World Health Organization
COUNTRY OFFICE FOR India

MAPPING OF INDIAN CIVIL SOCIETY ORGANIZATIONS FOR PREVENTION AND CONTROL OF NONCOMMUNICABLE DISEASES

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The WHO Country Office for India commissioned mapping of civil society organizations to assess the scope of their involvement in prevention and control of noncommunicable diseases. Ms Shoba John of Stratcraft Mumbai conducted the study.

The NCD Programmes of several states provided contact details of civil society in their respective areas. The civil society networks such as the Advocacy Forum for Tobacco Control and the Healthy India Alliance helped to disseminate the survey and gather responses.

Civil society organizations from diverse fields responded to the online and postal surveys. The following civil society experts from diverse sectors that are relevant to NCD prevention and control enriched the mapping through key informant interviews.

Relevant sectors	Key informants
Public health	Dr K Srinath Reddy
Cancers	Dr Anil Dcruz
Cardio Vascular Diseases	Dr Mrinal Kanti Das
Diabetes	Dr V Mohan
Palliative care	Dr R Rajagopal
NCD research, tobacco control	Dr Prakash Gupta
Environment, road safety	Dr Anumita Roy Chowdhury
Alcohol control, women's rights	Drs Shanthi Ranganathan and V Thirumagal
Mental health	Dr Abhijit Nadkarni
HIV/AIDS	Dr Reynold Washington
Rural Development	Mr Girish Sohani
Worker association	Ms Sangeeta Singh
Indoor air pollution	Ms Smita Rakesh
Health Systems	Dr Amit Sengupta
Child rights	Mr Santanu Chakraborty
Maternal and child health	Dr J Krishnamurthy
Agriculture, food production	Dr R Rukmani

Acronyms

CSO	civil society organization
CSR	corporate social responsibility
CVD	cardiovascular disease
MNCH	maternal and newborn child health
NCD	noncommunicable disease
NGO	nongovernmental organization
NHM	National Health Mission
NPCDCS	National Programme For Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke
WCO	WHO Country Office
WHO	World Health Organization

Glossary

Civil society

Nongovernmental organizations, people's movements, professional bodies, workers' associations, research and academic institutions, but does not include businesses, media and government agencies.

NCD CSOs

Civil society organizations whose programme of work directly address NCDs or their risk factors.

Other CSOs

Civil society organizations whose work is relevant to the prevention and control of NCDs, but are yet to address them intentionally.

Civil society sub-streams

Sections of civil society focused on specific public concerns. For instance, NCD civil society sub-streams include those working on cancers or physical inactivity, whereas other civil society sub-streams refer to those addressing women's rights or concerns of poverty.

Geographical scope

The geographical area that was the main focus of the respondent's work – be it across a continent, national, state, district, sub district, city level or any other.

Geographical spread

Main Indian states where the respondents work.

Executive summary

This mapping aimed at understanding the profile, activities, needs and priorities of civil society organizations (CSOs) of relevance to noncommunicable diseases (NCDs) and their risk factors, and exploring their scope to improve their response to the issue. An online survey gathered responses of CSOs from 22 of the 29 states and two of the seven union territories, covering those working on over 20 public concerns. This was supplemented through interviews with key informants from 20 civil society sub-streams of relevance to the issue. Over half of the survey respondents were health nongovernmental organizations (NGOs) and 65% worked at subnational levels, mostly in urban centres.

NCD CSOs: As many as 84% CSOs reported working directly on NCDs or their risk factors. Among the major NCDs, cancers received greater civil society attention; among the risk factors, tobacco and alcohol control figured prominently. The NCD civil society action is largely focused on awareness generation and creating access to services for patients, with policy advocacy gaining attention with increasing years of work. Political and systemic challenges in the external environment, and financial constraints and lack of coordination within the CSO movement, significantly retard their progress. Recent entrants to the NCD movement considered health promotion, capacity building and resource mobilization as among their top priorities for the future, whereas those with over 5 years of work were keen on policy advocacy, monitoring Government commitments, facilitating access to treatment and networking. The NCD CSOs sought capacity building in resource mobilization, best practices on reduction of NCD risk factors, advocacy and campaign skills. Orientation to national NCD plans and facilitating access to relevant government ministries could enhance their work.

Other CSOs: These included CSOs working on issues other than NCDs like rights-based, developmental, rural–urban and health concerns, and were yet to address NCDs. They were mainly engaged in public education initiatives, community services and mobilizing vulnerable groups on issues of their focus. They were inclined positively to the potential integration of NCD concerns in their programming; they anticipated additional funds, improved outcomes for core programmes, broadened support to campaigns, expanded reach to new Government sectors and shared benefits that could economize core work. Educational and training programmes, monitoring Government's NCD commitments and policy advocacy were the preferred NCD activities for integration into their programming. Introduction to NCD organizations, their networks, new donors and Government ministries, sensitization workshops, joint interventions with NCD CSOs and information on co-benefits of NCDs to their programmes were identified as measures that could equip them for addressing NCDs and their risk factors.

The experience of other public concerns suggests that the expansion of civil society action on NCDs in the country urgently require actionable evidence, policy and programmatic framework for Government–CSO partnership, sustainable funding and systematic capacity building. A critical first step in this direction would be to engage civil society in the country's NCD programmes. The respondents sought the support of intergovernmental and development partners in resourcing civil society, providing evidence for action, integrating NCDs into existing development programmes and building civil society monitoring mechanisms for Government's NCD commitments.

Introduction

Background

The UN High Level Meeting on Noncommunicable Diseases (NCDs) recognized the role of civil society in the multisectoral response to NCDs. Further, the WHO Global Action Plan on NCDs identified potential contributions of civil society organizations (CSOs) in its implementation and monitoring.

The CSOs in India have made concerted efforts for advancing NCD prevention and control in the country. The World Health Organization Country Office (WCO) for India commissioned a mapping of CSOs relevant to NCD prevention and control in India to help capture their contributions, identify areas for future action and inform future strategies for enhanced civil society engagement. The mapping aimed at:

- describing the profile, activities and achievements of Indian civil society in addressing the NCD concerns;
- identifying the priorities and capacity needs of civil society in contributing to the prevention and control of NCDs; and
- exploring the scope of involving civil society engaged in related areas to address the NCD issues.

Methodology

The mapping consisted of an online survey and selected key informant interviews of CSOs. For the purpose of this mapping, civil society included nongovernmental organizations (NGOs), medical professional bodies and research and academic institutions.

The online and postal survey was intended to identify the profile, activities, challenges, needs and priorities of Indian CSOs whose work is relevant to the NCD response. It included CSOs working on NCDs and other health and non-health sectors that are of relevance to the issue.

The survey being the first of its kind for CSOs relevant to NCDs, snowballing technique was followed to ensure maximum reach and parity through the survey. The broad range of sectors that are relevant to the major NCDs and their risk factors, either in terms of contributing to the problem or having a role in reducing them, were mapped out. The known contacts within each of these sectors were approached to secure contact details of CSOs within their reach. Care was taken to ensure that CSOs in all Indian states and union territories had equal opportunity to respond to the survey. The online survey was broadcast to lists of e-mail addresses of over 1200 CSOs gathered from a variety of sources.

These sources included:

- diverse programmes of the WCO India
- contacts received from the state tobacco and NCD control programmes
- NCD-related networks in the country
- members of international NCD federations
- databases of CSOs in relevant sectors that were publicly available.

The survey questionnaire (in English) was duly pretested and finalized. The questionnaire had four sections. Its profile section was common to all respondents. The second section had questions tailored for CSOs working directly on NCD concerns. The third section meant to capture the work of CSOs working on other issues and a concluding section sought responses to issues of common concern.

The online survey was open across the first two weeks of January 2016 and potential respondents received three intimations during this period. A paper questionnaire was arranged for CSOs where e-mail addresses were not available. There were 248 responses to the survey. After data cleaning, 204 responses were considered for analysis.

Key informant interviews aimed at gathering in depth information on the specific landscape of various sub-streams of CSOs in the health and non-health sectors relevant to the NCD dialogue, their foci, strategies, lessons learnt, priorities and capacity needs. In addition to topical experience, geographical diversity was sought in determining the interviewees. The informants were carefully drawn from geographical areas that were reported to have either concerted action or informants with years of experience on issues of relevance to NCDs. The in depth interviews also explored their inputs on national priorities for actions to address NCDs and their risk factors, and ways to organize a collective response to the issue. Key informants from over 20 sub-streams contributed to this mapping, taking into account geographical and gender representation. The qualitative data was analysed separately by major themes and presented in synchronization with the survey data in this report.

Scope of the mapping

The pan-India reach of the survey provided the equal opportunity to CSOs from all states and union territories that is required for a national mapping exercise of this nature. The significant responses to the survey and interviews from sub-national levels improved the representativeness and inclusivity of this mapping, making it a helpful tool for future planning of CSO activities on NCDs in the country. The postal survey helped to address challenges in electronic access. The survey also got responses from CSOs working on a vast array of issues – as many as 20 public concerns, bringing in the perspectives of a broad cross-section of the Indian civil society.

The key informant interviews brought depth to the mapping in terms of the work, challenges and priorities of specific sub-streams of civil society that are relevant to the prevention and control of NCDs in the country. These made the mapping exercise fairly comprehensive and largely representative of the targeted constituency for a first-time exercise. It further provided a baseline for further exploration of some of the themes that have emerged in its results.

