INTENTION TO ACTION SERIES

REGIONAL REFLECTIONS

Analysis from informal regional consultations with people living with noncommunicable diseases and mental health conditions

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Contents

Acknowledgements

Acronyms

CSO	civil society organization
GCM/NCDs	Global Coordination Mechanism on NCDs
NCDs	noncommunicable diseases
NGO	nongovernmental organization
WHO	World Health Organization

Introduction

Setting the scene

In 2019, 74% of all deaths were due to noncommunicable diseases *(1)* (NCDs), and one in eight individuals were living with a mental disorder *(2)*. The challenge of addressing these interconnected epidemics requires a sustained multilevel and multistakeholder approach.

No longer thought of as predominantly high-income challenges, these interconnected epidemics are now known to transcend all income groups. In 2019, more than three quarters (77%) of all NCD deaths and and 77% of suicides occurred in low and middle-income countries *(3–5)*. In addition, in 2019, 86% of premature deaths from an NCD between the ages of 30 and 69 years occurred in low-and middle-income countries, largely driven by demographic trends and health transitions *(1, 6)*. For individuals living simultaneously with NCDs, mental health conditions and neurological conditions (hereby referred to as individuals with lived experience), the short- to long-term impacts are often significant not only for the individual, but also for their caregivers, families and communities.

The COVID-19 pandemic continues to disrupt the ability of health systems to effectively respond to individuals with lived experience, exacerbating individual and societal impacts linked to health, and exposing the profound social inequities and fractured health systems around the world. The presence of pre-existing health conditions dramatically increases the risk of developing severe COVID-19 illness, accompanied by higher mortality rates *(7–12)*. The prevalence of anxiety and depression also increased

25% worldwide in the first year of the COVID-19 pandemic with a range of short- and long-term stressors including isolation, the impact of the virus on health, concerns over financial and employment security and disruption to mental health services as contributing factors *(13)*.

Regional and country perspectives

Key global public health stakeholders require new forms of collaboration to develop effective and contextually appropriate ways for stepping up action to address the complex challenges posed by NCDs and mental health. This requires a move away from "one size fits all" interventions and strategies to those involving a bottom-up, intersectional co-creation process that incorporates a diversity of views, experiences and expertise to better understand and address the root causes and determinants of health conditions. Individuals with lived experience of health conditions from different geographical, cultural, political, economic, social and religious contexts are invaluable to understanding barriers and identifying solutions to current programmes, policies and services.

Integration of lived experience in the co-creation of programmes, policies and services can lead to more inclusive and sustainable interventions at national and regional levels. These efforts will ultimately improve health outcomes.

Learning from the perspectives, experiences and initiatives of WHO regional offices (ROs) relating to the meaningful engagement of

individuals with lived experience provides a practical and valuable entry point to support these goals. Regional and country perspectives also serve to contextualize key principles, definitions and enablers of meaningful engagement and provide important nuances to the concept of meaningful engagement of lived experience within the NCD and mental health agenda.

Aims of this report

This report is the second publication in the Intention to action series – a series of resources that aims to enhance the limited evidence base on the impact of meaningful engagement and address the lack of standardized approaches on how to operationalise meaningful engagement. The *Intention to action series* aims to do this by providing a platform from which individuals with lived experience, and organizational and institutional champions, can share solutions, challenges and promising practices related to this cross-cutting agenda. The Intention to action series also aims to provide powerful narratives, inspiration and evidence for the Fourth United Nations High Level Meeting on NCDs in 2025 and achieving the 2030 United Nations Sustainable Development Goals.

To this end, this report includes analysis from informal regional consultations in the African Region, the Caribbean and North America, Latin America, South-East Asia Region, European Region, Eastern Mediterranean Region, alongside three forums in the Western Pacific Region *(14)*.

It analyses the overarching similarities, regional nuances and priorities raised across the six WHO regions for the meaningful engagement of individuals with lived experience. It outlines the key learnings derived from the priorities and the implementation gaps identified at regional and national levels that will inform the co-creation and implementation of the WHO Framework on Meaningful Engagement of People Living with NCDs, Mental Health Conditions and Neurological Conditions (referred to in this report as the WHO Framework). The WHO Framework will provide WHO and WHO Member States with a strategic vision, principles, guidance and actions to support operationalization of the meaningful engagement of individuals with lived experience.

Methodology

Between February and May 2022, the GCM/NCD co-hosted, in collaboration with all six WHO regional offices, informal consultations with individuals with lived experience of NCDs, mental health conditions and neurological conditions.

Figure 1. Arnstein's Ladder, outlining degrees of citizen participation
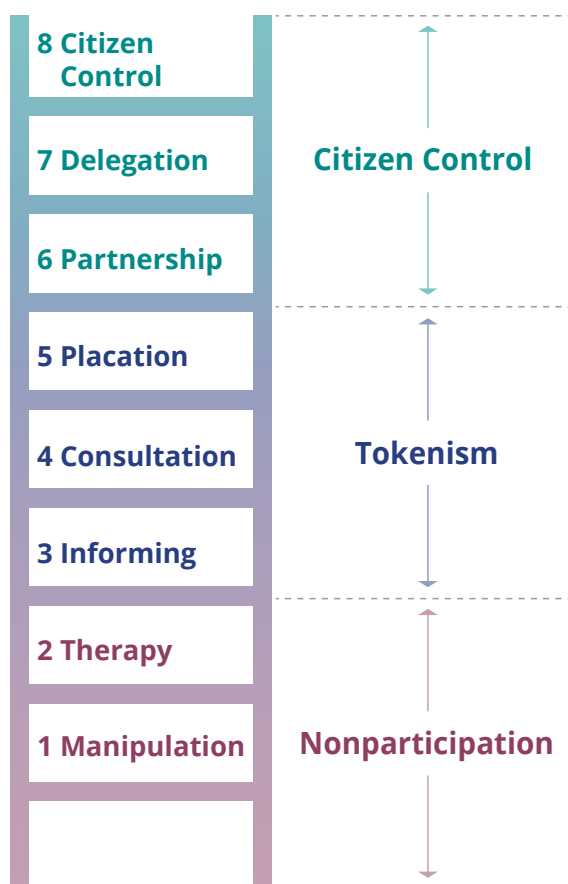
The method for these consultations was based on the WHO Global Informal Consultation with People Living with NCDs, held in December 2020, and the Informal Consultation with People Living with Diabetes, held in March 2021. One of the principles of these consultations was that individuals with lived experience should co-design and lead the consultation process, with all participants being able to contribute (15). The aim of these consultations was to foster a participatory approach that moved away from

the "tokenism" section of Arnstein's Ladder of Participation (specifically level 4, consultation, which typically includes attitude surveys, community meetings and public enquiries) and reach level 6, partnership, where power is redistributed through negotiation between citizens and power holders (see Fig.1).

To achieve this goal, a strong participatory approach was undertaken that included shared planning and decision-making responsibilities between individuals with lived experience and WHO throughout the co-design and delivery of the event.

Participant recruitment and selection

An expression of interest form was created by the GCM/NCD, in consultation with the WHO regional offices, that invited individuals with lived experience of NCDs, mental health conditions and neurological conditions to self-nominate or nominate others. The form gauged lived experiences, geography, gender, age and language preferences, and provided a comment box inviting shared expectations and any questions for the WHO Secretariat. The expression of interest was shared with regional and country networks and directly with Member States and UN agencies. Organizations with official relationships with WHO, GCM/NCD participants, and other relevant civil society actors also shared the expression of interest through various external networks. All non-state actor attendees (NGOs, academia and independent bodies) were required to complete a declaration of interest form, as per the mandatory due diligence processes aligning with the WHO's Framework of Engagement with NonState Actors.

Co-designing the consultations

To ensure that individuals with lived experience were engaged in the preparatory phase of the consultation, an informal consultative group of 10–15 individuals with lived experience from each region were invited to co-design the event. These included individuals identified by the regional office and/or individuals with whom the WHO GCM/NCD had previously engaged across a range of activities, including consultations, focus group discussions and workshops. The organizing team used the following factors as part of the selection criteria: lived experience, place of residence, gender, age and identification with being from a community that is marginalized. The feedback from the informal consultative group helped to shape the agenda, structure and messaging of the event, alongside nominating individuals for roles such as co-chairs, speakers and facilitators.

Formats and outputs

The virtual, participant-led consultations ranged from one to two days in length with each day lasting three to four hours. Individuals with lived experience led the discussions as co-chairs, speakers, participants and/or facilitators. Activities included presentations from a range of experts and breakout sessions, which were designed to encourage participants to unpack topics. These topics focused on key definitions, principles and enablers of meaningful engagement and strategies to operationalize meaningful engagement such as capacity building, advocacy and partnerships. Additionally, "pass-the-mic"

sessions were included to support an open forum atmosphere where individuals could share perspectives that were not necessarily tied to formal agenda topics. WHO rapporteurs took detailed notes from each session which were then collected and reviewed by the organizing teams.

The Western Pacific Region forums were co-led with the WHO Western Pacific Regional Office, which directly and specifically engaged the country offices of Cambodia, Malaysia, and the Philippines. One three-hour forum was held per country and involved 10–15 individuals with lived experience. Forum participants were individuals or representatives from organized groups of individuals with lived experience of NCDs, representing a diversity of health conditions and socioeconomic backgrounds. In addition to gathering regional and country-level insights and approaches to meaningful engagement, the Western Pacific Region forums also aimed to hear and share individuals' experiences regarding access to promotive, preventive and therapeutic services at the community level. WHO Regional and Country Office staff facilitated the discussions and took notes.

Key insights from the consultations and forums were distilled into regional harvest reports. The evidence from all harvest reports was consolidated and grouped into several categories using thematic analysis. This method highlighted many overarching similarities in data across all regions, which are summarized in this report. In addition, analysis of the frequency and uniqueness of insights respective to each region highlighted important regional priorities and nuances which are outlined.

