## SYSTEMATIC REVIEW



## **REVISED** Access to longitudinal mental health data in Africa:

## Lessons from a landscape analysis by the INSPIRE network

## datahub

[version 2; peer review: 1 approved with reservations]

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## Abstract

## Background

Data from longitudinal mental health research in Africa is critical to understanding the complexities of mental health disorders in the continent's diverse contexts. To be useful, data need to adhere to the FAIR principles of Findability, Accessibility, Interoperability, and Reusability.

## Methods

A literature search from 1970 to 2022 identified longitudinal studies on depression, anxiety, and psychosis in was done. Using Artificial Intelligence (AI) and Natural Language Processing techniques, the search found data from more studies. The search engaged stakeholders in understanding data sharing practices and barriers and categorizing methods and challenges for sharing data.

## Results

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Any reports and responses or comments on the article can be found at the end of the article.

The initial search yielded 18,019 articles, of which 284 were eligible for review, and 226 passed quality assessments. A significant effort to access data directly from researchers yielded positive responses for 100 articles with available data statements, from which datasets were requested through online repositories and direct correspondence. Analysis revealed significant disparities in the distribution of mental health research across countries, with a concentration of studies in specific areas and on certain conditions. The study also highlighted a varied adherence to FAIR principles, with only 17 (17%) datasets adhering to data-sharing practices.

## Conclusions

Despite the challenges encountered in data accessibility and the manual adjustments required, the study's findings irradiate the path toward a more equitable and effective mental health research ecosystem on the continent. By fostering collaboration and embracing advanced methodologies and technologies, this study advocates for a concerted effort to improve the accessibility, interoperability, and reusability of mental health data. Ultimately, the project aims to contribute to understanding data-sharing dynamics in Africa, paving the way for informed interventions and policies.

## **Plain language summary**

This publication emphasizes the importance of longitudinal research in understanding mental health issues in African cultural contexts. Mental health is crucial for individuals to manage life's challenges and contribute to society effectively. Over a billion people worldwide suffer from significant mental health problems, which account for 16% of Disability-Adjusted Life Years (DALYs). Longitudinal studies provide essential insights into the development of mental health conditions and help identify the interplay between heredity, environment, and individual factors by tracking changes over time.

The review focuses on three conditions: psychosis, depression, and anxiety, which affect millions worldwide and have become more common since the pandemic. The INSPIRE Network Datahub is leading this research, emphasizing the FAIR data management principles (Findability, Accessibility, Interoperability, and Reusability) to advance knowledge of these mental health conditions. A systematic search approach combining established scoping review techniques was employed to examine relevant longitudinal studies. The integration of data science models enhanced the review, providing insights into mental health trajectories. Artificial intelligence greatly aided the refinement of literature selection, ensuring that studies emphasize the importance of longitudinal research and align with African contexts.

## **Keywords**

Depression, Anxiety, Psychosis, Longitudinal Mental Health Research, FAIR Guiding Principles, Data Sharing, Data Request Process, Africa

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## **REVISED** Amendments from Version 1

Following the reviews we received from the reviewer, We have reworked on the entire introduction section, we have also revised the pain summary of the project, updated to include search phrases should be included as well as the databases searched, we have also updated the results section by including the study region, provided information why years vary for the different conditions, depending on when the articles were published, we have also edited the discussion section to explain why we have more prospective compared to retrospective studies for depression and anxiety. The figures and images have been updated accordingly. For example, "Figure 5. Tools usage\_across\_countries\_anxiety" will be renamed to "Figure 5. Tools usage across countries depression". In response to the GHQ, we have explained why, though it is not a tool specific to depression or depressive symptoms, it was utilized to screen psychiatric disorders because one of the four subscales is used to assess depression within the specific study. We have also highlighted the trends in conducting longitudinal research that arise from the review, as advised. More of the details of the revised manuscript are available in the response note.

Any further responses from the reviewers can be found at the end of the article

#### Introduction

Longitudinal mental health research is needed in Africa to understand the incidence, management and resolution of mental health disorders within the continent's multifaceted cultural contexts. Mental health is fundamentally about achieving a state of well-being where individuals can effectively manage life's stressors, utilize their abilities, and contribute meaningfully to their community. The World Health Organization, estimated that 116 million Africans were living with mental health disorders<sup>1</sup>. Despite its importance, mental health remains a challenging goal globally; as of 2019, over one billion people worldwide suffered from mental and addictive disorders. These conditions not only lead to personal suffering but also contribute significantly to global disease burden, accounting for 418 million (16%) Disability-Adjusted Life Years (DALYs)<sup>2,3</sup>. Longitudinal studies are uniquely suited to mental health research as they allow for examining changes over time, providing valuable insights into causal relationships and the dynamics between individual and environmental influences. This type of data is indispensable for understanding the chronic nature of mental health conditions. For example, the Avon Longitudinal Study of Parents and Children (ALSPAC) provided insights into how early-life factors influence mental health trajectories into<sup>4</sup>. These findings validate using longitudinal approaches to decipher the complex interplay of genetic, environmental, and personal factors over time.

Globally, the availability of comprehensive mental health data is limited. For instance, the global coverage of prevalence data for mental disorders like depression is alarmingly low, highlighting the pressing need for improved data collection and sharing practices<sup>5</sup>. In high-income countries, initiatives like the Catalogue of Mental Health Measures have been developed to facilitate access to longitudinal mental health data, underscoring the importance of such resources in advancing mental health research<sup>6</sup>. In the African context, the challenges are more pronounced. The continent faces a growing mental health crisis exacerbated by limited funding, cultural barriers, and a shortage of trained professionals<sup>7</sup>. Despite the critical need for longitudinal data to inform effective interventions, there is a dearth of accessible datasets. The INSPIRE Network has highlighted the importance of harmonizing longitudinal population health data across Africa to enhance research and promote data-driven decision-making through the adoption of FAIR (Findability, Accessibility, Interoperability, and Reusability) data principles<sup>8,9</sup>.

The study highlighted the significance of systematic methodologies in understanding and managing these conditions, emphasizing the role of longitudinal data in establishing causality and progression of disorders. A systematic search strategy was employed to ensure comprehensive coverage and maximize the discovery of relevant studies. Traditional and novel methodologies were integrated to introduce fresh perspectives and innovative analytical techniques<sup>10</sup>. Integrating machine learning models in the longitudinal data analysis was important for predicting mental health outcomes from large datasets.