Limitations of the exercise

The absence of a comprehensive national CSO database in the country makes systematic mapping of this nature challenging. The limited response to the survey and interviews from the north-eastern states points to the continuing access and capacity concerns specific to that region. The relatively lesser response from CSOs working on issues other than NCDs limits the scope of analysis of the data received from these organizations.

The relatively early stage of NCD action in the country, limited primarily to pockets of concerted action, in itself could explain some of the data trends presented in this report.

Geographical spread of the respondents

The survey got responses from CSOs registered in 22 of the 29 states in the country and two of the seven union territories. While around one fifth of the respondents were from the National Capital Territory, five more states (Jharkhand, Tamil Nadu, Kerala, Karnataka and Maharashtra) had over 5% respondents each. Despite concerted efforts, the response from the north-eastern states was limited to Assam and Tripura.

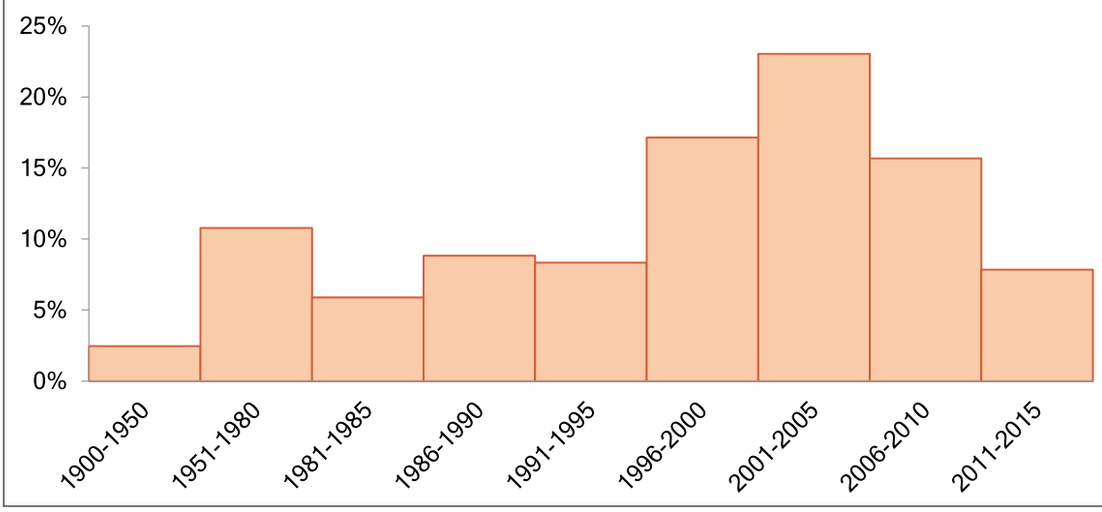
However, it was noteworthy that several of the respondents had reach beyond the states where they were legally registered, indicating potential coverage of all 36 states and union territories in the country. For instance, CSOs in West Bengal reported reach to the North-Eastern states; those in Tamil Nadu to Puducherry; those in Maharashtra to the Union Territories of Daman and Diu and Dadra and Nagar Haveli. Further, several of the states that recorded limited direct response to the survey such as Rajasthan, Uttar Pradesh, West Bengal, Bihar and Andhra Pradesh were each reported to be areas of strength by over 15% of the respondents.

1 Profile of the CSOs

Genesis of the CSOs

Nearly two thirds of the respondent CSOs were formed in the last two decades (1996–2015), and the remaining one third of the organizations was established across the nine decades prior to 1995. The two oldest respondent CSOs were established prior to 1900. Given that majority of the respondents (76%) have been in existence for over a decade or more, the overall mapping results could be considered to represent reasonable levels of experience among the civil society.

Fig 1. Year of formation of CSOs

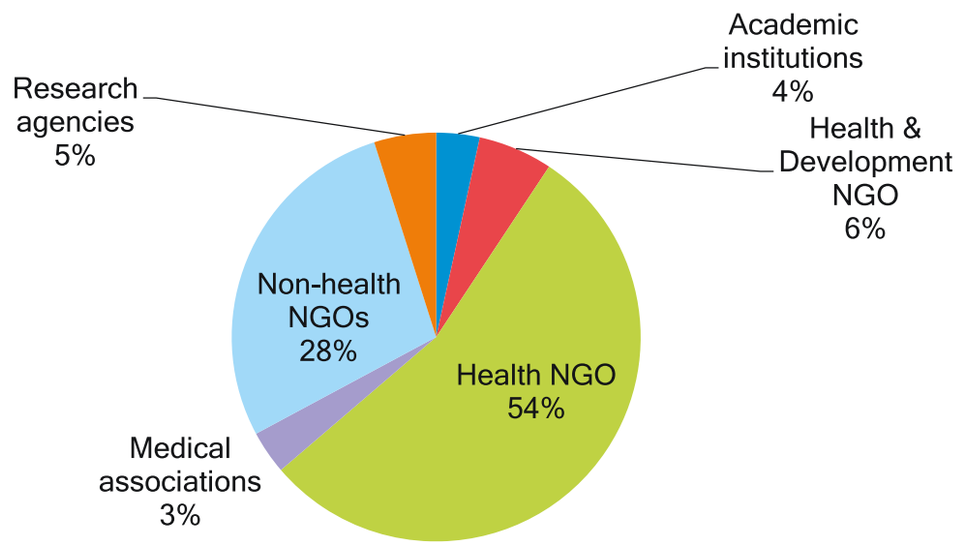


Many of the CSOs were started either by affected individuals themselves or their families, or medical professionals closely engaged in these issues. The cancer landscape offers several examples of NGOs started by survivors or those like the Laryngectomee clubs supported by physicians. The initiative of survivors and their families brought much passion and commitment to the NCD cause, though these efforts often remained localized without the resources for scaling up.

Nature of the CSOs

Over half the respondents in the survey were health NGOs. They worked primarily on communicable and noncommunicable diseases, health system strengthening, health concerns of vulnerable groups such as women, children, indigenous communities and issues of urban and rural health. A significant one fourth of the respondents were non-health NGOs. They focused on concerns of women, children, education and rural development. Notably, 6% of the respondents reported working on both health and development issues – a constituency that could serve as a bridge between the health and non-health sectors. There were a limited number of CSOs that were research agencies, academic institutions and medical associations.

Fig 2. Type of CSOs

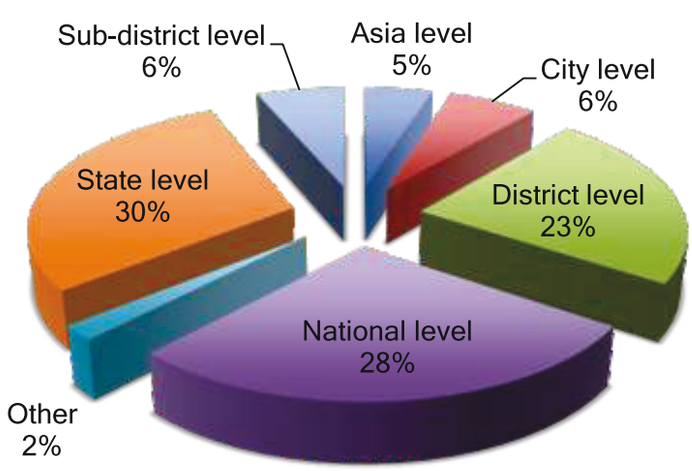


The analysis of interviews with key informants provided a detailed picture of the nature of CSOs that are active within the various sub-streams of civil society relevant to the prevention and control of NCDs, their geographical spread as also additional groups whose presence could strengthen work. This analysis is summarized in Annex 1.

Geographical scope

The survey explored the geographical reach of the CSOs at the national and subnational levels. Nearly 30% of the respondents cited states to be their area of strength, followed by 28% who reported being active at the national level, 23% at the district and 6% each at the sub-district and city levels. The interviews corroborated that significant political opportunity for action on NCDs exist at the state level.

Fig 3. Geographical scope

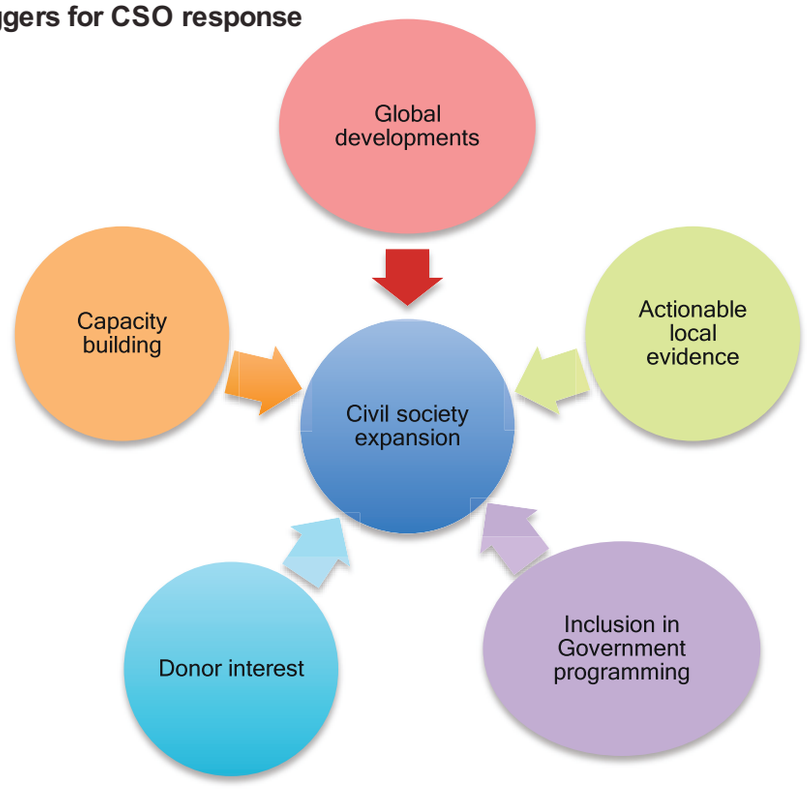


Analysis of the in depth interviews showed that CSO presence was mostly restricted to major cities and certain urban centres within states. The exception to this is those CSOs involved in tobacco control, which have seen a rapid expansion from the 1990s onwards and are today present in all states and union territories , including at district level in several states. A similar trend was observed among CSOs working on issues outside the NCD sector such as HIV/AIDS, environmental concerns and children's issues, which also reported pan-India presence at national, state and community levels. Annex 1 elaborates the geographical coverage of civil society relevant to NCD prevention and control as also identifies the groups that are additionally required to enhance action.

