



Research with Disadvantaged, Vulnerable and/or Marginalized Adolescents

Colette L. Auerswald,¹ Amber Akemi Piatt,¹ Ali Mirzazadeh²

¹ UC Berkeley School of Public Health; Innovations for Youth (I4Y)

² UCSF Global Health Sciences and WHO Collaborating Centre for HIV Surveillance, Kerman, Iran

Innocenti Research Briefs - Methods

Produced by the UNICEF Office of Research, this series of briefs on research methods is intended to share contemporary research practice, methods, designs, and recommendations from renowned researchers and evaluators. The primary audience are professionals, including UNICEF staff, who conduct, commission or interpret research and evaluation findings in development contexts to make decisions about programming, policy and advocacy.

This brief is one of seven on research methodologies designed to expand and improve the conduct and interpretation of research on adolescent health and well-being in low- and middle-income countries (LMICs). Building on the recent [Lancet Commission on Adolescent Health and Wellbeing](#), these briefs provide an overview of the methodological quality of research on adolescents. They cover topics including: indicators and data sources; research ethics; research with disadvantaged, vulnerable and/or marginalized populations; participatory research; measuring enabling and protective systems for adolescent health; and economic strengthening interventions for improving adolescent well-being.

The briefs are written by leading experts in adolescent health and well-being. To read other briefs in this series, visit <https://www.unicef-irc.org/adolescent-research-methods/>

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INTRODUCTION

Disadvantaged, vulnerable and/or marginalized adolescents (DVMAs) are individuals aged 10–19, who are excluded from social, economic and/or educational opportunities enjoyed by other adolescents in their community due to numerous factors beyond their control. These include factors at the social level (such as economic inequality, violence, stigma, racism, migration), family level (including neglect and abuse) and individual level (e.g. disability, ethnicity). DVMAs include adolescents who are immigrants or refugees; sexual minorities; orphans; incarcerated; those who have run away or been turned out of their homes following neglect and/or abuse; those who are trafficked; and those who belong to a stigmatized indigenous, ethnic, tribal or religious groups. *Though gender plays an important role within each of these categories and for the group as a whole, in this brief we do not treat all girls and young women as DVMAs.*

As a result of their social exclusion, DVMAs suffer from health inequities, or avoidable inequalities in their health and well-being compared to the well-being of other adolescents. Research is needed to inform ways to address these inequities.

When carrying out research with DVMAs it is necessary to address not only the obstacles to research with adolescents overall (see Brief 3 in this series, '[Inclusion with Protection: Obtaining informed](#)

consent when conducting research with adolescents'), but also the added practical challenges to their inclusion in research due to their marginalized status. These include, but are not limited to, frequent lack of committed parental or guardian involvement, stigma, and undocumented or criminalized status. In addition, research with DVMAs may be further impeded by stigmatization by healthcare providers, teachers, policy-makers, funders and even researchers. Together these factors contribute to the dearth of researchers trained and methods designed to include such adolescents in research. Thus, for multiple reasons, the adolescents who are most likely to benefit from research may be those most likely to be excluded from research.

Clearly, DVMAs stand to benefit from research that assesses their experiences, contexts and assets, and that informs steps to change the circumstances that disadvantage and marginalize them. However, it is recognized that not only adolescents, but also their community and the quality of the research, stand to benefit greatly if young people are included as participants in the research process. For more on this topic, please refer to Brief 5 in this series, 'Adolescent Participation in Research: Innovation, rationale and next steps'.

In addition, it is worth noting the specific multi-level benefits to be gained from involving DVMAs in research on their well-being.¹ *Benefits to adolescents* include connection to kind adults, social safety net services and supportive peers. Furthermore, participation may help reverse internalized stigma, promote skills in community agency and a sense of empowerment, increase civic and social competencies, and lead to an improvement in social capital for the young people involved. *Benefits to the community* include increased ability to address community needs and the recruitment of a new generation of community leaders. Finally, *benefits to research* may include access to hard-to-reach DVMAs through young people's collaboration, increased uptake of the research secondary to increased buy-in, and greater relevance and validity of the findings, as well as improved effectiveness of resulting interventions. Such input also benefits the ethical impact of the project, as discussed further herein.

¹ See Act for Youth, 'Benefits of Youth Participatory Evaluation', 2016, <www.actforyouth.net/youth_development/evaluation/benefits.cfm>, accessed 15 January 2017.

In this brief, we:

- summarize the health and well-being inequities experienced by DVMAs and the need for research with this group
- review the challenges and barriers to their inclusion in research
- share practical implications and best practices for their inclusion in research that will promote their well-being
- address the ethical challenges and approaches to research with DVMAs.

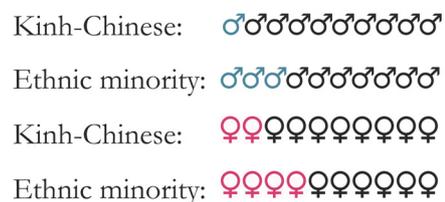
Box 1. Summary of key points

1. Disadvantaged, vulnerable and/or marginalized adolescents (DVMAs) include individuals aged 10–19 who are excluded from social, economic and/or educational opportunities relative to other adolescents in their community through factors beyond their control. As a result of their social exclusion, they suffer from avoidable inequalities in their health and well-being relative to the well-being of other adolescents. Research is needed to inform ways to address these inequalities.
2. There are additional challenges to research with DVMAs beyond the usual challenges to conducting research with adolescents as a whole.
3. Best practices for greater inclusion of DVMAs in research include:
 - employing community-based participatory approaches with adolescents whenever possible and methods that are developmentally appropriate and inclusive
 - prioritizing sex-aggregated sampling of marginalized adolescents (aged 10–19) for national surveys
 - sampling DVMAs by employing approaches that maximize representativeness of the sample and using validated methods to count and characterize the sub-populations of DVMAs
 - including contextual variables and measurements of the social determinants of health and well-being
 - implementing longitudinal studies when possible
 - disseminating findings to maximize the benefit of the research to adolescents.
4. Exclusion from research is harmful to DVMAs. Guidelines for the ethical inclusion of DVMAs are proposed that simultaneously prioritize inclusion in data collection and benefit to participants, as well as protection from potential risks.

