** The initiative is a broad CSO-academia collaboration between three universities — University of Southern California Institute for Global Health, Office of Global Health, Department of Internal Medicine, Yale University and Center for Global Health, Aarhus.

# BACKGROUND AND INTRODUCTION

Non-communicable diseases (NCDs) such as cancer, cardiovascular disease, chronic respiratory diseases and diabetes have in the recent past increasingly affected more people globally than infectious diseases. These diseases are linked to common risk factors such as tobacco use, harmful use of alcohol, unhealthy diets and physical inactivity among others.

NCDs disproportionately impact on low- and middle-countries (LMICs) and represent a significant challenge for sub-Saharan Africa, compounded by road traffic injuries. Of the 36 million NCD deaths every year, 80% occur in LMICs. While the NCD epidemic is increasing worldwide, the largest relative increase in NCD deaths globally in the next decade is expected to occur in Africa, where NCDs are projected to become the leading cause of death by 2030.

In addition to the five major NCDs, the NCD burden in East Africa is also attributable to rheumatic heart disease, haemoglobinopathies (in particular sickle cell disease), mental disorders, violence and injuries, oral and eye diseases.

NCDs and NCD-related mortality occur at younger ages in sub-Saharan Africa than in other regions, impacting on economic productivity. Two-thirds of years of life lost (YLLs) and disability-adjusted life years (DALYs) due to NCDs and injuries in sub-Saharan Africa are in individuals younger than 40 years.

The double burden of communicable and non-communicable diseases in the East African Community (EAC) and the associated disabilities and premature deaths increase pressure on existing vulnerable health systems and national economies. NCDs impede economic growth by impacting on labour productivity, resulting in foregone national income, and entrenching household poverty.

The UN High-Level Meeting on NCDs held in September 2011 committed the global community to taking action on NCDs, issuing a sixty five point UN Political Declaration which noted that NCDs present a challenge of epidemic proportions which threatens to undermine social and economic development throughout the world. The Political Declaration recognised that NCDs can be largely prevented and controlled through collective and multisectoral action by all Member States and other relevant stakeholders, including civil society, the private sector, the media and academia. The key provisions of the 2011 Political Declaration are to reduce risk factors and create health promoting environments, strengthen national policies and health systems, foster international cooperation, including collaborative partnerships, and research and development.

Following up on commitments in the Political Declaration, WHO Member States adopted a global target of a 25% reduction in premature mortality from NCDs by 2025 at the 65th World Health Assembly (WHA). A voluntary Global Monitoring Framework (GMF) on NCDs, including nine targets and 25 indicators, was subsequently adopted at the 66th WHA. This Global Monitoring Framework is one of the three critical parts of the Global NCD Framework (the GMF, the WHO Global NCD Action Plan 2013–2020, and the Global Coordination Mechanism for NCDs) expected to inform NCD actions globally, regionally and nationally over the next decade.

In the coming months, the UN will convene another High-Level meeting, the 2014 UN High-Level Review and Assessment for NCDs, to assess how the international community has responded in tackling the global NCD challenge and plan for a way forward on how to include NCDs in the post-2015 development agenda. It is a major opportunity to take stock of progress, identify gaps and challenges, and commit to take actions to accelerate progress at national, regional and global levels.

To inform these global processes, and ensure the perspectives and priorities of the EAC on NCDs are reflected, the East African NCD Alliance Post-2015 Initiative convened a stakeholder conference and developed a Charter, which will be shared at the UN High-Level Review on NCDs on 10–11 July.

## Scope of the Assignment

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The East African NCD Alliance Post-2015 Initiative commissioned this benchmarking study in four East African countries — Rwanda, Uganda, Kenya and Tanzania (including Zanzibar) to provide evidence-based information, which would in turn inform the writing of the Charter.

The survey sought to understand and assess the EAC response to NCDs, from a civil society perspective. It highlights best practices and identifies areas for further action. It provides an evidence-based platform, from which civil society can monitor progress as well as complement regional and national NCD policies and programmes.

## Approach

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The study largely employed qualitative methods, which were participatory in nature. The qualitative approach ensured that every step of the study was in itself a learning process for the key respondents. This minimised the danger of the study being extractive, but rather provided learning for all stakeholders consulted. Furthermore, the qualitative techniques enhanced ownership of the study findings.

## Methods

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The methodology of the study is based on the NCD Alliance benchmarking tool, which is structured around the six objectives of the WHO Global NCD Action Plan 2013–2020. The six priority objectives are: raising priority of NCDs through international cooperation and advocacy; strengthening national capacity, multi-sectoral action, and partnerships for NCDs; reduce NCD risk factors and social determinants; strengthen and reorient health systems to address NCDs; promote national capacity for research and development on NCDs; and monitor and evaluate progress on NCDs.

For the purpose of this study the benchmarking tool was adapted to the East African context. It was used to guide discussions and solicit information from the targeted respondents during semi-structured Interviews with civil society representatives, NCD focal persons in the ministries of health, and health personnel. The benchmarking tool is attached to this report in Annex 2.

Alongside this, a desk-based literature review on key policy documents was conducted, which informed contextualisation of not only the study but also interpretation of the findings and drawing conclusions.

