

Nothing for Us

Without Us

Opportunities for meaningful engagement of people living with NCDs

Meeting report

Nothing for us, without us. Opportunities for meaningful engagement of people living with NCDs: meeting report

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Chapter 1

Introduction

In 2020, global health priorities were rapidly transformed, making it increasingly challenging to provide relevant policies and programmes for noncommunicable 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. This approach was adopted by WHO Member States in the Alma Ata Declaration (1978) (1), 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 outcome document of the Rio+20 Conference, the Future We Want, recognizes that "opportunities for people to influence their lives and future, participate in decisionmaking and voice their concerns are fundamental for sustainable development".

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. 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 (2).

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 buyin 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 personcentred 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.

Recognition of people living with NCDs (PLWNCDs) as a community of health advocates with specific knowledge and expertise enhances opportunities to promote and achieve health for all and ensure that NCD and mental health services leave no one behind. This will accelerate progress towards the Sustainable Development Goals (SDGs) through the provision of comprehensive, equitable, person-centred health systems to address the health and well-being of PLWNCDs throughout their life-course.

"PLWNCDs" is a broad term that encompasses people with a wide range of diseases, experiences and perspectives (3). Attention to the value and role of PLWNCDs in the NCD response has evolved from an emerging topic to a central pillar of NCD advocacy in global public health. There is widespread acknowledgement of the importance of engaging PLWNCDs in the global health arena, valuing their voices, expertise and input, from the design to the implementation and evaluation of programmes and services, in addition to their role as key drivers of various political processes. The benefits of meaningful engagement of PLWNCDs have not been fully explored, and its practice should be documented, innovative techniques tested and new evidence generated to support the approach.

The concept of the "patient expert" came to fruition in the 1980s and has been applied to various health challenges, including chronic disease management programmes (4). While the concept was originally applied to selfmanagement, so that health care recipients could be autonomous in managing their conditions, it developed into a partner-like relationship, with patients providing input to treatment programme development to enhance community-based services. This placed the patient at the centre and thus transformed the continuum of care.

Patient-centred approaches to care have also been established for young people living with NCDs. Many of the models are family-centred, designed to improve access

to care and treatment. Despite these efforts, most young people living with NCDs do not routinely receive services to which they, their family or other caregivers can make a meaningful input (5). There is still limited understanding of the impact of meaningful integration of lived experience into the NCD agenda, while it has had resounding successes in programmes for HIV/AIDs, tuberculosis and other infectious diseases. Potentially, lessons from successful application of this approach could be adapted and adopted by NCD policy-, programme- and practice-makers to ensure more inclusive, effective local NCD and mental health agendas.

The term has evolved from "patient-centred", which, in some cases, could be viewed as "victimizing" to a more inclusive, participatory "person-centred" approach. The purpose of this evolution is to empower people with lived experience and make them autonomous. It also addresses the dichotomy between patients and clinical professionals, the latter of whom are the traditional leaders and creators of public and global health agendas. A personcentred approach could ensure that people with lived experience and expertise shape policies and programmes and sit at decision-making tables, from creation to implementation, to ensure that the decisions are acceptable to the target population.

Inclusive health systems must capture the heterogeneity of populations, which requires acknowledgement of all their facets and their potential intersection. "Intersectionality"

describes an analytical framework for understanding how aspects of a person's social and political identities combine to create various types of discrimination and privilege.

Examples are gender, caste, sexual orientation, race, ethnicity, class, socioeconomic status, religion, disability and physical appearance. Combinations of these also determine an individual's experience of living with a disease.

Whether an individual is experiencing a single or several NCDs, their intersectionality will give them a unique lived experience, perspective and expertise. In addition, some PLWNCDs work in the health workforce and can provide both professional and personal lived experience. Understanding and accessing these intersections and layers of experience and expertise can help health professionals and decision-makers to understand the complex factors and potential contextual obstacles and ultimately co-design solutions that account for and are responsive to the multitude of experiences (6).

Unfortunately, current studies of meaningful engagement of PLWNCDs have primarily explored the lived experience of specific NCDs, with little regard to intersectionality or extrapolation to the wider NCD community. They thus exclude or do not accurately account for the many critical contextual factors, or intersectionality, that influence how PLWNCDs navigate the health-care and health systems, which directly impacts their health outcomes. It is essential to acknowledge the intersectionality of PLWNCDs, to

understand that one size does not fit all and to ensure meaningful engagement of a diverse, representative community of PLWNCDs, including professionals, organizations, institutions and all income brackets.

While intersections relevant to NCDs can bring valuable nuance to contextual and inclusive approaches to addressing NCDs, people living with other diseases, such as communicable diseases, including HIV/AIDS, tuberculosis and malaria, should be included in discussions to learn from their experiences, find commonalities and improve integrated people-centred health responses. Involving people with lived experience in various programme areas can build inclusive, resilient, people-centred primary health care and support an approach to universal health care.

1.1 The NCD epidemic and intertwined "syndemics"

Emerging and re-emerging infectious diseases coupled with the growing epidemic of NCDs represent a contemporary global public health challenge. As global health priorities change, there is a risk that hard-fought gains for NCDs could be side-lined in favour of urgent global health security. The COVID-19 pandemic has entered its second year, and it has become evident that the risk of severe COVID-19 infection increases with both an individual's age and the presence of underlying health conditions. Global modelling data (7) suggest that more than one in five people globally are at increased risk of severe COVID-19 as a result of an underlying NCD. However, understanding that over 1.7 billion people worldwide who live with one or multiple NCDs are at higher risk of COVID-19 complications and death has not systematically shaped national response and recovery strategies.

NCDs are the greatest contributors to mortality and morbidity globally. NCDs – cardiovascular diseases, cancer, chronic respiratory diseases and diabetes – and mental health conditions impose a devastating burden on individuals, households, health systems and national economies, especially in low- and middle-income countries. The 2020 Global Health Estimates (8) show that 7 of the 10 leading causes of death are now NCDs, while they

represented 4 of 10 leading causes 20 years ago. WHO estimated that of the 55.4 million deaths in 2019, NCDs were responsible for 40.8 million, or 74% of global mortality. NCDs and mental health conditions are leading causes of mortality and morbidity for women globally. It is of particular concern that 15.7 million of the deaths due to NCDs worldwide were of people aged 30–70, and 85% of this premature mortality occurred in low- and middle-income countries (8, 9).

While NCDs are typically considered to be conditions that emerge in adulthood, millions of PLWNCDs are identified during childhood and youth. For example, cancer is diagnosed in 300 000 children under 18 years of age each year (10), and asthma is diagnosed in approximately 339 million people globally, most of whom are children (11).

The COVID-19 pandemic is one of the most disruptive forces of the 21st century. As COVID-19 continues to spread, the deadly interplay with the NCD epidemic is becoming increasingly clear. The presence of a pre-existing NCD dramatically increases the risks of severe COVID-19 illness and mortality, and emerging research also indicates that COVID-19 may complicate existing NCDs or induce an NCD in a previously healthy individual (12). COVID-19 response measures such as lockdowns have curbed healthy behaviour and contributed to a reduction in public demand for health services because of concern about the risk of infection. Constricted household incomes have also disrupted disease prevention and management, and social

isolation has increased mental health conditions (13). The novel coronavirus has exposed profound social inequity, as the pandemic has disproportionately affected the poor, immigrants and other low-income and marginalized populations, who are typically more vulnerable to NCDs (14).

This deadly interplay is compounded by the fact that programmes for NCD prevention, diagnosis, treatment and palliative care have been disrupted because of overloaded health systems. A recent rapid assessment of service delivery for NCDs during the COVID-19 pandemic conducted by WHO (15) revealed a strong relation between the transmission phase of the COVID-19 pandemic and disruption of essential NCD services; the more severe the transmission phase of COVID-19, the more NCD services are disrupted. For instance, during community transmission of COVID-19, 66% of countries disrupted services for hypertension management, and 64% disrupted services to treat diabetes and its complications (15).

