Eurasian Women's Network on AIDS

Sexual and Reproductive Health and Rights of Women Living with HIV

Guidance for Community-Led Research
on Sexual and Reproductive Health and Rights
of Women Living with HIV

2022

Guidance for Community-Led Research and Monitoring the Quality of Sexual and Reproductive Health Services of Women Living with HIV: Sexual and Reproductive Health and rights of women living with HIV.

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Kovtun O. Guidance for Community-Led Research on Sexual and Reproductive Health and Rights of Women Living with HIV: Sexual and Reproductive Health and Rights of Women Living with HIV / Eurasian Women's Network on AIDS. – Tbilisi, 2022. – 63 p.

Tool for Monitoring Service Quality in Community Leadership on the Sexual and Reproductive Health of Women Living with HIV describes the basic principles for planning, preparing, conducting and disseminating the findings of the study on Sexual and Reproductive Health and Rights of Women Living with HIV and is a comprehensive resource for women living with HIV who plan to conduct this study in their country.

This tool provides a direct description of each of the stages of the study — from planning to presenting findings; a study checklist, which serves as a self-assessment tool for the study team and makes sure that the researchers are ready to start the project; examples of the study toolkit and supporting documentation that can be used as templates.

The author would like to thank the study national coordinators **Irina Klintukhova** (Belarus), **Elena Bilokon** (Kazakhstan), **Irina Goreaceaia** (Moldova), **Takhmina Khaydarova** (Tajikistan), **Evgeniya Korotkova** (Uzbekistan), who shared their own experiences in conducting the study, for their participation in the interviews and assistance in the preparation of this tool, and the entire team of the Eurasian Women's Network on AIDS for advisory support, technical assistance and support at all stages of the tool development.
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The tool was developed as part of the project "Thinking Out of the Box: How to Overcome Challenges in Community Advocacy for Sustainable and High-Quality HIV Services", supported by the Robert Carr Fund for Civil Society Networks and implemented by the Eurasian Regional Consortium of three networks — the Eurasian Harm Reduction Association (EHRA), the Eurasian Coalition on Health, Rights, Gender and Sexual Diversity (ECOM) and EWNA. Guidance design and translation in English was supported by UNFPA, the United Nations sexual and reproductive health agency. The views expressed in this publication are those of the authors, and do not necessarily represent the views of UNFPA, the United Nations or any of its affiliated organizations.

CONTENTS

ABBREVIATIONS AND ACRONYMS

EECA – Eastern Europe and Central Asia region,
AIDS – Acquired Immune Deficiency Syndrome,
HIV – Human Immunodeficiency Virus,
EWNA – Eurasian Women's Network on AIDS,
FGD – focus group discussion,
SRH – sexual and reproductive health

INTRODUCTION

Eurasian Women's Network on AIDS (EWNA) was established in 2013. It was officially registered in Georgia on May 05, 2015. EWNA is a network of women leaders and activists who advocate for the rights of women living with HIV and vulnerable to HIV in the Eastern Europe and Central Asia (EECA) region. These rights are related to access to healthcare services, including reproductive health, the elimination of violence against women, and the right to be involved in political and public discussions on which their lives and health depend.

EWNA is part of the Eurasian Regional Consortium of three networks — the Eurasian Harm Reduction Association, the Eurasian Coalition on Health, Rights, Gender and Sexual Diversity and EWNA. The consortium conducts advocacy and community building activities to ensure the financial and programmatic sustainability of high-quality, evidence-based, non-discriminatory and gender-responsive HIV services for key communities in the EECA region within the project "Thinking Out of the Box: How to Overcome Challenges in Community Advocacy for Sustainable and High-Quality HIV Services", supported by the Robert Carr Foundation for Civil Society Networks. The project part of EWNA is aimed at strengthening the capacity of the women's network and increasing the participation of women in advocacy activities in the EECA region. EWNA conducts women's community-led research on the sexual and reproductive health and rights of women living with HIV and provides technical assistance to carry them out.

The study on Sexual and Reproductive Health and Rights of Women Living with HIV is a unique community-led study. It is designed, planned and implemented by women living with HIV among women living with HIV for the purpose of improving the quality of services that are provided to these women. Therefore, planning and implementation, including data collection, analysis of findings, and advocacy of findings, are carried out directly by HIV-positive women.

The underlying premise of the Sexual and Reproductive Health and Rights of Women Living with HIV study is that the well-being of HIV-positive women is based on an integrated approach to health and human rights. The right to sexual and reproductive health is an integral part of the right to health, and its provision is envisaged in two Sustainable Development Goals until 2030 — "Good health and well-being" [1] and "Gender equality" [2]. HIV-positive women may not only be deprived of equal access to quality healthcare, but also experience multiple forms of violence, stigmatization and discrimination that lead to violations of sexual and reproductive rights.

The goal of the study is to identify the key issues and needs of women living with HIV related to sexual and reproductive health through the prism of human rights, as well as to identify priorities for introduction of the measures to address the HIV/AIDS epidemic, taking into account gender aspects and the rights of women living with HIV, into national strategies and action plans.

Tool for Monitoring Service Quality in Community Leadership on the Sexual and Reproductive Health of Women Living with HIV sets forth the basic principles for planning, preparing, conducting and disseminating the findings of the study on Sexual and Reproductive Health and Rights of Women Living with HIV and is a comprehensive resource for women living with HIV who plan to conduct this study in their country.

To prepare the tool, a desk analysis of primary documentation and analytical reports of previous studies on sexual and reproductive health and the rights of women living with HIV was used:

[1] - Goal 3. Ensure healthy lives and promote well-being for all at all ages, https://www.un.org/sustainabledevelopment/ru/health/
[2] - Goal 5. Achieve gender equality and empower all women and girls, https://www.un.org/sustainabledevelopment/ru/gender-equality/

- “An express assessment of the challenges and needs of women living with and affected by HIV, representatives of key populations during the COVID-19 pandemic in Kazakhstan” (Kazakhstan),
- “Realisation of the right to reproductive health of women living with HIV in the Republic of Moldova” (Moldova),
- “Sexual and reproductive health of HIV-positive women: access to services, gender equality and violence” (Russia),
- “Key issues of sexual and reproductive health of women living with HIV in Tajikistan through the prism of human rights” (Tajikistan),
- “Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine” (Ukraine),
- “Studying the reproductive health needs of women living with HIV to support the elimination of mother-to-child transmission” (Uzbekistan),
- “Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Belarus” (Belarus),

as well as the results of interviews with the study coordinators in five countries: Belarus, Kazakhstan, Moldova, Tajikistan, Uzbekistan.

This tool provides a direct description of each of the stages of the study — from planning to presenting findings; a study checklist, which serves as a self-assessment tool for the study team and makes sure that the researchers are ready to start the project; examples of the study toolkit and supporting documentation that can be used as templates.

GOALS AND OBJECTIVES

The goal of the study on Sexual and Reproductive Health and Rights of Women Living with HIV is to identify the key issues and needs of women living with HIV related to sexual and reproductive health through the prism of human rights, as well as to identify priorities for introduction of the measures to address the HIV/AIDS epidemic, taking into account gender aspects and the rights of women living with HIV, into national strategies and action plans.

The objectives of the study are to:

- form a social portrait of women living with HIV in a country,
- identify the impact of various life factors of women living with HIV, including violence, on their sexual and reproductive health,
- study the experience of women living with HIV in accessing sexual and reproductive health services,
- identify the level of accessibility and utilization of sexual and reproductive health services by women living with HIV,
- identify key factors affecting women living with HIV's access to and opportunities for various social services,
- identify barriers to accessing medical and social services, legal assistance, government services for women living with HIV in order to preserve and maintain sexual and reproductive health of women living with HIV,
- develop recommendations to uphold the rights and increase access of women living with HIV to sexual, reproductive health and other social services, as well as recommendations to address the HIV/AIDS epidemic through gender-sensitive and gender-transformative national strategies.

The above list of objectives can be adjusted or supplemented with other objectives that are relevant for the community in your country. The indication of any objective is the basis for the creation of the questionnaire and further analysis, and shall be determined by the community when planning the study.

METHODOLOGY

Study design

The study consists of two stages:
1) survey of women living with HIV (including collecting life stories) and
2) focus group discussions (FGDs) with activists and providers of services for women living with HIV.

Face-to-face studys of women living with HIV using a standardised questionnaire make it possible to identify and define the needs and challenges they face based on socio-demographic and other characteristics.

As part of the study, the interviewer asks participants, who have negative or positive experiences in areas related to the study theme, to describe such cases. Life stories are documented as answers to open-ended questions.

FGDs are carried out to obtain expert opinion on the situation of HIV-positive women, develop recommendations for improving the legal and normative framework and the quality of access to services, as well as receive proposals on the prevention of violence against HIV-positive women.

Criteria for inclusion and exclusion of participants

Each of the study participants should meet a number of characteristics (by self-declaration):

Women living with HIV, as part of the questionnaire process	Aged 18 and over
	Diagnosis of HIV infection
Women living with HIV, for the purpose of collecting life stories as part of the questionnaire process	Aged 18 and over
	Diagnosis of HIV infection
	Experience of violence, rights violations and gender inequality
	Experience in accessing and successfully obtaining services to preserve or maintain sexual and reproductive health
Women living with HIV, service providers, as part of the FGDs	Women living with HIV who are service providers of governmental and non-governmental organizations providing direct or indirect assistance to women living with HIV, including in the field of sexual and reproductive health and/or HIV response
	Women living with HIV who are experts or activists in the field of sexual and reproductive health and/or HIV response
	Women living with HIV who are experts or activists in responding to situations of gender-based violence, violations of women's rights and gender inequality

The criteria for exclusion of women living with HIV from the study at each stage are:
- participation more than once in each of the stages of the study;
- lack of informed consent to participate in the study;
- the condition that does not allow understanding and answering the questions of the questionnaire/tool, and the behaviour of the respondent threatens her own safety or the safety of others.

Subject to availability of resources, the study will target hard-to-reach subgroups of women living with HIV. For example, women who are in prison at the time of the study, residents of rural areas, HIV-positive women who, for one reason or another, are not registered and/or do not receive treatment.

For the purposes of the study, it is important to try to reach a diverse subgroup of HIV-positive women. Following the data collection and at the stage of data analysis, it is necessary to analyse which subgroups of women living with HIV were not included in the sample and indicate the relevant information as study constraints in the report. For instance, if the study failed to reach HIV-positive women from rural areas, the report should indicate this and, accordingly, mention that the study findings apply only to HIV-positive women from oblast centres/large cities and/or indicate the names of settlements if their number was small.

Geographical scope and sample of the study

When selecting the regions of the study, the presence of non-governmental organisations or associations of women living with HIV, having access to the target group and the necessary human resources for conducting the study, should be taken into account, but the final decision should not be influenced. It will be useful to understand this aspect when planning, including during the training of the study team in the field, and, if necessary, more intensive training of regional specialists.

The sample for the study shall be calculated taking into account the HIV prevalence among the female population, i.e. the number of registered HIV-positive women shall be taken into consideration in absolute terms and as a percentage of all HIV-positive people in the country or individual regions. In addition, the sample design shall take into account the age distribution of women living with HIV in the country to form study quotas.

To determine the geographical scope and sample of the study, the information/statistical data on the situation with HIV/AIDS among women in the context of individual regions/districts/settlements should be taken into consideration. It is convenient to use a table format with indicators in a column, and the names of regions in a row. Such summarised information will be useful not only at the stage of sampling and determining the geographical scope of the study, but will also indicate a rational and thoughtful approach to the selection of cities/regions for the study.

The study provides for FGDs, the number of which shall be determined by the study team in each country. At least one FGD should be conducted among women living with HIV who are experts and activists in the relevant field, and at least one — with the providers of services for HIV-positive women.

The number of FGDs shall be determined by a study team in each country. Tentatively, two discussions could be carried out, each with a different category of respondents (e.g. service providers and HIV-positive women who are not service providers). This will make it possible to understand and systematise the experience/thoughts/opinions of each subgroup, and subsequently analyse the data obtained more precisely. If the study includes a large number of regions or, for example, rural areas, the number of FGDs can be increased to four. For example, two FGDs in the capital or major cities, and two FGDs in district or rural areas. This will reveal the specifics of the situation with sexual and reproductive health, the rights of HIV-positive women in different regions of the country. The recommended number of participants in one FGD is 8-10 people. A larger number of respondents may adversely affect the quality of the data obtained (the duration of the FGD is limited, and not all participants will be able to fully express themselves on a particular issue) and the comfort of the moderator's work (she will be forced to track the thoughts of a large number of participants and coordinate the dynamics of the group).

PREPARATORY STAGE

Study Protocol

For high-quality planning, data collection and analysis, it is necessary to create a Study Protocol — a document that establishes the basic principles for the implementation of the study at all its stages.

The Study Protocol contains several sections, most of which are covered in this tool. The indicative structure of the document is as follows:

- Cover page indicating the name of the study, version and city (e.g. version 1.0 of December 12, 2021, Kyiv, Ukraine),
- Researchers (Lead Researcher, co-researchers, study partners) [3],
- Summary of the study (a summary of the objectives, geographical scope, sample and methods, indicating the funding organisation and/or project under which the study is being carried out),
- Justification,
- Goals and objectives of the study,
- Methodology (study design, criteria for inclusion and exclusion of participants),
- Geographical scope and sample of the study,
- Preparatory stage (National Reference Group, local data collection team, the study staff training, the pilot testing of the tool),
- Study procedures (participant recruitment, screening and data collection),
- Data analysis,
- Data management (participant unique identifier, data access and data security, data quality assurance),
- Use of data and dissemination of findings,
- Ethical basis of the study (ethical review, obtaining consent from participants, protecting participants from risks, Protocol deviations, compensation),
- Study schedule,
- Annexes (all the necessary tools and accompanying forms that are used in the study).

