

# Guidelines for Collection of Strategic Information on HIV among Gay Men and Other Men Who Have Sex with Men and Trans People in the CEECA Region

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#### **List of Abbreviations**

AIDS Acquired immune deficiency syndrome

ART Antiretroviral medication for HIV

**CEECA** Central and Eastern Europe and Central Asia

**CSO** Civil society organization

**DHS** Demographic and Health Survey

**ECOM** Eurasian Coalition on Male Health

Gay men and other MSM Gay men and other Men who have Sex with Men

**GFATM** Global Fund to Fight AIDS, Tuberculosis and Malaria

**HA** Health Accounts

**HIV** Human Immunodeficiency Virus

**IBBS** Integrated Bio - Behavioral Surveillance

ICT Information and communications technology

**KP** Key Population

**LGBTQI** Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and Intersex

NASA National AIDS Spending Assessments

NGO Non-governmental organization

**PLH** Person or people living with HIV

**PrEP** Pre-exposure prophylaxis

**RAGSI** Regional Advisory Group on Strategic Information

**SE** Size estimation

SI Strategic Information

**SRHR** Sexual and Reproductive Health and Rights

**STI** Sexually transmitted infection

**VCT** Voluntary counseling and testing (largely for HIV)

#### **Main Definitions**

**Strategic information:** Information that is interpreted and used for planning and decision-making to improve the direction and focus of a program. Relevant data may be derived from a wide variety of sources (for example, monitoring systems, evaluations, program reviews, surveys and case studies) and should be analyzed holistically and strategically to improve the direction of the program.

Gay men and other men who have sex with men (Gay men and other MSM) refers to all men who engage in sexual and/or romantic relations with other men. The words "men" and "sex" are interpreted differently in different cultures and societies and by the individuals involved. This term encompasses the wide variety of settings and contexts in which male-to-male sex takes place, regardless of the motivation for engaging in sex, self-determined sexual and gender identity, and identification with specific communities or social groups.

**Trans people i**s an umbrella term for people whose gender identity and expression do not conform to the norms and expectations traditionally associated with the sex assigned to them at birth; it includes people who are transsexual, transgender or otherwise gender non-conforming. Transgender people may self-identify as transgender, female, male, transwoman or transman, trans-sexual or, in specific cultures, as hijra (India), kathoey (Thailand), waria (Indonesia), mahu, fa'a fafine and fakaleiti (Pacific Island) or one of many other transgender identities. They may express their genders in a variety of masculine, feminine and/or androgynous ways. The high vulnerability and specific health needs of transgender people necessitate a distinct and independent status in the global HIV response. This population is often socially excluded, leading to a reliance on transactional sex as a means of economic survival, with consequent increased risk of exposure to HIV.

#### Introduction

Gay men and other men who have sex with men (MSM) have long been recognized as a population at increased risk of HIV transmission in the world. The situation of trans people in the region of Central and Eastern Europe and Central Asia (CEECA) is especially concerning. According to a recent UNAIDS report<sup>1</sup>, globally, gay men and other MSM accounted for 18% of new infections in 2017, while in the region of Eastern Europe and Central Asia (EECA) this figure is 21%. The data from the UNAIDS report confirms the information collected in ECOM's epidemiological survey "HIV among MSM in Eastern Europe and Central Asia", which found that HIV prevalence among MSM in EECA continues to increase and has already reached the level of a concentrated epidemic in most countries of the region<sup>2</sup>.

Although MSM are recognized as a key population (KP) in most national HIV programs in the region, national budgets allocate little to no resources to HIV interventions that target MSM. In most CEECA countries, there are only a few HIV prevention services targeting MSM. These services are primarily available in major urban areas and are mainly funded by international donors, particularly the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM)<sup>3</sup>.

It is obvious that the gap between the needs and the coverage of services for MSM and trans people is one of the widest among KP in the region. The HIV cascade fails MSM and trans people in CEECA at every stage of the HIV continuum of care: from a realistic and credible estimate of the population sizes of MSM and trans people, to the number reached by HIV prevention services, to the number of people living with HIV (PLH) from these populations that know their status, to the proportion of HIV-positive MSM and trans people enrolled in clinical monitoring, to the proportion of those on antiretroviral therapy (ART), to the proportion of those achieving viral suppression. The ambitious 90-90-90 targets, established by UNAIDS<sup>4</sup>, will not be achieved by 2020 in the CEECA region unless programming for MSM and trans people is drastically improved.

The situation with respect to trans people and HIV in CEECA is even more concerning. There is virtually no data on the HIV epidemic among this group in the region. Although trans people are recognized at the global level as a KP in the HIV response, they are not included separately or as a subgroup of another KP in most national HIV/AIDS programs in CEECA.

Throughout CEECA, the quality of data available to monitor and evaluate responses to HIV remains inadequate. Size estimations (SE) of the populations of KP are often sub-standard, due to inadequate sampling methodologies and, in some cases, political motivations to downplay the existence of certain subgroups. In addition, much data on access to services along the continuum of care cannot be disaggregated by KP, gender, or by other important demographical characteristics<sup>5</sup>. In some settings, there are significant challenges to developing a harmonized picture that shows services provided by both governmental and non-governmental entities. Unique identifier codes employed by NGOs to track clients are rarely harmonized with government records of patients, making it impossible to determine whether individuals receiving prevention or community-based testing services are ever effectively linked with care and treatment services, thus limiting the availability of robust data on the continuum of care.

The situation is aggravated by the fact that gay men and other MSM and trans people are often socially marginalized due to cultural, religious and socio-political factors, which lead to the denial of their health-related rights and other needs. Gay men and other MSM and trans people in this region are often driven underground by severe stigma, discrimination and even persecution. Thus, a combination of factors, including the lack of reliable data, ineffective national policies, inadequate funding, stigma and discrimination, human rights violations, and a lack of community involvement, explains why the current response to HIV in CEECA is failing two of the most vulnerable groups, MSM and trans people<sup>6</sup>.

<sup>&</sup>lt;sup>1</sup> http://www.unaids.org/sites/default/files/media\_asset/miles-to-go\_en.pdf

<sup>&</sup>lt;sup>2</sup> https://ecom.ngo/en/eeca\_unaids-data/

<sup>&</sup>lt;sup>3</sup> http://ecom.ngo/wp-content/uploads/2015/09/ECOM\_EECA\_RegProg\_descr\_ENG.pdf

<sup>&</sup>lt;sup>4</sup> UNAIDS. Fast Track: World AIDS Day Report 2014. Geneva, 2014

 $<sup>\</sup>label{lem:continuous} \begin{tabular}{ll} $^5$ http://www.harm-reduction.org/sites/default/files/pdf/eeca\_position\_document\_hlm.pdf \end{tabular}$ 

<sup>6</sup> http://ecom.ngo/wp-content/uploads/2016/01/ECOM.EECA-Reg-Prog-Desc-ENG.pdf

#### **Using This Document**

Given the factors mentioned above, it is extremely important to have reliable and well-analyzed strategic information on HIV among gay men and other MSM and trans people. During the last several years, a number of publications have been released in which strategic information (SI) on health and HIV have been examined (see reference list). In 2017, the first-ever "Assessment of Existing Strategic Information on HIV among MSM and Trans People in Armenia, Belarus, Georgia, Kyrgyzstan, and Macedonia" was developed with the support of ECOM under its GFATM-funded regional program. In 2018, the same assessment was carried out in Estonia (See the assessment tool in Annex 1).

