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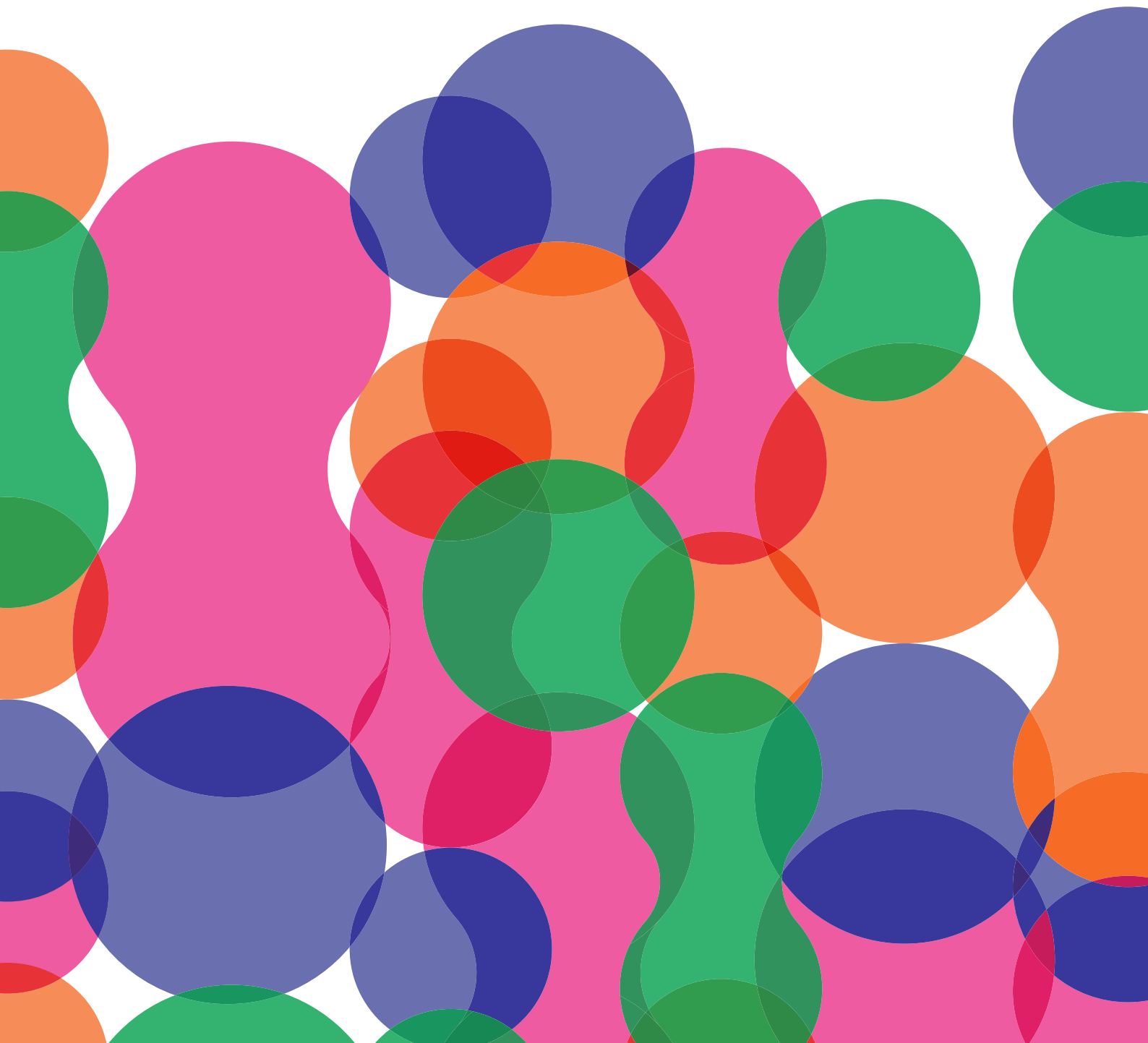
WHO framework for meaningful engagement

of people living with noncommunicable diseases, and mental health and neurological conditions

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World Health Organization

Contents

Foreword

The silent pandemic of noncommunicable diseases (NCDs), and mental health and neurological conditions is a crucial global health challenge which transcends borders, sectors, languages, ethnicities and political divides, endangering lives, livelihoods and global development. Their drivers are social, environmental, commercial and genetic, and their presence is global. Every year, NCDs claim the lives of 17 million people under the age of 70 – one every two seconds. The COVID-19 pandemic took an especially heavy toll on people living with these health conditions, highlighting how these diseases undermine the very foundations of good health. Unfortunately, most of these premature deaths are preventable, but require concerted efforts, with a whole-of-government, whole-of-society response across countries, sectors and communities.

As we look ahead to building a healthier, safer, and fairer world, we must work together to accelerate progress towards achieving the health-related SDGs through the "triple billion" targets of WHO's 13th Global Programme of Work . These priorities are underpinned by what WHO calls the "five Ps": Promoting, Providing, Protecting, Powering and Performing for health. These five Ps support the SDG vision of leaving no one behind. However, people when meaningfully engaged, can also act as an accelerator for change around the world.

The right to participate is an essential feature of the right to the highest attainable standard of health. People have the right and duty to participate individually and collectively in the planning and implementation of their health and wellbeing. The meaningful participation of individuals with lived experience of health conditions provides powerful expertise and narratives critical to shaping inclusive and equitable health policies, programmes and services.

This is translated into the WHO Constitution which outlines that "Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people" which is why this framework is so timely.

This framework will ensure WHO and Member States can meaningfully engage and empower people with lived experience to fully participate in related health processes, addressing the systemic inequalities and inequities experienced around the world. When meaningfully engaged, individuals with lived experience can provide invaluable understanding of barriers and gaps and can inform innovative, inclusive and contextuality appropriate solutions, catalysing much needed change from local to global.

This framework will support the transfer power to the people, embrace individuals with lived experience with dignity and respect, free of stigma and discrimination, integrated into the wider health and well-being agenda and institutionalized within WHO and Member States.

WHO is committed to the meaningful engagement of people living with NCDs, and mental health and neurological conditions. This framework will support the transition from intention to action and will continue the path of listening and learning from people with lived experience as we ensure the right to participate.

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Acknowledgements

Acronyms

COVID-19	coronavirus disease 2019
NCD	noncommunicable disease
SDG	Sustainable Development Goals
UHC	universal health coverage
UN	United Nations
WHO	World Health Organization

WHO framework for meaningful engagement of people living with
noncommunicable diseases, and mental health and neurological conditions

Glossary

Various keywords, definitions, concepts and approaches associated with meaningful engagement of individuals with lived experience in global public health are used in the framework. In view of the importance of contextualizing practice within the global framework, however, the following definitions can be adapted to each setting and context. The aim of this glossary is not to provide universal definitions for related concepts and terms but to outline how the terms are used in the framework and more broadly in the relevant literature and in practice.

Biomedical model: a model in which it is assumed that disease is fully accounted for by deviations from normal measurable biological (somatic) variables *(1)*.

Biopsychosocial model: a model in which disease is viewed as complementary biomedical (somatic) and psychological (mental) causes influenced by the sociological (societal/social) context *(1)*.

Capacity-building: provision of knowledge, skills, commitment, partnerships, structures, systems and leadership to enable effective health actions *(2)*.

Related concepts: capacity strengthening, health systems strengthening

Co-creation: active engagement of diverse stakeholders in understanding and solving complex problems in order to design, implement, monitor and evaluate relevant solutions together *(3)*.

Related concepts: co-design, co-development, co-production, participatory approaches

Community: group of people who may or may not be spatially connected but who share common interests, concerns or identities; local, national or international group with specific or broad interests *(2)*.

Community mobilization: empowerment of community members, groups or organizations to plan, conduct and evaluate activities in a participatory, sustained manner to improve their health and other needs, either on their own initiative or through health advocacy by others *(2)*.

Decolonization: active work to recognize, examine and undo the legacies of colonialism in all domains of society, including social, political and epistemological *(4)*.

Disability: result of the interaction between health conditions and/or impairments that a person experiences, such as dementia, blindness or spinal cord injury, and contextual factors related to environmental and personal factors, including societal attitudes, access to infrastructure, discriminatory policies, age and gender *(5)*.

Discrimination:

- direct discrimination: when one person is treated less favourably than another because of their background or certain personal characteristics;
- indirect discrimination: laws, policies and practices that apply to everyone in the same way and that may appear neutral but have a worse effect on some people than on others;
- intersectional discrimination: the complex, multi-faceted dimensions of discrimination on the grounds of social categories or personal characteristics *(6)*.

Empowerment: a process through which people gain greater control over decisions and actions that affect their health *(2)*.

Enabling: taking action in partnership with individuals or communities to facilitate greater empowerment – through mobilization of community and material resources – to promote and protect health *(2)*.

Ethnicity: a social construct in which people are categorized according to characteristics such as spoken language, values, cultural factors, behaviour or ancestral geography. Racial and ethnic categories and structures of exclusion overlap, as groups of people who share ancestry, language and culture, for example, are also likely to share physical phenotypes *(4)*.

Global governance: the complex of formal and informal institutions, mechanisms, relationships and processes between and among states, markets, citizens and organizations, both intergovernmental and nongovernmental, through which collective interests on the global plane are articulated, rights and obligations are established and differences are mediated *(7)*.

Global health: health equity at global level achieved by addressing transnational health issues, determinants and the interventions and formal structures that are beyond the control of national institutions *(2)*.

Health: a state of complete physical, social and mental well-being and not merely the absence of disease or infirmity *(2)*.

Health equity: is the absence of unfair, avoidable or remediable differences in health status among population groups defined socially, economically, demographically or geographically *(2)*.

Health for all: the attainment by all the people of the world of a level of health that will permit them to lead a socially and economically productive life regardless of who they are or where they live *(2)*.

Health literacy: the personal knowledge and competence that accumulate through daily activities, social interactions and across generations; mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them *(2)*.

Health outcome: a change in the health status of an individual, group or population that is attributable to a planned intervention or series of interventions, regardless of whether the intervention was intended to change health status *(2)*.

Intersectionality: the interconnected nature of identity, relationships, social constructs and categorizations such as ethnicity, skin colour, socioeconomic status, gender, sex, sexual orientation, nationality, refugee or asylum seeker status, migration or visa status, language, religion, ability, age, housing status, residence, medical status and mental health as they apply to a given individual or group.[1]

Leaving no one behind: entails reaching the poorest of the poor and combatting discrimination and rising inequities within and among countries and their root causes. This is grounded in the United Nations (UN) normative standards, including the principles of equality and non-discrimination that are foundational principles of the Charter of the UN, international human rights laws and national legal systems throughout the world. As part of the pledge to leave no one behind, countries must take action to identify who is being marginalized, including those facing discrimination and exclusion *(8)*.

Legal framework: a broad system of rules that governs and regulates decision-making, agreements, laws and others *(9)*.

Lived experience: what someone has experienced themselves, especially when it gives the individual knowledge or understanding that people who have only heard or learnt about such experiences do not have *(10)*.

Related terms: experts by experience, lived expertise, living experience, patient expert

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[1] Defined by the framework evidence base (see Annex 1 for more information)

Meaningful engagement: respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people; valuing lived experience as a form of expertise and applying it to improve health outcomes.[1]

Related concepts: Active engagement, active participation, consumer and community involvement, community engagement, community interventions, community participation, greater involvement, meaningful inclusion, meaningful involvement, patient and public involvement, patient engagement, patient empowerment, patient involvement, patient inclusion, participatory approach, person-centredness, civic participation, social participation

Member State: a country that is a member of the UN and may become a member of WHO by accepting its Constitution. Other countries, territories and areas may be admitted as members when their application has been approved by a simple majority vote of the World Health Assembly. The 194 Member States of WHO are grouped into six regions.

Mental health condition: A broad term covering mental states associated with significant distress and impairment in functioning. A person with a mental health condition may or may not have received a formal diagnosis but nevertheless identifies as experiencing or having experienced mental health issues. The term "mental health condition" is used throughout this report to bring together and speak to the widest group of stakeholders possible (11).

Noncommunicable disease: also known as chronic disease, tends to be of long duration and is the result of a combination of genetic, physiological, environmental and behavioural factors. The main types are cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes (12).

Neurological condition: disease of the central or peripheral nervous system, i.e. the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junctions and muscles (13).

Palliative care: a crucial part of integrated, people-centred health services. Relieving serious health-related suffering, be it physical, psychological, social or spiritual, is a global ethical responsibility. Thus, whether the cause of suffering is cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, end-stage chronic illness, acute trauma, extreme birth prematurity or extreme frailty of old age, palliative care may be necessary and must be available at all levels of care (14).

Participatory approach: conceptualized as a continuum in research, policy and decision-making in which different levels of participation imply different degrees of community control over the process and outcomes. Community members are empowered as equal partners to define and execute research as well as to determine its applications (15).

Related terms: civic participation, community action research, community-based participation research, community empowerment, community participation, implementation research in social development, participatory action research, participatory research

Power: the ability to influence and control material, human, intellectual and financial resources to achieve a desired outcome. Power is dynamic, played out in social, economic and political relations between individuals and groups (16).

Power relation: recognition that processes and systems of power interact to shape experiences of privilege and disadvantage between and within groups. A person can experience power in some contexts and oppression in others (17).

Primary health care: an overall approach to the organization of health systems that encompasses three aspects: multisectoral policy and action to address the broader determinants of health; empowering individuals, families and communities; and meeting people's essential health needs throughout their lives *(2)*.

Privilege: typically unearned, exclusive benefits given to people who belong to specific social groups *(16)*.

Psychosocial disability: includes people who have received a mental health-related diagnosis or who self-identify with the term. Use of the word "disability" is important in this context because it highlights the significant attitudinal and environmental barriers that hinder the full, effective participation in society of people with actual or perceived impairments and the fact that they are protected under the Convention on the Rights of Persons with Disabilities. Examples of such barriers are discrimination, stigmatization and exclusion *(18)*.

Public health: an organized activity of society to promote, protect, improve, and – when necessary – restore the health of individuals, specified groups or the entire population. A combination of science, skills and values that functions through collective societal activities and involves programmes, services and institutions for protecting and improving the health of all people *(2)*.

Racism: an ideological construct that assigns a certain race and/or ethnic group to a position of power over others on the basis of physical and cultural attributes, as well as economic wealth, involving hierarchical relations in which the "superior" race exercises domination and control over others *(19)*.

Re-orienting health services: requires optimizing fair access, putting people and communities at the centre and strengthening the contribution of health services to prevention, public health and health promotion *(2)*.

Safe space: environment that is free of discrimination and stigmatization, allowing individuals to share their perspectives, experiences and feelings in an open, supportive manner *(5)*.

Stigmatization: a complex, multilevel, social process that encompasses the elements of labelling, stereotyping, separation, status loss and discrimination in the context of a power situation *(20)*.

Sustainable Development Goals: a call for action by all countries – developed and developing – in a global partnership to recognize that ending poverty and other deprivations must go hand in hand with strategies to improve health and education, reduce inequality and spur economic growth –while tackling climate change by working to preserve our oceans and forests *(2)*.

Universal health coverage: ensures that all people have access to the health services they need, of high quality, when and where they need them, without financial hardship throughout the life course. It includes the full range of essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care *(2)*.

Well-being: a positive state experienced by individuals and societies. Similar to health, it is a resource for daily life and is determined by social, economic and environmental conditions *(2)*.

Xenophobia: fear or hatred of or discrimination against people who are considered to be foreigners. The targets of xenophobia are often groups or individuals perceived as outsiders to the nation and undeserving of the benefits associated with citizenship or national membership *(4)*.
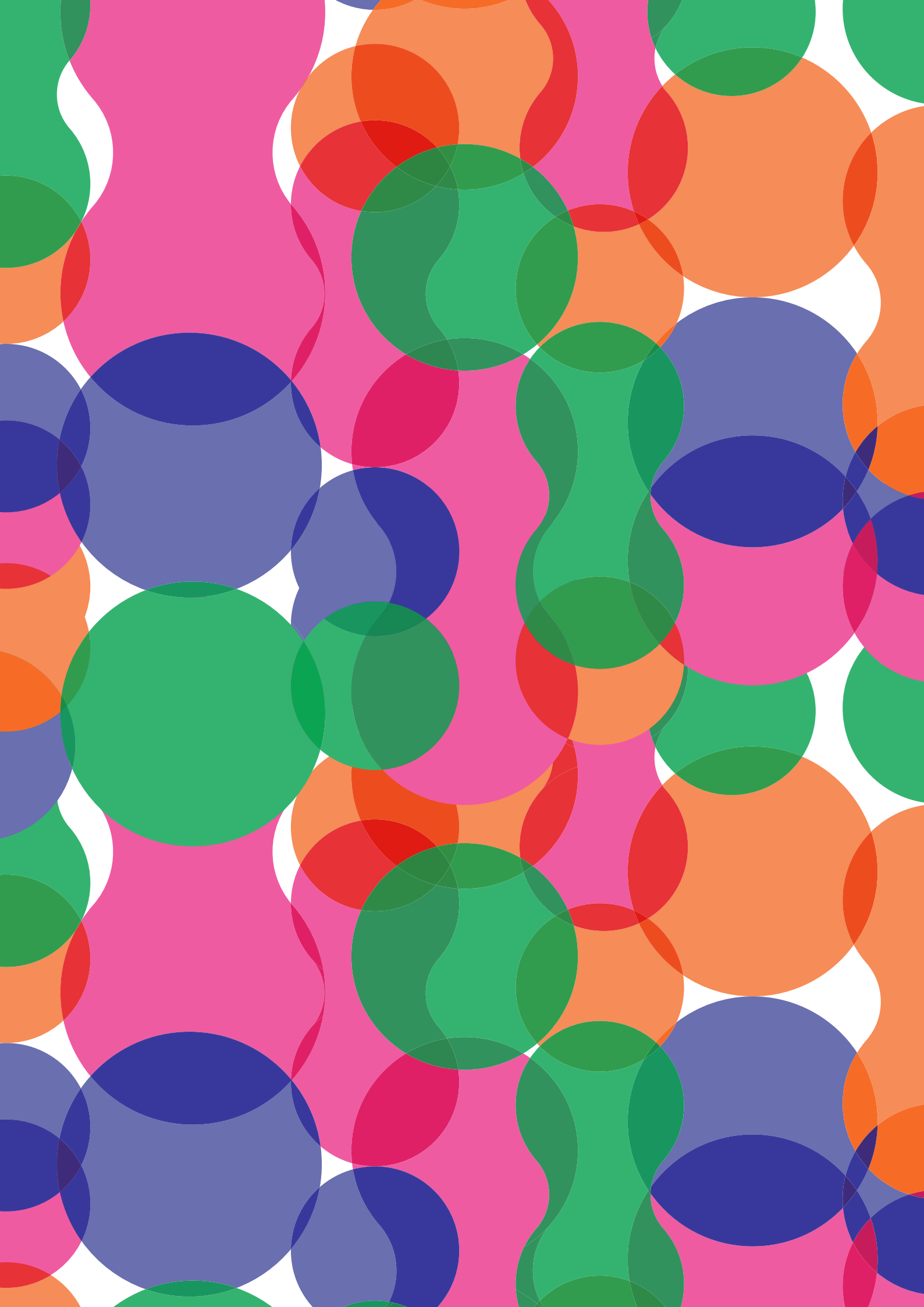
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Background

The WHO framework for meaningful engagement of people living with noncommunicable diseases (NCDs), and mental health and neurological conditions is a WHO technical product. WHO defines a technical product as a set of norms or standards, data and research products that are applicable to many countries and developed rigorously at global, regional and national levels to have an impact *(21)*. This framework acknowledges and builds on evidence, technical guidance and frameworks developed by academia and civil society on participatory approaches and the principles and enablers of meaningful engagement in global public health.

The overall objective of the framework is to support WHO and Members States in meaningful engagement of people living with NCDs, and mental health and neurological conditions (hereafter referred to as "individuals with lived experience") to co-create and enhance related policies, programmes and services. This framework will contribute to advancing understanding, knowledge and action on meaningful engagement and related participatory approaches from an evolving evidence base. It provides practical guidance and actions for transitioning from intention to action to operationalize meaningful engagement.

Further, the framework will support WHO and Member States by:

- setting norms and standards for engaging individuals with lived experience in the co-creation, implementation, monitoring, evaluation and governance of related policies, programmes and services;
- providing a framework for Member States and WHO headquarters and regional and country offices in generating data and information to support individuals with lived experience in their contexts;
- further advancing local and global evidence-based research and innovation in WHO global, regional and country offices and with Member States, by offering a framework of actions for meaningful engagement of individuals with lived experience; and
- build the capacity of WHO, Member States and key partners to avoid tokenistic engagement of individuals with lived experience *(22)* and to collaborate and co-create NCD and mental health policies, programmes and services *(23)*.

1.1 Readership

The aim of the framework is to guide people working at WHO and in Member States (Table 1) in ensuring meaningful engagement with individuals with lived experience. WHO will advocate for, provide technical assistance and operationalize implementation at its three levels (headquarters, regional and country offices) and will support Member States in implementation at national level through established processes and procedures.

