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# Mental Health Challenges Among Children and Adolescents Associated With HIV Status Disclosure: A Systematic Review and Meta-Analysis Protocol

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## Abstract

**Background:** Prenatally acquired HIV is highly prevalent among children and adolescents globally. HIV status disclosure to children is recommended to start from 8 years and older and has shown several benefits. However, HIV status disclosure is also associated with high risks of mental health challenges. This review and meta-analysis aim at describing the prevalence of mental health challenges and associated factors among children and adolescents living with HIV.

**Methods:** The study will involve conducting a systematic review and meta-analysis of the existing literature on the burden of mental health challenges including stigma, depression, anxiety and suicidality after HIV status disclosure among children and adolescents aged 8-17 years. Searches for both observational and interventional studies will be performed in PubMed, Medline, Embase, CINAHL and APA Psych Info from 2000 to the date of the review. Statistical heterogeneity will be assessed using  $I^2$  test and visual inspection of the forest plot. Data will be extracted using an investigator designed data extraction form by two independent people and any disagreements will be solved by involving a third person. Using the RevMan software, a random effects model will be applied to calculate a standardised mean estimate of the prevalence of mental health challenges. A narrative will be presented for the factors associated with the mental health challenges. Risk of bias will be assessed using the appropriate study design tool and results will be reported following the PRISMA 2015 guidelines.

**Conclusion:** The review will provide valuable results that will shed light on the burden of mental health challenges associated with HIV status disclosure and the influencing factors among children and adolescents. This will inform clinical practice about the importance of assessing and managing the challenges according as well as designing health policies regarding the same.

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## List of abbreviations

- **ART:** Ant-retroviral therapy
- **CALHIV:** Children and Adolescents Living with HIV
- **HIV:** Human Immunodeficiency Virus
- **HRQoL:** Health Related Quality of Life
- **LMIC:** Low and Middle Income Countries
- **MHC:** Mental health challenges
- **MUST:** Mbarara University of Science and Technology
- **WHO:** World Health Organisation

## Background

There are many children living with perinatally acquired HIV worldwide and majority reside in low and middle income countries [1][2]. Vertical transmission is mainly perinatal/mother to child transmission whereby a pregnant person transmits HIV to their child either during pregnancy, child birth or breastfeeding [3][4]. During early years of life, many children living with HIV receive HIV care without knowing their HIV status because of various reasons such as stigmatization, fear of disclosing the mother's status or considering that the child is still too young to understand, among others [5][6]. However, World Health Organisation recommends that children need to know their HIV status by adolescence and this should be done incrementally depending on the child's cognitive abilities starting from 8 years of age [7]. HIV status disclosure is a complex multifaceted process of informing another person about one's serostatus and this may be voluntary or involuntary [8] and has different types such as full disclosure, partial disclosure, non-disclosure and deception [9] and can be associated with various mental health challenges which may vary in different settings [10]. Adolescence, for instance is characterised by several rapid physical, neurodevelopmental, psychological and social changes which have health and

behavioural consequences [11]. It is a critical stage in which the individual tries to adapt and understand the multiple changes occurring in their environment and life as well as forming their identity and strong relationships with both peers and adults [11][12][13]. Hence HIV status disclosure at such a critical stage may tend to worsen the complexity of comprehending these life changes due to the multiple psychosocial issues that result. Additionally, these children and adolescents' self-esteem and confidence tend to be affected by the feelings of stigmatisation and discrimination resulting from their HIV status [14][15]. Consequently, these children and young adolescents are at a high risk of developing multiple mental health problems including anxiety, depression and suicidality [14][15][16] following disclosure, which most times go unattended to. These mental health challenges can hence affect their overall health, antiretroviral treatment outcomes and affect the individual's quality of life [17][18]. Therefore, this systematic review aims at reviewing and synthesising the existing literature regarding prevalence of mental health challenges among children and adolescents related to HIV status disclosure globally.

## Research questions

1. What is the prevalence of mental health challenges after HIV status disclosure among children and adolescents living with HIV (CALHIV) globally?
2. What factors are associated with mental health challenges after HIV status disclosure among children and adolescents living with HIV (CALHIV) globally?

