Improving Retention, Adherence & Psychosocial Support within PMTCT Services

A Toolkit for Health Workers

ICAP
International Center for AIDS Care and Treatment Programs
MAILMAN SCHOOL OF PUBLIC HEALTH
Columbia University

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Foreword and Acknowledgements

Over the last several decades, HIV infection has ravaged families and communities throughout many parts of the world. Despite noteworthy scientific advances and increased access to prevention and treatment services in HIV high prevalence settings, it is estimated that worldwide approximately 1,000 children are born each day with HIV infection. The vast majority of these infections can be attributed to vertical transmission, acquired during pregnancy, delivery, or through breastfeeding. Without proper treatment, more than half of these children will die before their second birthday. Similarly, many of their mothers continue to suffer the consequences of untreated HIV infection and succumb to an early death.

In Central Harlem, New York City, where I began my work more than 25 years ago, I witnessed the extraordinary success of efforts to prevent mother-to-child transmission. In the early days of the epidemic, the hospital wards were filled with infants and children living with HIV, many too ill to be cared for at home, others orphaned or abandoned. Over time, however, the hospital wards slowly emptied and we stopped attending funerals as fewer children were being born with HIV infection and those who became infected were effectively treated, no longer succumbing to the disease. Instead, we spent our time in busy clinics treating families, celebrating birthdays and holidays, and planning weekend outings and summer camps as successful treatment and prevention efforts enabled many children and families to lead long, healthy lives. A series of scientific discoveries throughout the 1990s provided the foundation on which we built effective prevention of mother-to-child transmission (PMTCT) programs. Women were tested for HIV during pregnancy and routinely received antiretroviral treatments for their own health and to prevent transmission to their unborn child. By the turn of the century, mother-to-child transmission rates were reported as low as 1-2%, down from 25-30%, in countries where resources for prevention and treatment were routinely available. In my clinic in Central Harlem, like many other clinics in Europe and North America, many of the children we cared for at the start of the epidemic are now transitioning into adulthood and starting families of their own.

Similar success has been difficult to achieve in many parts of the world where HIV is more prevalent and resources more constrained. Many factors have contributed to this failure to more effectively prevent new pediatric infections. Among others, there has been limited geographic expansion of PMTCT programs, an over-reliance on the use of short-course prophylaxis regimens, a failure to recognize and effectively address the health needs of the pregnant woman who requires treatment, and until recently, few feasible and safe options to prevent transmission during breastfeeding. Furthermore, health workers caring for women and children in clinics and hospitals often find themselves poorly prepared and supported to effectively implement PMTCT, a complex series of interventions that start during pregnancy, continue throughout breastfeeding, and include the mother, child, and oftentimes partner and family members.

The year 2010 marks the beginning of a new era for PMTCT. International leadership is championing the health of women and children throughout the world, with special attention to those affected by HIV. UN agencies, national governments, and implementing partners have launched an MTCT elimination campaign aimed to lower transmission rates to less than 5% worldwide. In addition, the 2010 revision of WHO guidelines denotes an important turning point in approach to PMTCT, emphasizing the need to initiate antiretroviral treatment for eligible pregnant and postpartum women, and recommending more potent regimens for prevention during pregnancy, as well as antiretroviral prophylaxis to the mother or baby throughout breastfeeding. If these guidelines are well implemented,

rates of new infections in children should drop dramatically in the years ahead. In addition, we can expect to see significant improvements in maternal health outcomes.

At the forefront of the epidemic are the health workers tasked with translating these guidelines into effective interventions in the field. In the HIV clinic in Central Harlem, NY, as well as the PMTCT clinic in Maseru, Lesotho, the nurses, midwives, counselors, and peer educators form the bridge to good health for the community. And, in this case, health workers in the maternal and child clinics will be the ones to help women and their partners effectively engage in PMTCT and HIV care and treatment services. What these frontline health workers understand and what they communicate to their clients will dramatically impact the health outcomes of millions of women, children, and families.

This PMTCT Toolkit was developed in an effort to support health workers in this daunting task. It aims to provide a simplified, step-by-step approach to the many components of PMTCT care, with a particular emphasis on retention, adherence, and psychosocial support. It should enable health workers to systematically provide key information to their clients as they progress through pregnancy, delivery, breastfeeding, and planning for future pregnancies. It should enable health workers to effectively communicate important health messages to their clients and facilitate effective engagement in care. This work is built on two basics concepts: parents will go to extraordinary lengths to protect their children, and health workers are deeply committed to helping families stay safe and healthy. This Toolkit offers health workers and families a means towards more effective PMTCT services and healthier lives for women, children, and families living with HIV.