In addition, given the multisectoral and multistakeholder responses required both to address and to respond to challenges associated with NCDs, and mental health and neurological conditions and to operationalize meaningful engagement of people with lived experience, the publication may also be useful for relevant government ministries and departments, such as of industry, commerce, sustainable development, education, environment, transport, social services, housing, and infrastructure. Non-State actors, including civil society, associations,

Table 1. Examples of roles and functions within WHO and Member States relevant for use of the framework

WHO	Member States
☑ Senior management and programme directors in establishing strategic operational plans	☑ Ministers of health and their advisers when establishing strategic operational plans
☑ Programme directors and unit heads who engage Member State representatives	☑ Programme directors when engaging the minister of health and other ministers
☑ Programme directors and unit heads who plan programmes	☑ Managers in health sector planning, implementing, monitoring, evaluating and/or financing health interventions
☑ Technical officers who develop technical and policy guidance at country, regional and global levels	☑ Technical advisors and staff who design and implement health-related policies and programmes
☑ Communication officers who prepare communication and advocacy products at country, regional and global levels	☑ Communication advisers and staff developing communication and advocacy products at national, regional and local levels
☑ Technical, communication and external relations officers who arrange multi-stakeholder events at country, regional and global levels	☑ Technical, communication and external relations advisers and staff when arranging multi-stakeholder events at country, regional and global levels
☑ Resource mobilization officers and administrative staff who manage budgets	☑ Resource mobilization and administrative advisers and staff when managing budgets

organizations or groups led by individuals with lived experience, and academia are key partners in working towards this common goal. Many non-State actors have close ties to communities with lived experience, and civil society should be recognized as an important conduit to achieving the goals of the framework.

1.2 Alignment with WHO's work

WHO's 13th General Programme of Work is based on three interconnected strategic priorities to ensure healthy lives and well-being for all at all ages: achieving universal health coverage (UHC), addressing health emergencies, and promoting healthier populations *(24)*. Effective, equitable prevention and control of NCDs and the promotion, protection and care of mental health are integral to the three interconnected strategic priorities.

The framework is aligned with WHO's "triple billion targets" *(25)* and supports co-creation of contextually appropriate policies, programmes and services for NCDs and mental health with target populations, which could support wider efforts for UHC. It also harnesses the knowledge of people with lived experience to co-create, co-design and improve policies, programmes and services for NCDs and mental health in their contexts. Empowering people and communities will also result in healthier populations in WHO Member States, as people become enabled to take control of their health and lead fulfilling lives with a sense of meaning and purpose through education, culturally relevant health literacy and meaningful engagement *(26)*.

Further, the framework complements, supports and is aligned with other WHO activities for NCDs, mental health and

related issues, including the implementation road map 2023–2030 for the global action plan for the prevention and control of NCDs 2013–2030 *(27)*, the Global NCD compact *(28)*, the global campaign on the lived experience of people affected by cancer *(29)* and the Global diabetes compact *(30)*, and the WHO Comprehensive mental health action plan 2013–2030 *(31)* overseen by the WHO Department of Mental Health and Substance Abuse.

1.3 Development of the framework

This framework was co-created with individuals with lived experience, WHO, Member States and relevant non-State-actors. WHO proactively prioritized and included individuals with lived experience in various evidence-generating activities and processes, including participatory research and focus groups, global and regional informal consultations, a landscape narrative review, key informant interviews and other outputs, including short films, case studies and reports. In a bottom–up approach, the insights and expertise of lived experience

led development of the evidence base on which this framework is built. This evidence base and the participatory approaches will continue to evolve with the contributions of individuals with lived experience as part of WHO's commitment. For more information, see Annex 1.

1.4 Intended application

This framework provides practical guidance and actions on meaningful engagement of people with lived experience through principles, enablers and actions (Fig. 1). WHO and Member States should consider this framework as a starting point for considering, improving or scaling up efforts to meaningfully engage individuals with lived experience. The framework is designed to be practical and agile, given the diverse needs of WHO and Member States to implement it in different geographical settings and political and cultural contexts, and its various technical applications across policies, programmes and services.
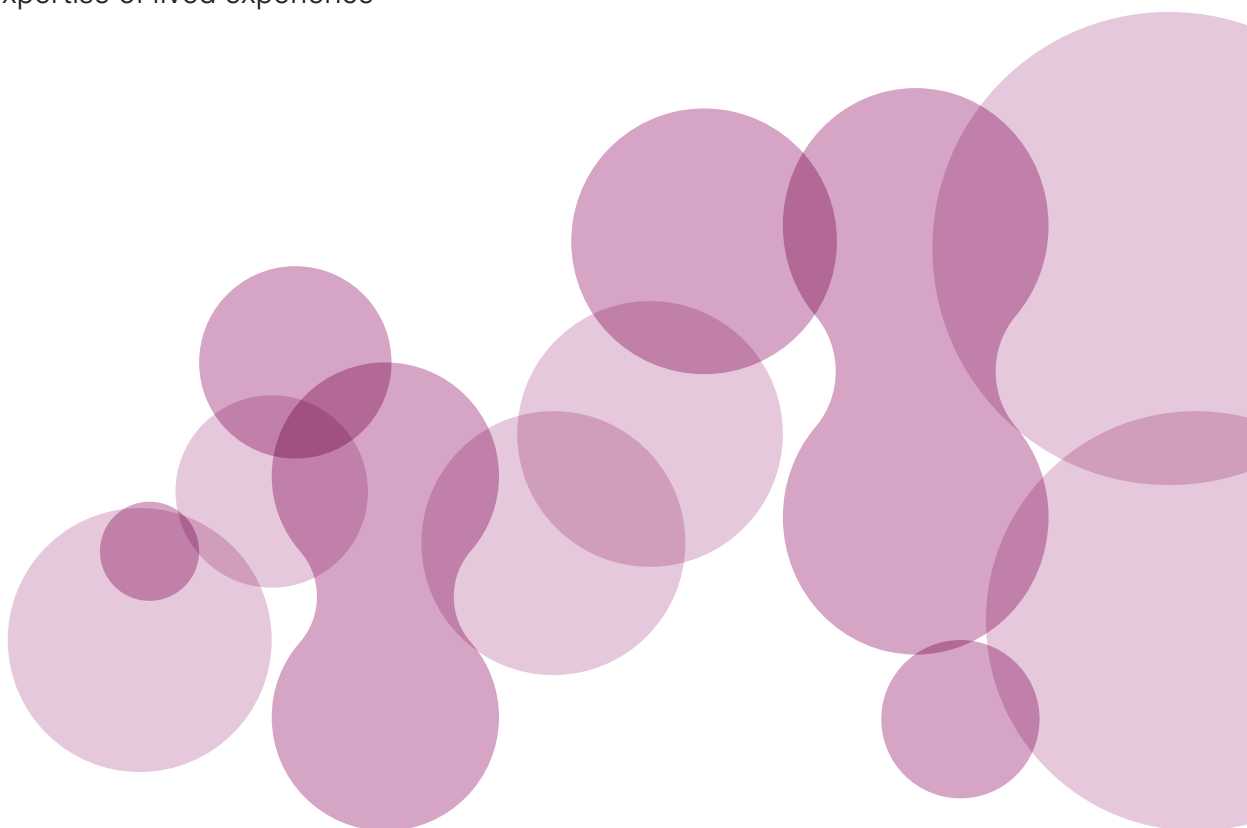
Figure 1. Interconnected principles, enablers and actions in the framework

PRINCIPLES

Dignity and respect Power and equity Inclusivity and intersectionality Commitment and transparency Institutionalization and contextualization

ENABLERS

Sustainable financing Redistributing power Elimination of stigmatization Integrated approaches Capacity-building Institutionalizing engagement

ACTIONS

Actions for WHO Actions for member states

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WHO's new operating model *(32)* defines the roles of its country offices, regional offices and headquarters more clearly. Country offices lead WHO's engagement with governments according to the country's needs and priorities in translating normative work into policy and work with UN country teams and partners to attain shared goals, amplifying the impact of WHO's normative work. Regional offices lead WHO's technical cooperation, ensuring that its normative work meets the needs of countries and is translated into impact; regional offices are the primary providers of technical support by experts on specific topics. Headquarters focuses specifically on producing global health goods for Member States, such as norms and standards, research, data products and the tools to apply them. Headquarters provides specialized technical assistance and surge capacity as requested.

The framework will be implemented at the three levels of the Organization in order to bridge the gap between global and local by institutionalizing meaningful engagement throughout WHO and its Member States. The framework is therefore available in the six official UN languages and can be further adapted and translated into other languages, as required by WHO and Member States. Additional resources and derivative products for implementation of the framework are listed in the Conclusions.
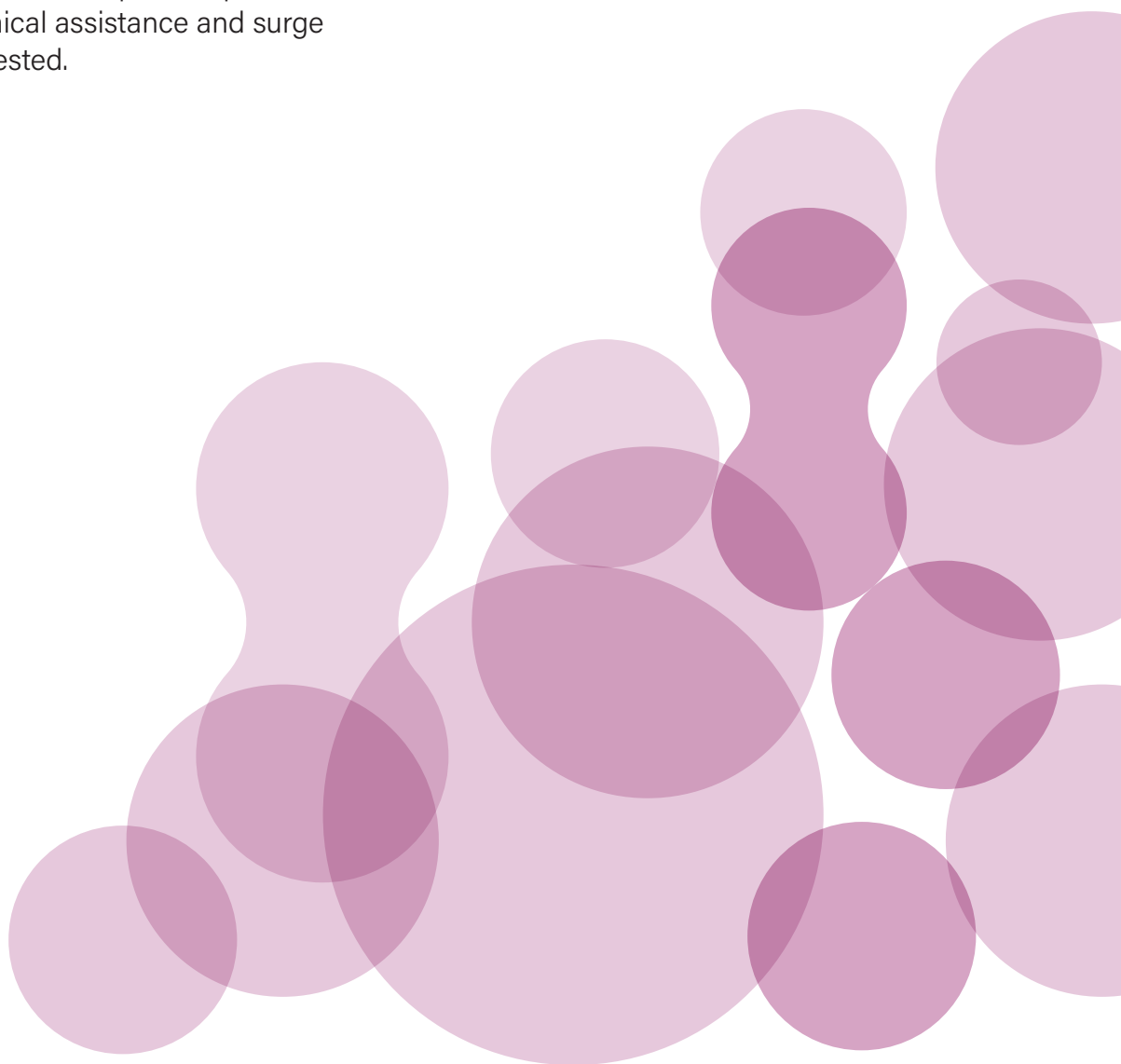
Introduction

2.1 Setting the scene

The global challenge of addressing NCDs, and mental health and neurological conditions requires a sustained multilevel, multistakeholder approach. In 2019, 74% of all global deaths were due to NCDs *(33)*, and one in eight individuals was living with a mental condition *(11)*. In the past 30 years, these two epidemics have challenged not only high-income countries but affect all countries indiscriminately. In 2019, 77% of NCD deaths *(34, 35)* were in low- and middle-income countries, where 77% of all suicides worldwide occur *(36)*. Urgent action is required, as each year 17 million people die from an NCD before they reach 70 years of age, and 86% of these premature deaths occur in low- and middle-income countries *(37)*.

In adults, neurological conditions are the leading cause of disability-adjusted life years and the second leading cause of death globally, accounting for 9 million deaths per year *(38)*. In 2016, the largest contributors to neurological disability-adjusted life years were stroke (42.2%), migraine (16.3%), dementia (10.4%) and epilepsy (5%) *(37)*. Global trends over the past three decades, driven by demographic changes and population ageing, suggest that these numbers will continue to increase. Almost one in three people globally will develop a neurological condition at some time in their life, with nearly 80% of the burden on low- and middle-income countries, where the workforce for neurological health is 70 times smaller than in high-income countries *(38)*.

The short- and long-term impacts for individuals living with these health conditions, who are also likely to have comorbidities, are often significant, not only for themselves but also for their formal and informal caregivers and families alongside their wider communities. Disability is strongly linked to NCDs, and mental health and neurological conditions. For example, people living with NCDs may develop secondary impairments, which can restrict their activity and their participation, especially if they are not adequately supported by their community or the environment in which they live. People with disabilities are also more vulnerable to NCDs, and mental health and neurological conditions, often because of exclusion from health-care services or due to other health inequities *(39, 40)*.

2.1.1 Impact of COVID-19

COVID-19 has disproportionately affected high-risk populations, including those who live in chronic poverty, older adults and people with underlying health conditions. Populations at higher risk need better protection against severe illness, more transmissible variants of coronavirus and death due to COVID-19 infection *(41)*. The COVID-19 pandemic has also further exacerbated the challenges posed by NCDs, and mental health and neurological conditions, exposing profound social inequities and fractured health systems around the world. Disaggregated national data show a consistent pattern of higher rates of COVID-19 morbidity and mortality among groups that experience racial discrimination *(41–43)*. Existing health conditions and comorbidities dramatically increase the risk of severe COVID-19 and higher mortality rates *(44–48)*. Individuals with NCDs, and mental health and neurological conditions were also

at greater risk of health complications due to systematic disruption of health-care services (screening, diagnosis, treatment, care and rehabilitation), with a disproportionate impact on low-income populations, people at high-risk and communities that are marginalized. Centrally controlled pandemic responses in many countries, which enforced lockdowns and led to disruption of essential health services, neglected the role of community engagement and whole-of-society approaches to emergency preparedness, as called for by the World Health Assembly at is Seventy-fourth session *(49).*

WHO's *Rapid assessment of service delivery for NCDs during the COVID-19 pandemic (50)* demonstrated the strong relations 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 were disrupted. Although 91% of the 130 countries investigated included all or some services for mental and neurological conditions and substance use in the list of essential health services, 93% of the countries reported disruptions in one or more of their services during the third quarter of 2022 *(51).* Despite early evidence of service recovery, nearly all countries are still affected by the COVID-19 pandemic: 92% of 129 countries reported continued disruption to services during the 6 months before submissions for the third survey (June–November 2021). Comparable figures were reported in the first quarter of 2021 and the third quarter of 2020, which was a concern in view of the waves of the delta and omicron variants of SARS-CoV-2 *(52).*

The worldwide prevalence of anxiety and depression has increased by 25% during the COVID-19 pandemic. The short- and long-term stressors include isolation, health effects of the virus, concern about financial and employment security and disruption of mental health services *(53).* NCD risk factors

also strongly affect COVID-19 outcomes. People with an alcohol use disorder are at greater risk of COVID-19 not only because of the impact of alcohol on their health but also due to the increased risk of houselessness or incarceration *(54).* Alcohol consumption and smoking increase the risk of complications and death after COVID-19 infection.

2.1.2 Addressing health inequalities and inequities

Unfair, unacceptable inequities in health outcomes are strongly associated with the social, economic, political, cultural and environmental conditions in which people live. Individuals living with NCDs, mental health conditions, or neurological conditions often experience marginalization and exclusion due to their socioeconomic status, ethnicity, gender identity, sexual orientation, disability, age, nationality or immigration status, and these factors often influence health more strongly than health care or lifestyle choices *(55).* Action on NCDs and mental health should thus be integrated, not only in health sectors but also to improve education and employment conditions, eliminate poverty, improve housing and living conditions, and end discrimination in all forms *(56).* Thus, people living with or at risk of NCDs, mental health conditions and neurological conditions should be supported by addressing the drivers and risk factors of those conditions by making health systems more resilient, investing in health security, and preparing for future pandemics, epidemics and other health challenges *(57).* Importantly, individuals with lived experience should no longer be excluded from the solutions that impact their health and well-being.

Stakeholders in global public health should therefore find new forms of multistakeholder collaboration to develop effective, contextually appropriate solutions to accelerate action and improve health outcomes. The COVID-19 response has presented barriers for

multistakeholder action, as non-State actors were prevented from supporting government responses, and the acute nature of the crisis resulted in exclusion and lack of transparency *(58)*. Stakeholders should move from the status quo of top–down "one size fits all" interventions and strategies, which exclude individuals with lived experience, to interventions based on bottom–up co-creation with a diversity of views. Lived experiences should be considered through an intersectional approach to better understand and address the root causes and management of health conditions.

The lived experience of individuals in different geographical, cultural, political, economic and social contexts is invaluable for understanding barriers, identifying solutions, and planning policies, programmes and services, while aiding accountability and governance nationally and regionally. The right to participate in one's health is a human right, which is reflected in the Constitution of the WHO as "Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people *(59)*."

2.2 Political action and global goals

While progress has been made towards achievement of many of the Sustainable Development Goals (SDGs), the world was still struggling to meet SDG target 3.4: reduce by one-third premature mortality from NCDs through prevention and treatment, and promote mental health and well-being by 2030 (Figs 2 and 3). The COVID-19 pandemic will set the world further off track as resources and policy are diverted from longer-term goals *(60)*. Three UN high-level meetings on NCDs *(61, 62)* have provided a strong political argument for accelerating action and for sustained action on NCDs and mental health. This argument was confirmed by extension of the WHO Global NCD action plan until 2030 *(27)* and the Comprehensive mental health action plan 2013–2030 *(31)*. The political declaration of the high-level meeting on UHC during the UN General Assembly in 2019 also called for multisectoral engagement and partnerships, including participatory engagements linked to NCDs, and mental health and neurological conditions *(63)*.

Figure 2. Probability of dying between the ages of 30 and < 70 years from cancer, cardiovascular disease, diabetes or respiratory illness: observed and projected versus SDG target, by WHO region and globally, 2000–2030
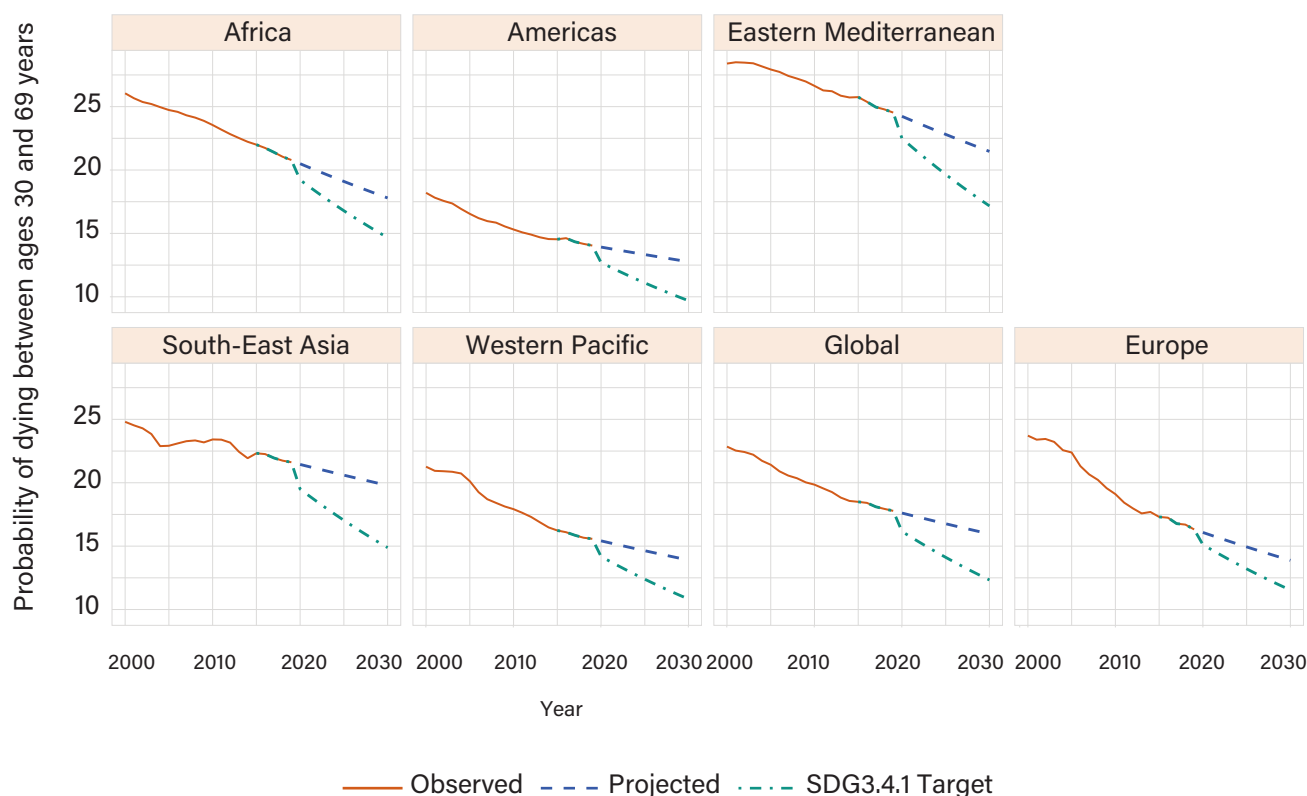
Source: WHO (Page 36) (41)

Figure 3. Crude suicide rates (per 100 000 population), 2019

Source: WHO (33)

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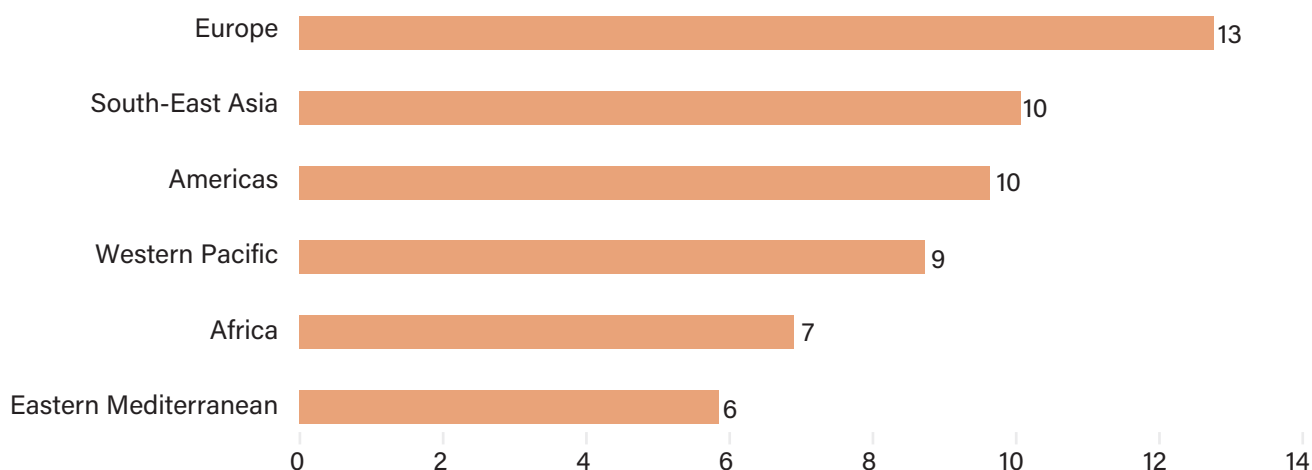
The importance of meaningful engagement was also raised in recommendation 5 of the WHO Independent high-level commission on NCDs *(64)*, which states that WHO should play a role in supporting governments to encourage and promote meaningful engagement with civil society for the prevention and control of NCDs and the promotion of mental health and provide opportunities for people affected by NCDs to contribute to decisions on laws, policies, health-care services and other systemic NCD decisions.

