

# NCD Alliance Review

**Final Report**

April, 2012

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# Background

*The Ahimsa Group was commissioned by the NCD Alliance to conduct a review of the Alliance's performance and to gather feedback on future priorities and direction. The review was conducted between December 2011 and March 2012 and included electronic surveys and in-depth interviews with respondents.*

This report summarizes key findings of the NCD Alliance Review. We note that the interviews and survey responses were rich and candid and key informants were particularly open and thoughtful in their remarks. In addition, the key informants were, overall, supportive of the Alliance's work to date and all wished the NCD Alliance future success in its endeavors.

## The review focused on three major themes:

- 1) Evaluation of the performance of the NCD Alliance leading up to the United Nations High-level Meeting on Non-Communicable Diseases (UN Summit), held in September 2011 to determine the Alliance's:
  - *Success influencing the UN Summit on NCDs*
  - *Ability to coordinate with multiple stakeholders on messaging and actions leading up to and during the UN Summit*
  - *Performance in sharing information on UN/World Health Organization (WHO) processes, statements, and actions on NCDs.*
- 2) Interviews with key informants to gather feedback on the NCD Alliance's future direction as a civil society organization, post UN Summit. The informants were asked to comment on future goals and activities of the NCD Alliance relative to the Political Declaration and outcomes of the UN Summit.
- 3) Interviews on potential structures, including governance structure of the NCD Alliance.

## Electronic survey and in-depth interviews

The Ahimsa Group, in discussion with the NCD Alliance Steering Group members and the Secretariat, developed an electronic survey and identified a slate of key informants for in-depth interviews. The electronic survey was sent to the Common Interest Group (CIG) members and the Partners Group of the NCD Alliance.

The in-depth interviews were conducted by telephone, were confidential and primarily focused on the Secretariat, Steering Group, Partners Group, Supporters Group and selected individuals who asked for an interview based upon the electronic survey.

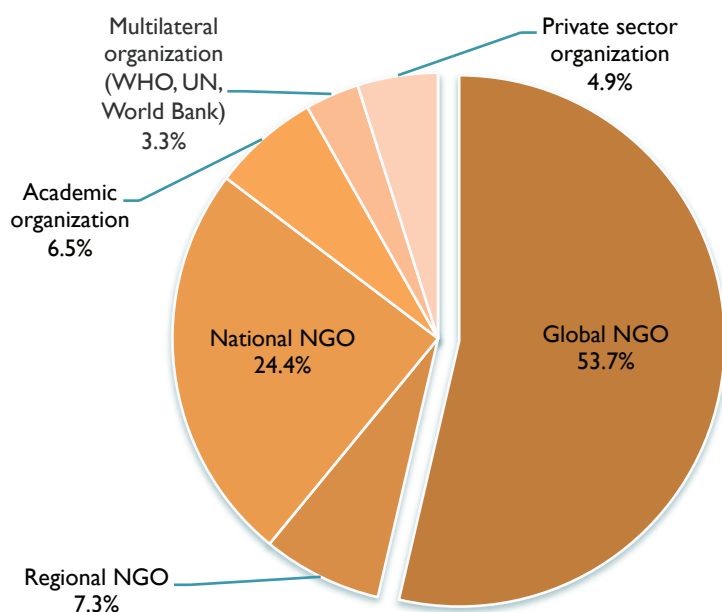
In-depth interviews with key informants	
NCD Alliance staff and federations	16
Supporters Group	6
Partners Group	17
Working Groups	5
Others (WHO, NCD experts)	7
<b>Total interviews</b>	<b>51</b>

# Electronic Survey

The electronic survey was sent to approximately 300 members of the NCD Alliance network. As of February 26, 2012, there were 132 responses (44%). This response rate is low, despite two reminders sent to non-respondents. The survey was designed to elicit a “snapshot” view of members’ thoughts about the Alliance’s overall performance and future direction. The survey was also intended to give an opportunity for CI&G members to provide feedback on the Alliance’s performance and future direction as well as to provide input on potential governance and management structures for the Alliance.

