REGIONAL MEETING ON STRENGTHENING NCD CIVIL SOCIETY ORGANISATIONS, WHO SEARO
New Delhi, 9-10 July 2015

Background Paper

Mapping of NCD Civil Society Organisations in the WHO South East Asia Region

World Health Organization
Regional Office for South-East Asia

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I. BACKGROUND

The WHO Regional Office for South-East Asia (SEARO) in collaboration with the NCD Alliance is organizing a Regional Meeting on strengthening NCD Civil Society Organizations in the region, in New Delhi on 9-10 July 2015. The meeting aims to strengthen the Noncommunicable Diseases (NCD) civil society movement in the region.

The specific objectives of the Regional Meeting are to:

a) Review the current status and facilitate sharing of experiences among regional NCD civil society organizations;

b) Strengthen the capacity of NCD civil society organizations in forming alliances to drive advocacy, policy, and accountability;

c) Foster effective collaboration between CSOs within and across countries, with governments and WHO to better support implementation of regional NCD priorities.

WHO SEARO and the NCD Alliance commissioned a mapping of civil society organisations (CSOs) working on NCDs in the region to inform the discussions at the Regional Meeting. The mapping aims to describe the current status of civil society action on NCDs in the region, its challenges, gaps and needs. It also explores effective strategies that have worked to advance work on NCDs in SEAR countries in the South East Asia Region (SEAR) and potential partnerships that could accelerate civil society action.

The SEAR NCD Civil Society Meeting is part of a series of such meetings in various WHO regions that are being organised in preparation for the first ever Global NCD Alliance Forum in Sharjah in November 2015. The outcomes of the SEAR meeting and the results of the preceding mapping would therefore inform the future directions of the larger civil society action on NCDs around the world.

II. MAPPING METHODOLOGY

The mapping exercise comprised of an online survey among civil society organisations working on NCDs in the region and in-depth interviews with key informants from SEAR countries.

Survey: The online survey was administered between 18 and 26 June. The in-depth interviews were conducted from 23 June to 3 July.

The respondents were selected by purposive sampling. A multi-pronged approach was adopted to maximise response from the sample population within the limited timeframe of the survey. The sampling frame for the online survey consisted of the following:

- Participants of the Regional Meeting for NCD Civil Society Strengthening in WHO South East Asia Region (SEAR)
- SEAR members of six of the international NCD Alliance federations
- Civil society list of the NCD programmes of the WHO country offices in SEAR
- National NCD Alliances in SEAR

An online questionnaire was developed, pre-tested and administered using Survey Monkey software application. The survey received responses from 9 out of the 11 SEAR countries.

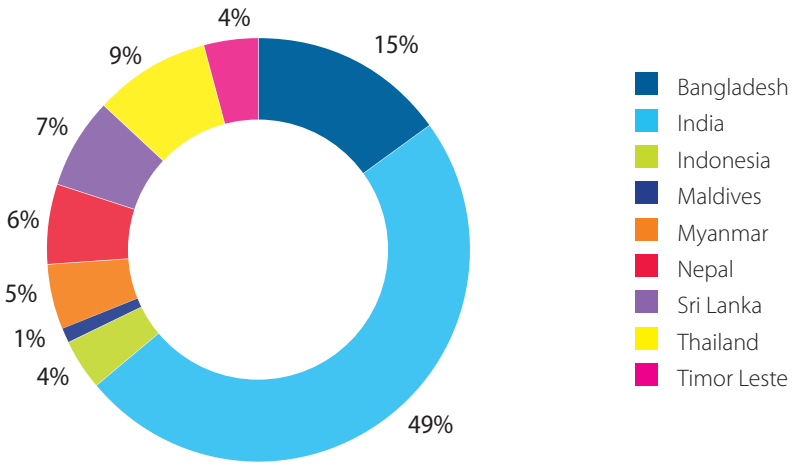

Fig 1. Respondents by Country

Out of the 101 responses to the survey, 21 incomplete or duplicate responses were excluded from the data. The remaining 80 responses were analysed. The questionnaire is in Annex 1.

A large proportion of the survey response has been from civil society working on NCDs in India though there are responses from eight other countries in the SEAR region as well. The proportion of response from countries seems to correspond to the perceived size of the NCD civil society movement therein. Notably, the survey received responses from Myanmar, Timor Leste and Maldives, where civil society initiatives for NCDs are in their early stages of development.

Key Informant Interviews: In-depth interviews were conducted using a discussion guide (Annex 2) with 10 key contacts drawn from various SEAR countries. A key informant from each major NCD and from each of the common risk factors and Alzheimer's Disease was interviewed. The discussion guide explored the survey variables in detail and information was analysed along thematic lines. The details of key informants can be found in Annex 3.

III. SCOPE AND LIMITATIONS

This is the first ever mapping of civil society organisations working on NCDs in WHO SEARO. It is extensive in that it covers all the countries where NCD-related civil society is known to exist in WHO SEARO (9 out of 11 countries). Between the online survey and in-depth interviews, the mapping has also made a reasonable attempt to cover the civil society response to all the major NCDs and their risk factors in the researched countries. The results provide an indication of the overall trends in civil society involvement, achievements, needs and challenges on NCDs in SEAR.

However in the absence of a verifiable database of NCD civil society in the region, the sample of responses analysed cannot be claimed to be a true representation of the population of organisations working on these issues. While every attempt has been made to provide equal opportunity to all CSOs working on NCDs in SEAR to participate in the survey, there may be certain organisations working on these issues that might not have been covered by the survey. Where these gaps in data have been observed in the survey, every attempt has been made to address them specifically through in-depth qualitative interviews of country key contacts. Despite best efforts, no information on NCD related civil society in Bhutan and Democratic People's Republic of Korea could be accessed for this mapping.

IV. SURVEY AND INTERVIEW RESULTS

The analysis of the survey results and interview data were synthesised against major themes. The synthesis is discussed below.

1. Profile of NCD Civil society in WHO South East Asia Region

a)Type of Organisations: Majority of the respondent organisations (60%) working on NCDs in the region appear to be health NGOs. However, the involvement of non-health NGOs in the SEAR NCD civil society movement appears to be significant. Notably, there were more non-health NGO (15%) respondents than those from medical associations* (6%), research agencies (6%) and academic institutions (8%). Several of the interviewees confirmed the role of non-health or rights-based organisations in NCD work in their countries. This needs to be factored into the design of capacity building interventions and advocacy strategies, so as to maximize the multisectoral response required for NCD prevention and control.

