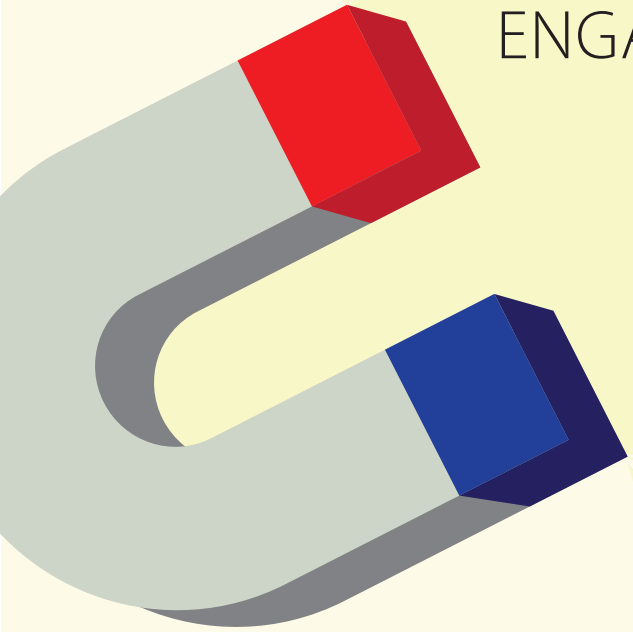
East Europe & Central Asia Union of PLWH

INCREASING COMMUNITY ENGAGEMENT IN MONITORING, EVALUATION AND STUDY OF QUALITY OF SERVICES

Methodological guide



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The guide is the result of a workshop and consensus meeting on the development of a common position on the role of key community groups regarding the study, monitoring and evaluation of the quality of services in the Eastern Europe and Central Asian (EECA) region. The representatives of key community groups, non-governmental, research and donor organizations took part in the meeting.

The materials for the meeting and the methodological guide were developed by the independent consultants:

Lela Serebryakova (lela.serebryakova@gmail.com)
Denis Kamaldinov (dkamaldinov@yahoo.com)

The following individuals have made an immense contribution to the development of approaches and concepts of this guide:

Ganna Dovbakh, Eurasian Harm Reduction Association
Elena German, Eurasian Coalition on Male Health
Vladimir Zhovtyak, East Europe and Central Asia Union of People Living with HIV

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INTRODUCTION

The importance of community engagement in the provision and evaluation of services is emphasized by all international organizations and donors working in the field of HIV, and by the key populations. Unfortunately, in practice, during the implementation and service provision, the role of communities is often diminished and, at times, ignored.

The guide is not aimed to analyze and discuss the reasons why key community groups are often omitted from the decision-making processes. On the contrary, the document is aimed to provide recommendations on how communities can increase their role by engaging in the processes related to service provision and assessing its quality, as well as in the processes related to study, monitoring and evaluation of those services.

In the modern world, the "correctness" of a decision often depends on how much it is based on evidence. Therefore, when one or another view is advocated, it is very important to argue this view by providing the necessary evidence (and we get evidence through such processes as monitoring, evaluation, study, etc.).

Service quality is not an exaggerated demand. It is rather an essential part of services. Indeed, the community and service recipients have both the need for continuous service improvement, and a unique position in the process of assessing its quality.

This guide was designed to help communities increase their role (engagement) in the monitoring, evaluation and study of service quality. Therefore, in this paper, we have gathered information on existing approaches and methods.

To develop this guide, a working meeting was held with the participation of community representatives, experts and donors from the EECA region at the initiative of the Eurasian Regional Consortium. As part of this meeting, issues related to the existing approaches of community engagement in the process of monitoring, evaluating and study of service quality were discussed, including:

- **how can communities use these approaches?**
- **what challenges do they face and how can they be addressed?**

1. MONITORING, EVALUATION AND STUDY

In colloquial speech, we do not always distinguish the concepts of "monitoring", "evaluation" and "study ". In fact, these terms are very often used interchangeably.

"Monitoring" and "evaluation" are often understood as the same process. Even the abbreviation "M&E" is commonly used, which also emphasizes the idea that these two processes are integral parts of one process.

On the other hand, “study”/research is often used as a substitutive term for "monitoring" and/or "evaluation". In this section of the paper, we define and explain how they differ in terms of their goals, applications, and results.

MONITORING

MONITORING can be defined as "systematic and regular data collection from projects and programs". It is an **organized process** that controls the progress towards established plans and checks compliance with particular standards (for example, the content of a service).

The monitoring focuses on what is being done and how it is being done; therefore, monitoring **should** include the views of the beneficiaries and the stakeholders at the community level. The monitoring is usually carried out by people implementing the project/program. The monitoring results are used to change the implementation of the project, if necessary, so that the project may achieve the intended goals or outputs.

The monitoring usually focuses on key indicators of the project implementation or behavior change. The indicator can be quantitative or qualitative, which provides a fairly simple and reliable basis for evaluating achievements, changes and effect. These indicators are usually developed at the beginning of the project cycle, and in order to understand how we will evaluate the results at the end of the project, we conduct a baseline evaluation at the beginning of its implementation. At the end of the project/program the progress, achieved as a result of their implementation, will be reviewed in comparison with the baseline evaluation.

Specific types of monitoring are monitoring of results, monitoring of process (activity), monitoring of compliance, monitoring of situations, monitoring of beneficiaries, financial monitoring and organizational monitoring.

EVALUATION

EVALUATION is used to draw conclusions about the relevance of the project/program, its effectiveness and sustainability. The evaluation is a **process** of analyzing and/or interpreting the collected data. It reviews the outcomes and the overall impact of the project/program.

The evaluation can be carried out by those who are interested in obtaining information on how effective a particular project is, while the organizations that implement the projects, in most cases, do not possess the resources to carry it out. In order to hold the evaluation, a team with specific qualification and experience in conducting evaluation studies, analysis, and data interpretation is required.

There are several types of evaluations, including final and mid- evaluation, real-time evaluation, meta-evaluation, formative evaluation, and others.

WHY M&E IS NEEDED?

The monitoring and evaluation process is important for NGOs, as it is a way to demonstrate to the stakeholders how a project/program is being implemented, and how effective it is. The monitoring and evaluation allows the organization to present its achievements and the projects implemented.

The main difference between the monitoring and evaluation is the time and the answers we want to get (a focus of evaluation).

Monitoring is a continuous process and it tends to focus on what is going on; while evaluations are conducted at specific points of time in order to evaluate progress of the project and how it affects its beneficiaries. Results of monitoring are typically used by managers and applied to ongoing projects, for tracking activities, budgets, compliance with procedures, and other administrative functions (do we accomplish what we planned to do on time? how much money do we need? etc.).

Evaluation can be carried out during the project implementation (for example, a mid-term evaluation). However, evaluations are less frequent and they mostly study changes (outputs) that require greater methodological rigor in the analysis, in order to measure the impact and relevance of the intervention.

By recognizing those differences, it is also important to remember how monitoring and evaluation are interlinked: monitoring usually provides data for evaluation, and components of evaluation(s) (arise in the course of the monitoring.

STUDY

A study/research is a descriptive process that is used to study any phenomena and processes, asking questions such as "what is/was?" or "what's the difference?", “what happens when there are certain conditions?".

Evaluation and study, in fact, can use the same methods/actions for data collection; and the process of their implementation may be the same. But the evaluation, in contrast to the research, is an evaluative process; therefore its findings/observations are evaluated against standards to aid decision-making. In this case, we ask questions such as "what is/was good?", "what would be better?", or "what conditions are best for obtaining the desired results?". The evaluation is carried out in order to make management decisions in the implementation of subsequent programs/projects.

A research/study would not necessarily include any type of evaluation. However, an evaluation will always include a research.

The difference among monitoring, evaluation and research/study are presented below:

MONITORING	EVALUATION	STUDY
The monitoring is a continuous process throughout the project/ program.	The evaluation evaluates the entire project cycle.	The study is a scientific process that is associated with the acquisition of new knowledge, and the statement of facts.
The monitoring is a regular part of project or program management. It focuses on the project implementation, comparing reality with the plan.	The evaluation evaluates the results of the project/ program and considers whether the implementation course was the best for achieving these results.	The purpose is confirmation or refutation of theory, testing and generalization of conclusions
The monitoring is usually carried out by people directly involved in the project/program implementation.	The evaluation is best done by independent individuals/organizations that can be impartial.	The study is usually conducted by researchers, scientists.
	The evaluation and the study can be viewed as mutually exclusive processes, as well as processes that are integrated into each other. This difference is determined by the contextual and analytical basis.	
The data collection and information during the monitoring is then submitted and used by the evaluation process.		

2. ETHICAL ASPECTS OF STUDY, MONITORING AND EVALUATION

The ethical principles for monitoring, evaluation and study may differ depending on the selected method. In addition, there are certain ethical principles specific to the communities for which this guide was written.

Let's start with the general concept of ethics.

Literature reviews on ethics in the process of monitoring, evaluation and research conducted by several reputable organizations[1], confirm that the definition of ethics or the provision of ethical principles are vague. Moreover, ethics can be understood in different ways.

It is noteworthy that the difference among monitoring, evaluation and research is very reasonable when it comes to ethics and ethical principles. While the research and, especially, public health research, or any study involving human subjects has the strictest ethical structure and even regulations, there is a general lack of such principles in monitoring and evaluation.

The ethics research framework of the Economic and Social Research Council (ESRC) offers the following interpretation of ethics as "the moral principles defining research, from its inception to its completion and publication of results and beyond its limits". However, there may be a different understanding of ethics among key affected communities that the authors of this guide did not have the opportunity to analyze in details; but an understanding of ethics should be discussed with a view to the subsequent use in the work of NGO communities.

In general, ethical is considered to be something "good" and is associated with the "right practice". This very simplified definition is what we "adopted" and used to guide our discussion. An important aspect of ethics is that it acts differently on a personal, professional, and global level, as Kolero suggests.

1 For example, such a review was conducted for the DFID and the document can be found at the following link: https://www.oecd.org/dac/evaluation/DFID-Ethics-Principles-Report.pdf). There are publications in scientific journals, for example, Gopichandran V, Indira Krishna AK Monitoring 'monitoring' and evaluating 'evaluation': an ethical framework for medical ethics 2013;39:31-35

We found it useful to classify various ethical considerations in three main categories:

Levels: personal, organizational, community and global/common.

Purpose: monitoring, evaluation and study;

Organization of the process: development, implementation, analysis and publication/distribution.

3. SERVICES: QUALITY, AVAILABILITY AND SATISFACTION

OVERVIEW OF THE MODEL/CONCEPT OF QUALITY AND AVAILABILITY

This information will help us in formulating questions and developing research tools in which the community will be involved.

Quality and availability of services are the most important characteristics of services that are provided to people belonging to key groups. In documents and studies there is no single approach to the definition of these terms:

Sometimes the definition of "quality" includes the following criteria:

- Quality services are affordable: you do not have to pay for them, or the amount to be paid is not a barrier
- Quality services are accessible: the service provider is close / can be reached easily; working hours and days are convenient for users.

Sometimes the understanding of "accessible services" includes such concepts that go beyond physical or financial access:

- Service security
- Privacy and anonymity of the beneficiaries
- The attitude of medical personnel to the beneficiaries, etc.

Lack of a clear understanding of quality can be a barrier in the course of research. Different models for understanding quality that can help users formulate their understanding of quality are presented below. In the framework of the Consensus Meeting, a concept of quality referred as Donabedian's Triad Model was proposed, since this model defines the components of the "quality of services" and allows us to use a different understanding of the quality concept itself.

An important characteristic of services is their **acceptability**. The acceptability of services for patients is determined by the combination of all the parameters of services and how they impact subjective perception of service by a patient. Patients will not use services that are not acceptable

(at least voluntarily). For example, HIV testing at the workplace: if a person knows his or her HIV status or suspects that the infection is present, he/she will most likely avoid taking part in an organized testing campaign at the workplace.

As we have indicated above, there is no consensus in the world in understanding the concept of availability and quality of services. For example, the patient association "Patient Access Partnership"[2] developed the "5A" concept, and in the definition of availability included 5 components as shown in the table below:

TABLE 1.

