Commentary

Core Principles of International Research: Lessons From the National Adolescent Mental Health Surveys

Holly E. Erskine, Ph.D. a,b,c,*, Meaghan E. Enright, M.P.H. a,b, Sarah J. Blondell, Ph.D. a,b, Jamileh Shaddi a,b, James G. Scott, Ph.D. b,d,e, and Harvey A. Whiteford, Ph.D. a,b,c

aSchool of Public Health, The University of Queensland - Herston, Herston, Queensland, Australia
bQueensland Centre For Mental Health Research, Wacol, Queensland, Australia
cQueensland Centre For Mental Health Research, Wacol, Queensland, Australia
dInstitute For Health Metrics and Evaluation, Seattle, Washington
eQIMR Berghofer Medical Research Institute, Herston, Queensland, Australia

The majority of mental disorders have their first onset during adolescence [1] and are among the leading causes of disability in this age group [2]. However, there are limited commensurate prevalence data [3]. In low- and middle-income countries (LMICs) in particular, prevalence data remain severely limited despite these countries having higher proportions of adolescents in their populations [3,4]. Prevalence data are required for generating accurate epidemiological and burden estimates, while also informing service planning and efficient resource allocation.

Existing studies from LMICs which report mental disorder prevalence in adolescents often utilize symptom scales rather than diagnostic measures, small nonrepresentative samples, or clinical services data which only represent individuals who can and do seek help. A recent study found that only 4.5% of the population aged 5–17 years living in LMICs was represented by studies using diagnostic measures of mental disorders in samples representative of the general population [3]. Further disparities were seen within the LMIC grouping, e.g., with no region within sub-Saharan Africa having greater than 1% prevalence data coverage [3]. Beyond issues of limited prevalence data coverage, there are questions regarding the applicability of mental disorder diagnostic criteria [5] to adolescents within these countries, and whether cultural considerations have been sufficiently factored into survey methodology to allow for accurate interpretation of findings.

The National Adolescent Mental Health Surveys (NAMHS) aims to address the lack of prevalence data for mental disorders among adolescents in LMICs. NAMHS will conduct nationally representative household surveys of the prevalence of mental disorders in adolescents aged 10–17 years in Kenya, Indonesia, and Vietnam. Led by the University of Queensland (UQ; Australia), NAMHS is a joint initiative among UQ, the African Population and Health Research Center (APHRC; Kenya), the Center for Reproductive Health of Universitas Gadjah Mada (UGM; Indonesia), the Institute for Sociology (IOS; Vietnam), and Johns Hopkins Bloomberg School of Public Health (JHSPH; USA). The methodology of NAMHS is underpinned by four core principles which inform all aspects of the study: collaboration, cultural relevancy, capacity building, and translation of findings. Collaboration was a key element of NAMHS from the outset of the study, building on the distinct yet complementary skills and experience of all investigators involved. APHRC brings extensive expertise in designing, conducting, and managing adolescent research projects in sub-Saharan Africa. The Center for Reproductive Health of UGM has a longstanding track record of undertaking large-scale surveys focusing on sexual and reproductive health and maternal and child health in Indonesia. Similarly, IOS has wide-ranging experience conducting surveys on health and social issues designed to inform national policy and social development in Vietnam. Furthermore, all three in-country organizations have linkages with their respective Ministries of Health and have been involved in the Global Early Adolescent Study led by JHSPH. JHSPH brings these existing collaborations with APHRC, UGM, and IOS to NAMHS, along with comprehensive knowledge of the characteristics and factors influencing adolescent health, and an extensive track record leading adolescent health surveys in LMICs as part of the Global

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* Address correspondence to: Holly E. Erskine, Ph.D., Queensland Centre for Mental Health Research, The Park - Centre for Mental Health, Locked Bag 500, Archerfield, Queensland 4108, Australia.
E-mail address: h.erskine@uq.edu.au (H.E. Erskine).

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Early Adolescent Study. The experience and strengths of each organization was maximized by investigators from all five countries working together to collaboratively establish the methodology for NAMHS, rather than each organization working bilaterally with UQ. This collaborative approach was applied to all aspects of NAMHS and reinforced the other core principles.

The cultural relevance of NAMHS methodology and findings to each country has been informed by this collaborative approach. For example, community consultation prior to data collection has been identified as critical for acceptance of the survey and will be conducted. However, the actual approach to community consultation will be determined by the in-country investigators based on cultural considerations, logistics, and experience in previous surveys.

Balancing the need for consistency (i.e., to allow for cross-national comparison and comparison with future studies) with the requirement to culturally adapt measures (i.e., to generate meaningful data) can be challenging. In NAMHS, the Diagnostic Interview Schedule for Children, Version 5 (DISC-5) [6] was closely assessed over several iterations by in-country investigators and clinicians to identify potentially problematic questions or concepts. Modifications were made for each country in consultation with one of the co-creators of the DISC-5 to allow for cultural variation while maintaining the diagnostic integrity of the instrument. Furthermore, NAMHS involves a parallel clinical calibration to compare diagnoses made by the DISC-5 to diagnoses made by in-country clinicians. This will allow an investigation into whether the diagnostic criteria [5] that form the basis of the DISC-5 scoring algorithms are applicable to LMICs.

Capacity building within all five organizations has also been a key feature of NAMHS. APHRC, UGM, and IOS were recruited to lead NAMHS in their respective countries based not only on their expertise and track record of adolescent data collection with JHSPH, but also on their ability and willingness to include adolescent mental health on their research agendas moving forward. Although the measurement of mental disorder diagnoses is new to each in-country organization, all three provide crucial expertise in both developing and adapting the survey instrument for use in their populations and generating new knowledge about how to use standardized diagnostic instruments such as the DISC-5 in LMICs. This marks a major contribution to global mental health.

Furthermore, mental health research capacity has been developed within all organizations through training and sharing of research methods and resources necessitated by NAMHS. For example, a “training-of-the-trainers” model was employed whereby UQ delivered in-person training to the in-country investigators covering key concepts in adolescent mental health, the mental disorders included in NAMHS, the DISC-5, and the other mental health-related concepts measured in NAMHS. UQ worked with each in-country organization to develop this training program that the in-country investigators will then use to deliver the interviewer training for NAMHS, building capacity within the organization for future research and within UQ for adapting and delivering similar training in future. The methodology developed by NAMHS also builds capacity within the country and wider region through establishing a gold standard methodology that can be feasibly employed in low resource settings. This facilitates opportunities for future research in adolescent mental health.

Finally, translation of data into policy and provision of services is the ultimate goal of NAMHS. This involves the translation of data within each country, the respective region, and internationally. Each in-country organization engaged their respective Ministry of Health and other relevant stakeholders from the outset, involving them in the collaborative NAMHS process and engaging them in specific project components. Furthermore, the NAMHS methodology has been developed to ensure that the data meet the requirements of the Global Burden of Disease Study [2,7] so it can be included in burden of disease modeling to give more accurate estimates. These estimates are freely available and used by governments and international agencies worldwide in priority setting, research, and advocacy. UQ’s direct role in the burden estimation of mental disorders in Global Burden of Disease Study further facilitates this, again highlighting the role and importance of collaboration.

The core principles of NAMHS developed organically through the collaboration of all five countries and have become further cemented as NAMHS has progressed. It is apparent that the evolution of these principles, and their crucial role in NAMHS, has lessons for any collaborative international study. This is especially relevant for research in LMICs, particularly where led by organizations based in high income countries, to ensure genuine capacity building within the collaborating countries and to effect tangible real-world change.

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