Bridging the Gap on NCDs
From global promises to local progress
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Bridging the Gap on NCDs: From global promises to local progress

Since the first United Nations High-Level Meeting (UN HLM) on NCDs in 2011, the NCD community has been able to point to many successes on the global stage: Noncommunicable Diseases (NCDs) are recognised as the world’s biggest killer and cause of disability, constituting a global health crisis that requires an urgent policy response. This was acknowledged by world leaders at three UN HLMs on NCDs, meriting a dedicated target in the Sustainable Development Goals (SDGs) for 2030.

And yet, almost ten years after the first UN HLM on NCDs and five years after adoption of the SDGs, leaders have not yet followed up on their international commitments. The promises made at the UN to meet targets for 2025 or 2030 have not translated to necessary action at home.

According to NCD CountDown 2030, at the current slow rate of progress, SDG target 3.4 to reduce premature death between 30-70 years of age from the major NCDs will only be achieved by fewer than one-fifth of countries by 2030. Most of these are high-income countries which already have low NCD mortality, and countries in Central and Eastern Europe which have made more rapid progress. An additional 35-50 countries could meet the 2030 target if action is stepped up. But half of all countries (86-97 countries) are off track, and need urgent policy action to reverse current mortality trends. Alarming, the first NCD CountDown report shows that premature NCD death rates have stagnated or increased since 2010 for women in 15 countries and for men in 24 countries.

A 2019 NCD Alliance survey of national and regional NCD alliances reflects this reality: only 20% of alliances believe that their country is on track to meet either the 2025 or 2030 NCD targets, considering current NCD prevention and control policies. This reflects both the failure to tackle the major NCD risk factors – tobacco, alcohol, unhealthy diet, lack of physical activity and air pollution – as well as the disappointing progress on delivering universal health coverage (UHC). For example, just two countries, Brazil and Turkey, have implemented all five of the tobacco demand reduction measures of the Framework Convention on Tobacco Control. Only a small minority of national health systems worldwide currently have the capacity to provide the necessary treatment and care for everyone living with NCDs. Only one-third of countries, for example, provide drug therapy and counselling to prevent heart attacks and strokes; and just 40% of countries provide palliative care in primary healthcare or in the community. A vast majority of people living with NCDs globally cannot access the care they need, either due to lack of availability or because it is locally unaffordable.

The NCD mortality figures do not tell the whole story of the global NCD burden. The figures – only capturing deaths and only relating to cardiovascular disease, cancer, respiratory diseases and diabetes – conceal a much larger number of people living with many different NCDs worldwide, including mental health conditions, and fail to capture deaths under 30 or over 70 years. For example, 3.5 billion people worldwide live with the potential debilitating impacts of untreated tooth decay and other oral health conditions, but are excluded from measures of NCD progress.

As a result of these hollow promises and inaction, the NCD epidemic continues to cut lives cruelly short and cause unnecessary pain and hardship. NCDs are an indiscriminate killer, but disproportionately affect the poorest countries in the world and the poorest people in every country. Inaction is exacerbating inequality. NCDs are responsible for 7% of deaths globally, which represents over 41 million people killed by NCDs every year. 15 million of these people are under 70 years old, including 8.5 million people in lower and lower-middle income countries. The outrage is that the majority of this death and suffering, the impact on families and communities all over the world, is preventable.

Thanks to decades of research, policy development and country experience, the recipe for success has been tried-and-tested. Governments know what needs to be done. They know which policies will make a difference to the lives of people living with and at risk of NCDs. And they know that, if done well, implementation of these “best buy” policies saves money as well as lives. So, after ten years of experience, we have to ask: what’s stopping them?

This paper outlines the gaps in the first decade of the NCD response. Calling on the experience of NCD Alliance’s global network of people living with NCDs, advocates, campaigners and experts collected via several surveys, as well as the latest data from the World Health Organization and peer reviewed literature, the following pages identify what has been lost in translation of the global targets for NCD reduction and describe the major barriers to meaningful progress.

The five gaps identified here – Leadership, Investment, Care, Community Engagement, and Accountability – are not exhaustive and are intended as the basis for strategic debate. The gaps identified are based on survey data gathered from national and regional NCD alliances, who cite inter alia lack of political will and leadership, lack of financial resources, lack of government staff capacity / technical expertise, industry interference, and insufficient accountability mechanisms as key barriers limiting governments from scaling up NCD actions. The gaps highlighted are intended as focus areas to fast-track future action within the framework of sustainable development, going beyond the NCD community and beyond the health sector to mainstream NCDs at the level of political and public attention that they merit.

We are just five years away from 2025 and a fourth UN meeting of world leaders on NCDs. We must dramatically accelerate the response and change course in order to achieve significant and sustainable progress, and to make sure that more people, more communities, and more families are spared the pain and cost of NCDs by 2030. Following each gap described here, actions for civil society are proposed that can potentially bridge the gaps to change the future for people living with and at risk of NCDs. These are synthesised into the NCD Civil Society Compass as a proposal for further NCD community development, discussion and action.