5A Concept - Definition of "Availability"

In English	In Russian	Definition
Availability	Доступность	First of all, is this service available/does it exist?
Adequacy	Адекватность	Is there adequate and continuous access to available services?
Accessibility	Доступность (физическая)	Are services actually accessible to users? Access measured in terms of use, i.e. how many/which part of the people who need services use them (this can also mean, for example, the time of receiving the necessary medical care).
Affordability	Финансовая доступность	The medical services financing system is such that people do not experience financial difficulties in using them.
Appropriateness	Уместность	Available services should be appropriate for different groups of the population in terms of their health needs, material and cultural conditions and values. In other words, the available services must meet the needs of different groups of the population.

The World Health Organization (WHO) offers one of the most common approaches to characterizing the availability of health care workers. The model is called AAAQ, it stands for "Availability" (the number of health care workers with relevant knowledge), "Accessibility" (arrangement according to the rule of geographical or demographical distribution, etc.), "Acceptability" (age, culture, gender, etc.) and "Quality" (competencies, skills, etc.)).

2 www.eupatientaccess.eu

The UN Committee on Economic, Social and Cultural Rights recommends that participating states apply standards of equality and non-discrimination to ensure that social protection programs meet the standards of the right to health:

EXISTENCE. The participating state should have a sufficient number of functioning health institutions, goods and services in the field of health and medical care, as well as relevant programs. The exact nature of these institutions, goods and services will vary depending on a number of factors, including the level of development of the participating state.

AVAILABILITY. Health institutions, goods and services should be available to everyone without discrimination of any kind that falls under the jurisdiction of the participating state. The availability has four interrelated aspects:

- **Non-discrimination**: Health institutions, goods and services should de jure and de facto be available to all, especially the most vulnerable or socially excluded groups of the population, without discrimination on any of the prohibited grounds;
- **Accessibility**: Health institutions, goods and services should be in physical access for all groups of the population, especially for vulnerable or socially excluded groups, such as ethnic minorities and indigenous peoples, women, children, adolescents, the elderly, people with disabilities as well as HIV-infected and those who suffer from AIDS.
- **Affordability**: Everyone should have access to health institutions, goods and services: payment schemes for medical care, as well as services related to the provision of fundamental health prerequisites, should be based on the principle of equity, which guarantees all, including socially excluded groups, the availability of these services in both the private and public sectors. The principle of equity means that less well-off households should not bear the disproportionately high costs of health care compared to better well-off households;
- **Availability of information**: The availability includes the right to seek, receive and disseminate information and ideas relating to health issues. However, the availability of information should not prejudice the right to privacy of personal medical data.

ACCEPTABILITY. All health institutions, goods and services must comply with the principles of medical ethics and cultural criteria, i.e. culture of individuals, minorities, peoples and communities, take into account gender and lifestyle requirements, and be focused on maintaining confidentiality and improving the health status of the persons concerned.

QUALITY. In addition to their cultural adequacy, health institutions, goods and services should also be scientifically and medically acceptable and of high quality. This, in particular, requires the availability of qualified medical personnel, scientifically tested and suitable medicines and medical equipment, safe drinking water and adequate sanitation.

Defined by WHO, UNODC and UNAIDS[3] "Quality includes the scope, completeness, effectiveness, efficiency and safety of interferences and, importantly, acceptability for the target group"[3].

3 WHO, UNODC, UNAIDS Technical Guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users 2012 revision

QUALITY COMPONENTS

Quality is a complex concept that can be understood in different ways and formulated variously in different fields. A general definition is presented below:

QUALITY is a set of characteristics of the object, related to its ability to meet the established and assumed needs.

In the field of medicine, the understanding of quality is a very debatable issue. On the one hand, it is most difficult to judge the quality of medical services; on the other hand, high-quality services are important, as the patient's life often depends on them. Therefore, approaches and models of quality measurement are most developed in the field of medicine.

THE QUALITY OF MEDICAL CARE is a set of characteristics confirming the compliance of the provided medical care with the patient's current needs, expectations, the current level of medical science, technologies and standards.

NOTE 1.

Consumers make daily decisions related to quality evaluation. But buying everyday things is different from "buying"/consuming health care services.

For example, if you are to buy bread, you can easily designate what quality criteria will justify you choice: taste, freshness, smell, clean shop and seller, price, etc.

But the definition of quality in health care is different from buying bread.

What do we want to "buy" when we visit a doctor?

- Health ... One health? Two health...? BUT **Health can't be sold and it can't be bought.**

And what do the doctors "sell" to us instead?

- Medicines – we can't say for sure that they will cure us, it is unpleasant to take them, etc.
- Medical services – we can't say for sure that they will cure us; they are painful, we can die during surgery...

As a result, we have a "quasi" product and "quasi" services, since we do not buy the product we want; and we buy services that are associated with pain and risk to health in the **hope** of getting a true "object of desire".

THE CLASSICAL MODEL OF QUALITY

The classical model of quality (or the Donabedian's Triad Model) has a long history. The model was developed by doctor Avedis Donabedian at the University of Michigan in 1966. Although there are other quality assurance models, for example, that of WHO[4],

4 WHO (2006) "Quality of care: a process for making strategic choices in health systems", https://www.who.int/management/quality/assurance/QualityCare_B.Def.pdf

The Donabedian's model continues to be the dominant approach for evaluating quality in medicine, as well as in other fields. The model focuses on the provision of services (although it can be applied in other industries, such as manufacturing) with a focus on identifying specific aspects that can be improved. The model has the most common use, but ironically, it does not provide a definition of quality.

The model defines three types of information that can be collected in order to draw conclusions about the quality of services:

STRUCTURE

The structure includes all factors affecting the context in which the service is provided. This includes infrastructure, equipment and human resources, as well as organizational characteristics, such as personnel training and payment methods. It is usually easy to examine a structure since it is usually represented by "visible" resources (although there are also "invisible" structures, for example, infection control).

PROCESSES

A process is the sum of all actions that makes up service provision. For example, the process includes diagnosis, treatment, prevention, and instruction of patients. The processes can be further classified as technical processes, interpersonal, or methods of assistance (the relationship between the recipient and the service provider). Information about the process can be obtained from records/internal regulatory documents, interviews with clients or through observation of the service provision process.

RESULT

The result contains all the consequences of medical care for an individual patient or population group, including changes in health status, behavior or knowledge, as well as patient satisfaction and health-related quality of life. The results are sometimes considered as the most important quality indicators since their achievement is the main goal of service provision. However, accurate measurement of the results achieved is very difficult. Identifying the connection between the process and the results often requires conducting a study among a large number of people on a random basis and long-term observations, since it takes considerable time for the results to become “visible”.

ENVIRONMENTAL ASPECTS/PATIENT CHARACTERISTICS

As mentioned above, the Donabedian's model has been known for more than 50 years, but it still continues to remain the dominant approach to evaluate the quality in medicine. One of the major changes in this model is the addition of a fourth component affecting the quality of services. This component is an environment and patient characteristics, which are important factors for evaluating the quality of treatment. The researchers Coyle and Battles suggest that these factors are very

important to fully understand how effective medical care is. Patient characteristics include genetics, social demographics, lifestyle, beliefs, attitudes, and preferences. Environmental factors include cultural, social and political factors[5].

1. Quality of the structure	2. Quality of the process	3. Quality of the result	4. Environment and patient characteristics
Terms for providing assistance, including qualifications of personnel, availability and condition of equipment, a condition of premises, provision of medicines, etc.	Medical services; technologies of prevention, diagnosis, treatment, rehabilitation (compliance with principles and standards)..	Changes in the patient's condition, including his/her satisfaction with services	Genetics, social factors, environment...

CLIENT'S UNIQUE KNOWLEDGE: SATISFACTION WITH SERVICES

Satisfaction with services is one of the key factors that affect the use of and adherence to service, medication, attitude to treatment, etc. All businesses measure Evaluation client satisfaction as a method of maintaining their customer base. In health care sector, it has also been proven that satisfaction has a positive effect on the clinical results of treatment.

Service recipients have knowledge/information that can be used to evaluate quality. For example, much information can be learned from patients, including. the components of the service quality:

- Quality of the structure: good building, good equipment, quality of medicines, knowledge of a doctor or other representatives of the medical personnel
- Quality of the process: Has the right treatment approach been chosen? How correctly was the diagnosis made?
- Quality of the result: Is there an optimal solution to health problems?

Apart from the patient, the same questions can be asked to other people who can be the sources of information. For example, the quality of such infrastructural components of a building is probably better checked by experts who can evaluate not only the visual side of the building, but also its seismic stability, safety in the event of a fire, how architecturally the building helps control infections, the separation of "clean" zones from "dirty" zones, protection of anonymity, etc.

However, there are aspects of the services received which only the patient knows, only he/she can evaluate these services: **Is he/she satisfied: (1) with the services and (2) with the results that he/she has received from treatment?**

5 More detailed information can be obtained on the Agency for Healthcare Research and Quality website: https://www.ahrq.gov/professionals/quality-patient-safety/index.html

MEASURING SATISFACTION

Satisfaction is a subjective phenomenon, therefore, approaches to its measurement are usually associated with the collection of qualitative data, for which the following methods are most often used: focus groups, opinion surveys, individual interviews, etc.

It is very difficult to use qualitative data. Therefore, in order to evaluate satisfaction, a lot of tools were developed, which allow calculation of indices and provide comparative data. For example, for OST there are at least 3 validated (confirmed to be valid measures) instruments: Verona Service Satisfaction Scale for Methadone treatment (VSSS-MT), SASMAT-METHER, SASMAT-BRUNER, PEQ-ITSD and others. **Creation of an instrument requires a careful analysis of the literature; after the development of a primary document, it should be validated (checked and confirmed that this instrument will accurately measure the aspects we are examining). This is a lengthy process , which will be difficult for the most of NGOs to accomplish with decent quality. Therefore, it is recommended to use existing instruments, or adapt them (to fit your needs).**

FIVE ASPECTS OF THE SATISFACTION

In many studies, "satisfaction" is understood differently. Therefore, it is very important to define what is included under the term "satisfaction".

There are **five basic aspects of satisfaction** that are important to measure from a perspective of the recipient of services:

1. Service availability
2. Acceptability of services for users
3. Continuity
4. Links between the services
5. Service security

Despite the fact that we have identified satisfaction as an area where the position of the recipient of the services is unique and indispensable when conducting research, the recipients of services and the community can and should be involved in evaluating other aspects of quality (structure, process, environmental characteristics, etc.). However, this process will require some basic knowledge and skills. Interest in the service quality, which the community has, is very important for maintaining and improving service for key groups.

4. THE ROLE OF COMMUNITY IN MONITORING, EVALUATION AND STUDY

There are several terms in English that refer to community participation in the research, monitoring and evaluation. In many texts, they are used as synonyms, or donors/large organizations formulate their taxonomy of terms and use only one term to denote the whole spectrum of community involvement of in the processes.

During the Consensus Meeting, this taxonomy was discussed with a view to reaching a consensus and a common understanding of these terms. We focused on two key terms:

- **Community-based - based on the communities/with the participation of the communities**
- **Community-led, or community-driven**

The differences between these terms are not always clear. Very often, authors/organizations do not think about how these terms are used. One of the academic works that study the conceptual origins of these terms for donors in the field of development summarizes that community-led/driven is part of community-based approaches, and is a criterion for determining that community-led/driven as **initiated by the community**[6].

