ECOM

GUIDE ON DEVELOPING, ANALYZING, AND USING A CASCADE OF CONTINUOUS HIV SERVICES FOR TRANS* PEOPLE

September 2021

The Guide provides assistance in collecting, analyzing, and using data on the availability and coverage of services within a suggested comprehensive package of HIV services for trans* people at a country level.

This Guide is intended for various organizations working with trans* people, donors, AIDS centers, other medical institutions, analytical groups and think-tanks that create strategic information on key populations or work to develop, implement and monitor HIV programs in Eastern Europe and Central Asia.

The publication of the document is highly relevant as there is a critical lack of strategic information on trans* people in the context of HIV. Integrated biobehavioral studies among trans* people were conducted only in two countries of the region (Armenia and Ukraine)[1]. Limited information on HIV epidemic among trans* people is available from few other countries of the region. There is no data on the availability of the HIV services continuum for trans* people in the countries of Eastern Europe and Central Asia.

At the time of the Guide development, no tools or guidelines on collecting information about the cascade of HIV services for trans* people were available in other regions of the world.

This Guide is based on a UNDP-UNFPA 2016 tool «Implementing Comprehensive HIV and STI Programmes with Transgender People» (TRANSIT)[2] and has been adaptated using the «Guide on developing, analyzing, and using a cascade of continuous HIV care for MSM» developed by ECOM in 2017. For specific information on the design, implementation, and monitoring of trans* specific HIV programs, readers are advised to refer to TRANSIT which contains detailed description of a comprehensive continuum of HIV services for trans* people.

The document is aimed at identifying gaps in the continuum of HIV services for trans* people, generating an understanding of what level of progress has been made in achieving the 95-95-95 targets, and encouraging intersectoral efforts to ensure comprehensive evidence-based response to the HIV epidemic among trans* people in the EECA region.

Each country and organization can tailor the content of the cascade of continuous HIV services based on their own context and needs. To this end, this Guide presents various examples and algorithms of actions, e.g. suggesting to focus on the pre-exposure prophylaxis cascade, or to track the HIV treatment services for trans* people living people, and to monitor HIV prevention services.

If you are from a community-based or civil society organization and would like to learn more or have challenges in using this Guide for developing a cascade of HIV services in your country, you can request technical support from ECOM.

The Guide was prepared by Daniyar Orsekov for ECOM — Eurasian Coalition on Health, Rights, Gender and Sexual Diversity as part of the ECOM regional program «Thinking outside the box: overcoming challenges in community advocacy for sustainable and high-quality HIV services» supported by the Robert Carr Civil Society Networks Fund.

Questions and comments on the Guide can be sent to contact@ecom.ngo.

September 2021

---

[1] https://ecom.ngo/wp-content/uploads/2018/12/IBBS_ARMENIA_2018_eng_FINAL.pdf

[2] https://www.who.int/hiv/pub/toolkits/transgender-implementation-tool/en/
TRANSIT was translated into Russian language and adapted by experts from trans* community., Please contact UNFPA Regional Office for Eastern Europe and Central Asia to receive the document before its publication

CONTENTS

ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ARV therapy	Antiretroviral therapy
CD4	Type of lymphocytes (white blood cells); the number of CD4 and their ratio to other lymphocytes show how well the human immune system is functioning
CDC	United States Centers for Disease Control and Prevention
CEECA	Central and Eastern Europe and Central Asia
Chemsex	Use of substance / drugs to enhance sexual experiences particularly among gay, bisexual and trans* men who have sex with men
ECOM	ECOM — Eurasian Coalition on Health, Rights, Gender and Sexual Diversity
EECA	Eastern Europe and Central Asia
HIV	Human immunodeficiency virus
KP	Key population
LGBT	Lesbian, gay, bisexual and trans* people
M&E	Monitoring and Evaluation
MSM	Men who have sex with men
NGO	Non-governmental organization
PLH	People living with HIV
PrEP	Pre-Exposure Prophylaxis, when HIV- people take an antiretroviral drug to prevent HIV infection
PS	Psychoactive substances
IBBS	Integrated Biological and Behavioural Surveillanc
STI	Sexually transmitted infection
SW	Sex worker
TB	Tuberculosis
TG	Transgender (trans*) people
TM	Trans* men
TPLH	Trans* people living with HIV

TRANSIT	Implementing Comprehensive HIV and STI Programmes with Transgender People: Practical Guidance for Collaborative Interventions
TW	Trans* women
UN	United Nations
UNAIDS	Joint UN Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
WHO	World Health Organization

TERMINOLOGY

Cascade	A tool to describe the sequential interrelated services (continuum of services), as well as the coverage by these services of those who need them. The cascade begins with determining the size of the group of people who need the package of services, and gradually tracks the «movement» of those needing the package from one service to another, showing where «losses» occur and providing an opportunity to accurately determine the direction of analysis and work to improve policies and comprehensive programs.
Gender confirmation interventions	A set of voluntarily received medical services to change/correct one's body, which are sought by trans* people to achieve harmony with their gender identity. These may include feminizing or masculinizing hormone therapy, soft tissue fillers, or surgery
Trans-competent	Services that are provided taking into account the needs and medical and social specificities of trans* people with technical competence, while excluding stigma and discrimination and respecting human rights
Trans* woman (TW)	A woman assigned as male at birth
Trans* MSM	A trans* man who has sex with men. In EECA, the needs and requirements of trans* MSM are only beginning to be discussed. Existing prevention programs are currently only aimed at cis men who have sex with men and trans* women
Trans* man (TM)	A man assigned as female at birth
Transgender (trans*) person	A person whose gender identity (internal sense of one's own gender) differs from the sex assigned at birth (and indicated in one's birth certificate)

Transphobia	Prejudice aimed at trans* people because of their actual or perceived gender identity or self-expression. Transphobia may be structural, in other words, it manifests itself in policies, laws, and socio-economic mechanisms that discrimination against trans* people. It can also be social, when trans* people are rejected or subjected to abusive treatment. Transphobia can also be internal, when trans* people accept and reflect this prejudice towards themselves or other trans* people. Transphobia, including internal transphobia, actively influences the ability of trans* people to seek care and receive medical services. Transphobia may be complicated by misogyny or xenophobia, when identity and social status are combined, for example a trans* woman migrant worker involved in sex work
Cisgender (cis-) person	A person whose gender identity (internal sense of one's own gender) coincides with their sex indicated in their birth certificate

THANKS

The author thanks M. Kasianczuk and V. Djuma for providing meaningful comments and edits on the Guide. The author expresses special gratitude to G. Roshchupkin for the detailed proofreading and editorial work done on the content.

1

CASCADE OF SERVICES FOR TRANS* PEOPLE

1.1 WHAT IS A CASCADE OF SERVICES FOR TRANS* PEOPLE

A cascade of continuous HIV care for transgender people (trans* people) is a situation assessment, planning, advocacy, and monitoring tool that shows the relationship between those who need services and those who receive them. A cascade is based on a continuum of services: the continuum lists the services that are needed, and the cascade is a tool for measuring the availability and accessibility of these services. Ideally, a cascade is as a chain of similar indicators that can measure the behavior of people and care systems, the values of which are rigidly related to each other, but change under the influence of a large number of various external factors. Sequentially connected, they form descending steps.

Developing a cascade of services allows you to:

- Identify in the system of care for those services that are not sufficiently available;
- Determine the direction of the analysis of the reasons for the insufficient effectiveness of programs (why people do not use the services they need);
- Determine the direction of solutions to improve the work of the system and to increase the demand for services (achieving the necessary coverage of services for effective control of the HIV epidemic)[3].

A cascade is useful for measuring and visually presenting the progress made in achieving national and international goals agreed upon by our states.

In particular, the new «Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030», adopted by UN member states in June 2021[4], commits:

- «to achieve the 95–95–95 testing, treatment and viral suppression targets within all demographics and groups and geographic settings, including children and adolescents living with HIV»

This was a logical continuation and improvement of the 90-90-90 targets set up in the previous 2016 Political Declaration on HIV and AIDS[5].

The governments of all countries of EECA have signed both Declarations, thus recognizing the new 95-95-95 targets and the previous 90-90-90.

While the HIV treatment cascades for the countries of Europe and Central Asia, and elsewhere, published until now, mostly refer to the 90-90-90 targets, new cascades will be aligned with the updated 95-95-95 targets[6,7]. An example of such cascade is shown in Figure 1.

---

[3] Adapted from the MSMIT: United Nations Population Fund, Global Forum on MSM and HIV, United Nations Development Programme, World Health Organization, United States Agency for International Development, World Bank. Implementing Comprehensive HIV and STI Programmes with Men Who Have Sex with Men: Practical Guidance for Collaborative Interventions. New York: United Nations Population Fund; 2015.

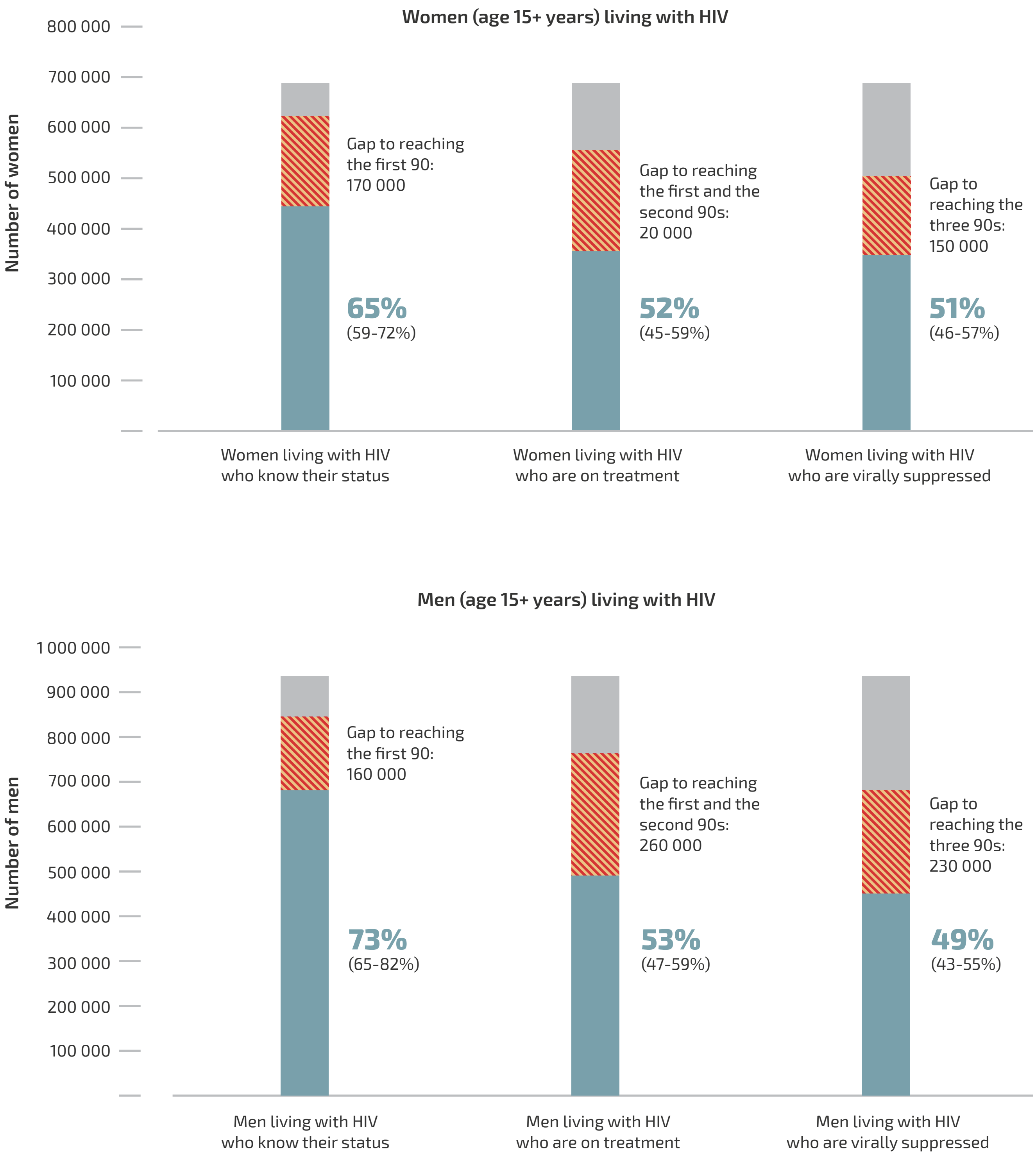
[4] UN General Assembly. Resolution A/75/L.95, adopted 8 June 2021

[5] UN General Assembly. Resolution A/RES/70/266, adopted 8 June 2016

[6] UNAIDS. Ending AIDS: progress towards the 90–90–90 targets, p. 167

[7] European Centre for Disease Prevention and Control (ECDC). Thematic report. Continuum of HIV care. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia. 2017. Progress report. Publication available at: https://ecdc.europa.eu/sites/portal/files/documents/Continuum-of-HIV-care-2017.pdf

Figure 1. HIV Teasting abd Treatment Cascade, Women (Aged 15+ Years) compared to Men (Aged 15+ Years), Eastern Europe and Central Asia, 2020. Source: Global AIDS Update 2021, UNAIDS



The cascade of services for people living with HIV presumably includes data on the availability of services for trans* people living with HIV, but it does not provide for the disaggregation of this data in order to see the specific situation of trans* people living with HIV. For example, national programs may not be able to collect separate data: there are no revised and updated electronic databases and documentation that have the ability to include trans* people in statistical reporting, outreach workers and other employees are not informed about the importance and possibility of including trans* people in the provision of services, and medical specialists are not sensitized. **Other factors may also affect the invisibility of trans* people in national cascades**:

- Trans* people, primarily trans* women, are registered in reports of medical institutions and sometimes NGOs as MSM or SW;
- Trans* people, primarily trans* men who have sex with men, are not aware of their level of risk and vulnerability, which does not create the need to seek services;
- Programs do not have marketing strategies aimed at trans* MSM; trans* MSM themselves often do not visit organizations and medical institutions out of fear of misunderstandings and ridicule related to their sexual practices;
- Trans* people are afraid to visit medical institutions due to a lack of understanding of their needs by employees, prejudice, stigma, discrimination, or breaches of confidentiality;
- Trans* people refuse to be part of programs due to the general unavailability of trans-competent health services, and their non-recognition as part of key populations at the national level;
- Trans* people may be afraid to find out their HIV status, fearing even greater stigma related to both transgender identity and HIV+ status, the risk of higher healthcare costs, greater social isolation or the incompatibility of ARV therapy with hormone replacement therapy.

Despite the fact that in some EECA countries, the high level of vulnerability of trans* people to HIV is recognized, and they are identified as a separate target group in national HIV programs or in country applications submitted to the Global Fund, in many countries, it is still not possible to assess the accessibility and effectiveness of services for trans* people living with HIV, to understand existing gaps in the continuum of services, to compare the current situation with the established "95-95-95" targets, or to use data to further advocate for eliminating gaps in the continuum of services for trans* people.

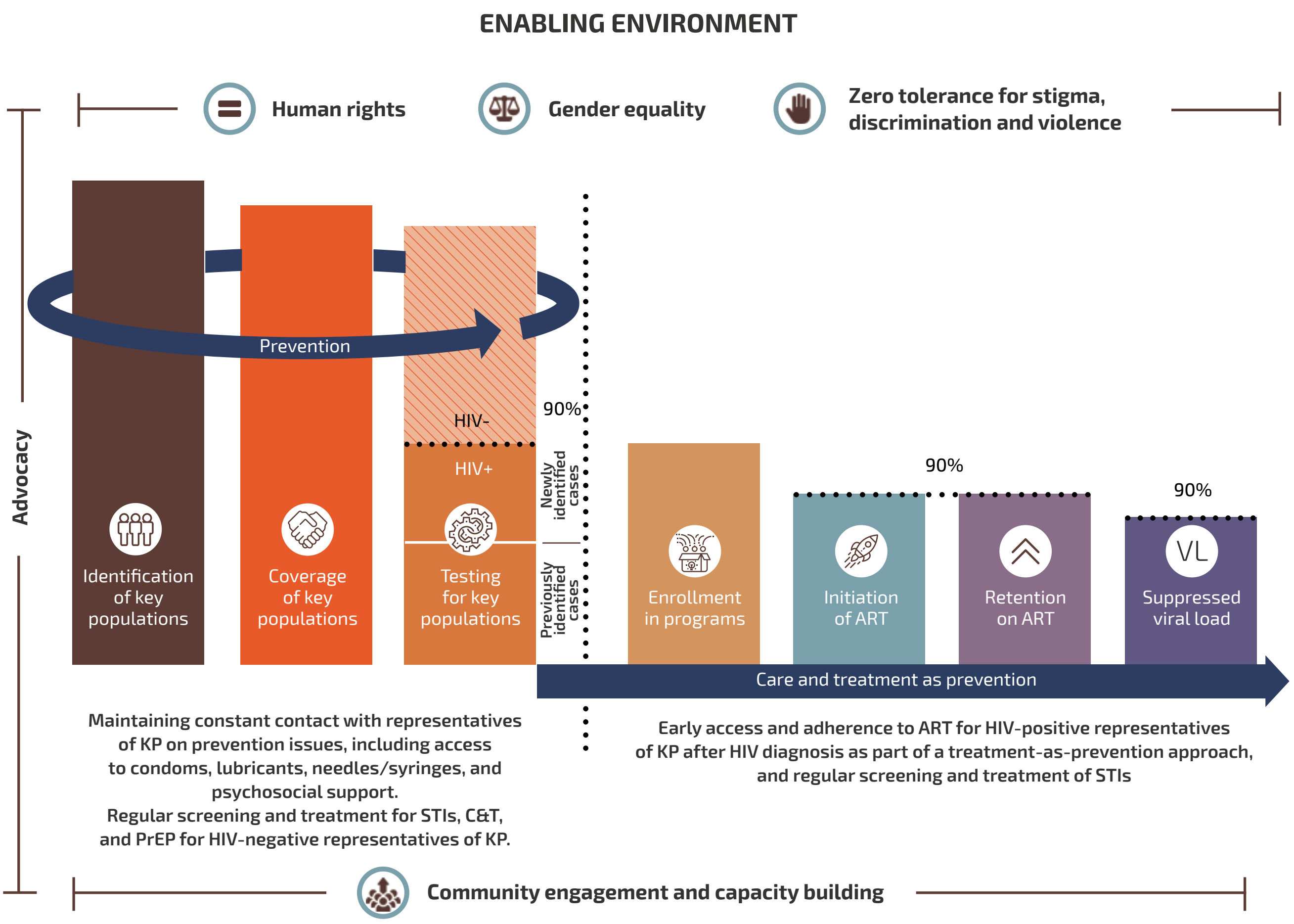
It is important that the cascade begins with an estimate of the population size of the group itself, and includes issues related to testing/diagnosis, treatment, as well as prevention. Figure 2 provides a general outline of a cascade of the continuum of continuous HIV care for trans* people recommended in the TRANSIT.

