

ACHIEVING 25 x 25 THROUGH CIVIL SOCIETY COALITIONS

A situational analysis of
national and regional NCD alliances

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Acronyms and abbreviations

ACT+	Aliança de Controle do Tabagismo + Saúde (Brazil's NCD coalition)
AIDS	Acquired Immune Deficiency Syndrome
CEO	Chief Executive Officer
CISU	Danish Civil Society Fund
CSOs	Civil society organizations
DANIDA	Danish International Development Agency
EMR	Eastern Mediterranean Region
LMICs	Low- and middle-income countries
HCC	Healthy Caribbean Coalition
HICs	High-income countries
HIV	Human Immunodeficiency Virus
MOU	Memorandum of understanding
NCDs	Noncommunicable diseases
NCDA	NCD Alliance
PAHO	Pan American Health Organization
SDGs	Sustainable Development Goals
SEAR	South East Asia Region
STEPS	WHO STEPwise approach to surveillance
UNHLM	United Nations High-level Meeting
UNDAF	United Nations Development Assistance Framework
USA	United States of America
USAID	United States Agency for International Development
WHO	World Health Organization

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Accelerating the response to NCDs calls for greater attention and investment in the early years of life, particularly during childhood and adolescence.



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The situational analysis is the collective effort of national, regional and international partners. Such effort would not have been possible without the active support of the lead contacts of the subnational, national and regional NCD alliances who not only informed the surveys and interviews but also helped to mobilize responses from their members. Members of the alliances enriched the survey through their responses.

The Steering Group of the NCD Alliance lent its support to the situational analysis, while its constituent federations⁹ helped to identify and reach several of the respondents involved in this exercise through their respective networks. The NCD Alliance project team reviewed the report and contributed to making it fit for purpose. Thanks to those who helped with French and Spanish interviews, translation of tools and data, statistical analysis, editing, design, production and dissemination.



⁹ International Diabetes Federation, World Heart Federation, International Union Against Cancer, International Union Against Tuberculosis and Lung Disease, Framework Convention Alliance, Management Sciences for Health and Alzheimer's Disease International constitute the Steering Group of NCDA.

I. BACKGROUND

In 2011, the United Nations High-level Meeting (UNHLM) on the prevention and control of noncommunicable diseases (NCDs) declared this a global priority and governments committed to take action to address the crisis. The related UN Political Declaration clearly stated that an effective response to NCDs would need to involve all sectors of society and government. The UNHLM was crucial to the WHO Global Action Plan based on an overall 25 x 25 target: a 25% reduction in NCD-related mortality by 2025. This target was adopted at the World Health Assembly in 2012.

The NCD Alliance (NCDA) was established in 2009 and campaigned effectively for the UNHLM. NCDA has since been mobilizing civil society action to help governments meet the 25x25 target. NCDA, through its member federations, unites over 2,000 civil society organizations (CSOs) from 170 countries by means of a vision of a future free from preventable suffering and death caused by NCDs. It convenes the NCD civil society community, provides thought leadership on global policy, sets priorities for the global NCD response, and mobilizes civil society action at national and regional levels.

CSOs make critical contributions to the whole-of-society approach to NCDs that the UN Political Declaration upholds. Their close connections with communities enable them to incorporate the voice of people affected by NCDs in the processes of policy-making, decision-making and service delivery. CSOs often provide the evidence base for action. They engage with and apply concerted pressure on governments to ensure resources and services are reaching and benefiting the affected communities. They can bring about positive change to policies, practices and service delivery in areas that have an impact on the quality of people's lives and wellbeing. CSOs also hold governments and other service providers accountable to ensure that they fulfil their duties and deliver their promises.

Thus, the national and regional coalitions of CSOs present a collective force that is uniquely positioned to inform, support, influence and monitor action on NCD programmes and policies at the local level. In fact, the past few years have seen the organic emergence of NCD alliances across the world, at both regional and national levels. However, as the NCD civil society movement is very young, many alliances are fragile.

As these alliances emerge, they require support to build strong, sustainable coalitions and maximize their advocacy impact in areas as broad as organizational

development, strategic planning, management and governance, resource mobilization, and technical expertise. A variety of in-country and international partners need to step in to build their capacity and create enabling environments for their effective contributions to complement the work of national governments, which are ultimately responsible for meeting the health needs and upholding the human rights of their citizens.

The UNHLM created a favourable political environment to develop or strengthen NCD plans and policies at the national level. This presents a unique opportunity for CSOs to advocate new and effective NCD policies and support and monitor the implementation of existing ones.

The recent adoption of the UN Sustainable Development Goals (SDGs) denotes another landmark in the global response to NCDs. NCDs have been included as standalone target 3.4 within SDG 3 on health, alongside other priority targets including achieving universal health coverage, implementing the WHO Framework Convention on Tobacco Control (FCTC), and improving access to medicines. These can be leveraged to drive political attention and resources to address the emerging NCD epidemic in countries.

In recognition of these developments, NCDA is playing an increasingly proactive role in civil society capacity building at national and regional levels. In November 2015, NCDA will convene the first Global NCD Alliance Forum in Sharjah, United Arab Emirates (UAE). This forum will bring together national and regional NCD alliances from around the world for the first time. Her Highness Sheikha Jawaher bint Mohammed Al-Qassimi, wife of the Ruler of Sharjah, is the forum's patron as part of her commitment to cancer and NCDs.



Family members in Mulindi village, Kazungula District, Zambia, listen as Dr. Mattea Clarke shows them how to manage their daughter's asthma.

In the lead-up to the forum, NCD Alliance commissioned an independent situational analysis of national and regional NCD alliances from two external consultants^A and ^E. The situational analysis had a two-fold purpose. Firstly, it was to provide input into NCD Alliance's strategic planning process, in particular its national strategy, capacity-building initiatives and relationship with national and regional alliances. Secondly, it would inform the discussions at the forum and provide insight into the future priorities and course of the global NCD civil society movement, in particular action at the national and regional levels.

The situational analysis, commissioned in June 2015, aimed to:

- Understand how NCD alliances have developed and how their growth can be accelerated and sustained;
- Obtain a snapshot of national/regional priorities and advocacy, with a basic inventory of advocacy activities currently being undertaken;
- Identify key challenges and support needs and inform NCD Alliance's capacity-building programme;
- Identify key assets and opportunities for potential cooperation between countries;
- Inform the development of NCD Alliance's national strategy and its 2016-2020 strategic plan.

This report presents the findings of the situational analysis to the global health and development communities^F.

^A Shoba John supports advocacy campaigns, including those on NCD concerns, in Asia and internationally. Based in Mumbai, she has over 15 years of experience in leading national, regional and international alliances, which has given her deep insight into the challenges and winning strategies for building and sustaining effective coalitions.

^E Judith Watt is a former executive director of the NCD Alliance and coordinated its campaign in the run-up to the UN summit in 2011. Based in London, she has over 25 years of international experience in working with NGOs, governments and international agencies on tobacco control and other health priorities.

^F An internal report based on the situational analysis informed NCD Alliance strategy planning.

A local health communicator shows videos about adolescent health and HIV/AIDS to a group of young girls in rural Gaibandha, Bangladesh.



II. METHODOLOGY

1. Data collection, sampling and analysis

The situational analysis comprised:

- An online survey of all members of national/regional alliances;
- In-depth interviews with lead contacts of alliances;
- Reports of the regional preparatory meetings for the Global NCD Alliance Forum.

Survey

The online survey was sent out to a number of national and regional alliances that were known to NCDA. Links to the pre-tested questionnaires in English, French and Spanish were sent to the lead contacts of 38 national and 5 regional alliances using an online survey tool. The survey was intended to capture the responses of the lead contacts and members of the alliances*. It was open for a month from 26 June 2015 to 26 July 2015.

Twelve alliances on the original NCDA list either did not respond (after three reminders) to the survey or were unable to participate; one did not exist; and one alliance that was not on the NCDA list was included. Of the 74 responses received, 14 incomplete or duplicate responses were excluded. The remaining 60 responses were analysed using descriptive measures, employing analyses of variables independently and in conjunction with other key variables.

Interviews

In-depth telephone interviews were held with the lead contacts of all of the known national and regional alliances (Annex 1). Interview guides were developed in English, French and Spanish and conducted in the preferred language of the lead contacts. Information from the interviews of 29 alliances (24 national, one sub-national and four regional alliances) was included in the analysis.

Regional meetings

NCDA, along with the WHO and other partners, organized a series of regional preparatory meetings ahead of the global forum. The regional meetings brought together alliances and NCD-related CSOs in the Caribbean, Latin America, the South East Asia Region (SEAR), the Eastern Mediterranean Region (EMR) and African region to take stock of the NCD scenario in their countries and regions and identify priority areas for collective action. Background papers and the reports and recommendations of all the regional meetings were reviewed and key insight obtained to further contextualize and enrich the findings of the survey and the interviews.

The quantitative analysis of survey responses and qualitative analysis of the interview data and input from the regional meetings were synthesized according to broad themes and developed into a cohesive report.

* Unless otherwise specified, alliances in the report refer to the subnational, national and regional NCD-specific alliances that were included in this situational analysis.

2. Scope and limitations of the analysis

Scope of the situational analysis

Every effort was made to make this exercise as representative a sample as possible. A total of 31 alliances (from all but the EMR) responded to the survey, registering a response rate of over 70%. The responses seem to be commensurate with the relative number of regional/national alliances across continents. The results could, therefore, be considered as broadly representative of the situation of alliances across regions. In addition, all four of the country income groups as per the World Bank classification⁶ have been covered by the survey sample.

The survey data have been supplemented by in-depth interviews with the lead contacts of a significant number of the alliances, including some who did not respond to the survey. The data from the survey, interviews and regional meetings were synthesized to present a comprehensive scenario of NCD alliances and coalitions.

Given that the majority of the alliances are young, this report presents in-depth information on the genesis and organization of alliances, reflecting their focus on coalition-building activities in the early stages of development. A follow-up situational analysis in two to three years, by which time the alliances will have undertaken concrete actions, could provide more insight into their actual directions and outcomes.

Limitations of the exercise

As an exploratory effort, little was known about the number of members in the alliances when designing the situational analysis. Since then, the response rate from alliance members has been found to be low compared to their strength reported via the survey. The low response rate from members could be due to multiple factors: inadequate dissemination of the survey by the lead contacts; little response from members to the requests of lead contacts; and competing priorities

of lead contacts/members or lack of familiarity of alliances with NCDA. Nevertheless, in the absence of any previous such surveys and with significant responses from the lead contacts with wide-ranging backgrounds, this analysis can be considered to have adequately covered the landscape of NCD alliances and coalitions.

Given the relatively small number of respondents among lead contacts and members (30 respectively), it was decided that a joint analysis of the data from these two categories would be performed. The survey results therefore need to be considered jointly with the interview data and information from the regional meetings to gain a comprehensive understanding of the alliances.

It has been noted that members of some alliances responded in greater numbers to the survey than others. The survey results should, therefore, not be construed as proportional to the strength of members across alliances. The current survey would inform better sampling strategies for similar exercises in the future.

The analysis of the survey responses required classification by income level of the country in which the alliances were based. To this end, the regional alliances were assigned the income levels of the countries in which their secretariats were based. While this may not accurately represent the economic status of all the member countries in any given regional alliance, the approach was deemed to be a reasonable alternative to omitting their responses from the analysis. It should also be noted that, for the purposes of survey analysis, Australia was treated as a region. This was done primarily because the responses from Australia varied from the rest of Asia and, therefore, merging the responses from Australia with those from Asia would have skewed the data for both entities.

⁶ World Bank Country & Lending Groups - <http://data.worldbank.org/about/country-and-lending-groups>

3. Respondent profile

As Figure 1 indicates, Latin America, with the highest number of known national and regional alliances, each with sizeable memberships, accounted for over one-third of the respondents. Relatively fewer responses (17/18%) were received from Europe and Africa, despite the fact that they have several alliances. This appears proportional to the relatively smaller number of members per alliance in these regions. Asia has relatively fewer known national alliances compared to other regions. There is only one known NCD alliance in the EMR, and there was no response from this region to the survey or the interview. Information about the region has therefore been sourced primarily through documentation from the regional meeting.

Over two-thirds of the respondents were from high- and upper-middle-income countries (Figure 2). Only one-third of the respondents were from low- and lower-middle-income countries (Annex 2). According to the WHO, NCDs disproportionately affect the populations of low- and middle-income countries (LMICs), in which nearly three-quarters of the deaths from NCDs occur¹. This points to the urgent need for increased attention to mobilize NCD civil society alliances in LMICs to curb the epidemic.

The respondents were evenly split between lead contacts and members of alliances. Exactly 50% of the respondents were lead contacts of either regional or national alliances.

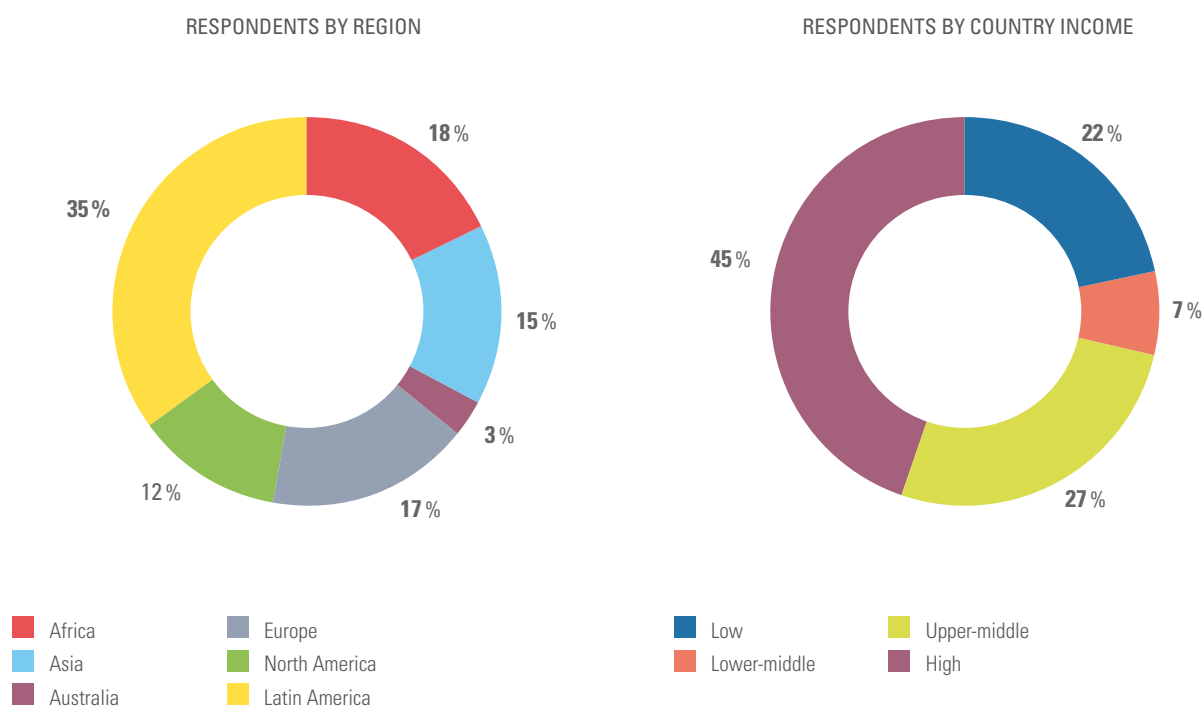


Fig 1.

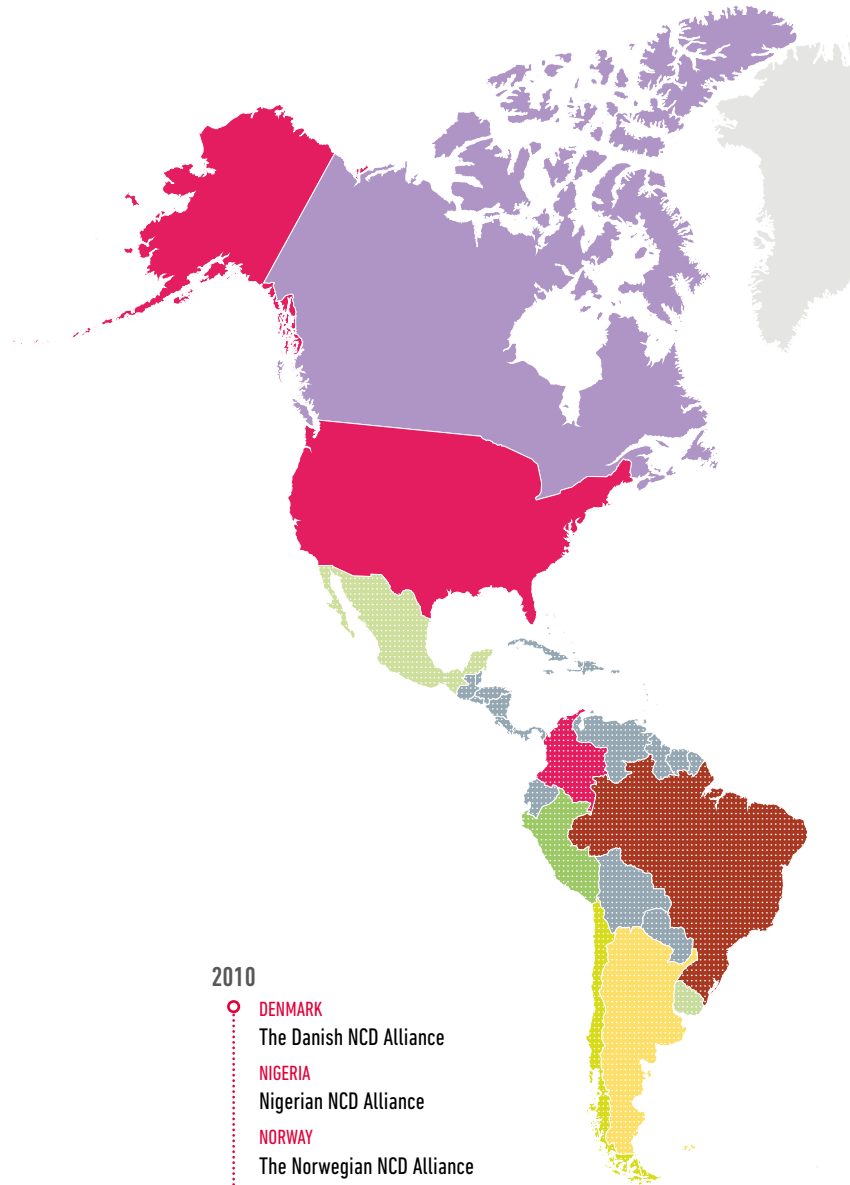
Fig 2.

¹ Noncommunicable diseases. World Health Organization fact sheet. <http://www.who.int/mediacentre/factsheets/fs355/en/>, updated January 2015.