Key insights – similarities across regions

The key insights described below emerged as common themes across all WHO regions. Many principles of meaningful engagement and aspects of living with NCDs, mental health conditions and neurological conditions transcend borders and cultures, resulting in many similarities across all regions. At the same time, these similarities do not negate specific nuances and priorities relevant to each region (see "Additional regional priorities" section). Overall, the strong similarities across all regions strengthen the case for a consolidated global WHO Framework that allows for adaptation and implementation approaches to meet the specific contexts of each region.

Principles and enablers of meaningful engagement

1. Inclusiveness

Lived experiences of NCDs, mental health conditions and neurological conditions around the world are often compounded by a range of social determinants of health. Individuals with lived experience endure marginalization and exclusion on the basis of their socioeconomic status, ethnicity, gender identity, sexual orientation, disability, age, nationality, immigration status and/or other power dynamics. These can lead to individuals with lived experience encountering systemic and structural discrimination, trauma and stigma, and a disconnection with communities and society.

Meaningful engagement of people with lived experience must involve the creation of safe spaces which are inclusive and welcoming for all. In particular, participants identified communities that are marginalized in their countries as people living in rural areas, indigenous populations, minority groups, children and older adults. Inclusiveness must thus entail engaging groups that are marginalized in a dignified, respectful, empathetic and collaborative manner.

The principle of inclusiveness also extends to the supportive community that surrounds individuals with lived experience, particularly their families, caregivers, peers, health-care providers and religious and community leaders. This is because individuals with lived experience often rely on support from their communities to manage their health conditions. The co-creation, co-development and co-implementation of any public health intervention must therefore include the community networks that surround individuals with lived experience for successful contextualization of NCD and mental health policies, services and programmes.

"Bring the table" to groups that are marginalized

Reframing the adage of "taking a seat at the table", participants also emphasized the need to "bring the table" to underserved communities. Policy-makers, health-care providers, nongovernmental organizations (NGOs), advocacy groups and other stakeholders should reach these groups in the local settings where they reside, particularly in rural or remote areas. A community-centred approach should also be used to engage communities that are marginalized. Due to their direct knowledge of networks within local communities, community leaders and local peer-support groups and networks have a key role in identifying and inviting individuals with lived experience, particularly those with experiences of margalization, to participate in training sessions and events. This "first-mile" approach ensures that underrepresented individuals are the first to be reached in engagement efforts and that the engagement is neither tokenistic nor risks further exclusion and harm. To facilitate inclusiveness, representation and equity in health interventions and engagements, data registration, collection and recording systems should also be adapted to support meaningful engagement. This involves data collection not just on the incidence and prevalence of NCDs, mental health conditions and neurological conditions, but the ability to disaggregate data by key indicators such as age, gender, socioeconomic status and comorbidities.

Accessibility of information

Health information and resources should be relevant, easily available, accessible and understood by all individuals with lived experience, and in particular by communities that are marginalized. This includes digitizing resources for use in increasing post-pandemic virtual environments, and also providing non-digital resources, such as printed reports and pamphlets, and contextually relevant forms of information. This will ensure the engagement remains inclusive to communities with low health and digital literacy and limited Internet access. Written and digital resources should be user-friendly, with accessible text, captioning and descriptions for those with visual or hearing impairments. Language used should be simple, appropriate to the context, and jargon-free with local languages being used and/or availability of translation services wherever possible.

2. Reducing stigma

Stigma creates multiple barriers to health and well-being for individuals with lived experience. It can prevent them from seeking the care they need, and from accessing and maintaining effective treatment. It can render them "invisible" or even "hyper-visible" within society, whereby they are perceived more as a person with health condition(s) than as a person with a wide range of attributes and experiences. It was noted by some individuals that stigma contributed to institutional, severe and traumatic forms of treatment that became harder to cope with than the

medical condition itself. Much of this stigma is systemically and socially entrenched, attributable to many complex structural and behavioural factors, and can be particularly prevalent for those living with mental health conditions.

Stigma can take many forms, such as **attributing blame** to individuals with lived experience and implying they are "responsible" or "at fault" for their conditions. Blame attribution *(16)* refers to a phenomenon in public health where responsibility is placed on the individual to modify their behaviour rather than on broader socioeconomic, commercial or environmental determinants of health. Individuals living with type 2 diabetes often hear that their condition results from unhealthy diets rather than a lack of access to affordable healthy foods or safe environments that support physical activity. As such they are often treated without respect or empathy.

Stigma can also take the form of **dehumanizing** or **overmedicalizing** individuals with lived experience, particularly in health-care settings. This can occur when health-care professionals relate to individuals with lived experience primarily in terms of their symptoms or health conditions rather than as a person with their own circumstances, challenges and goals. It contributes to discriminatory behaviours in health-care settings, which results in weakened engagement between health-care providers and individuals with lived experience. This can lead to reduced commitment to treatment and follow-up, and ultimately poorer health outcomes. As expressed by a participant in a regional consultation:

"The hospital often referred to me as the "brain tumour". I was no longer the person "Emma". I was my brain tumour. And that made me feel reduced and incompetent. It made me want to investigate and work with health-care professionals to improve the situation."
- Emma Skoglund, Cancer Advocate, Sweden

Action areas

✓ Language and literacy

Ensuring a stigma-free environment can be partly achieved through improving the health literacy of individuals, communities and organizations through education on risk factors, determinants and symptoms of NCDs, mental health conditions and neurological conditions. This also includes education on the negative effects of stigma, not just for individuals with lived experience but also for family members, caregivers, health-care providers, educators and community or peer leaders. Using empowering and dignifying language in relation to individuals with lived experience is also important, as is increasing and improving public awareness about the concept of lived experience, meaningful engagement and health conditions.

Terms to avoid	Terms to use instead
"Patient"/ "subject"/ "case"	Personal names/ titles (e.g. Mr X; Dr Y)/ "individual"/ "person"
"Adherence"/ "compliance" "/ "commitment"	"Concordance"
"Mentally ill"/ "crazy"	"Mental health conditions"
"Victim"/ "suffering from"/ "affected by"	"Living with"/ "has a diagnosis of"/ "being treated for"

✓ Policies and legislation

There is also need for clear and well-implemented policies and legislative tools to reduce stigma. National anti-discrimination laws and policies can be reviewed, and, if required, expanded to cover individuals living with NCDs, mental health conditions and neurological conditions. Laws that protect the rights of individuals with lived experience could also help to address stigma by educating relevant stakeholders about human rights and dignity. Laws can also guide families, health-care professionals and other relevant stakeholders on stigma-prevention strategies, appropriate communications,

and encourage regulatory bodies to hold health-care professionals accountable. The application of anti-discrimination acts in other health contexts such as HIV/AIDS can offer useful lessons in this regard.

Even when implemented effectively, anti-discrimination laws alone are not enough. Individuals may not seek recourse from discrimination because they fear stigmatization after disclosing their condition, also known as "label avoidance" *(17)*. For the best outcomes, anti-discrimination laws must be accompanied by anti-stigma campaigns that address the many structural and behavioural components of stigma. These are required to reach beyond legislation and promote awareness of the real causes and risk factors of NCDs, mental health conditions and neurological conditions in order to address misconceptions and misinformation.

3. Redistributing power to individuals with lived experience

In traditional engagement environments within global public health, power balances are typically weighted towards those in power, such as governments, medical or legal professionals, intergovernmental organizations and the private sector. Individuals with lived experience, communities that are marginalized and civil society groups are often overlooked and excluded from meaningful participation in these spaces. Inclusion can also be tokenistic, for instance by informing, consulting or placating individuals with lived experience after a decision has already been made or ensuring the impact of their vote is limited by design. Meaningful engagement of individuals with lived experience thus requires an equitable redistribution of power from traditional power brokers to individuals with lived experience, ensuring that these spaces are always supportive, safe and inclusive of all relevant views.

⊙ **Action areas**

⊘ **Value lived experience as expertise**

Individuals with lived experience are experts by experience and therefore lived experience is a form of expertise. Just as doctors, lawyers and policy-makers have expertise in their respective fields, so do individuals with lived experience in terms of understanding their health conditions, treatment and making decisions about their care. Formal written policies, standard operating procedures and protocols that mandate engagement of individuals with lived experience can help to reinforce and normalize their role and legitimacy as experts and establish consistency in efforts to meaningfully engage. Health-care providers, policy-makers, funders, insurers and other traditional power brokers can be further educated and sensitized to treat individuals with lived experience as partners rather than as "patients" or passive recipients of services.

When individuals with lived experience are treated with dignity and respect as experts, meaningful engagement can be further understood as a mutual bi-directional exchange of knowledge, skills and even perspectives and disagreements. Individuals with lived experience can provide their expertise to support the development, contextualization and implementation of

relevant public health interventions alongside the establishment of new frameworks, mechanisms and programmes to operationalize meaningful engagement. In return, they should be provided with information about their conditions, support in accessing care, and training to better advocate for themselves and their communities.

✓ Compensate individuals with lived experience

A concrete demonstration to value individuals with lived experience is to financially compensate their expertise, effort and time. For example, individuals with lived experience are often asked to spend valuable time preparing for and speaking at events but are rarely paid for these engagements as other non-lived experience professionals and experts are for similar engagements. Compensating lived experience speakers and contributors at rates commensurate with that of other types of experts is thus essential to reorient and redistribute power. This will also signal that their lived experiences are as valuable as other professional experiences. Eliminating financial barriers such as time away from work, transport and/or childcare costs also enables individuals with lived experience to continue their vital work and advocacy in a self-sustaining way.

4. Consistent and continuous engagement

Engaging individuals with lived experience cannot be a one-time event, a "tick-box exercise" or only done when it suits a specific need. Instead, engagement must be standardized and built in throughout the process, beginning at the point of diagnosis and extending through the co-creation and co-implementation of related policies, programmes and services. Doing so requires a supportive and organized environment that makes the engagement of individuals with lived experience a core principle underpinning the co-creation process.