The continuum of HIV prevention, diagnosis, treatment, and care services is a practical diagnostic, advocacy, planning, and monitoring tool that applies to all actors in the HIV response. The continuum has the following goals: 1) provide coverage for HIV- trans* people with the necessary prevention and support services, 2) help them stay HIV- for as long as possible, and 3) diagnose HIV infection as early as possible, and then without delay, refer HIV+ people to the treatment and care system, and facilitate their adherence to treatment (retain them in treatment).

The continuum shows how all these goals are interdependent.

By analyzing targets, it is possible to identify points where transgender people are unable to access services, understand the reasons for this situation, and make recommendations for improving programs. By understanding where coverage is insufficient within the continuum, it is possible to find the most effective solutions to close the gaps and strengthen efforts to reach and retain as many people as possible.

Figure 2. Continuum of HIV prevention, diagnostic, treatment and care. ource: FHI 360/LINKAGES Key population program implementation guide; 2017



Maintaining constant contact with representatives of KP on prevention issues, including access to condoms, lubricants, needles/syringes, and psychosocial support.
Regular screening and treatment for STIs, C&T, and PrEP for HIV-negative representatives of KP.

Early access and adherence to ART for HIV-positive representatives of KP after HIV diagnosis as part of a treatment-as-prevention approach, and regular screening and treatment of STIs

Source: FHI 360/LINKAGES Key population program implementation guide. Washington, DC: FHI 360/LINKAGES; 2017.

A continuum-based cascade of services begins with recognition of trans* people as a key population, which requires estimating the group's population size, identifying places where trans* people socialize, as well as assessing the level of risk, existing health needs, and their coverage by comprehensive HIV prevention services. It is important for HIV- trans* people to have access to quality STI diagnosis and treatment, HIV counseling and testing, and pre-exposure prophylaxis for HIV. For trans* people living with HIV, it is important to have the opportunity for early diagnosis of HIV infection, and to start immediate ARV therapy. The figure shows that a continuum of services rests on the foundation of an involved community with a developed capacity and is supported by an enabling environment, where, along with the protection and primacy of human rights and gender equality, there is zero tolerance for violence and discrimination

1.2

THREE MAIN TYPES OF CASCADES OF SERVICES FOR TRANS* PEOPLE

In practice, it is difficult to develop a comprehensive cascade as reflected in the TRANSIT scheme: not all services exist in reality (which must be shown in the cascade), some data may be missing or is extremely fragmented and incomparable with each other, prevention services are very difficult to build in a sequential chain that is the same for all clients (for example, service «B» can only be obtained if service «A» is received, when the availability and effectiveness of service «B» depends on the quality and availability of service «A»). In this regard, when it comes to the availability of HIV services, we recommend considering four different options for cascades for trans* people (the design of cascades and their indicators can be found in Tables 1, 2, and 3 in section 2.1):

1. **A cascade** on progress towards achieving the **95-95-95 targets for trans*** **people living with HIV**;
2. **A prevention cascade** to measure access of trans* peoples to prevention services;
3. **A cascade of pre-exposure prophylaxis** for HIV-negative trans* people to measure the needs and access in relation to this key innovative prevention service.

It is important to note that each of these cascades measures a different set of services. Assembling a cascade of services for trans* people may be challenging due to a lack of data, however, by compiling and publishing a cascade, it is possible to initiate and sustain discussion on the following issues:

- **which important data is missing**?
- **Is current existing data** of sufficient quality?
- How and with whom can the needed data be collected?
- To what extent does the government's data ccorrelate (reflect) with the experience and assessments of community experts?

Constructive discussion can help determine whether community organizations should independently collect data in the absence of such in official reports of the government, discuss the openness of the methodology and transparency of the national Integrated Biological and Behavioural Surveillance (IBBS) data collection process, etc.

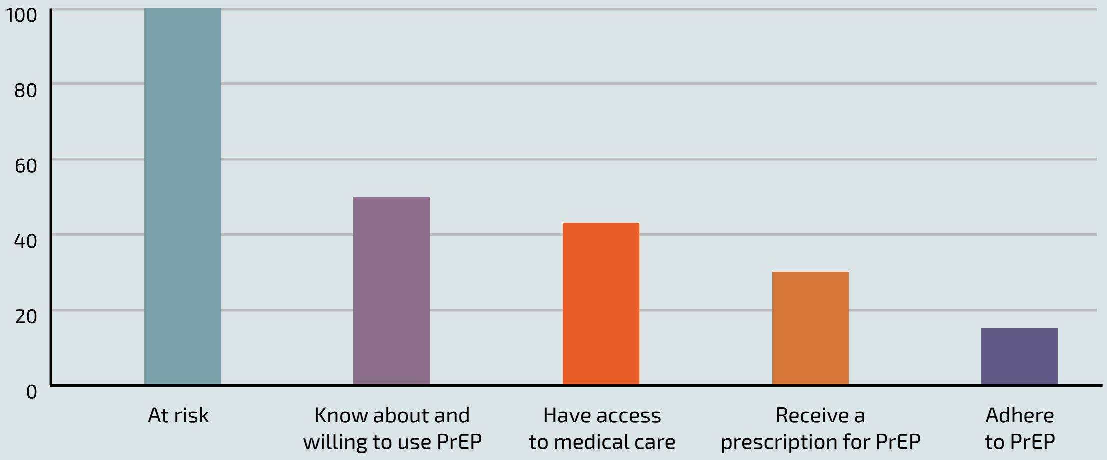
Data collection can be time-consuming and may depend on the will of the country, demonstrated by the acceptance of trans* people as key populations and subsequent changes to statistical tools (for example, reporting forms, research protocols). In this regard, trans* people are not a unique community. In some EECA countries, despite the large outflow of citizens as part of labor migration to countries with high HIV prevalence, migrants are not recognized as a key population group. The selection of data collection tools may depend on the amount of resources and capacity of trans- or LGBT communities in the country advocating for the collection by the government of disaggregated data on trans* people. The quality of data may depend on the degree of involvement of the communities themselves, the use of up-to-date and correct terminology, geography of the study, the use of social media, and the friendliness and confidentiality of this work.

The use of pre-exposure prophylaxis is currently more developed in Eastern Europe than in Central Asia. According to the WHO, PrEP is an effective intervention for HIV prevention in all populations at high risk of HIV infection[9]. Trans* people are at significant risk of contracting HIV and should have the same access to PrEP as cisgender people. From November 2017 to March 2019, the pilot project «Strengthening prevention activities among MSM/TG — PrEP» was conducted in Ukraine, in which one trans* woman participated. Following the pilot, a PrEP project for the general population was initiated, however, there is no data yet on the number of trans* people participating in this project

Below, you can see examples of a pre-exposure prophylaxis cascade[10].

A pre-exposure prophylaxis cascade can be developed for HIV- representatives of the community. The illustrations below show several examples of cascades in terms of approaches to detail, consideration of various subgroups of MSM, and presentation (along with the «95-95-95» cascade on diagnosis and treatment):

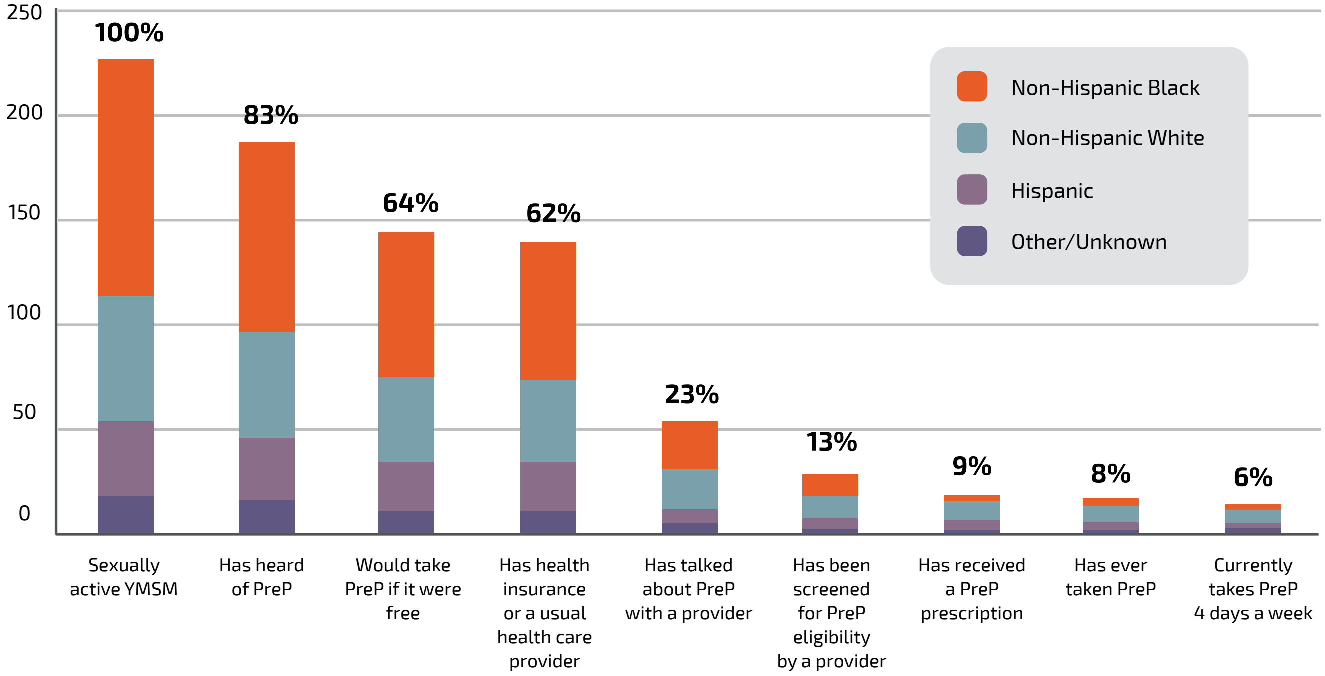
Figure 3. Pre-exposure prophylaxis care cascade for men who have sex with men in Atlanta (USA). Source: Kelley CF et al. Applying a PrEP Continuum of Care for Men who Have Sex with Men in Atlanta, Georgia. Clinical Infectious Diseases, online edition, 2015 Nov 1



---

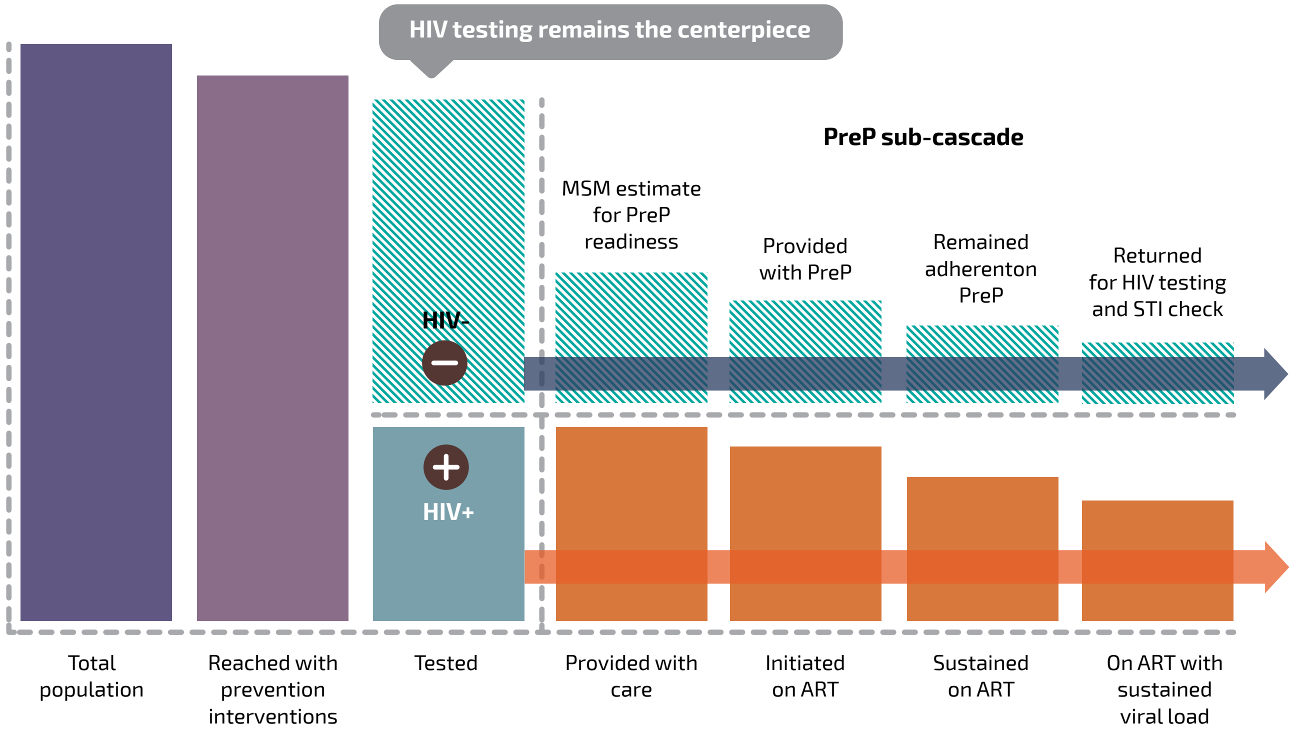
[9] Liu A, Cohen S, Vittinghoff E, et al. Adherence, sexual behavior and HIV/STI incidence among men who have sex with men (MSM) and transgender women (TGW) in the US PrEP demonstration (Demo) project. 8th International AIDS Society Conference on HIV Pathogenesis, Treatment, and Prevention. Vancouver, July 19–22, 2015. AbstractTUAC0202.
[10] Due to the fact that no examples of a PrEP cascade for trans* people were found, examples of PrEP cascades for MSM are provided.

Figure 4. A detailed PrEP cascade in Washington (USA) by ethnic group of young MSM



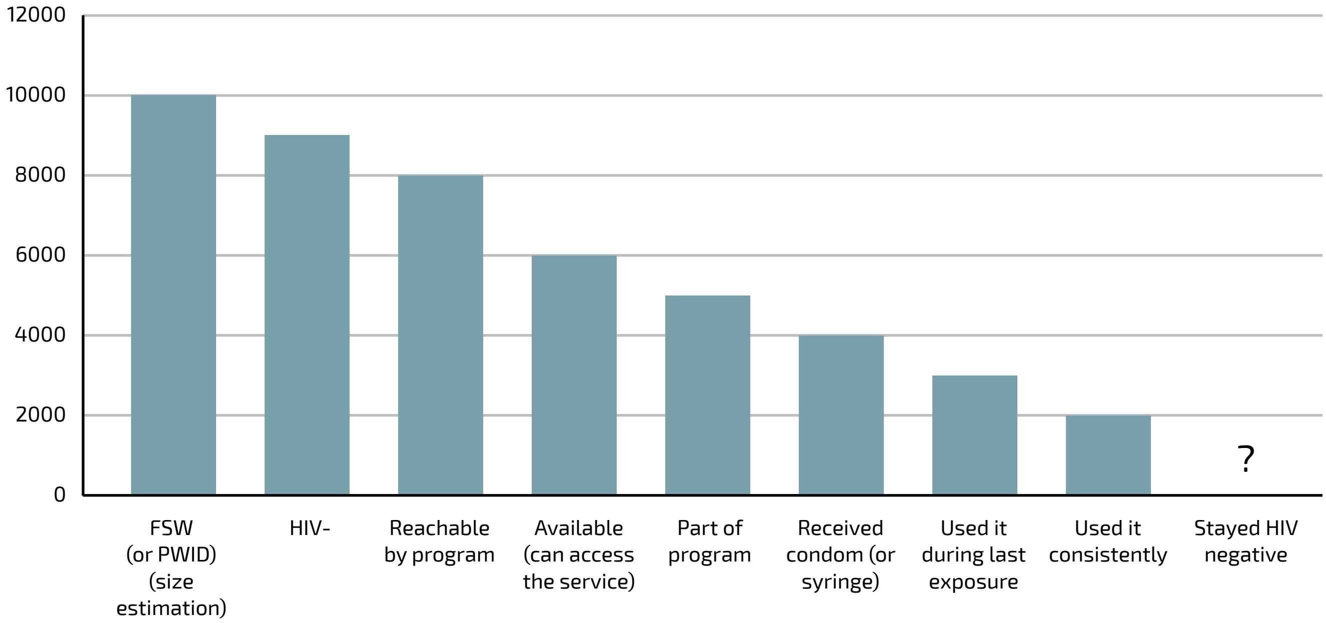
**The proportion of sexually active YMSM, by race/ethnicity, who cumulatively met all previous steps of the PreP care continuum were assessed. For each step, the racial/ethnic composition of all participants who cumulatively met that step are presented.*

Figure 5. PrEP cascade integrated into the overall cascade scheme in parallel with the treatment and care cascade for HIV+ MSM. Source: USAID, PEPFAR, Linkages, FHI360. HIV Cascade Framework for Key Populations, 2015



To analyze prevention services among key populations, for example, a cascade on access to, receipt, and use of preventive medicines/products can be considered (see below). Data for such a cascade is available in the program information on services (i.e. in project reports).