The use of artificial intelligence (AI) in refining the search selection and double check the internet for any missed relevant literature represented a significant advancement in research methodology. This technological application facilitated the identification of studies aligning with geographical and thematic priorities relevant to Africa and demonstrated the potential of longitudinal approaches to unveil the temporal dynamics associated with mental health conditions<sup>11,12</sup>.

The scarcity of longitudinal mental health data in Africa impedes the development of effective, context-specific interventions and policies. Addressing this gap is essential to improve mental health outcomes across the continent. This research aims to assess the availability, accessibility, and quality of longitudinal mental health data in African settings, focusing on depression, anxiety, and psychosis. By identifying existing datasets and evaluating their adherence to FAIR principles, this study seeks to inform strategies for enhancing data sharing and utilization, ultimately contributing to more effective mental health interventions and policies in Africa.

#### Background of the study

The prevalence of mental health conditions varies across age groups, influencing research priorities. Anxiety and depression may require more research in younger populations, while substance use disorders peak in young adulthood<sup>8</sup>. Conditions with stable prevalence, like bipolar disorder, require consistent research, and less prevalent conditions, such as eating disorders, should not be overlooked<sup>12</sup>.

#### Methods

# Prompters to categorize methods and challenges of data sharing

"Prompters" are the factors or prompts that initiate discussions or considerations regarding data sharing in mental health. In that case, "prompters" can be understood as the catalysts or triggers that lead to discussions or actions related to data sharing. In the prompted mental health realms; various prompters are used to categorize methods and challenges of data sharing. Some of the key ones are:

- Ethical Guidelines: Data sharing boundaries, anonymization, and consent processes.
- Legal Frameworks: HIPAA, GDPR, etc.
- Data Security: Protection from breaches and misuse.
- Interoperability Standards: Effective data sharing between systems and databases while maintaining data integrity and security.
- Anonymization: Protection of patient's privacy during sharing.
- Consent Mechanisms: Informed consent and exceptions.
- Data Ownership and Governance: Define rights on the data and oversight.
- Technical Infrastructure: Secured data processing, storage, and transmission.
- Stakeholder Collaboration: Involve key parties in policy development.
- Risk Assessment: Identify and address potential datasharing risks.

#### Search strategy

We used a systematic search strategy to explore mental health research, including access to longitudinal data and its quality. This involved English-language articles from 1970 to 2022 and leveraging AI and NLP for efficient database searches. The search leveraged on the International Digital Health and AI Research Collaborative (I-DAIRS) global research map (GRM)<sup>13</sup> to navigate the vast landscape of African scientific publications in mental health. This platform performs searches across various databases such as PubMed, Google Scholar, WHO Global Health Observatory, Clinical-Trials.gov, World Bank Open Data Open Science Framework (OSF) and FAIRsharing.org.

#### Selection criteria

Articles were selected based on their original research in Africa, containing keywords related to mental health disorders and being longitudinal studies with at least one follow-up.

#### Dataset filtering

From the original pool, the review removed entries with missing titles, duplicate titles, and papers not about African research, resulting in a refined list. Further filtration was conducted based on titles and field of study specifics to identify relevant mental health topics.

#### Study selection

The remaining articles were categorized into different types of studies: control trials, cross-sectional, reviews, meta-analyses, and case reports. Particularly, the focus was on longitudinal studies, which were then sub-categorized based on mental health conditions of interest: depression, anxiety, and psychosis. This ensured the inclusion of pertinent studies for further in-depth analysis. A link to the code used for selection criteria can be found HERE. The details of the archived software used was GNU general public licence is available in the R source code folder<sup>14</sup>.

#### Search outcomes

The initial search yielded 18,019 articles, narrowed to 284 eligible studies after applying exclusion criteria related to duplicates, geographic relevance, and study design.

#### Quality assessments, data extraction, and data request

From the 284 eligible articles, 226 satisfied our quality criteria. Data extraction focused on crucial study parameters was conducted by two independent reviewers. Further information on mental health screening instruments, availability of data statements in the article, study cohort, study site, age group of participants, mean age of participants, and sample size was added to the database at this stage. Out of the 226 articles that met the quality check criteria, 100 had availability of data statements in the articles. A targeted effort to request data from these studies involved drafting letters to corresponding authors, yielding a notable response.

#### Access to longitudinal mental health datasets

A significant stride was the systematized process to access longitudinal datasets from African researchers. This included both virtual access to repositories and formal requests, showcasing the diverse data acquisition channels crucial for analysis.

#### Statistical analysis

Beyond the scoping review, exploratory quantitative analysis was performed on the articles and datasets received. Out of the total datasets, 10 were accessed via online repositories, and seven were obtained through formal requests. This analysis utilized R software version 4.3.1 (2023-06-16), facilitating a nuanced exploration of distribution across countries, regions, and specific mental health conditions. Additionally, a metaanalysis was conducted on the accessed longitudinal datasets, providing a comprehensive overview of depression, anxiety, and psychosis within the African context. This multi-layered analytical approach underscores the diverse methodologies employed to deepen our understanding of African longitudinal mental health research.

#### Study design

The landscape analysis study evaluated the current state of African longitudinal mental health research using various methods, including data analysis from scientific literature, datasets, and stakeholder engagements. The study used prompters to extract insights about data access and sharing, involving stakeholders and identifying key barriers. The participatory approach enriched the understanding of data-sharing practices and identified challenges and opportunities in mental health research, informing future research directions. The detailed flow chart diagram is shown in Figure 1.

#### Results

Table 1 summarizes the overview of the type of study of theeligible articles grouped by region, country, mental health



Figure 1. The landscape flowchart.

condition, availability of data, and access to the data. Regarding the type of study, there is a relatively balanced distribution between prospective (104) and retrospective (122) studies. Most of the studies investigated depression (58.4%), followed by psychosis (42.0%) and anxiety (29.2%).