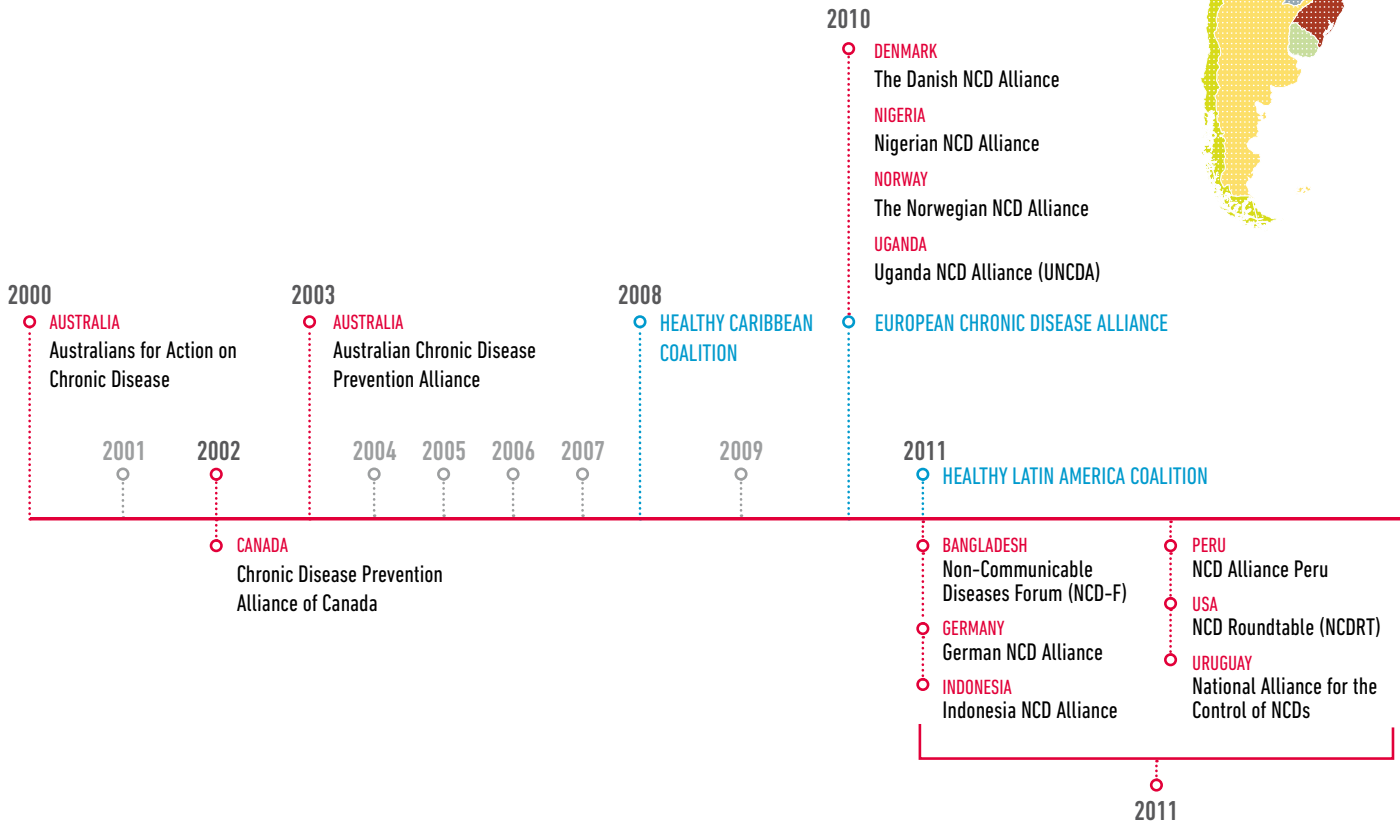
Map of national and regional NCD alliances

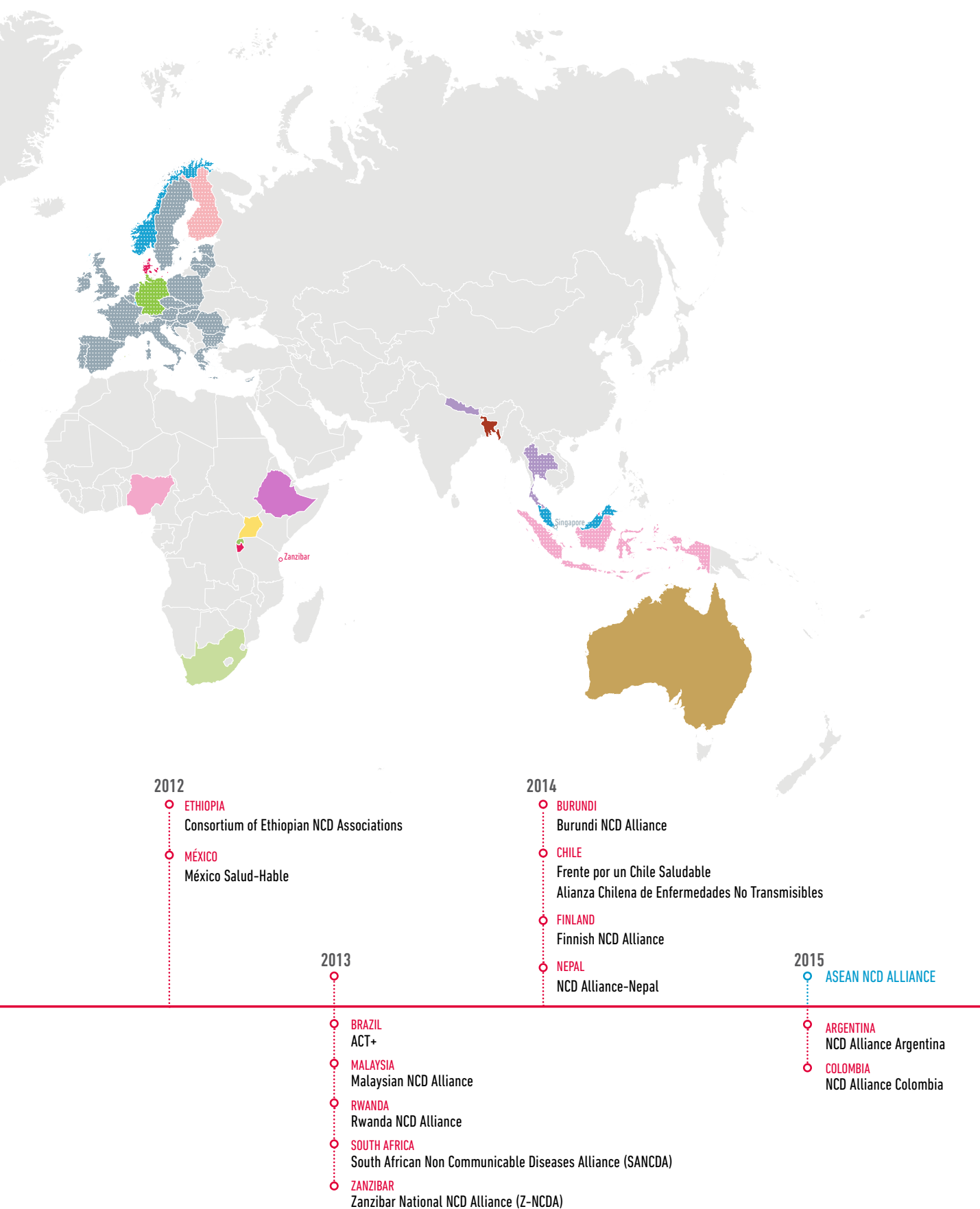
This map does not reflect the regional and national alliances that (1) did not respond (2) those that the NCD Alliance became aware of only after the exercise, (3) alliances that began to form only after the exercise, and (4) any not known to the NCD Alliance.

● Countries covered by regional alliances



YEAR OF FORMATION OF ALLIANCES





A nurse in Than Hoa, Vietnam, provides information to a mother about the benefits of the cervical cancer vaccine for her daughter



III. FINDINGS

A. Profile and governance of alliances

This section discusses the major factors and organizations that inspired the formation of alliances, the members who constitute the alliances and their growth plans. It further explores the various governance models adopted by the alliances in terms of their legal status, structures for organization of work and decision-making patterns.

KEY MESSAGES

- Global events such as the UNHLM on the prevention and control of NCDs and the UN SDGs were among the top external triggers for the formation of the alliances, followed by the support of regional and international organizations.
- Most of the alliances have disease-specific groups, followed by medical professional organizations. Greater involvement of risk factor and non-health organizations is desired for advocacy with multiple sectors.
- Two-thirds of the alliances were informal networks; fundraising prospects appear to motivate the alliances to seek legal status.
- Alliance structures need to be fit for purpose. Latin American alliances prefer horizontal structures with membership open to individuals and organizations to facilitate inclusiveness and democratic decision-making; those in Europe and East Africa usually have tiered structures with limited membership of select organizations that enable smoother decision-making and focused action.

1. Genesis of the alliances

The survey results indicate that the national and regional NCD alliances are very young and the global NCD civil society movement as a whole is in its early stages of development. Over two-thirds of the alliances have emerged in the past five years (see Figure 3) in contrast to just three known national NCD alliances (all in HICs) established prior to 2005.

Alliances cited a broad range of socio-political stimulants for their formation. Nearly one-third of the respondents mentioned the UNHLM on NCDs in 2011 as one of the factors that contributed to the birth of their alliance. Figure 3 illustrates this, with greater momentum in alliance formation observed from 2010 – the year leading to the UNHLM. The meeting proved a major impetus for civil society coalition building across low- and high-income countries, with the number of alliances more than doubling since 2010.

Notably, global discussions regarding the SDGs have inspired civil society mobilization in some regions, such as the initial meeting of alliances in Latin America. The NCD Alliance Argentina was formed and the Uruguayan NCD Alliance was revitalised in 2015 – around the time the SDG discussions gathered momentum.

Funding opportunities also facilitated the formation of several alliances, such as the Danish International Development Agency (DANIDA) funding via the Danish Civil Society Fund (CISU) in East Africa, the NCDA in-country capacity-building programme supported by Medtronic Philanthropy in emerging economies such as Brazil and South Africa, and the Caribbean Development Bank funding in that region.

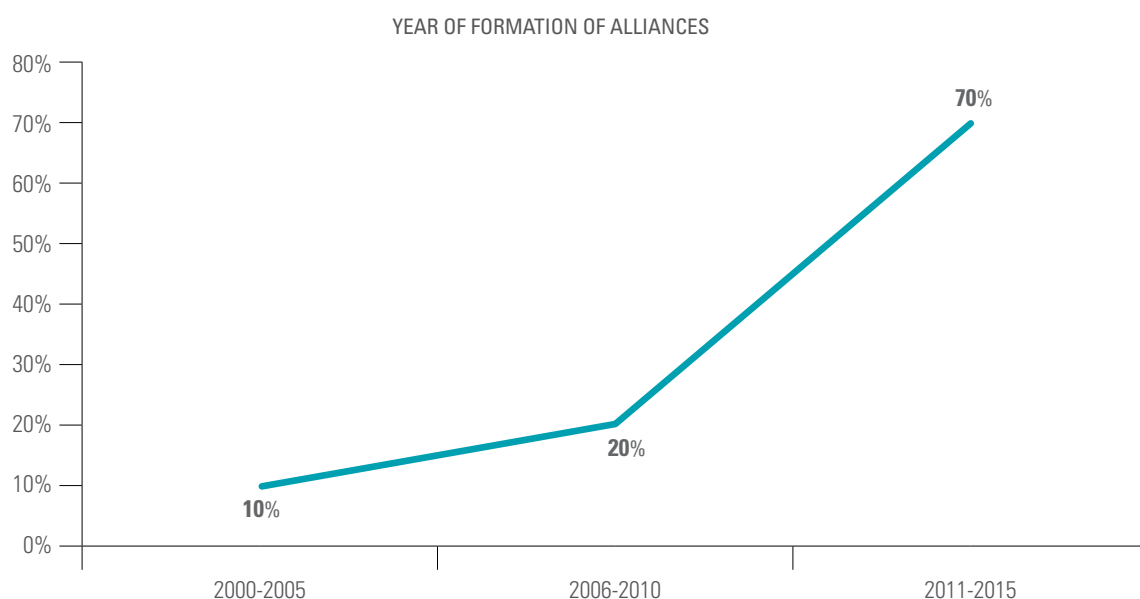


Fig 3.

There also appears to be a domino effect at the regional level, in which the formation of an alliance in one country promotes the emergence of more alliances in neighbouring countries. This is particularly evident within Latin America and East Africa. For instance, the Rwanda NCD Alliance was established on prompting from the Ugandan NCD Alliance. An interesting 12% of the respondents cited suggestion by the government as having led to the formation of their alliance. In Norway and Australia, the alliances emerged as a one-stop-shop of NCD civil society organizations to work with the government. Most of the national alliances in Latin America, including those in Argentina, Brazil, Chile, Colombia, Mexico, Peru and Uruguay, are either extensions of tobacco control coalitions or built on the momentum and experience of running them.

MAJOR CATALYSTS FOR THE FORMATION OF ALLIANCES

EXTERNAL	INTERNAL
UNHLM on NCDs, 2011	Scope to build on existing NCD-related networks
Support of alliances within the region, and regional and international organizations	Visionary leadership of individual medical professionals
Government prompting	Recognition of strength in joint action
Funding opportunities	Need for coordinated action
SDGs	Shared goals

Table 1.

National and regional alliances are yet to emerge in most Asian countries, with the exception of Bangladesh, Nepal and the emerging ASEAN NCD Alliance. However, a recent mapping of NCD CSOs in the WHO SEAR indicated distinct stages and actors in the evolution of NCD civil society action across countries. Thus, in the early stages of NCD action in these countries, medical professionals generate interest in the issue by presenting the evidence base, health NGOs follow up with advocacy and, some years later, non-health NGOs take the advocacy to sectors beyond health².

While few alliances were known to exist in the WHO EMR, a recent meeting of NCD CSOs in the region has led to the rapid formation of national alliances in countries such as Saudi Arabia and Egypt. A similar trend was also observed in other regions, in which all of the regional meetings identified the formation of national alliances as a priority and facilitated their development.

Regional and international organizations appear to have played a facilitating role in the formation of some alliances. For instance, the Pan American Health Organization (PAHO) and the InterAmerican Heart Foundation supported the formation of alliances in Latin America and the Caribbean, and the Asia Pacific office of the International Union Against Tuberculosis and Lung Disease facilitates the development of the ASEAN NCD Alliance. The Danish NCD Alliance has raised funds and supported the formation of three alliances in East Africa (Uganda, Tanzania and Zanzibar) along with, more recently, an East Africa NCD Alliance Initiative that convenes all alliances in the East Africa Community (EAC). NCDA was mentioned as having supported the formation of several alliances, primarily through guidance regarding membership and governance matters and its in-country capacity-building programme.

Apart from these socio-political factors, recognition of the strength in joint action seems to be the major motivator for forming the alliances (63%). The need for coordination and cohesion and shared goals among NCD-related organizations in the country/region were the next most cited factors (42% and 40% respectively) for alliance formation. Several alliances also coalesced around trusted leaders in the NCD world – often senior medical professionals – as in Nigeria and the Caribbean. The Burundi NCD Alliance informed about how interaction with the wider NCD community broadened their horizon to think beyond the specific NCD each organization was addressing.

Early initiators of alliances

The initiative for alliance building came from organizations of varied backgrounds. In Brazil, Uruguay and Peru, the tobacco control coalitions approached other NCD-related organizations to set up a national alliance. In Colombia, two parallel movements for tobacco control and consumer rights came together to adopt a rights-based approach to NCD prevention and control. Networks of heart professionals initiated the formation of the European Chronic Disease Alliance (ECDA). A cancer survivors' group and lung disease association steered the discussions on the formation of the ASEAN NCD Network. In South Africa, a patient network reached out to other NCD-specific organizations to form the country's national alliance. Several of the East African countries reported that the Danish NCD Alliance approached and held meetings with key in-country NCD organizations to establish national alliances. The alliance in Ethiopia was brought together by a cancer organization. A diabetes patients' group brought four major NCD groups together to form the German NCD Alliance. The Finnish Medical Society, a medical professional body, invited other NGOs to form the Finnish NCD Alliance. In all these cases, the initiators and potential partners decided to go beyond their specific areas of focus to address broader NCD concerns.

² Mapping of NCD Civil Society Organizations in the WHO South East Asia Region. Background Paper. Regional Meeting on Strengthening NCD Civil Society Organizations, 9-10 July, New Delhi. WHO SEARO & NCD Alliance.



From left: Laura Tucker-Longworth, Healthy Caribbean Coalition, Constance Kekihembo, CEO, Uganda NCD Alliance, and Rohan Greenland, National Director, Government Relations at National Heart Foundation of Australia, and Director, Asia-Pacific Heart Network, discuss how to strengthen the NCD civil society movement.

2. Profile of alliances

The alliances appear to vary greatly in terms of the number and type of members and their expansion plans. Funding and country and regional contexts play a role in determining the profile of alliances.

Size

As Figure 4 shows, the highest proportion of respondents, nearly 40%, belonged to alliances with five or fewer members. About 20% of the respondents were from medium-sized alliances with 11-20 members, whereas relatively fewer respondents (16%) reported that they were from alliances with more than 20 members.

The African and Australian alliances that responded to the survey had five or fewer members. The European alliances had 20 or fewer members, whereas the Asian alliances were spread across the categories in terms of membership strength. The Americas were the only region reported to have alliances with more than 50 members, and they had none with fewer than six members. In fact, the Healthy Caribbean Coalition (HCC) and Healthy Latin America Coalition have over 130 and 170 organization members respectively.

However, irrespective of the reported strength of the alliances, the members of several alliances in turn are networks with significant membership, thus making the indirect constituency and combined reach of the alliance far greater than what is anticipated from the officially listed members. For instance, the 11 members of the European Chronic Disease Alliance are themselves Europe-wide federations on specific issues include the European Respiratory Society, the European Society of Hypertension, and the European Association for the Study of the Liver. These organizations represent many thousands of health professionals, researchers and advocates across Europe who are now routinely briefed on, and drawn into working on, NCD policy developments at European and global levels.

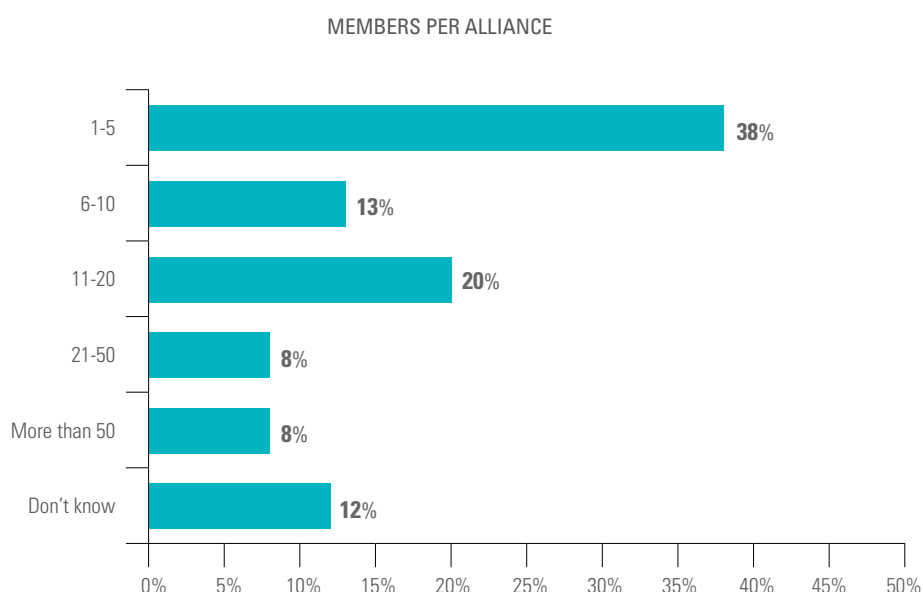


Fig 4.

Members

The survey asked whether the alliances permitted organizations and individuals as members. Over two-thirds of the respondents came from alliances that permitted only organizations as members, whereas 27% of the respondents said that individuals could join their alliance. A few alliances, such as the Bangladesh NCD Forum, had more individual members than organization members, and the Malaysian NCD Alliance currently has only individual members. By and large, alliances from HICs appear to have only organization members, whereas some of those across the rest of the income categories have individual members as well.

Some alliances have an open-door policy regarding membership, while others have restrictions about who can join. For instance, alliances in Brazil and Bangladesh admit applicants who meet membership criteria and administrative requirements and have been vetted by their steering group. In general, Latin American alliances keep their membership open for continued recruitment, whereas other alliances accept new members by invitation only (Finland), and still others restrict membership to existing members (Nepal, Denmark and Uganda). The ASEAN NCD Alliance, which is in its early stages of development, has chosen to include members by invitation, largely mirroring the Steering Group of NCDA. Alliances with restricted membership often maximize their

outreach on issues beyond their direct focus either through their member organizations or by working with other relevant NCD-related organizations on specific activities and campaigns.