What triggers expansion of civil society response on public concerns?

While civil society often triggers national and global responses to public concerns, a host of factors seem to propel the further expansion of these movements at the national level in terms of their strength and reach. The global developments on these issues, availability of actionable evidence, policy and programmatic action by the national government, resources from international donors and capacity building efforts by active CSOs were the reported drivers for increased civil society response to them. For example, in the case of maternal and child health, its positioning in the Millennium Development Goals mobilized multiple national and international players to support efforts in countries. The evidence helped to identify the high-risk districts in North India. The evidence also led the Government to give the issue high priority within the National Health Mission (NHM), with special focus on the priority high-risk districts. The NHM recognized the reach NGOs have to vulnerable and hard-to-reach populations and provided for their inclusion in service delivery. Meanwhile, the international donors were assigned specific priority districts for investment. The resources from the Government and funding agencies enabled increased recruitment and participation of CSOs in the national Maternal, Newborn and Child Health (MNCH) programme in the North Indian states.

Fig 4. Triggers for CSO response



Target audience

Most CSOs targeted more than one group for their interventions. As many as 86% of the respondents targeted the general public for their interventions, followed by 66% targeting governments, 49% focusing on other CSOs and nearly an equal percentage working with NCD-affected groups such as cancer survivors or alcohol addicts. Media, businesses and multilateral agencies were the target audience for relatively fewer CSOs.

The civil society movement on NCDs is in its early stages of active response to the issue. The overwhelming focus on raising public awareness among the respondents could be a reflection of this early phase in the life of CSOs, when they could be expected to target stakeholders within their direct reach and immediate influence. Organizations that have existed for long such as those of tobacco and alcohol control CSOs were found to focus increasingly on the government, media and businesses in addition to the public.

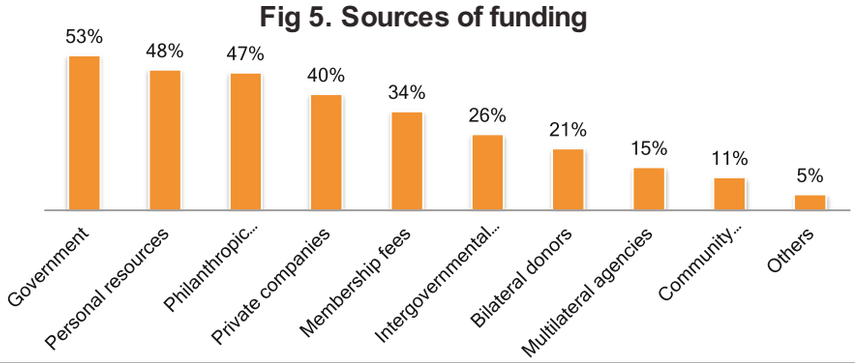
What prompts CSOs to target audiences beyond the public with increasing years of work?

This question calls for further explorative research. One possibility is that the longer duration of existence, functioning and the resultant experience naturally bring in more time, resources and access to target stakeholders other than the public. Another reason could be a realization with time that advocacy with the media and Government for macro-level policies are essential to get ahead and curb the rapidly expanding NCD epidemic. Tobacco control and environmental movements shed some light in this regard. The shift from their initial focus on public education to policy advocacy with the Governments has yielded cost-effective, macro level policies enabling coverage of large populations in a relatively shorter timespan. Yet another scenario could be that the public opinion from the early years of public education creates an enabling environment to influence other stakeholders such as businesses, media and the Government. The identification of the specific reasons for the expansion in target groups among the movements with longer history could be instructive to initiatives that are starting up.

Financial sources

Many organizations received funding from more than one source. The Government was cited as the major source of funding by 53% of the respondents, followed by philanthropic foundations (47%) and private companies (40%). Membership fees, bilateral and multilateral agencies contributed to a lesser extent. Nearly half the respondents reported personal resources supporting their efforts where 11% of the respondents received community contributions such as from friends, volunteers and well-wishers. This could be considered as an indication that a significant part of CSO initiatives relevant to NCDs in India run on personal finances. This draws attention to the need to have more sustainable sources of funding for the long viability of these programmes.

Fig 5. Sources of funding



The survey did not enquire specifically about funding for NCD programmes. However, the interviews indicated a clear distinction between funding available for NCDs in relation to other relevant issues. While CSOs working on issues such as HIV/AIDS, women and children's issues reported receiving significant funding from Government and international sources, the funding reported for NCDs from these sources were few and far between. The clear guidelines on involvement of NGOs under the National Health Mission and Maternal and Child Health Programme is cited as being responsible for their relatively active contribution to this sector. Interviewees from the NCD stream observed that Government of India is yet to establish such a mechanism for funding civil society action on NCDs. The limited CSO funding for NCDs appear to be coming from international foundations such as the Bloomberg Initiative to Reduce Tobacco Use, intergovernmental agencies such as the World Health Organization (WHO), bilateral donors such as the Swedish International Development Agency and private companies.

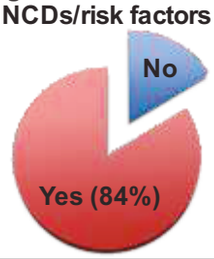
Most of the available funding reportedly goes to CSOs in major cities and urban centres. Funding from government agencies is mainly for research and some for health system strengthening. The resources from businesses usually fund medical professional conferences, seminars, public education, early diagnoses, drug trials and patient care and support. The funding for risk factor-focused advocacy is mostly for tobacco control and some for alcohol control, both from international donors. Limited funding for physical activity has been reported from businesses, mostly for car-free initiatives, promotion of cycling and maintenance of parks and open spaces. There were no resources mentioned for monitoring of either NCD-related commitments made by governments or activities of industries that contribute to the NCD burden.

Funding from corporate social responsibility (CSR) initiatives of private sector companies was an emerging source of funding for CSO efforts in the country[α]. These resources have made their way to the NCD sphere as well, particularly to technology-based interventions. For instance, sustainable fuel sources to address indoor air pollution has seen much CSR investment; early diagnosis and treatment of NCDs have attracted funding from medical technology firms and pharma CSR initiatives. While CSR has been recognized as an additional source of funding, most interviewees considered it to be transient, limited and driven by private sector interests rather than the real needs of the community. A few instances of conflicting interest have also been cited such as soda companies funding water conservation projects of organizations working on rural development or pharmaceuticals supporting drug trials in vulnerable communities serviced by health NGOs.

Focus on NCDs

As many as 84% of the respondents worked directly on NCDs or their risk factors. Sixteen percent of the respondents reported not addressing NCDs directly, but working on other issues that were of relevance to NCDs. Nearly two thirds of the latter worked on women's issues, while 39% each addressed educational concerns and rural development. Health system strengthening, access to medicines, primary health care, child rights, environment, urban development, farming, poverty reduction, communicable diseases, employment generation, healthy cities, urban transport, rural development, workers and consumers rights were among the other areas of work of those who were not currently addressing NCDs.

Fig 6. Direct work on NCDs/risk factors



[α]India's Companies Act mandates firms with Rs 5 crore or more net profit or Rs 1000 crore turnover or Rs 500 crore net worth to pay 2% of their 3-year average annual net profit on CSR activities in each financial year.

2 Work and needs of CSOs working on NCDs

The analysis in this section is based on the data from 84% of the survey respondents who reported working directly on NCDs or their risk factors. They are being collectively referred hereinafter as NCD CSOs for the purposes of this report. The survey analysis has been supplemented with inputs from the interviews of informants from the NCD sub-streams of the civil society.