Based on a review of existing literature and the recent assessments conducted, it was decided to create these guidelines in order to combine and adapt all relevant information regarding SI on HIV among gay men and other MSM and trans people into one structural and compact document. The document will be useful for researchers, people involved in planning, implementing, and managing HIV programs, NGOs and community-based organizations working in the field of HIV prevention, as well as for community activists and LGBTQI advocates.

#### Acknowledgement

The development of these guidelines would not have been accomplished without the active involvement of members of the Regional Advisory Group on Strategic Information (RAGSI)<sup>9</sup>, which is made up of representatives of NGOs, community organizations, international organizations, and academia working in the CEECA region. This document was discussed and approved as a guiding document for collecting SI on HIV among gay men and other MSM and trans people during a RAGSI meeting that took place on September 17-18 in Minsk, Belarus (a list of RAGSI members can be found in Annex 2).

# Why Collect Strategic Information?

Strategic information is information collected to inform policy and program decisions. The axiom "Know your epidemic, know your response" characterizes the SI necessary for the response to HIV. It recognizes that epidemics and their contexts differ from place to place. Knowing who is affected, how they became infected and where they are, is crucial. Thus, researchers, and those collecting and interpreting data should focus their efforts on the right people, in the right places, with the right practices 10 (Table 1. Three R's principles).

Table 1. Three R's principle- Right people, right place, right practices

Right People	Gay men and other MSM, trans people, young people etc.
Right Place	Priority areas, such as major metropolitan areas, rural areas etc.
Right Practices	Community-based HIV testing, HIV self-tests, PreP, early ART, etc.

An effective response to HIV at the country level requires SI that is systematically collected and consolidated, analyzed and applied. SI must go beyond basic epidemiological data to address service access, coverage, quality and acceptability. It needs to support quality services along the cascade of health services.

SI should also lead to a deeper understanding of the context of the epidemic, such as the vulnerability of certain communities, the risks to which certain individuals and populations are exposed, and the options for actions to alleviate the burden of HIV and mitigate its impacts.

<sup>&</sup>lt;sup>7</sup> Assessment of Existing Strategic Information on HIV among MSM and Trans people in Armenia, Belarus, Georgia, Kyrgyzstan, and Macedonia. 2017

<sup>&</sup>lt;sup>8</sup> Assessment of Existing Strategic Information on HIV among MSM and Trans people in Estonia. 2018

<sup>&</sup>lt;sup>9</sup> Regional Advisory Group on Strategic Information (RAGSI) on HIV among Gay men and other MSM and Trans people in CEECA with a focus on Armenia, Belarus, Georgia, Kyrgyzstan, and Macedonia (but not limited to) was established to assess the quality of existing data on HIV among gay men and other MSM and trans people in the region, as well as to develop, monitor and/or analyze guidelines, protocols and survey results in order to improve the quality of existing SI

<sup>&</sup>lt;sup>10</sup> https://obamawhitehouse.archives.gov/blog/2015/07/30/2020-vision-our-updated-national-hivaids-strategy

Public health efforts are only as sound as the evidence on which they are based. Proven prevention and treatment initiatives must be strategically focused on the populations and settings in greatest need, and these programs need to be tailored to address the specific needs and circumstances of each target population. For groups at high risk of HIV infection, countries need timely, robust and reliable data on the size of each population, the burden of HIV (including prevalence and incidence), the prevalence and nature of behaviors that increase HIV risk and vulnerability, coverage of key HIV prevention and treatment services, and on social and structural factors that affect HIV risk and the utilization of key services. National surveys have long provided critical SI on HIV prevalence, sexual risk behaviors, HIV testing, and data regarding general populations in the EECA region. However, these national surveys yield no meaningful information about gay men and other MSM and trans people.

As gay men and other MSM have long been recognized as an important factor in national epidemics in the region, some form of SI regarding MSM is being provided by countries. However, some countries have failed to provide necessary information or have not provided any information at all. Understanding the size and HIV prevalence for each KP is critical for service planning and estimating service coverage. A number of countries have used integrated bio-behavioral surveys (IBBS) to generate useful SI on HIV risk behaviors, HIV burden, service utilization and the experience of stigma or discrimination among men who have sex with men. However, no reliable surveys have been carried out in the region to gather data on trans people<sup>11</sup>.

# Guiding Principles for Collecting Strategic Information<sup>12</sup>

- **Simple to generate**, by relying on data from a minimal set of core indicators.
- Easy to use and interpret by a variety of implementers, with minimal outside technical assistance.
- Adaptable, according to the data needs at program, local, provincial, or national levels.
- **Consistent**, by using the same set of recommended indicators and clearly outlining the location, time period, and population represented in the analysis.
- **Supportive of data use** that strives to continually improve the HIV service system.
- Constructed with the active participation and leadership of key populations throughout the development, collection, analysis, presentation, and use of data.

## **Use of Strategic Information at Various Levels**

With the overall goal of optimizing programs and maximizing their benefits for affected populations (including gay men and other MSM and trans people), SI on HIV plays three roles:

- 1. To understand the epidemic and the extent of change resulting from interventions;
- 2. To track and measure the health sector's response to HIV, particularly the health system inputs, intervention coverage, quality of services, and outcomes and impact;
- 3. To inform program improvement, assuring quality and maximal return on resources invested and helping to identify bottlenecks and opportunities.

SI provides the critical evidence that policy-makers, program directors and line managers need to make informed decisions to improve programs. Some examples include:

 Tracking ART expansion following revision of national ART eligibility criteria by monitoring the number of people initiating ART at various CD4 levels;

<sup>&</sup>lt;sup>11</sup> UNAIDS RST EECA, Presentation "HIV epidemic in EECA region" at the Regional Consultation on the Integration of Human Rights in National HIV Plans. Yerevan, March 2015

<sup>&</sup>lt;sup>12</sup> http://www.fhi360.org/sites/default/files/media/documents/linkages-hiv-cascade-framework-oct15.pdf

- Identifying opportunities for prevention services along the health sector cascade, for those testing positive for HIV and for those testing negative, as well as by population and location;
- Routinely reviewing retention on ART over time at the facility level to improve efforts to keep patients in care, and conducting special studies to investigate drop-outs from care;
- Assembling data on HIV testing uptake from various approaches and venues (for example, testing campaigns, voluntary counseling and testing (VCT), community outreach testing etc.) to determine which strategies are most effective for increasing HIV testing, and case identification among MSM and trans people;
- Monitoring the cascade of HIV care and treatment among gay men and other MSM and trans people to identify gaps, and estimating the potential for improvements in the cascade of services;
  Etc.

The clear weight of the evidence provided by SI has given decision-makers the courage to go forward even where some sectors of society have opposed certain initiatives. For example, condom use proved to be effective at reducing HIV transmission, and so almost all countries have launched condom programs. SI and evidence is often the critical basis necessary for negotiating difficult programmatic issues in countries and among partners with different approaches.

The rapid growth of treatment programs over the past decade has underscored the importance and role of SI for program planning and evaluation. Documenting impact is crucial to the focus and sustainability of programs; indicators of program outcomes, including retention in treatment and viral load suppression, are particularly important. However, such program expansion has generated more indicators, partly to meet funding requirements, but also to support quality services, and has increased the reporting burden on health-care workers. Proper guidance and establishing a minimal set of indicators/data for collection of high quality SI (Table 2) should help to reduce that burden.

