

Counting adolescents in: the development of an adolescent health indicator framework for population-based settings



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Summary

Changing realities in low- and middle-income countries (LMICs) in terms of inequalities, urbanization, globalization, migration, and economic adversity shape adolescent development and health, as well as successful transitions between adolescence and young adulthood. It is estimated that 90% of adolescents live in LMICs in 2019, but inadequate data exist to inform evidence-based and concerted policies and programs tailored to address the distinctive developmental and health needs of adolescents. Population-based data surveillance such as Health and Demographic Surveillance Systems (HDSS) and school-based surveys provide access to a well-defined population and provide cost-effective opportunities to fill in data gaps about adolescent health and well-being by collecting population-representative longitudinal data. The Africa Research Implementation Science and Education (ARISE) Network, therefore, systematically developed adolescent health and well-being indicators and a questionnaire for measuring these indicators that can be used in population-based LMIC settings. We conducted a multistage collaborative and iterative process led by network members alongside consultation with health-domain and adolescent health experts globally. Seven key domains emerged from this process: socio-demographics, health awareness and behaviors; nutrition; mental health; sexual and reproductive health; substance use; and healthcare utilization. For each domain, we generated a clear definition; rationale for inclusion; sub-domain descriptions, and a set of questions for measurement. The ARISE Network will implement the questionnaire longitudinally (i.e., at two time-points one year apart) at ten sites in seven countries in sub-Saharan Africa and two countries in Asia. Integrating the questionnaire within established population-based data collection platforms such as HDSS and school settings can provide measured experiences of young people to inform policy and program planning and evaluation in LMICs and improve adolescent health and well-being.

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Introduction

The world's 1.2 billion adolescents (aged 10–19 years), 90% of whom live in low- and middle-income countries (LMICs) in 2019, will play a vital role in creating a sustainable and equitable future for all.¹ Promoting LMIC adolescents' health and well-being is, therefore, a

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Research in context

Evidence before this study

There is a lack of well-defined indicators that can readily be populated with data that has hampered progress and investment in adolescent health in low- and middle-income countries (LMICs). Historically, indicator frameworks for adolescent health have had little comparability. They captured limited aspects of adolescent health in resource-constrained settings and mapped poorly to available data.

Added value of this study

Using a systematic and iterative approach, we developed a questionnaire for measuring adolescent health and well-being indicators that can be used in population-based settings in LMICs. We propose to cover seven key domains encompassing major health needs, health risks, and social determinants of health. These specifically designed indicators and questions are used to capture adolescent well-being and health changes as adolescence progresses through epidemiological transitions. In addition, we

describe our piloting of the questionnaire in seven African countries and two Asian countries. We believe that this is the first comprehensive and systematic effort initiated at the grassroots level by a large network of organizations in LMICs.

Implications of all the available evidence

Adolescent needs are changing rapidly in LMICs, and indicators reflecting the capacity of health, education, and employment need to keep up. To ensure targeted and accountable action, surveillance systems of low-cost but reliable data are also needed on the changing realities of adolescents' health and well-being in these countries. Adolescent health indicators provided here provide an important context for this task within the larger UN Global Strategy framework for women, children, and adolescents' health and well-being. Using this framework, researchers and funders could focus their efforts on adolescent health research in LMICs.

global health priority. Adolescence is increasingly recognized as a distinct phase of life involving profound changes in all domains of development—physical, cognitive, psychosocial, and emotional—as well as a time of changing health trajectories, which are different from those of both children and adults.² At the same time, the unmet health needs of adolescents can affect their growth and development now, during their health trajectories across the life course, and affect the health of the next generation.

Recognizing the centrality of adolescents to a healthier future world, multiple organizations have called for actions on adolescent health and well-being. For example, the Sustainable Development Goal (SDG) of “ensuring healthy lives and promoting well-being for all at all ages” is at least as important for adolescents as for any other age group.³ Adolescents are explicitly mentioned in 12 health-related SDG indicators, including nutrition, reproductive health, sexual and intimate partner violence, child marriage, education, and employment.⁴ The United Nations Global Strategy for Women's, Children's, and Adolescents' Health, built in the context of SDGs, recognizes that adolescents will be central to its overall success, and highlights the need for sound health data to drive accountability.⁵ The Lancet Commission for Adolescent Health and Well-being⁶ and the Global Accelerated Action for the Health of Adolescents⁷ emphasize the need for high-quality data to identify priorities and monitor progress in adolescent health.

Health, development, and well-being patterns among adolescents vary greatly across settings.⁸ Geographical, gender and socioeconomic inequalities leave particular groups (poorest households, rural areas, females, etc.) at

greater risk of poor health than their counterparts. These inequalities are further exacerbated by the current COVID-19 pandemic. Data and indicators, therefore, play a crucial role in setting priorities for investments in adolescent health, education, and social development.⁵ Data can be passively gathered from routinely collected registries or actively collected through surveys. While the former method is convenient, it rarely captures the whole population—particularly when subgroups systematically avoid settings where such registries are made (e.g., young males at health clinics)—and do not always allow longitudinal tracking of individuals.⁹ Registries also often collect data on specified outcomes for a population defined by a particular disease, condition, or exposure that serves primarily clinical purposes.

Indicators provide a framework for decision-making, help set goals and target outcomes, and can serve as a measure of policy and program success. The United Nations Children's Fund (UNICEF), World Health Organization (WHO), and academics have defined reporting frameworks for adolescents' health, social development, and well-being indicators.^{10–14} Multiple individual indicators are combined to provide a population-level picture of adolescent health and well-being, based on measures of distinct aspects of development and growth trajectories. Adolescent development and well-being are also measured by ‘indices’, which are the results of combining multiple indicators into a single measure.¹⁵ These have the benefit of brevity and comprehensibility but can hide important heterogeneities. For example, the Global Youth Well-being Index intends to offer a comprehensive view of multiple domains including health but currently covers only 29 countries.¹⁵

Nevertheless, the systematic longitudinal measurement of adolescent health and well-being is still uncommon, especially in LMICs,⁷ as evidence for health indicators is primarily provided by repeated cross-sectional surveys.¹⁶ The main adolescent health data sources in LMICs are either school-based surveys, such as the Global Early Adolescent Study (GEAS),¹⁷ the Health Behavior in School-aged Children (HBSC),¹⁸ the Global School-based Health Survey (GSHS),¹⁹ and the Global Youth Tobacco Survey (GYTS),²⁰ or household surveys such as the Demographic and Health Survey (DHS),²¹ and the Multiple Indicator Cluster Survey (MICS).²² While both school- and community-based modalities can provide nationally representative data among eligible adolescents, there are several shortcomings to adolescent health and well-being measurement in LMICs.