The justification for conducting a study often involves a statement of facts, statistical data that confirm its relevance. It is considered a good form to apply a deductive approach in presenting the relevance/justification of the study, i.e. first it is worth to indicate the overall HIV situation in the country by gender (for example, the number of HIV-positive women registered in the country; the cascade of HIV services for women). Then you can indicate the specifics of individual districts/regions of the country in which you plan to conduct your study. After general information about the number of women living with HIV and available official statistics in your country, it is recommended to focus on those aspects that you plan to study in the current study. For example, there is some data about the violation of the rights of HIV-positive women, legislative changes, etc. At the end of this section, it is important to answer the question "Why do the study?" and what gaps it closes.

[3] - Annex 1. Study Team Template

National Reference Group

The preparatory stage begins with the formation and meeting of the National Study Implementation Reference Group, a community-based advisory body that supports the study team at all stages of project implementation and ensures that the study is carried out in a way that meets the needs and interests of women living with HIV. It is important to include in the working group women living with HIV from different subgroups, thereby respecting the principle of diversity and inclusiveness (for example, women who use drugs, sex workers, LBT women, young women or those living in a discordant couple).

Consultants may be invited to the meetings of the National Reference Group for discussion and expertise on specific issues of the study implementation. For example, professional researchers who do not belong to the community of HIV-positive women, but are "friendly" to it.

Involving a professional sociologist in the study may require additional financial resources (if no agreement on cooperation on a free basis has been reached). Accordingly, this should be taken into account when budgeting for the study and/or obtaining grant assistance to pay for the work of a consultant. Based on the findings of the interviews with coordinators in different countries, all leaders noted the importance of involving a professional sociologist for the qualitative study implementation. This can be both full-fledged support from the moment of planning the study, starting from the involvement of an expert in the process of creating a questionnaire and ending with the preparation of a report (desirable option), or case-by-case involvement, for example, only for preparing a report. The fact that a woman from outside the community is involved in a study does not cause embarrassment to the study team, and, on the contrary, increases their confidence that the collected data will be properly analysed and presented to stakeholders. In addition, since in most countries facilitators have experienced distrust and prejudice against the results of their work and towards the community as a whole, the presence of a qualified sociologist in the study team reduces these risks and indicates the desire of facilitators to provide the audience with a quality product.

The National Reference Group shall be responsible for providing advice on:

- planning, data collection, analysis and dissemination of the study findings in a country,
- relevance and ethics of the study questions, their conformity with the goals of the study,
- compliance with the Protocol and tools, geographical scope and sample of the study in a country,
- ensuring the safety of the study participants and organisers,
- implementation of the methodology for conducting and ensuring the quality of the study data collection at all stages of its implementation,
- relevant interpretation of the obtained data.

The frequency and number of the National Reference Group meetings shall be agreed with the group members and researchers, but at least five such meetings shall be provided for:

- when planning a country study to discuss the design, geographical scope and sample, as well as the main aspects and issues that need to be monitored,
- after creating/adapting the tool to finalise and plan the launch of the field stage (data collection),
- when collecting data to monitor data quality and, if necessary, discuss emerging challenges and ways to address them,
- after data collection and if preliminary findings are available for their discussion and taking into account the results of the meeting during the final analysis and preparation of the project report,

- upon completion of the study report to approve the final version of the document and plan further actions to disseminate the findings (i.e. holding a national consultation with key stakeholders to present and discuss the study findings) and advocate for the proposed recommendations.

Meetings can take place both online and offline, depending on the agreements with the National Reference Group and the epidemiological situation with COVID-19 in the country. If it is necessary to receive additional comments or agree on certain issues that are not provided for during the meetings, electronic communication shall be possible (for example, to collect comments on the questionnaire).

Local Data Collection Team

A Local Data Collection Team shall be formed in each locality under the leadership of the Local Study Coordinator. In addition to the Local Coordinator, the team shall consist of interviewers and moderators from among HIV-positive women. Team members are expected to be peer consultants with experience in studying and/or holding FGDs and established contacts within the target group to effectively organise and conduct data collection in the field.

The responsibilities of the Local Data Collection Team members shall be assigned as follows:

Role in the team	Responsibilities
Coordinator	Coordination and control over the day-to-day work of the study team, communication with the National Coordinator, reporting on the situation in the region
Interviewer	Conducting a study and explaining the questions of the questionnaire to the study participant
Moderator	Conducting FGDs, recruiting participants and agreeing with them on a study

Since the issues of the toolkit and the themes that are raised can be sensitive for both participants and interviewers/moderators, it is recommended that a psychologist is involved in the study. It is possible to cooperate with a psychologist in different forms based on the agreements reached: if there is a situation when a participant and/or a representative of the study team needs psychological help and support; constant support of the study team during data collection; referral of study participants to see a psychologist after completion of the study and/or FGDs.

In addition, researchers may consider holding group meetings between a psychologist and study staff during data collection. Such meetings will allow both minimising and relieving psychological stress (which may be caused by the experiences shared by the participants), as well as increasing motivation, preventing emotional burnout, retraumatization, and providing psychological relaxation (since study can be energy-consuming and even traumatic for a local team).

Study staff training

As part of the preparation and for the purpose of high-quality study implementation, all team members shall be trained on issues, which may go beyond the following themes:

- goals, objectives, methodology and procedures of the study,
- compliance with professional ethics during the study, the procedure for obtaining informed consent,

- conducting a study and FGDs, skills in working with a questionnaire and a toolkit,
- interaction between the study team members,
- study reports,
- other project documentation and procedures.

All local team members will be trained within the framework of the study (interviewers, moderators) in order to be able to implement the study in the absence of an individual specialist for a certain period of time. The training will consist of a theoretical part and practical exercises to work through each of the study stages..

Since the study is led by a community of HIV-positive women who may not have much study experience, the training will focus on a general basic study training and study skills (e.g., basic concepts of the study, types of data collection methods and their differences, the concept of sample and the importance of observing it, working with printed and electronic documentation, reporting on the study findings, etc.). In addition to questionnaires and guides, all study staff will be provided with a Study Guide [4] and a Focus Group Discussion Guide [5].

A separate informative training block should be devoted to conducting a study with the participation of people as objects and the corresponding ethical requirements. In addition, all study team members are recommended to take a Russian-language course on ethical standards for conducting a study “Protection of Study Participants” on the ProfiHealth [6] online platform and receive a certificate.

Although community-led research collects data from the community members, cases of the intentional violation of the rights of study participants cannot be ruled out. Training on the ethical issues of conducting a study, including its preparation, is a good practice example, a guarantee of a responsible approach to the project implementation that also adds value to the study when presenting it to an “external” audience (e.g., minimises possible doubts about the reliability of the findings, especially in terms of highly sensitive questions, such as questions about the experience of violence). You are free to choose another course on ethical research that is available in your country. The one indicated in the text above is one of the examples and is a free Russian-language version of the Protecting Human Research Participants course developed by National Institutes of Health, translated by the International Charitable Foundation “Alliance for Public Health” (Ukraine).

If time and human resources are available, it is recommended to pay attention to certain themes within the framework of the training, namely:

- issues of sexual and reproductive health, human rights with an emphasis on the aspect of gender. Including this block will allow both to deepen knowledge in the study theme and to correctly interpret the questions/statements contained in the toolkit. If women living with HIV who are involved in the study team will be interested in a more detailed study of this theme and/or their awareness of sexual and reproductive health issues will be insufficient, they will be recommended to additionally take the Sexual and Reproductive Health online course at ProfiHealth [7] online platform,
- improving communication skills and presenting a study (both ideas and findings) to an audience, in particular government officials, international partners. This block of training is aimed primarily at building the skills of researchers in presenting themselves and their work, building confidence and a comfortable sense of self in communicating with donor organisations, decision makers in the country and in general with an external audience,

[4] - Annex 4. Study Guide for Interviewers
[5] - Annex 8. Moderator Guide for Focus Group Discussions
[6] - Protection of Study Participants online course, https://profihealth.org.ua/ru/courses/11
[7] - Sexual and Reproductive Health online course, https://profihealth.org.ua/ru/courses/7

- mental health (emotional burnout, stress resistance) and motivation in conducting a study in the country to change the current situation. Motivational sessions have a positive effect on the psychological mood of the data collection team and reduce the possible stress caused by the complexity of the project or the lack of experience of local activists in conducting such studys.

Piloting the tool

Piloting the tool ensures that all the questions of the questionnaire and the tool are unambiguous for future participants, have a sufficient level of sensitivity, and the total length of the study is acceptable.

Five HIV-positive women in one of the study cities shall be selected to pilot the tool. The selection of participants for piloting the tool shall be carried out in accordance with the approach and criteria for including respondents in the study. Interviewers shall provide participants of the pilot testing with tools without collecting any identifying information. Because the participant's signature on the informed consent form may be the only record that links the participant to the study, interviewers shall receive a verbal informed consent [8]. Each of the participants in the pilot testing of the tool shall receive compensation in the amount determined by the study team for the time spent and working through the tool [9].

The local coordinators and/or interviewers shall report the results of piloting the toolkit to the Principal Researcher and, if necessary, suggest adjustments. In case of major changes in the toolkit, they shall be agreed with the National Reference Group, and the documents shall be re-submitted for ethical review.

[8] - Annex 2. Verbal Informed Consent to Piloting the Tool
[9] - Annex 3. Journal of Compensation for Piloting the Tool

STUDY PROCEDURES

Conducting a survey involves recruiting participants; doing initial screening to verify that the woman is HIV-positive and eligible to participate in a study; obtaining informed consent for a study; conducting a survey lasting about 30 minutes (may vary depending on the experience of the participant and/or additional blocks/questions provided for by a study in a particular country); issuing compensation to the participant for the time spent.

Participants shall be recruited by interviewers through cooperation with the communities of women living with HIV, specialised organisations and institutions, such as healthcare facilities that provide HIV treatment; anonymous consulting rooms; non-governmental organisations that provide care and support for HIV-positive people, advocacy and protection of rights, provide other services to HIV-positive women. Using various recruiting channels ensures that the local team reaches out to different subgroups of respondents, not limited, for example, to those who regularly visit healthcare institutions to receive antiretroviral drugs.

Social workers, doctors, psychologists or other representatives of the above organisations invite an HIV-positive woman to undergo a study, and if the potential respondent agrees to participate, she shall be redirected to the interviewer. Before the start of the survey, the interviewer shall re-screen for eligibility to be included in the study and receive a verbal informed consent to participate [10].

To ensure a safe and friendly atmosphere, a survey shall be organised on the basis of a non-governmental organisation or conducted in any other place convenient for the study participant. During the survey and communication between the interviewer and the respondent on the survey theme, there should be no third parties in the room, including respondents' relatives, husbands or children.

FGDs shall be held on the basis of a non-governmental organisation or in any other place chosen by the Regional Coordinator and convenient for the participants of this stage.

The local team collects data using standardised questionnaires (at the study stage[11]) and guides (at the FGD stage) [12, 13].

The questionnaire is an adaptation of a study tool on the reproductive and sexual health of HIV-positive women conducted in 2014 by the Salamander Trust, an HIV activist organization, to update the WHO guideline on sexual and reproductive health and rights of women living with HIV [14]. The continuity of the toolkit will allow for a comparative cross-country analysis of the data obtained. The questionnaire contains questions that reflect the following aspects:

1. Socio-demographic characteristics of the participants,
2. Human rights and experience in obtaining sexual and reproductive health services,
3. Experiences and challenges in various aspects of the day-to-day life of women living with HIV in the field of sexual and reproductive health and other areas:
    - healthy sex life,
    - pregnancy and fertility,
    - violence and discrimination against HIV-positive women,
    - mental health and HIV,
    - burden of family caregiver,
    - HIV treatment and side-effects,
    - economic opportunities and access to social services.

The questionnaire consists of closed-ended and open-ended questions, which are designed to receive suggestions and recommendations from the target group, and make it possible to record the experiences of receiving certain services.

[10] - Annex 5. Verbal Informed Consent for Study Participation
[11] - Annex 6. Study Questionnaire
[12] - Annex 10. Focus Group Discussion Questionnaire
[13] - Annex 11. Focus Group Discussion Guide
[14] - https://salamandertrust.net/project/salamander-trust-study-sexual-reproductive-health-human-rights-women-living-hiv/

Recording life stories

Once the questionnaire is completed, the interviewer shall invite the study participant to share her history of receiving sexual and reproductive health services in the context of positive or negative experience.

The story should show the facts as accurately as possible:
- what happened and where?
- what were the consequences for life and health?

It is important that the story is not more than three (3) years old at the time of the study. The standard text size is no more than one 12 font page. The recommended number of life stories may vary depending on the sample: on average, up to 30 stories (15 positive and negative experiences each). Life stories shall be recorded on a voice recorder with the possibility of verbatim transcription.