## Materials and Methods

A systematic review will be conducted on the burden of mental disorders after status disclosure among children and adolescents. The study protocol development and reporting of systematic review items will be in accordance to Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocol (PRISMA-P) 2015 checklist [19].

### Study selection

The studies to be considered for the review will be selected based on the inclusion and exclusion criteria described below

#### Inclusion criteria

All quantitative studies conducted among children and adolescents aged 8-17 years living with HIV worldwide that assessed mental health outcomes or challenges after HIV status disclosure. These will include studies published since 2000 (start of ART era) of the search databases up to the time of the systematic review. These studies may be observational or interventional in design. The studies must have assessed disclosure and also used the appropriate tool or scale to measure the outcome variables and must be written in English.

#### Exclusion criteria

Studies lacking full texts and review articles will be excluded from the review as.

## Study population and setting

The study population for the studies to be included must be children and adolescents living with HIV aged from 8 to 17 years. This is because 8 years is the minimum recommended age for HIV status disclosure. The study may have been conducted anywhere in the world.

**Exposure:** The main exposure for studies to be include in this review must be HIV status disclosure. Whereas full disclosure will be of main interest, partial disclosure will also be considered. The main comparator will be no disclosure or deception.

**Outcome:** The primary outcome for this review will be prevalence of mental health challenges including stigma and mental disorders: depression, anxiety and suicidality. Any study that appropriately assessed any of the above challenges will be included and the associated factors will also be captured from each included study.

Measure of effect for the outcome will be weighted mean prevalence which will be expressed as a proportion. Secondary outcomes will include quality of life, HIV treatment adherence and functioning.

## Search strategy

**Search question:** What is the prevalence of mental health challenges and associated factors after HIV status disclosure among children and adolescents living with HIV (CALHIV) globally?

For relevant articles, we shall search PubMed, Medline, Embase and APA PsychInfo databases via the OVID database. We shall also search the CINAHL Plus database.

Searches will be performed suing Medical Sub-Headings (MeSH) terms and keywords to increase specificity and sensitivity free texts will also be used as indicated below. Initial search for articles will be by title, abstract and keywords JK, FK and AK. The search terms will be combined using the “OR” Boolean operator, while terms of different concepts will be combined using the “AND” Boolean operator. The full text article will then be and further assessed for eligibility by JK and CAE. Any disagreements between the two persons regarding an article will be resolved by involving a third person – SA or GZR. The searches will be conducted in accordance to the PECOS framework as indicated in table 1 below.

**Table 1.** The PECOS framework showing search terms for the research question.

		MeSH/search terms
<b>Population</b>	Children and Adolescents	Child OR Adolescent
<b>Exposure</b>	HIV status disclosure	HIV OR HIV-1 OR HIV-2 AND disclosure
<b>Comparison</b>	No disclosure	
<b>Outcome</b>	Mental health challenges	Mental disorder OR mood disorder OR anxiety disorder OR depression OR suicide OR stigma
<b>Setting</b>	Worldwide	