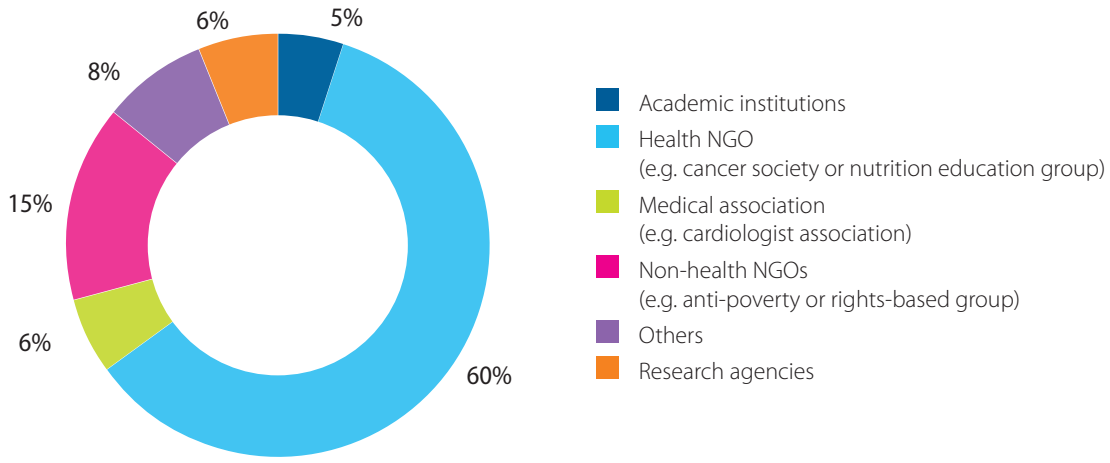

Fig 2. Nature of Organisations

b) Years of Work on NCDs: Nearly one-third of the respondent organisations have been working on any one or more of the NCDs or their risk factors for over twenty years. There seems to have been a slight increase in the number of organisations working on NCDs newly in the last five years (19%), after a dip in the previous 5-year term (down to 16% from 24% 10 years back). In depth interviews corroborated that the increasing global attention on NCDs (e.g. UN High Level Summit of 2011, subsequent World Health Assembly discussions) has drawn the attention of civil society organisations to NCDs in SEAR countries in recent years. Two-thirds of the organisations worked at the national level, 30% at the sub-national level and the rest in multiple countries in the region.

In depth interviews with key informants from SEAR countries reveal an interesting pattern in terms of the stage of entry of various types of civil society organisations into the NCD arena. Medical professional associations and medical professionals seem to play a critical role in the initial phase of NCD civil society movement in SEAR countries. They build and present evidence on NCDs making the public health case and preparing a fertile ground for later action. Health NGOs and risk factor groups come along next, and translate the evidence to messages for the public

* Organisations representing medical professionals and specialists.

and Government, and advocate for policy changes. Non-health organisations tend to join the movement in its more advanced stages, helping make the socio-economic and environmental case for action on NCD and creating in-roads to non-health parts of the Government and the broader public. Several key informants of this research stressed the need for the movement to rope in risk factor, advocacy and non-health groups to translate the evidence to policy ends.

Thus, SEAR countries that have had a relatively long history of NCD action such as Bangladesh, Nepal, Sri Lanka, Thailand, India and Indonesia, by now have active risk factor groups in the NCD civil society arena, following initial stage-setting by medical associations. Notably, in most of these countries involvement of medical associations in NCD advocacy have dwindled in recent years. They seem to be focussing more on matters affecting the profession or treatment options. However, countries where civil society action on NCDs is in its early stages such as Myanmar, Maldives and Timor Leste, medical bodies are at the forefront of initiating the dialogue on NCDs, whereas risk factors groups are yet to emerge.

2. Action on NCDs

a) Target Groups: In terms of target groups, 50% of the respondents considered the public to be the priority target of their interventions, followed by over 25% working with the government. Health NGOs tend to have the broadest variety of targets ranging from the public, NCD affected groups, Government to WHO. However, medical associations seem to work largely within their membership, NCD affected groups and Government, with no reported work targeting the public, media, NGOs and WHO. A similar trend is observed with academic institutions and research agencies too. This points to the need to create more channels for the transfer of subject expertise from such centers to inform a broader range of stakeholders.

Analysis of top priority target audience with number of years of work on NCDs indicates that organisations across the age spectrum appear to be catering to the public as well as government. However the two largest groups in the survey in terms of years of work on NCDs (21+ years and 10-15 year groups) seemed to be catering largely to the public and working with fewer stakeholders. The newest organisations in the NCD space reported targeting primarily government agencies, though they do work with other stakeholders as well.

b) Focus within the NCD agenda: Tobacco control seems to receive the most attention from the surveyed SEAR civil society followed by cancer and the other major NCDs and their risk factors. Indoor air pollution and mental health tend to be areas that receive least civil society attention (Figure 3). Other NCDs that were reported in the mapping include Alzheimer's and Thalassemia. Country interviews indicate that civil society action on unhealthy diet is also in its nascency throughout the region.

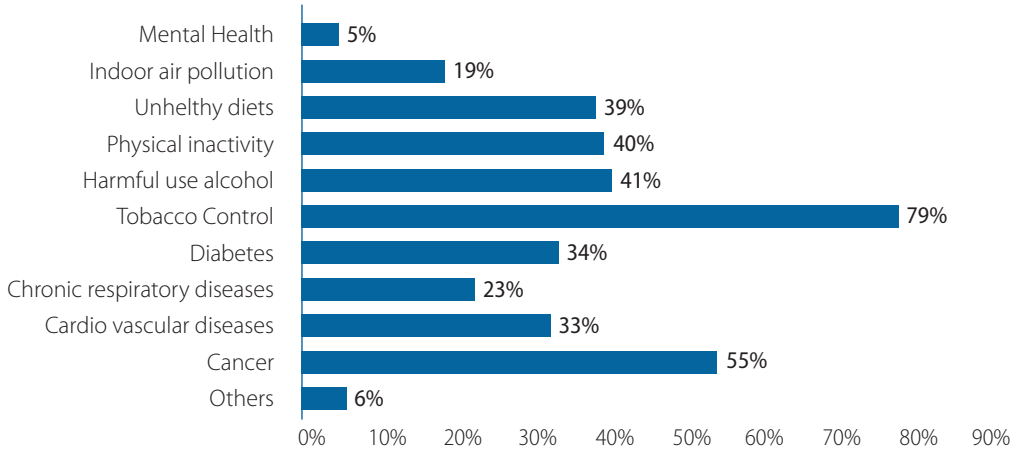

Fig 3. Focus of Work

C) Priority Area of Interventions: As Figure 4 indicates, 40% of the surveyed CSOs consider reducing exposure to risk factors as their primary area of intervention, followed by early diagnosis (16%). This seems to suggest that prevention and early detection of NCDs seems to be the priority focus areas for a large number of organisations working on NCDs in the region. Mobilising civil society response to NCDs, patient care and rehabilitation figure prominently among the second priority focus.

Further analysis of the number of years of work on NCDs with the type of interventions undertaken in Figure 5 provides some interesting insights. Firstly, all groups appear to be working to reduce exposure to risk factors. Secondly, organisations in the 10-15 years and 21+ years have the broadest variety of interventions on NCDs. If these information are coupled with the earlier-stated finding about these two groups working primarily with the public, then it could be deducted that their work with the public is geared largely to reduce exposure. Organisations in the 1-5 years group who are also working on risk factor reduction could therefore be primarily targeting Governments. Organisations in 21+ category also appear to be focused on early diagnosis which ties in with an earlier finding that the overall emphasis of CSOs appears to be more on prevention than treatment and care.

