The HESHIMA Project

Honoring Experiences & Shared Humanity In Mobilizing for Action

2024 Assessment Report & Participatory Toolkit

Multisystemic Mental Health and Psychosocial Support (MHPSS) Research, Monitoring and Evaluation with Older Refugees and Refugees Living with Disabilities in Nairobi County, Kenya

DEVELOPED BY:

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Project Overview

In recent years, global initiatives have expanded mental health support in low- and middle-income countries affected by disaster, conflict and forced migration. However, older refugees (OR) and refugees living with disabilities (RLWD) remain underrepresented in research and often encounter barriers to accessing interventions.

The HESHIMA Project focuses on closing this gap by fostering inclusive humanitarian mental health and psychosocial support (MHPSS) among marginalized refugees living in Nairobi County, Kenya. Led by an international team of collaborators across four institutions, including researchers, humanitarian and human rights personnel, and refugee stakeholders, this work aims to ensure the unique needs of OR and RLWD are addressed in MHPSS research, program design, and the monitoring and evaluation of interventions.

The HESHIMA Project culminates in two key outputs:

1. **HESHIMA Assessment Report:** This report presents the findings of our work, highlighting critical insights into the MHPSS needs and experiences of OR and RLWD in Nairobi County, Kenya.

2. **HESHIMA Participatory Toolkit:** This toolkit provides resources to support participatory data collection for MHPSS research, specifically tailored for OR and RLWD in Nairobi County, Kenya. Developed with direct input from refugee partners and participants, the toolkit focuses on what matters most to them, aiming to improve humanitarian responses in urban settings.

About the HESHIMA Toolkit

This guide is designed to foster participatory and inclusive humanitarian mental health and psychosocial support (MHPSS) research, program design, monitoring and evaluation with older refugees and refugees living with disabilities in Nairobi County, Kenya. Although the findings and tools found in this document may be relevant to other settings, it is important to consider the specific contexts that influence mental health among these groups. Thus, we encourage anyone using this guide partner with local communities, stakeholders and experts to ensure application is culturally centered and locally relevant. This collaborative approach ensures MHPSS assessments and responses are not only effective but also respectful of local norms and practices, thereby enhancing their sustainability and impact.

What Does “HESHIMA” Mean?

Heshima, which is Kiswahili for “respect,” refers to **Honoring Experiences and Shared Humanity in**

Working meeting of the HESHIMA community advisory board (CAB) at Amref International University in Nairobi, Kenya.

Mobilizing for Action and is an anchoring keystone for inclusion and equity. At the heart of the HESHIMA Toolkit is the underlying principle of *participatory humanitarianism*. This approach emphasizes the importance of involving those directly affected by humanitarian crises in decision-making and leveraging community expertise and wisdom for impactful and empowering MHPSS action.

Why Older Refugees and Refugees Living with Disabilities?

Older refugees and those living with disabilities face unique challenges that can diminish their mental health, while also making it more difficult to access MHPSS resources. Risks for poor mental health include isolation, loss of community and familial roles, physical health issues that impair daily functioning and quality of life, discrimination, and a lack of accommodations for specific needs. Moreover, there is limited information about MHPSS among older refugees and refugees living with disabilities. By centering our efforts on these groups in Nairobi County, the HESHIMA Toolkit addresses identified gaps while promoting inclusive MHPSS to enhance the humanitarian response.

Who is This Toolkit For?

The HESHIMA Toolkit is crafted for a diverse audience of professionals working within the urban humanitarian sector in Nairobi. This audience includes program developers, assessment coordinators, monitoring and evaluation specialists, researchers, and policy decision makers. The toolkit is designed to empower professionals by providing them with inclusive, evidence-informed data collection strategies to enhance the effectiveness of MHPSS response while promoting the dignity of older refugees and refugees living with disabilities.

Concepts & Definitions

Mental Health and Psychosocial Support (MHPSS)

MHPSS is an umbrella term referring to any activities aimed to promote psychosocial well-being and/or prevent or treat mental disorders (UNHCR, n.d.). These activities include delivering clinical interventions, peer support and group psychosocial programs, and ensuring dignified community integration and access to basic services. Refugees often experience acute and chronic psychological stress resulting from exposure to conflict and violence, separation from or deaths of loved ones, discrimination and xenophobia, and adjustment challenges in host countries. To be most effective, MHPSS should be integrated across all humanitarian sectors, such as livelihoods, education, and health (UNHCR, n.d.a.).

The MHPSS Pyramid (Figure 1) depicts the multi-layered approach to MHPSS developed by the Inter-Agency Standing Committee (IASC) Reference Group on Mental Health and Psychosocial Support in Emergency Settings (IASC, 2007). This model illustrates how interventions, programs and policies should be designed to meet increasingly specialized needs — from the broad bottom base of the pyramid to the narrow top.

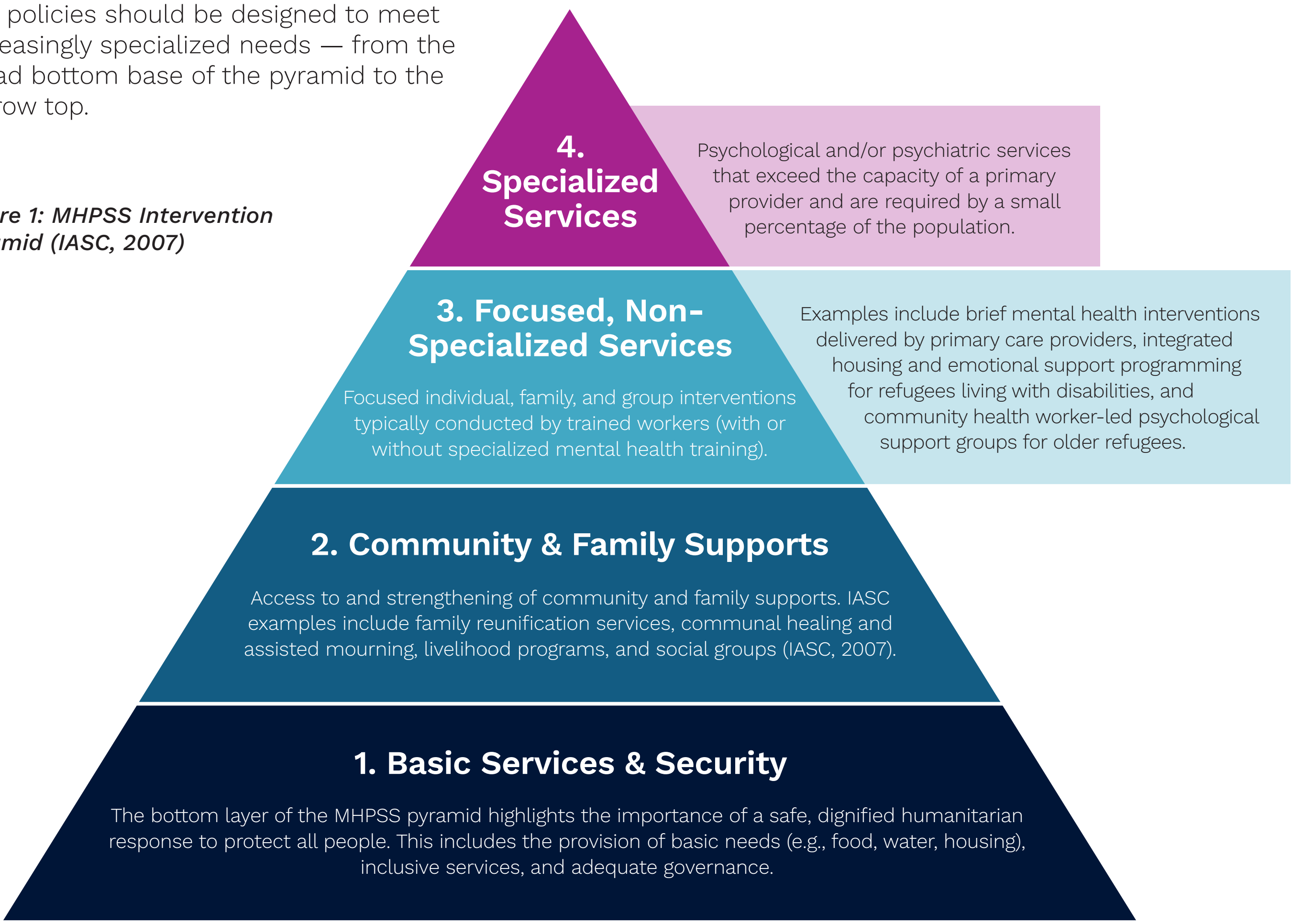

Figure 1: MHPSS Intervention Pyramid (IASC, 2007)

4. Specialized Services

Psychological and/or psychiatric services that exceed the capacity of a primary provider and are required by a small percentage of the population.

3. Focused, Non-Specialized Services

Focused individual, family, and group interventions typically conducted by trained workers (with or without specialized mental health training).

Examples include brief mental health interventions delivered by primary care providers, integrated housing and emotional support programming for refugees living with disabilities, and community health worker-led psychological support groups for older refugees.

2. Community & Family Supports

Access to and strengthening of community and family supports. IASC examples include family reunification services, communal healing and assisted mourning, livelihood programs, and social groups (IASC, 2007).

1. Basic Services & Security

The bottom layer of the MHPSS pyramid highlights the importance of a safe, dignified humanitarian response to protect all people. This includes the provision of basic needs (e.g., food, water, housing), inclusive services, and adequate governance.

Urban Refugees

Urban refugees are individuals who were forced to flee their home countries due to conflict or persecution and who live in cities or towns instead of designated refugee camps. Those residing in urban settings live alongside the local host population. Depending on the setting, urban refugees experience unique stressors, such as lack of availability of formal humanitarian supports, difficulties accessing public services, and discrimination and harassment from police and host community members (Campbell, 2006; Pavanello et al., 2010; Tippens et al., 2021). Many of those living in Nairobi are in what the United Nations Refugee Agency calls “refugee-like situations,” an inclusive category that encompasses persons fleeing conflict and persecution but have not been granted legal refugee status (UNHCR, 2013). In this report and toolkit, “refugees” includes both those with formal refugee status and in refugee-like situations.

Older Refugees (OR)[1]

Older persons account for approximately 4% of refugees globally and may represent more than a quarter of the population of concern in specific humanitarian situations (Kaga & Nakache, 2019; UNHCR, n.d.b.). Older refugees include individuals who migrate at an older age and those who age in postmigration settings (Austin et al., 2007). The World Health Organization (WHO) uses age 60 to describe the onset of older age (WHO, 2022). It is also important to consider the sociocultural aspects of aging and acknowledge understandings of what it means to be an older person may be based on milestones, like becoming a grandparent, in some contexts. In consultation with partners and the community advisory board, we use the age 60 or older to refer to older refugees. Effective MHPSS for older refugees should address both vulnerability and resilience factors, ensuring interventions are culturally sensitive and appropriately tailored to promote older people's well-being in displacement settings.

Refugees Living with Disabilities (RLWD)[1]

The WHO International Classification of Functioning, Disability and Health (ICF) and the UN Convention on the Rights of Persons with Disabilities (CRPD) use a biopsychosocial model of disability that is not based on individual traits, but instead a contextual result of societal-individual interactions (ICF, 2001; UNHCR, 2019). Adopting this approach, refugees living with disabilities can be understood as including "those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, hinder their participation in society on an equal basis with others" (UNHCR, 2019, p. 9). There are no official statistics of the global prevalence of RLWD; however, a conservative estimate of 12 million people in forced migration contexts are living with disabilities (International Organization for Migration [IOM] | Migration Data Portal, 2023). In refugee settings, persons with disabilities often face barriers that restrict their access to essential services, such as healthcare, psychosocial services, education and employment opportunities. The unique challenges faced by refugees living with disabilities necessitate specialized and inclusive MHPSS strategies that address specific needs, leverage individual and community strengths, and promote dignity.

Refugee Status Determination (RSD)

RSD is the process of determining whether asylum applicants are granted refugee status — based on guidelines established in the 2021 Refugees Act of Kenya and the 1951 UN Refugee Convention. RSD is managed by the Kenyan Department of Refugee Services. As of January 2024, Kenya has nearly 170,000 pending cases (UNHCR, 2024c).

Social and Structural Determinants of Health (SSDOH)

SSDOH are non-medical factors that influence health outcomes, such as the conditions in which people are born, grow, live and age (WHO, n.d.). Upstream factors, including societal norms, global and national economic investments, and social policies, play a pivotal role in health and well-being (Braveman & Gottlieb, 2014). These determinants shape a wide range of health and quality of life outcomes and risks relevant to MHPSS. Addressing these social and structural determinants of mental health requires integrated efforts that go beyond the capacity of any single sector to reduce disparities and promote mental health equity.