The study areas are split into Eastern (Kenya, Uganda, Tanzania, Sudan, Ethiopia); Northern (Egypt, Tunisia, Morocco); Southern (South Africa, Zimbabwe, Botswana, Zambia), and Western Africa (Burkina Faso, Ghana, Mali, Nigeria). Southern Africa has the most significant representation, with South Africa having the highest number of studies (39.8%), followed by Nigeria (16.4%) and Tunisia (15.0%). Northern Africa has the highest proportion of retrospective studies (36.9%). Out of 226 articles, 100 included data availability statements, with prospective studies having the highest proportion of data availability (67 out of 100). Retrospective studies accounted for 33 out of the 100 articles with data availability. The trend shows increased transparency in studies from 2005 to 2022, with all including data availability statements<sup>15</sup>.

# Overview of eligible depression, anxiety, and psychosis articles

Table 2 provides an overview of the distribution of articles across various regions in Africa. It categorizes articles by study region, country, type of study, the presence of mental health

conditions studied, the availability of data statements and data access methods.

The distribution of articles across different African regions showed similar patterns in terms of focusing on depression, psychosis, and anxiety. Northern Africa had the second-highest proportion of study articles for psychosis and anxiety, with 30 (31.6%) and 15 (22.7%) respectively. South Africa exhibited a significant focus on mental health research with the highest number of articles on all three conditions. Most studies were prospective, with depression studies having the highest prevalence compared to anxiety and psychosis studies. There was a higher prevalence of depression studies (132 articles) compared to anxiety (66 articles) and psychosis (95 articles), suggesting a prioritization of research resources or the perceived burden of these conditions within the African context.

# Outcome of the letters sent to request for access to datasets

From the 100 data request letters sent out, the response rates were as outlined in Table 3: Outcome of request to access datasets is described in Table 3, showcasing response rates and data accessibility. Most responses came from Southern Africa (71.4%), with South Africa contributing the majority of datasets. The majority of datasets focused on depression (88.2%) and were mostly prospective studies (88.2%).

Variable	Category	Overall N = 226	Туре о	of Study	Availabili state	ty of data ment
			Prospective n = 104	Retrospective n = 122	No n = 126	Yes n = 100
Source year published	Range	1978 - 2022	1993 - 2022	1978 - 2022	1978 - 2021	2005 - 2022
	Eastern Africa	37 (16.4%)	27 (26.0%)	10 (8.2%)	8 (6.3%)	29 (29.0%)
Study region	Northern Africa	54 (23.9%)	9 (8.7%)	45 (36.9%)	45 (35.7%)	9 (9.0%)
Study region	Southern Africa	94 (41.6%)	60 (57.7%)	34 (27.9%)	43 (34.1%)	51 (51.0%)
	Western Africa	41 (18.1%)	8 (7.7%)	33 (27.0%)	30 (23.8%)	11 (11.0%)
	Botswana	1 (0.4%)	0 (0.0%)	1 (0.8%)	0 (0.0%)	1 (1.0%)
Study country	Burkina Faso	1 (0.4%)	0 (0.0%)	1 (0.8%)	1 (0.8%)	0 (0.0%)
	Egypt	17 (7.5%)	2 (1.9%)	15 (12.3%)	9 (7.1%)	8 (8.0%)
	Ethiopia	19 (8.4%)	11 (10.6%)	8 (6.6%)	2 (1.6%)	17 (17.0%)
	Ghana	2 (0.9%)	2 (1.9%)	0 (0.0%)	0 (0.0%)	2 (2.0%)
	Kenya	7 (3.1%)	7 (6.7%)	0 (0.0%)	2 (1.6%)	5 (5.0%)
	Mali	1 (0.4%)	0 (0.0%)	1 (0.8%)	1 (0.8%)	0 (0.0%)
	Morocco	3 (1.3%)	0 (0.0%)	3 (2.5%)	2 (1.6%)	1 (1.0%)
	Nigeria	37 (16.4%)	6 (5.8%)	31 (25.4%)	28 (22.2%)	9 (9.0%)
	South Africa	90 (39.8%)	57 (54.8%)	33 (27.0%)	40 (31.7%)	50 (50.0%)
	Sudan	1 (0.4%)	0 (0.0%)	1 (0.8%)	1 (0.8%)	0 (0.0%)
	Tanzania	1 (0.4%)	1 (1.0%)	0 (0.0%)	1 (0.8%)	0 (0.0%)
	Tunisia	34 (15.0%)	7 (6.7%)	27 (22.1%)	34 (27.0%)	0 (0.0%)
	Uganda	9 (4.0%)	8 (7.7%)	1 (0.8%)	2 (1.6%)	7 (7.0%)
	Zambia	1 (0.4%)	1 (1.0%)	0 (0.0%)	1 (0.8%)	0 (0.0%)
	Zimbabwe	2 (0.9%)	2 (1.9%)	0 (0.0%)	2 (1.6%)	0 (0.0%)
Type of Study	Prospective	104 (46.0%)	—	_	37 (29.4%)	67 (67.0%)
	Retrospective	122 (54.0%)	_	—	89 (70.6%)	33 (33.0%)
Depression	Yes	132 (58.4%)	78 (75.0%)	54 (44.3%)	60 (47.6%)	72 (72.0%)
Anxiety	Yes	66 (29.2%)	37 (35.6%)	29 (23.8%)	31 (24.6%)	35 (35.0%)
Psychosis	Yes	95 (42.0%)	19 (18.3%)	76 (62.3%)	75 (59.5%)	20 (20.0%)
Availability of data	No	126 (55.8%)	37 (35.6%)	89 (73.0%)	—	—
statement	Yes	100 (44.2%)	67 (64.4%)	33 (27.0%)	—	—
	Corresponding author	71 (31.4%)	40 (38.5%)	31 (25.4%)	0 (0.0%)	71 (71.0%)
Llow to proceed	Data repository	24 (10.6%)	24 (23.1%)	0 (0.0%)	0 (0.0%)	24 (24.0%)
data	Link in Article	5 (2.2%)	3 (2.9%)	2 (1.6%)	0 (0.0%)	5 (5.0%)
	No availability of data statement	126 (55.8%)	37 (35.6%)	89 (73.0%)	126 (100.0%)	0 (0.0%)