First, these measurements do not equally cover all adolescent subgroups, with evidence gaps being largest for males, younger adolescents aged 10–14 years, adolescents of diverse genders, ethnicities, and religions, as well as those out of school and migrants. Second, age-disaggregated data are often lacking—due in part to incomplete age coverage—limiting their use for program planning. Third, several aspects of adolescent health are inadequately covered including mental health, substance use, injury, sexual and reproductive health among unmarried adolescents, and positive aspects of adolescent health and well-being. Fourth, the definitions and assessment methods used across adolescent health indicator frameworks are inconsistent. For example, adolescent overweight and obesity—a major cause of non-communicable diseases and a public health risk for future and intergenerational health—is inconsistently captured across indicator frameworks and strikingly absent from the SDGs. Fifth, current adolescent health data systems often lack intersectoral coordination beyond health (e.g., with education, water and sanitation, and social protection systems) and suffer from irregularities in coverage and timing.⁶ Finally, both school- and community-based approaches to measuring adolescent health and well-being in LMICs are typically cross-sectional, limiting inference regarding within-person transitions and trajectories over the life course.

In this paper, we argue that integrating consistent adolescent health and well-being measures into population-based data surveillance systems such as Health and Demographic Surveillance Systems (HDSSs), MICSs, DHSs, and school-based surveys can fill key knowledge gaps in adolescent health and well-being in LMICs. Specifically, these indicators are expected to help describe trends over time, identify inequalities across groups, identify the priority for policy action and program designs, and monitor the effectiveness of health actions and investments in LMICs. We describe a process of developing adolescent health and well-being indicators and a questionnaire aimed at

harmonizing adolescent health and well-being measurement, using population surveillance systems and schools that can support national and regional governments, funding agencies, and non-government organizations in tracking progress in adolescent health. Lastly, we describe our strategy for implementing the questionnaire through in-person longitudinal surveys with adolescents in Africa and Asia.

Platforms for adolescent health surveillance

Demographic and Health Survey (DHS) and Multiple Indicator Cluster Survey (MICS)

The DHS program of the United States Agency for International Development (USAID),²¹ and the MICS program of UNICEF²² are nationally representative household surveys conducted in countries throughout Africa, Asia, Eastern Europe, Latin America, and the Caribbean. These surveys provide data for a range of monitoring and evaluation indicators in the areas of population, health, and nutrition, as well as opportunities for linking survey data with data from other sources. DHS and MICS surveys collect detailed information from the head of the household or the knowledgeable adult member of the household for each household member. Additionally, information is also collected from women of reproductive age (15–49 years old) in the household. Typically, mothers provide information on their children under 5 years of age. Some HDSS sites additionally interview older adolescents (e.g., those aged 15 and above) as part of individual-level interviews.

Health and demographic surveillance system (HDSS)

An HDSS longitudinally monitors the demographic and health characteristics of a population living in a well-defined geographic area, via a baseline census followed by regular updates of key demographic events (i.e., births, marriages, divorces, deaths, and in-and out-migration) and health status.^{23,24} HDSSs provide information that is complementary to, rather than duplicative of, national censuses and DHSs since they collect more detailed and frequent data at a local level. Methodological standardization and systematic cross-site comparison have been central to many HDSS projects, including the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH).²⁵ During the first round of survey and subsequent rounds of updates, the head of the household or an adult member of the household typically provides information on each household member.

School-based health and education surveys

Several major global school-based databases on adolescent health and education in LMICs exist, including those maintained by international agencies such as UNICEF and WHO, national governments in high-income countries, and non-profit organizations such

as the Population Council. For example, the WHO's GSHS provides data on school-going adolescents' health and behaviors in 94 countries using a standardized sample selection process and core questionnaire modules.¹⁹

The UNESCO Institute for Statistics also collects annual data on literacy and educational attainment based on censuses and national and international household surveys such as MICS from more than 200 countries and territories.²⁶ Solely focused on adolescent educational assessment, the Organization for Economic Co-operation and Development (OECD)-led Program for International Students Assessment (PISA) evaluates educational systems by measuring 15-years-old students' scholastic performance in mathematics, science, and reading and writing skills to meet real-life challenges.²⁷

These multiple platforms are underexplored for systematically collecting vital data on adolescent health and well-being in LMICs, despite offering multiple advantages.²⁴ First, these systems—especially HDSS—provide a well-defined population census in settings where vital registration systems are non-existent or weak. Second, existing longitudinal data collection on these platforms allows adolescent health to be evaluated in the context of broader demographic, family, social, and environmental factors and their interactions, in a developmental framework that encompasses the entire life course. Third, platform program staff are usually experienced researchers and accepted by the local community (not least because they are often residents of the same communities²⁴), factors that maximize the chances of successful, high-quality data collection. Finally, nesting cohort studies in existing population-based data surveillance systems is likely to be cost-effective and maximize follow-up over time.

The ARISE network and adolescent health

The Africa Research Implementation Science and Education (ARISE) Network was established in response to a compelling need for a greater and more sustainable public health capacity in Africa.²⁸ As a collaborative effort between leading African institutions, the ARISE Network serves as a platform for robust research and cutting-edge education in the region. The Network comprises 21 member institutions from nine sub-Saharan African countries, with collaborators in Europe, Asia, and North America. In 2014, the ARISE Network initiated an adolescent health study in sub-Saharan Africa (SSA). As a part of this study, the Network has completed two distinct multi-country cross-sectional surveys. In a first of its kind, the ARISE Network conducted a community-based survey of 8075 adolescents aged 10–19 in nine communities from seven SSA countries; six of these communities were HDSSs.²⁹ By working within the existing HDSS infrastructure, which led to efficient study implementation,

this survey provided proof-of-concept for the integration of adolescent-specific research into HDSSs. In a second project, the ARISE Network conducted a school-based survey of 4995 adolescents aged 10–15 years in five SSA countries.³⁰ Both questionnaires covered multiple domains of adolescent health and were cross-sectional in design. Several domains covered in these pilot studies and not included in the present study include oral hygiene, antimicrobial resistance, socio-emotional health, violence, suicide behavior, parental connection and regulation, self-rated health status, life satisfaction, school connectedness, and educational outcomes.