Figure 6. Condom use cascade for sex workers (or people who inject drugs)



Since there is no cascade of prevention services generally accepted by international organizations, you can develop your own set of indicators for this cascade.

You can make a comprehensive, mixed cascade combining two or all three cascades.

1.3

OVERVIEW OF THE STAGES OF WORK ON THE CASCADE

Before beginning to draw up the cascade, it is necessary to consider and plan all stages of work. During the preparatory stage, you must determine the scope of work, the timeframe, and decide what you are ready to do yourself, and where you will need the help of experts/consultants. Ideally, the whole process is divided into the 4 stages shown below. In this chapter, we focus on the second stage. The last stage deals with measures to improve services and develop advocacy, which deserves its own guide. Since such guides already exist, for instance, the TRANSIT, we will not duplicate them in this publication. The sections and parts of this Guide that correspond to the listed stages are shown below and can be easily identified by the colors used to indicate them.

STAGE 1: PREPARATORY

- Identifying the goal, main parameters of the cascade, and drafting a work plan.
- **Section 1.4**

STAGE 2: DEVELOPING THE CASCADE

- Elaboration of the cascade indicators.
- Identifying sources of data.
- Data collection.
- **Part 2**

STAGE 3: GAP ANALYSIS AND RECOMMENDATIONS

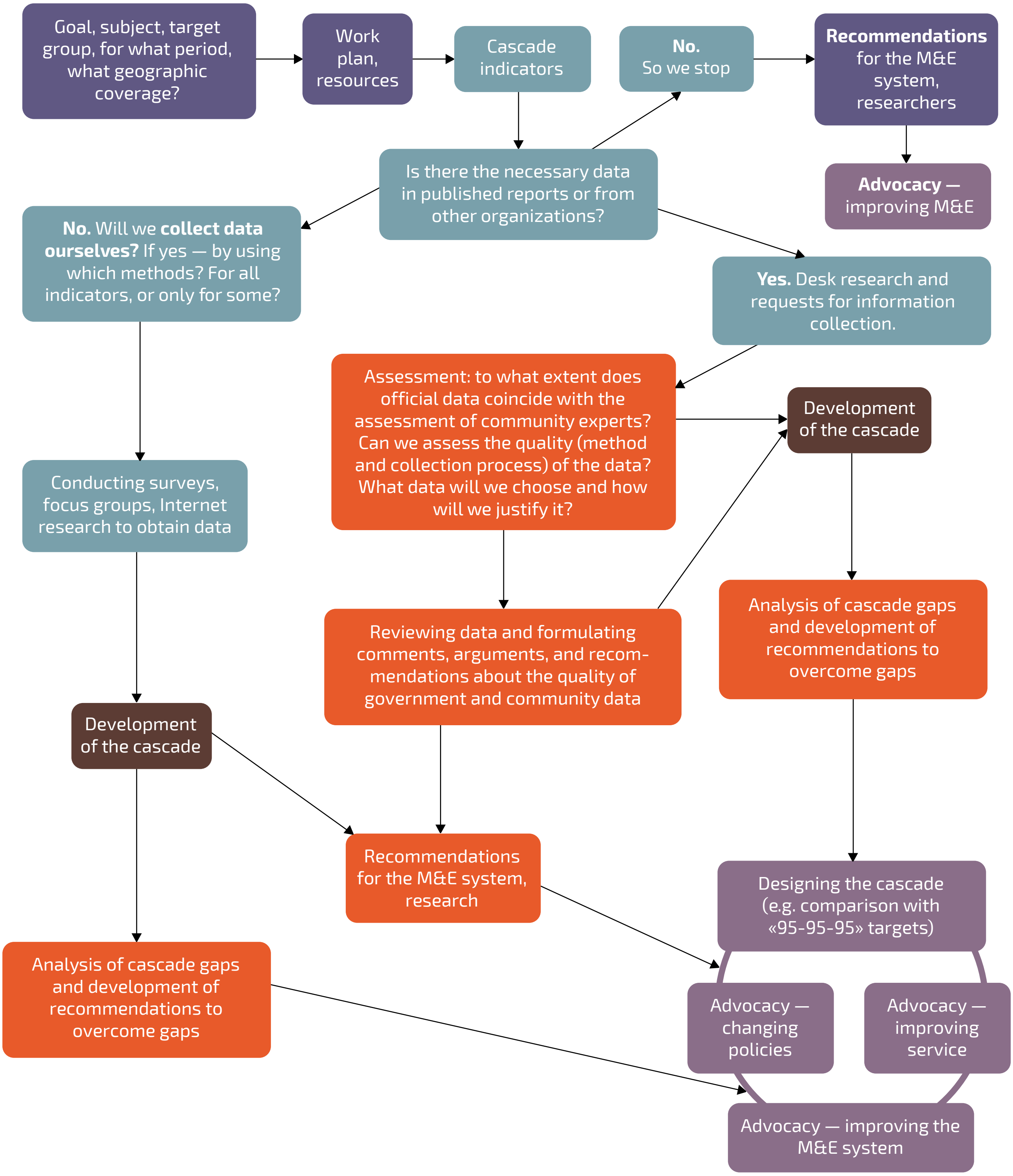
- Development of recommendations for M&E.
- Assessment of gaps and barriers.
- Drafting recommendations to overcome barriers.
- **Часть 3**

STAGE 4: USING THE CASCADE FOR ADVOCACY

- Using the results.
- Improving service.
- Changing policies.
- Impoving the M&E system.
- **Part 4**

The flow of work and possible steps within these four stages will depend on your goals, the availability of data, and the resources available to you for working on developing the cascade. An approximate scheme of work is presented below. Descriptions of the various components of these stages are included in relevant parts of this publication

LOGICAL FRAMEWORK: WORK FLOW FOR CASCADE



1.4 PREPARATORY STAGE: PLANNING

EXAMPLE OF A GOAL AND OBJECTIVE

Goal: Advocacy to achieve the national «95-95-95» targets for trans* people

Objectives:

- Identify the main gaps in data on trans* people based on available official statistics;
- Assess the quality of data using community experts and prepare recommendations for improving the M&E system to improve the integrity and quality of data;
- Collect community expert assessments on achieving the «95-95-95» targets on issues for which there is no government data, when such data is of poor quality, or when such data contradicts the reality of working projects;
- Prepare recommendations from the communities on what needs to be improved in terms of the data collected, and in the provision of services, including services at the community level;
- Promote the use of the prepared data in national reports of the government and various organizations on the implementation of the national HIV program

PREPARATORY STAGE: CHECKLIST OF RESULTS

- Goals;
- Preliminary ideas/assumptions, their possible use in future work;
- Main aspects of the cascade: type, indicators, and potential sources of information, possible problems with data;
- Description of work on developing the cascade for internal and external use;
- Expert committee with partners and experts (terms of reference, membership);
- Work plan with deadlines, resources, stages, experts, and responsible persons;
- Project team.

At the preparatory stage, the goals, objectives, and scope of work should be determined, and a preliminary plan of action should be drawn up indicating resources and responsible staff members/consultants. For planning (as well as for beginning/ending each stage of work on the cascade), it is worth organizing a meeting with partner organizations (NGOs, as well as state agencies). Before the meeting, you can prepare the proposals and questions that should be discussed with your partners.

In view of the fact that the cascade is a tool for dialogue with government agencies and service-provision organizations, in order to develop this dialogue, it is worth involving not only representatives of community and service NGOs, but also those of government and academic institutions, AIDS centers or infectious disease clinics, UN agencies (UNAIDS, UNDP, UNFPA, World Bank, etc.), and of international technical agencies, such as the US Centers for Disease Control and Prevention (CDC). They will help improve the methodology, recommend experts, or offer their assistance. All this will contribute to the recognition of the results of the work by important partners (the government, international agencies), and will also help in conducting advocacy using the data collected.

Below are five aspects that are particularly important to clarify during the preparatory stage:

1. **Setting goals and objectives, why are you developing the cascade, and how will you use it**. At this stage, it is important to determine how you will use the cascade — what kind of work are you planning with the resulting product. Below are just a few options for questions:
    - *Is it important for you to develop any, even a very simple, cascade of services for trans* people, since you never had anything like that before?*
    - *Is the cascade needed to improve planning and service provision by doing specific work with essential service providers, where the biggest gaps are possible?*
    - *Do you need a cascade of services as a tool to monitor the needs of trans* people, and do you wish to pilot a data collection project in order to establish regular collection and comparison of data on the availability and quality of services?*
    - *Is it important for you to get a comparison of the situation in different countries in order to facilitate an exchange of experiences or organize a regional advocacy campaign?*
    - *Do you need data to understand gaps and incorporate activities into your strategic program or work plans?*
    - … and many other possible goals and objectives…
2. **Identifying the group (groups), geographic coverage, and time period for the review**. The choice of geographic coverage of the cascade will affect the selection of sources of information and experts, so this should be done at the initial stage of work. The described group of trans* people may include, for example, only those who were diagnosed with HIV in the last two years. In addition, the group could include all trans* people who were diagnosed with HIV since the beginning of the epidemic in the country (national level). The group can be formed according to the behavioral principle (involvement in sex work, drug use (including those who practice chemsex), etc.), or by age, or place of residence.
3. **Type and cascade indicators**. Based on the main goal, discuss and determine the list of questions to which you want to receive an answer through data collection. Perhaps you want to focus on a particular service? What kind of indicators are used in existing programs and projects being implemented in the country, and what indicators are used in international initiatives? In other words, what do you need to synchronize your cascade, and how can you do this? Are you collecting data for comparison with other cascades in your country, or for comparison with other countries? Do you want the cascade you are collecting to become part of regular national monitoring, which will also affect the choice of indicators and sources of information?
4. **Assessing existing resources for work, identifying responsible persons and experts**. The first thing to do is to distribute tasks among your team members. It is necessary to identify those responsible for collecting information from official sources, conducting an assessment among the community on the quality of the service or the reasons for the lack of access to services, clarifying the wording of indicators, and compiling data, as well as those who will be responsible for presentation and advocacy. In the process, you may want to consult with experts, therefore, you need to prepare a list of necessary experts. If, in addition to collecting information from official sources, you will conduct an assessment and focus groups with community representatives, you will need to involve experts with experience in sociological research and people with access to the wider trans* community.

It is important not to try to collect too many indicators in a cascade; all efforts should be focused on compiling the cascade. From the very beginning, you should remember the steps that follow data collection: gap analysis, developing recommendations, and conducting advocacy.

5 **Opportunities for advocacy and cooperation within 1-2 years — how this affects timeframes and approaches**. You should think about what you want to change in the future using the results of the cascade, and what important processes you can use to develop advocacy (for example, your own strategic planning, evaluating the national program, revising national or global monitoring and evaluation systems, drafting a new country application to the Global Fund, etc.). Are you aiming to ensure that, in the future, academic institutions and services responsible for monitoring and evaluating the HIV response and epidemiological research are committed to developing a cascade of services based on your example? If yes, these institutions and services should be involved in the process of identifying indicators. Perhaps IBBS is planned in the next six months, and you will be able to influence the process of designing the questionnaire and the approach to collecting and analyzing information? These possibilities and processes will help you initially to think about how you will use your product. In addition, you will be able to determine a strict timeframe for completing the development of your cascade, as well as a list of organizations and projects with which it will be important to coordinate your work on data collection.

Based on the results of the first (preparatory) stage, you will be able to determine what particular kind of cascade best suits your goals (only on «95-95-95», only on PrEP, only on prevention, or a combined cascade), how detailed it should be, and what needs to be adapted in it for your objectives. This Guide primarily concentrates on a standard HIV treatment cascade. However, it is very important to remember that it is possible and necessary to clarify the content of the future cascade depending on the specifics of your country and your own work. You need to do this before you begin collecting data.

We strongly recommend making your own cascade comparable to at least the national HIV program indicators and those of the global Sustainable Development Goals. The «95-95-95» targets are just one example of such global indicators

2

DEVELOPING A CASCADE OF SERVICES FOR TRANS* PEOPLE

KEY STEPS AT THE STAGE OF DEVELOPING A CASCADE OF SERVICES FOR TRANS* PEOPLE

- Identifying cascade indicators;
- Identifying the main sources and methods for collecting information;
- Determining your approach if data is missing or unreliable;
- Designing and conducting desk research for data collection;
- Data collection via requests for information;
- Data collection by communities and experts.

2.1

CASCADE INDICATORS

The selection and adaptation of indicators of the cascade of continuous care will depend on the parameters determined during the preparatory stage: what are the goals/objectives, geography, group/subgroup, etc.

An approximate list of possible indicators is presented in the tables below. These indicators cover the «prevention cascade», the cascade of services for trans* people living with HIV for achieving the «95-95-95» targets, as well as the PrEP cascade for trans* people. The indicators shown (see Table 1, 2 and 3) are just recommendations. If desired or necessary, they can be adapted to specific situations or needs. You can add additional intermediate indicators that will reflect intermediate stages of a person's movement from one service to another. They are useful when you need to analyze the reasons for large «dropouts» of people from the field of services (for example, dropouts between HIV testing and receiving ARV therapy may be related to registration in outpatient care). However, you can also omit some indicators, thereby simplifying the cascade to the three most important indicators: «95-95-95».

The more indicators there are, the more data must be collected and verified.

Before providing comments on possible subtleties in data collection from official statistics, and recommendations for possible additional and intermediate indicators, we will provide general recommendations in the next two sections on what principles should be followed while collecting information, and on what steps to plan for when developing cascades.

Indicators for an HIV prevention, diagnosis, and treatment cascade for trans* people.

Table 1. Prevention cascade

CASCADE INDICATOR	1. ASSESSMENT OF THE POPULATION SIZE OF TRANS* PEOPLE	2. COVERAGE BY SPECIFIC PREVENTION SERVICES	3. COVERAGE BY TESTING
Indicator and additional indicators for TPLH and HIV-trans* people	**1. Estimated number of trans* people in the country** 1.1. Estimated number of trans* people in the country, preferably broken down by each subgroup: trans* women, trans* men, non-binary persons. 1.2. Estimated number of TPLH and their percentage out of all trans* people, preferably by each subgroup.	**2. Number and percentage of trans* people who are covered by information and support activities through outreach work and other means** to prevent HIV infection 2.1. Number and percentage of trans* people who are covered by information and support activities through outreach work and other means.	**3. Number and percentage of trans* people who have been tested for HIV, received related counseling and know their test result** 3.1. Number and percentage of trans* people who in the last 6[11] or 12[12] months have been tested for HIV, received related counseling and know their test result.
Percentage = Numerator/ Denominator	**1. Represented as a number and 100%**. 1.1. Estimated number of TPLH	**Numerator**: Total number of trans* people reached through outreach work and other means in the country/region/city during a given period (year or quarter, depending on national definitions); **Знаменатель**: Estimated number of trans* people in the country/region/city for which the cascade was developed, divided by 100%[13].	**Numerator**: Number of trans* people who received HIV counseling and testing in the last year (or twice a year depending on national guidelines) and know their test result; **Знаменатель**: Estimated number of trans* people divided by 100%..
Possible sources of information	Data from the most recent IBBS on trans* people.	Data from the most recent IBBS on trans* people. Data from the most recent population size estimate of trans* people.	Data from the most recent IBBS on trans* people. Data from the most recent population size estimate of trans* people.

---

[11] In accordance with WHO recommendations.

[12] Most often, data is collected for 12 months.

[13] Practical example. Suppose your country has program data (obtained from organizations that cover trans* people with prevention programs) showing that outreach workers covered, in other words provided services to, 400 trans* people in a year. The latest IBBS data indicates that there are 2,000 trans* people in the country. Put cells in Excel in percentage format. The formula for determining the percentage of coverage with information and support through outreach will look like this: = 400 / (2000/100%), after which you get 20%. The cascade indicates that 20% of trans* people are covered by information and support through outreach work.