The interaction between the COVID-19 pandemic, the NCD epidemic and existing and emerging inequities has been classified as a "syndemic", occurring at the same time, in the same place and driven by the same social and economic factors in populations in various income settings (16). This is not, however, the only syndemic in which NCDs are a part: a recent Lancet Commission addressed the interplay among obesity, undernutrition and climate change (17), demonstrating the synergies between food

production, the changing climate and malnutrition and the systemic social and economic determinants. Further, the WHO-UNICEF-Lancet Commission on the future of the world's children examined the links among human rights, governance, accountability and commercial determinants of child health and well-being throughout the life-course and over generations (18). The same complex combination of factors can be found in the WHO manifesto for health recovery from COVID-19, which addresses the challenges and opportunities linked to human and planetary health through nature, water and sanitation, clean energy, food systems, urban environments and air quality (19). NCDs and, particularly, PLWNCDs are an integral part of these broad syndemics, and the burden of NCDs will be reduced only by using diverse lived experiences at these intersections to address the drivers and determinants of the development of NCDs and mental health conditions.

1.2 Potential opportunities to build back better

A multi-stakeholder approach and community engagement are essential to sustain and accelerate progress towards achievement of SDG 3.4 for people in all income settings. PLWNCDs can offer unique, invaluable insights into the contextual challenges in the prevention and control of NCDs and mental health conditions, which can be used in setting priorities for effective NCD programmes, policies and services to meet the challenges and needs of communities. Lived experience and first-hand knowledge and expertise of aspects of NCDs, including treatment, care, support, promotion, prevention, stigmatization and discrimination, can make interventions more effective, efficient and inclusive. Meaningful involvement of PLWNCDs in decisionmaking at all levels of governance is crucial to shape, drive and implement efforts to build back better from the COVID-19 pandemic.

Meaningful engagement of PLWNCDs is directly aligned with the United Nations Decade of Action, which calls on all sectors of society to mobilize at three levels: global action to secure better leadership, more resources and smarter solutions for achieving the SDGs; local action for transitions in the policies, budgets, institutions and regulatory frameworks of governments, cities and local authorities; and action by people, including youth, civil society, the media,

the private sector, unions, academia and other stakeholders, to generate an unstoppable movement towards the necessary transformations. The inclusion of PLWNCDs in this transformation is fundamental for sustainable development and essential if the United Nations Decade of Action is to catalyse achievement of target 3.4 (20) and NCD-related goals and targets such as SDG target 16.7, which is to "ensure responsive, inclusive, participatory and representative decision-making at all levels" (21).

1.3 Why WHO?

As the leading global health agency in the UN system, WHO recognizes its strategic role in supporting Member States to meaningfully engage PLWNCDs, including by providing a convening platform, generating and leveraging evidence-based information and best practices, co-creating through knowledge collaboration, and engaging lived experience in decision making processes. This was highlighted by WHO Director-General, Dr Tedros Adhanom Ghebreyesus in his video address:

As we work to build back better, we must engage with civil society and individuals with lived experience to hold WHO and political leaders accountable and to drive change... WHO values your voices, your expertise and your inputs. I am also committed to leveraging WHO's role in supporting our Member States in doing the same.

The thought was echoed by Dr Svetlana Akselrod, Director of the Global NCD Platform at WHO:

To date, engagement of lived experience has largely been an untapped resource not only for health providers but also for political leaders, policymakers, intergovernmental organizations and civil society. This is exacerbated with the lack of data on PLWNCDs in general, and specifically concerning multimorbidity. We must use this momentum to make transformative changes to ensure we respond to the call of "nothing for us, without us".

Referring to the impact of COVID-19 on the NCD agenda and the need for reliable data, Dr Bente Mikkelsen, Director of the Department of NCDs, added:

We need reliable data to act ... COVID-19 has laid bare how the world has failed to meet the healthcare needs of people living with NCDs in the majority of Member States. It's time to transform the NCD development strategy, learning from the HIV/AIDs movement. One of the main learning points, we need to listen to and give power to people living with NCDs. We have seen examples of how co-creation for solutions during the pandemic is leading the way. We need to redouble our efforts, so that we reclaim what we lost.

This work also builds on the long-standing engagement of PLWNCDs through the Global Coordination Mechanism on the Prevention and Control of NCDs (GCM/NCD), including the global working groups and communities of practice, the WHO Knowledge Action Portal on NCDs, WHO global dialogues, NCD Labs and the WHO Civil Society Working Group on NCDs. It also complements and supports work on the broader NCD agenda both at WHO headquarters and in the regional offices. Examples include the soon-to-belaunched WHO Global Compact on Diabetes, NCD Sprints and the WHO Global Childhood Cancer Initiative.

WHO also acknowledges the work of many non-State actors, including participants in the GCM/NCD, who have been trailblazers and who continue to champion the voices of PLWNCDs. Many of them supported the design of this consultation on PLWNCDs and increased its reach through their extensive networks, ensuring inclusive and diverse insights and expertise. As we move forward, the work will build on their experiences, lessons and support, possibly with the engagement of more individuals, partners and networks

Chapter 2

Consultation

Format

The GCM/NCD Secretariat invited WHO colleagues, representatives of United Nations agencies, members of the WHO Civil Society Working Group and additional civil society actors, including individuals with lived experience, to a virtual consultation to identify opportunities and challenges in meaningful engagement of PLWNCDs. The consultation was the first dedicated WHO global exercise on meaningful engagement of PLWNCDs.

The consultation was participatory, from its design to its implementation. Crucial to the consultation was establishment of the meaningful participation of PLWNCDs as co-creators and drivers of the agenda, conversations and outcomes (22). Active meaningful engagement was established by co-designing the agenda with an expert group of people with lived experience and those working in the NCD space. This was a dynamic process, in which the consultative group provided input to the concept note and proposed structures for each day, suggestions on participants and speakers and comments on ensuring meaningful engagement. The goal was to ensure that at least 50% of participants at the consultation had lived experience.

Two co- chairs with lived experience were identified for each of the three days, one being a youth voice. The six co-chairs, representing diverse lived experiences and various geographical settings, provided guidance, comments and input throughout their respective day, in consultation with the other co-chairs. The co-chairs were supported by guidance documents but were encouraged to shape and direct the narrative autonomously.

The aim of the consultation was to initiate discussions in a diverse community to map current activities and opportunities for engagement, find synergies in different areas and to identify models of engagement and evidence gaps to guide operationalization of meaningful engagement of PLWNCDs in the governance, design, implementation and evaluation of policies, programmes and services.

The objectives of the consultation were to:

#1

engagement building on lessons learned in other health programmes

#2

Identify activities,
workstreams and
platforms that
offer engagement
opportunities for
PLWNCDs globaly,
regionaly and nationaly

#3

Define the next steps for operationalizing meaningful engagement with PLWNCDs in 2021-2022

To generate data for these objectives, a questionnaire was administered to record demographic information, individual professional and lived experiences and their expectations of the consultation, and the three-day interactive, participatory, virtual consultation was held, combining presentations, in-depth discussions in working groups, a panel discussion and virtual polls.



2.1 Survey

Before the meeting, a survey was administered to all participants to collect relevant data on PLWNCDs to inform the secretariat about participants' demographics, areas of interest, experiences and opinions. The information was used in developing the consultation agenda and for the various group and breakout discussions.

The survey was answered by 112 individuals, of which 108 were answered fully. Demographic information on the survey participants is available in Annex 1. The results suggest that participants' motivation to join this consultation was linked to their current employment and professional interest (78%), a desire to include lived experience in their work (57%) and having a person living with NCDs in their family (48%).

More than half of all participants had previously been involved in activities relevant to meaningful engagement of PLWNCDs, either as organizers or participants. They identified the activities with the most impact as involvement of PLWNCDs in the design and implementation of programmes and policies, advocacy campaigns, networking and collaborating with others.

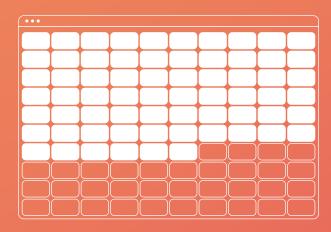
They identified the most significant challenge or barriers to engaging PLWNCDs as lack of financial resources, lack of models, strategies and tools, and lack of opportunities. Tokenistic approaches and lack of understanding of the benefits and importance of engaging PLWNCDs were highlighted as significant barriers.

While lack of models, strategies and tools was considered a barrier, more than half of the participants were aware of models, strategies and tools to support meaningful engagement of PLWNCDs.