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[1] We use 'OR' and 'RLWD' for older refugees and refugees living with disabilities, respectively. These are not common initialisms and we solely did this to enhance clarity and readability in the report and toolkit. We wish to acknowledge that we adopted the person-first language considered respectful in our settings and used in the UN Convention on the Rights of Persons with Disabilities, but that what is considered respectful terminology varies across regional, sociocultural and individual contexts (UNHCR, 2019).

HESHIMA Assessment Report

Assessment Overview & Key Findings

A Snapshot of Kenya as a Refugee-Hosting Country

Kenya is one of the top five refugee-hosting countries in Africa and ranks as the 13th largest asylum country globally in 2024 (UNHCR Kenya, 2024a). Most refugees and asylum seekers in Kenya are from protracted situations (UNHCR Kenya, 2024a), remaining in exile for more than five consecutive years because it is unsafe to return to their countries of origin. Many spend decades in limbo — unable to return home or integrate into Kenya's socioeconomic fabric.

As of July 2024, Kenya hosts 782,468 registered refugees and asylum seekers (UNHCR, 2024b), 86% of whom reside in the Dadaab refugee camp complex and the Kakuma camp and Kalobeyei settlement areas. The remaining 14% of individuals reside in cities and towns (UNHCR, 2024b). Importantly, the numbers of urban refugees in Kenya have steadily increased over the past decade, following global urbanization trends. The largest numbers of refugees and asylum seekers in Kenya originate from Somalia (55.9%) and South Sudan (24%). Smaller populations include those from the Democratic Republic of the Congo (DRC; 7.8%), Ethiopia (5.1%), Burundi (4.1%), Sudan (1.5%), Uganda (0.5%), Eritrea (0.5%), Rwanda (0.4%) and other countries (0.2%) (UNHCR, 2024b).

In Nairobi, Kenya's capital city and the primary location for refugees outside of encampment areas, more than 100,000 refugees and asylum seekers live alongside Kenyans and seek to integrate into the host society. Those from DRC and Somalia make up the largest shares of refugees in Nairobi. There are also large communities from Ethiopia and South Sudan as well as several smaller groups from the Great Lakes and Horn of Africa sub-regions (UNHCR, 2024b). In some instances, groups may congregate in specific neighborhoods in Nairobi, such as in the Eastleigh neighborhood that has been nicknamed "Little Mogadishu" due to the large number of both Somali refugees and ethnic Somali Kenyans (Carrier & Kochore, 2019; Jansen, 2019). Many Oromo refugees from Ethiopia also call Eastleigh home, as socio-religious characteristics have facilitated their integration into the largely Somali economy of the neighborhood (Carrier & Kochore, 2019). Others, including those from DRC, live in different neighborhoods across Nairobi; however, many ethnic Banyamulenge Congolese refugees prefer the outskirts of the city due to historical persecution and ongoing discrimination from other Congolese nationals (Lyytinen, 2015, 2017; Tippens, 2017). Although this description does not provide a comprehensive portrayal of all refugee populations in Nairobi County, it highlights the intersecting ecological, social and structural factors that shape belonging and inclusion among diverse refugee communities in an urban humanitarian setting.

REFUGEE-HOSTING COUNTRY IN AFRICA

+780k

REFUGEE/ASYLUM SEEKERS IN KENYA

COUNTRY OF ORIGIN	
Somalia	**55.9%**
S. Sudan	**24%**
DRC	**7.8%**
Ethiopia	**5.1%**
Burundi	**4.1%**
Sudan	**1.5%**
Uganda	**0.5%**
Eritrea	**0.5%**
Rwanda	**0.4%**
Other	**0.2%**

Importantly, the Refugees Act that was signed into law in November 2021 provides a comprehensive legal framework aimed at improving the lives of refugees in Kenya. The Refugees Act outlines several provisions for better integration, such as the right to work, access to education and greater freedom of movement (Kituo Cha Sheria, 2021). However, full implementation of the Act has faced challenges, and critical steps are still necessary to allow refugees to live with dignity and contribute to Kenyan society (Refugees International, 2023).

Partnership Approach & Methods

Overview

Amref Health Africa, Amref International University, the Albinism Society of Kenya, HelpAge International Kenya and the University of Nebraska–Lincoln partnered with a community advisory board (CAB) to develop a participatory Mental Health and Psychosocial Support (MHPSS) assessment with older refugees (OR) and refugees living with disabilities (RLWD) in Nairobi. The CAB, comprised of OR and RLWD, determined the direction of research and scope of the toolkit to enhance local relevance for MHPSS stakeholders on the ground.

To inform toolkit's development, CAB members were asked to provide insight into the following areas:

- Stressors experienced by OR and RLWD.
- Signals of emotional and psychosocial distress.
- Coping strategies and resources.
- Experiences of and recommendations for inclusion in decision-making.

Methods

Since the voices of OR and RLWD are largely absent in the humanitarian research, the community assessment provided an opportunity to better understand MHPSS experiences, perspectives and priorities of diverse groups of OR and RLWD in Nairobi. Thus, we used a participatory, qualitative approach to privilege participants' expertise.

Participant Recruitment & Data Collection

OR and RLWD participants were recruited by CAB members and implementing partners at the Albinism Society of Kenya and HelpAge International Kenya.

Amref International University, HelpAge International Kenya, and the Albinism Society of Kenya

Sociodemographic Characteristics Among RLWD & OR

GENDER

12 RLWD
18 OR

20 RLWD
35 OR

AVG. AGE

41	62
RLWD	OR

AVG. YEARS IN KENYA

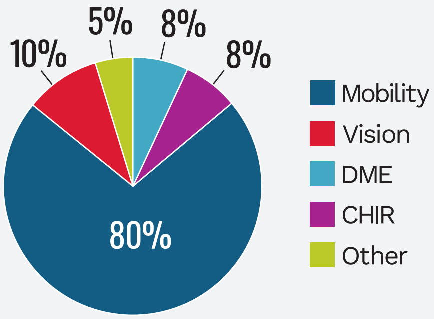
12	14
RLWD	OR

RELIGION

40 Christian
40 Muslim
12 Other

TYPES OF DISABILITIES AMONG REFUGEES

**Some participants listed more than one disability.*



COUNTRY OF ORIGIN

DRC

Ethiopia

Somalia

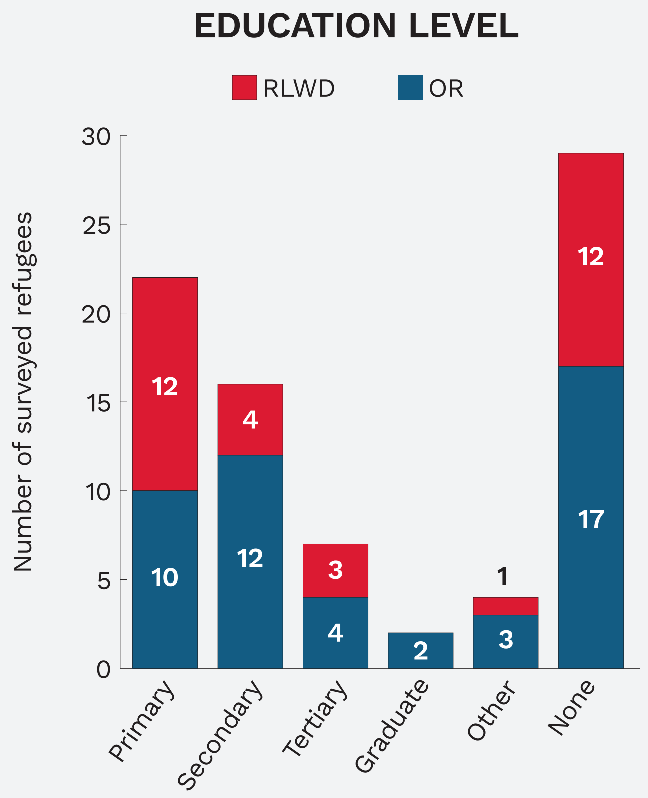
South Sudan

Other

collaborated to recruit research assistants (RAs) with prior experience in data collection and focus group facilitation. Six RAs were trained by Amref International University faculty in research ethics and data collection. RAs conducted 22 focus group discussions with 92 OR and RLWD. Focus groups were disaggregated by nationality, gender, age and disability status to allow for comparisons among diverse groups of participants. Focus groups were conducted in participants' preferred languages, including Aafan Oromo, Dinka, English, Kiswahili, Nuer and Somali. RAs were fluent in English and Kiswahili, and interpreters assisted with all other focus group discussions. A mental health counselor from the Albinism Society of Kenya, who himself lives with albinism, was present for all focus group meetings to support anyone experiencing distress during or after discussions.

Analysis

Researchers at the University of Nebraska–Lincoln led the analysis of focus group discussion data. Focus groups were transcribed verbatim and translated into English. A matrix analysis approach was used wherein data were systematically arranged in a tabular format to facilitate the comparison and contrast of themes across different sociodemographic variables, such as nationality, age, disability status and gender (Averill, 2002). This visual analytic approach is particularly effective for exploring how various social identities and systems of oppression intersect and interact to create unique, complex experiences for OR and RLWD.



Amref International University investigators held two half-day workshops with CAB members to share preliminary findings and gain feedback and additional insights. This additional step is aligned with participatory procedures and helped ensure data analysis and interpretation was aligned with the lived experiences of community members represented in the report and toolkit.

Limitations & Areas for Future Research

Most refugees in Nairobi originate from the DRC, Ethiopia, Somalia and South Sudan. Due to time and resource constraints, our efforts to recruit CAB members and participants predominantly focused on individuals from these countries. Although there were no exclusion criteria based on nationality, and we had CAB members from Burundi and Uganda and participants from Rwanda, individuals from smaller communities were underrepresented in our research. Future MHPSS assessments should identify ways to include these groups as they have unique perspectives and may feel excluded in research (Omata, 2019, 2020).

Our decision to hold focus groups in community settings meant that we were unable to reach OR and RLWD who may be confined to their homes. Housing was a primary concern among participants and future research could examine how OR and RLWD experiences shape experiences with housing and houselessness, the latter defined in the Expert Group Meeting on Affordable Housing and Social Protection Systems for All to Address Homelessness Proceedings in Nairobi (2019) as "a condition where a person or household lacks habitable space, security of tenure, rights and ability to enjoy social relations, including safety. [Houselessness] is a manifestation of extreme poverty and a failure of multiple systems and human rights." This definition is aligned with participants' experiences and would benefit from additional investigation of housing/houselessness as a core determinant of OR and RLWD mental and psychosocial health.

Finally, we chose not to collect data on participants' ethnicity for several reasons: time and resource limitations, concerns from partners about potential perceptions of exclusion or favoritism and the possible sensitivity of ethnic identification in focus group settings. These decisions could limit the granularity of the findings and their applicability to refugee groups across Nairobi County.

Key Findings

Multisystemic Social & Structural Determinants of Mental Health

OR and RLWD emphasized emotional and psychological distress were related to their experiences as refugees in a challenging sociopolitical setting. As such, participants described this as “life stress” rather than “mental stress,” which has significant implications for Mental Health and Psychosocial Support (MHPSS) research, programming and policy decision-making. For example, evidence-based MHPSS interventions using psychoeducational or cognitive reframing techniques are most effective as part of a comprehensive approach that addresses the structural, policy and socioeconomic conditions that affect well-being. This framing also highlights the relevance of a life-course approach to MHPSS for OR and RLWD.

Participants’ descriptions of the causes of distress aligned with the social and structural determinants of health (SSDOH) model, as illustrated in the multisystemic MHPSS conceptual model (Figure 2). Multiple overlapping structures and systems, such as migration status within their host country and lack of access to basic services, were identified as the root causes of psychological distress by OR and RLWD participants. The nesting of these factors within the broader ecosocial-structural model in Figure 2 underscores the interconnectedness of individual, community and systemic influences on mental health and the need for a holistic MHPSS approach.

Migration-Related Determinants of Mental Health & Psychosocial Well-Being

Country of Origin Context

Each refugee has experienced unique threats to safety and well-being, compelling them to leave their homes in search of safety in another country. Several OR and RLWD came from situations where — despite potentially having better economic status or social standing — they faced unbearable conditions, such as war or persecution, that drastically altered their lives. Such experiences are deeply personal and significant sources of trauma, as highlighted by an older Congolese man who fled DRC after witnessing the murder of his family: “My wife died during the war times. That’s why I migrated from Congo to here, in Kenya. She was killed there during the war. My first daughter was shot in front of me; that saddened me, and I decided to migrate to Kenya.”