▶ Action areas

Concrete mechanisms are needed to ensure such forms of engagement are effective and sustained. These include legally mandatory inclusion of individuals with lived experience in related processes, and clear policies, alongside regulations and incentives to guide policy-makers, health-care providers and other key stakeholders in the engagement process. Adequate funding and time are needed to ensure commitment, alongside ensuring mechanisms are regulated and audited to ensure implementation is active and effective. The "Capacity-building for individuals with lived experience" subsection in this report provides additional insights and recommendations for how consistent and continuous engagement can be ensured in practice through key knowledge, skills and resources for individuals with lived experience.

5. Contextualization – local languages, cultures and practices

Approaches to meaningfully engage individuals with lived experience must account for local contexts, languages, cultures and practices in order to be effective and sustainable. Often, the use of dominant global languages, such as English, inhibits the development of contextualized terminology in some countries, which can further impede health literacy development at local levels. Culturally appropriate methods of engagement that account for the cultural and societal background, religious beliefs, their individualistic or communal societal structures, and the languages they speak will be more likely to result in buy-in from the target population and lead to better health outcomes.

⊘ Contextualization or adaptation guides

Any global, regional or national frameworks, action plans or policies on meaningful engagement should be adapted to local contexts. This should include a contextualization or adaptation guide for use by local legislators, health-care professionals, educators, community leaders and individuals with lived experience. Guides should account for factors such as key local stakeholders to engage, resource availability and health-system arrangements at the local level. Guides should also be available in local languages and dialects to facilitate transfer of knowledge and implementation.

⊘ Account for diversity and intersectionality

When engaging a diverse group of collaborators, including individuals with lived experience, it is important to account for intersectionality. This refers to ways in which aspects of a person's identities combine to create various types of power and privilege – for example a person's gender, caste, sexual orientation, ethnicity, religion, occupation, socioeconomic status, health status and disability. Combinations of these also determine an individual's experience of living with a health condition alongside related societal stigma and discrimination. Acknowledging these intersections and layers of experience can help decision-makers understand the complex factors and potential contextual obstacles that impede access to health and well-being and ultimately co-create solutions that are responsive to the multitude of experiences *(15)*.

6. Political commitment

The meaningful engagement of individuals with lived experience and the right to participate must be guaranteed through government commitment and support at all levels. At the 75th World Health Assembly,

WHO Member States recognized that meaningful engagement of individuals with lived experience of NCDs should be a key element in co-developing health interventions *(18)*. Political commitment at the highest level can send a strong signal to the rest of government and society and can galvanize all stakeholders to ensure meaningful engagement is embedded into national policies and laws. Political commitment is also critical for ensuring that meaningful engagement initiatives are adequately resourced, and designed to be inclusive, responsive, sustainable and formally institutionalized.

⊘ Legal mandates

Commitments, resolutions or calls-to-action made by governments and policy-makers at national and subnational levels must be backed by legislation to mandate the inclusion of individuals with lived experience. As previously discussed, this should also include a particular focus on accessing and supporting groups that are marginalized. Ministries of health can lead by example by mandating the engagement of individuals with lived experience in the co-creation of public health interventions, employing them in the co-development of national health plans and promoting a multisectoral approach to meaningful engagement.

⊘ Accountability

To ensure effective and transparent political and legal mandates for meaningful engagement, there must be strategies and safeguards to minimize dishonesty and abuse of power at all levels. Mechanisms or working groups to monitor progress based on transparent metrics and hold implementers accountable is essential. This can be supported by establishing participatory governance mechanisms that involve

stakeholders with clear roles and responsibilities from multiple sectors alongside individuals with lived experience and civil society organizations (CSOs).

Recruiting and engaging collaborators

Key stakeholders to engage

The process of recruiting stakeholders in the co-creation of a public health intervention has two purposes *(19)*. The first is to ensure that the individuals involved in co-creation are representative of the end-users, so that the outcome can be effectively used by that group and scaled to the population level. The second is to ensure there is representation of all necessary expertise from relevant stakeholder groups. This includes identifying important characteristics to cover a spectrum of relevant expertise, perspectives and roles. All stakeholders have a role in evaluating the process and the outcome(s) of an intervention, which allows for continual learning, adaptation and improvements to public health.

Based on this methodology, participants identified the following stakeholder groups as important partners to engage:

1. Communities

"Communities" was used as a broad term to encompass individuals with closer, more frequent and supportive interactions with individuals with lived experience. This includes family members, peers and caregivers (both formal and informal), as well as individuals recognized and respected as leaders within their communities, such as religious leaders, traditional rulers and opinion or thought leaders.

2. Educators

Participants emphasized that "educators" have a key role in improving awareness, understanding the health literacy needs around NCDs, mental health conditions and neurological conditions, as well as advancing evidence-informed approaches to NCDs and mental health issues. This includes stakeholders from teachers and researchers to curriculum planners, administrators and personnel across primary, secondary and tertiary educational institutions.

3. Policy-makers

"Policymakers" refers to officials across all levels of government, from local legislators and representatives to parliamentarians and national authorities. In addition, policy-makers from various sectors should be included, from health, labour, food, gender and related multisectoral committees. Importantly, legal professionals such as lawyers and judges were also identified as key stakeholders in wider policy- and decision-making spaces.

4. Health-care professionals

"Health-care professionals" include members of the health workforce, such as caregivers, counsellors, social workers, frontline health workers, nurses, doctors, specialists and hospital administrators. This term also includes pharmaceutical and insurance companies, health technologists and professional medical bodies and societies.

5. Organizations

Participants identified various civil, professional and industrial collectives of individuals under the umbrella term "organizations". These include NGOs, CSOs and professional associations from key sectors such as health, pharmaceutical, agriculture, food, transport, youth, culture, sport and media.

Capacity-building for individuals with lived experience

Capacity-building for individuals with lived experience emerged as a strong and consistent theme across all regional consultations. Participants highlighted their desire to learn as well as to educate, train and empower individuals with lived experience to better advocate for themselves and their communities. This will also help WHO and Member States to redress power imbalances and support all key stakeholders in a consistent and continuous process of meaningful engagement for improved health outcomes.

1. Funding

Without funding, individuals with lived experience and the organizations representing them may be unable to perform effectively and sustainably. Increased funding to organizations and associations representing individuals with lived experience is critical to sustaining their work – for example through hiring staff, increasing the number of trainings and other capacity-building initiatives, amplifying their advocacy, affording better resources, accessing new spaces and covering operational costs.

2. Knowledge on (health) policy decision-making process

Individuals with lived experience must be trained on how to work more effectively within political and health-care decision-making processes. This includes understanding the rights-based approaches available for individuals with lived experience

and being able to understand and scrutinize NCD and mental health policies, frameworks, legislation and legal documents – as well as how these are developed. Individuals with lived experience should also be trained on the range of policy options available around NCDs, mental health conditions and neurological conditions in their countries, which will enable them to better organize their advocacy for stronger policy and health outcomes.

3. Stakeholder engagement

Knowing the right partners to engage and how to engage can improve and strengthen advocacy efforts. This includes key decision-makers in key sectors such as government, health care, media, academia, CSOs and the private sector, alongside the interconnected nature of politics and global public health. To amplify their voices, participate and be heard in the right spaces, individuals with lived experience can be trained on how to conduct strategic stakeholder engagement and build intersectoral partnerships and critical alliances that sustain their cause.

WHO could play a stewardship role in connecting governments with individuals with lived experience and can set a global standard for meaningful engagement by normalizing joint meetings with governments, individuals with lived experience, CSOs and NGOs. To bridge the gap from national to local, Member States and WHO could also provide CSOs and NGOs with more information on formal engagement mechanisms and opportunities to engage policy-makers. This should also include the information or documents that local NGOs or CSOs need to engage in international or national policy environments. Brief profiles and contact information of focal points within governments and organizations can be made available online to facilitate accessibility.

4. Direct and persuasive communication skills

To successfully engage stakeholders such as WHO and Member States, participants highlighted the importance of confidence-building and persuasive communication techniques. Examples include public speaking, developing a personal or public narrative and using personalized approaches such as effective storytelling backed by evidence and data. Other methods of direct and persuasive communication include social media marketing to strengthen engagement with desired audiences, policy writing and engaging with traditional media outlets through, for example, letters to the editor.

5. Research and training opportunities

Basic knowledge of research methods can better enable individuals with lived experience to identify and use empirical evidence to support their advocacy. Organizations or associations representing individuals with lived experience could partner with academics and researchers to equip individuals with essential research skills. More broadly, governments and academic institutions should provide funded research opportunities around lived experience of NCDs, mental health conditions and neurological conditions to increase evidence and understanding on this topic.
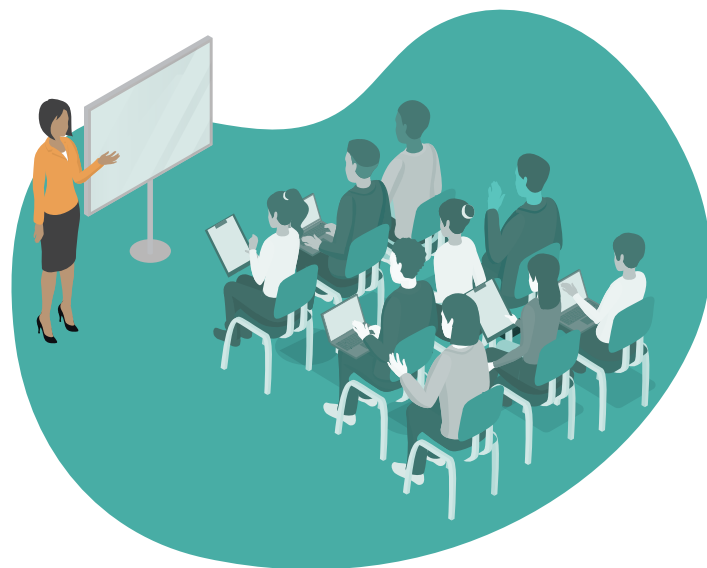
Findings, promising practices and outcomes from research, consultations and engagement opportunities must be shared to enable access by a wider community of individuals with lived experience and partners. Open-source information-sharing through both digital and non-digital channels must be a priority of any research communication initiative around NCDs, mental health conditions and neurological conditions to ensure accessibility.