Prioritization of meaningful engagement of individuals with lived experience is directly aligned with the aims of the UN 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 young people, civil society, the media, the private sector, unions, academia and other stakeholders, to generate an unstoppable movement towards the necessary transformations. The inclusion of individuals with lived experience in this transformation is fundamental for sustainable, equitable development and to catalyse achievement of SDG targets 3.4 *(65)*, 3.8 *(65)* and 16.7 *(66)*,

which is to "ensure responsive, inclusive, participatory and representative decision-making at all levels". In addition, many of the principles, enablers, actions and outcomes in this framework are aligned with the UN Secretary-General's report, *Our common agenda (67)*, which was issued for the seventy-fifth anniversary of the UN. The agenda is to promote global cooperation and to reinvigorate inclusive, networked, effective multilateralism in global health. Like the framework, it includes the priorities of trust, human rights, gender equality, partnerships, preparedness, reformation of the UN and ensuring that nobody is left behind (Fig 4).

Meaningful engagement of individuals with lived experience, including their caregivers, families and communities, can also catalyse political action and commitments for the prevention and control of NCDs and the promotion, protection and care of mental health. The momentum comes as the global community shapes a transformative agenda in preparation for the fourth UN High-level meeting on NCDs in 2025 and to ensure that WHO and its Member States achieve the commitment of the Global NCD compact 2020–2030 to meaningfully engage 1.7 billion people living with NCDs by 2030 *(68)*.
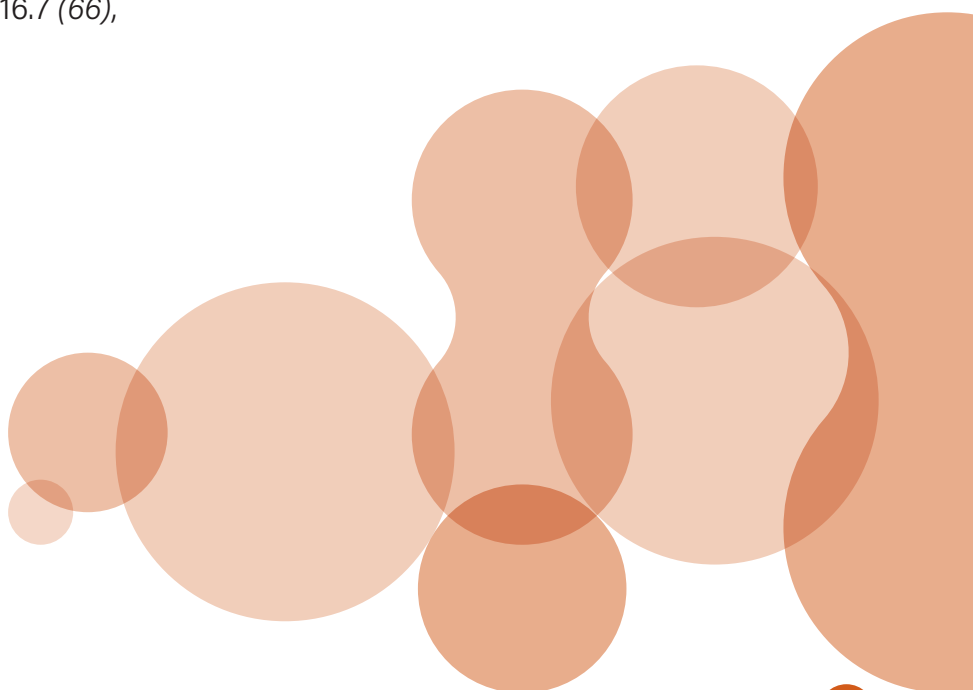
Figure 4. Relevant priorities from the UN Our Common Agenda that are aligned with the framework

Leave no one behind

- Renewed social contract anchored in human rights
- New era for universal social protection, including health care and basic income security, reaching the 4 billion unprotected
- Reinforce adequate housing, education and lifelong learning and decent work
- Digital inclusivity
- World Social Summit in 2025
- Identify measurement that complement GDP

Place women and girls at the centre

- Repeal of gender-discriminatory laws
- Promote gender parity, including through quotas and special measures
- Facilitate women's economic inclusion, including investment in the care economy and support for women entrepreneurs
- Include voices of younger women
- Eradication of violence against women and girls, including through an emergency response plan

Abide by international law and ensure justice

- Human rights as a problem-solving measure, including by comprehensive anti-discrimination laws and promoting participation
- Application of human rights online and to frontier issues and new technologies
- Universal access to the Internet as a human right
- Human rights mechanisms on a more sustainable financial footing

Boost partnerships

- Annual meetings between the United Nations and all heads of regional organizations
- Stronger engagement between the United Nations system, international financial institutions and regional development banks
- More systematic engagement with parliaments, subnational authorities and the private sector
- Civil society focal points in all United Nations entities
- United Nations Office for Partnerships to consolidate access and inclusion, including accessibility online

Build trust

- Global code of conduct that promotes integrity in public information
- Improve people's experiences with public institutions and basic services
- Inclusive national listening and "envisioning the future" exercises
- Action to tackle corruption in line with the United Nations Convention against Corruption
- Reformed international tax system
- Joint structure on financial integrity and tackling illicit financial flows

Be prepared

- Emergency Platform to be convened in response to complex global crises
- Strategic Foresight and Global Risk Report by the United Nations every five years
- On global public health:
  - Global vaccination plan
  - Empowered WHO
  - Stronger global health security and preparedness
  - Accelerate product development and access to health technologies in low- and middle-income countries
  - Universal health coverage and addressing determinants of health

Upgrade the United Nations

- High-level Advisory Board on Effective Multilateralism, led by former Heads of State and Government
- System-wide policy that puts people at the centre, taking into account age, gender and diversity
- More listening, participation and consultation (including digitally), building on the seventy-fifth anniversary declaration and Our Common Agenda
- Gender parity within the United Nations system by 2028
- Re-establish the Secretary-General's Scientific Advisory Board
- "Quintet of change" for United Nations 2.0, including innovation, data, strategic foresight, results orientation and behavioural science

Source: reproduced with permission from United Nations, 2022 *(67)*

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

2.3 Potential of meaningful engagement and participatory approaches

With growing recognition of the value of meaningful engagement and other participatory approaches as core strategies in person-centred care, many studies have shown that this approach can improve outcomes in health and health systems. Meaningful engagement of young people and adults in settings for addressing mental health and substance use has reduced hospital readmissions, improved adherence to treatment, increased the well-being and engagement of service users (including communities that are marginalized) and provided educational opportunities for the health workforce *(69–74)*.

Meaningful engagement can also improve quality of life by increasing access to specialized health-care professionals, equipment, medication and health services and increasing acceptance and support by family members, caregivers, peers and the community *(75, 76)*. Active involvement of individuals living with HIV and AIDS in discussions and decisions on their care has resulted in better adherence to antiretroviral therapy, longer survival, better clinical outcomes and quality of life, and removal of stigmatization and discrimination in health-care settings *(77–80)*.

Leveraging the power of individuals with lived experience and local communities to design, implement and evaluate appropriate, equitable, context-specific policies, programmes and services for NCDs and mental health supports their relevance and

uptake by the target population. Insights from individuals who are experiencing health challenges, including navigating complex and/or inadequate health service delivery, can indicate contextual challenges and opportunities such as in health literacy, health behaviour, barriers to accessing, affording and sustaining health care, and the limitations of siloed rather than person-centred health interventions. Application of these insights can accelerate operationalization of health agendas by bridging gaps between global and local and between design and implementation.

WHO has outlined the economic argument for investing in the prevention and control of NCDs and in promotion, protection and care for mental health. The additional cost of implementing the "NCD best buys" in 76 low- and lower- to middle-income countries is less than US$ 1 per person per year and could save nearly 7 million lives. The return on investment of each NCD intervention could accumulate to over US$ 230 billion when the economic and social benefits of improved health are included *(81)*. Further, it is estimated that the annual global burden of common mental health conditions results in US$ 1 trillion of lost economic output globally per year *(82)*. An integrated package of cost–effective mental health care and prevention can be delivered in community settings in low- and middle-income countries for US$ 3–4 per capita *(83)*. By meaningfully engaging individuals with lived experience and integrating their lived experience into the design of interventions, health investments become more effective, equitable and sustainable and could lead to a greater return on investment.

3

Overview of participation and participatory approaches in health

3.1 Health and participation

Participation and participatory approaches have wide applications to health. This section presents an overview of various related theoretical models and concepts, their historical significance and their relations to power, discrimination and health inequity.

3.1.1 Utilitarian and empowerment models

The two main models of participation and participatory approaches for improving health are the utilitarian and the empowerment models *(84)*. The utilitarian model views participation as a tool for using lived experience as a "good" in current health systems and global governance. Lived experience is used to enhance the "value" and the "effectiveness" of policies, programmes and services, resulting in better health *(85)*. This may be viewed as a moral obligation (of, for example, duty bearers in Member States) or as a way to maximize utility (of populations broadly) *(85)*.

In the empowerment model, people gain control over the factors and decisions that shape their lives by increasing their assets and attributes to build their capacity to gain access, partners, networks and/or a voice, thus becoming more autonomous *(86, 87)*.

3.1.2 Induced and organic participation

In these theoretical models, participatory approaches can be either induced and/or organic. Induced participation is initiated by those in power, often a Member State or governing organization, whereas organic participation covers various civic activities linked to social movements, with bottom–up approaches that empower groups that are marginalized *(88)*.

A technical tool (such as this framework) that can be used by WHO and Member States is an example of induced participation. Induced participation can also support organic participation as it can strengthen the capacities of individuals and communities, leading to further empowerment, greater autonomy and mobilizing community action. Organic participation, such as social movements like Black Lives Matter and MeToo, can place pressure on those in power to initiate new or additional actions and commitments that result in induced participation.

3.1.3 Historical significance of participation

The concept of civic participation is as old as the idea of democracy. It is seen in different cultures, such as policy decisions in ancient Athens, public debate in Hinduism and Buddhism, local deliberative institutions in South Asia in the fifth century BC, and promotion of mutual consultation (*shura*) on communal affairs in the Quran *(89)*. In

the late 19th century, civic participation and democracy were central to societies in many countries around the world, including through decentralized systems of power and governance. During the period of colonialization, centralized power and governance in many countries allowed colonial administrators to extract wealth efficiently. Following the wave of decolonization that began in the 1940s, the focus of international development began to shift to community development. The concept of participation as "community development" was popularized by the UN during the 1950s and it was applied in programmes on global health, such as agriculture, industrialization, democracy and governance *(89)*.

The decolonization of global health has regained prominence over a half a century later in parallel with social movements for anti-racism and anti-discrimination, with the explicit aim of dismantling systems of dominance and power to improve population health and ensuring that lived experience is considered *(89)*. Participatory approaches can support redistribution of power from institutions, policy-makers, health providers and health workers to people with lived experience, aligned with work to decolonize global health *(90, 91)*.

3.2 Power, discrimination, and health inequity

Ensuring the participation and meaningful engagement of individuals with lived experience requires a review of historical power differentials, which may not be evident because of natural implicit or explicit biases and underlying structural drivers. If these factors are not addressed, they can result in the opposite of empowerment – powerlessness and cynicism (92). This especially applies for individuals with lived experience in groups that are marginalized who experience discrimination that results in health inequities.

Neoliberal influences on health should be considered a central structural driver of health inequality. Neoliberalism promotes economic restructuring, deregulation, free markets and privatization, limits public expenditure and promotes individual responsibility. Since the 1980s, this has led to increased inequalities in income and service failure due to austerity measures, leading to further inequality and poverty (93). Social determinants of health are driven by neoliberal policies that directly exacerbate NCDs, and mental health and neurological conditions.

3.2.1 Hierarchical power and separation

Asymmetrical power, oppression, discrimination and other forms of social categorization are omnipresent and associated with the concepts of hierarchical power and separation. "Hierarchical power" refers to a system in which society is stratified according to constructed categories, whereby those at the top are actively afforded privilege, capability and capital in all domains of life, while others are actively disadvantaged. These structures were created and maintained for the purpose of retaining power. Understanding how these structures still result in dominance is key to reducing health inequities *(4)*.

Hierarchical power is ingrained in the global health architecture and rooted in asymmetrical power and relations. Power differentials operate through colonialism and neocolonialism, imperialism, patriarchal norms and practices, and neoliberal influences on health, including its commodification and emphasis on the free market rather than the right to health *(94)*. An example of such hierarchical power is the fact that the headquarters of 85% of the global organizations that are active in global health are based in Europe and North America *(16)*. Furthermore, more than 70% of leadership positions in global health are held by men and fewer than 5% by women from low- and middle-income countries.

Inequalities in global income continue to increase, resulting in exclusion of millions of people from accessing affordable, life-saving medicines and treatment *(16)*. These power differentials decide who sets the agenda, who funds the agenda, and who is allowed to participate in that agenda.

Through "separation", humans view themselves as different from other animals and species and also different from other humans. Thus, some humans categorize people according to social constructs, resulting in "othering", including within health systems. In global public health, individuals with lived experience are separated from other stakeholders, such as health professionals, academics and policy-makers *(95)*.

The toxic combination of separation (resulting in categorization) and maintenance of power structures leads to and is due to discrimination. Separation and hierarchical power remain the common denominator, regardless of the type of discrimination and the level at which it is imposed *(95)*.

3.2.2 Racial discrimination and its impact on health equity

Racial discrimination is a relevant, tangible link between health equity and power in this context. Discrimination is, however, intersectional, and "othering" can be seen in various dimensions and due to various grounds. For groups that are marginalized, discrimination according to social categories such as gender identity and sexual orientation, religion, language, legal status, disability, age, migrant or refugee status, class or other status, can interact, intersect and exacerbate disadvantages and health inequity.

Discrimination, racism and xenophobia exist in every society and are expressed in individual behavioural, physiological and psychological responses, resulting in preventable health conditions and mortality in groups that are already marginalized *(4, 95)*. The health inequities that affect populations that face discrimination are rooted in racism shaped by the legacies of colonialism, slavery, imperialism and xenophobia. These inequities are reflected and result in persistent, multigenerational social and economic disadvantages *(96)*.

Discrimination and racism affect every institution and system of social governance, many of which uphold and exacerbate power imbalances *(94)*. Racial discrimination, racism or exclusion on the basis of characteristics or identity results in unequal power relations, which lead to establishment of unequal policies, programmes and services. Racism and racial discrimination therefore remain fundamental social determinants of health. It is essential to address these health inequities to ensure that "no one is left behind" and to achieve SDG 10, to "reduce inequality within and among countries" *(94)*.

The failure of health systems and global governance has contributed to and perpetuated such imbalances, resulting in long-standing challenges *(4)*. Health systems play a vital role in reducing health inequity but can also exacerbate or extend them. Health systems can thus influence and be influenced by racial discrimination *(96)*. Many populations that experience racialization have suffered discrimination within health systems and are affected by intergenerational racial trauma *(97)*. The same is true for social inequality associated with sexism, heterosexism, ableism, discrimination by religious belief, education, income and other social determinants, resulting in unequal health outcomes *(98, 99)*. Examples of aspects of health systems that influence or are influenced by racial discrimination are shown in Box 1 *(4)*.

Structural discrimination in health systems:

Health systems reflect the societies in which they operate. Without action to address the disadvantages faced by populations who experience discrimination or marginalization, health systems can perpetuate inequity. Health systems can also present barriers due to language, lack of awareness of specific cultural needs, and financial barriers.

Differential user preference due partly to different worldviews and partly to past experience of discrimination:

The different health practices, preferences, and beliefs of populations that experience discrimination can result in discrimination in access to health care services.

Differential treatment within health systems:

Potentially discriminatory and paternalistic attitudes of health-care providers and lack of cultural awareness can exacerbate health inequities. Racism and conscious and unconscious bias may also result in misdiagnosis, mistreatment, poorer concordance, and weaker relationships between individuals and health-care providers.

Health systems that address health inequities:

Equity-oriented health systems can reduce the health inequities experienced by populations who suffer from racial discrimination. Health systems can provide evidence and advocate for multisectoral, multistakeholder action to reduce racial discrimination as a social determinant of health.

The aim of this framework and its cross-cutting principles and enablers is to acknowledge and address these power dynamics, eliminate all forms of stigmatization and discrimination in participatory approaches, and ultimately promote health equity. This will be explored further, with additional products to add to the evidence on health inequities and individuals with lived experience.

3.3 Origins of participation in global public health

Given the strong historical links between participation, power, discrimination and health equity, the following describes how participation was established and its significance to global public health. The participation of individuals with lived experience provides powerful expertise and narratives to shape policies, programmes and services, inspire other individuals with

lived experience to join the movement as agents of change, and inform communities and individuals of their right to participate in creating and delivering their health care *(23)*. The right to participate is an essential part of the right to the highest attainable standard of health *(59)*. 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 to achieve health for all. These global public health aims, principles and goals are long-standing and well-established.

3.3.1 Rights-based approach to health

The concept of "participation" is deeply rooted in human rights, power, social justice and social action. The right to the highest attainable standard of health as codified in Article 12 of the International Covenant on Economic, Social and Cultural Rights, General Comment No. 14 *(100)* includes "the participation of the population in all

health-related decision-making at the community, national and international levels". The inclusion of participation in the highest instances of human rights has been effectively leveraged in other areas, including disability, law and treatment for HIV, and can be used as a powerful tool for ensuring legality and implementation in countries.

3.3.2 The Alma-Ata Declaration

The Declaration of Alma-Ata (101), signed in 1978, called for urgent action by all governments, all health and development workers and the global community to protect and promote the health of all people. It sets out principles for community participation in designing resilient, responsive health systems through primary health care. Since adoption of the Declaration by Member States, the participation of individuals with lived experience has evolved from "patient-centred care" to an approach for inclusive, stigmatization-free, person-centred care (102). This pivotal change in terminology was stimulated by people with HIV and AIDS, who refused to be stigmatized on the basis of their diagnosis as part of wider efforts for inclusive, equitable access to health care.

3.3.3 The HIV/AIDS movement

From the 1980s, individuals living with HIV and AIDS were subject to discrimination and stigmatization, socially disadvantaged, culturally and religiously ostracized, experienced inequality due to their health condition, and lacked access to essential health-care services. The causes of HIV/AIDS were reduced to behavioural or lifestyle choices, with responsibility placed on the individuals, resulting in further systemic discrimination, stigmatization and marginalization of men who have sex with men, transgender people, sex workers, drug users and other populations at risk (103). Widespread misinformation on how the virus was contracted and transmitted and

failure to establish, contextualize or adapt health interventions resulted in loss of trust between health professionals and people living with HIV and AIDS. The slow public health response of governments and the UN, fuelled by panic, fear and denial combined with lack of political support, resulted in millions of preventable deaths at all income levels (104). The initial public health response was to provide treatment according to the biomedical model, with no consideration of the behavioural and social determinants of the disease (56, 105).

The transformation that followed was largely initiated and directed by "AIDS activists" seeking to improve health outcomes by increasing access to treatment. This was achieved by advocating for the rights of individuals with lived experience, challenging and dismantling systems of power, eradicating stigmatization and discrimination, addressing social inequalities in areas such as education, employment and housing, and driving political change. While many drivers and levers were involved in this change, the inclusion and integration of "personal experience" was crucial for action. The concept originated in the Denver Principles in 1983 (106) and evolved into the principle of "Greater involvement of people living with HIV" at the AIDS summit in Paris, France, in 1994 (107). The principles was agreed by 42 countries, which called for "greater involvement of people living with HIV at all … levels … and to … stimulate the creation of supportive political, legal and social environments".