The Global Fund, which is one of the main donors of programs for key affected communities in the EECA region, uses the term "community-based", and considers that this term includes all possible efforts of key communities. During the discussion of these approaches, the working group focused on two main differences between these terms:

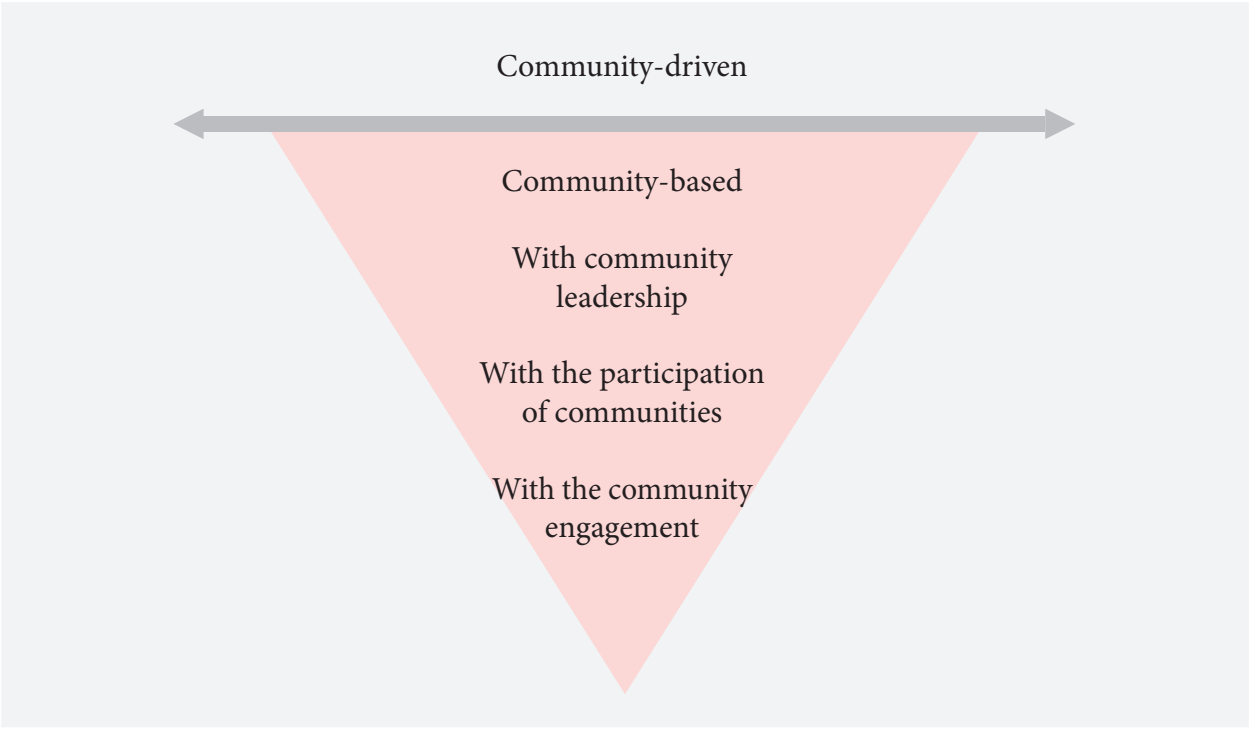
INITIATIVE: very often, the initiators of studies on matters related to key groups are not members of the community groups. For example, IBBS studies, which are conducted in almost every country and receive financial support from the GF, are usually initiated by institutions responsible for public health in a country[7]. Such studies the working group assigned to the "community-based"

6 http://www.edaethiopia.org/images/DR%20Blog/Community%20Driven%20Development%20Vs%20Community%20Based%20Development%201%20Final.pdf

7 Although there are exceptions, for example, Ukraine, where the initiator of such epidemiological research is the community.

research group. Also, the stigma index is very often initiated by the community; and even if the research itself is not conducted by the community itself, such research should be classified as "community-driven".

STAGES OF THE COMMUNITY ENGAGEMENT: within each study, there are separate stages (see 6. Study). If the community leads in the majority of stages and is necessarily the initiator and customer of the research, they should be considered as "community-driven".

Initiation	Customer/ executor	Planning	Holding	Analysis	Use of results
Held by the community	Held by the community	Held by the community	Held by the community	Held by the community	Held by the community
					
Held by other stakeholders (UN, funds, etc.)	Held by other stakeholders (UN, funds, etc.	Held by other stakeholders (UN, funds, etc.)	Held by other stakeholders (UN, funds, etc.)	Held by other stakeholders (UN, funds, etc.)	Held by other stakeholders (UN, funds, etc.)

As can be seen from these definitions, community-based research is understood as an approach that requires higher involvement and expert knowledge from communities. In fact, conducting research entirely by the community can be an impossible and unrealistic task. There are technical aspects of the study process that affect the quality of research and require special education, experience and expertise, for example, statistical analysis, sampling design, questionnaire development, visualization of results, etc. Not every community organization will have these skills within the organization. The use of expert resources during research will not reduce the role of the community if it is the "consumer" of such work and should not be perceived as a departure from the leading role of key affected communities.

The above-mentioned discussion reflects the situation with the study and evaluation since these two processes have many common approaches; they, in fact, use the same tools. Situation with monitoring is slightly different:

Monitoring is systematic and regular data collection from projects and programs. Monitoring by the community (i.e., when the representative of the community conducts monitoring) or monitoring with the participation of the community (i.e., when the person who monitors is not a member of the community) can strongly influence the results that are collected from the beneficiaries. The phenomenon that causes these differences is called the perspective of the appraiser (shared experiences). In fact, on the one hand, this can lead to more subjective evaluation, but on the other hand, only a person who understands the situation of key affected communities can identify/see some specific problems of this community. Despite this, each NGO employee who belongs to key affected communities and is a monitoring specialist must undergo special training in order to minimize his/her subjective influence on the processes. However, when the community member takes part in monitoring, we simply take into account this unique position and plan monitoring based on this factor.

As we know, and as WHO and other organizations dealing with public health issues have pointed out in their documents, social factors such as poverty, education, place of residence, social status, etc. determine human health (and even affect such health indicators of PLHIV as a sustained viral load suppression, although in the context of community participation we do not investigate which mechanisms lead to this). Social factors play the most important role in determining the health of key groups. Community initiatives are believed to help with this challenge[8].

If documents are monitored, for example, financial documents, then the main factor of the "influence" of the monitoring specialist is the competence of this person, the skills of communicating with people, etc., his/her belonging to this or that community may not affect the monitoring process.

8 Jane Dailly and Alan Barr, in a publication prepared for the Scottish government "Understanding a Community-led Approach to Health Improvement" (2008), offer a very interesting and well-developed model and description of approaches: https://static1.squarespace.com/static/5943c23a440243c1fa28585f/t/5bfd61e021c67c2cdd6a326d/1543332329487/Understanding+a+community-led+approach+to+health+improvement.pdf

5. COMMUNITY- BASED MONITORING: THE GLOBAL FUND'S METHODOLOGY, APPROACH AND EXPERIENCE

GENERAL OVERVIEW

The Global Fund Board affirmed its commitment to enhance participation of civil society and communities in the Global Fund Strategy for 2017-2022 aimed at ending the epidemics. In particular, Strategic Objective 2 “Creating Sustainable Health Systems” recognizes communities as critical actors for ensuring open access to health care and commits to strengthening community systems and responses.

At the global level, the implementation of community-based monitoring programs (CBM) is insufficient. Only ~ 1 out of 5 concept notes included CBM elements. Regional applications that focus on advocacy and providing support to socially vulnerable groups almost always include CBM program elements. Most of the concept notes that included CBM elements were filed on HIV, as part of the "Strengthening Communities" module. In the current grant cycle (2017-2019) in the EECA region, only Kazakhstan included CBM - totaling 75 thousand US dollars. In the previous cycle (2014-2016), CBM activities were included in grants of such countries as Georgia, Moldova, Russia, Ukraine, as well as the EECA regional grant totaling 717 thousand US dollars.

COMMUNITY-BASED MONITORING: GF DEFINITION

The GF defines community-based monitoring as a **process in which the service users or local communities collect and use information on the provision of services or information on conditions affecting the efficiency of service delivery, with the aim of increasing their flexibility, quality and equal access, as well as identifying responsible persons and organizations providing these services.**

CBM within the framework of health issues can be general (for example, an assessment sheet for analyzing medical services at the community level), or specific for a particular disease or program (for example, monitoring access to HIV treatment or legal barriers to key groups). Recently there has been a tendency to move away from CBM tools being specific only for HIV or TB, to more general, universal ones.

PRINCIPLES OF EFFECTIVE MONITORING

- **Autonomy:** the operation of the CBM system is independent of the services or programs that are monitored
- **Accountability, transparency and feedback:** service or program providers can provide feedback to the community by providing access to data on the quality of work and ensuring the confidentiality of feedback
- **Goal setting based on community priorities:** The communities of key groups of the population will monitor exclusively those aspects that are most important in their opinion, without using abstract indicators.
- The monitoring involves not only processing large amounts of data or, ultimately, changes at the political level. The results of CBM should, first of all, become the basis for changes at the **local** level, taking actions and subsequently - long-term changes.
- **Effectively** organized monitoring is based on effective **interaction and community mobilization**: it is not enough to lay the foundations and provide funding for the monitoring system, it is important to create mechanisms for effective interrelations within.
- The monitoring should create a **basis for real actions:** communities will interact when they know that their efforts will lead to real changes.
- **Reliability of data:** CBM approaches must be reliable and verifiable
- **Comprehensive nature** of CBM – communities are interested in creating better conditions for the whole environment in which they live, thus an effective monitoring system goes beyond the scope of the implemented programs.
- **Trust and security:** communities take the risk in the process of implementing the monitoring of the service quality, human rights; service providers and funds must make efforts to reduce them.
- **The ability for continuous development and adaptation:** The effective CBM system is evolving under the influence of ever-changing problems, and adapts to new concepts and context changes.

THE COMMUNITY-BASED MONITORING MODELS

The community-based monitoring models offered by the Global Fund have been developed by the London School of Economics, the University of Copenhagen and the International HIV/AIDS Alliance. They include:

Model 1 – "DOWNWARD ACCOUNTABILITY" is a model in which services include mechanisms that allow their users to give feedback and, as a result, enforce levers of influence on medical services (for example, the system of handling claims and complaints).

Model 2 – "CITIZENS AS SERVICE DELIVERY WATCHDOGS" is a model in which citizens mobilize to organize independent monitoring of services (for example, documentation on the stock-outs of essential drugs).

Model 3 – "LOCAL HEALTH GOVERNANCE MECHANISMS" is a model in which the role of the monitoring is provided to the health bodies, within which there are representatives of the community (for example, regional health departments)

Model 4 – "SOCIAL AUDIT" – community members undergo training and obtain skills for evaluating the work of medical institutions, participate in public hearings in order to bring to justice those who provide services. This approach is complex, it includes a wide range of tools and processes, in some cases regulated by government bodies.

EXAMPLES OF THE COMMUNITY-BASED MONITORING MODELS IN THE FRAMEWORK OF THE GLOBAL FUND GRANTS

Model 1	How is the monitoring conducted?	Who is involved?	Why is it important?	Data collection methodology
"Downward accountability" ITPC project in 10 West African countries	Community Treatment Observatories — carry out systematic information collection to track changes in access to HIV treatment throughout the cascade and take appropriate actions.	National networks of PLHIV	• Strengthening communities: community, being informed, get the right to vote • Evidence base: quality of data collection process • Advocacy: call and promotion of social responsibility ideas • Strengthening partnerships	• A team responsible for monitoring data monitors key stages of information generation — for quality control and triangulation at the country level. • Team responsible for data collection - responsible for primary data collection • Observatories collect quantitative and qualitative information

Model 2	How is the monitoring conducted?	Who is involved?	Why is it important?	Data collection methodology
Citizens as Service Delivery Watchdogs UCOP +, Democratic Republic of Congo	Alert systems to monitor the absence of antiretroviral drugs and other products **Given that a key aspect of this model is monitoring the lack of drugs, important elements of the analysis are also the monitoring of purchases and supplies, stocks and storage**	UCOP+ and researchers from the community.	• Reduce the risk of situations with the lack of ARVs • Provide access to quality medical services • Provide better health care coordination	• Mobile application • Questioning

Model 3	How is the monitoring conducted?	Who is involved?	Why is it important?	Data collection methodology
Local Health Governance Mechanisms: Community observatories for treatment implemented by the Network of PLHIV organizations in Côte d'Ivoire	Monitoring and warning system to identify cases of ill-treatment to PLHIV in medical centers and stocks of ARVs.	Social workers warn of potential drug shortages after an information audit and data triangulation from: PLHIV communities accessing medical centers; local pharmacies and HIV program coordinators	It allows you to implement a warning system and a mechanism for collecting and monitoring and analyzing information It helps to reduce situations with ARV deficiency, as well as other services provided in medical centers Ability to better control the supply chain of ARVs, materials and other laboratory equipment in order to provide quality services Increasing community awareness at local and national levels	• Communities of PLHIV warn of any and potentially possible deficiencies of ARVs • Data collected by the community is carried out at the level of health centers.

