**The INSPIRE network: Building a data science platform for integration and harmonization of longitudinal data on mental health in East Africa**

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# TABLE OF CONTENTS

[TABLE OF CONTENTS 2](#_Toc143517345)

[LIST OF ACRONYMS 4](#_Toc143517346)

[SCIENTIFIC ABSTRACT 6](#_Toc143517347)

[Background 6](#_Toc143517348)

[Objectives 6](#_Toc143517349)

[Methods 7](#_Toc143517350)

[Study Duration 7](#_Toc143517351)

[LAY SUMMARY 7](#_Toc143517352)

[1. INTRODUCTION 9](#_Toc143517353)

[2. PROBLEM STATEMENT AND STUDY AIMS 9](#_Toc143517354)

[3. REVIEW OF LITERATURE 11](#_Toc143517355)

[3.1 Definitions and Measurement Tools for Mental Health in the African Context 13](#_Toc143517356)

[3.2 Variability in mental health Longitudinal Literature in East Africa 15](#_Toc143517357)

[3.3 The Value of Harmonizing, Standardizing and Sharing Data on Mental Health 16](#_Toc143517358)

[4. RESEARCH OBJECTIVES 16](#_Toc143517359)

[5. RESEARCH QUESTIONS 17](#_Toc143517360)

[6. METHODS 18](#_Toc143517361)

[6.1. Study Sites 18](#_Toc143517362)

[6.2. Data Collection Phase I: Landscape and Scoping Analysis 18](#_Toc143517363)

[6.3. Data Collection Phase II: Primary Data Collection 19](#_Toc143517364)

[6.4. Data Analysis 20](#_Toc143517365)

[6.5. 6.1 Methods for Synthesizing Literature 22](#_Toc143517366)

[6.6. Methods for creating a mental health platform within the INSPIRE Data Mesh 23](#_Toc143517367)

[6.7. Components of the Mental Health Data Platform 24](#_Toc143517368)

[7. ETHICAL CONSIDERATIONS 25](#_Toc143517369)

[8. RISKS, LIMITATIONS, AND MITIGATIONS 26](#_Toc143517370)

[9. PLAN FOR COMMUNICATING FINDINGS 27](#_Toc143517371)

[10. WORK PLAN/TIMELINES 28](#_Toc143517372)

[11. BUDGET AND BUDGET JUSTIFICATION 28](#_Toc143517373)

[12. MANAGEMENT AND ORGANIZATION OF STUDY 29](#_Toc143517374)

[12.1. Project team, Expertise and Responsibilities 29](#_Toc143517375)

[12.2. Steering and Advisory Committee 30](#_Toc143517376)

[13. REFERENCES 30](#_Toc143517377)

[14. APPENDICES 33](#_Toc143517378)

[14.1. APPENDIX I: DATA COLLECTION TOOLS 33](#_Toc143517379)

[14.2. APPENDIX II: FOCUS GROUP DISCUSSION GUIDES 39](#_Toc143517380)

[14.3 APPENDIX III: CONSENT FORM 40](#_Toc143517381)

# LIST OF ACRONYMS

**AMREF** African Medical and Research Foundation

**APHRC** African Population and Health Research Center

**BASIS-R** Behavior and symptom identification scale

**CAPs** Contemporary and alternative practitioners

**CIDI** Composite international diagnostic interview

**CODATA** Committee on Data for Science and Technology

**DASS21** Depression Anxiety and Stress Scale

**DUP** Duration of untreated psychosis

**EPDS** Edinburgh postnatal depression scale

**GAD** Generalized anxiety disorder

**HDDS** Health and demographics surveillance system

**INSPIRE** Implementation network for sharing population information from research entities

**KEMRI** Kenya Medical Research Institute

**LSHTM** London School of Hygiene and Tropical Medicine

**LMIC**  Low- and middle-income countries

**MH** Mental health

**OHDSI** Observational Health Data Sciences and Informatics

**OMOP**  Observational Medical Outcomes Partnership

**OMOP CDM** Observational Medical Outcomes Partnership Common Data Models

**PHQ-9** Patient health questionnaire 9-item

**PPD** Post-partum depression

**SRQ-20** Self-reporting questionnaire 20-item

**SSA**  Sub-Saharan Africa

**WG** Working group

**WHO**  World Health Organization

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# SCIENTIFIC ABSTRACT

## Background

Mental health constitutes a significant portion of the global burden of disease, with profound impact on individual well-being, socio-economic development, and healthcare systems. Yet, there is very little attention given and little or no investment directed towards mental health. On average, African governments spend less than one percent of their health budget on mental health, compared to between six and 12 percent in Europe and North America. In the East African region, as is the case with many other regions in the global South, the understanding and management of mental health conditions face unique challenges. Socio-economic disparities, stigma, cultural nuances, and limited health infrastructure significantly impede the delivery of mental health care and services. The undertaking of robust research is also grossly affected by the lack of standardized methodologies, limited access to reliable data sources, and inadequate funding and support for researchers in the field. Synthesizing longitudinal mental health data from selected health and demographic surveillance sites (HDSS) in Kenya, Uganda and Tanzania will provide insights into issues such as *what information is available on mental health conditions, and how the immediate environment (physical, social, and political) affects mental health outcomes*. Harmonizing longitudinal mental health data from multiple sources will allow comparisons between different settings to enhance effective management and treatment of mental health conditions in the East African region , while informing evidence-based decision making about mental health programs and policies. Ultimately, we will build on this evidence to produce a dashboard and central catalog that can be used to access and answer key questions about symptoms, causes, and management of mental health in African settings.

## Objectives

The project aims to assess the burden of mental health conditions, specifically depression, anxiety and psychosis in three Health and Demographic Surveillance Systems (HDSS) sites in Kenya (Nairobi HDSS), Uganda (Mayuge HDSS) , and Tanzania (Magu HDSS). The project will also collect new and existing longitudinal data from people with lived experiences, vulnerable populations and clinical data sources. The project will then augment and refine standard mental health vocabularies, ensuring they resonate within the African context. This initiative is instrumental in ensuring that our discussions, analyses, and interventions in mental health are deeply rooted in the lived experiences of the African populace. We aim to provide stakeholders with an interactive dashboard – a user-friendly tool designed to visually represent the intricacies of the mental health landscape in Africa. This dashboard will specifically spotlight conditions such as depression, anxiety, and psychosis, particularly within the East African region.

Recognizing that manifestations and experiences of psychosis might be influenced by cultural beliefs and experiences, the project will also focus on understanding how psychosis is perceived and expressed in different East African communities. To validate and contextualize existing data collection tools, BASIS-R tool for assessing psychosis will be evaluated for its sensitivity, specificity, reliability, and cultural appropriateness.

The project will also strengthen the capacity of partner institutions to conduct, communicate, and utilize mental health research to develop evidence-based mental health policies and interventions and to sustain this work beyond the project. This will in turn promote effective data collection, data accessibility, reporting, and translation of research into policy actions to address mental health conditions across East Africa.

## Methods

We will conduct a longitudinal mixed-methods study combining quantitative and qualitative data collection and analysis approaches through surveys and clinical data and observations and focus group discussions respectively. Primary data collection will be preceded by landscape analysis of current mental health research in East Africa. Synthesizing existing data on the prevalence of mental health conditions across the population sites will also be conducted. A systematic review and comparative analysis on the access to mental health data and services will also be conducted. Comparing longitudinal mental health data from various sources offers insights into how community dynamics, household environments, and broader environmental factors shape mental health outcomes. In effect, amalgamating findings from diverse studies will empower us to examine and evaluate the distinct variables traditionally used to depict mental health conditions.

## Study Duration

The project will run for 24 months (between 1st July 2023 to 30th June, 2025). The estimated budget for this project is €496,750 (approx. KES 77,979,815).

## LAY SUMMARY

This project is designed to improve our understanding of the burden of key mental health conditions including psychosis, depression, and anxiety disorders in Kenya, Uganda and Tanzania, and provide tailor-made tools to help manage mental health conditions more effectively.

To start us off, we will conduct a large-scale landscape/scoping analysis and review of available evidence to understand how common mental health conditions are across Africa. The project will use various tools to collect primary data to fill in the gaps on mental health data. The team will assess the performance of various tools in assessing mental health conditions in the local context by translating them into locally-relevant, clear guidelines for a variety of stakeholders including mental health professionals.

In addition to assessing and documenting access to mental health services by our study populations, the effectiveness of these services, and how existing services can be improved, the project will also aim to determine if, and how, people's social networks and coping mechanisms help them to access and benefit from mental health care and services.

One of the unique aspects of this project is that it will build the capacity to generate, interpret and use mental health data by researchers and mental health professionals to inform research and policy. Involvement of people with lived experiences and vulnerable populations across the study sites, in the generation of data and interpretation of findings will be a key consideration for the project.

Finally, we will build a dashboard: an online tool that presents our findings in a clear and visually interactive way. The dashboard will make it easier for anyone interested - from policymakers and healthcare professionals to researchers and the general public – to access quality, up-to-date data on mental health and use it to increase the uptake of evidence-based mental health interventions.

