



Building Communication and Advocacy Skills among People Living with Non-Communicable Diseases

A TRAINING MANUAL

NOVEMBER, 2021



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ACRONYMS AND GLOSSARY

CVD: -----	Cardiovascular disease
HIV: -----	Human immunodeficiency virus
IDF: -----	International Diabetes Federation
WHO: -----	The World Health Organization
SEAR NCDA: -----	South-East Asia Regional NCD Alliance
HIA: -----	Healthy India Alliance (India NCD Alliance)
NCDA: -----	NCD Alliance
ADVOCACY: -----	Achieving systems change. A strategic approach to influence decision makers to create new policies, laws, regulations, programmes, processes, procedures and so on, or to modify or discard existing ones.
EVALUATION: -----	A process that assesses the value delivered by a training or facilitation exercise.
FACILITATING: -----	Making an action or process easier. Facilitators help people develop their own knowledge or skills in order to achieve their goals.
NARRATIVE: -----	A story, which might be spoken or written.
NCDS: -----	Non-communicable disease ¹ , such as cancer, cardiovascular disease, chronic respiratory disease, diabetes and mental health disorders, along with a range of other diseases and conditions.
PEER LED TRAINING: -----	Training that is led by people who share something in common with the participants, for example people living with NCDs.
PEER TRAINING: -----	Training that involves people with shared experience of something, for instance people living with NCDs or people with lived experience.
PUBLIC NARRATIVE: -----	A leadership practice that translates values into action by linking your own story with shared experiences or values and the action you want to be taken.
REFLECTION: -----	A process that provides time and space to think about what you have experienced, witnessed or heard and what your response will be. This might be a thought, feeling or action.
TRAINING: -----	Teaching someone a skill or behaviour by sharing information and taking them through activities. Trainers share knowledge and help people learn new things.

¹Noncommunicable diseases (who.int)

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INTRODUCTION

Non-Communicable Diseases (NCDs) pose a significant and critical burden to the overall global public health scenario. While several efforts and initiatives have been underway over the years to address this burden and put forth workable solutions to the challenge of managing these illnesses better, not enough has been done to support key stakeholders who can drive change.

The aim of this manual is to offer guidance to multiple stakeholders as they work together to strengthen the community, effectiveness and impact of people living with Non-Communicable Diseases (NCDs) as well as stakeholders from countries of the South-East Asia Region (SEAR). This manual is designed for an online workshop with People Living with Non-Communicable Disease to support them in becoming strong advocates for the NCD agenda, communicate effectively and collaborate to build a call to action around NCDs through regional and country level networks. The key objectives of this skills-building initiative are:

- ▶ To develop and strengthen communication and advocacy skills of people living with NCDs to advocate for issues related to NCD prevention and control,
- ▶ To highlight the importance of people-centered approach through capacity building of those with lived experiences.
- ▶ To provide support in developing and implementing country-level action plans focusing on meaningful involvement of people living with NCDs in the Regional, National and sub-national NCD response.

Overview of the Burden of NCDs

Globally, health systems are failing to provide effective treatment, care and support for people living with NCDs. NCDs often affect communities differently, highlighting the need for tailored approaches to preventing and treating NCDs effectively and ensuring equitable access to treatment and care. The 2018 UN Political Declaration on NCDs, marked a transition from a '4x4' approach to NCDs (encompassing four leading risk factors and four major diseases) to a more comprehensive '5x5' response to include air pollution as the fifth risk factor and mental disorders as the fifth NCD.



Cardiovascular diseases (CVDs)



Chronic obstructive Pulmonary Diseases (CoPDs)



Cancer



Diabetes



Mental Disorders

The matrix also includes five behavioural risk factors:



Unhealthy Diet



Tobacco Use



Alcohol Use



Physical Inactivity



Air Pollution

NCDs have become even more significant as a major public health burden, during the Covid-19 era. With co-morbidities having been recognized as a serious confounding factor in the overall COVID-19 response, it is clearly evident that an adaptive response to account for the needs and priorities of People Living with Non-Communicable Disease has to be built and strengthened with urgency. The recent pandemic has resulted in a high proportion of people with various NCDs such as CVD, diabetes and cancer, besides other conditions, being hospitalized with severe manifestations of COVID-19. In addition, the pandemic has caused grave disruptions in routine healthcare services. Measures to contain COVID 19 infection including physical isolation at home among family members has put the people of all age group at serious mental health risk. A WHO survey² conducted in mid-2020 reported that services for diabetes and diabetes-related complications had been partially or completely disrupted in around half of the countries surveyed. In addition to these challenges, people living with NCDs often experience stigma, resulting from lack of awareness and myths and misconceptions about the disease in their communities.

² <https://www.who.int/news/item/01-06-2020-covid-19-significantly-impacts-health-services-for-noncommunicable-diseases>

Regional Landscape of NCDs in the SEAR

Globally, about 71% (41 million) of all deaths are attributed to NCDs³. An estimated 8.5 million people die every year from NCDs in the SEAR⁴. While NCDs are the leading cause for death in the region, CVDs, CRD, diabetes and cancer are the major killers⁵. In SEAR, 62% of all deaths are caused by NCDs, and the proportion of NCD deaths in the region among people below the age of 70 years is 48%. Disproportionately affected are Low and Middle-Income Countries (LMICs) which account for about 86% of all premature NCD deaths⁶. The burden and rise of NCDs constitutes a major public health challenge that threatens to hinder the achievement of reducing premature mortality from NCDs by one-third in 2030.

Overall, NCDs are estimated to account for the following percentages of deaths in SEAR countries –

67% in Bangladesh, 69% in Bhutan, 63% in India, 84% in Democratic People’s Republic of Korea, 73% in Indonesia, 84% in Maldives, 66% in Nepal, 68% in Myanmar, 83% in Sri Lanka, 74% in Thailand and 45% in Timor-Leste⁷.