Model 4	How is the monitoring conducted?	Who is involved?	Why is it important?	Data collection methodology
Social audit Community observatory for monitoring access to medical services (Burkina Faso, Niger, Guinea)	The Independent Observatory of key groups of the population of the communities, which provides an impartial and regular presentation of real-time information about bottlenecks related to access to medical services, products and care for HIV, malaria and tuberculosis. The focus is on monitoring stocks of medicines and other medical supplies, the cost of medical services, the health care system (poor decentralization of medical services)	PLHIV, people affected by tuberculosis and malaria	• It allows communities to contribute to improving access and quality of care at the national level • It creates a warning and monitoring system, as well as a permanent collection of information on the factors that impede access to health services for PLHIV and people affected by malaria and TB. • It sets vector and informs decision-makers, based on evidence, when appropriate action is taken	Questionnaires; Reviews in medical centers; Helpline; Radio

ADVANTAGES AND DISADVANTAGES OF THE MODELS

Model type	+	–
Downward accountability	• Ease of implementation, there are standard tools (community helplines, community boards) • Ensuring the confidentiality of information and complaints, thereby reducing the risk of punitive measures from service providers	• Largely managed by the service providers; as a consequence, the ability of communities to influence execution and penalties for violations is limited • Verification and processing of complaints require a lot of time and resources
Citizens as Service Delivery Watchdogs	• Wide audience coverage, especially using online and/or SMS methods • High potential for advocacy • It often combines community activism with community-based research • Promotion of health literacy aspects among communities	• The availability of ICT, especially among hard-to-reach groups of the population, is doubtful, it is difficult to increase the coverage of key groups of the population • Verification of reports requires a lot of time and resources
Local Health Governance Mechanisms	• In addition to monitoring, the community has a role in health management (planning and review, budgeting) • Communities are empowered to influence decision making at the state level	• socially unprotected key groups of the population are often excluded. • slowly reacts to new problems with the provision of services • Difficult to manage groups with conflicting interests
Social audit	• High potential for expanding coverage, support from the state • The possibility of ensuring the responsibility of all partners involved • Scientifically based and result-oriented planning of the work of medical organizations • Empowering communities to participate in decision making	• requires a lot of resource investments: social auditors must undergo preparatory training and possess the tools to conduct such monitoring • An efficiency-based approach can create a hostile environment and conflict of interest among service providers.

ASPECTS OF THE COMMUNITY-BASED MONITORING

It is impossible to consider CBM as an isolated, one-time event. It should be a permanent part of the program activities. The monitoring should include mechanisms that can provide the necessary changes, including at a political level.

Local community priorities should be the focus of monitoring, and the process should take into account the representativeness and inclusiveness of various key groups of the population.

Community-based monitoring provides an opportunity to find solutions for a wide range of issues, including:

- **Access to services**
- **Barriers related to gender and human rights**
- **Quality of services**
- **Budget monitoring**
- **The most urgent needs of the community**
- **Local nature of decisions**

6. REVIEW OF THE EXPERIENCE OF COMMUNITY-LED STUDIES IN EECA

In the countries of the EECA region much has already been done by the communities with respect to generation of evidence. The representatives of communities regularly participate in conferences and present their experience and the results of their research.

As part of the preparation of this methodological guide, information was collected on studies conducted in the EECA region from the participants of the meeting. Summarized information provided in Annex 2: Available community-driven studies in EECA.

A review of studies conducted in the region shows, the most frequently used study design is cross-sectional. A more detailed description of the different types of study designs is presented below (see p. 7. Study methods). Cross-sectional study design does not reveal a causal relationship between the variables. For example, using this method, it will not be possible to draw conclusions that the phenomenon we are measuring (for example, adherence to treatment) is consequently caused or not caused by the programmed actions or interventions.

In most publications, in the literature review part, there is often no information on how the study design was formulated. Basically, the literature review is used to give a general description of the situation and to substantiate importance of topics being studied . Obviously, this is an important question, but literature review should also look at methods and study designs used by other researchers for studying the same topic (and evaluate strength and weaknesses of those approaches).

Since the most frequent tool for data collection used by communities in EECA is survey, more attention should be paid to development of proper instruments and to their validation. A valid (validated) toolkit, which allows us to calculate the appropriate index of the phenomena studied by us, allows us to transform qualitative information into quantitative and use this data for comparative analysis.

7. STUDY PROCESS

Despite the fact that study may differ in approaches: starting from the survey to the literature review, there are 4 important steps in each study process:

1. **Planning,**
2. **Data collection,**
3. **Analysis**
4. **Communication of results**

A study is a systematic process that can lead us to conclusions. These steps are used in all studies and in all evaluation projects, regardless of the methods used. In the process of research, all steps are documented in such a way that the other person could repeat all steps, and would arrive to exactly the same result - this is the defining principle of scientific research.

STEP 1: PLANNING

1.1. IDENTIFY THE PROBLEM: The first step in this process is to identify the issue; this step is also called the formulation of the research question.

1.2. LITERATURE REVIEW: When a problem has been identified, the researcher should learn more about the topic of study - conduct a review of the literature related to the research problem. This step provides basic knowledge of the problem area. The literature review also informs the researcher about what other researches have been done in the past, how they were done, and what were the findings. This information helps the researcher to understand the scale of the issue and to recognize future consequences.

Exactly for this, it is important that the individuals who conduct research publish their results. Only when published, their findings can be accessed by others and be used to improve knowledge related to the topic.

1.3. CLARIFY A PROBLEM/DEFINE A FOCUS: usually, the initially highlighted problem would be large. After a literature review, when the researcher already understands the scope of

the problem, it is necessary to narrow the focus of his/her future research and to focus on specific aspects of the problem. This can only be done after the literature review.

1.4. CLEARLY DEFINE TERMS AND CONCEPTS: Terms and concepts are the terminology used in the description of the research and then in the report. Terms and concepts should have clear wording, as they can often be understood differently depending on who reads the research.

1.5. DETERMINE THE POPULATION: Research projects usually focus on certain groups of people, objects, etc. For example, the research can study a specific age group, men or women, people living in a particular geographic area or belonging to a particular social group. The task of the research and the researcher is to precisely determine this group so that it is as homogeneous as possible (uniform, consistent). The group in the research is called "population".

For example, if we investigate the reasons for cessation of antiretroviral therapy, and we need to interview people who have stopped taking medications, it is necessary to clearly define who is included in this group: people who did not take medicine one day? 2 days? 1 week? 1 month?

1.6: DEVELOP STUDY DESIGN AND INSTRUMENTS (PROTOCOL): A clear design (methodology) of the research is reflected in the document we call the protocol. In addition to the above aspects, the protocol includes the following aspects: how, when and where the research is conducted, how data is collected, etc. An instrument is a way to collect data. For example, if we conduct a survey, an instrument will be a questionnaire; in a desk review, an instrument is a format for searching information that we will analyze (keywords, in what publications, etc.).

STEP 2: DATA COLLECTION

In fact, the research begins with data collection. Data collection is a critical step in the research. **Each study involves collecting data of a specific type to give an answer to the research question.** Thus, data can be collected using questionnaires, using observations or from the literature.

STEP 3: DATA ANALYSIS

The analysis is almost the final stage of the study. The analysis plan should be described in the research protocol.

3.1. DATA ENTRY: The collected data must be entered in a specific form that allows them to be analyzed. For example, information collected through questionnaires is entered into special statistical programs, which help to perform an analysis. Qualitative information that we have collected by observation, or in-depth interviews can also be entered into special analytical programs, or grouped by topic and then analyzed - for example, if we have 5 interviews from key informants, we transcript interviews and then look what they said about one particular topic, and then these answers are aggregated for analysis.

3.2: STATISTICAL DATA ANALYSIS: if quantitative data is collected, a statistical analysis shall be carried out. There are two main types of statistical analysis: descriptive, which describes the frequency of certain variables (for example, 48% of the respondents were men (n: 96), and 47% (n: 94) - women, the rest chose not to indicate the gender), or their key parameters (mean, median, max, min).

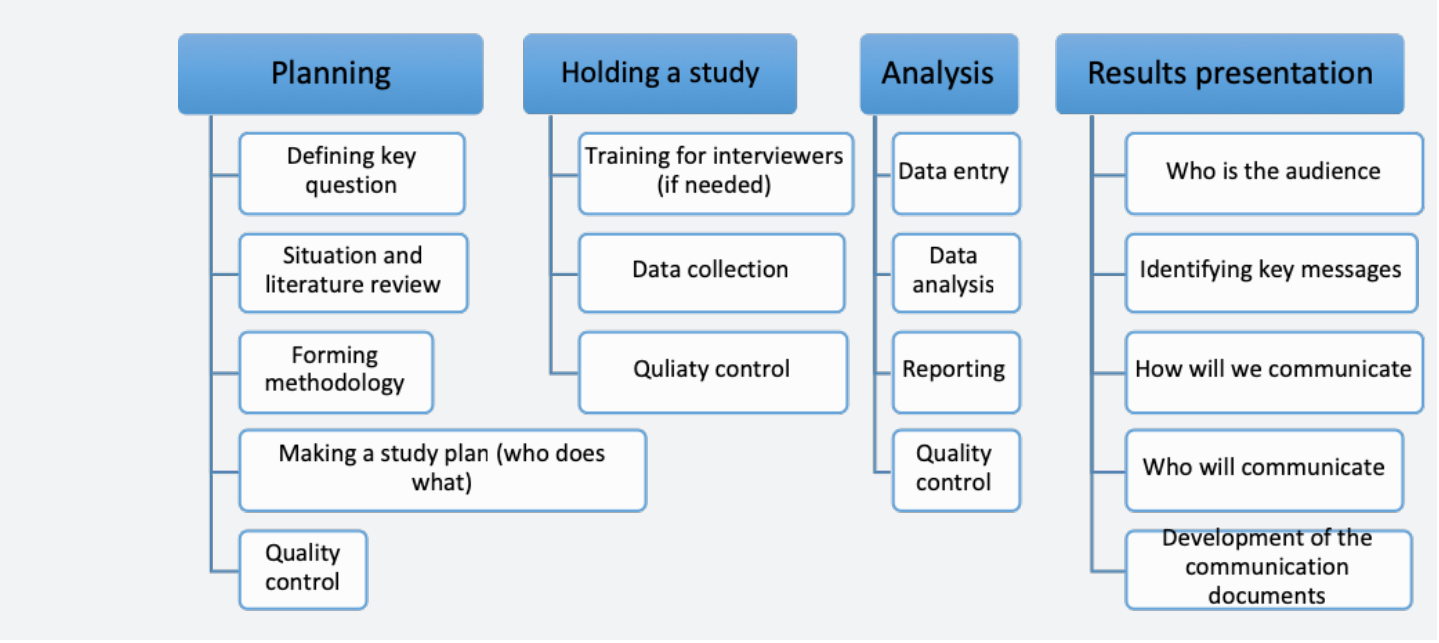
The second type of analysis is inferential statistics, which is used to identify the relationship (correlation) between variables.

3.3. Analysis of the results: the initial results should be analyzed to give the reader information on how these results provide an answer to the study question.

STEP 4: DATA PRESENTATION

Data presentation is one of the most important steps in the study process. This process is discussed in detail in the following section of the document: Applied example 1: Data presentation.