3 NCD CountDown 2030: 35 (9%) for women and 30 (8%) for men.
4 NCD CountDown 2030: 50 (27%) countries for women and 35 (19%) for men.
5 NCD CountDown 2030: 86 (46%) countries for women and 97 (52%) for men.
6 NCD CountDown 2030: 15 (8%) countries for women and 24 (13%) for men.
7 NCD Alliance network survey. 2019.
8 World Health Organization, 2019. Available at: https://www.who.int/ncd/publications/estimates/en/
NCDs are a challenge beyond the health sector. The causes, impacts and solutions are often beyond the remit and influence of Ministries of Health, and therefore require a whole-of-government and whole-of-society response, including economic and societal actors. For this reason, leadership of the NCD response needs to come from the Heads of State or Government to achieve impact, as emphasised by the WHO independent High-Level Commission on NCDs and Mental Health.10 This is essential to tailor the national response, avoid duplication, manage potential conflicts of interest, navigate trade-offs, and ensure coherence in policies in order to meet national NCD targets.

### Political leadership

To date, too few national leaders have had the vision to lead the fight against the world’s biggest killer and cause of disability, simultaneously putting their economies on a more sustainable path. There have been some valuable exceptions: The Caribbean Community (CARICOM) leaders who signed the Port of Spain Declaration in 2007, which kicked off the movement for global NCD action; the Pacific Islands leaders who convened the first Pacific NCD Summit in 2016; and the Presidents of Uruguay, Finland and Sri Lanka, who were among the co-chairs of the WHO independent High-Level Commission on NCDs. At the UN HLM in 2018, Heads of State and Government reiterated their commitment to provide strategic leadership by promoting policy coherence and coordination through whole-of-government and health-in-all-policies approaches.11 The sections below outline priorities to take this commitment forward.

### Good governance and policy coherence for health

Good governance relies on effective governing frameworks12 rooted in transparency, accountability and participation of all affected, and should result in policy coherence. Transformative leadership takes different shapes in different parts of the world, but there are common failings, which can be traced back to poor governance affecting the ability of policy-makers to take evidence-based decisions, implement policies and ensure alignment between different sectors.

The number of countries with established national NCD plans and targets in place is a visible indicator of good governance and political leadership. In 2019, 57% of countries reported to WHO having an integrated multi-sectoral national plan in place for NCDs which addresses the four main NCDs and four main risk factors.13 Two-thirds of countries reported national targets in place for NCD reduction by 2025. Absence of coordinated multi-sectoral action has been identified as a key barrier to NCD action.14 Less than half of countries have a multi-sectoral commission on NCDs in operation, and it is notable that 30% of these do not include civil society. Top-level leadership is essential for prioritisation, to ensure coordination towards the common national NCD plan, a single set of NCD targets, and one national coordinating authority (the so-called “Three Ones” principles, as pioneered in the HIV/AIDS response).15

The concepts of ‘health in all policies’ and ‘governance for health’ mean that decisions made in other policy areas must not harm public health. But they have too seldom been put into practice. Some rare exceptions include governments in Finland, Norway and Wales who are obliged to undertake wellbeing impact assessments for proposals across all policy areas. Current governments in Iceland, Scotland and New Zealand pride themselves on being ‘Governments for Wellbeing’, providing an instructive model from the top of government for a public health ethos at the heart of their policy programmes and national budgets.

In the context of health systems development, availability and affordability of care and treatment, it is noted that “corruption is embedded in health systems”16 and remains a major obstacle to health in every country.17 The highest level of leadership is essential to root out corruption to secure necessary resources for health. It is estimated that “each year, corruption takes the lives of at least 140 000 children, worsens antimicrobial resistance, and undermines all of our efforts to control communicable and non-communicable diseases.”18 The hundreds of billions of dollars stolen each year from health systems (estimated to be at least 25% of US$7.5 trillion in global health spending) exceed WHO estimates of the funding needed to reach UHC globally by 2030.19

### Unhealthy industry interference

National leaders must ensure that citizens’ wellbeing is prioritised above short-term aims and signals across government how to deal with conflicting demands from different sectors. Strategic interference from unhealthy commodity industries who see their vested interests threatened by NCD prevention policies is a well-documented challenge.20 Interference by the alcohol, food and beverage industries has been persistent throughout negotiation of global policy development to prevent NCDs.21 According to the survey of national and regional NCD alliances, just 7% believe that their government has sufficient mechanisms to manage conflicts of interest in health policy and NCD decision-making processes.
Incompatible partnerships

The Sustainable Development Goals call for an “integrated and indivisible approach”, breaking down the silos between goals and issues for win-win solutions for societal, economic and environmental gain. In order to achieve this, partnerships in the SDG era need to be aligned and coherent with all goals, including health and NCD prevention. There is, however, a worrying trend of incompatible partnerships between multilateral agencies and unhealthy commodity industries (alcohol, big soda, tobacco, fossil fuels), which are blindly focusing on one issue, whilst putting other health goals at risk.

It is inappropriate for global health organisations to partner with companies whose products cause harm to health and have devastating track records of subverting science and undermining public policies to protect health. It became crystal clear at the time of the Global Fund to Fight AIDS, Tuberculosis and Malaria’s proposed partnership with Heineken23, given alcohol’s role as a risk factor for the transmission of sexually transmitted diseases, NCDs, mental health issues and violence, that there cannot be a place for alcohol in regulatory partnerships for the health and SDGs as a whole.24 The same can be said for Coca-Cola, who intensively lobbies to protect the health of children from obesogenic advertising, provision of clear, unbiased information to consumers, and the introduction of health taxes.