Table 2. List of the minimal set of indicators/data for collection of SI

	Indicators selected
People living with HIV	Number and % of people living with HIV
MSM and trans SE	Estimated size of KP
Health spending on HIV	Proportion of national health budget allocated to HIV
programs	
Spending on HIV programs	Proportion of total HIV spending allocated to
targeting MSM and trans people	prevention/treatment programs targeting MSM and trans people
HIV testing coverage of MSM	% of people from KP who received an HIV test in the last 12
and trans people	months and who know the results
ART coverage of MSM and	% of KP living with HIV who are receiving ART
trans people	
Viral load suppression	% of KP living with HIV who are on ART and have achieved a
1,100	suppressed viral load
HIV prevalence among MSM and trans people	% of members of KP who are infected with HIV
Experience of MSM and trans	% of members of KP who experienced discrimination by health
people with discrimination by	workers
health workers	
Condom use among MSM and	% of men reporting condom use during last anal sex with a male
trans people	partner
Knowledge about HIV among	% of MSM and trans people who correctly
MSM and trans people	identify ways of preventing the sexual transmission of HIV and
D. CD	also reject major misconceptions about HIV transmission
PrEP coverage	% using PrEP among KP
PEP availability	Percentage of health facilities with post-exposure prophylaxis
	available for MSM and trans people

While governments have the overall responsibility for SI systems, NGOs, communities and civil society as a whole should, in a spirit of transparency, have access and contribute to the collection, analysis and use of this information as a global public good. The dissemination and sharing of SI within and among nations promote both understanding of the dynamics of epidemics as well as a

consensus about how best to respond to HIV issues among gay men and other MSM and trans people. In addition, the consistency and availability of information are central to the accountability and transparency of decisions in the health sector. These decisions are further strengthened by analysis and regular formal review of the data with the involvement of key stakeholders and communities in order to improve programs. Overall, the use of SI on HIV should lead governments, civil society organizations (CSO), community organizations, donors and United Nations agencies (particularly UNDP, WHO, UNAIDS and UNFPA) to increase efforts to better understand the situation and to coordinate better programing of actions at the national, subnational and global levels<sup>13</sup> (Table 3).

Table 3. Use of SI at service, national/subnational and global levels

Level		use			
Service level (for health-	>	Ensuring good clinical patient management (service quality)			
-					
care providers)	<i>&gt;</i>	Monitoring drop-outs from care			
		Monitoring HIV drug resistance			
	$\triangleright$	Monitoring access to and coverage of services for MSM and			
		trans people			
	$\triangleright$	Improving facility management			
	$\triangleright$	Establishing accountability for work			
National and subnational	$\triangleright$	Developing program targets and linkages between HIV			
levels (for health program		testing and ART services			
managers)	$\triangleright$	Adjusting the focus of outreach interventions and			
, ,		programming for MSM and trans people			
	>	Estimating the number of HIV-positive MSM and trans people			
		for targeting HIV prevention/treatment programs			
	>	Projecting needs based on current use of services			
	<b>A</b>	Measuring the equity of services			
	<b>A</b>				
		Developing business plans			
	>	Informing policy			
		Informing resource allocation			
	<b>\(\rightarrow\)</b>	Evaluating interventions/innovations/pilot tests			
Global and national levels	$\triangleright$	Monitoring impact: national or subnational incidence,			
(for ministries of health,		prevalence, mortality trends among MSM and trans people			
international health	$\triangleright$	Measuring outcomes: coverage and access			
programs and agencies)	>	Costing calculations			
	>	Lives-saved calculations			
	>	Triangulating data for projection of unmet needs/modeling			

# **Ensuring Data Quality**

A wide range of policies and process are needed to ensure data quality. One guiding principle is to reduce the necessary amount of information to a "minimum dataset". This will then reduce the burden of data collection, which alone should improve data quality. Other management actions to improve data include regular local quality control and data-use checks, the use of clear definitions of data elements, up-to-date training, and frequent feedback for data collectors and users. When electronic communication facilities are available, data can be entered at decentralized locations to provide immediate reporting to all levels<sup>14</sup>.

Strong SI systems ensure that data meets high standards of reliability, transparency and completeness. It is important to assess source data and the statistical techniques and estimation methods used to generate indicators. The following criteria can be used to assess the quality of HIV-related SI among MSM and trans people (Table 3).

#### Table 3. Criteria for Quality of SI

<sup>&</sup>lt;sup>13</sup> Framework and standards for country health information systems / Health Metrics Network, World Health Organization.

<sup>– 2</sup>nd ed. 2012

<sup>&</sup>lt;sup>14</sup> Assessing the National Health Information System: An Assessment Tool. WHO. 2008

Timeliness	The period between data collection and its availability on a		
	wider level, or its publication		
Periodicity	The frequency with which an indicator is measured		
Consistency	The internal consistency of data within a dataset as well as		
	consistency between datasets and over time; and the extent		
	to which revisions follow a regular, well-established and		
	transparent schedule and process		
Representativeness	The extent to which data adequately represents the		
	population and relevant subpopulations		
Disaggregation	The availability of statistics stratified by sex, age,		
	socioeconomic status, major geographical or administrative		
	region and ethnicity, as appropriate		
Confidentiality, data security	The extent to which practices are in accordance with		
and data accessibility	established standards (may differ from country to country)		
	for storage, backup, transfer of information (especially over		
	the Internet) and retrieval.		

## **Transforming Data into Information**

Although data is the raw material, it has little essential value in and of itself. Only after data has been compiled, managed and analyzed does it produce SI. Information is of far greater value, especially when it is integrated with other information and evaluated in terms of the issues confronting the health system. At this stage, information becomes evidence that can be used by decision-makers. This synthesis of evidence becomes even more powerful when it is formatted for presentation, communication or dissemination to decision-makers in a form that changes their understanding of health issues and needs. This is the process of transforming evidence into knowledge, and once applied can result in decisions which will have a direct impact upon health and health equity among KPs<sup>15</sup>.

At present, the necessary data for HIV-related SI in many low- and middle-income countries tends to be "data-rich" but "information-poor". This is a consequence of the belief that data can be used directly for decision-making without a value-added approach. In reality, raw data alone is rarely useful. The point of SI is not just to generate high-quality data and hope that it will be used, but to convert it into credible and compelling evidence that informs local health system decision-making. High-quality data stored in a well-structured repository is of little value if it cannot be accessed by users to generate information for decision-making.

If data is extracted and then integrated into a data repository, it can be synthesized and triangulated with other sources and compiled into usable statistics and information for deeper analysis and comparison. A key aspect of this is the integration, synthesis, analysis and interpretation of information from multiple sources, examining inconsistencies, and identifying and accounting for biases.

Such analysis provides estimates (such as knowledge of disease burden, risk-behavior patterns, health service coverage, testing coverage, trends in indicators, etc.). These can then be made available through user dashboards, reports, queries and alerts. Such formatting or packaging of information for decision-makers is a core function of the SI system in demonstrating the value of the data it contains. There have been many recent innovations in information and communication technology (ICT) in preparing complex information and evidence in formats that can catch the attention of decision-makers and effectively communicate the messages embodied in the information. Some approaches take advantage of web- or computer-based access to repository or observatory data displayed in an interactive format. Some new computerized analysis tools generate standardized reports rich in graphical (and even cartographical) representation of information. Standardized reporting formats, profiles and briefs are also highly effective. Such formats should guide decision-makers by providing interpretations based on the potential

<sup>&</sup>lt;sup>15</sup> Framework and standards for country health information systems / Health Metrics Network, World Health Organization.