## Validity of findings

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In compiling this report it was necessary to summarise a considerable body of data provided by the respondents. Inevitably the need to summarise data results in a loss of detail, some of which may be of interest to readers.

In addition, it is acknowledged that had there been more time and resources available, complementary approaches to data collection, such as in-depth interviews and document analyses, could have helped to verify and elucidate the data here presented. The authors have done their best within the time and resources available to present an accurate picture at the time the study was done, and comments and questions on any aspects of this report are welcomed.

Despite these potential shortcomings, it is believed that overall an accurate account is given that significantly advances knowledge and understanding of the responses to NCDs within East Africa and provides a basis for action.

# FINDINGS

This section presents findings from responses to the respective national questionnaires.

## Priority 1: Raising priority of NCDs through international cooperation and advocacy

### Inclusion of NCDs in national health and development plans

As a starting point for national governments to scale up efforts to address NCDs, it is imperative they are reflected as a priority in both national health and development plans. NCDs are now widely recognised as a challenge for sustainable human development, but remain generally under-prioritised in the various national development policy frameworks and underfunded by bilateral development agencies. Inclusion of NCDs in national development plans (or equivalent) is crucial to re-orient development assistance for health towards NCDs, because donor governments are committed to aligning aid to country priorities (as enshrined in the Paris, Accra, and Busan declarations on aid effectiveness).

The survey assessed whether each country included NCDs in National Development Plans (NDPs). All countries included in the benchmarking survey have a NDP or equivalent (for example, Poverty Reduction Strategy Papers). It emerged that NCDs are reflected in the NDP or equivalent in Uganda, Rwanda, Tanzania, and Zanzibar, but not in Kenya. However the research unveiled the variations in how NCDs are reflected in these NDPs, particularly demonstrating the absence of specific targets or indicators for NCDs which are pivotal in inspiring and monitoring progress. The Zanzibar NDP is the only plan to have dedicated NCD targets.

In Zanzibar, NCDs are prioritised in the NDP and Growth and Poverty Reduction Strategy 2010–2015 as a key health constraint. The Strategy includes a goal to “improve health delivery systems particularly to the most vulnerable groups”, and “reducing the morbidity and mortality due to NCDs” is an operational target to achieve this goal. The Zanzibar strategy identifies the most prevalent NCDs nationally as hypertension, diabetes, asthma, cancer, road accidents and mental health. The core strategies for NCDs are:

- Ensure adequate control and management of NCDs mainly diabetes, hypertension, cancer (especially breast, cervical, prostate), filariasis, leprosy, fistula, asthma, mental health illness and others;
- Control the spread of non-communicable and emerging diseases and enhance effectiveness of treatment of NCDs;
- Attain better understanding of the incidence, prevalence and risk factors of NCDs in Zanzibar;
- Improve prevention, early detection and management of five priority NCD diseases;
- Improve awareness and management of injuries and congenital condition.

The Rwanda Economic Development and Poverty Reduction Strategy 2013–2018 has four thematic priority areas — economic transformation, rural development, productivity and youth employment, and accountable governance. “Quality, demand and accessibility of primary health care” is identified as a foundational issue, and “HIV/AIDS and NCDs” are identified as a priority cross-

cutting issue. Consequently, there is no specific target or indicator on NCDs in the Rwanda PRSP.

In the Uganda NDP, health and nutrition is grouped under the “social sector”. The Ugandan NDP recognises NCDs as:

*“Non-Communicable Diseases are an emerging problem and include hypertension, cardiovascular diseases, diabetes, chronic respiratory diseases, mental illness, cancer conditions, injuries as well as oral diseases. Cancers are on the increase in Uganda and some of them are linked to STDs such as HIV/AIDS and Human Papilloma Virus. The increase in NCDs is due to multiple factors such as adoption of unhealthy lifestyles, increasingly ageing population and metabolic side effects resulting from lifelong antiretroviral treatment”.*

In the Uganda NDP, NCDs are also mentioned under constraints to the performance of the health and nutrition sector, stating that “despite an increase in prevalence of NCDs, there is inadequate capacity among specialised units, and an absence of an elaborate framework to address NCDs”. Other major challenges of controlling NCDs are that the health system “is not designed to take care of chronic conditions like NCDs” and “the high cost of medicines/supplies for treatment”. Mental disorders receive specific mention, grouped within substance abuse.

There are eight objectives for health and nutrition, of which two have interventions specifically related to NCDs. Objective 2, to “ensure universal access to the Uganda National Minimum Care Package (UNMHCP)” includes “developing and implementing appropriate strategic plans and treatment guidelines for the emerging NCDs.” Objective 3 is to “improve nutrition status of Uganda population”, and includes the strategy to “build community and institutional capacity for management of malnutrition, including promoting nutrition in patients with...non-communicable diseases”. However, there are no specific targets or indicators for NCDs in the NDP.

In Tanzania’s NDP 2011–2016, health is included as part of “human capital development and social services”. “Prevention of non-communicable diseases” is one of 13 strategic interventions under the health goals, but there is no associated target to inspire or monitor progress. With regard to improving provision for control and prevention of NCDs at the primary healthcare level, the NDP has a dedicated budget allocation to train responsible personnel for prevention and control of NCDs from 2011–2016.