The false promise of ‘self-regulation’

Health-harming industries should have no role in the development of national or international NCD policy. “Despite the common reliance on industry self-regulation and public–private partnerships, there is no evidence of their effectiveness or safety. Public regulation and market intervention are the only evidence-based mechanisms to prevent harm caused by the unhealthy commodity industries.”25

This conclusion is formed by experiences across the NCD Alliance global network. Many NCDA members have engaged with self-regulatory platforms and voluntary industry commitments. There are numerous examples in the area of healthier diets and alcohol harm reduction which have collapsed because of failure to deliver, including the Responsibility Deal in England26, the Mexican Observatory on NCDs (Observatorio de ENT)27, alcohol advertising self-regulation in Australia28, the EU Forum on Alcohol and Health29, and the EU Platform for Diet, Physical Activity and Health.30

Demand leadership and coherence for health

Civil society should request that national leaders establish NCD coordination mechanisms to deliver on national targets. CSOs and academia can also carry out Health Impact Assessments of proposals in other policy areas, importantly including international trade policies.

Monitor industry interference and raise awareness

Many national and regional NCD alliances31, 32 play a crucial role in addressing industry influence. Civil society, supported by academic research and progressive media, can significantly advance global and national discussions by raising awareness of incompatible partnerships and health-harming tactics to influence policy-makers.

Develop guidance on private sector engagement

In relation to engagement with the private sector including partnerships, national governments are requesting guidance on how to identify and manage potential and real conflict of interest, interference and corporate capture, and ensure that the public good is the bottom line. Civil society can work together with WHO or the UN to develop such guidance.28, 29

Adapt to work with different political administrations

To keep the NCD response moving forward and ensure health-supporting policies are not rolled back, civil society organisations must find ways to engage all parties across the political spectrum and demonstrate public support for policies in force.

Develop future leaders from the NCD movement

We must continue making the case to today’s politicians. But the NCD movement can also shape and inspire future leaders. Today’s young NCD voices will soon become the next generation of decision-makers and leaders, not only in health, but across all sectors. If our current crop of politicians is unwilling to become NCD champions, we have to grow our own.

References

28 Jones, S. C., Hall, D., Munro, G. How effective is the revised regulatory code for alcohol advertising in Australia? Drug Alcohol Review. 2008. 29 27–38
29 de-Cornes, P. and Gilmere, L. Long overdue: a fresh start for EU policy on alcohol and health. The Lancet. 16 December 2019. Available at: https://dx.doi.org/10.1016/S0140-6736(19)33103-4
34 Colin et al (2017) conclude that given the widespread recognition that the interests of alcohol and food manufacturers fundamentally conflict with public health objectives, “it seems clear that health governance and research require more coherent approaches to the terms within which they engage with unhealthy commodity producers. This could involve examining how the adoption of tobacco control practices and norms, including those arising from FCTC Article 5.3, might inform measures to improve transparency and governance across NCD policy dialogues.
35 Collin, Jeff; Hill, Sarah E.; Eltanani, Mor Kandlik; Plotnikova, Evgeniya; Ralston, Rob; Smith, Katherine E. Can public health reconcile profits and pandemics? An analysis of attitudes to commercial sector engagement in health policy and research. PLoS One. 2017. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5635073/
In recent years, the NCD community has made a conscious shift from talking about health expenditure to talking about health investment. For too long, NCD action has been branded as an expenditure, when many of the ‘best buy’ policy actions are in fact low cost, affordable for every country, and represent a smart and strategic investment. In low- and middle-income countries (LMICs), for every dollar invested in NCDs, there is a return to society of at least US$7 in increased employment, productivity and longer life. Annual GDP losses range from 3.5% - 5.9%, costing LMICs alone US$7 trillion between 2011 and 2025, which is equivalent to the combined GDP of France, Spain and Germany. The bottom line for governments is clear: invest now, save later. The return on investment in NCD action significantly outweighs the costs.

Over the past decade, funding for NCDs and global health has been at the forefront of international policy discussions and meetings. In 2011, at the first UN HLM on NCDs, world leaders committed to explore the provision of ‘adequate, predictable and sustained resources’ through various channels, and the commitment was reitered in the 2014 UN High-Level Review on NCDs. The adoption of the 2015 Addis Ababa Action Agenda on Financing for Development recognised that taxation of tobacco could represent a source of revenue for countries and reduce consumption, providing a means to achieve SDG target 3.4 on NCDs by 2030. At the third UN HLM on NCDs in 2018, world leaders committed to accelerate their responses within the context of the SDGs. And, in 2019, the Political Declaration of the UN HLM on UHC, recognised price and tax measures as a potential revenue stream for governments that also reduces consumption, and therefore NCD prevalence, which is an important component of the NCD response.

And yet, despite the catastrophic global burden of NCDs and the numerous global commitments, the proportion of total global health financing dedicated to prevention and treatment has remained at an abysmal 1-2% for nearly twenty years. The latest data shows that in 2018, US$778 million, or just 2% of development assistance for health (DAH), was allocated to NCDs. This lack of attention to funding NCDs occurs at all levels: international, regional, and national. At the domestic level, only half of all funding NCDs occurs at all levels: international, regional, and national. At the domestic level, only half of all governments included NCD line items in their budgets in 2011, and this number has not significantly increased since then. This is a far cry from the investment needed to translate global commitments into transformative national action.

