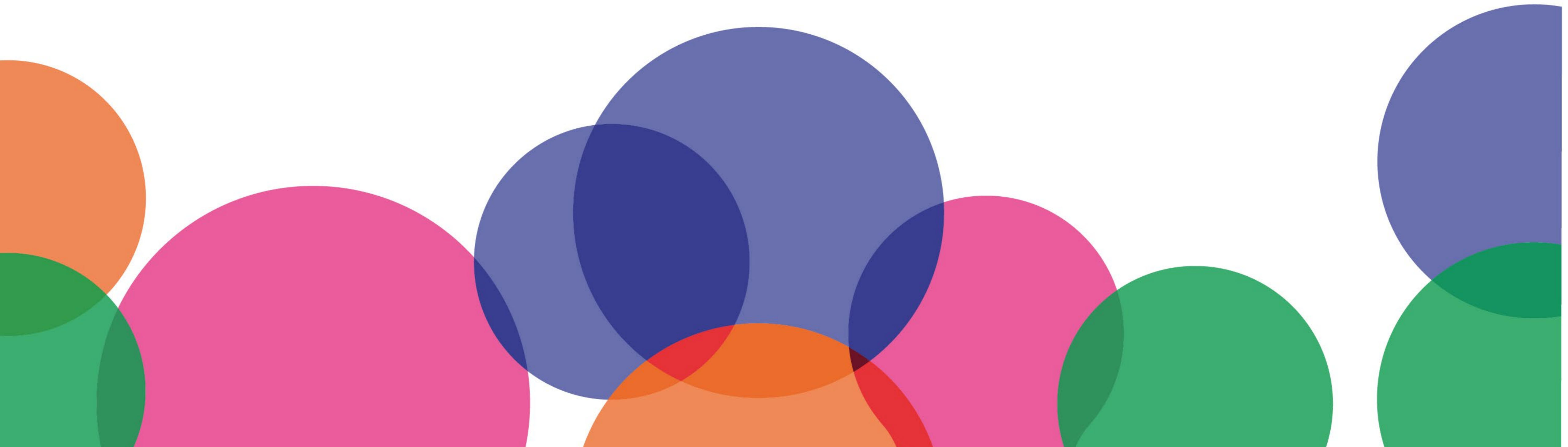


WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health and Neurological Conditions

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WHO Global Coordination Mechanism on NCDs