BACKGROUND: HEALTH AND WELL-BEING INEQUITIES EXPERIENCED BY DVMA_s

In 2016 the Lancet Commission on Adolescent Health and Well-being described the factors that determine lifetime well-being as follows: ‘During adolescence, an individual acquires the physical, cognitive, emotional, social, and economic resources that are the foundation for later life health and wellbeing. These same resources define trajectories into the next generation.’² These factors include the social determinants of health and well-being, or ‘the conditions in which people are born, grow, live, work, and age’.³ According to the World Health Organization (WHO), health inequities are avoidable inequalities in health outcomes or in determinants of health between groups of people within countries and between countries.⁴ DVMA_s bear a disproportionate burden of the negative social determinants of health and well-being, such as adverse childhood events, poverty, malnutrition and exposure to violence or discrimination.⁵ As a consequence, they suffer not only from inequities in morbidity and mortality, but also from greater obstacles to their well-being and a successful transition to adulthood.⁶ An example of this is the difference in prevalence of early marriage (a social determinant of health and well-being) by ethnic group in Vietnam, illustrated in Box 2.

Box 2. Early marriage inequities in Vietnam



The Kinh–Chinese are the ethnic majority in Vietnam. There are over 50 recognized ethnic minorities in Vietnam, most notably the hill tribes, who are disproportionately impacted by stigma and poverty. These data illustrate the differences in early marriage, a social determinant of health and well-being, by ethnic status. In the survey assessment of Vietnamese adolescents administered by the WHO and UNICEF, 17 per cent of respondents overall aged 14–25 were ever married. However, there were great differences between Kinh–Chinese and ethnic minority respondents: 9 per cent of Kinh–Chinese males but 25 per cent of ethnic minority males were or had ever married; similarly, 19 per cent of Kinh–Viet females but 37 per cent of ethnic minority females were or had ever been married.

* See The World Health Organization’s “Health of Adolescents in Viet Nam” (2009) for more information.

2 Patton, G. C., et al., ‘Our Future: A Lancet commission on adolescent health and wellbeing’, *Lancet*, vol. 387, no. 10036, 2016, pp. 2423–2478, <https://www.researchgate.net/publication/302593577_Our_future_A_Lancet_commission_on_adolescent_health_and_wellbeing>, accessed 15 January 2017.

3 Patton et al., ‘Our Future’.

4 For more information see ‘Backgrounder 3: Key concepts’, from Commission on Social Determinants of Health, *Closing the Gap in a Generation: Health equity through action on the social determinants of health*, World Health Organization, Geneva, 2008, <www.who.int/social_determinants/final_report/key_concepts_en.pdf?ua=1>, accessed 15 January 2017.

5 Woan, J., Lin, J. and Auerswald, C., ‘The Health Status of Street Children and Youth in Low- and Middle-Income Countries: A systematic review of the literature’, *Journal of Adolescent Health*, May 2013.

6 For more information, see Patton et al., ‘Our Future’; World Health Organization, *Health for the World’s Adolescents: A second chance in the second decade*, WHO, Geneva, 2014, <<http://apps.who.int/adolescent/second-decade/>>, accessed 15 January 2017.

CHALLENGES AND BARRIERS TO CONDUCTING RESEARCH WITH DVMAS

Though there is a growing interest in conducting research and collecting data on adolescents and specifically DVMAAs, conducting such research successfully can be challenging. We will review three challenges to conducting robust research with DVMAAs:

- the inadequate existing baseline data on DVMAAs in most LMICs
- the challenges to recruiting adolescents and obtaining a representative sample of DVMAAs
- the use of developmentally inappropriate approaches to research and interventions.

The ethical challenges specific to undertaking research with DVMAAs and the practical implications of how they should be approached are discussed below.

Inadequate existing baseline data on DVMAAs in most LMICs

The first challenge to conducting robust research is that there is a profound lack of robust, age- and sex-disaggregated data on DVMAAs globally. This includes data on the size and characteristics of sub-populations of DVMAAs, primarily because they are often not included or identified in national census data, household surveys, education surveys and/or ministry of health surveys. For example, adolescents who are incarcerated are unlikely to be included in such surveys. Similarly, adolescents who are out of school are unlikely to get picked up in school-based surveys like HBSC and GSHS,⁷ which are an important source of information about this age group for decision-makers. The lack of inclusion of DVMAAs in current data systems is an example of under-coverage bias. In addition, even if surveyed, DVMAAs may not disclose their status or involvement in risk behaviours leading to an under-reporting bias. Without such data, policy-makers and providers are less likely to identify and prioritize the needs of DVMAAs in the context of the more well-documented needs of other populations.

A corollary to the lack of data is the lack of data on contextual variables, resiliency outcomes, positive developmental outcomes (such as educational or vocational outcomes vs risk outcomes) and/or data to document the effects of potentially modifiable social determinants on the health and well-being of DVMAAs. Research on DVMAAs to date has generally focused on individual-level variables, thus leading to systematic blindness to the role of modifiable factors that are amenable to change through policy, funding or other means (and which are generally beyond the control of affected adolescents). For example, research on young members of a stigmatized ethnic group is more likely to document their risk behaviours and negative outcomes rather than the stigma or laws that lead to marginalization, lack of opportunity, increased risk and inability to meet young adult milestones. Such a focus on individual-level variables too often 'blames the victim' for their situation and leads to further stigma of marginalized populations. (See Box 3 for a discussion of types of variables in research.) For more on the measurement on the social determinants of health, see Brief 6 in this series, 'How to Measure Enabling and Supportive Systems for Adolescent Health'.

⁷ HBSC stands for Health Behaviour in School-Aged Children. This cross-national survey of school students in 45 countries collects data on 11-, 13- and 15-year old adolescents' health, well-being, social environment and health behaviours. See: <<http://www.hbsc.org/about/index.html>>; GSHS stands for Global School-Based Student Health Survey. It surveys adolescents aged 13-17 from over 100 countries in 10 key areas, to assess behavioral and risk factors. See: <<http://www.who.int/chp/gshs/en/>>

Box 3. Why variables matter: 'individual-level' vs 'contextual' variables, and 'risk factors' vs 'protective factors'

Research has often focused on individual-level variables – the characteristics of individuals (e.g. their age, race or ethnicity, religion or housing status) to explain their health (e.g. rates of sexually transmitted diseases) or well-being (e.g. their hopes for the future). Though useful for pointing out disparities or differences in outcomes, they can only point to the characteristics of individuals as the causes of their poor outcomes (e.g. the higher rates of sexually transmitted infections are due to an adolescent's membership in an ethnic minority or because they are living on the street). This carries the risk of increasing stigma and offers little information on how to intervene to improve the outcome of affected adolescents.