Closing the resource gap for NCDs will require multiple financing sources tailored to each country’s disease burden and epidemological conditions, fiscal capacity, donor relationships, strength of the private sector, and other factors. The expected result will be a “blended” stream of financing, including creating and optimising fiscal space for NCD investment domestically, exploring novel financing mechanisms (including taxation of unhealthy commodities such as tobacco, alcohol, sugary drinks and fossil fuels), multilateral/bilateral funding, private sector engagement, and catalytic mechanisms. Many of these streams remain untapped for NCDs at global and national levels.

The financing gap: Where will the money come from?

International donors are still heavily focused on funding specific diseases and conditions aligned with the Millennium Development Goals (MDGs), instead of shifting to the more comprehensive targets outlined in the Sustainable Development Goals (SDGs), thus overlooking NCDs. Using IHME’s 2015 Global Burden of Disease study and 2016 Financing Global Health report (excluding funding for NCDs, where RTI’s estimate was used instead of IHME’s), calculations for dollars spent per attributable disability-adjusted year of life (DALY) were collected on NCDs, maternal disorders, neonatal disorders, tuberculosis, HIV/AIDS, and malaria for 2015. NCDs represent the biggest burden worldwide, but received the lowest funding by far, with US$ 0.79 billion per DALY compared to maternal disorders (US$ 309.33), HIV/AIDS (US$ 166.41), neonatal disorders (US$ 44.33), malaria (US$ 42.67), and tuberculosis (US$ 32.89) (see Figure 1 below).

To tackle the high burden of NCDs, mobilising domestic resources will be crucial for all countries. Domestic financing for NCDs includes ensuring that the NCD response is included in national annual budgets for health, as well as implementing policies such as taxation of unhealthy commodities and the phasing out of subsidies for health-harmful products, which can provide a significant source of revenue for governments. Data from the latest WHO Country Capacity Survey on NCDs indicates that only 38% of countries have implemented taxes on sugar-sweetened beverages and only 6% on high fat, sugar, and salt foods – however, the number of countries implementing these policies has increased significantly over recent years. A growing number of countries are also earmarking tax revenues (46%) for the NCD response. National health spending was most prevalent for health care and treatment (90% of countries), followed by health promotion activities (88%), primary prevention (88%), early detection and screening (87%), surveillance, monitoring and evaluation (84%), capacity building (79%), palliative care (68%) and research (65%)..

While these figures suggest that countries are adequately funding the NCD response, the reality on the ground is regrettable different (see also the Care gap below). Not nearly enough is being done to implement health-promoting fiscal measures, and more focused attention is needed on funding NCD-specific programmes and policies as part of UHC.

Figure 1: Funding (US$Bn) compared to disease burden (disability adjusted lifeyears (DALY) for global health priorities. Graph from Rachel Nugent at RTI International.

41 ibid.
Though domestic resource mobilisation is an important component of financing NCDs, there is still a large gap that the international community needs to fill, and DAH will remain catalytic for countries currently allocating less than 5% of their GDP to health. A valuable new initiative from the Norwegian government is a world-first country-level donor commitment to allocate at least 2% of their GDP to health. A valuable new funding avenue for NCDs is the launch of the Global Health 2035: a world converging within a generation, led by a global coalition of philanthropies, governments, and international agencies. Under the auspices of the UN Interagency Task Force on Health and Development, WHO and UNDP are now providing technical support to low- and middle-income countries (LMICs) to integrate NCDs into UNDAF design and implementation. Yet, according to a recent review of UNDAFs rolled out in 2014-2015, only 20 out of 54 UNDAFs included NCDs (37%), demonstrating that NCDs are still not sufficiently represented in development planning processes at the country level.

Development of innovative financing instruments had been expected to support the transition from MDGs to SDGs, including the NCD response. But so far, around 98% of the funding raised for innovative instruments has remained disease specific and linked to the MDG health targets — there has been no “grand convergence in health” as advocated by the Lancet Commission in Investing in Health. This urgently needs to change, with all donors representing NCDs as part of their overall health and development strategy focused on combatting NCDs, rather than just individual diseases. Figure 2 shows that the majority of funding for NCDs comes from the non-profit sector, and there is a need for both international donors and governments to step up their response.

The data gap

There is an urgent need for more and better data on resource flows for NCDs. Current data on domestic financing is almost non-existent, in part due to the absence of NCDs in National Health Accounts, and the challenge of tracking expenditure across all government departments. Important lessons could be drawn from the climate change community, with Climate Public Expenditure and Institutional Reviews (CPEIRs) providing valuable analyses of the allocation and management of public expenditures across all government departments and guiding strategic investments.

Some progress has been made, with the inclusion of a purpose code for NCDs in the OECD Creditor Reporting System (CRS), which will begin reporting in 2020. It will be important to make data surveillance, monitoring, collection, and evaluation more systematic.

Advocate for governments to include NCDs in their national health budgets and plans
National and regional NCD alliances can work with governments to integrate NCDs, multi-morbidity, health system strengthening, and health workforce capacity into their national plans and proposals to international donors.

Advocate for governments to phase out subsidies and implement taxation of unhealthy commodities (sugar, tobacco, alcohol, fossil fuels) and use funds to support health systems strengthening, particularly for NCDs
Health-promoting fiscal measures can decrease consumption and provide a source of revenue for governments to reinvest in their health systems. Civil society engagement can be instrumental in mobilising public support for recommended measures and holding governments to account.

Increase national civil society participation in country missions of the UNIATF, including preparing and promoting investment cases
Engagement of civil society in preparation and follow-up of missions and investment cases significantly increases chances of successful implementation. Civil society can provide important perspectives of the realities on the ground, and support governments in the implementation of recommendations.