<sup>- 2</sup>nd ed. 2012

consequences of alternative decisions and scenarios. Information can also disseminated through workshops, medical journals, peer meetings and the media.

Once the collected data has been converted into SI, it should be used regularly at meetings and displayed where staff and the public can see it. Following such use, the SI and its quality and usability can gradually be improved by a cyclical learning process. Hands-on experience can identify problems, define new needs and add features to be refined and improved upon in the next cycle.

Establishing an information architecture as a shared resource at national, subnational and district levels is an essential step in improving information practices and enabling the necessary high-quality analyses. It is from this level of analysis that results are used for policy development and strategic planning. Such analysis, interpretation and advocacy do not take place spontaneously. They require the formatting, communicating and dissemination of evidence in a format and language accessible to senior level policy and executive decision-makers – a generally neglected aspect of most health information systems.

# **Use of Strategic Information for Decision-Making**

SI on HIV among MSM and trans people can be used at various levels of health system management, planning, advocacy and policy development. Each level has a broad range of users from different technical disciplines and vocations with associated vocabularies and communication methods. A principle of SI is that country information should be made a core part of the day-to-day management of health system planning and delivery. Thus, access and use should be integral to activities aimed at strengthening the health information system.

The dynamic links between demand, supply and quality of information should be addressed by encouraging a culture in which SI is demanded and its use promoted. In practical terms, this will require the establishment of institutional mechanisms and incentives to create a culture of evidence-based decision-making. Experience shows that the most effective mechanisms involve linking data/information to actual resource allocation (budgets) and developing indicator-driven planning.

After the packaging and communications stage, SI should be used for decision-making. However the capacity for data analysis is often lacking at peripheral levels where the data is generated and results should be used for planning and management (especially at community levels). Bringing together a comprehensive analysis of the health situation and trends with data on health inputs (such as health expenditure and system characteristics) is particularly important. Developing such analytical capacity requires planning, investment and tools.

One important function of the SI system is to connect data production with its use. Those responsible for collecting data should also benefit from its use. Users comprise those delivering care and managing and planning health programs. More broadly, users include those financing health-care and HIV prevention programs both within countries (health and finance ministries) and externally (donors, development banks and technical support agencies etc.). Decision-making around country health priorities necessarily involves the wider community (including civil society and communities of KP, such as LGBTQI communities, etc.), as well as policy-makers at senior levels of government.

Among the many advantages of developing a culture of evidence-based decision-making is that diverse types of users can all benefit from SI in line with their own needs and requirements. HIV program planners and managers responsible for tracking epidemiological trends, and the response of the health system generally, need more detailed data than policy-makers who require it for broader strategic decision-making and investments<sup>16</sup>.

<sup>&</sup>lt;sup>16</sup> Consolidated strategic information guidelines for HIV in the health sector. WHO. 2015

# Guiding Principles for Strategic Information System Development

Implementation of the HIV-related SI Framework should be based upon a set of common principles<sup>17</sup>:

#### Principle of country leadership and ownership

The process of strengthening country HIV-related SI systems should be focused on empowering countries to undertake broad health system strengthening activities. It is therefore essential that any given national leadership is engaged and owns the implementation process. The role of partners will be to offer flexible support, information and guidance, as well as to actively engage in the process of harmonizing SI, which has been globally informed by country experience.

#### Principle of responding to country needs and demands

Strengthening country HIV-related SI systems should always begin with a recognition of the need for this process by the country itself. The process should then focus on the needs of SI users. It is important that implementation takes into account what can be achieved within the framework of available resources and capacities. A comprehensive vision of SI should:

- Address institutional and organizational constraints (including human and financial resources);
- Serve as a coherent framework for international support in improving SI on HIV;
- Be flexible enough to adapt in response to changing needs.

#### Principle of building upon existing initiatives and systems

Wherever possible the implementation process should build upon existing initiatives, systems and knowledge. Strengthening of SI should not take place in a vacuum but should be linked to (and build upon) similar initiatives, especially national and international strategies for the development of statistics. Coordination mechanisms for the strengthening process should use any appropriate existing structure, and initial assessments of the health information system should draw on all available information.

#### Principle of building broad-based consensus and stakeholder involvement

Broad-based consensus-building is a crucial first step because much of the data needed by the health sector is generated by other sectors, and the resources required to strengthen health information systems generally come from constrained national budgets. Although the input of external partners and donors is initially important to catalyze action, countries themselves must sustain the necessary longer-term investments.

#### Principle of a gradual and incremental process with a long-term vision

The process of improving SI is best approached as a gradual and incremental process. It is generally more effective to deal with one aspect of the system at a time (such as a subsystem for disease surveillance or household surveys) or to address a specific need (such as introducing indicators related to HIV/AIDS). Once improvements have been secured, the strengthening process can then identify a further set of priorities for action. Whether the scope is narrow or broad, the long-term goal should be a balanced, coherent and comprehensively developed health information system. This will require consistent long-term investment.

<sup>&</sup>lt;sup>17</sup> http://www.who.int/healthinfo/country\_monitoring\_evaluation/who-hmn-framework-standards-chi.pdf

The overall HIV response has reached millions of people with HIV services. However, there are specific populations like MSM and trans people that still have high number of unmet needs. Monitoring HIV disease burden and coverage of related services by age, sex, and other characteristics will assist with better focusing services for the KP who need them most and with monitoring equity<sup>18</sup>.

Disaggregation is the separation of data into component parts in order to identify and highlight differences within data aggregates. Disaggregation makes it possible to focus a country's responses on the people, places and situations where they will achieve impact. At regular intervals, data should be disaggregated by sex, age, KP and location (e.g. subnational or site level). Disaggregation of indicator data provides the information needed to tailor responses to the specific epidemic situation and the populations that are most affected. Disaggregation of data is especially critical to guiding the response to HIV among MSM and trans people. This approach helps countries to target their investments more strategically, and ensure that marginalized or populations at higher risk for disease are being reached with services<sup>19</sup>. While it is not cost-effective to capture disaggregated data for all indicators, it is recommended to disaggregate for key strategic areas. Data is most commonly disaggregated by KP and location, which was also done while assessing the SI on HIV among MSM and trans people in the EECA region.

#### **Disaggregation by Key Population**

KP are groups of people who are at increased risk for HIV across epidemic settings due to specific behaviors. Legal and social barriers further contribute to their vulnerability. Overall, the risk behaviors and vulnerabilities of KP and their networks greatly affect the dynamics of all types of HIV epidemics. MSM and trans people are especially vulnerable and are the focus in this document.

Due to their higher risk of HIV transmission and the presence of barriers to prevention and care services, KP require services that are specifically tailored to their needs. Disaggregating indicators by KP enables programs to specifically monitor and evaluate the epidemic and the response for each relevant population group.

SI about MSM and trans people and about PLH, whether they are from KP or not, must be collected and stored securely. A breach of the confidentiality of this information may not only jeopardize future data collection and seriously damage people's trust in the health services system, but may even put people's well-being and lives at risk if they are subjected to social stigma or legal repression. Thus, the utmost care must be taken to ensure confidentiality, security and the participation of KP in data collection efforts.