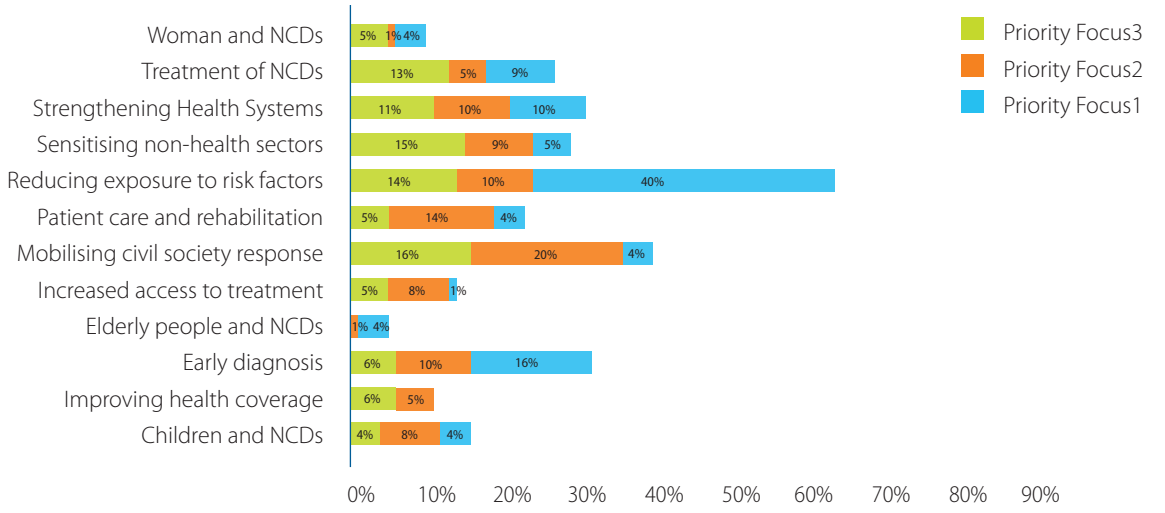

Fig 4. Priority Focus of Interventions

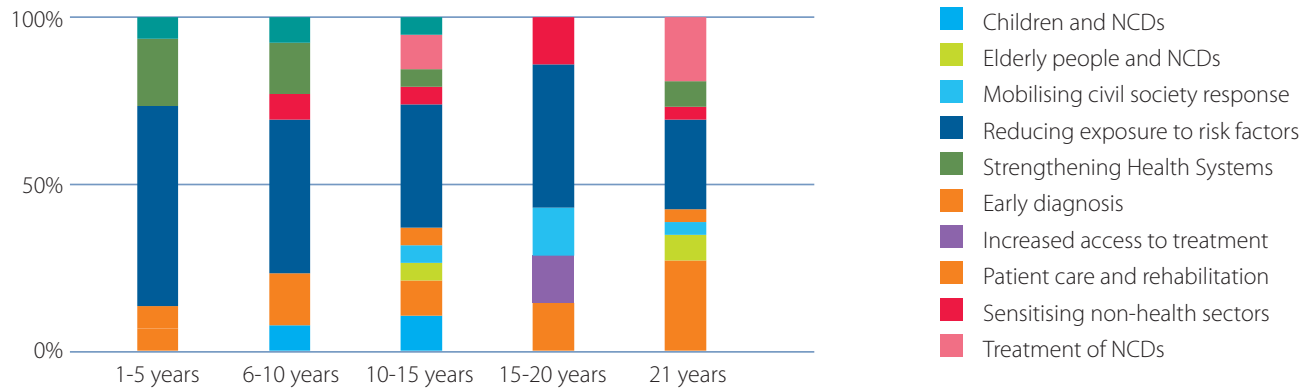

Fig 5. Vintage of Organisation Vs Primary Focus Areas Identified

3. Challenges, Gaps, Solutions and Capacity Needs

a) Challenges: The online survey also enquired about the key challenges to civil society action. The major challenges faced by organisations working at national and sub national levels tend to be largely in the policy and political arena. The responses indicate the biggest challenges to be lack of political will and poor implementation of programmes and policies along with inadequacy of policies designed to target NCD prevention or control. Insufficient funds were reported as a challenge at sub national, national and regional levels, but second only to policy challenges. Lack of understanding of NCDs outside the health sector and interference by industry with conflicting interest were reported as key second priority challenges.

While several SEAR countries have National NCD Plans in line with the WHO Global Action plan, there has been limited to no civil society involvement in their development and implementation. The tuberculosis prevention and control programme in most SEAR countries has guidelines for NGO involvement that has facilitated extensive Government-CSO partnership right from development to implementation of its plans. It is important to urgently develop such guidelines and draw on civil society strengths in NCD programme implementation as well.

Interviewees also mentioned several challenges that are intrinsic to NCDs. One being that NCDs and their risk factors present a complex cluster of issues, each of which require distinct action across multiple sectors. Another challenge revolves around making NCDs a national priority in SEAR countries, which are still dealing with the burden of communicable diseases, maternal and child health concerns and other competing health and development priorities. Thirdly, NCDs are often wrongly projected to be about individual responsibility to reduce exposure to its risk factors, which builds resistance to behaviour change, health promotion and community mobilisation. Lastly, some of the NCD concerns such as unhealthy diet cannot have standardized messaging, but require nuanced communication relevant to local context.

There are country-specific challenges, geography being one among them. Effective roll out of NCD prevention activities, policy implementation and service delivery becomes difficult in countries with large geographies such as India, those with hilly terrains such as Nepal, Bhutan and Myanmar, or those that are island nations such as Maldives, Timor Leste, Indonesia and Sri Lanka. With NCDs accounting for 62% of globaldeaths, in the SEAR region with 25% of the world population the sheer scale of interventions to cover its massive population is a challenge unique to Governments and civil society in the region. Several of the countries do not have adequate specialists, screening, treatment and care facilities and are dependent on countries in the neighbourhood for these services. This makes civil society support in this arena more challenging. Political instability has also been delaying the advocacy for NCD policies in certain countries in the region.

b) Gaps: The respondents identified a range of gaps in civil society response to NCDs at the country level. Financial constraints, lack of coordinated response at national level and limited interest of NGOs at large in NCDs were the most reported gaps. Low engagement of non-health NGOs, lack of continuity in civil society response and lack of technical expertise each were also reported by nearly half the respondents (Figure 6).