As a next step, ARISE Network investigators identified the need to define a brief, systematically identified a core set of priority adolescent health and well-being indicators and measures to capture them that could be efficiently collected longitudinally to evaluate progress towards strategic goals and to inform the development and evaluation of adolescent health interventions. Indicators were identified through a systematic process as described in the next section. The ARISE Network subsequently formed collaborations with HDSS programs in six countries in SSA and one in Asia (India) to establish routine longitudinal measurements of key adolescent health indicators, and with education departments in two further SSA countries and one in Asia (China) to conduct longitudinal school-based surveys.

We identified adolescent health and well-being domains and indicators guided by the Lancet Series on Adolescent Health's conceptual framework for defining health needs and actions in adolescents and young adults (hereafter 'youth').^{2,6} This framework identified three levels of adolescent health needs: current health problems and causes of youth deaths; risks for health problems in adolescence, adulthood, or the next generation; and proximal social determinants of health during youth (e.g., education and employment, marriage and parenthood, media, universal health coverage). Acknowledging the epidemiological transitions occurring, the commission also emphasized three burdens of disease: 1) poverty-related conditions, including malnutrition, sexual and reproductive health problems, and infections such as HIV; 2) injuries and violence; 3) physical, mental, and substance abuse disorders. We used this three-by-three rubric to consider what domains to include and how to measure them.

Indicator development for adolescent health and well-being

The ARISE Network conducted a multi-stage, iterative, and collaborative process to develop an adolescent health and well-being indicator set, and a list of questions to capture these indicators. We began by mapping key domains, then drafted questions for each domain, invited internal and external reviews, and finally finalized the questionnaire (Fig. 1).

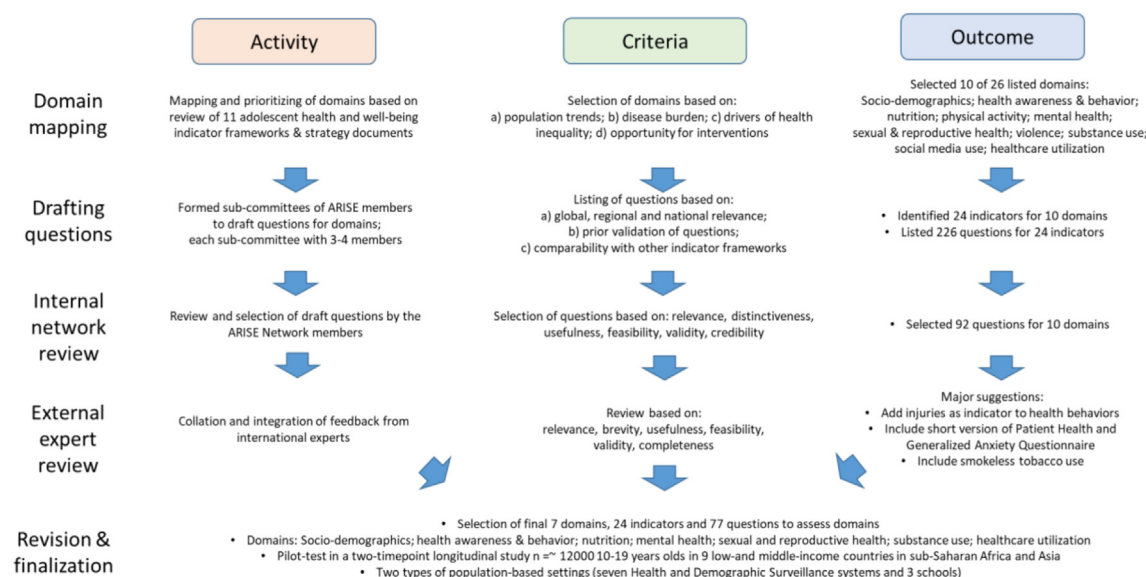


Fig. 1: Development process for adolescent health and well-being indicators.

Step 1: domain mapping

We reviewed existing adolescent health and well-being indicator frameworks, strategy documents, and the earlier ARISE Network adolescent health study questionnaires to identify the major domains that contribute to adolescent health and well-being. Broadly, these indicator frameworks and strategy documents captured disease burden, health risks, and prominent social determinants of health during adolescence. The indicator frameworks and strategy documents had to meet three inclusion criteria: (1) provide recommendations about the measurement of adolescents' health and well-being; (2) include indicators for "adolescents" covering the adolescent age range (10–19 years) in the whole or part; and (3) be global or regional in scope. We identified and reviewed 11 documents: i) the indicator and monitoring framework for the Global Strategy for Women's, Children's and Adolescents' Health⁵; (ii) the Lancet Commission on Adolescent Health and Well-being⁶; (iii) the Global Accelerated Action for the Health of Adolescents (AA-HA!);⁷ (iv) the Global Action for Measurement of Adolescent (GAMA) health initiative^{13,14}; (v) the GSHS¹⁹; (vi) the DHS²¹; (vii) the MICS²²; (viii) three past ARISE Network adolescent health studies,^{29–31} and (ix) UNICEF's Adolescent Country Tracker.³² Domains were mapped and selected using brainstorming, prioritizing, and discussion methods. As part of the brainstorming process, group members suggested around 52 dimensions of adolescent health and well-being. These dimensions overlapped and needed to be merged into broad domains. In order to select the final list of dimensions, the Network members prioritized and discussed the suggested dimensions.

We selected and organized adolescent health and well-being domains based on four key aspects of adolescents in LMICs: a) population trends; b) disease burden; c) drivers of health inequality; and d) opportunity for interventions. African countries have a proportionally large youth cohort and some countries in the region are yet to begin the demographic transition, that is, the fertility rate is barely declining in these countries, while the number of women reaching childbearing age is rising, creating larger groups of young children and adolescents. Young people's immediate and future health can be positively impacted by these transitions, but it also carries new risks. This critical age group requires increased attention due to its increasing demands. For example, in 1950, Africa was home to just one-tenth of the world's children. In under 50 years, this proportion has almost doubled and will double again by the middle of the 21st century, leaving Africa with nearly a billion children under 18 by 2050.¹ Adolescence marks an extended critical transition period from childhood to adulthood, characterized by different changes in physical, psychological, and social status at different ages. While these transitions carry new risks, they also present opportunities to positively influence adolescents' health immediately and in the future.^{6–8} Therefore, we designed the instrument to be appropriate for the full age range of adolescents.