*Note: The results of the entire survey and written responses can be downloaded at [www.ncdalliance.org/Review](http://www.ncdalliance.org/Review). Please note that the electronic survey is a topline review and not necessarily representative of all partners of the NCD Alliance.*

**Table 1: Demographics of respondents**



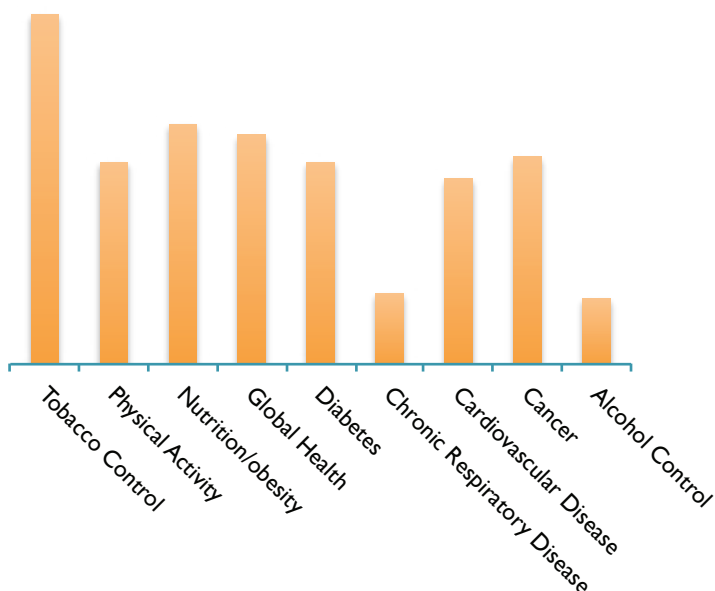
## Demographics of respondents

- o The survey respondents were predominately from North America (32%) and Europe (37%).
- o Fifty-four percent of respondents indicated that they were from a Global NGO vs. only 24% from a National NGO (Table 1).

## Primary focus of respondents interest

Survey respondents were asked to identify their area of health interest. Over 50% of survey respondents identified tobacco control, followed by nutrition (35%) and finally, global health (34%). We surmise that the dominance of tobacco control is primarily indicative of the fact that the Framework Convention Alliance (FCA) forwarded the survey to its membership, while other groups may not have. The Secretariat had encouraged partner organizations to forward the survey to its members, but it is not known which other groups, if any, forwarded the survey.

**Table 2: Focus area of interests on NCDs**



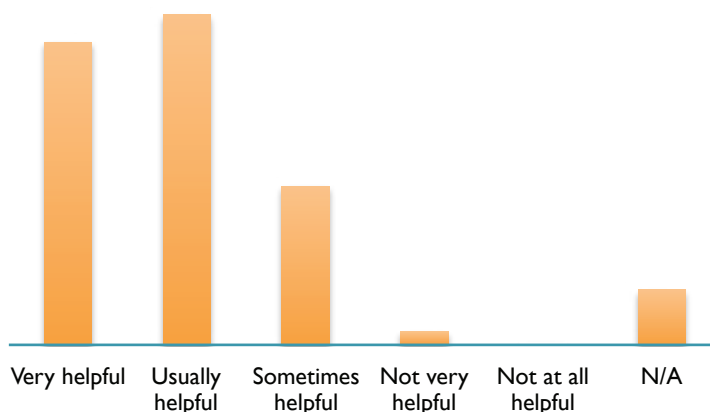
## Review of NCD Alliance’s advocacy activities leading to the UN Summit

Over one-third of the survey questions were targeted to the NCD Alliance’s performance on development and dissemination of advocacy tools, policies and information sharing. Table 3 shows that approximately 73% of respondents found NCD Alliance materials very helpful or usually helpful.

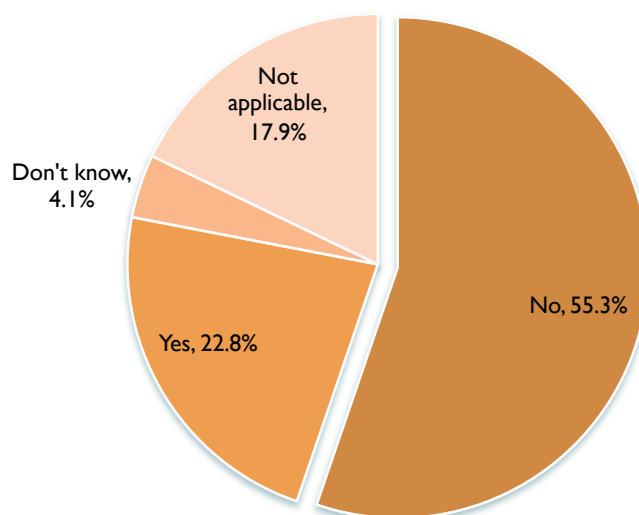
A series of questions were asked about specific tools or advocacy documents (press release templates, Proposed Outcomes Document). Fifty-five percent of respondents said they did not use the press release template to send to national governments (Table 4). However, many of the telephone informants cited that the press templates were useful in helping them tailor their own press releases for the media. Despite a lack of use of the press templates, more respondents said they had seen an increased awareness of NCDs in the media, following the UN Summit (Table 5).