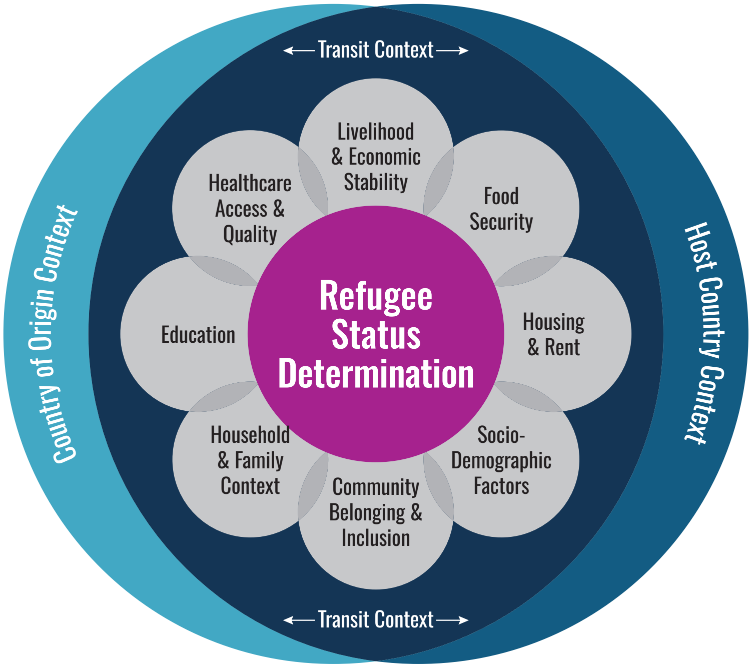


Figure 2: Conceptual Model of Multisystemic MHPSS Among OR and RLWD in Nairobi

Transit Context

The transit phase refers to the migration period between leaving one’s home to reaching Nairobi. This time is often marked by high levels of risk and insecurity as refugees navigate irregular and sometimes dangerous routes, facing risks such as trafficking, exploitation and severe deprivation. These experiences can have profound psychological impacts and may require targeted and integrated MHPSS strategies to address both immediate safety needs and mental health concerns.

Host Country Context

The host country setting is a crucial determinant of quality of life and integration possibilities for refugees. Factors such as local immigration laws, societal attitudes toward refugees, economic opportunities, community support, and availability and quality of health and social services shape emotional and mental health outcomes.

Among OR and RLWD participants, **refugee status determination (RSD) was an intersectional determinant of mental health and psychosocial well-being**. Indeed, analysis of focus groups revealed RSD to intersect with all other social and structural determinants of health (SSDOH). In the past decade, researchers have begun to examine migration as a specific SSDOH (Castañeda et al., 2015). In this conceptualization, forced migration is simultaneously a result of SSDOH, such as war or persecution, and a determinant because it so singularly represents a culmination of policy, sociohistorical, and economic factors (e.g., Castañeda et al., 2015).

Individuals fleeing their homes due to war or persecution enter a process of seeking formal refugee status, often referred to as obtaining a “refugee identification (ID)” by participants. As depicted as a key intersectional mental health determinant in Figure 2, obtaining formal status is crucial because it affects nearly every aspect of their daily lives in Nairobi. This formal status results in better livelihood opportunities (e.g., ID required to obtain work permits), education for themselves and their (grand)children, and access to healthcare and life-sustaining services. Those without refugee IDs or who had family members without IDs described a sense of uncertainty, limbo and hopelessness, which are major risk factors for common mental disorders (Gambaro et al., 2020; Patel & Kleinman, 2003).

Proximal Determinants of Mental Health & Psychosocial Well-being

Livelihood and Economic Stability

For OR and RLWD, securing a stable livelihood is fraught with challenges that are both physically and emotionally draining. Across focus groups, financial stressors emerged as a primary source of psychological distress, compounded by barriers such as lack of documentation for work permits, physical limitations, agism, ableism and widespread discrimination.

An older Ethiopian man shared his perspective on the importance of financial stability for mental health: “If someone gets a job, a business or any means to help pay rent at the end of the month, that’s the first thing. [...] If [there is money for food and rent], someone’s stress can reduce by 70%.”

Importantly, the desire for meaningful and dignified work extends beyond financial security for many OR and RLWD. As an older Congolese man shared, “When I got to Kenya, I wasn’t allowed to work, yet I have the capability to work. That caused me problems, to live poorly [despite] having an education and the capability to work. That disturbs me.”

This example highlights that distress not only arises from economic insecurity but also from the inability to use one’s skills and education.

Food Security

Many participants faced significant challenges with food insecurity, largely due to difficulties in finding stable employment. Those responsible for providing for their families experienced considerable distress when they were unable to ensure enough food for everyone. The impact of food insecurity was particularly pronounced among those who also had health issues. For instance, an older Congolese woman shared her struggles with managing high blood pressure in the absence of adequate nutrition: “I was afraid to take [the medication] because if you take them without eating, you might collapse. I told [the organization] I wasn’t able to take the medication, to please help me with a little food. [...] I really get worried to the point where I can’t even sleep.”

Housing and Rent

Securing stable and affordable housing presents significant challenges for refugees, often leading to distress and anxiety about the future. The pressure to pay rent on time can be overwhelming, especially in the context of inconsistent employment and financial instability. This stress is deeply felt in the days leading up to rent due dates, as described by a Somali man living with a disability: “Right now, the owner says if the house is not paid by [due date], the house is locked. If they come for your money and you do not have it, what will you do? Will you sleep outside on the road?”

Healthcare Access and Quality

Access to quality healthcare is a hurdle for many urban OR and RLWD. Participants described issues of mobility, discrimination and inadequate service provision. Attempts to receive medical treatment are often fraught with complications and inefficiencies. An older Ethiopian woman described the frustration of going to a government hospital to be told “refugees should go to [charity health center]”. The health center staff did not treat her and told her to return to the government hospital. These encounters are frustrating and expensive, wasting limited resources and increasing stress.

Education

The inability to access educational opportunities or afford school fees places immense pressure on refugee families. A Congolese woman living with a disability lamented: “Many things cause me stress. The first one is seeing my children just sitting there while others are studying. I don’t feel good about that.”

Another Congolese woman in this discussion agreed, stating that “sometimes the child is sent away from school [because of unpaid fees] and you feel disgraced. Sometimes you are forced to lock them inside the house and tell them not to get out so that no one sees them.”

The educational journey is also challenging for RLWD. A young South Sudanese woman who had lived in Kakuma refugee camp prior to relocating to Nairobi shared that although secondary education was free in the camp, discrimination disrupted her schooling: “As you walk from home to school, struggling on the way [due to a physical disability], we were abused. It’s very tough [and] even caused me to miss school.”

Household and Family Contexts

Household dynamics and family relationships deeply influence the emotional health of OR and RLWD in Nairobi for many, family responsibilities and challenges intensify displacement hardships. For example, a Somali woman living with a disability described distress related to the pressure she felt for her daughter to marry, attributing this to “thinking too much,” a common idiom of distress (Backe et al., 2021; Kaiser et al., 2015).

> **Many things cause me stress. The first one is seeing my children just sitting there while others are studying. I don’t feel good about that.**
>
> *-Congolese woman*

> **Old, mature people like us, we have a vision we wish to fulfill [to] leave our child or grandchild an inheritance. But we’ve been denied that opportunity to fulfill our dreams. Nobody wants to invest in old people.**
>
> *-Congolese man*

> **As a refugee, you don’t feel complete. You feel like you’re in the middle. It’s like a child beginning to stand up, learning how to walk.**
>
> *-Somali woman*

Separation from loved ones due to displacement was another source of psychological and emotional pain for participants. An older Ethiopian man articulated the emotional toll of this separation: "When you flee and come to Kenya, you separate from your family that you've made and love; that's another stress."

Among parents and grandparents, the fear of not being able to provide a better future for their children loomed large. An older Congolese man stated: "Old, mature people like us, we have a vision we wish to fulfill [to] leave our child or grandchild an inheritance. But we've been denied that opportunity to fulfill our dreams. Nobody wants to invest in old people."

Community Belonging and Inclusion

The journey toward community belonging presents a complex landscape of challenges and support for refugees in Nairobi, impacting their mental health and sense of dignity. Discrimination, isolation and stigma were participant-identified barriers to meaningful inclusion, affecting refugees within the host society and their ethnic communities. For example, a Congolese participant shared how Kenyan coworkers and neighbors would yell at her to "go back home to [country of origin]" and mock her for having a disability. She said she eventually began to self-isolate in her room. Similarly, a Somali man described how being nicknamed "one eye" for a facial characteristic by others in his ethnic community negatively affected his sense of self-worth.

Despite these hardships, there were stories of support and encouragement that highlight the potential for positive community interactions. The same Congolese woman said that sharing her struggles with a church friend and community elders helped her: "They told me not to hide myself anymore. I can go to [friends] and talk, or if I can share advice, I will do that. But I no longer hide myself." Other participants described how Kenyan neighbors supported them during difficult times, providing food, paying rent and offering friendship.

Sociodemographic Factors

The experiences of OR and RLWD are shaped by a complex intersection of factors, such as age, (dis) ability, sex (biological) and gender (social), ethnicity and nationality and refugee status determination. These elements intertwine in ways that affect mental health risks, resilience processes and protective factors in humanitarian settings. They also influence experiences of displacement, perceptions of mental health, coping strategies, and access to basic services and resources that promote well-being.

Sensemaking: How OR & RLWD Communicate Experiences of Distress

OR and RLWD experience significant physical health challenges. Participants discussed both visible and invisible health conditions and disabilities, such as severe, chronic pain, back and shoulder injuries, swollen feet and low vision. Several individuals stated their physical pain was so pervasive it created mobility problems. OR attributed their physical health problems to older age; however, both OR and RLWD said their physical health issues were related to high levels of stress and anxiety. They discussed chronic headaches, stomach pain and inability to sleep. Conversely, some OR and RLWD talked about being so distressed that sleeping for the entire day was a way to avoid their realities and relieve anguish, especially when experiencing hunger.

Participants also talked about their significant mental health challenges. They discussed intense feelings of anger, frustration, sadness (e.g., "it makes your soul very weary"), hopelessness, "thinking too much" and lacking a sense of purpose.

One older Congolese man described his mix of physical and mental health challenges in the following way: "You feel like your soul wants to leave your body: some chills, unnecessary heat. Another thing is you might walk with no purpose… you don't know where you're going, you just go. You don't have anything, but your heart just tells you to go. That way, you know your head is disturbed."

"You Feel Like You're in the Middle"

Many refugees experience significant stress when embarking on a new life in a new country, navigating unfamiliar systems, languages and sociocultural norms. OR and RLWD described feeling a sense of inadequacy and explained their constrained circumstances in an unfamiliar nation to newborn infants. For example, a Somali woman living with a disability said: "As a refugee, you don't feel complete. You feel like you're in the middle. It's like a child beginning to stand up, learning how to walk."

Some participants likened refugee status to a form of disability. They reported policy gaps in the provision of support for basic necessities, such as employment, sustenance and access to healthcare. As one man living with a disability from DRC stated: "Being a refugee is a life disability. They see they don't have a job; they don't have food to eat; it's like [policymakers have] abandoned me, and I have that disability."

> **The first thing that can make me happy is having meetings. Meetings are good. When you talk to people and listen to their issues, you might feel that someone has more challenges than you, or he got helped because he talked to people and his anger disappeared. Those meetings are important things that might help someone when stressed.**
>
> *-Congolese woman*

Coping With & Supporting Each Other to Survive

Many OR and RLWD employed self-care strategies to effectively manage stress. They engaged in walking and reading to alleviate tension. Many participants expressed an affinity for reading anything from novels to magazines to the Bible or Quran. One participant described reading as being transported to an alternate realm, providing temporary relief. Some Congolese participants preferred to self-isolate and listen to music to calm their nerves. Nearly all participants expressed having deep faith, depending on God, singing religious hymns or praying to cope.

Moreover, a significant proportion of refugees cope with stress through active participation in social networks, provision of support and helping their fellow refugees. They expressed their affinity for engaging in meetings with fellow refugees. During meetings, they engage in conversations with fellow refugees who face similar difficulties. This experience made some OR and RLWD more appreciative of their own circumstances, motivating them to confront their anger and unhappiness with the situation.

As a Congolese woman stated: “The first thing that can make me happy is having meetings. Meetings are good. When you talk to people and listen to their issues, you might feel that someone has more challenges than you, or he got helped because he talked to people and his anger disappeared. Those meetings are important things that might help someone when stressed.”