They agreed unanimously that more guidance was needed to support operationalization of meaningful engagement of PLWNCDs in policy development. 37

Countries represented in the WHO Informal Consultation of PLWNCDs







participants were females 32 % were males



54%

participants identified as a PLWNCD



16%

participants identified as individuals living with a disability

Motivation to work for and with PLWNCDs

My employment/professional interest connects me to the topic

78%

I feel that is fundamental to include the lived experience in my work

57%

I have a family member living with NCDs

48%

Stakeholder groups

66% From non-governmental organizations

13 %

WHO and **United Nations** 9 % Academia 6 %

Independent

2.2 Participatory consultation structure

The consultation took place virtually on the Zoom platform over three days (9–11 December 2020) for approximately 3.5 hours each day. Each participant was either a specialist in lived experience engagement, was familiar with a specific subset of the NCD population and/or had lived experience themselves. The consultation was organized to respond to the following questions:

What does meaningful engagement mean? (Day 1)

How do we engage meaningfully? (Day 2)

Where do we go from here? (Day 3)

To optimize participation, virtual presentations, discussions and breakout sessions led and/or facilitated by PLWNCDs were conducted over three sessions. The design of the consultation ensured that one third of the time was for presentations and the remaining two thirds for group and breakout discussions.

People with lived experience provided input through presentations, as reflections in active discussions, in the survey, in answers to polling questions, as reflections and in discussions in the wider group chat.

Worksheets and notes were completed by the session rapporteurs during the plenary session and in the group discussions and breakout sessions. All documents and polling data were collected, and audio and video recordings were uploaded onto YouTube.

All the data were then collated and synthesized by the data collection team to produce a report immediately after the event.

2.3 Emerging themes

All the discussions were recorded, compiled and compared. Analysis of the data revealed three main themes:

Theme 1: Meaningful engagement activates agents of change and builds on what is meant by meaningful engagement of PLWNCDs.

Theme 2: From talking the talk to walking the walk shows how the process should be conducted.

Theme 3: Actions we want to see indicates the methods the participants consider should be used to support active, participatory engagement of PLWNCDs.

The findings for each of these main themes are presented in the following sections, with a constitutive organizational structure of the main theme and the sub-themes.

2.3.1 Theme 1: Meaningful engagement activates agents of change

This theme reflects the participants' definition of meaningful engagement of target populations. Overall, there was a clear shift from the individual as a passive user to one who is empowered and acts as an agent of change and is respected, valued and included in a range of activities and processes, from start to finish. They should be able to equitably influence the design of policies, programmes and practices in a protected environment, and their diverse and intersectional perspectives should be incorporated.

Additional support should be given to minority and marginalized groups who may not be captured by current agendas, services or policies.

Sub-theme 1.1

Meaningful engagement can reorientate power to agents of change

The participants in the consultation wanted to influence decisions on the NCD agenda. Their influence should extend from simply having a seat at the table to being active participants with equal or greater possibilities to provide input and shape outcomes. The sharing of power should extend from boardrooms to the design, delivery and implementation of policies, programmes and health services, in which their diverse knowledge, experience and perspectives should be used to co-design, inform and

support implementation, governance and evaluation. Their input should be used to address specific issues and barriers to human rights and equity, overcome stigmatization and discrimination and target the marginalized groups that are often at greatest risk.

Mechanisms should be in place to support meaningful engagement built on legally binding mandates for standardized inclusion of lived experiences, such as by using a human rights approach to "the right and duty to participate individually and collectively in the planning and implementation of their health care" as a salient feature of the right to the highest attainable standard of health, or examples of government targets for meaningful involvement of people living with HIV/AIDs. Their involvement should also be supported financially, both in terms of building capacity for effective, inclusive participation and facilitating sustained participation, identifying appropriate individuals and providing support for logistics and for their time. These mechanisms should be established in health system areas such as organizational governance, policy development and community engagement.

Sub-theme 1.2 Diverse perspectives and equitable representation from marginalied populations

The participants recognized the importance of collecting the intersectional, diverse perspectives of individuals with different backgrounds and recommended that this approach be scaled up rapidly. They emphasized that people outside the health system or policy development should be included and that relationships should be built with communities that are underrepresented, misrepresented or marginalized. Specifically, they requested better representation of people living with disabilities, youth, women, lesbian, gay, bisexual, transgender and intersex people, members of minority groups, indigenous people, internally displaced persons and non-nationals, including refugees, asylum seekers and migrant workers. Materials should be available in local and lay languages, and the content should reflect the situation, context or country.

Sub-theme 1.3
Creating an "enabling and protective environment" can allow lived experiences to thrive

The participants suggested that models for meaningful engagement be co-designed, structured and mobilized before decision-making to ensure that they have the desired impact. Engagement should be carefully planned, to ensure that individuals with diverse lived experiences are meaningfully and strategically involved, avoiding tokenism. An enabling, "protective" environment should be created to ensure that PLWNCDs are free from stigmatization, discrimination and criticism and can openly convey their experiences to be heard and eventually thrive. The environment should be free of judgement or hierarchy and should support and integrate lived experiences, encourage a productive power balance, address issues of equity, stigmatization and discrimination and make human rights and lived experiences central to all phases of programmes and policies.

2.3.2 Theme 2: From talking the talk to walking the walk

There was consensus in the group that more effort is required to transition from intention to action when engaging with PLWNCDs. It was suggested that a "tick box" exercise is inappropriate for engaging PLWNCDs, and a multi-faceted approach is required, in which accountability is shifted from PLWNCDs to governments and health-care providers. The group recognized, however, that regions and countries are at different stages of participatory engagement of PLWNCDs in development of the NCD and mental health agenda.

Sub-theme 2.1 Moving from intention to action

The group noted that, as part of the essential move from dialogue to action, more voices should be identified and brought into the NCD community. Galvanizing a community by identifying commonalities among diverse lived experiences has been successful in the past, e.g. in Greater involvement of people living with HIV (GIPA) for the HIV/ AIDs agenda. The participants suggested further mapping and leveraging of diverse experiences to join the voices of PLWNCDs to advocate for change from the bottom up.

The participants recognized that lobbying for a political or global agenda can be complex and challenging. Often, access to the high-level forums and platforms at which most

such discussions are held is privileged. More action to break down the barriers to championing diversity and inclusion is essential for meaningful, representative, sustained engagement. While the participants in the consultation were a diverse but geographically balanced group, greater effort is needed to ensure that equal representation of lived experience, including that of marginalized groups, is achieved at all levels of engagement. This also extends to ensuring a human rights-based approach and establishing models for engagement which champion diversity, respect and inclusivity with financial support and recognition.

The group indicated that a universal model for mobilizing PLWNCDs might not be appropriate, mainly because each country and context has a different level of engagement with PLWNCDs. Furthermore, contextually appropriate, responsive methods are required in engagement with PLWNCDs. For example, some communities do not have Internet connectivity, might have low mobile phone penetration or might have low health literacy.

Sub-theme 2.2

Transferring power to the people with lived experience

Turning the tables and transferring power to those with lived experience is essential to ensure that the principles of respect, value and dignity in meaningful engagement are met. The stories, knowledge and expertise of individuals with diverse lived experience are powerful narratives that

can inspire others to join the movement as agents of change while influencing and informing those in power. Additional consideration should be given to people outside the current health or social care system, as the most disadvantaged groups can often provide equally, if not more, valuable perspectives and input on the challenges and opportunities at various levels of health care delivery. The communication should be creative and contextually and culturally specific and at the same time accessible, adapted, translated into local languages and positively framed.

To support the cultural changes required to ensure meaningful engagement at all levels, people with lived experience need the right tools and resources to influence and to speak as a community and as a group of people. The group highlighted the concept of influence, whereby those with lived experience are provided with the skills to further engage, influence and understand the right mechanisms for stakeholders in order to achieve specific outcomes. This will require capacity-building in global health.

Sub-theme 2.3
Utilising and integrating PLWNCDs into meaningful engagement networks, strategies and frameworks

While individuals with lived experiences in the NCD community are often part of a unique, complex ecosystem, lessons can be learnt from successful responses to other health challenges. This feeds into many of the elements

already highlighted, bringing in their successes, models of engagement, established communities and frameworks, with agents of change (23). The diverse NCD lived experience agenda could be united under one umbrella with other health-related communities, such as people living with or affected by HIV/AIDs, disability and COVID-19, and with other movements such as those that support universal health coverage, people-centred primary health care, a gender equity and human rights-based approach to health and achievement of the SDGs.