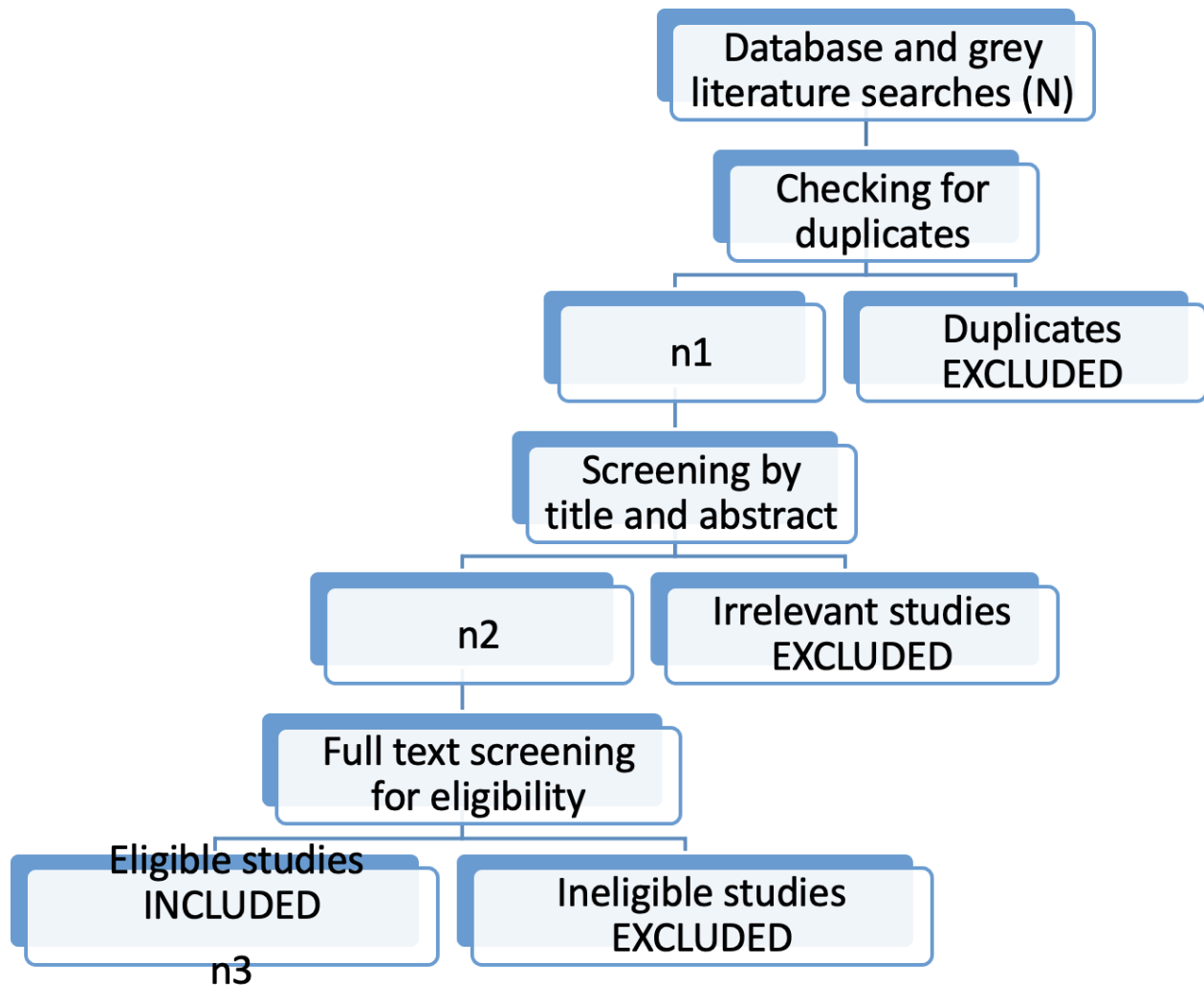
Sample search strategy using PubMed database:

Search term – ***children and adolescents***

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((("child"[Title/Abstract] OR "adolescent"[Title/Abstract]) AND "hasabstract"[All Fields]) OR (("child*" [Title/Abstract] OR "adolescen*" [Title/Abstract] OR "teen*" [Title/Abstract] OR "p?ediatric"[Title/Abstract] AND "hasabstract"[All Fields])) AND (fha[Filter])
```

*Gray literature* will be searched mainly via google scholar to retrieve any unpublished articles. Also other relevant organizational databases such as World Health Organisation will be searched for any additional literature. For all the eligible articles, forward and backward searches will be conducted for any additional relevant articles for this review. Experts in the field of HIV/AIDS and mental health research will also be contacted to provide any possible additional literature relevant for this review.

Review of retrieved studies will be done by two independent members of the team and any disagreements will be resolved by involving the principal investigator. The search will be conducted as indicated in figure 1 below.



**Figure 1.** Flow diagram showing how the search for eligible studies will be conducted.

### Risk of bias and quality assessment

For all studies that meet the eligibility criteria, methodological quality of cross-sectional, cohort and case control studies will be assessed using the appropriate NIH quality assessment tool <sup>[20]</sup>. This will include assessing appropriateness of tools used to measure study variables for each study.

Risk of bias for clinical trials will be assessed using the Cochrane Collaboration tool for assessing risk of bias <sup>[21]</sup>.

Publication bias and selective reporting of studies will be assessed through visual inspection of funnel plot or using the Egger's regression test (if eligible studies are at least ten).

### Data extraction

Two members of the team will extract data from retrieved studies based on piloted investigator-designed data extraction forms using covidence software. This data will include, study design, study type (community or institutional/hospital

based), PECOS framework items including both primary and secondary outcomes, year of publication, country where study was conducted, age of participants (mean or median) and sample size. Also, factors associated with MHC will be extracted from each study. For any missing information corresponding authors of the respective articles will be contacted accordingly.

## Data analysis/synthesis and reporting

Extracted quantitative data will be analysed using RevMan software. Studies will be assessed for heterogeneity by visual inspection of the forest plot or calculating *I*-squared ( $I^2$ ) statistic.

For  $I^2$  statistic value less than 75%, the studies will be considered homogenous and a meta-analysis using the fixed effect model will be conducted and pooled mean estimates for prevalence will be calculated [22]. If  $I^2$  statistic value is greater than 75%, then the studies will be considered as having significant heterogeneity hence the random effect model will be used and a standardized mean estimate will be calculated. Additionally, the results will also be presented as a narrative in case of significant heterogeneity.

*Subgroup and sensitivity analysis:* Subgroup analysis will be conducted for country categories (low and middle income versus high income) age categories, sex and disclosure type/status. Sensitivity analysis will be conducted during data analysis as necessary.

The results will be summarised in tables and graphs such as forest plots with corresponding narratives for the factors associated with the mental health challenges. Strength or certainty of the body of evidence will be assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) framework [23].

For each study risk of bias results will be reported.

## Ethical considerations

All included studies must have statement indicating that they underwent ethical review and obtained required ethical approval. The protocol will be registered with PROSPERO and also published in a peer reviewed journal.

## Dissemination plan

Manuscripts will be written and submitted for peer review and publication in relevant medical journal. Conference posters will be designed and presented in the MUST Annual research dissemination conference. The results will also be presented in other relevant medical conferences both locally and internationally. Policy briefs will be extracted and made available to the respective health policy makers for consideration for integration into existing policies.