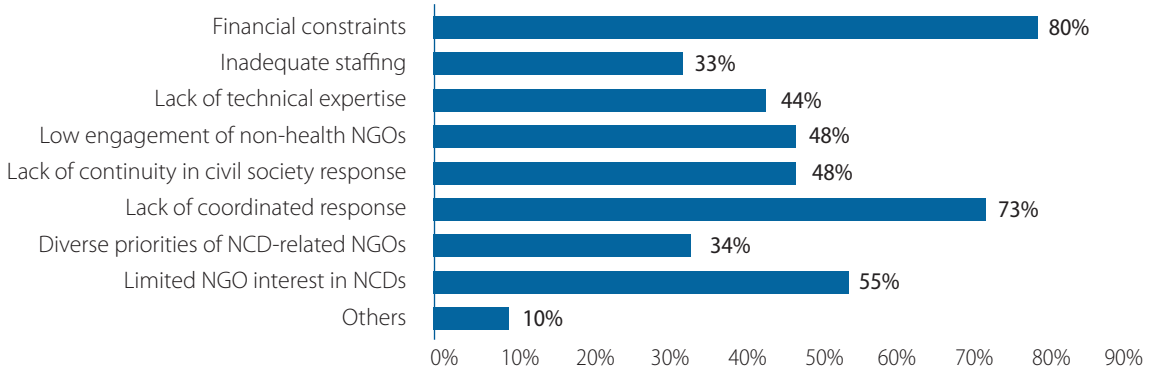

Fig 6. Major Gaps in Civil Society Response

Several interviewees mentioned gaps specific to the civil society response to unhealthy food, contrasting it against tobacco control advocacy strategies. Thus, civil society campaigns on unhealthy food are yet to develop clear policy goals and target groups, generate outrage against industry manipulations and its implications, delineate approaches to tackle small, medium and large businesses and mobilise public health and other groups for advocacy. Industry influence over government, civil society and other key stakeholders was also cited as a barrier to action on unhealthy food. Several countries in the region reported a recent surge in diversionary campaigns by food and beverage companies that project promotion of physical activity while defocusing unhealthy eating. These campaigns often rope in civil society players to earn legitimacy with the target audience.

Similarly, indoor air pollution and chronic respiratory diseases (perhaps with the exception of tuberculosis) seem to suffer from low prioritisation by civil society groups. The reported gaps include limited involvement of CSOs in consolidating evidence on solid fuel use and their implications, exploring affordable, safer alternatives, lack of engagement of grassroots organisations for community level changes in the use of solid fuel, neglect of indoor air pollution by environmental groups and absence of regional platforms to mobilise lung health professionals.

c) Solutions & Capacity Needs: Respondents recommended civil society capacity building, integration of NCDs into existing programme priorities and building coalitions as top solutions to the highlighted problems (Figure 7). Some of the top capacity building needs identified by respondents include building skills in the areas of strategy and campaign planning and advocacy and campaigning (Figure 8). Support for resource mobilization, access to NCD best practices and orientation to good governance and organization building followed closely.

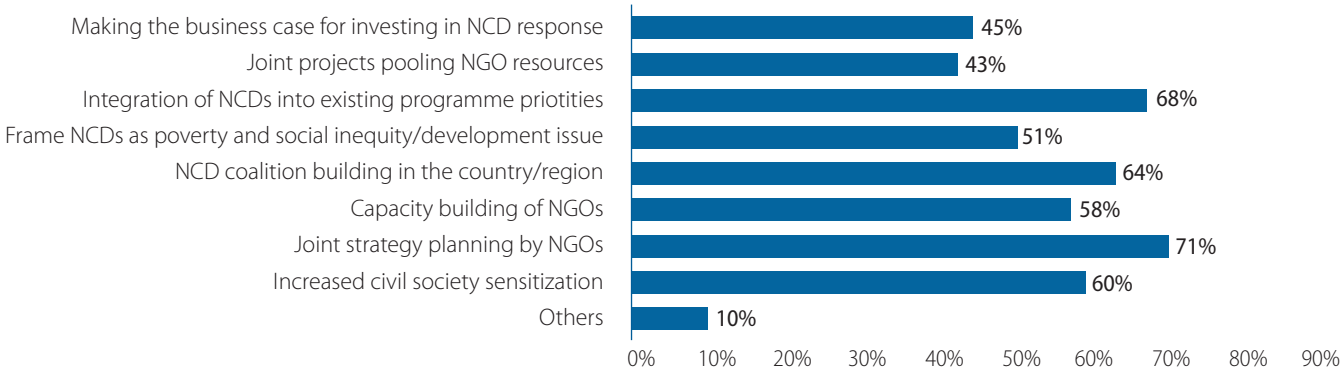

Fig 7. Solution to Address Gaps

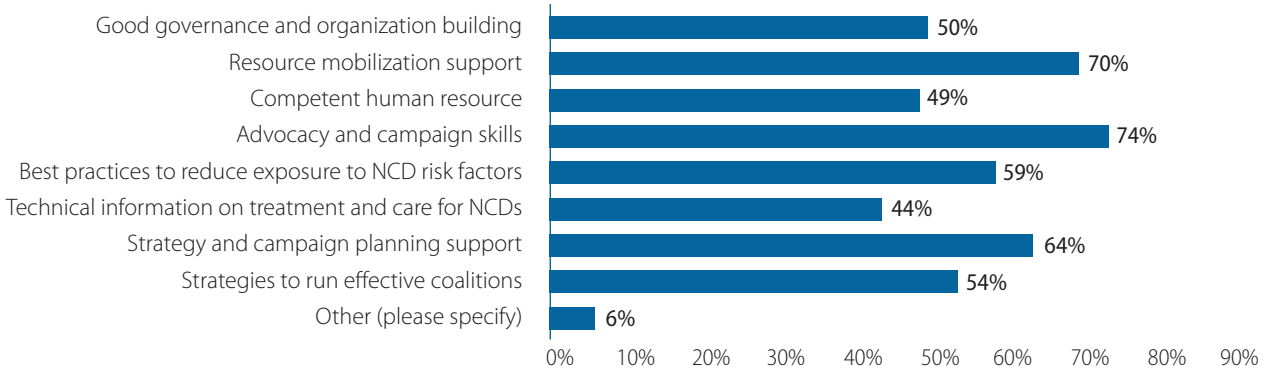

Fig 8 . Major Capacity Needs

A cross analysis of gaps in civil society response with capacity needs indicates areas for future interventions and investments. The call for support in resource mobilization as a prime area of capacity need to address financial constrains, which was identified to be a major gap in civil society response to NCDs drives this point home. One possibility is that the need for finances could come down if the capacity needs could be met in kind such as by helping in grant proposal development. Similarly, the respondents identified a series of capacity needs in terms of strategies to run effective coalitions, strategy and campaign planning support, advocacy and campaign skills to address the lack of coordinated response to NCDs.

The gaps in civil society response to NCDs were also examined against the nature of organisations in Figure 9 to see if there is any divergence in response. Lack of coordinated response, financial constrains and lack of interest of NGOs in NCDs was cited irrespective of the nature of the respondent organisations. However, lack of engagement of non-health NGOs in NCDs was more likely to be identified as a gap by health NGOs when compared to other types of organisations. This could be an indication of a "felt need" of this constituency for greater involvement of non-health NGOs who could in turn provide access to non-health sectors of the government for NCD advocacy. Notably, medical associations, academic institutions and research agencies tend to notice this gap to a lesser extent.