ИНДИКАТОР КАСКАДА	1. ОЦЕНКА РАЗМЕРА ПОПУЛЯЦИИ ТРАНС* ЛЮДЕЙ	2. ОХВАТ ТЕМИ ИЛИ ИНЫМИ УСЛУГАМИ ПРОФИЛАКТИКИ	3. ОХВАТ ТЕСТИРОВАНИЕМ
Possible sources of information	Official statistics or published data from assessments conducted by both national and international expert organizations (e.g.government agencies, UN agencies, universities, international development programs, other similar sources). This data can also be found in national/local HIV programs, or in applications for funding submitted to the Global Fund.	Program databases of organizations that conduct outreach work or organize/monitor such work.	Databases of organizations providing testing services, e.g. MSM/LGBT/trans* service organizations, state AIDS centers/clinics. Note: It is better to use IBBS data when IBBS is carried out at a sufficient level, with community involvement and good geographical coverage, as well as when the quality of program data may be questionable (for example, if duplication of people is possible). If the country/city has not yet or does not conduct IBBS among trans* people, program monitoring data can be used: testing in projects that provide such services, or testing in state AIDS centers or other medical institutions.

Table 2. «95-95-95» targets cascade for trans people living with HIV (TPLH)*

CASCADE INDICATOR	1.1 ASSESSMENT OF THE POPULATION SIZE OF TPLH	4. KNOWLEDGE OF THEIR HIV+ STATUS	5. INCLUSION IN TREATMENT AND SUPPORT PROGRAMS FOR HIV+ PEOPLE: TPLH UNDER REGULAR MEDICAL EXAMINATION IN ACCORDANCE WITH NATIONAL STANDARDS AND WHO RECOMMENDATIONS	6. RECEIVING ARV THERAPY	7. ACHIEVING SUPPRESSED VIRAL LOAD
Indicator	**1.1. Estimated number of TPLH and their percentage out of all trans* people**	**4. Number and percentage of trans* people living with HIV who know their HIV+ status and have received relevant counseling about their rights as PLH, and the medical, social, and legal assistance available in the country.**	**5. Number and percentage of TPLH who began using specialized support and medical care for HIV out of all those who know their HIV+ status.**	**6. Number and percentage of TPLH who receive ARV therapy in accordance with national protocols.**	**8. Number and percentage of TPLH on ARV therapy who have a confirmed suppressed viral load.**

CASCADE INDICATOR	1.1 ASSESSMENT OF THE POPULATION SIZE OF TPLH	4. KNOWLEDGE OF THEIR HIV+ STATUS	5. INCLUSION IN TREATMENT AND SUPPORT PROGRAMS FOR HIV+ PEOPLE: TPLH UNDER REGULAR MEDICAL EXAMINATION IN ACCORDANCE WITH NATIONAL STANDARDS AND WHO RECOMMENDATIONS	6. RECEIVING ARV THERAPY	7. ACHIEVING SUPPRESSED VIRAL LOAD
Percentage = Numerator*Denominator **Percentage = Numerator/ Denominator**	**1. Represented as a number and 100%.** 1.1. The estimated number of TPLH = estimated HIV prevalence (%) X estimated number of trans* people (indicator 1).	**Numerator**: Number of trans* people living with HIV who know their status based on a diagnosis made in accordance with national diagnostic standards and are currently living; **Denominator**: Estimated number of trans* people living with HIV divided by 100%. If possible, the percentage of TPLH who know their HIV status and who received counseling about living with HIV and about available medical, social, and legal assistance in accordance with national standards/recommendations when receiving their diagnosis can be assessed separately.	**Numerator**: The number of PLH in outpatient care and regularly undergoing clinical examination in accordance with national guidelines during the last 12 months. **Denominator**: Number of trans* people alive at the time of data collection who know their HIV+ status based on a diagnosis made in accordance with national HIV diagnostic standards divided by 100%.	**Numerator**: Number of trans* people who know their HIV+ status and regularly undergo HIV-related medical examination, who, at the time of the study, are receiving ARV therapy in accordance with protocols. **Denominator**: Number of PLH in outpatient care and regularly undergo medical examination in accordance with national recommendations during the last 12 months, divided by 100%. Here, you can also calculate the percentage of those receiving ARV therapy out of all TPLH who know their HIV+ status, as well as the percentage of those receiving ARV therapy from the estimated number of TPLH.	**Numerator**: Number of TPLH receiving ARV therapy for at least 12 months, who have HIV viral load values below a certain level (according to national standards or recommendations for viral load measurement). **Denominator**: Number of TPLH who have received ARV therapy for at least 12 months in accordance with national protocols, divided by 100%. Here, you can also calculate the percentage of TPLH with suppressed viral load from all TPLH who know their HIV+ status, and the percentage of TPLH with suppressed viral load from the estimated number of TPLH.

CASCADE INDICATOR	1.1 ASSESSMENT OF THE POPULATION SIZE OF TPLH	4. KNOWLEDGE OF THEIR HIV+ STATUS	5. INCLUSION IN TREATMENT AND SUPPORT PROGRAMS FOR HIV+ PEOPLE: TPLH UNDER REGULAR MEDICAL EXAMINATION IN ACCORDANCE WITH NATIONAL STANDARDS AND WHO RECOMMENDATIONS	6. RECEIVING ARV THERAPY	7. ACHIEVING SUPPRESSED VIRAL LOAD
Possible sources of information	Official statistics or published data from assessments conducted by both national and international expert organizations (e.g.government agencies, UN agencies, universities, international development programs, other similar sources). This data can also be found in national/local HIV programs.	Data from the most recent IBBS for trans* people, and, if available, statistics from the database of registered HIV cases. In the absence of data from official state or local monitoring, data from studies and surveys conducted by NGOs or international organizations can be used. If there is both official data and data from NGOs and international agencies, it should all be cited, and in case of significant discrepancies between them, the possible reasons for this should be clarified.	Database of patients of AIDS centers and/or infectious disease hospitals. Data from the most recent IBBS for trans* people. In the absence of data from official state or local monitoring, data from studies and surveys conducted by NGOs or international organizations can be used. If there is both official data and data from NGOs and international agencies, it should all be cited, and in case of significant discrepancies between them, the possible reasons for this should be clarified	Database of patients receiving ARV therapy. Data from the most recent IBBS for trans* people. In the absence of data from official state or local monitoring, data from studies and surveys conducted by NGOs or international organizations can be used. If there is both official data and data from NGOs and international agencies, it should all be cited, and in case of significant discrepancies between them, the possible reasons for this should be clarified	Database of patients receiving ARV therapy. Data from the most recent IBBS for trans* people. In the absence of data from official state or local monitoring, data from studies and surveys conducted by NGOs or international organizations can be used. If there is both official data and data from NGOs and international agencies, it should all be cited, and in case of significant discrepancies between them, the possible reasons for this should be clarified.

Table 3. Pre-exposure prophylaxis cascade for HIV- trans people*[14]

CASCADE INDICATOR	1 ESTIMATED NUMBER OF TRANS* PEOPLE IN THE COUNTRY, WITH AN INDICATION OF THE ESTIMATED SIZE OF EACH SUBGROUP: TRANS* WOMEN, TRANS* MEN, NON-BINARY PERSONS	2. ESTIMATED SIZE OF TRANS* POPULATION IN NEED OF PREP	3. KNOWLEDGE ABOUT PREP	4. STARTING PREP	5. TRANS* PEOPLE WHO REMAIN HIV-
Indicator	**Absolute number of trans* people and their percentage of the total population of the country/territory.**	**Estimated number of HIV-trans* people who are at significant risk of HIV infection (according to the definition of risky behavior in the national HIV program/strategy and/or the WHO definition[15])**	**Of these — number and % of HIV- trans* people who have correct knowledge about pre-exposure prophylaxis for HIV infection using ARV drugs**	**Of those HIV-trans* people who know about PrEP, the number and % of those who began taking pre-exposure prophylaxis**	**Of those — number and % who remain HIV-12 months after starting PrEP.**
Possible sources of information and comments	National or local studies to estimate the population size of trans* people. If there are no such studies, you can use the assessments of experts (doctors, other experts from government agencies and institutions, community experts, and experts from international organizations).	Data obtained through IBBS or other studies of risky practices among trans* people (with an indication of subgroups of trans* people), or program data. If there is no such data, you can use the assessments of experts. The WHO recommends PrEP for trans* people, mentioning both trans* women and trans* men[16] It is worth following the recommendations of the WHO and other international organizations in including them in national definitions.	Data from the most recent IBBS or other study among trans* people (with an indication of subgroups of trans* people, where possible). If there is no such data, you can use the assessments of experts.	Data from the most recent IBBS among trans* people or program data from PrEP programs.	Data from the most recent IBBS among trans* people or program data from PrEP programs.

---

[14] No recommendations were found for a PrEP cascade for trans* people. There is no single recommendation for a PrEP cascade for MSM. The previous sections presented various examples from Washington, DC. Another approach is suggested in San Francisco in Liu, A. et al. *The Spectrum of Engagement in HIV Prevention: Proposal for a PrEP cascade*. IAPAC.

[15] The WHO has published a strategic planning module «WHO Implementation Tool for Pre-Exposure Prophylaxis (PrEP) of HIV Infection». It provides guidance on prioritizing groups to whom PrEP is recommended.

[16] The WHO discusses gaps in clinical knowledge in the context of PrEP among trans* people. Available information suggests that there are no significant drug interactions between PrEP and hormone replacement therapy. https://apps.who.int/iris/bitstream/handle/10665/255889/WHO-HIV-2017.17-eng.pdf;jsessionid=0515801438CF1C4F1CB8752DA4A5D930?sequence=1

2.2 STEPS

We have indicated possible data sources in the lists of example cascade indicators. In the process of collecting information (see Table 4), it is necessary to assess the quality of the collected data with the help of experts, both from the community and professionals in the field of sociology or epidemiology. If data is not available or if, according to experts, it is of low quality, then you must determine how prepared you are and whether you have the resources to begin collecting data yourself using alternative methods (provide an expert assessment, conduct a study and focus groups, and subsequently extrapolate the data to the entire population of the country/territory for which you are developing the cascade, etc.). By conducting additional focus groups and surveys, in addition to obtaining quantitative indicators for the cascade, you can, in parallel, try to clarify the reasons for gaps in the cascade, which is what is planned for the next stage of the cascade analysis (see Part 3).

If you are not prepared to collect the necessary data yourself, it is important, at a minimum, to indicate in the cascade report that data is not available and should be collected in the future. Discuss with experts the reasons for the lack of data and what needs to be done so that it is collected and used in decision-making in the future. The opinions and recommendations of experts should be included in the report on the results of the development of the cascade.

When processing the collected data, you may need to submit an additional request for information or to clarify the data and its method of collection. Some important data may be collected as part of IBBS. However, trans* people may not be included as a group studied in IBBS. In such a case, advocacy for the inclusion of trans* people in future IBBS could be the next planned step for working with the government. It is possible that data on trans* people was not provided as part of the general published report, and you may need to specifically contact the researchers who conducted the IBBS, so that they do an additional analysis of the data collected as part of the IBBS.

Table 4. Steps for gathering information: sources and methods of collecting information

STEP	EXAMPLE OF SOURCE	EXAMPLE OF DATA
Step 1. Definition of cascade indicators		
Step 2. Desk research for data collection from published reports and other documents	Estimate of the population size of trans* people.	● Estimated number of trans* people in the country, broken down by subgroup (trans* women, trans* men, non-binary persons);
	Bio-behavioral study on HIV and STI among trans* people in the country and/or IBBS (most recent studies).	● HIV prevalence. Compliance of the methodology used for the study with accepted national standards and/or WHO/UNAIDS recommendations. ● Availability of evidence of the quality of the data collection process: existence of an opinion of an ethics committee before the start of the study, quality control of data collection during the study, and availability of a report on this.

STEP	EXAMPLE OF SOURCE	EXAMPLE OF DATA
		● Access to prevention, testing, treatment services. ● Description of risky behavioral practices (use of psychoactive substances, chemsex, refusal of condoms, involvement in sex work, etc.), types of sexual practices. ● Frequency of cases of violence, rights violations, discrimination, and the forms in which they occur.
	National HIV program	● Estimated number of trans* people in the country. ● Program target indicators for trans* people, including the «95-95-95» targets in the national program. ● Determination of the criteria for monitoring the coverage of services (what set of services, what quality, and for how long should they be provided to one representative of the target group for him/her/them to be considered covered by services).
	Country application to the Global Fund	● Estimated number of trans* people in the country. ● Determination of the criteria for monitoring the coverage of services. ● Coverage targets for the provision of specific HIV prevention, treatment, and support services to trans* people.
	Program monitoring data of various projects.	● Determination of the criteria for monitoring the coverage of services. ● Coverage by prevention (including PrEP), testing, treatment, care, and support services.
Step 3. Requests for information	AIDS centers or other institutions responsible for diagnosis and treatment	● Number of trans* people with an HIV diagnosis made in accordance with the national diagnostic standard. ● Determination of the criteria for monitoring the coverage of services. ● Number of trans* people living with HIV receiving outpatient care. ● Number of trans* people living with HIV who started ARV therapy.

STEP	EXAMPLE OF SOURCE	EXAMPLE OF DATA
		● Number of trans* people living with HIV who started ARV therapy who have achieved an undetectable viral load in accordance with national protocols/ guidelines.
	National HIV monitoring center or organization-manager of prevention among trans* people (for example, the primary recipient of a Global Fund country grant). International organizations that support or carry out prevention programs among trans* people in the country/territory. National organizations providing HIV prevention services to trans* people (many NGOs collect data as part of their internal M&E system; data should be on unique users, i.e. how many different people received services, even if these services were repeated)	● Determination of the coverage of services; ● Coverage of trans* people by prevention measures.
Step 4. Preliminary development of the cascade and assessment of data quality and integrity		
Step 5. Determining the need for additional data collection. If yes — determine the parameters and methods of collection. If no — proceed to the next stage of work on the cascade		
Step 6. Collection of additional data through focus groups, surveys, and expert assessments. **Here, provide for the need to include questions to assess the reasons for gaps in the cascade (see Section 3.4)**	Focus groups among trans* people living with HIV and other trans* people.	● Gaps in prevention; ● Experience and practice of diagnostics, practice of outpatient care, treatment, and the percentage of those achieving a suppressed viral load, opportunities for improving services and demand for services from communities.
	Focus groups or surveys among experts from services and NGOs providing prevention services for trans* people.	● Expert assessment of the number of people according to a certain cascade indicator. ● Assessment of the causes of significant gaps (lagging behind targets) in the cascade. ● Making recommendations for improving services in order to achieve target indicators and reduce gaps in the cascade.

STEP	EXAMPLE OF SOURCE	EXAMPLE OF DATA
	Semi-structured interviews, focus groups, secondary analysis of already published data If the above is not possible due to a lack of resources, then conduct a survey of trans* people (for example, using a short, 10-15 question, anonymous online survey).	● Assessment of the reasons for use or non-use of various services. ● Collection of recommendations for improving services in order to achieve target indicators and reduce gaps in the cascade (for example, increasing the willingness of the community to use PrEP, changing the opening hours of institutions and NGOs, preventing discrimination and stigma on the part of employees of institutions and NGOs).

2.3 APPROACH TO DATA COLLECTION

Some of the recommendations that you can make based on data analysis will relate to improving the availability, accessibility, and quality of data in various institutions and NGOs, (see section *3.1. Recommendations for a monitoring and evaluation system*). It is important to make these recommendations as precise and specific as possible.

When collecting data using the efforts of community organizations and their partners, we recommend that you adhere to the following principles:

1. **A more in-depth understanding of data sources, quality, and limitations**. It is worth assessing where data came from, how it was collected, and what limitations there are in terms of its quality and its use. Limitations in collected data are primarily indicated in the description of the research methodology, but can also be determined by analyzing the research process. It is good if the study was assessed by an independent ethics committee and had people observing adherence to the methodology. In addition, speaking with the researchers who collected/processed the data can deepen understanding of what it indicates and to what extent it meets your needs, etc. Specialists with research experience can be included in the expert group of your cascade project.

   - It is necessary to assess the quality of the data collected, and determine how reliable it is. For example, some data may seriously conflict with the experience and data of service organizations or community representatives.

   - In some cases, it is necessary to clarify data, for example, in order to find out how many people know their HIV+ status. It is also necessary to exclude dead people from the number HIV cases registered in the country, which can be difficult in the countries of Eastern Europe and Central Asia. If this is not done, the data will show that case detection works better, and that there is more loss between diagnosis and medical care. If you use data on the results of testing conducted in both medical institutions and through community organizations, it is necessary to clarify whether these numbers reflect the number of tests or the number of people tested, taking into account the number of repeat tests.

   - When requesting program data on various projects that took place at the same time and in the same territories, it is necessary to clarify whether there is coordination between them on the registration and coding of unique clients. If there is no coordinated system for registering clients, this should be noted in the report.