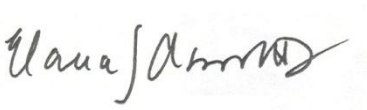
I have had the privilege of working with countless talented individuals committed to improving the health of women, children, and families living with HIV. The PMTCT Toolkit brings together the collective experience of hundreds of people who have worked in this area and who have willingly shared their learning and insights. The Toolkit is presented as a set of generic tools that can be easily adapted by Ministries of Health, health care facilities, and other organizations seeking to improve the quality and outcomes of PMTCT services. I am hopeful that the availability of these tools reflecting our collective learning and experiences will further efforts to eliminate new pediatric infections, and contribute to the good health of families infected with and affected by HIV throughout the world.

I would like to express my appreciation and gratitude to all of the individuals who contributed a significant amount of their time and effort to the development of this Toolkit. Special thanks go to Tayla Colton, independent consultant, for her technical support, expertise, and inspired and informed approach to material development; Leah Westra, ICAP Project Officer, for coordination and editing of the materials; Sara Riese, ICAP PMTCT Program Officer, Fatima Tsiouris, ICAP Associate Program Director for PMTCT, and Xoliswa Keke, ICAP-South Africa Technical Advisor-Care and Support, for their thoughtful contributions throughout the development process; Anne Schoeneborn, ICAP Project Assistant, for her superb drafting and editing skills; Erin Dowling, independent consultant, for layout and production of the materials; Petra Röhr-Rouendaal, artist, for her beautiful illustrations; and Cristiane Costa, ICAP Southern Africa Region Program Director, for bringing everyone together to create this important and excellent product. Special thanks to Peter Sasowsky, independent film producer, for contributing his time, expertise, and creativity to the production of the video, to the ICAP South Africa staff, and to the cast who so eagerly offered their time, energy, and insights to help spread the important messages of PMTCT. Also, a note of thanks to three nurses from Central Harlem, Maxine Frere, Monica DiGrado, and Jacquelyn Brinney, who so skillfully and lovingly cared for countless children and families living with HIV. I admire the talent and vision of each of these individuals and am inspired by their commitment to improving the health and wellbeing of women, children, and families affected by HIV.

This work would not have been possible without the support of the MTCT-Plus Initiative. The MTCT-Plus Initiative was the first multi-country, family-centered HIV care and treatment program and it supported services in 14 centers in 9 countries in Sub-Saharan Africa and Thailand. The Initiative is recognized as a leader in family-focused HIV care and in addressing the special needs of pregnant and postpartum women and their children. Funding for the MTCT-Plus Initiative was provided by the Bill & Melinda Gates Foundation, the William and Flora Hewlett Foundation, the Robert Wood Johnson Foundation, the Henry J. Kaiser Family Foundation, the John D. and Catherine T. MacArthur Foundation, the David and Lucile Packard Foundation, the Rockefeller Foundation, the Starr Foundation, and the U.S. Agency for International Development.

The MTCT-Plus Initiative was the first program providing the foundation for the formation of ICAP, the International Center for AIDS Care and Treatment Programs. ICAP is an important partner in the global effort to expand access to quality PMTCT and HIV care and treatment services. ICAP, in collaboration with national and local governments and Ministries of Health, supports the design, development, and implementation of a diverse range of initiatives providing HIV prevention, care, and treatment services in resource-limited settings. ICAP endeavors to build sustainable programs that address the ongoing clinical and psychosocial concerns and needs of PLHIV, as well as their partners, families, and caregivers. ICAP programs are funded by a variety of U.S. government and private sources, including the U.S. Centers for Disease Control and Prevention (CDC) under the President's Emergency Plan for AIDS Relief (PEPFAR), the U.S. Agency for International Development (USAID), the Department of Defense, the National Institutes of Health,

I am hopeful that this Toolkit will help individuals, agencies, governments, and organizations in their efforts to eliminate new pediatric infections and to keep women and their families healthy and safe.



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Introduction to the Toolkit

I.