## Table 1. Overview of landscape studies.

Variable	Category	Depression	Anxiety	Psychosis
		n = 132	n = 66	n = 95
Source year published	Range	1983 - 2022	1987 - 2022	1978 - 2021
	Eastern Africa	27 (20.5%)	9 (13.6%)	13 (13.7%)
Ctuch una si a s	Northern Africa	23 (17.4%)	15 (22.7%)	30 (31.6%)
Study region	Southern Africa	60 (45.5%)	28 (42.4%)	34 (35.8%)
	Western Africa	22 (16.7%)	14 (21.2%)	18 (18.9%)
	Botswana	1 (0.8%)	1 (1.5%)	1 (1.1%)
	Burkina Faso	0 (0.0%)	0 (0.0%)	1 (1.1%)
	Egypt	12 (9.1%)	10 (15.2%)	5 (5.3%)
	Ethiopia	12 (9.1%) 5 (7.6%)		8 (8.4%)
	Ghana	2 (1.5%)	1 (1.5%)	0 (0.0%)
Chultananta	Kenya	7 (5.3%)	3 (4.5%)	1 (1.1%)
	Mali	1 (0.8%)	0 (0.0%)	0 (0.0%)
	Morocco	2 (1.5%)	1 (1.5%)	2 (2.1%)
Study country	Nigeria	19 (14.4%)	13 (19.7%)	17 (17.9%)
	South Africa	57 (43.2%)	25 (37.9%)	31 (32.6%)
	Sudan	1 (0.8%)		1 (1.1%)
	Tanzania	0 (0.0%)	0 (0.0%)	1 (1.1%)
	Tunisia	9 (6.8%)	4 (6.1%)	23 (24.2%)
	Uganda	7 (5.3%)	1 (1.5%)	2 (2.1%)
	Zambia	0 (0.0%)	0 (0.0%)	1 (1.1%)
	Zimbabwe	2 (1.5%)	2 (3.0%)	1 (1.1%)
Tupo of Study	Prospective	78 (59.1%)	37 (56.1%)	19 (20.0%)
Type of Study	Retrospective	54 (40.9%)	29 (43.9%)	76 (80.0%)
Depression	Yes	_	55 (83.3%)	29 (30.5%)
Anxiety	Yes	55 (41.7%)	—	10 (10.5%)
Psychosis	Yes	29 (22.0%)	10 (15.2%)	_
Availability of data	No	60 (45.5%)	31 (47.0%)	75 (78.9%)
statement	Yes	72 (54.5%)	35 (53.0%)	20 (21.1%)
	Corresponding author	47 (35.6%)	25 (37.9%)	18 (18.9%)
	Data repository	21 (15.9%)	7 (10.6%)	0 (0.0%)
How to access the data	Link in Article	4 (3.0%)	3 (4.5%)	2 (2.1%)
	No availability of data statement	60 (45.5%)	31 (47.0%)	75 (78.9%)

Table 2. Overview of depression, anxiety and psychosis articles.<sup>1</sup>

<sup>1</sup> The sum of n>226 since some articles covered more than one mental health condition

Variable	Category	Status	data request n	= 100	Data rece Responded r	eived from equest N = 35
		Email Bounced n = 6	No Response n = 59	Responded n = 35	No n = 18 (51%)	Yes n = 17 (49%)
Source year published	Range	2007 - 2021	2005 - 2022	2007 - 2022	2007 - 2022	2008 - 2022
	Eastern Africa	2 (33.3%)	20 (33.9%)	7 (20.0%)	1 (5.6%)	6 (35.3%)
Ctudy region	Northern Africa	1 (16.7%)	6 (10.2%)	2 (5.7%)	1 (5.6%)	1 (5.9%)
Study region	Southern Africa	2 (33.3%)	24 (40.7%)	25 (71.4%)	15 (83.3%)	10 (58.8%)
	Western Africa	1 (16.7%)	9 (15.3%)	1 (2.9%)	1 (5.6%)	0 (0.0%)
	Botswana	0 (0.0%)	0 (0.0%)	1 (2.9%)	1 (5.6%)	0 (0.0%)
	Burkina Faso	—	—	—	-	—
	Egypt	1 (16.7%)	5 (8.5%)	2 (5.7%)	1 (5.6%)	1 (5.9%)
	Ethiopia	1 (16.7%)	13 (22.0%)	3 (8.6%)	0 (0.0%)	3 (17.6%)
	Ghana	0 (0.0%)	2 (3.4%)	0 (0.0%)	_	_
	Kenya	0 (0.0%)	3 (5.1%)	2 (5.7%)	1 (5.6%)	1 (5.9%)
	Mali	_	_	_	_	_
	Morocco	0 (0.0%)	1 (1.7%)	0 (0.0%)	_	_
Study country	Nigeria	1 (16.7%)	7 (11.9%)	1 (2.9%)	1 (5.6%)	0 (0.0%)
	South Africa	2 (33.3%)	24 (40.7%)	24 (68.6%)	14 (77.8%)	10 (58.8%)
	Sudan					
	Tanzania	_	_	_	_	—
	Tunisia	_	_	_	_	_
	Uganda	1 (16.7%)	4 (6.8%)	2 (5.7%)	0 (0.0%)	2 (11.8%)
	Zambia	_	_	_	_	_
	Zimbabwe	_	_	—	_	_
Tupo of study	Prospective	5 (83.3%)	31 (52.5%)	31 (88.6%)	16 (88.9%)	15 (88.2%)
Type of study	Retrospective	1 (16.7%)	28 (47.5%)	4 (11.4%)	2 (11.1%)	2 (11.8%)
Depression	Yes	5 (83.3%)	36 (61.0%)	31 (88.6%)	16 (88.9%)	15 (88.2%)
Anxiety	Yes	3 (50.0%)	21 (35.6%)	11 (31.4%)	7 (38.9%)	4 (23.5%)
Psychosis	Yes	1 (16.7%)	15 (25.4%)	4 (11.4%)	2 (11.1%)	2 (11.8%)
How to access	Corresponding author	6 (100.0%)	57 (96.6%)	8 (22.9%)	6 (33.3%)	2 (11.8%)
the data	Data repository	0 (0.0%)	2 (3.4%)	22 (62.9%)	12 (66.7%)	10 (58.8%)
	Link in Article	0 (0.0%)	0 (0.0%)	5 (14.3%)	0 (0.0%)	5 (29.4%)

Table 3. Outcome of request to access datasets.

Distribution of longitudinal studies on depression, anxiety, and psychosis by country

Two main themes were identified for longitudinal studies: clinical/retrospective and population/prospective. Several studies of both types were carried out across the continent, with some countries showing a greater emphasis on one type over the other. Figure 2 shows the studies on anxiety in  $Africa^{16}$ .