As seen in Figure 5, an overwhelming majority of alliances (94% of respondents) appear to have disease-specific organizations among their members and about 60% of the respondents mentioned having medical professional bodies within their alliances. Groups working specifically on NCD risk factors and non-health organizations were reported by only about one-third of the respondents – mostly Latin American alliances. In some alliances, disease-specific organizations and medical professional group members address NCD risk factors as part of their regular work.

Notably, alliances in Latin America tend to include a broader cross-section of civil society, such as labour unions, human rights bodies, women and children's organizations, farmers' groups, resident associations, parent-teacher bodies and community and consumer organizations. In fact, some, such as the budding alliance in Argentina, focus on recruiting such groups to boost their advocacy for prevention policies across non-health sectors of government.

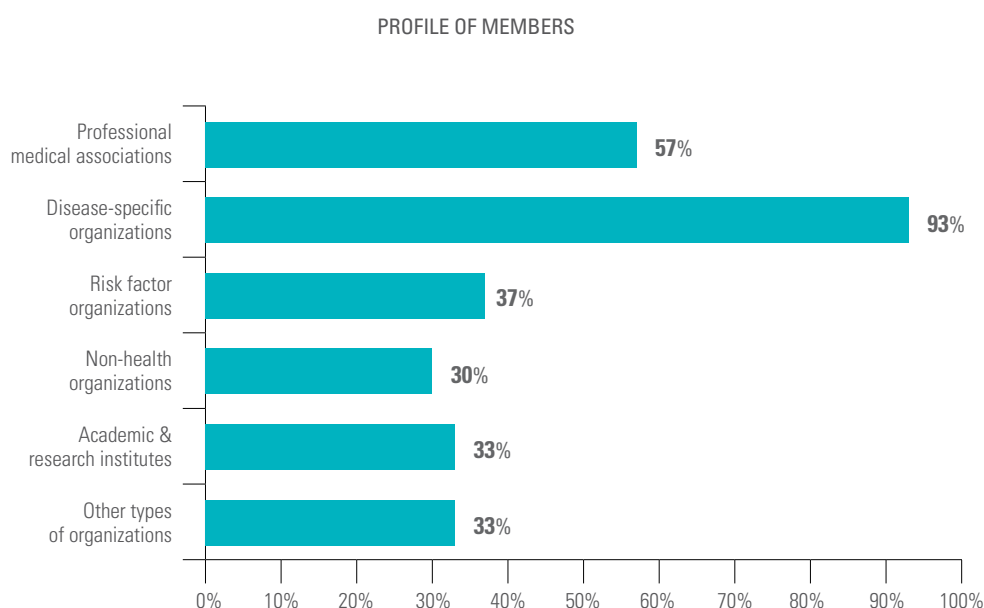


Fig 5.

Reflecting this regional trend, the meeting of Latin American alliances in Panama highlighted the importance of engaging a broad spectrum of organizations that have different expertise and experience in the health sector, as well as potentially influential contacts. The numerous consumer rights organizations that participated in the meeting lent a powerful voice to campaigning to protect children from the marketing of unhealthy products. The decision by the meeting participants to focus on this campaign is expected to lead to the rapid expansion of membership of consumer rights networks.

A mapping of civil society organizations in WHO EMR countries ahead of the regional preparatory meeting in August 2015 indicated that over half of the respondents (55.3%) were from health NGOs, but a considerable proportion of the total respondents (25.5%) had a non-health focus, spanning humanitarian issues, education and development³.

Expanding the membership

The interviews with the lead contacts sought to find out whether the alliances intend to expand their membership base. The alliances with fewer members preferred to remain as they were, though the reasons varied. In some instances, the relative ease of managing a smaller alliance reinforced the intention to keep the membership small. Other alliances that are not fully functional have yet to consider expanding from the original limited numbers. In other cases, funding terms with donors meant that membership had to be restricted, as in the case of some of the East African alliances. Several of the East African alliances mentioned the need and pressure to open up membership to a broader range of organizations relevant to NCDs and are currently exploring ways to do so.

³ Mapping of NCD Civil Society Organizations in the WHO Eastern Mediterranean Region. Background Paper. Regional Meeting on Strengthening NCD Civil Society Organizations, Cairo, 1-2 September 2015. WHO EMRO & NCD Alliance.

The preference to involve more members increases with the size of the alliance. The relatively large alliances in Latin America reported being open to new members, citing inclusiveness as driving the expansion. In most such cases, membership is by open application, which is then vetted by the board or steering committee. Other alliances include members on invitation as per need. For instance, the Finnish NCD Alliance is in discussions to expand its member base of disease-specific and medical professional organizations to include a physical activity group, as none of the existing members sufficiently addresses the issue.

Several alliances, including the German and European alliances, are currently considering engaging with the mental health sector. The Caribbean and Norwegian alliances already include members who focus on Alzheimer's disease. The longer-established Chronic Disease Prevention Alliance of Canada has two members from the broader mental health field.

Rights-based approach to NCDs in Colombia

Colombia's National Round Table for NCDs brought two parallel movements on tobacco control and consumer rights together to work on broader NCD concerns in 2015. They addressed concerns about the ongoing health financing crisis in the country. The initiative has been advanced by an organization addressing the impact of consumption on human and environmental health, tobacco control groups, a foundation of public health researchers working on nutrition and tobacco control and a professional social medicine body. They are building on Colombia's writ protection (*tutela*) for the legal defence of health rights under the constitution. Anchoring their work in health and human rights, members of the round table advocate tobacco taxes and graphic warnings on tobacco packaging and regulations on the marketing of baby formula, and are exploring the feasibility of a framework convention on unhealthy diet.



Karen, 27 years old. After a lengthy struggle with MDR-TB, she is now cured and free to enjoy a healthy and fulfilling life in Medellín, Colombia. The photo is part of The Union's Cured exhibition of photos depicting the lives of people who have all been cured of MDR or XDR-TB. The photographer

3. Governance

Legal status

Information on the legal status of alliances was gathered solely from lead contacts⁴. Over two-thirds of the respondents were from informal alliances that are not legal entities.

Further, as Figure 6 indicates, the legal status of alliances appears to be inversely related to country income categories. Thus, there were nearly four times as many respondents from HIC alliances that are informal entities than those that are registered. The gap reduced down the income ladder with the trend reversing in the lowest income country category, in which there were slightly more respondents from registered alliances than from informal ones.

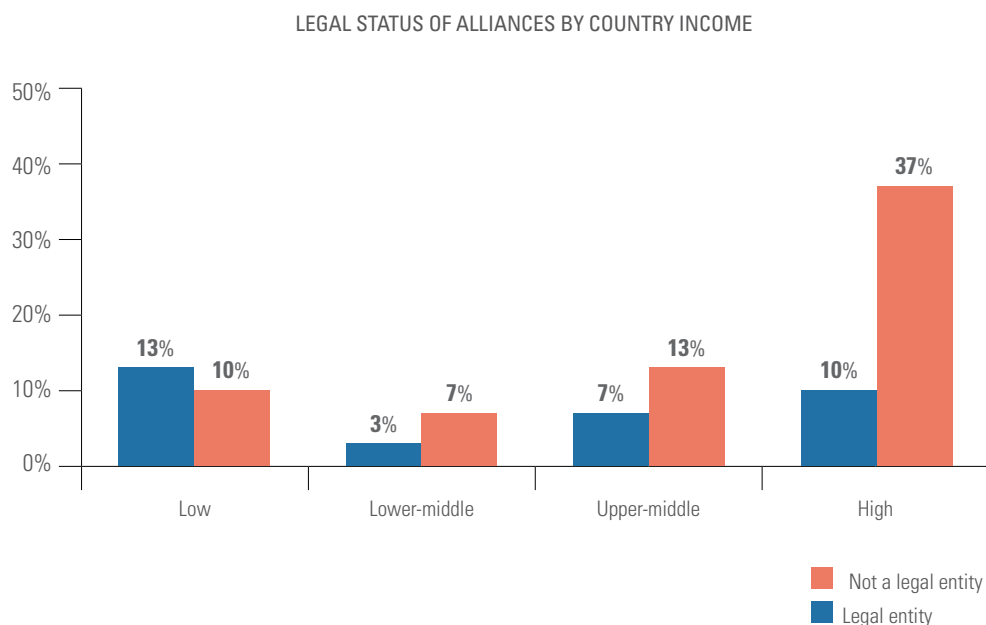


Fig 6.

Further, alliances sustained by funding from members, government and other sources appear to be more likely to remain informal. On the other hand, those that raised finances from philanthropic institutions, international NGOs and the private sector were more likely to be legally registered (see Figure 7). As most HIC alliances are self-funded, there might be less need for them to set up such legal structures. External funding, therefore, seems to be among the factors prompting low-income country alliances to seek legal status. Across the board, the finances of informal alliances are managed by member organizations.

By region, Africa, Asia and North America appear to have an equal number of alliances that are formal and informal entities. Several African alliances reported legal registration as a prerequisite for government recognition, which partly explains their largely formal status. On the other hand, Latin America appears to have more alliances that are informal entities than legally registered ones. This seems to be in line with their

⁴ This improves the validity of the responses and reduces the scope for data inconsistencies regarding the legal status of alliances.

preference for informal structures, which is discussed subsequently. The European and Australian¹ alliances that responded to the survey were not legal entities. The lead contacts from some LMIC alliances also cited the cumbersome administrative and reporting procedures for legal entities that could potentially drain limited volunteer time and resources as a deterrent to seeking such status.

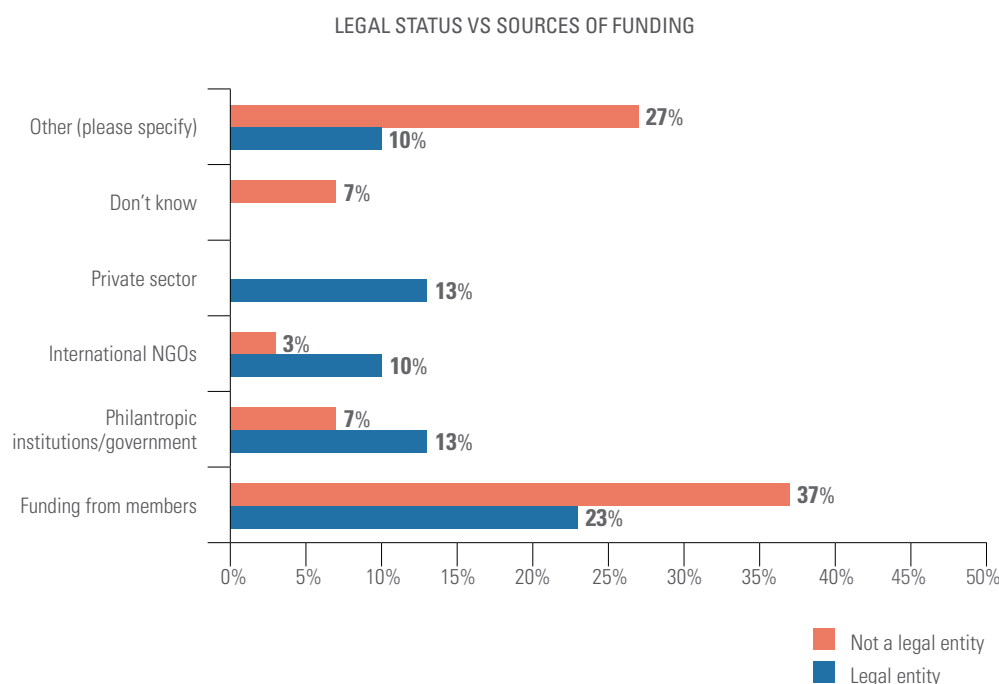


Fig 7.

Structure

Alliances organize themselves in a variety of ways in accordance with their objectives and local context. Those with legal status normally have a formal board or executive committee with functionaries as per the legal requirements. For example, the Consortium of Ethiopian NCD Associations (CENDA) is a legal entity and has a board comprising representatives of its five founding members. It has a general body of 30 members – six members from each of the five member organizations. While the board is the decision-making body of the alliance, annual plans and strategies are discussed in the general body. Some alliances choose to nominate members to their board while others elect them. Similarly, the functionaries of the board are elected in some cases and nominated in others.

Less formal alliances often have a steering/executive/coordination committee made up of representatives of member organizations which selects the functionaries. Informal alliances often operate on the basis of a memorandum of understanding (MOU) that is developed among members. In some informal

alliances, such as the Norwegian NCD Alliance and the Australian Chronic Disease Prevention Network, the steering committee consists of the CEOs of the four/five member alliances who meet regularly to take decisions. In such cases, the alliance CEO then implements the decisions taken by the steering committee with the help of senior officers of the member organizations. The need to have CEOs (and not board members) of member organizations on alliance boards/steering committees for effective decision-making was emphasised by some such alliances.

A few alliances have an additional advisory committee comprising government and WHO representatives and other people of standing in the NCD community who play an advisory role. Other informal networks, such as those in Argentina, Colombia and Germany, do not have a steering committee, but coordinate through regular meetings on issues, with operational assistance from a member organization that provides secretarial support.

¹ As explained under Methodology, Australia was considered as a region in all analysis by region.

Formal-informal hybrid structure: Healthy Caribbean Coalition

The Healthy Caribbean Coalition (HCC) has broad representation from 16 countries in the region drawn from 19 disciplines, including agriculture, academia, faith-based, trade unions, youth, urban planning and the media, as well as many international partners. Since 2012, it has been an independently-registered NGO with a deliberately small board of directors to allow for carefully planned and sustainable growth. However, it also operates as a large informal network, which is easy to join via e-mail or the website.

The coalition's diversity is managed through multiple categories of membership: health and non-health NGOs, academia, private sector supporters from the Caribbean, international supporters and individuals. An annual general assembly of members is held and significant effort goes into fundraising to cover travel and accommodation for representatives from around the region. The HCC bylaws stipulate that only health NGOs from the Caribbean (currently 49) are eligible to vote for board members. Currently, there are five members of the board, with up to ten allowed by the bylaws. The standalone secretariat headed by the CEO reports directly to the president of the board.

While members of the larger informal network do not have voting rights at the general assembly, they play an active role in coalition activities.

In other informal networks, such as the Coalición México Salud-hable (Mexican NCD Alliance), there is a coordination committee of about eight or nine volunteers from among the members to decide on alliance matters. This alliance has consciously chosen to maintain a horizontal structure with facilitators rather than leaders, each supporting the work of various thematic work groups. They consider that this informal structure provides flexibility and inclusiveness and purposefully avoids power struggles and political manoeuvring.

Terms of functionaries in formal and informal structures tend to be fixed (about two to three years), with the position of chairperson rotating annually in most cases. Some alliances also mentioned challenges in finding acceptable replacements for effective chairpersons of their board/committee.

It has been observed that, in HIC alliances, member organizations are able to allocate the contributions of member CEOs and other representatives as part of their job descriptions and key responsibilities.

Good governance practices of alliances

- An MOU stating the terms of reference of partnership within the alliance;
- Egalitarian and inclusive structures with rotational leadership;
- Advance selection of chairs to facilitate preparatory phase and smooth handover;
- Consensual decision-making;
- Agreed goals, priorities and work plan;
- Independent secretariat;
- Annual strategy planning meetings with member CEOs and chairpersons;
- Dedicated time of member organizations to alliance's work;
- Communication and conflict of interest policies;
- Use of technology to facilitate meetings of large alliances/long-distance meetings.



Key elements of effective alliances

Visionary leadership

Shared values and goals

Common work plan

Winnable early tasks

Dedicated human resources

Resource mobilization strategy

The latest in a series of five Regional Meetings on Strengthening Civil Society took place on 2-3 October 2015 in Nairobi, Kenya.

These then translate into regular meetings, follow-up and even the time available to a person to coordinate the alliance. This enables the member organizations to provide concerted input – technical and financial – for the work of their alliances, thus helping the alliance to function in a focused and organized manner.

Despite earnest intentions, members of few alliances in LMICs seem to have the resources to volunteer staff time to alliance work. Several of these alliances mentioned the resulting discontinuity as a major challenge to their work. This comes through clearly when comparing the alliances in East Africa that have funding for staff positions and are able to run sustained advocacy and explore sustainable funding with others that have to stretch limited member resources that barely cover sporadic programming. This points to the need for member organizations and external partners to prioritize and fund staff positions in LMIC alliances, which could in turn lead to their sustainability. It is also important for alliances to decide on legal status and adopt structures that best enable them to meet their shared goals and purposes.

Secretariat (location, staffing and reporting)

In resourced alliances, there is normally a secretariat that implements the decisions of the board/steering committee. A director or CEO who reports to the

board manages the rest of the staff in such cases. The strength of the secretariat in such alliances varies from one part-time person to 2.5 full-time equivalents. In northern alliances, membership fees cover core costs, including staff salaries, or member organizations devote the time of their own staff to the work of the alliance. For example, the board of the German Diabetes Association approves the significant amount of time devoted by its CEO to manage the German NCD Alliance and its marketing and PR manager to support its communications. In less resourced alliances, steering committee members volunteer to undertake the operational tasks and programmes by themselves or through their organizations.

In one of the self-resourced alliances, the secretariat rotates every two years with the leadership of the steering committee. While this facilitates a close working relationship with the alliance chairperson, frequent rotations seem to raise several administrative challenges for the secretariat. Alliances that are externally funded tend to hire secretarial offices. Another funded alliance set up its secretariat as an independent unit for neutrality, while the CEO reports to the chairperson of the board. Management Services Health provided office space to the Consortium of Ethiopian NCD Associations, whereas a private company lent space for the operations of another alliance in return for the payment of maintenance and overhead charges. Some alliances in very early stages of development have yet to set up a secretariat.

4. Management

Decision-making

Most alliances stated that they take decisions by consensus within the decision-making unit of their regular meetings. In some alliances in which chairpersons are held in high esteem, the steering committee tends to be guided by the chairperson's recommendations. Others, such as the European Chronic Disease Alliance have detailed decision-making guidelines in their MOU, which are carefully followed.

For urgent matters, such as media interaction, alliances tend to act in accordance with the majority decision and use the organization logos of consenting members. In large alliances, members are consulted through annual general meetings on key decisions and alliance plans. The lead contact of an alliance had this practical advice to offer: "Give enough time for people to opt out of backing a position. If they have time to think about it, they will go with it."

Members' input into decision-making in alliances is either through the organizations represented on the board/committee or via the general body. The Uganda NCD Alliance has set up five committees on diverse programme and operational matters, as can be seen in Figure 8.