   - Stigma and discrimination can affect the extent to which trans* people are willing to reveal their trans* identity and the specifics of their sexual behaviors or drug use to healthcare workers, especially with respect to trans* women, whose transgender transition may be less visible to others. The fear of being open with healthcare workers on this issue is reflected in the accuracy of quantitative data. Due to fears of encountering misunderstandings or aggression from medical specialists, trans* women may say that they are MSM, which makes trans* people «invisible» in statistics. This may also apply to the possible registration of trans* women using the code for sex workers without mentioning that they are transgender.

   - National data collected by professional researchers based on a representative sample using methodology approved by national experts or WHO/UNAIDS is considered to be of higher quality.

   - The quality of data and its objectivity may be questionable if, for example, the questions formulated in the questionnaire were incorrect or offensive, or insensitive to the specificities of trans* people, or if the sample was small or unreasonably limited geographically.

   - If, due to a lack of national studies, data from other countries is used and extrapolated to the national situation of your country, this should be indicated as a limitation to the conclusions and recommendations developed based on the cascade, and the collection of national data should be recommended

- Data collected by national trans- or LGBT community organizations may also be of insufficient quality, so it is important to carefully examine it for limitations and indicate these limitations in the report.

2. **Preparedness for the possibility that all or part of the data may be missing**. A lack of disaggregated data for different key populations, including trans* people, or simply a lack of any sort of data, will create difficulties in the cascade development process. In many countries, monitoring systems do not track statistics on specific key populations and their access to treatment, care, and support, due to political or technical reasons.

   We recommend that you collect missing data yourself only if it does not require complicated methods and significant resources. Examples of methods and what information can be collected using them are shown in Table 4, section 2.2 (step 5).

   However, regardless of whether you collect data yourself or not, it is very important to indicate its absence in state and local health statistics and recommend that this situation be corrected in the future.

3. **Data consistency and comparability**. Data in different sections of the cascade should reflect the same geographic parameters, groups or subgroups of trans* people, and, if possible, be from the same source. Ideally, this should be national data, for example, the results of IBBS among trans* people officially obtained from the AIDS center or the Ministry of Health. If there is no such data at the national level, in exceptional cases, the principle of harm reduction can be used: data is collected only from large cities or in 1-2 regions, or even on the basis of a small sample of the community — through surveys, focus groups, or even an expert assessment. In this case, the data cannot be extrapolated to the whole country, but it can be assumed that «if the situation is the same in all regions, then…».

4. **Data collected by communities**. If data is collected through widespread anonymous surveys, focus groups, or interviews with experts, it is important that the methodology for such assessments be carefully developed. For this process, it is worth involving sociologists, and experts in research planning, data collection, describing methodology, and analyzing results. Such assessments can be of great help to community organizations, especially when there are no government or government-recognized statistics on trans* people.

5. **Definitions of what «covered» by a service means**. If you are comparing how services develop over time in accordance with national target indicators, it is worth using the wording of the indicator and definition of «service coverage» of the national program (or of the Global Fund funding application). If you propose your own definitions of indicators for the cascade, it is important to clearly explain this in the descriptive section of the cascade: why you propose a different definition than the one in the national program, why it is better, and how it can be correlated with the content of the national program.

6. **Tracking methodology and limitations**. One of the products of your work is the description of methodology, sources of information, and the limitations of the data collected. It is important to do this not only for the data collected by the community as indicated in point 4, but also for all statistics and assessments. When presenting the report on the cascade, the limitations of the data used and recommendations for improving data availability, accessibility, and quality should be presented separately. Therefore, from the very beginning, it is worth paying attention to tracking the sources of information and doing the following (boring but) important work: for each number, indicate in your internal documents the exact wording that is used in the answers you received to official inquiries, or in the publications used, indicate the data collection period and place of publication, as well as in which official response they are reflected, what was the collection methodology, and what limitations there are to the data, etc.

2.4

COMMENTS ON INDICATORS, SOURCES OF INFORMATION, AND ADDITIONAL INDICATORS

1 **Estimates of the trans* population size**. As you begin to design the cascade, you may be faced with the fact that there is no available data on estimates of the trans* population size in the country or city.

Data on the population size of trans* people can be difficult to obtain, since many trans* people are unwilling to identify themselves. It also happens that some trans* people are unlikely to be involved in research. They may be too young to be sexually active, or belong to an older generation, in which being transgender was stigmatized, which now affects their willingness to identify themselves and discuss this issue with healthcare providers.

Nevertheless, some countries already have or are planning an assessment of the population size. It is important for key stakeholders in the field of health to agree on methodologies for such an assessment in order to reach a national consensus on the population size of trans* people:

1) who are considered as trans* people, is it only trans* women and trans* men, or non-binary people as well, is there significance to the experience of medical and/or legal transition, or the social experience of living in a perceived gender, how important is a person's gender self-identification, etc.?

2) are only citizens of the country counted, or also foreigners who have lived in the country for a considerable amount of time (how long?) and who have all the necessary permits to remain in the country, or maybe even those who do not have such a permit?

3) how to ensure the meaningful participation of the trans* community to guarantee the necessary quality of the study?

4) what vocabulary should be used when developing research questions, for which questions is it important to use the vocabulary of the community, and for which questions should scientific language be used?

5) how ethical and safe are the research methods used, do they guarantee confidentiality and friendliness to participating trans* people, do respondents have the opportunity to speak openly about their sexual behavior and various practices without any fear?

In the absence of relevant research, population size estimates can be based on various data sources, such as the decisions of commissions that trans* people go through to receive a diagnosis, mental health centers where trans* people are observed for transitioning, medical centers with trans-specific services, where trans* people can receive referrals for hormone therapy or gender confirmation interventions, LGBT or MSM organizations and initiatives that provide services for trans* people, data from military commissariats (if being transgender is a basis for exemption from military service), data from civil registry offices, or other government agencies that are responsible for changing documents in case of trans-transition. In general, however, each of these sources has a number of disadvantages; therefore, data should be collected from all sources available in the country in order to obtain the most comprehensive information possible.

For example, data was collected that showed the coverage of 20, 50, and 200 trans* people by various institutes and organizations. In the absence of any complaints about the quality of the data, it can be concluded that a conservative estimate of the population size of trans* people will be no less than 200 people (the largest recorded number of real people who received services).

Studies from neighboring countries can also be used, and their estimates of the population size of trans* people can be extrapolated to your country using the ratio of the sizes of the general population of a certain age of the two countries. Thus, if country X has conducted an assessment of the population size of trans* people, and this was only carried out for trans* women between the ages of 15 and 49, then accordingly, the percentage of trans* women among the so-called male population obtained in country X can be extrapolated to the male population of the same age range in your country. Here again, this will be an assumption rather than a confirmed fact, which must be clearly indicated in the report.

It is possible that representatives of civil society may not agree with the population size assessment approved by the government. In such cases, it is worth noting this in the report on the cascade and recommending relevant future work to carry out/improve the assessment of the size of the trans* population in the country: study the methods and process used to carry out the assessment, consult national and foreign experts in the field of population estimates, request expert assistance from the UN and other international organizations, actively participate in the development of the terms of reference, and in the selection of the assessment methodology (if a new study is planned), and take an active part in conducting the study and discussing the results.

It happens that estimating population size is not only a research issue, but also a political one, requiring the coordination of the positions of various parties, including ones that are diametrically opposed. For example, if the government claims that there are no trans* people in the country, this position can be accepted as a hypothesis, and when creating a cascade of services, you can set out to provide convincing information about the existence of trans* people in the form of reliable data (for example, from state medical institutions), and, on the basis of this, propose a revision of the existing estimate, clarifying the benefits of this for national public health.

2 **Prevention coverage**. For data collection, it is necessary to determine which country information is more reliable: program data on coverage or data from IBBS. There are pluses and minuses to each of these sources. IBBS is best used if the study was conducted with the involvement of the community and has good geographic coverage, or when the quality of program data may be in doubt (for example, there may be duplications of people in the databases of service providers, or indicators for monitoring coverage do not exist or are unclear). In addition, in IBBS, data can be broken down by various characteristics, including HIV status. However, IBBS does not take place every year and is expensive, so in some countries, it may be difficult to carry out such a study after the end of financial assistance from the Global Fund.

If you plan to collect and analyze the cascade annually, then the dynamics will be shown by the program data. If program data is used (i.e. reports on the work performed by organizations and institutions providing services), it is necessary to clarify all definitions used in order to obtain data on the number of people who received the required package of services, and not just the number of contacts or visits to services.

The definition of prevention coverage may differ from project to project. If the goal for advocacy is to develop the national program, and accordingly, you want to compare target levels of coverage with the levels of coverage achieved, then it is worth collecting data on coverage based on the definitions used in the national program. However, if you do not agree with the national definition, it is worth developing a well-justified, new wording that will be used in the cascade. (In accordance with the Political Declaration on HIV/AIDS signed by our governments in 2016, the recommended coverage of key populations by prevention should aim for 90%[17].)

[17] «Political Declaration on HIV and AIDS: On the Fast Track to Accelerating the Fight against HIV and to Ending the AIDS Epidemic by 2030», http://www.unaids.org/sites/default/files/media_asset/2016-political-declaration-HIV-AIDS_ru.pdf

3. **Testing coverage**. Based on the specificities of the country and the needs of the trans* people living in it, it is necessary to determine the method of collecting this data (program data or IBBS data). When using program data, statistics on testing and counseling often show the total number of tests and counseling sessions, rather than how many people have used the service. One person could be tested several times in the same or different institutions. It is often necessary to refine the data in order to exclude repeat tests. In addition, it is important to decide over what period of time one person should be tested once, in other words, who should be considered covered by testing? In accordance with WHO recommendations, in the case of a PrEP program client, HIV testing should be done once every 3 months, and for other trans* people, once every 6 months, while national standards may refer to testing once every 12 months. In any case, if more than 12 months have passed since testing, a sexually active person cannot be considered to be covered by testing.

4. **Knowing your HIV+ status**. In relation to trans* people living with HIV who know their HIV+ status, it is important to pay attention to the fact that information is needed on living people. Often, published data only shows cumulative reported HIV cases, whether the person is alive or not.

   In countries with high levels of stigma and patriarchal attitudes, trans* people may hide their gender identity during official registration of HIV cases. Trans* women who may appear masculine and who are afraid to reveal their identity may either pass as MSM or hide their sexual contacts with men. Trans* men who have anal sex with men or trans* women may fear stigma and refuse to discuss their sex lives. In general, trans* people may be wary of being honest with medical workers in relation to HIV and may have negative experiences with other workers: national studies in EECA countries show a high level of stigma and discrimination against trans* people by healthcare workers . It is worth studying and taking into account the experience of trans* people living with HIV during the registration of their diagnosis in a medical institution (for example, this question can be included in a survey among trans* people living with HIV and/or in future IBBS).

   If the level of stigma and discrimination based on transgender identity, sexuality, and sexual behavior is high, this creates a very significant risk that the number of officially reported HIV infections among trans* people will be significantly underestimated. Furthermore, this will affect the reliability of all other parts of the cascade. This point must be indicated as a limitation of the data used for the calculation of the cascade.

5. **Receiving medical care for HIV**. A person is registered in outpatient care if all necessary tests (CD4 count, viral load, and others) have been carried out in the last assessed year, and he also has access to the diagnosis and treatment of concomitant infections, including tuberculosis, hepatitis, and STIs, and non-communicable diseases, in particular, those related to mental health and aging. This should all be assessed based on the national standard/protocol or recommendations. However, in many EECA countries, registration in outpatient care simply means the entry of data about a person into an index card, and is not associated with actual diagnostics and receipt of medical advice and treatment.

   If this is the case in your country, you will not use national program definitions for your cascade. At the same time, it should be pointed out that these formulations may not correspond to international recommendations, and an indicator can be added to show how the cascade will look if the WHO-recommended service packages and criteria for inclusion among those registered in outpatient care are applied.

   On the other hand, if national criteria are in line with WHO recommendations, be sure to indicate this in the comments to the cascade to acknowledge the quality of the national policy!

---

[18] https://ecom.ngo/library/regional-context-and-trans-people-of-eeca/

6 **Receiving ARV therapy**. The WHO and European AIDS Clinical Society recommend starting ARV therapy as soon as HIV is diagnosed. However, in a number of countries, the rules for the initiation of ARV therapy have not yet changed. In this case, it is necessary to clarify how many trans* people living with HIV met the national criteria for initiating therapy and what percentage of them were provided with ARV therapy. (Again, if this information is not available, this should be indicated in the cascade in order to later negotiate with the Ministry of Health to collect such data and transition to the standard on initiating ARV therapy recommended by the WHO).

7 **Achieving a suppressed viral load**. In the recommendations of various international agencies, the definition of what number of viral copies is considered a «suppressed viral load» or «suppression» of the virus is different. The WHO Strategic Information Guidelines recommend tracking the percentage of patients on treatment with a viral load below 1000 copies/ml[19], while the European and American recommendations define this level as less than 200 copies/ml[20]. At the same time, the WHO recognizes that the risk of HIV transmission from an HIV-infected person through sexual intercourse is reduced to almost zero when the viral load is 200 copies or less per ml.[21] UNAIDS documents recommend that viral loads are considered to be undetectable when 50 or less viral particles per ml are found in the blood[22].

Note that there is a difference between «suppressed» and «undetectable» viral loads. «Undetectable» is a viral load below 50 copies/ml, which is below the detection capabilities of the most commonly used test systems[23,24].

When designing cascades, we recommend using the national definition of what is considered a ***«suppressed»*** viral load, by which the health risks to an HIV+ person are minimized.

Other program indicators that can be used as additional indicators to more accurately describe the quality of services:

Supplement to the indicator on knowing your HIV+ status:

- Percentage and number of trans* people living with HIV who are registered in outpatient care whose sexual partners have been tested for HIV within the last 12 months.

Supplement to the indicator on remaining in outpatient care:

- Average CD4 level of a trans* people living with HIV who has been diagnosed with HIV. (Trans* people living with HIV are asked about their CD4 level, or this data is received from doctors while maintaining patient anonymity, and the average for the group is calculated).

---

[19] WHO. Consolidated strategic information guidelines for HIV in the health sector. 2015

[20] Gourlay AJ, Pharris AM и др. Towards standardized definitions for monitoring the continuum of HIV care in Europe. AIDS 2017, 31:2053–2058.

[21] Viral suppression for HIV treatment success and prevention of sexual transmition of HIV? July 20, 2018. https://www.who.int/news/item/20-07-2018-viral-suppression-for-hiv-treatment-success-and-prevention-of-sexual-transmission-of-hiv

[22] Undetectable = Untransmitable. Public Health and HIV Viral Load Suppression, UNAIDS, 2018, https://www.unaids.org/sites/default/files/media_asset/undetectable-untransmittable_en.pdf

[23] The tests used to measure viral load have a lower cut-off below which they cannot reliably detect HIV; generally this is 40 or 50 copies/ml; thus, if a person has a viral load below 50 copies/ml, he has an undetectable viral load.

[24] European AIDS Clinical Society (EACS). Recommendations 9.0, October 2017, p. 13.

Other program indicators that can be used as additional indicators to more accurately describe the quality of services:

Supplement to the indicator on receiving ARV therapy:

- Percentage and number of trans* people living with HIV, who began ARV therapy within 30 days of being diagnosed with HIV.
- Percentage and number of trans* people living with HIV on ARV therapy who pick up their medication on time.
- Percentage of months in the last year, when there were no disruptions in the supply of ARV drugs to sites dispensing them to patients.

Additional «intermediate» indicators are needed to track the trends in services. When measured regularly, the additional indicators listed above will show the stability and efficiency of medical institutions over a long period of time. Additional indicators can be selected to take into account current trends and to assess progress over the past 2-3 years. Progress to improve the link between HIV testing and registration in outpatient care, and between first being registered for outpatient care and retention in care, can be tracked annually or every two years. To track new trends in services, you need to add the following so-called «intermediate» indicators:

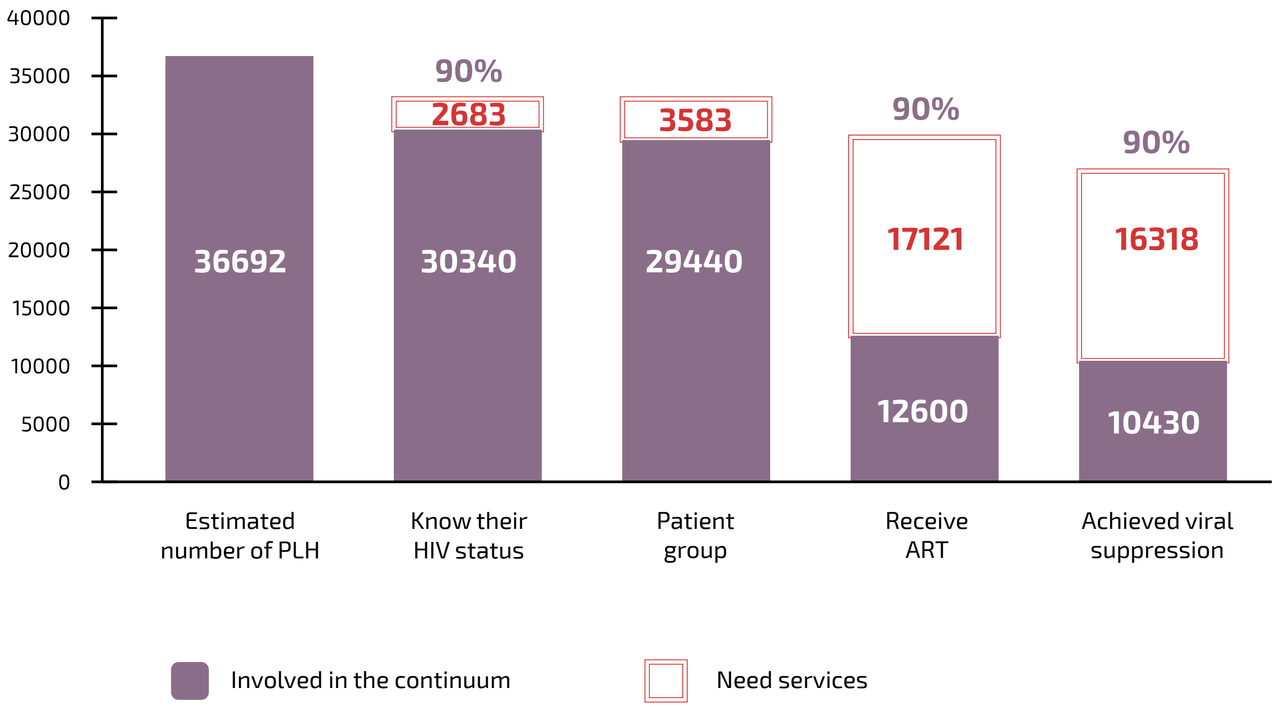
- The percentage of trans* people adhering to outpatient care (in other words, they undergo all tests and procedures recommended by their doctor) within 12 months (or 24 months) after being registered in outpatient care, out of the number of all trans* people living with HIV who were placed in outpatient care for HIV during the analyzed period;
- The percentage of trans* people living with HIV who are alive and demonstrate good adherence to ARV therapy 12 months after starting ARV therapy.