In both Kenya’s Poverty Reduction Strategy Paper and NDP entitled “Vision 2030”, health is included under the social pillar, which is described in the poverty reduction strategy as “achieving cohesive society enjoying equitable social development”. However, there is no mention of NCDs in either.

In addition to reviewing the inclusion of NCDs in NDPs, the benchmarking study also assessed the inclusion of NCDs in national health plans and strategies. Often the inclusion of NCDs in national health plans is a precursor for inclusion in national development plans, and this is demonstrated in the East African context. All East

Africa countries that have NCDs as a priority in the NDP (Uganda, Tanzania, Zanzibar and Rwanda) also include NCDs as a priority in national health plans. For example, in addition to the explicit reflection of NCDs in the Zanzibar NDP, the health strategic plan prioritises addressing NCDs as a health intervention. The Uganda Health Sector Investment Plan also provides for efforts to address NCDs. In Rwanda, NCDs are mentioned in the Third Health Sector Strategic Plan (HSSPIII) 2012–2018.

### Operational national NCD alliance/coalition/network of NGOs that engages People Living with NCDs

For all the countries, it was indicated that there is civil society efforts to engage with patients, or People Living with NCDs (PLWNCDs). Civil society organisations provide information to PLWNCDs on care, management and treatment of NCDs. Civil society has also worked with PLWNCDs in increasing public awareness about NCDs and also involved them in advocacy and influencing policy to take into consideration the interests and concerns of PLWNCDs.

The national CSO alliances that engage with PLWNCDs are:

- **Uganda Non Communicable Disease Alliance (UNCDA):** Member associations are Uganda Heart Foundation, Uganda Cancer Society and Uganda Diabetes Association.
- **NCD Alliance Kenya (NCDAK):** Member associations are Kenya Cardiac Society (KCS), Kenyan Heart-National Foundation, Diabetes Management and Information Centre (DMIC), Kenya Diabetes Association (KDA), Kenya Society for Haemato-Oncology (KESHO), Kenya Association for prevention of Tuberculosis and Lung diseases (KAPTLD), The Neurological Society of Kenya, Rheumatological Society of Kenya and Consortium for NCD Prevention and Control in sub-Saharan Africa (CNCD-Africa).
- **Tanzania NCD Alliance (TANCD):** Member associations are Tanzania Diabetes Association, Tanzania Heart Foundation, Tanzania Cancer Association and Tanzania Association for Respiratory Diseases.
- **Zanzibar NCD Alliance (Z-NCDA):** Members associations are Zanzibar Diabetes Association and the Zanzibar Cancer Association.
- In Rwanda, while lacking a formal NCD alliance, there are some CSOs that engage with the country's MoH to increase awareness and control of NCDs such as Rwanda Heart Foundation, Rwanda Diabetes Association, Cardiac Patients' Network, and many others, including those representing cancers, disabilities, oral and eye health.

Governments in the region have recognised CSO efforts in engaging with PLWNCDs, and there is strong collaboration and partnership between MoH and CSOs across the East Africa region. This collaboration takes many forms — including advocacy, awareness raising activities, and technical work including developing NCD plans and policies.

For example, governments have invited NGOs to participate in NCD awareness activities — although these activities are developed and implemented in an ad hoc manner. In Kenya and Uganda, governments — through Members of Parliament (MPs), regional



Zanzibar NCD Alliance community outreach to promote NCD prevention.

governors, senators, and local government representatives - have supported NGOs engaging PLWNCDs to mobilise the public during NCD medical camps and awareness raising events. In Uganda, the Ministry of Health in collaboration with UNCDA hosts an annual conference which brings together MPs and other stakeholders to share evidence-based information on NCDs. The annual conference is also used as a forum to lobby MPs to advocate for inclusion of NCDs in national policies. With support from UNCDA, the MPs have formed an NCD Parliamentary Forum, currently comprising of about 80 members, to lobby and interest fellow MPs to integrate NCDs in debates and eventually in policies.

### Government-led, supported or endorsed national NCD conference/summit/meeting held in the last 2 years with active participation of NGOs.

As an indicator of political commitment to the NCD agenda, the benchmarking survey assessed if governments had organised an NCD conference or meeting in the last two years. Of the countries in the region, Kenya, Rwanda and Uganda have held NCD summits or conferences in the last two years.

In Kenya, the government endorsed and participated in the following conferences: Diabetes East Africa Summit, NCD stakeholder forum, NCD forum with the Parliamentarians on Health Committee and Rheumatic Heart Diseases Forum. In all the conferences, there was participation of NGOs.

In Rwanda, the Ministry of Health hosted the conference that launched NCD Synergies Network, which focuses on promoting collaboration between countries fighting Non-Communicable Diseases of poverty.

In Uganda, the Ministry of Health in collaboration with UNCDA hosts an annual conference which brings together MPs and other stakeholders to share evidence-based information on NCDs. The annual conference is also used as a forum to lobby MPs to advocate for inclusion of NCDs in national policies. With support from UNCDA, the MPs have formed an NCD Parliamentary Forum, currently comprising of about 80 members, to lobby and interest fellow MPs to integrate NCDs in debates and eventually in policies.



Tanzania NCD Alliance awareness raising activities on World Cancer Day.