SCHEMATIC DESCRIPTION OF KEY STAGES OF RESEARCH:

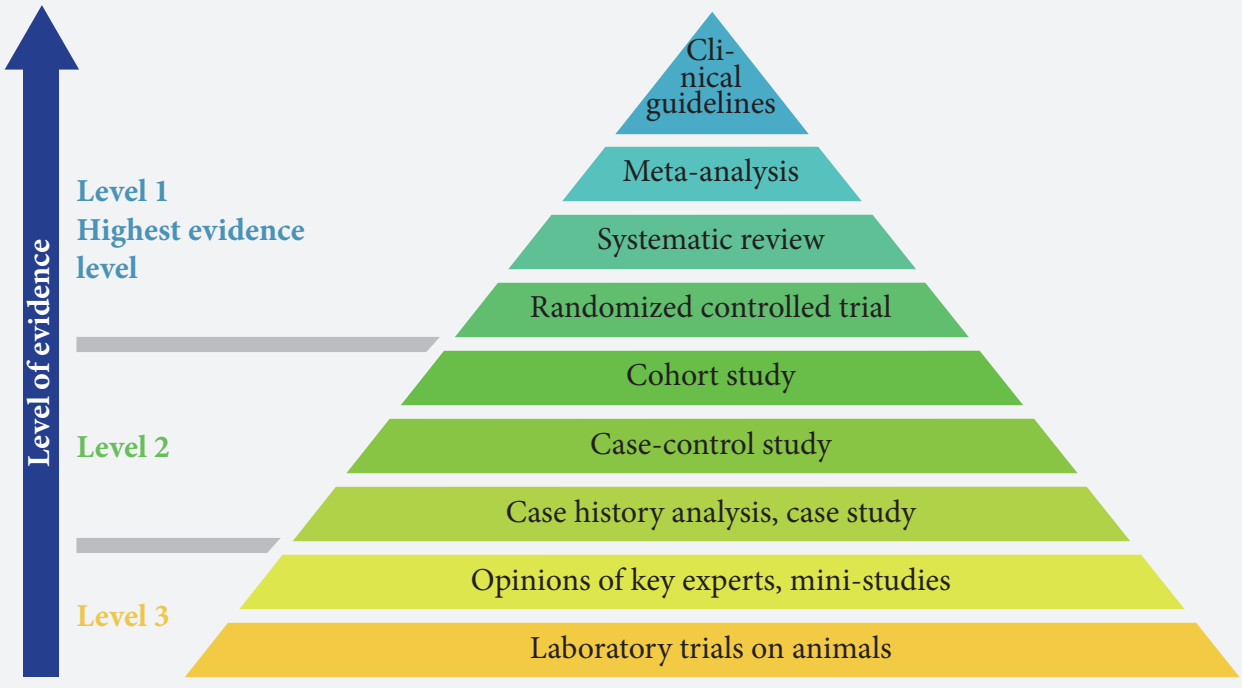


8. STUDY METHODS

A study is a scientific process of finding answers to questions using data. There are several important reasons why a study is conducted:

- we want to learn something new,
- we want to test the hypothesis,
- we want to establish a causal relationship between variables (to establish causality).

Studies are conducted to obtain results, which will be evidentiary. Not every study method gives results, and their "evidentiary" weight is not always the same. Below, we outline a schematic representation of the classification of study methods according to their level of evidence.



CLASSIFICATION OF RESEARCH METHODS

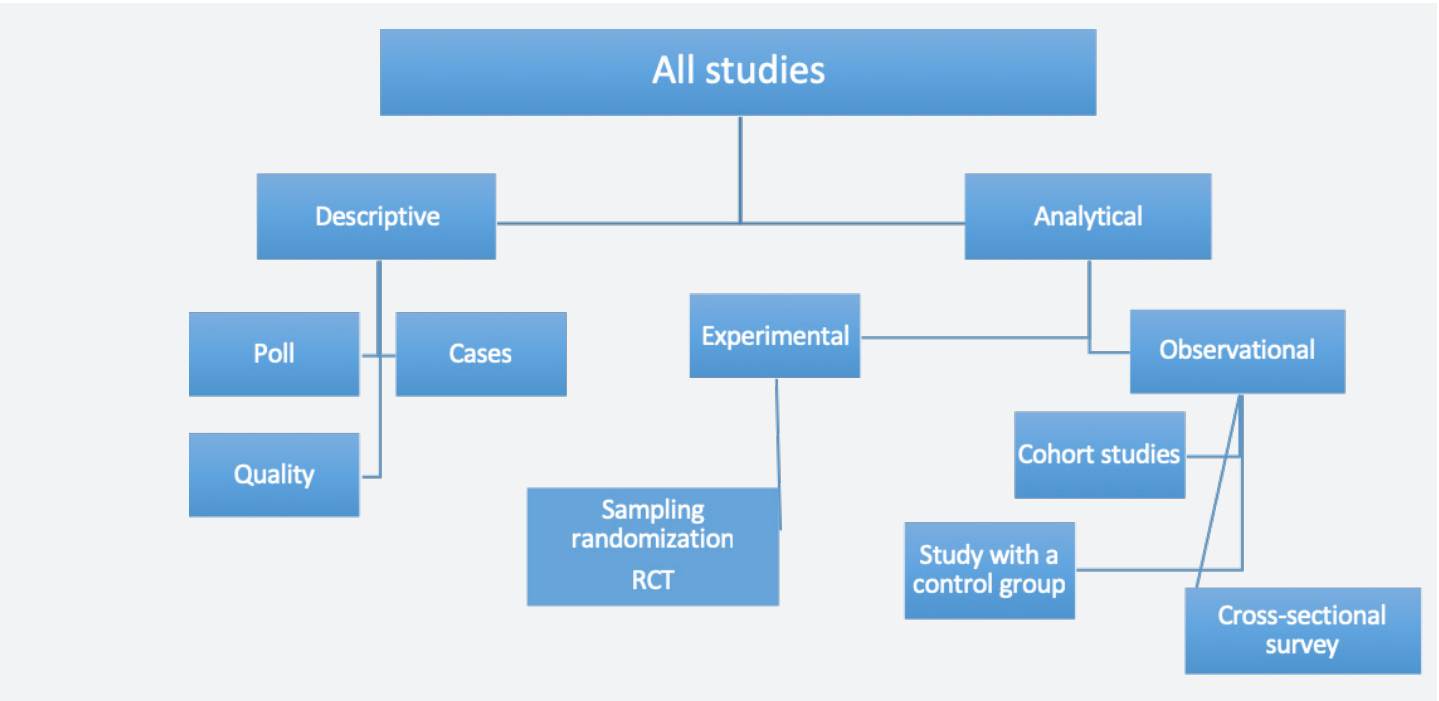
There are many research methods; but not all methods are "suitable" for answering the question we asked. It is convenient to initially distinguish between several major types of research:

1. **Biomedical research**: including all biological, medical and clinical trials, as well as the development and evaluation of biomedical products.
2. **Population studies**: including epidemiological, demographic and socio-behavioral studies.
3. **Policy research:** including studies on policies, systems, and services. Research, such as economic analysis, is also part of this research group.

The studies that are most often carried out by community representatives fall into the second or third group. Studies of the first group often use an experimental design.

It is important to distinguish between **fundamental and applied studies**. As early as in the 17th century, Francis Bacon distinguished two types of experiments: experiments to create light (knowledge) and fruits (results). The fundamental studies create knowledge, and as a result, expand our understanding of the world. Applied research "applies" this basic knowledge to interventions that improve people's lives. Despite the fact that the results of the applied research are very important, and we use them/apply them to solve existing problems, only knowledge gained from basic research allows us to carry out applied research.

Another important difference is the difference between **qualitative and quantitative studies**. They cannot be considered incompatible. The researcher may begin with a quantitative study. For example, think about a stigma index that transforms individual subjective views and experience into numerical data that can be compared among different groups. On the other hand, qualitative data may help to understand quantitative information. For example, when we have information about HIV prevalence in different subgroups, collecting qualitative data helps to identify differences between groups and can provide us with valuable information for understanding the HIV epidemics in the country.



MAIN STUDY METHODS

AN EXPERIMENT is a method of scientific research in which objects are immersed in an artificially created environment, and the experimenter controls their behavior. The main goal of such study is to test a hypothesis, search for new facts that can answer important questions for science.

There are two main types of an experiment:

- Controlled/laboratory/field: comparison occurs between 2 groups (sample) in controlled environment; clinical trials are an example of such study; in this case subjects are randomly allocated to study and control groups by the method defined by the experimenter and intervention is controlled;
- Natural/quasi-experimental: when the experiment is conducted in a natural setting and randomization takes place due to the factors outside the control of the experimenter, while he/she observes the changes

OBSERVATION is a research method in which the observer studies the properties of the object under study and notes activities changes, which happen to them. An intervention to the natural environment is minimal. It includes (1) the subject/observer, (2) the object of observation (the one under study) and (3) the means of observation.

There are several main types of observation:

- Field (in daily life) and laboratory,
- Undisguised and disguised,
- Direct and mediated
- Participant (which can be undisguised or disguised) and non-participant,
- Direct and indirect
- Complete and selective (according to certain parameters).

The following stages of observation are defined:

- Definition of the subject of observation (behavior)
- Object selection and data registration (individual (one person) or group)
- Developing a surveillance plan (situation-object-time)
- Choosing a method for processing results
- Processing and interpretation of the obtained data

Note: What are statistical significance and reliable results?

Statitisical significance: when the differences between the groups are large enough, so that the difference cannot be explained by a simple chance.

Statistically reliable: the level at which we believe that the results are significant.

p value: 0.05 (95%), 0.1 (90%)

QUALITATIVE STUDY METHODS: exploratory research that helps to understand the motivations and attitudes of people regarding the subject under the study.

The main types of qualitative study are:

- **Focus groups** (focus group discussions)
- **In-depth interviews**
- **In-depth interviews with experts**

FILTERED DATA: a special type of research, which is based on an analysis of already conducted studies. There are two types of analysis:

- **Meta-analysis** – analysis based on combining the data obtained in different studies;
- **Systematic review** - analysis of research, the essence of which is reduced to the thematic selection and study of all available articles on a specific topic.

OBSERVATIONAL STUDIES

- **Cross-sectional survey**: determines whether there is a connection between the exposure and the result at the moment, for example, studying a certain key group of people and their preferences for safe sex at the moment, (e.g. prevalence); these studies will not help us establish causality (cause-effect relationships).
- **Cohort studies**: observation is carried out on a group of healthy people, selected according to a certain criteria, among whom we do not observe the "results" of our interest (e.g. disease). We measure susceptibility to the disease, the influence of certain factors on the appearance of a "result". These studies are long-term and also do not determine causality (cause-effect relationships).
- **Case-control**: "inverted" cohort study, i.e. sample is selected from people who exhibit the "result" of our interests and exposure to potential causes is investigated retrospectively (e.g. individuals with HIV are asked about their risk behavior).

HOW TO CHOOSE A METHOD: «3 QUESTIONS» SCHEME

1. What is the purpose of the study?

- Describe population → descriptive
- Quantify the relationship between factors → analytical.

2. If analytical, was the random distribution (randomization) applied?

- Yes → RCT
- No → observation

For the observational study, the main types will depend on the time of measurement of the result, and therefore the third question:

3. When were the results determined?

- Some period of time after the exposure → cohort study ("prospective study");
- At the time of the study (at the same time as the result) → cross-sectional survey;
- Prior to determining exposure → case-control.

APPLIED EXAMPLE 1: DATA PRESENTATION

When the study is completed, it is especially important to present the results and communicate your "findings"/results to others. Although this looks like an obvious aspect of the study, many organizations and researchers, in fact, do not reach this stage. And if they did, the presentation of the results is not always adequate, or the full report is uploaded on a web page, which can be lost over time. While printed reports lie and gather dust in the offices.

In academic circles, the publication of research results in the form of an article and a monograph is considered one of the most important stages of work. Scientists may even try to publish their article for years. Also, the published data can be used by other researchers, while the number of such cases – citation – is the greatest reward for a scientist. Even before the era of the Internet and digital libraries, articles and other types of publications were available in libraries.

So, if this is so valuable, why do NGOs and communities not always reach this stage, and if they do, then this is often done inadequately? Finally, these studies are conducted with the aim to tell others what we have found, don't they?

Very often the research is funded by donors. As the results are updated and reported to the donor, some organizations no longer use the results of their own research. The reasons may be different: starting with the fact that the organization does not need these results for its advocacy work; the results obtained are of low priority; an organization may simply not have the resources to properly present the data, such as funds for design, infographics, a text editor, etc.

Currently, more and more donors request a results communication/presentation plan as part of an application for a research grant. This means that the recipient of such a grant will not be able to "close" the contract without using the results. However, if it is not explicitly requested, you can still include the communication/presentation plan as part of your research project, since research without communication of results does not produce any results.