By 2001, 189 UN Member States had expressed support for the principles as part of the Declaration of Commitment on HIV/AIDS, and, in 2006, 192 Member States adopted the political declaration at the High-level Meeting on AIDS, which advocated for greater involvement of people living with HIV (108). Now, 40 years since the first cases of AIDS were recorded, millions of people

living with HIV enjoy long, healthy lives, and the numbers of new HIV infections and AIDS-related deaths are decreasing. While inequality persists, the aim of the global public health community to end AIDS as a public health threat by 2030 can be realized, with new diagnostics, tools for prevention and treatments. UNAIDS has stated that community experience (including of people living with HIV and AIDs) continues to be key to the HIV response and crucial to ending AIDS *(109)*.

In this framework, therefore, the concept of meaningful engagement and its application in global public health is considered to have originated from the HIV/AIDS movement. That experience also influenced other global health policies and practices, such as in maternal and child health, other communicable diseases such as tuberculosis and malaria, movements around primary health care and UHC, alongside work in engagement of young people *(110, 111)*.

3.4 Recent progress in participatory approaches in global public health

Use of meaningful engagement and related participatory approaches throughout global public health continues. While the spectrum of application is broad, there are many common, intersecting principles and goals. Meaningful engagement of individuals with lived experience of NCDs, and mental health and neurological conditions has been championed by many civil society organizations *(112)*, and sustained advocacy and community mobilization has influenced those in power in shaping health-related policies, programmes and services. Today, participatory approaches are recognized as a core component of the prevention and control of NCDs and in promotion, protection and care in mental health.

Recent examples include the scaling-up of the WHO QualityRights initiative *(113)* to support governments and policy-makers in transforming mental health systems so that they are based on recovery, rights and inclusion. In addition, a WHO handbook on social participation for UHC *(114)* provides guidance for governments on meaningful engagement with populations, communities and civil society in making national decisions about health. Meaningful engagement should be seen as a core strength on which to build evidence and experience and to further operationalize, standardize and institutionalize these practices and approaches for NCDs, mental health and global public health.

A similar transformative change is the participation of individuals with lived experience in movements for disability and mental health. The disability rights movement has made progress in reducing health inequity through the Convention on the Rights of Persons with Disabilities *(115)*, ratified in 2006, which requires States Parties to recognize that people with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. States Parties are also committed to provide people with disabilities with the same range, quality and standard of free or affordable health care and programmes as are provided to other people, including sexual and reproductive health services and population-based health programmes. Similarly, the WHO QualityRights initiative engages people with psychosocial disabilities and their representative organizations in the design and delivery of training *(40)*. Training is also provided for health workers, policy-makers, carers, community members and people with lived experience of disability in advocating for a human rights-based approach to mental health and to support people with disabilities in advocating for their rights *(116)*.

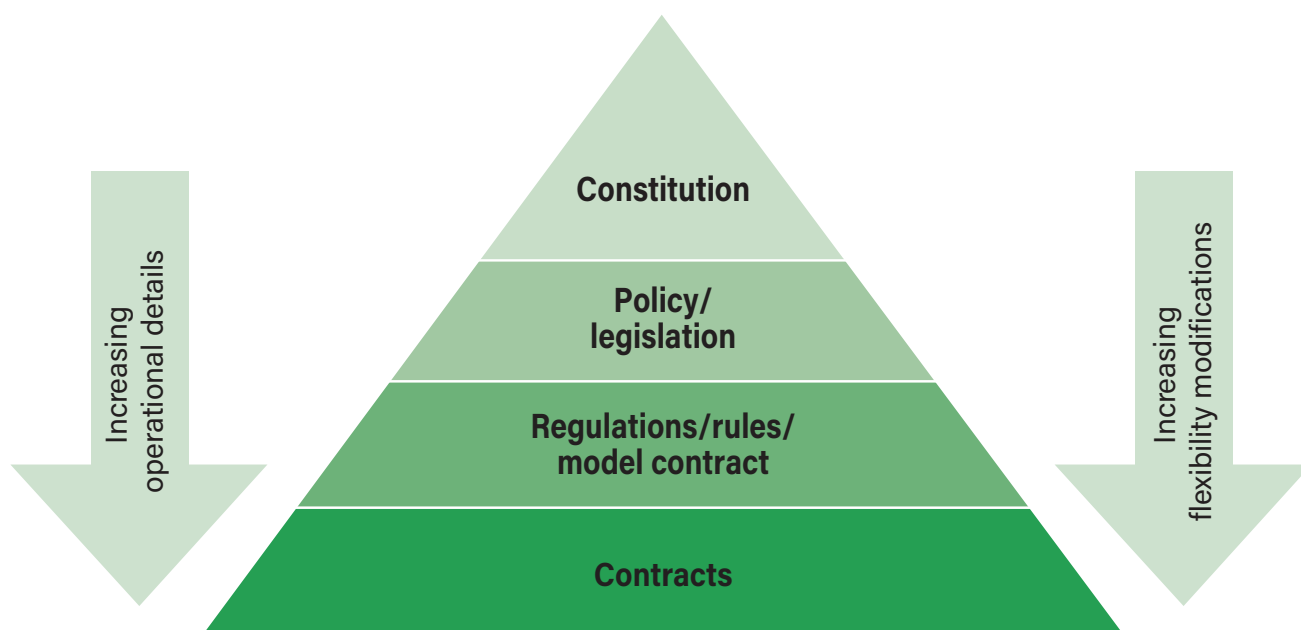### 3.4.1 Rights-based approaches through legal frameworks

The concept of the human right to health is inextricably linked to participation. Participation should therefore be viewed not only as an instrument to improve engagement and health but as a fundamental right. The Constitution of WHO states that enjoyment of the highest attainable standard of health is a fundamental right of every human being, without distinction by social constructs such as race, religion, political beliefs or economic or social condition (59). The human right to health is also integrated into international human rights treaties, regional instruments and more than 100 constitutions around the world.

Rhetoric and legal frameworks are not, however, always translated into reality, and the COVID-19 pandemic has further highlighted this disparity. Global health should undergo a transformational shift to bring about the necessary reforms and establishment of models that are "fit for purpose" to ensure that human rights and rights-based approaches are used to enhance health as a global good for all (117).

Member States and government officials, as duty bearers for realizing the right to health, are thus obliged to put in place policy-making tools, legal frameworks and participatory governance mechanisms to ensure the participation of the population in health matters. WHO's Research for Health Department is exploring how to include citizen engagement in evidence-informed policy-making (118). Legal frameworks (collections of legal instruments) can provide support for meaningful engagement in participatory spaces when used effectively (Fig. 5). Although implementation may be influenced by social and political factors, establishment of a legal framework provides a net benefit (115).

Figure 5. A legal framework for meaningful engagement

Increasing operational details

Constitution

Policy/ legislation

Regulations/rules/ model contract

Contracts

Increasing flexibility modifications

Source: adapted from WHO *(9)*.

3.5 Participatory approaches within the framework

While participatory approaches are long established in public health, application of the concept of meaningful engagement of individuals with lived experience in the broad area of NCDs and mental health is new. There is no universal defined concept of "meaningful engagement", and various definitions have been used of this and other participatory approaches. There is also no "gold standard" for the associated practices *(119, 120)*. This long-standing challenge is reflected in current peer-reviewed evidence for theories, frameworks and the value of participatory approaches as applied to global public health *(121, 122)*. Answers are required to critical questions in defining participation, selecting an approach for participation, identifying participants, applying insights, and measuring the impact of engagement (Box 2).

Creation of an environment conducive to participation that is representative, inclusive,

impactful and sustainable is resource intensive *(112)*. While gaps exist, the evidence will evolve and become stronger through practice and implementation, particularly in low- and middle-income countries. Because of the importance of contextualization, several working definitions and terms are provided in the glossary as they apply to this framework. Further, in view of the importance of language in describing these concepts and terms, Member States and WHO regional and country offices can adapt and contextualize them, with a standardized approach to their application.

While the framework is centred on the concept and principles of "meaningful engagement", many terms are used to define "participation", and there are many examples of participatory approaches for different groups in global public health (Box 3). While there are many types of participation, "continuum" models of a set of stages are the most popular. Examples include Arnstein's ladder *(124)*, Eyben's six-rung ladder *(125)* and Wilcox's five-rung ladder *(126)*. These types of participation have in common a transition from a setting with actions

---

Box 2. Selected critical questions in participatory approaches

Participatory approaches

- What does participation mean in practice?
- What approaches can be used for global to local participation?
- Who does and does not participate?
- Why do people wish to participate?
- How do people participate?
- How will their insights be used?
- How can the impact of participation be measured?

Rights-based approaches

- What does the right to participate entail?
- What is the content and scope of the right?
- Who are the bearers of the right to participate?

- What are the duties of States Parties in respect of the right to participate?
- What recourse is available for a breach of the right?

Power redistribution

- How are power imbalances acknowledged?
- How can the power imbalances that exist in every society be mitigated to ensure a participatory space?
- How can a more equitable power balance be created in this environment?
- How can participants express themselves without fear of reprisal or undue consequences?

> **Box 3. Examples of participatory approaches**
>
> In-person, open-for-all forums, e.g. citizen assemblies, citizen forums, public hearings, open-microphone events, town-hall meetings
>
> Consultative methods – attendance by invitation, e.g. consultative meetings, policy dialogues, stakeholder consultations, and focus groups
>
> Deliberative engagement – smaller, selective groups, e.g. citizen panels, citizen juries, planning cells, consensus
>
> conferences, deliberative polling, scenario workshops
>
> Formal mechanisms with fixed seats for populations, communities, and/or civil society institutions that may have a legal basis, e.g. health councils, health committees, district committees, citizen advisory boards, representation on steering groups and review boards
>
> *Source:* Adapted from WHO *(9)*.

that, in theory, result in low participation and tokenism to high participation, active involvement and maximum output. A limitation of the "continuums" is the binary framing of participation as a step-by-step process managed and influenced by the organizer (often those in power). This does not account for the contextual and relational aspects of power dynamics in participation. Given the importance of transferring power to people, "continuums" could potentially reinforce traditional power dynamics *(6)*. New models should be established or existing ones updated to promote a more fluid, balanced, pragmatic approach to participation simultaneously in all areas. This will be explored in the implementation phase of the framework (see section 6.3).

3.5.1 Defining a participatory approach for the framework

The framework outlines the vision and pathway to involving individuals with lived experience in co-creating relevant policies, programmes and services, i.e. what matters to them. In view of the importance of contextualizing this practice in the global

framework, the following working definition of meaningful engagement can be adapted to different settings and contexts. The aim is not to provide universal definitions of related keywords, definitions, concepts and approaches but to outline how they are referred to and applied in the framework and more broadly in the literature and practice.

Meaningful engagement is the respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people; valuing lived experience as a form of expertise and applying it to improve health outcomes. As defined in the glossary, this definition aligns and builds on other related terms and practices in participatory approaches.

The vision is systematic inclusion, integration and institutionalization of lived experience through meaningful engagement and other participatory approaches by WHO and Member States in the co-creation of policies, programmes and services for NCDs and mental health to improve the health and well-being of all.
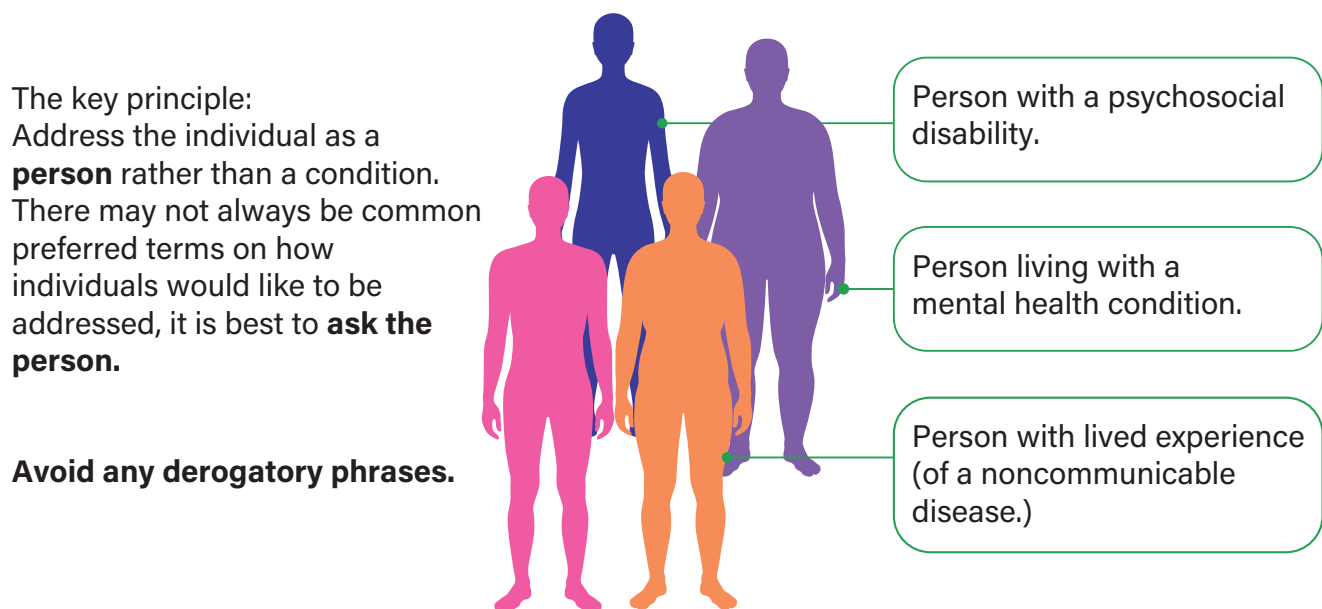
3.5.2 Ensuring inclusive, destigmatizing language

While the terms used to describe meaningful engagement and its practice are flexible, they should not detract from the importance of language in this context. Language can be stigmatizing and lead to further discrimination of individuals with lived experience *(127)*. Directly or indirectly, use of unacceptable terms, phrases and framing can result in further alienation, marginalization and rapid loss of trust by individuals with lived experience and their communities. A recent WHO survey on values-based messaging in diabetes showed that language should be used not only to provide information but to frame values and principles to improve public understanding, strengthen the argument for investing in health and enhance political support *(128)*.

While some discretion can be used in selecting terms according to an individual's preferences and context, the framework recommends mindful, proactive consultation with individuals and communities on their preferences for the language to be used in direct and/or indirect communication. Non-stigmatizing, "person-first" language should be used (Fig. 6), except when the preference is for "identity-first" language *(127)*. This should be respected by both WHO and Member States as they communicate and influence other stakeholders, such as family members, caregivers, health-care providers, educators, community or peer leaders, and the wider public. Use of empowering, dignifying language in referring to individuals with lived experience is important, as is increasing and improving public awareness of the concept of lived experience, meaningful engagement and related public health concepts. This principle should be applied to all forms of language used in communication – verbal, written, auditory and visual *(127)*.

Figure 6. Principle of "person-first" language

The key principle:
Address the individual as a **person** rather than a condition. There may not always be common preferred terms on how individuals would like to be addressed, it is best to **ask the person.**

Avoid any derogatory phrases.

Person with a psychosocial disability.

Person living with a mental health condition.

Person with lived experience (of a noncommunicable disease.)

Source: reproduced with permission from Thornicroft G et al., 2023 *(127)*.

Box 4. Commonly used language to be avoided

Patient	Many individuals with lived experience prefer not to be referred to as patients. This can dehumanize the individual and perpetuate the power imbalances between the person with lived experience and the related professional. *Related terms to avoid: cases, subject, victim*	**Alternatives:** personal names, Titles of individuals, Individual with lived experience, Person with lived experience.
Person with (X) disease	Explicitly referring and associating an individual with a disease or health condition can result in overmedicalizing and dehumanizing the individual. An individual with lived experience is much more than just a person with a disease or health condition. *Related terms to avoid: (X) disease patient/ case/subject, suffering from, survivor of*	**Alternatives:** being treated for, living with, affected by, no evidence/ presence of.
Blaming language	Attributing blame to any individual for their health condition or lived experience can be deeply traumatic and stigmatizing. The direct and indirect determinants of health are complex and should not be reduced to the sole responsibility of the individual or individual risk factors or determinants. *Related terms to avoid: adherence, attributable, burden, commitment, compliance, disadvantaged, lifestyle choices, lifestyle diseases, vulnerable*	**Alternatives:** concordance, suggesting active role for individuals with lived experience and the need for agreement between individuals and healthcare providers/professionals.

These concepts and terms may vary with the context, the language or dialect spoken, geographical location and cultural and religious factors. Box 4 gives examples of commonly used language that should be avoided where possible or only after extensive consultation, with proposed alternatives.

In addition to what is said, it is also important to recognize who is saying it and how it is said. A person delivering a message is likely to have their own experiences and perspectives, which could be influenced by their power and privilege (see section 4.2). Unacceptable language delivered by an unaware or insensitive messenger can further alienate and stigmatize groups who are experiencing marginalization. The messenger should be aware of this complex mixture of individual, social, religious and cultural elements, which are sometimes intersecting, in communicating to diverse groups. The impact of stigmatization on individuals with lived experience who have several stigmatized characteristics, such as ethnicity or sexuality, may be especially severe *(78)*.

" My vision for the future is we need to make mental health information available to the people in the patient's life, this could be caregivers, family or friends. To encourage informed decision making it is crucial to create an environment where you can easily access information. This information needs to be accurate and in simple language. To have a relationship where you can be heard. If you have that relationship, when there are issues you are able to smooth them out, and that builds trust in the doctor and the system."

Patrick Boruett, Kenya
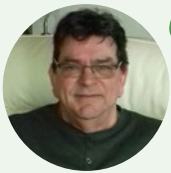
" My vision for the future is in an ideal world there would be an international platform of patient voices. A network that ensures those with lived experience are involved at every stage; in research, in prevention and in education. There is greater investment in communities and in empowering the voice of those with lived experience. A global effort, with global patients and a global patient platform to address the key issues that aren't going away and to share experiences, knowledge and understanding."

Phil Collis, United Kingdom of Great Britain and Northern Ireland

Access full publication

Box 5 reproduces of the visions of the future from two individuals with lived experience. See Fig. 10 for more information on the People Power case studies.

WHO created a short documentary that illustrates the experiences of people living with NCDs and mental health conditions in various countries. *Nothing for us, without us: listening and learning from people with lived experience* shows the experiences of six individuals with diverse health conditions: rheumatic heart disease, type 1 and type 2 diabetes, cancer, bipolar affective disorder and auto-immune disease in Australia, Brazil, Lebanon, Nepal, Nigeria and the United Kingdom of Great Britain and Northern Ireland (Fig. 7). These individuals provide their expertise and evidence of why including the voices of people with lived experience are critical in the co-design of relevant policies, programmes and health services. In addition to the full-length film, the experiences of the individuals can be followed in a short film series.

Figure 7. Overview of the WHO films of people with lived experience

66 Helena received a diagnosis of an autoinflammatory disease in 1997. In 2007, she had to give up her work because of multiple, worsening disabilities. In 2009, she received a diagnosis of cancer.

▷ **Watch her film**

66 Ali received a diagnosed of type 2 diabetes in 2017. He helps motivate others in his community to adopt healthier lifestyles through diet and physical activity.

▷ **Watch his film**

66 Anu found out that she had rheumatic heart disease at the age of 11. She has undergone open-heart surgery twice, including an operation to insert a mechanical heart valve.

▷ **Watch her film**

United Kingdom

Lebanon

Nepal

Nigeria

Brazil

Australia

66 Mark received a diagnosis of type 1 diabetes as a child. He is now a global advocate for improving diabetes care and prevention and is the Founder and Director of the ADJ Diabetes Brasil Young Leaders Program.

▷ **Watch his film**

66 In 2013, Hauwa was sexually assaulted. Two years later, she received a diagnosis of bipolar disorder, and, a few months later, she attempted to take her own life. Hauwa then created a platform on which she could share her experiences as a Nigerian living with a mental health condition.

▷ **Watch her film**
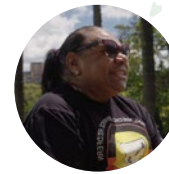
66 LaVerne received a diagnosis of breast cancer in 2018. She is a breast cancer survivor, a mother and a leader in her community.

▷ **Watch her film**

Principles of meaningful engagement

This section outlines the basic principles, the theoretical concept and practical application of meaningful engagement in this framework (Fig. 8). "Meaningful engagement" can mean different things for different individuals with lived experience, for communities and for stakeholders who wish to operationalize it. The five principles of dignity and respect, power and equity, inclusivity and intersectionality, commitment and transparency, and institutionalization and contextualization should be considered the basis and foundation of engagement with individuals with lived experience. They should not be considered in isolation, as all should be applied in each engagement. Section 5, *Enablers for operationalizing meaningful engagement*, outlines how the principles can be applied to enablers and examples of operationalization.