## Discussion

This systematic review aims at reviewing and synthesising the existing literature regarding prevalence of mental health challenges among children and adolescents related to HIV status disclosure globally. Several studies indicate that mental health challenges following HIV status disclosure vary widely among children and adolescents in different parts of the world [16][24]. This review will help to analyse existing evidence from the different parts of the world and provide summary results for prevalence of different mental disorders. The meta-analysis option will provide summary result of prevalence of the respective mental disorders associated with HIV status disclosure. By subgroup analysis such as low and middle income versus high income countries, sex, age categories, and disclosure type/status, the review and meta-analysis will demonstrate the distribution of these disorders. For-example, anxiety, depression and suicidal attempts are more common among females compared to males, however, this is not known in relation to HIV status disclosure [25][26].

The systematic review will help to describe factors associated with different psychiatric disorders which may also vary widely. Most existing literature shows that mental disorders such as depression and suicidality are more prevalent among people living in high income compared to low and middle income countries. [27] Conversely, anxiety disorders tend to be higher among high income countries compared to low and middle income countries [28][29].

However, the variations of these disorders among children and adolescents living with HIV is unclear especially in the context of HIV status disclosure since no review has synthesized the existing literature to summarise the individual study findings.

Therefore, the findings will be key in providing summary findings about prevalence of mental health challenges globally as well as their distribution across sub groups and also synthesize the distribution of common influencing factors for these disorders. The outcomes will be key in informing health research in this field especially that directed towards designing context specific interventions against these challenges. It will also inform HIV/AIDS related policies related to mental health and HIV status disclosure in different settings. As a result, this will be a positive step in the achievement of sustainable development goal of ensuring good health and well-being for all persons [30].

## Statements and Declarations

**Ethics approval and consent to participate:** Not applicable

**Availability of data and material:** Not applicable

**Competing interests statement:** The author(s) declare no competing interests.

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## Author contributions



- JK conceptualized the idea, provided initial draft and coordinated input from all co-authors and
- CBZ, GZR and SA conceptualized the idea, read and contributed to all drafts of this manuscript, provided technical guidance and approved the final draft.
- AA read and contributed to all drafts of this manuscript, provided technical guidance and approved the final draft.
- EW and CO provided technical guidance and support throughout the writing process and read and approved the final draft of the manuscript.
- CAE, FZ, KL and HB read and contributed to all drafts of this manuscript, proof read and approved the final draft.

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## References

1. <sup>^</sup>UNAIDS, "Despite great progress since the early days, the HIV response is still failing children," *UNAIDS Children*. <https://www.unaids.org/en/keywords/children> (accessed Oct. 01, 2020).
2. <sup>^</sup>B. E. A et al., "Mode of transmission of HIV infection among orphans and vulnerable children in some selected States in Nigeria," *J AHR*, vol. 11, no. 5, pp. 47–51, Sep. 2019, doi: 10.5897/JAHR2019.0493.
3. <sup>^</sup>"Perinatal (Mother-to-Child HIV Transmission) - Minnesota Dept. of Health." <https://www.health.state.mn.us/diseases/hiv/prevention/perinatal.html> (accessed Aug. 20, 2021).
4. <sup>^</sup>CDC, "HIV and Pregnant Women, Infants, and Children," *Centers for Disease Control and Prevention*, Aug. 06, 2021. <https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html> (accessed Aug. 20, 2021).
5. <sup>^</sup>A. C. Ubesie et al., "HIV status disclosure rate and reasons for non-disclosure among infected children and adolescents in Enugu, southeast Nigeria," *SAHARA J*, vol. 13, no. 1, pp. 136–141, Sep. 2016, doi: 10.1080/17290376.2016.1226942.
6. <sup>^</sup>E. Gyamfi, P. Okyere, A. Enoch, and E. Appiah-Brempong, "Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana," *BMC International Health and Human Rights*, vol. 17, no. 1, p. 8, Apr. 2017, doi: 10.1186/s12914-017-0114-6.
7. <sup>^</sup>World Health Organization, "Guideline on HIV disclosure counselling for children up to 12 years of age.," p. 47, 2011.
8. <sup>^</sup>R. W. Eustace and P. R. Ilagan, "HIV disclosure among HIV positive individuals: a concept analysis," *Journal of Advanced Nursing*, vol. 66, no. 9, pp. 2094–2103, 2010, doi: 10.1111/j.1365-2648.2010.05354.x.
9. <sup>^</sup>E. Glaser, "Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations," p. 74, 2016.