Contextual-level variables focus on factors beyond the individual that may affect their health or well-being. These might include availability of healthy food, experiences of discrimination in a community, incarceration, neighbourhood poverty, access to free education or presence of a mentor. By including these variables in research, one opens the opportunity to understand how differential exposure to these positive and negative contextual factors may not only explain differences on outcomes for DVMAAs, but also provide clues to interventions.

Similarly, by choosing to study protective factors (such as positive role models) as well as risk factors (such as violent environments), researchers can develop interventions that not only minimize risk, but also promote protection against negative outcomes.

Challenges to recruiting adolescents and obtaining a representative sample of DVMAAs

The second challenge to conducting robust research is that there are important challenges to obtaining a representative and generalizable sample of DVMAAs. It is difficult to obtain a representative sample of adolescents because there is no global consensus on which groups or individuals should be treated as DVMAAs. The use of varying, non-standardized definitions of who is a member of a specific marginalized population affects our ability to compare findings between studies or to assess to whom the findings of a study apply. An even greater challenge to obtaining a representative sample of adolescents is that young people often avoid the services and/or authorities entrusted with their care and well-being because of

their concerns of stigma, lack of identification with stigmatized sub-groups, past negative experiences, lack of confidentiality and cost. This avoidance, along with the high degree of mobility common to DVMAA populations, renders them particularly hard to engage in activities related to services and data collection. The way that data on adolescents are collected is also often a barrier to obtaining a representative sample of DVMAAs. School-based surveys do not collect information on adolescents who are out of school and household surveys and censuses are unlikely to include information on those who live on the street, in institutions or other situations outside households. The groups that are excluded from these surveys are often made up of individuals who are disadvantaged, vulnerable and/or marginalized, resulting in a dearth of valid and representative information about this population.

This points to an important limitation to the generalizability of most current data on DVMAAs. Because of the hidden nature of DVMAAs, the vast majority of studies consists of small cross-sectional studies of convenience samples of adolescents recruited from health or social service programmes. However, these studies thus systematically exclude individuals who are not able or willing to access those programmes. Thus these studies, though informative on adolescents who do access services, cannot be generalized to the entire DVMAA population.

Use of inappropriate approaches to research and interventions

The third challenge to conducting robust research is the need for a developmentally appropriate, trauma-informed and culturally appropriate approach to research with DVMAAs (as described also in Brief 6 in this series, 'How to Measure Enabling and Supportive Systems for Adolescent Health'). Research approaches or interventions need to be tailored to the specific needs of DVMAAs. Too often, approaches, measures or interventions designed for disadvantaged, marginalized and/or vulnerable adults or, equally inappropriately, for young children under the age of 10, are applied to DVMAAs with little or no adaptation. This is particularly true of approaches to consent for marginalized adolescents. See Brief 3 in this series, 'Inclusion with Protection: Obtaining informed consent when conducting research with adolescents', and the section here on 'Ethical issues'.

PRACTICAL GUIDELINES FOR INCLUDING DVMA^s IN RESEARCH

In this section we provide a researcher's guide to promoting the health and well-being of DVMA^s. With the challenges and barriers to conducting research with DVMA^s discussed above in mind, we review best practices to improve inclusion of DVMA^s in research. Though our focus is on best practices, these are intended as guiding principles and should not discourage more limited forays into data collection with and about DVMA^s, as long as they follow ethical guidelines.

Use community-based participatory research approaches

Whenever possible, use community-based participatory research approaches. Adolescents, and perhaps particularly DVMA^s, are too often relegated to the role of passive participants in research – to the detriment of researchers and adolescents alike. Researchers should start by engaging DVMA^s as partners in the research design process to elicit their concerns and priorities. Together, researchers and DVMA partners can then develop research questions that will be relevant to adolescents' experiences and select appropriate approaches, methods and tools to answer their questions, intervene and/or evaluate. See Brief 5 in this series, 'Adolescent Participation in Research: Innovation, rationale and next steps', for more considerations and details.

Integrate local advocates and researchers in the design and implementation of research

The inclusion of local advocates and investigators who have a deep understanding of the local contexts and issues will increase the likelihood of the research question being relevant, of the research implementation being ethically and culturally appropriate, and of the interpretation of data and conclusions being sound.

Include questions that address modifiable structural factors

Research is more likely to improve the successful transition to adulthood of DVMA^s if it addresses modifiable contextual variables as well as protective factors. See Box 3 above for further discussion of this best practice.

Include sex-disaggregated samples of DVMA^s

Include data about adolescents, including DVMA^s,

in national and regional data collection efforts, as the Lancet Commission recommended in 2016.⁸ Disaggregate data and findings by sex and age (ages 10-14; ages 15-19). Include DVMA^s and their health, social and economic inequities in planning national efforts to meet the Sustainable Development Goals.

Maximize representativeness

Sample DVMA^s using approaches that maximize representativeness.⁹ Recruitment of a representative sample from a largely hidden and marginalized population is compromised by the inability to recruit a truly random sample from a list of the members of the target population (e.g. it is impossible to generate a comprehensive list of adolescents who have been trafficked). Because the members of DVMA populations cannot be sampled from a comprehensive list, researchers have traditionally studied convenience samples of adolescents recruited from service settings, such as shelters or clinics dealing with sexually transmitted infections. However, as discussed above, samples of service-based adolescents generally comprise a lower-risk sub-sample of the larger DVMA population. Appropriate sampling and a clear understanding of the limitations of any approach can improve the generalizability and validity of data and their usefulness for informing policy and planning.