The aims of the study include:

* Collect new and existing data from population and clinical data sources on: (1) longitudinal mental health conditions; (2) mental health signs, symptoms, and biomarkers; (3) mental health treatment interventions in the African context, using data from selected African Counties; and (4) mental health risk factors in Africa.
* Integrate and augment the vocabularies used by mental health researchers in the metadata used by data science applications to describe mental health conditions in Africa.
* Provide a dashboard and central catalog that can be used worldwide to inform and describe African mental health conditions. This will allow policymakers and researchers to visualize the prevalence, geographic distribution, and perhaps even trends over time of depression, anxiety and psychosis in the East African region.
* Identify and answer key questions about the causes and management of mental health in African settings through cohorts identified in the Observational Medical Outcomes Partnership (OMOP) database.
* Conduct advanced causal inferential analyses on the impact of community, household , and environmental exposures on mental health across a federated cloud-based environment \_ across multiple online storage systems that are linked together on the internet.

# INTRODUCTION

Historically, public health policymakers in Africa have focused on communicable diseases, such as malaria, tuberculosis, and HIV/AIDS. However, non-communicable diseases, such as cancer, heart disease, diabetes, and mental health conditions are increasingly becoming the main cause of mortality in Africa. According to the World Health Organization (WHO), across the African region, an estimated 116 million people were living with mental health disorders pre-pandemic [1]. The Coronavirus disease-2019 (COVID-19) has exacerbated mental health conditions due to unexpected deaths, lack of social interactions, school shutdowns, and economic decline, which have led to an estimated 25% global increase in the prevalence of depression and anxiety [1,3].

There is a continuous need for essential data on mental health prevalence and services in East Africa to assist in improving the appropriateness and accuracy of mental health screenings and to develop a more nuanced and culturally appropriate mental health database. Data on the causes, consequences, and impacts of mental health conditions in the African population , therefore, needs to be collected and harmonized. This data needs to capture and account for physical exposures, socio-economic forces, health opportunities , and lifestyles, often referred to as the external exposome [2], which impact mental health. This necessitates data from longitudinal research, which could also show the effectiveness of interventions to improve mental health in the East African region.

Longitudinal population mental health data include observations that follow individuals over time and connect exposures to changes in mental health. This data provides a deeper understanding of the mental health life course by examining interactions between individuals, the environment, and health services. Comparing longitudinal mental health data across different literature will be useful to understand how community, households, and environmental exposures affect mental health outcomes. Combining studies will allow the assessment of the different variables used to define mental health conditions to be explored. Analyzing this data will enhance the scientific understanding of the current variables that define mental health conditions in the African setting, effective ways to manage different conditions, and explore what works under what circumstances. Ultimately, our analytical approach aims to enhance the scientific comprehension of the prevailing variables that characterize mental health conditions in the African context. The focus here is to leverage integrated digital platforms to source and analyze this data. In doing so, we aspire to discover efficacious management strategies for diverse conditions and discern the specific circumstances under which they prove most beneficial.

# PROBLEM STATEMENT AND STUDY AIMS

Mental illness remains an unspoken epidemic across Africa. Despite its pervasive impact, many African countries continue to offer substandard access to mental health care, due to structural and systematic barriers. For instance, the proportion of Africans who receive mental health treatment is extremely low. Illustratively, the rate of visits to mental health outpatient facilities globally is 1,051 per 100,000 population, while the rate is only 14 per 100,000 in Africa [3]. This limits the capacity to comprehend the full spectrum of mental health conditions across the region [4]. The paucity of mental health data in Africa significantly hampers the understanding and treatment of mental health conditions in the region. Although previous research has been conducted on mental health, gaps exists in the accuracy, accessibility, and availability of mental health data in the African region, and more specifically in East Africa the scarcity of such vital data has led to misinformed policies, inadequate prevention measures, and insufficiently targeted interventions.

Several limitations surround mental health research, which in turn hamper the availability of mental health data in the region. These include underdevelopment and understaffing of mental health facilities, coupled with limited resources, which further exacerbates the problem of lack of sufficient data. Additionally, there are debates on the cultural perceptions of mental health in the region, with some communities stigmatizing mental health disorders, leading to underreporting and underdiagnoses of mental health conditions. Another limitation that causes rise in misconception is the role of traditional healing practices in mental health treatment. Traditional healers across the region are consulted to offer treatment for mental health conditions. Limitations on access to and sharing of data inhibits knowledge sharing..

The lack of comprehensive longitudinal data on depression, anxiety and psychosis conditions signs, symptoms, risk factors, and treatment interventions in East Africa hampers the ability to make evidence-based decisions that would optimally address the mental health needs of the African population. There is also an existing gap in addressing the vocubularies that describe mental health and its management in African settings. The underutilized potential of the Observational Medical Outcomes Partnership Common Data Models (OMOP-CDM) database in identifying relevant mental health cohorts and provide answers to many research questions remains unexplored.. The impact of various factors including community, household , and environmental exposures, are still largely unexplored, limiting the scope of mental health interventions.

Evidence in the literature has linked various environmental elements to psychiatric diseases including, physical exposures, socio-economic factors, lived experience, lifestyle, and toxic/non-toxic chemical exposure [5]. Research on mental health in Africa has primarily centered on identifying the causes of conditions that are specific to African contexts, developing low-cost interventions to help those affected, and monitoring the impact of mental health services on those receiving them. Harmonizing longitudinal mental health data using multiple sources, people with lived experiences and data from vulnerable populations will facilitate evidence-based decisions about mental health conditions and allow comparisons that enhance or impede effective treatment.

These factors collectively affect the ability to meet the increasing demand for accurate, accessible, up-to-date mental health data, which in turn negatively affects evidence-based decision-making, policy formulation, and service delivery in the mental health sector. This research will address these critical gaps, thereby enhancing the understanding and management of mental health in East Africa.

This research project proposes to explore mental health conditions in East Africa, an area of critical global health concern that has remained inadequately addressed. As earlier discussed, there is a substantial gap in the availability, accessibility, and quality of mental health data and services across different demographic and socioeconomic backgrounds in the region. This study intends to contribute to the understanding of mental health in Africa by conducting scoping, synthesis, comparative and systematic reviews and analyses to inform augmentation of standard vocabularies describing depression, anxiety and psychosis conditions, thus providing a culturally relevant framework for discussion and analysis. This will then lead to the creation of an interactive dashboard that presents a user-friendly tool for estimating and characterizing mental health observations.

The project therefore primarily aims to collect a comprehensive set of both new and pre-existing longitudinal mental health data from designated study regions. It particularly zeroes in on understanding specific mental health conditions, their accompanying symptoms, treatments, and dominant risk factors within the unique African milieu. Recognizing the importance of using culturally appropriate and resonant language, the project will also augment and refine standard mental health vocabularies. This endeavor will ensure that discussions, analyses, and interventions related to mental health are rooted in the lived experiences of Africans. Furthermore, the project commits to dissecting the multilayered effects of various factors — be they community-oriented, family-centric, or environmental — on mental well-being, leveraging data across seamlessly connected digital platforms. Additionally, to make this wealth of data both user-friendly and actionable, the project will develop an interactive dashboard. This tool will provide visual insights into the mental health dynamics, specifically spotlighting conditions such as depression, anxiety, and psychosis prevalent in East Africa. Harnessing the Observational Medical Outcomes Partnership (OMOP) database.

# REVIEW OF LITERATURE

Mental health disorders are increasing worldwide. Demographic shifts including changes in age distribution, birth rates, death rates, immigration, or urbanization, among other factors have caused a 13% increase in mental health conditions in the last decade [6]. Mental health data in most developed countries is captured through. In Western society, mental health conditions are seen as medical conditions attributable to endogenous disease processes in the central nervous system and are usually treated with medication [7]. Structured mental health systems and diagnosis tools are used to track mental health data in developed countries. Conversely, in African settings, mental health systems have insufficient funding, resources, skilled staff shortages, and inadequate policy frameworks. Culture and religion play a major role in mental health, as many people seek mental help from contemporary and alternative practitioners (CAPs): traditional and spiritual healers. Due to more complex views on mental conditions in the African region [7], the collection of comprehensive mental health data may be insufficient and underdeveloped.

Mental healthcare in sub-Saharan Africa (SSA) is inefficient, inadequate, and inequitable. Africa has approximately one mental health worker per 100,000 people, compared to the global average of 9 health workers per 100,000 people [8]. High treatment costs and an insufficient number of mental healthcare workers across the continent leaves people in sub-Saharan Africa no choice but to live with untreated mental illnesses or seek treatment from traditional and religious leaders. Local healing traditions are prevalent in most low and middle-income country (LMIC) settings and are usually the first option chosen to seek help. Research has indicated that approximately 50% of people in SSA visit a CAP before seeking mental healthcare services [9]. Between 2000 and 2015, Africa's population grew by 49%. However, during the same period, there was a 52% increase in the number of years lost to disability resulting from mental and substance use disorders. [4].

Depression, anxiety, and psychosis are among the most common mental health problems affecting young people in African region and more specifically in Kenya, Uganda and Tanzania [10]. However, mental health disorders in Africa may be underrepresented due to factors including misdiagnosis, lack of diagnosis, and unpublished data, therefore contributing to the underestimation of the burden of mental health in the region [10]. Depression and anxiety disorders can manifest in different ways, and they can affect the mental, physical, and emotional well-being of individuals.