Dignity, Belonging & Inclusion

Living in a country where they do not enjoy full citizenship, OR and RLWD described experiencing a state of limbo or “in-betweenness.” Participants felt separated from Kenyans and suspended between their countries of origin and the host country context. Many OR and RLWD wanted simply to be recognized as fellow human beings with basic needs, desires and skills. As one participant said, referencing the importance of being included in livelihood opportunities: “Inclusion is helping us so we can help ourselves, our health and our children.”

OR and RLWD said full inclusion would mean complete integration into Kenyan society wherein they have the same rights as citizens. For example, participants talked about the inability to create stable futures when their children were denied citizenship and the right to work in Kenya. Importantly, there is no clear path to citizenship for refugees or their children, including those born in Kenya (Hassan, 2002; Nandia, 2020), and this challenge is absent in the 2021 Refugees Act. Participants discussed waiting for several years for initial RSD and renewals. Several focus group discussions centered on the right to vote, fair wages, land ownership and access to government assistance for older people and those living with disabilities as fundamental to full inclusion. As one participant said, “We did our part, and we want you to recognize it.” Another participant added, “Don’t wait when we die to say that those refugees helped in the development of Kenya.”

Finally, participants wanted to be included in decision-making processes and for their experiences and perspectives to be considered. OR and RLWD participants felt excluded from policymaking, such as the Refugees Act of 2021. They also advocated for broader representation of OR and RLWD beyond tokenism. Thus, participation in developing solutions was a key indicator of meaningful inclusion for OR and RLWD.

Recommendations

1 Prioritize & Expand Multidisciplinary Collaborations to Strengthen Integrated & Cross-Sector Mental Health and Psychosocial Support (MHPSS) Research

- Insights from OR and RLWD highlighting the distinction between “life stress” and “mental stress” underscore the necessity for a comprehensive approach to MHPSS that addresses various social, economic and structural determinants of health.
- Effective interventions would benefit from the integration of knowledge from multiple disciplines, such as urban planning, public health, social work, anthropology, psychology, and notably, the arts and humanities.
- Taken together, such collaborations can provide a deeper understanding of the multifaceted nature of refugees’ experiences and address the systems that exacerbate mental health challenges.
- Incorporating the arts and humanities into humanitarian MHPSS research can help glean nuanced insight into lived experiences and offer alternative ways to spread findings. For example, photo essays, poetry or music related to findings may help reach different audiences.

2 Prioritize Participatory Research Approaches to Strengthen Data Relevance & Impact of MHPSS Research

- Participatory research methods engage directly with the populations under study, privileging their lived experiences and expertise to involve them in all stages of research. For example, the HESHIMA Community Advisory Board of OR and RLWD directed the scope of this assessment, urging the team to highlight the ecosocial-structural determinants of health.
- By incorporating the perspectives of refugees themselves, participatory research ensures findings and interventions are directly relevant and tailored to the needs and strengths of target communities. This enhances the validity of research and increases the likelihood of research and intervention success.

3 Foster Opportunities for Refugees to Engage Directly with Decision-Makers & Hold Decision-Making Roles

- Engaging refugees directly in decision-making processes — whether for research, programming or policy — shows respect for refugees’ problem-solving skills, while improving alignment with their needs and assets.
- It is important to identify shared governance roles for refugees and integrate their feedback and ideas into all phases of research, from strategic planning to implementation to dissemination.
- Possible avenues for shared governance in MHPSS include community advisory boards, co-design communities, leadership roles in non-governmental organizations or funding with refugee-led organizations as the lead decision-makers. Establishing structured forums and platforms where OR and RLWD can regularly meet with policymakers, program directors and other key stakeholders is another step to facilitate meaningful dialogue and promote refugees’ influence in policymaking.

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HESHIMA
Participatory
Toolkit

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DEVELOPED BY:

Toolkit Overview

The HESHIMA Participatory Toolkit provides tools, activities and reflection/discussion prompts to support the ethical and effective implementation of mental health and psychosocial support (MHPSS) research with older refugees (OR) and refugees living with disabilities (RLWD).

Target audience: Diverse professionals working within the urban humanitarian sector in Nairobi, including program developers, assessment coordinators, monitoring and evaluation specialists, researchers and policy decision-makers.

Toolkit resources are organized within four research topics:

- Ethical Considerations
- Participatory Planning to Enhance Partnerships
- Multisystemic MHPSS Data Collection
- Disseminating & Reporting Findings

Each topic addresses specific aspects of the research process, from ethics and participatory strategies to data collection and dissemination. The toolkit offers practical guidance, ensures ethical standards and promotes inclusive research practices.

Implementation Roadmap

Use this roadmap to navigate the toolkit and select appropriate resources to enhance the impact and integrity of your research, assessments, monitoring and evaluation projects.

Ethical Considerations

1. Overview of MHPSS Research, Monitoring & Evaluation Ethics
2. Ethics Case Scenarios & Guiding Questions
3. Ethical Research Checklist
4. Plain Language Informed Consent Template
5. Probing Consent Questions to Enhance Research Inclusion Among Refugees Living with Intellectual Disabilities

Participatory Planning to Enhance Partnerships

1. Participatory Research Principles
2. Stakeholder Mapping Activity
3. Listening Sessions
4. Give-Get Grid
5. Partnership Roles & Activities Planning Template
6. Inclusive Budgeting Considerations
7. Dimensions of Sustainability: Partner Discussion Prompts

Multisystemic MHPSS Data Collection

1. Inclusive MHPSS Data Collection Considerations
2. Pile Sorting for Multisystemic MHPSS
3. Participatory Resource Mapping

Disseminating & Reporting Findings

1. Collaborative Dissemination Planning: Reflection Prompts
2. Engaging Strategies in Community Dissemination
3. Academic Publication & Authorship Roles: Discussion Prompts
4. Authorship Agreement Template

HESHIMA PARTICIPATORY TOOLKIT

Ethical Considerations

Resources At-a-Glance:

1. Overview of MHPSS Research, Monitoring & Evaluation Ethics
2. Ethics Case Studies & Guiding Questions
3. Ethical Research Checklist
4. Plain Language Informed Consent Template
5. Probing Consent Questions to Enhance Research Inclusion Among Refugees Living with Intellectual Disabilities

Overview of MHPSS Research, Monitoring & Evaluation Ethics

Mental health and psychosocial support (MHPSS) research ethics provide guidelines to uphold the protection, dignity and rights of participants, while maintaining research integrity (WHO, n.d.). Refugees often experience restricted rights in asylum countries and may be vulnerable due to power imbalances within the host society and humanitarian aid organizations.

Older refugees and refugees living with disabilities face compounding difficulties relating to discrimination, exploitation, isolation, and access to vital services and resources. Moreover, many refugees — including those in our assessment — are frustrated by continued research engagement without seeing the results of studies or experiencing improvements to their situations.

There is a tension between the need to collect data for evidence-informed approaches with the duty to protect refugees from possible harms related to research participation (Leaning, 2001; Seagle et al., 2020). Regardless of the purpose of data collection — whether for exploratory or intervention research, monitoring or evaluation—all investigations that include refugees as participants should be conducted responsibly, with safety and dignity at the forefront. Therefore, all research-related activities should, at minimum, adhere to beneficence, justice and respect for persons (Belmont Report, 1979).

In addition to these three principles, those collecting data with refugees face a "dual imperative" to ensure both the soundness (i.e., design, implementation and analysis to produce good results) and policy relevance of research (Jacobsen & Landau, 2003).

Key Principles of Research Ethics

- **Beneficence** means "do no harm." The potential benefits of research participation should outweigh the possible risks.
- **Justice** refers to the fair distribution of benefits and burdens of research. Older refugees and refugees with disabilities have largely been neglected in research that informs humanitarian programs; just or fair research strives to include these historically excluded populations.
- **Respect** for persons[1] means treating individuals as autonomous and providing additional protections to those with diminished autonomy. This principle underscores the importance of obtaining informed consent and reminding participants that their involvement is entirely voluntary, and that they can stop participating at any time.

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[1] Respect for persons in specific sociocultural contexts may be better understood as **respect for communities**. It is therefore important to work in partnership with local stakeholders to understand respectful engagement with both communities and the individuals who make up these communities.

Ethics Case Scenarios & Guiding Questions

The following case studies provide examples of ethical situations that may occur during Mental Health and Psychosocial Support (MHPSS) research. These examples emphasize the importance of upholding **beneficence**, **justice** and **respect for persons**. Guiding questions are meant to facilitate conversations among researchers, assessment teams, monitoring and evaluation (M&E) specialists and data decision-makers, supporting efforts to design inclusive research procedures that uphold the human dignity and protection of refugees in their own specific contexts.

BENEFICENCE

CASE SCENARIO 1A: Potential Re-Traumatization

Description

Researchers are planning a community assessment to understand mental health and psychosocial support (MHPSS) priorities among older refugees. They want to use in-depth interviews to gain deeper insight into the contexts affecting mental health and help-seeking among elders. None of the interview questions specifically probe for past trauma; however, researchers are concerned about the potential for re-traumatization of participants who have experienced conflict and human rights violations.

Guiding Questions

- How can researchers develop a trauma-informed approach to support the emotional well-being of participants during and after data collection?
- What psychological or psychosocial resources are available for older refugees who may experience distress during in-depth interviews?
    - » How accessible are these for those experiencing limited physical mobility, have limited transportation or lack authorization to reside outside of a refugee camp?

CASE SCENARIO 1B: Refugee Status Determination

Description

A humanitarian think tank team is interested in examining associations between refugee status determination (or a “Refugee ID”) and mental health outcomes among refugees living in Nairobi. Although the 2021 Refugee Act introduced new rights for refugees living outside of camps, including participation in social and economic sectors, urban refugees remain vulnerable to extortion and harassment, especially when lacking a refugee ID card.

Guiding Questions

- What steps can be taken to ensure the confidentiality and anonymity of participants, especially concerning sensitive information about their legal status and mental health?
- What information about potential risks should be included in discussions with community members and individuals regarding informed consent?

⊕ JUSTICE

CASE SCENARIO 2A: Disability Inclusion

Description

A humanitarian NGO is evaluating the effectiveness of a group-based psychosocial program aimed at improving urban refugees' emotional well-being. To reduce the stigma associated with MHPSS programs, groups meet at community centers and are facilitated by a community health worker. About halfway through the 12-week intervention, NGO staff realized 90% of participants were able-bodied and that they had unintentionally excluded refugees with disabilities. Moreover, interventions based on these findings may benefit mainly able-bodied refugees.

Guiding Questions

- What mid-course corrections can be taken to address the identified issue? How might such corrections affect the results and what are the broader implications of these changes?
- What steps can be taken to reach refugees living with disabilities? And how can this be integrated into the intervention/program design?
- How can the NGO team distribute the potential benefit of research among refugees equally, regardless of age or disability status?

CASE SCENARIO 2B: Inclusion of Minoritized Ethnic/Nationality Groups

Description

A local refugee-led organization (RLO) received funding to establish a community advisory board (CAB) of older refugees and refugees with disabilities to enhance inclusive MHPSS monitoring and evaluation (M&E) data collection to guide programming. The grant provides stipends for 10 CAB members. RLO leadership decided to select members from nationalities with the largest populations in the area. When members of smaller ethnic communities heard about the CAB, they felt overlooked and wanted the CAB to be expanded to share their unique perspectives as underrepresented communities. Many also said it was unfair that only select nationalities/ethnicities were able to benefit financially (i.e., the stipend) and expressed concern that they might be excluded from M&E data collection in the future without representation on the CAB.

Guiding Questions

- How can the RLO enhance inclusion of underrepresented community members on the CAB, particularly with limited resources?
- Should the CAB be expanded to include all groups, regardless of population size?
- Are there processes to distribute possible benefits (e.g., financial, social) of CAB membership across groups?

⊕ RESPECT FOR PERSONS

CASE SCENARIO 3A: Community Consent

Description

Researchers at a university in Nairobi are interested in evaluating whether cash transfers affect mental health outcomes among older refugees and those living with disabilities. Before study enrollment, the team meets with RLO leaders to learn if this would be appropriate in the local context. Although researchers showed respect by first approaching community leaders, there were no elders or persons with disabilities present during these stakeholder meetings.

Guiding Questions

- How can researchers identify and engage older refugees and those with disabilities who are the target study population?
- How will ongoing engagement with older refugees and refugees living with disabilities be maintained throughout the research process, including sharing findings with these stakeholder groups?

CASE SCENARIO 3B: Informed Consent Intellectual Disability

Description

Zawadi is a 26-year-old refugee from the eastern Democratic Republic of the Congo who lives with her mother. Zawadi has had a mild intellectual disability since birth. A local disability rights coalition is evaluating access to disability-inclusive services among refugees. Before conducting a survey with Zawadi, data collectors described the study to her mother and received permission from her as the caregiver; however, Zawadi was in the other room at the time and not present to learn about the assessment purpose, procedures or voluntary nature of participation.