The participants indicated that understanding how and when to engage PLWNCDs at selected points in the design of NCD and mental health programmes, policies and services could further support meaningful engagement. They recognized, however, that it would be difficult to find relevant individuals and expertise and, potentially, to create a subgroup within the wider community. Therefore, the capacity for community mobilization should be enhanced and built through existing networks in order to establish new communities and ensure that no one is left behind. It was suggested that village leaders could build capacity, connect diverse lived experience and disseminate messages on NCDs. They could be supported by translators and assisted in translation of messages from regional or local dialects.

Sub-theme 2.4
Optimizing diversity and inclusion through outreach and engagement of new voices in new places

The group highlighted the importance of involving relevant governance officials in the design of NCD principles, policies and programmes. Governance systems are often involved after programme development, which may leave the nuances of policy-makers and programmes open to interpretation. The principles or policies that are being contextualized into programmes and translated into practice are thus left open to interpretation, which may compromise outcomes. Intentional engagement of governance systems throughout can ensure that feasible monitoring and evaluation systems are built in from the outset, which can prevent misadaptation. Governance systems include lived experiences in their governance and accountability mechanisms, as seen in programmes for HIV/AIDs, disability and indigenous and first-nation communities.

2.3.3

Theme 3: Taking the next step towards a more inclusive, diverse and mobilized NCD community

Before and during the consultation, the group stressed the importance of identifying actionable, practical, tangible next steps with concrete actions. There was a sense that a new community had been formed in the wider NCD context, and there was a desire to nurture the collective, potentially activating other lived experience to achieve real, meaningful change for the PLWNCDs community.

Sub-theme 3.1 Establishing an approach through the WHO ensures sustainability, legitimacy and integrity

The importance of WHO in prioritizing sustained involvement in the mobilization of PLWNCDs was recognized. Leadership by WHO highlights the integrity of the efforts and also adds legitimacy and, potentially, sustainability through the extensive WHO network.

The participants acknowledged the opportunity to leverage WHO's ability to convene, support and align Member States and other key stakeholders in meaningfully engaging PLWNCDs. The leadership and convening role of WHO has been demonstrated once again during the COVID-19 pandemic, as it builds and collaborates on evidence-based

information and guidance to address the links between NCDs and COVID-19 and the comprehensive efforts required to build back better. There is an opportunity to build a community to support bidirectional exchange of knowledge with WHO and relevant decision-makers, with inclusive, diverse representation and attention to the necessary balance of power between those with lived experience and established or new governance structures at all levels. Establishment of a movement and a community would better support PLWNCDs in navigating and participating in complex multinational systems.

Sub-theme 3.2 Calls for participatory action and engagement to co-create the NCD global and regional agenda

The participants agreed that the consultation should not be a stand-alone event but a stepping-stone to the future. They acknowledged that support for communities strengthens the entire system, from local to global. There was a call for better engagement of health-care providers and ethical, meaningful engagement of PLWNCDs and governments to address stigmatization and shaming with regard to NCDs, particularly in the context of COVID-19. The next steps should include mechanisms to coordinate, connect and align bottom-up and top-down efforts and initiatives and support global knowledge exchange on NCD programmes,

policy and practice. The participants emphasized the need for real participation and visionary game-changers to ensure that WHO and Member States recognized the needs and experiences of people living with NCDs and communicated them to people currently in positions of power. WHO has opportunities to speak to a broader audience, to set specific targets for NCD risk factors and diseases, standardize meaningful participation, shift power dynamics and support co-creation of activities, programmes and policies.

Chapter 3

Next Steps to

Operationalize

Meaningful

Engagement of

People Living

with NCDs

The themes outlined above and the discussions of the participants in the WHO Informal Consultation on PLWNCDs resulted in recommendation of the following next steps.

3.1 Map best practices and case studies of meaningful engagement

A literature review of existing best practices, models of engagement, established mechanisms, case studies and practical field examples of successes and challenges would benefit the community. A knowledge base of what exists, what works, the lessons that have been learnt and what can be adapted and scaled will be of significant value in supporting the community's work.

3.2 Explore alignment and integration with other lived experience communities

Find and use the synergies and lessons learnt from other programmatic health areas, such as communicable diseases and maternal, child and adolescent health, and should seek opportunities to align with and feed into other global health movements, such as those for universal health coverage, people-centred primary health care, the global action plan on SDG3 and a gender-, equity- and human rights-based

approach to health. Practical steps should be outlined for supporting, aligning and, when possible, integrating these frameworks and strategies to build a comprehensive, integrated, resilient systems approach to the fundamental right to health.

3.3 Conduct extensive stakeholder mapping

Stakeholders should be mapped to identify in detail the voices of those at risk of being left behind and of marginalized groups, who have the most to offer with the fewest opportunities to contribute. Ways must be found to identify who is being left behind and why, with attention to challenges in voice, agency, access and participation, such as the digital divide, which discriminate against contexts with low connectivity or digital penetration and individuals with low digital literacy. Further consideration should be given to using the extensive networks represented at the consultation and to collaborate with other stakeholders to support the community's wider goal of reaching grassroots voices.

3.4 Conduct additional focused contextual consultations to bring together diverse voices

Further engagement and research will be required to contextualize some of the findings of the consultation and to dig deeper into some of the issues that were raised. This could involve further mainstreaming of meaningful engagement in governance and programme delivery mechanisms for NCD principles, policies and programmes at regional and national levels, and also for future activities in other WHO programmes. This can be done through additional regional, sub-regional and national meetings and collaboration on knowledge- and capacity-building workshops and consultations. These should bring together additional lived experiences, with a focus on marginalized and grassroots voices, addressing context-specific challenges and finding contextual solutions. This could incite the GCM/NCD to build on the new community established during the consultation to adapt, support and align with other activities, initiatives and platforms at WHO headquarters, regional offices and country offices. Specific reference was made to WHO country offices and to the inclusion of Member States in future consultations. When possible, the consultations should build and support advocacy to develop new activities and scale up existing efforts for the fourth United Nations High-level Meeting on NCDs in 2025. I, sub-regional, and national meetings, knowledge collaboration and capacity building workshops

and consultations. These should bring together additional lived experiences, with a specific focus on marginalized voices and grassroots voices, addressing context-specific challenges and producing contextual solutions. This can leverage the GCM/NCD to further build on this new community, established through the consultation, to adapt, support and align to other activities, initiatives and platforms at WHO Headquarters, Regional Offices and/or Country Offices. Specific reference was made to ensure WHO Country Offices are leveraged and the inclusion of Member States as part of future consultations. Where possible, the consultations should build and support an advocacy component to develop new, and scale up existing, efforts in the lead up to and delivery of the fourth UN High-Level Meeting on NCDs in 2025.

3.5 Renew advocacy supporting agents of change

While the group acknowledged the advocacy conducted to date, they called for a new narrative that shifts the focusof lived experience from primarily patients, passive recipients or victims to PLWNCDs who are enabled and involved to co-create an inclusive NCD agenda, building on their experience, evidence, knowledge and expertise. An enhanced narrative should also incorporate further data, evidence-based interventions and storytelling and provide a platform for PLWNCDs. This could be supported by additional platforms, such as global dialogue and

forums for those with lived experience to exchange ideas, experiences, best practices and skills and coordinate existing and develop new advocacy. Existing advocacy materials, experiences and expertise are available in the NCD community to support broader, sustained activities in the lead up to the fourth United Nations High-level Meeting on NCDs in 2025 and throughout the United Nations Decade of Action.

3.6 Outline funding options and models for the inclusion of people living with NCDs

The group acknowledged the ethos of respect and dignity and called for exploration of options and models for sustainable financing to include PLWNCDs in activities.

These should include mapping various funding models used by WHO, Member States and non-State actors to ensure the creation and sustaining of capacities and activities and effective identification, engagement and adequate support and empowerment for the diverse people with lived experience with the necessary resources, skills and capacities to sustain their insights, expertise and time.

3.7 Co-create an action plan with people living with NCDs to support WHO and their respective Member States

engagement

in adopting meaningful

As each of the WHO regions is at a different stage of adopting meaningful engagement, the community should 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 PLWNCDs at country level. This could be strengthened by co-development of targets and indicators of progress in the adoption of meaningful engagement of PLWNCDs and advocating with Members States to include this action in their national NCD or multi-sectoral action plan. This could be supported by the development of a WHO framework for meaningful engagement of PLWNCDs



Chapter 4

Conclusion

The purpose of the consultation was to launch an innovative participatory approach at WHO for meaningful engagement of PLWNCDs. The aim was to convene a relevant, representative community of PLWNCDs to share first-hand experiences, layers of insight and expertise with leaders who shape global, regional, national and local NCD agendas, in order to co-create and embrace a platform that could be joined by other individuals with lived experience.

