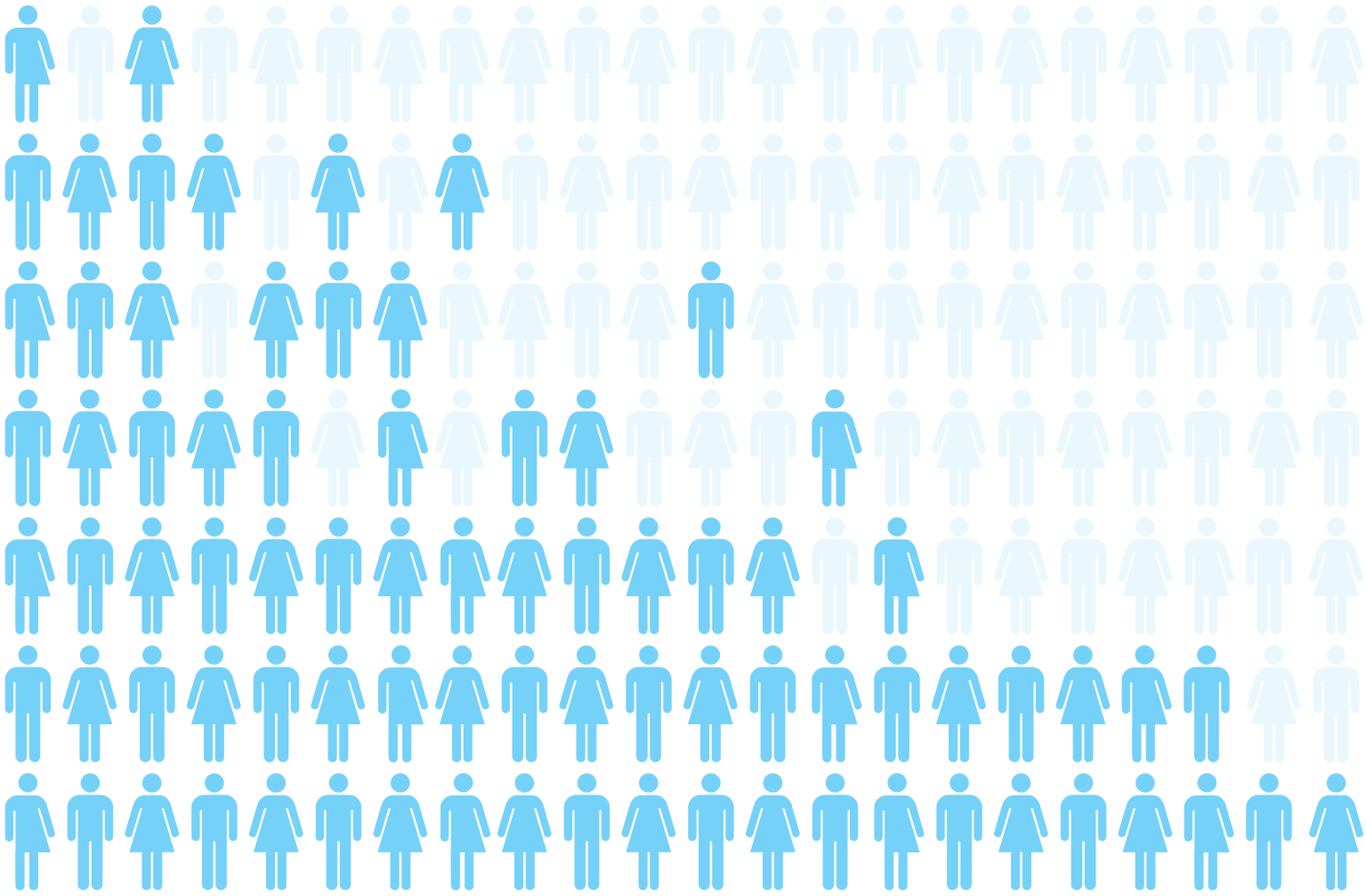
Global HIV Strategic Information Working Group

Biobehavioural Survey Guidelines

For Populations At Risk For HIV



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Foreword

To address a public health problem, you first have to measure it accurately. Biobehavioural surveys have proven to be invaluable tools for measuring and addressing HIV, which remains the world's biggest public health challenge. This current iteration of the *Biobehavioural survey guidelines* is a welcome addition to the list of useful documents targeting those who plan to conduct biobehavioural surveys of HIV and HIV-risk behaviours in their countries. The guidelines can be applied across different countries, and to this end the document provides questionnaire modules that can be adapted to various contexts. The guidelines are presented in a logical and coherent manner, covering all survey aspects, from conceptualization of the survey to dissemination of the report and data use.

The major focus is on key populations, which are often hidden and difficult to measure as part of general population-based surveys. This is particularly important because key populations are at high risk for HIV, and for exclusion from HIV and other health services. Estimating the size of these populations and their burden of HIV disease is extremely challenging, and these guidelines are a valuable resource for survey specialists as they undertake the surveys.

The guidelines fill a gap in providing tools for surveying HIV prevalence in key populations, and the included questionnaires may also inform general population surveys. The 2000 Behavioural Surveillance Survey guidelines, while still useful, needed to be updated with newer survey methodology techniques and to incorporate biomarker testing. The guidelines will also serve as a textbook for students interested in working for research institutions that embark on epidemiological surveys.

Currently, many researchers undertake surveys using country-specific indicators. These guidelines standardize the conduct of biobehavioural surveys to permit comparisons between as well as within countries over time. The use of common indicators allows for uniformity in the measurement of items and production of data that can be used by various global, regional, national and local actors in planning prevention and treatment services, tracking progress in the provision of HIV prevention and treatment services, and identifying gaps in access to services. The appendix on indicators will help scientists and data specialists to harmonize data management with a view to collaborating across countries using common yardsticks.