Advocate for international donors to support smart investments in prevention interventions and health systems strengthening
Investments can be designed to encourage domestic resource mobilisation, and should consider how to galvanise efficiency improvements and include stringent monitoring and evaluation, so as to avoid creating dependence and to maximise public benefit for the investment.

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THE CARE GAP

Faced with a lack of external investment for NCDs as described here, LMICs have been left to respond to increasing burdens of NCDs within their own underfunded, weak health systems that are not adapted to manage chronic diseases. Governments are juggling a backlog of common infections, the double burden of malnutrition, and maternal mortality together with the growing burden of NCDs, pandemics and the health impacts of climate breakdown. Budgets and health systems are crippled by increasing demand, meaning that few low-income countries can provide care for NCDs in their benefit packages and over 60% of people living with NCDs (PLWNCDs) have experienced catastrophic health expenditure.

Inequitable access to NCD medicines and technologies

Once diagnosed with an NCD, an individual can face many hurdles in accessing treatment and care. Access to essential medicines and technologies for NCDs is often poor in many LMICs. In many countries, medicines for NCDs are not available when needed, and if they are available, are unaffordable for people living with NCDs. Low availability can be caused by a lack of sufficient and sustainable public resources or under-budgeting, inaccurate demand forecasting, poorly managed supply chains, and inefficient procurement and distribution. This often forces people seeking treatment to the private sector, where generic medicines are sometimes two to three times more expensive, causing further financial strain on household budgets. When medicines are available, the quality and safety may sometimes be in question, and there is a rising number of cases of counterfeit medicines for NCDs to fill the gap of insufficient public sector availability of essential medicines.

Ensuring availability of affordable, safe, quality NCD medicines is an important component of achieving universal health coverage, and requires health systems strengthening, efficient procurement and distribution of medicines, and monitoring and evaluation of both availability and affordability. According to the 2020 WHO NCD Country Capacity Survey, only 34% of countries are providing the full range of drug therapy and counselling to prevent heart attacks and strokes, while only 39% provide palliative care in primary health care facilities. This snapshot of just two aspects of the NCD response demonstrates that, despite numerous global commitments, there is still a long way to go to deliver.

Ensuring the availability and affordability of essential NCD medicines and technologies is only one piece of solving the broader access challenge. In many countries, there is strongly ingrained stigma and discrimination against certain NCDs, reducing the likelihood that people will seek out diagnosis and treatment for a condition that may result in a negative social label. When medicines, technologies, and services are available, many people in LMICs must travel far distances to their local health facility, resulting in an additional hardship, especially for women who are often the primary caregivers in their homes and unable to transfer the duties to another family member. For those that are able to reach the health facility, there must be a well-equipped and trained health workforce, able to manage NCDs throughout the lifespan as well as the increasing prevalence of multi-morbidities.

Inadequate health workforce for the NCD challenge

The growing burden of NCDs and shifting demographics will generate demand for an additional 40 million health workers globally by 2030, requiring that the global health workforce essentially doubles in order to avoid an estimated shortfall of 18 million workers. This shortage is a significant challenge to the sustainability of primary healthcare and the achievement of UHC. And for people living with NCDs, continuous access to well-trained and resourced health care workers is essential to adequately manage their disease(s) and help optimise their physical and mental health and wellbeing. The distribution of health providers is problematic across all countries of all income levels. Especially notable is the shortage of health workers in rural areas – more health workers are present in urban areas, making it difficult for those in rural areas to reach health care services. There is also a disproportionate shortage of health workers in LMICs, which is far more severe than in higher-income countries.

Reorienting health systems for chronic conditions and health for all

Historically, health systems have been designed on a “disease model” that focuses on treating illnesses as and when they arise, instead of focusing on them at the primary health care level, prioritising health promotion and disease prevention and responding to the lived experience and views of patients. This model has been effective in treating infectious diseases and maternal and child mortality, but has not addressed the treatment and care of chronic conditions. As the burden of disease shifts and the prevalence of multi-morbidity increases, health systems are inadequately prepared to respond effectively. Many NCDs are not present in isolation – people with NCDs are often living with one or more conditions, including mental health conditions such as depression and anxiety. This also holds true for people living with infectious diseases such as HIV and tuberculosis, which often results in a higher risk of developing certain NCDs.

Health systems that are responsive to and prepared for chronic care prevention, treatment, and management link people with proactive health care teams that are well-trained and resourced to provide person-centred care. Continuous monitoring, surveillance, and evaluation is necessary to track outcomes and ensure that systems are efficiently and effectively meeting the needs of the populations they are meant to serve.

ADDITIONAL RESOURCES:
More challenges and solutions, as well as case studies, are available in the NCD Alliance’s report Protecting Populations, Preserving the Future: Optimising the health workforce to combat NCDs and achieve UHC.
Recommendations and case studies of how to overcome barriers to more integrated models of care are available in the NCD Alliance’s report Shaping the Health Systems of the Future.
Advocate for governments and donors at national, regional and international levels to integrate health systems that meet the needs of people and address the realities of multi-morbidity

Integrated health systems rooted in strong primary health care are necessary to treat people as a whole and not in disease silos, and can deliver better care across the lifecourse. These systems, together with a well-trained and resourced health workforce, can also be better prepared to respond to the needs of people living with two or more concurrent conditions, and should engage people living with NCDs as advisors in health system design and development.