Table 1 lists several approaches to sampling DVMA^s, with their strengths and weakness. Choosing the sampling approach for an individual study depends on available options and resources, the characteristics of the target population, and careful formative research and planning to ensure that the chosen method is feasible, acceptable and effective. (See UNICEF's brief on data collection and analysis methods in impact evaluation for a general discussion of sampling approaches.¹⁰) Such non-probability sampling approaches have also been employed widely by governmental authorities charged with HIV surveillance, which may themselves have sampled DVMA^s.¹¹

8 Patton et al., 'Our Future'.

9 Dayton, R., et al., 'How Can We Better Serve Adolescent Key Populations? Strategies to encourage and inform future data collection, analysis, and use', *Global Public Health*, 2016, pp. 1–13.

10 Peersman, Greet, 'Overview: Data collection and analysis methods in impact evaluation', Methodological Briefs: Impact Evaluation 10, UNICEF Office of Research, Florence, 2014, <https://www.unicef-irc.org/publications/pdf/brief_10_data_collection_analysis_eng.pdf>, accessed 15 January 2017.

11 UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, *Guidelines on Surveillance Among Populations Most At Risk for HIV*,

Table 1. Approaches to sampling DVMAAs

Sampling method	Definition	Strengths	Weaknesses
Convenience	Based on the recruitment of DVMAAs who are easy to reach, often those who are accessing services. Examples are studies that recruit <u>street-based adolescents</u> from shelters or drop-in centres, or sex workers from clinics for sexually transmitted diseases.	<ul style="list-style-type: none"> • Readily available • Cost-effective • May be able to build on relationships with providers 	<ul style="list-style-type: none"> • Non-probability sample • Results biased towards adolescents who access services (often lower risk); not representative of those who do not • Limitations of this commonly employed approach are often overlooked • The probability of selecting a member of the population of interest is unknown
Purposive	A non-probability sampling method based on the recruitment of participants with specific characteristics within a population.	<ul style="list-style-type: none"> • Can be used to ensure the inclusion of all sub-sets of a population if the characteristics of the population are well known 	<ul style="list-style-type: none"> • The probability of selecting a member of the population of interest is unknown • May introduce a systematic bias
Targeted venue-based	Based on sampling DVMAAs from venues or places where they live, work or socialize. Formative research using qualitative and/or quantitative data to construct a list of sites where adolescents may be found and recruited.	<ul style="list-style-type: none"> • Target population is visible • High-quality formative research can maximize validity • Can ensure inclusion of sub-groups through selection of venues where members of sub-groups spend time • Can be effective for sampling highly mobile populations • Can adjust sampling in response to information in the field • Can be paired with outreach interventions 	<ul style="list-style-type: none"> • Non- probability sample • Sampling may be biased and difficult to replicate • Sampling of venues may not represent the proportion of adolescents from that venue in the target population of interest; the sample may not be representative • Leaves out those who do not attend venues • Over-represents frequent venue-goers • The probability of selecting a member of the population of interest is unknown • Labour intensive • May require difficult hours of operation • Safety of staff and of population may be an issue, depending on venues

Sampling method	Definition	Strengths	Weaknesses
Time location	A variant of targeted venue-based sampling that approximates a random sample by employing a comprehensive list of venues, and includes days of the week and time periods to create venue, day and time (VDT) periods. Investigators then conduct random selection of VDTs, followed by systematic counting, approaching, consenting and recruiting of eligible adolescents who attend at the venue.	<ul style="list-style-type: none"> All advantages listed for venue sampling above The probability of selecting a member of the population of interest can be calculated – approximates a probability sample Statistical methods are available to produce unbiased estimates 	<ul style="list-style-type: none"> Leaves out those who do not attend venues Over-represents frequent venue-goers Hard to statistically adjust Labour intensive May require difficult hours of operation Safety of staff and of population may be an issue, depending on venues
Snowball	Based on sampling people through their social connections or networks. Initial adolescents recruited by research staff are requested to recruit eligible participants who may be from their social contacts to refer them to the study for participation. Snowball sampling is particularly useful for recruiting DVMA who are hard to reach but tend to know each other, such as adolescents involved in street-based <u>sex work</u> .	<ul style="list-style-type: none"> Targets hidden population May be the best available option for some populations May be faster and less expensive than locating and recruiting people with research staff Peers know each other better than researchers Peer recruiters can also recruit people for interventions 	<ul style="list-style-type: none"> Non-probability sample Biased towards the socially well connected; leaves out the socially isolated The probability of selecting a member of the population of interest is unknown There is no statistical method to produce unbiased estimates
Respondent-driven*	Respondent-driven sampling (RDS) is a modified form of network sampling. To recruit a respondent-driven sample, eight to ten 'seeds' are recruited from the target population, based on initial formative research. After study data collection, seeds are given coded tickets to distribute to eligible individuals from their social network. Their network contacts then come to the study site, contribute their data, and are in turn given tickets to distribute. Individuals are reimbursed for their own participation and further reimbursed if those they recruit are enrolled (secondary reimbursement). Participants report the size of their network and their relationship to the individual who referred them to the study. With mathematical modelling software available freely online (the RDS analysis tool, or RDSAT), data are used to estimate the characteristics of the population of interest.	<ul style="list-style-type: none"> All advantages of snowball sampling Probability of selecting a member of the population of interest can be calculated; it approximates a probability sample Statistical methods available to produce unbiased estimates High-quality formative research can maximize validity 	<ul style="list-style-type: none"> Inaccurate estimates in communities with sub-networks Bias towards the socially well connected; leaves out the socially isolated Statistics for analysis difficult and debated Findings sometimes inconsistent with qualitative research Theoretical assumptions hard to meet and to verify Sometimes peers fail to recruit others and so RDS fails Secondary incentives may be coercive or commoditized

* For more information see Abdul-Quader, A.S., et al., 'Implementation and Analysis of Respondent-Driven Sampling: Lessons learned from the field', *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, vol. 83, suppl. 1, 2006, pp. 1–5; Bøås, M. and Hatley, A., *Living in a Material World: Children and youth in alluvial diamond mining in Kono district, Sierra Leone*, Fafo, Oslo, 2006.

Use appropriate approaches to count and characterize populations of DVMA

If DVMA are counted, they will be more likely to be visible to policy-makers who are then more likely to consider their needs. Population size estimation and

characterization can promote inclusion of DVMA in national research and policy efforts. Though there is currently no gold standard method for counting DVMA, a number of methods have been proposed and tested. We briefly review some of these in Table 2.