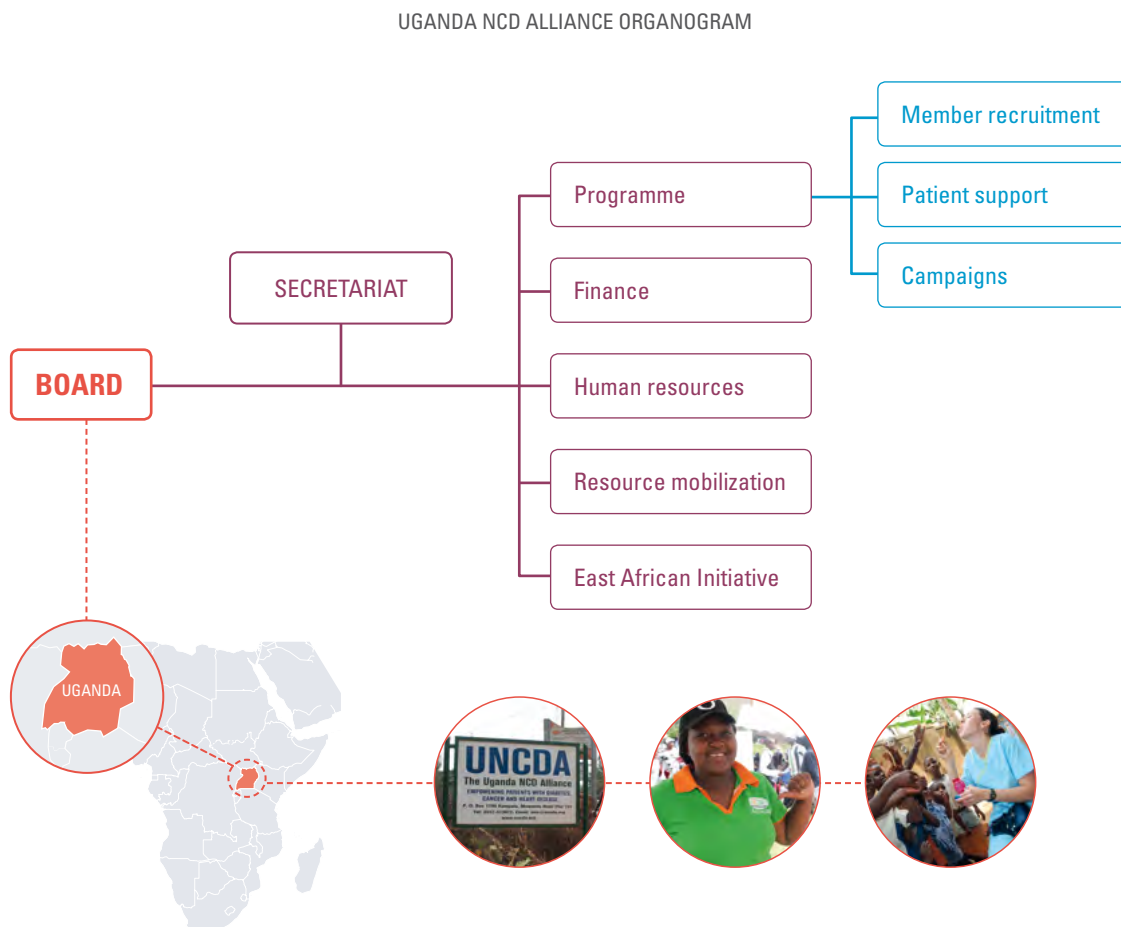


Fig 8.

Joint statements in the European Chronic Disease Alliance

On joint positions, members are given five working days to express disagreement with the content to the secretariat. All joint positions by the alliance whose content has been agreed upon unanimously bear the alliance logo. Should one or more members request to opt out, then the action in question will no longer bear the alliance logo and will not be supported by the secretariat. In such cases, those members who wish to carry on with the specific action have to coordinate it among themselves. For urgent matters, the secretariat asks members for a positive reply within 48 hours.

A board member heads each of the committees and reports on committee work to the board. While the board is limited to three founding organizations, the committees provide opportunities for those who are in turn members of the founding organizations to inform and contribute to the alliance's work.

Planning

Some alliances operate according to annual work plans. Others undertake strategic planning exercises to develop three- to five-year plans. Funded alliances or those actively seeking funding options seem to undertake concerted planning exercises with member involvement. The Healthy Caribbean Coalition, for instance, conducted a survey and consultation among members and set up a drafting group to develop its five-year plan and has since secured funding for several of its strategic priorities. The relatively smaller Australian Chronic Disease Prevention Alliance organizes an annual planning session with the chairpersons and CEOs of its members at which the priorities are identified. This was reported to have helped them, particularly when it came to securing support from member boards.

Alliances starting with limited or no resources tend to work on a more ad hoc basis on different activities. They normally observe key NCD days, support members' existing training and awareness-building programmes or focus on a specific policy campaign. Member input into the planning process in such cases is mainly through annual general meetings or coordination meetings.

Coordination and communication

Some alliances manage to meet regularly with a specific agenda and follow up actions while others struggle to have meetings. In large countries, physical distance has been cited as a barrier to regular meetings. The South African NCD Alliance,

with its steering committee spread across different cities, overcomes the geographical challenge through Skype calls and e-mails. Competing commitments and busy schedules of steering committee members seem to have stunted the growth of a handful of alliances. This is particularly relevant in alliances that are run exclusively by volunteer steering committee members. Inclusion of work for the alliance as part of the performance indicators of the CEOs of member organizations and any member organization serving as the secretariat was recommended to improve their contribution to the alliance and foster a shared approach to accessing resources.

Chairpersons/presidents and members of the board/steering committee were mentioned as the most common alliance spokespeople with the public, media and funders. On occasion, they delegate the task to the alliance CEO or the member organization managing the secretariat. Decisions about representation at conferences and external partners are normally made by the steering committee.

Funding

Two-thirds of respondents said that their alliance received funding from members. This includes a variety of sources. Some HIC alliances have membership fees, while others raise funds from members on a project basis. Several lead contacts from LMICs said that membership fees were not affordable for their members. However, their members undertake and fund joint activities with the alliance.

Figure 9 (see overleaf) suggests that philanthropic institutions and foundations are the next major source of funding for alliances, followed closely by national governments. Philanthropic institutions mentioned during the interviews include Bloomberg Philanthropies and a local philanthropist in the case of the Chilean NCD Alliance (Alianza Chilena de

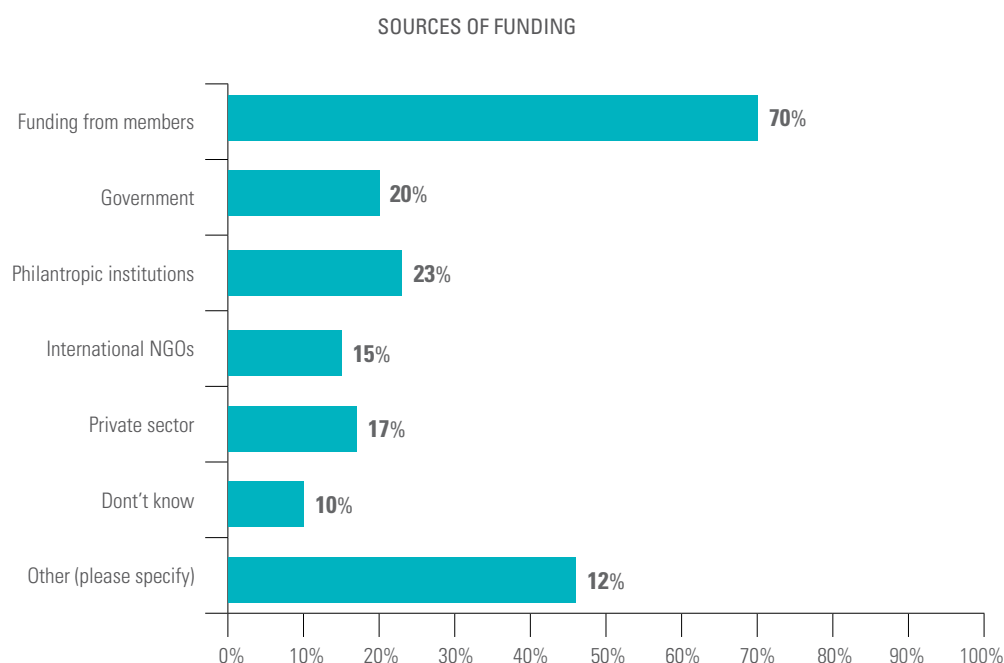


Fig 9.

Enfermedades No Transmisibles). Funding reported as coming from international NGOs could include funds donated by the Danish NCD Alliance to East African alliances (financed by DANIDA) and from the NCD Alliance to national/regional alliances (financed by Medtronic Philanthropy). Several alliances mentioned receiving funds from the private sector. This included largely pharmaceutical and insurance companies, gymnasiums, banks and a supermarket group.

Government funding to alliances ranges from occasional event-specific resources, such as for awareness-raising on NCD days, to sustained funding for national work in the case of Norway and international work in the case of Denmark. Notably, the Caribbean Development Bank made a significant contribution that ensured multisectoral participation from across the region in the meeting that led to the formation of the Healthy Caribbean Coalition. The other sources of funding for alliances include revenue from conferences, investments and individual contributions. Funding from international NGOs and the private sector constitute a relatively small proportion of the overall funding for alliances. Overall, the survey indicates that, to date, there is limited external funding for alliances from government, philanthropic institutions, international NGOs and the private sector.

Encouragingly, some alliances in Latin America are exploring ways to increase domestic funding for NCDs by taxing products that contribute to the NCD burden. Thus, ACT+ (Brazil's NCD coalition) has been advocating tobacco and alcohol taxation as a source of revenue for the under-funded national health system, including for NCDs. As a result, this was recommended as a new source of revenue in the national health system financing document produced by the financing commission of the national health council.

Legally registered alliances manage their own funds, mostly by the organization housing the secretariat. For those that are not legally registered, one of the member organizations is usually tasked with managing the resources through an independent bank account for the alliance.

While a lack of financial resources constrains the work of most alliances, few reported having a resource mobilization plan or carrying out fundraising activities. Where plans exist, they are mostly required by donors, as in the case of the DANIDA-funded alliances in East Africa. As alliances with fundraising plans seem to attract donor interests, this may be something that all alliances want to make an integral part of their growth plans.

Resource mobilization needs to be planned: Zanzibar's approach

As part of its CISU grant, the Zanzibar NCD Alliance received training from the Danish NCD Alliance to prepare members for resource mobilization for themselves and the alliance. Following the training, the alliance drew up a resource mobilization plan, the aim of which is to raise funds from a host of sources from within Zanzibar, within the country, within the region and internationally.

After drawing up the plan, the alliance managed to secure in-kind support from local banks and members of parliament for NCD screening camps. They are developing proposals for the capacity-building of their cancer association and for addressing risk factors for diabetes (two priorities for the alliance) aimed at regional donors. They are also exploring funding for tobacco control activities from international foundations such as Bloomberg Philanthropies.

Contributions of members

As Figure 10 shows, member support to alliances comes in many forms. Primarily, members contribute human resources and provide input into strategy and campaign planning, as well as communication support. A smaller proportion of members make other in-kind contributions such as hosting meetings, making office space available and providing other logistical or administrative support and financial contributions. The financial contributions could be membership fees, funding projects or underwriting alliance activities.

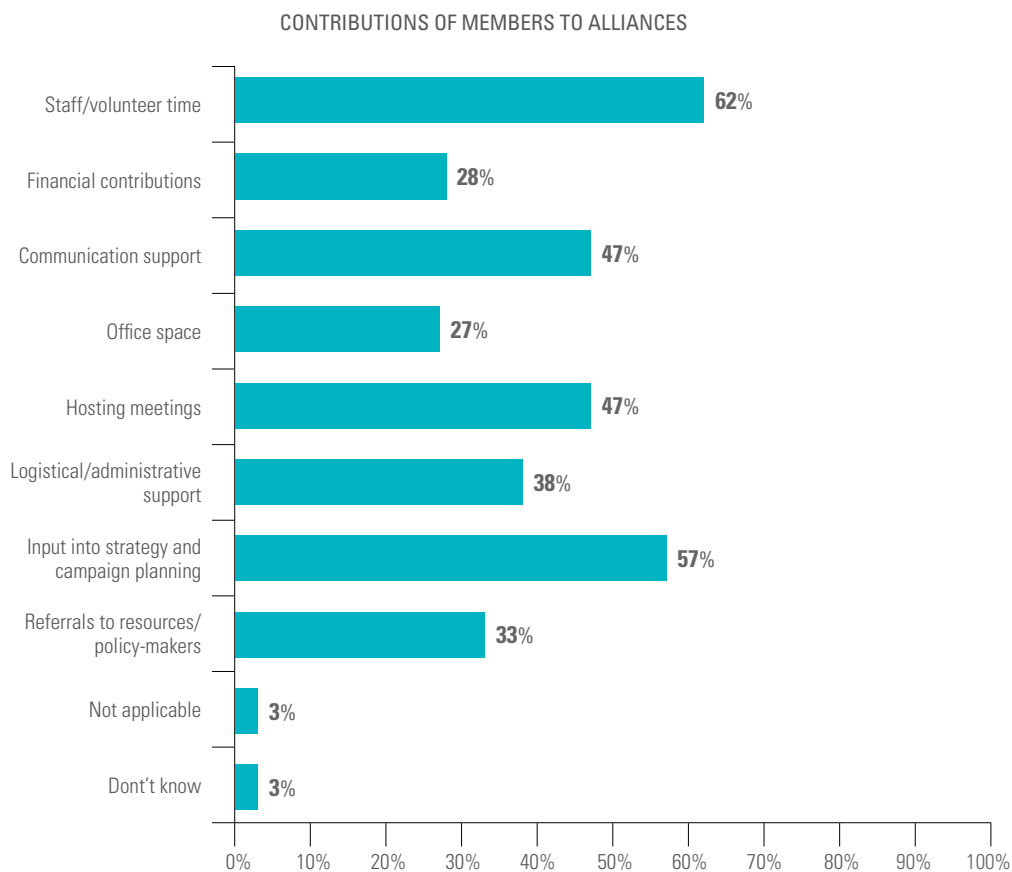


Fig 10.

B. Programmatic focus

This section discusses how the alliances approach the major NCDs and their common risk factors, core strategies, key activities and major achievements.

KEY MESSAGES

- While the major focus of the alliances appears to be NCD prevention by securing policies to address risk factors, this seems to be more the case in high-, upper-middle- and lower-middle-income countries. Low-income countries appear to focus more on the immediately visible challenges of access to diagnosis and treatment.
- Advocacy with governments and media for policy change is the priority activity for the alliances of nearly half the respondents. Involvement in government NCD mechanisms and monitoring of government NCD commitment requires greater attention from civil society.
- Engaging non-health NGOs and advocacy with non-health sectors of government yields high returns, but is under-explored by alliances.
- In a short period of time, most alliances have been successful in engaging key civil society partners, influencing government decisions and advocating and supporting the development of NCD-related policies.

1. Advocacy agenda

Approach to NCDs

A majority of the respondents said that their alliances focused on preventing NCDs by addressing the risk factors (87%), followed by those that focused on national NCD plans and policies (78%). One-third of respondents reported patient empowerment as part of their priority focus.

The income level of the country has some bearing on the issues the alliances choose to focus on. If the top focus issues are examined in conjunction with income, as can be seen in Figure 11, alliances across all income levels appear to give priority to the prevention of NCDs by addressing risk factors and working on national NCD plans/policy-related issues. Additionally, alliances from high-income countries focus on specific vulnerable groups such as women, children and the elderly. On the other hand, a greater number of respondents from low-income national alliances have indicated the need for access to essential medicines – a known challenge in their countries.

Priority strategies

In line with their focus of work and activities, 42% of respondents identified securing policies to reduce exposure to NCD risk factors and ensuring civil society participation in official NCD mechanisms as top priorities of their respective alliances. The next priorities were supporting multisectoral action on NCDs and monitoring progress of government NCD commitments, as reported by 38% of respondents. Nevertheless, it may be noted that monitoring NCD commitments by governments does not figure prominently among the activities reported by the alliances (only 20%, as can be seen in Figure 14). It could be that, while alliances consider this a priority strategy, they are yet to put it into action with concrete monitoring efforts and tools. Respondents from alliances with resources from members tend to adopt two broad streams of priorities: one pertaining to securing NCD policies and plans, and the other to improving stakeholder engagement in the NCD response.

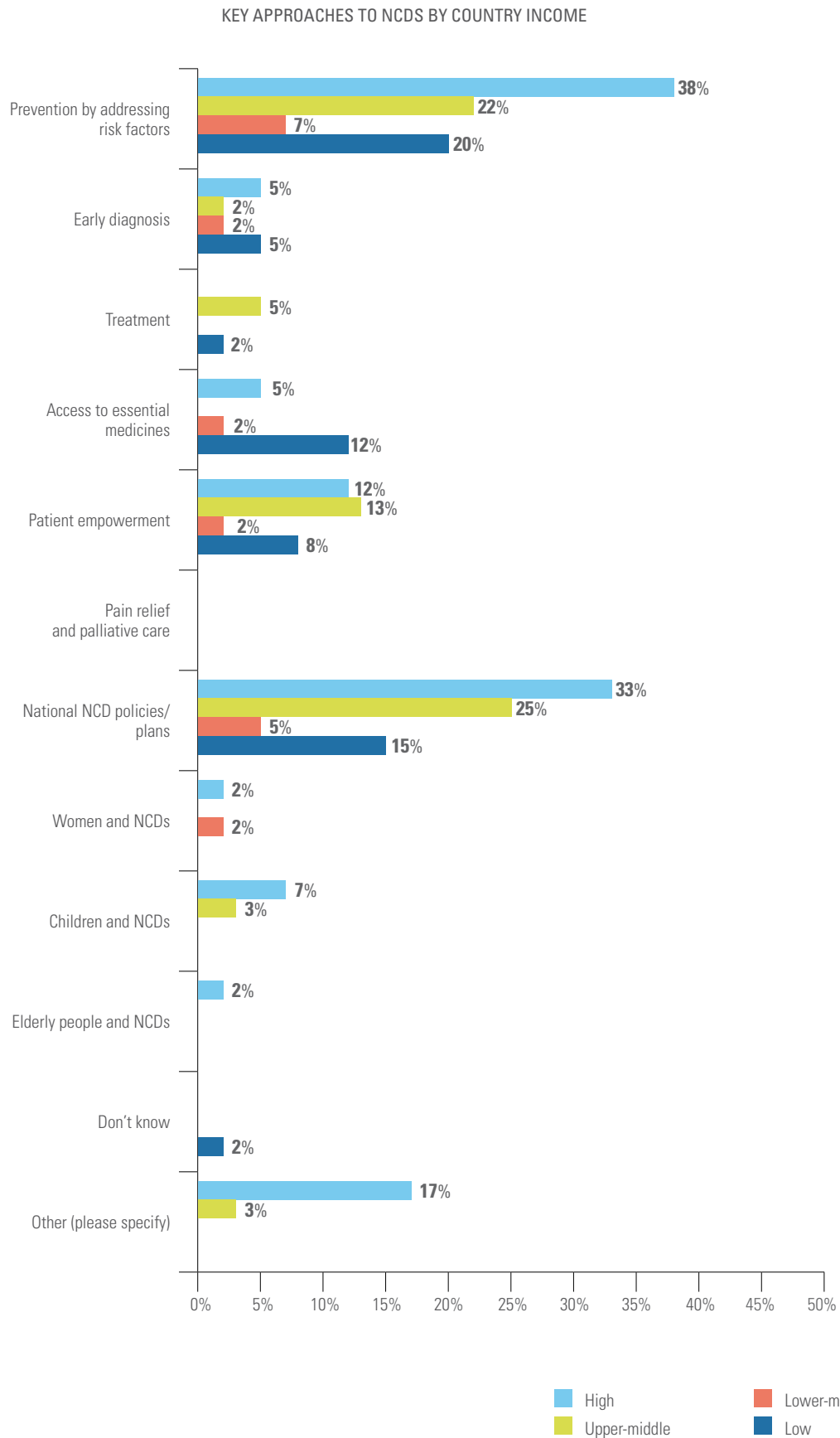


Fig 11.

Patient engagement in NCD advocacy: the South African approach

Following on their leadership in the global HIV/AIDS movement since the 1990s, South African CSOs, in particular patient groups, are now playing a leading role in drawing attention to issues facing those affected by NCDs. A patient network, the Patient Health Alliance of Non-Governmental Organizations (PHANGO), initiated the South African NCD Alliance (SANCDAs) in 2013 and continues to coordinate its work. As far back as 2008, PHANGO made a presentation to the government and the national human rights commission about the lack of attention and resources given to NCDs.

Other SANCDAs members (cancer, diabetes and heart and stroke associations) also have patients' groups within their networks. SANCDAs work focuses on patient empowerment. Patient advocates are included in meetings with government representatives, the patient's voice is routinely included in communications and patient organizations are consulted while forming policy positions on issues.

SANCDAs advocates improved access to diagnosis and treatment at the provincial level. Currently, it is working on a provincial project to screen people for hypertension and diabetes. On one hand, the alliance is helping the government to develop a screening protocol for the provinces. On the other hand, it is holding meetings with governments and NGOs to put the issue on the agenda of the premiers and politicians of the provinces.



Vicki Pinkney Atkinson of South Africa NCD Alliance and Dr Sibongiseni Dhlomo, Member of Executive Council for Health of Kwa Zul Natal (KZN) province, at a stand of the Heart and Stroke Foundation of South Africa at the KZN NCD Indaba (Zulu for meeting).