Examples of life stories:

"While serving my term, I had health problems. I was bleeding for almost six months. I was given practically no assistance, was not taken to the hospital, just being stuffed with pills over all six months, but they did not help me. The nurse constantly hinted that I was already a walking corpse, about to die, who still demanded treatment. My mom wrote complaints, nothing helped. I was cut off from my pills, because why give them if they still do not help. "Be grateful that despite your HIV you are like cheese swimming in butter here". Hearing that I started to swear and they clubbed me over the head. When I was released, I was diagnosed with cancer, and if I had been cleaned and treated then, I could have avoided this" (Belarus)

"After I was diagnosed in 2017 during pregnancy, I turned to a gynaecologist at my place of residence in the city of Vahdat. But they turned down my appointment because of my HIV and I was redirected to the AIDS Republican Centre. Doctors helped me, put me on a temporary register, and I was under their supervision until the childbirth. I gave birth to a healthy child, and I am very grateful to the doctors from the AIDS Centre, especially the gynaecologist" (Tajikistan)

Filling out questionnaires

1. *By the interviewers*

According to the classical methodology, the interviewer asks the respondent the questions of the questionnaire and notes the answers. To make a study more convenient, the questionnaire should provide for a preamble (brief introductory information right before the list of questions) and the use of cue cards that suggest a list of answer options for a particular question that is transmitted to the respondent. Often, cue cards are used for questions that contain many statements and/or answer options, and the whole list can be difficult to perceive.

2. By the respondents

Since the questionnaires contain questions on sensitive issues, at the request of the study participant, the questionnaire can be autocompleted. In this case, the interviewer will be ready to advise or explain this or that question, if individual phrases or words remain incomprehensible to the participant.

3. By the respondents online

Another possible option to fill out the questionnaire is when respondents come to the office of a non-governmental organisation, where they are provided with a computer/tablet/phone to fill out the questionnaire on their own. This option does not require further data entry from paper questionnaires, but also involves the presence of an interviewer next to the respondent for consultation and clarification of a particular issue, if necessary.

The idea of conducting a study in a completely online format, taking into account quarantine restrictions due to COVID-19, was not supported by the coordinators, which is due to the following factors:

- ***possible closeness and lack of trust among the study participants in connection with the subject of the project, the sensitivity of questions and the lack of personal contact on the "peer-to-peer" principle, which reduces the honesty of answers to questions;***
- ***lack of or insufficient access to the Internet and devices for completing the study among potential participants, which increases the risks of not including HIV-positive women with low socioeconomic status or from more vulnerable subgroups in the sample;***
- ***lack of psychological support and assistance from the interviewer for the participant in case of undesirable emotional reactions, for example, re-experiencing a traumatic experience associated with violence.***

If there is a worsening of the epidemiological situation in connection with the COVID-19 disease in your country at the time of planning the study, please discuss with the researchers the possibility of conducting it online and possible ways to minimise the above risks.

Focus group discussions

The FGD guides contain issues related to policies and practices, gender-based violence, antiretroviral therapy, sexual partners and children of HIV-positive women, their participation in HIV/AIDS coordinating councils and in the development, review, and evaluation of HIV/AIDS programmes.

FGDs shall be conducted by moderators who have completed training and have the skills to work with the study toolkit. FGDs shall be recorded on a voice recorder with the possibility of verbatim transcription and further thematic analysis [15].

Depending on the country context, the toolkit may contain additional thematic blocks. For example, for Ukraine, such a thematic block was related to services for HIV-positive women who suffered from the armed conflict in the Eastern Ukraine and the annexation of Crimea.

All study tools is developed in the national language of the country. It is recommended to add translation into other most common languages in the country. For informational purposes, e.g. for international partners or funding organisations, translation into English may be provided.

[15] - Annex 9. Verbal Informed Consent for Focus Group Discussion

DATA ANALYSIS

The quantitative data of the questionnaires will be processed and analysed using appropriate software. The Lead Researcher and co-researchers will consider two options for implementing the data processing and verification stage, preparing the data sets, depending on the resources available to them (financial and human).
Namely:

- data entry from paper questionnaires into an electronic database and subsequent processing shall be carried out directly by the study team representatives who have the necessary experience with large databases, computer literacy and knowledge of Microsoft Excel, IBM SPSS Statistics or other similar programmes. Subsequently, the electronic database shall be transferred to the involved sociologist for analysis and preparation of the first version of the report;
- data entry, processing and analysis shall be carried out by a skilled researcher, followed by the preparation of the first draft of the report on the study findings.

Data analysis shall be discussed by the study team in cooperation with the involved sociologist, based on the needs of the community and the expectations of donor organisations, international partners for the presentation of the study findings.

An example of how the analysis can be carried out is given below:
One- and two-dimensional descriptive statistics will be used for data analysis. Significance of percentage differences between different groups will be tested using a chi-squared test or Fisher's test when expected frequencies are less than 5. For quantitative variables, the significance of differences in average values will be tested by Student's t-test (normal distribution) or in medians by the Kruskal-Wallis test (non-normal distribution).

Qualitative FGD data will be transcribed from audio recordings and notes in Microsoft Word. Then the files will be entered into the MaxQDA qualitative data analysis programme for encoding. The researchers will conduct a thematic analysis to create a system of codes that meet the objectives of the study. Once the coding system is established, 10% of the transcripts will be coded by individual researchers to ensure a double coding and quality control procedure. After double coding, the researchers will discuss the identified differences using the constant comparative method. After that, the researchers will encode the rest of the transcripts; texts with similar codes will be sorted and categories will be created, which will then be combined into more general topics and contain answers to the study tasks.

DATA MANAGEMENT

All study staff will be trained in the protection of participants' privacy as part of the preparatory training and will sign a Data Use and Privacy Agreement [16], which shall explain the procedures for dealing with confidential data and responsibility for their violation.

The study team shall use the following forms and toolkit:

1. Verbal Informed Consent to Piloting the Tool
2. Journal of Compensation for Piloting the Tool
3. Study Guide for Interviewers
4. Verbal Informed Consent for Study Participation
5. Study Questionnaire
6. Journal of Compensation for Study Participation
7. Moderator Guide for Focus Group Discussions
8. Verbal Informed Consent for Focus Group Discussion
9. Screening of Participants for Focus Group Discussions
10. Focus Group Discussion Guide
11. Journal of Compensation for Focus Group Discussion
12. Data Use and Privacy Agreement
13. Local Study Team Report (optional) [17].

The above list is the basis and may be supplemented by the title of the documentation used in your research.

All forms shall be linked by a unique identifier and not contain information that can identify the participant. All completed forms shall be collected by the Local Coordinator from the representatives of the Data Collection Team. The Regional Coordinator shall verify the completeness and correctness of filling out the forms, cross-check the number of records between the forms. Each month, the Local Coordinator shall give paper versions of the forms to the National Coordinator in sealed envelopes, and until then, keep them in a locked cabinet in her office.

Participant unique identifier

Each participant of the study shall have a code that ensures data privacy and minimises the risk of information disclosure. Each participant shall receive such a code from the Local Team before the start of the study or FGD.

For study participants, the code shall be generated based on the name of the city, the serial number of the study participant, and the age of the participant. For example, **Kyiv_23_35**, where:

- Kyiv – the name of the city,
- 23 – the serial number of the study participant,
- 35 – the number of the full years of the participant.

For FGD participants, the code shall be generated based on the number of the focus group discussion, the age of the participant, a short coding of involvement in the study theme, and the number of the discussion participant. For example, **2_35_activist_1**, where:

- 2 – second FGD,
- 35 – the number of the full years of the participant,
- activist – a brief description of the type of activity of the participant,
- 1 – the serial number of the FGD participant.

[16] - Annex 13. Data Use and Privacy Agreement
[17] - Annex 14. Local Study Team Report

Data access and data security

Only the Lead Researcher and co-researchers have access to the data and documents. The distribution of responsibilities between the staff (primary data and coding, data entry, analysis and report preparation) will also be ensured. Documents and computers will be password protected (at least one lowercase letter, one uppercase letter, one number, and a symbol).

Data will be entered from paper forms into electronic format by Individual specialists who will not have access to the participants and will be involved only at the stage of entering information into the data array. Each of the specialists shall sign a Data Use and Privacy Agreement which minimises the risk of data misuse. The Principal Researcher shall check and systematise all the reporting forms of local teams.

The Local Coordinator shall be responsible for storing documents in a safe located in her office. During data collection, the Local Coordinator shall report weekly on the recruitment of participants and the main findings of the sample, which will make it possible to quickly receive systematised information. The Local Coordinator shall immediately inform the Lead Researcher of any unforeseen situations with paper forms for instructions on next steps.

Data quality assurance

In addition to the questions, the questionnaire shall contain an explanation of the main concepts and formulations for a better understanding of the essence of the issue by the respondents. For example, within the framework of the study, gender-based violence refers to four types of violence specified in the Istanbul Convention — physical, sexual, psychological, economic. However, not all respondents can correctly interpret these types of violence and, accordingly, understand the essence of questions or answer options. Additional unified explanations in the questionnaire or on a separate cue card will, on the one hand, allow the participant to understand the content of the question in more detail and more accurately, and on the other hand, ensure the same interpretations and minimise the influence of the study team members on the respondents' answers.

All FGD data shall be recorded on an audio device after obtaining an informed consent, transcribed verbatim in the language of the participants. Transcripts will be reviewed for accuracy. The audio recordings will be destroyed after the transcripts have been verified. Paper forms with information about the participants shall be kept by the researchers and entered into the electronic form during transcription. Forms will be destroyed after successful data entry. Copies of the databases will be made available to researchers for analysis. The National Study Coordinator shall be responsible for the study documentation and maintain records of those who received a copy of the study databases.

USE OF DATA AND DISSEMINATION OF FINDINGS

The report will contain a block of recommendations based on the study findings, which may be useful for organisations and individual specialists working in the field of ensuring the quality of reproductive and sexual health services for HIV-positive women, as well as dealing with HIV prevention and treatment among the target group. In particular, recommendations will address (if necessary) changes at the level of:

- normative and legal acts and coordination,
- healthcare professional communities,
- non-governmental organisations,
- the community of HIV-positive women.

The data obtained during the study and the report with the findings are an evidence base and an advocacy tool for:

- non-profit organisations, initiative groups and activists, donors, public experts, representatives of resource centres providing information, consulting, educational, methodological and other types of support to non-governmental organisations and the community of women living with HIV,
- stakeholders working in the field of public health, HIV prevention and assistance to women living with HIV, maintaining and supporting women's reproductive health,
- feminist and human rights organizations that deal with the rights of women suffering from multiple discrimination.

The study findings will aim at:

- identifying the problems and needs of women living with HIV in the field of sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV,
- advocating for the interests of the community of HIV-positive women in order to remove legislative and other barriers to their access to healthcare, social and legal assistance, including assistance in situations of violence,
- monitoring, evaluating and developing recommendations to overcome the HIV/AIDS epidemic through gender-sensitive national strategies,
- highlighting priority issues for inclusion in the national agenda in order to form a policy and strategy regarding activities in response to the HIV/AIDS epidemic in the country,
- creating favourable conditions and opportunities for advocacy focused on HIV-positive women at the national and local levels,
- ensuring the participation of women living with HIV in the coordination bodies responsible for policy-making in the field of sexual and reproductive health,
- using the study findings in the preparation of shadow/alternative reports to the UN treaty bodies,
- using the study findings to submit abstracts to national and international conferences on relevant topics,
- identifying aspects and areas of life of HIV-positive women that require additional research.

The following are some examples of using the study findings in previous years:

- including recommendations in the National HIV Programme (Tajikistan),
- revision of the Law "On Counteracting the Spread of the Disease Caused by the Human Immunodeficiency Virus "HIV Infection" (Uzbekistan),
- adoption of the Law "On the Protection of the Reproductive Health of Citizens" — allowing IVF, and including women who take ART, are in remission, in the list of women living with HIV (Uzbekistan),
- adoption of the Law "On Prevention of Domestic Violence" (Uzbekistan),
- revision by the Ministry of Health of the Standards for the provision of special social services in the field of social protection of the population in conditions of temporary stay — removing drug addiction and HIV infection from the criteria for refusing assistance (in progress, Kazakhstan),

- development of an advocacy plan with a set of measures for decision makers to remove barriers for HIV-positive women in the social sphere (Kazakhstan),
- the opportunity to participate in the preparation of an application for a new grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria and to act as a sub-recipient in the application (Belarus),
- inclusion in the working group on the roadmap for the validation of the elimination of mother-to-child transmission of HIV (Uzbekistan, Ukraine),
- inclusion of study data in two shadow reports to the UN Committee on the Elimination of Discrimination against Women (CEDAW) in 2017 and 2020 (Ukraine),
- inclusion of study data in the government's national review of the implementation of the Beijing Declaration and Platform for Action (1995) and the final documents of the 23rd Special Session of the UN General Assembly (2000) in the context of the 25th anniversary of the Fourth World Conference on Women and the adoption of the Beijing Declaration and Platform for Action in 2019 (Ukraine),
- allocation by the city Health Department of two rooms for peer-to-peer counselling HIV-positive women, accompanying them to a gynaecologist to maintain sexual and reproductive health (Kazakhstan),
- development of a long-term strategy and work plan for a non-governmental organisation that provides services to HIV-positive women (Tajikistan),
- raising awareness about the organisation that provides services to HIV-positive women at the country level (Belarus).

Following the preparation of the report, at least one meeting — National Consultation — will be held with stakeholders and decision makers to discuss the findings and coordinate follow-up actions based on them. In the future, the study findings will be presented at meetings and events related to one or another aspect of the study, as well as disseminated in the media. For the purpose of informing stakeholders and the media, a press release will be prepared based on the results of the study presentation [18].