Table 2. Approaches to counting and characterizing DVMA

Approach	Description	Advantages	Weaknesses	Possible biases
Capture–recapture*	DVMA are surveyed initially and ‘tagged’ in some way (perhaps by being given a small token). The DVMA population is then resurveyed later, when participants are asked if they participated or were tagged during the earlier survey. The size of the population in each survey and the size of the overlap provide the basis to estimate the total population size.	<ul style="list-style-type: none"> Scientifically rigorous and well-developed methods for analysis 	<ul style="list-style-type: none"> Four assumptions that are hard to meet: required matching individuals captured on both surveys, closed population (no significant in or out migration), each individual has the same chance of being included, independent rounds Although an option, this approach may be difficult to implement with DVMA 	<ul style="list-style-type: none"> If the two data sources are correlated, the counts will be underestimated
Key informant estimates	The target area for which the populations of DVMA are being counted is divided into zones. Key informants are then asked about the hotspots, size and typology of DVMA at every hotspot within zones.	<ul style="list-style-type: none"> Easy to implement Does not require direct counting and field work Involves stakeholders and key informant in the process 	<ul style="list-style-type: none"> Requires well-defined and tangible zones May generate outdated information that cannot be verified by direct observation and counting Wide range of estimates Potential duplication of counts 	<ul style="list-style-type: none"> Biased towards key informant’s perspective and area of work and expertise Approach to extrapolation of a local setting to a whole region is unclear
Mapping and enumeration**	A comprehensive list of venues where DVMA meet or work is generated through qualitative interviews with key informants (service providers, DVMA activists, non-government organization (NGO) staff, police, taxi and bus drivers, and DVMA themselves). Direct observation, counting and/or surveys are carried out at the identified adolescent-serving venues.	<ul style="list-style-type: none"> Tend to produce robust estimates Count target groups that are visible and could be reached for services 	<ul style="list-style-type: none"> Mobility, duplication and absence of the DVMA at the hotspots or venues may produce over- or underestimated counting Requires going to field so safety is always an issue Hard, labour intensive and expensive to conduct nationally 	<ul style="list-style-type: none"> Under-reporting as only able to count the visible part of the DVMA population

Approach	Description	Advantages	Weaknesses	Possible biases
Multiplier methods***	Similar to capture–recapture (see above), multiplier methods employ two sources of data of which at least one represents the target DVMA population. Two variations are service multiplier and unique object multiplier methods. In both, the total number of DVMA who received the service or a unique object at a certain period, and the proportion of DVMA in the subsequent survey who report using such services or receiving the unique object, are used to estimate the DVMA population size.	<ul style="list-style-type: none"> • Can be easily integrated in surveys of DVMA • Different multipliers can be used at the same time, which yields more confidence about the plausibility of counts 	<ul style="list-style-type: none"> • Highly dependent on availability and quality of data collected for other purposes • Participants may not remember visiting a service • Highly variable results 	<ul style="list-style-type: none"> • If the two data sources are correlated, the counts will be underestimated
Network**** and/or RDS-based	Use of the ordered sequence of observed social network sizes of participants in an RDS survey to produce a population size estimate.	<ul style="list-style-type: none"> • At no additional cost or time, RDS data can be used for estimation of population size 	<ul style="list-style-type: none"> • Requires specific software to analyze • Highly variable results if the RDS network data or prior information are not informative 	<ul style="list-style-type: none"> • Overestimation and underestimation are possible; both are hard to investigate or validate
Network scale-up*****	Members of the general population (not necessarily DVMA themselves) are asked about the overall numbers of members in their overall network and the numbers of DVMA they know in their networks. If a large, representative number of people in a community is asked this question, the collective information can provide a robust estimate of the DVMA population size as a whole.	<ul style="list-style-type: none"> • Do not require a study of DVMA themselves • Can estimate more than one key population in one round • Can be integrated in national surveys among general populations and so produce national counts 	<ul style="list-style-type: none"> • Hard to define what you mean by 'know' a friend • Requires access to a population-based survey • May need to add many questions to the survey 	<ul style="list-style-type: none"> • Transmission error: people do not tell others they are DVMA • Barrier effect: people may live away from where DVMA are • Recall error: people do not always remember they know a DVMA • Stigma error: people may not like to admit they know a DVMA
Wisdom of the crowd	This method assumes that, in aggregate, the responses of a sufficient quantity of DVMA on their numbers will provide a good estimate of the actual number of their population.	<ul style="list-style-type: none"> • Easy to implement • Only need a few questions to be added in a survey tool • Can produce point and confidence bounds 	<ul style="list-style-type: none"> • Participant may have difficulty in understanding the question and giving a rational estimate • Requires probing for correct answers • Highly variable results 	<ul style="list-style-type: none"> • Can produce both low and very high estimates depending on the understanding and perspective of the respondents

* Tilling, K., 'Capture-Recapture Methods – Useful or misleading?', *International Journal of Epidemiology*, vol. 30, no. 1, 2001, pp. 12–14.

** Emmanuel, F., et al., 'The HIV/AIDS Surveillance Project Mapping Approach: An innovative approach for mapping and size estimation for groups at a higher risk of HIV in Pakistan', *Aids*, vol. 24, supp. 2, 2010, pp. S77–84.

*** Johnston, L. G., et al., 'Incorporating the Service Multiplier Method in Respondent-Driven Sampling Surveys to Estimate the Size of Hidden and Hard-to-Reach Populations: Case studies from around the world', *Sexually Transmitted Diseases*, vol. 40, no. 4, 2013, pp. 304–310.

**** Handcock, M. S., Gile, K. J. and Mar, C. M., 'Estimating the Size of Populations at High Risk for HIV Using Respondent-Driven Sampling Data', *Biometrics*, vol. 71, no. 1, 2015, p. 258–266.

***** Sulaberidze, L., et al., 'Population Size Estimation of Men Who Have Sex with Men in Tbilisi, Georgia; Multiple methods and triangulation of findings', *PLoS ONE*, vol. 11, no. 2, 2016.