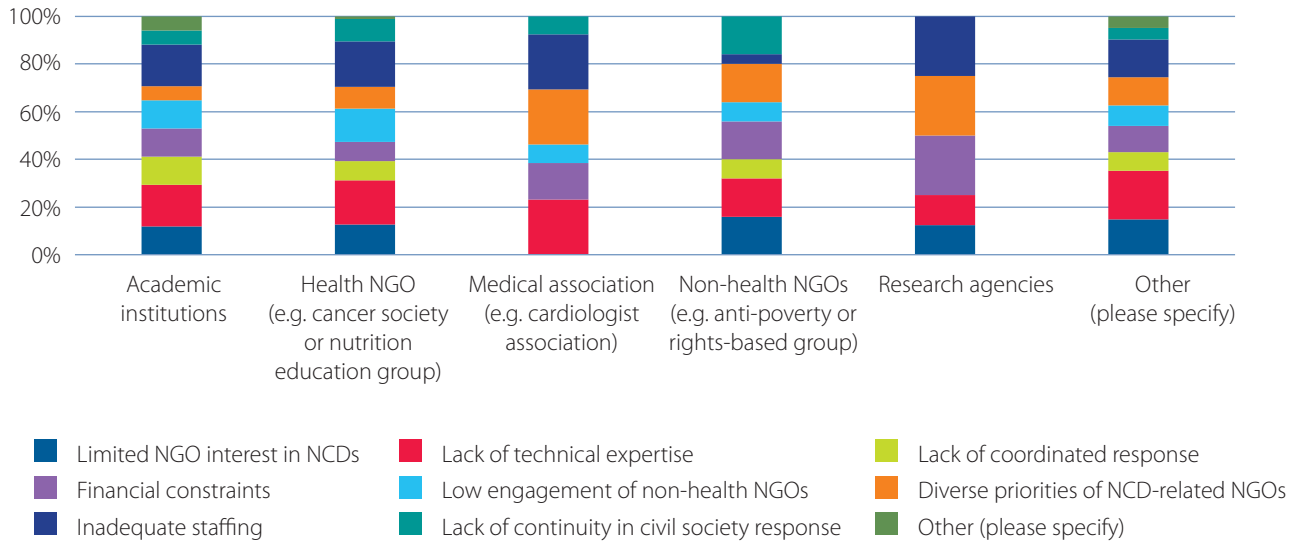

Fig 9. Major Gaps in Civil Society Response to NCDs Vs Nature of NGOs

4. Opportunities and Good Practices

a) Opportunities

While the survey did not specifically enquire about the opportunities, nearly all the interviewees mentioned the United Nations High Level Meeting on NCDs in 2011 as invigorating in-country civil society action on the issue. The political declaration of the meeting represents both the mandate as well as the opportunity for civil society action to help Governments to translate their commitments to action in countries.

SEAR countries are at different stages of development and implementation of National NCD Plans. Lack of accountability seems to be a major factor impeding progress of these plans in most SEAR countries. This presents an opportunity for proactive civil society advocacy and monitoring to stimulate and hold the government accountable for its action/ inaction.

Adoption of the Framework Convention on Tobacco Control (FCTC) was identified as a factor that galvanized tobacco control civil society in the region. The legally binding nature of this international treaty presents an opportunity to press for its accelerated implementation in countries.

In the area of physical activity, some interviewees reported the emergence of health clubs and gymnasiums and sports physicians in urban centres as an opportunity that could improve the community's health consciousness and health seeking behaviour. Given that several countries in the region are contemplating the development of new cities, there are opportunities for civil society to advocate that they provide for healthier lifestyles, health care and public transport facilities.

Recent technological and media advances present opportunities for NCDs as well. Increasing use of mobile phones and social media in SEAR countries could prove an asset in health promotion, industry monitoring as well as social mobilization for policy change.

b) Snapshot of Good Practices

Civil society across countries in the region reported tried and tested strategies that contributed to meaningful outcomes in NCD prevention and control. Below is a snap shot of good practices that are emerging from the region. A deeper elaboration of country civil society best practices is required to provide a comprehensive presentation.

Using courts to advance tobacco control: India has a long history of using Public Interest Litigations (PILs) to move public policy. CSOs working on tobacco control have effectively engaged this tool to challenge Government apathy, expedite policies and implementation, defend sound policies and oppose industry interference. Thus, India's national tobacco control law was the results of a PIL. Subsequent litigations have successfully defended regulations banning advertising, pictorial health warnings and exposed and terminated industry interference in national and sub-national courts.

Diabetes educators in community health system: Access to timely diagnosis and treatment is a challenge in most island nations. The Diabetes Society of Maldives (DSM) along with the World Diabetes Foundation initiated "Project 200 Islands" in 2009 to address the gaps in quality diabetes care in the island nation of Maldives. The project aimed to address the gap by training and contracting a diabetes educator for every one of the 200 inhabited islands in the country. Health care workers from the health system were trained to this end, serving as a sustainable model helping local communities to take timely preventive, diagnostic and early treatment steps across the islands.

Improving accessibility and affordability of medicines: In Sri Lanka, early campaigns by several medical associations and renowned professionals have led to the development of a national drug policy that provides essential medicines, including for NCDs, at affordable prices to the public. Sustained and targeted campaigns led to two specific outcomes: a) medical practitioners increasingly prescribe generic drugs that are affordable to the masses and b) public behaviour change whereby people now demand generic alternatives from their doctors.

"Sin" tax for resourcing NCD control: Thailand provides a significant example of the impact of civil society advocacy for sustainable resourcing for NCDs. In 2001, the Government of Thailand in partnership with key civil society players set up the Thai Health Promotion Foundation funded by a 2% excise tax surcharge on tobacco and alcohol produced or imported into the country. The Foundation's annual revenue of USD 120 million has become a sustainable source of funding that has set up civil society groups, commissioned research to inform policies and funds advocacy for policies addressing NCD risk factors.

Lessons from environmental and human rights campaigns: Interviewees repeatedly cited environmental and human rights movements to be offering relevant lessons to NCD civil society. The visibility offered by dramatic actions that are part of environmental and rights-based advocacy helps gain public and policy maker attention and creates a favourable climate for public dialogue and policy formulation.

5. Regional Priorities, Mechanisms and Partnerships

a) Regional Priorities: The top regional priorities identified were strategies to address NCD issues with cross border implications (e.g.: cross-border promotion, taxation and trade of tobacco, alcohol, unhealthy food, automobiles) and monitoring NCD commitments made by governments (Figure 10). It is important to note that respondents also indicated development of such monitoring mechanisms prominently among areas for support from intergovernmental and international organisations that is discussed later. Such a mechanism needs to monitor policy actions, evidence of impact in terms of outcome indicators and ultimately impact on equity. Networking and capacity building of NGOs figured significantly among the second priority for regional action.