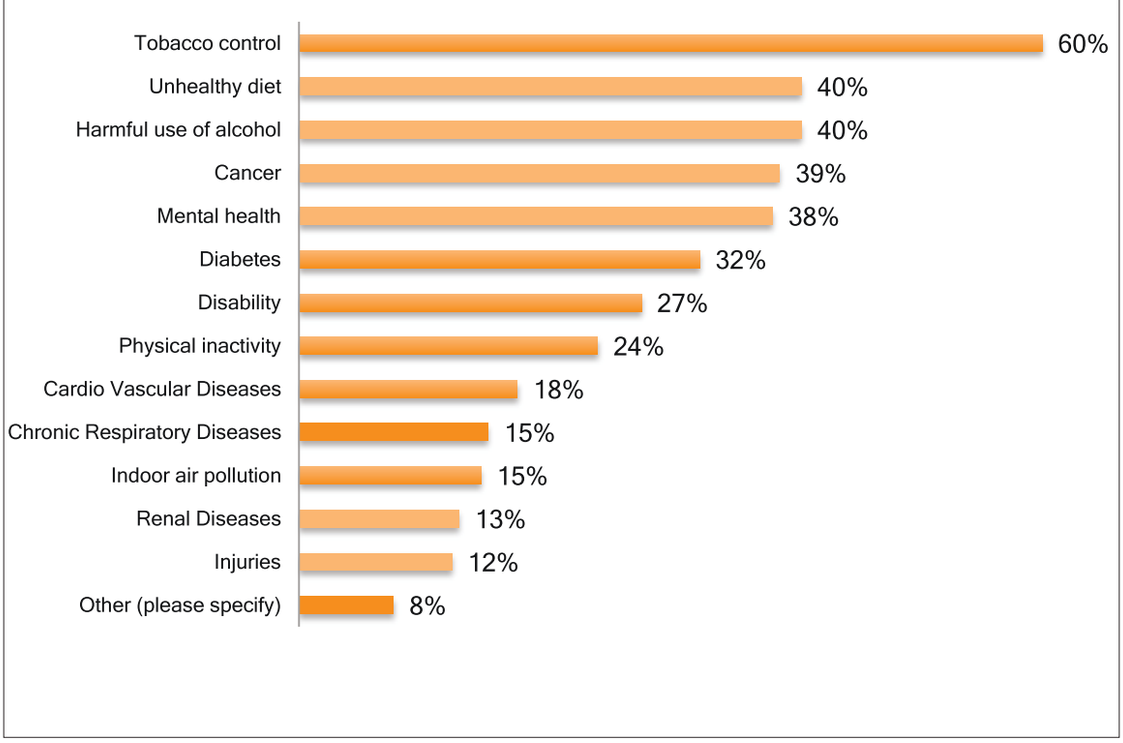
Years of NCD work

Nearly 70% of the NCD CSOs began to address NCDs in the years since 2000, reflecting the increasing attention the issue has gathered across the world and in the country since the turn of the century. About 14% of the respondents have been working on NCDs for 16–20 years and the rest for 21 years or more.

Focus of work within the NCD spectrum

Tobacco control received maximum attention of the NCD concerns among Indian CSOs, with 60% of the NCD CSOs working on the issue. Alcohol use and unhealthy diet were reported by 40% each, followed closely by cancers (39%) and mental health (38%). In comparison, diabetes (32%), cardiovascular diseases (18%) and chronic respiratory diseases (15%) got lesser CSO attention. Injuries, disability and renal diseases were reported by 12%, 27% and 13% of NCD CSOs, respectively. Among the NCD risk factors, physical inactivity and indoor air pollution were yet to gain significant CSO attention.

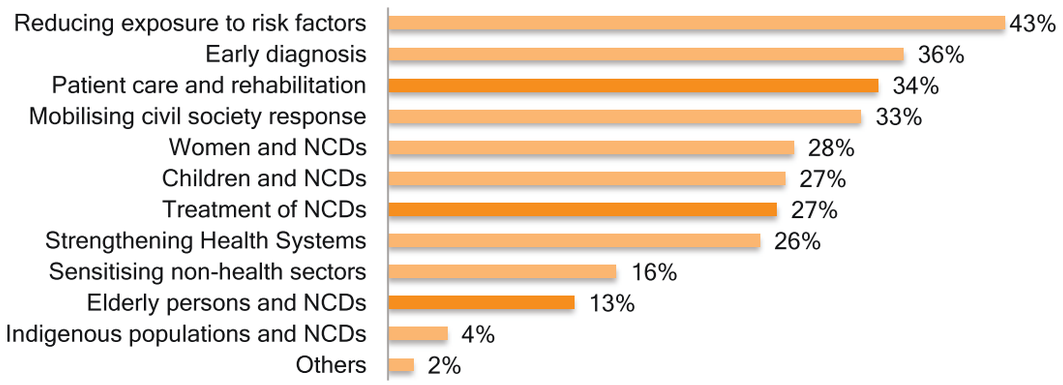
Fig 7. NCDs – risk factors addressed



Strategies used to address NCDs

Reducing exposure to risk factors was the most preferred strategy, as cited by 43% of the NCD CSOs. This was followed by 36% that engage in early diagnosis, 34% in patient care and rehabilitation and 33% in mobilizing civil society action. While there has been some focus on NCDs among women and children (28% each), focus on the elderly (13%) and indigenous populations (4%) have been abysmally low. Only 27% of the NCD CSOs reported health system strengthening. Sensitizing of non-health sectors – a strategy critical to the NCD response – was reported by only 16%.

Fig 8. Strategies to address NCDs/risk factors



NCD activities

Majority of the NCD CSOs were involved in public education activities (64%), followed by patient services (49%). Notably, the NCD CSO involvement was considerably low in roles traditionally associated with the civil society, such as advocacy for improved policies (26%), technical support to government agencies (13%), media advocacy (11%), influencing or participating in government committees (8%), monitoring industries with conflicting interest and monitoring Government's NCD commitment (3% each).

Key informants' interviews identified these latter as cost-effective interventions that would help cover large populations and provide higher returns on investment. Tobacco control was cited as an example for its higher returns from increased attention by CSOs on advocacy for policies relative to public education.

CSO activities tend to vary across specific NCDs and their risk factors in the country. Thus, while there is much focus among diabetes organizations on awareness generation and early diagnosis, the cancer community is additionally active in patient-related activities. The cardiovascular disease (CVD) civil society is gradually expanding its focus beyond treatment to primary prevention. The civil society working on chronic respiratory diseases has been largely focused on treatment concerns. The risk factor groups by and large focus on educational efforts. The exception is the tobacco control movement, which began with educational initiatives but moved on over the last decade to undertake policy advocacy.

Notably, the years of work on NCDs appear to make a difference in the choice of activities by the NCD CSOs. The more recent entrants in the NCD CSO arena chose to undertake public education on NCDs and their risk factors, with this trend decreasing with increasing years of work in NCDs. Thus, a greater percentage of CSOs that began to address NCDs in the last

five years reported public education efforts, whereas those who have been working on NCDs for over a decade tended to focus more on patient services, capacity building of other CSOs, advocacy with policy makers and influencing or participating in Government committees. NCD-related research also tends to be the focus of organizations with more years of work in the NCD arena. Further inquiry is needed to determine if public education is dropped from the portfolio of CSOs' action over time, or if it is that additional activities are added to it.

Patient engagement in NCD response

Most NCD CSOs engage with patients in some manner. The practice to include "patients' voice" in communications seems to be the most prevalent practice, as reported by 37% of these organizations. Actions that require greater effort such as including patients in meetings with the Government (30%), extending them organizational membership (29%), consulting them while forming policy positions (22%), engaging them as media spokespersons (26%) and need for a clear written policy on patient engagement (8%) were reported to a lesser extent. While 4% of the respondents reported patient-specific services, 9% did not include patients in their work and 13% did not find it applicable in their organizational context.

Civil society research on NCDs

The research agencies and academic institutions have made significant contributions to NCD research in the country. These researches have revolved primarily around cancer and diabetes, with some focus on CVDs and to a much lesser extent on chronic respiratory diseases and mental health concerns.

Among the risk factors, civil society research groups have led epidemiological research on tobacco use, exploring its health and socioeconomic implications over the decades. In recent years, there has been increasing focus on policy-oriented research on tobacco, such as those exploring the scope for tax increases, public opinion surveys regarding tobacco packaging, smoke-free public places and alternative livelihood options for those dependent on tobacco production. The Indian civil society has also undertaken research on the social and economic implications of alcohol use, in particular its impact on women's rights and households. While there has been much research on the prevalence and implications of undernutrition, there has been limited attention paid to obesity, unhealthy eating and lack of physical activity. Civil society research on air pollution issues has been lesser on its implications for health and households and more on exploring sustainable cooking and lighting options.

Major civil society contributions towards NCDs

CSO efforts have contributed significantly to addressing the NCD epidemic in India. Below are some selected outcomes that provide a glimpse into the nature of achievements and their implications for NCD prevention and control in the country.

Actionable evidence: The epidemiological research by CSOs has established benefits of low-cost, macro-level interventions to address the relationship between NCDs and related issues. Thus, research on the reproductive health outcomes of use of smokeless tobacco provides the evidence base to integrate tobacco prevention measures in the country's well-established Maternal and Child Health Programme and thus improve the outcomes of both the programmes.

Public awareness: The overwhelming focus of the respondents of this mapping on public education activities appear to have translated into increased public awareness about NCDs. The Prevention Awareness Counselling Evaluation (PACE) Project on diabetes in Chennai is a case in point. Following the project's intervention, the awareness about diabetes was shown to have increased from 75% in 2001–02 to 81% in 2007[ɣ]. Similarly, those working among agrarian communities reported that culturally relevant health messaging increased their awareness about health issues as also led to improvements in health-seeking behaviour.

Secondary prevention and treatment: Consistent efforts of medical associations have led to the establishment of cardiology departments that offer specialized CVD treatment in the country's medical institutions, as also developed CVD treatment guidelines.