Secondly, mortality patterns differ significantly among adolescents in high-, middle-, and low-income countries.^{11,13,16} While maternal mortality, tuberculosis, and HIV are the leading causes of adolescent death in low-income countries, road traffic deaths, suicides, and homicides are more prevalent in middle-income settings. It is estimated that by 2030 adolescents in all

LMICs will face a triple burden of infectious diseases, non-communicable diseases, and injuries.¹⁶ Gauging the impact of disease and disability on adolescents, from the onset of illness to the outcome is important in laying the foundations of good health in adulthood. We, therefore, selected a wide range of domains and indicators to cover all these areas.

Finally, inequalities in health outcomes are systematic differences between different populations that have significant social and economic costs. These inequalities are linked to a number of socio-ecological factors, including residential location, education, employment, income, housing, discrimination against race/ethnicity, gender, religion, sexual orientation, location, mental health, and disabilities. Health, education, and employment systems in LMICs, however, have not adapted to changing socio-economic realities.^{7,8,10} For example, gender inequality remains a key driver of poor adolescent health in LMICs, with three times more 15–24 years old women than men who are not in education or employment,^{6,7} due in part to high rates of adolescent births disrupting education and in turn limiting employment prospects. Further, adolescent girls and adolescents with diverse sexual orientations tend to receive less education and information relevant to their sexuality and reproductive health needs, have poorer access to health, education, and employment, and have greater vulnerabilities to acquiring and contracting sexually transmitted infections.³³

Furthermore, the relationship between health and quality education is bidirectional in adolescence: preventative knowledge is essential for leading a healthy and productive life while health and nutrition are essential to effective learning.³⁴ Education has additional health benefits in later life, insofar as it affects employment, income, and thus access to health protection. Water and sanitation are central to avoiding ill health—which again impacts educational achievement—and thus attaining healthy growth.³⁵ Moreover, social media access can expose adolescents to health and education opportunities, as well as potentially negatively affect their physical, social, and mental health.³⁶ Consequently, we included indicators for education, engagement in paid work, pregnancy, access to drinking water, health insurance, and social media usage.

Within each domain, we identified a small subset of key indicators based on the breadth of their applicability to LMIC adolescents and their usefulness to policymakers and programmers in identifying areas that require detailed assessments. Due to the deliberate selection of only priority domains and questions, we will not be able to capture the full range of adolescent needs in LMICs, but we acknowledge that other domains may be important to incorporate based on engagement with stakeholders, including adolescents themselves in the future. Depending on the context or the volatility of a situation, such as epidemic outbreaks, pandemics, natural calamities, or natural disasters, other domains or indicators may be added.

Step 2: drafting questions within domains

ARISE Network members were assigned to sub-committees in the domains most closely aligned with their area of expertise, with 3–4 members per committee. Sub-committees were instructed to develop a set of 5–10 questions for their assigned domain that cover the most important metrics that should be collected at regular intervals. Sub-committees were asked to select questions that were relevant to all adolescents globally and specifically in LMICs, while also identifying additional questions relevant to adolescents in specific regions, countries, or specific subgroups. Where possible, sub-committees referred to the GSHS, the WHO's adolescent health indicators,^{13,14,16} the SDGs,⁴ and the previous ARISE adolescent health study questionnaires^{29–31} to ensure comparability and to consider prior validation. Sub-committees were additionally asked to provide a set of 5–10 socio-demographic questions addressing the broader socioeconomic, cultural, and environmental context of adolescents' lives, such as educational status, employment, and access to clean water.

Step 3: internal review and revision

Based on sub-committee recommendations, ARISE Network members selected a draft list of domain-related and socio-demographic questions, guided by six criteria: relevance, distinctiveness, usefulness, feasibility, validity, and credibility (based on operational definitions in Box 1).^{10,13,14,37} Using a nominal group technique consisting of rating and group discussion, draft questions were evaluated and selected for each domain. After each member rated the draft questions on a three-point Likert scale, an average score was calculated for each question,

Box 1.

Criteria for selection of refinement of domain-wise questions

Relevance: There is a clear relationship between the indicator and global adolescent population trends, disease burden in adolescents, drivers of health inequality, relevance for Sustainable Development Goals, and contexts of various regions where the ARISE Network is currently operating.

Distinctiveness: The indicator is not redundant and does not measure something already captured by other indicators.

Usefulness: The indicator helps to formulate strategies for adolescent health and well-being policies and programs in the context of the ARISE Network countries.

Feasibility: The indicator can be captured with reasonable and affordable effort.

Validity: The indicator has been field-tested, proven an effective indicator of adolescent health in past global adolescent health studies and fully covers the topic it aims to measure.

Credibility: Leading global and local experts and/or organizations such as WHO, UNICEF, USAID, and UNFPA have recommended or are using the indicator.

Brevity: The indicator is easier for respondents to understand and faster for them to complete.

Completeness: The indicator has been sufficiently captured by the number of questions listed.

followed by consensus development by discussion. Relevance was evaluated by considering the worldwide and regional trends in population, global and regional contexts of disease burden, and alignment with global health and well-being indicators and frameworks. Distinctiveness focused on selecting measures that encapsulated concepts not captured elsewhere. For example, one of the factors that contribute to the coexistence of overnutrition (overweight and obesity) alongside undernutrition (stunting and wasting) at all levels of the population (country, city, community, household, and individual) –also known as the double burden of malnutrition– is nutrition transition, characterized by shifts in dietary patterns and quality.³⁷ Our measure of diet quality, which is not covered in earlier adolescent indicators, combined with anthropometric (height and weight) and biometric (hemoglobin level in blood) assessments allows the identification of the double burden of malnutrition as well as indication of poor nutrition and poor health in adolescents. Usefulness evaluated an indicator's ability to shape contextually relevant health and well-being policies and programs for adolescents, feasibility considered cost implications and length, validity reviewed past field-testing and formal measure validation where appropriate, and credibility assessed whether measures had been previously recommended by global organizations. Team members also identified and discussed potential measurement gaps.