Guiding Questions

- What could the data collectors do to rectify the failure to obtain consent? What could they have done differently? Why might these different actions be important?
- What procedures can be implemented to fairly assess Zawadi’s capacity to give informed consent? Who should be involved in this assessment and what expertise might they need?
- How can data collectors ensure Zawadi is appropriately informed of what data will be collected, the purpose(s) of the data collection, and how and with whom the data will be shared?
- How can teams design assessments that include persons with intellectual disabilities at all stages of research?

Ethical Research Checklist

This checklist[2] is designed to assist with navigating the complex ethical landscape of Mental Health and Psychosocial Support (MHPSS) research with refugee populations. While not exhaustive, it provides a foundation for teams to adapt and expand, depending on specific project needs and goals. Use this as a starting point to ensure research practices uphold ethical standards and protect refugee participants from research-related risks.

	Ethical Engagement Strategies	Helpful HESHIMA Tools
Planning Phase	☐ Identify and engage diverse stakeholders to assess priorities, determine data needs, and enhance policy and practice implications. ☐ Prepare a desk review to identify existing data to potentially reduce the burden of over-research on refugees (Greene et al., 2017). ☐ Identify under-researched refugee groups (Omata, 2020) — such as OR, RLWD and those in small communities — to understand their unique lived experiences, privilege their voices, and gain nuanced insights into MHPSS needs and assets. ☐ Consider potential research risks among specific individuals or communities and establish a protection protocol (e.g., heightened privacy for LGBTQI+ individuals). ☐ Budget for ethical practices, such as compensating participants for their time, providing meals or providing support services needed due to distress caused by research participation.	• Listening Sessions • Stakeholder Mapping Activity • Give-Get Grid • Partnership Roles & Activities Planning Template
Implementation Phase (e.g., recruitment, data collection, analysis)	☐ Include ethical guidance in data collector training and role-play potential scenarios. ☐ Work with community members to determine when and where data collection should take place (e.g., avoiding home-based data collection during mealtimes so families do not feel obligated to share scarce resources, considering prayer times of diverse religious communities). ☐ Ensure potential participants know their rights in research and provide them with informed consent copies. ☐ Consider iterative consent, as well as creating visual informed consent forms, to account for lower literacy among some participants. ☐ Provide participants with free or low-cost MHPSS resources available to refugees. ☐ Consider having a mental health counselor present during group discussions to aid those experiencing distress.	• Overview of MHPSS Research, Monitoring & Evaluation Ethics • Ethics Case Scenarios & Guiding Questions • Plain Language Informed Consent Template • Probing Consent Questions to Enhance Research Inclusion Among Refugees Living with Intellectual Disabilities
Reporting, Sharing & Dissemination Phase	☐ Ensure anonymity and confidentiality in all reports and presentations. ☐ Share preliminary findings with participants, community members and other stakeholders. ☐ Provide research findings in diverse and accessible formats, such as community forums, multilingual reports and infographics.	• Collaborative Dissemination Planning: Reflection Prompts • Engaging Strategies in Community Dissemination • Academic Publication & Authorship Roles: Discussion Prompts

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[2] Seagle et al. recommended several of these strategies and additional ethical considerations in their review of refugee research ethics (see section references).

Plain Language Informed Consent Template

Consent forms must use clear, concise and well-organized language to help potential research participants understand what is involved and allow them to make an informed decision about joining a study. Use the following template of a plain language informed consent form to ensure the information is accessible to a wide range of people.

Invitation to Join [Study Name]

Overview

Thank you for thinking about joining our mental health and psychosocial support assessment. We are [organization name(s)] and we want to learn more about the experiences of [specific group(s), such as older refugees] to improve supports and resources in [location/community].

We reached out to you because [Reason(s) for Inclusion, e.g., age, ethnicity].

- Do you have any questions about why we are doing this assessment?

Participation Details

If you decide to join, you might do one or more of the following:

- Take part in an interview or group discussion, which will last about [length of time].
- Fill survey, which will take about [length of time] to complete.

Voluntary Participation

You do not have to participate if you do not want to. You can also stop at any time or skip any questions that make you feel uncomfortable. Not participating will not affect [relationships or benefits, such as those associated with our organization or access to services].

Confidentiality

We will keep your information safe and secure [describe storage method, such as in a password-protected digital folder]. Only our assessment team will have access to it. However, we can't control what others might do with information shared in a group setting. We will remove any details that could be used to identify you in our reports.

Benefits and Risks

You may not benefit directly from participating. However, you will be helping us improve services for others. Talking about your personal or sensitive issues might be upsetting; support will be available during and after if needed [describe available support, such as a mental health counselor].

- Do you have any questions about participating in this assessment?
- Is there any reason you might not want to participate?

Consent

By signing this consent form, you are voluntarily choosing to participate in [study name].[3]

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[3] Please note that consent may be verbal; this decision is best made with community stakeholders and ethical review boards.

Probing Consent Questions to Enhance Research Inclusion Among Refugees Living with Intellectual Disabilities

Although there is growing guidance on enhancing disability inclusion in research, those with intellectual disabilities remain particularly excluded because they may be perceived as lacking capacity to provide informed consent (Horner-Johnson & Bailey, 2013; Tanabe et al., 2018). However, many individuals with intellectual disabilities can understand information and make informed decisions with appropriate approaches and support (Tanabe et al., 2018).

In a participatory research project with RLWD, Tanabe et al. (2018) used an interactive, iterative consent (adults)/assent (minors) process during recruitment to enhance communication between the research team and potential participants. This included three opportunities for RLWD to learn about research procedures and determine if they wished to participate:

1. Community and home visit awareness raising.
2. Initial participant recruitment.
3. Final consent immediately prior to research activities.

Probing Consent Questions

Tanabe and colleagues (2018) also used six questions to improve understanding of the research purpose, activities, risks and benefits, and participant rights. The questions are similar in nature to the six-question assessment developed by Horner-Johnson & Bailey (2013) to assess capacity to consent. Such tools can help expand inclusion of refugees living with intellectual disabilities, and lead to a better understanding of their unique needs and experiences.

During the initial recruitment period, potential participants were asked:

1. What will we be talking about in the activity?
2. How long will the activity be?
3. Can you think of a reason why you might not want to participate?
4. If you do not want to answer any questions, what can you do?

Participants were required to answer questions 1 and 4 correctly to participate. If they did not answer the required questions and still wished to participate, the research team sought consent from a caregiver or family member.

Immediately prior to activities, the facilitator repeated questions 1-4 and added:

5. When would I have to tell someone else what you have told me?
6. Are you still happy to take part in this study?

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HESHIMA PARTICIPATORY TOOLKIT

Participatory Planning to Enhance Partnerships

Resources At-a-Glance:

1. Participatory Research Principles
2. Stakeholder Mapping Activity
3. Listening Sessions
4. Give-Get Grid
5. Partnership Roles & Activities Planning Template
6. Inclusive Budgeting Considerations
7. Dimensions of Sustainability: Partner Discussion Prompts

Participatory Research Principles

Ethical Mental Health and Psychosocial Support (MHPSS) research with refugees is nuanced, requiring specific approaches that are adapted to fit the unique contexts in which they live. One way to enhance ethics in research is by using participatory research, monitoring and evaluation strategies, including older refugees and refugees living with disabilities in **all stages** of project planning, recruitment, data collection and analysis, and findings dissemination.

Key Principles for Participatory Research

Dunia, a refugee from the DRC and a member of the community advisory board, holds a sign in Lingala that says, "Nothing About Us, Without Us!"

Israel et al. (2005) established the following key principles to guide community-based participatory research:

- Recognize the community as a unit of identity.
- Build on community strengths and resources.
- Facilitate collaborative and equitable partnerships across research stages.
- Promote co-learning and capacity building among all partners.
- Balance research and action for the benefit of all partners.
- Emphasize local relevance of challenges and ecological perspectives to attend to the multiple determinants of health.
- Involve a continuous and iterative process to establish and sustain community-academic partnerships.
- Disseminate findings and knowledge gained to all partners and involve all partners in dissemination processes.
- Establish a long-term process and commitment that considers sustainability.

Stakeholder Mapping Activity

An important step in participatory Mental Health and Psychosocial Support (MHPSS) research, assessment, monitoring and evaluation is engaging diverse stakeholders. Stakeholder maps enhance research by enabling teams to identify and analyze the roles, influence and interests of relevant persons, groups and organizations. This information can be used to develop partnerships, create tailored engagement strategies across humanitarian sectors, and ensure diverse voices are heard and valued. Use this helpful tool to identify stakeholders, organize stakeholder information and identify relevant individuals to engage in the research.

Stakeholder Mapping Steps

STEP 1: Identify Stakeholders

Name	Role in the Project or Community	Organization	Potential Interest(s)	Contact Information
Ex. Bahati	*Community leader*	*Refugee-led organization (RLO)*	*RLO has peer outreach MHPSS programming*	*Bahati@luck.com*

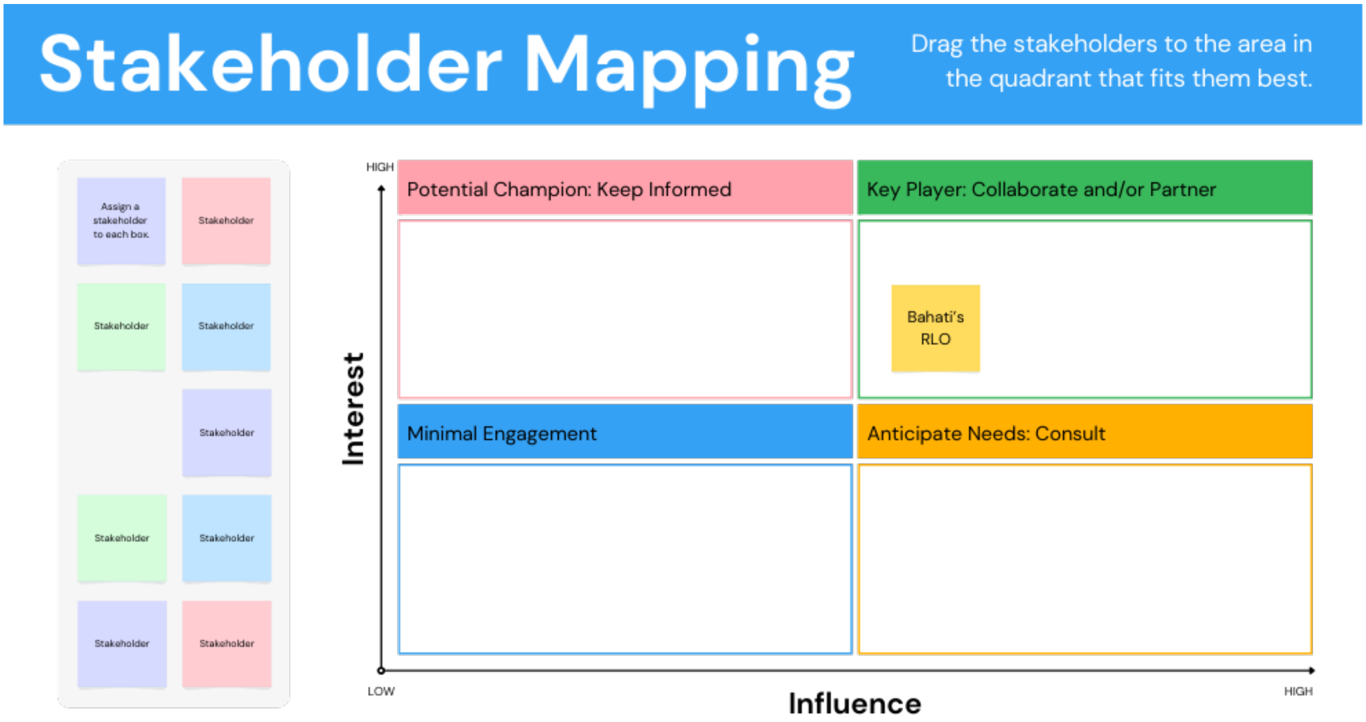
STEP 2: Complete Stakeholder Map

Stakeholder maps are based on two dimensions: **interest** and **influence**. These dimensions are often displayed on a quadrant where each section represents:

- *High interest–high influence*
- *High interest–low influence*
- *Low interest–high influence*
- *Low interest–low influence*

Stakeholders who are high in both interest and influence are the most likely partners and should have the highest engagement. These people may play decision-making roles, such as advisory board members. On the other hand, low interest–low influence stakeholders require lower engagement and could be kept informed at regular meetings or through newsletters.