2.5 COMBINING DATA IN CASCADE FORMAT

It is recommended to collect data in the form of a table and supplement it with information on methodological aspects. As a result of collecting information, you should have one table with indicators, their value, data source, and comments on data quality. In addition, you will have a document describing the methodological aspects: the beginning and end of data collection, to where official requests were sent, and from where answers were received or not received, etc.

Using the table, you will be able to make a diagram/graph of the cascade (using the program «Excel»). An example of formatting a cascade can be found below:

Figure 7. Example of a final cascade graph



2.6 ADDITIONAL DATA COLLECTION

In addition to quantitative information on access to services, the cascade can also reflect important factors affecting these services, such as the use of certain approaches, the existence of programs, etc. One example of such a comprehensive approach is the HIV testing and treatment cascade for EECA countries presented in a UNAIDS publication.

If you are ready for such a comprehensive approach when developing the cascade, a table is presented below summarizing the recommendations from the TRANSIT on comprehensive HIV services for trans* people with information on legal aspects, human rights programs, reducing stigma and discrimination, and on mobilizing the community, all factors that affect the availability and quality of services (and therefore, the cascade indicators). Columns can be added to this table to collect information. Some of this data can be used in a simplified form to conduct a quick assessment, for example, either, on three of these parameters or just on the first one (existence or legality):

Existence of service in the country**:**

1. exists — in more than one service or in sufficient volume;
2. exists — in one service;
3. implementation is planned;
4. does not exist.

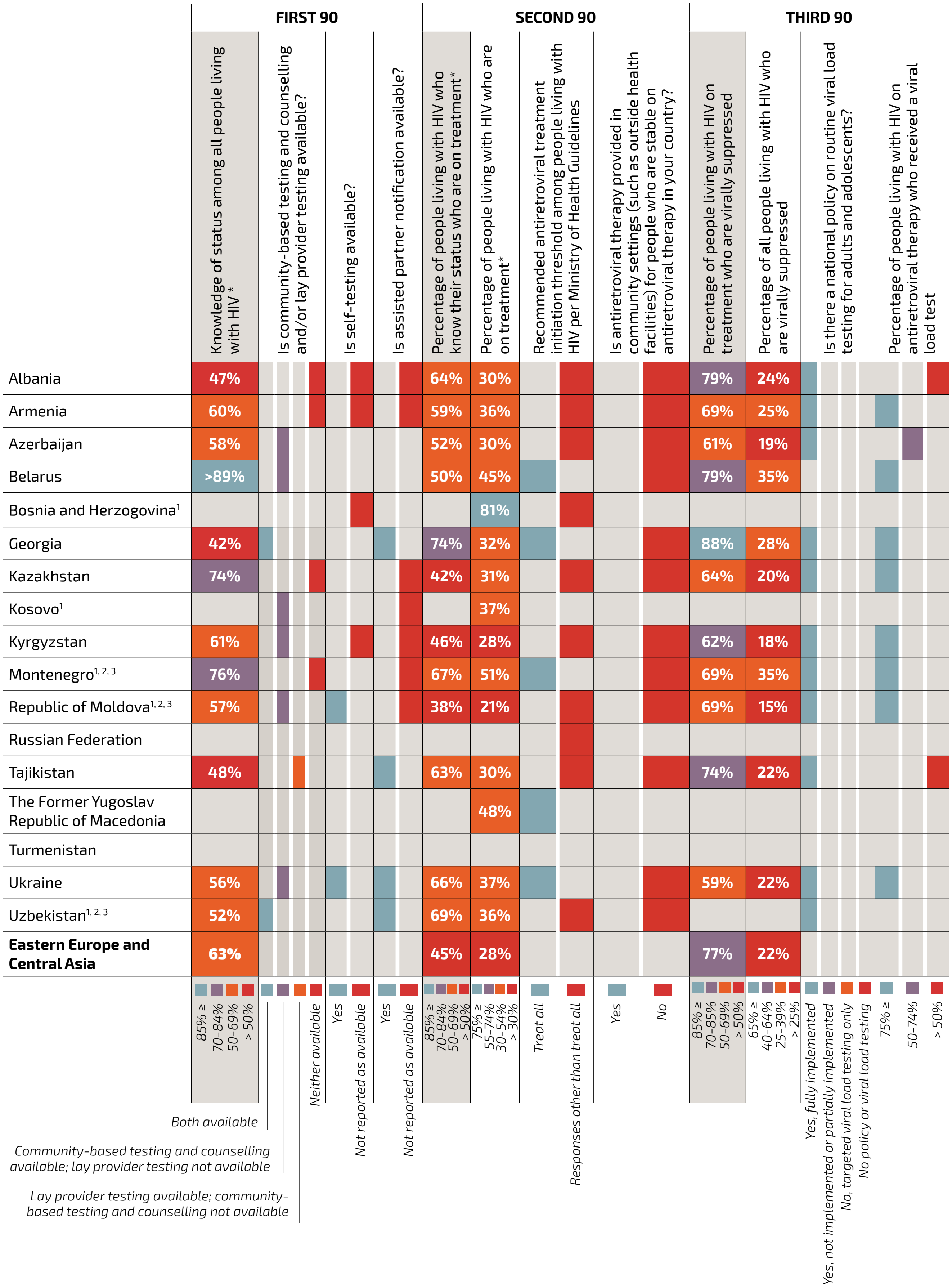
Relevance of changes or implementation in order to improve trans* health and the HIV response

1. not important;
2. important, but there are other more relevant interventions;
3. important;
4. priority.

Since this data will be used in the cascade to illustrate subsidiary factors and barriers for certain indicators, it is worthwhile to immediately determine the link between this aspect and corresponding indicators in your country. The table below shows such a link (see Table 5).

In addition to the table on comprehensive services, the TRANSIT has additional program indicators on ensuring access to and increasing demand for condoms and lubricants, community development, expanding participation, observing rights, and on highlighting the importance of gender equality and combating gender-based violence, etc. It also highlights the importance of access to and the quality of services related to gender confirmation interventions, the economic insecurity of trans* people, and the lack of safe spaces, violence from intimate partners, etc., which can also be used to assess the completeness of the range of services and measures to improve the cascade.

Figure 8. Example of a 95-95-95 testing and treatment cascade



	FIRST 90									SECOND 90							THIRD 90								
	Knowledge of status among all people living with HIV *	Is community-based testing and counselling and/or lay provider testing available?				Is self-testing available?		Is assisted partner notification available?		Percentage of people living with HIV who know their status who are on treatment*	Percentage of people living with HIV who are on treatment*	Recommended antiretroviral treatment initiation threshold among people living with HIV per Ministry of Health Guidelines		Is antiretroviral therapy provided in community settings (such as outside health facilities) for people who are stable on antiretroviral therapy in your country?		Percentage of people living with HIV on treatment who are virally suppressed	Percentage of all people living with HIV who are virally suppressed	Is there a national policy on routine viral load testing for adults and adolescents?				Percentage of people living with HIV on antiretroviral therapy who received a viral load test		
	🟦 85% ≥ 🟪 70-84% 🟧 50-69% 🟥 > 50%	🟦 Both available	🟪 Community-based testing and counselling available; lay provider testing not available	🟧 Lay provider testing available; community-based testing and counselling not available	🟥 Neither available	🟦 Yes	🟥 Not reported as available	🟦 Yes	🟥 Not reported as available	🟦 85% ≥ 🟪 70-84% 🟧 50-69% 🟥 > 50%	🟦 75% ≥ 🟪 55-74% 🟧 30-54% 🟥 > 30%	🟦 Treat all	🟥 Responses other than treat all	🟦 Yes	🟥 No	🟦 85% ≥ 🟪 70-85% 🟧 50-69% 🟥 > 50%	🟦 65% ≥ 🟪 40-64% 🟧 25-39% 🟥 > 25%	🟦 Yes, fully implemented	🟪 Yes, not implemented or partially implemented	🟧 No, targeted viral load testing only	🟥 No policy or viral load testing	🟦 75% ≥	🟪 50-74%	🟥 > 50%
Albania	47%				🟥		🟥		🟥	64%	30%		🟥		🟥	79%	24%	🟦						🟥
Armenia	60%				🟥		🟥		🟥	59%	36%		🟥		🟥	69%	25%	🟦				🟦		
Azerbaijan	58%		🟪							52%	30%		🟥		🟥	61%	19%	🟦					🟪	
Belarus	>89%		🟪							50%	45%	🟦			🟥	79%	35%					🟦		
Bosnia and Herzegovina[1]							🟥				81%		🟥											
Georgia	42%	🟦						🟦		74%	32%	🟦			🟥	88%	28%	🟦				🟦		
Kazakhstan	74%				🟥				🟥	42%	31%		🟥		🟥	64%	20%	🟦				🟦		
Kosovo[1]			🟪						🟥		37%													
Kyrgyzstan	61%		🟪				🟥		🟥	46%	28%		🟥		🟥	62%	18%	🟦				🟦		
Montenegro[1, 2, 3]	76%				🟥				🟥	67%	51%	🟦			🟥	69%	35%	🟦				🟦		
Republic of Moldova[1, 2, 3]	57%		🟪			🟦			🟥	38%	21%		🟥		🟥	69%	15%	🟦				🟦		
Russian Federation													🟥											
Tajikistan	48%			🟧				🟦		63%	30%		🟥		🟥	74%	22%	🟦						🟥
The Former Yugoslav Republic of Macedonia											48%	🟦												
Turmenistan																								
Ukraine	56%		🟪			🟦		🟦		66%	37%	🟦			🟥	59%	22%	🟦				🟦		
Uzbekistan[1, 2, 3]	52%	🟦						🟦		69%	36%		🟥		🟥			🟦						
Eastern Europe and Central Asia	63%									45%	28%					77%	22%							

* The complete set of 95-95-95 measures and testing and treatment cascade data for countries can be found at aidsinfo.unaids.org Source: UNAIDS special analysis, 2017; 2017 Global AIDS Monitoring; UNAIDS 2017 estimates; 2017 National Commitments and Policy Instrument; European Centres for Disease Control and Prevention Continuum of HIV care 2017 progress report.

[1] Estimates of people living with HIV that inform progress towards 95-95-95 are country-supplied and have not been validated by UNAIDS.

[2] All measures of progress toward 95-95-95 and the testing and treatment cascade are for 2015. Policy measures are as of 2016.

[3] Data from European Centres for Disease Control and Prevention Continuum of HIV care 2017 progress report.

Table 5. Adapted plan for the package of prevention, diagnosis, treatment, and care services for trans people recommended by the WHO (TRANSIT, 2016). (Two columns are added on the right to fill in information using the scales shown at the top)*

AREA AND SERVICE ***(possible correspondence to indicators from the Table of section 2.2 Steps or cascade indicators)***	**TRANS* PEOPLE** (note if needed by trans* women or trans* men, or by HIV status)	**SERVICE AVAIL-ABILITY IN THE COUNTRY** ***(score 1, 2, 3 or 4)***	**RELEVANCE FOR IMPROVEMENT OR IMPLEMENTA-TION** ***(score 1, 2, 3 or 4)***	**COMMENTS**
IDENTIFY THE POPULATION SIZE OF TRANS* PEOPLE (indicator 1)				
1. Trans* people in the country are not prosecuted under criminal or administrative law.	--	Yes/no		
2. The country has approved and humane (more or less suitable for trans* people) procedures for legal transition.	--			
3. The country has approved and humane (more or less suitable for trans* people) procedures for legal medical transition.	--			
4. LGBT or trans* organizations are established and operate.	--			
5. Representatives of trans* or LGBT communities are involved in the development of HIV policies.	--			
PREVENTION (indicators 2, 3)				
6. Outreach work, distribution of condoms and compatible lubricants, provision of safe spaces, community mobilization.				
7. Pre-exposure prophylaxis (PrEP) for trans* people with significant long-term risk of HIV infection.	HIV-			
8. Post-exposure prophylaxis (PEP) in case of suspected infection.	HIV-			

AREA AND SERVICE ***(possible correspondence to indicators from the Table of section 2.2 Steps or cascade indicators)***	**TRANS* PEOPLE** (note if needed by trans* women or trans* men, or by HIV status)	**SERVICE AVAILABILITY IN THE COUNTRY** ***(score 1, 2, 3 or 4)***	**RELEVANCE FOR IMPROVEMENT OR IMPLEMENTATION** ***(score 1, 2, 3 or 4)***	**COMMENTS**
9. Behavioral change interventions to reduce the risk of infection.				
10. Brief counseling on sexual practices.				
11. Screening for anal cancer.	HIV- TW, TM HIV+ TW, TM			
12. Screening for breast cancer (for TM, it makes sense to carry out screening even after a mastectomy)	HIV- TW, TM HIV+ TW, TM			
13. Screening for prostate cancer.	HIV- TW HIV+ TW			
14. Screening for STIs.				
15. Harm reduction for trans* people who use drugs (needle and syringe exchange programs, opioid substitution therapy[25], treatment of other drug addictions, prevention and management of cases of opioid overdoses, chemsex counseling and information with the provision of condoms and lubricants, provision of sterile injection equipment for injecting hormones or silicone).				
HIV TESTING (indicator 3)				
16. Testing at least every 12 months, and, if necessary, much more often if there is a high, long-term risk; same for sexual partners.	For HIV-			
17. For sexual partners.	For HIV+			
18. Community-based testing.				
19. Self-testing.				

---

[25] There is no evidence of interaction between opioid substitution therapy drugs and drugs used for gender confirmation interventions; however, the number of such studies that have been carried out is very limited.

AREA AND SERVICE ***(possible correspondence to indicators from the Table of section 2.2 Steps or cascade indicators)***	**TRANS* PEOPLE** (note if needed by trans* women or trans* men, or by HIV status)	**SERVICE AVAILABILITY IN THE COUNTRY** ***(score 1, 2, 3 or 4)***	**RELEVANCE FOR IMPROVEMENT OR IMPLEMENTATION** ***(score 1, 2, 3 or 4)***	**COMMENTS**
REPEAT AND CONFIRMATION TESTING, AND DIAGNOSIS (indicators 3, 4, 5)				
20. Retesting prior to the initiation of ARV therapy, or when testing is linked to service delivery after testing within the community.	For HIV+			
21. Retesting at least every 12 months prior to the initiation of PrEP, and much more often, if necessary, if there is a high long-term risk.	For HIV-			
22. Programs to reduce stigma and discrimination in healthcare institutions.				
TREATMENT AND ACHIEVEMENT OF SUPPRESSED VIRAL REPLICATION, PREVENTION, OTHER MEDICAL SERVICES (indicators 2, 6 and 7)				
23. Antiretroviral therapy	For HIV+			
24. Assessing the need for and the provision of vaccines, such as for viral hepatitis B.				
25. Testing and treatment for viral hepatitis B and C.				
26. Co-trimoxazole for chemoprophylaxis.	For HIV+			
27. Improving diagnosis of TB cases, and linking TB diagnosis and treatment.	For HIV+			
28. Provision of isoniazid preventive therapy.	For HIV+			
PREVENTION AND ACHIEVING SUPPRESSED VIRAL REPLICATION, OTHER SUPPORT SERVICES (indicators 2, 6, 7)				
29. Psychological and mental health services.				
30. Psychological counseling, counseling for support and treatment	For HIV+			

AREA AND SERVICE ***(possible correspondence to indicators from the Table of section 2.2 Steps or cascade indicators)***	**TRANS* PEOPLE** (note if needed by trans* women or trans* men, or by HIV status)	**SERVICE AVAILABILITY IN THE COUNTRY** ***(score 1, 2, 3 or 4)***	**RELEVANCE FOR IMPROVEMENT OR IMPLEMENTATION** ***(score 1, 2, 3 or 4)***	**COMMENTS**
31. Endocrinological counseling				
32. Support for disclosing one's status and notifying partner, provision of psychological assistance to the partner.	For HIV+			
33. Legal services.				