It should also be noted that 52% used the Proposed Outcomes Document for purposes of advocacy. In the end, the increased media coverage, post-UN Summit, would indicate that a combination of materials from the NCD Alliance was used to advocate for media awareness. Further exploration is needed to determine which advocacy tools are useful and what can be done to strengthen their development and distribution in the next phase of the NCD Alliance’s work.

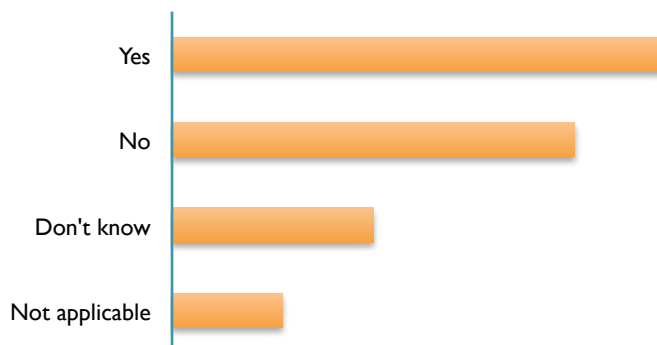
**Table 3: Usefulness of Communications from the NCD Alliance**



**Table 4: Use of NCD Alliance Template Press Release**



**Table 5: Increased Media Interest post UN HLM**



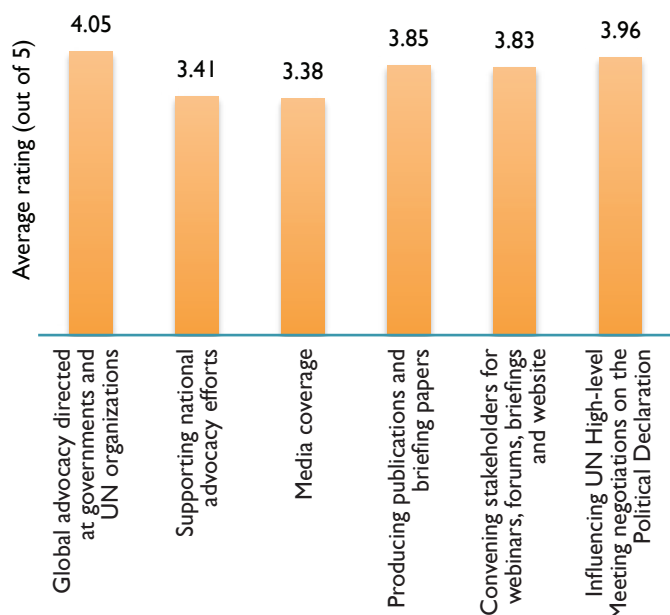
## Future directions

Electronic survey results showed that advocacy proved to be a high priority for the current and future direction of the NCD Alliance. The majority of respondents support global advocacy for NCD targets as well as campaigns for sustainable development goals for NCDs post-2015 (Table 8). Less priority was placed on access to medicines and country projects targeted to service delivery.

The overall take home message from the future directions questions in the survey is to continue:

- o improving and developing NCD Alliance’s tools and materials for advocacy,
- o support advocacy for global NCD targets,
- o support global campaigns for NCDs to be included in the 2015 UN sustainable goals process, and
- o review other activities at country level to determine the NCD Alliance’s role at country level.

**Table 6: Survey respondents’ current assessment of the priority of the Alliance by area**



## Survey ranking of three potential roles for the Alliance over the next two years:

- 1) Global Advocacy – 87% (leading campaigns, action alerts, etc)
- 2) Convening Stakeholders – 78% (multi-stakeholder meetings, communications, etc.)
- 3) Country Level Projects – 57% (demonstration projects, training and building civil societies, etc)

*It is important to note, however, that many respondents’ comments on the NCD Alliance priorities survey and key informant interviews specifically highlighted the need for building NCD Alliances at country level.*

**Table 7: “Post UN High-Level Meeting on NCDs, what roles do you think the NCD Alliance should prioritize over the next two years?”**