When planning the study, please include one final meeting (e.g. national consultation) on the study findings щin the list of activities to discuss with partners and decision makers. Subsequent more specialised meetings and discussions may not be taken into account in advance, since information about them is not available at the time of planning the study. When implementing the study, it is important to monitor thematic meetings and events where your team could present and discuss the current status or findings of the project, which increases the visibility of the study and your team.

In addition to presenting the findings to stakeholders and decision makers, it is important to present the study findings and discuss them with the local teams that collected the data and the study participants. Holding such a meeting will allow women living with HIV involved in local teams to show the results of their work, and the study participants — to be sure that the stories and personal experiences they shared have been taken into account and, based on them, further actions and/or changes are under way at the country level. This will have a positive effect on strengthening the potential of the community itself, the readiness of its representatives to be involved in the study in the future and, in general, will increase the confidence in such projects on the part of the target group.

[18] - Annex 15. National Consultation Press Release Template

ETHICAL CONSIDERATIONS

Ethical review

The Study Protocol and toolkit will be submitted to the Ethics Commission for review on human rights issues. The results of the review will comply with: the provisions and principles of the Declaration of Helsinki adopted by the General Assembly of the World Medical Association (1964-2000), the Council of Europe Convention on Human Rights and Biomedicine (1997), the relevant provisions of WHO and the Council for International Organisations of Medical Sciences.

Documents will be submitted to the Ethics Commission after agreement with the National Reference Group of the final versions of the documentation, including taking into account the results of pilot testing of the toolkit. Data collection (study and FGD) will be started only upon receipt of a favourable opinion from the Ethics Commission.

Each country has its Ethics Commission that deals with the issues of verifying the study protocol and toolkit for compliance with the rights of the study participant. A favourable opinion of the Ethics Commission means that the study is conducted in compliance with all requirements and norms for the protection of the rights of the study participants, does not bear risks for participants and team members, and if there are any, the study team provides ways to minimise them. Passing the review of the Ethics Commission and the presence of a favourable opinion of the study is a prerequisite for publishing the study findings in international peer-reviewed publications, and also indicates the quality planning (and implementation, if it is carried out according to the Protocol) of the study.

In most countries, there are several such commissions, including those operating free of charge or on paid terms. When choosing a commission that will deal with the study ethical review, you can be guided by both personal preferences, feedback from other researchers on the quality of their work, and the preferences of the funding organisation, since some of the donors have their own internal ethics commissions or cooperate with certain national ones within the country. Whichever commission is chosen, it must be officially registered with the Office for Human Research Protections Database of the U.S. Department of Health and Human Services and have an FWA ("Federal Guarantee") registration number. For a list of officially registered Ethics Commissions in your country, please visit https://ohrp.cit.nih.gov/search/irbsearch.aspx?styp=bsc.

Obtaining consent from participants

Participants will be provided with answers and explanations for all their questions. Before the start of the study or FGD, potential participants will be informed that participation in the study is completely voluntary, and they can withdraw their informed consent and stop participation at any time [19, 20, 21]. Refusal to participate in the study at any stage will not result in any consequences for the participants. Participants will be informed that any data obtained from them during the course of the study is confidential — no information that can identify participants will be used, and nothing but aggregated information about all participants will be included in the report. Participants will also be informed of all potential risks and benefits of participating in the study.

[19] - Annex 2. Verbal Informed Consent to Piloting the Tool
[20] - Annex 5. Verbal Informed Consent for Study Participation
[21]- Annex 9. Verbal Informed Consent for Focus Group Discussion

Protecting participants from risks

Sensitive questions, such as those relating to violence or rights abuse experiences, may make participants uncomfortable. Participants will be informed that they may not answer questions that are uncomfortable for them, and no responses will be shared with other participants. Conducting the study and FGDs by representatives of the community of HIV-positive women will minimise possible psychological discomfort and provide a comfortable atmosphere for communication. The study will be conducted face-to-face only in the presence of the interviewer and the respondent in a convenient place for the latter. During the FGD, there will be no outsiders in the room, and the venue will be chosen by the study team in agreement with potential participants.

The informed consent will contain the name and contact information of the organisations that are involved in the study and individual professionals. Participants will be informed that they can contact someone on the list if they have questions or comments about the study, or if they feel that their rights as participants in the study have been violated or they have been harmed by participation.

Protocol deviations

All Protocol deviations, new or unexpected findings, changes in the study context will be documented and immediately reported to the local study teams, the national study team and the Ethics Commission. Any concerns, questions, or complaints regarding the study will be responded to immediately to ensure rapid monitoring of the study impact on participants. All necessary measures will be taken to address the relevant situations.

Compensation

Study participants will receive compensation for the time spent and travel costs in the amount set by the study team for pilot testing of the toolkit, completing the study, and participating in the FGD. Compensation shall be issued by the interviewer or moderator after the study or FGD [22, 23, 24].

Compensation can be in the form of a monetary reward, food, hygiene kits or telephone payments. Collecting needs from HIV-positive women and/or consulting with the target group service providers, as well as understanding the specifics and requirements of national legislation, will help decide how to compensate for participation. When choosing compensation in the form of food or hygiene kits, it should be taken into account that they should be universal and their content should be useful for HIV-positive women from different regions or different subgroups. It is possible to use different contents of the kits depending on the region or the needs of the study participants, but the total cost of one such kit should be the same within the study.

[22] - Annex 3. Journal of Compensation for Piloting the Tool
[23] - Annex 7. Journal of Compensation for Study Participation
[24] - Annex 12. Journal of Compensation for Focus Group Discussion

STUDY SCHEDULE

The study schedule shall be established by the study team in consultation with the funding organisation and the National Reference Group. When drawing up the schedule, the human resources and planned activities within the framework of the study shall be taken into account.

The study schedule is often presented in the form of a table, where each activity is represented in a row, and the month (week) of its implementation — in a column. As an example, study activities for a schedule might be as follows:

- Development of the Protocol and study toolkit, agreement with stakeholders.
- Submission of the Protocol and toolkit to the Ethics Commission, and their approval.
- Local team building and recruitment.
- Conducting trainings for regional teams.
- Piloting and finalising the toolkit.
- Conducting a study of HIV-positive women.
- Conducting focus group discussions.
- Data cleaning and processing.
- Statistical analysis of study data.
- Qualitative analysis of focus group discussions.
- Development of a preliminary report.
- Coordination and approval of the final version of the report.
- Presentation of the study findings.

STUDY CHECKLIST

Before starting the study (data collection), please review the statements from the table below and mark the status of their implementation. This checklist is a self-assessment tool for the study team and it helps make sure that your team is ready to implement the study, and that the preparation itself is of high quality and all aspects of the study have been taken into account.

No.	Statement	Yes	No	Comments
STUDY PREPARATION				
1	Goals and objectives of the study agreed with the donor and the community of HIV-positive women			
2	The budget for the study received and planned			
3	The National Reference Group consisting of women living with HIV formed			
4	Protocol, study toolkit and accompanying forms prepared			
5	Feedback received from the National Reference Group on the Protocol, study toolkit and accompanying forms			
6	The schedule of the study and the main stages of its implementation developed and agreed with stakeholders. Notification letters sent to key partners (if necessary).			
7	The regions, the sample of the study and the criteria for including participants in the project determined			
8	The study Protocol and toolkit approved by the Ethics Commission			
9	The composition of the study team determined and local data collection teams formed			
10	Agreements reached and a professional researcher involved in the team (if necessary)			
11	The frequency of the Working Group meetings, preferred channels of communication and further interaction agreed and discussed			
12	Study staff received all necessary training within the framework of the project			
13	All specialists involved in the study signed a Privacy Agreement within the framework of the project			
14	Local teams are aware and trained on the implementation of the field study			
15	Study specialists trained for other roles, which will allow them to replace each other if necessary			
DATA COLLECTION				
16	Recruiting and screening process for study participants defined			
17	A list of non-governmental organisations, healthcare institutions etc. formed and respective agreements regarding their involvement in the process of recruiting participants reached			
18	Toolkit, informed consent and additional forms (if necessary) translated into all relevant languages			
19	The entire toolkit has been piloted, finalised, and its final version being used during data collection			
20	The unique identifiers of the participants determined and used by the team			
21	An algorithm for participation in the study agreed upon and defined, including where, when and in what sequence the participants take the study or take part in the focus group discussion			
22	A process for referral and/or psychosocial support to participants agreed and defined			
23	The form of compensation (money, food packages, hygiene kits, etc.) to the participants for the allocated time determined and agreed with the community			

DATA PROCESSING AND ANALYSIS				
24	The data flow agreed and approved within the team - who, at what stage and in what form submits paper documents for data entry			
25	Local control provided and the actions in case of force majeure situations, for example, the loss of questionnaires, determined			
26	An algorithm for data quality control defined and agreed			
27	Data entry for further processing and analysis agreed and ensured			
28	Data analysis plan (or structure of a future report) agreed and developed			
DATA USE				
29	All study documentation stored in a secure location that only researchers have access to			
30	An algorithm of actions planned after receiving the first version of the report (for example, who and in what sequence gives their comments to the document, makes changes)			
31	Programme and participants of the final meeting (national consultation) to present the study findings to stakeholders, donors and decision makers planned and agreed			
32	A presentation for the final meeting (national consultation), which includes objectives, methodology, main findings and conclusions, prepared			
33	A final meeting to discuss and present the study findings to local teams and study participants planned and agreed			
34	Recommendations and further ways of using the study findings identified (for example, a list of documents that will be revised, created, etc.)			
35	A plan to finalise and publish the study report, including its design, implemented			

FRAGMENTS OF INTERVIEWS WITH STUDY COORDINATORS IN EECA COUNTRIES

Please share your general impression — how difficult is it to be a researcher? What do you feel after the study?

After that study, I got the impression that I was more frightened by the new experiences. In fact, on the contrary, it was interesting for me to understand how real these numbers are, I was curious … I faced different situations in the regions, and was also surprised. I mean, this study was useful even to me as a woman, as a person, as a specialist, there is nothing wrong with it… I think that when you are in partnership relationships, when you cooperate with people, when you have funding — you can do it easily. (Moldova)

Each study, something like this one, gives you a lot of experience and you already know ... For example, I already see that I plan to conduct it again... I plan to conduct it in 2024. I already know what to pay attention to and every challenge, difficulty, and experience we've had in doing this study gives us confidence. For example, without even opening my report, I know how, where and what it was, because from the very first step, from the very beginning, I was involved in the study. I remember and know all the moments. And if I decide to conduct such a study again, I know what to pay attention to, what should be emphasised, who should be invited and how information should be presented to decision makers and international organisations so that they pay attention to it. I am already more confident, and as an expert I can speak more boldly and conduct this or that study. [....] The most interesting thing is that this report showed us what types of violence exist, and how they can manifest themselves even in family life by one's intimate partner or husband. This is also an experience, and this also affects... Knowledge also affects life, the quality of life. You already know that "this is normal, but that is impossible". I'm a human being, I'm a woman — you can't do that with me. (Tajikistan)

You know, I probably became more confident that now they will hear us. I always say that in order for us not to be verbose — look here. Here is the data. On violence? Here it is, on violence. On access to healthcare and social services? Here it is. On access to services? We have it too. I always remember that officials are used to believing only figures. (Kazakhstan)

Double feeling. A lot of nerves, but real results made me forget about them. It's hard, it's not easy. [….] There were unpleasant moments when it came to feedback from the state. But, at the same time, I was proud, because we did it. I used it everywhere I could. And it was cool, it was an argument, and any discussions that it didn't matter and it was unnecessary immediately stopped. It needs to be done. (Uzbekistan)

ANNEXES

ANNEX 1. STUDY TEAM TEMPLATE

Lead Researcher:

[First and last name], [position]
[organisation name]
[e-mail]
Responsible for [list of activities]

Co-researchers:

[First and last name], [position]
[organisation name]
[e-mail]
Responsible for [list of activities]

The Lead Researcher is often the Head of the Project. The number of co-researchers is unlimited.

Local partners and members of "the field" study teams are not included in the list of co-researchers, but are listed as partners.

If organisations/individual consultants need to be listed, please use the example below:

Study partners:

[First and last name], [organisation name], [city]
….

Possible activities that are prescribed as areas of responsibility of study team members:

- ***development/adaptation of the Protocol and tools,***
- ***submission to the Ethics Commission,***
- ***coordination of the field stage and regional teams,***
- ***adherence to the Protocol,***
- ***data management and quality assurance,***
- ***data analysis,***
- ***data dissemination,***
- ***presentation of findings to regional, national and international partners,***
- ***project management.***

ANNEX 2. VERBAL INFORMED CONSENT TO PILOTING THE TOOL

The text below is a sample that can be used as a template and modified/supplemented in your study.

Hello! My name is [your name], I represent [organisation name]. We are conducting a study on the sexual and reproductive health and rights of women living with HIV. We ask you to take part in the study in order to test our questionnaire and/or guide. We are going to ask you questions not only to get answers, but also to receive your feedback and comments on the wording of questions and answer options.

Procedures, personal data and confidentiality. The study will last approximately 30 minutes. During it, questions that relate to your experience in obtaining sexual and reproductive health services, human rights violations will be asked. If you agree to participate in the study, we will protect your personal data. All interviews are anonymous. The paper forms are kept locked up and will be used to refine the questionnaires before they are used in the main study.