Policy outcomes: A landmark achievement of civil society advocacy on tobacco control has been the passage of India's Tobacco Control Act in 2003. Similarly, the street food vending community upholds the Livelihood Protection Act, 2014 as a milestone in its work to improving the working conditions of its members, including facilitation for producing safer and healthier food. The decades of advocacy by palliative care CSOs in the country led to amendments to the National Drug and Psychotropic Substances Act in 2014, which improved accessibility to morphine for palliative care.

Strengthened health system: The civil society recommendations on mental health policy has led to improved access to treatment through training and engagement of non-specialists workers in primary health centres in states like Goa. The CSOs working on maternal and child health issues also reported success in enlisting frontline health workers in improving awareness and access to health systems among vulnerable groups.

Government investment in health: Civil society advocacy initiatives such as the public health movement on the necessity for Government interventions in health systems led to the genesis of the National Rural Health Mission in 2005 (now the National Health Mission). The mission now facilitates several programmes, including some that are of relevance to NCDs.

National plans and programmes: National plans and programmes have been a vehicle for civil society action in the county. The Newborn Action Plan brought more financial and technical resources for child rights CSOs to address issues relating to child survival.

Technological innovations: The years of civil society advocacy for cleaner energy sources to tackle indoor air pollution has seen an increased focus on renewable energy technology for cooking and lighting instead of polluting coal-based sources.

Monitoring Government commitments: The civil society economic research agencies have closely monitored Government budget commitments for health and highlighted shortfalls and underutilization of resources that have led to greater Government investments in health programmes.

[ɣ]Somannavar S, Lanthorn H, Deepa M, Pradeepa R, Rema M, Mohan V. Increased awareness about diabetes and its complications in a whole city: effectiveness of the "prevention, awareness, counselling and evaluation" [PACE] Diabetes Project [PACE-6]. J Assoc Physicians. 2008;56:497–502.

Challenges in NCD civil society's external environment

The respondents were asked about the challenges they face in the external environment of their work. They cited obstacles ranging from active opposition from related industries to those intrinsic to the systems and stakeholders around.

Systemic challenges: Nearly half the NCD CSOs identified poor implementation of existing programmes and policies by Government as the major challenge in their line of work, followed by 33% citing insufficient funds as a challenge. The funding challenge had two facets – lack of sustainable funding and the resultant dependence on temporary resources. Unlike some of the other public health issues such as HIV/AIDS and maternal and child health, Government funding for civil society action on NCDs is yet to emerge in the country. This increases the dependence of CSOs on funding from international sources or the private sector for addressing the NCD concerns. However, these are mostly sporadic in nature and do not offer sustainable resources to address the deep-rooted systemic socioeconomic determinants of NCDs such as poverty and inequity. The HIV/AIDS and maternal and child health initiatives of the Government developed specific avenues for CSO funding, which led to extensive and sustainable civil society contributions in these arenas. Similarly, it is critical to develop specific guidelines under the National Programme For Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) for funding civil society action.

Actions of stakeholders: Interestingly, lack of political will, inadequate policies, insufficient civil society advocacy and monitoring, lack of understanding of NCDs outside the health sector and interference by industries with conflicting interests were each cited by over 15% of these organizations. However, as discussed earlier, CSO action is yet to emerge to address these challenges and therefore these denote areas for capacity building.

Relationship between government and civil society: The key informants across sectors identified that relationship with the Government often poses challenges to their work. While some considered lack of awareness about NGO strengths, lack of acceptance of NGO roles and lack of recognition of NGO contributions as stumbling blocks, others reckoned the defensive reactions to civil society advocacy and the bureaucracy of the system to be retarding progress.

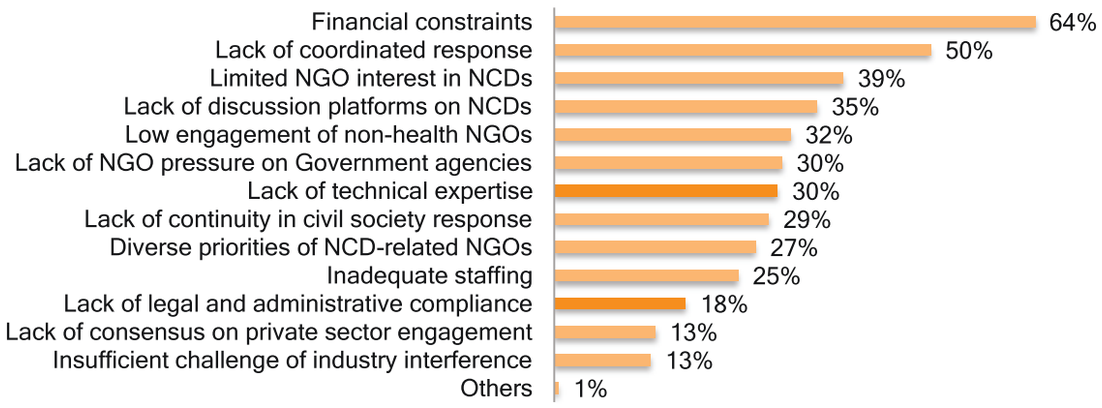
Issues intrinsic to NCDs: Some of the NCD issues such as mental health and women's cancers carry social stigma, which impedes timely diagnosis, treatment and care.

Accessibility issues: The geographical spread of the country, hard-to-reach terrains and the large population were also cited as challenges for pan-India civil society response to the NCDs.

Challenges internal to the NCD civil society movement

Financial constraints constituted the biggest internal stumbling block to CSO action on NCDs, as reported by 64% of NCD CSOs. Lack of coordinated response was the next major identified challenge (50%). This, together with lack of discussion platforms (35%), lack of continuity (29%), lack of NGO pressure on the Government (30%) and diverse priorities of NCD CSOs (27%), all point to the need for coordination and collaboration among CSOs. The limited CSO interest in NCDs (39%) and low engagement of non-health CSOs in the work (32%) call for sensitization and equipping beyond the health sector CSOs.

Fig 9. Internal gaps of NCD CSOs



Some key informants pointed out that coopting of civil society following Government funding affects their ability to hold Government accountable and poses an internal challenge to the CSOs. Any future Government funding for civil society therefore needs to ensure independence of CSOs and their ability to act in public interest. There is also the danger of CSOs losing focus of the affected communities amidst the technical work and financial compulsions.

One interviewee contrasted the civil society response to NCDs with that for HIV/AIDS. While HIV/AIDS initiative has been widely recognized to have been led by civil society in India and abroad, the global agenda on NCDs is perceived to have been driven by intergovernmental agencies and the private sector, with the civil society following their lead. This has been pointed out to have particularly blunted the civil society's ability to hold these agencies accountable and expose the industry's role in aggravating the NCD crisis.

Lack of unity among CSOs has been identified as a challenge to coordinated efforts. The competition for limited funding, power struggles and disconnect between national and subnational CSOs and lack of understanding among different types of CSOs (NGOs/medical organizations/research agencies) seem to account for the disjointed efforts.

The civil society action on public issues in the country has largely been person-centric, revolving around charismatic personalities. As such leadership can hardly be replicated, civil society movements tend to disintegrate post the tenure of such leaders.

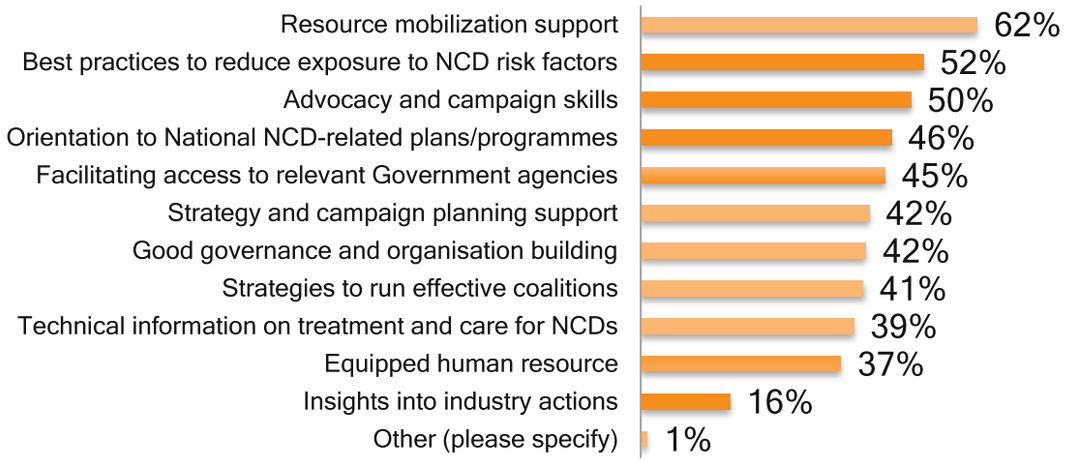
Solutions to address gaps in civil society response to NCDs

Of the NCD organizations, 56% identified capacity building activities as the solution to address gaps in the civil society response, followed by 52% who cited increased civil society sensitization and joint strategic planning. The other major solutions suggested include creating linkages with expert agencies (40%), integration of NCDs into existing programme priorities (39%), joint projects that pool NGO resources and NCD coalition building in the country (37%). There was lesser interest among NCD CSOs in a rights-based approach to NCDs (33%), framing NCDs as a developmental concern (29%) and making a business case for investing in NCDs (22%). This points towards the need to orient NCD CSOs to the socioeconomic approaches to addressing NCD concerns.

Capacity needs

The survey sought to identify the specific areas in which NCD CSOs desired to build their capacity for enhanced response to the issue. The data indicates that NCD CSOs mostly needed support in resource mobilization (62%), best practices on reduction of NCD risk factors (52%), advocacy and campaign skills (50%), orientation to national NCD plans (46%) and facilitating access to relevant Government ministries (45%).

