

# Innovative Framework for Brain Health Care in Low- and Middle-Income Countries: The Living Lab Approach

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**B**rain health is a major concern worldwide, especially in low- and middle-income countries (LMICs) where resources for diagnosis and care are limited. Conventional approaches and treatments developed in high-income countries, in populations with vastly different cultural, social, and genetic contexts compared to LMICs, are not necessarily applicable. For example, drawing- and reading-based screening tools can mischaracterize people who have not had the opportunity of formal education. Similarly, responses of people in communities where multiple languages are spoken often depend on the language in which the screening tool is administered. To tackle these and other issues, the Aga Khan University Brain and Mind Institute (BMI) has deployed a Living Lab approach to address brain health across multiple communities with unique cultural and socioeconomic characteristics in East Africa and South Asia.

We see the Living Lab construct as a real-world ecosystem, which leverages multi-sectoral platforms, such as health, education, social welfare, community and religious institutions to broaden ownership, impact, and sustainability. A Living Lab model for brain health is “a user-centered, iterative ecosystem, integrating concurrent clinical care, research and innovation processes” that ultimately improves brain health outcomes.<sup>1</sup> The effectiveness of the Living Lab approach in fostering health care innovations and research has been documented in other contexts,<sup>2</sup> including for brain health research and innovation.<sup>3</sup> We postulate that Living Lab-based brain health care also has immense potential to improve preventive, promotive, and clinical care

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and patient outcomes in LMICs. By enabling scientists and communities to co-create culturally sensitive, pragmatic, and effective solutions, it can enhance access to and delivery of brain health care along a continuum that is rooted in local contexts.

At BMI, we have designed a process called **INSPIRE**, which underpins partnerships with communities for research into brain and mental health. This process entails:

**Invite:** Engage community members from the start.

**Negotiate:** Work together to set research priorities.

**Share:** Share power and exchange perspectives and ideas.

**Problem-solve:** Collaborate on finding solutions.

**Implement:** Put solutions into practice together.

**Review:** Assess outcomes and make adjustments.

**Effect Change:** Apply results to policies and practice.

By developing Living Lab sites in diverse urban and rural communities in South Asia and East Africa, we are thoughtfully testing and adapting tools and measures in unique and sometimes



**TOP** Engaging communities in Vishakani, Kilifi County, Kenya, around the Living Lab concept for brain and mental health research. **ABOVE** In dialogue with a group of women in Northern Pakistan to better understand issues related to brain health faced by the community, in particular the aging populations.

marginalized settings, while incorporating strategies to harmonize and compare initiatives and outcomes across sites.

Results to date have shown promise. In Kenya and Pakistan, the Living Lab approach has fostered active engagement with communities to identify priority areas for brain health research, such as the impact of climate change, substance use, mental health, and dementia. By working with community advisory boards, we have been able to identify novel brain health risk and resiliency factors to include in research protocols. Collaborations with community health promoters (mostly volunteers) and peer-led pathways to resilience building have increased the scope, reach, and inclusivity of our interventions. In connection with local civil society organizations, health systems, and school systems, for example, we

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are establishing screening for early identification of mental ill-health and developing novel referral pathways for specialized care. Alliances with community leadership have helped reduce stigma related to brain health, and created space to broach controversial topics, including violence and conflict as mental health stressors. Finally, we are actively learning from those with lived experience of brain and mental ill-health, and their caregivers, so that they are part of shaping the research and intervention landscape. These successful efforts point to expected benefits of the Living Lab approach in advancing brain care, including:

**A. More effective (and potentially cost-effective) screening:** Tools designed to consider unique contexts and validated against so-called “gold standards” will more accurately identify risk factors and ill-health early on. Similarly, tools designed to enable task shifting to non-specialist providers can also catalyze early identification of disease.<sup>4</sup>

**B. More effective diagnosis and treatment:** Research accounting for specific genetic, biological, and cultural characteristics of diverse populations can result in more appropriate diagnostic tests, pathways, and treatments. For example, we are collecting saliva and blood from participants in South Asia and East Africa to determine if genetic and molecular drivers of dementia differ from those discovered in people of European ancestry.