6. Collaborative platforms

More public spaces and platforms must be created to facilitate collaboration and exchange of ideas between individuals with lived experience and key stakeholders in health and public policy. Examples include support groups, thematic forums and committees, public hearings and networks. Platforms must also provide individuals with lived experience with opportunities that guarantee their participation.

Dedicated educational platforms are needed to build the capacity of individuals with lived experience and equip them with the necessary skills to further develop their roles as advocates and champions. Such platforms could be used to train individuals with lived experience in research, communication and advocacy skills, and on understanding and navigating health-care and political systems.

Additional regional priorities

While there was strong alignment across the regions on key areas of meaningful engagement, participants also highlighted priorities and nuances within each region. These regionally contextual priorities pertain to various aspects of meaningful engagement, from principles and enablers to key stakeholder groups to engage, reflecting the unique opportunities and challenges in each region.

African Region
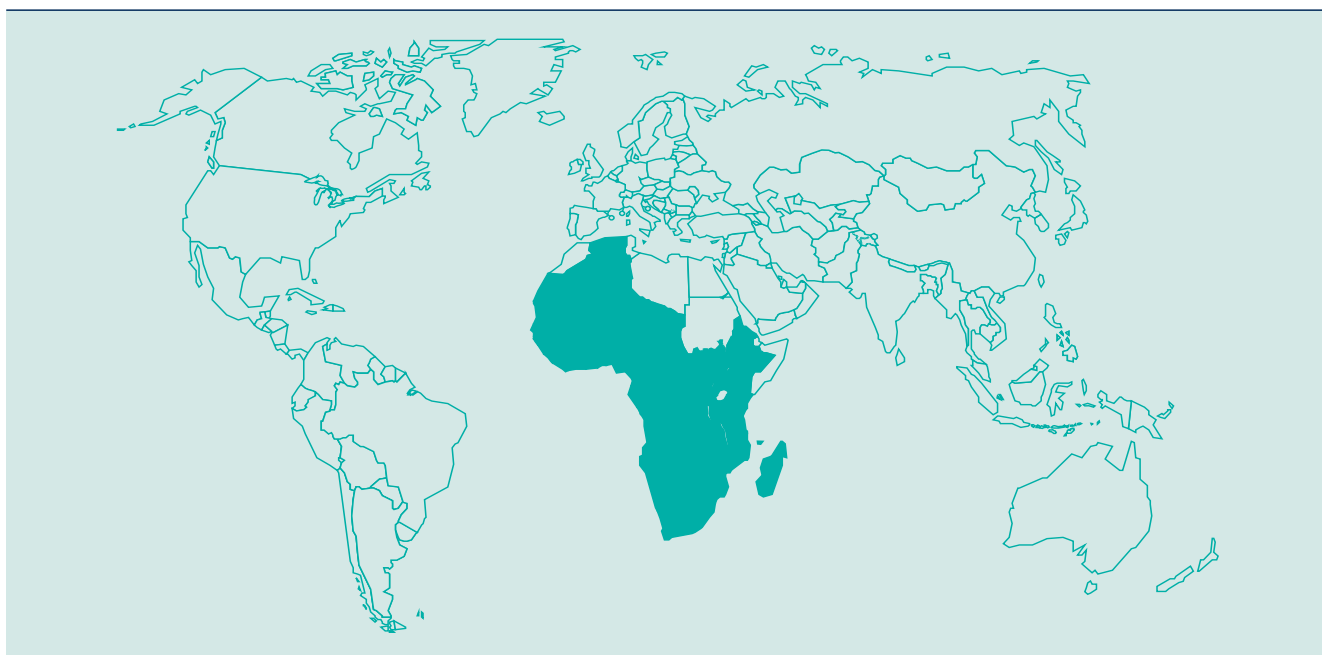
Recruiting and engaging collaborators

1. Traditional leaders

As custodians of social values in many communities, traditional, spiritual and religious leaders are important to engage in decision-making around NCDs, mental health conditions and neurological conditions. Traditional healers, marabouts, fetishists and other actors in traditional medicine were also highlighted as key stakeholders. They have close ties to the community and a strong understanding of local customs and practices regarding health care. At the same time, many traditional leaders may also perpetuate myths and misconceptions about NCDs, mental health conditions and neurological conditions, which could have harmful consequences for their community. By addressing some of these biases through health literacy training, the legitimacy that many of these traditional leaders hold among members of their community make them important partners to engage in reducing stigma and raising awareness.

2. Groups that are marginalized– internally displaced persons (IDPs), refugees and undocumented migrants

Participants identified IDPs and refugees among the most vulnerable groups in their countries. Around 30 million IDPs, refugees and asylum-seekers lived in the African Region in 2021 *(20)*. Those living with NCDs, mental health conditions and neurological conditions are often unable to access essential services and treatment, which exacerbates the health challenges they face. Representatives of this group must therefore be accounted for and engaged in decision-making processes around NCDs, mental health conditions and neurological conditions, with necessary translations available for their meaningful participation.

Enablers of meaningful engagement

▶ Action areas

1. Education and community awareness to reduce stigma

In addition to its many causes and effects outlined above, stigma can also lead to familial or spousal abandonment in some communities, which results in further uncertainty for already vulnerable groups such as women and children. Many individuals with mental health conditions and their family members also turn to spiritual support before seeking and accessing health-care facilities. It is thus crucial to educate families and their spiritual leaders on what NCDs, mental health conditions

and neurological conditions entail, and what care is available and needed to improve their quality of life. More community awareness efforts with community leaders and partners in the media are needed to reduce stigma and discrimination against individuals with lived experience, both in rural and urban areas.

2. Increase awareness and visibility of individuals with lived experience

Individuals with lived experience must be at the forefront of advocacy efforts, which includes the ability to share their stories publicly to increase visibility and raise awareness. Individuals with lived experience play an important role in educating families and communities about NCDs, mental health conditions and neurological conditions. Health-care providers must also be involved in raising awareness and supporting individuals with lived experience in educating their communities.

Knowledge of neglected and underrepresented conditions in the region, such as Sickle Cell Disease and Wilson's Disease, is low, and health literacy around these should also be included in the broader NCD agenda to prevent misdiagnosis, poorer health outcomes and preventable mortality. Engaging individuals living with neglected conditions is key to ensuring that decision-making spaces remain inclusive and representative of the wider population of individuals with lived experience.

3. Elevate local, contextual solutions

Local challenges require local solutions. Strategies, innovations and plans to address NCDs, mental health conditions and neurological conditions in the region, including efforts to meaningfully engage individuals with lived experience, must be localized and context-specific. Further plans should be developed in local languages and dialects, without copying or importing "western" or "global north" solutions.

Individuals with lived experience must be engaged contextually and holistically, accounting for the many ways in which the rich cultural, religious and social diversity of the African Region plays out in their lives.

Funding for NCD and mental health programmes and services in the region should also be obtained from African corporations or organizations, rather than from donor countries and charities. Funds should be allocated transparently by government bodies and local NGOs. African countries must mainstream and nurture African voices to speak on global stages to decolonize global health.

4. Cross-learning from other health areas

Learning from the successes and failures of past programmes tackling other diseases in the region, such as HIV and AIDs, malaria and tuberculosis, can provide valuable information on what could be improved in the context of NCDs, mental health conditions and neurological conditions. The social stigma and barriers to accessing health services experienced by individuals living with HIV and AIDS can shed light on effective approaches to support individuals living with NCDs, mental health conditions and neurological conditions who face similar challenges.

Policy-makers and practitioners can benefit from understanding how primary health care at the grassroots level has been strengthened by other disease programmes. This includes learning from HIV and AIDs and other communicable disease integration and how this can be extended and adapted to integrate NCD services. For example, engaging women living with HIV in developing guidelines for breastfeeding revolutionized the understanding of scientific guidance in the region. This could offer many useful applications for the meaningful engagement of individuals with lived experience.

Region of the Americas – the Caribbean and North America
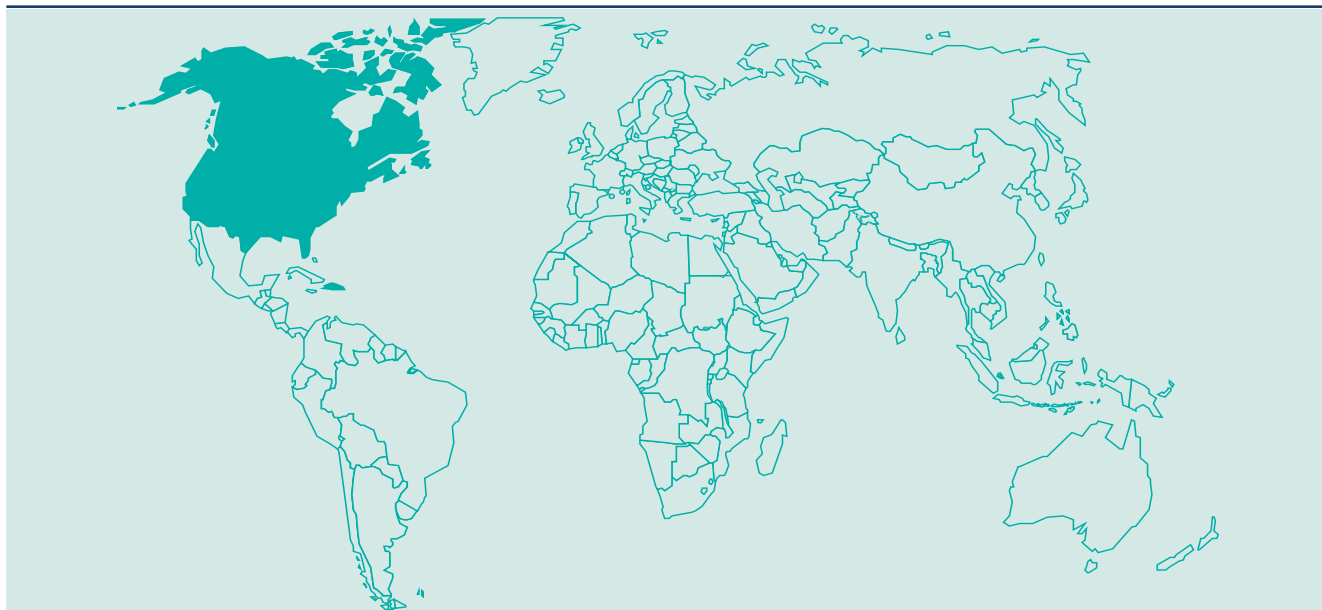
Recruiting and engaging collaborators

1. Traditional community leaders

Religious and spiritual leaders, rural community leaders and cultural informants of knowledge and wisdom such as elders were identified as important partners to engage when co-creating NCD and mental health interventions. Participants emphasized that connections must be strengthened between spiritual leaders, the medical community and social services to provide more holistic support and care to individuals with lived experience.