Use triangulation or mixed methods research

If it is not possible to recruit a representative sample of DVMAAs for a study, collecting data employing triangulation or mixed methods research can increase the validity of the findings. Triangulation of data is the use of multiple sources of data or multiple points of view in order to answer a question when a gold standard method of research is not available, thereby increasing the validity of the findings. For example, in order to understand the experience of adolescents who are immigrants in the school environment, one could conduct interviews with immigrant students. However, the picture would likely be more complete if one complemented those interviews with other sources of data. These might include holding interviews with immigrant

students who have dropped out of school and with parents of immigrant students, observing the school environment, and collecting data on attendance and rates of detention of adolescents in the school. An example of triangulation of data is presented in Box 4: a case study on how to count the number of street children in Tehran.

Mixed methods research entails collecting and analysing quantitative and qualitative data together in a single study. It offers the advantage of not only answering questions on who faces – or the numbers facing – an inequity when studying inequities employing quantitative data, but also exploring why inequities exist or the reasons for unexpected findings through qualitative research.

Box 4. Case study: counting street-based adolescents in Tehran



Researchers in Tehran, Iran, in collaboration with UNICEF, the University of California at San Francisco and the San Francisco Department of Public Health, are employing multiple methods to estimate the size of the population of street-based adolescents.*

1. Employing multiplier methods, the investigators employed service provider data and data from a modified time location sampling survey together to estimate the size of the population of street-based adolescents in Tehran. Service providers who collect unduplicated data on street-based adolescents under their care (e.g. social welfare, housing, food stamps and NGOs) were asked for their count of adolescents served over a specific time period (e.g. 2015). A subsequent time location sampling survey of street-based adolescents assessed the proportion of study participants who reported having accessed such services in the same time period. Given these two sources, their estimate of the total number of street-based adolescents in Tehran is:

$$\frac{\text{number of adolescents accessing services}}{\text{proportion of time location sampling adolescents accessing services}} = \text{total number of street-based adolescents}$$

2. Estimates from a literature review, mapping and enumeration, and the wisdom of the crowds will also be gathered.

3. The final estimate will result from a review of these estimates and validation by a Delphi expert panel discussion.

* Vameghi, M., et al., 'A Methodological Paper: Rapid assessment and response to high risk behaviors of street children in Tehran', *Iranian Journal of Epidemiology*, vol. 11, no. 1, 2015, pp. 31–41.

Use appropriate data collection methods

Employ methods of data collection that are developmentally appropriate, inclusive and recognize the inherent power differential between individuals gathering data and DVMAAs themselves. Qualitative data collection methods, mixed method approaches and participatory action methods can be inclusive ways to obtain data. See Brief 5 in this series, 'Adolescent Participation in Research: Innovation, rationale and next steps', for a discussion of these issues and examples of the use of youth-led participatory action research as a way to engage adolescents, including DVMAAs. (For guidance on qualitative data collection methods, see UNICEF's brief 'Interviewing'.¹²)

Explore whether technology can increase the access to and comfort of adolescents with research activities. DVMAAs globally have increasing access to social media or technology, especially with mobile phones, despite a persistent digital divide with some sub-groups. Please refer to Brief 5 in this series, 'Adolescent Participation in Research: Innovation, rationale and next steps', or read more about UNICEF's Short Message Service (SMS)-based U-Report,¹³ for examples.

Include contextual variables in data collection

Given the importance of social determinants in the health and well-being of adolescents, and the greater burden of negative social determinants among DVMAAs, research and data systems should include not only individual but also contextual variables in data collection (see Box 3). Similarly, the use of positive developmental outcomes, such as school completion, vocational training or locally relevant measures of civic engagement, can assist policy-makers who are allocating resources, to focus on not only the avoidance of risk, but also on supporting adolescents in successful transition through adolescence to adulthood. Such indicators are often highly relevant to programmatic decisions.¹⁴

Employ standard definitions

For readers to evaluate the rigour of a study, the definitions of the target population, and of the variables studied need to be clearly defined. The use of standard definitions (e.g. the use of UNICEF definitions of the adolescent age range¹⁵) allow those reading a study to compare the findings to other research studies with the same population or on the same topic. Standard definitions are often those most often used in the literature. If there is no clear standard, the choice of a specific definition for inclusion in a DVMA sub-group should be justified.

Conduct longitudinal studies when possible

Conduct longitudinal studies when possible, as encouraged by the 2016 Lancet Commission call for research that can identify interventions that can contribute to positive outcomes ('a second chance') for DVMAAs.¹⁶ Specifically, longitudinal data collection is required to document not only the outcomes of DVMAAs, but also how interventions might alter those outcomes. However, longitudinal studies of DVMAA cohorts are rare, particularly in LMICs. There are obvious reasons for this, including, but not limited to, the lack of expertise in conducting longitudinal research with adolescents, the expense of and insufficient funding for such work, and the challenges of keeping young people in studies over time. One possible way to retain adolescents is to partner with the service organizations that maintain longitudinal relationships with them. Though working with service organizations limits generalizability, as discussed, this limitation can simply be acknowledged. Governments and NGOs may not be in the position to conduct longitudinal research themselves, but are in the position to signal their interest in such work. The importance of longitudinal studies of children and young people and an example of best practices is discussed in a 2015 Innocenti Research Brief, 'Tracking the Children of the Millennium'.¹⁷

12 McDonald, B. and Rogers, P., 'Interviewing', Methodological Briefs: Impact Evaluation No. 12, UNICEF Office of Research, Florence, 2014, <https://www.unicef-irc.org/publications/pdf/brief_12_interviewing_eng.pdf>, accessed 15 January 2017.

13 See <<http://www.ureport.in/>> accessed 15 January 2017.

14 Dayton et al., 'How Can We Better Serve Adolescent Key Populations?'

15 UNICEF, *The State of the World's Children 2011*, UNICEF, New York, 2011, <https://www.unicef.org/adolescence/files/SOWC_2011_Main_Report_EN_02092011.pdf>, accessed 15 January 2017, p. 6.

16 Patton et al., 'Our Future'.

17 Dorman, P., Knowles, C. and Banati, P., 'Tracking the Children of the Millennium: Insights from a longitudinal cohort study', Innocenti Research Brief 2015-03, UNICEF Office of Research – Innocenti, Florence, 2015.