The next aim was to generate data on opportunities, challenges, best practices and gaps to guide the next steps in co-creation of effective, inclusive, equitable responses to NCDs, mental health issues and their risk factors and determinants. While the consultation had a high level of participation by PLWNCDs and other stakeholders, further research and activities are necessary to consider additional opportunities, challenges, best practices and gaps in the agenda, to further prioritize and mainstream the experiences and expertise of PLWNCDs as a rich source of data and evidence.

The results of this consultation demonstrate that more should be done, urgently, to support the involvement of PLWNCDs in decision-making through meaningful, ethical engagement. The insights, experiences, expertise and perspectives and the diverse, multi-layered lived experiences shared within the group not only enriched and guided all those who participated but also provided a platform for the collective to "walk the talk" by identifying,

developing and sustaining the impact through meaningful engagement and co-leadership of PLWNCDs. The outcome is a new community, brought together in a meaningful, respectful, inclusive environment.

A strong theme throughout the three days was the importance and urgency of scaling up the representative inclusion of the diverse voices of PLWNCDs with lived experiences at all levels through proven and/or innovative opportunities, models and frameworks. These efforts should be enshrined, when possible, in legally binding frameworks or mandates, in governance structures and in processes and platforms for the development, implementation and evaluation of principles, policies and programmes throughout WHO, its Member States and partners. Existing models, strategies and frameworks should be identified and reviewed for further collaboration on how they can be adapted and scaled in different contexts. New frameworks will be established such as the WHO framework for meaningful engagement of PLWNCDs. To achieve this, appropriate, inclusive, well-resourced contextual platforms, with sustained financing and an appropriate balance of power, must be established at different levels.

Finally, the consultation signals the first of many activities and collaborations of this newly established community, which comprises PLWNCDs, WHO, United Nations agencies and relevant civil society representatives and organizations. The consultation made a number of

recommendations to be considered and evaluated. WHO remains committed to meaningful engagement of people with lived experience of NCDs and mental health issues in governance and decision-making and as essential partners in the design, implementation and evaluation of health services, programmes and policies. WHO needs lived experience, expertise and passion to co-design and cocreate innovation and impact in the lead-up to the Fourth United Nations High-level Meeting on NCDs in 2025 and to achieve the SDG NCD-related targets by 2030. It would be unacceptable if the meaningful participation of PLWNCDs were not operationalized. As highlighted at the meeting, "nothing for us without us" is a seismic but welcome shift. With the support of this consultation and the community it launched, WHO can make meaningful strides in the United Nations Decade of Action to support countries in accelerating progress towards achieving SDG 3.4.

Involving PLWNCDs in the co-design of NCD principles, policies and programmes will support health for all by providing a bottom-up method for creating holistic health systems. It builds on existing community structures and community knowledge for the design of contextually appropriate services for communities. It represents a transition from global health provision by clinical professionals to a person-centred design.

References

- Declaration of Alma-Ata. International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. Geneva: World Health Organization; 1978 (https://www.who.int/publications/almaata_declaration_en.pdf)
- 2 Hirsch LA. Is it possible to decolonise global health institutions?. Lancet. 2021;397(10270):189-90.
- Meaningfully involving PLWNCDs report. Geneva: NCD Alliance; 2020 (https://ncdalliance. org/ sites/default/files/resource_files/MeaningfullnvolvingPLWNCDs_Report_FINAL_0.pdf, accessed 16 November 2020).
- 4 Xiao Y. The "expert patient" approach for non-communicable disease management in low and middle income settings: When the reality confronts the rhetoric. Chron Dis Translational Med. 2015;1(3):145–51.
- National, region, and state health care transition performance for youth with and without special health care needs. The National Survey of Children's Health 2018–2019. Washington DC: Got Transition; 2020 https://www.gottransition.org/resource/?state-regional-national-hct-performance-yschn Accessed 16 November 2020.
- 6 Bauer GR. Incorporating intersectionality theory into population health research methodology: challenges and the potential to advance health equity. Social Sci Med. 2014;110:10–7.
- 7 Clark A, Jit M, Warren-Gash C, Guthrie B, Wang HH, Mercer SW et al. Global, regional, and national estimates of the population at increased risk of severe COVID-19 due to underlying health conditions in 2020: a modelling study. Lancet Global Health. 2020;8(8):e1003-17.
- 8 Global Health Estimates 2019: Deaths by cause, age, sex, by country and by region, 2000–2019. Geneva: World Health Organization; 2020 (https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates)
- 9 Global Health Estimates 2019: Disease burden by cause, age, sex, by country and by region, 2000–2019. Geneva: World Health Organization; 2020 (https://www.who.int/data/gho/data/ themes/mortality- and-global-health-estimates
- 10 Steliarova-Foucher E, Colombet M, Ries LA, Moreno F, Dolya A, Bray F et al. International incidence of childhood cancer, 2001–10: a population-based registry study. Lancet Oncol. 2017;18(6):719–31.
- 11 Vos T, Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F et al. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet. 2017;390(10100):1211–59.
- 12 Rubino F, Amiel SA, Zimmet P, Alberti G, Bornstein S, Eckel RH et al. New-onset diabetes in Covid-19. NEJM. 2020;383(8):789–90.
- 13 Coetzee BJ, Kagee A. Structural barriers to adhering to health behaviours in the context of the COVID-19 crisis: considerations for low-and middle-income countries. Global Public Health. 2020;15(8):1093–102.
- 14 Ren G. COVID-19: Exposing & exacerbating global inequality. Health Policy Watch, 28 April 2020 (https://healthpolicy-watch.news/covid-19-exposing-worsening-global-inequality, accessed 14 July 2020

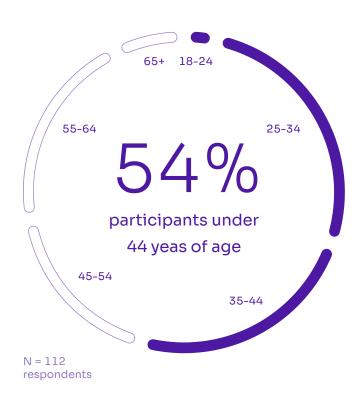
- 15 Rapid assessment of service delivery for NCDs during the COVID-19 pandemic. Geneva: World Health Organization; 2020 (https://www.who.int/publications/m/item/rapid-assessment-of-service-delivery-for-ncds-during-the-covid-19-pandemic, accessed 17 November 2020.
- 16 Horton R. Offline: COVID-19 is not a pandemic. Lancet. 2020;396(10255):874
- 17 Swinburn BA, Kraak VI, Allender S, Atkins VJ, Baker PI, Bogard JR et al. The global syndemic of obesity, undernutrition, and climate change: the Lancet Commission report. Lancet. 2019;393(10173):791–846.
- 18 Clark H, Coll-Seck AM, Banerjee A, Peterson S, Dalglish SL, Ameratunga S et al. A future for the world's children? A WHO- UNICEF-Lancet Commission. Lancet. 2020;395(10224):605– 58.
- 19 WHO Manifesto for a healthy recovery from COVID-19. Geneva: World Health Organization; 2020 (https://www.who.int/news-room/feature-stories/detail/who-manifesto-for-a-healthy-recovery-from-covid-19, accessed 17 November 2020.
- 20 SDG decade of action. New York City (NY): United Nations; 2020 (https://www.un.org/sustainabledevelopment/decade-of-action/, accessed 16 May 2020.
- 21 Information for integrated Decision-Making & Participation. New York City (NY): United Nations; 2020 (https:// sustainabledevelopment.un.org/topics/information-integrated-decision-making-and-participation, accessed 11 November 2020
- 22 Advocacy agenda for people living with NCDs. NCD Alliance; 2020 (https://ncdalliance.org/sites/default/files/resource_files/MeaningfulInvolvingPLWNCDs_Report_FINAL_0.pdf, accessed 16 November 2020