2. Groups that are marginalized– indigenous populations, migrant communities and houseless persons

Indigenous populations, migrant communities (including first-generation migrants) and undocumented persons living with NCDs, mental health conditions and neurological conditions in the Region must no longer be left out of decision-making circles. The concept of "peer support" used within the context of the United States of America (USA) must not lose sight of historical disparities that perpetuate inequities for immigrant communities, indigenous groups and people of colour. Instead they should be inclusive to groups that continue to be experience systemic marginalization. Organizations with care responsibilities for these populations, including faith-based and non-profit organizations, should also be included in decision-making circles so their expertise can inform ongoing care deliberations.

Houseless persons *(26)* are less likely to be able to seek the care they need, while being more likely to live with poor health or mental health conditions, including substance abuse disorders. Houseless persons are also less likely to receive appropriate care, treatment and support, with many being criminalized and incarcerated in long-term institutions instead.

3. Inclusion of children in NCD and mental health agendas

Children can be born with and/or develop NCDs, such as diabetes, and experience mental health or neurological conditions such as epilepsy, developmental disabilities, depression, anxiety and behavioural disorders from a very young age *(27)*. Ten per cent of children and adolescents worldwide experience a mental disorder, but the majority of them do not, or are not supported to, seek help or receive care. The consequences of neglecting mental health in children extends to adulthood and limits opportunities for leading fulfilling lives. To meaningfully engage children, there is a need for safe and supportive environments, including awareness raising in school settings and supportive adults to ensure their voices are heard and understood. Information materials and resources should also be available in child-friendly versions, such as information play kits, and their input sought by appropriately trained and skilled professionals. Broader policy development should also consider children and young populations as important stakeholders in the NCD and mental health response.

Enablers of meaningful engagement

▶ Action areas

1. The right to choose

To redistribute power to individuals with lived experience, they must be allowed to take ownership of their care and choose how they wish to live. This requires a person-centered approach that provides individuals with lived experience with a range of needs-based and culturally appropriate care options with which they can make informed decisions. Individuals with lived experience must be supported and empowered to have autonomy and the ability to make healthy choices.

2. Address historical barriers to health

The social determinants of health must account for historical and structural barriers that drive health conditions. Racial disparities in health outcomes and life expectancy are rooted in historical inequalities that continue to disadvantage some communities. For example, racial and ethnic minority groups in the USA experience higher rates of illness and death across a wide range of health conditions, including diabetes, hypertension, cancer, obesity, asthma, cardiovascular disease and kidney disease *(28, 29)*. Factors such as race, ethnicity and the lived experiences of individuals that are marginalized must be incorporated into the research and development of public health interventions.

3. Democratize language and communication

Often, uneven power structures are implied and perpetuated through language or terminology used. The term "power", for example, can be viewed as paternalistic due its connotations with an authority making decisions on behalf of others. The language and terminology used in health-care settings or policy-making spaces should be easily understood and accessible by all stakeholders. Open communication strategies, where all stakeholders can share their experiences, such as mass communication platforms and formal engagement conducted by governments, can be a great leveler and help to democratize experiences and issues.

Region of the Americas – Latin America

Recruiting and engaging collaborators

1. Groups that are marginalized and stigmatized

Meaningful engagement efforts cannot leave stigmatized and vulnerable groups behind. Individuals who live with substance abuse disorders, houseless persons or children and youth in conflict with the law are less likely to be able to seek and receive the care they need, while being more likely to live with poor health conditions. Issues such as substance abuse disorders are often treated as matters of criminal justice rather than public health, and as a result further marginalize users and create a vicious cycle of punishment. Meaningful engagement can catalyze a more holistic public health approach to support stigmatized and vulnerable populations.

2. Inclusion of Youth in NCD and mental health agendas

As many Latin American countries are young democracies, the role of youth as activists and future leaders is of particular significance. Young people need to have

a sense of belonging and ownership in their communities and countries in order to impact public policy. Initiatives such as young leaders' programmes could promote civic participation among young people, equip them with leadership skills and enable them to co-create policies and laws alongside legislators. The "Empowerment Ladder" approach *(30)*, which has been used to train young people living with type 1 diabetes to play active roles as leaders and changemakers in their community or society, can be a useful reference in this regard.

At the same time, young people continue to miss out on vital health interventions. Suicide is among the leading causes of death for individuals aged 10–19 years in Latin America *(31)* and has been exacerbated due to the COVID-19 pandemic. Community mental health services in the Region must be strengthened with support ensured for young people.

Enablers of meaningful engagement

▶ **Action areas**

1. Meet essential needs of individuals with lived experience

Low-income populations in the Region tend to be more exposed to risk factors and are hardest hit by NCDs, mental health conditions and neurological conditions. Engaging individuals with lived experience in consultations or forums without acknowledging and addressing the very real and acute barriers of poverty they face could be perceived as tokenism or lip

service. To better support individuals with lived experience, their basic needs, such as housing, food and access to public services, must first be acknowledged and addressed.

Capacity-building for meaningful engagement

1. Pan American Health Organization (PAHO) in the community

The PAHO/WHO Office for the Region of the Americas should have more visibility and presence at community level, communicating and promoting its mandate and offering resources and support. The PAHO/WHO Office for the Region of the Americas can also strengthen the stewardship of the ministries of health and local governments to enhance the management of NCDs, mental health conditions and neurological conditions and engagement with individuals with lived experience. For example, Colombia recently instated Comprehensive Healthcare Pathways, a model that promotes a shift from treatment to prevention and recognizes the active role of individuals, families and communities in the maintenance and recovery of health *(32)*. The PAHO/WHO Office for the Region of the Americas could provide support and resources on the aspects of this plan that relate to meaningful engagement, which includes requesting that governments provide seats for individuals with lived experience in the planning and implementation of their policies and programmes.

South-East Asia Region
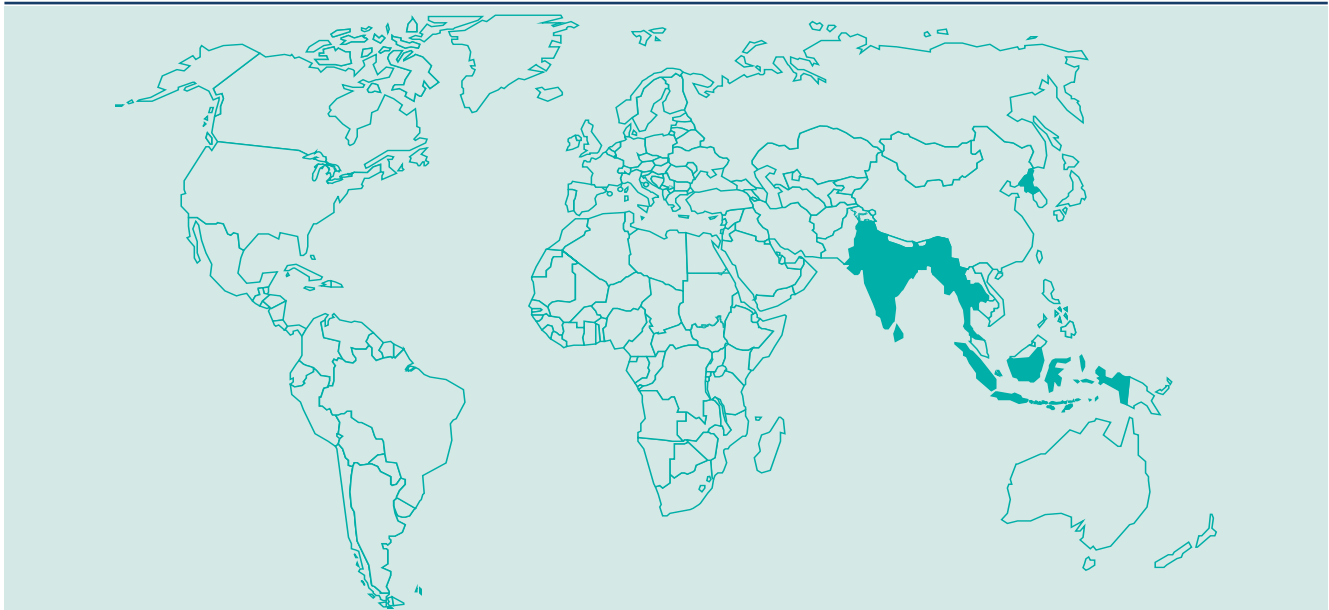
Recruiting and engaging collaborators

1. Groups that are marginalized – at-risk communities

It is essential to engage at-risk communities such as people living in rural areas, indigenous populations and ethnic minorities when making decisions around NCDs, mental health conditions and neurological conditions. Individuals from these large communities are disproportionately impacted by NCDs, mental health conditions and neurological conditions.