Strategic priorities of the Healthy Latin America Coalition

By way of preparation for the Panama regional meeting, the Healthy Latin America Alliance conducted a prioritization exercise among members to help decide on which prevention measures they should focus on together. In assessing possible interventions for each major risk factor, they asked members to consider (and score) level of impact, quality of evidence, political feasibility, cost of intervention, social acceptability, and national relevance. This exercise informed their discussion and helped them reach an agreement on the following priorities for the regional alliance:

1. Restrict industry's marketing strategies for ultra-processed foods, soft drinks, alcoholic beverages, and tobacco;
2. Rights to drinking water in various environments such as schools and work;
3. Measures to increase offer of healthy food, i.e. fiscal policies, agricultural incentives and the like;
4. Measures to reduce the obesogenic environment in schools.

However, when the strategies were analysed in accordance with the country income of the respondents' alliances (Figure 12), those from low-income countries tend to consider early diagnosis, access to treatment and mobilizing civil society as more of a priority, whereas the high-income alliances list securing policies to reduce risk factor exposure, civil society participation in official NCD mechanisms and supporting national NCD plans among their top priorities. A similar trend is observed across regions, whereby respondents from alliances in Asia, Africa and Latin America indicated early diagnosis and treatment as a priority. One could therefore consider that these are not priority areas for alliances in the high-income countries that are mainly in Europe, North America and Australia. This corresponds with the known disparities in NCD diagnosis and treatment services between low- and high-income countries and corresponding civil society response, thus presenting a scenario akin to the HIV/AIDS treatment scenario in the early 1990s.

Interestingly, respondents from low-income countries did not recognize combating industry influence as a priority strategy for their alliances. One plausible reason could be that alliances in low-income countries are trying to address the immediately visible and unmet need for diagnosis and treatment for people with NCDs, and are in the initial stages of mobilizing the key civil society partners required for policy advocacy. Resource availability could also be determining the ability of CSOs in low-income countries to combat industry influence. As the HICs are more likely to have better NCD diagnosis and treatment services, alliances in those settings are likely to be able to focus more on combating industry influence.

A review of the documents from regional preparatory meetings in the run-up to the global forum presents some interesting observations regarding their priorities. The agenda of the Latin American meeting indicates a focus on specific prevention policies as opposed to treatment and control of NCDs⁵. The Caribbean meeting was also concerned with building national alliances⁶. On the other hand, discussions at the South East Asia meeting reflect interest among CSOs to work on a range of NCD interventions from prevention, diagnosis and treatment to palliative care⁷. The EMR meeting witnessed much interest in mobilizing resources and forming national alliances and a regional alliance⁸. The Africa meeting built on the benchmarking of the NCD response performed in some countries and the sub-region of East Africa. It brought to light ongoing efforts in countries in the region to integrate NCDs in national development plans and the UNDAF and led to the consolidation of the East Africa NCD Alliance Initiative and emergence of a new pan-African NCD network⁹.

⁵ Preliminary agenda. Healthy Latin America Coalition (CLAS) Regional NCD workshop: Strengthening Civil Society Response. Panama, 8-10 June 2015.

⁶ Concept note & programme. Caribbean Civil Society Regional Preparatory Meeting, 6 June 2015 | Courtyard Marriott Hotel, Barbados.

⁷ Report of the South East Asia regional meeting on strengthening NCD civil society organizations, New Delhi, India, 9-10 July 2015. WHO SEARO.

⁸ Summary report of the regional meeting on strengthening partnership with civil society organizations for the prevention and control of noncommunicable diseases. 1-2 August 2015, Cairo. WHO EMRO.

⁹ Provisional programme. Strengthening NCD Civil Society Organizations in the WHO African Region, Nairobi, 2-3 October 2015. NCD Alliance & East Africa NCD Alliance Initiative.

PRIORITY STRATEGIES OF ALLIANCES BY COUNTRY INCOME

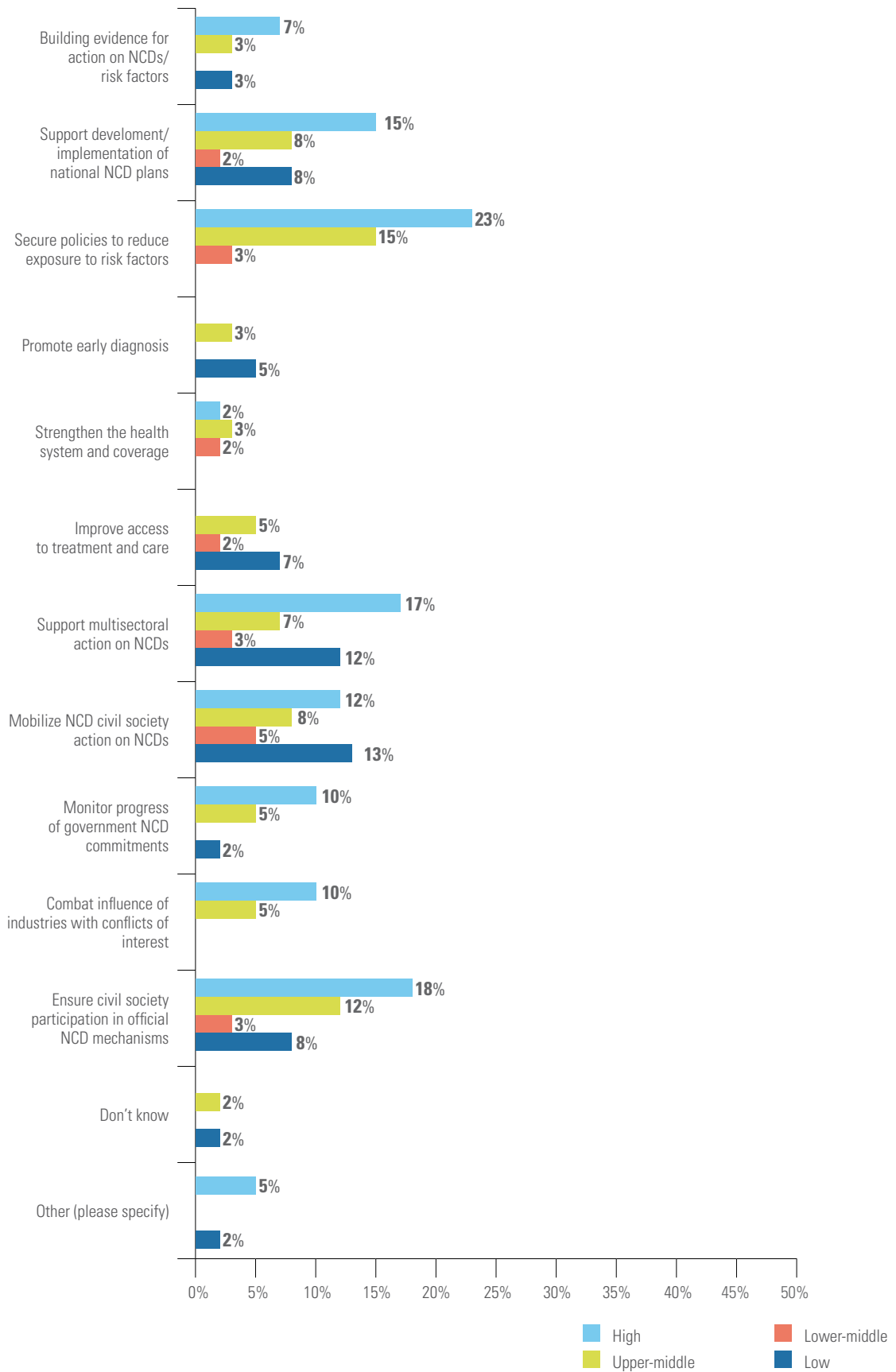


Fig 12.

Engaging NCD-affected people and prioritizing their concerns

The priority that alliances accord to patient engagement and empowerment can be gauged on the basis of their levels of engagement of those affected by NCDs and their focus on patient services.

Patient engagement: As Figure 13 indicates, membership (52%) is the main form of engaging people living with NCDs among alliances. Given that an overwhelming majority of the alliances have disease-specific groups among their members, affected populations could be considered as represented among their membership. Involvement of patients in the alliances' work seems to be largely in the realm of interaction with external agencies, such as the media (28%) and government (23%). Like the HIV/AIDS movement, NCD alliances seem to consider engaging patients as important to their work.

Interviews confirmed that the leaders of several alliances and their constituent members were themselves affected by NCDs. These alliances by default therefore had NCD-affected spokespersons. In one alliance, the chairperson has diabetes, while the vice-chair had hypertension and a third member of the steering committee is a cancer survivor. Patient engagement tends to serve multiple purposes in alliances. In the case of the Malaysian NCD Alliance, patient engagement provides the rationale for training, propels action and helps in mobilizing resources at national level. However, the alliance considers that it would require the involvement of risk factor groups to drive advocacy for macro-level prevention policies. It is worth noting that there are alliances that do not currently engage patient groups, as they consider that this would divert their agreed focus on prevention to treatment issues.

38% of the respondents whose alliances receive member funding (the major form of funding in the sample) indicated patient organizations as members. However, the engagement of patients as members is roughly 20% higher than the next most common responses: inclusion of their voice in alliance communication and as spokespersons. Inclusion in the member base is probably the easiest form of patient engagement, whereas more active forms of engagement require greater efforts in equipping and creating space for patients.

Patient services: Patient engagement in an alliance's work does not necessarily mean increased attention to patient-related issues. Only 13% of the respondents reported patient-related services among the activities of their alliance (Figure 14). Respondents from alliances in LMICs in Asia, Africa and Latin America reported patient-related issues such as early diagnosis and access to treatment as a priority for their work.

African alliances in particular undertook a range of activities that have implications for the treatment and care of people affected by NCDs. While some developed policy papers on access to essential medicines, others set up clinics for NCD counselling, and still others advocated reinforcing the public health system with NCD-related services. Among Latin American alliances, the Colombian alliance advocates affordable treatment options for NCDs as part of the citizens' right to health. An organization led by HIV advocates – Grupo de pacientes de enfermedades de alto costo, or high-cost disease patient group – is one of its most active members and the one with the most experience in litigation. Analysis of patient engagement strategies by region indicates that alliances from HICs in Europe, Australia and North America tend to focus less on these issues. This seems to be in line with the known differences in the need for patient services across regions and country income categories and therefore explains in part the corresponding difference in the priorities of the alliances.

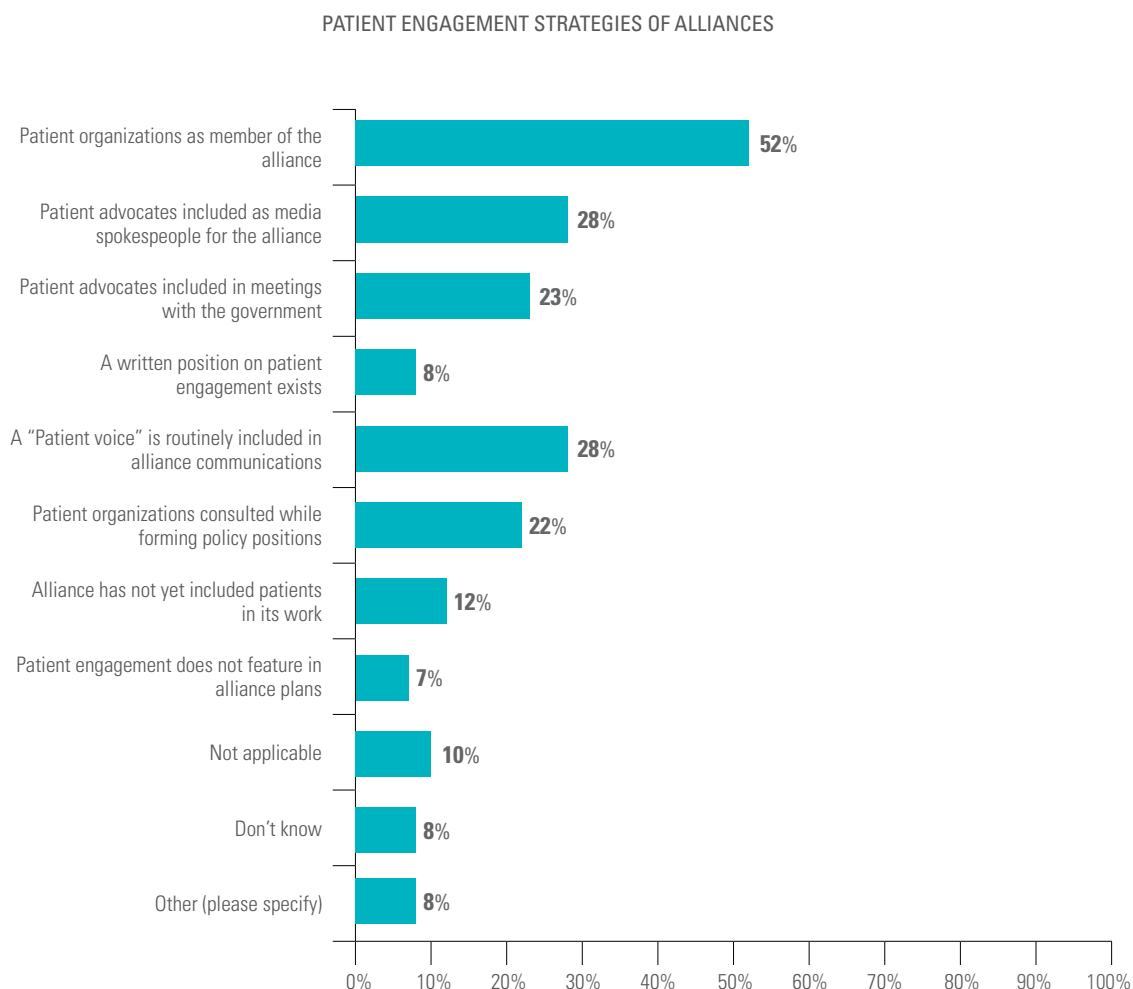


Fig 13.

Activities

As Figure 14 shows, 60% of the respondents mentioned that their alliances engage in direct advocacy with government, followed by 47% that use the media for advocacy and 38% that coordinate civil society action on NCDs. For instance, alliances in Latin America advocate an increase in tobacco taxes as a means of domestic funding for NCDs. ACT+ (Brazil's NCD coalition) is advocating legislation and government litigation that would require the tobacco industry to bear the costs of tobacco-related diseases.

Only around one-quarter of the respondents reported that their alliances influence or participate in government NCD coordinating mechanisms (e.g. national NCD commissions) and public education, whereas even fewer reported monitoring their government's NCD commitments and building the capacity of stakeholders as a major activity (20% respectively). The legal status appears to have little bearing on the choice of activities, with respondents from alliances that are registered and otherwise undertaking a broad range of activities to address NCDs.

Most alliances reported extensive preparations ahead of meetings with their government for advocacy purposes. For instance, the chairperson of the South African NCD Alliance's steering committee prepares briefing materials with input from its members. The steering committee then holds an in-person preparatory meeting and decides on meeting strategy and talking points.

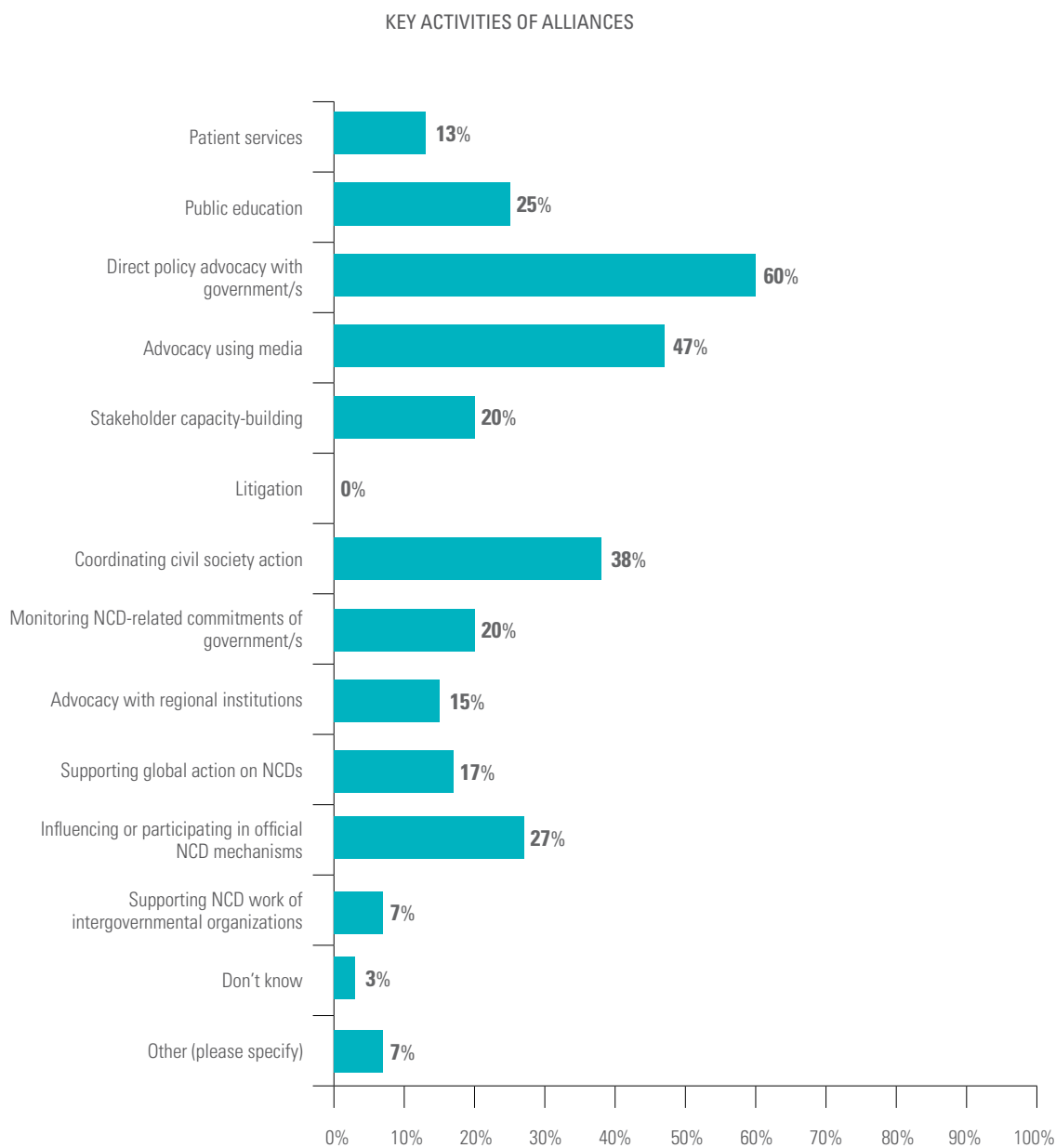


Fig 14.

Some alliances face the challenge of members misusing such opportunities to gain access to the government to advance the objectives of their own organizations rather than pursuing the shared goals of the alliance.

As part of the advocacy efforts, the alliances reported taking public positions on key NCD issues. Policy briefs on identified priorities seem to be the popular route to reach common positions. These papers are discussed extensively with members before the steering committee/board approves them. Thus, the German NCD Alliance prepared a paper on obesity, while the Zanzibar NCD Alliance developed a paper on essential medicines and a cancer registry to focus its advocacy on the two immediate priorities for the country.