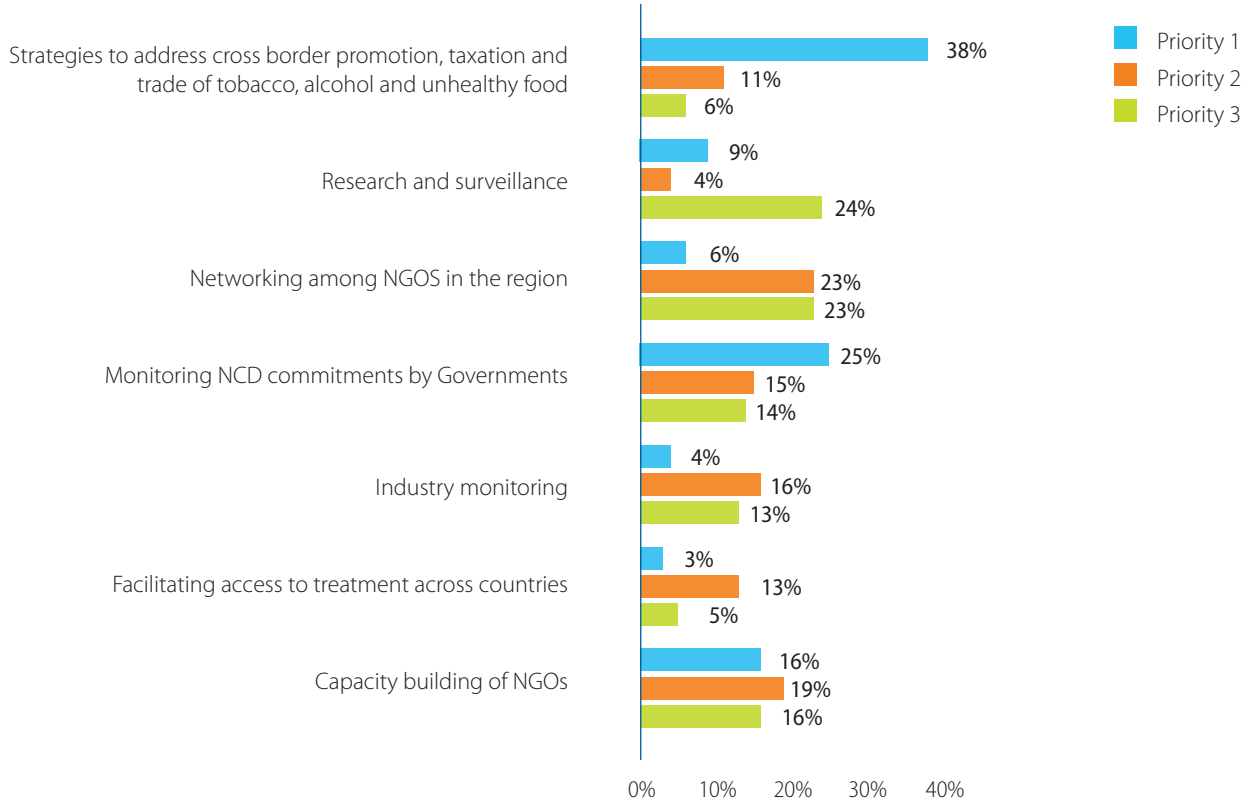

Fig 10. Priorities for Action at Regional Level

b) Mechanisms for Regional Collaboration: Networking opportunities and information sharing platforms were the most preferred means of regional collaboration that were reported to enhance work in SEAR countries. It is noteworthy that a regional coalition was the second lowest priority among the respondents, coming only after identifying areas for joint action, access to NCD information and good practices from other countries and establishing platforms that offer advocacy support.

Interviewees reflected this matured approach to regional civil society collaboration. Some pointed to the differences in political systems, resources and cultures within the SEAR that limits the scope for collaboration. Others pointed to common issues that could mobilise issue-based, short term campaigns through informal coordination.

Interviewees elaborated that a regional mechanism could begin as an informal information platform that i) facilitates sharing of knowledge, tools and best practices, ii) identifies areas of convergence iii) supports campaigns across borders, and iv) form temporary issue-based partnerships. It was also suggested that existing regional networks of NCD federations such as of the International Diabetes Federation in South East Asia consider expanding the scope of their programmes to address NCDs and their risk factors more broadly.

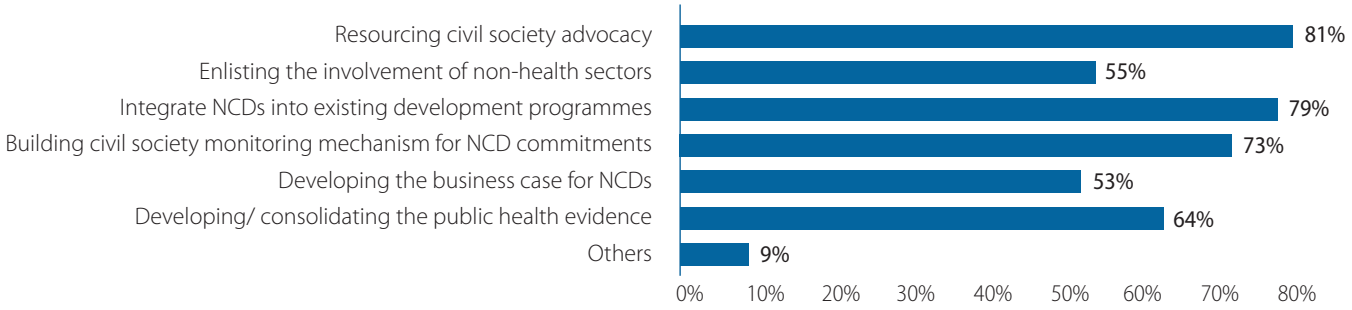

Fig 11. Areas for Support from Intergovernmenal/ International Organisations

c) Partnerships: The survey asked how multilateral agencies such as the WHO or UNDP can support civil society action on NCDs in the region. As Figure 11 indicates, the most reported responses include support for civil society advocacy, integration of NCDs into existing development programmes, and the creation of a civil society monitoring mechanism for NCD commitments.

In turn, civil society can support the work of intergovernmental agencies by building political will (81%), preparing local communities (78%), developing best practice models for effective intervention (78%) and advocating for integration of NCDs in national development plans (76%).

Most interviewees called for closer partnerships between civil society and WHO in countries and at regional level, with civil society building the political environment for WHO's proposed NCD targets, while having the opportunity to inform and contribute to the technical and programmatic work of WHO country and regional offices in this area. Some also mentioned that WHO could facilitate civil society's contribution through national NCD monitoring mechanisms.

Several of them also referred to on-going partnerships between UN agencies and civil society in SEAR countries for a host of health and development issues and called for their extension to address NCDs. For example, UNICEF's maternal and child health nutrition programmes in the region could be broadened to address concerns around unhealthy diet. Similarly, UNDP's climate mitigation initiative could promote alternatives to solid fuel use for cooking and help reduce indoor air pollution, and UNAIDS health care delivery programmes could be leveraged to deliver NCD treatment as well. Integration of NCDs in National Development Plans is an area that was also identified for close work with UNDP country offices. Orientation of civil society to the development planning process within the countries and that of UNDP was suggested as the first step in this direction.