## Government-led or endorsed public media and awareness campaigns on NCD prevention, partnering with NGOs and held in the last 2 years

There are some ad hoc interventions by governments to increase awareness about the diseases. For example in Kenya, the government, together with partners, organised and attended the Diabetes East Africa Summit, an NCD stakeholder forum, NCD forum with the Parliamentarians on Health Committee and Rheumatic Heart Diseases Forum. Kenya and Rwanda governments, together with development partners and CSOs, have also recognised and celebrated some of the globally established NCD campaign days such as World Heart Day, World Diabetes Day, World Kidney Day, Mater Heart Run, and World

Cancer Day among others to raise awareness through charity walks and media campaigns. In Rwanda, the MOH in collaboration with different NCD clusters and CSOs, have organised an annual NCD Awareness Campaign since 2012 (see case study below). In Uganda, the government through the NCD Unit organised an awareness event for the media to interest them in reporting on NCDs. In Zanzibar, the NCD unit of the MoH developed a documentary on NCDs and promoted it through the media to increase public awareness on NCDs.

Though on a limited scale, national governments in East Africa have made an effort to engage and sensitise the media to increase NCD awareness. The government efforts have been supplemented by donor partners, due to limited national budgetary allocations for NCDs. The media, considered key in delivering messages to the wider population, has in the past not been very vigilant in reporting on NCDs. This in part was due to limited awareness and publicity of the NCD burden.

### Case Study: Rwanda 2013 NCD Awareness Week

The 2013 NCD Awareness Week, held in Rwanda in September 2013 included a 6 kilometre walk for NCD awareness, over-subscribed NCD screenings and referrals, and strong collaboration with national media on news articles and radio shows giving an overview of NCDs and for each NCD cluster (cardiovascular, cancers, renal metabolic and diabetes, injuries and disabilities, and oral, eye, and ear health). Radio shows included representatives of government, providers, civil society, and where possible, patients or caregivers. In addition, national radio ran awareness ads for NCDs. The theme of the week was *"Get screened for diabetes, blood pressure, asthma, cancer, and other non-communicable diseases; know your health."*

## Priority 2: Strengthening national capacity, multi-sectoral action, and partnerships for NCDs

To strengthen national capacity with multi-sectoral participation for NCD health care, there must be concerted efforts which must be coordinated and harnessed within a specified framework. This framework can best be defined in a national strategic plan on NCDs.

Countries in East Africa are at varying stages in formulating National NCD Plans, but across all East African countries there is a strong precedent for engaging civil society in the consultations to develop national NCD plans. Zanzibar and Tanzania have a National NCD Strategic Plan 2009–13. These were developed in consultation with the ministries of education, health and agriculture (nutrition units) and CSOs. In Rwanda, a Technical Working Group has been convened, which consists of governmental agencies, expert clinicians and researchers, and civil society organisations, for the purpose of developing the National Strategic Plan for NCDs, which is due to be released by July 2014. The working group also supports broader education, awareness, and advocacy efforts in the country.

Kenya and Uganda are in the process of developing national NCD strategies and policies (see case study on next page). The development of these plans and policies is coordinated by the NCD units that are established in the ministries of health. Efforts are being undertaken by governments to involve NGOs in the development of these NCD



First Kenya National Forum on NCDs

initiatives. This demonstrates the willingness of government to use a multisectoral approach in the development of plans and policies.

Beyond involvement of NGOs in the formulation of policy documents for prevention and scaling up awareness about NCDs, some of the East African governments have involved NGOs in implementing NCD programmes and initiatives. For example, in Tanzania, the government is implementing a diabetes program with the Tanzania Diabetes Association (see case study to the right). In Uganda, the government provides budget support to both the Cancer Institute and the Uganda Heart Institute especially to extend palliative care to PLWNCDs. These are government agencies established by statutory laws.

It was reported by countries where NCD units exist within the Ministries of Health, there are limited budgetary allocations to support them to function effectively. The budgetary allocations normally cover salaries of staff members and a limited portion of the operational costs. For example, for Uganda a budget of UGX 40 million (approximately USD 15,000) is allocated annually to the NCD Unit in the MoH. This is not sufficient even to cover operational costs of the Unit. Amidst the financial constraints of regional governments, however, a marginal budget allocation to NCDs partially demonstrates limited attention of national governments to NCDs health care and management.

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

*Under this priority area, the report presents how the governments of EA have responded to mitigate the key NCD risk factors such as tobacco smoking, alcohol consumption, unhealthy diets and physical inactivity.*

#### Tobacco

The survey included specific questions on ratification and implementation of the WHO Framework Convention on Tobacco Control (FCTC). Implementation was measured using the MPOWER measures.

All countries in the region have ratified the WHO Framework Convention on Tobacco Control (FCTC), which demonstrates in part their concern over tobacco smoking. CSOs have taken advantage of this ratification by initiating campaigns to reduce, and or control or ban public smoking and have, indeed received government attention. Among others, these campaigns advocate for having designated places for smoking. However implementation of the FCTC across the EAC has been inconsistent.