Figure 8. Overview of framework principles, enablers and actions
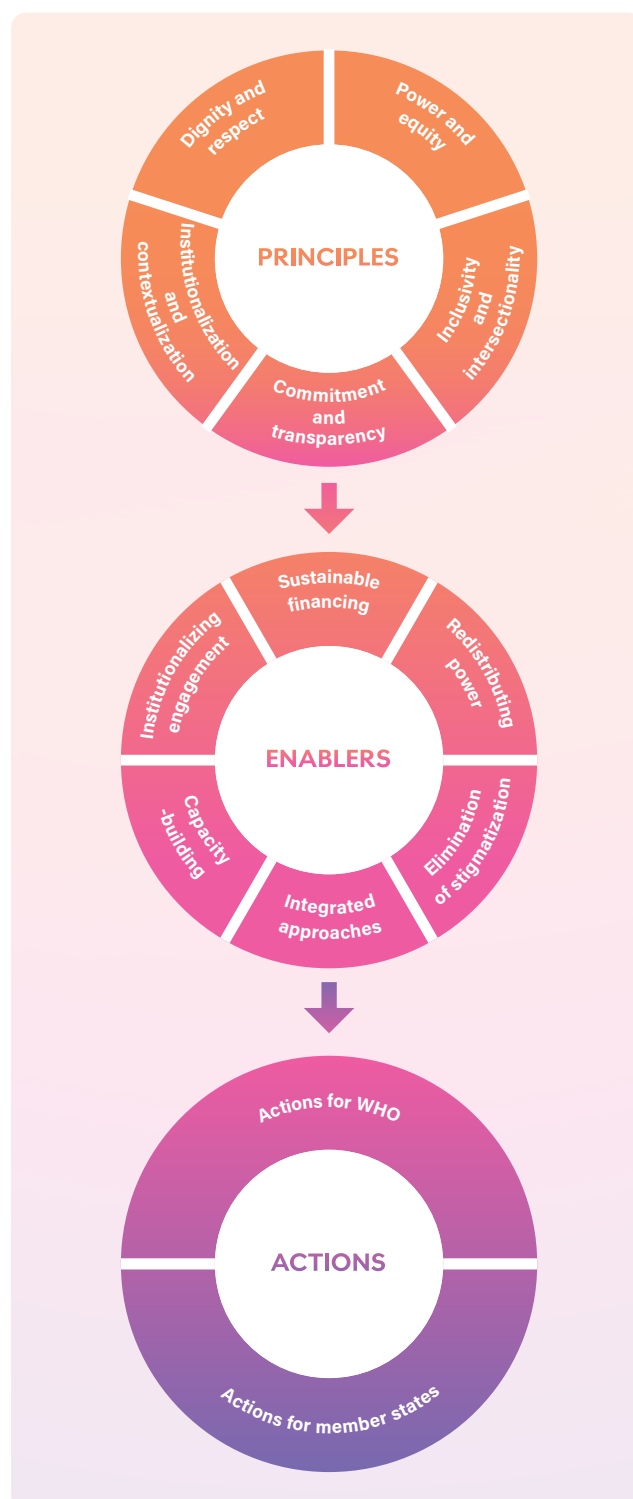
4.1 Dignity and respect

Individuals with lived experience must be treated with dignity and respect. Participation is a human right. Their lived experience should be considered a form of expertise, alongside and on a par with traditional forms of evidence and data in global public health policy and practice.

In all engagements, individuals with lived experience should be treated in a dignified, respectful manner, as people with several attributes and experiences, rather than just as "patients" or people who are solely responsible for their health condition(s). Failure to address such individuals in this way often causes stigmatization and discrimination. Dignified, respectful forms of engagement show recognition that the individual can offer experience and expertise, understand their health condition and treatment, and make decisions about their care. When individuals with lived experience are unable to speak for themselves, dignity and respect must be extended to their caregivers.

Several practical approaches can promote dignity and respect (see also section 5). They include acknowledging individuals with lived experience as equals with other stakeholders, such as policy-makers, academics and other individuals in power. Lived experience should be seen as a valuable form of expertise and insight, alongside traditional forms of evidence, in global public health policy and practice. Those in power should respect the individual nature of lived experience and the associated autonomy. Previous engagements in which individuals with lived experience were not treated in accordance with these principles should be acknowledged with steps taken to ensure that future engagements rectify the situation. Individuals with lived experience should be seen as a crucial part of multistakeholder responses and integrated into multistakeholder environments and activities in various influential and supportive roles.

Engagement with individuals with lived experience should be a mutual partnership, in which engagement is bi-directional, beneficial to both parties, with redistributed power and equal decision-making. While individuals with lived experience may wish to share their experiences and expertise with those in power, they may also wish to receive feedback from WHO and Member States on the path forward. In addition, when consensus cannot be reached, as in other bilateral discussions between stakeholders, openness to engage in constructive dialogue will further foster respect and dignity.

Box 6 represents the view from an individual with lived experience on dignity and respect. See Fig. 10 for more information on the People Power case studies.

Box 6. Lived Experience Quote

> We have to respect and listen to people living with NCDs, involving them in decision-making processes, because others do not understand what it is like to live with NCDs.... It will be regarded as important to take into account their thoughts and experiences.
>
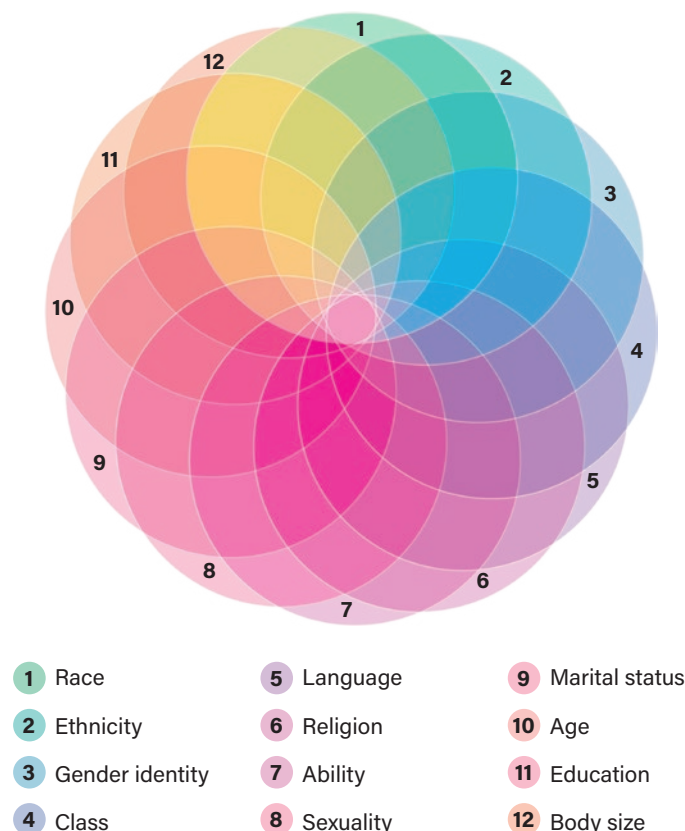> **Anu Gomanju, Nepal**

[📖] **Access full publication**

4.2 Power and equity

Health systems and global governance are built on systems of oppression. They perpetuate discrimination and exacerbate health inequity. Participatory approaches require acknowledgement of and action to remove systemic and structural challenges, neutralization of power imbalances, and elimination of all forms of stigmatization and discrimination.

In order to improve health outcomes through meaningful engagement of individuals with lived experience, WHO and Member States will have to address power imbalances and promote health equity. This will require acknowledgement of power imbalances and establishment of enabling environments with equitable power dynamics through communication (see section 3.5.2), recognition (understanding the added value of amplifying people's voices), and technical skills (to create safe spaces so that everyone

to can contribute meaningfully) in practical steps described in section 5. It will also require that the systemic and structural barriers to unequal power distribution among stakeholders be addressed, with a reinvigorated political commitment to achieve much-needed progress in tackling health inequity. Systemic and structural discrimination persist in every institution with a governance function, including WHO and Member States. If this is not addressed or, worse, ignored, power imbalances and health inequity will be perpetuated. The imbalances are rooted in long-standing economic, environmental, racial and gender inequality and reinforce the structural, institutional, cultural, political and behavioural dimensions of power and oppression *(16, 129–131)*. Viewed through an intersectional lens, power and discrimination affect individuals in many ways, often overlapping with social categorization that influences and compounds oppression and disadvantage *(132)* (Fig. 9).

Figure 9. Intersectionality wheel

1 Race	**5** Language	**9** Marital status
2 Ethnicity	**6** Religion	**10** Age
3 Gender identity	**7** Ability	**11** Education
4 Class	**8** Sexuality	**12** Body size

Source: reproduced with permission from Duckworth, 2020 *(133)*.

While meaningful engagement of individuals with lived experience can overcome some of those barriers, many will persist, given the deep structural and societal transformation required. Achieving action through participatory approaches will require acknowledging and addressing systemic and structural challenges, neutralizing power imbalances, eliminating all forms of stigmatization and discrimination and alignment with work to decolonize global health *(134)*. This will include promoting and practising critical "allyship" and an anti-racism, anti-oppression, anti-colonialism, anti-discrimination stance, with a rights-based, pro-equity approach to engagement *(135, 136)*.

The intention and performance of engagement must lead promptly to progressive, transformative action to address these complex, persisting challenges. WHO and Member States will have to commit themselves to listen and learn from individuals with lived experience in the long term and to apply insights from lived experience as expertise into processes, procedures, contexts and structures. This will include reforming and even dismantling existing structures and models, acknowledging their origin in oppression and their role in perpetuating health inequity and establishing new models aligned with the principles of power and equity. It will also require that WHO and Member States engage civil society meaningfully to further connect with community networks and strengthen the representation and empowerment of groups that are marginalized.

While this principle can be applied in various ways, stakeholders must first acknowledge and address power and health inequities through meaningful engagement and other participatory approaches. Failure to apply these approaches or use of lived experience as expertise would constitute tokenistic engagement, which would result in loss of the trust of individuals with lived experience, reinforcing power imbalances and exacerbating health inequity.

4.3 Inclusivity and intersectionality

Lived experience is heterogeneous, complex and varied, often intersecting with other health conditions and diverse social factors. Meaningful engagement should account for intersecting identities, strive to be inclusive and accessible, and take into consideration the broad social context of being an individual with lived experience.

Lived experiences of NCDs, and mental health and neurological conditions often includes environmental, behavioural, commercial and other social determinants of health. Individuals with lived experience thus have diverse expertise, experience and views of a number of health conditions, which can be captured by meaningful engagement. All engagements should thus be as inclusive as possible, through active, transparent recruitment of individuals with diverse backgrounds, especially from groups that are underrepresented or marginalized. The individuals should include those living in poverty, in rural or under-resourced communities, Indigenous and First Nation populations, ethnic and minority groups, people living with disabilities, and people of different ages, such as adolescents, children and older adults. Such inclusivity will avoid overrepresentation of individuals with advantaged or privileged backgrounds or participation of the same individuals in several engagements. This should include more communities that are marginalized, enhancing discourse, and improving the relevance and effectiveness of co-created solutions to meet the needs of the wider population and addressing health inequities.
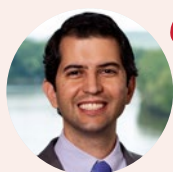
Meaningful engagement of individuals with lived experience should comprise a community-centred approach. Members of local communities provide essential, sustained, daily support to individuals with lived experience; they include families, formal and informal caregivers, support groups and organizations, religious leaders, and community health workers.

The principle of intersectionality, defined in the glossary as the interconnected nature of identity, relationships and social categorizations, encourages a shift from the over-medicalized clinical approaches of biomedical models to a broader bio-psycho-social model for global public health. Individuals with diverse lived experiences often have priorities and insights that transcend health conditions, geographical borders and socioeconomic factors. Consideration of intersectionality is essential, while also acknowledging individual contexts and the lived experience of specific health challenges. Such consideration will avoid perpetuation of the siloed approach in global public health. Member States, as duty bearers, must uphold their populations' right to influence policies, programmes and services. Participatory governance can support meaningful engagement and other participatory approaches, ensuring that policies, programmes and services are more responsive to their populations' needs.

To avoid tokenistic engagements and to ensure inclusiveness and intersectionality, engagements with individuals with lived experience must be systematic and intentional through mapping and tracking all activities, building trust in communities and leveraging their networks to ensure diversity and representation (see section 5.6). When there is limited capacity to recruit or include individuals with lived experience, priority should be given to those who were least represented in previous engagements. Inclusion only of individuals considered to be relevant by people in positions of power and influence should be avoided. Environmental barriers may impede or prevent meaningful engagement with some individuals with lived experience; therefore, the accessibility of consultations and participation must be considered and actions taken to reduce barriers to all engagements.

In view of the multidimensional determinants and challenges associated with NCDs, and mental health and neurological conditions, it is essential to understand that individuals with lived experience often do not define themselves by a health condition or biomedical classification. They are often also sisters, brothers, mothers, fathers, peers, friends, employees, volunteers, community leaders and valued members of society. Consideration should therefore be given to the broader social context of individuals who are experiencing or managing several complex health conditions,

balancing living a fulfilling life with an extended model of health and well-being *(137)*. Use of person-centred, inclusive language that respects the dignity and preferences of those being referred or spoken to is important in creating safe spaces for participation.

4.4 Commitment and transparency

WHO and Member States should commit themselves to meaningful engagement of individuals with lived experience as a matter of urgency and priority. All forms of engagement should include a consistent process and full transparency at every stage.

WHO and its Member States are required to fully commit themselves to meaningful engagement of individuals with lived experience, urgently and as a priority. Senior management in WHO should therefore lead in operationalizing meaningful engagement of individuals with lived experience. This is essential both for the strategic leadership, mobilizing support for implementation and providing guidance and diplomacy for the required reforms within WHO. The same commitment is required from all duty bearers and particularly ministers and mid-level civil servants.

Individuals with lived experience should be engaged in all processes and procedures and not only for specific or individual engagements or outcomes. "Tick-box" and one-off engagements organized at the last minute are often perceived as tokenistic, disrespectful or undermining. Engagement should thus be seen as a continuum of activities and outputs, and consistency and transparency should become standard practice in engagement. Relevant

stakeholders should ensure standardization and continuity of the modalities, processes and principles of meaningful engagement, so that each engagement builds on others iteratively and progressively. Failure to commit to such practices and approaches can result in engagement being tokenistic, which, in turn, leads to loss of trust and regression in engagement with individuals with lived experience, regardless of the short- or medium-term gains.

Building trust through a committed, consistent process also requires transparent collaborative approaches and clear communication when engaging individuals with lived experience. Transparency about who will and will not be engaged, how and when they will be engaged, and how they will participate in co-creation are essential. Individuals with lived experience should be given the opportunity to state their expectations, be told how their input will be used, for whom, and the time and resources that will be required. Their input should include influencing and shaping outputs from the start to the finish, establishing and receiving updated reports on monitoring and evaluation, and holding stakeholders accountable for ensuring consistency in the delivery of outcomes. Transparency should be ensured not only when those in power consider it "comfortable" but also with regard to "uncomfortable" challenges and barriers. All potential risks and conflicts of interest in engagement must be mitigated through due diligence, and diverse stakeholders must be represented in meetings and as leaders.

Transparency in meaningful engagement requires clear communication. While the form of communication will depend on the type of engagement, communication should be ensured as early as possible, in plain or lay language and throughout the engagement. It should be consistent, inclusive and accessible

to people with varied communication skills and preferences, including those with lower levels of education and functioning. Communication should include the requirements and expectations of the engagement, which should be decided with the individuals with lived experience, their role and the expected outcomes and outputs, including what will or might not be achieved. Any barriers and challenges to meaningful engagement that are foreseen should be discussed pragmatically and diplomatically with individuals with lived experience and, when possible, solved.

4.5 Institutionalization and contextualization

Meaningful engagement must be formally integrated and embedded into institutional and organizational practice and culture. Additional work is required to contextualize and adapt such work at regional and local levels to support implementation.

Meaningful engagement and integration of lived experience should be institutionalized in all Member States and at WHO headquarters and regional and country offices. This will ensure that meaningful engagement is an integral part of the culture and operations in the shift to inclusive, respectful, equitable health systems and governance. Institutionalization includes engagement in global processes such as meetings, UN high-level meetings and political processes, from national discussions on policy and governance to local programme design and implementation. To date, global and national engagement has been limited, resulting in gaps in global-to-local exchange.

To maximize the opportunities presented by meaningful engagement, WHO and its Member States should proactively support engagement at global, national and local levels to complement exchanges of perspectives among those levels. For example, individuals with lived experience of local contexts should be invited to national and global discussions, and clear translation of global and national discussions and agendas should be presented to communities.

Bridging the gap from global to local meaningful engagement should account for local contexts, languages, cultures and practices in order to be effective and sustainable. Culturally appropriate methods of engagement that account for the languages, cultural nuances and norms, socio-economic backgrounds and religious beliefs of individuals with lived experience are more likely to result in uptake by the target population and result in better health outcomes. This can be achieved only by engaging local stakeholders and further contextualizing and/or adapting frameworks and materials to support operationalization of meaningful engagement. Given the urgency of prioritizing marginalized communities in this work, better engagement of communities will not only provide more diverse perspectives but will also result in establishment of networks, diversifying national and global representation.

As outlined in section 5.6, legal frameworks and instruments for participation can be used to institutionalize participatory processes globally, regionally and nationally and ensure a sustainable impact. This will sustain engagement over time and protect legal frameworks and instruments from potential national or geopolitical influences.

Box 8. Lived Experience Quote
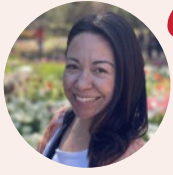
> Community engagement is wonderful because we see this ripple effect. We educate someone and that person will replicate this effort and help new people. We are constantly translating information and requesting personal stories so that they can empower someone else. The community keeps growing. We are now trying to build an international community of people helping each other. Community engagement is not only a couple of voices, it includes everyone.

Mariana Gómez, Mexico

Access full publication
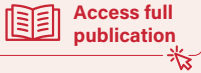
Box 8 represents the view from an individual with lived experience on sustained and inclusive community engagement. See Fig. 10 for more information on the People Power case studies.

People power: The perspectives of individuals with lived experiences of NCDs and mental health conditions are illustrated in six case studies by 12 individuals with lived experience of various health conditions (Fig. 10) *(138)*. They explore the topics of power dynamics and reorientation of power to individuals with lived experience; informed decision-making and health literacy; community engagement in broader health networks and health systems; lived experience as evidence and expertise; exclusion and the importance of involving communities experiencing marginalization; and advocacy and human rights.

These powerful narratives provide evidence of the critical role of the voices of those with lived experience in co- creation of relevant policies, programmes and services.
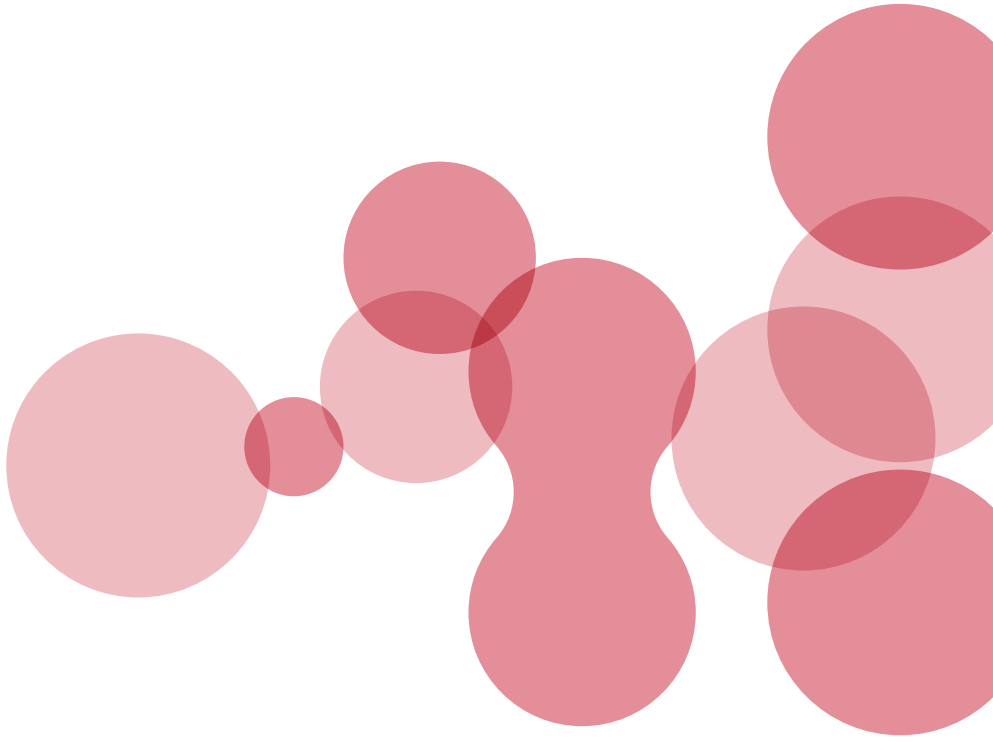
Figure 10. Overview of "People power" case studies

> 66 I always thought that science can change the world and that's why I chose biology to study. But after I learned that such an awful system of psychiatry still exists in the 21st century and despite the knowledge collected by science, they still fail to apply even primitive knowledge. So I switched my life path to civil rights activism."
>
> **– Olga Kalina**

> 66 I feel living experience for me is my life and it is my being. It is not just about a day or two, every moment of my life is decided by my lived experience. It is the foremost thing that decides what my day is going to look like. It plays a role in how the rest of my life will turn out and what sort of decisions I make, personal and professional"
>
> **– Prachi Kathuria**

Georgia

Kuwait

India

South Africa

Australia

> 66 I would like to see more of an interactive system, maybe even to add an expanded health literacy and advocacy component to all hospital systems. A Department of Patient Advocacy and Health Literacy that can act as a collaborative component between patient advocacy and informed decision making with health literacy and health education. To shift gears from the hospital setting, to a community support setting."
>
> **– Allison Ibrahim**

> 66 We need socially and culturally appropriate services and care of the right quality. Scientifically and medically approved, influenced and shaped by people living with noncommunicable diseases. The right to participate, the right to access and the right to care which is equal."
>
> **– Kwanele Asante**

> 66 We need a whole government, whole society response, including sustainable economic models and systems that move away from hierarchy to inclusivity and partnership. We need empathy, love, compassion, culturally led, community driven, social justice-based communities that talk about power and how to share power."
>
> **– Matthew Jackman**

Access full publication

5

Enablers for operationalization of meaningful engagement

The framework includes six enablers for operationalizing meaningful engagement based on the principles of the conception and practice. The enablers are core areas, which, if fully implemented, can achieve and sustain meaningful engagement. All the principles are embedded in each enabler, and all the enablers must be present to operationalize meaningful engagement. The framework outlines the actions required by WHO and its Member States for each enabler, in a phased approach (bronze, silver and gold). While the context of application may require more enablers, the core enablers are outlined below, with examples of practical actions. The complete list of actions is given in Annex 2.