Advocate for governments to include essential, quality, affordable NCD medicines and technologies as part of UHC national benefit packages

Governments must meet the global targets upon which they have agreed and ensure consistent availability of essential, quality, affordable medicines and technologies at all levels of health care delivery.

Advocate to establish independent accountability mechanisms for UHC

To date, no independent accountability mechanisms are in place to monitor implementation of UHC commitments. These mechanisms must include civil society and people living with NCDs to help monitor, track, and evaluate the efficiency and effectiveness of national plans and policies.

Advocate for more robust, disaggregated data to support national targets on health systems strengthening, provision of essential NCD medicines and technologies, and access to treatment and care

Better data capturing and reporting systems are necessary for governments, donors, and civil society, to understand the true burden of disease, including multi-morbidity, how policies are implemented, and whether services are utilised by the people most in need.

Momentum in several health and sustainable development issues, notably HIV/AIDS, Ebola and climate change, have repeatedly reinforced the critical role of civil society organisations (CSOs) and community-led efforts in accelerating action from local to global levels. Civil society actors are proven demand creators, mobilisers and campaigners, change agents, innovators, experts, implementers, and watchdogs. However, a long-standing gap for the NCD response is that the international community and governments have been slow to recognise and meaningfully involve CSOs in the response.

The lack of a rights-based, equitable response

Inaction on NCDs is fundamentally a failure to respect people’s basic right to enjoyment of the highest attainable standard of physical and mental health, which was enshrined in the Constitution of the WHO in 1946, the 1948 Universal Declaration of Human Rights, and the International Covenant on Economic, Social and Cultural Rights. Failure to act is exacerbating inequality between and within countries.

Currently, many groups are poorly served by the NCD response; risk factors unevenly impact different groups in society, and many people living with NCDs are still left behind and are unable to access the treatment and care they need. People left behind in the NCD response vary in each region and country, but frequently include women, youth, elderly, religious and racial minorities, LGBT+ people, refugees and migrants, indigenous communities, rural or geographically isolated communities, people living with disabilities and those with mental health conditions. Many of these groups are also protected by binding international conventions, for example against racial discrimination, for the rights of women, children, and people with disabilities, and others.

The foundation for an explicit, human rights-based approach is reflected in key policy documents on NCDs, and provides a strong basis for civil society to hold governments accountable.

47 These include the WHO Global NCD Action Plan, the WHO Report of the Commission on Ending Childhood Obesity, which links to the United Nations Convention on the Rights of the Child; United Nations Global Strategy for Women’s, Children’s and Adolescent Health, and most recently the 2018 United Nations General Assembly Political Declaration on NCDs.
NCD civil society - a crucial force to beat NCDs

Civil society organisations are non-state, not-for-profit entities formed by people in the social sphere with commonly held values, beliefs, or causes.48 Comprising non-governmental organisations (NGOs), community groups, informal social movements, patient groups, consumer groups, women’s groups, indigenous community groups, youth organisations, faith-based organisations, professional societies, foundations, academia, and think tanks, NCD civil society is diverse.49 National and regional NCD alliances unite disease and risk factor interest groups efficiently and effectively, coordinate advocacy, reinforce each other’s priorities, and amplify efforts to achieve common objectives. Today, there are over 65 strong national and regional NCD alliances across the world.50

Civil society has an important agenda-setting role in NCDs, raising public demand for policies, laws and action and ensuring that services reach communities. Through close connection with PLWNCDs and their communities, CSOs can provide unrivalled knowledge of the lived experience that could otherwise be inaccessible to policymakers. They address service gaps for people most excluded, and when needed, deliver health-promoting and lifesaving services. Crucially, CSOs can hold governments accountable to deliver on promises made. The NCD Alliance summarises these roles of civil society as the “Four A’s”: advocacy, awareness, access, and accountability.

Lack of meaningful involvement of civil society and people living with NCDs

Given the size of the challenge of NCDs, governments have readily signed up to a whole-of-society approach that calls on all sectors to step up. The 2018 UN Political Declaration on NCDs specifically includes a commitment to “promote meaningful civil society engagement and amplify the voices of and raise awareness about people living with and affected by NCDs”. But to date, the specific role of civil society and people living with NCDs has been too absent from the political narrative, and efforts to engage civil society within health governance, planning, and accountability have been – at best – tokenistic at global and country levels.

A recent WHO survey shows that less than half of countries have multi-sectoral NCD commissions in operation, and that around one third of these do not include NGOs/civil society. This echoes a recent NCD Alliance survey, which found that only one quarter of NCD alliances view local and national decision-making bodies as accessible to civil society organisations, including grassroots and patient organisations. While individual reasons may differ, the lack of mechanisms to engage civil society in decision making processes is considered by NCD alliances as one of the top three challenges limiting their work.51

Involvement of PLWNCDs, communities with unique needs and strengths, and young people has also been broadly neglected and undervalued. Only 24% of national NCD alliances believe that their government’s policies, programmes and laws are inclusive enough to ensure that no one is left behind in the NCD response.

The UN and governments must walk the talk on their commitment to meaningful engagement of civil society. They need to move beyond tokenistic efforts and create truly inclusive processes at all levels of policy and programme design, governance and service delivery, and creation and implementation of accountability mechanisms to provide PLWNCDs and civil society with opportunities to engage and contribute as equal partners and experts in their own right.