#### **Disaggregation by Location**

To better understand the epidemic and to focus services to respond effectively, disaggregation by location is crucial to the effectiveness of the health sector response to HIV. Collecting, analyzing and disaggregating data by the geographical location of HIV transmission and of service coverage and uptake provides valuable information for HIV program managers. High rates of HIV transmission, morbidity and mortality are often concentrated in specific locations. Data collection and analysis should also be sensitive to emerging geographic trends, such as increasing prevalence along a transportation route. Disaggregation by location also allows tracking of access to and use of services in selected locations over time, such as HIV testing services or other types of care. Location information can reveal possible inequities in access to and use of services affecting KP or environments (for example, rural, urban or suburban), thereby drawing greater attention to underserved communities. Conversely, finding better program performance in particular locations could spotlight innovative prevention, care and treatment activities, from which the entire program could learn. Mapping exercises have also been important for focusing outreach and prevention services on specific sites, places and populations.

<sup>18</sup> https://www.ncbi.nlm.nih.gov/books/NBK299491/

<sup>&</sup>lt;sup>19</sup>https://www.theglobalfund.org/media/5198/me\_monitoringandevaluation\_brochure\_en.pdf?u=636723359670000000

# Confidentiality of Strategic Information on Key Populations

MSM and trans people face significant stigma and discrimination and are often subject to punitive laws and penalties. There have been some instances in different countries of authorities using information from mapping exercises to conduct raids or arrest members of KP.

Members of KP commonly have increased concerns about the reliability and safety of data collection and may not readily see advantages to participating in efforts to collect SI. Engaging the community, their organizations and leaders to be fully involved in surveys can improve trust. At the same time, confidentiality must be maintained. Policies and resources need to be in place to protect the confidentiality of any data with personally identifying information, including patient medical records. There should be commitment from authorities and legal provisions that prohibit the use of such data for purposes other than improving services. Staff responsible for collecting and storing data should receive appropriate training on protecting confidentiality. Data that cannot be properly secured should not be collected. Data on KP is necessary for an effective program response for these populations. At the same time, privacy, confidentiality and safety are major concerns and should be carefully addressed in the collection and use of such data<sup>20</sup>.

# Overview of Sources of Strategic Information on HIV among Gay Men and Other MSM and Trans People

**Patient monitoring data:** extracted from individual patient records. Data is entered into electronic databases or, in paper-based systems, transferred to written registers and aggregated on routine reporting forms. Includes data from laboratory and pharmacy records.

**Case reporting data:** from routine surveillance, based on newly diagnosed HIV cases reported to central health authorities by health facilities and providers, preferably in the form of individual electronic records with key information (age, sex, transmission mode, CD4 and viral load at diagnosis).

**Outreach data:** based on records, maintained by NGOs conducting outreach and/or by community health and outreach workers, who may or may not be linked to a facility, of peer education, HIV testing (or referrals) and linkage to care for MSM and trans people.

**Financial and health systems data:** budgets, financial records, health accounts, national AIDS spending, procurement and supply management system data, human resources data and key policies related to HIV, prevention, treatment and care.

**Integrated Bio- and Behavioral Surveys (IBBS)** among MSM and trans people.

Sentinel surveillance data collected over time at sentinel sites.

Minimal set of indicators/data for collection of high quality SI in countries.

Documented cases of advocacy activities/campaigns.

#### **Patient Monitoring Data**

Facility information systems routinely collect data on the clinical management of individual patients. All health facilities serving PLH should routinely collect a minimum set of monitoring data to ensure continuity of care and to monitor the quality of clinical care provided. Performance assessments at the facility level allow for timely corrective action as needed. In addition, key data (without patients' identification information) are reported periodically (for example, quarterly) for sub-national and national program management.

Patient records take different forms, depending on the country and type of facility. In some situations, healthcare providers enter patient information directly into a computer database. More

<sup>&</sup>lt;sup>20</sup> http://apps.who.int/iris/bitstream/handle/10665/164716/9789241508759\_eng.pdf?sequence=1

commonly, healthcare providers write clinical management information on facility-held patient records and/or patient-held cards; this information is later abstracted and entered into an electronic database or a paper register for monitoring purposes. In paper-based systems, data is aggregated at the facility level from paper registers and reported to the district or provincial level in a specified template for data entry or import into the national database.

The patient monitoring system can generate both cross-sectional and cohort data related to:

- Use of services: characteristics of clients (demographic and baseline data) and proportion of eligible patients who received different types of services;
- Retention across the cascade of HIV services: proportions and characteristics of those in each step or moving from one step to the next in the cascade of care and treatment;
- Clinical and immunological parameters: for example, CD4 levels, clinical progression, treatment regimens;
- HIV treatment outcomes: for example, survival, viral suppression rate, etc.

The routine monitoring system provides data to enhance the quality of patient care and management of facility services, as well as to meet national reporting requirements. Electronic data systems can also maintain a central database of anonymous individual-level data that can be used to assess the health sector response and generate summary population-level statistics on uptake and outcome of treatment, and to measure the quality and impact of service delivery.

#### **Case Reporting**

HIV case reporting is a form of passive (routine) surveillance based on newly diagnosed cases reported to the central level by health facilities and health-care providers. As HIV epidemics have evolved and more people are being tested, HIV case reporting is becoming both more extensive and more relevant. HIV case reporting is a component of second-generation surveillance. Its objectives are to detect any spike or other unusual increase in the number of cases (especially in areas of generally low prevalence); and to provide qualitative and quantitative information on the distribution of the epidemic (who is infected and where and by what mode of transmission).

#### **Outreach Data**

Outreach data is based on records maintained by NGOs and/or community health and outreach workers, who may or may not be linked to a facility. Depending on local policies, laws and practices, NGOs/communities may provide HIV testing services (or referrals), offer peer education and support, and ensure critical follow-up and linkage to care for the KP (MSM and trans people) they serve. Their records provide important information on the link between health facilities and communities.

NGO/community outreach registers may include data on MSM and trans people, including the reach of HIV prevention services, referrals for HIV testing, and treatment follow-up. NGO/community records may also provide the basis for estimating the size of KP and contribute to the sampling frame for surveys to assess treatment coverage and treatment outcomes among KP or other populations. The records of community health and outreach workers include data on the numbers of people in the community who are on ART.

A formal link for data management needs to be established among health facilities, NGO outreach programs, and communities in a given area. This arrangement should cover recording, reporting and referral procedures and tools to record and forward essential information while protecting confidentiality both within and outside health facilities.

#### Financial Data Sources

Health expenditure data is collected to inform policies at the national level, as well as for reporting internationally. To understand the financing context, it is important to describe the complete flow of funds from the source to those who decide how to spend the funds, to those receiving the funds and providing care, and ultimately to those who receive the care. Health expenditure data can also describe what has been purchased with the funds (for example, salaries, commodities) and for what purpose (for example, preventive, curative).

Two international standards systems currently exist for tracking health spending by function or spending category, by beneficiary and by funding source: the National AIDS Spending Assessment

(NASA) and the System of Health Accounts (SHA)<sup>21</sup>. In countries, these systems provide the most complete information available on HIV/AIDS and on overall health spending.

The World Health Organization (WHO), together with the Organisation for Economic Cooperation and Development (OECD) and Eurostat, released global standards for reporting health expenditures, the System of Health Accounts 2011 (SHA 2011)<sup>22</sup>. SHA 2011 standardizes reporting and allows comparisons within the country and across countries over years. SHA 2011 recommends that health expenditures be fully distributed across beneficiaries and described in terms of disease (for example, HIV/AIDS), age, sex and location. A full distribution can describe the relative allocation of expenditures by disease, for example, HIV/AIDS expenditures as a percentage of current or capital health expenditures. A full distribution of health expenditures by disease provides greater technical rigor, as it standardizes the allocation of joint expenditures such as health service delivery expenditures at the facility level.