- South Africa conducted a total of 90 studies, mainly population/prospective.



Figure 2. Studies on anxiety in Africa.

- In Nigeria, there were 37 studies, majority being clinical/retrospective.
- Tunisia and Egypt focused on clinical/retrospective studies, with 27 out of 34 and 15 out of 17 studies, respectively.
- Ethiopia had a balanced mix, with 8 clinical/ retrospective and 11 population/prospective studies.

#### Longitudinal studies on anxiety

Anxiety research in Africa is varied. Nigeria, Egypt, South Africa, Uganda, Kenya, and Tunisia have different levels of research engagement. Nigeria and South Africa have the highest research activity, while Uganda, Kenya, and Tunisia have a smaller but noteworthy research presence. Uganda and Kenya, show a smaller but still noteworthy research presence, with 1 (approximately 1.5%) and 3 (around 4.5%) studies, respectively. Finally, Tunisia, situated northwest of Africa, accounts for a smaller share, with 4 longitudinal studies, which translates to roughly 6.1% of the marked research efforts.

The overview from Figure 2 shows the distribution of longitudinal anxiety studies across the African continent. The disparity in study percentages across the countries highlights not only the uneven allocation of mental health research resources but also the potential differences in the perceived or actual burden of anxiety disorders within these distinct regions.

#### Top 10 most utilized tools for anxiety

In 66 studies from various countries, 70 anxiety assessment tools were identified, with 43 tools (61.4%) classified as most frequently used. South Africa and Nigeria were the leading users, with South Africa employing 24 different tools in 24 studies and Nigeria using 20 tools in 13 studies. In Nigeria, the State-Trait Anxiety Inventory (STAI) and the Depression Anxiety Stress Scales (DASS-21) were the most common, used four and three times, respectively. In South Africa, tools like the General Health Questionnaire-28 (GHQ-28) and the Revised Children's Manifest Anxiety Scale (RCMAS) were predominant, each used three times. Other countries, such as Ethiopia, Kenya, Egypt, and Tunisia, also utilized various anxiety assessment tools. Figure 3 provides the geographical distribution of tool usage of anxiety. The Table 4 below also outlined the distribution of the tools used for anxiety in Africa.

#### Longitudinal studies on depression

The distribution of depression studies across Africa varies greatly between countries, likely due to differences in funding, infrastructure, and local research capacities.

- South Africa leads with 57 studies (43.2% of the total).
- Tunisia has 9 studies (6.8%).
- Uganda and Kenya each have 7 studies (10.6% combined).
- Egypt has 12 studies (9.1%).
- Nigeria has 19 studies (14.4%).

Ghana presents 2 studies, which comprise around 1.5% of the studies. Similarly, Morocco, located in the northwest, also shows only 2 studies, constituting approximately 1.5%. The map in Figure 4 on studies on depression in Africa illustrates the geographic distribution of longitudinal mental health studies on depression across various African nations, each marked with a numbered pin indicating the number of studies. The disparities necessitate attention to ensure a more equitable distribution of research efforts, which is essential to

comprehensively address mental health needs across the continent. The figure on studies on depression in Africa is also found in the extended data folder<sup>16</sup>.

#### Top 10 most utilized tools for depression

Table 5 summarizes the usage of 139 assessment tools in 132 depression studies across African countries. The most used tool is the Center for Epidemiological Studies-Depression (CES-D) scale, predominantly in South Africa. The Edinburgh Postnatal Depression Scale (EPDS) is mainly used in Ethiopia and South Africa. The Patient Health Questionnaire (PHQ-9) is frequently used in Ethiopia and South Africa. The Beck Depression Inventory (BDI/BDI-II) and the Mini International Neuropsychiatric Interview (MINI) are notable tools. The General Health Questionnaire-28 (GHQ-28) and the Hospital Anxiety and Depression Scale (HADS) are also widely used. The Diagnostic and Statistical Manual of Mental Disorders-4th Edition (DSM-IV) is exclusively used in Egypt. The data reflects varied methodological preferences across different nations for studying depression. Detailed information is shown in Figure 5 and in Annexure 2, 2.1 in the extended data.

#### Longitudinal studies on psychosis

The landscape of psychosis research in Africa still falls behind that of depression and anxiety. South Africa emerges as the leading country in psychosis longitudinal research, with 31 studies accounting for approximately 32.6% of the



Figure 3. Tools\_usage\_across\_countries\_anxiety.

#### Table 4. Top 10 tools used for anxiety in Africa.

Anxiety Tools	Overall	Botswana	Egypt	Ethiopia	Kenya	Morocco	Nigeria	South Africa	Tunisia	Uganda	Zimbabwe
	N = 70	N = 1	N = 11	N = 3	N = 2	N = 1	N = 20	N = 24	N = 4	N = 1	N = 3
Depression Anxiety Stress Scale (DASS-21)	6	0	0	2	0	0	3	1	0	0	0
	8.6%	0.0%	0.0%	66.7%	0.0%	0.0%	15.0%	4.2%	0.0%	0.0%	0.0%
General Health Questionnaire- 28 (GHQ-28)	6	0	0	1	0	0	2	3	0	0	0
	8.6%	0.0%	0.0%	33.3%	0.0%	0.0%	10.0%	12.5%	0.0%	0.0%	0.0%
Hospital Anxiety and Depression Scale (HADS)	6	0	2	0	0	0	2	0	2	0	0
	8.6%	0.0%	18.2%	0.0%	0.0%	0.0%	10.0%	0.070	50.0%	0.0%	0.0%
Spielberger's State-Trait Anxiety Inventory (STAI)	6	0	0	0	0	0	4	1	1	0	0
	8.6%	0.0%	0.0%	0.0%	0.0%	0.0%	20.0%	4.2%	25.0%	0.0%	0.0%
MINI International	4	0	2	0	0	0	0	2	0	0	0
for Children and Adolescents (MINI-Kid)	5.7%	0.0%	18.2%	0.0%	0.0%	0.0%	0.0%	8.3%	0.0%	0.0%	0.0%
Revised Children's Manifest	4	0	0	0	1	0	0	3	0	0	0
Minkley Scale (Reivins)	5.7%	0.0%	0.0%	0.0%	50.0%	0.0%	0.0%	12.5%	0.0%	0.0%	0.0%
General Health Questionnaire-	3	0	1	0	1	0	0	1	0	0	0
12 (011Q-12)	4.3%	0.0%	9.1%	0.0%	50.0%	0.0%	0.0%	4.2%	0.0%	0.0%	0.0%
Structured Clinical Interview for	3	0	1	0	0	0	1	1	0	0	0
	4.3%	0.0%	9.1%	0.0%	0.0%	0.0%	5.0%	4.2%	0.0%	0.0%	0.0%
Symptom Checklist-90-R (SCL-	3	0	1	0	0	0	2	0	0	0	0
30-N)	4.3%	0.0%	9.1%	0.0%	0.0%	0.0%	10.0%	0.0%	0.0%	0.0%	0.0%
Beck Anxiety Inventory (BAI)	2	0	0	0	0	0	1	1	0	0	0
	2.9%	0.0%	0.0%	0.0%	0.0%	0.0%	5.0%	4.2%	0.0%	0.0%	0.0%
Others	27	1	4	0	0	1	5	11	1	1	3
	38.6%	100.0%	36.4%	0.0%	0.0%	100.0%	25.0%	45.8%	25.0%	100.0%	100.0%