National efforts spearheaded also mainly by CSOs, have resulted in passing of tobacco-control legislation, although the extent of implementation is limited. In Zanzibar, the Public and Environmental Health Act of 2012 regulates smoking in public places. In Kenya, the Tobacco Control Act of 2007 restricts smoking in public places. In Tanzania, the Tobacco Products (Regulation) Act of 2003 prohibits smoking in health care and education facilities. In Uganda, the legislation is in draft form and being spearheaded as a Private Members Bill. There is also a draft National Tobacco Control Strategic Plan, which seeks to provide various mechanisms for controlling tobacco use as well as exposure to tobacco and tobacco smoke that cause hazardous effects. Rwanda's anti-tobacco policy includes a ban on tobacco

#### Case Study: Draft Uganda NCD Strategic Plan

##### Vision:

A Ugandan population free of suffering from all NCDs.

##### Mission:

To reduce morbidity, mortality, and disability due to NCDs in populations at risk while providing the best possible preventative, curative, palliative, and rehabilitative health services.

##### Goal:

To contribute to other policies and programs which aim to improve the standard of health for all people in Uganda by reducing the burden of diseases (morbidity, disability and premature mortality) due to NCDs.

The policy puts emphasis on prevention of NCDs and promotion of healthy lifestyles so as to reduce the occurrence of chronic NCDs in the country with priority areas being: national and local political leadership, prevention, treatment, partnerships and collaborations, monitoring, and financial sustainability.

#### Case Study: CSO engagement with Government in developing NCD Plans

The Tanzania Non-Communicable Diseases Alliance (TANCDAA) was established in 2012 by the Tanzania Diabetes Association, Heart Foundation of Tanzania, Tanzania Association for Respiratory Diseases and Tanzania Cancer Association. TANCDAA works closely with the Ministry of Health and Social Welfare (MoHSW), including recently supporting the development of the Strategic Plan for the Prevention and Control of NCDs 2014–2020. TANCDAA led a consultation process with various stakeholders to elicit input on the Strategic Plan.

advertising and on smoking in public places, as well as non-smoker rights to ask others to stop smoking; the legislation is reflective of cultural views on tobacco use.

One clear result of the campaigns and legislation to regulate use of tobacco use is the visible and clear health warnings that cover almost half of the cigarette packs. The warning reads "Smoking Causes Heart Disease, Lung Cancer and death". For Uganda, Kenya, Tanzania and Zanzibar, these warnings are both in English and Swahili. These campaigns and legislation have also led to restrictions on tobacco advertising, for example with advertising or direct tobacco marketing in the media prohibited. Advertising is however allowed in certain areas, for example pubs and night clubs.

There have been tax increases on tobacco, but this has not necessarily been portrayed by governments as a mechanism to control tobacco use. Rather, it has been portrayed as a mechanism of increasing government revenue.<sup>1</sup> Empirical evidence however suggests that increase in prices of cigarettes leads to reduction in demand for tobacco. For example, WHO estimates that by increasing tobacco taxes by 50%, all countries would reduce the number of smokers by 49 million within

<sup>1</sup> The allocation of this revenue is not necessarily earmarked for tobacco control activities or towards NCD prevention and control.

the next 3 years and ultimately save 11 million lives (WHO 2012). High prices are particularly effective in discouraging young people (who often have more limited incomes than older adults) from taking up smoking. They also encourage existing young smokers to either reduce their use of tobacco or quit altogether.

## Alcohol

For alcohol, just like tobacco, there is legislation to control harmful use of alcohol but with limited implementation. There are limited resources, both financial and non-financial, to facilitate the implementation. This is coupled with an apparent lack of political will to effectively implement legislation and policy guidelines. For example, while legislation and policy guidelines address restricted drinking timeframes as well as the amount of alcohol consumed, disregard for these guidelines is not uncommon. Bars open almost whenever they want and drunken people are frequently on public roads.

While there has been an increase in taxes on alcohol, the effect has not been felt as people still consume it. In essence, the increase in taxes has not affected the propensity of people to spend on alcohol. Until now, the East Africa region still ranks highly among the major consumers of alcohol worldwide, according to the WHO alcohol consumption status reports. For example, the WHO global status report on alcohol released in (2004, 2007) showed that in Uganda, 19.47 liters of pure alcohol are consumed per capita each

year, a figure which is nearly 4 times higher than the worldwide average and 5 times higher than the African region average, making Uganda number one of the 189 WHO member states. No wonder then that a recent study carried out by Uganda Youth Development Link (UYDEL) found that 46 per cent of the youths aged between 12 and 18 consume alcohol.

Just like tobacco control, higher alcohol excise taxes significantly reduce both the frequency of drinking and the probability of heavy drinking. This follows the fundamental law of economics that the higher the price, the less the demand.

## Unhealthy diet

In relation to strategies to control unhealthy diet, only Tanzania and Kenya reported having Nutritional Strategies, which focus on promoting healthy diets. However, implementation of the strategies is weak.

Rwanda has a national nutritional program. Multiple countries in East Africa have programs to fight maternal and childhood malnutrition. These programs will be important in reducing future incidence of type 2 diabetes, to which children who are malnourished in the womb and during early childhood are pre-disposed.

Related to unhealthy diet, there is no country in the region with statutory controls and policies on marketing foods high in sugars and fats to children. Similarly, no country in the region has regulatory controls on salt reduction.

## Physical activity

For all the countries there are no explicit strategies that target improved physical activity, except for the physical education guidelines provided for in the education curriculum of primary and secondary schools. However, there is no strict follow up by governments to ensure that these guidelines are implemented.