The results of the study should be adequately presented to the target audience. As with any communication strategy, the presentation of study results should answer **five basic questions:**

1. ***The purpose and objectives of the presentation/communication:*** why do we want to communicate the results of our research? We want to improve the knowledge and understanding of certain issues, do we want to change the opinion of government officials? Goals vary according to different target audiences. This is the norm in advocacy campaigns since the primary and secondary target audiences should be reached in different ways and probably should get information through various communication channels.

2. ***Develop key messages that effectively communicate your message to the target audience:*** key messages must be adapted for the target audience. You may need to prepare different versions of the message to reach different audiences. For example, the message that "violence against women who use drugs is a violation of human rights" can be understood in different ways: by the parliamentarian, the population or the community itself. It may need to be adjusted to better understand. It is also important to consider who will deliver the messages.

3. ***Identify effective communication channels, methods and tools:*** when it comes to publishing results, printing a report is just one of the ways to transfer results. It is considered necessary to have a report in which all the details of the study will be presented, including all data, tools used, references, etc. However, using such a report as a way of presenting the results of a study would be a good choice - only if you are a student at the university and this is your coursework

or dissertation. Therefore, since research based on communities' data is more often carried out for other purposes than obtaining a diploma at a university. Therefore, carefully review how you want to report the results.

It is hard to imagine that only one communication format will be chosen, and this will be enough to reach your target audience. Starting from interpersonal channels (one-on-one contact), to public channels using existing social networks and media channels (including modern media such as radio and television, new media, such as the Internet and SMS), all of them are at your service to find the most suitable modes of communication. Ask yourself what are the methods and communication tools/channels that are likely to effectively reach your target audience(s)?

4. ***Access to communication resources:*** includes, for example, access to free airtime or the work of experts; availability of suitable materials from others (for example, international and national), such as templates for infographics, etc.

5. ***Develop your plan for the transfer of results:*** to achieve your goals, it is especially important to develop a plan - detailed activities for the transfer of research results, identify the responsible parties, the necessary resources and timelines. You also need to monitor implementation. This not only helps you stay in "shape" but also allows you to make some changes if you see that some approaches do not work.

REMINDER 1

Transfer of research results requires time and resources. Plan it.

REMINDER 2

Your research should generate two types of results:

1. Research results: the data you collected as part of your research. For example, 37% of respondents said they had to face problems in accessing HIV prevention services; 85% of respondents said that service centers are too far from the place where they live.

Such "dry" facts need to be analyzed in order to get to the real "results" (the analysis can be statistical or just interpretive - as you can see the results): "the majority of respondents are faced with the problem of reaching HIV services."

2. Discussion, conclusions or recommendations: although all of these terms mean several different things, the basic idea is that this refers to a section of your work when you draw some conclusions and interpretations of these data: "distance (or rare HIV centers) represent a serious barrier to access to services."

Most often, your research will collect much more data then is needed to formulate the key findings of your research. Although ideally, you report all your data in a report, for the communication, however, you will need to select only a few points that you will use to convey the results to your target audience.

Very often, despite the presence of a large amount of data, p**eople tend to "come" to conclusions that are not actually based on this data** (this is called "contextually unfounded"). Make sure your data truly supports the conclusions you made.

> «… the main writing task [about our studies] includes the development, how to find contextually substantiated theoretical insights regarded as a contribution by disciplinary readers?»
>
> (Golden-Biddle & Locke, 1997, p. 20)

Various people can call the same thing with different names. For example, the second part of this reminder, "discussion, conclusion, or recommendation," is often referred to as "analysis" in many papers. At its core, an analysis is a process: "I have analyzed the data," and the results of this process are more accurately called "results", "conclusions", "outcomes", etc. Statistical analysis is never a conclusion. Even if you use complex statistical analysis, such as factor analysis, the results of these analytical tests, still, should be analyzed separately, and only after that, they **should be presented as a conclusion/outcome.**

A STANDARD FORM OF A STUDY REPORT

Study reports usually have standard formats - this approach has long been used in academic circles, scientific journals, etc., and, as a rule, readers are accustomed to reading text that is structured in this format. Although, without this standard format, you will not publish the work in a scientific journal, for other purposes you can determine the innovative format yourself.

However, as we agreed above, every study **should generate a report** (no matter how boring it may seem, this is the best way to document your work, known to humanity so far).

In the diagram below, you will find the standard sections that should be included in the study report:

Section of a study report	Key elements
1. Title and abstract	A. Clear, informative title. B. "Structured abstract" summary, including the definition of the structure of the study.
2. Background and purpose	A. Background information about the intervention/phenomenon under study. B. The purpose of the study, including the research question(s) that the study is trying to answer.
3. Methods	A. Description of the study (for example, place and time). B. Description of the survey sample (including the number of sample members and how they were brought into the survey). C. Specific details of the intervention and how they differ from what happened in the control/comparison group. D. A description of how and when the results were measured (including evidence that the tests/tools used for the measurement are reliable and valid). E. Statistical methods used to compare results for intervention and control/ comparison groups (or results before and after intervention).

Section of a study report	Key elements
4. Results	A. Indicators of whether the survey was successful (for example, a low non-response rate). B. Any descriptive data on how the intervention under study is implemented. C. Findings
5. Discussion	A. Interpretation: what results confirm the effectiveness of the intervention. B. The extent to which the results can be generalized to other groups that receive or may receive an intervention. C. The significance of results for politicians and researchers. D. Factors that may explain the effect of the intervention (or its absence). E. Any study limitations (for example, small sample size)

THE FORMAT OF RESULTS PRESENTATION BY RESEARCH TYPE

EXPERIMENTAL STUDIES

Experimental results are almost always presented separately from the discussion.

- Present the results in tables and figures.
- Use tables and figures to introduce the reader with the information on key results.
- Note differences and relationships and provide information about them.
- Include negative results (then try to explain them in the discussion section)

QUANTITATIVE RESEARCH METHODS

There are generally accepted guidelines for presenting the results of statistical analysis of data on a population or groups of people. It is important that the results are presented in an informative way.

- Demographic data describing the sample is usually presented first.
- Remind the reader of the research question or hypothesis to be tested.
- Highlight a condition that has significant differences.
- Highlight important trends and differences/comparisons.
- Indicate whether the hypothesis is supported or not.

QUALITATIVE RESEARCH METHODS

Presentation and discussion of qualitative data are often combined. Qualitative data is difficult to present neatly in tables and figures. Usually, they are expressed in words, and this leads to a lot of written material through which you must guide the reader. Therefore, the structure of the report is very important.

Try to ensure that your sections and subsections reflect topics arising from data analysis, and so that your reader knows how these topics developed. Headings and subheadings, directions for the reader are the pointer forms that you can use to make it easier to navigate through these chapters.

VISUAL DATA: FEEL THE DIFFERENCE

Visual data is a very important component in presenting research results to readers. Even if the data is not quantitative, but qualitative, finding a way to convey it through a visual image, you influence your reader more, as the pictures and text are perceived by different parts of the brain and the impression is thus more memorable.

In this part, we decided to concentrate on providing quantitative data.

NUMBERS

In a short report, you are likely to select a few main results of your research and will provide readers with data related to these results. It is necessary to take into account several "golden" rules:

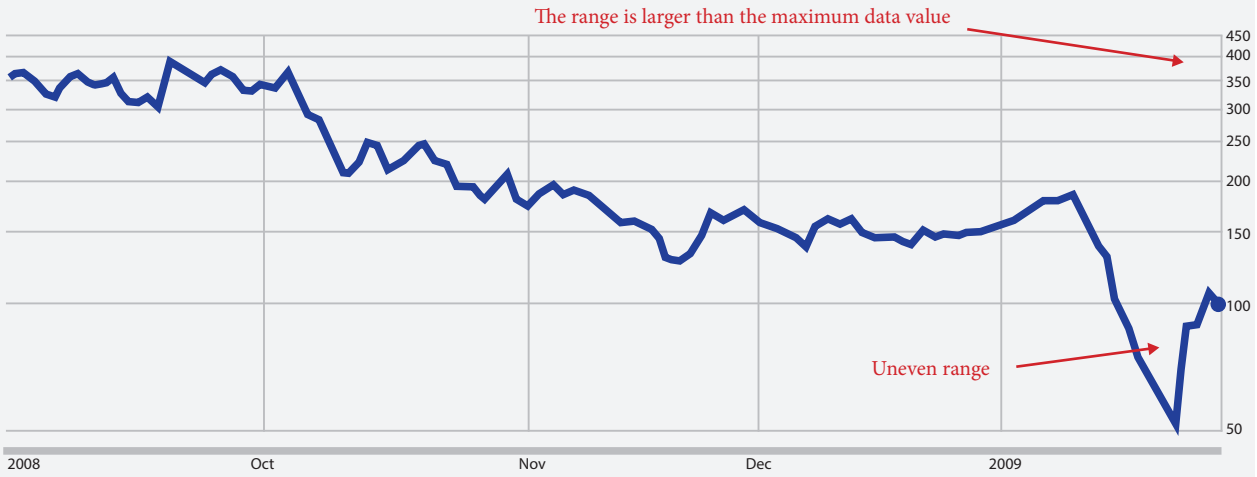
- Table: if the data is presented in the form of a table (which is very convenient for data that varies with some interval; for example, in a period of time, or in groups), then all data should be presented in one unit and the format should coincide. For example, if it is weight, then all data should be in kilograms or grams. The reporting unit should be clearly indicated.
- Numbers: if the number is large, in thousands or millions, the best part is to write the words: instead of "3 000 000.00" write "3 million". So, the information is easier perceived and remembered.
- It is more convenient to write with words that "one participant answered", "two cases of violation of the reporting instructions were revealed"; but if the number exceeds a single number, it is best to reflect them in numbers: 24 participants, 33 tests.

CHARTS

Line charts: Line charts are often used to display data (specific quantities, such as the number of HIV cases) over a period of time. Such data is sometimes called time-series data.

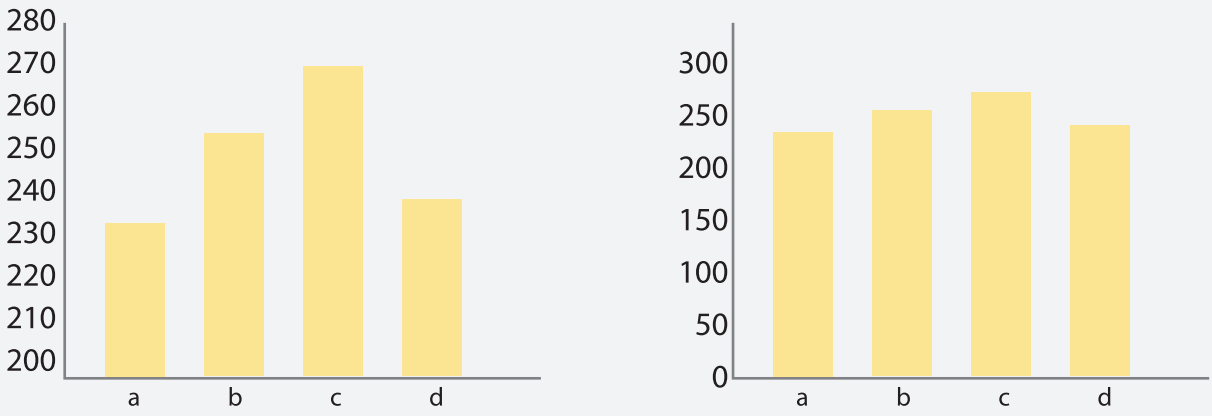
In order for the line chart to be informative, the starting point of the chart (that is, the value on the vertical axis where it intersects with the horizontal axis) is often chosen so that the chart reflects changes in the data. Consider a few rules:

- Usually, time data is indicated on the horizontal axis;
- If the time data is marked on the horizontal axis, the last point of the range on the vertical axis must be greater than the maximum indicator of the data plotted on the chart.
- If several graphs are given that describe comparative data, then in the graphs the ranges of both axes should be the same (e.g. the spread of HIV in several regions).
- The scale of the range must match. For example, in the graph below, the scale on the vertical axis is not the same, which suggests to the reader that the changes in the last period were more radical than in reality.



Bar chart: Bar charts can be used for data of different types, for example, indicators for women and men in different age groups.