Stakeholder Map Example



Objective

To organize and visualize stakeholder information and identify relevant individuals to engage in research.

Materials Needed

Stakeholder mapping can be done with physical materials:

- Flipchart
- Sticky notes
- Markers, pens or pencils

This process can also be done using digital tools. Examples with existing templates and collaborative spaces include:

- Canva Whiteboard[4] (canva.com)
- FigJam (figma.com/figjam)
- LucidSpark (lucidspark.com)
- Microsoft Whiteboard (whiteboard.office.com)
- Miro Visual Workspace (miro.com)
- Mural (mural.co)

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[4] The stakeholder visualization in this toolkit was created using the Stakeholder Mapping Whiteboard template in Canva.

Listening Sessions

When working to improve mental health among older refugees (ORs) and refugees living with disabilities (RLWDs), it is important to hear directly from people who are living and working in these communities. The Stakeholder Mapping Activity can help you identify these individuals and how to best engage them.

Our findings suggest many refugees feel excluded from policy planning efforts by organizations, governmental agencies and researchers that are designed to improve their lives. ORs and RLWDs feel that communication and action planning often occur *about* them — but not *with* them. Thus, they want a "seat at the table" and the opportunity to inform any policies and efforts that are directed toward them. Efforts should be made to have a wide diversity of ORs and RLWDs to ensure future actions have meaningful representation and effectiveness.

Hosting inclusive listening sessions is one way to hear perspectives from diverse **community members** and **other stakeholders**.

Key Considerations for Inclusive Listening Sessions

- When working with community members, researchers and organizations should be prepared to communicate with ORs and RLWDs in person, as many community members may not have access to technology.
- Researchers and organizations should prepare to compensate community members for their time in various ways, including money, food and transportation reimbursement.
- Translators should be available to provide services in refugees' preferred languages.
- Community conversation guides can be used to facilitate discussion about what community members and stakeholders believe is most important in creating meaningful social change.
- Ask open-ended questions to encourage active participation and to hear new and possibly unexpected thoughts, ideas and perspectives.
- Some participants may be more vocal than others in responding to questions. One way to encourage more participation is to ask everyone to write thoughts, ideas and questions on note cards or Post-it notes. This ensures everyone has a chance to express their ideas, even if they do not verbally share them.
- If stakeholders (e.g., government agencies, humanitarian organizations) need to meet online, consider using tools such as Google Jamboard or Miro, interactive digital visualization and collaboration spaces. These online tools use digital Post-it notes to record and organize participants' thoughts, ideas and questions.

Engaging Other Stakeholders

When working with stakeholders, efforts should be made to contact a wide variety of people who can inform any future research and action planning. For efforts involving ORs and RLWDs, possible stakeholders include government agencies overseeing refugee policies, global humanitarian organizations; and local, regional, and national non-profit organizations to advocate on behalf of refugees. [The Stakeholder Mapping Activity and Give-Get Grid in this toolkit are useful in stakeholder identification and action planning.]

Listening Session Questions

Below are some questions you may ask community members to capture a broad range of responses, ideas and perspectives. This is not an exhaustive list, and teams may wish to add or refine these example questions based on specific project goals.

1. Is there anyone who is not here who should be here?
2. What do you think is important for us to know about what it is like to be an older adult refugee and/or a refugee living with disabilities?
3. What should policies include to better help older adult refugees and/or refugees living with disabilities?
4. What programs should exist to best support older adult refugees and/or refugees living with disabilities?
5. What decisions do you need to make in your role(s)? What types of data or information do you need to make these?
6. What resources do you need to better help older adult refugees and/or refugees living with disabilities?
7. Is there anything we have not covered in this listening session that we should? *Or* What else would you like us to know?
8. Who else needs to know about these topics/research findings?

Building Trust and Enhancing Data Relevance

Several OR and RLWD in the HESHIMA project expressed frustration about research findings not being shared with them after their participation in research, monitoring and evaluation projects. During initial listening sessions, it is helpful to plan a future meeting or workshop to share findings/results and seek participant feedback prior to finalizing the project. This iterative approach shows respect for community expertise and strengthens the accuracy and relevance of research findings and evidence-based recommendations.

Give-Get Grid

Research partnerships work best when everyone involved knows what they can expect to gain and the contributions they are expected to make.

The Give-Get Grid is a powerful tool designed to foster transparent and equitable partnerships (Behringer & Richards, 1996; Southerland et al., 2013). Using this grid early in the partnership and project phases helps align partner expectations and contributions. The structured format facilitates the discussion of anticipated benefits (“gets”) and contributions (“gives”) among collaborators, fostering mutually beneficial relationships built on collective strengths and assets. By incorporating the Give-Get Grid into participatory MHPSS projects, users can create more structured, effective and equitable collaborations.

How to Use the Give-Get Grid

1. Initial Set Up

- Explain the purpose of the Give-Get Grid to ensure all partners understand the importance of clear and honest communication.
- Introduce the grid as an essential tool to establish a common understanding and align partnership goals.

2. Fill the Grid

- **Individual Reflection:** Ask partners to respond to the following questions:
  - » (i) How do I, or does my organization, hope to benefit from this partnership/project?
  - » (ii) How can I, or can my organization, contribute to this partnership/project?
- **Group Discussion:** Ask partners to share their entries in a facilitated discussion. This process helps clarify expectations, reveal any misalignments, and foster mutual understanding and shared decision-making.

3. Analysis and Negotiation

- **Identify Common Goals:** Use the entries to identify common interests and goals that benefit all parties. This can help create shared objectives.
- **Discuss and Adjust:** Discuss potential discrepancies or conflicts in the grid. Partners should negotiate to find balanced solutions that address the needs and contributions of all collaborators.

4. Action Planning

- Develop an action plan that outlines action steps based on the agreed upon “gives” and “gets.” The plan should include specific tasks, responsible parties and timelines.

5. Monitoring and Evaluation

- Set regular intervals to update the action plan and reassess expected benefits and contributions of partners. Use these check-in times to evaluate the balance of “gives” and “gets” among partners.

Give-Get Grid Example

Researchers from a Nairobi-based university are teaming up with leaders of a local refugee-led organization (RLO) to evaluate a peer-based mental health intervention. In responding to the Give-Get assessment questions, researchers aim to expand their impact into the community and understand the real-world application of an MHPSS model. They also hope to contribute research expertise. RLO leaders are interested in identifying low-cost program models and mental health training to enhance well-being in the communities they serve in Nairobi. They inform the team that they can serve as community liaisons and provide staff to implement the evaluation.

Partner	Gives (Contributions)	Gets (Expected Benefits)
University	• *Expertise in research design and data analysis.* • *Training for RLO members on research and mental health techniques.* • *Leadership on publications and reports.*	• *Real-world application of MHPSS theoretical model.* • *Enhanced reputation through community engagement.* • *Access to authentic field data.*
RLO	• *Access to local communities and community trust.* • *Local knowledge and cultural insights.* • *Staff to implement project and collect data.*	• *Capacity building in research skills and mental health techniques.* • *Development of tailored MHPSS for local communities.* • *Increased visibility and influence within and beyond the community.*

Give-Get Grid Template

Partner	Gives (Contributions)	Gets (Expected Benefits)

Partnership Roles & Activities Planning Template

This template is designed to help implement participatory principles in research, assessment, monitoring and evaluation efforts with refugees. Based on the participatory principles outlined by Israel et al. (2005), this tool outlines roles and activities for community and organizational partners throughout the various research phases. By emphasizing collaboration, promoting co-learning and building on community strengths, this template helps ensure activities benefit all partners involved and that standards of respect, empowerment and equity are embedded into research processes.

How to Use the Planning Template

1. Review the different stages of research projects with partners.
2. Discuss the activities needed to complete the project and decide who should complete these activities based on each partner's specific needs and strengths.
3. Customize the template to fit the local context and project goals, and assign roles and activities for each partner.

Partnership Roles and Activities Planning Template Example

Note: The template below includes examples of typical research roles. Roles will vary for different projects.

<table>
<tr><th colspan="3">STEP 1: Identification of Research Priorities & Question</th></tr>
<tr><th>Community-Based Participatory Research (CBPR) Principles*</th><th>Community Partner Roles & Activities</th><th>Organization Partner Roles & Activities</th></tr>
<tr><td>• Recognize the community as a unit of identity.
• Involve a cyclical and iterative process to develop and maintain community/research partnerships.
• Achieve a balance between research and action that mutually benefits both science and the community.</td><td><i>Examples:</i>
• <i>Determine project scope.</i>
• <i>Share community priorities and concerns.</i></td><td><i>Examples:</i>
• <i>Identify benefits for the project and community.</i>
• <i>Conduct monthly informational meetings (e.g., advisory boards).</i></td></tr>
<tr><th colspan="3">STEP 2: Research Design</th></tr>
<tr><td>• Build on the strengths and resources of the community.
• Promote co-learning among research partners.
• Focus on local relevance of public health problems and ecological perspectives that address the multiple determinants of health.
• Facilitate a collaborative, equitable partnership in all phases of research.
• Involve an empowering and power-sharing process that attends to social inequalities.</td><td>• <i>Develop recruitment and data collection strategies and methods collaboratively.</i>
• <i>Share ideas on how to tailor measures and methods to fit the community and cultural context.</i></td><td>• <i>Provide potential research designs and strategies.</i>
• <i>Develop recruitment and data collection strategies and methods collaboratively.</i>
• <i>Obtain IRB approval.</i></td></tr>
</table>

STEP 3: Data Collection		
• Achieve a balance between research and action that mutually benefits both science and the community. • Facilitate a collaborative, equitable partnership in all phases of research. • Involve an empowering and power-sharing process that attends to social inequalities.	• *Assist in participant recruitment.* • *Participate as key informants and stakeholders.* • *Promote the research study.*	• *Conduct recruitment, focus group discussions and cognitive interviews.*
STEP 4: Data Analysis		
• Facilitate a collaborative, equitable partnership in all phases of research. • Involve an empowering and power-sharing process that attends to social inequalities. • Involve a cyclical and iterative process to develop and maintain community/research partnerships.	• *Review preliminary analysis and findings.* • *Provide feedback and interpretations.*	• *Receive input and feedback from community members on findings, interpretations and recommendations*
STEP 5: Dissemination & Sustainability		
• Disseminate knowledge gained from the CBPR project to and by all involved partners. • Require long-term commitment from all partners. • Facilitate a collaborative, equitable partnership in all phases of research. • Involve an empowering and power-sharing process that attends to social inequalities.	• *Assist in identifying appropriate methods and avenues for dissemination.* • *Participate in dissemination.*	• *Disseminate findings to the community (e.g., town halls, social media, flyers, brochures).* • *Plan next steps based on findings (e.g., policy briefs, follow-up research, support and sustain programs).*

Key principles of CBPR based on Israel et al. (2005). Please note that these principles may appear at different phases depending on the uniqueness of specific MHPSS projects and contexts.

Partnership Roles and Activities Planning Template

STEP 1: Identification of Research Priorities & Question		
Community-Based Participatory Research (CBPR) Principles*	Community Partner Roles & Activities	Organization Partner Roles & Activities
STEP 2: Research Design		
STEP 3: Data Collection		
STEP 4: Data Analysis		
STEP 5: Dissemination & Sustainability		

**Please refer to Isreal et al.'s key principles of CBPR in the Participatory Research Principles document on page 33.*

Inclusive Budgeting Considerations

A project budget is a reflection of values. An ethical budgeting approach prioritizes fairness, transparency and inclusion, which are crucial for allocating support in Mental Health and Psychosocial Support (MHPSS) projects involving older refugees (OR) and refugees living with disabilities (RLWD). Emphasizing community partnership and ownership helps ensure participants are not excluded or disadvantaged due to financial oversight. Moreover, transparent and collaborative budgeting also increases credibility, trust and sustainability ,while demonstrating a commitment to ethics (Murphy et al., 2022).

Components of Ethical Budgeting[5]

1. **Equitable Allocation of Resources**. Ensuring budgetary allocations reflects the specific needs of partners and participant groups, including age- and disability-specific accommodations.
2. **Transparency**. Making financial decisions and budget allocations transparent by sharing documentation with all partners to ensure clarity and accountability.
3. **Compensation and Incentives**. Providing fair compensation for participants' time and contributions to avoid exploitation in research, monitoring and evaluation. This may include transportation costs, caregiver support and other necessities that enable participation.
4. **Accessibility and Inclusivity**. Allocating funds to make all research stages accessible. This may include investing in accessible venues, printing materials in large print or Braille, sign language interpretation, using plain language, and other modifications discussed with OR and RLWD as budget partners.
5. **Community Engagement**. Including provisions for engaging with diverse stakeholder groups through consultations and feedback sessions to ensure the project is locally relevant.
6. **Dissemination**. Allocating funds for diverse forms of dissemination beyond academic publications. This includes community feedback forums, infographics, webinars or reports for lay audiences.
7. **Sustainability and Capacity Building**. Considering training and capacity building for local researchers and frontline mental health workers (e.g., community health workers, peer support specialists) to ensure the sustainability and broader impact of research.