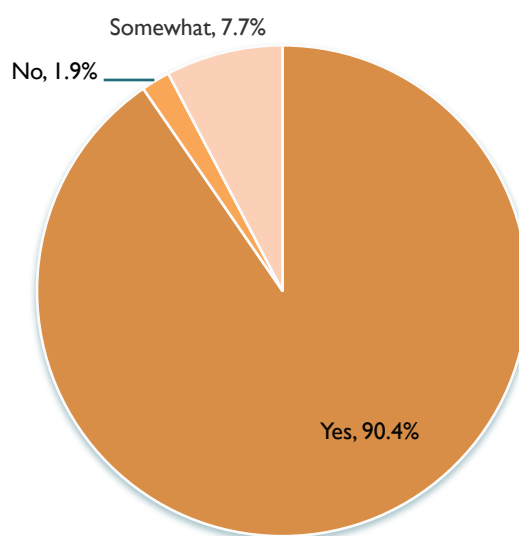
# Federation Board Member Survey

The NCD Alliance's founding members are the International Diabetes Federation (IDF), World Heart Federation (WHF), Union for International Cancer Control (UICC) and The International Union Against Tuberculosis and Lung Disease (The Union). These four federations came together in 2009/10 to form the NCD Alliance. Their leadership has been at the forefront for achieving the goals of the UN Summit in September 2011 and for building civil society's advocacy for NCDs. The four federations comprise a total of 74 Board members. These Board members were electronically surveyed as part of the NCD Alliance Review. All of the Board Chairs were also interviewed as part of the key informant interviews. Seventy four percent (51) of those surveyed responded to the survey. The following are the topline findings from this survey.

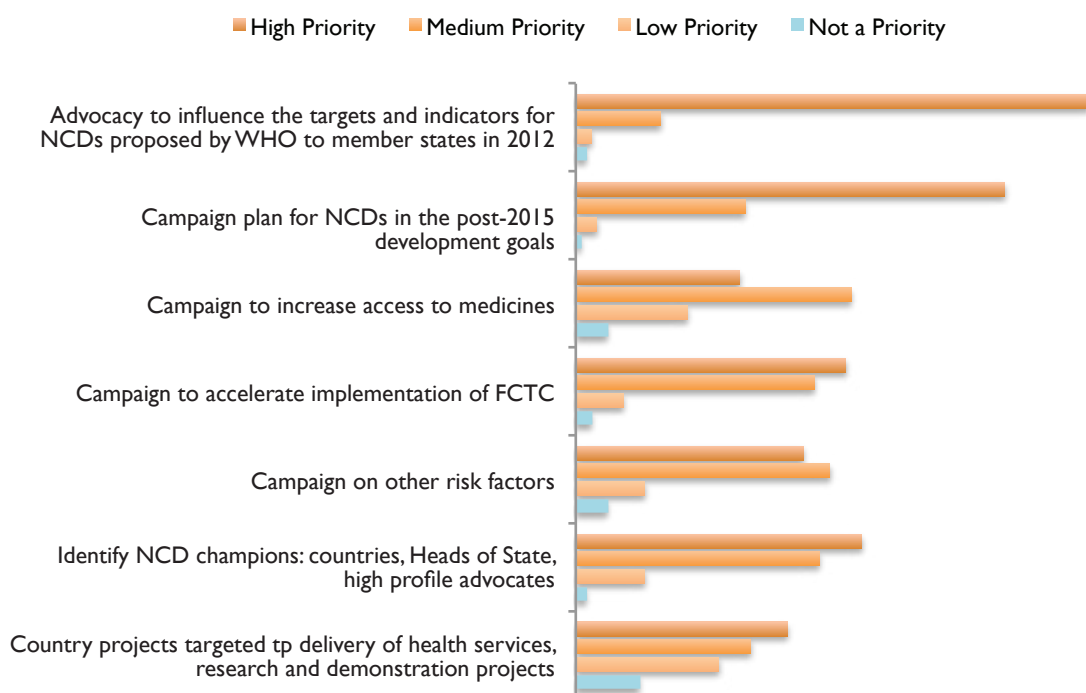
The majority of federation Board members agreed that their federation had benefited from the NCD Alliance relationship (Table 9). Board members' comments included:

- o The work with all the NCDA partners has widened the scope, brought in wider perspectives and enriched the advocacy campaign
- o Raised awareness of diabetes globally and put IDF on the map.
- o It has made us more aware of chronic diseases and their burden. It is helping our organization focus.