Tobacco tax advocacy: winning strategies from Latin America

Several Latin American alliances, including those in Argentina, Brazil, Mexico, Chile and Colombia, have been consistently campaigning for increase in tobacco taxes – the single most effective measure to reduce tobacco use. Some alliances built on the opportunity of broader tax reforms in the country to make the case for tobacco tax increases, whereas others pitched it in the context of national financial crisis. The tobacco industry reportedly opposed the proposals overtly and covertly. Some winning strategies emerging from these campaigns are discussed below:

- Broad-based coalitions that consistently lobbied the diverse government agencies involved in tax increases;
- Economic analysis that examined tobacco demand, price and income elasticity and evaluated the existing tax structure led to the development of models to simulate the potential impact of policies and tobacco product affordability and the potential regression of fiscal measures in relation to vulnerable sectors, resulting in recommendations for tax scenarios and best practices that would ensure a reduction in consumption alongside revenue generation;
- Fact sheets produced for different categories of government agencies, decision-makers and the general public;
- Multi-target advocacy and policy dialogues with diverse government ministries and agencies. This included ministries of health and finance, departments that decide on revenue sharing across ministries, government expert commissions that develop evidence and guidelines for tax reforms, and the legislature, which enacts tax laws;
- Capacity-building workshops on tobacco taxation for legislators and policy-makers with nationally recognized academic institutes, international experts and international organizations such as the WHO and World Bank;
- Formal memoranda with recommendations and tax scenario models to expert bodies and ministries;
- Social media campaigns using Twitter, media advocacy and public demonstrations to build public support and mount pressure on policy-makers.

As a result, Brazil witnessed an annual increase in tobacco taxes from 2011 to 2015. In Chile, the excise tax increased significantly, resulting in a price increase of 20% as of March 2015. The country also changed its tax structure, reducing the ad valorem tax on tobacco products by 30%. In 2010, Mexico instituted 7 pesos of tax per pack of 20 cigarettes. This translated into a 25% increase in the price of the best-selling brand in the country. The Mexican alliance is currently trying to get the taxes adjusted for inflation. The Colombian alliance is expecting its tax proposal to be approved after the national election next year. While Argentina is yet to see a tobacco tax increase in recent years, the industry opposition indicates that the campaign has elevated the issue to the public agenda.

Policy briefs: a popular activity among alliances

A popular early activity among alliances across regions, income groups and legal status seems to be the development of policy papers on issues of common interest. The papers:

- Are a low-cost activity
- Work across alliance structures
- Allow for broad participation
- Draw on member expertise and goals
- Lead to agreed positions on issues
- Generate tools for advocacy
- Build credibility and influence with governments

Alliances engage a range of media strategies in their advocacy efforts. Some use mainstream media, such as newspapers and television. In most regions, alliances mentioned engaging NCD-affected people as spokespersons in such media programmes. The Nepal NCD Alliance has strategically included a journalist on its steering committee, resulting in media focus on NCD issues in the country's leading daily newspaper. Some of the African and Latin American alliances regularly use television programmes to broadcast their messages. Interestingly, several alliances, such as the Malaysian and ASEAN alliances, considered their launch to be a great occasion for media and public engagement. The German NCD Alliance benefits from communications expertise and assistance provided by the member organization that currently holds the position of chairperson in the alliance. Some alliances, such as the Mexican one, are social media-savvy. They used Twitter for their campaign to demand an increase in tobacco taxes.

Activities of alliances display a wide spectrum of strategies with diverse target groups. Some, such as the Bangladesh NCD Forum, have tried to generate local evidence on NCDs by advocating the inclusion of NCDs in national urban health surveys. Several of the LMIC alliances, such as the Nepal NCD Alliance, undertake training programmes for primary healthcare workers and nurses on primary and secondary prevention in remote regions so as to enhance the capacity of the public health system to respond to NCDs. Alliances across Latin America have undertaken campaigns to increase tax on tobacco and soft drinks. Some, like the Chilean NCD Alliance and Peruvian NCD Alliance, have been advocating the integration of NCDs in national health and development plans.

Dividends from working with non-health sectors: Peru's experience

The Peruvian NCD Alliance has been engaging with the country's ministry of foreign affairs and its offices in New York and Geneva regarding the global NCD and development agenda. Similarly, it has been liaising with Peruvian negotiators on the Trans-Pacific Partnership and firmly advocating a carve-out for tobacco in the agreement. In addition to influencing Peru's position on NCDs on global platforms, this has reportedly earned it recognition with the ministry of health and other sectors within the country.

The alliance now advocates the integration of NCDs on Peru's national development plans and the UNDAF. To this end, it is currently trying to expand and strengthen its own membership base by including NGOs working on the environment, agriculture, human rights, and women's rights.

Leveraging social media for NCD prevention

Social media can be an effective tool to reach a wider audience and policy-makers. In April 2014, the Frente por un Chile Saludable (Front for a Healthy Chile) – a coalition of civil society associations promoting healthy environments – launched a social media campaign to advocate a healthy tax reform. As a way of increasing awareness among key stakeholders, the coalition organized a “Twitterazo” (a Twitter storm).

For one-and-a-half hours, members of the coalition gathered at a moment of high activity on Twitter (in the case of Chile, Sunday between 9 p.m. and 10.30 p.m.) and tweeted and retweeted each other’s comments on Twitter. This was done three times during the campaign and results were recorded through prior registration of the hashtag on Symplur*.

During the period between 1 April and 31 October, the campaign received 13 million impressions, 6,900 tweets and 1,277 participants, with an average of five tweets per participant. More importantly, it engaged several politicians and members of parliament, who in later conversations acknowledged that they were aware of the campaign. It is noteworthy that the top influencer of the campaign was a member of parliament (with 584,000 followers) who engaged only a few times but, given his large number of followers, caused a great impact. His support had been arranged previously.

The success factors of this Twitter storm strategy include:

- Using a common hashtag that allowed participants to follow previous discussions and engage more actively;
- Having a group of at least 10 participants committed to tweeting actively for one-and-a-half hours;
- Preparing ready-made phrases and tweets with key information;
- Creating a list of Twitter accounts of senators and other key stakeholders;
- Engaging previously supportive politicians to help disseminate the tweets.



*Symplur is a social media analytics programme.

Government engagement

The relationship of alliances with their governments covers a broad spectrum. At one end, there are alliances such as the Healthy Caribbean Coalition, which, while working together with governments, prefer not to seek government funding so they can maintain independence for their advocacy and monitoring roles. This independent standing has been crucial to the HCC's major programme of work on the status of national NCD commissions in the Caribbean. Similarly, the Australian Chronic Disease Prevention Network received government funding in its early years but decided to operate independently through member resources.

At the other end of the spectrum are alliances such as the Bangladesh NCD Forum, which consciously includes a government representative on its advisory committee, or the Front for a Healthy Chile, which is run by the NCD focal point of the municipality of Santiago. Several alliances considered that the close involvement of government officials was helpful in opening doors within the government, thus facilitating advocacy. Others, such as the Consortium of Ethiopian NCD Associations and the Finnish NCD Alliance, align their programmes with government priorities, whereas the Australian Chronic Disease Prevention Alliance plays an "elder statesman" role vis-à-vis the government. 20% of the respondents reported that their alliances were receiving government funding (Figure 9). In LMICs, such funding tends to be ad hoc and for specific activities such as observing key NCD days. However, alliances in some northern countries, such as the Norwegian NCD Alliance, receive project funding from their government.

Given that responses to NCDs call for multisectoral actions, several alliances have managed to make inroads to the non-health sectors of government. For instance, several of the Latin American alliances working to address the obesogenic environment are in dialogue with their ministries of education and those advocating tobacco tax increases are in talks with the ministries of finance.

The Danish NCD Alliance has made exemplary progress in securing its government's support for action on NCDs internationally. After 10 months of detailed preparation and careful negotiation with the CISU, the Danish NCD Alliance has secured funding to advance NCD civil society action in East Africa.

The governments of Nigeria and Norway invited CSOs to provide input relating to the countries' position at the UNHLM, while Denmark and Finland had CSO representatives on the government delegations to the meeting in 2011.

Governments have engaged several alliances in their NCD governance structures and policy-making processes. For instance, the European Chronic Disease Alliance has been involved in devising the European Union Reflection Process on Chronic Diseases since 2010. As a result of its active involvement in the follow-up actions emanating from the Council Conclusions on Chronic Diseases and the EU Chronic Diseases Summit in April 2014, it has come to be seen as the main interlocutor on chronic diseases in the EU landscape. Similarly, NCD commissions in some of the Caribbean countries such as Barbados include CSO representatives, while government NCD committees in African countries such as Ethiopia and Rwanda include alliance members.

However, it is noteworthy that some respondents across Asia, Africa and Latin America indicated unwillingness on the part of their governments to involve CSOs. Advocacy with governments, as some would say, is a work in progress!

2. Achievements

Given that the global NCD civil society movement is in its nascent years, the emergence of a significant number of active alliances across regions in a short time span needs to be recognized as a major achievement in itself. The visibility and credibility several of these alliances have gained with their governments and other key stakeholders should also be recognized. Nearly two-thirds of the respondents considered the work of their alliances to have increased policy-makers' interest in NCDs. 57% said that their alliance had mobilized key CSOs in the country for collective action and 47% considered this to have led to greater involvement of civil society in government decision-making on NCDs.

Other achievements include increased media coverage (40%) and greater public interest (27%) in NCDs. The reported increase in domestic resource allocation for NCD prevention and control (20%) could be the result of increased advocacy with the stakeholders, including policy-makers, donors, CSOs and the media. There were other achievements that were reported to a lesser extent, but they can still be considered as steps in the right direction and include greater involvement of international partners (7%) and building skills in the area of NCD prevention and control (5%).

Despite limited resources, several alliances have made progress in advancing work on NCDs in strategic areas in their countries and regions. Their achievements range from building broad-based, functional alliances to developing policy briefs and model interventions, participating in government committees, securing prevention policies, monitoring government commitments and raising resources for NCD work internationally. Some of these are discussed below to illustrate the wide variety of outcomes of the work of the alliances.

Building civil society capacity

The annual conferences, webinars, workshops and the establishment of regional alliances by the Chronic Disease Prevention Alliance of Canada led to the creation of platforms that facilitated information exchange and mutual learning among its members. The Uganda NCD Alliance has channelled its resources to build the organizational capacity of relatively new members working on cancer and heart disease that do not enjoy government support. The Latin American alliances have formed a rapid response resource group of in-country experts to help the alliances in the region address urgent industry challenges.

Generating evidence for action

The Bangladesh NCD Forum's advocacy has led to the inclusion of NCD-related questions in the country's national urban health survey. This could potentially generate evidence for addressing NCDs as part of urban health and development initiatives. Advocacy by the Uganda NCD Alliance expedited the administration of the WHO STEPS survey, thus generating baseline data on NCD risk factors in the country. Separately, a recent study by the US NCD Roundtable tracked the US Government's investments in NCDs globally between 2010 and 2014, across all government departments. This study made the case for the US Government to increase its international financial and technical contributions to NCDs via USAID and multilateral agencies.

Raising the political will

The Mexican NCD Alliance effectively raised the political profile of NCDs through events involving candidates for the presidential and Mexico City Federal District legislature from different political parties during the country's elections. The Front for a Healthy Chile managed to get an MP with a considerable Twitter following to support its Twitter campaign for tobacco tax increases, which in turn enhanced the campaign's reach.

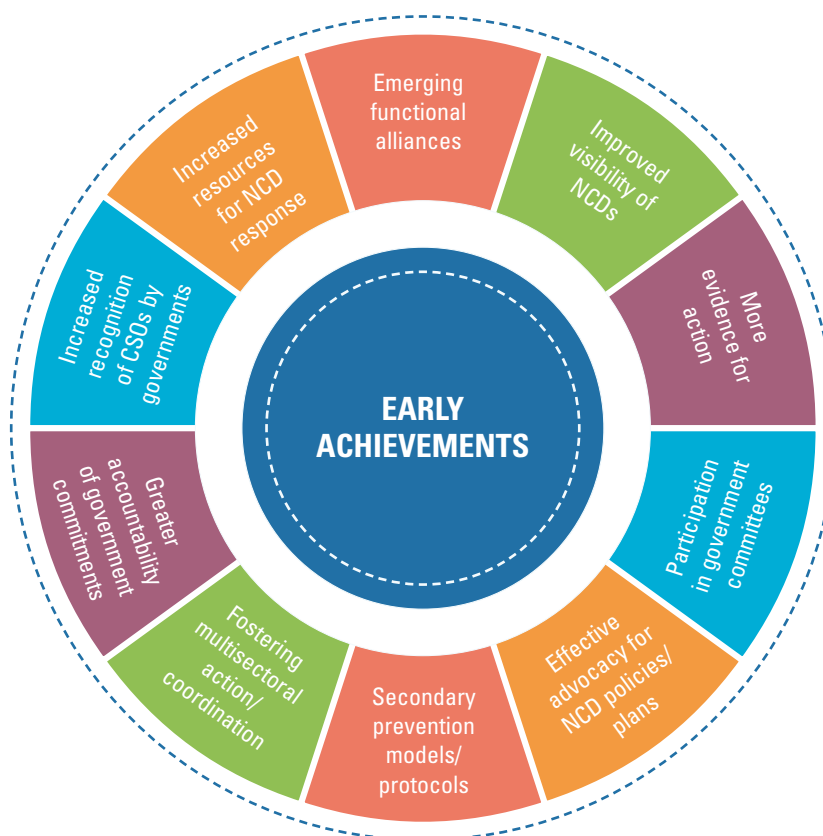


Fig 15. Achievements of alliances

Contributing to government committees

The Consortium of Ethiopian NCD Associations serves on several government committees and has secured a national cancer control plan under the national NCD plan. The European Chronic Disease Alliance’s advocacy with the European Union for a comprehensive European strategy and action plan on chronic diseases has earned it the position of interlocutor on chronic diseases in the European landscape. In Barbados, where CSOs form part of the national NCD commission, private sector entities with conflicts of interest do not dilute the country’s NCD prevention measures. The coordinated front of the Australian Chronic Disease Prevention Alliance has been consulted by the government on key NCD issues.

Getting unpaid media coverage

The alliances across the regions have earned free media coverage, particularly by leveraging the observation of key NCD days. The Nepal and Bangladesh alliances have secured free space for regular features and case studies on NCDs in leading national dailies. The German NCD Alliance’s release of its strategy document on NCD primary prevention earned much media coverage and several policy-makers began to use its core message (“Stop the Tsunami of NCDs”) as part of their own communications.

Securing NCD polices

A tobacco tax advocacy campaign by the Frente por una Reforma Tributaria Saludable together with its member organization, Chile Libre de Tabaco, helped reform the country's tobacco tax structure. The government reduced the ad valorem tax on tobacco from 60% to 30% and increased the excise tax by 12.8%, resulting in a price increase of 20% until March 2015. Similar advocacy by ACT+ led to an annual increase in tobacco taxes from 2011 to 2015 in Brazil. The Zanzibar NCD Alliance advocated and secured a cancer registry and subsidized essential medicines for NCD treatment in the country. The Finnish NCD Alliance actively contributes to the formulation of the national public health programme, as well as the integration of health promotion and prevention activities in the social services and healthcare plans of the government.

Building model interventions

Several of the African alliances have built prototype interventions for early diagnosis and healthcare interventions for comorbidities for replication by their governments. Thus, the alliances in South Africa, Zanzibar and Uganda have developed joint screening programmes for hypertension and diabetes, along with protocols for government use in health centres. The Nepal NCD Forum has developed model training programmes for community health workers on early diagnosis and prevention.

Fostering multisectoral coordination

The South Africa NCD Alliance organized a Health System Strengthening *Kopano* (meeting) of national and provincial health departments and other civil society stakeholders, which contributed to the deputy minister of health instructing inclusive and coordinated action among the national and provincial health departments and other stakeholders. Similar action by the Peruvian NCD Alliance has opened doors to the ministries of trade and foreign affairs on NCD matters.

Ensuring government accountability

The Healthy Caribbean Coalition produced a status report on the NCD commissions in the region and recommends measures for improving them. The HCC also produced a report monitoring the commitments of governments in the region as per the Port of Spain Declaration^f. The East African NCD Alliance Initiative's benchmark report on countries in the region has brought to light the major challenges and gaps in implementing their commitments in accordance with the WHO Global Action Plan on NCDs and led to the East Africa Civil Society NCD Charter, which calls for priority measures by all stakeholders.

Raising domestic resources

While the Zanzibar NCD Alliance engaged elected representatives to fund its screening camps, the South Africa NCD Alliance tapped provincial government resources to improve NCD health services for the community. The Norwegian NCD Alliance received government funding to run a campaign promoting physical activity. The Uganda NCD Alliance raised resources for hypertension screening camps through local marathons. The HCC organized a meeting with the private sector that identified its role in workplace interventions and local communities.

Mobilizing resources to support international work

The Danish NCD Alliance has successfully advocated and secured international development aid from DANIDA that has led to the formation and work of NCD alliances in East Africa. The US NCD Roundtable makes the case for the US Government to enhance its support to international work on NCDs.

^fThe Port of Spain Declaration by the Heads of the Caribbean Community in September 2007 laid a road map for governments in the region to combat NCDs. http://www.caricom.org/jsp/communications/meetings_statements/declaration_port_of_spain_chronic_ncds.jsp

C. Challenges and capacity needs

Young as the majority of the alliances are, they face common challenges and share similar capacity needs. These are discussed in detail here, along with potential initiatives to address the needs.

KEY MESSAGES

- Financial and human resource constraints were the greatest internal challenges of the alliances. Differing views about the private sector also appear to be a common challenge for alliances.
- Major external challenges of alliances pertain to the political and policy environments: competing national priorities, inadequate policies and poor implementation. Interference by industries with conflicting interests is also a challenge, most recognized in Latin America, Europe and Australia.
- Support for resource mobilization is a major area in which the alliances require capacity-building, followed by strategy and advocacy training.

1. Challenges faced by alliances

Internal challenges

Respondents identified a lack of financial (88%) and human (62%) resources as the primary challenges affecting their operation. Most alliances in LMICs without external funding are not staffed, which affected their functioning. A lack of technical expertise, poor coordination and an inability to attract non-health NGOs were reported in some cases.

Differing views on engagement with the private sector and addressing conflicts of interest were reported as challenges in some of the Latin American and Asian alliances. The involvement of politicians raised challenges in a number of alliances. Competing commitments of alliance leaders were also reported to slow down the decision-making and work of many alliances. The legal status did not make much difference to the nature of internal challenges facing the alliances. Notably, very few respondents mentioned the lack of formal structures as a constraint in relation to their work (17%).

External challenges

The major external challenges of the alliances pertain to the level of political commitment and the policy environment for NCDs within the country or region. Thus, competing priorities of governments (47%), inadequate government policies for NCD prevention and control (47%) and their poor implementation (57%) figured among the top challenges. These could be among the reasons for the respondents identifying actions involving governments (secure policies to reduce exposure to NCD risk factors, ensure civil society participation in government official NCD mechanisms and support development/implementation of national NCD plans) among the priority strategies for their alliance. As discussed earlier, they are beginning to see encouraging results in terms of increased willingness on the part of governments/policy-makers (62%) to engage on this issue. 17% of the respondents, mostly from Africa, Asia and Latin America, reported unwillingness on the part of government to engage with CSOs as a barrier to their work.

Interference by industries with conflicting interests was also reported as one of the top challenges facing alliances. Respondents from Latin America, Europe and Australia reported industry interference as a major challenge. Asian and North American alliances also find this an issue to some extent, while in Africa this is not perceived as a major challenge.

Private sector involvement

Alliances seem to have varying positions on the involvement of the private sector. Some, such as the Malaysian NCD Alliance, have a written policy on conflict of interest and accept resources only from private sector companies with no direct conflict of interest such as banks. Tobacco and alcohol companies are excluded by most alliances. One of the European alliances excludes organizations receiving pharmaceutical funding from its meetings, but involves them in activities. They also do not partner with food companies, although they might enter into dialogue with them. Others, such as the US NCD Roundtable, Healthy Caribbean Coalition and Nigerian NCD Alliance, allow pharmaceutical companies membership and access to meetings (often as non-voting observers), and are open to pharmaceutical funding.