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[5] Murphy, Evans and Minutti-Meza recommended several of these strategies and additional participatory procedures in their article on Participatory Budgeting as Community-Based Work (see section references).

Dimensions of Sustainability: Partner Discussion Prompts

Following community-based participatory research (CBPR) guidelines, a long-term commitment to community priorities is essential in meeting the community's goals for social change (Key et al., 2019). Several OR and RLWD expressed frustration about participating in projects without being informed of results or benefiting from research. This is often called "helicopter research," where researchers parachute in to conduct research and leave once data are collected (LaVeaux & Christopher, 2009). Thus, it is critical that researchers meaningfully involve refugees in all stages of the research process (Filler et al., 2021). An ongoing challenge in participatory research is defining, measuring and evaluating sustainability efforts. Some sustainability goals are more appropriate than others, depending on a specific project's objectives. Following Scheirer et al. (2017), we suggest researchers and community members co-create sustainability goals.

Dimensions of Sustainability & Partner Discussion Prompts

For each dimension, we developed prompts to help partners develop sustainability goals:

☐ Sustained Benefits for Individuals

Determining whether benefits or outcomes for consumers, clients or patients are continued after the study/intervention ends (if services to individuals are provided).

- How will we assess if the study/intervention has created a positive change for community members?
- How will we assess if community members have sustained benefits over the long-term?

☐ Continuation of Program Activities

Continuing the program activities or components of the original study/intervention.

- Which parts of the study/intervention do we want to continue after the study/intervention is finished?

☐ Maintenance of Partnerships

Maintaining community-level partnerships or coalitions developed during the funded program.

- How do we want to continue to work together after this study/intervention ends even if the study/intervention does not continue or we do not have funding?

☐ Maintenance of Organizational Practices, Procedures & Policies

Maintaining new organizational practices, procedures and policies that started during program implementation.

- Do we have any practices, procedures and policies that we want to continue after the study/intervention is finished?
- How will we continue these practices, procedures and policies?

☐ Sustained Attention

Sustaining attention to the issue or problem the program aimed to address.

- How do we plan to maintain attention to the issue(s) we are trying to improve through our organizations, in the public and/or through media coverage?

☐ Program Diffusion & Replication

Program diffusion and replication in other sites.

- Do we know if other sites or locations would like to implement our study/intervention?
- What organizations and stakeholders might find our data useful in their efforts to work toward policy inclusion with older refugees and refugees with disabilities?

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HESHIMA PARTICIPATORY TOOLKIT

Multisystemic MHPSS Data Collection

Resources At-a-Glance:

1. Inclusive MHPSS Data Collection Considerations
2. Pile Sorting for Multisystemic MHPSS
3. Participatory Resource Mapping

Inclusive MHPSS Data Collection Considerations

As demonstrated in our findings with older refugees (OR) and refugees living with disabilities (RLWD) in Nairobi, mental health is influenced by a complex interplay of individual, social and structural health determinants. It is important to understand and address these immediate and broader factors to make mental health and psychosocial support (MHPSS) effective, inclusive and relevant to the local community.

Components of Inclusive MHPSS Data Collection[6]

1. **Ecosocial-Structural Perspective in Research Design**
   - Use an approach that considers the broader environmental, policy, social and economic contexts impacting mental health.
   - Examine these factors to gain a holistic understanding of MHPSS, as well as implications for broad strategies to enhance mental health (e.g., advocating for timely registration for urban refugees, as recommended by Tippens et al., 2021).
2. **Age and Disability Team Representation**
   - Partner with OR and RLWD as team members so they have input across **all stages of research**, from topic conceptualization to data collection and analysis to dissemination.
   - Consider creating a community advisory board (CAB) or partnering with organizations that focus on OR and RLWD.
   - Tanabe et al. (2018) found that having persons living with disabilities as part of a research team helped raise awareness and highlighted the capacities and skills of those with disabilities in the broader community.
3. **Tailored Recruitment Strategies**
   - Develop recruitment methods that directly address barriers faced by OR and RLWD. This includes using accessible communication channels, outreach through community-based organizations and personalized assistance to guide individuals through the recruitment process.
4. **Accessible Data Collection Methods and Tools**
   - Ensure physical data collection environments are private, socially and culturally appropriate and physically accessible for OR and RLWD.
   - Provide materials in appropriate formats, such as large print, plain language, audio and Braille formats.
   - Adjust language levels, pay attention to cognitive load (e.g., using the short version of validated instruments), use tools (e.g., translator pens) and respect cultural norms around disclosure and mental health.
5. **Modified Informed Consent Processes**
   - Conduct the informed consent process in a flexible and iterative manner that accommodates sensory or cognitive impairments.
   - Use plain language and allow extra time for questions to ensure participants fully understand their rights and the scope of research.
6. **Collaborative Data Collection**
   - Engage participants as active collaborators by including feedback mechanisms that allow them to suggest changes to the data collection tools based on their experiences.

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[6] Tanabe et al. recommended several of these strategies and additional participatory procedures in their article on participatory action research with persons with disabilities in humanitarian settings (see section references).

Pile Sorting for Multisystemic MHPSS

Pile sorting, also known as card sorting, is a participatory research technique used to explore how individuals categorize information based on their knowledge, perceptions and priorities (e.g., Bourey et al., 2012). Participants are given a set of items, such as cards bearing words or images, and asked to group these into piles according to criteria that make sense to them, revealing underlying patterns and association in their thinking. Try the following pile sorting activity to enhance inclusive MHPSS

Pile Sorting Activity Example

Note: This activity can also be used with OR and RLWD, community and refugee-led organization leaders, nongovernmental organization personnel and policy decision-makers to gain different perspectives. Prompts and scenarios should be adapted according to participants. This example specifically relates to participants in Nairobi.

Objective

To facilitate a deeper understanding of the ecological, social and structural aspects of MHPSS.

Materials Needed

1. Piles of blank cards or printed images representing the social and structural determinants of mental health (see the Figure 2 Conceptual Model under Key Findings in the HESHIMA Assessment Report).
2. Piles of blank cards to capture any ideas or concepts that are not represented in the existing card piles.
3. A large collaborative work area, such as a tabletop, with large blank sheets of paper or poster boards.
4. Markers or pens for writing.

Additional Considerations

Ensure there are enough people to facilitate this activity. Roles for each small group may include facilitators, notetakers and research aides who are able to foster inclusion.

Steps

1. **Introduction (10 minutes)**. Introduce the concept of MHPSS. Discuss the objective of the activity: To sort different aspects of MHPSS and facilitate discussions about their relevance and importance among OR and RLWD.
2. **Preparation (5 minutes)**. Divide participants into small groups of 3-5 people. Place the piles of cards or images representing the ecosocial and structural determinants of mental health at the center of each group's table.
3. **Sorting Activity (20 minutes per prompt)**. Use specific prompts to help participants determine how to sort the cards. These prompts are best developed with local partners. Below are some possible prompts and scenarios:
   - **Prompt 1**: Prioritization. Given limited resources, work together to prioritize the aspects of MHPSS in Nairobi that are most crucial for the emotional or psychological well-being of OR and RLWD. Use the existing cards and create/add new cards as needed. Explain the reasoning behind your choices.
   - **Prompt 2**: Identifying Gaps in Community Support. As an OR and/or RLWD in Nairobi, what types of support are available to you? Create two piles. The first pile should include areas where you know services or resources are available. The second pile should include areas where there is no available support. Use the existing cards and create/add new cards as needed. Explain the reasoning behind your choices.
   - **Prompt 3**: Advocacy and Action. Imagine you are advocating for improved MHPSS support for OR and RLWD in Nairobi. What specific actions or policy changes would you propose to local authorities or organizations? Use the existing cards and create/add new cards as needed. Explain the reasoning behind your choices.
4. **Discussion (20 minutes)**. Bring the larger group back together and invite a representative from each small group to present their sorting choices, one topic at a time. Facilitate a discussion on the reasons behind each group's sorting decisions, encouraging participants to share personal experiences and insights. Emphasize the interconnectedness of different aspects of MHPSS and the need for holistic approaches to support mental and psychosocial wellbeing.
5. **Reflection and Action Planning (15 minutes)**. Have participants reflect on how insights gained from the activity can inform their own actions or community initiatives. Brainstorm practical steps or advocacy strategies for improving MHPSS.
6. **Conclusion (5 minutes)**. Summarize key takeaways from the activity and discussion. Express gratitude to the participants for their engagement and insights.

Participatory Resource Mapping

Participatory resource mapping actively involves community members in identifying and documenting the resources available and accessible to them within their environments. This is an empowering way to give OR and RLWD a voice in research processes, identify service gaps and opportunities, foster community-centric solutions, and coordinate Mental Health and Psychosocial Support (MHPSS) services and advocacy.

Participatory Resource Mapping Steps

STEP 1: Preparation and Planning

- Clarify what types of resources you need to map based on community and stakeholder listening sessions (e.g., mental health providers, social services, community centers).
- Assemble a team that includes community leaders, older refugees, refugees living with disabilities, caregivers and MHPSS professionals.
- Conduct a training session to familiarize the team with the resource mapping goals, tools (e.g., maps, makers, data sheets, digital mapping tools) and ethical considerations, such as confidentiality and respectful engagement.

STEP 2: Data Collection

- Decide whether you will collect data in one location (e.g., participants co-creating maps on a piece of paper during a focus group discussion) or through activities such as walking or driving tours.
- Determine if you will use blank paper for community-created maps, map printouts or digital tools.
- Organize workshops for participants to identify and discuss the resources they know about.
- Provide assistance to ensure accessibility for all participants.

STEP 3: Data Visualization

- Using the information collected, create a visual map that displays identified resources.
- Ensure the map is accessible (e.g., large print or readable by screen readers).
- Identify gaps by pinpointing areas with insufficient resources or services that are not accessible.

STEP 4: Analysis and Reporting

- Hold community and stakeholder discussions to interpret the maps and understand the implications of findings in the local context.
- Prepare a report that includes visuals, resources, gaps and participant-identified solutions.

STEP 5: Action and Advocacy

- Develop action plans in partnership with community members and other stakeholders based on identified gaps.
- Use the maps and data in advocacy to secure support and resources.

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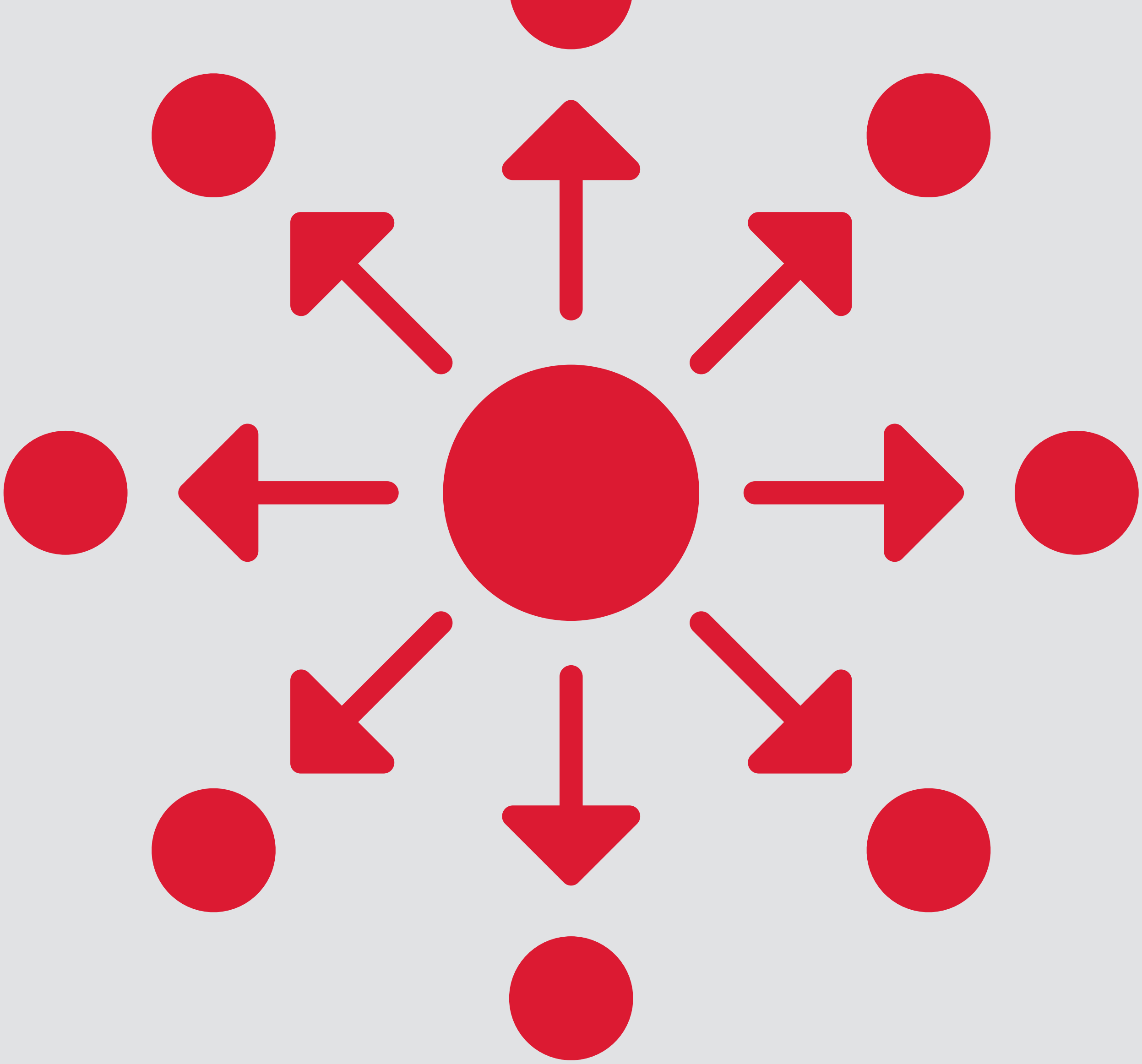