**Table 9: "Overall has your Federation benefited from working within the NCD Alliance?"**



**Table 8: "How would you prioritize the following activities for NCDA in the next two years?"**



The Board members also agreed that the Alliance's success over the last two years was due to the leadership of the four federations and their members, followed by the financial and advocacy support of the Alliance's supporters and partners, their communication, and mobilization of civil society (Table 10). Overall, these comments parallel the findings from the in-depth interviews and electronic survey of CIG members.

One of the findings of the in-depth interviews was that many respondents commented that they thought moving forward, the Alliance should expand the Steering Group to include other groups or sectors. The majority of Board members also thought the Steering Group should be expanded moving forward. Comments from the members were instructive in explaining their concerns about expanding the Steering Group. The following comments are

illustrative of the group wanting expansion and those who felt expansion at this time was not necessary:

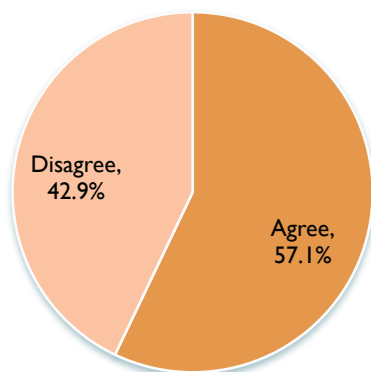
- o *There needs to be a small workable management structure but there should be collaboration and inclusion of other groups in some form of collaborative process e.g. a small working "board" and subcommittees or council.*
- o *It is important to have a strong and coordinated leadership. More organizations could dilute our objectives and operational structure.*
- o *We need to steer the path between being inclusive and losing focus.*

Lastly, federation Board members felt that their organization had benefited from the relationship with the NCD Alliance. The majority of respondents (83%) believed their federation's reputation had been enhanced by being a part of the Alliance.

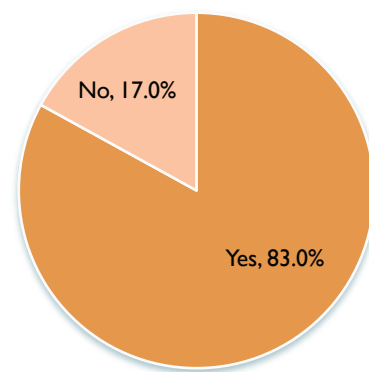
	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
Leadership of the 4 federations in forming the NCD Alliance to convene their 1000 member associations to advocate for NCDs	32	16	1	0	1
Advocacy and financial support (cash and in-kind) given by the Alliance's supporters including private sector, federation members and partners	14	26	5	4	1
NCD Alliance communications capacity and advocacy materials and information	23	24	1	0	1
NCD Alliance's efforts to provide information and the latest inside information on UN processes to civil society organisations	25	21	3	0	1
Ability of the 4 federations and Alliance partners to mobilise civil society organisations including their members to lobby and advocate for NCDs to their national governments	23	21	2	2	2

**Table 10: "What do you think were the critical factors that helped to achieve the Alliance's success over the last two years?"**

**Table 11: "One of the recommendations from the review is that the NCD Alliance management model should change, from being an informal collaboration with a MOU agreed upon by the four federations, to a more formal NGO with recognition of the four federations as permanent board members and expansion to include additional representatives from other NCD sectors. Do you agree or disagree?"**



**Table 12: "Has the reputation of your Federation been enhanced or not by being a part of the NCD Alliance?"**



# Key Informant Interviews

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*Ahimsa conducted 51 phone interviews with key informants representing the Secretariat, Steering Group, Partners Group, Common Interest Group and Supporters Group. The key informants were all very thoughtful in their comments and almost all provided positive feedback on the Alliance. Many were thankful to the Alliance for conducting the review process and for being interviewed.*

The following is a synthesis of the informants' comments, opinions and recommendations for each of three areas of questions: 1) NCD Alliance performance leading up to UN Summit; 2) future direction of the Alliance; and 3) governance and leadership. This summary is not meant to be an exhaustive list of comments, but rather to emphasize major themes of concern, challenges, opportunities and opinions of the key informants.