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

Within the East African region, there is an evidently limited presence of Government initiatives to strengthen the health systems to address NCDs. Even where these initiatives exist as outlined in National NCD Plans, implementation is limited, in part due to limited capacity and resources (financial and non-financial, for example human resources for health) and in the other part, due to limited political will to address NCDs. Uganda NDP clearly mentions how NCDs are not integrated in the health system: the NDP states:

*"...another major challenge of controlling NCDs in the country is the health system not designed to take care of chronic conditions like NCDs..."*

One of the initiatives for integrated management of NCDs, is the NCD Synergies Network, with which Rwanda and Kenya are leading collaborators. This initiative is described in detail in the case study left.

While the countries reported that the majority of NCD medicines are included in the list of essential drugs to be procured and

### Case Study: Planning collaborations in Rwanda and Kenya: the NCD Synergies Network

The NCD Synergies Network was launched at a conference hosted by the Rwanda Ministry of Health in Kigali in July 2013. It is the product of years of collaboration between Rwanda Ministry of Health and the NGO Partners In Health (PIH) on integrated NCD treatment systems. The Synergies Initiative responds to the growing body of evidence that NCDs are not simply an epidemic of excess. NCDs represent a significant proportion of the burden of disease and mortality among people living in extreme poverty. Insufficient global attention has been paid to the need to integrate NCD services into health systems of low-income countries. If successful, the Network will facilitate knowledge sharing, elaboration of new programmatic approaches to NCDs in low resource settings, and resource mobilisation.

The NCD Division at Rwanda Biomedical Center has partnered with NCD Synergies in its ongoing work to expand NCD services in Rwanda. In Kenya the NCD Control Unit collaborate with NCD Synergies to support strategic and operational planning. The Network is designed not simply to support low-income countries in meeting the UN mandate for strategic planning for NCD prevention and treatment, but also as a step toward a transnational "science of integration" that can help build those programs sustainably within health systems. It will foster community leaders in multiple countries to advance planning for new integrated NCD services, identification of people living with NCDs and provision for their long term care.

Over the two-year startup phase, the project will also fund an electronic "Collaboration Hub" and webinars to foster knowledge sharing on endemic NCDs of poverty and country level planning for NCD integration.

distributed by the respective national drug authorities and agencies, the medicines are not widely available in health centres, at primary health care levels. Specialised NCD medicines are available, though still to a limited extent, at regional referral health facilities. But even at this level, drug stock-outs are common in the health facilities.

The survey highlighted the severe shortage and imbalanced distribution of skilled health workers in East Africa for NCDs. It is a significant obstacle for health systems and NCDs. The capacity of health personnel at lower level health facilities, for example primary health care, to diagnose and provide treatment to PLWNCDs is still very low. However, governments have initiated training programmes to increase the capacity of health workers to better manage NCDs in order to address this. But the number of beneficiary personnel is still small. Basic essential knowledge of NCDs is still limited especially among the non-medical-doctor clinicians and nurses. Because of this, treatment and management of NCDs remains a huge challenge across the countries in the region.

The health facilities, especially the lower level ones, lack equipment to diagnose and treat NCDs. These, however, can be found at higher facilities such as regional referral and national hospitals. Essentially, diagnosis and treatment of NCDs is largely provided by private health providers and yet the majority of the PLWNCDs cannot afford the necessary associated costs. Some countries including Uganda and Kenya have specialised facilities for treatment and palliative care for NCDs, particularly cancer and heart diseases run and managed by government. However, they charge a fee, which the majority of patients cannot afford. Patients resort to going to public health facilities where they can access basic treatment. In some cases, they resort to using local traditional medicine, including herbs, which are often ineffective.

Some CSOs and private sector actors have made efforts in providing therapeutic centres for drug-related addicts of alcohol and tobacco. They charge a fee for their services, which limits accessibility of many patients.

Whereas guidelines for treatment and palliative care of NCDs exist, they are not widely circulated in the public domain and there is limited follow up to monitor the extent to which they are implemented. The guidelines for Uganda “*Screening for Major Non Communicable Diseases: Guidelines for healthcare workers in Uganda*” exist, but as in other countries across the region, they are not effectively utilised for primary care of NCDs — due to reasons including, limited resources and lack of capacity among health workers.

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

Most countries indicated that there are limited national research agendas for NCDs, which in the majority of cases are implemented in partnership with CSOs and international academic institutions. In Tanzania, a research initiative is being implemented by Muhimbili University of Health and Allied Sciences. In Uganda the NCD Unit is in the process of initiating a study on NCDs and Yale University is collaborating with UNCDA on a project which aims to build NCD capacity of the health system.

In Kenya, two multi-country studies are being undertaken: *Electrolyte and Nutrition study* (2012–2014) and, *Partnership for Child Nutrition* (PCN) (2012–2015). The studies among others aim to assess salt effects on NCDs. Further, the CSO movement in Kenya has developed a knowledge sharing portal for NCDs, a one-stop



The NCD Synergies Meeting in Kigali, Rwanda July 2013.



Volunteers conducting screenings at the Uganda NCD Alliance support centre in Kampala.

information hub on NCDs for public health practitioners, researchers, health care providers, policymakers and the general public (<http://ncdinfo-kenya.org>).