3

ANALYSIS OF THE CASCADE OF SERVICES AND DEVELOPMENT OF RECOMMENDATIONS

During the stage of analyzing data collected for the cascade, it should be presented to your partners for preliminary recommendations and assessments on various aspects. Only after this can it be used to plan your work and/or to advocate for improvements in services and for the protection of rights.

3.1 RECOMMENDATIONS FOR A MONITORING AND EVALUATION SYSTEM

Based on the results of the development of the cascade of services, recommendations should be made for improving the monitoring and evaluation system and data collection.

As part of this work, you can ask the following questions.

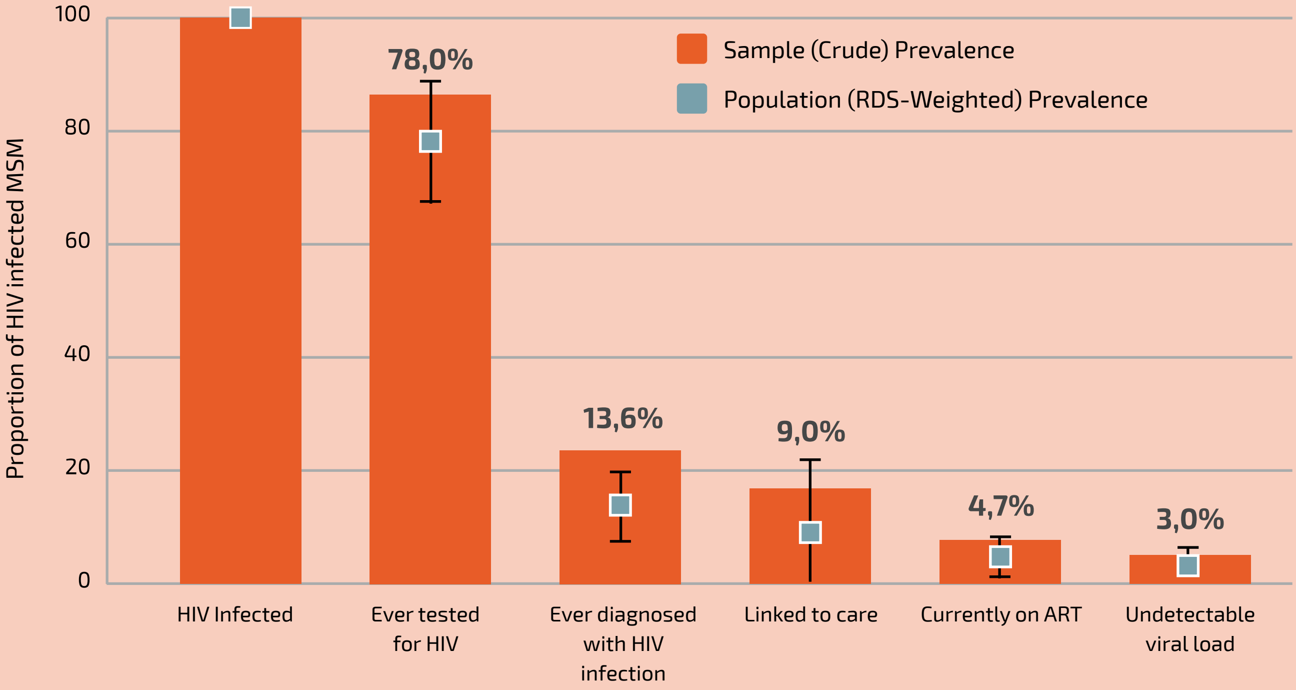
1. **For what key points is there no data on trans* people?**
    - How important is this data for assessing access to the full range of services?
    - How can missing data be collected? What is the role of community organizations in this process?
    - How can data collection be made inexpensive and regular, rather than just a one-off exercise, and consistent with ethical principles, and the interests of community members?

EXAMPLE. INTEGRATION OF THE CASCADE MEASUREMENT INTO IBBS

Specialists from Johns Hopkins University (USA) together with colleagues from the Regional Public Organization «AIDS Infosvyaz» conducted IBBS in Moscow (Russia). The survey included questions that allow for tracking the movement of HIV+ MSM along the cascade, including information about the number of people living with HIV enrolled in outpatient care for HIV, the number receiving ARV therapy, and the number with a suppressed viral load. It is important that the data in different columns of the cascade is comparable, since comparison between the columns is carried out within the same group.

Such use of epidemiological research among MSM can be a good approach to obtaining data for the cascade of HIV services for MSM, especially in cases where a number of MSM do not indicate homosexual sex as the possible path of infection when diagnosed with HIV. To use IBBS, it needs to be supplemented with several indicator questions for the cascade. However, it is important to note that in countries with low levels of HIV infection among MSM, the sample of HIV+ MSM may be too small to obtain statistically reliable data. Therefore, you need to discuss with the researchers carrying out IBBS about how you can reduce data limitations.

Figure 9. HIV testing and care cascade for MSM in Moscow



Source: Wirtz AL, Zelaya CE et al. The HIV care continuum among men who have sex with men in Moscow, Russia: a cross-sectional study of infection awareness and engagement in care. Sex Transm Infect. 2016 March; 92(2): 161–167.

2 What data raises doubts of the community about its reliability?[26]

Why? How can the reliability of data be improved this year or within 2 years? What can community activists and organizations do to improve the reliability of data, and what resources are needed for this?

3 For which services is it important to analyze their availability in more detail?

What information is important? Who will collect it and how?

[26] For example, the population size of trans* people in Armenia is 150 people according to the SS conducted in 2018. The local organization, New Generation, organized several meetings with communities, other organizations, and representatives of the Global Fund in Armenia to discuss the data obtained and future SS planned for 2021.

3.2

COMPARISON OF DATA ON TRANS* PEOPLE WITH NATIONAL OBJECTIVES AND PROGRESS AMONG OTHER GROUPS

Typically, all cascades compare progress against international targets. If a country has its own effective system for setting national targets for the country HIV program, then it would be more appropriate to compare the results of the cascade with national targets. It should also be noted that, in addition to one variant of the cascade, you can make several variants of it, where you will compare part of or the whole cascade with other population groups. For example, you can compare what percentage of trans* people living with HIV know their HIV status compared to people living with HIV from other groups, what percentage of trans* people living with HIV receive treatment and achieve viral suppression, etc. You can also find out how the cascade for trans* people in your country differs from the cascade of other countries.

3.3

IDENTIFYING SUCCESSES

In the steps of the cascade, attention should be paid to both gaps, as well as to those areas and stages where trans* people successfully receive and use services. After establishing that significant progress has been made in these areas towards achieving international and national goals, it is necessary to discuss the following aspects:

- **Why this is possible**, i.e. what measures and approaches achieved this success, and what needs to be continued in the future?
- **How does this affect the overall response to the HIV/AIDS epidemic?** If trans* people living with HIV have a high level of coverage by treatment and long-term viral suppression, this means a reduced risk of transmission of the virus from this group to their long-term or casual sexual partners.

3.4

IDENTIFYING MAJOR GAPS (INTERRUPTIONS) IN THE CASCADE OF SERVICES AND RECOMMENDATIONS TO ELIMINATE THEM

When discussing this topic, the following questions should be asked[27]:

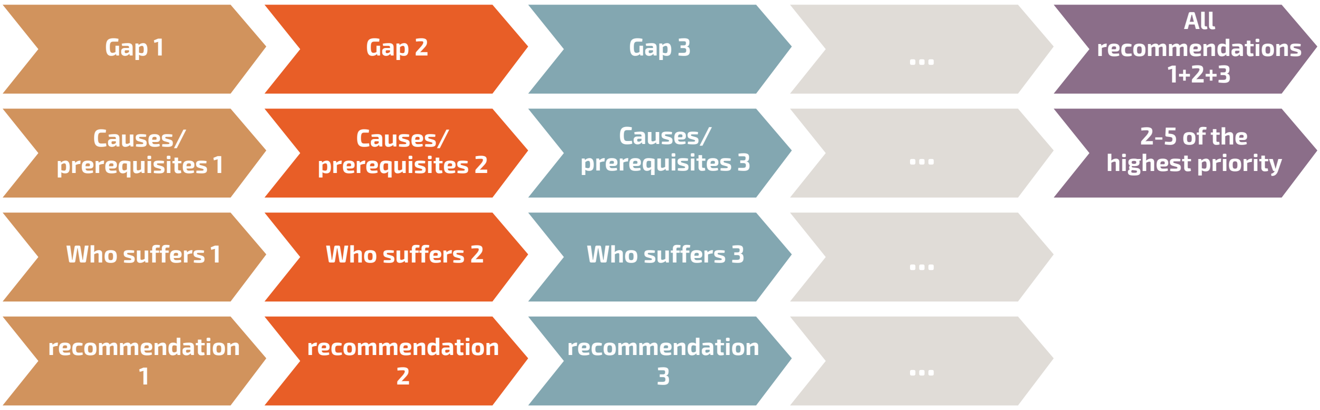
- **Where are the largest gaps (interruptions)?** Dropouts of people will be observed throughout the cascade. However, there will be more in some areas than in others. Therefore, identifying such gaps is essential to improving the continuity of care. Often, the biggest gaps are identified between stages such as «coverage of trans* people» and «tested», or a gap occurs after testing and before the stage of «initiation of and retention in ART», which means the person's inclusion in programs, or the person's involvement in HIV-related medical care (starting with registration in outpatient care). Determining where to focus efforts to improve service quality is critical in the interpretation of cascade data.

---

[27] Adapted from the publication by USAID, PEPFAR, Linkages, FHI360. HIV Cascade Framework for Key Populations, October 2015.

- **Why are there interruptions?** Together with representatives of trans* communities, individual trans* leaders, trans-, LGBT or MSM service organizations, and other stakeholders, the reasons for interruptions and their preconditions should be reviewed. Reasons for interruptions can include the following:
  - Availability and demand for services (to what extent services are available geographically, how convenient are working hours, how much do people know about the services, is the service fee acceptable, etc.)
  - Quality of services (to what extent do medical professionals have the necessary training and exhibit kindness and respect, were there previously transphobic or extremely negative cases of verbal abuse from a medical professional, what can trans* people tell each other, can trans* people be sure of the confidentiality of their transgender identity, especially in small cities where family ties can be strong?)
  - Structural barriers to the demand and availability of services (do legislation and policies help or hinder access, effect of stigma, etc.);
  - Data quality: possibly due to data limitations, interruptions are not fully reflected, or, vice-versa, they are exaggerated.
- **Who is most affected by interruptions in the cascade?** Is there data disaggregated by certain characteristics of trans* people, for example, age, income level, gender, or involvement in a particular type of activity? If yes, what differences exist between subgroups and their access to services, demand and uptake of services, and retention in services.
- **What is the best way to address gaps?** What can significantly improve access where there is the biggest interruption in the cascade, so that people seek services, and so that services are available and acceptable for representatives of communities, especially for those who are not currently receiving them? A number of recommendations for improving the service environment, services, and demand for them are presented in the TRANSIT.

To identify key gaps between different levels of services, a graphical representation of access should be developed. The discussion should be organized in such a way as to identify the reasons/preconditions for each gap, and to develop recommendations:



Gap 1	Gap 2	Gap 3	...	All recommendations 1+2+3
Causes/ prerequisites 1	Causes/ prerequisites 2	Causes/ prerequisites 3	...	2-5 of the highest priority
Who suffers 1	Who suffers 2	Who suffers 3	...	
recommendation 1	recommendation 2	recommendation 3	...	

Reasons and preconditions may be specific to trans* people or common to the general population, other key populations, or to all PEOPLE LIVING WITH HIV. This is worth indicating in the process of reviewing problems and determining recommendations on how to improve the situation for trans* people with respect to key gaps.

The discussion process itself should be planned in several stages:

1. **Literature review**, if any exists, for example:
    - Report of the WHO mission to assess HIV services in the country;
    - Assessment of ECOM cascades;
    - Assessment of cascades and causes of gaps developed in 2016 by the «Eastern European and Central Asian Union of People Living with HIV" (Ukraine) and the "Eurasian Harm Reduction Network» (Lithuania) for the following countries: Azerbaijan, Belarus, Kazakhstan, Kyrgyzstan, Russia, Uzbekistan, and Estonia;
    - Assessment of access to HIV and TB services for key populations in 5 cities conducted by the ICF «Alliance for Public Health» (Ukraine) and «AFEW International» (Netherlands) with city teams in Almaty, Balti, Odessa, Sofia, and Tbilisi (documents will be collected by September 2017).
2. **Conducting interviews or focus groups[28] with community representatives**. At this stage, differences between representatives of the community and their diverse experiences can be reflected: do they receive services or face difficulties obtaining them, do they live in the capital or in another city/town, are they from the dominant ethnic group in the country or from another ethnic group, do they use psychoactive substances, are they involved in sex work, what various age groups are they in, and what are their various economic conditions, etc. You can also conduct focus groups separately for trans* women and trans* men.
3. **Conducting separate focus groups with specialists** from institutions, services, and organizations whose work is related to those areas where there are significant gaps in other important services.
4. **Conducting meetings with cascade developers and close partners** to discuss gaps, recommendations, and the prioritization of recommendations using the intermediate results for all stages of work.

Recommendations should be divided into several parts:

- for service organizations *(for example, how services are provided, which services are lacking, how to improve the qualifications of employees, how to best organize the interaction between services)*;
- for the role of community structures *(for example, how to improve the demand for services from the community itself)*;
- for changing policies and dialogue, i.e. for your advocacy *(for example, identifying structural barriers: analyze whether the legal and policy environment helps or hinders the receipt of services)*.

In addition to these recommendations, the next stages of the discussion will use other recommendations you have developed to improve the monitoring and evaluation system. A similar meeting can be used to plan the next part of the cascade: presenting and using the results.

---

[28] We recommend conducting focus groups using trained specialists with experience in planning, conducting, and documenting this type of research. In this context, a detailed analysis of interviews and focus groups based on coding should not be carried out. It is preferable to draft summary reports with an overview of the main points with quotations if possible. More detailed information on conducting focus groups can be found at: https://www.unodc.org/documents/balticstates//EventsPresentations/Management_HR_Programmes/Needs_assessment.pdf

As with any research involving people, it is important to respect ethical requirements. For example, if you are planning a large-scale study as part of the development of a cascade and/or publication in scientific or academic journals, then you will need to contact the ethics committee for expertise. If this is not planned, then when conducting focus groups, it is sufficient to inform the respondents/participants about the conditions of anonymity, their right to refuse to participate at any time, and that participation or non-participation will not infringe on their rights. They should also be informed about possible risks.

4

PRESENTING AND USING RESULTS TO IMPROVE SERVICES AND ADVOCACY

In the previous stage, you developed recommendations on four different areas or on some of them:

- improving service (including your organization);
- the role of communities;
- improving policies and human rights protection;
- improving the monitoring and evaluation system.

4.1

DEVELOPING A CASCADE, DESCRIBING METHODOLOGY, AND A SUMMARY OF THE RESULTS

Based on the results of the previous stage, you should have 1) a cascade, 2) a description of the methodology for collecting information, 3) an interpretation of the cascade and the gaps identified, and 4) a set of recommendations. This can be drawn up in the form of an electronic presentation or even a short (up to 4-6 pages) document. In such a document, depending on the goals, you can add data on the importance of investing in programs for trans* people (for example, from the OPTIMA study), or an example of an important approach from the TRANSIT.

It is worth paying special attention to the design of the cascade itself, which will certainly be used and displayed many times for different audiences. General recommendations are presented in the inset.

GENERAL RECOMMENDATIONS FOR THE DESIGN OF THE CASCADE

- **Name**, which reflects the type of services, geography, target group (trans* people), and period/year of data collection.
- **Vertical axis**. It can display either people (in ones, hundreds, thousands...), or percentages of the group. On the axis, you need to indicate exactly what it reflects.
- **Horizontal axis**. The cascade should use the names of columns or steps that will be used elsewhere, and that are accepted at the national level in your country.
- **Values of the columns in the cascade**. Indicating a numerical value helps service providers to interpret data and use it to improve services.
- **Proportions**. Between columns, it is worthwhile to indicate a comparison, how many people from the previous step reach the next, etc.
- **Data source**. Where possible, at the bottom of the graph/chart, indicate the data sources, even in abbreviated form.