**C. Interventions designed and adapted with end-users in real-world settings:** End-user engagement promotes the design of more acceptable interventions and increases the likelihood of local responsibility for sustaining efforts. For example, in Northern Pakistan, we adapted the widely tested Thinking Healthy Program<sup>5</sup> — originally designed for peer volunteer-led one-on-one counseling of women with perinatal depression — to peer-led support groups, which resulted in less stigma for individuals with depression. We also engaged partners of young women in support groups to promote wellbeing of the family.

**D. Expedited implementation, uptake, and scale up of effective health care solutions:** The iterative nature of living labs can speed up the process of getting new solutions from the development phase into everyday practice at scale. For example, new digital diagnostic tools for detecting brain ill-health conditions such as dementia and depression.<sup>6</sup>

**E. Improved patient experience:** By involving end-users, such as young people, in the co-design of solutions, we can better meet their needs and requirements.<sup>7</sup>

**Expanded community-centered care:** This approach brings health care out of the exclusive ambit of formal health systems and leverages opportunities available in workplaces, schools, religious spaces, sports grounds, and more to

prioritize, prevent, and build appropriate referral pathways into health systems.<sup>8, 9, 10</sup>

We encourage funders, policy makers, and scientists to include the development of community-led approaches in their efforts. We also advocate for moving away from exclusive dependence on conventional diagnostic and screening tools, and support the selection, adaptation, and validation of indigenously informed cognitive and psychological health screening tools. Cultural realities need to be considered when selecting cognitive screening tools so that healthy agers are not inappropriately diagnosed with cognitive impairment.

The Living Lab Approach represents a significant shift in how we address brain health issues in LMICs and aligns with the movement to decolonize research in health<sup>11</sup> and more equitably include diverse populations in research. For example, communities disadvantaged by historic developments, geography and terrain, social norms, and economic realities. By engaging communities, respecting local contexts, embracing diverse knowledge frameworks, and working together, we can develop solutions that are effective, culturally sensitive, impactful, and sustainable. This approach not only improves health outcomes but also enables communities to take an active role in their health and well-being. •

<sup>1</sup> S, R., et al., Brain Health Living Labs - PubMed. The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry, 2021 Jul. 29(7).

<sup>2</sup> N, Z., et al., The relationship between the living lab approach and successful implementation of healthcare innovations: an integrative review - PubMed. BMJ open, 06/28/2022. 12(6).

<sup>3</sup> Santonen, T., et al., Cocreating a Harmonized Living Lab for Big Data-Driven Hybrid Persona Development: Protocol for Cocreating, Testing, and Seeking Consensus. JMIR Res Protoc, 2022. 11(1): p. e34567.

<sup>4</sup> Alam, R.B., et al., Role of Community Health Workers in Addressing Dementia: A Scoping Review and Global Perspective. Journal of Applied Gerontology, 2021. 40(12): p. 1881-1892.

<sup>5</sup> Organization, W.H. Thinking healthy: a manual for psychosocial management of perinatal depression, WHO generic field-trial version 1.0. 2015.

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<sup>8</sup> E, B., et al., Role of Co-creation for Large-Scale Sustainable Adoption of Digitally Supported Integrated Care: Prehabilitation as Use Case - PubMed. International journal of integrated care, 10/07/2022. 22(4).

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<sup>10</sup> Whitfield, J., et al., Successful ingredients of effective Collaborative Care programs in low- and middle-income countries: A rapid review. Global mental health, 2023. 10: p. e11-e11.

<sup>11</sup> Thambinathan, V. and E.A. Kinsella, Decolonizing Methodologies in Qualitative Research: Creating Spaces for Transformative Praxis. International journal of qualitative methods, 2021. 20.



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