ETHICAL ISSUES

Ethical concerns can discourage investigators and governments from engaging DVMAAs in research. However, by excluding DVMAAs from research, we may harm them by also excluding them from the potential benefits. Thus, investigators must simultaneously prioritize the inclusion of DVMAAs in data collection as well as protection from the potential risks of research. To accomplish this goal, it is incumbent on researchers working with DVMAAs to ensure that in designing their research they prioritize adherence to both international ethical standards and community ethical norms. The most effective ways to meet this requirement are for researchers to be familiar with these norms and guidelines, to consult researchers experienced in working with DVMAAs when possible and, most importantly, to collaborate with community members who are entrusted with caring for DVMAAs. Thus they must ensure that research is reviewed by a local institutional review board for their feedback and guidance, and that local researchers are engaged in research funded by outside entities.

Brief 3 in this series, '[Inclusion with Protection: Obtaining informed consent when conducting research with adolescents](#)', describes how the principles of justice, beneficence and respect for persons are the foundation of research ethics. *The principle of justice* dictates that the general population must have equitable and fair access to research and its benefits. Thus researchers must ensure that DVMAAs have equitable and fair opportunities to participate in research that accounts, for example, for their developmental needs, literacy and ability to consent (see Box 5 for more on consent). Use of pictures, stories or interactive modes of data collection can increase the accessibility of research to adolescents. In addition, the consent process for adolescents and unaccompanied minors should be explained. With such supports, adolescents can and should be allowed to participate in research within the boundaries of local laws. Justice dictates that participants will not be unfairly burdened by research activities, so there is an obligation to be sensitive to the burden and over-exposure to research that DVMAAs sometimes experience.

Box 5. Emerging debates: the principle of justice, consent for research, and the inclusion of marginalized adolescents

In our experience, the consent process for research with marginalized adolescents is far from standardized and is often not described even in reports and papers. Though this general topic is described in detail in Brief 3 in this series, '[Inclusion with Protection: Obtaining informed consent when conducting research with adolescents](#)', we share examples of approaches to research consent with street children in western Kenya, which could be adapted to other studies of marginalized young people.

The Vijana Wetu project in Kisumu, Kenya, studied HIV prevalence and risk factors in street children and young people aged 13–21. Study staff, in collaboration with local providers for street-based children and adolescents, obtained written consent from participants using a form that was read in participants' preferred language. Participants who were unable to sign their name made a mark in the presence of a witness. Kenya's national HIV testing guidelines allow for minors at least 15 years old to consent for voluntary HIV counselling and testing and for minors under the age of 15 to provide their own consent if engaged in behaviours that put them at risk of HIV infection. Participants under 15 years old completed a short quiz to assess their understanding of the consent form, for which they had to receive a score of 70 per cent to be eligible to participate in the study. No potential participant was excluded because they had a low score. Participants received a meal voucher from a local food vendor for their participation, a level of compensation that was not found to be coercive in a prior pilot study.*

Investigators engaged in research with street children in Eldoret, Kenya, have outlined additional principles for the engagement of minors, including integration of the research into community consent and community services, the appointment by adolescents of an adult who can support them in their consent process, and the engagement of peer outreach workers for recruitment of adolescent participants and for input into the research process.**

Depending on local guidelines and in discussion with the local institutional review board, researchers may conclude that anonymous or oral consent is most appropriate, particularly when signed consent is the only documentation tying adolescents to a study.

* Goldblatt, A., et al., 'Prevalence and Correlates of HIV Infection among Street Boys in Kisumu, Kenya', *PLoS ONE*, vol. 10, no. 1, 2015.

** Embleton, L., et al., 'Adapting Ethical Guidelines for Adolescent Health Research to Street-Connected Children and Youth in Low- and Middle-Income Countries: A case study from western Kenya', *BMC Medical Ethics*, 2015, vol. 16, p. 89.

The principle of beneficence dictates that investigators pay particularly close attention to the increased vulnerability of disadvantaged, vulnerable and/or marginalized sub-populations of adolescents and protect them from harm. Research guidelines further require that participating marginalized adolescents themselves, especially minors, not simply the population overall, must benefit from participation. Given the requirement to protect vulnerable research participants and the fact that DVMAAs may not have adults in their lives who are looking out for their best interests, the investigator is responsible for protecting adolescents not only from possible physical harm, but also from possible emotional and social harm from research. As DVMAAs are frequently vulnerable legally, this requires investigators to protect the identities of participants and the confidentiality of study data in order to prevent disclosure of their marginalized status and/or further stigma. Measures may need to be taken to protect a database from illegal disclosure.

Beneficence further requires multiple measures to minimize the risks inherent to research, by accurately taking participants' views, rights and needs into account. These may include formal staff training in research ethics, protection of data, confidentiality and adolescent rights; and minimizing the stigma and potential dangers of participation. A non-stigmatizing name should be chosen for the study or project, ideally with the input of members of the target population. Sensitization of the local authorities, particularly the police, may be necessary to ensure their support of the activities and that adolescents' participation does not pose an increased risk of identification, arrest or detention.

Beneficence also requires that researchers ensure the provision of care to adolescent participants, preferably through referrals to collaborating community partners or, when available, to providers who can provide adolescent-friendly, confidential, long-term care after the study or research ends. It also requires researchers to plan for the referral and care of young people who are in imminent danger or are a threat to themselves or others. Again, collaboration with community partners and the local institutional review board is critical. If the appropriate resources for a research project to be completed ethically are not available, it may be more appropriate to focus on work that could increase the availability

of necessary resources first, or to scale down the objective of the project.

Furthermore, beneficence requires that a well-formulated dissemination and uptake strategy directed at policy-makers be formulated to maximize the study's potential to improve the lives of adolescents. DVMAAs should be informed of the link between the research they participate in and the potential improvements in services and programmes that the research is intended to bring about. Researchers should maximize the benefit of dissemination of findings without harm or increased stigma to the target population. DVMAAs should be targeted in the dissemination of results and included as actors in dissemination activities when possible.