Introduction to the Toolkit

The Global Situation: Progress and Challenges

Despite significant challenges, in the past decade the global expansion of prevention of mother-to-child transmission of HIV (PMTCT) and HIV care and treatment programs has been dramatic. This expansion is particularly evident in sub-Saharan Africa. By the end of 2009, 5.25 million people living with HIV (PLHIV) globally were receiving antiretroviral treatment (ART), representing 52% of those in need. In addition, over half of the 1.4 million pregnant women living with HIV had received antiretroviral drugs (ARVs) for PMTCT, up from 15% in 2005. Despite these successes, however, many countries are still using simplified, less-efficacious PMTCT regimens and many pregnant women with advanced HIV infection are not starting lifelong ART for their own health. Further, according to the World Health Organization (WHO),[1] only 35% of HIV-exposed infants received ARVs for PMTCT in 2009 and only 15% received an HIV test within the first two months of life.

Rationale for Developing the Toolkit

With this rapid expansion of services, as well as the gaps that remain in service access and uptake, comes the need to develop innovative and responsive approaches to support clients' and family members' retention in care, and adherence to care and medicines over the long term. Recently, the lack of guidance and tools for health workers to address issues surrounding clients' adherence and psychosocial support has been identified as a crucial gap in PMTCT programs. Further, the recently updated WHO guidelines, which recommend that mothers start taking ARVs earlier in pregnancy and that mothers or their babies continue prophylaxis for an increased length of time postpartum, necessitate heightened support for adherence to PMTCT services and medications. In response, The International Center for AIDS Care and Treatment Programs (ICAP) at Columbia University's Mailman School of Public Health (MSPH) developed this Toolkit to specifically support retention, adherence, and psychosocial support within PMTCT programs.

The materials in this Toolkit are designed to aid multidisciplinary care teams in providing women, families, and babies with increased support for retention, adherence, and psychosocial wellbeing throughout the continuum of PMTCT care. The materials are intended to improve the knowledge, skills, and confidence of a range of professional and lay health workers within PMTCT programs, thus enhancing the scope and quality of services available to PMTCT clients and their families. In addition, the forms and guides included in the Toolkit are intended to support the development of the systems needed to successfully improve retention, adherence, and psychosocial wellbeing among all PMTCT clients. All of the materials included in the Toolkit are generic in form, and thus allow Ministries of Health, provincial and district authorities, health facilities and health workers, and implementing partners to adapt the content to suit specific programmatic and policy contexts.

[1] WHO/UNAIDS/UNICEF (2010). *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector. Progress report 2010.* Geneva, Switzerland: WHO/UNAIDS/UNICEF. Available at: http://www.who.int/hiv/pub/2010progressreport/report/en/index.html

Overview of the Toolkit

The Toolkit contains 6 major sections, each marked with a tab:

Section 1 provides an overview and introduction to the Toolkit.

Section 2 provides guidance and tips on adapting the Toolkit materials to specific country and program settings.

Section 3 consists of an implementation workshop curriculum, including a Trainer Manual, Slide Set, and a Participant Manual. The curriculum reinforces the importance of retention, adherence, and psychosocial support within PMTCT services, introduces participants to the Toolkit materials, and guides participants in developing an action plan to improve retention, adherence, and psychosocial support services as well as in integrating the materials into their work.

Section 4 contains a series of PMTCT Counseling Cue Cards. Each counseling cue card focuses on a specific topic important to the care and support of pregnant women living with HIV, their children, and families, across the PMTCT continuum of care. These cue cards are intended to serve as important job aides and reminders of key information for counselors and other health workers to cover during clinical sessions with pregnant women and newly delivered mothers, their partners, family members, and supporters.

Section 5 contains adaptable templates of forms and guides that can be used by health workers to support and assess clients' retention in, and adherence to, PMTCT services and medicines, as well as their psychosocial wellbeing. The forms and guides include:

- *PMTCT Pre- and Post- HIV Test Counseling Checklists* to be used by health workers when providing pre- and post- test counseling to PMTCT clients.
- *A PMTCT Psychosocial Assessment Guide and Reporting Form* to be used by health workers when conducting initial and follow-up psychosocial assessments with PMTCT clients.
- *Adherence Preparation and Support Guides* to be used by health workers to help clients prepare to adhere to their own (and their babies') care and treatment plans and when providing ongoing adherence support.
- *Adherence Assessment and Follow-up Guides* to be used by health workers to assess adherence and to learn more about adherence challenges the client may be facing, as well as to provide ongoing adherence support.
- *Appointment book and appointment reminder card templates* to be adapted and implemented by clinics in order to keep track of appointments and to help trace patients lost to follow-up, as well as to help clients keep track of upcoming appointments.