Major risk factors contributing to NCDs⁸ include tobacco use, harmful use of alcohol, unhealthy diet, and physical inactivity, and air pollution.

Alcohol use is the cause for more than one in 20 deaths in the SEAR and across the world. Per capita, alcohol consumption has substantially increased in the SEAR since 2010 and is projected to increase further if it remains business as usual⁹.

³ World Health Organization, Global Health Observatory. Noncommunicable Diseases: Mortality.

<https://www.who.int/data/gho/data/themes/topics/topic-details/GHO/ncd-mortality>

⁴ World Health Organization Regional Office for South-East Asia. Noncommunicable diseases in South-East

Asia. <https://www.who.int/southeastasia/health-topics/noncommunicable-diseases>

⁵ World Health Organization. NCDs Overview. <https://www.who.int/southeastasia/activities/noncommunicable-diseases-are-the-no.-1-killers-in-the-who-sear>

⁶ NCD Alliance, Why NCDs, <https://ncdalliance.org/why-ncds/NCDs>

⁷ Noncommunicable diseases country profiles 2018. Geneva: World Health Organization; 2018

⁸ Noncommunicable diseases (who.int)

⁹ World Health Organization. Regional Office for South-East Asia. (2019). Making South-East Asia SAFER from alcohol-related harm: Current status and way forward. World Health Organization. Regional Office for South-East Asia. <https://apps.who.int/iris/handle/10665/326535>

Smoking is observed to be common in the region. More than 8 million people's lives claimed due to tobacco globally, 1.6 million lives are from the SEAR. Moreover, 22% of the world's tobacco users are from the SEAR¹⁰. About 35.3% (37.8 million) of all adults were found to be tobacco users in Bangladesh in 2017¹¹, 28.6% in India (a 6% reduction was observed from the previous survey in 2009) in 2016-2017¹², and 36.1% in Indonesia in 2011¹³.

Globally, obesity has almost doubled between 1980 and 2014 with 11% adult men and 15 % of women reported to be obese¹⁴. In Asia, combined effects of rapid economic and social change, urbanization, globalization, are transforming the way people eat – from traditional diets to those high in empty calories, sugar, salt, and saturated fat which are primary causes of diet-related NCDs¹⁵. Among countries in the SEAR, dietary habits such as low intake of fruits in Bangladesh, high intake of sodium in Thailand, and low intake of whole grains in India were leading dietary risk factors for deaths and Disability-Adjusted Life Years (DALYs)¹⁶.

Prevalence of insufficient physical activity was seen to be the lowest in South-East Asia (15%) in 2014, however, there is a substantial variation in data from Prevalence of insufficient physical activity was seen to be the lowest in South-East Asia (15%) in 2014¹⁷, however, there is a substantial variation in data from countries¹⁸. With only 3.5% insufficiently physically active adults, Nepal is the most active country in the region whereas Maldives has the highest prevalence of insufficient physical activity (45.9%).

Air pollution is estimated to have contributed to 2.4 million premature deaths in 2016, with the burden of the SEAR being the largest in the world¹⁹. The social and economic burden of NCDs can be a potential threat to development for developing countries. Estimates suggest that between 2012 and 2030, India stands to incur a cost of \$4.58 trillion due to NCDs and mental health conditions^{20,21}, of which CVDs and mental health are said to account for majority of the costs. All countries in WHO SEAR have Action Plans in place to tackle NCDs, however, optimal implementation is key to achieving global targets and SDGs²².

¹⁰ World Health Organization. Tobacco Control in South-East Asia. <https://www.who.int/southeastasia/health-topics/tobacco>

¹¹ Bangladesh Bureau of Statistics and National Tobacco Control Cell. Global Adult Tobacco Survey Report, Bangladesh, 2017. Dhaka: Bangladesh Bureau of Statistics and National Tobacco Control Cell, 2019. https://ntcc.gov.bd/ntcc/uploads/editor/files/GATS%20Report%20Final-2017_20%20OMB.PDF

¹² Ministry of Health and Family Welfare, Government of India. Global Adult Tobacco Survey Report – 2, India, 2016-2017

¹³ World Health Organization. Regional Office for South-East Asia. (2012). Global adult tobacco survey: Indonesia report 2011. WHO Regional Office for South-East Asia. <https://apps.who.int/iris/handle/10665/205137>

¹⁴ World Health Organization. Global status report on noncommunicable diseases 2014. Geneva, Switzerland; 2014. (Global Status Report, 2014)

¹⁵ Kaneda T, Naik R. Young people are Asia's key to curbing the rise of noncommunicable diseases. Population Reference Bureau. Jul 2016. www.prb.org/Publications/Reports/2016/ncd-risk-youth-asia.aspx

¹⁶ GBD 2017 Diet Collaborators (2019). Health effects of dietary risks in 195 countries, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet* (London, England), 393(10184), 1958-1972. [https://doi.org/10.1016/S0140-6736\(19\)30041-8](https://doi.org/10.1016/S0140-6736(19)30041-8)

¹⁷ Global Status Report, 2014

¹⁸ Status report on 'physical activity and health in the South-East Asia Region': July 2018. New Delhi: World Health Organization, Regional Office for South-East Asia; 2018.