WHO framework for meaningful engagement

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



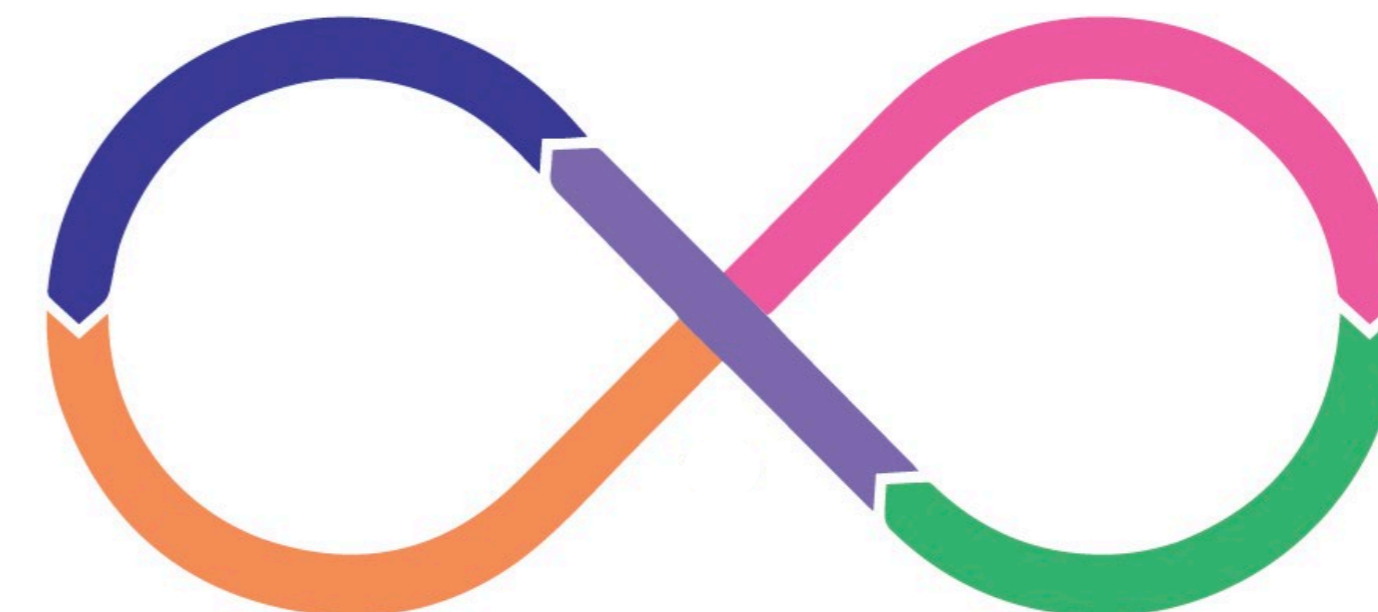
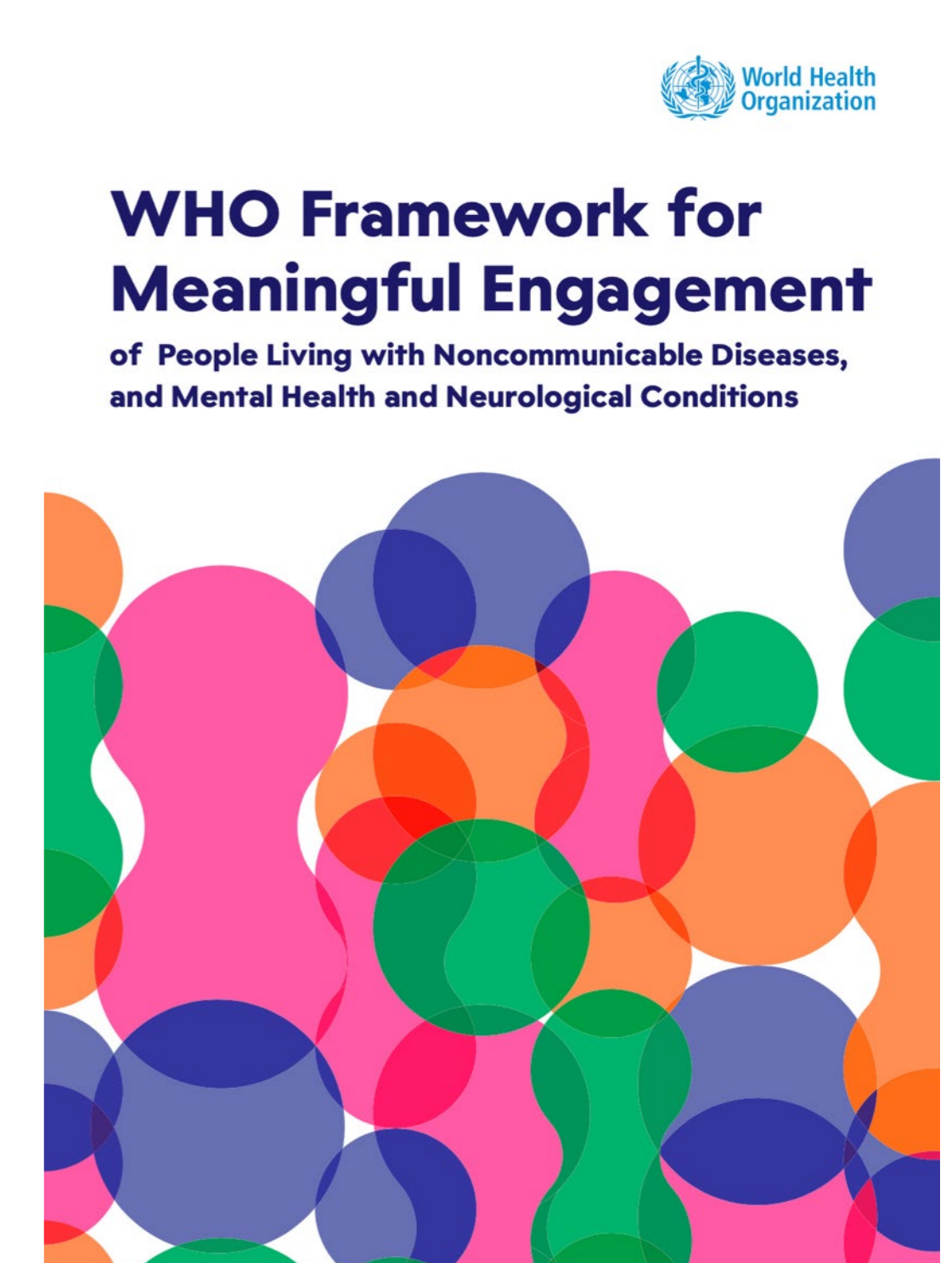
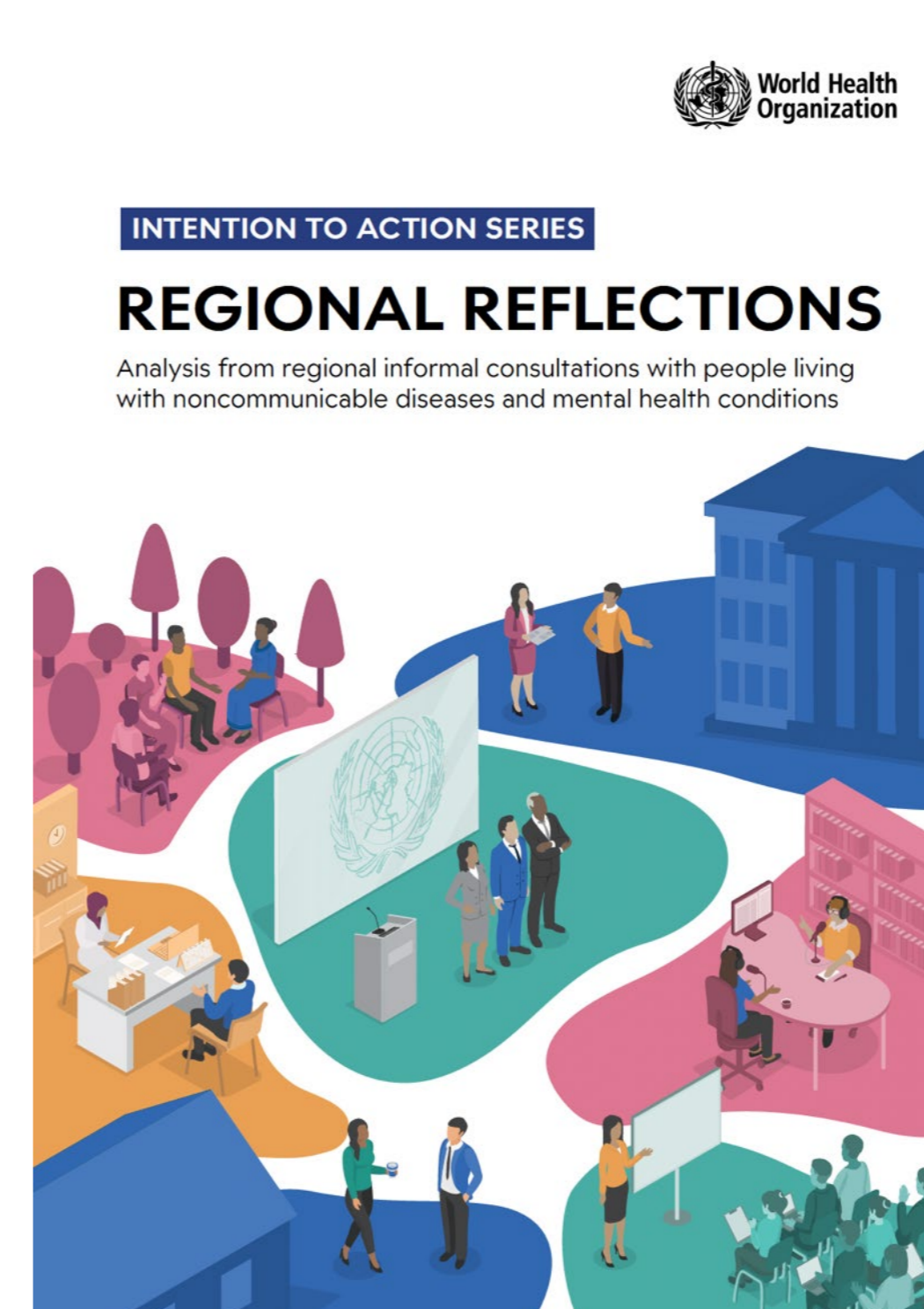