The provision of ART and prevention among KP are two essential components where sufficient, stable, and predictable funding is needed. This can be measured by:

- The level of resources mobilized by the national response (standardized, for comparability, by number of PLH);
- The share of health expenditures devoted to HIV health services (distributed by funding source);
- The share and composition of expenditures on HIV prevention;
- The domestic public contribution to HIV spending, including the current situation and past trends.

#### Surveys in the General Population

With the advance of testing technologies in the past decade, many countries have included HIV testing in nationally representative surveys such as the Demographic and Health Survey (DHS), which includes questions about population, health, HIV, and nutrition, or the AIDS Indicator Survey (AIS), which only collects data on HIV. These household-based surveys are typically conducted every five years and target the general population (although they may sometimes be carried out only within certain age or sex/gender groups). In addition to HIV testing, information is collected on self-reported risk behaviors, service utilization, knowledge and/or attitudes about HIV-related stigma and discrimination, availability of services, and on other variables. Recently, measures of HIV incidence, CD4 count, viral load or antiretroviral testing have been incorporated into these surveys. Surveys provide a "snapshot" of the status of HIV-related indicators in a representative sample of the population. The results can be used for program planning, particularly to identify gaps in services and areas to where additional resources should be allocated. When analyzed together, as a set of indicators, data about knowledge, attitudes, behaviors and HIV prevalence provides insights into the inter-relationships among these variables, which research and evaluation studies can explore further. When surveys are repeated over time, trends can be analyzed to monitor progress towards country-specific and global goals. They can also be used together with other data sources to determine the effectiveness of the overall HIV response and/or its components and to identify where improvements are needed. In addition, they can provide estimates of CD4 levels, HIV incidence and the number of people receiving ART.

#### Surveys among MSM and Trans People

#### Estimated Sizes of Key Populations (MSM and Trans People)

KP are, by definition, crucial to the dynamics of any HIV epidemic. Estimating the sizes of MSM and trans populations is important for assessing and ensuring that services and support are adequate to meet the needs of people from these populations.

In addition to prioritizing the allocation of program resources, estimates of the size of MSM and trans populations can also be used for advocacy purposes. For example, information on KP helps to support requests for increased resources, attention and prioritization for these groups. Population SE also provide essential denominators for calculating a number of M&E indicators. SE methods include census and enumeration, programmatic mapping, capture and re-capture, the multiplier

<sup>&</sup>lt;sup>21</sup> http://www.aidsdatahub.org/sites/default/files/documents/NASA\_Guide\_to\_Produce\_NASA.pdf

<sup>&</sup>lt;sup>22</sup> http://www.oecd.org/publications/a-system-of-health-accounts-2011-9789264270985-en.htm

method, and the network scale-up method (NSUM). In recent years, various new methods and approaches have also been proposed and used, including "wisdom of the crowds" and the proxy respondent method. Most methods require surveys, such as an IBBS survey. The UNAIDS/WHO Global Surveillance Working Group has developed guidelines for population SE<sup>23</sup>. Different methods often yield different estimates. Therefore, using several methods can be helpful to understanding the sensitivity of the estimates. Estimates should be rounded to the nearest 100 or 1000 to suggest that these are indeed estimates and not exact counts. In addition, the geographic validity of the data must be considered, as well as how data collected in relatively small areas can be extrapolated to larger administrative areas, up to the national level. Countries can convene a stakeholder meeting, with the involvement of representatives of KP, to consider various estimates and decide on a plausible number. The goal is to generate sound and agreed upon estimates for scaling up services for KP. Since population SE do not change dramatically from year to year, the process can be conducted at intervals of three to five years.

#### Integrated Bio-Behavioral Surveillance among MSM and Trans People

Integrated bio-behavioral surveillance surveys (IBBS) among KP at higher risk for HIV infection, such MSM and trans people, are needed to obtain representative data on their seroprevalence, risk behavior, and on service provision and utilization. IBBS are particularly important where national strategies focus on KP. Even in generalized epidemics, KP, including MSM and trans people, can contribute significantly to the HIV burden, as their prevalence and incidence rates may be several times higher than those of the general population. IBBS data provides information on the burden of disease and treatment needs among KP, and informs resource allocation and priority-setting for HIV programming at the local level.

When conducting surveys among MSM and trans people, high mobility, stigmatization and behaviors that are illegal in many countries make selecting a representative sample difficult. Special sampling methods are required. The two most commonly used are time-location sampling (TLS) and respondent driven sampling (RDS). Special sampling methods like these contribute to making IBBS resource intensive.

Due to cost, IBBS are usually conducted in selected locations at intervals of two to three years. Typically, trained data collectors or evaluators conduct IBBS. IBBS should be carefully planned and included in the national monitoring and evaluation (M&E) plan. Local involvement and community participation ensure that survey findings are both pertinent and that they are used to their full potential.

#### Sentinel Surveillance

Protocols vary, but generally sentinel surveillance is an annual or biennial seroprevalence survey conducted at a fixed selection of sites among specific populations. Sentinel surveillance methods were developed early in the global response to HIV to track the trends and the magnitude of HIV prevalence among populations experiencing the impact of evolving HIV epidemics. Most countries employ some type of sentinel surveillance system as a core component of their second-generation HIV surveillance system.

Surveillance data is the basis for periodic estimates and projections of the number of PLH. These estimates are then used as the population denominator for a range of indicators, including those for monitoring the cascade of services. Sentinel surveillance is not intended as a method for diagnosing individuals and referring them for treatment. HIV testing and counselling should be offered independently of the surveillance procedures.

Sentinel surveillance is conducted regularly, its frequency largely determined by the populations covered and the methods used. The number of sites and the populations included are based on the characteristics of the epidemic, its severity and diversity, and most often on the available resources and the feasibility of regular seroprevalence surveys. The most common populations involved are KP. For quality assurance and trend analysis, sero-surveillance should follow well-established procedures that meet the standards of best practices and that are fully documented. Since 2000, the second-generation surveillance strategy has promoted tailoring the surveillance system to the epidemiological profile of the country<sup>24</sup>. This entails:

<sup>24</sup> Guidelines for Second Generation HIV Surveillance. WHO.2013

<sup>&</sup>lt;sup>23</sup> http://data.unaids.org/pub/manual/2010/guidelines\_popnestimationsize\_en.pdf

Focusing surveillance resources where they will yield the most needed and reliable information;

- Concentrating data collection among KP considered most at risk of becoming infected with HIV:
- Strengthening information systems to monitor trends in HIV prevalence and sexual and drug injecting behaviors, as well as the impact of interventions;
- Making effective use of other existing sources of information to more fully understand the HIV epidemic.

#### **Documented Cases of Advocacy Activities/Campaigns**

A core element of community strengthening is to create an enabling environment for advocacy for improving the policy, legal and governance environments, and for affecting the social determinants of health. Community empowerment processes reach beyond the community to influence policy and create enabling environments through advocacy. Advocacy is how rights are realized and respected and is the consequence of empowered communities. It involves community organizing, educating policy-makers, raising public awareness, documenting the lived experiences of community members, training, demonstrations, litigation and lobbying. Advocacy can result in substantive changes in law, policies, funding, treatment costs and access to HIV services<sup>25</sup>.