Further, as a result of increased efforts spearheaded by CSOs, together with development partners and governments, the media is increasingly reporting and publishing articles on NCD, which increases public awareness about NCD risk factors.

## Priority 6: Monitor and evaluate progress on NCDs

Of the countries reviewed, only Kenya has agreed national NCD targets and indicators to monitor and evaluate progress on NCDs. In addition, the national health information and management systems do not prioritise NCDs and where NCDs are gaining recognition, it has been difficult to gather relevant data due to limited capacity of health personnel at the lower health units to capture this information.

Countries reported that some population-based NCD mortality data is included in the national demographic and health surveys, conducted normally every 3 years. Rwanda, Tanzania and Zanzibar have conducted national STEPS surveys and Uganda is in the process.

# KEY RECOMMENDATIONS

Based on the benchmark survey and these findings, below are some recommendations to enhance the response to NCDs in East Africa. These recommendations are targeted at three stakeholder groups — governments, CSO's and development partners, and the private sector. They are further elaborated in the East Africa Civil Society NCD Charter:

## To Governments

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- **Ensure NCDs are a priority for National Development Plans:** All countries' National Development Plans (NDPs) should be reviewed periodically to ensure that they are consistent with development needs and priorities of the respective citizens. Considering the burden, NCDs should be a priority in all National Development Plans and specific targets to measure progress and outcomes should be included. There is a need for sustained efforts, specifically spearheaded by the ministries of health, to ensure NCDs are prioritised, and that donors align their aid to these priorities. Relatedly, the national planning guidelines issued by central governments to subnational governments should explicitly provide for integration of NCDs into plans at that level.
- **Develop and implement National NCD Plans:** It is vitally important for all countries to review (the existing), develop (for those that do not have) and implement National NCD Plans. These strategic plans should be consistent with priority NCD intervention areas identified in the national development plans. Again, the ministries of health should take lead in developing National NCD strategic plans with involvement of NCD CSOs.
- **Increase budgetary allocations to NCDs:** For NCD initiatives to be implemented there is need for adequate, predictable and sustained resources to be provided. National and subnational governments should prioritise NCDs in national health budgets, as well as seek priority for NCDs across other government department budgets. National and subnational governments should allocate sufficient budgetary resources for control of NCDs and proper service delivery.
- **Build strategic partnerships for NCDs:** Governments cannot work in isolation in responding to NCDs. For greater impact and effectiveness, governments need to adopt a "whole of society" approach and develop strategic alliances with a wide range of actors, including civil society, the media and the private sector. This will result in increased public awareness, reduced exposure to risk factors, and cost-effective treatment services. Governments could carefully regulate these partnerships through signing of memoranda of understanding with the actors.
- **Strengthen and implement policies and legislation to prevent NCDs:** There are many risk factors that cause and exacerbate the NCD crisis. To prevent these factors, the legal and policy framework must be strengthened to combat the risk factors. Policies and laws must not only be put in place, but must also be enforced. Policies and legislation on tobacco, alcohol, unhealthy diets (through food and nutrition policies and legislation), physical activity should be put in place. The legal framework should be backed by structural changes for effective implementation.
- **Capacity building for health personnel:** There is need to build the capacity of health personnel to effectively diagnose, treat and manage NCDs. This could be done through trainings and mentorship programs for health workers. Improved support supervision by more knowledgeable health workers in NCDs could provide an opportunity for learning and sharing skills with less knowledgeable counterparts. Besides improving their capacity, there is need to increase the numbers of NCD health workers so that they can effectively deliver on NCDs.
- **Integrate NCDs into existing health systems:** Utilise the available opportunities to integrate NCD prevention and control into existing health platforms such as HIV/AIDS, reproductive health, maternal and child health. Pilot programs need to be run for innovative health system strengthening through integration and successful models could be shared in the region.
- **Establish rigorous surveillance and monitoring systems:** NCD indicators need to be integrated into the existing health management and information systems. There is need to strengthen measures of capturing information on NCDs at all levels of health facilities and analysis of this information. This will facilitate tracking of NCDs incidences and designing appropriate strategies.

## To CSOs and Development Partners

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- **Advocacy and policy influencing:** Civil society organisations and development partners should hold governments accountable on the implementation of the NCD response. CSOs are well placed to hold governments to account and should do so with regards to delivery of NCD services. CSOs could come together to form national and regional active coalitions and issue-based alliances to gain a louder voice.
- **Sensitise communities and the general public on NCDs:** CSOs have a long tradition of working closely with communities and the wider general public to raise awareness. Therefore, they should capitalise on this role and sensitise the public on NCDs — from the risk factors to treatment and management of NCDs.
- **Supplement efforts of treating and managing NCDs:** Some specialised CSOs provide treatment and care for NCDs, as well as patient support and empowerment. With access to resources and partnership with governments and other actors, CSOs could continuously play this function and reach out to PLWNCDs.
- **Technical and financial support:** Development partners should provide technical and financial support to governments to accelerate the NCD response. Alongside this, development partners should set up a funding mechanism to support civil society capacity development and advocacy activities.