2. Groups that are marginalized– older adults, children and adolescents

Participants emphasized that older adults, children and adolescents were underrepresented in the virtual consultation. Home to many rapidly ageing countries, older adults in the South-East Asia Region must be reached in the local settings where they reside to enable their meaningful engagement in decision-making processes around NCDs, mental health conditions and neurological conditions. Many of the region's 533 million young people do not receive access to NCD or mental health services and treatment. Advocacy and awareness raising around NCDs and mental health should begin in schools as they are often under-diagnosed in children and adolescents. Early intervention programmes can also lead to improved and more sustainable long-term health outcomes for youth. Parents, caregivers and teachers are key partners in engaging young people, equipping them with essential knowledge about skills to advocate for individuals with lived experience.

# Capacity-building for meaningful engagement

1. Learning from and collaborating with other sectors

Meaningful engagement is still uncommon in the region, with CSOs and NGOs mainly prioritizing risk-factor reduction and early diagnosis through education and advocacy *(33)*. Collaboration between sectors in the region is also weak. Priority health areas in which meaningful engagement has been operationalized at varying levels include examples in tobacco control (Voices of Tobacco Victims India), childhood cancer (CanKids India), and mental health (Komunitas Peduli Skizofrenia Indonesia). Further, the WHO South-East Asia Regional Office and the South East Asia Regional NCD Alliance as part of World Diabetes Day in 2021 co-hosted a diabetes panel discussion on meaningful engagement of people living with diabetes and NCDs. Taken as a starting point, commonalities and lessons learned from meaningful engagement in these areas should be shared and integrated across NCD and mental health initiatives in the region, with coalitions and collaborations strengthened across sectors to build capacity.

2. Individuals with lived experience as leaders and role models

Individuals with lived experience can act as role models for others who experience similar conditions and live in similar social, economic or cultural settings, thus breaking barriers to inclusion in health and policy decision-making spaces and addressing stigma and discrimination faced by this group. For a true shift from awareness to engagement of individuals with lived experience, they must not only be supported, but also empowered, championed and trained to take ownership of these issues. They should also be provided with opportunities to become leaders in their communities and particularly for children and adolescents living with NCDs, mental health conditions and neurological conditions. For example, motivating individuals with lived experience to share their stories is among the main capacity-building priorities of the South East Asia Region NCD Alliance, alongside providing them with physical and mental support, formal training, and opportunities to take on leadership roles in settings such as medical associations.

European Region
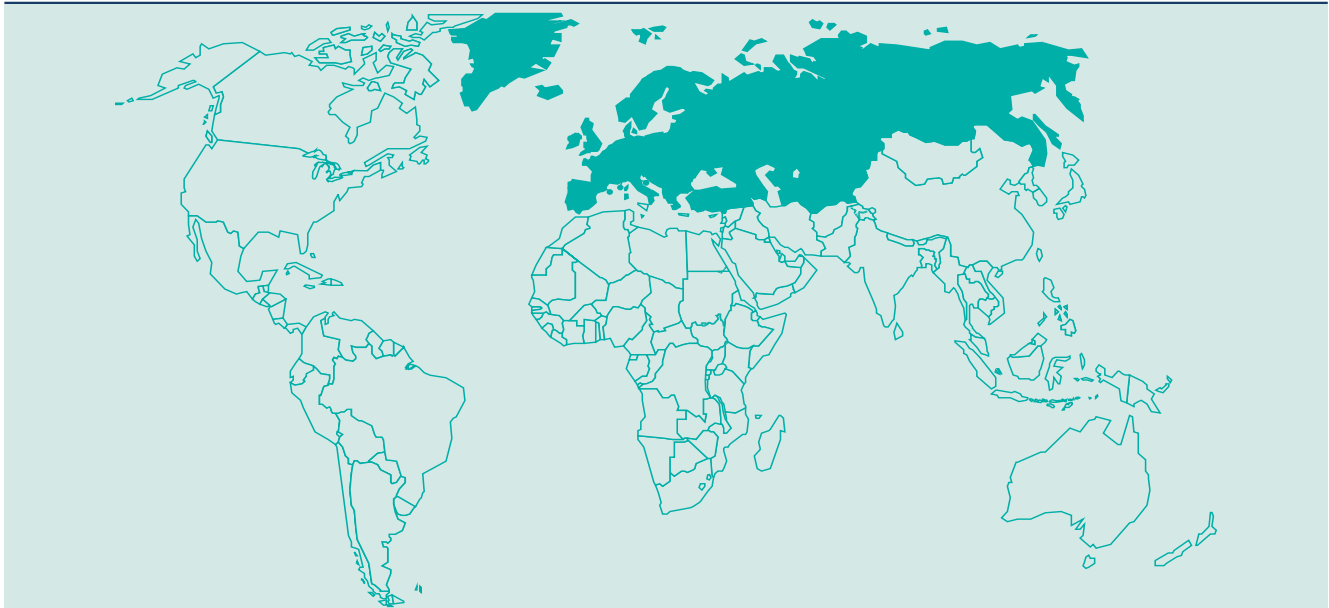
Principles of meaningful engagement

1. Meaningful engagement is an essential requirement

Meaningful engagement should not come in the form of "goodwill", which is defined as an act of approval or benevolence, often predicated on hidden power imbalances between the benefactor and the recipient. Instead, meaningful engagement with individuals with lived experience is now seen as an essential, obligatory requirement for WHO and Member States. It is an obligation, based on the right to participate, that must be followed through with political commitment and legal guarantees.

2. Humanistic health outcomes

Humanistic health outcomes, which include quality of life, well-being, mental and social health, are rarely valued and measured in the same way as clinical or economic outcomes of health conditions. The Global Burden of Disease *(24)*, for example, mainly captures premature death and disability through indicators such as years of life lost and years lived with disability. The humanistic aspects of health must be incorporated in broader measurements of disease impact for a comprehensive understanding of how NCDs, mental health conditions and neurological conditions affect individuals with lived experience. Humanistic and quality of life measures that capture an individual's physical and emotional functioning while living with a health condition also reflect the complex and multidimensional lived aspects of NCDs, mental health conditions and neurological conditions. This will further respect and dignify individuals with lived experience beyond their role as just "patients".

3. Acceptance, not just awareness

Awareness campaigns around NCDs, mental health conditions and neurological conditions promote greater understanding of these conditions. However, it is important that awareness campaigns are designed by individuals with lived experience to avoid stereotypes, biases and pathologization of

these conditions. Lessons learned from the autism community show the need to go beyond awareness towards acceptance. Autism acceptance refers to recognizing the basic human rights of autistic people, while also acknowledging their behavioural differences. This principle underpins the preferences of some in the autistic community to use "identity-first" (autistic) rather than "person-first" language (person living with autism). More broadly, this reinforces the importance of listening to and engaging individuals with lived experience so as not to perpetuate harmful practices.

Recruiting and engaging collaborators

1. **Groups that are marginalized– individuals living with underrepresented NCDs, mental health conditions and neurological conditions**

There are many NCDs, mental health conditions and neurological conditions, such as asthma, autism, bipolar disorder, dementia and other neurological conditions, that are underrepresented in engagement spaces and present additional barriers to participation. Individuals living with underrepresented conditions, such as aphasia and cognitive impairments, should be recruited and supported with financial assistance, alongside additional facilities to enable their participation. In addition, their caregivers or family members should be effectively engaged in order to learn from their experiences, and compensated for their time and expertise.

Enablers of meaningful engagement

▶ **Action areas**

1. **Address burnout in health care**

Many health-care providers experience burnout due to long working hours and high-pressure working environments. Burnout in health care has been especially pronounced during the COVID-19 pandemic and is a symptom of the deeper issues of undervaluing and underinvesting in health-care systems and the health workforce. Acknowledged as a safety risk, burnout has become an urgent priority to strengthen national health systems and health security in Europe *(25)*. Burnout issues must be adequately addressed for the well-being of health-care professionals and because they are key partners in meaningfully engaging and supporting individuals with lived experience.

2. **Active listening**

Health-care providers must be trained to actively and effectively listen to individuals with lived experience. They should ask and listen to individuals about their needs and lived experience, which can avoid serious misdiagnosis and medication errors and also reveal important details about an individual's condition that might otherwise be overlooked. Active listening is an important technique in communication, policy-making and other decision-making spaces to ensure inclusive and respectful engagement of individuals with lived experience.

Eastern Mediterranean Region
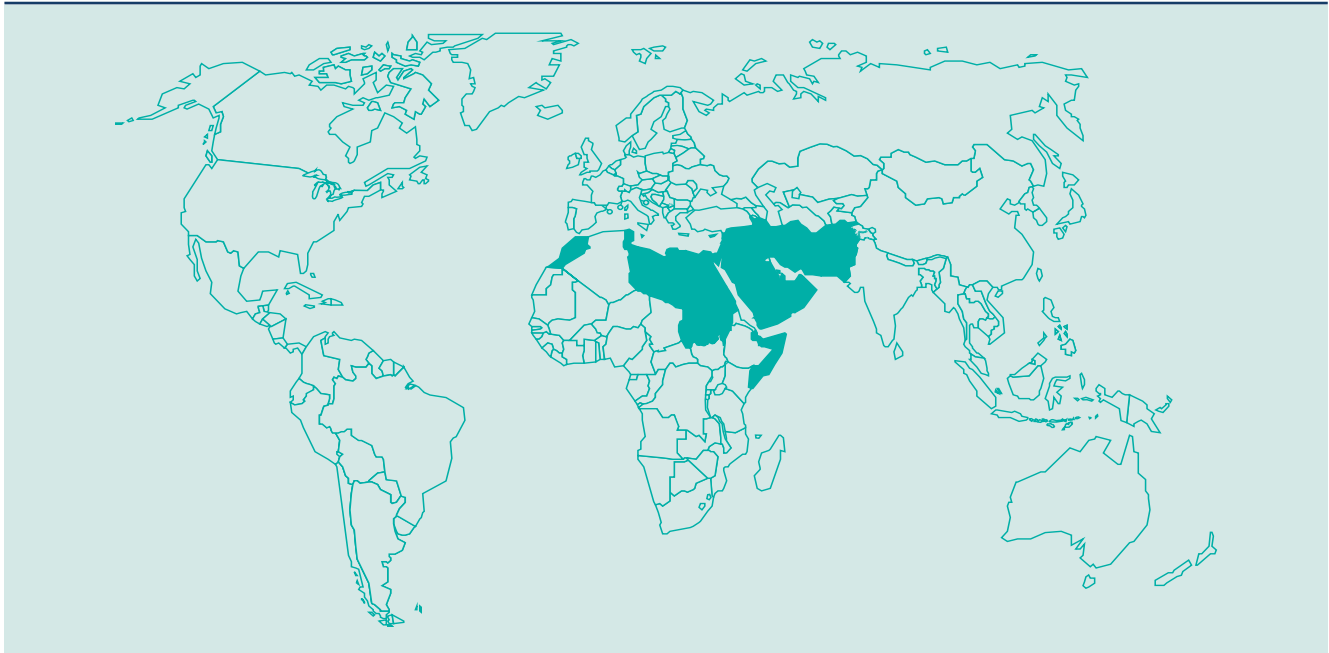
Principles of meaningful engagement

1. Reducing stigma

Stigma experienced by individuals with lived experience, particularly of mental health conditions, can be deeply traumatic and harmful to their well-being. The region has a deep cultural context, understanding and perception associated with mental health that may be a contributing factor for this urgent need to address stigma. Health-care professionals may also exacerbate stigmatization of individuals by labelling and perpetuating negative attributes against individuals living with mental health conditions, such as depression, dementia or Alzheimer's disease, which results in underdiagnosis and/or inadequate treatment of these conditions.