Step 4: external expert review and finalization

We asked 24 international domain and adolescent health experts, identified through the ARISE Network's contact network, to review the draft questionnaire for relevance, usefulness, feasibility, and content validity. For review at this stage, brevity and completeness have been added instead of distinctiveness and credibility. We defined brevity as the use of precise and concise language in questions and response categories, and completeness as the number of questions necessary to assess each indicator.^{10,13,14,37} Experts were asked to suggest changes to proposed indicators that would align better with existing global efforts on adolescent health and well-being indicator development and data collection and to suggest additional questions if needed. Eleven experts completed reviews, which were then collated and integrated into the original draft by the ARISE Network team. Further, the questionnaire was also field tested with a convenience sample of 45–50 adolescents at each site (described below) between February and April 2022. The main objectives of the field testing were to avoid ambiguities in questions and response categories, minimize bias in framing questions, reduce repetition of questions, and adjust word choice for authenticity, resulting in the current version of the tool. To elicit information on the above-mentioned areas, the draft questionnaire was administered one-to-one and followed by a group discussion.

Adolescents were selected based on availability from the same HDSS households or schools at each site, but they were not included in the final sample. The interviews were conducted with signed informed consent from all adult participants, and guardian consent and participant assent from all minor participants. Several suggestions, including word choice, question framing, and examples of questions offered by adolescents were incorporated into the country-specific final versions.

Questions for measuring adolescent health

Six key domains emerged from our review: health awareness and behaviors; nutrition; mental health; sexual and reproductive health; substance use; and healthcare utilization. We identified 77 questions covering the six health domains plus socio-demographics, aligned with existing frameworks and indicators. Below we provide a summary of each domain; a detailed description of all the domains along with sub-topics and questions is provided in [Table 1. Additional Online File 1](#) contains the complete questionnaire.

Socio-demographic variables are included in the questionnaire to contextualize responses and assist in planning future interventions. Questions include participant age, sex, current educational enrollment, years of full-time education completed, reading and writing ability, engagement in paid work, and living arrangements. Participants will also be asked to answer questions about their mobile phone and social media use, household drinking water sources, how drinking water is made safe to drink, and their subjective household social status.³⁸

Adolescence is a crucial stage for learning healthy behaviors and acquiring skills. We included questions about the most common health concerns in LMIC adolescence, e.g., unintentional injuries are the leading causes of LMIC adolescent death, 81% of LMIC adolescents are insufficiently physically active, and 60% of LMIC adolescents do not practice good hand hygiene even when provided with access to water and soap.^{42–44} Past-year serious injuries are captured by questions on frequency and type, physical activity indicator includes a question about being physically active for at least 1 h every day of the week and hand hygiene based on handwashing frequency in the past month; all questions were based on the GSHS³⁹ and ARISE adolescent health study.^{29,30} We also included questions around COVID-19 covering awareness of symptoms and preventive behavior, sourced from the ARISE Network adolescents COVID-19 study.³¹

LMICs are experiencing an increase in non-communicable diseases (NCDs), including type 2 diabetes mellitus, cardiovascular disease, and chronic respiratory disease. NCDs and NCD-related risk behaviors adversely affect growth, development, and maturation during adolescence, resulting in compromised adult health and a shorter life expectancy.^{45,46} According

Domain	Sub-topic	Items	Source
Socio-demographics	Demographics	- Age - Sex - School enrollment status - Educational attainment - Reading and writing proficiency - Engagement in paid work - Living arrangements	Global School-based Student Health Survey, ¹⁹ & ARISE Network Adolescent Health Study Questionnaires ^{29,30}
	Household socio-economic status	- Source and quality of drinking water - Perception of family's socio-economic status	ARISE Network Adolescent Health Study Questionnaires ^{29,30} MacArthur Scale of Subjective Social Status ³⁸
	Mobile phone and social media use	- Access to own and others' mobile phone - Use of social media platforms	ARISE Network Adolescent Health Study Questionnaires ^{29,30}
Health awareness and behaviors	Injuries	12 months history of injuries	Global School-based Student Health Survey ¹⁹
	Physical activity	Frequency of physical activity	ARISE Network Adolescent Health Study Questionnaires ^{29,30}
	Hand hygiene	Frequency of handwashing after using the toilet	WHO Questionnaire for an interview with young people ³⁹
	COVID-19	- Symptoms of COVID-19 infection - Prevention strategies practiced	ARISE Network Adolescent COVID-19 Survey ³¹
Nutrition	Diet quality	Food group consumption over the past month	ARISE Network Adolescent Health Study Questionnaires ^{29,30}
	Growth status	- Height - Weight	
	Anemia	Hemoglobin in blood	
Mental Health	Symptoms of depression	- Loss of interest/pleasure - Feeling down/depressed	Patient Health Questionnaire ⁴⁰
	Symptoms of anxiety	- Feeling nervous/anxious - Unable to stop/control worrying	General Anxiety Disorder (GAD) Questionnaire ⁴¹
Sexual and reproductive health	Sexual activity	- Sexual activity status - Age of sexual debut	WHO Questionnaire for an interview with young people ³⁹
	Pregnancy	- Ever been/made someone pregnant - Pregnancy outcome	
	Contraceptive use	Contraceptive used during last sex	
	Marriage	Marital status and age at marriage	
	HIV	- Awareness of HIV - Source of knowledge about HIV - Ever tested for HIV	
	Menstruation (females only)	- Age of menarche - Ever missed school because of menstruation - Reasons for missing school when having a menstrual period	
Substance use	Tobacco	- Ever smoked tobacco - Tobacco smoking in the past 30 days - Ever used tobacco or tobacco products - Use of tobacco or tobacco products in the past 30 days	Global School-based Student Health Survey, ¹⁹ ARISE Network Adolescent Health Study Questionnaires, ^{20,29} & WHO Questionnaire for an interview with young people ³⁹
	Alcohol	- Ever drank alcohol - Alcohol drinking in the past 30 days	
	Other drugs	- Ever used illegal drugs - Use of illegal drugs in the past 30 days - Type of illegal drugs ever used	
Healthcare utilization	Hospital and clinic care	- Primary care visit to clinic, hospital, or pharmacy/drug store in the past 12 months - Inability to use health services - Received homecare for a health problem - Health facilities used for physical examinations and/or pathological tests - Reason for accessing health service last time - Satisfaction with service received in the health facility	Global School Student Health Survey ¹⁹
	Healthcare costs	- Insurance enrollment status - Cost of health services	

Table 1: Domains of adolescent health and well-being and their measurement.