Social support refers to the resources that individuals receive from their social networks, including emotional, informational, and tangible support. Social support plays a crucial role in promoting mental health and preventing mental illness. This includes the availability of help or resources from individuals or groups that can reduce stress, improve coping, and enhance psychological well-being [18]. Coping mechanisms refer to the strategies that individuals use to manage stressors. Adaptive coping mechanisms have been found to be associated with better mental health outcomes. A lack of social support and coping mechanisms have been found to increase the likelihood of mental health conditions with several studies highlighting their importance in predicting mental health outcomes. For instance, in a study conducted in the United States by Murry aimed to examine the impact of parenting practices on the mental health outcomes of African American youth [19]. The study utilized a sample of 233 African American families with adolescent youths aged between 11 to 13 years old. The participants completed questionnaires on their parenting practices, adolescent youth’s mental health symptoms, and demographic characteristics. The findings of the study indicated that parental monitoring, positive parenting, and involvement in their children's lives were associated with lower levels of depression and anxiety among African American youth. These insights may also be applicable to other populations and highlight the role of social support in promoting mental health outcomes.

These mental health issues lead to poor academic performance, social isolation, substance abuse, and extremes of suicide [11,19]. The World Health Organization (WHO) has reported that although the African region represents about 10% of the global burden of mental disorders (5.4% and 3.2% for depression and anxiety), there is a shortage of literature on mental health disorders [20]. Only a few countries in Africa present mental health data, thereby limiting generalization and synthesis across studies. Lack of data prevents policymakers from understanding the depth of mental health problems across the continent hence making uninformed decisions regarding awareness creation, prevention, and treatment.

## 3.1 Definitions and Measurement Tools for Mental Health in the African Context

The occurrence of mental health conditions can be assessed through various indicators that indicate the existence of disorders such as depression, anxiety, and psychosis symptoms. These can be measured using a number of screening tools. These tools consist of a set of questions that assess symptoms associated with the targeted mental health conditions. They are designed to be administered in a standardized way, which allows for accurate and reliable measurement of mental health symptoms. Depression is a mental health disorder that can cause persistent feelings of sadness, hopelessness, and loss of interest in life and productivity. It can also affect one's sleep patterns, appetite, and ability to concentrate. Depression can be caused by a variety of factors, including genetics, life events, and brain chemistry. Additionally, the WHO reports that depression is a significant problem that affects over 29.19 million people in Africa. Psychosis is a mental health disorder characterized by a disconnection from reality which might manifest as hallucinations (sensory experiences without external stimuli, such as hearing voices), delusions (strong beliefs not based on reality), or disorganized thoughts and speech. Individuals with psychosis might find it challenging to differentiate between what is real and what isn’t­\_ and depressive and anxiety disorders.

Health professionals with mental health expertise in Africa are not as copious as in Europe or North America, so diagnostic tools training may not be as effective. Even with proper training, lack of time and resources makes it difficult to analyze and diagnose mental health disorders. Diversity in dialect and culture creates further complications with diagnosis; a tool used in one cultural setting may or may not be applicable in a different setting, population, or country.

Many different screening and diagnostic tools and measures are used when dealing with mental health disorders in the African context [21]. The prevalent tools used in longitudinal mental health research that have been reviewed include the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder (GAD-7). These tools are used to screen for depression and anxiety, respectively. To use the PHQ-9, for example, participants would be asked to rate on a scale of 0-3 how often they have experienced each of the nine symptoms listed in the tool over the past two weeks. Scores range from 0-27, with higher scores indicating greater symptom severity. The GAD-7 is administered in a similar way, with participants rating on a scale of 0-3 how often they have experienced each of the seven symptoms associated with anxiety. A notable longitudinal study where PHQ-9 was used is the “Association of depression and epilepsy in Rwanda: A prospective longitudinal study”. The study addresses a crucial aspect of comorbidity in persons with epilepsy (PwE) - the prevalence, incidence, and impact of depression. Conducted over a period from February to June 2018, the study longitudinally followed PwE, implementing quarterly mental health screenings using the PHQ-9, a widely used tool for the preliminary detection of depression symptoms. On identification of signs of depression through the PHQ-9, participants were further evaluated with the Hamilton Depression Rating Scale (HDRS), a comprehensive tool for diagnosing depression and gauging its severity. Individuals identified with moderate to severe depression (MSD) subsequently received treatment and were followed up for an additional year. The study provides valuable insights into the co-occurrence of epilepsy and depression, unveiling both the prevalence and incidence of depression within the sampled cohort [20,21].

Other tools used to screen mental health disorders in Africa include the Self-Reporting Questionnaire 20-item (SRQ20), the Depression Anxiety and Stress Scale-21 (DASS-21), and the Edinburgh Postnatal Depression Scale (EPDS). The SRQ20 and EPDS are used to screen for the presence of maternal psychological distress and depression symptoms in pregnant women and women in postpartum. The DASS-21 is used to screen for the emotional states of depression, anxiety, and stress. The Composite International Diagnostic Interview (CIDI) is like a detailed questionnaire used by professionals to determine if someone has a mental health issue. It follows specific guidelines from two major manuals (ICD-10 and DSM-IV) that list and describe various mental health conditions. Think of it as a thorough checklist that helps doctors or therapists decide if someone's experiences match a known mental health condition; The Behavior and Symptom Identification Scale (BASIS-R), a 24-item self-report questionnaire designed to assess the severity of mental health symptoms and their impact on daily functioning in adults. It covers several dimensions including psychosis, depression/anxiety, interpersonal problems, substance abuse, and self-harm; The MINI International Neuropsychiatric Interview (MINI), a short structured diagnostic interview developed for DSM-IV and ICD-10 psychiatric disorders; Kessler Psychological Distress Scale (K10), a 10-item questionnaire intended to yield a global measure of distress based on questions about anxiety and depressive symptoms in the most recent 4-week period; Brief Symptom Inventory (BSI), a highly sensitive self-reporting instrument that screens for psychological symptoms across nine primary symptom dimensions, including depression, anxiety, somatization, and psychoticism; Social Phobia Inventory (SPIN), a 17 item self-rating scale for assessing the social Anxiety disorder developed by [21]. The SPIN assesses fear, avoidance, and physiological discomfort in social situations, indicative of social anxiety disorder; and the Panic Disorder Severity Scale-Self Report (PDSS-SR), which is a self-report scale that measures the severity of panic disorder symptoms, including sudden attacks of fear and anxiety.For this study, the tools used will be based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) Fifth Edition created by the American Psychiatric Association. These tools are PHQ-9, GAD-7, and BASIS-R. Although these tools are used globally, there is still the question of whether these tools work effectively in different cultural and socioeconomic contexts. The BASIS-R tool is like a measuring tape for certain mental health issues. But right now, it's made with a more Western perspective. We need to adjust it so it fits African cultures and experiences better. By doing this, we can gather better information on mental health and come up with solutions that really work for people in Africa.

## 3.2 Variability in mental health Longitudinal Literature in East Africa

Focus on longitudinal mental health studies has been put on pregnant and postpartum women. Previous longitudinal research conducted regarding mental health conditions and pregnancy in Africa, specifically, Kenya, found that the number of children, antenatal depression, economic stress, and partner conflicts are associated with postpartum depression (PPD) [22]. Similarly, research conducted in Ghana found that socio-demographic and socio-economic factors play a role in PPD, with antenatal depression having the strongest association [23]. Moreover, women with PPD were more likely to report economic stress and partner conflicts [23]. Another study done in Nairobi, Kenya analyzed depression during pregnancy and preterm birth. Results found that the risk of preterm birth was four times higher among women with depressive symptoms [15]. Thereby, illustrating the need for screening for mental health disorders during the prenatal period to help reduce adverse outcomes in Kenya.

However, most mental health research is largely limited to anxiety and depression. Of the 3,521 filtered articles across different search engines including PubMed, EMBASE, PsycINF and google scholar, using the terms depression, anxiety, psychosis, mental health disorders, and mental disorders, only a few longitudinal studies on psychosis were available. One study done on children with early-onset schizophrenia found that factors associated with poor functional outcomes included a history of complications at birth, a longer duration of untreated psychosis (DUP), and the presence of more negative symptoms at the onset of illness [24]. Similarly, another study that investigated DUP and its outcome in first-episode psychosis in South Africa among individuals ages 16- 55 found that longer DUP is associated with more negative outcomes [25]. Therefore, the importance for early detection and intervention strategies for both children and adults with mental health disorders to help reduce negative outcomes.

The lack of variability in mental health longitudinal literature is still a major concern. Not having substantial amounts of literature across population groups creates barriers to understanding mental health problems in the African context. It also makes it difficult to create evidence-based interventions, programs, and policies that efficiently and effectively address mental health conditions in Africa. Longitudinal mental health research in Africa needs more exploration of socio-demographic and socio-economic factors associated with mental health conditions among all population groups to better understand mental health across cultures, populations, and countries. Therefore, this study aims to create a platform that will make mental health research more accessible for African researchers, policy makers, practitioners and other stakeholders to see where innovation can be implemented to improve and develop more effective policies, interventions, and treatments.