studies across the African continent. Tunisia follows with 23 studies, contributing nearly 24% to the research output, reflecting a substantial engagement in this field. East African region has a total of 4 longitudinal studies on psychosis.

Egypt and Nigeria have made further contributions to longitudinal research in psychosis. Egypt conducted 5 studies, which is about 5.3% of the total noted in Figure 6. Nigeria has undertaken 17 studies, representing approximately 17.9% of the psychosis research efforts showcased. These figures, while lower in comparison to South Africa and Tunisia, indicate a growing recognition of the importance of studying psychosis within these countries. Figure 6 shows the studies on psychosis in  $Africa^{16}$ .

#### Top 10 tools used for psychosis in Africa

The assessment of psychosis in various African nations has been examined through 95 studies, highlighting the use of 60 different assessment tools. The Positive and Negative Syndrome Scale (PANSS) emerged as the most widely used tool in 10 (16.7%) instances, particularly in South African studies where 8 (42.1%) of the 19 tools employed across 31 studies were the PANSS, underscoring its use in the regional psychosis research landscape. Other commonly utilized tools include the Brief



Figure 4. Studies on depression in Africa.

Psychiatric Rating Scale (BPRS) in Nigeria, and the Composite International Diagnostic Interview (CIDI) and the Schedule for Clinical Assessment in Neuropsychiatry (SCAN) in Ethiopian research. Figure 7 visualizes the detailed distribution of tools used for psychosis.

A singular approach to psychosis assessment is observed in Burkina Faso, Morocco, Sudan, and Zambia, where a single tool—clinical diagnosis for Burkina Faso and Sudan, and DSM-IV for Morocco and Zambia—is reported in their respective single study on psychosis. In contrast, Egypt, within its 5 psychosis studies, applies 1 (25%) tool, the Structured Clinical Interview for DSM-IV (SCID-IV), and 3 other studies used other tools. A detailed table of tools used for psychosis and how the tools are distributed across African countries is in Annexure 3 and 3.1, respectively. The table below details the assessment tools utilized in studies of psychosis across various African nations within the context of longitudinal research.

Schizophrenia's stable prevalence in adulthood highlights the need for sustained research into long-term management, considering the chronic nature of the condition and the associated psycho-social burdens. Figure 8 shows the disease burden from WHO report of 2023. Table 6 outlines the distribution of tools used for psychosis in Africa.

Therefore, while the absolute prevalence of a condition is an important determinant of research focus, the current research landscape must also consider the broader impact on health, quality of life, and the healthcare system<sup>14</sup>.

#### Discussion

The discussion paper highlights the importance of landscaping longitudinal data in Africa, particularly focusing on depression, anxiety, and psychosis studies. It raises concerns about the lack of transparency and data statements in nearly half of the studies for each condition, emphasizing the need for improved data sharing methods such as repositories or providing links within articles. This is crucial for replicating research outcomes in the field of mental health research in Africa.

Recent trends show a rising interest in depression and anxiety studies, indicating a growing focus on these areas. The distribution of longitudinal studies on depression, anxiety, and

Table 5. Top 10 tools used for depression in Africa.



Figure 5. Tools\_usage\_across\_countries\_depression.

psychosis by country varies and may be influenced by factors such as available funding, research infrastructure, and public health priorities. For example, the prevalence of more population and prospective studies in South Africa suggests the country's forward-thinking approach to public health research and its capacity to invest in long-term studies tracking health outcomes over time. On the other hand, the prominence of clinical and retrospective studies in countries like Nigeria and Kenya may indicate a different stage of development in research capacities, focusing on leveraging existing data before moving to more resource-intensive prospective studies.

Despite efforts to advance research on psychosis, the numerical distribution suggests that Africa lags behind in this area. Cultural beliefs, stigma surrounding mental health disorders, and the influence of traditional healers create challenges in recognizing, diagnosing, and researching psychosis within a medical framework. The top 10 tools used for psychosis in Africa reflect the perceived utility and screening fit of each tool, as well as the underlying research infrastructures, available expertise, and methodological preferences that shape the landscape of psychosis research in Africa. There is a need for the harmonization of screening and assessment strategies to facilitate a more cohesive understanding of psychosis across diverse African settings.

Policies geared towards developing and enhancing research infrastructure are pivotal. They play a determining role in undertaking longitudinal studies that can yield insights into the prevention, diagnosis, treatment, and monitoring of mental health conditions. As the research conducted by 17 indicates that improvements in research infrastructure are essential for the validity and efficiency of longitudinal studies.

Local expertise and research capacities, including the availability of trained mental health researchers and clinicians, are crucial for conducting and sustaining longitudinal studies. Examining educational programs, continuous professional development, and opportunities for researchers within the African context will be pertinent here. The research findings suggest that it is imperative to consider the cultural nuances and resource constraints inherent in LMIC settings, ensuring that mental health interventions are not only imported but also adapted, accepted, and embedded within the community.