5.1 Sustainable financing

Meaningful engagement should be supported by sustainable financing for all engagements with individuals with lived experience remunerated at a rate equivalent to that for technical experts.

Lived experience is a form of expertise, and individuals with lived experience should be remunerated accordingly. The remuneration of technical experts and external consultants for participation in engagements should be applied on equal terms for individuals with lived experience. Funding should also be made available to improve access to both digital and in-person engagements and remove barriers to participation,

such as facilitating child or dependant care. The funds should be provided to individuals without constraining conditions and allow for independent inputs within multistakeholder settings.

Financing should also be allocated for recruitment, engagement, capacity-building (see section 5.5) and related activities. Funding should be provided directly by the organization or institution within an established resource mobilization plan or as part of existing donor agreements.

WHO and Member States should explore expansion or inclusion of individuals with lived experience in relevant staff roles, aligned with measures to ensure diversity, equity and inclusion in their working environments. Explicit inclusion of lived experience and professional attributes in descriptions of jobs associated within NCDs and mental health will further promote professionalization and institutionalization of lived experience perspectives in organizational practices and outputs.

In view of the lack of investment globally in NCDs and mental health, application of lived experience through meaningful engagement and other participatory approaches may be seen as a catalyst for finding additional resources. Sustained financing from a range of sources is essential to achieve the vision of the framework and the wider global goals for NCDs and mental health.

Actions related to sustainable financing.

Stage	WHO	Member States
Bronze	• Remunerate individuals with lived experience for individual engagements (< 50%) at a rate equivalent to that for technical experts. • Provide funding for individual engagements and activities at WHO headquarters and regional offices to operationalize meaningful engagement. • Develop a plan for resource mobilization for meaningful engagement and activities in WHO.	• Remunerate individuals with lived experience for individual engagements (< 50%) at a rate equivalent to that for technical experts. • Provide funding for individual engagements and activities to operationalize meaningful engagement. • Develop a plan for resource mobilization for meaningful engagement and activities within teams working on NCDs and mental health.
Silver	• Remunerate individuals with lived experience for most engagements (> 50%) at a rate equivalent to that for technical experts. • Provide funding for engagements and activities at WHO headquarters and regional offices to operationalize meaningful engagement. • Implement and scale up resource mobilization for meaningful engagement and activities within WHO.	• Remunerate individuals with lived experience for most engagements (> 50%) at a rate equivalent to that for technical experts. • Provide funding for engagements and activities of the government to operationalize meaningful engagement. • Implement and scale up resource mobilization for meaningful engagement and activities in the ministry of health and subnationally.
Gold	• Remunerate individuals with lived experience for all engagements (100%) at a rate equivalent to that for technical experts. • Provide funding for sustained engagement and activities at all levels of WHO to operationalize meaningful engagement. • Fully fund meaningful engagement and relevant activities in the WHO Programme Budget.	• Remunerate individuals with lived experience for all engagements (100%) at a rate equivalent to that for technical experts. • Provide funding for sustained institutionalized engagement and activities at all levels of government to operationalize meaningful engagement. • Fully fund meaningful engagement and relevant activities in the national fiscal budget.

5.2 Redistributing power

To address unequal power structures and systems, power must be redistributed and shared with people with lived experience. This can be achieved by creating more opportunities for participation, establishing safe spaces, and ensuring respect, inclusiveness and diversity in all roles, while establishing new models and systems.

Equitable power dynamics ensure that spaces for meaningful engagement are safe and conducive to the participation of individuals with lived experience. Such spaces must ensure use of the correct language, a culture of acceptance, active listening and engagement, and no tokenism, stigmatization or discrimination of any kind. Lived experience should be considered and used as a form of expertise equivalent to more traditional sources of information and evidence.

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

To address systemic and structural power dynamics, which are barriers to engagement, WHO and Member States should create more equitable, inclusive, empowering opportunities for the participation of individuals with lived experience. Empowering individuals with lived experience to make decisions about their own health and well-being will respect the inherent right of individuals to do so and thereby reorient the balance of power in health systems and governance. This will require acknowledgement and a commitment to address long-standing economic, environmental, racial and gender inequalities that are reinforced by the structural, institutional, cultural, political and behavioural dimensions of power and oppression. By using participatory approaches, WHO and Member States can also address power asymmetries by promoting and practising critical "allyship" and taking stances on racism, oppression, colonialism and discrimination, with a rights-based, equitable approach to engagement.

Representation of individuals with lived experience is essential, especially of those who are marginalized, oppressed and disadvantaged. This does not necessarily mean only ensuring individuals with lived experience have "a seat at the table" but bringing the "table" to those who are most marginalized, such as by organizing additional engagements in local settings, rather than only at organizational headquarters or urban centres. This will ensure that individuals with lived experience can fully participate and take advantage of inclusive opportunities to shape agendas, priorities, strategies and decisions. While power redistribution may be difficult at first for those in power, it is fundamental to ensure that individuals with lived experience are empowered to participate fully.

The principles of inclusiveness and intersectionality will ensure representation of diverse individuals and an equitable balance of power for individuals with lived experience. Too few individuals with lived experience or too many from one demographic or with the same health condition could also create a power imbalance. When there are too few seats, more seats should be provided for individuals with lived experience with wider diversity according to gender, sexuality, disability, religious beliefs, ethnicity and other social factors to ensure a balanced power environment.

The roles of individuals with lived experience, which depend on their personal preferences and their link to their lived experience, individual attributes and interests. It is essential to ensure inclusivity, equity and balance of power in the distribution and allocation of roles. For example, individuals with lived experience can be given a minor role, such as an observer or a participant in an online survey that requires knowledge of the subject matter, or they may be given a more prominent, powerful role, such as chairperson or board member with influence on decisions. Various participatory approaches should be used to accommodate the diversity of individuals engaged and their preferred roles. Their selection should be transparent to ensure that the design and format of participation are representative, legitimate and reflect diverse constituencies, themes, experiences and backgrounds, with particular consideration of groups that are marginalized. All these factors influence the complex power dynamics in the context of meaningful engagement and will shape the environment, the interactions between stakeholders and the outputs.

Actions related to redistributing power.

Stage	WHO	Member States
Bronze	▪ Acknowledge and commit to addressing power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. ▪ Review and reform diversity, equity and inclusion practices in relevant activities and processes. ▪ Establish and implement a standard operating procedure for inclusion of diverse individuals with lived experience in all relevant departmental activities and processes.	▪ Acknowledge and commit to addressing power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. ▪ Review and reform diversity, equity and inclusion practices in relevant activities and processes. ▪ Establish and implement a standard operating procedure for inclusion of diverse individuals with lived experience in all relevant departmental activities and processes.
Silver	▪ Actively address power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-coloniality, anti-discrimination, rights-based and pro-equity approach to engagement. ▪ Review and reform diversity, equity and inclusion practices in relevant departmental activities and processes. ▪ Establish and use a standard operating procedure for inclusion of diverse individuals with lived experience in all relevant global, regional and national activities and processes.	▪ Actively address power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based and pro-equity approach to engagement. ▪ Review and reform diversity, equity and inclusion practices in all relevant ministry of health activities and processes. ▪ Establish and use a standard operating procedure for inclusion and diversity of individuals with lived experience in all relevant government activities and processes.
Gold	▪ Systematically address power asymmetries by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. ▪ Review and reform existing diversity, equity and inclusion practices in all relevant global, regional and national activities and programme areas. ▪ Modify or establish governance structures to include individuals with lived experience in all relevant global, regional and national activities and processes.	▪ Systematically address power asymmetries by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. ▪ Review and reform existing diversity, equity and inclusion practices in all relevant government activities and programme areas. ▪ Modify or establish governance structures to include individuals with lived experience in all relevant government activities and processes.

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

5.3 Elimination of stigmatization

Stigmatization and discrimination take many forms and are major barriers to meaningful engagement. In all engagements, all forms of stigmatization and discrimination should be acknowledged, addressed and eventually eliminated to promote health equity.

Meaningful engagement requires that all forms of stigmatization and discrimination be addressed with a view to eliminating them. The various forms of stigmatization include self-stigmatization (individuals view themselves as lesser), stigmatization by association (stigmatization of close associates of an individual with lived experience), public stigmatization (societal view of individuals with lived experience) and structural discrimination (systemic factors such as legal frameworks, policies and organizational practices) *(128)*.

Stigmatization – intentional or unintentional – can be severe and traumatic for individuals with lived experience and their caregivers and families. It can take many forms, including blaming the individual for their health condition, using unacceptable language and overmedicalizing and dehumanizing them. Many forms of public stigmatization originate from and are influenced by knowledge, attitudes and beliefs *(128)*. The framework considers stigmatization to be a social construct that can be influenced and dismantled. Through this framework, stigmatization can be reduced by creating enabling environments and safe spaces in all engagements.

While the framework considers a broad range of health conditions, stigmatization and discrimination are greatest globally for mental health conditions *(128)*. The dominance of biomedical models in mental health and overmedicalization of individuals living with such conditions can reinforce stigmatization and discrimination and lead to poorer health outcomes *(139)*. Institutional stigmatization

and discrimination should therefore be acknowledged and addressed, starting, for example, with use of appropriate language (see section 3.5.2), proactive elimination of stigmatizing actions in institutions, and using a holistic approach to health and well-being by challenging traditional biomedical models.

Within the framework, WHO and Member States should review and reform existing organization-wide practices and processes to prevent stigmatization and discrimination, such as by establishing independent mechanisms and governance structures to review and monitor anti-stigmatization and anti-discrimination. Long-term cultural change will require institutional promotion and inclusion of diverse lived experiences and using an intersectional lens in all health activities and engagements.

Clear, well-implemented legal frameworks are necessary to reduce stigmatization. Established legal frameworks to reduce broad stigmatization and discrimination and to promote equality should be reviewed and, if required, extended to individuals living with health conditions, including NCDs, and mental health and neurological conditions. Legal frameworks to protect the rights of individuals with lived experience could also address stigmatization by introducing rights-based approaches to health and supporting the participation of individuals with lived experience in education and employment *(140, 141)*. Legal frameworks can also guide families, health-care professionals and other stakeholders in prevention strategies and appropriate communication and guide regulatory bodies in holding health-care professionals accountable. Application of legal frameworks in other health contexts, such as HIV/AIDS and disability, can provide useful lessons and inspiration.

Box 9 represents the view from an individual with lived experience on the importance of eliminating stigma and discrimination. See Fig. 10 for more information on the People Power case studies.

Actions related to elimination of stigmatization.

| Stage	WHO	Member States
Bronze	• Review and reform existing and recent practices and processes for preventing stigmatization and discrimination. • Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating. • Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant departmental activities and programmes.	• Review and reform existing and recent practices and processes for preventing stigmatization and discrimination. • Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating. • Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant ministry of health activities and programmes.
Silver	• Review and reform existing and recent departmental practices and processes to prevent stigmatization and discrimination. • Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating, showing how WHO will proactively eliminate them in the future. • Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant global, regional and national activities and programme areas.	• Review and reform existing and recent ministry of health practices and processes to prevent stigmatization and discrimination. • Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating, showing how government will proactively eliminate them in the future. • Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant government activities and programme areas.
Gold	• Review and reform existing and recent Organization-wide practices and processes to prevent stigmatization and discrimination. • Establish independent mechanisms and governance structures to review and monitor work to prevent stigmatization and discrimination. • Change the Organization culture by promoting and including diverse lived experiences through an intersectional lens in all relevant health activities and engagements.	• Review and reform existing and recent government-wide practices, processes and national legal instruments to prevent stigmatization and discrimination. • Establish independent mechanisms and governance structures to review and monitor work to prevent stigmatization and discrimination. • Change the government culture by institutional promotion and inclusion of diverse lived experiences through an intersectional lens in all relevant health activities and engagements.

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

" We had to make a lot of adjustments to the house, and our house was not a suitable house for someone who is disabled. But we loved where we lived. One of the social workers just sort of said, 'Why don't you just move house, that would be easier.'

That was a very upsetting remark, I found that very difficult to cope with. It was like, well, it doesn't matter anymore because you're disabled, so, you know, you live where it's best for someone who's disabled, not where it's best for you as a person.
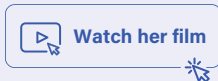
Helena Davies, United Kingdom of Great Britain and Northern Ireland

▷ **Watch her film**

5.4 Integrated approaches

An integrated approach can bring together lessons from several lived experiences and related health areas to address determinants of health inequity. This approach can strengthen areas such as primary health care and achieve UHC.

Individuals with lived experience and lived experience as a form of expertise should be integrated into all relevant processes, procedures and programme areas, with proactive support for diversity, equity, inclusion and intersectionality. Functions, services and organizational structures in all health systems and global governance should be included. Integration will bring about real change, with a move from siloed, disease-specific approaches and will address broader health challenges and determinants. This will also require a health systems approach, including whole-of-government and whole-of-society collaborations.

In view of the intersectionality of lived experience, meaningful engagement of people living with NCDs, and mental health and neurological conditions should also be aligned and integrated with the lived experience of people with other health conditions. Integration should be systematic, and relevant rules, processes and protocols should be

adapted and modified to support inclusion and integration. There are strong arguments for the value of this approach. For example, many lessons can be learnt from communities with lived experience, such as those with HIV and AIDS, tuberculosis, maternal and child health, healthy ageing, and disability, that can be applied to lived experience of NCDs, and mental health and neurological conditions. In addition, many individuals living with HIV and AIDs are living longer due to better access to better antiretroviral therapies but are also experiencing co-morbid conditions such as NCDs, and mental health and neurological conditions *(142)*. Health systems that have achieved huge gains in infectious disease control and treatment, maternal, newborn and child health care, and sexual and reproductive health can be adapted to support action on NCDs and mental health.

WHO guidance on integrating the prevention and control of NCDs into national responses to HIV/AIDS, tuberculosis and reproductive health to strengthen health systems states that integration of services must begin with people, who are the recipients of integrated health services. To ensure people-centredness, individuals with lived experience should be included in planning, implementing, monitoring and shaping services and ensuring accountability for the outcomes. Integration strategies can ensure individual and community participation through education on

health, self-care and social control and through satisfaction surveys *(143)*. This approach can also support integration of meaningful engagement and other participatory approaches into national commitments and health action plans and improve community engagement in primary health care and UHC globally, regionally and nationally.

An integrated approach should be the priority for maximizing resources in view of current and projected funding restrictions for global health and development aid for NCDs and mental health *(144)*.

Actions related to integrated approaches.

Stage	WHO	Member States
Bronze	• Individuals with lived experience integrated into most (> 50%) relevant processes, decision-making bodies, procedures and programme areas • Active promotion and inclusion of diversity and intersectionality, with integration of lived experience as expertise in all NCDs and mental health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant global frameworks and action plans	• Individuals with lived experience integrated into most (> 50%) relevant processes, decision-making bodies, procedures and programme areas • Active promotion and inclusion of diversity and intersectionality, with integration of lived experience as expertise in all NCD and mental health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant national frameworks and action plans
Silver	• Individuals with lived experience integrated into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Active, sustained promotion and inclusion of intersectionality and integration of lived experience as expertise in all NCDs, mental health and other relevant activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant global and regional frameworks and action plans	• Individuals with lived experience integrated into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Active, sustained promotion and inclusion of intersectionality and integration of lived experience as expertise in all NCDs, mental health and other relevant activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant regional frameworks and action plans
Gold	• Institutionalization of integration of individuals with lived experience into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Institutional promotion and inclusion of intersectionality and integration of lived experience as expertise in all relevant health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant global, regional and national frameworks for community engagement, primary health care and achieving UHC	• Institutionalization of integration of individuals with lived experience into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Institutional promotion and inclusion of intersectionality and integration of lived experience as expertise in all relevant health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant national, regional and local frameworks and action plans, such as for community engagement, primary health care and achieving UHC

5.5 Capacity-building

WHO and Member States should support capacity-building for individuals with lived experience in health literacy, provide access to relevant information and establish networks for data collection and knowledge exchange. WHO and Member States should also build their own capacity-building to support meaningful engagement, rights-based participatory approaches and address health inequity.

While individuals with lived experience bring valuable knowledge, expertise and skills to engagements, WHO and its Member States should also provide training in engaging with people in power, practical skills on research, communication and advocacy, and the rights-based approach to health. Individuals with lived experience should be supported in achieving the appropriate health literacy in establishment of political, policy and legal frameworks.

The training should include agenda-setting and prioritization of policies and translation of decisions into practice. All training should be reinforced with the latest data, statistics and evidence-based tools. In line with the principles of inclusiveness and intersectionality, the language used in training should be accessible and appropriate and not reinforce power imbalances *(145)*. Mechanisms to acknowledge and accredit individuals for their participation in training, such as certificates or awards, should be provided by the organizers.

All stakeholders and particularly marginalized communities should be given an overview of how information is used by various stakeholders, platforms and forums and how it is accessed and applied. Knowledge-sharing and communication platforms should be established for exchanges among WHO, Member States and individuals with lived experience to ensure that those individuals have the most recent information on their

health condition and related policies, programmes and services. Such platforms can be scaled up by collaboration with relevant organizations and associations to complement and align with civil society resources and networks to promote collaboration and leverage platforms for collective action *(116, 146)*. Such exchanges of information could ensure the inclusion of individuals with lived experience in research on meaningful engagement, which would improve the quality, clarity and relevance of such research. Research and data gaps can be filled and new models established for disaggregated data collection, analysis and dissemination that are respectful, dignified and consider individual and community needs while ensuring privacy and confidentiality. Training should also account for cultural and contextual differences in health research in underserved areas such as the social constructs of "race" and ethnicity *(147)*.

WHO and Member States should also participate in capacity-building to recognize, learn skills and understand the value of lived experience and the use of lived experience as a form of expertise. They require technical skills for engaging meaningfully through participatory approaches and applying the skills in their respective environments. Health literacy should be developed for parliamentarians and policy-makers, who could also be educated in incorporating lived experience to enhance the health and well-being of people living with NCDs, and mental health and neurological conditions. Further, recognition of addressing power imbalances through participatory approaches is essential. Communication skills are necessary to ensure appropriate, respectful interactions and contribute to an enabling, equitable environment that fosters meaningful engagement *(113)*. Such training and use of participatory approaches should be part of a multistakeholder response that includes meaningful engagement of civil society. For

WHO, this could comprise learning from and alignment with the QualityRights initiative, focusing on mental health, in line with the UN Convention on the Rights of Persons with Disabilities and other international human rights standards *(115)*. The initiative could be extended to other, related areas within NCDs and mental health.

Actions related to capacity-building.

Stage	WHO	Member States
Bronze	• Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all relevant activities. • Review how data are collected and applied from feedback on lived experience of relevant activities and engagements. • Establish training, knowledge-sharing and communication platforms to support WHO and Member States in engaging individuals with lived experience.	• Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all relevant activities. • Review how data are collected and applied from feedback on lived experience of relevant activities and engagements. • Establish training, national knowledge-sharing and communication platforms to support Member States in engaging individuals with lived experience.
Silver	• Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all WHO activities. • Reform WHO guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in relevant activities and engagements. • Establish and multiply global and regional training for WHO and Member States in engaging individuals with lived experience in participatory approaches, in research, communication and advocacy, and in the rights-based approach to health.	• Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all ministry of health activities. • Reform government guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in all relevant ministry of health activities and engagements. • Establish and multiply national and regional training for Member States in engaging individuals with lived experience in participatory approaches, in research, communication and advocacy, and in the rights-based approach to health.
Gold	• Scale up training, knowledge-sharing and communication platforms for exchanges between individuals with lived experience and key stakeholders. • Reform WHO guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in all relevant programme areas. • Establish and multiply global and regional training for WHO and all Member States on engaging individuals with lived experience through participatory approaches and research, communication, advocacy skills and the rights-based approach to health.	• Scale up training, knowledge-sharing and communication platforms for exchanges between individuals with lived experience and key stakeholders. • Reform government guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in all relevant programme areas. • Establish and multiply national, regional and local training for Member States on engaging individuals with lived experience through participatory approaches and research, communication, advocacy skills and the rights-based approach to health.

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

" I would like to see people with lived experience afforded more local opportunities for training and capacity-building. So that they can contribute to policy and practice and engage more in service delivery. My prayer for us as a country is that we engage more people and are more open minded.

Odireleng Kasale, Botswana

Access full publication

Box 10 represents the view from an individual with lived experience on the importance of capacity-building. See Fig.10 for more information on the People Power case studies.

5.6 Institutionalizing engagement

Meaningful engagement must be formally integrated and embedded into all relevant programme areas and processes of WHO and Member States to ensure sustained action and impact.

While WHO and Member States may take initial steps to meaningfully engage individuals with lived experience informally or in specific engagements, a commitment must be made to formalize such engagements as soon as possible. The transition from informal to formal is a step-in operationalizing and institutionalizing meaningful engagement, which should include integration of lived experience into formal engagements. This includes policy development, research and advocacy with relevant stakeholders such as intergovernmental and civil society organizations, academia, and health-care providers. The goal should be engagement in all relevant programme areas and processes mandated in legal frameworks. Formal mechanisms should be introduced to promote diversity, inclusion and intersectionality in all areas and the inclusion of individuals

with lived experience in various governance processes, activities and engagements. Formalization of meaningful engagement will ensure its long-term sustainability, with stakeholders supported by legal frameworks to conduct engagement, enabling planning and budgeting and fostering of a culture of engagement.

Commitments or calls to action by national governments to mandate the inclusion of individuals with lived experience must be backed by a legal framework, particularly for inclusion of groups that are marginalized in relevant processes and programme areas. Duty bearers could lead by example by using legal frameworks for engaging individuals with lived experience in the co-creation of public health interventions, research and national health plans.