## NCD Alliance performance

- o The consistent message across all informants was that the Alliance played a key leadership role in galvanizing civil society's voice to influence the successful outcome of the UN Summit. Best stated by two of the informants as: "there wouldn't have been a Summit, nor would it have been so successful without the efforts of the Alliance," and "it was a heroic effort that changed the face of NCDs forever, on the global stage."
- o The second major message from the informants was the fact that the four federations came together to work for a common goal. Many people recognized how difficult this was and also unprecedented. Everyone recognized and gave credit to the four federations for aligning as one entity which meant putting their reputations, money and advocacy efforts to work to make a successful UN Summit on NCDs. They also recognized the leadership of Ann Keeling for her vision and zeal in first getting the UN/WHO to agree to host a High-level Meeting and her tenacity in helping to ensure the civil society voice in the deliberations.
- o Informants also praised the Alliance Secretariat for its work in understanding and reporting back UN and WHO happenings through webinars and teleconferences. Examples included: outcomes and messages from WHO/UN meetings with civil societies leading up to the UN Summit; UN/WHO positions on issues that were being used to create the Political Declaration; and "intel" on different Missions' positions and statements on the UN Summit.
- o Most of the key informants participated in work groups, webinars, and meetings and were recipients of NCD Alliance materials, tools and information. Many of the informants recognized that the Alliance and all civil societies were learning as they went through the process leading up to the UN Summit. They were respectful of the urgency and chaos surrounding the lead up to the UN Summit and realized that the Alliance leadership often needed to move things quickly or make decisions without consensus or even input from the partners. However, most stated that they would have liked to have had more time for "two-way" discussion and been able to have more input into some of the major issues that were being discussed at the highest level of the process, e.g. access to medicines, treatment and care, patients rights, or prevention of mental illness.
- o The overall take home message from the interviews regarding the NCD Alliance's performance and actions over the past two years is "bravo" for a job well done. Or, as was simply put by one informant, "thank God for their leadership and commitment."

## Future directions

Key informants had the most to say about future directions but not necessarily about strategic direction or major activities but rather on process and relationships. Although the informants were complimentary of the Alliance's efforts to develop a successful UN Summit, there were concerns or suggestions for change around four themes:

- o Role of the Partners Group, CIG members and Private Sector
- o Secretariat roles and functions related to communications and relationship with members
- o Strategic activities and objectives post UN Summit
- o Governance and leadership

## Roles and level of involvement

### Role of partners post UN Summit

It is unclear to some what the role of the Alliance should be in a "post Summit" world. As stated previously, the Alliance was praised for its efforts in catalyzing one voice for civil society and campaigning for the Political Declaration and outcomes of the UN Summit. However, there is no single, urgent campaign needed post UN Summit. The work to be done is more focused at country level on advocacy to support the implementation of the Political Declaration and continuing to monitor and advocate for sustainable goals for health and NCDs through the UN. Informants were most interested in discussing on how the Alliance will engage and utilize partners in the future to build advocacy and civil society capacity in a post UN Summit environment.

The partners would like more engagement in development of policy and strategy of the Alliance and more clarity on how the partners and the Alliance can coordinate mutual interest.

For example, in lead up to the 2014 review, how will the Alliance coordinate messaging and develop communication strategies with partners? Will it be as it was in the run up to the UN Summit; more top down or will partners be involved early in strategy and policy development?

## Inclusiveness of members and partners

CIG members and NGO partners who are not donors felt the Alliance was not as inclusive of them as they were of donor partners. Many of the non-donor partners wanted to contribute more to discussions and inputs into policies and issues but felt they were left out or ignored. In the future, many partners would like to have more opportunities for discussion and input into Alliance's policies either through teleconferences, meetings or other venues.

### Input into decision making and strategy development

Partner Group members requested more input into decision making and strategy development. Suggestions included: input into any key policy statements (e.g. Proposed Outcomes Document) the Alliance develops in the future; input and awareness of press releases before they are sent out; and opportunities to discuss urgent political/policy issues with NCD Alliance leadership. (NOTE: Many of the partners cited the work of Secretariat in including them in recent discussions pertaining to the WHO indicator and target statements as a positive example of the role for the Alliance.)

### Communication and interaction between members

Partner organizations that have members at national level questioned how the Alliance would interact with their members at country level. Informants asked if NCD Alliance would go directly to members at country level or through global organization. (Example: Would the Alliance send information directly to South Africa Heart Association or through the World Heart Federation to South Africa Heart Association?)

Most informants stated they would not want the Alliance going directly to members in countries but would prefer a relationship where the global partner was in the lead in sharing NCD Alliance information with their national constituencies.

### Private sector role and engagement

Informants from the private sector (corporate for-profit entities) were critical of the NCD Alliance. They were happy to participate and support the Alliance's work for the UN Summit but many

stated they now were ready to do more than “meet and talk.” They wanted to actually support projects or specific activities with the Alliance at country or global level. A few commented they would like to be more involved in providing input and suggestions into NCD issues and work with Alliance on supporting advocacy. They were concerned that the NCD Alliance did not treat or consider them as partners but rather just as funders. They appreciated the fact that the Alliance had members who were critical of the involvement of the private sector in any policy development. They also recognized that the private sector may be seen as trying to influence the Alliance’s policies, for the benefit of the for-profit industry. However, they would prefer to have a role in the Alliance that is beyond just funding. They felt that through development of an NCD Alliance conflict of interest (COI) policy they could work out a role that is satisfactory to the members of the Alliance.