The involvement of the private sector was reported as a matter of intense debate in several alliances in Latin America. Association with food and beverage companies has been entertained less and some alliances, such as the Healthy Latin America Coalition, have expelled members for associating with such companies. Alliances across regions expressed interest in receiving guidance on addressing conflicts of interest arising from partnerships with the private sector. It is worth exploring in any future research whether openness to private sector funding is related to the nature of the alliance members, for instance, whether those led by disease-specific groups and medical professional bodies are relatively at ease with private sector involvement, and whether those with members working on NCD risk factors such as tobacco, alcohol and unhealthy food (promoted by certain industries) are less certain to engage with the private sector.

Few specific examples of industry interference were provided by alliances. However, the Healthy Latin America Alliance reported significant pressure on some of its member alliances from the food and beverage industries. The HCC raised concerns about addressing the potential conflict of interest the private sector representatives on national NCD commissions in the region brought to those platforms.

Notably, industry interference is indicated by the highest proportion in the HIC category and a sizeable proportion of upper-middle-income alliances, whereas respondents from LMICs hardly mentioned it (Figure 16). This is more or less in line with the trend in prioritization of countering industry interference among alliances by country income discussed earlier. The respondents also identified certain uses of the bilateral and multilateral trade and investment agreements as a challenge to advancing work on NCDs. This gains significance in the context of several such agreements currently under negotiation between countries and regions that could potentially include provisions that aggravate the NCD epidemic across the world.

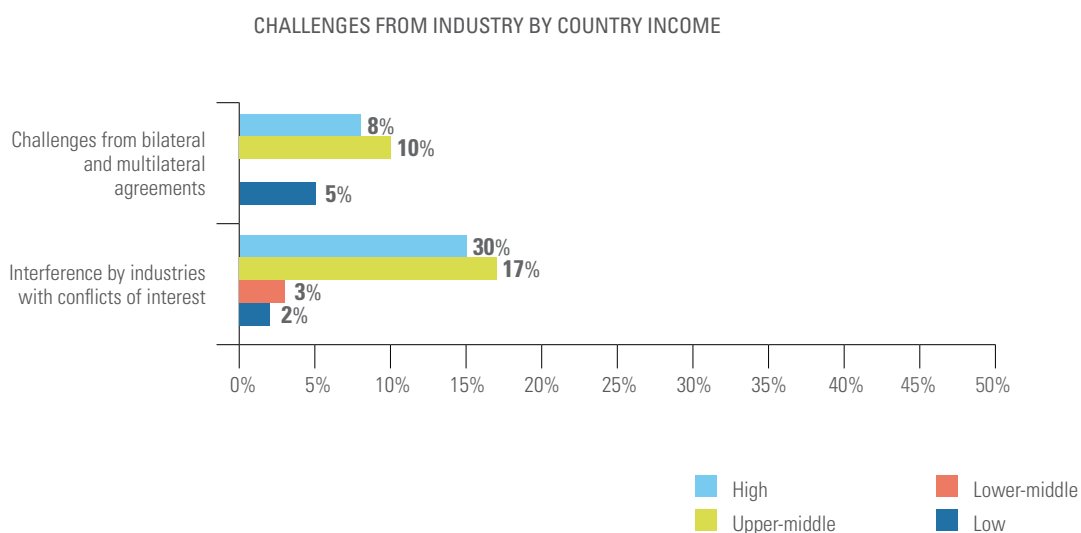


Fig 16.

2. Capacity needs of alliances

Capacity needs

Over two-thirds of the respondents indicated resource mobilization as their most important capacity need (Figure 17). Respondents from Latin America in particular articulated this need in more numbers. This resonates with the identification of lack of resources as one of the major internal challenges of the alliances. In addition, over 40% of the respondents signalled the need for capacity-building in strategy and advocacy planning, followed by training to run an effective coalition and technical and information support in a host of NCD interventions. The respondents from Asia, Africa and Latin America expressed the need to be trained in running effective alliances to a greater extent than their counterparts in other regions.

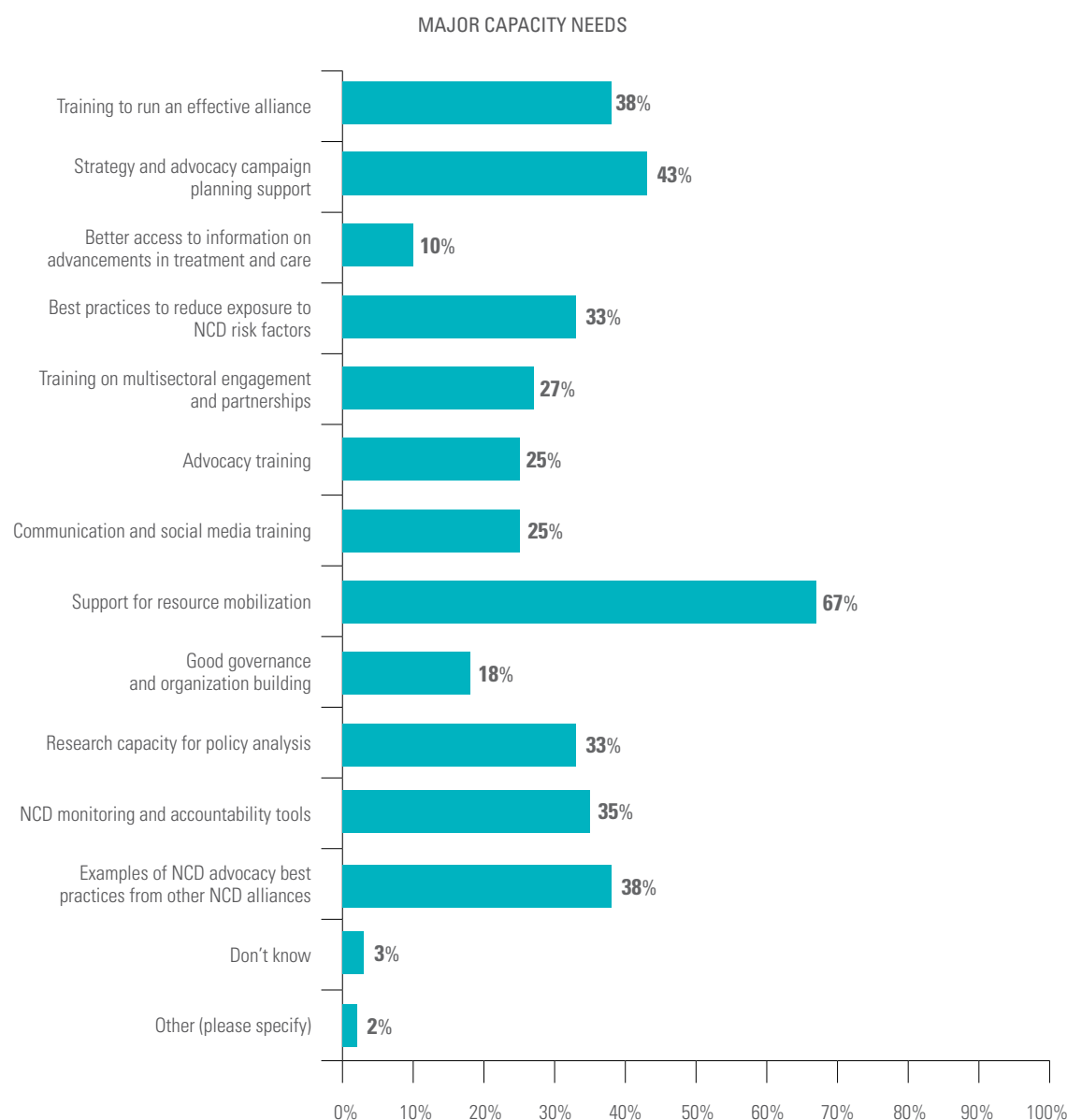


Fig 17.

3. Initiatives to build the capacity of alliances

As action on NCDs is shifting from global political commitments to commitments on national and regional levels, strengthening the capacity of NCD CSOs is critical to stimulate government action on NCD prevention and control and ensure public accountability for NCDs. The survey highlights major areas for investment in NCD NGO capacity-building which are insightful for NCDA's future work and that of other international organizations.

The survey respondents identified access to capacity-building grants as well as regular global gatherings as the most beneficial initiatives that could enhance their work (57% respectively). The high preference for capacity-building grants holds true for respondents from all regions except Australia (Figure 18). The grants could potentially help address the reported major internal challenge of lack of resources, the major external challenge of poor government response to NCDs and the most identified capacity need of greater support for resource mobilization discussed earlier. In the same vein, a regular global forum could provide a platform to address the internal challenge of lack of technical and advocacy expertise and the broad range of capacity needs identified earlier.

An information-sharing platform figured high in both the survey (50% of respondents) and interviews as a means to share experiences, tools and best practices. One interviewee suggested that NCDA could build and share a "taxonomy of knowledge," organizing and disseminating knowledge acquired from alliances around the world. Some of the resources and tools shared by alliances for this situational analysis could also be shared through such a repository.

Some LMIC alliances recommended that the NCDA summarize new science for NCD advocates. This is in line with the capacity need expressed by low-income countries for better access to information on treatment and care. This needs to be viewed in light of the fact that most alliances in LMICs will not have resources to access scientific and medical journals. A science bulletin could be a useful value addition to the NCDA weekly news updates.



Potential resource tools for new alliances

1. Alliance start-up kit
2. Work plan and budget template
3. Guidance to identify common issues
4. Guidance to develop common position papers
5. Communication and branding guidelines
6. Repository of resource opportunities



On 9-10 July 2015, the WHO South East Asia Regional Office and the NCD Alliance hosted the first-ever regional meeting for NCD civil society bringing together 95 participants from 9 of the 11 SEAR countries.

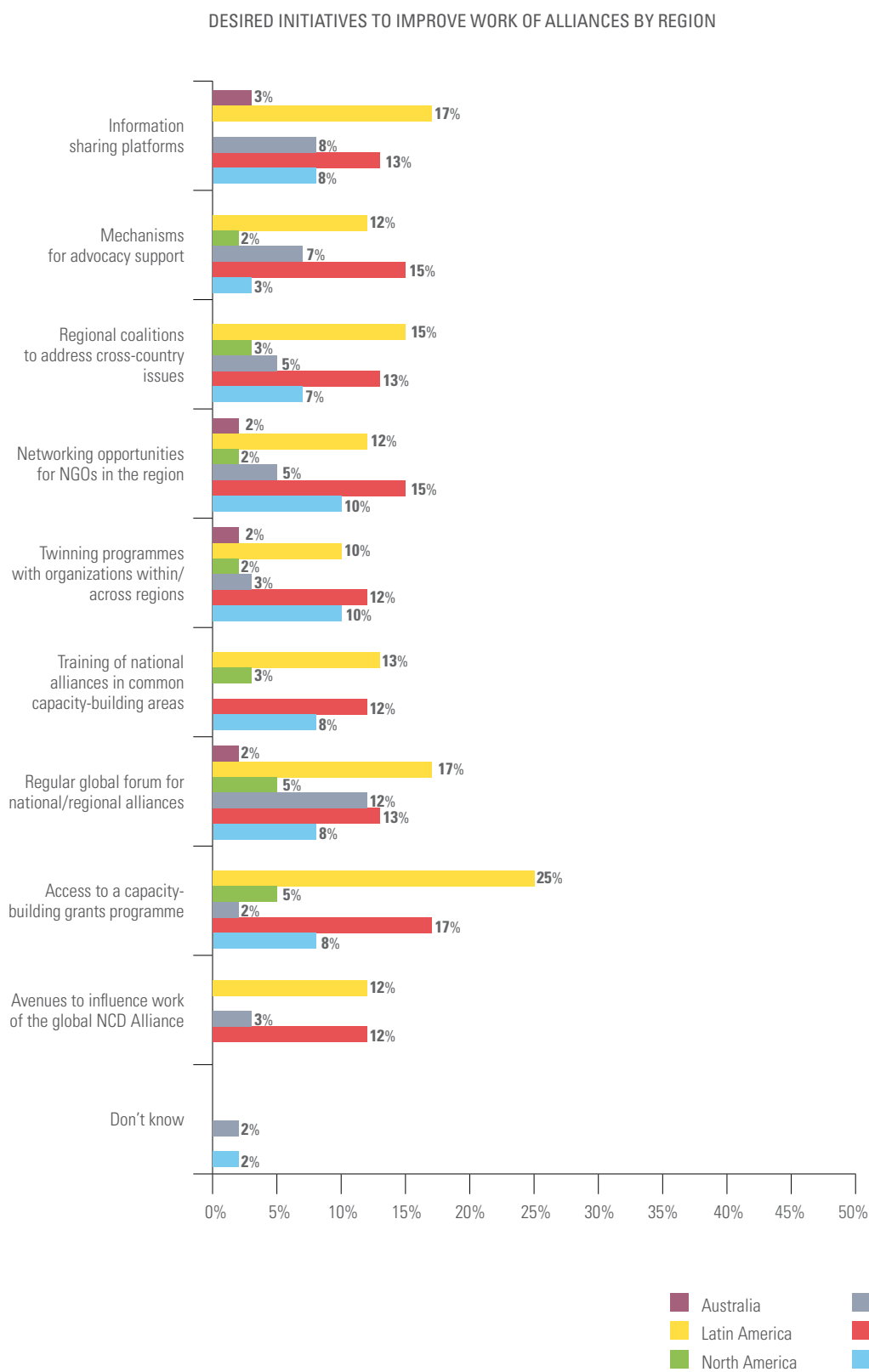


Fig 18.

D. Interaction between national, regional and global NCD alliances

The global NCD civil society community is dynamic, in that national alliances interact among themselves as well as with regional alliances and NCDA and its federations at the global level. The opportunities for strengthening national, regional and global interaction are explored herein.

KEY MESSAGES

- **NCDA webinars and e-mail updates are the main source of information on global NCD developments for the alliances. These require adaptation to country contexts.**
- **Alliances desire a closer association and role in NCDA governance and policy positions. They see a role for NCDA in providing tools and NGO capacity-building and supporting the development and implementation of projects at national and regional levels.**
- **A platform for the exchange of lessons, best practices and tools among alliances of comparable backgrounds and interests is essential and could be ensured through regular regional meetings and global forums.**

1. Interaction between NCDA and the alliances

Across the board, alliances expressed appreciation for the input from NCDA in terms of e-mail and web updates and webinars on global NCD developments. Several interviewees referred to these as their main source of information on NCD issues and events. The Bangladesh NCD Forum reported using these updates in turn in its newsletter. Spanish-speaking alliances expressed a keen interest in receiving such input in their language. French-speaking alliances mentioned their inability to share NCDA resources in their networks due to language barriers. It would be worth exploring updates in these languages for the wider use of NCDA resources. Some alliances also suggested that personalizing e-mail updates and requests and translating the implications of global events into the local context could attract greater attention and improve their utilization.

Alliances reported a range of matters on which they have interacted with the NCDA team. Overall, there is appreciation of the team's work and efficiency in raising the profile of NCDs across several global platforms. Some alliances, such as the ASEAN NCD Alliance, sought and received advice from the NCDA in forming their alliances and setting up governance structures. Alliances in Brazil, South Africa and the Caribbean have received grants from NCDA and were appreciative of the support from the NCDA team for project implementation. Sensitivity to local realities and needs was suggested to guide such projects in the future. Some alliances were encouraged by NCDA to raise resources and undertake twinning programmes, while others organized joint events with NCDA. A few alliances mentioned that they had not had any personal interaction with the NCDA team.

Over half of the respondents thought it would help to have a dedicated member of staff within the NCDA team solely to coordinate work with national/regional alliances and the NCDA team. An equal number asked for improved communication channels to share successes, challenges and needs across national/regional alliances. 52% expressed an interest in increased opportunities to inform the NCDA position on global policy issues. This was followed by about 35% who sought information and communication tailored to the local context and about 25% who desired greater clarity on the roles and relationship of the global and local alliances.



Public health advocates speak out against ultra-processed food industry in México.

Apart from NCDA, several of the alliances share close ties with one or more of the federations that constitute the NCDA Steering Group. The survey indicates that this is mostly through alliance members who in turn are members of the federations. The federations introduced some of the alliances and NCDA; in other instances, NCDA introduced in-country members of federations to form national and regional alliances. Some alliances reported that the cooperation between the federations on the NCDA Steering Group inspired them to either model their coalitions along similar lines or seek the participation of in-country members of federations in the national or regional alliances. A few alliances reported carrying out joint activities with NCDA and one or more of the federations, such as co-hosting an event or developing joint resource materials. Some thought that the partnership between NCDA and its federations has the potential to bring about greater synergy between members of the federations in countries, and suggested conscious action by NCDA and federations to foster such efforts.

NCDA capacity-building programme

Expanding Access to Care, Supporting Global, Regional and Country Level NCD Action programme launched in 2013 in partnership with Medtronic Philanthropy, currently works with alliances in Brazil, South Africa and the Caribbean to enable civil society to play its critical role in NCD advocacy. India was added to the programme in 2015.

The programme focuses on strengthening NCD advocacy to hold governments accountable for their commitments, civil society coalition building, promoting a multisectoral approach to NCD prevention and control, promoting a health system strengthening approach, and promoting patient engagement in NCD advocacy.

The programme has led to the formation of national alliances in Brazil and South Africa. It pioneered a method of civil society monitoring via a benchmark tool and the production of national/regional civil society status reports on NCDs. The advocacy activities under the project have attracted multisectoral partners to the alliances and earned them greater credibility and access to government decision-making. The programme has also created tools that are available more broadly to the global NCD community, including an advocacy toolkit and NCD benchmarking tool.

2. Relationship between NCDA and the alliances

Strengthening the relationship with NCDA

Over the years, NCDA and the alliances have evolved various channels of communication and partnership. NCDA is seeking ways to create more avenues for cooperation with the national and regional alliances. The alliances have reciprocated, with over three-quarters of the respondents indicating an interest in an official affiliation scheme with NCDA. The interviews reflected the interest among alliances to understand the scope and implications of such an association.

Role in NCDA decision-making

The survey analysis indicates that the respondents from Latin America, Africa and Europe to a limited extent are interested in engaging with the work of the global NCDA. Several alliances, mostly in LMICs, expressed a desire to have a role in NCDA governance and decision-making. Some felt that such a participatory approach within its Steering Group would strengthen NCDA's role as a true representative of global NCD civil society.

Others felt that the national and regional alliances have a broad range of partners beyond those belonging to the federations on the NCDA Steering Group, which should be reflected in NCDA's governance structure. One of the suggestions was for NCDA to hold elections among national/regional alliances, as done by many of its existing Steering Group members within their respective federations. Many interviewees expressed the need for inclusion of national and regional alliances in the strategic planning process of NCDA and also greater access and involvement in the development of its positions on global policy issues.

Potential role of NCDA at national level

Most respondents saw a significant role for NCDA in providing information and tools to support national advocates (63%) and capacity-building of the national and regional alliances (60%). In relation to the latter, respondents expressed a need for capacity-building mainly in the areas of fundraising, strategy planning and advocacy skills as discussed earlier. 57% of respondents indicated a role for NCDA in supporting the development and implementation of projects, national NCD plans (55%) and formation of national and regional alliances (30%).

While the respondents across most income groups expressed a range of roles for the global alliance at the national/regional levels, very few from LMICs envisaged a role for NCDA in supporting their formation (see Figure 19). The interviews also confirmed that LMIC national alliances tend to draw less on NCDA input in their formation and governance matters, except when they have strong international contacts. This could be partly because of their lack of awareness about the tools and support NCDA offers in forming national alliances. Better promotion of tools and the available guidance could support alliance building in low resource settings.