Recruiting and engaging collaborators

1. Groups that are marginalized – internally displaced persons, refugees and undocumented migrants

Participants IDPs, refugees and undocumented immigrants among the most vulnerable groups in their countries. The Eastern Mediterranean Region hosts two-thirds (16.7 million)) of the total number of refugees worldwide *(21)*. The number of IDPs has also been growing steadily in the region over the past decades, rising to 19.5 million in 2020 *(22)*. Half of the 22 countries in the Region are also experiencing long-term emergencies. The adverse impact of emergencies, including on health and social care systems, exacerbates the health conditions faced by these individuals. More

than one in five people who have experienced emergencies face depression, anxiety and post-traumatic stress disorder (PTSD). Representatives of this group are thus key to understanding the complex challenges faced by IDPs, refugees and undocumented migrants living with NCDs, mental health conditions and neurological conditions, and improving their treatment and care.

2. Older adults

Despite holding a wealth of knowledge and experience, older adults, especially those living with neurological conditions such as Alzheimer's or dementia, are sometimes regarded as burdens. This can lead to elder abuse, and lack of financial support, food, clothing and other necessities. The migration of younger people to cities also leaves many older adults living alone and without caregivers or resources to support them. Remaining caregivers find themselves stretched with limited resources and without respite. Not only must older adults be reached where they are, they must also be engaged as important stakeholders when co-creating related policies, programmes or services.

3. Religious leaders

Religious leaders are highly respected in many communities in the region. They were identified as important stakeholders to engage as spokespersons in health promotion efforts and anti-stigma campaigns. Religious leaders could be encouraged to take ownership of and participate further in policy, guideline and/or campaign development around NCDs, mental health conditions and neurological conditions in the region.

Enablers of meaningful engagement

▶ Action areas

1. Storytelling as a tool for advocacy

Effective storytelling is a traditional and powerful tool to communicate lived experience to a wider audience and can dismantle culturally rooted stigma against NCDs, mental health conditions and neurological conditions. Participants noted that individuals with lived experience should be encouraged and supported to tell their personal stories to directly reach legislators and foster attitude change within governments. Stories of lived experience should also be used in engagement formats such as region-wide campaigns and national health days, and should be supported by social media, television, theatre and literature.

2. Promote bottom-up, participatory modes of engagement

Individuals at the head of conventional hierarchies or power structures in the region often do not understand the challenges facing wider populations and communities – and yet they hold decision-making authority. Engagement methods and models that shed light on uneven power balances and promote bottom-up, participatory approaches are needed to redistribute power to individuals with lived experience. The power and voices of individuals with lived experience can be amplified through forming collectives and coalitions, which must be backed by funding and capacity-building. This was reflected in

a regional meeting co-hosted by the WHO Eastern Mediterranean Regional Office and the NCD Alliance, which recommended supporting NCD CSOs through coalition-building. The Eastern Mediterranean NCD Alliance also hosted a webinar series featuring lived experience speakers to emphasize the importance of people-centered NCD and mental health responses, and the need to amplify the voices of individuals with lived experience.

3. Increase visibility and cultural acceptance of mental health conditions

Before individuals living with mental health conditions can be meaningfully engaged, awareness and health literacy around mental health in the Region must be improved. This requires incorporating mental health curricula in schools, universities and for all service providers – especially at the primary care level. Parental awareness of mental health conditions should also be increased

due to frequent underdiagnosis in children and adolescents.

Health systems should prioritize and allocate more resources to mental health services and provide affordable and comprehensive care packages throughout the life course, including early screening and non-pharmaceutical interventions. The WHO Regional framework to scale up action on mental health in the Eastern Mediterranean Region *(23)* recommends that individuals with mental health conditions and their families are provided access to self-help and community-based interventions. These are important ways to shift perceptions of mental health away from archaic institutionalized settings and raise the visibility and acceptance of mental health conditions in the community.
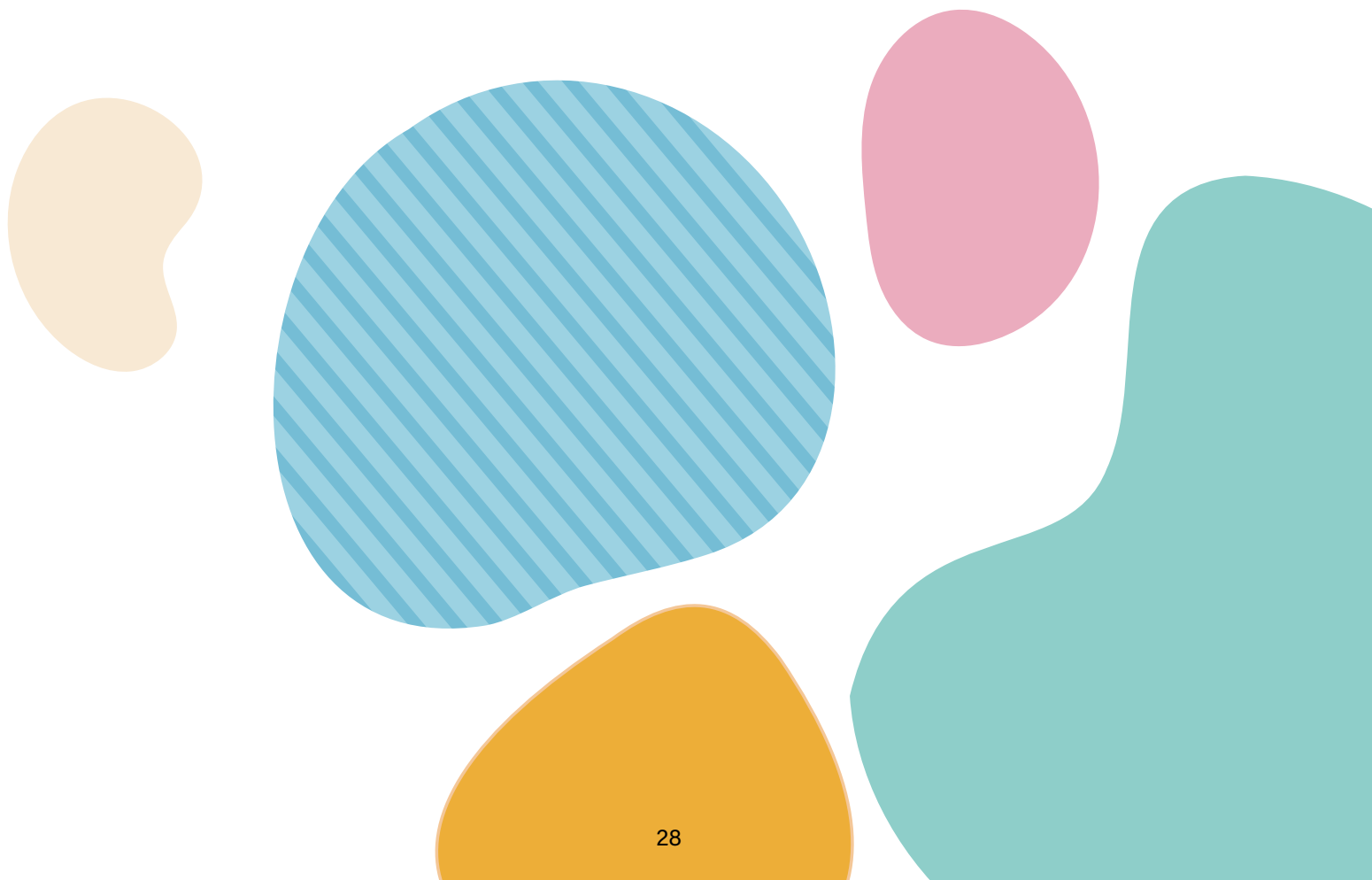
Western Pacific Region – Cambodia, Malaysia, the Philippines
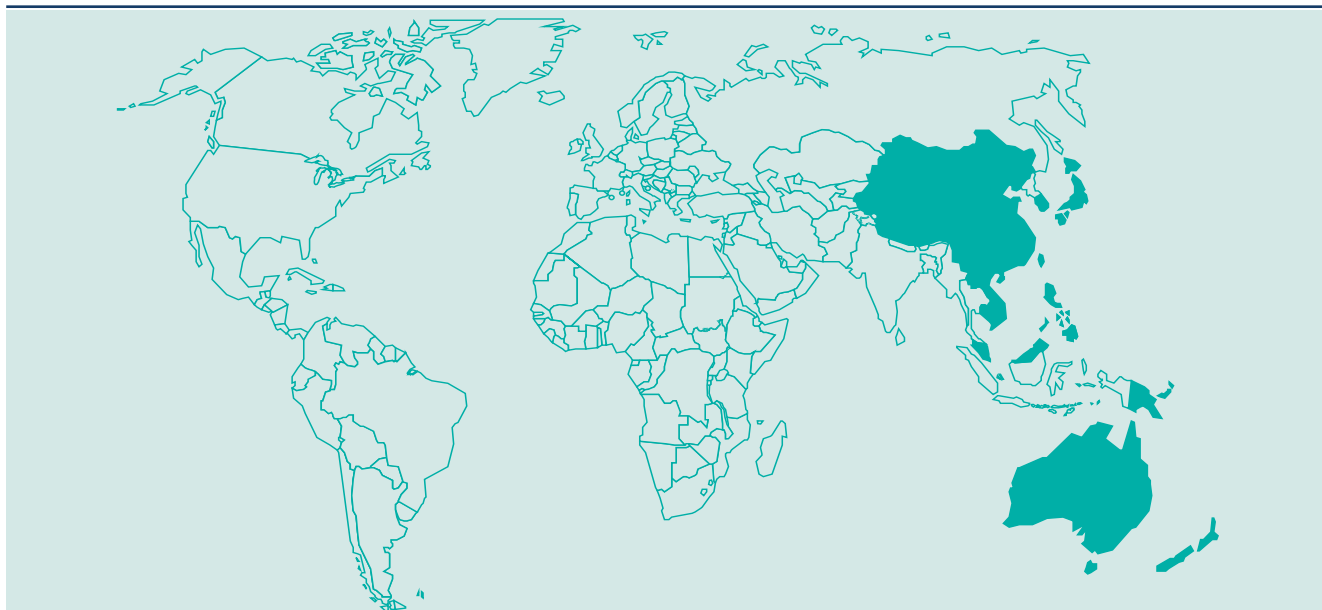
Barriers to health for individuals with lived experience