### **Partners’ view of private sector engagement**

There were two arguments discussed by partners regarding the role and involvement of the private sector in the Alliance. The first group supported the private sector’s involvement if there were clear guidelines for engagement of private-for-profits groups. The working relationships should be clearly defined in a policy on COI developed by the Alliance. The second group of informants was against any involvement, regardless of COI statements/policies. The latter group was in the minority but very adamant about exclusion of private sector. Of those who were interested in working with the private sector, they wanted the Alliance to develop a framework that would not only address COI, but would address opportunities for private sector and NCD Alliance to work together on building NCD movement.

### **Role and functions of the secretariat**

Informants were asked about strategic priorities and their opinion on future directions of the Alliance. There was universal acceptance that the Alliance is needed and should continue its work as a civil society organization. Most agreed that the success of the Alliance’s advocacy and communications efforts during and leading up to the UN Summit should continue. Many praised

the work of the Secretariat in providing “intel” on UN activities and leading up the UN summit. They also were very complimentary of the Secretariat’s role post Summit in addressing the WHO targets and indicators for NCDs process.

- **Informants were confused on the role of the Secretariat** particularly in terms of who spoke for the Alliance. People never really saw or heard from the Executive Director leading up to, or during, the UN Summit. They commented that they only heard the Steering Group members speaking for the Alliance. Many commented that the Executive Director should be the routine face and voice of the Alliance with support and backup from the Board in major events or when appropriate.
- **The Secretariat should continue to provide “intel”** on UN and country positions and actions on NCDs. They also recommended utilizing members to push out information to countries and policy makers. Just sharing information is not enough. Informants would like the NCD Alliance Secretariat to develop communication tools and messages; specific technical information, (economic analysis for NCDs), position statements or policy briefs, tools (press materials, messages, data on NCDs) and “intel” on what is happening at country level for members to use in their advocacy efforts at global and national level.
- **Working groups received a mixed review from informants.** Informants who were involved with a working group either by participation or by being aware of their products had different opinions on their success. Most were aware of the tobacco working group which garnered favorable comments regarding its process and the papers produced. Less favorable comments were received on the other working groups. Informants comments included:
  - *It was unclear to working group members what the expected outcomes were*
  - *The working group papers were not used or distributed widely and there were missed opportunities for advocacy*
  - *Working group members were often only technical and the groups could have benefited from other skill sets, e.g. policy, communications and health systems*

- *The Secretariat didn't manage the working groups processes (time, support for meetings, material development, etc) or provide very useful guidance on what was expected from the groups. Informants agreed that the working group concept is a role that Alliance could play but it would need to be better managed and have clear direction on purpose and outcomes.*
- **There was a lack of clarity on who made decisions and how** regarding the policy and programmatic input of the Alliance. Many people cited the process of developing the Proposed Outcomes Document as the example. There was not much time for input or even if some made comments they felt they were not heard or dismissed without proper discussion. They also mentioned that often times their input was not sought on sensitive issues that could have prevented future negative consequences or missed opportunities. Examples included: discussing US policy with US based NGOs on how to influence US government; language in the Proposed Outcomes Document was not shared with partners in advance of publication. In the future, partners would like to be more involved up front with providing input and opinions on key policy issues before the Alliance makes public a press release, position statements or other policy positions.
- **Governance should define the role of partners**, including the private sector, donor partners and federation partners. Because there were different groups established for sharing information and doing business with partners, e.g. CIG, Partners Group, Working Groups, Supporters Group; many were confused as to the role or contribution each group was making. As one person said, "it is not clear what the role of "pay to play" groups are doing and we assume the "payers" group has more influence on policy with the Alliance.

## Future strategic direction

Informants' comments and suggestions on specific strategies for the Alliance for the future were mixed as stated earlier. However there were some major themes and some suggestions for strategies that are worth mentioning:

## Advocacy campaigns for sustainable development goals

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There was agreement that the Alliance should support advocacy and action to move the agenda on Millennium Development Goals (MDGs) or the next version of UN sustainable development goals leading up to 2015. As with the UN Summit, the Alliance should continue to provide "intel" to partners, coordinate messaging with partners, use the network of members to advocate for NCDs and provide materials and advocacy tools to members.