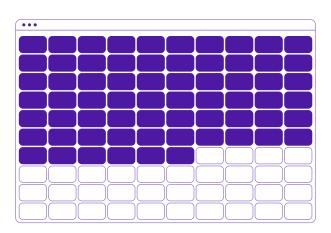
Annex 1

Survey
Results

37

countries represented in the WHO Informal Consultation of PLWNCDs





66%

participants were females

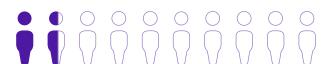
32 % Male N = 111 respondents



54%

participants identified as a PLWNCD

N = 111 respondents



16%

participants identified as individuals living with a disability

N = 96 respondents

Motivation to work for and with PLWNCDs

N = 106 respondents

My employment/professional interest connects me to the topic

78%

I feel that is fundamental to include the lived experience in my work

57%

I have a family member living with NCDs

48%

I choose to volunteer in this field

27%

Stakeholder groups

N = 112 respondents

66% From non-governmental organizations

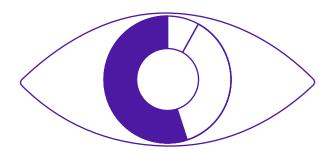
13 % WHO and **United Nations**

9% Academia

6% Independent

15% Belong to First Nations or indigenous communities

N = 111 respondents



participants were aware of models, strategies, or tools to support engagement with PLWNCDs

N = 103 respondents

99% says 'yes' to

66

There is a need for more guidance to support the organilization of the meaningful engagement of PLWNCDs in policy development process





N = 105 respondents

33%

Disability

57%

Risk factors

49%

Cardiovascular disease

45%

Cancer

54%

Diabetes

33%

Chronic obstructive pulmonary disease

45%

Mental or neurological disorder



N = 84respondents

Most common NCDs reported

20% cardiovascular disease

19% diabetes

15% mental health

Activities for Meaningful Engagement of PLWNCDs

N = 94 respondents

Involvement of PLWNCDs into design and implementation

Networking/collaborating

with others

Activities you have organized or participated

Most effective activities in advancing meaningful engagement

Advocacy campaigns

Meetings/webinars

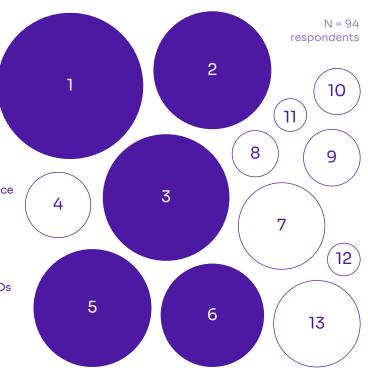
White papers/Policy briefs

Lobbying decision-makers

Inclusion of PLWNCDs into governance

Most significant challenge

- 1 Lack of financial resources
- 2 Lack of models, strategies, tools
- 3 Lack of engagement opportunities
- 4 Lack of political or civil society champions
- 5 Tokenistic approaches
- 6 Lack of understanding of the benefits and importance
- 7 Lack of alignment and coordination
- 8 Poverty or disadvantage
- 9 Health literacy
- 10 Limited access internet or smartphones by PLWNCDs
- 11 Limited or lack of research capacity
- 12 I don't know
- 13 Others



Annex 2



We are all suffering from mental health challenges associated with COVID-19. There is not one of us that has not been impacted. We are all in this together. In the age of COVID-19, people living with NCDs have a lot to teach people... our disease does not define us, we are special actors that can shape the global response to NCDs.



Ms Johanna Ralston
Chief Executive Officer
World Obesity Federation

I have a rare, life-limiting condition, complex medical needs, as well as a physical disability, so I have lots of different needs. Stories make a change, not statistics, it's people's real lived experience that reach people. How can we use people's stories and give them a platform? Nothing about us without us!



Ms Lucy Watts

Independent Consultant
Worldwide Hospice Palliative Care Alliance

We have the right to participate, "meaningful participation." We don't need to ask to be at the table, we demand to be, and we need to help set the table. Meaningful engagement is imprecise, and power brokers can invite us in and leave us out, so if we talk aggressively about being part of the conversation, we can gain legal ground. People being involved in the health sector isn't new, but we have been imprecise by what we mean in participation, not just being invited in when the pot is cooking, but we need to cut the vegetables together.



Ms Kwanele Asante

Secretary Treasurer, African Organization of Research and Training in Cancer Communities of people living with HIV are incredibly diverse. We need support for community mobilization and strengthening...Meaningful engagement needs to be thought through in advance because it requires the ability for PLWNCDs or People Living with HIV to be able to have an influence on the outcomes and processes.



Dr Laurel Sprague

Special Adviser Community Support, Social Justice and Inclusion, UNAIDS

Youth have been told repeatedly that we are the leaders of tomorrow, but in fact, the time has come to step up to become leaders of today. As young people, we should share our stories and push this agenda. Leadership needs to come from the youth and PLWNCDs, and not only as tokenistic inclusion.



Mr Moses Omondi

Project Officer Life & Peace Institute We need reliable data to act... COVID-19 has laid bare how the world has failed to meet the healthcare needs of people living with NCDs in the majority of Member States. It's time to transform the NCD development strategy, learning from the HIV/AIDs movement. One of the main learning points, we need to listen to and give power to people living with NCDs. We have seen examples of how co-creation for solutions during the pandemic is leading the way. We need to redouble our efforts, so that we reclaim what we lost.



Dr Bente Mikkelsen

Director
Department of Noncommunicable Diseases, WHO

Let's walk the talk and embed the ethos of nothing for us without us across NCD policies, programs and services, across WHO's own work in HQ and regional offices.



Dr Guy Fones

Unit Head Global Coordination Mechanism on NCDs, WHO



When we are talk about our lived experiences, it important to talk about the communities that they come from. There is a context to every illness and every condition. Understanding the context and the discrepancies between what's studied and the reality of experiencing a disease.



Ms Anjali Singla

Researcher and Adjunct Faculty
Banyan Academy of Leadership in Mental Health

If we don't speak for ourselves, nobody else will. ... Living with NCDs is not a boundary for people reaching their goals. I truly believe that inclusive language and representation are essential to mobilize people living with NCDs outside their formal organization.



Mr Bruno Helman
International Diabetes Federation and NCD Alliance

To date, engagement of lived experience has largely been an unused resource, not only for health providers but also for political leaders, policymakers, intergovernmental organizations and civil society. This is exacerbated with the lack of data on PLWNCDs in general, and specifically in relation to multimorbidity. We should use this momentum to make transformative changes to ensure we respond to the call of "nothing for us, without us.



Dr Svetlana Akselrod
Director, Global NCD Platform
WHO

We need to feel empowered while sitting at the table and provided with tools so we can be impactful.



Ms Diana Gittens

Advisory Committee Member, Guyana
Our Views, Our Voices Global Advisory Committee

Annex 3



Wednesday 09 December

Day 1: Exploring the value of meaningful engagement, building on lessons learned across other health programmes.

13:00-13:50

Consultation Launch

13:00-13:15

Welcome and Introduction

Dr Svetlana Akselrod, Director, Global NCD Platform, WHO Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer Mr Bruno Helman, International Diabetes Federation and NCD Alliance

13:15 - 13:20

Opening Remarks

Dr Tedros Adhanom Ghebreyesus, Director General, WHO

13:20-13:30

Persons Living with NCDs Perspectives

Dr Summer May Finlay, Lecturer, University of Wollongong

13:30 - 13:35

Global NCD Platform Opening

Dr Svetlana Akselrod, Director, Global NCD Platform, WHO

13:35-13:40

NCD Technical Unit Opening

Dr Bente Mikkelsen, Director, Department of Noncommunicable Diseases, WHO

13:40-13:55

Overview of Intended Outcomes and Group Check In

Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer Mr Bruno Helman, International Diabetes Federation and NCD Alliance

Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

13:55-15:50

Exploring Meaningful Engagement

13:55-14:05

People Living with NCDs Keynote

Ms Johanna Ralston, Chief Executive Officer, World Obesity Federation

14:05 – 14:15

Learning from those living with HIV/AIDs

Dr Laurel Sprague, Special Adviser, Community Support, Social Justice and Inclusion, UNAIDS

14:15 – 14:35

Group Discussion 1'Pass the Mic'

Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer Mr Bruno Helman, International Diabetes Federation and NCD Alliance

14:35-14:40

Break

14:40 - 14:45

Consultation Survey Results

Dr Katia de Pinho Campos, Technical Officer, Global Coordination Mechanism on NCDs, WHO

14:45-14:55

Introduction to Breakout Session 1

Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer Mr Bruno Helman, International Diabetes Federation and NCD Alliance

Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

14:55 - 15:50

Breakout Session 1 - Exploring Meaningful Engagement

15:50-15:55

Active Break

Ms Danielle Agnello, Consultant, Global Coordination Mechanism on NCDs, WHO

15:55-16:40

Current Actions

15:55-16:00

Presentation 1

Ms Tania Nakari, External Relations Officer, Health and Multilateral Partnerships, WHO

16:00 - 16:05

Presentation 2

Dr Bente Mikkelsen, Director, Department of Noncommunicable Diseases, WHO

16:05-16:10

Presentation 3

Ms Kira Koch, Technical Officer, Health Systems Governance and Financing, WHO

16:10 - 16:15

Presentation 4

Dr Monika Arora, Executive Director, Health Related Information Dissemination Amongst Youth (HRIDAY), Healthy India Alliance

16:15 - 16:20

Presentation 5

Dr Cristina Parson Perez, Capacity Development Director, The NCD Alliance

16:20-16:25

Presentation 6

Roy Small, United Nations Development Programme

16:25-16:30

PLWNCDs Keynote Listener Reflections

Mr Runcie Cheikeruba, Founder & Executive Director, Project PINK BLUE

16:30-16:40

Check Out and Closing

Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer Mr Bruno Helman, International Diabetes Federation and NCD Alliance

Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

Thursday 10 December

Day 2: Identify activities, workstreams and platforms that offer engagement opportunities for PLWNCDs in the global, regional and national contexts.

13:00 – 13:40 Day 2 Launch

13:00 - 13:20

Welcome and Recap of Day 1

Dr Mychelle Farmer, Immediate Past Chair, NCD Child Ms Chantelle Booysen, Independent Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

13:20 - 13:30

Consultation Survey Results

Dr Katia de Pinho Campos, Technical Officer, Global Coordination Mechanism on NCDs, WHO

13:30 - 13:40

Group Discussion 2 - 'Pass the Mic'

Dr Mychelle Farmer, Immediate Past Chair, NCD Child Ms Chantelle Booysen, Independent

13:40 - 16:30

How do we engage meaningfully?

13:40 - 13:50

Best Practices from other lived experiences

Ms Helena Davies, Worldwide Hospice Palliative Care Alliance

13:50 - 14:00

Presentation - Strategic Engagement

Ms Nellie Kartoglu, Project Manager, ADG Emergency Preparedness, WHO

14:00 - 14:10

Presentation - Community Mobilization

Ms Manjusha Chatterjee, Capacity Development Manager, NCD Alliance Ms Charity Muturi, Our Views, Our Voices

Global Advisory Committee

14:10 - 14:20

Presentation - Communities as part of systems for health

Dr Ani Shakarishvili, Special Adviser, Fast-Track Implementation, UNAIDS

14:20 - 14:30

Presentation - Models for engagement

Mr Andrew Seale, Technical Officer, HIV Department and Global Hepatitis Programme, WHO Ms Isadora Quick, Technical Officer, Office of the Chef de Cabinet DGO, WHO

14:30 - 14:40

PLWNCDs Keynote Listener Reflections

Ms Nyla Alexander, Diabetes Association of Trinidad and Tobago

14:40 - 14:45

Break

14:45 - 14:55

Introduction to Breakout Session 2

Dr Mychelle Farmer, Immediate Past Chair, NCD Child Ms Chantelle Booysen, Independent Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

14:55 - 16:10

Breakout Session 2 - How do we engage meaningfully?

16:20 - 16:30

Check Out and Closing

Dr Mychelle Farmer, Immediate Past Chair, NCD Child Ms Chantelle Booysen, Independent Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

Friday 11 December

Day 3: Defining the next steps for operationalizing meaningful engagement with PLWNCDs in 2021-2022

13:00 – 13:15 Day 2 Launch

13:00 - 13:15

Welcome and Recap of Day 2

Ms Johanna Ralston, Chief Executive Officer, World Obesity Federation Mr Joab Wako, Independent, Founder & Executive Director, Transplant Education Kenya Dr Guy Fones, Unit Head, Global Coordination

Mechanism on NCDs, WHO

13:15 - 16:10

Where do we go from here?

13:15 - 13:25

Framing - Medium to Long Vision

Ms Johanna Ralston, Chief Executive Officer, World Obesity Federation

Mr Joab Wako, Independent, Founder & Executive Director, Transplant Education Kenya

13:25 - 13:35

People Living with NCDs Perspectives

Viliame Qio, Program/Project Manager, Diabetes Fiji Inc

13:35 - 13:45

WHO Next Steps

Dr Bente Mikkelsen, Director, Department of Noncommunicable Diseases, WHO Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

13:45 - 13:50

Active Break

Ms Danielle Agnello, Consultant, Global Coordination Mechanism on NCDs, WHO

13:50 - 14:00

Introduction to Breakout Session 4

Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer Mr Joab Wako, Independent, Founder & Executive Director, Transplant Education Kenya Dr Guy Fones, Unit Head, Global Coordination Mechanism on NCDs, WHO

14:00 - 16:00

Breakout Session 4 - Mapping our way forward

16:00 - 16:10

Group Discussion 3

16:10 - 16:30

Consultation Wrap Up

16:10 - 16:20

People Living with NCDs Keynote

Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer

16:20 - 16:35

Closing

Mr Joab Wako, Independent, Founder & Executive Director, Transplant Education Kenya Ms Kwanele Asante, Secretary Treasurer, African Organization of Research and Training in Cancer

Dr Guy Fones, Unit Head, Global Coordination

Mechanism on NCDs, WHO

Dr Svetlana Akselrod, Director, Global NCD Platform, WHO

Annex 4

List of

Participants

WHO Civil Society Working Group on NCDs

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Ms Claudia Sartor	Deputy Chief Executive Officer
	The Global Mental Health Peer Network
Ms Anjali Singla	Researcher and Adjunct Faculty
	Banyan Academy of Leadership in Mental Health
Ms Rosie Tasker	Global Advocacy Manager
	International Union for Cancer Control
Ms Phaeba Thomas	Regional Manager – South Asia
	HealthBridge Foundation of Canada

United Nations Offices

Dr Ani Shakarishvili	Senior Adviser, Fast-track Implementation Joint United Nations Programme on HIV and AIDS
Mr Roy Small	Programme Specialist
	United Nations Development Programme
Dr Laurel Sprague	Special Adviser
	Community Mobilization, Community Support, Social Justice and Inclusion
	Joint United Nations Programme on HIV and AIDS

Other Participants

President / Member
Emirates Diabetes Society / International Society of Endrocrinology
Director
Breast Health Global Initiative
Founder and President
Caring & Living as Neighbours
Founder and General Manager
Intersectoral Forum to Fight NCDs in Brazil
Associate Professor
Swinburne University of Technology, Australia

Ms Sarah Belson	International Development Manager
	World Stroke Organization
Ms Chhavi Bhandari	Head, Advocacy and Policy Engagement
	The George Institute for Global Health
Ms Manjusha Chatterjee	Capacity Development Manager
	NCD Alliance
Ms Seema Chhabra	Senior Health Specialist
	World Bank
Mr Runcie C.W. Chidebe	Executive Director
	Project PINK BLUE - Health and Psychological Trust Centre
Dr Aastha Chugh	Research Associate
	Health Related Information Dissemination Amongst Youth / Public Health Foundation of India
Dr Helena Davies	Direct Stakeholder Trustee/Board Member
	Worldwide Hospice Palliative Care Alliance
Mr Ralph Emerson	Project Manager
Degollacion	Health Justice Philippines
Mr Josef De Guzman	President
	International Federation of Psoriasis Associations
Dr Ratna Devi	Chief Executive Officer
	Dakshayani and Amaravati Health and Education
Dr Jean-Luc Eiselé	Chief Executive Officer
	World Heart Federation
Dr Shandell Elmer	Senior Research Fellow
	Swinburne University of Technology, Australia
Dr Omnia El Omrani	Liaison Officer for Public Health Issues
	International Federation of Medical Students Associations
Ms Emma Feeny	Director, Global Advocacy and Policy Engagement
-	
	The George Institute for Global Health
Ms Silvia Fernández Barrio	The George Institute for Global Health President, Argentina