#### Data-sharing practices

The absence of data statements in many research articles raises concerns regarding the openness and reproducibility of research. Advocating for more robust data-sharing practices is crucial, while also addressing some plausible reasons for the low data sharing rate, such as lack of incentives, research support and



Figure 6. Studies on psychosis in Africa.

infrastructure, as highlighted in an article evaluating the perceptions of data sharing amongst Low- and Middle-Income Countries (LMIC) scientists<sup>18</sup>. Moreover, data access statements are powerful tools to enhance transparency, providing explicit insights into the availability of datasets and clear instructions for accessing them, whether through repositories or direct communication with the corresponding author. However, implementing such practices must also consider the challenges they pose, such as privacy concerns, intellectual property issues, and the capacity to manage data repositories effectively. Addressing these barriers is essential to ensure data sharing contributes positively to the scientific community and adheres to ethical standards.

#### Conclusion

In the realm of research, the ethos of data sharing stands as a cornerstone for fostering transparency, enabling collaboration, and ensuring the reproducibility of scientific findings, resonating strongly with the FAIR principles that champion the reusability of research data<sup>19</sup>. In longitudinal mental health studies, particularly in resource-limited regions such as Africa, the practice of sharing data becomes a conduit for maximizing

the utility of scarce research outputs. By sharing data, researchers can delve into the depths of existing datasets to unearth insights that can propel advancements in mental health outcomes.

Moreover, data sharing is instrumental in honing the effectiveness of mental health treatments and interventions. It permits a collective analytical approach wherein researchers and clinicians can discern the most efficacious therapeutic and preventive strategies for mental health ailments. This collaborative paradigm aligns with insights gleaned from research into the perceptions of individuals with mental health conditions regarding data sharing for scientific inquiry. Such studies illuminate the predominantly favourable stance toward data sharing, underscoring its potential to amplify scientific acumen and catalyze the innovation of enhanced treatment modalities.

It is also important to have specific ontologies and taxonomies that can integrate research on mental health disorders. One current approach in diverse African settings involves the development of network models using Sustainable Development Goal (SDG) indicators to understand the various



Figure 7. Tools\_usage\_across\_countries\_psychosis.



Figure 8. Disease Burden, World Health Organization (2023).

factors leading to mental illness. This model captures the social determinants of mental health (SDoMH) that individuals are exposed to in their lifetime, and analyzing this exposome may help identify crucial points and potential interventions.

Acknowledging the critical role of data sharing in enriching longitudinal mental health research and clinical practice invites a broader recognition among researchers and policymakers of its transformative impact. Yet, it is imperative to navigate the complexities of data usage carefully, safeguarding against potential misuse. By instituting rigorous, transparent, and ethical data-sharing protocols, the scientific community can bolster trust and cooperation amongst its members. Such concerted efforts in refining data-sharing practices can

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significantly amplify the collective capacity to address the myriad challenges posed by mental health conditions, thus reshaping the landscape of mental health research and enhancing the well-being of populations across the globe.

#### **Ethical approval**

Internal ethical approval was obtained from the African Population and Health Research Center (APHRC) (DOR/2023/047) on 23rd August 2023, while external ethical approval was obtained from the KEMRI Scientific and Ethics Review Unit (SERU) (KEMRI/RD/22) on 5th May 2024.

#### Data availability

Underlying data No data are associated with this article.

#### Extended data

Zenodo: Extended data for 'Access to longitudinal mental health data in Africa: lessons from a landscape analysis by the INSPIRE network data hub', https://doi.org/10.5281/zenodo.13762408<sup>16</sup>

This project contains the following extended data:

- Comprehensive list of tools used for anxiety
- Comprehensive list of tools used for depression
- Comprehensive list of tools used for psychosis
- Tools usage across countries for anxiety
- Tools usage across countries for depression
- Tools usage across countries for psychosis

#### **Reporting guidelines**

PRISMA-ScR checklist and flow diagram for 'Access to longitudinal mental health data in Africa: lessons from a landscape analysis by the INSPIRE network datahub' are found in the PRISMA extended folder, https://zenodo.org/doi/10.5281/zenodo.13315505<sup>20</sup>

Data are available under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0)

#### Software availability

The source used for the review is available from: https://github.com/APHRC-DSE/INSPIRE-Mental-Health-Project\_Landscape\_Analysis.

The archived software is available from: https://doi.org/ 10.5281/zenodo.12542524<sup>17</sup>

License: GNU General Public License version 3

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We appreciate the Wellcome Trust for their significant support in mental health research. Their commitment has been critical to our project's success.

Our gratitude extends to all project partners for their crucial expertise and collaboration. We also thank our health practitioners, data scientists, research teams, and public engagement teams for their dedication and hard work. Further, we acknowledge the stakeholders, participants, and the mental health research community for their valuable input, helping to make our work impactful.

Together, we are advancing towards improved mental health care and accessibility. Thank you for your support and belief in our mission.

#### **INSPIRE Network**

**Role of the members:** The INSPIRE network is a network of population health providers, with the objective of harmonizing, sharing and analyzing the data from the network. As such many members have contributed data, expertise and code to enable the network and the mental health work to succeed. For that reason, we would like to acknowledge the contributions of members across the whole network.

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Zoshicu Picki Pic

# **Open Peer Review**

## Current Peer Review Status: ?

Version 1

Reviewer Report 29 October 2024

## https://doi.org/10.21956/wellcomeopenres.24658.r104984

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Thank you for inviting me to review this interesting manuscript in which the authors review longitudinal research on depression, anxiety and psychosis in Africa; and data-sharing practices in these lines of research. The manuscript fills a critical research gap by summarising longitudinal research on major mental health disorders in mostly low- and middle-income settings. I suggest some areas in which the manuscript can be further improved:

## Title:

No comments.

## Abstract:

## <u>Methods:</u>

i. "The search engaged stakeholders in understanding data sharing practices..." This statement was not clear. Specifically, it is not clear who the stakeholders refer to or how they were engaged in understanding data sharing practices. These should be clarified.

## <u>Results:</u>

i. It would be useful to indicate how many further articles were identified by Artificial Intelligence (AI) and Natural Language Processing techniques; and these should be clarified in the Methods section of the manuscript.

ii. "...with only 16 datasets adhering to data-sharing practices." The proportion should also be included in parentheses to convey the magnitude more clearly.

## Conclusion:

i. "By fostering collaboration and embracing advanced methodologies and technologies, this study advocates for a concerted effort to improve the accessibility, interoperability, and reusability of mental health data." The first clause feels unnecessary i.e., how was collaboration fostered in the present study?