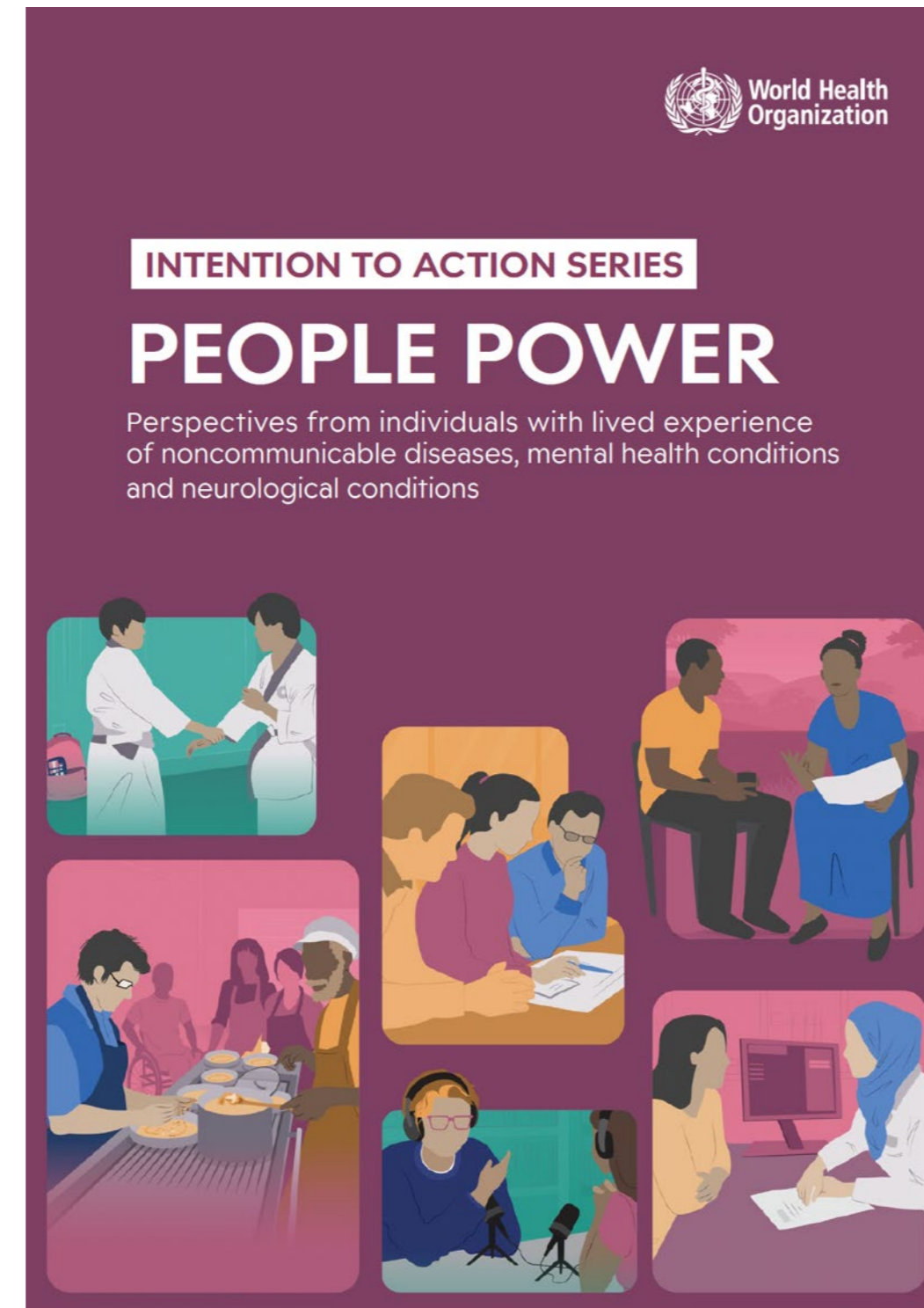
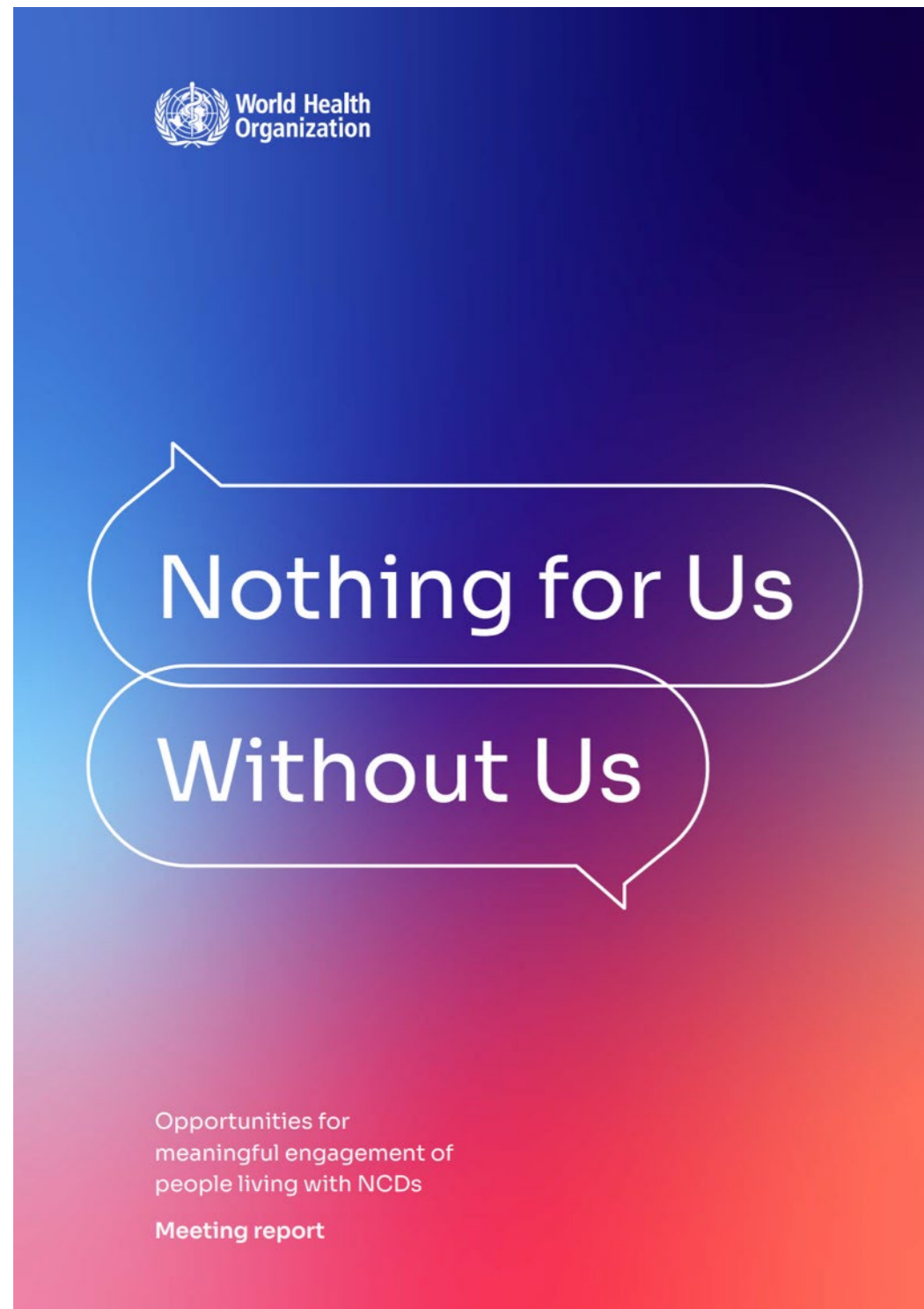
**The right to participate
is an essential part of
the right to the highest
attainable standard
of health**