## To the Private Sector

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- **Provide affordable, quality-assured essential NCD medicines and technologies:** Improve access and affordability of medicines and technologies for people living with NCDs, including through innovation and tiered pricing.
- **Manufacture and promote healthy foods:** Food processing and manufacturing companies should produce and promote food products consistent with healthy diets (for example low salt, low fats, low sugar etc) which are affordable, accessible and available.

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## ANNEX 2: BENCHMARK SURVEY (BASED ON NCD ALLIANCE BENCHMARKING TOOL)

Section	#	Question	Answer	Narrative/comment
1) Raise priority of NCDs through international cooperation and advocacy	1.1	Inclusion of NCDs in national development plans		
		If yes to 1.1, are NCDs included in subnational development plans?		
		If no to 1.1, are NCDs included in subnational development plans?		
		If no to 1.1, are NCDs included in the national health sector plan?		
	1.2	(If a high income donor country uses this indicator) inclusion on NCDs in Official Development Assistance		
		(If a low/middle income country uses this indicator) Government Inclusion of NCDs in UN Development Assistance Frameworks (UNDAFs)		
	1.3	Operational national NCD alliance/coalition/network of NGOs that engages People Living with NCDs (PLWNCDs)		
		If yes to 1.3, does the Government collaborate with the NCD alliance?		
	1.4	Government-led, supported or endorsed national NCD conference/summit/meeting held in the last 2 years with active participation of NGOs		
1.5	Government-led or endorsed public media campaign on NCD awareness of NCD prevention partnering with NGOs and held in the last 2 years			
2) Strengthening national capacity, multisectoral action, and partnerships for NCDs	2.1	Operational National NCD Plan (number of key elements outlined below): if score less than 4, please refer to 2.2		
		National NCD Plan with a 'whole of government' approach, i.e. with areas for action beyond the health sector		
		Functional national multistakeholder NCD commission/mechanism (incl. NGOs, People Living With NCDs and private sector)		
		National budgetary allocation for NCDs (treatment, prevention, health promotion, surveillance, monitoring/evaluation, human resources)		
		NGOs and PLWNCDs engaged in national NCD plan development		
	2.2	Number of subnational jurisdictions (state, district etc) with an operational NCD plan that meets the full criteria outlined above		
	2.3	Number of operational NCD public-private partnerships supporting elements of National NCD Plans. If yes, please list public-private partnerships		
2.4	National Government partnerships with NGOs on NCD initiatives. If yes, please describe the nature of the partnership and initiative focus.			
3) Reduce NCD risk factors and social determinants	3.1	Number of tobacco MPOWER policies/interventions in existence (of those listed below):		
		Existence of recent nationally representative information on youth and adult prevalence of tobacco use		
		National Legislation banning smoking in health-care and educational facilities and in all indoor public places including workplaces, restaurants and bars		
		Existence of national guidelines for the treatment of tobacco dependence		
		Legislation mandating visible and clear health warnings covering at least half of principal pack areas		
		Legislation banning tobacco advertising, promotion and sponsorship OR legislation comprehensively banning all forms of direct tobacco marketing, covering all forms of media and advertising		
		Tobacco taxation policy of between 2/3 and 3/4 of retail price		
	3.2	National strategies on the major NCD risk factors (out of total listed below)		
		Tobacco		
		Harmful use of alcohol		
		Unhealthy diet		
		Physical activity		
	3.3	Increased taxes on alcohol in last 5 years		
	3.4	National policies and regulatory controls on marketing to children of foods high in fats, trans fatty acids, free sugars or salt		
3.5	National action on salt reduction			
	National policies/regulatory controls on salt reduction			
	Number of voluntary private sector commitments/pledges to salt reduction. If any, please specify the voluntary commitments			
3.6	Physical education in schools with resources and incentives			

Continued next page

Section	#	Question	Answer	Narrative/comment
4) Strengthen and reorient health systems to address NCDs	4.1	Government initiatives strengthening the capacity of primary health centres for NCDs (out of the total listed below)		
		Cancer — number of evidence-based guidelines for the cancers prioritized in the National Care Plan		
		Cardiovascular disease		
		Chronic respiratory diseases		
		Diabetes		
		Mental health		
	4.2	Government initiatives strengthening the capacity of primary healthcare for NCDs (out of the initiatives listed below):		
		NCD health promotion and prevention (advocates to add own indicators)		
		Screening and early detection (advocates to add own indicators)		
		Treatment and referral (advocates to add own indicators)		
		Rehabilitation and palliative care (advocates to add own indicators)		
	4.3	Number of NCD medicines included in the country essential medicines list (EML) made available at low cost to patients with limited resources		
	4.4	National EML list updated since last time WHO updated EML? If yes, are NCD medicines included in the update.		
	4.5	NCD-related services and treatments are covered by health insurance systems. If only partially implemented, specify why.		
4.6	Operational NCD Surveillance system (number of elements below):			
	WHO STEPS Survey conducted (or equivalent)			
	Cause-specific mortality related to NCDs included in national health reporting system			
	Population-based NCD mortality data and population-based mortality data included in national health reporting system			
5) Promote national capacity for research and development on NCDs	5.1	National research agenda for NCDs		
	5.2	Government funding support for national research on NCDs		
	5.3	Number of published articles on NCDs in country in the last 5 years.		
6) Monitor and evaluate progress on NCDs	6.1	National NCD targets/indicator with monitoring mechanisms in place		