# **Capacity of Strategic Information**

Data analysis and use depend on an effective SI system, which in turn requires functional capacity in multiple areas. The technical elements of the HIV-related SI system (for example, data collection from multiple sources, data management systems, surveys and surveillance, evaluation and research) cannot function effectively without the support of organizational structures and processes, including human resources, coordinated planning and management of the M&E system, and adequate funding. Programs should have a plan for data analysis and synthesis with delineated roles and responsibilities, clear and transparent use of analytical methods, an annual report on progress and performance against objectives and targets, and good quality data available at subnational levels. In addition, data quality should be routinely monitored.

Another key aspect of the SI capacity is regular and effective data dissemination and communication. Indicators for national and global reporting should be produced in a timely fashion, and a feedback mechanism should operate at all levels. A data repository with an effective data sharing mechanism should be in place to provide public access to data and reports.

Managing SI functions requires adequate levels of staff at all levels trained in data management and analysis methods. This involves<sup>26</sup>:

- Securing dedicated (part-time or full-time) staff at various levels, from data clerks at facilities to M&E and management specialists at the national level.
- Job requirements that clearly define the types of staff needed at various levels (linked to their functions) and types of facilities.
- Ensuring that SI staff members have the skills to perform their functions, from data collection, entry, and management to analytical skills. Expectations need to be made explicit, and staff members need appropriate support for professional development.
- Training for stakeholders at all levels on the interpretation and use of data for evidencebased decision-making.

<sup>&</sup>lt;sup>25</sup> https://www.theglobalfund.org/media/6428/core\_css\_framework\_en.pdf?u=636679305320000000

<sup>&</sup>lt;sup>26</sup>http://apps.who.int/iris/bitstream/handle/10665/164716/9789241508759\_eng.pdf;jsessionid=6E1B7AB1E3162D4A97259 55BB57D087A?sequence=1

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## **Annex 1. Tool for Assessing Strategic Information**

(Assessment of Existing Strategic Information on HIV among MSM and Trans People in Armenia, Belarus, Georgia, Kyrgyzstan, and Macedonia. 2017)

Please carefully read the questions for each section. Make necessary notes and provide the links/references if available for each requested area (for both MSM and Trans people). At the end of each section there is a scoring tool/table (see instructions below).

#### Size Estimation

Have you estimated the size of the MSM population?

- If yes, when (year) was the latest estimation?
- If yes, what was the estimation by country?
- If yes, what was the methodology used to derive the size estimates?
- If yes, please provide the size of the MSM population by cities/sites (if available).
- If yes, what were the study limitations?
- If not, what were the reasons or main obstacles?
- If not, is there any size estimation study planned in the near future? By whom? Are funds available?

Have you estimated the size of the trans population?

- If yes, what is the number of trans men? (if available)
- If yes, what is the number of trans women (if available)
- If yes, when (year) was the latest estimation?
- If yes, what was the estimation by country?
- If yes, what was the methodology used to derive the size estimates?
- If yes, please provide the size of the trans population by cities/sites (if available).
- If yes, what were the study limitations?
- If not, what were the reasons or main obstacles?
- If not, is there any size estimation study planned in the near future? By whom? Are funds available?

Based on the answers to the questions above, please determine the score using the scoring table below. The column "Features" lists the information to be scored. In the column "Scores", you must select a score of 0 or 1. If the answer is yes, score 1. If the answer is no, score 0. In the column "Links/references provided", please provide links or references that can prove your scores. In the column "Comments", please make necessary comments to justify or explain your scores.

#### Scoring the Data on MSM and Trans people Size Estimation

Features	Scores		Links/references provided (If available)	Comments
	MSM	Trans		
Data exists at the national level				
If there is no data and the score is 0, please skip the entire table and go to the next scoring table.				
Data is reliable				
Reliable means that the data comes from a survey with statistical credibility.				
Data is up-to-date				
Data is updated regularly once every 2-3 years				
Data is used by the government				
Relevant data is shown and /or used in national plans and/or state-funded programs				
Data is used by NGOs and communities				
Relevant data is used for fundraising, project planning and/or advocacy purposes				
Data is available by cities/regions				
Segregated data exists at the city/regional level within the country				
Total score				

#### **Condom Use**

What is the number of MSM who reported that a condom was used the last time they had anal sex? What is the number of trans men and trans women who reported that a condom was used the last time they had anal sex?

- What are the sources for calculating this (IBBS survey, sentinel data, etc.)? Please provide links/references if available.
- Are there major variations within the country (by city or region) to be aware of?
- If not available as a disaggregated data set, are there proxies or estimations?
- Are there major, observable limitations in the current data or the data collection methodologies?

What is the number of MSM who reported having had anal sex with a male partner in the last six months? What is the number of trans men and trans women who reported having had anal sex with a male partner in the last six months?

- What are the sources for calculating this (IBBS survey, sentinel data, etc.)? Please provide links/references if available.
- Are there major variations within the country (by city or region) to be aware of?
- If not available as a disaggregated data set, are there proxies or estimations?
- Are there major, observable limitations in the current data or the data collection methodologies?

Based on the answers to the questions above, please determine the score using the scoring table below.

#### Scoring the Data on Condom Use among MSM and Trans Individuals

Features	Scores		Links/references provided (If available)	Comments
	MSM	Trans		
Data exists at the national level				
Data is reliable				
Data is up-to-date				
Data is used by the government				
Data is used by NGOs and communities				
Data is available by cities/regions				

#### Prevalence

What is the reported HIV prevalence among MSM?

- What are the sources for calculating HIV prevalence (IBBS survey, sentinel data, etc.)? Please provide links/references if available.
- Are there major variations within the country (by city or region) to be aware of?
- If not available as a disaggregated data set, are there proxies or estimations?
- Are there major, observable limitations in the current data or the data collection methodologies?

What is the reported HIV prevalence among trans people?

- What are the sources for calculating HIV prevalence (IBBS survey, sentinel data, etc.)? Please provide links/references if available.
- Are there major variations within the country (by city or region) to be aware of?
- If not available as a disaggregated data set, are there proxies or estimations?
- Are there major, observable limitations in the current data or the data collection methodologies?

What is the reported HIV incidence among MSM?

- If not available as a disaggregated data set, are there proxies or estimations?
- Are there major variations within the country (by city or region) to be aware of?
- Are there major, observable limitations in the current data or the data collection methodologies?
- Have there been significant changes in incidence in recent years? Are there any probable causes for this? (Consider whether testing access has increased or decreased, giving the impression that the epidemic is changing when in fact it is a change in access to diagnostics.)

What is the reported HIV incidence among trans people?

- If not available as a disaggregated data set, are there proxies or estimations?
- Are there major variations within the country (by city or region) to be aware of?
- Are there major, observable limitations in the current data or the data collection methodologies?
- Have there been significant changes in incidence in recent years? Are there any probable causes for this? (Consider whether testing access has increased or decreased, giving the impression that the epidemic is changing when in fact it is a change in access to diagnostics.)

Based on the answers to the questions above, please determine the score using the scoring table below.

#### Scoring the Data on HIV Prevalence among MSM and Trans People

Features	Scores		Links/references /references provided (If	Comments
	MSM	Trans	available)	
Data exists at the national level				
Data is reliable				
Data is up-to-date				
Data is used by the government				
Data is used by NGOs and communities				
Data is available by cities/regions				
Total score				

#### **Service Provision**

Nationally, what percentage of MSM are estimated to be regularly covered with basic HIV prevention services?

- What percentage of MSM are estimated to be regularly covered with basic HIV prevention services at the city level (If available)?
- What are the observable shortcomings in the available data on coverage (e.g. denominator is low based on faulty IBBS/PSE)?
- Please provide information on what is included in the basic package of services.
- Are the best/worst practices in service provision described/reported? If yes, provide the link.