The determination of a similar point (the intersection of the vertical axis with the horizontal axis) plays the most important role, how exactly the graph will be perceived by the reader. For example, two graphics below reflect the same information, but are visually perceived differently:



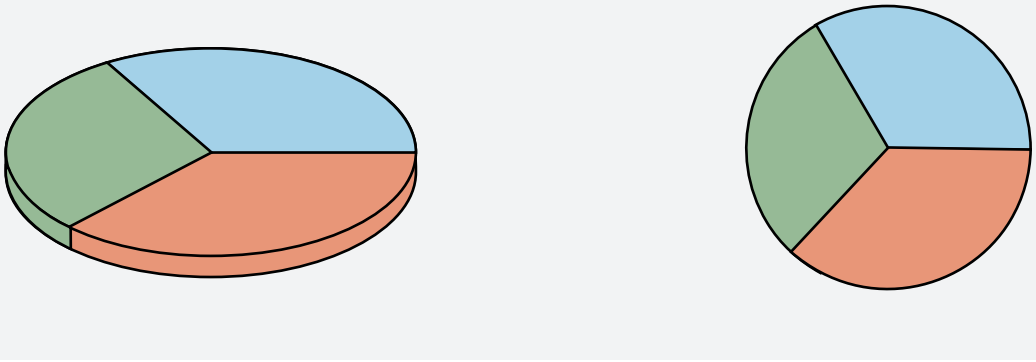
Pie Chart: Pie charts are some of the most common graphic images, although they are difficult to read and often misleading.

Pie charts are used to represent the distribution of "proportions of the whole." For example, if you survey 100 people, you can use a pie chart; in all other cases, the pie chart will display a portion of the 100% distribution. Therefore, it is important:

- When using some charts, except for the part (% of the whole), specify the amount of data, since the pie chart will, however, display a part of the whole, which consisted of 5 people and 1000.

It is also possible to mislead readers in their perception of a single chart. For example, in the pie charts below, the perspective of presenting the data may be confusing to any reader.

The use of visualization is ethical, without manipulating the opinions of readers.



APPLIED EXAMPLE 2: SAMPLING

Studies are conducted to identify an objective reality. Very often, the questions that we ask require a lot of effort to establish an objective reality. For example, if we are interested in finding out the growth of our neighbor, we can ask him or measure him and thus establish the truth. But if we are faced with the question of what is the average height of a person, then the information from our neighbor will no longer correspond to the truth. In order to answer this question, we need to interview all (or measure), collect this data and so derive the average.

Naturally, “polling everyone” is an impossible task in reality. Therefore, the concept of **sampling** was developed. **The general population** includes all the objects that interest us, and the **sampling** of it is only a part of the population.

When formulas are used, the parameters which characterize populations, they are denoted by Greek letters (θ, η, λ), and the Latin letters (x, s, etc.) are used to denote the sampling

We usually cannot investigate populations, that is, all objects of our interest, so sampling is selected for research, and the indicators (statistics) that are set for the sampling are used to estimate the parameters of a population.

There are 5 basic approaches for sampling:

1. **Random sampling:** when each object from the population has an even chance to get into the sample. It's like a coin toss, the chance that the front or the opposite side falls out is 50/50. This approach is considered the best, but very often it is very difficult to implement in a reality.
2. **Systematic sampling:** when objects from a population are selected into a sample group according to some counting principle, for example, every 9th falls into a research group.
3. **Convenience sampling** is the most common method since it is very easy to carry out, but, moreover, the most unfriendly. The sample is formed according to the principle "included are those who came first".
4. **Cluster sampling**: the population is divided into groups, so-called clusters, then the groups are randomly selected, and all members of the selected groups are examined. Usually, when developing clusters, the geographical principle is used.
5. **Stratified sample:** a population is divided into groups according to some principle (not geographical), which we call "strata" and then, from each stratum separately, a sample is taken according to a random principle or according to convenience. The most common "strata" means to divide the population into women and men, into age groups, etc.

HOW TO DETERMINE A SAMPLE SIZE

The determination of the sample size depends on a range of factors, which are only briefly discussed here. Since its size determines the reliability of your results, do not neglect the help of people who have expert knowledge in this area (statistics, epidemiologists, etc.).

The more respondents, the more reliable the results are (that is, the closer the sample size is to the size of the general population, the more reliable the research indicators will reflect the indicators of the general population). But, unfortunately, the sampling size is closely correlated with the costs of research, so very often we cannot afford to conduct a very large study.

Before calculating the sampling size, you must have an idea/answers to some questions (that is, when you bring in an expert to calculate the sample, he will also ask the same questions:

1. The size of the general population: the number of objects (people) that interest us. For example, if we want to study the satisfaction of PLHIV with HIV treatment services in our country, we shall first find out the number of PLHIV who are on treatment. If we need to know the reasons why PLHIV do not receive treatment, then we need to know the number of PLHIV who are not on treatment. These groups are called "general populations" or simply "populations".
2. Confidence interval (or Margin of Error): there is no perfect sample, so you shall determine what error limit you make. This limit reflects how much the obtained results can differ from the real ones: by +/- 5%? by +/- 1%? by +/- 10 %? During surveys, usually, 5% is considered an acceptable level.
3. Confidence level: how confident are you that your received results reflect the reality? It is difficult with a certain degree of confidence to say how confident we are that our results are true. But to be more precise, when from the general population we make a sample of a similar size using the same principle, then the results obtained from these groups will coincide with the results that we obtained (if the confidence level is 95%, it means, 95% of cases, the poll of the new sample shall give the same result).

On the Internet, freely available, there are special calculators that will help calculate the sampling size. There is a range of them and they can be used for preliminary calculations, although, based on the importance and technical complexity of a sample selection, it is better to either study the question yourself or use the help of experts, since the sampling will determine the reliability of all your results.

Free sampling size calculator:

https://www.surveysystem.com/sscalc.htm

9. MAIN BARRIERS DURING A STUDY AND HOW TO IDENTIFY THEM

Community organizations and community representatives themselves are not required to be research professionals and therefore, regularly face challenges during the studies. At the Consensus Meeting, we asked the participants to compile a list of the barriers they face.

1. CHALLENGES WITH PRIORITIZATION:

- Overstated customer expectations.
- Customers impose their priorities and opinions.
- A challenge of formulating needs based on global trends, rather than national issues.

Solution: in a study planning process, especially when it comes to a literature review, it is very important, on the one hand, to reduce the scale and focus the research question, and on the other hand, to provide a rationale for the research question.

2. LACK OF QUALIFICATIONS AND COMPETENCIES. ISSUES WITH INSUFFICIENT KNOWLEDGE AND SKILLS ARISE AT EACH STAGE OF THE STUDY. IT REDUCES THE RESEARCH QUALITY.

- Low data analysis skills
- Wrong choice of methods
- Lack of innovation/modern technology
- Low data quality (due to lack of qualification)
- Low qualifications of community interviewers (may miss questions)
- Lack of knowledge of "academic" approaches
- Unable to control the quality

Solution: Engaging experts, who have the necessary knowledge, is the most rational solution to these issues. Capacity building of your own experts from the community is also one of the possible

approaches. A literature review and familiarization with similar studies can help to clarify priorities and define the methods of your research.

3. FINANCIAL NEEDS:

- Lack of technology/voice recorders, video cameras, etc.
- Lack of financial resources for hiring experts
- Lack of resources to monitor field work
- Expensive software

Solution: the best solution to financial problems is to find a funding source. For this, it is important to draw up a clear plan and budget and negotiate to funding support with the donor. But this is not always possible. In terms of research, it is necessary to take into account approaches that minimize costs. For example, use a recorder in the cell phone, find free programs for analysis, etc.

4. PAYMENT FOR EMPLOYEES:

- The low motivation of interviewers, as they often have to work as volunteers, or receive low payment for their work

Solution: volunteer work is often taken into account in grant applications. Although the job of the interviewer and other workers can be quite a time-consuming and lead to the "burnout" of workers. It is recommended to always consider the payment of employees in grant applications for research work.

5. LANGUAGE BARRIERS:

- No access to tools/protocols in the native language

Solution: using validated tools improves the quality of research. Therefore, translation costs should be budgeted in the project. Each toolkit requires piloting after translation to confirm equivalence of translation.

6. CHALLENGES ASSOCIATED WITH DATA ANALYSIS:

- Lack of focus in the analysis
- Problems with data entry
- Lack of "baseline" data that you can build on with something to compare.
- Inability to control the quality of analysis
- Difficult language used report
- Inadequate analysis (does not give answers to what, why, who, etc.)

Solution: The analysis plan should be a part of the protocol, which helps to keep focus. If necessary, you can hire an external expert. Developing a clear plan for quality control of the research and including the costs associated with the implementation of these control measures should also be included in a proposal.

7. ISSUES ASSOCIATED WITH THE COMMUNICATION/PRESENTATION OF RESULTS:

- Issues with communication of results: presentation format, lack of skills.
- Difficulties with design and poor-quality of infographics
- ”Bargaining” with the results and policy decisions while interpreting results

Solution: The costs of presentation and communication of the results should be taken into account as part of the research budget. Also, developing a communication plan helps to keep focus and achieve initial goals.

8. OTHER PROBLEMS:

- Confidentiality and anonymity issues
- Few community representatives in groups to develop research priorities
- It is impossible to justify studies while there is no data
- Very few/lack of scientific articles
- Lack of literature review
- Unavailability of some groups
- Community-driven research does not provide real results.

A matrix on the selection of priority issues and research methods was developed during the meeting and is attached – see Annex 4: Table of key questions and approaches for community-driven study .

ANNEXES

ANNEX 1: GLOSSARY

- **Community-driven/community-led:** research which is led by the community at all stages of its implementation (especially in determining the research question, an initiator) and the use of its results.
- **Community-based:** a general term for all types of research where a community is involved.
- **With community engagement:** a study where the community acts only as a respondent or interviewer.
- **Monitoring:** a systematic and regular data collection from projects and programs. It is an organized process that monitors the progress of the established plans and checks compliance with the set standards
- **Evaluation:** is used to draw conclusions about the relevance of the project/program, effectiveness and sustainability. Evaluation is a scientific process of analyzing or interpreting the collected data. It considers the implications and the overall impact of the project/program.
- **Study/research:** is a descriptive process that is used to study any phenomena, by asking questions such as "what is/was?" Or "what are the differences?", Or "what happens when there are certain conditions?