## Plain language summary:

i. The second paragraph feels rather technical, can the authors simplify the language further?

## Introduction:

i. The link to the INSPIRE website in the second paragraph did not work. The authors should check that the link leads to the appropriate website – or remove it.

ii. A large portion of this section was used to describe the study without providing a justification for investigating longitudinal mental health research in Africa and data-sharing practices or introducing key terms. For example, the determinants of longitudinal mental health research in Africa such as stigma, resources including funding and technical know-how are not described. What are data-sharing practices in Africa and/or other low-/middle-income countries? What are the determinants of these and how can these impact on the quality of mental health research in Africa?

iii. Details about prompts and search mechanisms including the use of AI which is innovative may be better described in detail in the Methods section.

iv. Overall, I suggest that this section may be improved by clarifying the objectives of this paper and structuring the introduction to give the reader a background about the study and why it is important.

## Methods:

i. "Prompters to categorize methods and challenges of data sharing": The section was not clear to me: it appears more relevant to qualitative methodology (e.g., focus group discussions), than to a review. Was this section mistakenly included in the present manuscript? If so, it should be removed.

ii. "Search strategy": The search phrases should be included as well as the databases searched. Did the authors also exclude articles using the same datasets which would inflate the number of longitudinal studies? If so, this should be stated.

iii. "Search outcomes": Figure 1 should be included in this section. This can also be adapted to demonstrate the additional benefit of incorporating AI methodologies into the search strategy i.e., how many more articles did AI search strategies yield?

iv. "Study design": This section feels different from the review carried out, for example, how was a "participatory approach" used in this review of literature?

## **Results:**

i. Table 1

- The countries included in each study region should be specified e.g., as a footnote.
- The years used are inconsistent, can the authors provide a rationale for this in a footnote or use the ranges uniformly? (Same for Tables 2 and 3).
- The authors also clarify whether diagnoses or symptoms of the mental health conditions were investigated in the included studies. E.g., does depression refer to depressive disorders and/or depressive symptoms? Sasme for anxiety and psychosis.

## ii. Table 2

- Total n>266, the reason for this should be specified, for example, as a footnote to the table.
- Considering the greater amount of resources required for prospective compared to retrospective studies, it feels counterintuitive that there are more prospective compared to retrospective studies for depression and anxiety. Do the authors have any explanations for this observation?
- The meaning of "Yes" for the rows for Depression, Anxiety and Psychosis are not immediately clear. Can the authors please clarify this?

iii. Page 11: "The disparities necessitate attention to ensure a more equitable distribution of research efforts, which is essential to comprehensively address mental health needs across the continent." This statement is non-specific, and considering that it is an explanation for the study findings, it should be brought up in the discussion rather than in the Methods section.

iv. Figure 5: Name of heatmap should be corrected to reflect depression. The General Health Questionnaire is not specific for depression or depressive symptoms and this study should probably not be included among studies investigating depression.

v. Page 11: "These figures, while lower in comparison to South Africa and Tunisia, indicate a growing recognition of the importance of studying psychosis within these countries." This increase could be due to several other factors, and these should be considered in the discussion. For example, this may reflect increased ease of recruitment, funder priorities (if the studies are externally funded). The phenotype also needs to be defined more specifically, e.g., does psychosis include both schizophrenia and bipolar affective disorder?

vi. Page 12: "A singular approach to psychosis assessment..." This phrase is not clear, the authors should please clarify this further? Was clinical diagnosis the 'singular' tool that was used? And how is the DSM-IV different from clinical diagnosis? I ask the latter question because the DSM-IV also define criteria that are used in making clinical diagnoses. If a different classification system was used in Burkina Faso and Sudan, this should be specified.

vii. Page 13: "The table below details the assessment tools utilized in of psychosis across various African nations within the context of longitudinal research." A word appears to be missing between 'in' and 'of', possibly 'studies'?

## Discussion:

i. Paragraph 1: It would be useful to discuss possible reasons for the low rates of data sharing observed in the present study. This could include research being self-funded with no stipulations for data sharing, who the data is being shared with and the level of trust -especially if this involves

local versus international collaborators, infrastructural support for sharing data. E.g., see Bezuidenhout & Chakauya (2018) for a discussion of these factors.

ii. Paragraph 2: The distinction between prospective and retrospective longitudinal studies is being highlighted for the first time in the manuscript. It would be useful to have highlighted this earlier in the manuscript (e.g., in the introduction) along with the implications of each e.g., financial costs and ease of carrying out each type. This would provide a context for the relative disparities of both types of longitudinal research across different African countries.

iii. Paragraph 3: The discussion around the relatively fewer studies in psychosis observed by the authors could potentially be more nuanced: Can this be reflective of greater stigma around more severe psychiatric disorders which may make affected individuals difficult to identify and follow up? And were these studies predominantly prospective versus retrospective?

iv. It could be useful to give more details on the characteristics of the longitudinal studies e.g., what is the average duration of follow-up in the prospective studies? What are the methods for the retrospective longitudinal studies – are these only based on hospital records?

v. What are the possible factors that drive the use of either approach? This will help clarify statements like "For example, the prevalence of more population and prospective studies in South Africa suggests the country's forward-thinking approach to public health research and its capacity to invest in long-term studies tracking health outcomes over time... Page 13.

vi. The authors comment that the relatively higher publication in anxiety and depression reflect a higher burden. This may not necessarily be so because several factors go into deciding what disorders are investigated in longitudinal studies – including the prevalence which may mean that the sample size is easily attained if the prevalence is high; and funders' priorities.

## References

1. Hidden concerns of sharing research data by low/middle-income country scientists; Bezuidenhout, L. & Chakauya, E. *Global Bioethics*. 2018, 29(1), 39-54.

# Are the rationale for, and objectives of, the Systematic Review clearly stated?

Are sufficient details of the methods and analysis provided to allow replication by others? Partly

## Is the statistical analysis and its interpretation appropriate?

Not applicable

Are the conclusions drawn adequately supported by the results presented in the review? Partly

If this is a Living Systematic Review, is the 'living' method appropriate and is the search schedule clearly defined and justified? ('Living Systematic Review' or a variation of this term should be included in the title.)

Not applicable

*Competing Interests:* No competing interests were disclosed.

*Reviewer Expertise:* Behaviour genetics, mental health, child and adolescent mental health, sexual minority status

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.