## 3.3 The Value of Harmonizing, Standardizing and Sharing Data on Mental Health

Harmonizing, standardizing, and sharing mental health data will play a crucial role in shaping future disease interventions in East Africa. The rich diversity in sociocultural, economic, and political contexts across the region offers unique challenges and opportunities for mental health intervention strategies. The harmonization and standardization of data will significantly enhance understanding of the burden of mental health disorders in the region. By comparing data across different populations, settings, and time periods, the project team will be able to refine estimates of mental health disease prevalence and incidence and better comprehend the impacts of mental health conditions across East Africa.

The final shared and standardized dataset will be instrumental in improving mental health interventions. As researchers, policymakers, and other stakeholders including the project team will use the dashboard to assist in identifying future patterns, trends, and risk factors associated with mental health conditions, they will be able to develop, implement, and evaluate targeted interventions and policies designed to alleviate the burden of mental health disorders. Importantly, the standardized and shared data will guide resource allocation decisions across different Governments and donor projects in the region. Decision-makers at the policy and practice levels will therefore be better informed, ensuring that resources are directed towards areas and populations where they are most needed, thereby maximizing their impact on the overall mental health and well-being of the people. Moreover, the standardization of data will aid in reducing stigma and discrimination through the use of the platform and data available to raise awareness on the importance of mental health treatment. It will foster mental health literacy, nurturing a more understanding and supportive environment for affected individuals.

Data sharing will promote collaboration and cooperation between researchers, practitioners, and policymakers across regions and countries. This will facilitate the exchange of knowledge, skills, and best practices, ultimately enhancing the collective capacity for mental health research and intervention in East Africa. By enabling researchers to validate their findings, increasing the statistical power of studies, and encouraging transparency and reproducibility in research, the data available in the dashboard will play a pivotal role in advancing science by providing a robust basis for high-quality research, leading to new insights and advancements in the field of mental health.

# RESEARCH OBJECTIVES

The following are the main objectives of this study:

1. To conduct a comparative analysis of availability, accessibility, and quality of mental health data for individuals across different demographic and socioeconomic backgrounds.
2. To determine how mental health conditions are perceived and expressed in different East African communities.
3. To investigate the empirical evidence supporting the validity of BASIS-R, GAD 7 and PHQ-9 screening tools for depression, anxiety, and psychosis, with a focus on their sensitivity, specificity, reliability, and overall applicability in various settings.
4. To investigate the impact of social support and coping mechanisms services on the management of mental health conditions across East Africa
5. To augment the standard vocabularies for describing mental health in the African context, providing a culturally relevant framework for discussion and analysis.
6. To provide an interactive dashboard for estimating and characterizing mental health observations, offering a user-friendly tool for understanding and addressing mental health issues.

# RESEARCH QUESTIONS

The overarching research questions of this study:

1. How does availability, accessibility, and quality of mental health data and services vary across different demographic and socioeconomic backgrounds in East Africa?
2. How are mental health conditions perceived and expressed across various East African communities?
3. How valid and reliable are the existing screening tools for depression, anxiety, and psychosis in the African context in terms of sensitivity, specificity, and overall applicability?
4. What is the impact of social support systems and coping mechanisms on the treatment and management of mental health conditions in East Africa?
5. What are the existing vocabularies and descriptors of mental health conditions, and how can they be adapted and enhanced to better reflect and accommodate cultural nuances within the African context, specifically in East Africa?
6. How can an interactive dashboard that accurately characterizes and communicates mental health observations for use by a broad audience, including researchers, clinicians, policymakers, and the general public be designed and implemented?

# METHODS

A mixed-methods approach will be employed in two phases.

The first phase will involve landscape analysis of longitudinal cohorts within the African context at both dataset and variable levels. The second phase will involve the primary collection of data from health facility registers (hard-copy and electronic) to capture availability, accessibility, and quality of mental health data and services, and data collection from households across the selected HDSS sites. Data collection will be done using structured questionnaires for screening mental health conditions.

Data will be collected from adults aged 18 years and above from the households registered under the HDSS sites. Respondents from the households will be randomly selected. These proposed approaches will also include collection of primary data from selected vulnerable populations within the study region on depression, anxiety and Psychosis. For example, prisons often house individuals with untreated or undiagnosed mental health conditions, including depression, anxiety, and psychosis. By focusing on this often-overlooked population, the project will gain a deeper understanding of the prevalence and nature of these conditions, as well as the efficacy of social support systems and coping mechanisms available to vulnerable populations. By identifying and analyzing the existing vocabularies and descriptors of mental health conditions, the project aims to ensure that data is both comprehensive and reflective of the diverse experiences of those affected by mental health issues.

# Study Sites

The study will be conducted in health and demographic surveillance systems (HDSS) across three study sites namely Maguye in Uganda, Magu in Tanzania, and Nairobi in Kenya. The HDSS sites already collect demographic data ( on births, deaths, migrations), and other health and demographic variables, offering valuable longitudinal data that can provide insights into population health, particularly in low- and middle-income countries (LMICs) where vital registration systems might be weak or virtually absent.

# Data Collection Phase I: Landscape and Scoping Analysis

The team will obtain a comprehensive list of all African mental health researchers from the International Digital Health and AI Research Collaborative (I-DAIRS) Global Research Map of Mental Health and Well-being to help identify secondary data sources. Using this initial list, the team will develop inclusion guidelines to select appropriate research studies that meet the following criteria; i) Research work was conducted in an African population, ii) Cohort study or panel data with at least one follow-up visit, iii) Research is aligned to mental health conditions that focuses on anxiety, depression, and psychosis. Each entry in a catalog will take the form of structured metadata. On top of structured metadata, we will write a few queries through which the datasets would become findable. Research studies that meet the criteria will be officially contacted. The principal investigators and lead researchers will be contacted to seek their ability and willingness to provide access to the research datasets. The project team will provide information on the study objectives, rationale, and mode and request to share research datasets. This systematic/scoping synthesis will provide both the overall level of evidence of mental health conditions and the degree of consistency in longitudinal studies conducted. Queries that reach the variable level would be used in assessing interoperability. Appropriate use of cases from the datasets obtained from the mapping exercise will also be developed.

# Data Collection Phase II: Primary Data Collection

To ensure research findings validity, and to fill gaps of locations that have no secondary data. Primary data collection will involve using multiple sources of data for verification. In this case, data obtained from the systematic/scoping synthesis and primary data collected will be analyzed.

1. **Household Survey**

Data will be collected in the HDSS sites. The study will have one follow-up data collection after a period of eight months. Using semi-structured interview guides, data will be collected from 5,000 (five thousand) households representatives aged 18 years and above, in each of the three HDSS sites. The participants will be recruited using random sampling within the numeration Areas (EAs).

The table below outlines the variables of interest:

|  |  |  |
| --- | --- | --- |
| **No.** | **Variable of Interest** | **Specificity** |
|  | **Demographics** | Age |
| Gender |
| Marital status |
| Educational level |
| Occupation |
| Socioeconomic status |
|  | **Psychosis** | Presence of hallucinations (auditory, visual, tactile, olfactory) \_ (using a standardized BASIS-R scale) |
| Presence of delusions (paranoid, grandiose, somatic) |
| Duration and frequency of symptoms |
| Severity of symptoms |
|  | **Depression** | Presence and severity of depressive symptoms (using a standardized scale \_ PHQ-9) |
| Duration of the current depressive episode |
| Number of past depressive episodes |
| Suicidal ideation or attempts |
| Sleep disturbances |
| Changes in appetite or weight |
| Feelings of guilt or worthlessness |
| Treatment history and medication usage for depression |
| Marital status |
| Educational level |
| Occupation |
|  | **Anxiety** | Presence and severity of anxiety symptoms (using a standardized scale\_ GAD-7) |
| Specific type of anxiety disorder (e.g., generalized anxiety disorder, panic disorder, social anxiety disorder) |
| Presence of panic attacks |
| Avoidant behaviors |
| Treatment history and medication usage for anxiety |
| Presence and severity of anxiety symptoms |
| Presence of panic attacks |
|  | **Cultural and Local Beliefs** | Perception and beliefs about mental health conditions in the community |
| Stigma associated with mental health disorders |
| Preferred treatment modalities (e.g., traditional healers, prayer, western medicine) |
|  | **Healthcare Access and Utilization** | Access to mental health care services |
| Barriers to accessing care |
| Utilization of mental health care services |
|  | **Environmental and Social Factors** | Recent\_past 12 months\_life events (e.g., loss of a loved one, job loss, traumatic events) |
| Social support systems |
| Substance use and abuse |

1. **Focus Group Discussions**

Focus group discussions and observations will also be conducted with purposively selected participants from the HDSS sites. A minimum of ten (10) FGDs will be conducted, each comprising a maximum of eight participants. The aim of the FGDs will be to identify existing vocabularies and descriptors of mental health conditions in the three countries.