ANNEX 2: AVAILABLE COMMUNITY-DRIVEN STUDIES IN EECA

In the process of developing this document, the information was collected on the held community-driven research and the participants of the working meeting. The table below summarizes these studies

Name	Country	Key group	Donor/year/ type of a publication	Study type	Quality control	Limitations
Working together with key population groups in Kyrgyzstan who have a limited access to services: what works?	Kyrgyzstan	Sex-workers, PWID, lesbian, gay, bisexual and transgender people (LGBT)	Several 2016 Report	Operational study Cross-sectional design	The approach is described for data entry and analysis	Provided

Goals and objectives	Methodology	Literature review/ Sampling description/ Ethical aspects	Tools
1. Assess the socio-economic situation of key populations. 2. To establish what contributes to and what impedes access to services (including medical, legal and psychosocial). 3. Assess the degree of satisfaction and expectations of key populations from prevention programs (in particular, regarding the range of services provided, interaction with NGO staff and the provision of information materials). 4. Evaluate the quality of services provided by outreach workers by the following parameters: • informing on the work of organizations and programs for key populations; • distribution of medicinal and hygienic products; • counseling on HIV, STI, HBV, HCV and TB; • distribution of information and educational materials, informing about operations and their quality; • referral to medical institutions and other organizations; • forming trusting relationships. 5. Identify factors that may adversely affect the desire to participate in the program.	To achieve the study objectives, a combination of qualitative and quantitative data collection methods was used. The main method was a semi-structured in-depth interview, as well as formal interviews. Interviewed 437 representatives of three key groups - PUD, SW and LGBT - over 18 years old, who had previously participated in HIV prevention programs. The survey also involved 10 outreach workers and four managers of non-governmental partner organizations (NGOs), i.e. only 450 respondents. A data was collected by trained interviewers and community representatives.	Yes (very fragmented) Provided; respondent-driven sampling Are being discussed; written informed consent was collected from the participants. Approval from the bioethics committee received	

Name	Country	Key group	Donor/year/ type of a publication	Study type	Quality control	Limitations
A STUDY OF THE MANIFESTION OF DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV/AIDS, LGBT INDIVIDUALS AND INTRAVENOUS DRUG USERS IN VARIOUS SPHERES OF SOCIETY	Armenia	PLHIV, PWID, lesbian, gay, bisexual and transgender people (LGBT)	GF 2018 Report	Cross-sectional study/ Survey (not stated)	For data collection (field interview); details not provided	

Goals and objectives	Methodology	Literature review/ Sampling description/ Ethical aspects	Tools
This study aims to examine the manifestation of discrimination in family relationships, work, education, public health and the availability and provision of services in other spheres against 300 representatives from the aforementioned 3 groups living in the city of Yerevan and the regions of the Republic of Armenia A quantitative analysis was performed within the framework of the study, which aims to examine the manifestation of stigma and discrimination against the 3 groups – People Living with HIV/AIDS, LGBT Individuals, and IV Drug users in family relationships and the availability and provision of services in the spheres of employment, education, public health, and others. The study addressed the following questions: 1) Causes, Spheres, and Frequency of Instances of Discrimination 2) Types of Discrimination, 3) Factors Influencing Discrimination in Society, 4) Models of Behavior When Faced with Discrimination 5) Mechanisms to Combat Discrimination and Their Effectiveness	Semi-structured face-to-face interviews; the study claims to being able to identify "cause-and-effect" relationship, which is not scientifically possible in the given study design. Correlations have been calculated without statistically significant testing (ANOVA, T-test), meaning that the validity of results are questionable.	Not provided 200 individuals (sampling methodology not explained) Not covered	Provided

Name	Country	Key group	Donor/year/ type of a publication	Study type	Quality control	Limita-tions
Review of the experience of the community-led HIV testing implementation and recommendations for implementing these practices in East Europe and Central Asia Description of the recommended optimal model for community-led HIV testing, support and treatment using the example of Estonia	Estonia	PLHIV, PWID, lesbian, gay, bisexual and transgender people (LGBT)	GF 2018 Report	Cross-sectional (not provided)	Not provided	Yes

Goals and objectives	Methodology	Literature review/ Sampling description/ Ethical aspects	Tools
The goal of this review is to analyze and develop recommendations for the implementation of an approach to the community and NGO-led HIV testing, including accompaniment to treatment for the countries of East Europe and Central Asia (EECA). Objectives: • To study and analyze existing experience and international recommendations in the field of organizing community-led HIV testing, including support for treatment in countries of the EECA region. • Describe the successful cases of HIV testing organization by the communities. • Develop an optimal model for the provision of community-led HIV testing services, including cost structure and recommendations for Estonia. • Provide community representatives with sound information to advocate for the community-led HIV testing program in Estonia.	The methodology includes three main components: 1) analysis of documents describing existing experience and international recommendations on the organization of community-led HIV testing, including accompaniment for treatment in the countries of the East Europe and Central Asia region (EECA); 2) a description of experience, including successful models of organizing community-led HIV testing via an analysis of documents, interviews of key respondents, and a survey of the target population; 3) a joint development of an optimal model for the provision of the community-led HIV testing services and recommendations through the in-depth discussion and development of recommendations from all stakeholders.	Yes No No	Not provided

Name	Country	Key group	Donor/year/ type of a publication	Study type	Quality control	Limita-tions
Findings for evaluating barriers to scaling up coverage of HIV treatment	Kyrgyzstan	PLHIV	Not provided 2018 Report	Cross-sectional (not provided)	Yes (in the course of data entry and analysis)	Not discussed

Goals and objectives	Methodology	Literature review/ Sampling description/ Ethical aspects	Tools
Goals: To study challenges associated with connection of PLHIV ART and low adherence to ART among PLHIV receiving treatment, in order to develop further recommendations for their elimination. Objectives: 1. To study the factors that are barriers to initiating ART. 2. To study the factors affecting adherence to ART for PLHIV, related and not related to the main disease (demographic, social, factors of injection and sexual behavior, reasons for changing the ARV therapy regimen, psychological characteristics of PLHIV, etc.). 3. Development of recommendations and tools to create conditions for expanded coverage of ART and increase adherence to treatment among PWID/PLHIV. 4. Contribute to the implementation of recommendations and tools that will expand coverage and improve PWID/PLHIV adherence to HIV treatment at the national level.	The approach used involves qualitative and quantitative data collection methods, including: a review of literature and project documents, a survey of key respondents, focus groups and a survey/questionnaire of representatives of target groups of service recipients, as well as facilitated discussions of representatives of key stakeholders. Applied research according to the schedule using a combination of qualitative and quantitative research methods, including: • review of relevant documents; • in-depth interviews with key stakeholders; • in-depth interviews with employees of medical institutions; • PWID/PLHIV survey; • in-depth interviews with NGO representatives.	Yes Yes Yes, informed consent was obtained	Not provided

Name	Country	Key group	Donor/year/ type of a publication	Study type	Quality control	Limita-tions
Towards 90: Analysis of procurement and provision of ARVs in EECA countries	Armenia, Belarus, Kazakhstan, Kyrgyzstan, Moldova, Russia, Ukraine	PLHIV	Not provided 2018 Report	Cabinet study	No	No
Observance of the Rights of Sex Workers in the Kyrgyz Republic	Kyrgyzstan	SW	Soros Foundation-Kyrgyzstan 2014 Report	Cross-sectional (not provided)	No	No
Barriers to access to HIV testing for adolescents and youth in three EECA countries: Russia, Ukraine and Georgia	Georgia, Ukraine Russia	Youth	UNAIDS Regional Office in EECA region and ViiV Healthcare 2017 Report	Assessment	Not explained	Not listed

Goals and objectives	Methodology	Literature review/ Sampling description/ Ethical aspects	Tools
The main purpose of this document is to assist the efforts undertaken by the government bodies of the countries of East Europe and Central Asia in the fight against the HIV epidemic.	1. Analysis of legislation relating to the procurement and provision of ARVs 2. Analysis of procurement and provision of ARVs in 2017 3. Conclusions and recommendations on the results of the analysis.	No (analysis of typical research is not available, while the methodology itself is a review) No No	No
Describing SW groups and a situation linked to violating rights of sex workers	SW poll (n: 590) using semi-structured questionnaires Interviews with 33 police service employees	Yes Yes (partially) Yes, informed consent was obtained	No
Identify youth-friendly HIV services	Site-visits and evaluation using a pre-defined checklist	Not provided No No	Not included

Name	Country	Key group	Donor/year/ type of a publication	Study type	Quality control	Limita-tions
MONITORING STUDY OF CONDOM-LINKED BEHAVIOR AND AWARENESS OF SEX WORKERS ABOUT HIV AND STI IN THE KYRGYZ REPUBLIC	Kyrgyzstan	SW	UNFPA 2014 Report	Cross-sectional study (a part of the longitude study)	Not provided	Not discussed

Goals and objectives	Methodology	Literature review/ Sampling description/ Ethical aspects	Tools
The goal of the study is to evaluate the effectiveness of HIV/AIDS/STI prevention programs with sex workers in the Kyrgyz Republic over a decade of implementation. The study for the first time includes a special review of the use of the female condom. Objectives of the study: 1. Assess changes in the knowledge and attitudes of sex workers related to HIV/AIDS 2. Assess changes in the behavior of sex workers associated with the use of a condom 3. Assess changes in the behavior of sex workers associated with obtaining medical services	A survey using the tool of FHI - Family Health International	No Yes (Cluster)	Not provided

ANNEX 3: TABLE OF KEY QUESTIONS AND APPROACHES FOR THE COMMUNITY-LED STUDY

	What do we study? Questions of the study?	Who holds a study/ evaluation	How (methods)	Community role
STRUCTURE				
Prevention	1. Qualification of consultants 2. Availability and quality of consumables 3. Availability and quality of information materials 4. Availability of low threshold centers	1. Community and experts 2. Community 3. Experts and community 4. Community	1. Mystery shopper, compliance with approved standards 2. Survey 3. Survey 4. Mystery shopper	1. Partner 2. Community-driven 3. Partner 4. Community-driven
Testing	1. Availability and quality (location, opening hours, anonymity, confidentiality) of testing rooms 2. Availability and quality of tests 3. Availability and quality of customer support 4. HIV testing algorithm 5. Opportunity to diversify the production of self-test kits (prequalified by WHO)	1. Experts and community 2. Experts 3. Experts and community 4. Experts 5. Experts	1. Compliance with WHO recommendations and poll 2. Reference-lab 3. Mystery shopper, compliance with approved standards 4. Compliance with WHO recommendations 5. Market research	1. Partner 2. N/A 3. Engagement 4. N/A 5. N/A
Treatment	1. Qualification of medical staff and social workers 2. Access to treatment (as the involvement of medical staff of different specialties to increase coverage and accessibility)	1. Experts 2. Experts and community	1. Certification 2. Feasibility study and poll	1. N/A 2. Engagement

	What do we study? Questions of the study?	Who holds a study/ evaluation	How (methods)	Community role
PROCESS				
Prevention	How many clients can an outreach worker reach per unit of time to provide quality services?	Community	Questionnaire, analysis of secondary information, observation	Client, participant, implementer, presenter
Testing	How many clients can an outreach worker reach per unit of time to provide quality services?	Community	Questionnaire, analysis of secondary information, observation	Client, participant, implementer, presenter
Treatment	What are the main reasons for not taking ARVs?	NGO (independent experts), clinic, state facilities	Questionnaire, inquirer, interview	Client, participant, implementer, perform evaluation, presentation
Social support, human rights, and etc.	Where is palliative care most effective: at home or in hospice?	Service providers (state, non-state), independent expert	Observation, comparative analysis, questionnaire/ client interview, case analysis	Client, recipient and presenter

	What do we study? Questions of the study?	Who holds a study/ evaluation	How (methods)	Community role
RESULTS				
Prevention	The result of the quality of death prevention caused by overdose	With community engagement. Initiated by the community.	1. Research - Constructing an egocentric social network of people who inject drugs. 2. Planning base-line and final evaluation. 3. Analysis of documents and practices in fixing death. 4. Network mapping.	Initiator Interviewer Respondent
Testing	The result of the quality of testing and its availability among HIV pregnant women. (including pre-pregnancy period, as a part of family planning process, with aim that women know HIV status beforehand)	Communi-ty-driven	Study Quantitative Qualitative Check-list interview (evaluation of inter-vention to increase pre-pregnancy HIV testing) + study of patients' knowledge on basics of HIV testing	Initiator Interviewer Respondent
Treatment	1. The result of the quality of treat-ment of HIV/AIDS (satisfaction) and the presence of side effects (quality of life) 2. Cooperative analysis of ARV protocols	Community	Study Semi-structured poll	Initiator Interviewer Respondent
Social support, human rights, and etc.	The result of the quality of customer care in places of detention and in medical institutions	Community-driven	Case collection and analysis	Initiator Interviewer Respondent

	What do we study? Questions of the study?	Who holds a study/ evaluation	How (methods)	Community role
PATIENT CHARACTERISTICS				
Prevention	Estimation of the number of teenagers who use drugs What types of drugs are available for teenagers and what are the ways to use them? Is the type of drug related to high-risk practices (unsafe sex, general use of syringes)? What are the characteristics of this group (age, gender, wealth, education)? Do they know about the risk, ways of HIV transmission and how to protect against HIV?	Community-based organization	Face-to-face interview Quality survey	Initiator
Testing	Are there barriers to testing teenagers in the legal framework? Are these people tested at all and what is the reason? Is there a referral system in case of HIV positive result?	Community-based organization	Face-to-face interview Quality survey	Initiator
Treatment	Are the doctors willing to communicate with teenagers without parents? Can a teenager decide on treatment independently (without parents or guardians - the legal framework)? Are medications available for adolescents at the facility? How is adherence therapy maintained among adolescents? How one finds out about treatment interruption? What are the reasons?			
Social support, human rights, and etc.	Are there peer counselors for teens? Are there any social protection institutions for teens? Are there free psychological counseling for teens with addictions?			