Nationally, what percentage of MSM are estimated to be regularly covered by HIV testing? What percentage of MSM are estimated to be regularly covered by HIV testing at the city level (If available)?

- What are the observable shortcomings in the available data on coverage (e.g. denominator is low based on faulty IBBS/PSE)?

Nationally, what percentage of PLH-MSM are currently on ART? At the city level (If available)? What are the observable shortcomings in the available data on coverage (e.g. denominator is low based on faulty IBBS/PSE)?

Nationally, what percentage of trans people are estimated to be regularly covered with basic HIV prevention services? At the city level (If available)?

- What are the observable shortcomings in the available data on coverage (e.g. denominator is low based on faulty IBBS/PSE)
- Please provide information on what is included in the basic package services?
- Are the best/worst practices of service provision described/reported? If yes, provide the link.

Nationally, what percentage of trans people are estimated to be regularly covered by HIV testing? At the city level (If available)? What are the observable shortcomings in the available data on coverage (e.g. denominator is low based on faulty IBBS/PSE)?

Nationally, what percentage of trans PLH are currently on ART? At the city level (If available)? What are the observable shortcomings in the available data on coverage (e.g. denominator is low based on faulty IBBS/PSE)?

Based on the answers to the questions above, please determine the score using the scoring table below.

#### Scoring the Data on Coverage of MSM / Trans People by HIV Prevention Services (Basic Package)

Features	Scores		Links/references provided (If available)	Comments
	MSM	Trans		
Data exists at the national level				
Data is reliable				
Data is up-to-date				
Data is used by the government				
Data is used by NGOs and communities				
Data is available by cities/regions				
Total score				

#### Community-Driven Response/Community Involvement in Response

In what areas of service provision are MSM-led organizations, community groups or activists currently involved?

- provision of condoms and lubricants
- HIV prevention education and counseling
- testing
- psychological and social support to those infected with HIV
- supporting adherence to ART
- Other: please describe

Are there limitations on the involvement of these organizations in the provision of certain services required to counteract the HIV epidemic in the community (e. g. community-based HIV testing)? If yes, please describe.

In what other areas of the HIV response are MSM-led organizations, community groups or activists currently involved?

- monitoring access to HIV services and the quality of services
- monitoring human rights violations on the grounds of SOGI
- advocacy aimed at ensuring access to HIV services
- advocacy aimed at ensuring human rights protection

In what areas of service provision are organizations and community groups led by trans people or individual trans activists currently involved?

- provision of condoms and lubricants
- provision of safe injection equipment
- HIV counseling
- testing
- psychological and social support to those infected with HIV
- supporting adherence to ART
- Other: please describe

Are there limitations on the involvement of these organizations/groups in the provision of certain services required to counteract the HIV epidemic in the community (e. g. community-based HIV testing)? If yes, please describe.

In what other areas of the HIV response are organizations and community groups led by trans people or individual trans activists currently involved?

- monitoring access to HIV services
- monitoring human rights violation on the grounds of SOGI
- advocacy aimed at ensuring access to HIV services
- advocacy aimed at ensuring human rights protection

In what other areas of research are MSM-led organizations, community groups or activists currently involved?

- Planning of research/survey
- Implementing/carrying out research/survey
- Analyzing data
- Other: please specify

In what other areas of research are organizations and community groups led by trans people or individual trans activists currently involved?

- Planning of research/survey
- Implementing/carrying out research/survey
- Analyzing data
- Other: please specify

Based on the answers to the questions above, please determine the score using the scoring table below.

#### Scoring the Data on MSM Involvement in the Provision of HIV Prevention Services

Features	Scores	Links/references provided (If available)	Comments
Data exists at the national level			
Data is reliable			
Data is up-to-date			
Data is used by the government			
Data is used by NGOs and communities			
Data is available by cities/regions			
Total score			

#### Scoring the Data on the Involvement of Trans People in the Provision of HIV Prevention Services

Features	Scores	Links/references provided (If available)	Comments
Data exists at the national level			
Data is reliable			
Data is up-to-date			
Data is used by the government			
Data is used by NGOs and communities			
Data is available by cities/regions			
Total score			

#### **Advocacy Coverage**

In the last 3 years, what advocacy campaigns or activities have been undertaken by the LGBTI community aimed at increasing access to HIV services and/or the protection of human rights in the context of the HIV epidemic? Please describe the following for each campaign or set of activities:

- Was this campaign national, and/or was it active in provincial/municipal sites?
- Did it explicitly include trans issues, or was it primarily focused on MSM issues?
- Did it focus on LGBT human rights and/or access to HIV services for LGBT populations?
- Did it involve many local community members or was it carried out primarily by experienced community advocates/representatives?
- Did it include the documentation of cases of discrimination/human rights violations?
- Did it include strategic litigation?
- Who were the target groups of the campaign: government and/or municipal administrations; police officials and officers; medical professionals and specialists; other?
- What were the major results (if any)? (Such as service expansion, funding increases etc.)
- What were the major challenges/issues?
- Are the best/worst practices in advocacy activities targeting MSM and trans people described/reported? If yes, provide the link.
- What have been the major unmet needs in terms of advocacy activity for LGBT health issues? In other words, what kind of campaigns or activities really need to be undertaken, but have not yet been carried out? Please describe.

Based on the answers to the questions above, please determine the score using the scoring table below.

#### Scoring the Data on Advocacy Coverage among MSM and Trans People

Features	Scores		Links/references provided (If available)	Comments
	MSM	Trans		
Advocacy campaign focused on MSM only				
Advocacy covered both MSM and trans people				
Advocacy campaign process is well documented				
The process, participants and results of the campaign are described and reported				
Community-led NGOs or community activists were involved in the advocacy activities				
MSM and trans community representatives took part in policy dialogue meetings or in advocacy campaign				
Governmental sector was involved in the advocacy activities				
Government representatives took part in policy dialogue meetings or in advocacy campaign				
Total score				<u> </u>

## **Research and Strategic Information**

What research and/or studies on MSM and/or trans sexual and reproductive health, including HIV/AIDS, Hepatitis C, STIs, and human rights have been undertaken in the last 3 years? Please name the surveys and provide links/references.

What research and/or studies on MSM and/or trans sexual and reproductive health, including HIV, Hepatitis C, STIs, and human rights are planned to take place in the next 3 years? Please name the planned surveys and provide links/references if available.

Does the Ministry of Health or other corresponding national and/or municipal structures use WHO or other international recommendations related to sexuality, gender, mental health and HIV/STI/viral hepatitis prevention and treatment? If yes, in which areas? (Please describe).

Does the Ministry of Health or other corresponding national and/or municipal structures use survey results and strategic information in the planning of HIV prevention programs and/or treatment? If yes, please describe.

Based on the answers to the questions above, please determine the score using the scoring table below.

# Scoring the Data on the Use of Research Results and Strategic Information (Targeting MSM and Trans People)

Features	Scores		Links/references provided (If available)	Comments
	MSM	Trans		
Research on unmet SRHR needs conducted among MSM in the last 3 years				
Research findings used by government institutions				
Findings are shown and /or used in national plans and/or state-funded programs				
Research findings used by CSOs				
Findings are used for fundraising, project planning and/or advocacy purposes				
Strategic information derived from programs/projects is used by government				
SI is shown and /or used in national plans and/or state-funded programs				
Strategic information derived from programs/projects is used by CSOs				
SI is used for fundraising, project planning and/or advocacy purposes				
Total score				



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