HESHIMA PARTICIPATORY TOOLKIT

Disseminating & Reporting Findings

Resources At-a-Glance:

1. Collaborative Dissemination Planning: Reflection Prompts
2. Engaging Strategies in Community Dissemination
3. Academic Publication & Authorship Roles: Discussion Prompts
4. Authorship Agreement Template

Collaborative Dissemination Planning: Reflection Prompts

An important aspect of community-based participatory research (CBPR) is partnering with community members to share data and findings with the people who need it (McDavitt et al., 2016). Because community members, especially those from marginalized populations, such as OR and RLWD, are the ones most affected by research outcomes, community members should have co-ownership in deciding how to communicate findings to wider audiences. Examples of collaborative dissemination include sharing research findings with community advisory boards, creating a free and accessible way for the public to access findings (e.g., online toolkit) and co-authoring academic publications.

Since academic publications mainly reach academic researchers, they are just one way to share findings from a participatory research project. Community-based research partners should work together to find accessible and inclusive ways to share information with multiple stakeholders. These may include websites, online toolkits, infographics, presentations, webinars, curricula, fact sheets, posters, guides, newsletter entries, measures or assessment tools, policy and practice briefs, short videos and white papers (Goodman et al., 2017).

Reflection Prompts

Below are some helpful reflection prompts to support collaborative dissemination (McDavitt et al., 2016). Discuss these questions as a team with community members to develop an effective plan.

- Did we discuss the dissemination plan with community members at the beginning of the project?
- Is one research team member designated as the key point person to coordinate all communication efforts (e.g., questions, concerns, information) in the dissemination process?
- Have community advisory board members reviewed the initial findings to provide their feedback? Are the findings translated into their preferred languages?
- Which team members are reaching out to which contacts to identify organizations and audiences that would be most interested in the study findings?
- How are we considering building trust with our various audience members? Some helpful ways to consider building trust are to make presentations interactive, share a personal story of why the research study matters, and be open to criticism and feedback.
- How are we viewing dissemination as part of an ongoing dialogue with community members, even after dissemination efforts?

Tips to Sustain Engagement

Here are some ways to encourage continued engagement with community members:

- Meet one-on-one and hold follow-up meetings with interested stakeholders after the study ends.
- Encourage stakeholders to build on study findings for future projects by providing available white papers of research findings.
- Show how community member feedback from the project and presentations was integrated into ongoing research efforts.

Engaging Strategies in Community Dissemination

Embracing dissemination strategies outside of academic publishing is a proven way to engage community members as partners. It is also aligned with participatory principles of sharing findings with community members and using data for social change. Below is a selection of diverse approaches for sharing community insights. These tools are a powerful way to promote dialogue, highlight refugees' creativity and expertise, and connect OR and RLWD with leaders and decision-makers. This list is not exhaustive and is meant to serve as a starting point for discussions about alternative dissemination strategies.

Alternative Dissemination Strategies[7]

1. **Workshops and Town Halls**. These community forums provide an opportunity to foster discussion and action — both receiving feedback on preliminary findings and generating ideas for how to use data for action.
2. **Data Walks**. A data walk is an interactive event where community co-researchers lead walking tours to discuss research findings with other community members, organizational leaders and policy decision-makers (Murray et al., 2015). In addition to providing dissemination leadership opportunities to community partners, data walks provide an opportunity to receive real-time, contextual feedback from diverse stakeholder groups while in the community.
3. **Community-Led Trainings**. Community co-researchers can lead trainings for mental health professionals, service providers and policy decision-makers that delve into cultural norms and systemic barriers related to Mental Health and Psychosocial Support (MHPSS). Participants gain critical insights into delivering culturally responsive care and advocating for systemic change. Such training could also deepen practitioners' commitment to equitable and inclusive mental health services. ***Tip!*** If applicable in the specific setting, offering continuing education units (CEUs) could increase participation by fulfilling professional requirements.
4. **Community Radio or Podcasts**. Collaborate with local radio stations or community/university podcasts to broaden discussions about research findings, as well as community-institution research processes. The latter is an important way for other researchers and community members to learn about collaborative and participatory research strategies that they could use in their own work.
5. **Photo or Art Exhibits**. Participatory strategies, such as photovoice (Wang & Burris, 1997) — wherein participants take or create images and share their meanings in a facilitated group discussion — often use photography and art exhibits to disseminate findings to other community members and policy decision-makers.
6. **Community Events**. Organizing or participating in community festivals, fairs or health days are occasions to showcase relevant MHPSS findings, while providing social engagement opportunities.

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[7] Parent-Johnson and Duncan also provide excellent guidance on inclusive research dissemination with a focus on individuals with developmental and intellectual disabilities (see section references).

Academic Publication & Authorship Roles: Discussion Prompts

Co-authorship processes for academic literature — or rules for giving individuals credit on research publications — often do not meet community members' expectations. While standard publishing procedures typically involve all co-authors reading and providing feedback on academic manuscripts, some community partners may lack the time, desire or ability to engage with this very specific type of reporting. Yet, community-engaged and participatory research cannot be done successfully without the time, expertise, social trust and dedication of community partners. To maintain trust and integrity throughout the research process, it is important to have clear and early conversations with community members about authorship roles and to co-create shared authorship standards. Such conversations should address authorship versus acknowledgments, as well as how to report names of community co-authors (e.g., when refugees experience restricted rights and may not wish for their full names to be used).

Authorship Discussion Prompts

Below is a sample script with prompts to help start the conversation around co-authorship of academic publications. To ensure understanding, conversations should be translated in the preferred languages of collaborators and can include any combination of the following:

1. In publications that report our findings, we want to give credit to people who have contributed to the research in this project. This includes you because of your role in [project name]. What does credit look like to you? How would you like to be given credit?
2. This project would not have been possible without you. Therefore, we would like to invite you to be an author on this project. You do not have to be an author; we will give you credit either through authorship or acknowledgements. To be an author, you must — at minimum — read our article(s) and provide any feedback and/or your approval of the manuscript. It is important that you respond to us and review the article and let us know your opinion of it. If we don't receive your written feedback and approval of the article, we cannot ethically include you as an author without your consent.
3. It is possible that we will try to reach you to send you the article for you to review and we may not be able to reach you. If we cannot reach you after several attempts, we will instead credit you in the article's acknowledgments section. You do not have to be a co-author. We will credit you either as an author or in the acknowledgements section, and we want the choice to be yours.

Authorship Role Checklist[8]

Below are some helpful activities and roles and that can help determine authorship and authorship order on publications:

- ☐ Creating and refining research ideas/ questions.
- ☐ Creating quality relationships between and among researchers and community members.
- ☐ Searching literature.
- ☐ Creating and refining research design.
- ☐ Selecting methods.
- ☐ Designing methods (questions, scales, analysis).
- ☐ Collecting data.
- ☐ Preparing data.
- ☐ Performing data analyses.
- ☐ Drafting manuscripts/posters (first, second or third drafts).
  - ☐ Editing/reviewing a manuscript.
- ☐ Contributing in other ways through roles determined by the team.

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[8] Adapted from the American Psychological Association's Authorship Score Card Tool: https://www.apa.org/science/leadership/students/authorship-determination.pdf

Authorship Agreement Template

[Insert Project Name]

Data Access and Publication Agreement[9]

Data Access Agreement

The principle investigator of the ____________________ (TITLE) project, ____________________ (NAME), agrees to allow ____________________________________(NAME), who will work as a(n)_________________________________ (ROLE, e.g. project leader, graduate assistant, etc,), from _________________________________ (AFFILIATED INSTITUTION), and is sponsored by _________________________________ (PI, project leader), access to the project data for purposes of data analysis. Anonymized data will be shared with _____________ (NAME) via a shared ______________ (SOFTWARE) folder. Data must remain in this _________ (SOFTWARE) folder and is not to be saved locally. The ___________ (SOFTWARE) folder can be accessed from any machine you wish but cannot be moved from the folder. All data analysis must be conducted in the ______________ (SOFTWARE) folder. The data cannot be shared with others. Anyone with access to the data must have signed this data access agreement, including students. New people seeking access to the project data will be reviewed and confirmed by the Principal Investigator.

Each project undertaken and approved will be overseen and sponsored by a project leader. It is the responsibility of the project leader to keep other project leaders and the PI informed of project progress at monthly meetings of the team. Changes in project plans, timelines or overall scope must be reported to the PI and other project leaders. All project leaders should strive for consistent project wide findings, conclusions and results.

Publication Agreement

I. Funding Credit

A. All presentations and/or publications must include the following credit and disclaimer to our funding agency.

1. Funding for this project was provided by the ______________ (ORGANIZATION, GRANT NUMBER). Additional funding was provided by the _________________ (ORGANIZATION, GRANT NUMBER).

II. Presentation/Paper Proposal and Proposal Review Process

A. A written proposal for any presentation or paper (hereafter presentation/paper) using data from the project will be submitted to the Project Director ____ (NAME, EMAIL ADDRESS) prior to concluding data analyses. The proposal should briefly outline the general aims, the dependent variable(s) that will be the focus of the proposed paper and variables that will be used in the analysis, and the authors expected to be included. The proposals will be reviewed by the PI within one week and then project director will provide any feedback or prior conflicts.

B. Once a paper is assigned, a deadline will be set for its completion. The author may set his/her own deadline, not to exceed nine months from the date of the proposal. If the proposed paper is not completed by the deadline set by the author, the PI will contact the author about assistance or reassignment.

C. Each paper will go through an internal review prior to submission for publication by the others working on the project. This internal review will be for quality control that will include, but not be limited to, measures, analyses, literature cited and theory. Papers from the project are expected to build on common themes and measures. Please submit each paper for internal review to the project director for distribution. An internal peer review will be completed within three weeks of the submission of the paper.

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[9] This authorship agreement example was created by Kirk Dombrowski, Ph.D., and used by researchers in the Minority Health Disparities Initiative at the University of Nebraska–Lincoln.

III. **Authorship**

A. Project leaders and PI will have the right of refusal regarding co-authorship for publications. This does not imply automatic authorship. Decision about whether to exercise this right should take into account direct and indirect contributions to the paper. Although indirect contributions to papers (e.g., sweat equity in data collection) will certainly be taken into account, all co-authors must, at minimum, read and provide editing comments for which they wish their names to appear. This editing process will be part of the internal review and will be completed within three weeks. Failure to return comments in a timely fashion without arrangement with the first author will void rights of co-authorship.

B. Authorship order is the prerogative of the project leader. Ordinarily, the PI will appear as the final author.

I have read the terms of this agreement, and I hereby agree to abide by the conditions described in the agreement.

Printed Name

Signature

Date

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THANK YOU TO OUR PARTNERS

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HESHIMA community advisory board (CAB) at Amref International University in Nairobi, Kenya.

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