¹⁹ World Health Organization. Air Pollution. <https://www.who.int/southeastasia/health-topics/air-pollution>

²⁰ <https://www.who.int/news-room/articles-detail/lived-experience-advocacy-research>

²¹ World Economic Forum and Harvard School of Public Health. (November 2014). Economics of Non-Communicable Diseases in India Executive Summary.

https://iogt.org/wp-content/uploads/2015/03/WEF_EconomicNonCommunicableDiseasesIndia_ExecutiveSummary_2014.pdf

²² WHO NCDs Progress Monitor 2017 <https://apps.who.int/iris/bitstream/handle/10665/258940/9789241513029-eng.pdf;jsessionid=F11BA4102F49A35B099949525EE78100?sequence=1>

The Need for People Living With NCDs Networks At Regional & National Levels

It is crucial to establish a network of lived experience advocates at regional and national levels to be able to address the mounting issues present in the NCD landscape. A recent landmark in terms of meaningful involvement of people living with NCDs is evident through the development of WHO's Global Diabetes Compact. Responding to the increasing burden of diabetes around the world, the World Health Organization has recently launched the Global Diabetes Compact, to coincide with the 100th anniversary of the discovery of insulin. The WHO Global Diabetes Compact was launched at the Global Diabetes Summit, co-hosted by the World Health Organization and the Government of Canada, with the support of the University of Toronto, on 14 April 2021

The WHO Global Diabetes Compact has the vision of reducing the risk of diabetes and ensuring that all people who are diagnosed with diabetes have access to equitable, comprehensive, affordable, and quality treatment and care. The work undertaken as part of the Compact will also support the prevention of type 2 diabetes from obesity, unhealthy diet, and physical inactivity.

There is an urgent need to better prevent and care for diabetes in primary health settings, and for considering diabetes in plans to advance universal health coverage. Investment in training of health-care workers in diabetes prevention and management, and better integration of diabetes care at primary health care level, are fundamental building blocks. The Global Diabetes Compact will focus on supporting countries to implement evidence-based interventions based on country-specific needs, building on and integrating within existing systems. Specific interventions will also be tailored for resource-limited settings and humanitarian contexts. To improve the care that people receive to prevent and control diabetes, the insights and perspectives of people with lived experience with the condition are fundamental. Building on a first global consultation with people living with diabetes in March 2021, those with lived experience were invited to partner on, and continue to co-create, each of the eight priority areas for action.

In 2020, global health priorities were rapidly transformed, making it increasingly challenging to provide relevant policies and programmes for non-communicable diseases (NCDs) and mental health priorities that can be translated into regional or country contexts, while also responding to the interplay between novel coronavirus (COVID-19) and NCDs. Health-care systems are experiencing increased resource constraints, conflicting priorities, challenges related to emerging or re-emerging diseases, and difficulties in prioritizing NCDs in the midst of the global pandemic.

Sustainable alternatives are required to optimize the relevance of NCD and mental health priorities, policies, and practices at regional and national levels during COVID-19 and to build back better. This is a key opportunity to harness the power of community knowledge to tailor the priorities, programmes and practices so that they are contextually feasible, appropriate and attractive to the target populations.

²³ <https://www.who.int/initiatives/the-who-global-diabetes-compact>

²⁴ https://cdn.who.int/media/docs/default-source/diabetes/gdc_need_to_know_web.pdf?sfvrsn=7a4af558_4&download=true

This approach was adopted by WHO Member States in the Alma Ata Declaration (1978), which emphasizes the importance of community engagement in primary health care and states that improving the health of all people extends from care provision by clinicians, hospitals and biomedical advances to human rights, equitable access and affordability and community and individual self-reliance and participation.

The UN Omnibus on COVID-19 mentions importance of involving civil society and people living with disabilities (NCDs). UN Political Declarations on NCDs and UHC from 2018 and 2019 respectively highlight need to amplify voices of communities. The outcome document of the Rio+20 Conference, the Future We Want, recognizes that “opportunities for people to influence their lives and future, participate in decision- making and voice their concerns are fundamental for sustainable development”.

The Rationale for Skilling People Living With Non-communicable Disease for Meaningful Engagement

The current global health approach can be criticized as being a top-down, one-size-fits-all, or donor-driven model. Now, a bottom-up, contextual model is emerging, which empowers national actors, local communities, grassroots advocates, and individuals. Leveraging the power of local communities, individuals with lived experience, and advocates results not only in contextually appropriate programmes but also buy-in and the sustainability of health interventions. Insights from individuals who are experiencing specific health issues can show contextual influences on health literacy, health behaviour, barriers to accessing and sustaining health care, and limitations to the delivery of siloed rather than person-centered health interventions, which could accelerate the operationalization of health agendas worldwide by bridging from global to local. Engaging people with lived experience is the way to design appropriate, equitable, context-specific NCD policies, programmes and interventions, while ensuring their relevance and buy-in by the target population.

The meaningful involvement of people living with NCDs is a critical element of an effective and people-centred NCD response. From policy making to awareness raising, clinical trials, academic research, advocacy, organisational governance and more, people living with NCDs can contribute to different facets of the NCD response and act as role models breaking barriers to inclusion. In order to decode and promote meaningful involvement of people living with NCDs, [Our Views, Our Voices](#) an initiative of the NCD Alliance and people living with NCDs is dedicated to promoting their meaningful involvement in the NCD response, supporting and enabling individuals to share their views to take action and drive change.

The initiative was guided by the [Advocacy Agenda of People Living with NCDs](#), built with the generous input of nearly 2000 people living with NCDs who took part in the consultative efforts. The Advocacy Agenda serves as a compass for action for the NCD community and calls for the involvement of people living with NCDs in government decision-making bodies and processes.

It has four pillars: prevention, treatment, care and support, social justice, and meaningful involvement. In 2018, the UN HLM on NCDs offered a real opportunity to further the Advocacy Agenda of People Living with NCDs. As the result of concreted advocacy efforts, the contributions of people living with NCDs and civil society, as critical enablers of accelerated NCD responses, were acknowledged in the Political Declaration on NCDs adopted by the Member States during the meeting.