Potential risks, inconveniences and the right to abstain from participation. We do not ask you for any personal data and try to keep your responses confidential and anonymous. Participation in the interview is voluntary, you can choose not to answer questions or stop the interview at any time.

Expected benefit. Your answers will help us prepare the main study and make the questionnaire such that other women living with HIV can understand its questions and answer options.

Possibility of choice. You can refuse to participate in the study. If you refuse, you can continue to receive all available HIV services. Whether or not you agree to participate, you will not be denied any services or assistance you may need.

Expenses and compensation. We will compensate you in the amount of [amount in local currency] for your time and travel expenses for the study. Participation in the study will not create any expenses.

Information about the researchers. If you have questions or concerns about your rights as a study participant, you can anonymously contact the Regional Coordinator (_____) via phone (_____) or the National Coordinator (_____) via phone (_____).

Rights of the participant. If you agree to participate in the study, you are not deprived of your legal rights. This consent form means that you have heard or read information about this study and agree to participate in it.

Participation and withdrawal from the study. Participation in the study is voluntary. You have the right to refuse to participate. If you decide to participate in the study and then change your mind, you can refuse to participate. If you decide to participate, you have the right to stop it at any time.

ANNEX 3. JOURNAL OF COMPENSATION FOR PILOTING THE TOOL

City		Local Coordinator	

№	Date	Participant code	Amount / compen sation	Participant's signature	Full name of the interviewer	Interviewer's signature

ANNEX 4. SURVEY GUIDE FOR INTERVIEWERS

The Guide should contain instructions for interviewers on how to conduct a survey based on the chosen methodology and the algorithms established by the Protocol. Below, as a sample, is the Guide for Interviewers within the study "Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine" (Ukraine, 2016).

Guide for Interviewers

1. Get a group of potential respondents together for a specified time.

Attention! *During this time, people who are not participating in the study (particularly partners/husbands/relatives of the participants) cannot be in the room.*

2. Ask the respondent(s) to read the preamble to the study.

3. Succinctly answer their questions that relate to the study. It is important here not to enter into long dialogues and discussions.

4. Invite each of them to give their verbal informed consent to participate in the study.

Attention! *Questionnaire forms are issued only to those respondents who signed the Informed Consent.*

5. Make sure that the respondents have enough space in the room and do not interfere with each other in filling out the questionnaires, they cannot look at each other's answers and talk.

6. If the respondents start talking and asking questions to each other, come up and clarify any unclear points. Try to put the focus of conversation on yourself.

7. Ask the respondents to raise their hands if they encounter any difficulty completing the questionnaire.

8. Should there be any difficulty with the questions, especially those relating to intimate life, try to answer them quietly, sitting next to the respondent. If necessary, in order to answer, go to another room with her.

Attention! *Under no circumstances fill out the questionnaire instead of the respondent and do not dictate to her the "correct" answers.*

9. When accepting completed questionnaires, skim through them, especially the middle, without dwelling on individual points. If it is not filled out, ask the respondent to complete it. If everything is in order, proceed to the payment of remuneration, with the obligatory filling out of the journal.

Attention! *Do not put any marks on the questionnaires in the presence of the respondents!*

10. After the respondents leave, put your personal code and the number of the questionnaire in the upper right corner of the questionnaire.

ANNEX 5. VERBAL INFORMED CONSENT FOR STUDY PARTICIPATION

As a template, you can use the structure and logic of the template from Annex 2. Verbal Informed Consent to Piloting the Tool.

ANNEX 6. STUDY QUESTIONNAIRE

Below, as a sample, is the Questionnaire of the Study "Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine" (Ukraine, 2016).

Survey

Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine

CO "Positive Women" conducts a study of the needs of HIV-positive women in Ukraine, which consists of studying women living with HIV (a study of 1000 women from all regions of the country), consultations with communities (in the format of four focus groups) and expert analysis of policies and programmes on HIV/AIDS. We are determined to find out the most important aspects of their lives in relation to sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities. The identified priorities will contribute to the formation of the programme activities of the UN Women Office in Ukraine, and will also be used in the strategic planning and operational activities of the CO "Positive Women".

Questionnaire

We do not ask for your name. Names provided in responses will be removed. Any information that can identify you, such as names of places of residence or organisations, will also be removed. This is necessary to ensure privacy. Any other identifying data will be removed from the responses.

This question requires an answer.
1. I understand that filling in the study, I give my consent for my responses to be used in publications. Please, highlight "I agree" to be able to continue

1	I agree	You continue the study
2	I disagree	The study is over

This question requires an answer.
2. I am a woman living with HIV. Please highlight "Yes" to be able to continue

1	Yes	You continue the study
2	No	The study is over

Part 1 – Personal Data

Please tell us about yourself.

1. **Country where I am living now**	**2. Oblast and city**	**3. Age**

4. Relationship Status. Please highlight one answer:

1. I am not sexually active
2. I am sexually active, but do not have a partner
3. I have one or more partner(s) living with HIV
4. I have one or more partner(s) not living with HIV
5. I have two or more sexual partners, one or more is living with HIV and one or more is not living with HIV

5. Special issues. Please highlight all that apply to you:

1. I do or have done sex work
2. I inject/use or have injected/used drugs
3. My sexual partner(s) injects/uses or has injected/used drugs
4. I am/have been a client of opioid substitution therapy programme
5. I am/have been in prison
6. I am/have been in a detention centre
7. I am living with disability
8. I have or have had active TB
9. I have or have had Hepatitis C
10. I migrated from one country to another for economic reasons
11. I migrated from one country to another for political reasons
12. I am lesbian, bisexual or have sex with women
13. I am a trans woman
14. I am a heterosexual woman
15. I am married, or in a stable relationship
16. I am an internally displaced person from Crimea or Donbas
17. I am or have been homeless
18. Other (optional) _____

6. Marital status

1. Single
2. Married
3. In a civil marriage
4. Divorced
5. Widow

7. I have _____ children,

1. of whom **I gave birth to _____ children, having and HIV-positive status,**
2. of whom _____ **children have HIV.**

8. I learned about my HIV status during pregnancy: YES _____ NO _____

9. Education

1. Lower secondary education
2. Secondary education
3. Incomplete higher education
4. Higher education

10. Occupation

1. Student
2. Employed in the commercial sphere
3. Civil servant
4. Entrepreneur
5. Unemployed
6. Housewife
7. Retiree. The amount of the pension _____
8. Other _____

11. I am _____ employed

1. Officially
2. Unofficially
3. Unemployed

Part 2 - Human Rights

12. Please tell us about your experience of accessing sexual and reproductive health services as a woman living with HIV. (Please choose one answer for each statement and mark with an X)

No.	Statement	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
1	I experience the same service as any other women, when I go for sexual and reproductive health services	1	2	3	4	98
2	I am aware of sexual and reproductive health treatments, information, services and commodities that exist in my country	1	2	3	4	98
3	I can get free and quality sexual and reproductive health treatments, information, services or commodities, when I need them	1	2	3	4	98
4	I find the service providers well-trained and knowledgeable, friendly, and supportive	1	2	3	4	98
5	My experience of accessing sexual and reproductive health care has been good, and I have confidence in the advice and treatment I receive	1	2	3	4	98
6	I believe my service provider offers a full range of choices for sexual and reproductive health care, including family planning options and prevention, diagnosis and treatment of sexually transmitted infections (STIs)	1	2	3	4	98
7	I am given all the information I need to make a decision about proceeding with a service or treatment, without feeling any pressure from the service provider	1	2	3	4	98
8	I trust the service providers not to share my HIV status or any other details about me without my permission	1	2	3	4	98
9	My doctor listens to me, and gives advice based on my needs and realities as a woman living with HIV	1	2	3	4	98
10	I know my rights, and if I experience a rights violation within the health service, I know where I can go to make a complaint	1	2	3	4	98
11	If my rights as a woman living with HIV are violated, I know that I will receive the necessary legal protection	1	2	3	4	98

13. Please feel free to give more information on your experience of accessing your sexual and reproductive health and human rights if you would like to

14. What would you like to say to decision makers and policy makers in Ukraine about how they can help to promote and protect your sexual and reproductive health and human rights? Please try to be as specific as possible

15. What are the most important issues that you would like to see addressed in the legal and normative acts in order to make them the most useful tool? Please be as specific as possible

Part 3 – Context and realities for women living with HIV

3.1. Healthy sex life

Women living with HIV have the same right and possibility as all women to enjoy a healthy, safe and satisfying sex life, free from force, coercion, discrimination or violence.

16. Please tell us about your sex experience (Please **choose one answer** for each statement and mark with an X)

No.	Statement	Always	Usually	Some times	Never	Don't know	Not applicable
1	I want to have sex often/have strong feelings of sexual desire	1	2	3	4	98	99
2	I find sex pleasurable for myself and for my partner(s)	1	2	3	4	98	99
3	I have sex to satisfy my partner	1	2	3	4	98	99
4	I initiate sex with my partner(s) and make suggestions about how we have sex	1	2	3	4	98	99
5	I have sex when I want to	1	2	3	4	98	99
6	I have sex when my partner(s) want(s) to	1	2	3	4	98	99
7	I find it easy to "come"/have an orgasm during sex	1	2	3	4	98	99
8	My body makes enough lubrication (how "wet" you feel when you want to have sex)	1	2	3	4	98	99
9	I know where I can get information on sexually transmitted infections, safer sex, condom use, and contraception	1	2	3	4	98	99
10	I am able to have sex without fear of getting any sexually transmitted infections (STIs) from my partner	1	2	3	4	98	99
11	If I have an STI I am able to get diagnosis and treatment for it without fear of judgement from the health provider	1	2	3	4	98	99
12	I am able to have sex without fear of getting pregnant	1	2	3	4	98	99
13	I am able to have sex without fear of passing on HIV to my partner(s)	1	2	3	4	98	99
14	I feel safe with my partner(s)	1	2	3	4	98	99
15	I am able to talk to my health care provider about my sexual health and needs	1	2	3	4	98	99
16	I am able to access the products I need to have a good sex life (e.g. lubricants, dental dams, female condoms, male condoms, contraceptives)	1	2	3	4	98	99
17	I can afford to buy the products I need to have a good sex life (see above)	1	2	3	4	98	99
18	I am able to discuss in a friendly manner my HIV status with my partner(s)	1	2	3	4	98	99
19	My partner is happy to use a male condom if I want him to	1	2	3	4	98	99
20	I am able to use a female condom if I want to	1	2	3	4	98	99

17. As a woman living with HIV, what has helped you MOST to achieve a satisfying and enjoyable sex life?

18. What has been the BIGGEST barrier to you enjoying a satisfying sex life, or what do you think most urgently needs to change?

19. What would improve your sexual health, safety, well-being and pleasure? (These could be psychological, physical, sexual, spiritual financial, legal and/or institutional support – or something else. It's entirely up to you.) Please try to be as specific as possible.

3.2. Pregnancy and fertility

As women living with HIV, we have the same right as all women to make choices about when and whether we would like to have children, and to do this in a safe, informed and supportive environment, knowing that we can be healthy mothers to healthy children - or can be supported in our choice not to have children if we don't want to.

20. Please tell us about your experiences of pregnancy and fertility as an HIV-positive woman (Please **choose one answer** for each statement and mark with an X)

No.	Statement	Yes	No	Don't know	Not applicable
1	I have been supported by my partner(s) to make choices about my fertility (to decide whether or not to have a child/children)	1	2	98	99
2	I have been supported my by health provider to make choices about my fertility	1	2	98	99
3	I have been supported by my family and community to make choices about my fertility	1	2	98	99
4	I have been given advice about safe conception (getting pregnant without putting myself or my partner at risk of transmission of HIV or other sexually transmitted infections)	1	2	98	99
5	I have been given support with safe conception (without putting myself or my partner at risk of transmission of HIV or other sexually transmitted infections)	1	2	98	99
6	I can talk to my doctor/service provider about my fertility desires	1	2	98	99
7	I have been/am able to access free infertility treatment, assisted reproductive technology if I need it (e.g. I.V.F.)	1	2	98	99
8	I have chosen to test for HIV during pregnancy	1	2	98	99
9	I was given adequate counselling before and after the test for HIV	1	2	98	99
10	I have been given counselling on family planning and advice on child spacing	1	2	98	99
11	I have had one or more unplanned pregnancy	1	2	98	99
12	I have been given advice on how to disclose my HIV status to my partner(s) and my children	1	2	98	99
13	I have access to safe and free or affordable abortion, if I need it	1	2	98	99
14	I have access to post-abortion/-miscarriage care, if I need it	1	2	98	99
15	I know I can speak to other women living with HIV who will give me advice on healthy motherhood if I want to	1	2	98	99
16	I have been able to make choices about where I want to deliver my baby	1	2	98	99
17	I have been supported to make decisions about how to feed my baby without fear of what people will say	1	2	98	99
18	I can decide to have a(nother) child without fear of what people will say	1	2	98	99

19	I can decide NOT to have a(nother) child without fear of what people will say	1	2	98	99
20	I can access the family planning/contraception that I prefer	1	2	98	99
21	I am able to use the family planning/contraception that I prefer without resistance from my partner(s)	1	2	98	99
22	I have access to emergency contraception (the morning-after pill) if I need it	1	2	98	99
23	I can access legal counselling on adoption choices	1	2	98	99
24	I can access pre-exposure prophylaxis, if my partner needs it	1	2	98	99
25	I can access post-exposure prophylaxis, if I need it	1	2	98	99
26	I have regular check-ups/Pap smears for early detection of cervical cancer	1	2	98	99
27	I do regular breast screening	1	2	98	99

21. Prevention of mother-to-child transmission of HIV

No.	Statement	Yes	No	Don't know	Not applicable
1	I took ARV at the time of conception	1	2	98	99
2	I started taking ARV as a prophylaxis during pregnancy	1	2	98	99
3	I did not take ARV throughout my pregnancy	1	2	98	99
4	I took ARV only in childbirth	1	2	98	99
5	My child took syrup in the first days of his/her life	1	2	98	99
6	I am provided with artificial formulas by the children's polyclinic/AIDS Centre	1	2	98	99
7	My baby had a PCR before he/she was 2 months old	1	2	98	99

22. Describe the BEST experience you have had to support your decisions and desires about having children – or not having children.