WHO headquarters and regional and country offices should integrate individuals with lived experience in all governance and political decision-making processes associated with the World Health Assembly, Executive Board meetings and processes linked to UN General Assembly and UN high-level meetings. In addition, relevant strategic technical advisory groups and other formal groups and mechanisms of the Organization should mandate inclusion of lived experience. Accountability mechanisms should be in place to ensure that WHO and its Member States can effectively and transparently fulfil their commitment to meaningful engagement.

Actions related to institutionalizing engagement.

Stage	WHO	Member States
Bronze	- Explore establishment and adaptation of existing formal mechanisms to promote diversity and inclusion of lived experience in relevant areas of governance processes. - Individuals with lived experience included in most (> 50%) relevant strategic and technical advisory groups and other formal groups and mechanisms of the Organization - Transition from informal to formal engagements in all relevant departmental activities and processes	- Explore establishment and adaptation of existing formal mechanisms to promote diversity and inclusion of lived experience in relevant areas of governance processes. - Individuals with lived experience included in most (> 50%) relevant strategic and technical advisory groups and other formal groups and mechanisms of the government - Transition from informal to formal engagements in all relevant departmental activities and processes
Silver	- Individuals with lived experience included in most (> 50%) political decisions in the World Health Assembly, Executive Board meetings and processes linked to UN high-level meetings - Individuals with lived experience included in all (100%) relevant strategic and technical advisory groups and other formal groups and mechanisms in the Organization. - Transition from informal to formal engagements in all relevant Organization activities and processes.	- Individuals with lived experience included in most (> 50%) ministry of health activities and processes. - Individuals with lived experience included in all (100%) relevant strategic and technical advisory groups and other formal groups and mechanisms in government. - Transition from informal to formal engagements in all relevant government activities and processes.
Gold	- Individuals with lived experience included in all (100%) relevant political decisions in the World Health Assembly, Executive Board meetings and processes linked to UN high-level meetings - Mandated inclusion of individuals with lived experience (with leadership roles) in all (100%) relevant strategic and technical advisory groups and other relevant formal groups and mechanisms in the Organization - Most (>75%) engagements in all relevant activities and processes are formalized.	- Legislation supporting inclusion of individuals with lived experience in all (100%) relevant government activities and processes - Mandated inclusion of individuals with lived experience (with leadership roles) in all (100%) relevant strategic and technical advisory groups and other formal groups and mechanisms in government - Most (> 75%) engagements in all relevant activities and processes are formalized.

While WHO and Member States are engaging individuals with lived experience during this period of transition, individual engagements should be mapped and tracked throughout.

Tracking and recording of individuals engaged in this work will result in global, regional and national networks of individuals with lived experience, which will further support formalization of meaningful engagement.

Figure 11 summarizes *Regional reflections – Analysis from regional informal consultations with people living with noncommunicable diseases and mental health conditions (148)*, from informal virtual consultations conducted in the WHO African Region, Region of the Americas, South-East Asian Region, European Region and the Eastern Mediterranean Region and three virtual forums held in the Western Pacific Region *(148).*

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

The report shows similarities, regional nuances and priorities for meaningful engagement of individuals with lived experience in the six WHO regions. It outlines the lessons learnt from the priorities and implementation gaps identified regionally and nationally that informed co-development of the framework (see Annex 1 for more information). The analysis thus included insights and similarities in the regions on the principles and enablers of meaningful engagement, recruiting and engaging collaborators, and capacity-building for individuals with lived experience. These insights are paired with proposed action for operationalizing meaningful engagement.

Given the importance of contextualizing this agenda, additional regional priorities are highlighted, with additional action areas and next steps.

Figure 11. Regional reflections – Analysis from regional informal consultations with people living with noncommunicable diseases and mental health conditions

> " 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 healthcare professionals to improve the situation.

- Emma Skoglund

> " The solution is patient engagement. Let's revisit what has been mentioned in the Alma Ata Declaration. People have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.

- Hussain Jafri

Sweden

Jordan

Pakistan

India
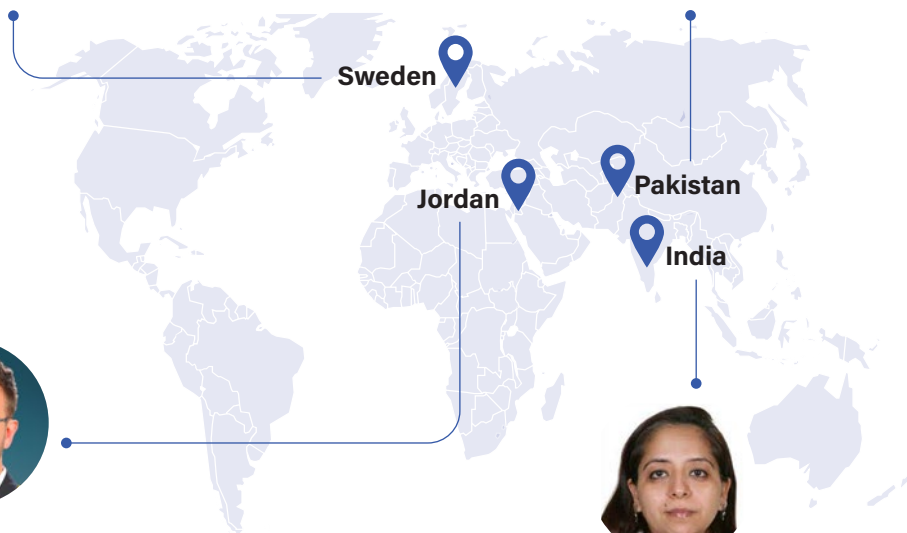
> " Students in medical school learn about different conditions and different diseases…. When you live an experience, it's completely different from just reading about it. All our knowledge of diseases and health and all the science of medicine is derived and taken from patients.

- Omar Abureesh

> " We are all people living with NCDs. Even if some of us may not be diagnosed with NCDs, we are caretakers of people living with NCDs.

- Dr Monika Arora

Access full publication

Conclusions

WHO is fully committed to using its position in global public health to operationalize meaningful engagement of people living with NCDs, and mental health and neurological conditions to deliver effective and equitable public health responses. The framework is a significant signal of intent to operationalize meaningful engagement within WHO and its Member States. Meaningful engagement and other participatory approaches should be seen not just as tools but as a rights-based approach to addressing health inequities and achieving health for all. Duty bearers have a moral obligation to fulfil this vision, and the framework outlines practical principles, enablers and actions for doing so.

While the framework is a milestone towards meaningful engagement, attention and resources are also required to sustain action, engage meaningfully and achieve the strategic vision. The evidence, projects and networks being generated will form strategic inputs to a transformative agenda that should accelerate national NCD and mental health responses for the fourth UN high-level meeting on NCDs in 2025 and for achieving the Global NCD Compact and SDG-related goals by 2030.

Use of lived experience through meaningful engagement and other participatory approaches can accelerate action and impact in NCD and mental health responses. To ensure this potential, WHO and Member States must take immediate, committed, substantial steps to harness this opportunity to improve health for all. This will require support from political leaders, civil servants, diplomats and institutional champions within and among governments and WHO to drive sustained, consistent change globally, nationally and in communities.

6.1 Alignment and coordination

Given the strong intersectional lens of the framework, including the promotion of a multistakeholder approach to meaningful engagement and improving health outcomes, implementation of the framework will continue to be aligned and coordinated with various technical areas. These include initiatives and programmes in and external to WHO on specific diseases and on broader health issues such as UHC, primary health care, healthy ageing, social and commercial determinants of health, gender, climate change, and cross-cutting topics. When possible, an integrated approach will be used for implementation, aligned and coordinated with existing global, regional and national initiatives.

The framework will continue to involve non-State actors, particularly civil society and individuals with lived experience associations, within its multistakeholder response, aligned with other initiatives for meaningful engagement of civil society organizations through required due diligence procedures.

6.2 Addressing gaps and advancing participatory approaches

Although evidence on this topic is increasing, there are still few articles in peer-reviewed journals about best practices in meaningful engagement of individuals with lived experience of NCDs, and mental health and neurological conditions. The largely siloed, disease-specific approach used in global health overlooks the broad, multifaceted

aspects of health conditions and the diverse, intersecting experiences of individuals with different health conditions.

Moreover, while there are examples of engagement of individuals with lived experience, there is limited evidence about whether this represents best practice. Evidence is also lacking on where meaningful engagement is being implemented, particularly in low- and middle-income countries. Further research should be conducted on the feasibility and impact of meaningful engagement and participatory approaches in health services, governance and programme development, implementation, monitoring and evaluation at various income levels.

While efforts are being made to include individuals with lived experience in engagement and activities, there continues to be overrepresentation of some experiences. Conditions such as diabetes and cancer are more often represented than others, such as mental health and neurological conditions and diseases that are more prevalent in low-income countries and communities. Groups that are underrepresented include those living in rural and remote areas, those with limited digital literacy or Internet access, groups that are marginalized, children, young people, people with disabilities and older adults.

Many individuals are excluded from participation because of factors such as insufficient knowledge, resources or confidence because of stigmatization and discrimination. As the evidence for the framework was derived mainly from English-language resources and activities, information on meaningful engagement in other languages was not fully captured.

Furthermore, while there is no shortage of advocacy tools, experience and enthusiasm, there is still little commitment by some leaders and stakeholders, such as health-care providers, policy-makers and researchers,

to consistent, system-wide application of meaningful engagement and participatory approaches. The reasons include limited understanding of meaningful engagement and lack of capacity and funding for the necessary NCD and mental health responses in many countries and settings. This can lead to lower priority of meaningful engagement than of issues such as access to and the affordability of essential services, diagnostics and prevention. The direct value and impact of meaningful engagement and participatory approaches in general are also not well understood, resulting in many lost opportunities for building sustainable mechanisms for engagement.

6.3 Next steps – Implementation, evaluation and derivative products

WHO is committed to addressing the theoretical, scientific and implementation gaps in meaningful engagement and other participatory approaches. A number of derivative products will address these gaps, support operationalization and achieve the vision of the framework. Once the framework is launched, the implementation phase will include additional activities to add to the evolving evidence, implement the framework, develop additional tools to support further contextualization and adaptation of the framework.

6.3.1 Adding to the evidence

Building on the insights and perspectives gained at individual, national and regional levels, the next steps include identifying further opportunities, barriers and gaps in implementation and aligning and integrating action into existing frameworks, action plans and other relevant initiatives regionally and nationally. A series of peer-reviewed

publications will be co-written with individuals with lived experience, and additional publications will be produced as part of the "Intention to action" series. The third publication in that series will describe promising practices, initiatives and projects for operationalizing meaningful engagement by topic and context at various levels. Additional derivative products will include policy briefs, regional and national adaptations of the framework, and toolkits for implementation.

6.3.2 Scientific working group

To explore wider participatory approaches further, including alternative models, monitoring and evaluation and implementation, a number of papers will be written and submitted to a working group on meaningful engagement and participatory approaches, to be established in 2023, consisting of experts in experience and other relevant scientific and philosophical areas.

6.3.3 Implementation, monitoring and evaluation

The framework will be implemented with the WHO regional and country offices in various ways. Monitoring and evaluation of implementation of the framework will include measurement of progress in the three stages of the recommended actions (Annex 2). WHO will support the implementation phase with additional tools and resources in a phased approach.

6.3.4 WHO symposium

A WHO symposium on people living with NCDs, and mental health and neurological conditions will advance meaningful engagement and greater involvement of individuals with lived experience in the lead up to the fourth UN high-level meeting on NCDs in 2025. The symposium will facilitate strategic alliances and coalitions among individuals with lived experience and WHO, the global NCD community and stakeholders in public health and policy sectors to increase awareness and support bold action for the NCD and mental health response. The symposium will be held annually in order to convene, formally recognize and leverage the knowledge and expertise of people with lived experience to inform the outcomes of the UN high-level meeting.

6.3.5 Collaborations, partnerships and resource mobilization

As this work continues to evolve, gain visibility and establish trust with individuals with lived experience, so will opportunities to bring in new voices and perspectives, with implementers and champions in WHO, Member States, civil society organizations and individuals with lived experience. Further resources will be mobilized to support WHO at its three levels in operationalizing meaningful engagement and achieving the vision of the framework.

Box 11 represents the views from individuals with lived experience on their vision for the future. See Fig. 10 for more information on the People Power case studies.

> The status quo is not currently anchored on the perspectives of those who are living with a chronic disease, and I firmly believe in the benefit of shifting it. Not only would quality of life for patients be improved, you may actually attract more people into the medical field if they feel they have a higher chance of making a substantive impact for people.

Paul Conway, United States of America

> Every citizen should have equal access and rights to medication and health care. We should not be subjected to challenges, hoops and obstacles that we must jump through to obtain the necessary care we need. It should be a basic right...

Pei Yan Heng, Singapore

Access full publication
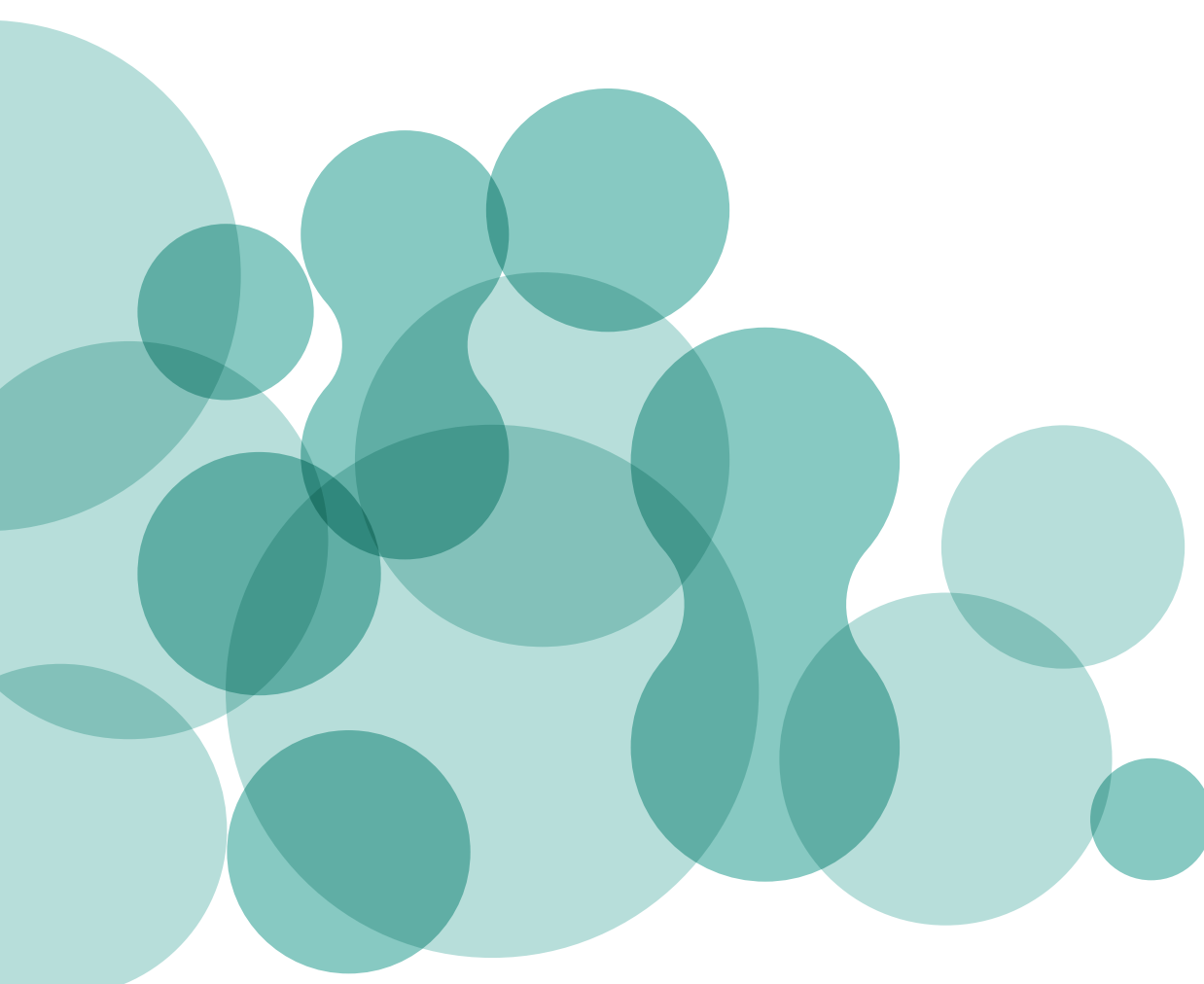
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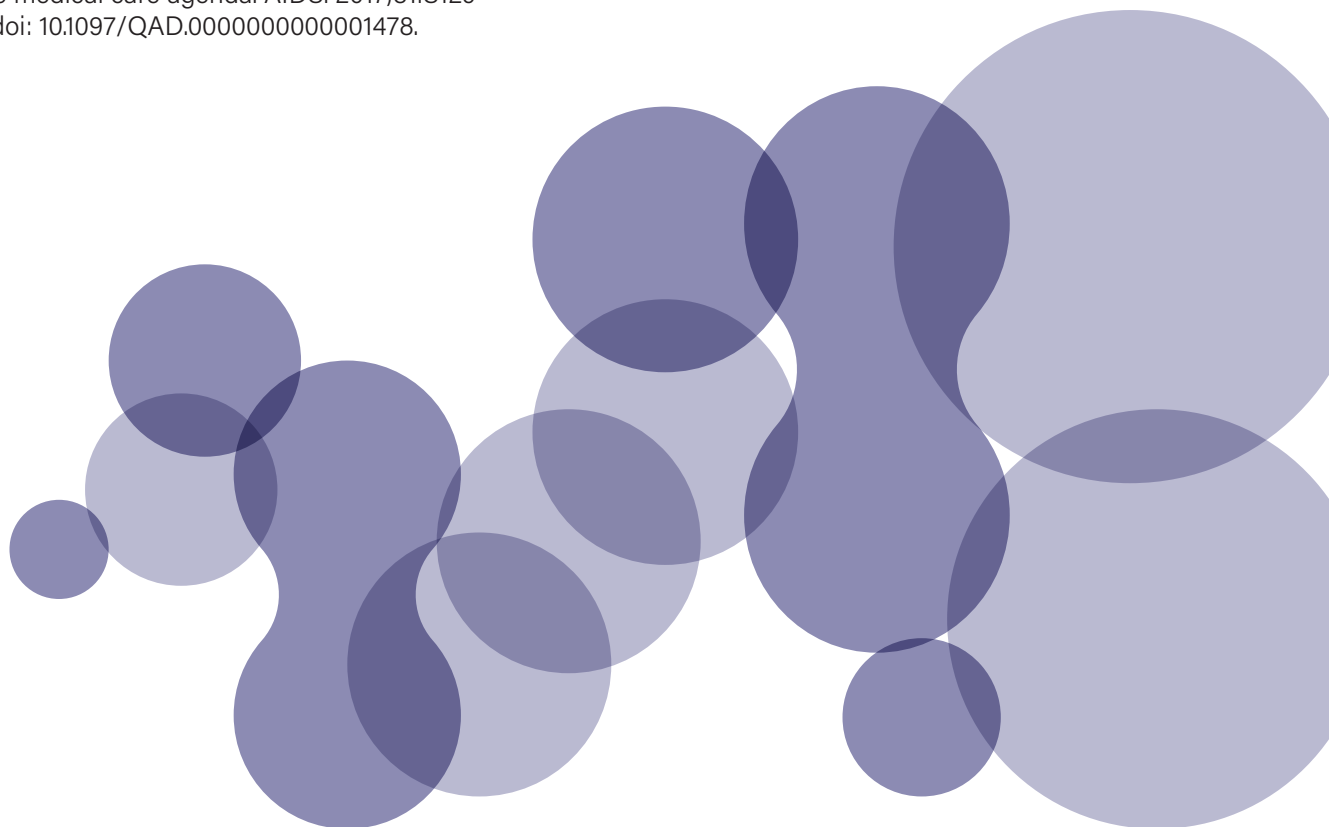
Annexes

Annex 1. Methods

The comprehensive evidence base for this framework was co-developed through a series of activities conducted between September 2020 and October 2022 with 700 individuals in 111 countries. The activities consisted of informal consultations; participatory research in the form of case studies, focus groups, in-depth interviews and a documentary film; and a literature review. The three types of activity resulted in research on meaningful engagement from different angles to provide a complementary, comprehensive understanding of the subject.

Evidence was collected iteratively, whereby the lessons learnt in each activity were used to review, adjust and test the approaches for subsequent activities (Fig. A1.1). The findings and data that emerged from each activity were analysed by both deductive and semantic approaches, grouped into thematic areas and consolidated to inform evidence-based positions for the framework.