to dietary guidelines, diet quality can be viewed as a dietary pattern or an indicator of variety across key food groups. High diet quality leads to better nutrient intake profiles and a lower risk of diet-related NCDs.⁴⁷ Furthermore, several factors can affect diet quality, including cultural and food environments, availability, affordability, and seasonality of foods as well as nutrition recommendations based on age, gender, country, and/or culture.⁴⁸ A poor diet can lead to both under-nutrition and overweight/obesity and is a leading contributor to the global burden of disease worldwide,⁴⁶ however, it is not part of existing population-based adolescent health surveys due to a lack of a standard, relatively simple, and validated tool to use across contexts. We included the Global Diet Quality Score (GDQS) questionnaire to assess diet quality based on the consumption of 16 healthy food groups, 7 unhealthy food groups, and 2 food groups (red meat and high-fat dairy) that are unhealthy when consumed in excess.⁴⁹ The food groups are then scored based on the frequency of consumption (e.g., never to once/week, 2 to 3 times/week, or 4 or more times/week) to arrive at a total score ranging from 0 to 49. The nutrition domain also includes hemoglobin and duplicate anthropometric (i.e., height and weight) measurements.

Mental health conditions are responsible for 16% of the global burden of disease and injury for adolescents.^{6,7} Globally the most common illnesses and disabilities among adolescents are depression and anxiety disorders, which begin by the age of 14 years, yet most go undiagnosed and untreated. To capture mental health, we included two validated two-item scales: the Patient Health Questionnaire (PHQ)^{40,50,51} and the General Anxiety Disorder (GAD) Questionnaire.^{41,52} The PHQ-2 is used to measure depression symptoms and the GAD-2 is used to measure anxiety symptoms. The recall period for both questionnaires is the last two weeks and the response set for the items is 'not at all', 'several days', 'more than half of the days', and 'nearly every day'. The total score ranges on each questionnaire from 0 to 6, with higher scores indicating more severe symptoms.

A secondary analysis of 1,231,068 adolescents aged 15 and older from 82 LMICs found a smoking prevalence of 16.5% and smokeless tobacco use prevalence of 7.7%.⁵³ Tobacco use alone is responsible for about 6.3 million annual deaths worldwide and accounts for 6.3% of the global burden of disease, mostly in LMICs. Tobacco is a gateway drug to other types of substance use including alcohol and illicit drugs. More than a quarter of 15-19-year-olds are active alcohol drinkers globally. Cannabis is the most widely used psychoactive drug among young people with about 4.7% of people aged 15–16 years using it at least once in their lifetime.^{6,7} Adolescent substance abuse is linked to risky behaviors like unsafe sex and dangerous driving, is common cause of injuries, violence, and premature deaths^{6,7,54}

and is associated with neurocognitive alterations that can result in behavioral, emotional, social, and academic difficulties in later life.^{2,8} Based on the GSHS¹⁹ and ARISE Network adolescent health study questionnaires,^{29,30} we included questions to capture current and lifetime consumption of tobacco, alcohol, and other illegal substances.

While the SDG agenda includes sexual and reproductive health, and reproductive rights generally, they can be brought into focus for this age group by establishing and tracking indicators specific to adolescents' sexual and reproductive health and rights.³ For example, approximately 12 million girls aged 15–19 years, and at least 777,000 girls under 15 years give birth each year in LMICs.^{6,7} While globally adolescents account for 10% of new HIV infections, 75% of which occur in girls, figures are higher and even more skewed in SSA with 15% of all infections among 10-19-year-olds of which 85% are in girls.⁵⁵ We included questions on six SRH sub-domains covering sexual activity, history of pregnancy or causing pregnancy, contraception use, marital status, knowledge of HIV, and menstruation (only for females)—based on the WHO's sexual and reproductive questionnaire for young people.³⁹ [Additional Online File 1](#) shows age-appropriate filters within this domain.

For health systems to meet adolescents' needs and positively affect their health, they need to build trust and access to services and potentially promote healthy behaviors.^{6,7} However, adolescents face numerous challenges in accessing quality and sustainable care, including financial constraints, geographic and physical inaccessibility, lack of friendly services, and inadequate health resources. Additionally, adolescents have difficulty utilizing health services due to healthcare providers' limited understanding of their health problems and development.⁵⁶ We included questions related to healthcare utilization in two domains—healthcare use and satisfaction, and healthcare costs—based on the Youth Health Care–Satisfaction, Utilization, Needs questionnaire⁵⁷ and ARISE Network adolescent health study.²⁹ Healthcare use and satisfaction questions cover the history of healthcare facility visits, reasons for recent service use, reasons for inability to access services, receipt of facility-based physical examinations or pathological tests, receipt of healthcare, and satisfaction with services received at healthcare facilities. Healthcare costs are measured through questions on health insurance and out-of-pocket expenditures at the last health facility visit.

Implementation of questionnaire in the ARISE network

Study design

Local ARISE Network members will interview adolescents at existing HDSSs in seven LMICs (i.e., Dar es Salaam, Tanzania; Harar, Ethiopia; Iganga, Uganda;

Mtubatuba, South Africa; Shai Osudoku/Ningo Prampram, Ghana; Nouna, Burkina Faso; and Pune, India) and at three school-based sites in LMICs (i.e., Funan County, China; Ibadan, Nigeria; and Tanga, Tanzania). Sites within the ARISE Network were included based on financial, human resource, and site infrastructure status. Three HDSS sites were urban—Dar es Salaam, Harar, and Ibadan—while the remaining four HDSS communities and all school sites were rural.

The study questionnaire will be fielded twice, approximately twelve months apart, with the baseline survey being completed by May 2023 at all sites. At the baseline, we will recruit 12,000 adolescents (1200 per site) aged 10–19 years. Using the prevalence of anemia, which ranges from 20 to 60% among adolescents across study sites, and an assumption of at least 1000 adolescents per site based on earlier ARISE studies and a 20% loss to follow-up would provide 80% power to detect at least a 10% difference in prevalence between sites.^{29,30}

Potential participants will be sampled from HDSS households or school censuses using either simple random sampling or multi-step stratified sampling that ensures proportional representation of sub-units (e.g., enumeration areas, age-groups, and sex). For community-based surveys, a random sample of households with at least one adolescent resident will be chosen from the list of households covered by the HDSS. For households with more than one adolescent, one randomly selected adolescent will be interviewed. For school-based surveys, a random sample of adolescents will be selected from each grade using the school registers. We will attempt to re-contact baseline respondents at the second time-point, accounting for any loss to follow up by recruiting additional participants. By using this strategy, we will be able to capture any changes in the population composition due to specific factors (e.g., migration) while tracking a portion of the stable sample to examine changes at the individual level over time. Neither the communities and schools that will be included in the study nor the samples of adolescents from each community or school will be selected to reflect the larger national or regional populations. Nevertheless, each site will use sampling methods that are intended to capture an accurate representation of the adolescent population in their community.