Fig 10. Capacity needs of NCD CSOs



Interviews with key informants indicated a range of capacity needs specific to various NCD sub-streams. Thus, while the cardiology community was interested in developing skills in policy and media advocacy strategies, the cancer and palliative care groups were keen to learn to scale up model interventions, and diabetes organizations were concerned about sustainability of civil society interventions.

The risk factor groups were interested in improving their ability to work across disciplines and sectors. They were also keen to build capacity to develop evidence that showcases the co-benefits of NCD interventions to other sectors. The interviewees were unanimous about paying special attention to building the capacity of CSOs from the north-east to address NCDs and their risk factors.

Opportunities

The increasing public awareness on NCDs in the country has been identified by nearly two thirds of the NCD CSOs as the biggest opportunity to advance action on NCDs in the country. The interviewees confirmed this and called for the next focus to be on turning the significant public awareness about NCDs into public opinion in support of policy and programme interventions. The various NCD-related programmes of the Government and increasing donor attention were each cited by 31% of these organizations. Twenty-four percent mentioned political support for NCD efforts, indicating the need to consider ways to improve it. The proposals for universal health coverage, expanded care networks, increasing media attention on NCD concerns, a sensitized judiciary, state preparedness, increasing evidence of the co-benefits of NCD interventions and the improving recognition of synergies between NCDs and non-health issues were among the other opportunities to accelerate NCD action.

Interviewees across board reported better political receptivity to develop NCD-related policies among state governments than by the National Government. This they thought presented an immediate opportunity for a bottom-up approach to the NCD epidemic. The ban on the sale of smokeless tobacco products by most Indian states, that of alcohol by several states and the regulation on unhealthy food by certain state governments points to this trend. All the same, most interviewees were quick to point out that countrywide targets, policies, frameworks and resources by the national government are essential both to meet its commitment to equitable service to its own people, as also to meet global commitments.

The presence of foundational policy and programme frameworks on some of the NCD issues were pointed out as opportunities on which further action could be built. The National Programme for Palliative Care announced with an initial budget allocation of Rs 650 crores in 2012 is a good example of a framework that can next help integrate palliative care in health-care systems. Those working on issues other than NCDs also pointed out several similar programmatic opportunities. For instance, the Protection of Children from Sexual Offences (POSCO) Act, 2012 changed the scenario for the safety of girl children in the country, where as the Constitution (Eighty-sixth Amendment) Act, 2002 brought inclusivity in education to all children who were outside the system.

Priorities

Respondents were asked to identify three top priorities for civil society action on NCDs in the country. Nearly one third each of the respondents considered facilitating access to treatment and care, health promotion and communication and advocacy for policies to reduce exposure to risk factors among their top priorities. Others stated networking among CSOs in the country, capacity building of NCD CSOs, monitoring government commitments, supporting resource mobilization, monitoring of conflicting industries, research and surveillance, improving patient engagement in civil society action, engaging with non-health sectors of the Government and recruiting and enabling other CSOs to relate their work to NCDs.

When the priorities of NCD CSOs were analysed by their years of work on the issue, health promotion and communication, capacity building of CSOs and supporting resource mobilization tended to be preferred more by recent entrants to this field (initial 5 years), whereas those with over 5 years of work on NCDs tended to consider advocacy for policies to reduce exposure to NCD risk factors, monitoring NCD commitments by the governments, facilitating access to treatment and networking among CSOs as priorities in relatively higher proportion. This calls for a dual approach to the civil society movement building on NCDs in the country, duly catering to the strengths and priorities of recent entrants to the arena as well as those with more years of experience.

Further, the priorities for future action on NCDs identified by the NCD CSOs seem to be along the lines of the current strategies they have reported. The following table presents the most reported current strategy vis-à-vis the most cited future priorities and gives an insight into their complementarity.

Areas of engagement

Current strategy	Future priorities
Reducing exposure to risk factors	Advocacy for policies to address risk factors Health promotion and communication
Early diagnosis	Facilitating access to treatment and care Health promotion and communication
Treatment of NCDs	Facilitating access to treatment and care Monitoring NCD commitments by state and Central governments
Patient care and rehabilitation	Facilitating access to treatment and care Health promotion and communication Supporting resource mobilization
Strengthening health systems	Facilitating access to treatment and care Health promotion and communication
Mobilizing CSO response	Networking among CSOs in the country Supporting resource mobilization
Sensitising non-health sectors	Advocacy for policies that reduce exposure to NCD risk factors Health promotion and communication
Women and NCDs	Networking among CSOs in the country Advocacy for policies that reduce exposure to NCD risk factors
Children and NCDs	Advocacy for policies that reduce exposure to NCD risk factors Networking among CSOs in the country
Elderly persons and NCDs	Facilitating access to treatment and care Monitoring NCD commitments by state and Central Governments
Indigenous populations & NCDs	Health promotion and communication Supporting resource mobilization

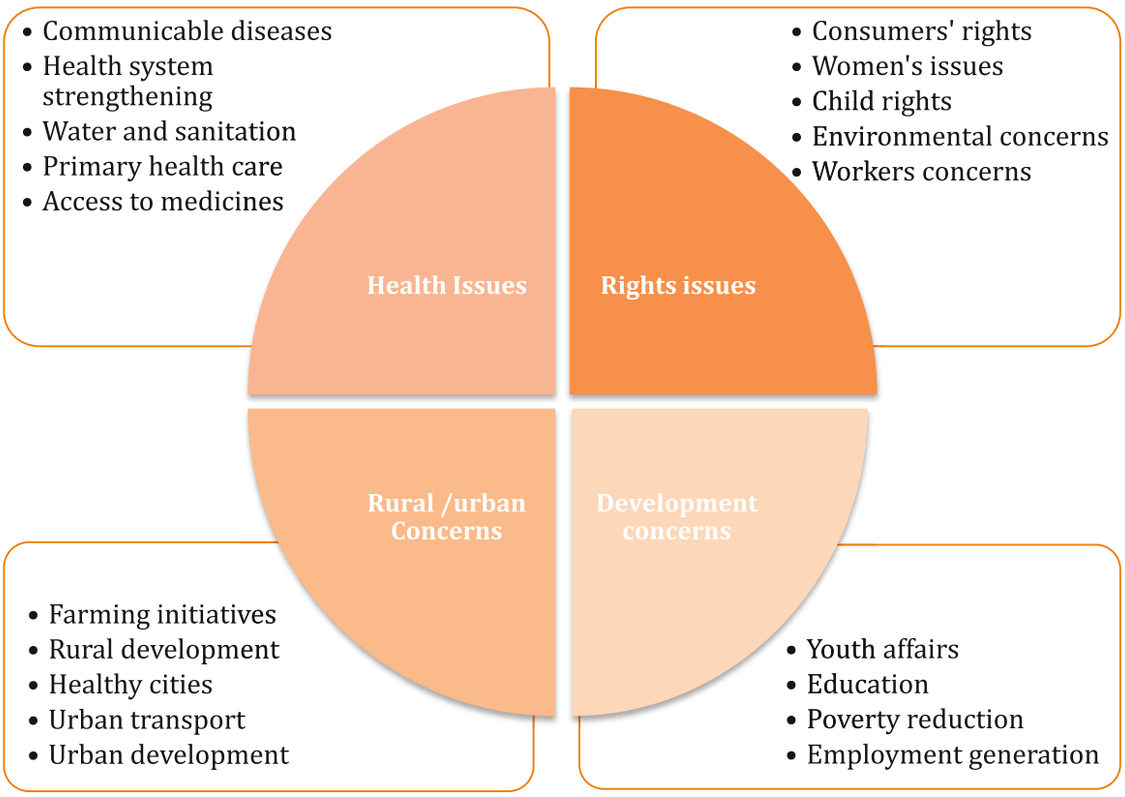
Avenues for NCD–civil society collaboration

Discussion platforms for sharing information were the most reported means of collaboration among NCD CSOs (62%). This was followed by 56% desiring to identify areas for joint action and 51% wanting networking opportunities among CSOs. Forty-eight percent desired guidance on NCD policies and good practices while 47% expressed the need for mechanisms to support advocacy campaigns. Interest in a national coalition to address pan-India issues was the least (46%). Interviewees across the board proposed a cautious approach to coalition building among CSOs on NCDs, largely based on their own previous experiences with similar initiatives. This perhaps explains the relatively lower preference of the NCD CSOs for a national coalition to address the issue.