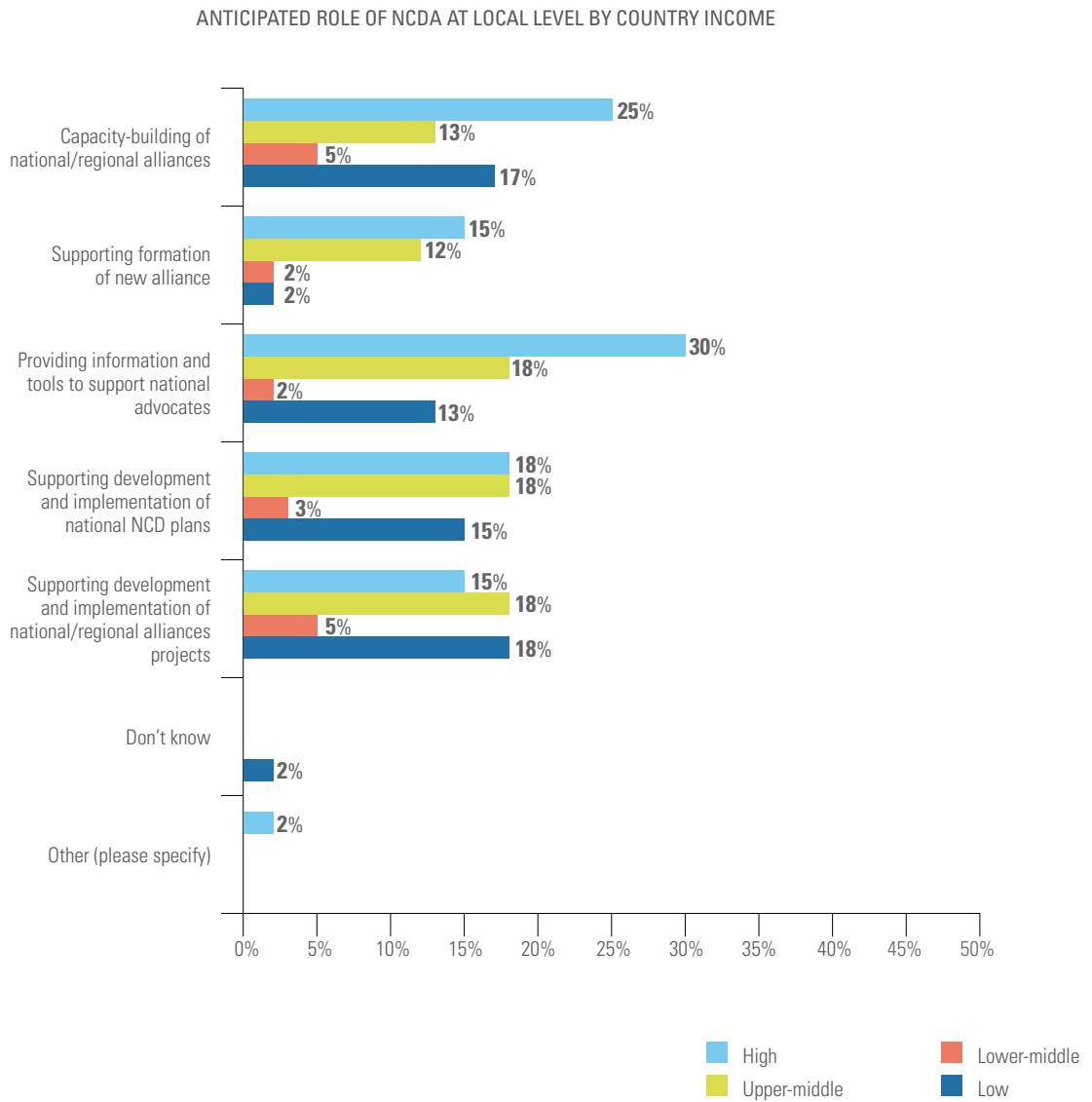


Fig 19.

3. Interaction among national/regional alliances

Some alliances mentioned having heard about the existence of others in the region, particularly in Latin America. However, most were not familiar with the details of the work of their counterparts in other countries, but they expressed much interest in learning about their experiences and sharing tools and best practices. The interest in such exchange was qualified to be beneficial when arranged with alliances of comparable backgrounds. Most interviewees envisaged the Global NCD Alliance Forum in Sharjah as an opportunity for networking and learning among alliances. The regional preparatory meetings ahead of the forum have proved to be a platform that has forged ties between NCD CSOs in countries and regions.

Some of the ongoing partnership programmes have also created channels for communication and exchange among partners. A case in point is the East Africa NCD Alliance Sustainability Initiative, whose members mentioned learning from each other's experience to improve their own efforts and engage in collective action. NCDAs in-country capacity-building programme has helped to create common platforms and alliances for organizations working on NCDs in Brazil and South Africa and helped to convene the Caribbean community. The NCD-UNDAF Integration Programme of the Framework Convention Alliance has similarly created a learning and advocacy community in Colombia, Peru and Uruguay in Latin America and three countries each in Anglophone Africa (Ghana, Kenya and Tanzania) and Francophone Africa (Chad, Côte d'Ivoire and Burkina Faso).

Twinning programmes

In recent years, alliances in different countries have embarked on partnership programmes to enhance action on NCDs. For example, the Danish NCD Alliance has worked with organizations in Uganda, Tanzania and Zanzibar, leading to the emergence of national NCD alliances and, more recently, the region-wide East Africa NCD Alliance Initiative.

The NCDAs were keen to learn if there was interest in similar twinning programmes between alliances. Some welcomed the idea, whereas others wanted to know whether the intention was to exchange ideas, technical resources or funds, or all of these things. By and large, the LMICs were more interested in exploring such partnerships.

While most suggested partnerships to be set up between alliances of comparable backgrounds (north-north and south-south), a few thought it would be good to have south-north partnerships. One thought that it would work in the same way the Danish NCD Alliance works with alliances in East Africa and build many more such collaborations. One particularly interesting suggestion was to form clusters of NCD alliances from similar backgrounds and interests, such as south-south cooperation, which eventually could come together to undertake specific funded projects. HIC alliances were interested in establishing contacts only with others with similar backgrounds.

Interviewees were asked about their interest in similar twinning programmes between alliances. Some welcomed the idea, whereas others wanted to know whether if it was meant to exchange ideas, technical resources, funds or all of these things. By and large, LMICs were more interested in exploring such partnerships.

Interestingly, the Healthy Caribbean Coalition had name recognition in most regions. Alliances in Latin America also seem to be aware of each other's work and even coordinate on campaigns and issues. This was attributed largely to the existence of two active networks (Healthy Latin America Coalition and Healthy Caribbean Coalition) that are bringing the national partners together. The Latin American experience accentuates the role of inclusive regional alliances in supporting NCD movement building in countries and facilitating action across countries, thus presenting a model for other regions.

Some of the African alliances were also inspired by work in neighbouring countries such as in East Africa. For instance, the Burundi NCD Alliance said that its interaction with alliances from other countries in the region gave it insight into the broader NCD concerns and a sense of belonging to a community beyond its borders. The participants at the regional meeting of African NCD alliances were hopeful that the momentum would spread from East to West Africa, and eventually the entire African continent.

Regional meetings: a launchpad for the alliances

The NCDA and partners organized a series of five regional preparatory meetings ahead of the Global NCD Alliance Forum in November 2015. The meetings brought together CSOs working on NCDs in countries within specific regions to form a common platform to take stock of their current work, identify gaps and determine priorities for joint action at national and regional levels. The meetings were organized in the Caribbean, Latin America, the WHO SEAR, the EMR and Africa and witnessed the emergence of several national and regional alliances.

Following the Civil Society Preparatory Meeting in the Caribbean in June 2015, NCD-related CSOs in Trinidad and Tobago launched a national alliance to coordinate advocacy and outreach activities and build the capacity of NGOs to effectively monitor the implementation of the government's global and regional commitments. In the short span of three months, its founding members have held three meetings and agreed on a strategic management framework. A working group to develop a governance structure and procedures was established and will present a draft charter to the alliance's founding members at the next meeting. At the formal launch, to take place in the latter part of 2015, the first year's work programme will be presented. Belize, in the Caribbean, is also in the early stages of forming a national alliance.

The Latin America meeting the same month resulted in CSOs in Argentina and Colombia formalizing their national NCD alliances, Bolivia strengthening its tobacco control alliance and embarking on forming an NCD alliance, and Peru reactivating its alliance.

Since the SEAR meeting in July 2015, an alliance has been formed in the Maldives, Bangladesh and Sri Lanka, and a fourth network is under discussion in India. The Sri Lankan NCD Alliance is currently developing its constitution and a road map of activities.

The Saudi NCD Alliance was formed at the EMR regional meeting in August 2015 and has already developed its governance structure and a website (<http://www.sncda.com/>). Egyptian organizations are also making efforts to form an alliance, as are those in Lebanon. A regional platform for the Middle East is also expected to emerge in the near future.

The Africa meeting has led to the formation of the Africa NCDs Network and strengthened cooperation in the sub-regional alliances, including East Africa. Similar meetings are being planned for the WHO European and Western Pacific Region in early 2016.

Women and girls participate in a free public yoga class held every morning in Yangon, Myanmar



IV. IMPLICATIONS FOR ACTION

The situational analysis highlights the significant number of national and regional NCD alliances that have emerged in the past five years around the world. It is notable that many alliances formed in the lead-up to or around global political milestones in the NCD response such as the 2011 UNHLM and the SDGs, reinforcing the importance of global advocacy to catalyze momentum at all levels. Whilst many are relatively new, it is clear that these alliances are playing an important role in stimulating government action on NCDs. By providing a platform for coordinated advocacy, they present a unique opportunity for progressing the NCD response in terms of both prevention and control.

The findings of this report demonstrate that the alliances are extremely diverse. No two alliances are the same, and therefore no entirely uniform approach can be formulated for working with them. The differences between alliances in HICs and LMICs are particularly stark, with often-differing priorities and different organizational arrangements. For this reason, facilitating opportunities for south-south and north-north cooperation, as well as north-south cooperation, will be important for strengthening the network.

Despite the fact that the movement is relatively young, the report identifies a wealth of good practices within alliances, ranging from governance and management to advocacy, information exchange and accountability. Most alliances have been successful in engaging key civil society partners, influencing government decisions, and supporting the development of NCD policies. Areas that have had less traction to date include the involvement of CSOs in government NCD mechanisms, CSO monitoring of government commitments, and engaging with non-health actors for advocacy efforts. There is a clear demand for improved mechanisms and platforms to share experiences and good practices between and across alliances, to avoid reinventing the wheel and to create a stronger community of practice.

To further strengthen this network of alliances, particularly in LMICs, this report brings to the fore a series of important capacity-building needs that should inform future initiatives by NCDA and other international and regional partners in the field of NCDs. These include coalition building, strategic planning and campaign planning, resource mobilization strategies, and working with the private sector. For these reasons, the Global NCD Alliance Forum in Sharjah in November 2015 is extremely timely, but it should be viewed as the beginning of a longer-term strategy for the in December of CSO alliances. Furthermore, a number of external factors are highlighted by alliances, such as poor implementation of national NCD plans and policies, which are also notable for a wide range of stakeholders committed to advancing the NCD response.

In summary, the following recommendations are made to advance the network of national and regional NCD alliances:

For national and regional NCD alliances

1



Establish governance structures for alliances that are manageable and fit for purpose.

2



Create avenues for engaging a broad range of civil society stakeholders, including patient groups and non-health actors, that are relevant to reaching the alliance goals.

3



Assess local needs, develop strategic plans and resource mobilization strategies to guide the work of the alliance.

4



Accelerate efforts to monitor government commitments to NCDs and advocacy for the inclusion of civil society in national/regional coordinating mechanisms.

5



Prioritize and advocate policies and programmes that maximize outcomes given the limited resources.

6



Identify and advocate sustainable sources of funding for civil society action.

7



Explore opportunities to learn from the experiences of other alliances and lend mutual support to newly forming alliances.

8



Actively contribute to the development of NCDA global policies and positions.

For partners (multilateral/bilateral/ government agencies)

1

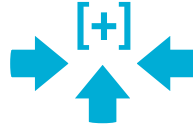
Enhance financial and technical support to CSOs as a means to strengthen and monitor the national response to NCDs.

2

Consider local culture, needs and priorities while determining the areas for support.

For the NCD Alliance

1



Prioritize support for the formation of alliances in LMICs.

2



Develop platforms for shared learning and information exchange among national and regional alliances.

3



Explore ways to formalize relationships and lend credibility to the work of alliances at national and regional levels.

4



Develop a long-term strategy to address the needs of national and regional alliances, including capacity-building initiatives on alliance building, strategic planning and campaign planning, communication and resource mobilization plans.

5



Adapt communication to translate global policy developments into the local context and languages, starting with French and Spanish.

6



Develop guidance on engagement with the private sector and addressing related conflicts of interest.

7



Create avenues for the alliances to inform the plans, positions and decisions of the NCD Alliance.

3

Promote CSO participation in government decision-making bodies, such as multisectoral NCD committees and coordination mechanisms.

4

Draw on civil society expertise in shaping NCD policies, plans and programmes.

5

Develop resources and opportunities to enhance CSO capacity in advocating and monitoring implementation of NCD commitments by governments.

Annexes



Annex 1

List of national and regional NCD alliances participating in the situational analysis.

National alliances

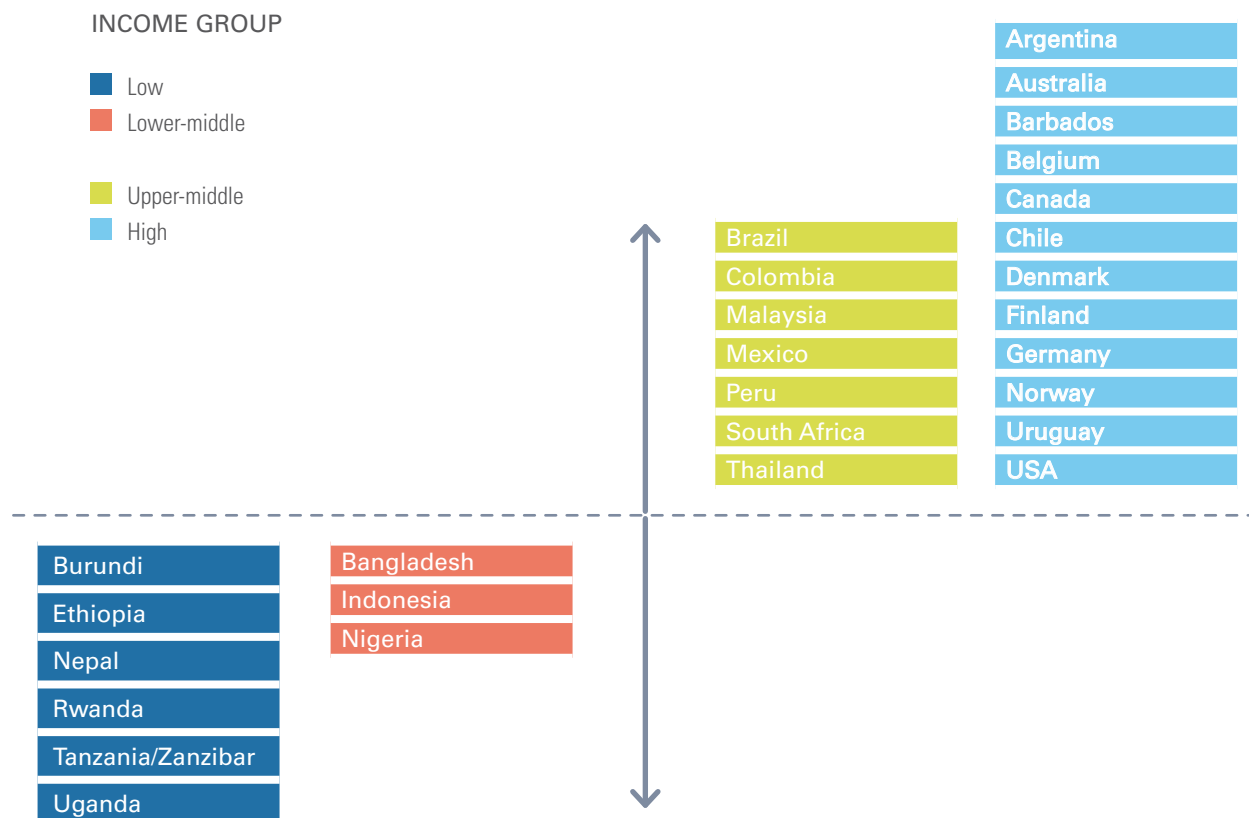
1	Argentina	NCD Alliance Argentina	2015
2	Australia	Australians for Action on Chronic Disease	2000
3	Australia	Australian Chronic Disease Prevention Alliance	2003
4	Bangladesh	Non-Communicable Diseases Forum (NCD-F)	2011
5	Brazil	ACT+	2013
6	Burundi	Burundi NCD Alliance	2014
7	Canada	Chronic Disease Prevention Alliance of Canada	2002
8	Chile	Frente por un Chile Saludable	2014
9	Chile	Alianza Chilena de Enfermedades No Transmisibles	2014
10	Colombia	NCD Alliance Colombia	2015
11	Denmark	The Danish NCD Alliance	2010
12	Ethiopia	Consortium of Ethiopian NCD Associations	2012
13	Finland	Finnish NCD Alliance	2014
14	Germany	German NCD Alliance	2011
15	Indonesia	Indonesia NCD Alliance	2011
16	Malaysia	Malaysian NCD Alliance	2013
17	Mexico	México Salud-Hable	2012
18	Nepal	NCD Alliance-Nepal	2014
19	Nigeria	Nigerian NCD Alliance	2010
20	Norway	The Norwegian NCD Alliance	2010
21	Peru	NCD Alliance Peru	2011
22	Rwanda	Rwanda NCD Alliance	2013
23	South Africa	South African NCD Alliance (SANCDA)	2013
24	Uganda	Uganda NCD Alliance (UNCDA)	2010
25	USA	NCD Roundtable (NCDRT)	2011
26	Uruguay	National Alliance for the Control of NCDs	2011
27	Zanzibar	Zanzibar National NCD Alliance (Z-NCDA)	2013

Regional alliances

1	ASEAN	ASEAN NCD Alliance	2015
2	Caribbean	Healthy Caribbean Coalition	2008
3	Europe	European Chronic Disease Alliance	2010
4	Latin America	Healthy Latin America Coalition	2011

Annex 2

World Bank classification of countries used in the survey analysis



Annex 3

Questionnaire of the NCD Alliance survey of national and regional alliances

1. What is the full name of your national/regional NCD alliance?
2. What is the name of your own organization?
3. If yours is a national NCD alliance, please state your country
4. If yours is a regional NCD alliance, please state your region
5. Are you responding to this survey as ... lead contact for your alliance or a member?
6. Does your national/regional alliance have a website?
7. In which year was your national/regional alliance formed?
8. Is your national/regional alliance a legal entity such as a registered charity or company?
9. Is your national/regional alliance open to individual members?
10. What is the total number of member organizations in your national/regional alliance?

Questions 11-16 are about the types of organizations that are members of your alliance.

17. How many organizations (not individuals) are members of your national/regional alliance?
18. How is the work of your national/regional alliance funded?
19. What are the major factors that led to your organization to form/join your national/regional alliance?
20. What are the major issues that your alliance focuses on?
21. What are the major activities of your national/regional alliance?
22. How does your national/regional alliance seek to engage patients in its work?
23. What do you consider are the TOP 3 early achievements of your national/regional alliance's efforts?
24. What are the major priorities for your national/regional alliance for the next five years?
25. What are the major capacity needs of your national/regional alliance?
26. What do you consider are the major internal challenges to achieving your national/regional alliance's priorities?

27. What do you consider are the major external challenges to achieving your national/regional alliance's priorities?
28. What major improvements do you suggest for better collaboration between national/regional alliances and the global NCD Alliance?
29. What kind of initiatives could enhance your national/regional alliance's work on NCDs?
30. What role do you think the global NCD Alliance can play at the national/regional level?
31. Would you be in favour of an official affiliation with the global NCD Alliance for national/regional alliances?
32. Please provide any other brief comments you think would help the global NCD Alliance better understand how your national/regional alliance works and how the relationship with the global NCD Alliance can improve.
33. Please indicate any international federations that your own organization is affiliated with.
34. In what ways does your organization contribute to the work of your national/regional alliance?



 NCD Alliance, 2015

Edited by NCD Alliance

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