Finally, *the principle of respect for persons* dictates that adolescents, including DVMAAs, have the right to express their views on matters that directly affect them, including the design of programmes to improve their lives. By including their voice in research activities, they can influence the decisions made on the basis of the resulting findings. A community or youth advisory board can fulfill this role. However, in developing such a board, it is important to avoid tokenism and not to forget that there are multiple communities of adolescents and of DVMAAs, and that adolescents may not be qualified to represent other adolescents just on the basis of being in the same age bracket. The principle of respect for persons also requires that DVMAAs, who may be foregoing activities to meet their basic needs in order to participate in research, be adequately compensated for their time and participation, in a way that is respectful of local guidelines. Therefore adolescents are often compensated with food or other basic needs (e.g. soap, lunch), not with cash. Conversely, it is critical that the compensation will not be so great or unusual as to be coercive, a determination that is context dependent and requires local input. Furthermore, it is important to take into account that what may be considered non-coercive for other adolescents may be coercive for those who are DVMAAs.

GLOSSARY

<u>Adolescents</u>	Persons aged 10–19 years, as defined by the WHO and UNICEF.
<u>Coercion</u>	The use of unnecessary or excessive influence to encourage someone to take part in a research study.
<u>Contextual variables</u>	Variables that describe the context of a person’s environment as opposed to characteristics of an individual. Contextual variables might include variables on a person’s family, education or economic environment.
<u>Cross-sectional studies</u>	Studies based on data collected at one point in time.
<u>Delphi expert panel</u>	A structured communication technique or method, originally developed as a systematic, interactive forecasting method which relies on a panel of experts who answer questionnaires in two or more rounds.
<u>Disadvantaged, vulnerable and/or marginalized groups</u>	People who, owing to factors usually considered outside their control, do not have the same opportunities as other more fortunate groups in society. Examples include unemployed people, refugees and others who are socially excluded.
<u>Formative research</u>	Preliminary research, often qualitative in nature, that is conducted to answer questions on the design of a study and which is intended to increase the validity of a study.
<u>Generalizable</u>	Findings of a study are generalizable if they can be applied to the population as a whole. Findings may not be generalizable if the study sample was not representative or if a bias existed in data collection or analysis.
<u>Human trafficking</u>	The recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of <u>coercion</u> , abduction, fraud, deception, abuse of power, or a position of vulnerability or the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation.
<u>Immigrants</u>	Persons who permanently reside outside their country of origin.
<u>Incarceration</u>	The state of being legally confined in prison or jail; imprisonment.
<u>Individual-level variables</u>	Variables that describe the attributes of people themselves, as opposed to attributes of their environment.
<u>Longitudinal studies</u>	Studies based on data collected more than once over a period of time.
<u>Mixed methods research</u>	Research that collects and analyses quantitative and qualitative data together in a single study or programme.
<u>Modifiable factors or variables</u>	Variables that describe attributes of a person or their environment that can be changed (for example through education, policy or services).
<u>Morbidity</u>	A measure of disease or disability in a given population.
<u>Mortality</u>	The number of deaths in a given population.
<u>Non-probability sampling</u>	An approach to sampling where all members of a population do not have an equal or known probability of being selected.
<u>Orphans</u>	Children who have lost one or both parents.
<u>Random sample</u>	A sub-set of individuals (a sample) chosen from a larger set (a population), in which each individual has the same probability of being chosen.
<u>Refugees</u>	Persons who have experienced a well-founded fear of being persecuted for reasons of race, religion, membership of a particular social group, or political opinion, and therefore are outside the country of their nationality or unable or unwilling to avail themselves of the protection of that country owing to fear.

<u>Representative sample</u>	A sample of members of a population that share the characteristics of the population as a whole.
<u>Resiliency outcomes</u>	Variables that describe people's success in the face of adversity (as opposed to variables that describe negative outcomes or risk).
<u>Sex work</u>	Activities where one receives money, goods or non-monetary items (such as food, drugs or shelter) in exchange for sexual services, either regularly or occasionally, whether or not the activities are consciously defined as income-generating.
<u>Sexual minorities</u>	People who do not meet gender norms for their biological sex and/or people who do not identify as heterosexual.
<u>Social determinants</u>	The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels.
<u>Stigma; internalized stigma</u>	An attribute that society defines as 'deeply discrediting', spoiling a person's identity and disqualifying them from full social acceptance. Persons experience <i>internalized stigma</i> when they identify themselves as having a stigmatized trait or identity, and see themselves fulfilling the negative stereotypes and assumptions associated with the trait or identity.
<u>Street-based adolescents</u>	Adolescents for whom the street in the widest sense of the word (e.g. unoccupied dwellings, wasteland) more than their family has become their real home – a situation in which there is no protection, supervision or direction from responsible adults.
<u>Target population</u>	The entire group of people the researchers are interested in studying and to whom they would ideally generalize their study findings.
<u>Trauma-informed</u>	An approach or framework that recognizes signs and symptoms of trauma, realizes the widespread impact of trauma, understands the potential paths for recovery, responds by integrating knowledge about trauma into systems, and seeks actively to resist re-traumatization.
<u>Triangulation of findings</u>	The use of multiple sources of data or multiple points of view in order to answer a question when a gold standard method of research is not available – this helps to increase the validity of the findings.
<u>Under-coverage bias</u>	A systematic deviation of the results of a study through lack of sampling or participation of a part of the population.
<u>Under-reporting bias</u>	A systematic deviation of the results of a study due to participants' systematic tendency not to report or share a behaviour or characteristic, often because of a concern about negative consequences or stigma.
<u>Validity</u>	The degree to which the findings of a study are objectively true or correct. Internal validity is the degree to which the findings of a study are correct for the sample that was studied. External validity is the degree to which the findings of a study are correct for the population which the sample is intended to represent.

READINGS FOR FURTHER EXPLORATION

Aitken, S. C. and Herman, T. (2009). Literature Review on Qualitative Methods and Standards for Engaging and Studying Independent Children in the Developing World, *Innocenti Working Paper* no. 2009-05, UNICEF Innocenti Research Centre, Florence. <<https://www.unicef-irc.org/publications/561/>>

Bell, R., Donkin, A. and Marmot, M. (2013). Tackling Structural and Social Issues to Reduce Inequities in Children's Outcomes in Low- to Middle-income Countries, *Innocenti Discussion Paper*, UNICEF Office of Research – Innocenti, Florence. <https://www.unicef-irc.org/publications/pdf/marmot_layout5.pdf >

Innovations for Youth (I4Y): <<http://i4y.berkeley.edu/>>

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