Shrinking space for civil society

NCD civil society has never been stronger and more unified. But the space in which civil society operates is increasingly being curtailed. Between 2012 and 2015, more than 120 laws restricting civic rights were introduced or proposed in 60 countries.52 These legislative changes are intended to undermine the effectiveness and independence of civil society actors, and restrict capacity to function and fulfil the role of challenging those in power to better deliver for the public good.

Sustainable financing for NCD civil society

More investment is urgently needed to support CSOs and community systems, particularly in LMICs. This is a valuable lesson from the AIDS response, with donors including the Bill and Melinda Gates Foundation and the Ford Foundation stepping in to channel funds to support CSOs and build skills in advocacy, budget tracking, and documenting best practice to professionalise the sector and deliver faster progress.

According to a recent NCD Alliance survey, financial constraints remain the number one challenge limiting the response across the global network of national and regional NCD alliances. There are few or no public resources available to NCD alliances in LMICs, and many NCD alliances lack capacity to effectively fundraise. To date, very few national or regional alliances have been able to mobilise international development funding, largely due to the lack of NCD-specific funds available. Twinning initiatives between HIC and LIC alliances have remained the exception, and the grants administered via the NCD Alliance Advocacy Institute have been small but vital to seeding newly founded alliances, and to scale-up the work of existing alliances.


53 “Defamation laws, criminalisation of previously permitted activities, bans on organisations funded by foreign sources, branding civil society organisations as foreign agents, and strict media reporting regulations are among just some of the legal measures that limit, or in some cases entirely suppress, civil society.” (Aho Emilie et al).


49 Don, K. A “whole of society” approach to non-communicable diseases must include civil society organisations. BMJ. 2018. Available at: https://blogs.bmj.com/bmj/2019/02/01/a-whole-of-society-approach-to-non-communicable-diseases-must-include-civil-society-organisations/


51 NCD Alliance. Bridging the Gap survey.


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Accountability is a crucial force for political and programmatic change, and key to tracking progress on NCDs. Defined as a cyclical process of monitoring, review and action, accountability enables the tracking of commitments, resources, and results and provides information on what works and why, what needs improving, and what requires increased attention. Accountability ensures that decision makers have the information required to meet the health needs and realise the rights of all people at risk of or living with NCDs, and to place them at the heart of related efforts.

Despite these agreed-upon approaches, implementation lags behind the evidence, and the economics of implementing all 16 WHO-recognised ‘best buy’ interventions – globally recommended, evidence-based, highly cost-effective policy interventions – would prevent 9.6 million premature deaths worldwide between 2018 and 2025.65 While implementation of recommended NCD policies is slowly increasing, on average just under half of the recommended policies have been implemented in-country.66 The least implemented of these highly impactful and cost-effective policies are tobacco taxation, tobacco mass media campaigns, provision of cardiovascular therapies, and alcohol advertising restrictions, revealing missed opportunities to improve and save lives and strengthen economies.

THE ACCOUNTABILITY GAP

The Community Engagement Gap

Call for and participate in inclusive NCD governance mechanisms, institutionalising the role of PLWNCDs and civil society in health decision-making at national, regional and international level

Learn from the AIDS response as a pioneer in establishing inclusive governance mechanisms. For example, NGOs are represented on the boards of the Global Fund, and civil society and PLWHIV are specifically included in the governance structure of UNAIDS.

Team up with legal experts to explore how a rights angle could accelerate NCD action

Explore how binding legal instruments and treaties can advance the NCD agenda, including legal measures against governments for failure to meet commitments to rights and equity.

Join forces with social movements representing people left behind, including environment and equity advocates, youth movements, indigenous communities and others advocating systemic reform

In addition to the strong links already forged with child rights, women’s health and HIV/AIDS movements, NCD civil society can make a common cause with campaigners for environment, climate, and others who campaign for wellbeing to be put ahead of short-term economic indicators in decision making. Ensure that social and environmental policies are also understood as health and wellbeing policies.

Coordinate civil society action across all SDGs

It is essential that CSOs across different sectors work more closely together, to ensure that there are no trade-offs between the different aspects of sustainable development.

Communicate effectively by leveraging outrage, rebuking injustice, translating evidence, sharing personal stories, celebrating successes, and campaigning collaboratively

Mobilise for the annual Global Week for Action on NCDs and other milestone days, weeks and political campaigns to use diverse communication strategies. Use traditional and social media to make noise, demand change, and put issues, insights and solutions in front of policy makers.

Celebrate and share successes

‘Yes We Can’ is a legendary political slogan that inspired a movement to believe that unprecedented change was possible, becoming a self-fulfilling prophecy. Showcasing successful and courageous NCD actions and leaders who implement effective measures can encourage and inspire others to emulate these successes for their own countries and people.

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Implementation lags behind the evidence, and the economics

Implementing all 16 WHO-recognised ‘best buy’ interventions – globally recommended, evidence-based, highly cost-effective policy interventions – would prevent 9.6 million premature deaths worldwide between 2018 and 2025.65 While implementation of recommended NCD policies is slowly increasing, on average just under half of the recommended policies have been implemented in-country.66 The least implemented of these highly impactful and cost-effective policies are tobacco taxation, tobacco mass media campaigns, provision of cardiovascular therapies, and alcohol advertising restrictions, revealing missed opportunities to improve and save lives and strengthen economies.