Data entry will be conducted using Research Electronic Data Capture (REDCap) tools—a web application and computer-assisted personal interviewing platform⁵⁸—eliminating paper-based data entry and including in-built quality checks. Identifiable data will be stored in secure databases accessible only to the study team. Interviewers and supervisors will be trained in research ethics, consenting procedures, and the collection of health data, including dietary assessments, anthropometric measurements, and point-of-care hemoglobin assessments. Informed consent will be obtained from all adult participants (18 and older), while

consent from the guardian and assent from the participant will be obtained for minor participants. Data collection will be monitored both locally by each ARISE partner and centrally at ARISE Network meetings; final datasets will be combined and cleaned centrally.

Each site assuming responsibility for data monitoring and quality will follow the following three stages: i) software development assuring in-built quality mechanisms such as input validation, skip rules, logic flow, and real-time monitoring; ii) development of an interviewer data quality control protocol for localized training and monitoring processes; and iii) data cleaning and processing for checking missing data, skewness and process-related data (e.g., travel time, time on site, number of interviews completed/in-progress/refused). Once the data is finalized, analysis of site-specific and cross-site data will be conducted. The ARISE Network team will develop a multi-modal dissemination strategy including the preparation of policy briefs, infographics, and scientific publications, as well as organizing meetings, seminars, and symposiums to engage with country-specific, regional, and global key stakeholders such as adolescents and young adults, guardians, teachers, community members, policymakers, funding agencies, and civil service organizations, to promote evidence-based decisions.

Our efforts for longitudinal adolescent health and well-being using population-based settings such as HDSS can be considered successful if the rounds of surveys are embedded within the HDSS. The quality of indicators will depend on the quality of data, including the data collection procedures and information management systems. In order to determine the success of the indicators, the ARISE team members from each site who would be more knowledgeable about the characteristics, strengths, and limitations of the data and derived information, would be engaged in collecting, analyzing, and interpreting data. By embedding rigor and reproducibility into longitudinal adolescent health data collection through HDSS, these markers can also serve as building blocks for similar efforts in other countries.

Future directions

Despite our best efforts, there are limitations to our approach. First, we did not seek the input of LMIC adolescents on the selected domains. Second, in deliberately selecting only priority domains and questions, our instrument will not be able to reflect all the needs of adolescents in LMICs. Third, despite the systematic approach to the development of indicators, our selected domains and questions do not reflect positive aspects of adolescent health and well-being. Fourth, attempting to build consistent questions across the wide developmental period of ages 10 to 19 necessarily required compromises, such that not all measures will fit key

indicators at all ages. Lastly, on the GDQS questionnaire, local food items are not visually represented to indicate the frequency of consumption, which might limit the precision of reported consumption.

To address all these concerns, we plan to conduct pilot testing, cognitive interviews, and discussions with adolescents at ARISE Network sites. For further refinement of our study instruments, we will consult with representatives of the ministries of education and health, civil service organizations, funding agencies, teachers, school administrators, and adolescents' guardians. ARISE Network has received two grants to enhance its efforts in SSA countries—one from the European Union-HORIZON (Grant no. 101095616)⁵⁹ and the other from the Federal Ministry of Education and Research, Germany (Grant no. 01KA2219B).⁶⁰ In seven SSA countries, we will establish a cohort of approximately 21,000 adolescents and young adults and follow them for four years through these grants. We will adapt our questionnaire through these two projects with 100 adolescents and young adults in each country as well as other relevant stakeholders. In addition to expanding current domains, this may lead to the inclusion of new domains such as social media use and online behaviors, bullying and violence, and subjective well-being, such as autonomy and social connectedness. The engagement of adolescents and other relevant stakeholders will also provide high levels of support and resources while promoting participation decisions, realistic influence potentials, and respect. It is in accordance with the UN Convention on the Rights of the Child, which stipulates that adolescents have a right to participate in decisions and measures that affect them, and their opinions should be acknowledged.

Discussion

The ARISE Network developed a concise yet systematic set of adolescent health and well-being measurements and integrated these measures into school- and population-based surveillance systems, to longitudinally track adolescents in representative settings in nine LMICs. To the best of our knowledge, this is the first such intentional and international, population-based longitudinal effort focused on adolescent health and well-being. Our measures complement existing indicators to generate actionable evidence for LMIC adolescents, which will guide future investments to improve adolescent health.

Our development approach was intentional with a focus on efficiency. Domains and questions were selected based on the most important areas for potential action, based on input from regional and international subject experts, intentionally avoiding duplication of indicators already covered by existing frameworks and guidelines. Through our systematic and comprehensive approach to measuring adolescent health and

development, we uncovered some key gaps in existing materials. For example, while mental disorders are a major adolescent health concern with substantial sequelae, measures were rarely included in key health indicator lists.^{61,62} Similarly, while adolescent healthcare use is important for current and future health outcomes, only one existing guideline—the WHO-initiated GAMA advisory group—included it in their rubric.^{13,14} By identifying these gaps, we have increased the comprehensiveness of our measures by including domains on mental health and healthcare utilization in our materials.

In seven SSA countries and two Asian countries, we are using standalone surveys in seven HDSS platforms and incorporating adolescent measurement in three school-based settings. Our approach has multiple advantages. First, we are able to include adolescents of a wide age range, ethnicities, and religions through population settings-based surveys across these countries. Second, the regular tracking of key indicators can inform policy and programs and advocate for adolescent health across several domains and sectors. Third, the data can be explored to assess the impact of risk factors on health and well-being outcomes, especially when collected longitudinally. Fourth, collecting data simultaneously in multiple countries will allow us to assess research questions across countries and contexts and share lessons learned. Finally, the data collected regularly can be used to train the next generation of healthcare professionals in adolescent health on how to use and analyze data. While the populations surveyed in our initial studies are not necessarily nationally or regionally representative, there is no reason that our approaches cannot be generalized to wider populations.