23. What has been the BIGGEST barrier for you to make choices about your fertility desires?

24. What would improve your reproductive health and human rights? (Psychological, physical, sexual, spiritual financial, legal and/or institutional support – or something else). **Please try to be as specific as possible.**

3.3. Violence against women

Violence against women: Any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life [25]. Violence against women includes child sexual abuse, rape, intimate partner violence, sexual violence and harassment, trafficking in human beings and harmful traditional practices, including female genital mutilation.

Intimate partner violence: Actual or threatened physical or sexual violence or psychological and emotional abuse directed towards a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner [26]. Intimate partner violence includes slapping, kicking, burning, strangulation (physical); coerced sex through force, threats, intimidation, etc. (sexual); isolation, verbal aggression, humiliation, stalking, economic violence, controlling victim's access to health care or employment (psychological).

Violence against women living with HIV: Any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV [27]. Violence against HIV-positive women is described in more detail below.

A: Violence from a sexual partner or spouse could include: hitting, kicking, punching; threats of physical or emotional violence (for example threatening to leave you); making you have sex when you don't want to; making you have sex without a condom; blame, name-calling; making you feel stupid; stopping you from seeing friends; working; leaving the house; seeking medical care for you or your children.

25. I have experienced violence from a sexual partner or spouse (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

B: Violence from a member of my family/neighbours could include: refusing to share food/utensils; name-calling; blame; rejection; abandonment; physical violence like hitting, kicking, or pulling hair; a member of the family or neighbour touching, kissing or making you have sex when you don't want to.

26. I have experienced violence from a member of my family/neighbours (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

C: Violence in the community could include: gossip, bad words, rejection, avoidance, children being stigmatized or avoided; being attacked or beaten by a stranger; being touched or made to have sex with someone who is not your partner when you don't want to; being raped because of your sexual orientation or gender identity ("corrective rape"); hate-motivated violence against trans women; any form of violence against sex workers by clients or strangers.

[25] - UN General Assembly 48/104
[26] - Saltzman et al, 1999
[27] - Fiona Hale and MariJo Vazquez, 2011

27. I have experienced violence in the community (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

D: Violence in a health setting could include: rude or judgmental service providers; denial of medical care; being asked how you came to be HIV-positive; disclosing your status without your consent; making you take an HIV test without telling you or without asking for your consent; refusing to give you all the information about available services; forced/coerced abortion or sterilization; making you wait until other clients have been seen; being refused a certain type of contraceptive, even when it is available; placing in separate or isolated rooms.

28. I have experienced violence in health settings (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

E: Violence from the police/military/prison or detention services could include: police harassment; arrest without giving a reason, or because you are carrying condoms, lubricant or clean injection equipment; threat of or actual sexual violence or rape by police, prison/detention guards, military personnel; denial of health care in prison or detention; disclosure of HIV status; refusal to provide services.

29. I have experienced violence from the police/military/prison or detention services (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

30. I have experienced fear of any form of violence (please mark all the answers that apply with an X)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	2	3	4	98

31. Please tell us about any of these experiences of violence in more detail

32. If you have experienced any of these forms of violence, were you able to access support services, and did they help you to deal with the situation/experience?

33. What do you think are the most important ways to address or prevent these forms of violence? (Please choose one answer for each statement and mark with an X)

No.	Statement	Critical	Important	Less important	Don't know
1	Remove laws which criminalise sex work	1	2	3	98
2	Remove laws which criminalise drug possession	1	2	3	98
3	Remove laws which criminalize HIV exposure/transmission	1	2	3	98
4	Ensure access to free rehabilitation and addiction treatment (alcohol, drugs)	1	2	3	98
5	Increase access to education and employment for women (entrepreneurship education, vocational training, scholarships, free courses, interaction with employment centres)	1	2	3	98
6	Provide for enhanced social protection for women and children (social benefits, free infant formula, prescriptions for free medicines, health resorts, especially for children with disabilities)	1	2	3	98
7	Ensure the availability of pre-school education (eliminate turns in kindergartens)	1	2	3	98
8	Increase access to harm reduction programmes for women who use drugs and sex workers by providing women-centred services	1	2	3	98
9	Focus the attention of healthcare workers on the rights of women living with HIV (through training of healthcare workers on working with HIV+ women, introduction of courses in medical schools/institutes/universities, conducting trainings in hospitals and polyclinics)	1	2	3	98
10	Increase access to quality support services for women survivors of violence (including sexual violence):				
10.1	Centres/shelters with the possibility of round-the-clock accommodation, including with children	1	2	3	98
10.2	Centres/shelters with the possibility of round-the-clock accommodation, including with children and for women who use drugs, sex workers and/or OST patients	1	2	3	98
10.3	24/7 hotline	1	2	3	98
10.4	Support groups	1	2	3	98
10.5	Professional counselling (doctor, psychotherapist, lawyer, social worker)	1	2	3	98
11	Provide a minimum free support after rape including post-exposure prophylaxis, emergency contraception, STI screening, social assistance and counselling	1	2	3	98
12	Provide legal protection against all forms of violence against women (free attorneys to handle litigations, street lawyers for women who use drugs and sex workers, mobile response teams, engagement with law enforcement to reduce police violence)	1	2	3	98
13	Recognize and address the issue of marital and date rape (analyze, build evidence, conduct education campaigns)	1	2	3	98
14	Provide effective mechanisms for filing complaints and redress in case of violation of rights in the healthcare service (hotline of the Ministry of Health of Ukraine or the oblast department of health, monitoring of violations and reports of community-based/patient organisations to coordination/supervisory boards)	1	2	3	98
15	Other (please specify_____)	1	2	3	98

3.4. Mental health and HIV

Many women living with HIV experience mental health problems, and this can impact on our ability to have a healthy sex life and about ability to make choices about our fertility desires and to claim our human rights.

Please think about whether you have experienced any of the following for extended periods of time – i.e. more than the usual "ups and downs" of life.

34. I have experienced extended periods of: (choose the answer for each issue)

No.	Statement	Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
1	Depression	1	2	3	4	98
2	Shame	1	2	3	4	98
3	Self-blame	1	2	3	4	98
4	Low self esteem	1	2	3	4	98
5	Feelings of rejection, including to accept one's diagnosis	1	2	3	4	98
6	A strong sense of isolation (fromfriends, family, partners)	1	2	3	4	98
7	Anxiety/fear/panic attacks	1	2	3	4	98
8	Insomnia/difficulty sleeping	1	2	3	4	98
9	Anorexia/difficulty eating	1	2	3	4	98
10	Difficulty going out and socializing	1	2	3	4	98
11	Loneliness	1	2	3	4	98
12	Suicidal feelings	1	2	3	4	98
13	Post-traumatic stress disorder (forexample, nightmares)	1	2	3	4	98
14	Drug and/or alcohol abuse	1	2	3	4	98

35. Please tell us more about the impact of these experiences on your sexual and reproductive health and human rights.

36. What do you think is the best way of supporting women living with HIV to deal with mental health issues?

3.5 Burden of care

37. The burden of care for other family members often falls on the shoulders of women living with HIV. Mark each line with an X only once.

No.	Statement	Never	Seldom	Some times	Often	Not applicable
1	I take care of a sick husband/partner at home	1	2	3	4	99
2	I take care of a sick husband/partner living with HIV at home	1	2	3	4	99
3	I take care of a sick child at home	1	2	3	4	99
4	I take care of a sick child living with HIV at home	1	2	3	4	99
5	I take care of sick relatives at home	1	2	3	4	99

6	My husband/partner takes care of me at home when I am sick	1	2	3	4	99
7	I take care of a sick husband/partner outside the home/in the hospital (I call a doctor, an ambulance, arrange transportation, collect medical tests, buy and deliver medicines, assist with medication, provide post-operative care, etc.)	1	2	3	4	99
8	My husband/partner takes care of me outside the home/in the hospital (calls a doctor, an ambulance, arranges transportation, collects medical tests, buys and delivers medicines, assists with medication, provides post-operative care, etc.)	1	2	3	4	99
9	I receive childcare financial assistance (government help)	1	2	3	4	99
10	I receive childcare non-state support (charitable/public organisations)	1	2	3	4	99
11	I receive support from the government to care for a sick husband/relative	1	2	3	4	99
12	I receive support from charitable/public organisations to care for a sick husband/relative	1	2	3	4	99
13	I receive help and support from women living with HIV to care for a sick husband/relative	1	2	3	4	99
14	I receive help and support from women living with HIV to care for a sick child	1	2	3	4	99

38. ❗ This question is to be answered only by those of you who **has a partner** and has been living with him **in the same territory for the last 3 months** (mark each line with an X only once)

No.	Activity	Only me	Only my partner	Together	Sometimes he, sometimes me	Other family members	Not applicable
1	Getting children ready to kindergarten/school in the morning	1	2	3	4	5	99
2	Cooking	1	2	3	4	5	99
3	Housecleaning	1	2	3	4	5	99
4	Laundry	1	2	3	4	5	99
5	Ironing	1	2	3	4	5	99
6	Taking children from kindergarten/school in the evening	1	2	3	4	5	99
7	Purchase of foodstuffs/household chemical goods	1	2	3	4	5	99
8	Purchase of household appliances	1	2	3	4	5	99
9	Children's clothing shopping	1	2	3	4	5	99
10	Payment of utility bills	1	2	3	4	5	99
11	Organisation of house parties	1	2	3	4	5	99
12	Organisation of parties outside the home	1	2	3	4	5	99
13	Attending parent-teacher conferences/children's events	1	2	3	4	5	99
14	Visiting a paediatrician/ purchasing medicine for children	1	2	3	4	5	99
15	Visits to the hospital/communication with doctors/purchasing medicines for adult family members	1	2	3	4	5	99
16	Taking care of sick children at home	1	2	3	4	5	99
17	Taking care of sick adult family members at home	1	2	3	4	5	99
18	Visiting social services, officials, social security, pension fund, migration service, etc.	1	2	3	4	5	99
19	Family budget income distribution (who should spend and for what)	1	2	3	4	5	99

3.6. HIV treatment and side-effects

Our sexual and reproductive health and human rights can also be affected by our experience of accessing anti-retroviral medicine (ARVs). If we have access to ARVs when we need them, and are able to take them regularly with food (in case of such prescriptions), we can stay well.

In this section, we ask you to reflect on some of these issues in relation to ARVs and our sexual and reproductive health and human rights.

39. How often do you see your doctor/HIV service provider?

_____

40. When was your last check on CD4 count? (Please highlight one answer)

1. Within the last 3 months
2. 3-6 months ago
3. 6 months – 1 year ago
4. More than 1 year ago
5. Never

41. What is your CD4 count? _____ (if you don't know, just write it so)

42. Are you taking antiretrovirals (ARVs)? YES ____ NO _____

43. If yes, what is the name of your medication?

_____

44. If no, please explain why.

_____

45. Do you regularly experience any of the following? (Please highlight as many as apply):

1. Fatigue/tiredness
2. Loss of libido/sexual desire
3. Vomiting
4. Diarrhoea
5. Constipation
6. Headaches
7. Rashes
8. Mood swings
9. Changes of body shape
10. Hair loss
11. Loss of appetite
12. Strange dreams
13. Menstrual disorders (e.g.) heavy bleeding, very long or painful periods)
14. I have no side-effects
15. Other (please specify) _____

46. When was your last check on viral load? (Please highlight one answer)

1. Within the last 3 months
2. 3-6 months ago
3. 6 months – 1 year ago
4. More than 1 year ago
5. Never

47. What is your latest viral load? _____ (if you don't know, just write it so)

48. Are there any problems with having an undetectable viral load? If so, please explain in your own words.

7. Income and economic opportunities

49. Income. Please indicate your personal monthly income (including salaries, pension, child allowances, financial assistance to IDPs, etc.) _____ UAH

50. Number of members of your family living in the same household (area) _____ people

51. Indicate the monthly income of your family _____ UAH

52. Indicate the desired level of average monthly income (how much you need for a prosperous life, including to take care of your own health) _____ UAH

53. Access to services. Which of these issues has the biggest impact on you or other women living with HIV in your community to access quality sexual and reproductive health care and well-being? (Please highlight all that apply)

1. Cost of services at point of delivery
2. Cost of travel to access services
3. The cost of preschool education, babysitting services, the queues for enrolling children in the kindergarten
4. Unequal inheritance and property rights
5. Divorce, widowhood, separation
6. Cost and burden of care for other family members
7. Lack of family support
8. Economic dependence on partner(s), family members
9. HIV-related stigma and discrimination in the workplace
10. Discrimination in the workplace based on gender, age or presence/lack of children
11. Other _____

54. Economic opportunities. Please choose one answer for each statement and mark with an X

No.	Statement	Always	Usually	Some times	Never	Don't know	Not applicable
1	I have access to higher education	1	2	3	4	98	99
2	I am economically dependent on my partner	1	2	3	4	98	99
3	I can apply to the employment centre if necessary	1	2	3	4	98	99
4	I have the opportunity to combine study and work (distance learning) without financial losses in wages (for example, losses — unpaid leave during the session)	1	2	3	4	98	99
5	I can take free (or at a price that I can afford) courses for additional specialty/to acquire new skills	1	2	3	4	98	99
6	I easily find a job (within my specialty or not)	1	2	3	4	98	99
7	I experienced sexual harassment during my studies	1	2	3	4	98	99
8	I experienced sexual harassment in the workplace	1	2	3	4	98	99
9	I have access to lending services in any bank in Ukraine	1	2	3	4	98	99
10	I know how to start my own business if I want to	1	2	3	4	98	99
11	I know where to ask for help to start my own business	1	2	3	4	98	99
12	I own real estate and other property	1	2	3	4	98	99
13	I have autonomy over my real estate or other property	1	2	3	4	98	99
14	I receive social benefits (including child allowances) and manage them independently/ freely/without coercion	1	2	3	4	98	99
15	Having a child has not affected my career path	1	2	3	4	98	99
16	Having a child has not affected my income (I have received all maternity benefits, there are prospects for salary increase in the future)	1	2	3	4	98	99

55. What are the priority changes in policy and practice that would help address these financial issues?

Thank you for your answers! Stay healthy and safe!