Mr Alex Filicevas	Executive Director World Bladder Cancer Patient Coalition
Dr Summer Finlay	Lecturer University of Wollongong
Mr Ranjit Gajendra Nadarajah	Manager Strategic Research, Programs and Partnerships Swinburne University of Technology, Melbourne, Australia
Mr John Gikonyo	President Renal Patients Society of Kenya
Ms Diana Gittens	Advisory Committee Member, Guyana Our Views, Our Voices Global Advisory Committee
Professor Sarah Hawkes	Director, Centre for Gender and Global Health University College London
Mr Tadeusz Hawrot	Senior Advocacy Coordinator European Federation of Neurological Associations
Mr Bruno Helman	Consultant International Diabetes Federation
Ms Allison Ibrahim	Independent Kuwaiti Diabetes and Obesity patient advocate
Ms Paula Johns	Co-Founder and Director Alliance for the Control of Tobacco and Health Promotion, Brazil
Ms Prachi Kathuria	Project Manager Health Related Information Dissemination Amongst Youth
Ms Christine Katusiime	Public Relations and External Affairs Manager Rheumatic Heart Disease Support Group, Uganda Heart Institute
Ms Karen Khoury	Public Relations and Communications Manager Children's Cancer Centre of Lebanon
Ms Lea Kilenga Masamo	PLWNCD advocate Africa Sickle Cell Organization
Mr Ted Kyle	Founder ConscienHealth

Mr Bent Lautrup-Nielsen	Head of Global Development and Advocacy World Diabetes Foundation
Ms Sarah Le Brocq	Member Global Obesity Patient Alliance
Ms Molly Lepeska	Project Manager Health Action International
Ms Melissa Lim	President Brain Tumour Society
Ms Cajsa Lindberg	Advisory Committee Member, Sweden Our Views, Our Voices Global Advisory Committee
Dr Lydia Makaroff	Vice President World Bladder Cancer Patient Coalition
Dr Susan Mandel	Professor of Medicine and Radiology & Associate Chief of the Division of Endocrinology, Diabetes, and Metabolism / Member Perelman School of Medicine, University of Pennsylvania /
Dr Elisa Martini	Program Officer, Policy and Advocacy
Ms Sara Mbithi	International Federation of Psoriasis Associations Women for Dementia Africa
Ms Sharon Mbugua	Director Amethyst Consulting
Ms Maria Rita Milanese	Advocacy and Projects Officer International Society on Nephrology
Ms Vicki Mooney	Executive Director European Coalition for People with Obesity
Ms Claire Morris	Director of Advocacy Worldwide Hospice Palliative Care Alliance
Ms Elsie Mulindi	Chief Executive Officer Kenyan Paraplegic Organization
Ms Clare Mullen	Deputy Director Health Consumers' Council Western Australia

Ms Charity Muturi	Advisory Committee Member, Kenya
	Our Views, Our Voices Global Advisory Committee
Ms Lily Mwai	T21 Families Support Organization
Ms Rosalia Nassour	Patients' Relations Officer
	Children's Cancer Center of Lebanon
Dr Pedro Nei Rueda	Member, Colombia
	International Society of Endocrinology
Dr Evans Nyambega	Founder & Chief Executive Officer
	Stroke Association of Kenya
Mr Stephen Ogweno	Founder and Chief Executive Officer
	Stowelink Inc.
Ms Maia Olsen	Program Manager
	NCD Synergies, Partners in Health
Mr Moses Omondi	Cancer advocate
	Non Communicable Alliance of Kenya
Ms Elizabeth Orlan	Associate Director, Research for the Food Policy Program
	Global Health Advocacy Incubator
Dr Richard Osborne	Distinguished Professor/Director
	Swinburne University of Technology, Australia
Ms Jeena R Papaadi	Pallium India
Dr Cristina Parsons Perez	Capacity Development Director
	NCD Alliance
Dr Carmen Parter	Co-Chair, Indigenous Working Group
	World Federation of Public Health Associations
Dr Ian Patton	Director, Advocacy and Public Engagement
	Obesity Canada
Ms Tiffany Petre	Director
	Obesity Collective Australia
	Obesity Collective Australia
Dr R. Guha Pradeepa	Senior Scientist and Head Research Operations

Ms Ashla Rani	Executive Assistant Pallium India
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Ms Tina Rawal	Consultant
	Health Related Information Dissemination Amongst Youth
Ms Emma Rawson	Co-Chair, Indigenous Working Group
	World Federation of Public Health
Dr Jamal Raza	Director
	National Institute of Child Health
Ms Nina Renshaw	Policy and Advocacy Director
	NCD Alliance
Dr Alafia Samuels	Honorary Professor & Deputy Dean for Research and Graduate Programmes, Faculty of Medical Sciences
	University of the West Indies
Ms Huyaam Samuels	Youth Ambassador
	Palliative Treatment and Care for children of South Africa (Patch South Africa)
Ms Shriya Singh	Manager
	Resource Mobilisation, Pallium India
Ms Aiste Staraite	Patient
	Patient organization
Ms Kate Swaffer	Chair, Chief Executive Officer and Co-founder
	Dementia Alliance International
Ms Anne Swakei	Programme Officer
	NCD Alliance Kenya
Ms Nyla Syne Alexander	Assistant Secretary
	Diabetes Association of Trinidad and Tobago
Ms Louisa Syrett	Global Advocacy Advisor
	The Fred Hollows Foundation
Mr Adrian Te Patu	Director
	Manu-Kahu Associates
Mr Michael Uchunor	Founder and Chairman
	Michael and Francisca Foundation

Dr Deepak Varughese	Public Health Physician Pallium India (Trivandrum Institute of Palliative Sciences)
Mr Qio Viliame	Project Manager Diabetes Fiji
Mr Joab Wako	Chief Executive Officer Transplant Education Kenya
Ms Lorna Warwick	Chief Executive Officer Lymphoma Coalition
Ms Lucy Watts	Independant consultant Worldwide Hospice Palliative Care Alliance
Ms Claire Wingfield	Director, Advocacy Global Health Advocacy Incubator
Ms Maria Francis Zaballa Roquero	President Accion Contra el Alcoholismo AC

WHO

Dr Svetlana Akselrod	Director Global NCD Platform
Dr Bente Mikkelsen	Director NCD Department Division for Universal Health Coverage, Communicable Diseases and NCDs
Mr Muhim Abdalla	Consultant Global NCD Platform
Ms Danielle Agnello	Consultant Health Workforce
Ms Annabel Baddeley	Technical Officer Vulnerable Populations, Communities and Comorbidities
Dr Nick Banatvala	Manager Global NCD Platform
Ms Daria Berlina	Consultant Global NCD Platform

Ms Fabienne Besson	Programme Assistant Global NCD Platform
Dr Alarcos Cieza	Unit Head Sensory Functions, Disability and Rehabilitation
Dr Tea Collins	Lead Global NCD Platform
Dr Katia De Pinho Campos	Technical Officer Global NCD Platform
Ms Corinne Desfarges	Assistant Global NCD Platform
Dr Hicham El Berri	Medical Officer Non communicable Disease Management Regional Office for the Eastern Mediterranean (EMRO)
Mr Jack Fisher	Technical Officer Global NCD Platform
Dr Guy Fones	Team Lead Global NCD Platform
Dr Heba Fouad	Technical Officer Noncommunicable Diseases Surveillance Regional Office for the Eastern Mediterranean
Mr Menno van Hilten	Cross-cutting Lead Strategy (NCDs) Division for UHC/Communicable Diseases and NCDs
Ms Martyna Hogendorf	Consultant Noncommunicable Diseases Integrated Service Delivery
Ms Nellie Kartoglu	Emergency Preparedness
Ms Kira Koch	Technical Officer System's Governance and Policy
Ms Taina Nakari	External Relations Officer Health and Multilateral Partnerships
Dr Chizuru Nishida	Unit Head Office of the Director Nutrition and Food Safety

Ms Isadora Quick	Technical Officer
	Office of the Chef de Cabinet, Director-General's Office
Mr Andy Seale	Adviser
	Cross-cutting HIV Expert UCN
Dr Mahshid Taj	Technical Officer
	Mental Health and Management of Substance Abuse
	Regional Office for the Eastern Mediterranean (EMRO)
Dr Juan Tello	Unit Head
	Harmful Use of Alcohol
Dr Giuseppe Troisi	Technical Officer
	Global NCD Platform
Dr Temo Waqanivalu	Programme Officer
	Noncommunicable Diseases Integrated Service Delivery
Dr Kremlin Wickramasinghe	Technical Officer, NCD Surveillance
	Regional Office for Europe