The authors of these guidelines considered key aspects of surveys, from survey planning, design, data collection, analysis, presentation of results and dissemination of reports to data use. These guidelines are a must-have for anyone planning to conduct surveillance, whether experienced or not. It is our hope that the guidelines will help to refine measurement of HIV and help countries to address the unmet needs of their communities, to further reduce the toll of the epidemic.

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Preface

Biobehavioural surveys (BBS) provide specific population-level estimates for the burden of HIV disease and HIV-related risk factors, and estimates for the coverage of prevention and treatment services for populations at increased risk for HIV. These key populations include men who have sex with men, sex workers, people who inject drugs, transgender individuals, prisoners and other vulnerable populations at increased risk for HIV infection. For many of these stigmatized and socially marginalized populations, there are no conventional sampling frames, meaning that complex sampling designs are needed for these populations. The most frequently used survey guidelines and tools to date are the *Behavioral surveillance surveys*, issued in 2000. However, new HIV prevention, care and treatment policies – coupled with the emergence of new data needs, methods and technologies – warranted a thorough update of the 2000 publication. Thus, the US Centers for Disease Control and Prevention, FHI 360, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) are publishing these new *Biobehavioural survey guidelines for populations at risk for HIV*. This revised publication outlines the latest approaches and methodologies, and includes updated questionnaires for planning and conducting BBS.

The new BBS guidelines are a comprehensive resource that covers all survey aspects, from conceptualization, planning, undertaking and costing of the survey to dissemination of a report and use of data. The ultimate goal of these guidelines is to facilitate the collection of high-quality survey data for informed public health action.

The new guidelines:

- update the overall approach and methodology of BBS in light of advances made during the past two decades;
- improve the quality of BBS by providing comprehensive guidance, particularly for sampling methods and the collection of interview and biomarker data;
- increase the relevance of survey data for public health programming by ensuring the collection of representative and actionable data; and
- promote the use of survey findings to improve service delivery, monitoring and evaluation, and policy development.

This document includes several new topics and features:

- formative assessment covers the initial collection of information about a population, to inform how best to prepare and conduct a BBS.
- respondent driven sampling covers this peer-driven chain-referral sampling method, which is particularly useful for hard-to-sample populations, and is currently viewed as the most suitable probability-based sampling design.
- biomarker considerations covers the entire range of biological measurements, from HIV serology to viral load, HIV recency, and biomarkers of other sexually transmitted infections. The document emphasizes the potential of population-level, aggregate viral-load metrics, such as prevalence of unsuppressed viral load.
- population size estimation provides guidance on using integrated methods to estimate the number of members of a population.
- questionnaire modules are included for collecting data on a wide range of topics, including exposure to and uptake of HIV-related services. Accompanying this publication will be electronic ready-to-use questionnaires, with the aim of keeping the questionnaires up-to-date as standards and indicators change.
- indicators appendix lists standard and newly proposed indicators for both data and biomarker-related metrics.

These guidelines, built on the lessons learned by experts and implementers from around the world, are intended to serve as a one-stop resource for survey planning and implementation, and dissemination of findings. They are expected to improve the quality of survey data through better survey design and implementation, and to promote the standardization of data measures to improve the comparability of survey data. Most of all, the guidelines should make it easier to plan and conduct BBS. By providing sample documents and guidance on every step of the process, we hope that these guidelines strengthen the capacity of public health workers to collect the information they need in a timely manner, allowing for an effective and strategic response to stop the HIV epidemic among key populations.

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Abbreviations and Acronyms

ACASI	audio computer-assisted self-interview
ART	antiretroviral therapy
ARV	antiretroviral
BBS	biobehavioural survey
CAB	community advisory board
CAPI	computer-assisted personal interview
CASI	computer-assisted self-interview
CCS	conventional cluster sampling
CDC	Centers for Disease Control and Prevention
CI	confidence interval
CRC	capture-recapture method
CT	*Chlamydia trachomatis*
DBS	dried blood spot
DEFF	design effect
DFA	direct fluorescent antibody
DNA	deoxyribonucleic acid
EIA	enzyme immunoassay
EMoS	estimated measure of size
EPS	equal probability sampling
FSW	female sex worker
FP	family planning
GoC	game of contacts
HBV	hepatitis B virus
HCV	hepatitis C virus
HIV	human immunodeficiency virus
HPV	human papillomavirus
HSRC	Human Sciences Research Council
HSV-2	herpes simplex virus-2
ID	identification number
IEC	information, education and communication
IRB	institutional review board
MoS	measure of size
MSM	men who have sex with men
NAAT	nucleic acid amplification test
NG	*Neisseria gonorrhoeae*
NGO	nongovernmental organization
PCR	polymerase chain reaction
PEP	post-exposure prophylaxis
PMTCT	prevention of mother-to-child transmission
PPS	probability proportional to size
PrEP	pre-exposure prophylaxis
PSU	primary sampling unit
PWID	people who inject drugs
QA	quality assurance
QDS	Questionnaire Development System
REC	research ethics committee
RDS	respondent-driven sampling
RNA	ribonucleic acid
RPR	rapid plasma reagin
RS	random start
RT	rapid test
SOP	standard operating procedure
SI	sampling interval
SRS	simple random sampling
STD/STI	sexually transmitted disease/sexually transmitted infection
SW	sex worker
TB	tuberculosis
TG	transgender person
TLS	time-location sampling
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UPC	unique participant code
VDRL	venereal disease research laboratory
VL	viral load
WB	western blot
YCS	Y chromosomal sequences

Table of Contents