ANNEX 7. JOURNAL OF COMPENSATION FOR STUDY PARTICIPATION

City		Local Coordinator	

№	Date	Participant code	Amount / compensation	Participant's signature	Full name of the interviewer	Interviewer's signature
1						
2						
3						
4						
5						
6						
7						
8						

ANNEX 8. MODERATOR GUIDE FOR FOCUS GROUP DISCUSSIONS

Below, as a sample, is the Moderator Guide within the study "Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine" (Ukraine, 2016).

Moderator Guide

PREPARATION

Participants: HIV+ women working in HIV-service NGOs, activists, volunteers who have expertise in providing services to:
- women PWID/OST
- HIV+ women
- sex workers
- displaced women
- women in prisons
- teenagers, young women;

as well as expertise in protecting the rights and interests of the above groups.
NB! Interviewers can participate in FGDs.

Number of participants: at least 8 people.

Duration of FGD: 2,5-3 hours

Materials and equipment: two questionnaires (at least 15 pieces of each), room with the door closed, 16-17 chairs, voice recorder, laptop and/or printed FG protocol (in your hands), a table for tea/coffee/biscuits/fruit, and a participant registration form in the form below.

CO "Positive Women"

Registration Form

Focus Group
within the study
Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine

City:
Data:
Moderator:

№	First and Last Name	Organisation	City	Position	Signature
1.					
2.					
…					

Keeping minutes: It is recommended to invite an assistant (possibly from among the interviewers), who will record the names of the discussion participants and briefly write down their answers.

COURSE

INTRODUCTION:

1. THANK THE PARTICIPANTS of the group.
2. PROVIDE INTRODUCTORY INFORMATION specified in the Preamble to the study: CO "Positive Women" conducts a study of the needs of HIV-positive women in Ukraine, which consists of studying women living with HIV (a study of 1000 women from all regions of the country), consultations with communities (in the format of four focus groups) and expert analysis of policies and programmes on HIV/AIDS. We are determined to find out the most important aspects of their lives in relation to sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities. The identified priorities will contribute to the formation of the programme activities of the UN Women Office in Ukraine, and will also be used in the strategic planning and operational activities of the CO "Positive Women".
3. SHARE THE BASIC PRINCIPLES for conducting a focus group: respect for confidentiality, respect for the right of each to their own opinion, not to talk about others.

STRUCTURE OF A FOCUS GROUP

Stage	Description	Document
1st stage	Studying participants as women living with HIV using a general questionnaire	Annex No. 1
2nd stage	Studying participants as activists and providers of HIV services	Annex No. 2
Break 15-20 minutes		
3d stage	Discussion of the following issues: access to SRH, policies and strategies, access to HIV services, gender equality, participation in the HIV/AIDS national and local policy-making, the impact of armed conflict	Annex No. 3

REPORTING

Within a week after the focus group, the following should be provided:

No.	Title	Format	To Whom
1	Participant Registration Form	Original and scanned copy	Study Coordinator
2	Focus Group Protocol	Original and scanned copy	Study Coordinator
3	15 questionnaires (Annex 1)	Original	Data Coordinator
4	15 questionnaires (Annex 2)	Original	Data Coordinator

ANNEX 9. VERBAL INFORMED CONSENT FOR FOCUS GROUP DISCUSSION

As a template, you can use the structure and logic of the template from Annex 2. Verbal Informed Consent to Piloting the Tool.

ANNEX 10. FOCUS GROUP DISCUSSION QUESTIONNAIRE

The Questionnaire contains questions that allow you to understand whether the characteristics of a potential participant match the criteria set by the Protocol, as well as additional questions in accordance with the study theme. Below, as a sample, is a Focus Group Screening Questionnaire within the study "Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine" (Ukraine, 2016).

Personal data

1. Living with HIV:
 1) 0-2 years
 2) 3-5 years
 3) 5-10 years
 4) Over 10 years

2. Activism experience:
 1) No
 2) 0-2 years
 3) 3-5 years
 4) 5-10 years
 5) Over 10 years

3. Experience in HIV services:
 1) No
 2) 0-2 years
 3) 3-5 years
 4) 5-10 years
 5) Over 10 years

Key issues

W**hich of these issues do you consider as the highest priority to address at the national level?** (Please choose one answer for each question)

1. Policies and strategies

No.	Issue	Absolutely	High priority	Low priority
4	Amend laws and policies with regard to decriminalisation of issues related to sexual and reproductive health (SRH) and HIV (including infection and transmission of HIV)	1	2	3
5	Ensure laws, policies and guidelines are based on respect for the human rights of women and girls living with HIV in all our diversity	1	2	3
6	Ensure rights-based approach to care for women and girls living with HIV in all our diversity	1	2	3
7	Provide comprehensive sexuality education and a choice of SRH services that promote sexual pleasure for women, respectful relationships, gender equality and human rights for all regardless of sexual identity, gender orientation and HIV status	1	2	3
8	Expand the evidence base on the relationship between HIV, gender equality, sexual and reproductive health and human rights for girls and women living with HIV at all stages of life	1	2	3
9	Create and expand opportunities for women living with HIV to participate meaningfully in decision-making and programming on SRH, gender equality and human rights	1	2	3
10	Provide integrated HIV and sexual and reproductive health services and referrals	1	2	3

11. Other priorities (if you wish to mention)

2. Gender-based violence

No.	Issue	Absolutely	High priority	Low priority
12	Recognize and address the issue of gender-based violence, including intimate partner violence, violence by other family members and violence against women living with HIV from key populations (sex workers, women who use drugs, women who have sex with women, transgender women)	1	2	3
13	Recognize and address all issues related to violations of the rights of women with HIV in healthcare facilities (e.g., stigma and discrimination; bias in the workplace; forced abortion or sterilization; lack of choice, privacy, or information, etc.)	1	2	3
14	Recognize and address the issue of gender inequality in society at all levels (e.g. ensure equal employment opportunities and equal pay for men and women; ensure equal property rights, etc.)	1	2	3

15. Other priorities (if you wish to mention)

3. Access to clinical care, treatment and support

No.	Issue	Absolutely	High priority	Low priority
16	Guarantee high-quality services based on dignity, respect and non-discrimination for girls and women living with HIV throughout their lives (e.g. no bias from healthcare workers, which can be a barrier to accessing services)	1	2	3
17	Ensure Universal Precautions in all healthcare settings (e.g. sterilisation or use of new equipment for each patient, regardless of previous patient's HIV status)	1	2	3
18	Ensure access to a full range of age-appropriate contraceptives for HIV-positive women	1	2	3
19	Provide services with an understanding of the relationship between taking antiretroviral therapy (ART) and family planning options, including safe medical and surgical abortion	1	2	3
20	Research and provide services with an understanding of the impact of HIV and/or ART on the libido and sexual pleasure of women living with HIV at all stages of their life	1	2	3
21	Research and provide services with an understanding of how HIV and/or ART cause menstrual irregularities, including heavy/irregular/long/painful periods; and other gynaecological diseases, including fibroids	1	2	3
22	Research and provide services with an understanding of how HIV and/or adherence to ART affects the onset, course and duration of menopause in women living with HIV	1	2	3
23	In planning and delivering services, understand, support and address the wide range of mental health issues faced by girls and women living with HIV (including chronic anxiety and depression)	1	2	3
24	In planning and delivering services, understand the impact of comorbidities, including tuberculosis, hepatitis C, cancer and sexually transmitted infections, in the context of the sexual and reproductive health and human rights of women living with HIV	1	2	3

25. Other priorities (if you wish to mention)

4. Sexual relations

No.	Issue	Absolutely	High priority	Low priority
26	Facilitate the participation of sexual partners (male and/or female) in accessing sexual and reproductive health services for HIV-positive women (e.g. HIV counselling and testing for couples, status disclosure, family planning, mental health)	1	2	3
27	Implement reliable and up-to-date guidance on the ability to conceive a child in couples with the same or different HIV status	1	2	3
28	Promote sexual health, well-being, safety and sexual satisfaction	1	2	3

29. Other priorities (if you wish to mention)

5. Care and support for children of women living with HIV

No.	Issue	Absolutely	High priority	Low priority
30	Ensure that women with HIV receive childcare support, regardless of the children's HIV status	1	2	3
31	Ensure that women with HIV receive the necessary social and legal support to protect the rights of children with HIV	1	2	3

32. Other priorities (if you wish to mention)

6. Sexual and reproductive health, gender equality and the rights of women living with HIV in all their diversity

Assess the factors that help women from different groups to have full access to sexual and reproductive health and human rights? (Please **choose one answer** for each question)

No.	Issue	Critical	Important	Less important	Not important	Don't know
33	Access to methadone or buprenorphine for women living with HIV, women who inject drugs and pregnant women	1	2	3	4	98
34	Sexual and reproductive health services specifically for lesbian, bisexual, transgender women or other women living with HIV who have sex with women	1	2	3	4	98
35	Comprehensive sexuality education	1	2	3	4	98
36	Continued access to treatment and adherence support for women in prison or in detention	1	2	3	4	98
37	Addressing HIV-related stigma and discrimination from prison staff and inmates	1	2	3	4	98
38	Implementation of modern practical guidelines for women living with HIV in prisons (e.g. obligations of prisons and colonies in terms of HIV care)	1	2	3	4	98
39	Special access to information and services for women with disabilities (people with disabilities)	1	2	3	4	98
40	Treatment and support for women with comorbidities such as hepatitis C and/or tuberculosis	1	2	3	4	98
41	Access to gender reassignment surgery for trans women	1	2	3	4	98
42	Measures to end and address violence and discrimination against sex workers	1	2	3	4	98
43	Eliminate age-related restrictive policies (please provide examples in the box below)	1	2	3	4	98

44. Other factors (if you wish to mention)

7. Participation of women living with HIV in coordination councils to fight tuberculosis and HIV-infection/AIDS

No.	Issues	Yes	No	Not sure	Not applicable
44	I have heard about the National Council to Fight Tuberculosis and HIV-infection/AIDS	1	2	98	99
45	I know how and why it works, I know its structure	1	2	98	99
46	I know who represents the interests of women living with HIV in the National Council to Fight Tuberculosis and HIV-infection/AIDS	1	2	98	99
	If you answered Yes, please provide names and organisations _____				
47	I have heard about the Oblast/City/Raion Council to Fight Tuberculosis and HIV-infection/AIDS	1	2	98	99
48	I know how and why it works, I know its structure	1	2	98	99
49	I know who represents the interests of women living with HIV in this/these Council(s) to Fight Tuberculosis and HIV-infection/AIDS	1	2	98	99
	If you answered Yes, please provide names and organisations _____				
50	I participated in the meetings of the Oblast/City/Raion Council to Fight Tuberculosis and HIV-infection/AIDS	1	2	98	99
51	I am a member of the Oblast/City/Raion Council to Fight Tuberculosis and HIV-infection/AIDS and/or its subgroups (committees)	1	2	98	99
52	I know how the agenda and work plan of the Oblast/City/Raion Council to Fight Tuberculosis and HIV-infection/AIDS is(was) formed	1	2	98	99
53	I know where I can study or request the protocols and protocol decisions of the Council(s) to Fight Tuberculosis and HIV-infection/AIDS	1	2	98	99

If you answered "Yes" to at least one of the last four questions, complete the following table:

Over the last two years, have the following issues been discussed and decisions been made at the meetings of the Oblast/City/District HIV-TB Council:

No.	Issue	Yes	No	Don't know
54	Sexual and reproductive health of women living with HIV (e.g. access to condoms, contraception, IVF., prevention of mother-to-child HIV transmission, access to prenatal and postnatal care)	1	2	98
55	Gender-based violence (e.g. police violence, domestic violence statistics, stigma and discrimination in maternity hospitals)	1	2	98
56	Provision of specific services for women who use drugs, women in prisons and sex workers, their access to harm reduction services, OST and rehabilitation, legal support	1	2	98
57	Home and community care (support group establishment, non-medical home care, day centres/rooms for children, drug delivery, child nutrition)	1	2	98
58	Developing the capacity of women living with HIV to effectively participate in political processes (for example, development of regional programmes and strategies, monitoring of social budgets, implementation of social orders, gender budgeting)	1	2	98