# Data Analysis

**Data Preparation and Cleaning**

Before any substantive analysis begins, the data collected will undergo a thorough cleaning process. Stata® will be used for the analysis. Any inconsistencies, outliers, or missing values will be addressed, ensuring the quality of the data. Given the diverse sources from which data will be pooled, particular attention will be paid to ensure uniformity and coherence in data types and scales.

**Descriptive Analysis**

Initial analyses will generate descriptive statistics to provide an overview of the mental health conditions reported across the HDSS sites. This will include frequency distributions, measures of central tendency, and measures of variability for variables of interest. Geographical and temporal sociodemographic trends in mental health conditions will be mapped to visualize disparities and patterns.

**Comparative Analysis**

Given the study's aim to understand variations across different communities, comparative analyses will be conducted to identify statistically significant differences in mental health prevalence and related factors across the three HDSS sites.

**Thematic Analysis**

For qualitative data from the FGDs, a thematic analysis approach will be used. Initial coding of the transcripts will be followed by the identification of recurring themes. This will be done using the NViVO Software. This will provide insights into the perceptions, experiences, and challenges related to mental health conditions in different community setups.

**Causal Inferential Analysis**

Advanced statistical models, like regression analysis, will be employed to ascertain causal relationships. This will be especially crucial when analyzing the impact of community, household, and environmental exposures on mental health.

**Vocabulary and Descriptor Analysis**

The existing vocabularies and descriptors of mental health conditions will be catalogued and analyzed. The aim is to integrate and augment these vocabularies for greater coherence in the metadata used by data science applications in the African context, and more specifically in East Africa. Conclusions on harmonization and standardization of data will then be drawn in comparison to relevant extensive literature.

**Cloud-based Federated Analysis**

With the data being across a federated cloud-based environment, integrated analyses will be conducted using specially designed algorithms that can handle vast and diverse datasets. This will allow for a more comprehensive understanding of the mental health landscape in East Africa.

**Visualization**

To aid in the interpretation and presentation of findings, various data visualization tools will be utilized. Interactive dashboards will be created, highlighting key findings, trends, and patterns in the mental health data across the study region.

**Validation and Sensitivity Analysis**

Given the importance of the findings for policy and intervention design, validation procedures will be implemented. Sensitivity analyses will be conducted to test the robustness of the study's findings. Upon completion of the analyses, the findings will be compiled and synthesized. The results will be contextualized within the broader literature on mental health in the African context. The insights derived will then guide recommendations for policy, intervention design, and further research in the region.

**Validation of Psychosis Data Collection Tool**

The project team will validate the Behavior and Symptom Identification Scale (BASIS-R) tool. This will be done by use of a mental health expert who will conduct blind interviews of one hundred (100) respondents who will have been interviewed by the data collection team across the different HDSS sites under study. The responses will be used to designate mental health “cases” or “non-cases” based on BASIS-R tool. Each individual’s data will be evaluated for their ability to discriminate between cases and non-cases of psychosis within the one hundred respondents. The validation process will also involve translating the tool into the local language, ensuring its cultural appropriateness, and testing its reliability and validity in the local context.

# 6.1 Methods for Synthesizing Literature

To optimally address these projects’ multifaceted objectives, a multidisciplinary team comprising data scientists will guide the identification of pertinent databases and repositories with longitudinal datasets on depression, anxiety and psychosis in East Africa, spanning medical archives, government health departments, NGOs, and academic institutions. With the sources pinpointed, the team will meticulously devise search strategies tailored for each database. This involves crafting detailed search terms, emphasizing specific mental health conditions like depression, anxiety, and psychosis, coupled with the geographical nuances of the region. A list of longitudinal datasets on the mental health conditions in study will b=then be extracted and researchers contacted for the purpose of sharing their data.

Once the relevant data is extracted, it is vital to ensure its quality and consistency. The datasets will undergo rigorous evaluation for their reliability, considering the study size, data collection techniques, and potential biases. Recognizing the varied origins of the data, a pivotal step is data harmonization. This ensures consistent categorization and recording, facilitating effective comparative analyses. However, pure data analysis is just one side of the coin. The socio-cultural fabric of East Africa and the wider region is rich and diverse. Hence, direct engagements with local communities, health professionals, and policymakers will be initiated. This not only provides invaluable contextual insights but also ensures that our findings resonate with ground realities. Qualitative interactions, perhaps in the form of interviews or focus groups, might offer depth to our quantitative findings.

To provide a visual guide of this comprehensive landscaping of longitudinal data in East Africa process, our team will craft a detailed flowchart. This will serve as a quick reference, elucidating each phase of the scoping process and ensuring all stakeholders are aligned in their understanding and expectations.

# Methods for creating a mental health platform within the INSPIRE Data Mesh

**Develop new vocabularies and metadata:** As part of the existing INSPIRE Awards, with input from African mental health researchers, the team is developing new vocabularies and metadata to incorporate into global standards for cross-domain data exchange. The relationship between data science and mental health proposed will facilitate the development of a new common vocabulary for demographic data on mental health in Africa. With recommendations from the Observational Health Data Sciences and Informatics (OHDSI) Africa Chapter, vocabulary development is needed to annotate a new set of questions and answers that can recognize specific signs and symptoms of mental health conditions in an African context.

The Mental Health Vocabulary Working Group (WG) that comprises data scientists working under INSPIRE Network will be tasked with reviewing and commenting on new population health tools. People with lived experience and mental health professionals will be consulted to ensure that the tools developed are applicable and address the needs of people with mental conditions in the African context. The WG will also include an advisor on the development of vocabularies. The new instruments and their vocabularies will be packaged into one or more proposals with support from the OHDSI African Chapter will be reviewed/accepted for inclusion in the OHDSI central vocabulary catalog called ATHENA.

**Build links required for data processes:** Finding, accessing, and collaborating with data providers who have mental health data, and providing support to ensure their data can be harmonized and shared are needed to build links for data processes. Mental health data providers will be part of the INSPIRE governance structure and influence decisions regarding data collection, data storage, and data access. We will also work with mental health professionals to ensure our off-ramp data usage practices are fit for purpose.

**Adapt OHDSI Causal Tools:** Observational Health Data Sciences and Informatics supports several studies designs for population level estimation of causality including the cohort method, the self-controlled cohort design, the case-controlled design and so forth. The analysis database identifies cohorts with particular characteristics and evaluates how different exposures affect outcomes. Additionally, the OHDSI analysis database supports the development of prediction models based on data points drawn from demographic information, environmental exposures, disease history and treatment history using a wide range of algorithms including regularized logistic regression, gradient boosting machines, random forest, and naive Bayes.

The OHDSI analysis database can host emulated clinical trials and/or natural experiments. In the African mental health cases an emulated trial might compare interventions/treatments in the context of age, gender, socioeconomic conditions, comorbidities, available biomarkers, etc. One example of this could be to evaluate the use of community resources to manage mental health, including the friendship bench and to assess how environmental factors alter the impact of the interventions. Therefore, adapting OHDSI Causal Tools will be useful for developing a scientific understanding of effective ways to address population mental health in Africa.

**Data quality checks via OMOP CDM:** Data quality checks will be run on each dataset before Extract, Transform, Load (ETLs) into the OMOP CDM.The use of the PaaS (OMOP CDM) will enable the construction and use of centrally developed resources through locally operated data pipelines. In the mental health platform, new pipelines will be developed for new data sources such as medications from community pharmacy records that result from self-medication or non-prescription data. The data science from this proposal will contribute to the Data Mesh architecture, by accumulating and coordinating the many types of mental health data and developing the data exchange standard.

# Components of the Mental Health Data Platform

The proposed platform for mental health data will have the following components.

1. *Data discovery:* Using metadata and vocabularies taken from the global diverse methods, including web-based search (e.g., crawlers and scrapers) to identify potential sources of longitudinal mental health data in Africa. We will partner with other existing networks such as the East African International Databases to Evaluate AIDS (IeDEA-EA) with longitudinal data on mental health among persons living with HIV. Data discovery will be jointly determined by data scientists working with mental health researchers so that analysts and policymakers understand and use the data available.
2. *Data standardization:* In collaboration with OHDSI and partners associated with OHDSI, we will build standardized vocabularies for longitudinal mental health conditions in African clinical settings.
3. *Data ownership and access:*  Data development and integration of pipelines into a Data Mesh for longitudinal data on mental health conditions in African populations will provide autonomy and flexibility for mental health data producers to experiment, innovate and contribute their data to standardized data pipelines. With aid from data mesh, data will be used as a product, and data owners will facilitate communication between distributed data across the different locations.

1. *Aggregate information model:* A central study catalog that describes and assists in the conduct of natural experiments and/or emulated clinical trials. A catalog entry includes computable descriptions of cohorts and the study we fashion on top of these cohorts. Each catalog entry also includes an enumeration of the databases across the data mesh that participate in a study. Finally, each catalog entry includes a human-readable methodology section that describes how the contributions from each database are aggregated. For example, aggregation might be at the summary level using more or less disaggregated aggregates37 or aggregation might be performed at the person level. In the case of the latter, the Data Mesh would include a central repository aka a portal.