WHO's commitment to meaningful engagement

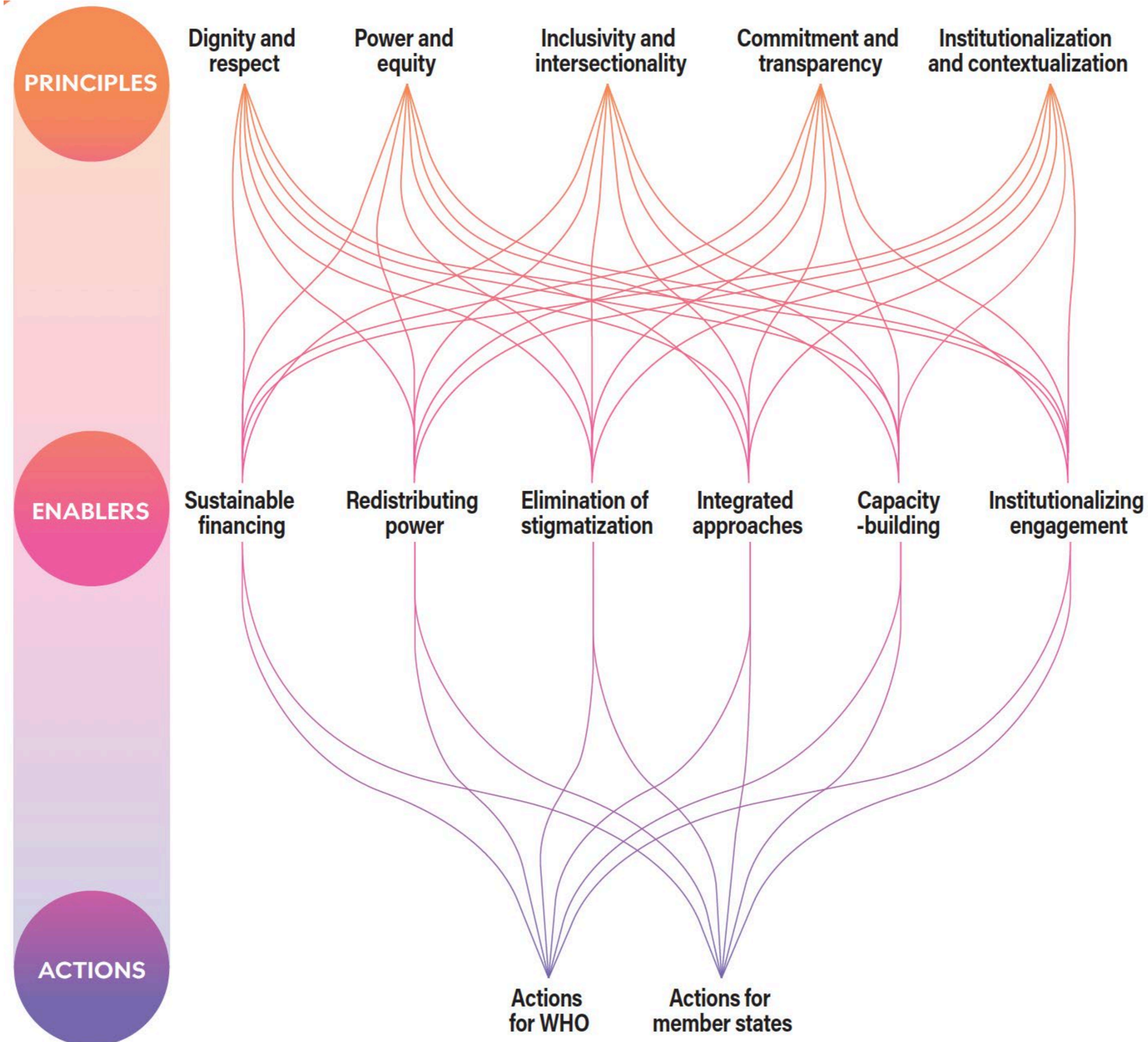
- WHO committed to leveraging its role in Global Public Health to operationalize meaningful engagement with individuals with lived experience.
- Technical Product to support **WHO and Members States** in the **meaningful engagement** of people living with NCDs, and mental health and neurological conditions to **co-create and enhance related policies, programmes and services.**



Publications – Participatory Research






Framework – Overview (Principles and Enablers)



Framework – Overview (Actions)

Actions related to elimination of stigmatization.

Stage	WHO	Member States
Bronze 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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.