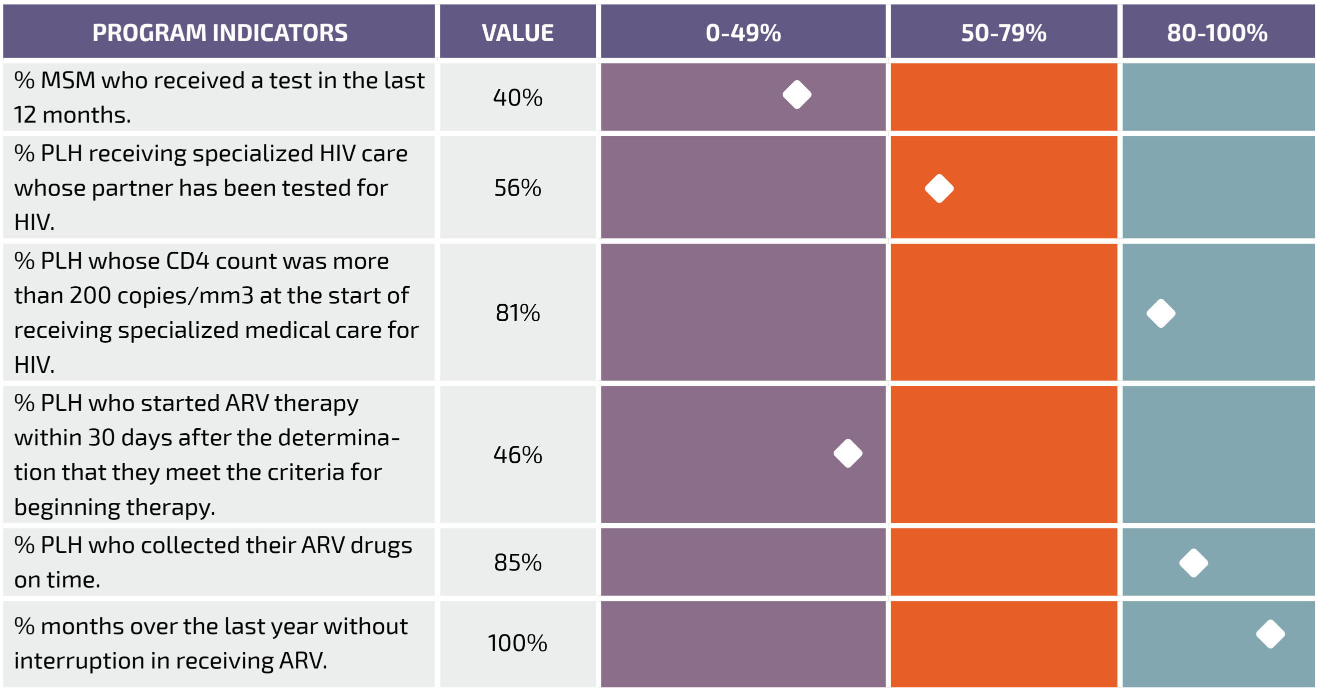
Adapted from the publication of USAID, PEPFAR, Linkages, FHI360. HIV Cascade Framework for Key Populations, October 2015.

The cascade can be displayed in a panel format, using traffic light colors, to assess according to which indicators targets have been achieved, and according to which indicators the country is close to achieving the targets (for example, 80-100% has been achieved). You can also analyze the indicators for which more than half of those in need receive services, but for which serious additional efforts are required to achieve the targets, and those for which less than half of those in need are receiving necessary services, and therefore, for which it is critically important to focus on improving work. This format is more convenient when precise data is not available, but, for example, expert assessments have been obtained. It is also useful when measuring data that is not fully consistent. For example, if you use an indicator that is not directly related to the previous one, and the value of the previous indicator is not used to assess it. Thus, the indicator «How many trans* people used condoms when last having anal sex» and the indicator «How many trans* people were tested for HIV in the last 12 months» are not directly linked. It is for such cases that the panel view of the cascade with color-coding of the level of achievement is suitable.

This format is also convenient for comparing a large number of countries. This is the format used by the European Centre for Disease Prevention and Control to compare data from HIV treatment cascades from numerous European countries as part of the report on the implementation of the Dublin Declaration on HIV[29] for 2014.

Below are examples of using the MSM programmatic data panel[30].

1st presentation option



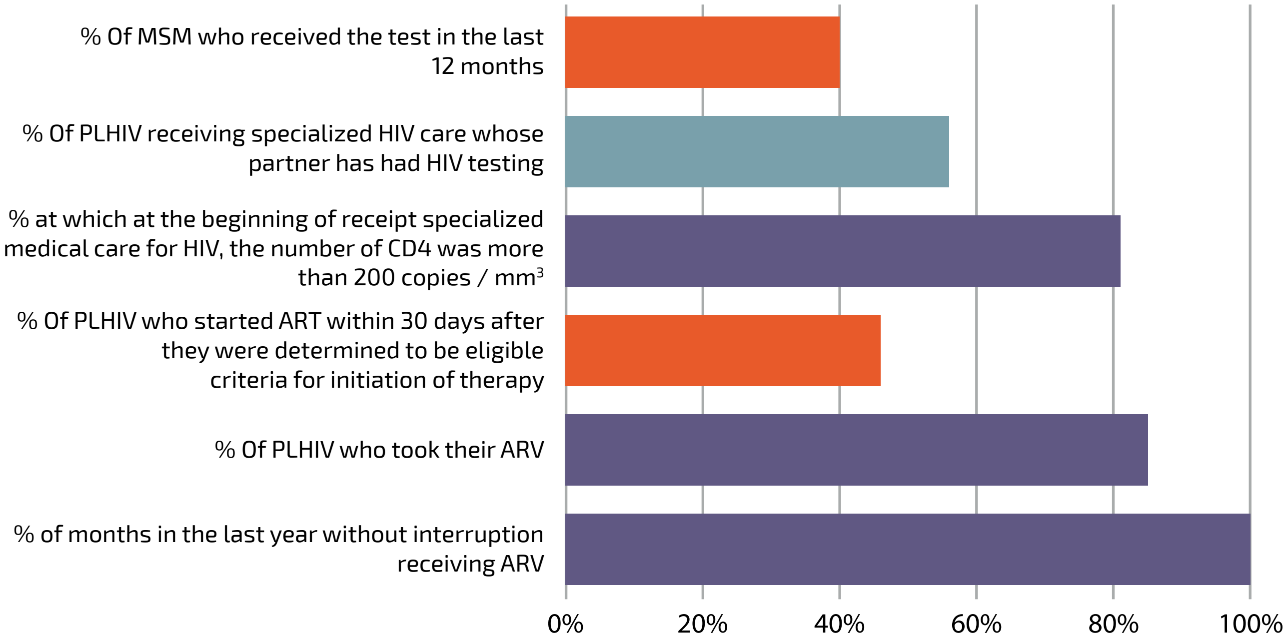
PROGRAM INDICATORS	VALUE	0-49%	50-79%	80-100%
% MSM who received a test in the last 12 months.	40%	◆		
% PLH receiving specialized HIV care whose partner has been tested for HIV.	56%		◆	
% PLH whose CD4 count was more than 200 copies/mm3 at the start of receiving specialized medical care for HIV.	81%			◆
% PLH who started ARV therapy within 30 days after the determination that they meet the criteria for beginning therapy.	46%	◆		
% PLH who collected their ARV drugs on time.	85%			◆
% months over the last year without interruption in receiving ARV.	100%			◆

---

[29] European Centre for Disease Prevention and Control (ECDC). Thematic report: Continuum of HIV care. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2014 progress report. Report available at: https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/dublin-declaration-continuum-of-care-2014.pdf

[30] Adapted from WHO, CDC, USAID, PEPFAR. Metrics for monitoring the cascade of HIV testing, care and treatment services in Asia and the Pacific.

2nd presentation option (ключ: orange 0-49%; blue 50-79%; purple >80%)



The importance of a high quality, detailed methodological description that will be read by statisticians and epidemiologists cannot be overemphasized. It will help you to answer questions about data sources and quality if they arise.

In addition to a more detailed version, you should prepare a short summary of the methodology and a description of its limitations, which can be shown before the presentation of the cascade itself. The presentation of the short version of the methodology should take no more than 2-6 minutes. By voicing any limitations of the data used at the beginning, you can avoid many suspicions and questions about the data, thereby giving you the opportunity to focus more on the results of the cascade.

4.2 PRESENTATION OF RESULTS

Based on the original purpose for developing the cascade, it is worth considering how best to disseminate the results of the cascade and the recommendations based on it. This relates in particular to those who can contribute or directly implement these recommendations.

Below are examples of the presentation of findings and recommendations.

- **Improving service:**
  - Meeting with your team and discussing the recommendations;
  - Individual meetings with key services and discussion of their results; using meetings to present the recommendations;
  - Discussing the results with organizers of technical assistance for service organizations, and integrating recommendations into the technical assistance plan;
  - Meeting with trainers who conduct trainings for service organizations, and discussing ways to integrate discussion and the implementation of recommendations at a specific event.
- **For the community:**
  - Discussing possible messages (for example, to change myths) and strategies to reach the community with LGBT community leaders and communication experts;
  - Establishing links with key Internet sites to conduct an information campaign.
- **General awareness, recognition of the problem, discussion of structural solutions:**
  - Disseminating information to members of the country coordinating committee on HIV and offering to give a presentation at a meeting of the committee;
  - Meeting with the monitoring and evaluation team for the country's HIV program;
  - Disseminating information to partners working in the fields of HIV and human rights;
  - Offering to use the document in the country report on progress made in the implementation of the political declaration on HIV or in shadow reports on the human rights situation;
  - Press release and information for journalists;
  - Development of abstracts for presentation at various conferences in the country and abroad;
  - Disseminating information among international networks and on your website.

When disseminating information, it is important to thank those who provided their time, data, and thoughts for carrying out the work: community representatives, employees of organizations and institutions, specialists who conducted IBBS, as well as institutions from which responses to official requests where received/not received, etc. When conducting surveys among representatives of the community, you have the opportunity to ask if respondents would like to share their own data in order to obtain results. At the final stage, you can send the results, information about their use, and lists of additional sources, and indicate additional opportunities for involvement in the next stages of work on improving the quality of life, and the physical and mental health of trans* people.

USEFUL RESOURCES

MONITORING, EVALUATION AND RESEARCH

- WHO/UNAIDS. Guidelines on Estimating the Size of Populations Most at Risk to HIV.; 2010.
- WHO/UNAIDS. Guidelines on surveillance among populations most at risk for HIV.; 2011.
- WHO. Consolidated strategic information guidelines for HIV in the health sector.; 2015.
- Markus, U et al. Estimating the size of the MSM populations for 38 European countries by calculating the survey-surveillance discrepancies (SSD) between self-reported new HIV diagnoses from the European MSM internet survey (EMIS) and surveillance-reported HIV diagnoses among MSM in 2009. BMC Public Health 2013 13:919.
- Abdul-Quader AS, Baughman AL, Hladik W. Estimating the size of key populations: current status and future possibilities. Current Opinion in HIV and AIDS. 2014;9(2):107–14. doi: 10.1097/COH.0000000000000041 [PubMed]
- Касянчук М., Чихладзе С., Прогресс за два года: оценка стратегической информации о ВИЧ среди МСМ и транс людей в Армении, Беларуси, Эстонии, Грузии, Кыргызстане и Северной Македонии; [Progress over two years: assessment of strategic information on HIV among MSM and trans people in Armenia, Belarus, Estonia, Georgia, Kyrgyzstan and North Macedonia]; 2020
- WHO. HIV and young transgender people; 2015
- WHO. Transgender People and HIV: Policy Brief; 2015
- ECDC. EMIS-2017. The European Men-Who-Have-Sex- With-Men Internet Survey. Technical report; 2019
- Шестаковский А., Ковтун О., Касянчук М., Муляр В., Еремин О., Йорский Ю., EMIS-2017: Результаты исследования в Беларуси, Молдове и Украине; [EMIS-2017: Results of the Study in Belarus, Moldova and Ukraine]; 2020

HIV PROGRAMMING AND MOBILIZATION OF TRANS* PEOPLE

- UNDP, IRGT, UNFPA, UNAIDS, WHO, USAID, PEPFAR, UCSF Center of Excellence for Transgender Health, Johns Hopkins Bloomberg School of Public Health. Implementing comprehensive HIV and STI programmes with transgender people. Practical guidance for collaborative interventions (TRANSIT); 2016
- Kasianczuk M., Trofymenko O. Analytical report: Population size estimation for transgender people in Ukraine; 2020
- National Center for AIDS Prevention of Ministry of Health of Armenia. Integrated biological-behavioral surveillance survey among people who inject drugs, female sex workers, men who have sex with men and transgender persons; 2018
- MSMIT: United Nations Population Fund (UNFPA), Global Forum on MSM and HIV, United Nations Development Programme (UNDP), World Health Organization (WHO), US Agency for International Development (USAID), World Bank. Implementing Comprehensive HIV and STI Programmes with Men Who Have Sex With Men: Practical Guidance for Collaborative Interventions (MSMIT). New York: United Nations Population Fund; 2015.
- International HIV/AIDS Alliance. Resources for Action for HIV and health programming with and for MSM.; 2016.
- UNAIDS. Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses.; 2012.

- ECDC. Public health guidance on HIV and STI prevention among men who have sex with men.; 2015.
- WHO. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations.; 2016 versio.
- WHO. Tool to set and monitor targets for HIV prevention, diagnosis, treatment and care for key populations.; 2016.

PRE-EXPOSURE PROPHYLAXIS

- WHO. WHO Implementation Tool for Pre-exposure Prophylaxis of HIV infection — Module 9: Strategic Planning. Other Modules.; 2017.
- WHO. WHO Implementation Tool for Pre-exposure Prophylaxis (PrEP) of HIV infection – Module 1: Clinical; 2017
- Зардиашвили Т., Доконтактная профилактика (ДКП) в Восточной Европе и Центральной Азии: первые уроки; [Pre-exposure prophylaxis (PrEP) in Eastern Europe and Central Asia: First lessons]; 2019

COMMUNITY-BASED RESEARCH AND ASSESSMENTS

- Орсеков Д., Региональный обзор транс* сообществ и контексты 12 стран Восточной Европы и Центральной Азии; [Regional overview of trans* communities and contexts in 12 countries of Eastern Europe and Central Asia]; 2020
- Рейна Артур кызы, Оценка потребностей трансгендерных людей в регионе ЦВЕЦА. Армения, Беларусь, Грузия, Кыргызстан, Северная Македония; [Assessment of the needs of transgender people in the CEECA region. Armenia, Belarus, Georgia, Kyrgyzstan, North Macedonia]; 2019
- Кыргыз Индиго, Лабрис, СОС. Оценка потребностей трансгендеров. Кыргызстан, Казахстан, Узбекистан, Таджикистан; [Assessment of the needs of transgender people. Kyrgyzstan, Kazakhstan, Uzbekistan, Tajikistan]; 2016
- Транс*Коалиция на постсоветском пространстве. Анализы страновых контекстов: Казахстан, Кыргызстан, Украина. [Analyses of country contexts: Kazakhstan, Kyrgyzstan, Ukraine]; Desk research. 2017
- Транс*Коалиция на постсоветском пространстве. Оценка потребностей транс*сообщества региона Восточной Европы и Центральной Азии в связи с пандемией COVID-19; [Assessment of the needs of the trans* community in the region of Eastern Europe and Central Asia in relation to the COVID-19 pandemic]; 2020
- Transgender Europe. Guidelines to Human Rights-based Trans-specific Healthcare; 2019
- Шваб М., Трофименко О., Касянчук М., Исследование отношения к ЛГБТ среди работников ключевых социальных сервисов; [Study of attitudes towards LGBT people among employees of key social services]; 2019
- Федорович И., Йорский Ю., Анализ национальных законодательств, связанный с правами ЛГБТК и ВИЧ, в 11 странах региона ЦВЕЦА; [Analysis of national legislation related to the rights of LGBTQ people and HIV in 11 countries of the CEECA region]; 2018
- Transgender Europe. Anti-trans hate crimes in Central and Eastern Europe And Central Asia; 2017
- The people living with HIV STIGMA INDEX www.stigmaindex.org
- International HIV/AIDS Alliance. All together now! Community mobilisation for HIV/AIDS.; 2006.

CASCADES OF SERVICES

- ECOM. Cascade of continuous HIV care for MSM in EECA. Overview of the results of national studies in the countries of Eastern Europe and Central Asia / Каскад непрерывной помощи в связи с ВИЧ для МСМ в ВЕЦА. Обзор результатов национальных исследований в странах Восточной Европы и Центральной Азии; 2020
- ECOM. Analysis of the cascade of comprehensive HIV prevention and treatment services for MSM in the countries of CEECA / Анализ каскада комплексных услуг профилактики и лечения ВИЧ-инфекции среди МСМ в странах ЦВЕЦА; 2018
- Касянчук М.Г., Недужко А. А., Мойсеева Н. Н., Обзор барьеров, препятствующих доступу к услугам в связи с ВИЧ-инфекцией для ЛЖВ, ЛУИН, СР и МСМ.[Overview of barriers hindering access to HIV services for PLH, PUID, SW and MSM]; Report on the results of the study; 2016.
- UNAIDS. 2021 UNAIDS Global AIDS Update — Confronting inequalities — Lessons for pandemic responses from 40 years of AIDS
- European Centre for Disease Prevention and Control (ECDC). Continuum of HIV care — Monitoring implementation of the Dublin Declaration — 2018 progress report
- Gourlay AJ, Pharris AM et al. Towards standardized definitions for monitoring the continuum of HIV care in Europe. AIDS 2017, 31:2053–2058.
- USAID, PEPFAR, Linkages, FHI360. HIV Cascade Framework for Key Populations; October 2015.

ECOM