1. *Data visualization:* Development of dashboards to describe the cohorts from data available in the Data Mesh. A complete list of the metadata available will be publicly available to enable users to request access for their analysis.
2. *Causal inference for mental health:* Establishing causation in mental health remains a critical aspect. What is of practical importance in mental health is the association between a risk factor and a disorder (Figure 3)38. Unlike in settings of randomized controlled trials where the risk factors are controlled by the researcher, using longitudinal mental health data from routine data producers provides an opportunity to establish the effect of exposures that are randomized by social or political processes. Using a combination of standardized datasets in the proposed data mesh allows the exploration of high-level federated research and analytics that will inform mental health care in Africa. We aim to use causal methods including regression discontinuity, propensity score matching, and marginal structural models that utilize inverse probability of treatment and censoring weighted estimators to balance those persons with exposed and unexposed risk factors. It is, however, important to note that all proposed methods are dependent on the variety of measured confounders and on agreed assumptions which will further be explored with the use of supervised and unsupervised data science algorithms.
3. *Knowledge and evidence transfer:* A learning mental health system to ensure that the data discovery and the knowledge generated are embedded in the daily mental health care for continued improvement of mental healthcare in Africa.

# ETHICAL CONSIDERATIONS

The importance of ethical and data protection policies in managing data and ensuring the correct data are used for each analysis are central to the project. The approach to data sharing has evolved over time and shifted towards creating platforms through which data is accessed remotely and harmonized. With this approach, the data remains in the places and hands of data producers, and researchers often demonstrate trust, confidence, and willingness to share data. INSPIRE team will work closely with the APHRC’s data protection team and the legal office at the London School of Hygiene and Tropical Medicine (LSHTM) and consult with international partner institutions, such as Committee on Data for Science and Technology (CODATA), to develop a comprehensive Governance framework for this Mental Health project data. For consistency with the principles of FAIR open science, the study will apply for and receive ethical clearance from the African Population and Health Research Center (APHRC) internal review committee, as well as from the Kenya Medical Research Institute’s (KEMRI) Ethics and Scientific Review Committee (ESRC). The HDSS sites in Uganda, and Tanzania will obtain ethics clearances from respective nationally recognized committees in the two countries. Preparing for the research will also include training and sensitization of the study teams on research ethics with an emphasis on ethical issues relating to mental health research and protecting human research participants. During the session, the team will learn some of the key considerations for ethics and research which will include relevance, leadership and ownership, self-determination, privacy and confidentiality, and safety.

All data included in the project will be de-identified, kept under secure protection, and shareable with only the relevant project team members. During the labeling process and use of the Observations and Measurements (O&M) model, Application Programming Interfaces (APIs) will be developed to deliver anonymized datasets. KEMRI SERU will monitor the project's progress to ensure that participants’ confidentiality is maintained throughout the project.

# RISKS, LIMITATIONS, AND MITIGATIONS

|  |  |
| --- | --- |
| **Identified Risk** | **Mitigation Plan** |
| **Risk I**: There is a risk of not having enough studies on mental health to make the platform useful. This may be driven by poor data quality of existing datasets, minimal efforts towards sharing of data, and a general lack of longitudinal datasets with well-labeled mental health outcomes. | **Mitigation I:** Connections will be leveraged across new and existing collaborations with Society of Economic Geologists (SEG) and the African Mental Health Research Initiative (AMARI). Through Dixon Chibanda and the MRC Unit in Uganda, and Mental Health Advocacy groups in Kenya to ensure comprehensive landscaping that uncovers enough datasets to at least demonstrate the usefulness and applications of the new platform and tools. |
| **Risk 2:** There is a slight risk of breach of confidentiality in which personal identifying data are made available in the study datasets. | **Mitigation 2:** The team will ensure that no personal identifying variables such as names of persons are shared during all stages of data gathering, data collation, data cleaning, during the development of ETLs, and during the transfer of data into OMOP. |
| **Risk 3:** The lack of unique identifiers to support record linkage might limit the possibility of accurate identification of long-term outcomes among persons diagnosed with mental disorders. | **Mitigation 3:** Baseline links with longitudinal outcomes may not be feasible in situations where record linkage is suboptimal. Probability- based matching will be used where possible as part of data management processes. |
| **Risk 4:** During the collection of primary data to augment the secondary data, there is a risk of obtaining inaccurate data from the respondents due to the stigma associated with mental health. Participants might provide answers that they deem suitable in a bid to protect themselves from any interviewer-induced bias. There is also a risk of local barriers causing participants with lived experiences not to disclose the information. | **Mitigation 4:** The team will train all data officers in effective and confidential data collection to protect respondents' anonymity and safety. Where possible, the data collection will be self-collected using ACASI (Audio Computer Assisted Self-Interviewing) to improve the quality and accuracy of responses. Follow-up interviews using focus group discussions, observation, and participants with lived experiences will also be used. |

# PLAN FOR COMMUNICATING FINDINGS

The project’s focus is for people who are affected by research and policy change to be able to have a voice in decisions that affect them. The findings will be used to develop an interactive dashboard for estimating and characterizing mental health observations. This will not only offer a user-friendly tool for understanding and addressing mental health issues globally but will also ensure accessibility, updating, and re-usability of mental health data. Mental health researchers and policymakers will have access to mental health cohorts with data that can be used for advanced causal analysis of screening and treatment interventions using methods supported by the platform including the emulation of randomized clinical trials and the comparative effectiveness of treatment pathways. Individual and aggregate data will be able to be requested to investigate the causes of mental health conditions and the outcomes and impact of interventions or environment on those identified with mental health conditions. The platform will provide outputs that can answer research questions relevant to mental health in African populations and will be available to all mental health researchers. The findings and availability of mental health data will inform the development of interventions and strategies to address mental health conditions by highlighting avenues for addressing gaps in prevalence and access to mental health services, which can guide efforts to recommend and evaluate mental health policy interventions across the region. Findings from this study will be disseminated to stakeholders through a variety of approaches including national and international scientific conferences and publications in peer- reviewed journals.

# WORK PLAN/TIMELINES

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Activity** | **JULY 2023 – JUNE 2024** | | | | **JULY 2024 – JUNE 2025** | | | |
| **Q3** | **Q4** | **Q1** | **Q2** | **Q3** | **Q4** | **Q1** | **Q2** |
| Protocol development and ethics review and approval |  |  |  |  |  |  |  |  |
| Workshops: mental health researchers and lived experience experts to redefine research questions |  |  |  |  |  |  |  |  |
| Capacity Building of Project team members |  |  |  |  |  |  |  |  |
| Primary Data Collection from HDSS sites |  |  |  |  |  |  |  |  |
| Development of mental health vocabularies |  |  |  |  |  |  |  |  |
| Development of ETLs and IGs for mental health data |  |  |  |  |  |  |  |  |
| Data collection and consolidation of new datasets to augment existing data |  |  |  |  |  |  |  |  |
| Data analysis using virtual trials |  |  |  |  |  |  |  |  |
| Dissemination of results with mental health stakeholders |  |  |  |  |  |  |  |  |
| Publications |  |  |  |  |  |  |  |  |

# BUDGET AND BUDGET JUSTIFICATION

|  |  |  |
| --- | --- | --- |
| ITEM | COST € | COST KES |
| Personnel | €200,000 | 31,428,000 |
| Data Collection and Fieldwork | €85,000 | 13,356,900 |
| Data Management and Technology | €60,000 | 9,428,400 |
| Training and Capacity Building | €40,000 | 6,285,600 |
| Stakeholder Engagement & Communication | €25,000 | 3,928,500 |
| Publication & Dissemination | €30,000 | 4,714,200 |
| Contingency (5% of total budget) | €24,835 | 3,905,261.90 |
| Administrative Overheads (7% of total budget) | €34,769 | 5,470,260.66 |
| Miscellaneous | €27,096 | 4,257,790.24 |
| **TOTAL** | **€496,700** | **82,775,413.76** |