“ 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

Box 5. Lived Experience Quotes



“ 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

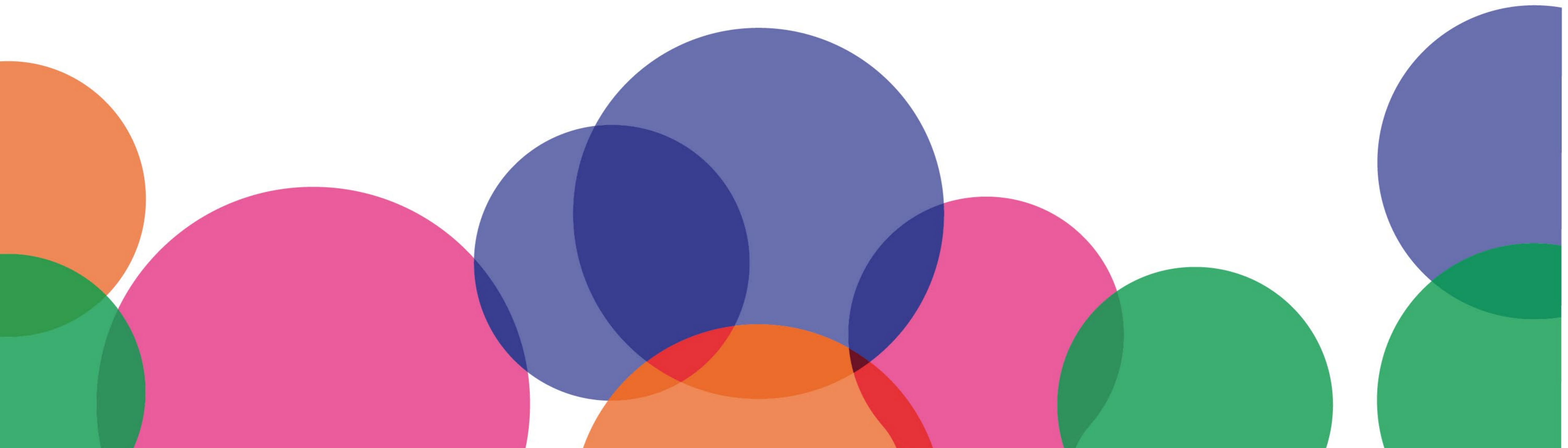


“ My vision for the future is in an ideal world there would be an international platform of patient voices. A network that ensures those with lived experience are involved at every stage; in research, in prevention and in education. There is greater investment in communities and in empowering the voice 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](#)

Three “Myths and Misconceptions” of Meaningful Engagement



Three “Myths” around Meaningful Engagement

- **Myth 1:** "Meaningful engagement" means having too many people at the table and can delay and complicate policymaking
- **Response:** Making policies without any people with lived experience can lead to less effective policies and lower uptake by the target population, resulting in poorer health outcomes. *Nothing for us without us.*



Three “Myths” around Meaningful Engagement

- **Myth 2:** Meaningful engagement will take too much time and resources
- **Response:** Meaningful engagement can actually be integrated into existing policies, programmes and practices. There are many ongoing and high-priority activities that can be efficiently enhanced through meaningful engagement.



Three “Myths” around Meaningful Engagement

- **Myth 3:** Including people with lived experience at the table can lead to very personal demands, rather than broader public health goals
- **Response:** Both individuals with lived experience and traditional decision-/policymakers need capacity-building to ensure that lived experience is treated as expertise and translated into effective policies and programmes. The Framework emphasizes this need for capacity-building on both sides for better communication and understanding.