Adolescent quantitative longitudinal data collection can be incorporated into population-based surveillance systems in two ways: (i) integrate the adolescent survey into the same sample of households during the HDSS visit, and (ii) conduct the adolescent survey in the same sample of HDSS households during an additional visit since adolescents may not be available or the main survey may take too long.^{21–25} The former approach would allow the tracking of changes in key health and well-being indicators at a low marginal cost. The latter approach would be costlier but would allow more in-depth surveys given their standalone nature that might be more suitable for identifying causes of change, examining health trajectories and transitions, and evaluating interventions. For example, the South African arm of the multi-country DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored and Safe) partnership—a package of interventions aimed at reducing HIV incidence among adolescent girls and young women—was evaluated within the HDSS site at the Africa Health Research Institute (AHRI) in Kwa-Zulu-Natal.⁶³ DREAMS implementation sites were selected based on epidemiological priorities, so

evaluation by a randomized trial was not feasible. The study team recruited and longitudinally followed a population-representative sample drawn from AHRI's population census. Pre-study data on participants' socio-demographics, sexual behavior, and HIV status helped the evaluation team measure the effectiveness of the DREAMS intervention.

Recruiting, interviewing, and retaining adolescents in longitudinal research is complex. However, working with HDSS sites, population-representative surveys and schools can mitigate some key challenges. Adolescents are often highly mobile, especially once they have left education and sought work,⁶⁴ making both initial contact and ongoing re-contact difficult. Older adolescent girls, in particular, may marry, move home, and potentially change their names.⁶⁵ All of this may lead to loss-to-follow-up. Digital technology, especially increasingly prevalent smartphones, can help researchers reach study participants, as well as offer opportunities for future surveys to be administered digitally. Nevertheless, advances such as caller ID and the primacy of text over voice among LMIC youth, as well as rapid phone number turnover, can limit actual contact.^{64,65} As part of this study, we will explore and report on the use of digital technology, including telephonic interviews and light-touch SMS interactions, both to regularly collect data and maintain longitudinal follow-up. At HDSS sites, we will also test methods for maintaining a connection with adolescents who have moved via family connections.

Population-based surveillance systems can limit concerns about unknown people contacting adolescents, due to their long-term engagement with the community. This engagement builds trust and awareness of the work surveillance sites conduct and the benefits it provides locally, as well as building a nuanced understanding of local migration patterns. These factors in turn minimize the risk of not finding adolescents initially or during follow-up as they move through life stages. Population-based surveillance platforms can also limit digital loss-to-follow-up by gathering regularly updated contact details for relatives within the household, who can then potentially put the adolescents back in touch with the study.

Within the interview, many key adolescent health topics including sexual behavior, substance use, and mental health are very sensitive, making home-based interviews difficult.⁶⁶ Moreover, self-reports are used to measure health risk behaviors. It is possible that some health risk behaviors may be difficult to recall and are perceived as socially desirable or undesirable, which can compromise the truthfulness and accuracy of these self-reports. However, HDSS sites have substantial experience in interviewing residents about topics including sexual behavior, substance use and mental health, and research assistants are trained in maximizing empathy and privacy during the interview. There is also potential

to use novel data collection techniques such as computer-assisted self-interviews, bi-directional text messaging, and social media-based messaging that enable participants to provide socially undesirable responses safely and comfortably without having to say them out loud.⁶⁷

Similarly, conducting regular adolescent surveys in schools has many advantages, including direct a group platform for sharing information and facilitating engagement and partnership with adolescents and their guardians to obtain individual-level assent and consent, respectively.^{18,64} Despite these advantages, school-based surveys have limitations, centrally that non-attending or frequently absent youth will be missed.⁶⁴ Adolescents who frequently miss school or drop out are at high risk for illnesses and social stressors, particularly poverty, food insecurity, and migration. Further, tracking adolescents after school years may be difficult because many adolescents move away from home to pursue higher education or jobs, or move home after marriage.⁶⁴ For both HDSS- and school-based approaches, one way to limit loss to follow-up is to link survey data to ongoing routine data collection systems, such as those in healthcare settings, to allow subsequent health outcomes to be linked to initial survey responses.

The demography, behaviors, and health of adolescents in LMICs are changing rapidly. Adolescent trajectories of health, education, social, and economic success in LMICs are poorly understood, and global resources for strategic investment in LMIC adolescent health are limited. There is, therefore, a compelling need to produce reliable, longitudinal data on key adolescent health and well-being indicators, to help understand the potential for strategic investments in adolescents to benefit them now and in the future. Population-based surveillance platforms such as HDSS, MICSS, DHSs, and schools have the potential to efficiently and effectively collect information on adolescents, especially when following up on youth over time to understand causal processes, acting as complements to nationally representative cross-sectional surveys. However, doing this requires careful planning to maximize benefits. The ARISE Network has, therefore, developed widely acceptable indicators of adolescent health and well-being, and will demonstrate their application in selected HDSSs and schools. This work will demonstrate the use of a uniform questionnaire to identify young people's health risks and burdens, identify opportunities to develop interventions, improve adolescent health policies and programs, and build research capacity relating to adolescent health and well-being in SSA and Asia.

Contributors

Sachin Shinde, Guy Harling, Anne Marie Darling, Lina Nurhussien, Till Bärnighausen, and Wafaie Fawzi led the study design and instrument development. All authors made substantial contribution to the development of domains and indicators for adolescent health and well-being

as well as the study instrument. The study is being implemented by Nega Assefa, Justine Bukenya, Angela Chukwu, Adom Manu, Ouhore Millogo, Mary Mwanyika-Sando, Jabulani Ncayiyana, Rutuja Patil, and Kun Tang at their respective sites. Sachin Shinde and Guy Harling drafted the manuscript. All the authors read, provided feedback, and approved the final manuscript.

Data sharing statement

All data generated and analyzed in this manuscript will be included in the published article or its supplementary information files. Data generated in the future by the processes described in the manuscript will be made available upon approval of a data request to the ARISE study team. Within 12 months of the completion of the study, the data generated through both rounds of surveys will be available in the Harvard Dataverse study repository. Upon completion of the study, the country-specific data will be hosted on the individual HDSS repositories, where available. The dataset will be anonymized before sharing, and the level of anonymization will be determined based on other factors such as consent from the original participants, research questions, and data transfer methods.

Declaration of interests

We declare no conflict of interest.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.eclinm.2023.102067>.

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