In 2021, NCD also launched the Global Charter on Meaningful Involvement of people living with NCDs. The ‘Global Charter on Meaningful Involvement of People Living with NCDs’, is based on the principle that people living with NCDs – including care partners (also known as carers or care givers) – should be meaningfully involved in every step of decision-making that affects their lives. The aim of the Global Charter is to have meaningful involvement of people living with NCDs embedded into organisational practices and mobilises all actors such as governments, international partners, private sector and civil society organisations.

The Global Charter calls on organisations and institutions to publicly endorse the Charter – and commit to fundamental principles and ten core strategies. These strategies will enable the meaningful involvement of people living with NCDs in decision-making at all levels - from the first stages of design, implementation to monitoring and evaluation and scale-up of NCD policies, programmes and services. SEAR NCDA, as one of the early endorser of the Charter is committed to operationalise the Global Charter by providing capacity building opportunities to those with lived experiences.

One of the core strategies of the Global Charter is to support people living with NCDs with training opportunities so this workshop can be positioned as a step to operationalize the Global Charter.

Promoting meaningful involvement requires the creation of enabling environments, including dedicated spaces for involvement, as well as fully supporting people living with NCDs to take action. This session helps participants to explore the concept and definition of meaningful involvement and discuss its relevance in the context of NCDs. It also offers a framework for meaningful involvement of people living with NCDs and identifies key skills required to achieve meaningful involvement.

To improve the care that people receive to prevent and control diabetes, the insights and perspectives of people with lived experience with the condition are fundamental. Building on a first global consultation with people living with diabetes in March 2021, those with lived experience will be invited to partner on, and continue to co-create, each of our eight priority areas for action.

Healthy India Alliance (India NCD Alliance): A sneak peak into country level prioritisation for a people centred NCD response

The Healthy India Alliance (HIA) is a coalition of 19 multi-disciplinary Civil Society Organizations (CSOs) engaged in multi-pronged action around NCD prevention and control, focusing on engaging with non-health sector partners and key stakeholders like people living with NCDs and youth. Since 2017, HIA has been closely involved with the Our Views, Our Voices initiative, leading the process of meaningfully involving people living with NCDs in the NCD response through regional and national community conversations and workshops. These workshops, unique and first of their kind, being led by HIA in India, helped build the India Advocacy Agenda of people living with NCDs. Since 2020, HIA also hosts the Secretariat for the South-East Asia Regional NCD Alliance.

As part of the Our Views, Our Voices initiative, HIA has been prioritizing meaningful involvement of those living with NCDs to call for people centeredness in policy formulation and programme implementation. In December 2019, HIA released the India Advocacy Agenda for People Living With NCDs. The year 2020 was focused on understanding the needs, priorities and challenges of people living with NCDs during the COVID-19 pandemic to inform agenda setting for the Alliance. Thereafter, since March 2021, HIA has been a part of the process of developing the Global Charter on Meaningful Involvement of people living with NCDs.

HIA, is now prioritizing engagement of sub-national stakeholders and decision makers to identify opportunities to provide people living with NCDs with a “voice at the table”. These sub-national efforts led by local partners are an effort to call for endorsements and support for the Global Charter even at the grassroots level, to help decode the benefits of meaningful involvement in decision making.