57 According to Allen et al, between 2015 and 2017, aggregate implementation scores rose in 109 countries and regressed in 32 countries. Mean implementation rose for all of the 18 policies except for those targeting alcohol and physical activity.
A recent systematic analysis of geopolitical and economic factors on NCD policy responses highlights that gross national income is not the decisive factor in policy implementation. Leaders’ willingness to invest in human capital by improving health and education may be a more important prerequisite than national wealth itself.

In LMICs alone, where action is most urgently needed, 8.1 million premature deaths could be avoided between 2018 and 2030, representing a reduction of almost 15% in total premature mortality from NCDs. In LMICs, implementing the ‘best buy’ policies would require an investment of US$1.27 per person per year between now and 2030, and generate an economic return of seven dollars per dollar spent. In the case of fiscal measures, the ‘best buy’ generate government revenue which could be reinvested in UHC, providing a double dividend for health and the economy by reducing the burden of disease and providing resources for health.

**National accountability mechanisms and action**

Accountability mechanisms, data collection and surveillance systems are crucial to fill the gap between promises, plans and effective implementation. A 2018 analysis of NCD policy processes in five African countries shows that while all countries had recently developed NCD strategic plans, these had not been adequately implemented due to inadequate political commitment and a lack of resources and technical capacity, as well as industry influence.

This is echoed by NCD Alliance’s survey findings: Although 62% of countries have indicators for national NCD targets, currently, only 15% of NCDs survey respondents believe that their country has sufficient accountability mechanisms to ensure the targets are actually met.

Data for the forthcoming WHO Progress Monitor report shows that an encouraging 84% of Member States report funding allocated from national budgets toward NCD surveillance, monitoring and evaluation. But in reality this is insufficient, as only around one fifth of national NCD alliances believe their country’s NCD surveillance, monitoring and evaluation capacity is adequate. This underlines the urgent need to hold governments accountable to their 2018 Political Declaration commitment to establish or strengthen transparent national accountability mechanisms.

Whilst significant improvements have been achieved in terms of strengthening accountability for NCDs at the global level, follow-up is needed at the most relevant political level. For national or regional politicians, the non-binding 2025 and 2030 NCD Targets are rarely discussed in national media or political debate, so have not been rendered politically salient outside of international fora such as the World Health Assembly or UN General Assembly. Policymakers typically prioritise short-term domestic wins – like economic growth, improvements in quality of life, national security – within the current political cycle, with the aim of securing re-election.

NCDs receive attention when the public and politicians understand that this preventable epidemic costs them dearly – including in terms of votes – and requires the highest level of government leadership and coherence across sectors. Public awareness and pressure are crucial, especially where commercial actors are lobbying to undermine public health policies that could challenge their business interests.

Progress requires comprehensive national NCD surveillance systems, including reliable registration of deaths by cause, disaggregation of data by gender, age, and socio-economic status, cancer registration, periodic data collection on risk factors, and monitoring of national responses.

**Independent accountability – the opportunities**

Existing WHO, UN and national accountability mechanisms for NCDs can be complemented by independent accountability mechanisms and initiatives at global, regional and country level. Independent (non-governmental) accountability exercises undertaken by civil society organisations are important to hold governments to account for their commitments, and ensure that they translate into real action and NCD progress. The results of independent evaluations are useful tools – an external assessment, index or ranking can often spur action by governments shown to be lagging behind or not measuring up to their peers’ progress.

Civil society is a vital actor in independent accountability, due to its proximity to the affected communities and independence from government and vested interests. One third of NCD alliances are engaged in accountability activities or mechanisms to monitor and evaluate the progress of NCD policies, programmes and laws in their country or region. Diverse and inclusive NCD Alliances and coalitions’ monitoring and shadow reporting can improve awareness and accountability at the national level. These processes can help support, complement or challenge government narratives, engage the media and influence public opinion by publicly communicating findings, and lift advocates’ position as trusted civil society voices on NCDs.

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60 These factors are: region, NCD burden, human and financial resources (i.e. personal wealth, tax burden), political ideology, and social solidarity.
62 Ibid.
64 Kenya, South Africa, Cameroon, Nigeria, Malawi.
65 NCD Countdown 2030 is an independent collaboration between WHO, The Lancet, NCD Alliance, the WHO Collaborating Centre on NCD Surveillance and Epidemiology at Imperial College London, and researchers and practitioners from all regions. The initiative aims to inform policies that aim to reduce the worldwide burden of NCDs, and to ensure accountability.
66 “Probability of dying from any NCD between birth and 80 years of age”
Next steps

This paper is intended as a basis for future discussion within and beyond the NCD community to tackle the gaps in the first decade of the NCD response. The gaps described above are all closely interconnected and action will be needed across the whole spectrum to address them. The Civil Society Compass outlines suggestions for NCD civil society to accelerate the response towards 2025 and 2030, and to bridge the gap between global commitments and effective action to prevent and treat NCDs in every region and every country. We invite civil society organisations to take up these ideas, adapt them appropriately to their local context, and propose their own actions in response to the challenges they face. We look forward to feedback on the gaps identified and actions suggested here, and to using this feedback as a foundation for future action together, in order to overcome the neglect of NCDs and accelerate overdue progress.
This paper outlines the gaps in the first decade of the NCD response. Calling on the experience of NCD Alliance’s global network of people living with NCDs, advocates, campaigners and experts collected via several surveys, as well as the latest data from the World Health Organization and peer reviewed literature, this paper identifies what has been lost in translation of the global targets for NCD reduction and describe the major barriers to meaningful progress.