1. Prohibitive health-care costs

Many people are unable to access basic health-care services due to the high costs of diagnostic procedures, medication and treatments. High indirect costs such as transport to health facilities are an added barrier in the Region. This deters many people from seeking treatment, leads to under-diagnosis and results in severe illness and even death from preventable causes.

Governments, with guidance and support from WHO, must identify more affordable technologies for screening, diagnosis and treatment of NCDs, mental health conditions and neurological conditions, as well as establish pooled procurement mechanisms for essential medicines to reduce costs. National insurance schemes should be expanded to cover diagnostics and regular tests for a wider range of NCDs, mental health conditions and neurological conditions. Health spending should be increased and the implementation of universal health coverage (UHC) accelerated.

2. Inadequate care systems

Across these three countries, some NCD and mental health services are available in hospitals, but less so in primary and community care settings. Many health services are also offered in isolation from each other, and often target a single or small group of health conditions. The capacity of the primary care sector should be expanded and integration of different primary, secondary and tertiary services in the health-care system should be strengthened to facilitate continuity of care. Health-care navigators can further support individuals with lived experience on referral pathways, sources of financial assistance and other important information.

Medications and treatments for some health conditions are also severely limited. In the Philippines, for diabetes patients there is an insufficient supply of insulin for individuals living with diabetes in the local population. Fewer treatments are available for children with type 1 diabetes, who are not treated as a priority. This leads to a dependence on international NGOs for insulin, which impairs the self-reliance and sustainability of the country's health-care system.

3. Low health literacy

Poor understanding of NCDs, mental health conditions and neurological conditions – including risk factors, causes, symptoms, treatment options and side-effects – limits health-seeking behaviours, reinforces common misconceptions about these conditions and drives stigma. Health literacy programmes and education and awareness campaigns for individuals with lived experience, communities and health providers are essential to addressing these barriers and improving health outcomes in the long term.

Health literacy efforts should also adapt to local languages and dialects, norms and habits to enhance relevance, uptake and long-term sustainability. For example, education campaigns on healthy eating should account for and incorporate locally sourced healthy food preferences so it is easier for individuals and families to incorporate the knowledge into their daily practices.

Enhancing meaningful engagement of individuals with lived experience

▶ Action areas

1. Formalized and integrated modes of engagement

The engagement of individuals with lived experience should be formalized with institutional support from policy-makers, health-care providers and relevant associations. Support groups should have regular and structured meetings with clear agendas, roles, responsibilities and rules of engagement. Family engagement must be a core principle and component in these formats. The representation of individuals with lived experience must be guaranteed in all governance platforms related to health. Engagement activities must be recorded and documented, with clear follow-up and plans of action.

2. Multilevel stakeholder engagement

Governments and non-state actors such as NGOs and associations of individuals with lived experience should strengthen collaborations to co-create policies, programmes and services. Links between networks at national, subnational and grassroots levels should be further strengthened to support efforts to operationalize meaningful engagement. Many

lessons can be learned from the Cambodian People Living with HIV Network (CPN+).

CPN+ works to strengthen the policy synergy between the HIV response at national and grassroots levels by meaningful involvement of People Living with and Affected by HIV (PLHIV) in the development of policies, plans and programmes. Since its establishment in July 2001, CPN+ works in collaboration with various stakeholders including governments and UN agencies, local and international NGOs and community-based organizations. It supports nearly 1000 self-help groups of PLHIV in partnership with networks in 19 provinces *(34)*.

Next steps

This report demonstrates strong alignment on priority areas and actions towards meaningful engagement of individuals with lived experience across all WHO regions. The analysis of the regional consultations provides a wealth of insights, evidence and expertise, which will be integrated into the WHO Framework for Meaningful Engagement of People Living with NCDs, Mental Health Conditions and Neurological Conditions.

The report also highlights several nuances and priorities raised in each WHO region, outlining implementation gaps, considerations for implementation of the WHO Framework, and regional and country-specific priorities and opportunities to align with other health activities and agendas.

The WHO Framework is a powerful signal of intent of WHO's commitment to this topic, including mobilizing high-level political commitment and support. In addition, further steps will be required to develop other ways to support further adaptation and contextualization of the WHO Framework on the road to implementation – including opportunities to align and integrate it with existing frameworks, action plans and other relevant initiatives across regional

and country contexts. This is particularly important when we consider the ultimate goal of operationalizing meaningful engagement, incorporating an intersectional lens of lived experiences of NCDs, mental health conditions and neurological conditions, within a global health setting with finite resources. Further, alignment to regional and country initiatives and priorities will not only ensure the contextual relevance of the Framework, but also greater efficiency and sustainability in its application.

Finally, there is scope to build upon the inclusive, informal consultations and focus groups held as the foundation of this report across the six WHO regions, specifically to make future engagements more accessible to individuals from groups that are marginalized. Subsequently, as this work continues to evolve, gain visibility and establish trust with individuals with lived experience, so will the opportunity to bring in new voices and perspectives, alongside implementors and champions across WHO, Member States, CSOs and individuals with lived experience.
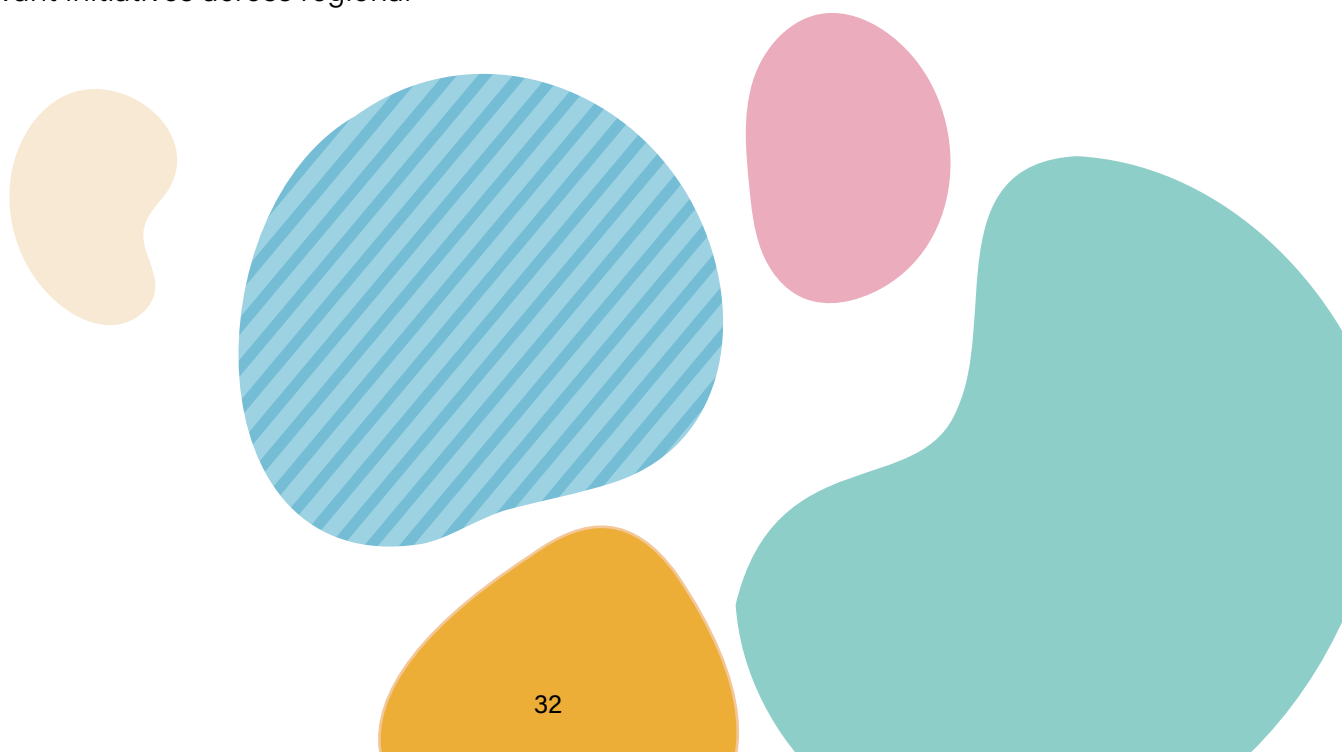
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