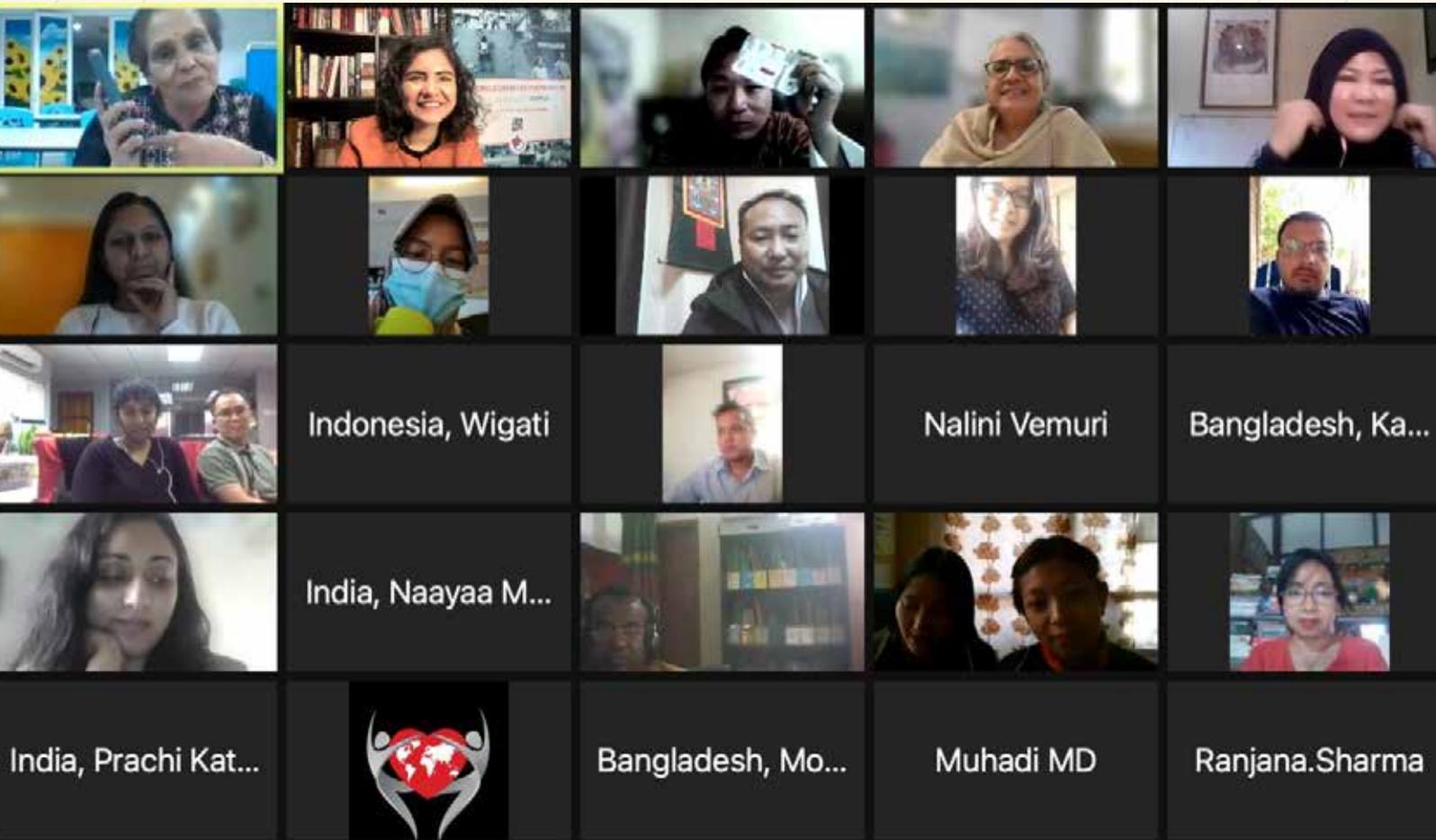


Nothing for Us, Without Us

The participation of individuals with lived experience provides powerful expertise and narratives to shape policies, inspire others to join the movement as agents of change and influence and inform those in power. Communities and individuals have a right and a duty to participate in the design and delivery of their healthcare. The right to participate is an essential feature of the right to the highest attainable standard of health. The transfer and reorientation of power to people with lived experience is essential to ensure adherence to the principles of respect, value and dignity in meaningful engagement and support for health for all.

A community may be considered a group of individuals who identify as having a common context, experience of living with a disease, experience of working with a disease or a duty of care to people who have experienced the disease. The community of people who live with one or more NCDs is indeed a unique collective that can drive a lot of the change and impact that the world needs around the management of NCDs. It is important, however, to allow participants to self-declare themselves as members of the community and not to assume that individuals are part of a community just because they have similar traits or experiences.

Working with communities and individuals who have first-hand experience and, in many cases, expertise regarding their health, health care and contextual factors and determinants is essential in designing effective, inclusive, equitable interventions that leave no one behind. This is also an important principle of the decolonizing global health movement.



Introduction to the Manual

Welcome to the Driving Change Workshop, a capacity enhancement initiative to Build Communication and Advocacy Skills among People Living with Non-Communicable Diseases. This Advocacy and Communication workshop aims to create a network of People Living with Non-Communicable Disease in SEAR and equip them with skills to become effective spokespersons to amplify the Advocacy Agenda to help improve the way the world is responding to NCDs as a public health challenge. Through improved advocacy and communication skills, People Living with Non-Communicable Disease can individually, or collectively, work towards building or strengthening an enabling environment in their country, region or even globally, for action to prevent and control NCDs.

This workshop is the first effort to bring together People Living with Non-Communicable Disease in the SEAR based on an urgent need of the hour - which is to collaborate, network and align as a collective in order to help each other, and to lend the voice of those most affected to a regional and global change agenda. While this particular workshop is a short programme, it may be viewed as a precursor to a deeper and intensified approach that can eventually lead to the creation and fostering of a group of master trainers. This group, in turn, can facilitate a cascade training model that could be adopted to offer continued skilling and capacity enhancement in order to keep the discourse on track, continuously bring up current issues for communication and advocacy, and help develop lasting and productive relationships with multiple stakeholders in order to bring lasting and positive change in the way NCDs are handled and managed.

The Workshop Framework

This manual guides workshop participants through a participatory approach designed to enable shared understanding of key concepts critical to NCDs as relevant to the potential role that People Living with Non-Communicable Disease can play in building an enabling environment for a more robust response to NCDs, regionally and globally. The selection of participants has been based on the following criteria:

- Experience of living with (which includes caring for someone with) an NCD, or multiple NCDs
- A willingness to share individual experience
- A collaborative and motivated approach to contribute to activities and group discussions
- The enthusiasm to learn and grow your NCD prevention and control efforts
- An understanding of what it means to be a spokesperson and have the qualities that will be needed to influence others and support positive activity

Overall, you will learn how to build, enhance and support diverse communication and advocacy efforts related to improving the response to NCDs. You will:

- Work closely as NCD champions and spokespersons with the SEAR NCDA and member alliances to build on a call for action (through a country-level action plan)
- Work closely with the Alliance members to prioritise the NCDs response agenda of people with lived experiences

In order to achieve all of the above, the following key domains shall be covered during the workshop:

- Learning to be an effective communicator
- Understanding the importance of advocacy, and its use to drive change through the development of an advocacy agenda
- Developing an understanding of leadership and how leaders can make a difference

The advocacy and communication workshop will take place over one and a half days, in an online format led by experts/resource persons from various sectors. The workshop will use adult learning principles and cover key areas as described above.

Workshop Guidelines

This is a virtual event. The entire workshop is conducted in a safe and respectful space for discussion, with confidentiality as a key principle. Broad guidelines that you are advised to follow are:

- ▶ Please be on time, and give your full attention to the entire proceedings

- ▶ Cross-check and ensure all training requirements beforehand, such as your Internet connection, lighting, the choice of a place where you shall be seated (to be quiet and noise-free and peaceful)

- ▶ Keep pen and paper at hand as a scribble pad so that you are able to capture all your observations, thoughts, participate in group work etc

- ▶ Have your video on all through the workshop

- ▶ Mobile phones are not allowed during the workshop

- ▶ Participate actively, communicate, bring up issues, use the “raise your hand” and chat options actively whenever you feel the need, engage with other participants

Module 1: Learning to be an Effective Communicator

Robust communication is one of the most critical and significant aspects of any process or initiative that seeks to drive change or build and strengthen an effective response to a public health challenge. The first module of the workshop addresses the importance of learning how to be an effective communicator in order to achieve key milestones in the change agenda of how NCDs are currently managed and the existing response.