Section 6 contains an educational video reinforcing key PMTCT messages and the importance of adherence to PMTCT services and medicines throughout the spectrum of care. This educational video can be shown and facilitated to a wide range of audiences, including PMTCT clients, family members, and caregivers of HIV-exposed and HIV-infected children. The video can be used in a variety of settings, including in clinic waiting rooms, as part of group education sessions, and in the community.

II.

Adapting the Toolkit Materials

Guidance on Adapting the Toolkit Materials

Below are 10 key steps recommended to adapt and roll out the Toolkit in specific country and/or program settings. ICAP welcomes any feedback and experience-sharing on the Toolkit adaptation process, from which other organizations and countries may learn.

For more detailed guidance on adapting, pretesting, and printing materials, see:

- WHO/HHS-CDC (2004, updated in 2008). *Prevention of mother-to-child transmission of HIV infection (PMTCT) generic training package. Adapting the package.* Available at: http://www.pmtct.org/wchiv?page=gtp-02-00
- Podhurst, LS, Pemberton, G. (2006). *Step-by-step description of the process of country-specific generic training package adaptation.* Newark, New Jersey: François-Xavier Bagnoud Center, UMDNJ. Available at: http://www.pmtct.org/wchiv?page=gtp-step-00
- WHO/UNICEF (2002). *IMCI adaptation guide.* Geneva, Switzerland: Department of Child and Adolescent Health and Development, WHO. Available at: http://www.who.int/child_adolescent_health/documents/imci_adatation/en/index.html
- PATH/FHI/USAID (2002). *Developing materials on HIV/AIDS/STIs for low-literate audiences.* Washington, DC: PATH/FHI/USAID. Available at: http://www.fhi.org/en/hivaids/pub/guide/lowliteracyquide.htm

Step 1: Establish a Toolkit Adaptation Team

The first step in the adaptation process is to form an adaptation team. The adaptation team should be interdisciplinary and can include: PMTCT experts, trainers, clinicians, PMTCT program managers, and if possible, PMTCT clients, such as peer educators or mother mentors. Members of the adaptation team may be drawn from implementing agencies, national technical working groups, the Ministry of Health, health facilities, and collaborating non-governmental organizations (NGOs). It is important that both the adaptation team and its members are assigned clear roles and responsibilities. In addition, a single person should be appointed to coordinate the entire adaptation process.

Step 2: Develop a Workplan and Budget

The adaptation team should develop a detailed workplan and budget for the adaptation and materials rollout processes. The workplan should map out the adaptation process, a specific time line for each activity, and the person/people responsible for implementing each activity. The workplan should also include activities to monitor and evaluate the rollout and use of the Toolkit materials (see Step 10 below). The workplan activities should be linked to a detailed budget for the adaptation and distribution processes.

Step 3: Adapt the Materials

The adaptation team should first collect and review country-specific PMTCT materials, including national guidelines and protocols, as well as tools, registers, and forms currently in use at the district and health facility levels. The adaptation team should meet to review the Toolkit materials and discuss specific areas to be adapted.

Questions for the adaptation team to consider when reviewing the Toolkit materials include:

- *How do the materials need to be revised to align with country-specific PMTCT policies, guidelines, and needs?*
- *How do the materials need to be adapted to reflect the local situation and context?*
- *Which materials will be adapted (all, some)?*
- *Is the language and wording in the materials appropriate?*
- *Will the materials need to be translated into local language(s)?*
- *Is the information and language conveyed in the materials culturally appropriate?*
- *Do the illustrations reflect the local context?*
- *Are the training methodologies used appropriate for the intended audience?*
- *Are the instructions and participant exercises easily understandable?*

Specific areas of the Toolkit requiring adaptation include:

- The PMTCT prophylaxis regimen ("option A" or "option B"). The adaptation team should revise the materials, selecting only one of the PMTCT prophylaxis options, according to the national PMTCT guidelines. Discussion of PMTCT prophylaxis and regimens should be updated accordingly in the implementation workshop curriculum (Trainer Manual, Participant Manual, and slide set) and counseling cue cards.
- The national infant feeding strategy. The adaptation team should revise the materials, based upon the country's infant feeding strategy for mothers living with HIV. Discussion of safe infant feeding should be updated accordingly in the implementation workshop curriculum, counseling cue cards, and relevant tools.
- Case studies throughout the implementation workshop curriculum may be adapted to better reflect the local context.