The South Asia Association for Regional Cooperation (SAARC) was identified as a geo-political body that must be leveraged to advance action on NCDs in South Asian countries within SEAR. Civil society action is urgently required to follow up on the NCD specific recommendations of the SAARC Technical Committee on Health and Population. A specific, time-bound opportunity in this context is the Sri Lankan SAARC President's commitment to NCD prevention and control that can be used to influence the SAARC agenda at the level of Heads of States.

Interviewees expressed a range of expectations about the NCD Alliance's role at the regional level. An oft-repeated one was sensitizing and mobilizing country members of the individual international NGO federations

that constitute the NCD Alliance for broader NCD advocacy. There was an equal call for the NCD Alliance to undertake capacity building activities of NCD civil society in advocacy skills, strategy planning, managing coalitions and resource mobilisation. Some thought the NCD Alliance could influence international donors to commit to funding NCD action in SEAR countries. Some were concerned that the work of NCD Alliance was currently limited to global fora and expected it to better represent country voices to shape national and international agendas.

V. MAPPING RECOMMENDATIONS

Based on the findings from this mapping, below are some recommendations for key NCD stakeholders in the SEAR region.

For Civil Society

- Increase advocacy on NCDs and their risk factors, with special focus on issues that are yet to receive government attention
- Improve engagement of medical associations, academic institutions and non-health NGOs in advocacy
- Participate in national and subnational NCD multisectoral bodies and support the government and other stakeholders in developing and implementing NCDs priority actions
- Monitor progress and hold the Governments accountable to NCD commitments
- Advocate for integration of NCDs into national health and development plans
- Liaise with intergovernmental agencies to integrate NCDs into existing programmes and platforms

For Governments

- Provide policy and programme frameworks to address NCDs and their risk factors
- Build NCD infrastructure at national and sub national levels, including human and technical resources
- Increase budgetary allocation to NCD programmes, including for civil society action
- Develop guidelines for greater CSO involvement in policy planning and monitoring of implementation of National NCD Plans

For WHO Country and Regional Offices

- Engage civil society in the development of technical resources for governments in the region
- Support civil society advocacy and capacity building to prepare the public and governments for action on NCDs
- Promote participation of civil society in policy formulating and monitoring mechanisms set up by governments and regional bodies
- Facilitate opportunities for civil society advocacy to leverage regional platforms at SAARC, ASEAN, SEAR and UN regional levels for NCD advocacy

For other multilateral agencies and development partners

- Help make the business case for NCDs
- Connect with relevant resources, ministries and help sensitise them on NCDs
- Integrate NCD prevention and control into existing in-country programming
- Involve NGOs in NCD-related programme implementation

For the NCD Alliance

- Identify and nurture civil society organisations in countries where it is yet to emerge
- Conduct capacity building activities to address gaps in advocacy, governance and resource mobilization
- Encourage international NCD federations to mobilise their members in WHO SEARO to actively engage in NCD advocacy and monitoring
- Develop communication, advocacy, monitoring and fundraising tools for civil society

For coordination among civil society

- Build multisectoral coalitions at national and sub national levels
- Establish regional platforms for networking, information sharing and advocacy support
- Build regional partnerships through SAARC and networks of NCD Alliance federations

VI. CONCLUSION

The civil society response to NCDs and their risk factors in WHO South East Asia Region has seen increases in recent years. But these seem to be concentrated in a few countries, addressing a limited number of issues within the NCD agenda. The response to NCDs and civil society movements in countries in the region are at different stages of development and consolidation, calling for unique approaches to address countries respective challenges and needs. A broad range of organisations, in particular non-health NGOs, play a significant role in advancing civil society advocacy on NCDs in the region. Future interventions and investments need to build on the strengths and needs of the broad variety of organisations working in this area and promote linkages among existing and future contributors to NCD civil society advocacy.

Author:
Ms. Shoba John, Programme Director HealthBridge (Mumbai, India).

ACKNOWLEDGEMENTS:
Sincere thanks to all respondents and interviewees who provided their inputs to the mapping exercise. WHO NCD teams in countries, key contacts of international federations and national alliances addressing NCDs and their risk factors helped actively to disseminate the mapping tools to potential respondents. But for the active support of the teams at WHO SEARO NCD Programme, the NCD Alliance and the statistical expert at Polizy Matters, it would not have been possible to complete the mapping in a timely manner.

Annex 1
Survey Questionnaire

NCD Civil Society Mapping in the WHO South East Asia Region

Purpose

This survey by the NCD Alliance aims to map the profile, activities, achievements to date, challenges, needs and potential collaborations of civil society organisations working on Noncommunicable Diseases (NCDs) and their risk factors in WHO's South East Asia Region.

Findings

An analysis of the findings will be shared with all respondents and a summary report will be presented at the Regional Meeting on Strengthening NCD Civil Society Organisations in South East Asia Region in July 2015.

Confidential

The responses will be anonymised – therefore not attributed to individual respondents. Any comments or attachments you indicate as confidential will be respected as such.

Instructions

The survey should take less than 15 minutes to complete. You will need to respond to all questions to enable its inclusion in the survey. Incomplete forms will need to be rejected. Please return the form latest by 29 June, Monday Noon to searomapping@ncdalliance.org

If you have any questions about the survey, please email us at the above email.

Thank you - we really appreciate your input!

Survey Questionnaire

1. What is the full name of your organisation?

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2. Which country does your organization work in? Choose from the drop down list.
(drop down list -Bangladesh, Bhutan, Democratic People Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand, Timor Leste).

3. What is the nature of your organization? Tick one that best describes your organization.

- ☐ Medical association (e.g. cardiologist association)
- ☐ Health NGO (e.g. cancer society or nutrition education group)
- ☐ Non-health NGOs (e.g. anti-poverty or rights-based group)
- ☐ Research agencies
- ☐ Academic institutions
- ☐ Other (please specify) .....
- ☐ Don't know

4. How many years has your organisation worked in the area of Noncommunciable Diseases (NCDs) or their risk factors? Tick the one that applies.

- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 10-15 years
- ☐ 15-20 years
- ☐ 21 years and more

5. The main strength of your organisation's work on NCDs is at: Tick the most relevant one.

- ☐ District level
- ☐ Provincial/State level
- ☐ National level
- ☐ South East Asia Regional level
- ☐ Other (please specify) .....

6. Who are the top three target audiences of your work? Tick only three.

- ☐ Public
- ☐ NCD-affected groups (e.g. survivors and families)
- ☐ Government
- ☐ NGOs
- ☐ Medical Associations
- ☐ Media
- ☐ WHO
- ☐ Other (please specify) .....

7. Which diseases/risk factors does your organization primarily focus on? Tick those most relevant.

- ☐ Cancers
- ☐ Cardio Vascular Diseases
- ☐ Chronic respiratory Diseases
- ☐ Diabetes
- ☐ Tobacco control
- ☐ Harmful use of alcohol
- ☐ Physical inactivity
- ☐ Unhealthy diets
- ☐ Indoor air pollution
- ☐ Other (please specify) .....