Session Objective:

- ▶ Understand the importance and key aspects of effective communication and being an effective communicator
- ▶ Identify major communication opportunities and challenges
- ▶ Develop and deliver communication messages to major stakeholders

Interactive Session: Moderated Discussion on the presentation addressing questions from participants, or any shared perspectives



Presentation: TELLING THE STORY

Key Principles of Communication; the What - Why - When - Where - With Whom framework; Understanding your strengths and challenges as a communicator.

The presentation (Annexure 1) will orient and sensitise participants in relation to the following:

- Communication is critical to driving change agendas, but for it to be strategically designed, planned and implemented, there is a need to develop a greater understanding of what exactly constitutes communication for change
- Communicating for policy change can be very different from communicating at the level of individuals or communities for behaviour change, and understanding this difference is critical
- What is the purpose of developing an effective communication strategy and message? How can the perfect message be developed? What is the best delivery channel, or communication approach, that needs to be adopted? Understanding different delivery modes
- The importance of a communication campaign
- Learning to be an effective communicator
- Understanding my audience, and different perspectives of a problem/issue/challenge for which communication is desired and designed

Group Work:

- The workshop participants are divided into four groups of 10 each, and one person is identified as key facilitator in each group. The same groups can work together through Module 2 also.
- Each group will work on developing a plan for a mass media campaign. The topic of the campaign is: THE EAT RIGHT-MOVE RIGHT CAMPAIGN - Spreading awareness about healthy choices to prevent NCDs
- Each group picks up one particular mass media approach (traditional news media, such as print or television; digital news media; social media; film; mid-media) and develops a quick campaign idea
- The campaign idea can be designed based on what participants have learnt in the presentation and interactive session just prior to the group work. But, the key resource person may also be required to provide major guidelines for developing a campaign idea. This can be communicated through one slide that encapsulated key activities that are required as part of a campaign
- The group work session ends with each group sharing back with the larger group about their campaign idea (In just two minutes each)

Module 2: Understanding Advocacy and how to use Advocacy for Change

Advocacy is a highly effective tool to drive change, but it is also a highly skilled craft and requires specific capacity. Using advocacy as a systematic and strategic process, we can work towards different aspects of a larger change agenda, initially focusing on the low-hanging fruit in terms of knowing what can bring success and progress.

Session Objective:

- Understand key advocacy issues and solutions
- Identify major advocacy opportunities and challenges
- Identify key steps in the advocacy process
- Learn about popular and effective advocacy techniques and their usage with different influencers



Interactive Session: A few participants are requested to share any example of successful advocacy that they have achieved. These examples are used to discuss a Policy Brief; Understanding the Need for Evidence; Evidence to Action.

Presentation: LET'S PUSH FOR CHANGE

Key Principles of Advocacy; the need to know what needs to change, and how; advocacy tools and techniques (a short class) The presentation (Annexure 2) will orient and sensitise participants in relation to the following:

- Advocacy is a very specialised activity that can be applied under any setting, but requires a clear understanding of what needs to change, how that change can be brought about and what needs to be done to succeed
- Data, evidence, facts and messages that convert evidence-driven knowledge into actionable: understand data, become familiar and comfortable with searching for relevant data, using it by converting the numerical narrative into a social narrative (what is evidence-based advocacy)
- Examples of advocacy leading to policy change
- Do you know your primary, secondary and tertiary target groups / stakeholders / audience? Who are the people or which are the organisations or what are the networks that can make a difference in shifting the discourse and influencing the change agenda impactfully? Do we know how to engage with each, work with each in order to facilitate the advocacy that is our goal?
- Developing the right advocacy tool for the right audience and using it

Group Work:

- Each group will work together to develop a Call to Action so as to advocate key issues with key stakeholders who can drive change and are influential across domain areas. In the Interactive Session prior to the group work session, the group is facilitated to pick up a few (four) key advocacy issues that are relevant to the region/country.
- A policy brief articulating the issue and pushing for a call to action is discussed in the group and its broad framework developed
- The same is shared between groups

Module 3: Developing an Understanding of Leadership and how Leaders can make a Difference

After learning about communication and advocacy, the workshop participants enter a session that explores the importance of having leaders who can be effective communicators, advocates and game changers. Leadership that is intelligent, strategic, active and impactful is one of the most critical features of successful campaigns and advocacy efforts that are targeted at achieving transformative results. In this last session of the first day of the workshop, participants are engaged in an interactive, facilitated session on understanding leadership, and learning how to lead, or support a leader.

Panel Discussion and Interactive Session:

What can a leader do? Am I a leader? What can I change? How can I help the cause?

This session addresses the importance of leadership – working with leaders, making efforts to become leaders and building and fostering strategic alliances to leverage leadership for the change agenda. The following principles of leadership shall be covered in this session:

- Understanding how certain individuals have the ability/position/skill/traits to be able to influence the thinking of many and actually drive change when it comes to contributing to the success of NCDs management and a global response that eventually leads to lesser burden of disease
- How can we facilitate the work of such leaders?
- How can we become leaders in the PLWNCD space?
- Understanding the importance of alliances, partnerships and collaborations in enhancing the impact of leaders



DAY ONE: Breathers and Icebreakers

- ▶ Introductions will be shared at the start of the workshop (5 mins) including sharing one fun fact about themselves. Breather: Towards the end of the workshop, all participants will be asked to say one interesting fact about each other (not themselves). By doing this activity (5 mins) we want to be able to ensure participants are observant, engaged and learn more about each other.