## Development of NCD Alliances in selected countries

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Many partners agreed that creating and supporting national NCD Alliances would be useful in assisting countries in implementing and monitoring the Political Declaration, building civil society's voice and raising awareness. Many suggested working in a few selected countries in the beginning. These should be countries who were champions of NCDs and ready for change. Building capacity in a few countries to implement the Political Declaration and showcase their efforts could be a winning strategy for building political will at country level.

## Monitoring of the Political Declaration

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The Alliance is best positioned as a civil society organization to play the role of "watchdog" to monitor multilaterals and national governments efforts to implement and support the commitments outlined in the Political Declaration. Suggestions were made that included: development of an annual ranking or scorecard of countries' status on implementation; press releases on status of Political Declaration and development of case studies or examples of countries that are role models for implementation of the Political Declaration. Informants also cautioned the Alliance to not get "too close" to WHO or UN but rather be objective and when needed use the Alliance's members and advocacy to challenge the multilaterals on their actions or lack of.

## Tobacco model for NCDs

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The tobacco control community has been very effective in monitoring the FCTC in countries and providing support to countries for tobacco

advocacy campaigns (public bans, taxation policy, health promotion, etc). It was noted by two informants, not from the tobacco control community, that NCD Alliance could learn from the tobacco control community's efforts in effecting political change and public awareness at country level. It was also suggested that the tobacco control NGOs and champions in countries could become the backbone of the NCD movement in country. The Alliance through its partnerships with tobacco control civil societies could begin to align some of its advocacy efforts in country to build more effective civil societies for NCDs.

### **Governance and leadership of the Alliance**

Most informants interviewed did not have specific suggestions on what the NCD Alliance governance structure should consist of, e.g. number/type of Board members, what kind of network, etc. They commented that whatever structure the Alliance develops it should include improved mechanisms for input and involvement of different partners and improved transparency around decision-making. They felt the NCD should become a legal or more permanent entity and that it should expand the Board beyond the four federations, but not become too big or inflexible.

The following are key points made by informants:

- o The Alliance should represent civil societies, but should be inclusive of all disease, risk factors, populations, and different sectors related to NCDs, including mental health, aging, women and children, patients, environment and social determinants.
- o The Steering Group should expand beyond the four federations to include other diseases and risk factors.
- o Most informants commented that NCD Alliance should have a more permanent governing structure but not too large or complex.
- o The Alliance should identify the different constituencies and roles for membership.
- o The Alliance should articulate guidelines/policy for managing conflict of interest for members.
- o The Secretariat should have an annual Board-approved budget and work plan and be responsible for implementing the work plan and making decisions on how to implement and expend funding.
- o The Board should empower the Secretariat to be a spokesperson for the Alliance on routine business and appoint a Board member or Chair to be the primary spokesperson for major issues.

# Summary

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*The respondents to the electronic surveys and interviews were open and candid in their responses and opinions of the Alliance. They were also passionate about the need for an NCD Alliance and praised the work of the Alliance in bringing civil society's voice to NCDs.*

*In summary, the major conclusions from the Review were the following:*

- o The NCD Alliance has been successful in changing the game of NCDs globally.
- o The UN High-level Meeting was a major achievement and turning point for NCDs.
- o There is substantial goodwill from the NCD community for the Alliance moving forward.
- o The four federations have played a major role in getting NCDs on the global agenda and should be commended.
- o Moving forward past the UN Summit the Alliance will need to:
  - *Develop a new strategic plan that encompasses advocacy and action at global and national levels on NCDs*
  - *Define a governance structure for the Alliance that allows for expansion of the Alliance's Steering Group and is more inclusive of other sectors*
  - *Clarify the role of the partners, supporters and common interest groups in the Alliance's organizational structure*
  - *Increase accountability and transparency in decision making and funding*
  - *Develop clear guidelines for engaging the private sector as partners not just funders*
  - *Continue to build capacity for civil societies to have an active voice for NCDs at national and global level.*

## **Acknowledgements**

This report would not have been possible without the generosity and honesty of the many informants who provided their knowledge and ideas to inform the review. We thank, in particular, the executive leaders of the four founding Federations, whose vision and continuing commitment have made the NCD Alliance what it is today. We have learned a great deal from this opportunity to work with the NCD community and look forward to seeing the Alliance rise to its immense potential to improve well-being and save lives.

## **NCD Alliance Review**

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