# MANAGEMENT AND ORGANIZATION OF STUDY

# Project team, Expertise and Responsibilities

|  |  |
| --- | --- |
| **INDIVIDUAL** | **ROLE IN THE STUDY** |
| Agnes Kiragga, PhD  Research Scientist and Head of Data Science Program  African Population and Health Research Center (APHRC),  Nairobi, Kenya | Agnes Kiragga is Senior Data Scientist at APHRC, PI for this project and the lead for the Management workstream in the INSPIRE network. She has over 15 years’ experience handling large, diverse non-conventional and conventional data including longitudinal population cohorts in Africa. Agnes is the Principal Investigator, and will support data sharing and application of novel data science techniques in the OMOP CDM, and coordinate the work with Mental Health Researchers and those with lived experience of mental health into the INSPIRE management team. |
| Jim Todd, MSc  London School of Hygiene & Tropical Medicine  London, England, United Kingdom | Jim Todd is Professor of Applied Biostatistics in LSHTM and founder member of the INSPIRE network. Jim is the Co-Principal Investigator and he will coordinate the work in LSHTM including the development of the OMOP CDM, some analysis components and the support for training modules. He will liaise with collaborators and provide supervision and mentorship to data scientists and students. |
| Jay Greenfield, PhD  Research Associate  Committee on Data of the International Science Council  (CODATA) | Jay Greenfield is a health informatics architect with expertise in data standards, data standard groups and terminologies to annotate medical data with metadata in order to facilitate search, research and discovery. Jay is grooming the OMOP CDM to become a cloud-based Platform as a Service (PaaS) fit for the purpose of African Open Science Platforms. Jay will use this expertise to lead the Data Mesh development, including the pipelines for mental health data. |
| Eugene Kinyanda, MB, PhD  Programme Leader-Track  London School of Hygiene & Tropical Medicine  London, England, United Kingdom | Eugene Kinyanda is a senior scientist and head of the mental health research project at the MRC/UVRI & LSHTM Uganda Research Unit on AIDS (MRC/UVRI). Eugene will lead the inputs on mental health expertise in INSPIRE drawing on his studies on psychiatric and psychosocial problems around HIV, war affected populations and the epidemiology of common mental disorders. Eugene will be invited on the governance panel for mental health data, and we have a number of people with lived experience of mental health he can bring onto the panel. |
| Frederick Murunga Wekesah, PhD  Associate Research Scientist and Chronic Disease Epidemiologist  Co-lead Mental Health Synergy Unit  African Population and Health Research Center  Nairobi, Kenya | Frederick Murunga Wekesah is a chronic diseases epidemiologist and mixed methods researcher at APHRC. He brings on board over 10 years of experience in research in non-communicable diseases and mental health. He co-leads the mental health synergy unit at APHRC, and is a principal investigator on ongoing studies in adolescent mental health.  He will support the design of the protocol, advice on data collection tools, and participate in the planning and project implementation, data collection, data analysis, report and paper writing and dissemination of the study findings. |
| Bylhah Mugotitsa PhD (c).  Project Manager  DSP\_Mental Health Program  African Population and Health Research Center (APHRC)  Nairobi, Kenya | Bylhah Mugotitsa is a senior researcher and PhD candidate, whose research explores how data can be computationally represented to inform public policy formulation and implementation. She is experienced in the design, coordination, and implementation of evidence-based practices. Bylhah will work under the guidance of the PIs to develop and execute strategies that plan for, respond to, and resolve the gap of availability and accessibility to quality mental health data. |

# Steering and Advisory Committee

The project will constitute a steering and advisory committee that will provide advice, ensure delivery of the project outputs and the achievement of project outcomes. The committee will be made up of researchers, mental health experts, representatives of key organizations working in mental health, some of whom will be drawn from partner organizations.

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# APPENDICES

# APPENDIX I: DATA COLLECTION TOOLS

1. GENERALISED ANXIETY DISORDER QUESTIONNAIRE 7 ITEM (GAD – 7)

|  |  |
| --- | --- |
| Over the last 2 weeks, how often have you been bothered by any of the following problems? | |
| 1. Feeling nervous, anxious or on edge? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| 1. Not being able to stop or control worrying? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| 1. Worrying too much about different things? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| 1. Trouble relaxing? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| 1. Being so restless that it is hard to sit still? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| 1. Becoming easily annoyed or irritable? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| 1. Feeling afraid as if something awful might happen? | 0 Not at all  1 Several days  2 More than half the days  3 Nearly every day |
| **Total= /21** |  |

***Note:***

*The GAD-7 originates from Spitzer RL, Kroenke K, Williams JB, et al; A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006 May 22;166(10):1092-7. GAD-7 © Pfizer Inc. all rights reserved; used with permission.*

The GAD-7 score is calculated by assigning scores of 0, 1, 2, and 3, to the response categories of 'not at all', 'several days', 'more than half the days', and 'nearly every day', respectively, and adding together the scores for the seven questions.

Scores of 5, 10, and 15 are taken as the cut-off points for mild, moderate and severe anxiety, respectively. When used as a screening tool, further evaluation is recommended when the score is 10 or greater.

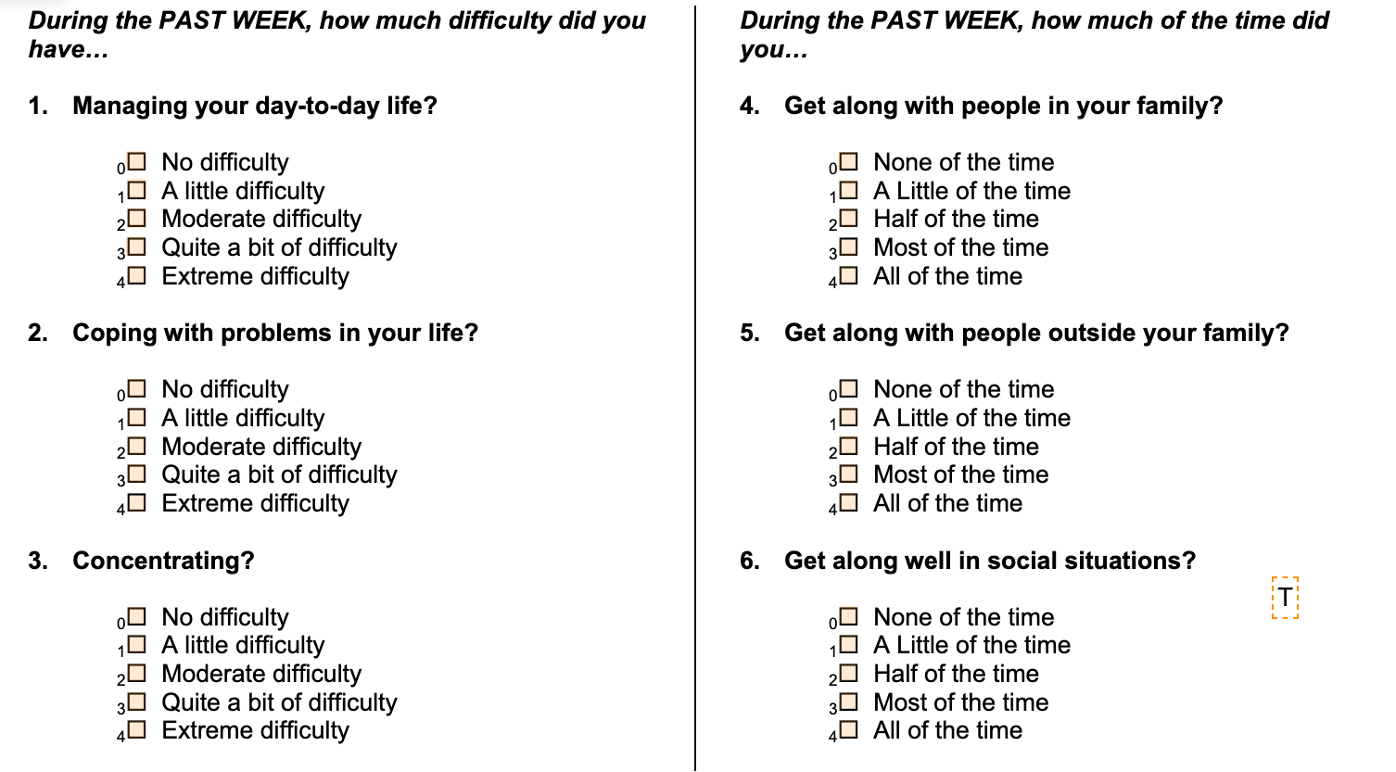
Using the threshold score of 10, the GAD-7 has a sensitivity of 89% and a specificity of 82% for GAD. It is moderately good at screening three other common anxiety disorders - panic disorder (sensitivity 74%, specificity 81%), social anxiety disorder (sensitivity 72%, specificity 80%) and post-traumatic stress disorder (sensitivity 66%, specificity 81%).[[3](https://patient.info/doctor/generalised-anxiety-disorder-assessment-gad-7#ref-3)]