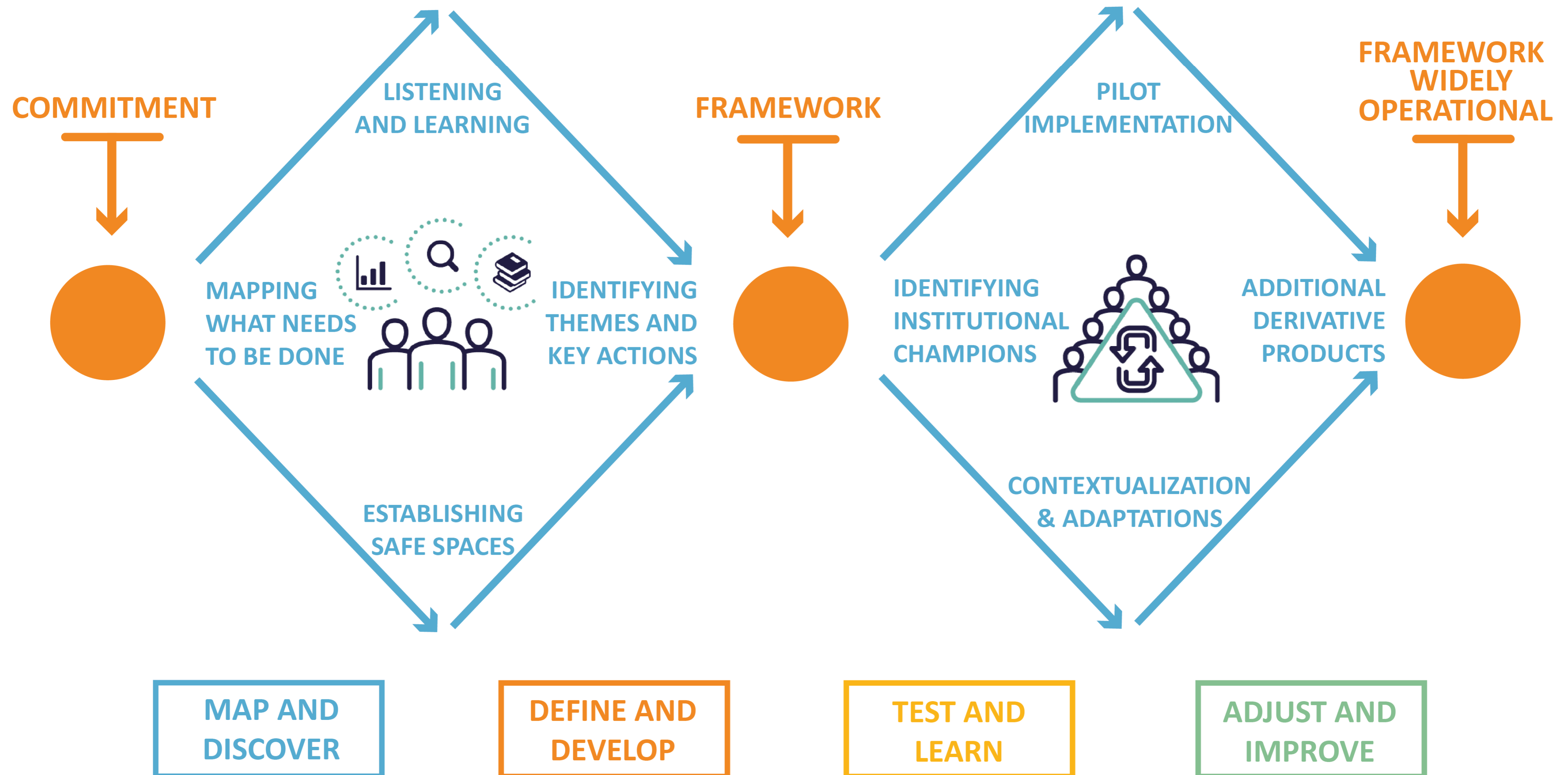


Evidence on the value of meaningful engagement*

- **Meaningful engagement of people living with HIV and AIDS has led to...**
 - Better concordance with antiretroviral therapies
 - Longer survival
 - Better clinical outcomes
 - Better quality of life
 - Removal of stigma and discrimination in healthcare settings
- **Meaningful engagement of young people and adults in addressing mental health conditions and substance use has led to...**
 - Reduced hospital re-admissions
 - Improved adherence to treatment
 - Increased wellbeing and engagement of service users
 - Provided learning opportunities for health workforce

*Refs 69-80 in Framework

Next Steps – Further Building and Operationalization



Next Steps – Global Leadership & Evidence Base

- 1. WHO Symposium with people living with NCDs, and mental health and neurological conditions**
- 2. WHO roster of consultants with lived experience of NCDs, and mental health and neurological conditions.**
- 3. Derivative products to continue to establish evidence base focused on implementation of meaningful engagement**
 1. Promising Practices publication – analyzing country level projects that have operationalized meaningful engagement (NSAs in 2023, MS in 2024)
 2. BMJ Collection on “Unleashing the power of lived experiences to accelerate action on NCDs, mental health, and neurological conditions”, led by lived experience authors
 3. Develop an initial scoping paper on alternative models for participatory approaches, for eventual operational toolkit or guide of Intention to Action materials
- 4. Opportunities for knowledge exchange via 2024 webinar series and shared learning on the Knowledge Action Portal**



Next Steps – Regional & Country-Level Implementation

1. Pilot project for the implementation of the WHO Framework of Meaningful Engagement for people living with cancer in the EMRO region

- Project across up to six Member States
- Inclusive, participatory processes across lived experience communities
- Pilot project will be: 1) Scoping review, stakeholder mapping, 2) Country multistakeholder dialogues, 3) Analysis of needs assessment with recommended actions for implementation of the Framework

2. Regional Policy Briefs

- Alignment of research areas and policy priorities for the implementation of the principles, enablers, and actions of the Framework

3. Promising Practices publication on successful examples of operationalizing meaningful engagement across member states planned for 2024



- Support WHO Regional and Country Offices, Member States **to incorporate meaningful engagement as part of ongoing NCD priorities and activities**
 - **Eastern Mediterranean Region**
 - Anti-stigma campaign for people living with mental health conditions
 - Policy brief to support meaningful engagement as part of campaign activities
 - **Pan-American Health Organization**
 - Using community engagement to integrate NCD services into primary healthcare
 - Policy brief to support meaningful engagement as part of community engagement efforts
 - **Western Pacific Region**
 - Formalizing engagement structures (e.g. hospital support groups)
 - **African Region**
 - Lessons learned from meaningful engagement in other health areas (e.g. HIV and AIDS)

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