3 Relevance of the work of other CSOs

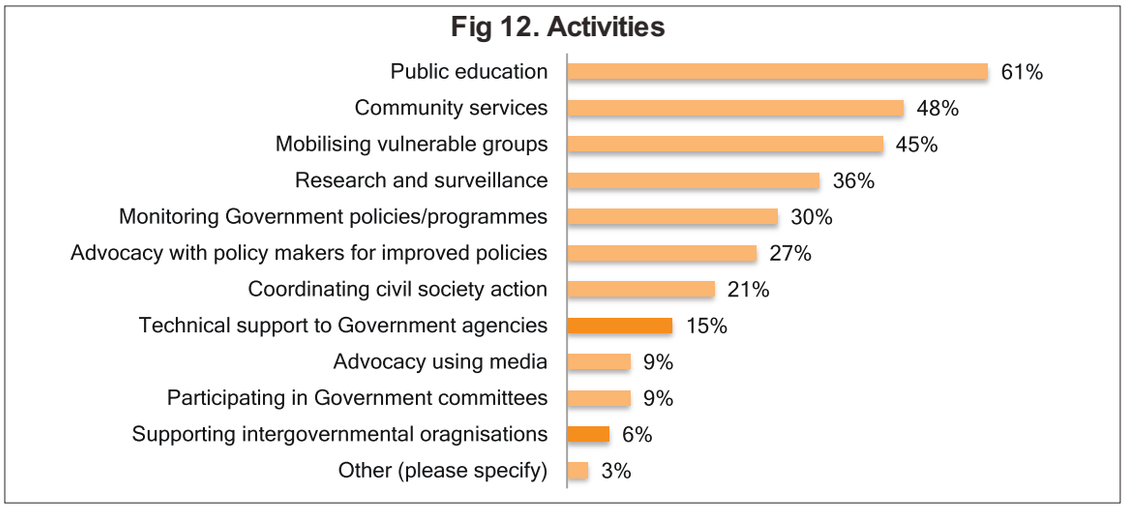
This section describes the work and priorities of CSOs whose work does not currently address NCDs but has relevance for the NCD response, and referred hereinafter as “other CSOs”. As described under the profile of the respondents, these include rights-based organizations, those working on urban and rural issues, poverty, environment and communicable diseases, among others. The survey results and key informant interviews with experts from non-NCD sub-streams of the Indian civil society informs this section.

Fig 11. Issues addressed by other CSOs



Activities

A majority of these organizations (61%) undertook public education initiatives, presenting an opportunity to include NCD components in their educational programmes. Community services were reported as among the activities of over half of these organizations, as also the ability to mobilize vulnerable groups. These could be leveraged to mobilize communities for their entitlements regarding NCDs as also improve the delivery of NCD services at the grass roots. These groups also appear to have significant research and surveillance capabilities (36%), and capability in monitoring government policies and programmes.



Good practices of other CSOs

Nearly three fourths were involved in grassroots mobilization, followed by 67% citing advocacy with policy makers and a close 64% reporting a rights-based approach to public concerns. Notably, these are areas of expertise that have been under-reported among the NCD CSOs. This points to the scope of engaging the other NGOs to build the capacity of NCD CSOs in grass roots mobilization, advocacy planning and building rights-based campaigns. Service delivery and monitoring government action (42% each), building coalitions and partnerships (39%), engaging media (33%), generating actionable evidence (27%), street action (18%) and using courts for legal action (12%) were the other good practices reported by these CSOs.

Strategies that worked for other CSOs

The availability of evidence was reported to be the key in advancing NCD issues across the board. Thus, the initial evidence of high prevalence of HIV/AIDS in the southern states informed early action and flow of resources to that part of the country. Similarly, data on maternal and child mortality helped to identify the 25 high-risk districts in the country where resources and interventions were channelled on priority.

Messages that speak to the heads and the hearts: Environmental campaigners stressed the need to base messages on health science and convey them in a manner that resonates with policy makers, communities and other stakeholders. For instance, the emerging evidence of air pollution on ischemic heart diseases or the greater harm from diesel vehicles needs to emerge in the policy and public dialogues.

Political strategies: CSOs working on child rights have engaged a gamut of strategies to mobilize political support for its campaigns for the legislations on children's rights to education and safety. This included children leading the campaigns, building of policy maker capacity, sensitizing leaders of political parties, equipping media and a robust parliamentary strategy.

Improving stakeholder acceptance of affected communities: This has been most evident in the case of street food vending communities who reported opposition to their business by various groups. The CSOs working with street food vendors organized street food festivals in various town and cities, with a focus on hygienic street food. These events helped to both improve the standards of street food as also build bridges with the public and policy makers.

The Minister of Housing and Urban Poverty Alleviation who was sensitized at such an event in Delhi in 2013 took up the issue in the Rajya Sabha (Upper House) and called for infrastructure for potable water to street vendors. Eventually, the Livelihood Protection Act, 2014 was legislated, and also the Rules under the Food Safety Standards Act, 2006 provided for their training in providing healthy food.

CSOs as "laboratories of model interventions": Rural development organizations experimented with delivery of improved technology for livestock improvement at farmers' doorsteps. The huge acceptance of the initiative received has since made it the industry-standard, duly replicated through Government programmes.

Engaging women as stakeholders has: been a strategy that has worked across issues. The discussions on clean cooking stoves initially revolved around men as technological innovations were then perceived to be largely a male domain. However, CSOs working on the issue reported marked embracement of cleaner cooking options once women were brought into the dialogue from design to use through self-help groups and community-based organizations. Similarly, greater awareness was reported among agrarian communities following nutrition education, cooking demonstrations and exposure visits on fruit preservation among women farmers.

Partnership with governments: The CSOs working on maternal, newborn and child health issues pointed out the significance of mutual respect between Governments and CSOs. CSOs are able to innovate; whereas government has the scale. Engaging government officers on CSO boards, participating in Government committees and joint programmes based on memoranda of understanding with the Government are some ways to build a cohesive partnership with the Government. In one case, the CSO team was physically located at the district health office offering additional human resources, while encouraging district health officers to champion the cause.

Monitoring industry actions: CSOs regularly acting as a watchdog of the pharmaceutical sector has enabled timely litigation against companies that sabotage accessibility and affordability of essential medicines, including those for cancers. Similar monitoring of tobacco companies has led to timely reporting and action against those flouting India's tobacco-advertising regulations.

Prioritizing response to NCDs among other NGOs

The other CSOs expected potential inclusion of NCDs to mostly have a positive influence on their programming. As many as 70% felt it would help secure additional resources, 67% thought it could improve the outcomes of their core programmes, 64% expected it to expand their reach to new Government sectors and 45% thought that shared benefits could economize their core work. Relatively fewer organizations thought that addition of NCDs to their programme could stretch their limited resources (24%), a few did not perceive any connection between NCDs and their programmes (18%) and 12% each were concerned that NCDs can reduce the impact of their core strategies or deflect attention from their core focus.

The interviews with key informants working on issues other than NCDs reiterated the findings from the survey in integrating NCDs in their sector's programme. NCD interventions can do the following:

- **Contribute to overall community wellbeing:** Rural development organizations are primarily focused on improving livelihood options or addressing water concerns. A healthy population, free from chronic diseases is essential to undertake the former pursuit.

- **Help sustain outcomes of existing programmes:** For example, anganwaadis under the Integrated Child Development Services Scheme could be used to raise awareness on healthy diets that will not only help tackle undernutrition but also address the emerging problem of obesity.

- **Improve the outcomes of core businesses:** The street vending community's experience in including health components in their business demonstrates this point. Street food festivals can be used to showcase hygienic food preparation practices and also promote healthier and nutritious alternatives to some of the unhealthy street food options currently in vogue. Safer, healthier food can bring value addition to the street food business.

- **Synergies with existing frameworks/infrastructure:** The HIV/AIDS initiatives in the country have established mechanisms and processes for its service delivery. NCDs such as cervical cancer share a close connection to HIV interventions. This provides room for delivery of primary and secondary NCD prevention components through the existing HIV infrastructure.

The overall openness of other CSOs to address NCDs is an opportunity for the NCD community to reach out and support the inclusion of NCDs in the former's programming. It is also important that evidence and guidance be extended to address any perceived negative impact of NCDs on their core programme.

Strengthening capacity of other CSOs

Sensitization workshops on NCDs and their risk factors, joining a network of NCD CSOs, joint interventions with them and resource mobilization opportunities emerged as the major capacity needs of these organizations.

Key informants from outside the NCD sector expressed the need to be trained in adapting their existing programmes to address NCDs and their risk factors. For example, how could agriculture development be more focused on nutritional crops and improve local availability of fruits and vegetables, thus improving healthy eating in local communities?

A common capacity need among CSOs working on NCDs as well as other CSOs is for support and opportunities for resource mobilization.

Preferred NCD interventions

Involvement in capacity building and raising public awareness about NCDs and risk factors were the preferred activities among other CSOs since it is easy to integrate these NCD interventions into their existing programmes. Organizations also expressed interest in monitoring achievement of NCD targets and policy advocacy. Research, media work, services for NCD patients and monitoring industries with conflicting interest received lesser attention.

Potential convergence between non-health programmes and NCD interventions

Several areas of convergence in programming vis-à-vis NCDs were identified by interviewees not currently working on the issue. Rural development programmes appear to hold solutions to address two of the NCD risk factors. The rural extension programmes can offer alternative livelihoods to tobacco farming and thus contribute to supply reduction. Similarly, Swarnajayanthi Swashaktikaran Yojana (which provides agrarian support to women in rural areas) of the Ministry of Rural Development was cited to have the scope of improving the availability of fruits and vegetables and therefore healthy eating in communities. The recently announced “smart city” initiative of the Ministry of Urban Development holds opportunities to integrate factors that promote healthier lifestyles, such as including footpaths and bicycle lanes that facilitate physical activity and thus help reduce hypertension and diabetes. Similarly, the non-polluting cooking and lighting options from the Ministry of Renewable Energy are important in reducing indoor air pollution and related chronic respiratory diseases. The extensive service delivery mechanisms of the programmes on HIV/AIDS and maternal and child health can be used for delivering NCD interventions to hard-to-reach communities.