59. What other coordination (advisory/supervisory) bodies (councils /structures/ commissions) that may impact the life, health and well-being of women living with HIV do you know and/or participate in (have participated in):

8. Participation of women living with HIV in the development, review or evaluation of HIV/AIDS programmes

8.1. National Target HIV Social Programme for 2014-2018

No.	Issue	Yes	No	Partially	Don't know
60	I have heard about the National Target HIV Social Programme for 2014-2018 (hereinafter - the Programme)	1	2	3	98
61	I know how the Programme was developed	1	2	3	98
62	I can name the approximate composition of the working group for the Programme development	1	2	3	98
63	Women living with HIV were part of the working group that developed the Programme	1	2	3	98
64	I can name sections of the Programme that affect the health and well-being of women living with HIV	1	2	3	98

8.2. Oblast/City Target HIV Social Programme for 2014-2018

No.	Issue	Yes	No	Partially	Don't know
65	I have heard about the Oblast Target HIV Social Programme for 2014-2018 (hereinafter - the Programme)	1	2	3	98
66	I know how the Programme was developed	1	2	3	98
67	I can name the approximate composition of the working group for the Programme development	1	2	3	98
68	Women living with HIV were part of the working group that developed the Programme	1	2	3	98
69	I can name sections of the Programme that affect the health and well-being of women living with HIV	1	2	3	98

9. Armed conflict and the annexation of Crimea

9.1. Services for women from annexed Crimea and occupied Donbas

No.	Issue	Agree	Partially agree	Disagree	Don't know
70	Me and/or the organisation I work for provide services to women living with HIV, internally displaced persons (IDPs) who came from Crimea or Donbas on an equal basis with other clients	1	2	3	98
71	Me and/or the organisation I work for provide specific services to women living with HIV, internally displaced persons (IDPs) who came from Crimea or Donbas	1	2	3	98
72	The state provides assistance at a sufficient level for women living with HIV, affected by the armed conflict or the annexation of Crimea	1	2	3	98
73	HIV-service organisations provide sufficient assistance for women living with HIV, affected by armed conflict or the annexation of Crimea	1	2	3	98

9.2. Priority of services for HIV+ women, internally displaced women who arrived from Crimea or Donbas

No.	Issue	Absolutely	High priority	Low priority
74	Issuance of passes (laissez-passer)	1	2	3
75	Registration at a new place of residence	1	2	3
76	Re-registration of pensions	1	2	3
77	Re-registration of child allowances	1	2	3
78	Applying for benefits as an IDP	1	2	3
79	Access to preschool education for children	1	2	3
80	Access to school education for children	1	2	3
81	Access to healthcare	1	2	3
82	Access to ARV treatment	1	2	3
83	Access to OST services	1	2	3
84	Employment	1	2	3
85	Housing assistance	1	2	3
86	Humanitarian assistance (clothing, shoes, household items)	1	2	3
87	Humanitarian assistance (foodstuffs)	1	2	3
88	Psychological assistance (psychological consultation, support groups)	1	2	3
89	Legal assistance (legal advice, consultations with social workers)	1	2	3
90	Prevention of domestic violence	1	2	3

91. Other (Please specify)

Thank you for your answers!

ANNEX 11. FOCUS GROUP DISCUSSION GUIDE

Below, as a sample, is a Focus Group Discussion Guide of the study "Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine" (Ukraine, 2016).

Focus Group
Issues for discussion

1. Policies and practice
Based on your experience, please tell us:
1.1. What laws and regulations improve the access of women living with HIV to services related to sexual and reproductive health (SRH) and HIV.
1.2. What laws and regulations impede the access of women living with HIV to services related to sexual and reproductive health (SRH) and HIV.
1.3. Examples of successful integration of Gender and HIV (gender-sensitive service delivery).

2. Gender-based violence
2.1. Name success stories of HIV-service NGOs in the field of combating gender-based violence.
2.2. Name government organizations where you observe institutionalized violence against women living with HIV.

3. ARV treatment and support
3.1. Could you please provide examples when developing adherence to ARV therapy had different approaches for men and women?
3.2. Have you been trained in different approaches in social support of ART for women of different ages, from adolescent girls to menopausal women, and have you put these approaches into practice? Describe these approaches.

4. Sexual partners
4.1. How often have you counseled sexual partners (male and/or female) on sexual and reproductive health issues for HIV+ women. Describe your experience.

5. Children of women living with HIV
Based on your experience:
5.1. Please assess the extent to which what the state offers in the field of care and support for children of women living with HIV meets their needs.
5.2. Describe what HIV-service NGOs offer for the children of women living with HIV.

6. Participation of women living with HIV in coordination councils on HIV/AIDS
6.1. Provide examples of effective participation of women living with HIV in HIV/AIDS coordination councils.
6.2. Provide examples of effective participation of women living with HIV in other coordination and/or advisory and/or monitoring structures.
6.3. What increases and what hinders effective participation.

7. Participation of women living with HIV in the development, review or evaluation of HIV/AIDS programmes
7.1. Describe the successes and challenges of the participation of women living with HIV in the development, review or evaluation of a national and/or local target social HIV programme for 2014-2018.

8. Armed conflict and the annexation of Crimea
8.1. Describe the range of services for HIV+ women, internally displaced women who arrived from Crimea or Donbas, both provided by the state and NGOs.
8.2. How war affects the health and well-being of women living with HIV

ANNEX 12. JOURNAL OF COMPENSATION FOR FOCUS GROUP DISCUSSION

City		Local Coordinator	

№	Date	Participant code	Amount / compensation	Participant's signature	Full name of the interviewer	Interviewer's signature
1						
2						
3						
4						
5						
6						
7						
8						

ANNEX 13. DATA USE AND PRIVACY AGREEMENT

Full name: _____
Role in the study: _____

The information obtained in the course of this study is strictly confidential and was provided to the study staff with the understanding that it will be kept confidential.

Please check each box and put your signature below the table to prove that you agree to abide by these rules.

No.	Commitments	Note
1	I will not attempt to identify the study participants	
2	I understand all aspects of data security and privacy and undertake to comply with them when implementing the project	
3	I will not provide data to any researcher other than those who are working on this study and have signed a copy of this Agreement	
4	I will not make data sets or information public for any purpose other than that specified by the Protocol or to comply with the requirements of the law	
5	I will not disseminate any part of the data sets to anyone who is not a member of the study team, except as required by law	
6	I agree not to attempt to re-identify the source of any information provided	
7	I understand that I am required to securely store all data (paper forms or electronic databases) that are available to me	

Signature _____ Date _____

Failure to comply with these rules will result in the denial of further access to the data and the imposition of any appropriate sanctions, including criminal liability, in cases where this is provided.

Thank you!

ANNEX 14. LOCAL STUDY TEAM REPORT

Most often, the report of the local team is based on a list of questions that provide an opportunity to understand the progress of the field study (for example, who, where and when conducted the study in the locality), the main difficulties and ways of solving them, comments on the current study and recommendations to take into account in future researches. It is important that such a technical report is not a formal document but reflects the real situation and is filled in by all members of the local team. This will provide an opportunity to hear feedback from each representative of the local team, take into account possible local specifics when analysing and interpreting data, and also form a number of practical recommendations for optimising/improving data collection for the future.

ANNEX 15. NATIONAL CONSULTATION PRESS RELEASE TEMPLATE

Below, as a sample, is a Press Release of the study "Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine" (Ukraine, 2016).

"Positive Women" held a national consultation on the gender dimension of the HIV epidemic

CO "Positive Women" presented to partners the preliminary findings of the unique study **"Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities for women living with HIV in Ukraine".**

"Such studys empower women to fight for their rights," said **Anastasia Divinskaya**, Gender Adviser and UN Women Head of Office in Ukraine, in her welcoming speech.

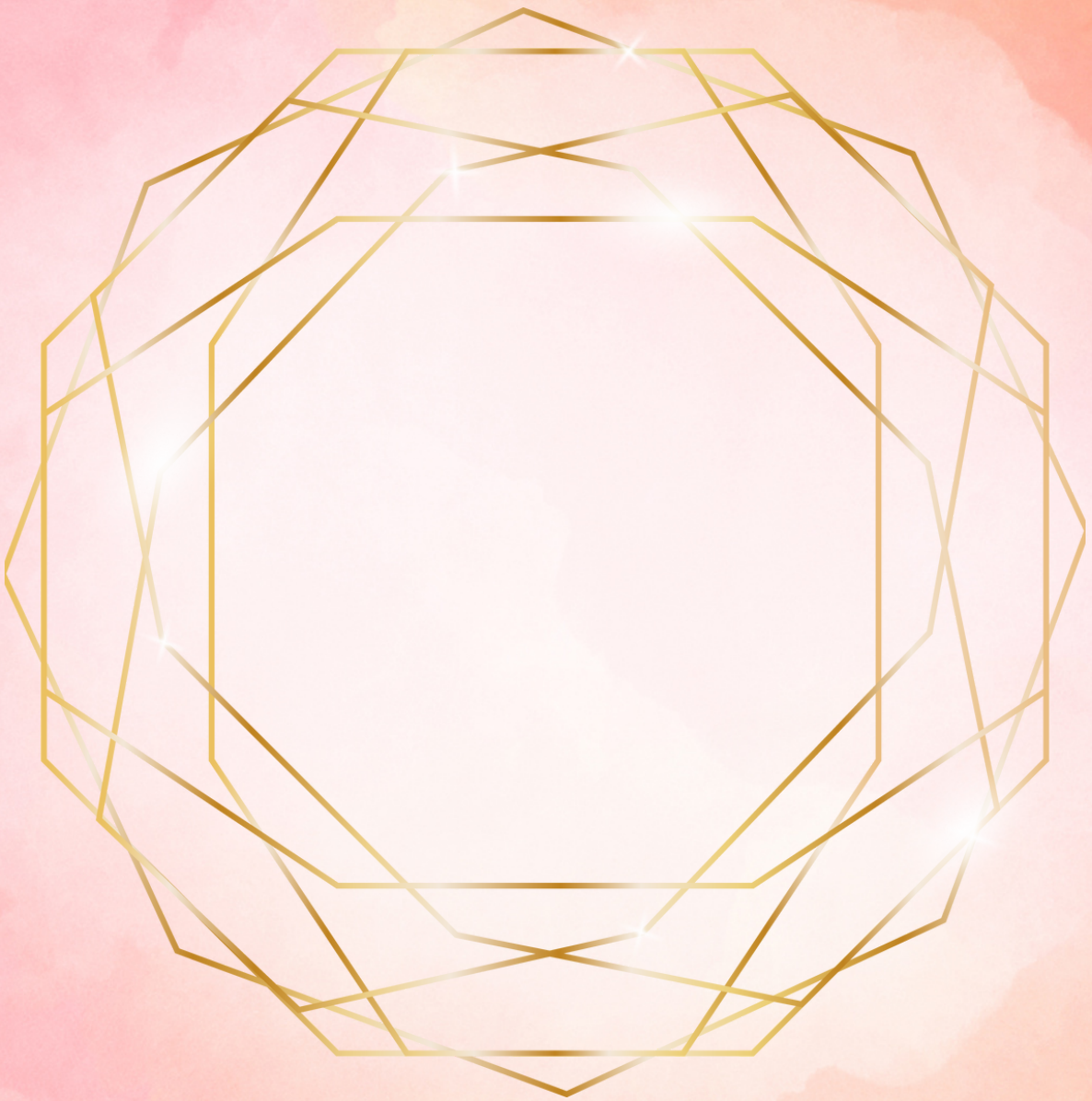
The study consisted of an interview of 1,000 women living with HIV from all regions of Ukraine, consultations with communities in the format of four focus groups, and expert analysis of policies and programmes on HIV/AIDS.

"Only 3% of focus group participants believe that the state fulfils its obligations towards PLHIV. 37% of the participants do not know or have not heard of the National Council to Fight Tuberculosis and HIV-infection/AIDS. Despite the fact that women make up 40% of the total number of members of regional councils, only 7% were included in their leadership, — **Elena Yeshchenko**, study consultant, Ph.D. in Medicines, commented on the data. — The need to address gender-based violence (98.3%) and violations of women's rights (98.2%) is an almost 100% priority for activists and service providers".

"In terms of its content, the study is comprehensive, it allows to identify problematic aspects in the field of reproductive health and determine the prevalence of manifestations of human rights violations, discrimination and stigma. The fact that the leadership, coordination and direct collection of primary information is carried out by women themselves ensures a high probability of obtaining reliable information, openness in answers, reduces the traditional evasion of answers for "acute" questions," stressed **Olga Balakireva**, Ph.D. in Sociology, Head of the Ukrainian Institute for Social Research after Olexander Yaremenko.

The study participants expressed the highest level of disagreement with the statements: "I can get free and high-quality treatment, information, services in the field of sexual and reproductive health when I need them" and "I believe that the healthcare workers who provide services are well trained, friendly, ready to support".

"We, as representatives of the community of HIV-positive women, will do our best to ensure that the findings of the study do not become a piece of paper hidden in a box. The obtained data and conclusions encourage us to build appropriate plans and actions. We are most aware of their value," concluded **Olena Stryzhak**, Study Coordinator, CO "Positive Women".



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