8. What are the top three focus areas of your work on NCDs? Number your choices 1-3 in the decreasing order of priority.

- ☐ Reducing exposure to risk factors
- ☐ Early diagnosis
- ☐ Treatment of NCDs
- ☐ Patient care and rehabilitation
- ☐ Strengthening Health Systems
- ☐ Improving health coverage
- ☐ Increased access to treatment
- ☐ Mobilising civil society response
- ☐ Sensitising non-health sectors
- ☐ Women and NCDs
- ☐ Children and NCDs
- ☐ Elderly people and NCDs

- ☐ Indigenous populations and NCDs
- ☐ Other (please specify) .....

9. **What are the top three NCD-related activities of your organization? Number your choices 1-3 in the decreasing order of priority.**

- ☐ NCD related research
- ☐ Public education on NCDs and risk factors
- ☐ Advocacy with policy makers for improved policies
- ☐ Patient support
- ☐ Technical support to Government agencies
- ☐ Monitoring Government's NCD commitments
- ☐ Evaluating NCD interventions
- ☐ Capacity building of NGOs
- ☐ Developing Information-communication materials
- ☐ Running information networks/ newsletters
- ☐ Using media for advocacy
- ☐ Sensitisation of media
- ☐ Litigation
- ☐ Other (please specify) .....

10. **What are the top three of your organisation's strategies that have led to specific outcomes vis a vis various targets groups. Please follow the example below and use the rows thereafter to provide details.**

TARGET GROUP 1	EDUCATION DEPARTMENT
STRATEGY USED	ENGAGED PARENT TEACHER BODIES IN SCHOOLS TO ADVOCATE HEALTHIER MEALS IN SCHOOL CANTEENS
ITS OUTCOME	DEPARTMENTAL GUIDELINES ON SCHOOL CANTEEN MENU
TARGET GROUP 1	
STRATEGY USED	
ITS OUTCOME	

11. **What are the top three challenges to work on NCDs in your country? Number your choices 1-3 in the decreasing order of priority.**

- ☐ Lack of political will
- ☐ Inadequate policies for NCD prevention and control
- ☐ Poor implementation of programmes and policies
- ☐ Lack of understanding of NCDs outside the health sector
- ☐ Insufficient civil society advocacy and monitoring

- ☐ Interference by industry with conflicting interest
- ☐ Challenges from bilateral and multilateral agreements (e.g. trade and investment agreements)
- ☐ Lack of technical expertise
- ☐ Inadequate human resources
- ☐ Insufficient funds
- ☐ Other (please specify) .....

12. **What do you see are the major gaps in the civil society response to NCDs in your country? Tick all that apply.**

- ☐ Limited NGO interest in NCDs
- ☐ Diverse priorities of NCD-related NGOs
- ☐ Lack of coordinated response
- ☐ Lack of continuity in civil society response
- ☐ Low engagement of non-health NGOs
- ☐ Lack of technical expertise
- ☐ Inadequate staffing
- ☐ Financial constraints
- ☐ Other (please specify) .....

13. **What do you think are the potential solutions to address the gaps in civil society response to NCDs in your country? Tick all that apply.**

- ☐ Increased civil society sensitization
- ☐ Capacity building of NGOs
- ☐ Joint strategic planning by NGOs
- ☐ NCD coalition building in the country / region
- ☐ Frame NCDs as poverty and social inequity/development issue
- ☐ Integration of NCDs into existing programme priorities
- ☐ Joint projects pooling NGO resources
- ☐ Making the business case for investing in NCD response
- ☐ Other (please specify) .....

14. **What are the major capacity needs of the civil society in your country in addressing the NCD concerns in your country? Tick all that apply.**

- ☐ Strategies to run effective coalitions
- ☐ Strategy and campaign planning support
- ☐ Technical information on treatment and care for NCDs
- ☐ Best practices to reduce exposure to NCD risk factors

- ☐ Advocacy and campaign skills
- ☐ Equipped human resource
- ☐ Resource mobilization support
- ☐ Good governance and organization building
- ☐ Other (please specify)

15. **What do you think are the top three priority areas for action at the regional level to combat NCDs in the South East Asia region? Number your choices 1-3 in the decreasing order of priority.**

- ☐ Strategies to address cross border promotion, taxation and trade of tobacco, alcohol and unhealthy food
- ☐ Facilitating access to treatment across countries
- ☐ Monitoring NCD commitments by Governments
- ☐ Industry monitoring
- ☐ Capacity building of NGOs
- ☐ Networking among NGOS in the region
- ☐ Research and surveillance
- ☐ Other (please specify)

16. **What kind of regional and global collaboration can enhance your work on NCDs? Tick all that apply.**

- ☐ Information sharing platforms
- ☐ Mechanisms for advocacy support
- ☐ Regional coalition to address trans-border issues
- ☐ Joint areas for action
- ☐ Networking opportunities for NGOs in the region
- ☐ Guidance on NCD policies and good practice
- ☐ Any other (please specify)

17. **What are the specific areas in which WHO, UNDP, World Bank and other international organizations could support civil society advocacy regarding NCDs in your country? Tick all that apply.**

- ☐ Developing/consolidating the public health evidence
- ☐ Developing the business case for NCDs
- ☐ Building civil society monitoring mechanism for NCD commitments
- ☐ Integrate NCDs into existing development programmes
- ☐ Enlisting the involvement of non-health sectors
- ☐ Resourcing civil society advocacy
- ☐ Any other (please specify)

18. What are the ways in which civil society can support WHO, UNDP and other international organizations to contribute to the prevention and control of NCDs?

- ☐ Building political will for NCD policies and programmes
- ☐ Improving community preparedness for NCD interventions
- ☐ Provide linkage to public and communities
- ☐ Developing best practice models for intervention
- ☐ Shadow reports on country commitments on NCDs
- ☐ Advocate for NCDs in national development plans
- ☐ Any Other (please specify)

19. Please provide any other brief comments you think would help the NCD Alliance better understand]your organisation's work.

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Please send any documents that complement your survey inputs to: SEARmapping@ncdalliance.org

Thank you. This is the end of the survey. If you are ready to submit your responses, please click on the "DONE" button below. The survey closes on Friday, 26 June 2015 5pm IST.

Annex 2
List of Key Informants

Dr. Sohel Chowdhury
National Heart Foundation Bangladesh
Bangladesh

Ms. DY Suharya
Alzheimer's Indonesia
Indonesia

Dr. Vijj Kasemsup
ThaiNCD
Thailand

Dr. Srinath Reddy
Public Health Foundation of India
India

Mr. Vimal Hooda
Cancer Relief Society
Nepal

Dr. Pubudu Sumanasekara
Alcohol and Drug Information Center
Sri Lanka

Mr. Amit Khurana
Centre for Science and Environment
India

Ms. Bungon Rithiphakdee
South East Asia Tobacco Control Alliance
Thailand

Dr Aishath Shiruhana
Diabetes Society of Maldives
Maldives

Dr Rana J. Singh
The Union South East Asia Regional Office
India