- ▶ 30 second game 'Show and Tell' - show an object that means something to your cause and explain. For example, an advocate living with diabetes in a country that does not have Universal Health Coverage, could show a vial of insulin and explain that access to life saving medication is essential for all people living with diabetes.

- ▶ One minute game 'True or False' - if the statement is 'true' then turn your camera ON, if 'false', then turn your camera OFF. For example, if the facilitator says "The meaningful involvement of people living with NCDs is a critical element of an effective and people-centred NCD response" then advocates can turn their camera on (or off) and explain why they believe the statement is either true or false. This game will test the participants' understanding of the issues discussed.

- ▶ Two minute exercise breaks (such as Zumba, stretching every one hour) - participants will be given a little time to do short bursts of activity or gentle stretching to ensure they are alert and get a small physical activity break every hour as well. During these breaks, we will arrange to have regional folk music to be played and even find out if people can guess the language (pre-decided by contacting specific participants).

Module 4: Developing a Country-Specific Communication and Advocacy Action Plan

On Day 2, you will get an opportunity to develop a sample Communication and Advocacy Action Plan for your country. Across the SEAR, each country is at a different stage of maturity, has a differing perspective, priorities and targets in terms of what needs to be achieved through communication and advocacy efforts related to the NCDs response.

The community could consider co-creating capacity-building initiatives and resources for programmers and decision-makers in all Member States so that they understand, embrace and implement the concept of meaningful engagement of People Living with Non-Communicable Disease at country level. This could be strengthened by co-development of targets and indicators of progress in the adoption of meaningful engagement of People Living with Non-Communicable Disease and advocating with Member States to include this action in their national NCD or multi-sectoral action plan. This could be supported by the proposed development of a WHO framework for meaningful engagement of People Living with Non-Communicable Disease

The workshop and training efforts aim to highlight the lived experience perspectives in strong, organised civil society movements that offer platforms to amplify voices and expertise of People Living with NCDs.

Group work:

Development of country level action plan focused on meaningful involvement of people living with NCDs

Intent:

This session will provide an opportunity to participants to combine their experiences and skills acquired during the workshop to plan and strategize activities to be implemented at the country level and to be submitted as Case study (template attached as Annexure 3).

Structure of the session

Break out groups - All the participants will be assigned to the 9 working groups, allocated on the basis country representation. The intent of the small working groups is to enable the participants to understand and decide WHAT action is needed and by WHOM. It would provide the participants with an opportunity, and a process, to develop activities under their country action plan.

TORs for group work:

Each group will choose a rapporteur to design a country action plan addressing most important issue which needs to be prioritised around meaningful involvement of people living with NCDs. These will include small group discussions led by facilitators. Each group will develop key messages based on the discussions.

Facilitator will briefly explain the components of the action plan that would be useful in the group work:

- ▶ What a goal is? (a desired end result)
- ▶ Goal Statement: What do you want to do? Go back to your reflection from the session. What change do you want to see?
- ▶ Results (what happens when the goal is achieved)

- Action to achieve a goal (usually we plan to create this action),

Tasks: The key steps required to accomplish your goal.

Who: The person/people responsible

When: The timeframe for the task

Resources: The necessary human, financial, and physical assets needed to accomplish the task

Supports: What you need to stay motivated in working to accomplish this goal

Points to remember:

Simple - clearly identifies the activities needed to achieve your goals

Actionable - prioritize and plan activities to help you work on the right thing to move forward

Achievable - available resources to work with

Relevant - campaign focus (what is important)

Session time - 30mins (Development of action plan)

Facilitators will be able to share their screen so they are requested to take session notes in screen share mode. Facilitators will note and inform the name of group representative for report back to host (Mr Aman Sehgal/Ms Prachi Katuria/Ms Tina Rawal) once decided. It's a time bound activity. Please ensure to wrap up the discussion within allocated time as the group.

REPORT BACK (IN COUNTRY GROUPINGS)

Intent: This session will be culmination of discussions and skills imparted during the two-days of the workshop. One action plan will emerge from each small group sessions.

One participant from each small group will present his/her group's action points during this session. The moderator will guide discussions to collate important points.

The action points will also serve as a roadmap for the participants to follow and lead activities in their countries, after the workshop.

Moderator	:	Ms Nupur Lalvani
Session time	:	15 min.
Presentation	:	Up to max. 2 slides/group (9 presentations (1/group))

Concluding Session: Reflections & the Road Ahead ---

Reflection is a tool that helps participants identify, consolidate and capture what they have learned. It can be used to highlight the relationships in the room or the strengths of the group, even the challenges they identify. More personally, individuals might reflect on what they, specifically, have learned and what future steps they might take to use or build on this learning.

In a brief session at the end of the workshop, the resource person will facilitate an interactive sharing among participants through the use of a few key, strategically packaged questions/discussion points. During this session, participants may freely use the chat option also, in case they are not keen to openly bring up an issue.

What is the one most significant learning you are taking away today and how would you consider using it to improve the way NCDs are currently managed in your country?

Do you believe a network can be more impactful than an individual? If so, is there any specific new knowledge you are taking away from here with regards to creating, fostering or using networks?

Telling Stories

How Health Communication can Strengthen the NCD Response

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WHAT DOES HEALTH COMMUNICATION MEAN TO YOU?

Influencing personal health choices by improving health literacy

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Meena

- ✓ Better literacy and knowledge
- ✓ Stronger recognition of behaviours that may require change
- ✓ The use of knowledge to act and seek health by changing behaviours

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Literacy is a bridge from misery to hope.

Kofi Annan
Charman diplomat and former Secretary-General of the United Nations

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BUT LITERACY IS NOT ALWAYS HEALTH LITERACY

9/10 PEOPLE
Lack skills needed to manage health and prevent disease

99% of Americans can read **BUT** only **12%** are HEALTH LITERATE

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And anyway, literacy is not for everybody is it?