4 Areas for potential support from international organizations

The survey respondents and interviewees considered intergovernmental and international organizations to have much to offer by way of support to improve civil society action on NCDs. Providing resources to civil society (64%), providing evidence for action (64%), integrating NCDs into existing development programmes (61%) and building civil society monitoring mechanisms for Government's NCD commitments (55%) were some of the areas where support from intergovernmental organizations such as WHO, United Nations Development Programme (UNDP) and Food and Agriculture Organization (FAO) were most desired.

CSOs also identified several ways in which they can strengthen the work of the intergovernmental and other development agencies. These build on inherent areas of strength of CSOs and include improving community preparedness for NCD interventions (67%), developing best practice models for intervention (65%), providing linkages with public and communities (60%), building political will for NCD policies and programmes (57%), advocacy for NCDs in national development plans (53%) and producing shadow reports on country commitments on NCDs (23%).

5 Way forward

For CSOs working directly on NCDs and their risk factors

- Identify priority areas for action and undertake issue-based advocacy campaigns to stimulate and support action on NCDs across the country through multisectoral networks;
- Effectively leverage current work of CSOs working on issues that are of relevance to NCDs to generate a multisectoral response to the epidemic;
- Develop model interventions and facilitate their scaling up by agencies with the relevant mandate and resources;
- Build capacity of CSOs and governments in prioritizing NCDs as a health and development priority;
- Improve understanding of conflicting industries and report violations of private sector actions that aggravate the NCD crisis.

For CSOs working on issues other than NCDs and their risk factors

- Identify areas of convergence with NCDs and explore ways to integrate NCD action into issues of focus;
- Facilitate access by government and other relevant stakeholders to the NCD response;
- Share lessons learnt from advocacy on other health and development policies.

For national and sub national governments

- Develop guidelines. Include CSOs in the effective implementation of the NPCDCS and provide financial and technical resources;
- Include CSOs working on NCDs and other relevant issues in NCD-related committees of the Government;
- Draw on CSO expertise in developing technical guidance, stakeholder capacity-building and monitoring industry compliance with NCD policies.

For WHO and other international organizations

- Help make the business case for NCDs across sectors and disciplines;
- Involve CSOs in own programmes;
- Facilitate CSO access and inputs to inform key Government programmes and policies.

Annexures

Annex 1 – Landscape of NCD-related CSOs in India

This table has been developed based on qualitative data from the interviews of key informants from specific areas of civil society work relevant to NCDs.

Area of work	Active contributors	Geographical reach	Potential recruits
Tobacco use	Public health NGOs, medical professional bodies, patients' groups, consumer associations, faith-based organizations, research and academic institutions and national and state level coalitions	Expanded from cities in limited states in the 1990s to currently present in all states up to the district and occasionally sub-district levels	Environmental groups, human rights organizations, poverty reduction groups
Harmful use of alcohol	NGOs, de-addiction centres, women's micro credit groups, faith-based organizations, localised anti-alcohol movements	Tamil Nadu, Kerala, Gujarat, north-eastern states like Nagaland, Manipur and Mizoram	Community-based organizations, mental health and counselling professionals, policy advocacy, road safety and women's groups
Unhealthy diet	NGOs, nutrition clinics, school and workplace interventions	Limited to Delhi and certain cities	Maternal and child health organizations, nutritionist associations, food campaigners, industry monitoring groups, farmers collectives, street food vendors
Physical inactivity	Car free movements, yoga centres, urban design and transport planning agencies, campaigns on air pollution and non-motorized transport and environmental protection agencies, resident welfare associations	Mostly large cities	Youth groups, gymnasiums, sports clubs, environmental NGOs, child rights groups, educational institutions, teacher unions, parent–teacher associations
Indoor air pollution	Sustainable energy organizations, technology-based initiatives, community based organizations, environmental organizations	Rajasthan, Tamil Nadu and Karnataka are among the states were action on clean lighting and cooking has picked up momentum. Action initiated recently in Assam, Meghalaya and Tripura	Public health organizations

Cancers	NGOs, survivors support groups, physicians' initiatives	Concentrated in the major cities, with some presence in state capitals, and occasionally in other towns	Paediatric care organizations, child welfare organizations, women's groups
Diabetes	Small NGOs attached to treatment clinics, patient clubs, private teaching institutions, research agencies, faith-based organizations and social clubs	Largely based in major cities with outreachto nearby rural areas	Professional associations of nutritionists, food campaigners, maternal and child health groups
Cardiovascular diseases	Medical professional associations, pharma-affiliated NGOs, hospital-linked foundations	Professional body branches active in select states like Kerala, West Bengal, Tamil Nadu, Jharkhand, Himachal Pradesh, Uttar Pradesh and Rajasthan	NGOs, patient support networks, nutrition and physical activity groups
Mental health	Service delivery organizations, policy advocates, medical professional associations, research agencies and individuals and families	CSOs are based in urban centres with recent outreach to rural pockets with greater coverage in southern and western India	NGOs, patient support networks
Palliative care	Service delivery organizations, policy advocates, medical professional associations, and individuals and families.	Concentrated in Southern states of Kerala, Karnataka and Tamil Nadu, capitals and cities of other states	HIV/AIDS groups, CVD community and palliation-specific groups across states
NCD research	Public health organizations located in cities and state capitals. Some of them are attached to academic institutions or hospitals while others are either part of large NGOs or stand-alone research centres		Environmental research agencies and nutrition researchers
Health systems strengthening	Service delivery organizations, research organizations, feminist organizations and trade unions	State and district level organizations as well as international NGOs	Medical professional bodies

HIV/AIDS	Large NGOs that are the Indian chapters of international NGOs, state level NGOs, community-based organizations, organizations working with vulnerable groups, access to medicines campaigns, legal initiatives	South Indian states have greater civil society presence compared to other regions	Organizations linking communicable and noncommunciable diseases, groups working with women and youth
Maternal and child health	Community based organizations, medical professional bodies, research and academic institutes	Select states mainly in Northern India such as Rajasthan, Karnataka, Uttar Pradesh, Jharkhand, Chattisgarh, Madhya Pradesh and Bihar	Professional associations of nutritionists, organizations working on adult nutrition
Environmental concerns	National level NGOs focused on policy, research and technical support, issue-specific grass roots groups, large groups building capacities of smaller groups, individual initiatives, social entrepreneurships and international organizations working in India	Spread across the country at national, state and grass roots levels	Public health organizations
Farming initiatives	Non-profit organizations working on food production, livestock care, resource management, livelihood issues, social entrepreneurs, farmers collectives, agrarian research agencies	National and state level NGOs	Policy oriented organizations
Street food vending	Rights based unions and NGOs working for the welfare of the street vending community	Good organizations in selective cities of the following states: South – Andhra Pradesh, Karnataka, Telengana; North – Bihar, Uttar Pradesh, Rajasthan; West – Maharashtra and Gujarat; North-east –Assam & Meghalaya	Food campaigners, research and testing agencies, medical associations, water campaigners
Child rights	Service delivery organizations, rights based agencies, organizations mobilizing action on behalf of children	Across the country, at national and state levels	Those having an interface with NCDs

Annex-2 – Survey questionnaire

1. What is the full name of your organization?
2. Please provide your organization's website address (if any):
3. In which Indian state or union territory is your organization legally registered?
4. In which year was your organization formed?
5. What is the nature of your organization?
6. The main strength of your organization's work is in:
7. Which are the top five states or union territories in India where your organization works?
8. Who are the top three target audiences of your organization's work?
9. What are your organization's major sources of financial support?
10. Does your organization's work directly address any of the major noncommunicable diseases (NCDs) or their risk factors?

Section I. For organizations focused on NCDs/risk factors

1. How many years has your organization worked in the area of NCDs or their risk factors?
2. Which NCDs/risk factors does your organization's work most relate to?
3. What are the top three focus areas of your organization's work within the NCD spectrum?
4. What are the top three NCD-related activities of your organization?
5. What are the top two of your organization's strategies that have led to specific outcomes vis-à-vis various targets groups?
6. How does your organization seek to engage NCD affected patients in its work?
7. What are the top three external challenges to work on NCDs in the country?
8. What do you see are the major gaps in the civil society response to NCDs in the country?
9. What do you think are the potential solutions to address the gaps in civil society response to NCDs in the country?
10. What are the major capacity needs of the Indian civil society in addressing the NCD concerns?
11. What do you consider are top three opportunities to advance civil society action on NCDs in the country?
12. What do you think should be the top three priority areas for civil society action at the national level to combat NCDs in the country?
13. What kind of civil society collaboration at national level can enhance your work on NCDs?

Section II. Questions for organizations with focus other than NCDs

1. What are the top three focus areas of your work?
2. What are the top three activities of your organization?
3. What are some good practices from your area of work that could help advance action on NCDs?
4. In what ways do you think addressing NCDs could influence the work of your organization's key focus area?
5. What could enhance your ability to contribute to NCD prevention and control?
6. Which top three NCD interventions would you find most suitable for integration in your existing programme(s)?

Section III. Concluding questions for all respondents

1. What are the top three ways in which you could enhance civil society action on NCDs?
2. What are the top three components you would appreciate in a civil society coalition addressing NCDs and their risk factors?
3. What are the specific areas in which WHO and other international organizations (e.g. UNDP, FAO) can support civil society advocacy regarding NCDs in the country?
4. What are the ways in which civil society can support WHO, UNDP and other international organizations to contribute to the prevention and control of NCDs?
5. Please provide any other brief comments you think would help the WHO to better understand your organization's work.