10. <sup>^</sup>A. Odiachi, "The Impact of Disclosure on Health and Related Outcomes in Human Immunodeficiency Virus-Infected Children: A Literature Review," *Front. Public Health*, vol. 5, 2017, doi: 10.3389/fpubh.2017.00231.
11. <sup>a, b</sup>WHO, "WHO | Adolescent development," WHO.

- [http://www.who.int/maternal\\_child\\_adolescent/topics/adolescence/development/en/](http://www.who.int/maternal_child_adolescent/topics/adolescence/development/en/) (accessed Oct. 01, 2020).
12. <sup>^</sup>J. H. Pfeifer and E. T. Berkman, "The Development of Self and Identity in Adolescence: Neural Evidence and Implications for a Value-Based Choice Perspective on Motivated Behavior," *Child Dev Perspect*, vol. 12, no. 3, pp. 158–164, Sep. 2018, doi: 10.1111/cdep.12279.
  13. <sup>^</sup>O. M. Angela, "Erik Erikson and Self-Identity - Child Development Theory: Adolescence (12-24)." [https://www.helenfarabee.org/poc/view\\_doc.php?type=doc&id=41163&cn=1310](https://www.helenfarabee.org/poc/view_doc.php?type=doc&id=41163&cn=1310) (accessed Oct. 01, 2020).
  14. <sup>a, b</sup>S. Adeyemo et al., "Depression and suicidality among adolescents living with human immunodeficiency virus in Lagos, Nigeria," *Child Adolesc Psychiatry Ment Health*, vol. 14, no. 1, p. 31, Aug. 2020, doi: 10.1186/s13034-020-00337-3.
  15. <sup>a, b</sup>S. Ashaba et al., "Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural Uganda," *African Journal of AIDS Research*, 2019, doi: 10.2989/16085906.2019.1637912.
  16. <sup>a, b</sup>M. Durteste et al., "Anxiety symptoms and felt stigma among young people living with perinatally or behaviourally-acquired HIV in Ukraine: A cross-sectional survey," *PLOS ONE*, vol. 14, no. 1, p. e0210412, Jan. 2019, doi: 10.1371/journal.pone.0210412.
  17. <sup>^</sup>A. D. Haas et al., "Mental health, substance use and viral load suppression in adolescents receiving ART at a large paediatric HIV clinic in South Africa," *medRxiv*, p. 2020.07.06.20147298, Jul. 2020, doi: 10.1101/2020.07.06.20147298.
  18. <sup>^</sup>L.-L. Rydström, M. Wiklander, L. Navér, B.-M. Ygge, and L. E. Eriksson, "HIV-related stigma and health-related quality of life among children living with HIV in Sweden," *AIDS Care*, vol. 28, no. 5, pp. 665–671, May 2016, doi: 10.1080/09540121.2015.1120267.
  19. <sup>^</sup>D. Moher et al., "Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement," *Systematic Reviews*, vol. 4, no. 1, p. 1, Jan. 2015, doi: 10.1186/2046-4053-4-1.
  20. <sup>^</sup>NIH, "Study Quality Assessment Tools | NHLBI, NIH," 2021. <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools> (accessed Jul. 02, 2022).
  21. <sup>^</sup>Cochrane, "Table 8.5.a: The Cochrane Collaboration tool for assessing risk of bias," 2011. [http://handbook-5-1.cochrane.org/chapter\\_8/table\\_8\\_5\\_a\\_the\\_cochrane\\_collaborations\\_tool\\_for\\_assessing.htm](http://handbook-5-1.cochrane.org/chapter_8/table_8_5_a_the_cochrane_collaborations_tool_for_assessing.htm) (accessed Jul. 02, 2022).
  22. <sup>^</sup>T. B. Huedo-Medina, J. Sánchez-Meca, F. Marín-Martínez, and J. Botella, "Assessing heterogeneity in meta-analysis: Q statistic or I<sup>2</sup> index?," *Psychological Methods*, vol. 11, no. 2, pp. 193–206, 2006, doi: 10.1037/1082-989X.11.2.193.
  23. <sup>^</sup>S. Reed and Gordon, "What is GRADE? | BMJ Best Practice," 2022. <https://bestpractice.bmj.com/info/toolkit/learn-ebm/what-is-grade/> (accessed Jul. 02, 2022).
  24. <sup>^</sup>B. J. Krauss, S. Letteney, A. J. De Baets, R. Baggaley, and F. A. Okero, "Disclosure of HIV status to HIV-positive children 12 and under: A systematic cross-national review of implications for health and well-being," *Vulnerable Children and Youth Studies*, vol. 8, no. 2, pp. 99–119, Jun. 2013, doi: 10.1080/17450128.2012.750774.
  25. <sup>^</sup>S. Ashaba et al., "Challenges and Fears of Adolescents and Young Adults Living with HIV Facing Transition to Adult HIV Care," *AIDS Behav*, Sep. 2022, doi: 10.1007/s10461-022-03856-6.
  26. <sup>^</sup>S. Ashaba et al., "Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural

Uganda,” *African Journal of AIDS Research*, vol. 18, no. 3, pp. 169–180, Sep. 2019, doi: 10.2989/16085906.2019.1637912.

27. <sup>^</sup>J. Wang et al., “Prevalence of depression and depressive symptoms among outpatients: a systematic review and meta-analysis,” *BMJ Open*, vol. 7, no. 8, p. e017173, Aug. 2017, doi: 10.1136/bmjopen-2017-017173.
28. <sup>^</sup>D. J. Stein et al., “Subtyping Social Anxiety Disorder in Developed and Developing Countries,” *Depress Anxiety*, vol. 27, no. 4, pp. 390–403, Apr. 2010, doi: 10.1002/da.20639.
29. <sup>^</sup>D. J. Stein, K. M. Scott, P. de Jonge, and R. C. Kessler, “Epidemiology of anxiety disorders: from surveys to nosology and back,” *Dialogues in Clinical Neuroscience*, vol. 19, no. 2, pp. 127–136, Jun. 2017, doi: 10.31887/DCNS.2017.19.2/dstein.
30. <sup>^</sup>United Nations, “THE 17 GOALS | Sustainable Development.” <https://sdgs.un.org/goals> (accessed Feb. 16, 2023).