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Lets Tell a Better Story

- ✓ Use every skill
- ✓ Every bit of knowledge
- ✓ Every tool that can work
- ✓ Train everyone
- ✓ Provide information to everybody
- Be available & reachable

... because good communication compels you to act and supports you to sustain behaviour change

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The creation of knowledge societies can be made easier, and communities engaged, educated and empowered to take the right decisions and make the right choices regarding their health.

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Influencing Actions, Direction, Changing Attitudes, Perceptions and Behaviours

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"A little knowledge that acts is worth infinitely more than much knowledge that is idle". - Kahlil Gibran



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The 21st Century Revolution is the Communication Revolution



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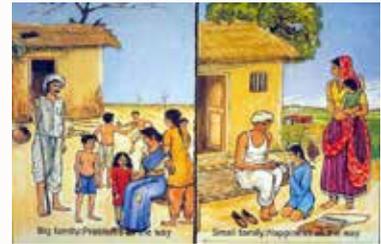


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HEALTH LITERACY HAS TO WORK FOR ORDINARY PEOPLE



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Communication for Behaviour Change:

- ~ Convincing
- ~ Straight and hard-hitting
- ~ Telling a story
- ~ Showing a better future

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UNDERSTANDING ADVOCACY

DRIVING CHANGE FOR A STRONGER NCD RESPONSE

Healthy Lifestyles will Reduce Diabetes

MENTAL HEALTH INTERVENTIONS ARE POPULAR AND STIGMA IS GONE

CHRONIC DISEASES ARE MORE ABOUT LIFESTYLE AND LESS ABOUT DOCTORS

Be the CHANGE you wish to see in the WORLD

What We Want to Achieve

The Change Agenda

LOCAL | NATIONAL | REGIONAL | GLOBAL

Demand

- Informed & Convinced Communities
- Affirmative Action for Behaviour Change

Supply

- Convinced & Motivated Providers
- Smooth & Effective Services

WHAT DO WE WANT TO CHANGE?

- Societies support active lifestyles
- The environment offers healthy food options to all
- NCDs treatment options are freely available and effective
- NCDs are prioritised by national health systems
- Effective policy-making and participation by people with lived experience

OUR STAKEHOLDERS ARE MANY

Primary
Secondary
Tertiary

The funny thing is: Everybody has the same GOAL!

Use their knowledge and place in life to work for societal development in some way or the other

But they do not speak the same language. Which is why advocating the right way becomes important

STAKEHOLDERS WHO ARE....

- Setting the agenda and raising public debate and discourse on key issues to advocate policy solutions
- Reinforcing social responsibility and influencing opinion-makers/policy-makers
- Supporting community empowerment in the long run

Convert knowledge to actionable evidence



But researchers are meant for greater stuff!!

Labs ~ Papers ~
Institution Building ~
Reputation ~ Power ~
Conferences Grants ~
Funding ~ Doctorates



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TELLING THE BIG STORIES OF IMPACT:

- PROCESSES
- PROGRESS
- OUTPUTS
- OUTCOMES



THE NCD DOSSIERS

Create and compile dossiers for all major initiatives when as high priority knowledge products. A dossier is relevant for multiple stakeholders and can be conveniently used by project/program staff according to specific needs. Broadly, a dossier can contain all/ some of the products as listed below:

- Film/ Brochure (Concept + Activity/ Initiative/ Progress)
- Short write-up/ Introductory write-up
- Detailed Report (3-6 pages or a number of pages) showing Process/ Progress/ Impact
- Technical Policy Brief/ Factsheet with Policy Aide
- Posters and Infographics (x number)
- Case Studies (Postcards from the Field)
- Film/ Animated videos/ Graphics (Slide Deck)
- Pan Dives with PPTs or other resources as relevant
- Success stories showing impact
- Scientific publications, if any



SUPPLY THE FACTS

Use of data still not completely understood

Health data are the lifeblood of modern public health practice

The collection of quality data is critical to achieving public health outcomes

COMMUNICATORS AND ADVOCATES SHOULDER RESPONSIBILITY, AS DO RESEARCHERS

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Use the Media!

- The media can make it happen
- Media is a watchdog – revealing, transparent and
- Beyond the Press Conference -- Multiple channels of media has brought change
- Penetration is enormous; television and visual digital platforms have broken the literacy barrier

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Your Media Mantra

- Be Flexible
- Be in tune with local realities
- Be ready to learn and do not view the media as an adversary but as a partner; media advocacy is not ALWAYS combative
- Long term planning and thinking is a great plus; meaning to say do not be discouraged by short-term setbacks – one bad story is not the end of the world

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	THE JOURNALIST	THE RESEARCHER
↑	Friend In search of news Watchdog Indian media robust Creator of opinion, policy, litigation Data thirsty	Knows the facts/generates the evidence Offers credible knowledge source Understands the problem and can offer a solution Many are media-sensitive and can engage
↓	Differing priorities in the profession What makes news Hard to comprehend complex, scientific, medical concepts/data: speaks different language...	Ineffective communicator Rigid about need for skills building for better public engagement Public health/medical institutions under-invest in public engagement

13-12-2021

"START WHERE YOU ARE. USE WHAT YOU HAVE. DO WHAT YOU CAN."

- ARTHUR ASHE

BUT BE THE CHANGE, PLEASE!



Annexure 3

CASE STUDY Submission format

Contact information (For Focal point and team members)

- Name
- Organisation/Affiliation
- Designation
- Country
- E-mail
- Phone

Summary

Problem statement (what was the issue at hand, which was addressed through the campaign)?

List down 2-3 objectives

Target Audience

Strategy, Execution and Outreach

Result/Outcomes (add numbers if possible)

Source/Supporting material (add photos/links wherever possible)