Figure A1.1. Iterative collection of information

Listen and learn

Analyse and review

Test

Collect and ideate

Consolidate and strategize
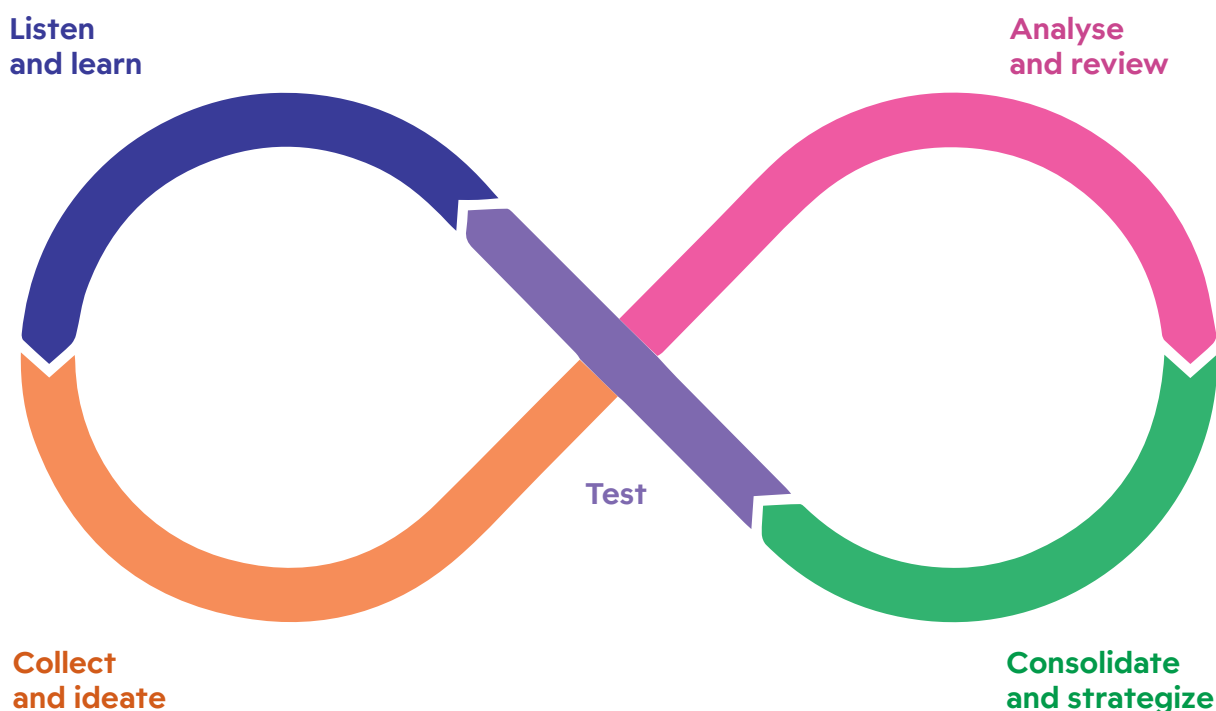
Informal consultations with individuals with lived experience

Six informal consultations and three forums with individuals with lived experience were held between December 2020 and May 2022 in the six WHO regions, representing lived experience with NCDs, mental health conditions and other health conditions. The informal consultations resulted in a broad range of perspectives on the value, principles and definitions of meaningful engagement and on strategies, tools and practices for operationalizing meaningful engagement in different settings.

The aim of the informal consultations was to foster a participatory approach that was not tokenistic on Arnstein's "ladder of participation" *(1)*, specifically level 4, "consultation", which usually includes attitude surveys, neighbourhood meetings and public enquiries, and reaches level 6, "partnership", in which power is redistributed by negotiation between citizens and power holders. Individuals with lived experience were therefore co-creators and drivers of the informal consultations, sharing responsibility for planning and decision-making on aspects such as the agenda, structure, speakers' roles and presentation topics. A mixed method consisting of several techniques was used, such as presentations, breakout sessions and "pass-the-mic" sessions, to maximize participants' ability to express their interests and convey their lived experience as effectively as possible in a virtual format.

The WHO Global informal consultation with people living with NCDs, held in December 2020, was the first dedicated WHO exercise on meaningful engagement of individuals with lived experience. The initial discussions were used to map themes and steps for defining and operationalizing meaningful engagement, which were documented in a meeting report entitled *Nothing for us without us (2)*.

Building on the main findings of the informal global consultation, the aim of the regional consultations held between February and May 2022 was to further contextualize the principles, definitions and strategies for operationalizing meaningful engagement in the six WHO regions and to learn from the experiences of the WHO regional offices. The findings of the regional consultations were analysed and summarized in a report in the "Intention to action" series, entitled *Regional reflections: Analysis from regional informal consultations with people living with noncommunicable diseases and mental health conditions.*[2] The work includes an analysis of activities between the WHO GCM/NCD and the NCD Department through the WHO Global Diabetes Compact. This included the Global Diabetes Summit (second segment), informal consultations with people living with diabetes and focus groups.

Participatory research

Case studies from focus groups and interviews

In November 2021, WHO organized a series of focus groups and interviews to explore individual perspectives in more depth. This qualitative process clarified the complex, interconnected aspects of living with NCDs, mental health conditions and neurological conditions and highlighted important, previously unexplored thematic areas.

After screening of possible participants according to their lived experience of NCDs, mental health conditions and neurological conditions, country, age and gender identity to ensure diverse, fair representation, 35 individuals in 18 countries were invited to participate in one of six focus groups. In each group, participants shared individual perspectives and experiences and often

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[2]   WHO (in press)

challenged perceptions of meaningful engagement and what it should be, notably those with intersectional lived experiences of several NCDs, mental health conditions and neurological conditions. A review and consolidation of the discussion points in all the focus groups gave rise to six themes.

As the discussions also indicated further exploration of individual experiences, seven individuals from the focus groups and five from the WHO GCM/NCD's network of people living with NCDs were invited to one-on-one interviews, in which they shared deeper reflections on the six themes. The focus groups and in-depth interviews demonstrated intersectionality in all the themes, suggesting that learning overlaps and is repeated, thereby reinforcing its significance. The findings from the focus groups, interviews and case studies will be published in the "Intention to action" series as *People power: Perspectives from individuals with lived experience of noncommunicable diseases, mental health conditions and neurological conditions*.

Documentary film

In September 2022, WHO issued a documentary film illustrating the experiences of individuals with lived experience as experts and agents of change in each of the WHO regions. The film is an additional platform, shaped by and amplifying the voices and expertise of individuals in translating and applying the knowledge in the co-design of NCD policies, programmes and health services. The film includes stories of grassroots advocacy, catalysing the sharing of ideas, expertise and best practices, and exploring the intersectionality of the lived experience of NCDs in different socioeconomic contexts.

The messages of the film centre on meaningful engagement of individuals with lived experience, highlight the strengths of meaningful engagement and suggest how WHO and its Member States could incorporate the process into the design of programmes, policies and principles in the future.

Literature review

There is limited evidence of the theoretical concept, application and impact of meaningful engagement of individuals living with NCDs, mental health conditions and neurological conditions, and there is no universal understanding of "meaningful engagement" for a clear response, standard operating procedures or established practices. To increase knowledge on this topic, mixed methods were used, comprising a literature review, interviews with key informants and case studies between June and December 2021.

The literature review addressed the key principles, established frameworks, best practices and strategies for meaningful engagement to improve the well-being of people living with NCDs and mental health conditions. The findings indicated that the concept of "meaningful engagement" includes building relationships and environments that enable individuals with lived experience, stakeholders, community members, health professionals, and policy-makers to work together for positive health impacts and outcomes. Best practices should be identified to ensure the meaningful engagement of people with lived experience, including active engagement, effective communication, enabling and protective environments, adequate representation and diversity of lived experiences, education and training of health-care providers, and addressing stigmatization.

Qualitative interviews based on formal research questions were conducted with key informants in the WHO and other international organizations. Seven interviews were conducted with WHO staff members who understood current policies and

perspectives for NCDs and/or meaningful engagement of individuals with lived experiences. The second stage involved interviews with 12 specialists working in international organizations, institutions or nongovernmental organizations to understand current thinking about NCDs and/or meaningful engagement of individuals with lived experiences. Content analysis and further interviews were conducted, and eight case studies were written to illustrate best practices in meaningful engagement of individuals with lived experience.

Web consultation on the zero draft of the framework

A web consultation on the zero draft of the framework was conducted between 23 October and 14 November 2022, which resulted in 65 responses from WHO, Member States, non-State actors and individuals with lived experience. The responses included over 750 comments, sent by e-mail and/or proposed changes and comments in the document. All the responses were reviewed, and many were included in the final version of the document. A webinar in early 2023 provided an overview of the feedback and changes made to ensure full transparency and accountability.

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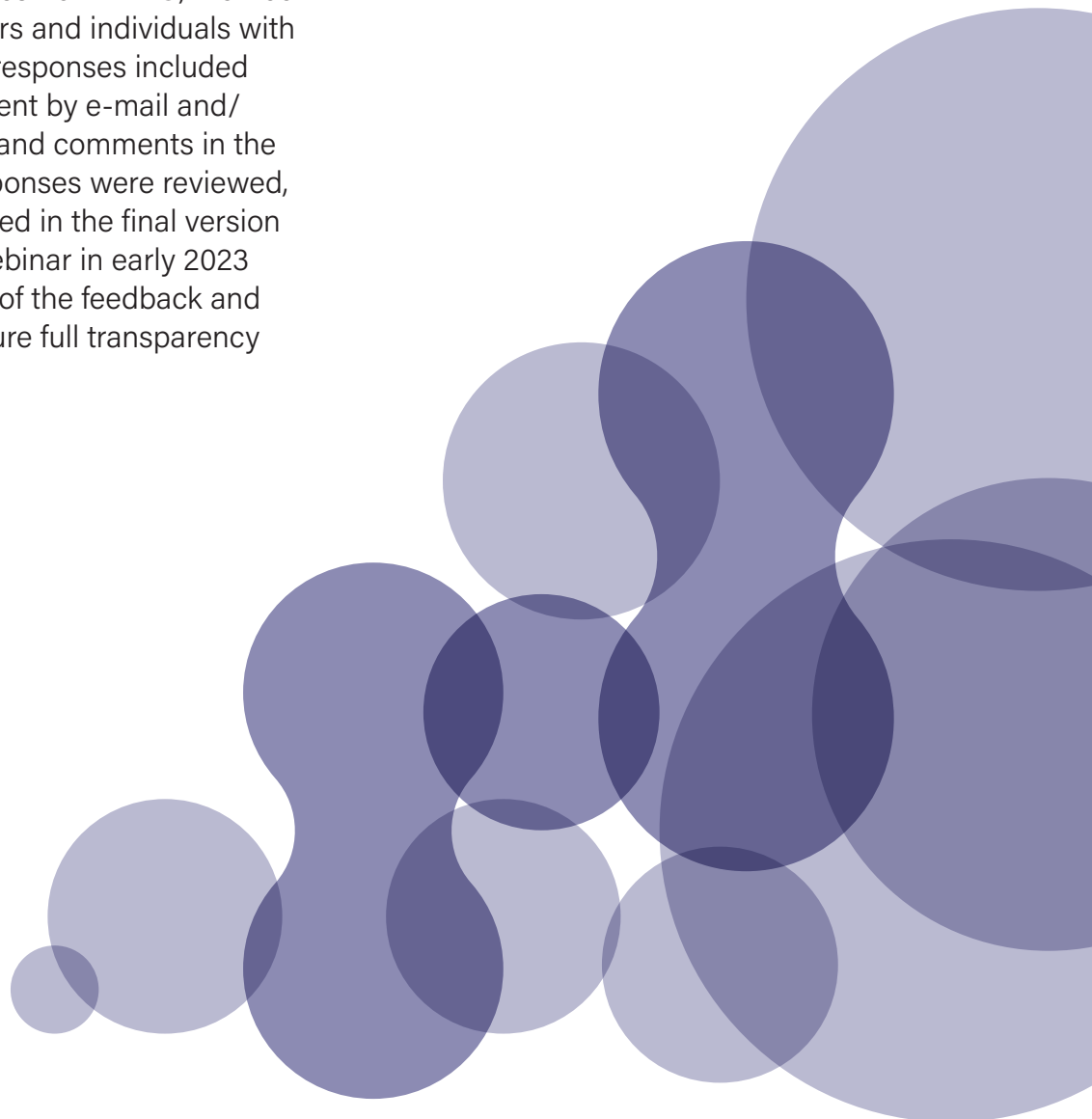
Annex 2. Practical actions for WHO and Member States

The table below lists practical actions related to the framework's enablers in a staged approach (bronze, silver and gold) for WHO and Member States. The list of actions is not exhaustive and is intended to allow additions, contextualization and adaptation, as outlined below. Additional key performance indicators and other monitoring and evaluation approaches will be established and supported by derivative products and additional research.

Enabler: Sustainable financing		
Stage	**WHO**	**Member States**
Bronze	▪ Remunerate individuals with lived experience for individual engagements (< 50%) at a rate equivalent to that for technical experts. ▪ Provide funding for individual engagements and activities at WHO headquarters and regional offices to operationalize meaningful engagement. ▪ Develop a plan for resource mobilization for meaningful engagement and activities in WHO.	▪ Remunerate individuals with lived experience for individual engagements (< 50%) at a rate equivalent to that for technical experts. ▪ Provide funding for individual engagements and activities to operationalize meaningful engagement. ▪ Develop a plan for resource mobilization for meaningful engagement and activities within teams working on NCDs and mental health.
Silver	▪ Remunerate individuals with lived experience for most engagements (> 50%) at a rate equivalent to that for technical experts. ▪ Provide funding for engagements and activities at WHO headquarters and regional offices to operationalize meaningful engagement. ▪ Implement and scale up resource mobilization for meaningful engagement and activities within WHO.	▪ Remunerate individuals with lived experience for most engagements (> 50%) at a rate equivalent to that for technical experts. ▪ Provide funding for engagements and activities of the government to operationalize meaningful engagement. ▪ Implement and scale up resource mobilization for meaningful engagement and activities in the ministry of health and subnationally.
Gold	▪ Remunerate individuals with lived experience for all engagements (100%) at a rate equivalent to that for technical experts. ▪ Provide funding for sustained engagement and activities at all levels of WHO to operationalize meaningful engagement. ▪ Fully fund meaningful engagement and relevant activities in the WHO Programme Budget.	▪ Remunerate individuals with lived experience for all engagements (100%) at a rate equivalent to that for technical experts. ▪ Provide funding for sustained institutionalized engagement and activities at all levels of government to operationalize meaningful engagement. ▪ Fully fund meaningful engagement and relevant activities in the national fiscal budget.

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions

Enabler: Redistribution of power		
Stage	**WHO**	**Member States**
Bronze	• Acknowledge and commit to addressing power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. • Review and reform diversity, equity and inclusion practices in relevant activities and processes. • Establish and implement a standard operating procedure for inclusion of diverse individuals with lived experience in all relevant departmental activities and processes.	• Acknowledge and commit to addressing power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. • Review and reform diversity, equity and inclusion practices in relevant activities and processes. • Establish and implement a standard operating procedure for inclusion of diverse individuals with lived experience in all relevant departmental activities and processes.
Silver	• Actively address power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-coloniality, anti-discrimination, rights-based and pro-equity approach to engagement. • Review and reform diversity, equity and inclusion practices in relevant departmental activities and processes. • Establish and use a standard operating procedure for inclusion of diverse individuals with lived experience in all relevant global, regional and national activities and processes.	• Actively address power asymmetry by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based and pro-equity approach to engagement. • Review and reform diversity, equity and inclusion practices in all relevant ministry of health activities and processes. • Establish and use a standard operating procedure for inclusion and diversity of individuals with lived experience in all relevant government activities and processes.
Gold	• Systematically address power asymmetries by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. • Review and reform existing diversity, equity and inclusion practices in all relevant global, regional and national activities and programme areas. • Modify or establish governance structures to include individuals with lived experience in all relevant global, regional and national activities and processes.	• Systematically address power asymmetries by promoting and practising critical "allyship" and taking an anti-racism, anti-oppression, anti-colonialism, anti-discrimination, rights-based, pro-equity approach to engagement. • Review and reform existing diversity, equity and inclusion practices in all relevant government activities and programme areas. • Modify or establish governance structures to include individuals with lived experience in all relevant government activities and processes.

Enabler: Elimination of stigmatization		
Stage	**WHO**	**Member States**
Bronze	▪ Review and reform existing and recent practices and processes for preventing stigmatization and discrimination. ▪ Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating. ▪ Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant departmental activities and programmes.	▪ Review and reform existing and recent practices and processes for preventing stigmatization and discrimination. ▪ Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating. ▪ Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant ministry of health activities and programmes.
Silver	▪ Review and reform existing and recent departmental practices and processes to prevent stigmatization and discrimination. ▪ Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating, showing how WHO will proactively eliminate them in the future. ▪ Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant global, regional and national activities and programme areas.	▪ Review and reform existing and recent ministry of health practices and processes to prevent stigmatization and discrimination. ▪ Acknowledge and apologize for any practices or processes that have been stigmatizing and discriminating showing how government will proactively eliminate them in the future. ▪ Establish and implement practical guidance on the prevention of stigmatization and discrimination in all relevant government activities and programme areas.
Gold	▪ Review and reform existing and recent Organization-wide practices and processes to prevent stigmatization and discrimination. ▪ Establish independent mechanisms and governance structures to review and monitor work to prevent stigmatization and discrimination. ▪ Change the Organization culture by promoting and including diverse lived experiences through an intersectional lens in all relevant health activities and engagements.	▪ Review and reform existing and recent government-wide practices, processes and national legal instruments to prevent stigmatization and discrimination. ▪ Establish independent mechanisms and governance structures to review and monitor work to prevent stigmatization and discrimination. ▪ Change the government culture by institutional promotion and inclusion of diverse lived experiences through an intersectional lens in all relevant health activities and engagements.

Enabler: Integrated approaches		
Stage	**WHO**	**Member States**
Bronze	• Individuals with lived experience integrated into most (> 50%) relevant processes, decision-making bodies, procedures and programme areas • Active promotion and inclusion of diversity and intersectionality, with integration of lived experience as expertise in all NCDs and mental health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant global frameworks and action plans	• Individuals with lived experience integrated into most (> 50%) relevant processes, decision-making bodies, procedures and programme areas • Active promotion and inclusion of diversity and intersectionality, with integration of lived experience as expertise in all NCDs and mental health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant national frameworks and action plans
Silver	• Individuals with lived experience integrated into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Active, sustained promotion and inclusion of intersectionality and integration of lived experience as expertise in all NCDs, mental health and other relevant activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant global and regional frameworks and action plans	• Individuals with lived experience integrated into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Active, sustained promotion and inclusion of intersectionality and integration of lived experience as expertise in all NCDs, mental health and other relevant activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant regional frameworks and action plans
Gold	• Institutionalization of integration of individuals with lived experience into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Institutional promotion and inclusion of intersectionality and integration of lived experience as expertise in all relevant health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant global, regional and national frameworks for community engagement, primary health care and achieving UHC	• Institutionalization of integration of individuals with lived experience into all (100%) relevant processes, decision-making bodies, procedures and programme areas • Institutional promotion and inclusion of intersectionality and integration of lived experience as expertise in all relevant health activities and engagements • Lived experience of NCDs, and mental health and neurological conditions integrated into relevant national, regional and local frameworks and action plans, such as for community engagement, primary health care and achieving UHC

Enabler: Capacity-building		
Stage	WHO	Member States
Bronze	▪ Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all relevant activities. ▪ Review how data are collected and applied from feedback on lived experience of relevant activities and engagements. ▪ Establish training, knowledge-sharing and communication platforms to support WHO and Member States in engaging individuals with lived experience.	▪ Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all relevant activities. ▪ Review how data are collected and applied from feedback on lived experience of relevant activities and engagements. ▪ Establish training, national knowledge-sharing and communication platforms to support Member States in engaging individuals with lived experience.
Silver	▪ Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all WHO activities. ▪ Reform WHO guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in relevant activities and engagements. ▪ Establish and multiply global and regional training for WHO and Member States in engaging individuals with lived experience in participatory approaches, in research, communication and advocacy, and in the rights-based approach to health.	▪ Provide individuals with lived experience access to relevant training and information, including the latest data, statistics and evidence-based tools for all ministry of health activities. ▪ Reform government guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in all relevant ministry of health activities and engagements. ▪ Establish and multiply national and regional training for Member States in engaging individuals with lived experience in participatory approaches, in research, communication and advocacy, and in the rights-based approach to health.
Gold	▪ Scale up training, knowledge-sharing and communication platforms for exchanges between individuals with lived experience and key stakeholders. ▪ Reform WHO guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in all relevant programme areas. ▪ Establish and multiply global and regional training for WHO and all Member States on engaging individuals with lived experience through participatory approaches and research, communication, advocacy skills and the rights-based approach to health.	▪ Scale up training, knowledge-sharing and communication platforms for exchanges between individuals with lived experience and key stakeholders. ▪ Reform government guidance and practice on the collection and use of data on the basis of feedback from people with lived experience in all relevant programme areas. ▪ Establish and multiply national, regional and local training for Member States on engaging individuals with lived experience through participatory approaches and research, communication, advocacy skills and the rights-based approach to health.

Enabler: Institutionalization of engagement		
Stage	**WHO**	**Member States**
Bronze	• Explore establishment and adaptation of existing formal mechanisms to promote diversity and inclusion of lived experience in relevant areas of governance processes. • Individuals with lived experience included in most (> 50%) relevant strategic and technical advisory groups and other formal groups and mechanisms of the Organization • Transition from informal to formal engagements in all relevant departmental activities and processes	• Explore establishment and adaptation of existing formal mechanisms to promote diversity and inclusion of lived experience in relevant areas of governance processes. • Individuals with lived experience included in most (> 50%) relevant strategic and technical advisory groups and other formal groups and mechanisms of the government • Transition from informal to formal engagements in all relevant departmental activities and processes
Silver	• Individuals with lived experience included in most (> 50%) political decisions in the World Health Assembly, Executive Board meetings and processes linked to UN high-level meetings • Individuals with lived experience included in all (100%) relevant strategic and technical advisory groups and other formal groups and mechanisms in the Organization • Transition from informal to formal engagements in all relevant Organization activities and processes	• Individuals with lived experience included in most (> 50%) ministry of health activities and processes • Individuals with lived experience included in all (100%) relevant strategic and technical advisory groups and other formal groups and mechanisms in government • Transition from informal to formal engagements in all relevant government activities and processes
Gold	• Individuals with lived experience included in all (100%) relevant political decisions in the World Health Assembly, Executive Board meetings and processes linked to UN high-level meetings • Mandated inclusion of individuals with lived experience (with leadership roles) in all (100%) relevant strategic and technical advisory groups and other relevant formal groups and mechanisms in the Organization • Most (> 75%) engagements in all relevant activities and processes are formalized.	• Legislation supporting inclusion of individuals with lived experience in all (100%) relevant government activities and processes • Mandated inclusion of individuals with lived experience (with leadership roles) in all (100%) relevant strategic and technical advisory groups and other formal groups and mechanisms in government • Most (>75%) engagements in all relevant activities and processes are formalized

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