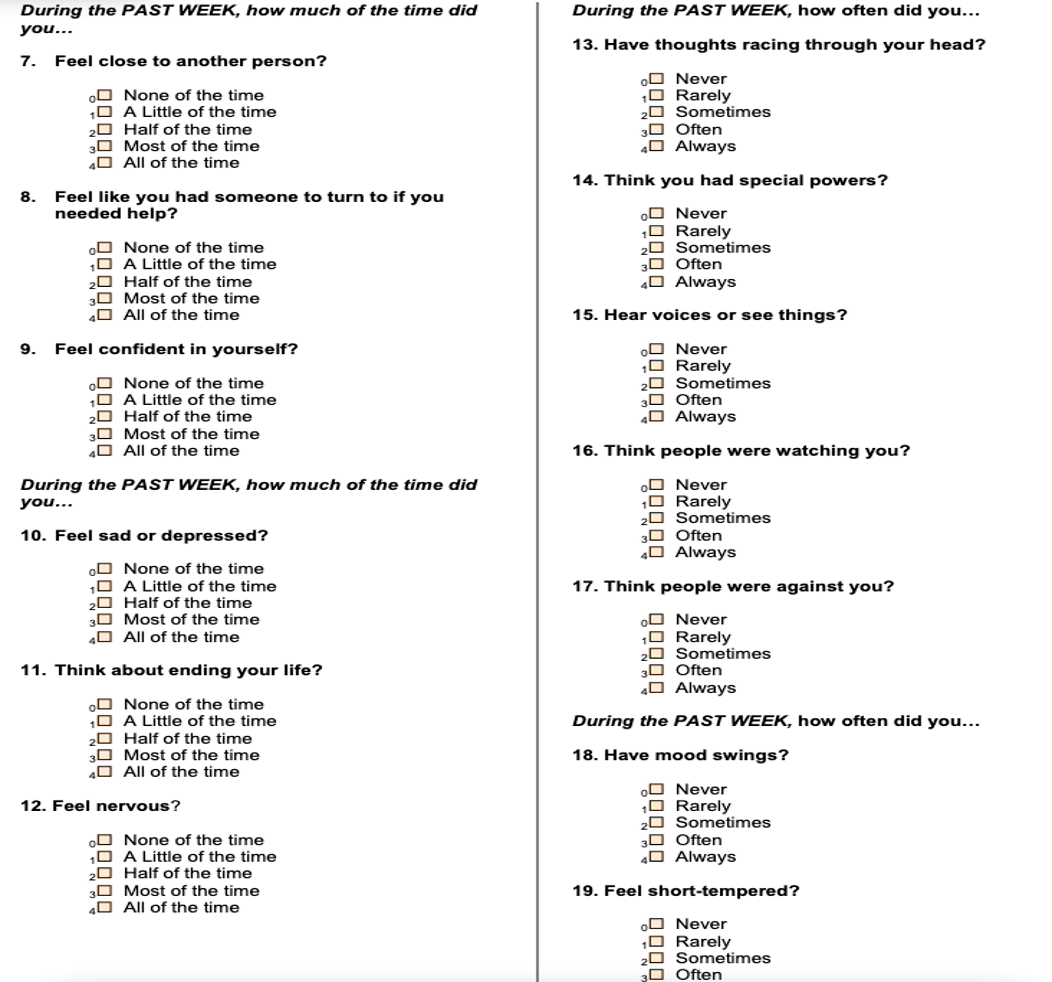
1. PATIENT HEALTH QUESTIONNAIRE 9-ITEM (PHQ – 9)

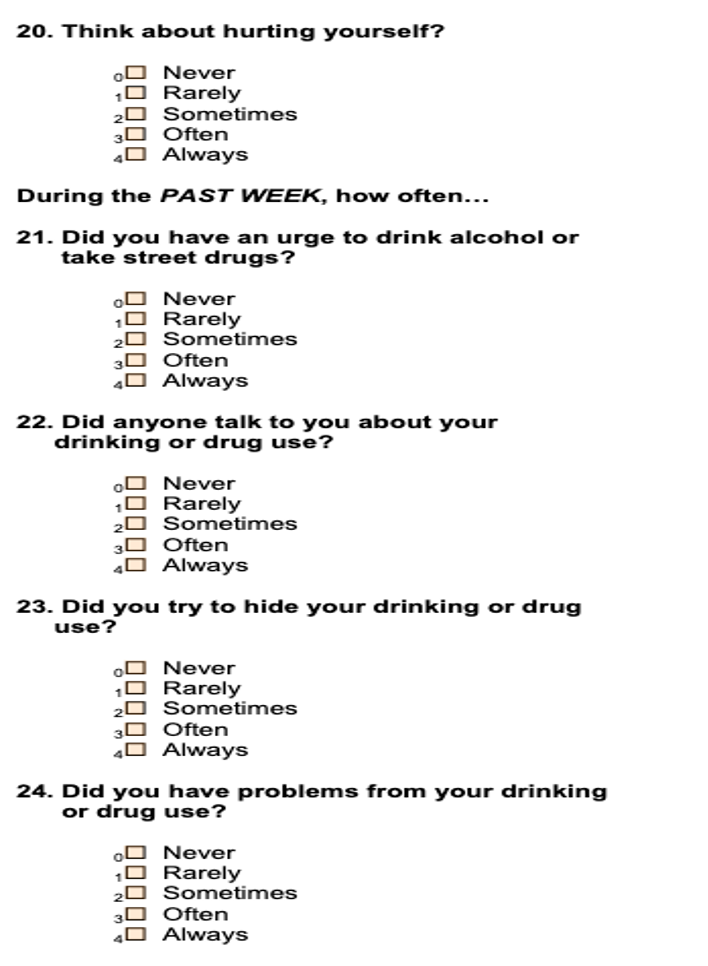
|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Over the past 2 weeks, how often have you been bothered by any of the following? | Not at all | Several days | More than half the days | Nearly everyday |
| 1. Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 1. Feeling down, depressed or hopeless | 0 | 1 | 2 | 3 |
| 1. Trouble falling or staying asleep or sleeping too much | 0 | 1 | 2 | 3 |
| 1. Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 1. Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 1. Feeling bad about yourself – or that you are a failure or have let yourself down | 0 | 1 | 2 | 3 |
| 1. Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 1. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 1. Thoughts that you would be better off dead or of hurting yourself in some way | 0 | 1 | 2 | 3 |

* **BEHAVIOR AND SYMPTOM IDENTIFICATION SCALE (BASIS-24®)** *“Have you had any strange or odd experiences lately that you cannot explain?”*
* *“Do you ever hear things that other people cannot hear, such as noises, or the voices of other people whispering or talking?”*
* *“Do you ever have visions or see things that other people cannot see?”*
* *“Do you ever feel that people are bothering you or trying to harm you?”*
* *“Has it ever seemed like people were talking about you or taking special notice of you?”*
* *“Are you afraid of anything or anyone?”*

Answering “yes” to any of these questions indicates the need for a more detailed assessment. It is also important to get corroborating information from caregivers or others who are close to the patient.







# APPENDIX II: FOCUS GROUP DISCUSSION GUIDES

**Introduction**

* Moderator introduces themselves.
* Explanation of the purpose of the FGD.
* Assurance of confidentiality and anonymity of participants/ signing of consent form.
* Seeking permission to audio-record the discussion.

**Ice-breaker/Opening Question**

1. Can each participant briefly introduce themselves and share one interesting fact about their work or community?

**Understanding Mental Health in the Community**

1. What are the common mental health challenges in your community face?
2. How do community members perceive individuals with mental health disorders?
3. Are you aware of any community-led initiatives or interventions to address mental health issues?

**Existing Data and Knowledge**

1. Are there existing databases or sources where mental health data from your community is stored or documented?
2. Have there been any recent studies or research initiatives on mental health in your HDSS site?

**Perceptions and Expressions of Mental Health**

1. How do people in this community describe or talk about conditions like depression, anxiety and psychosis?
2. Are there local terminologies or descriptors for these conditions? If yes, could you share them?

**Support Systems and Coping Mechanisms**

1. How do individuals with mental health issues cope in your community?
2. What types of support systems, either formal or informal, are available for these individuals?
3. Are you aware of any social support programs or initiatives aimed at helping individuals with mental health issues?

**Recommendations and Closing**

1. Based on today’s discussion, what steps would you recommend for successful treatment of mental health conditions?
2. Is there anything else you would like to share that hasn't been covered in our discussion today?

**Conclusion**

* Thank the participants for their time and valuable insights.
* Reiterate the importance of their input for the project's success.
* Provide information on how and when they can access the findings of the study.

# APPENDIX III: CONSENT FORM

**Study Title:** The INSPIRE network: Building a data science platform for integration and harmonization of longitudinal data on mental health in East Africa

**Research Institution:** African Population and Health Research Center (APHRC)

**Principal Investigator(s):** Agnes Kiragga, PhD (Research Scientist and Head of Data Science Program- APHRC)

**Introduction:**  
You are invited to participate in a research study focused on mental health in Africa. Before agreeing to participate, please read the following information carefully. This consent form outlines the nature of the study, its purpose, procedures involved, potential risks, benefits, and your rights as a participantt.

**Purpose of the Study:**  
The aim of this study is to understand the prevalence, causes, treatments, and perceptions of mental health conditions in East African communities, and to enhance the quality and accessibility of mental health data. Your insights will contribute to a better understanding of mental health conditions in Africa and inform future interventions.

**Confidentiality:**  
Your personal information and responses will remain confidential. Data will be stored securely and will only be accessed by the research team. Any publication or report will not identify you personally.

**Voluntary Participation:**  
Your participation is entirely voluntary. You can decline to participate without any consequences or withdraw at any time without penalty.

**Procedures:**  
If you choose to participate:

* You will be involved in a face-to-face interview or a focus group discussion.
* Questions will be about your experiences, knowledge, and perceptions related to mental health conditions and services.
* The session will last approximately 15 minutes
* Interviews and discussions will be audio recorded for accuracy but will be anonymized in subsequent reports to protect your identity.
* Some of the questions may be personal or sensitive in nature. You can skip any question or halt participation at any point.

**Questions:**  
If you have any questions regarding the study or your rights as a participant, you may contact [ ] at [Email: ] or [Tel: ].

**Consent:**  
I have read (or have had read to me) the above information. I have received answers to all my questions. By signing below, I give my consent to participate in the study.

**Participant's Name:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Participant's Signature:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **Date:** \_\_\_\_\_\_\_\_

**Witness Name:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Witness Signature:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **Date:** \_\_\_\_\_\_\_\_