The adaptation team should work together to draft the adapted materials. The most efficient way to go about doing this is to begin by adapting the specific counseling cue cards and other tools, then adapting the implementation workshop Trainer Manual and slide set, and finally by adapting the Participant Manual. It is important that any changes are made consistently throughout all of the Toolkit materials. A thorough review of the adapted materials should then be conducted.

Step 4: Translate and Back-Translate the Materials

At this stage, if determined to be important for use in health facilities, the materials should be translated (by qualified translators). Once translated, the materials should then be back-translated into English in order to check the quality of the original translation and to ensure that the simple, non-clinical, and client-friendly tone of the original materials is preserved. If the back-translated version does not match the original sufficiently, the translation will need to be revised. It is recommended to include members of the target audience (e.g. health workers, PMTCT clients) as part of the translation process.

Step 5: Review the Adapted Materials

The adaptation team should conduct a final review of all of the materials in order to ensure that they are responsive to national guidelines and that the translation is appropriate. At this stage, additional reviewers may also be incorporated, such as members of national technical working groups, project managers, and others.

Step 6: Copyedit and Layout the Materials

The Toolkit materials should be copyedited (for grammar, spelling, typing, etc.), formatted, and sample copies printed in preparation for the pilot test. This draft of the Toolkit should be treated as a near-final draft and should therefore be as polished and professional as possible. It is recommended that a professional designer be brought on to format and layout the materials, if possible.

Step 7: Pilot Test the Materials

Once printed, the Toolkit should be piloted in an agreed upon district and/or health facility with a group of health workers and PMTCT clients who are representative of the intended audience. The purpose of the pilot test is to gather information on how the materials (counseling cue cards, tools, implementation workshop curriculum) perform in real-world conditions, resulting in a detailed list of suggested revisions for the final drafts of the Toolkit materials. For more information on piloting methods, see the suggested resources at the beginning of this section.

Step 8: Revise, Finalize, and Print the Materials

The adaptation team should synthesize and discuss results of the pilot test and then revise the materials accordingly. If substantial changes are made after the initial pilot test, it is recommended that a second pilot test be conducted with the revised materials.

The final drafts of the materials should be reviewed one last time by the adaptation team and the Ministry of Health (or other key stakeholders) for sign off.

The adaptation team should oversee the final formatting and layout of the materials and plan for printing, including careful review of all proofs received from the printer. Sufficient numbers of materials should be printed in order to carry out the rollout strategy detailed in the adaptation workplan and budget. Keep in mind that it is often more economical to print larger volumes at one time instead of smaller volumes.

Step 9: Roll Out the Toolkit According to the Workplan

Once the materials have been finalized and printed, the Ministry of Health PMTCT Team, PMTCT technical working group and/or PMTCT Coordinator should ideally take full ownership of the materials and their distribution, with support from implementing partners. Orientations on the Toolkit and its contents should be held with all the national, district, organizational, and/or health facility-level trainers who will be leading implementation workshops and assisting sites to incorporate and use the Toolkit materials. Once the trainers have been oriented, site-level implementation workshops can be organized to launch the Toolkit materials.

Step 10: Provide Ongoing Mentoring and Monitor and Evaluate the Use of the Toolkit

As one aspect of a larger focus on improving retention, adherence, and psychosocial support within PMTCT programs, ongoing mentoring and supervision should be provided to health workers on using the Toolkit materials. Ministry of Health mentors and supervisors, supported by implementing partners, should follow up regularly with managers and staff at each of the sites using the tools, including one-on-one and group precepting and facilitating multidisciplinary team meetings to discuss any challenges with the materials and to review progress on the action plan created during the implementation workshop.

The Ministry of Health and its implementing partners should routinely revisit the monitoring and evaluation plan developed during the workplanning process. Monitoring and evaluation should determine whether the implementation workshops and materials:

- Are being rolled out as planned
- Are meeting the stated goals and objectives
- Are effectively improving retention, adherence, and psychosocial support within PMTCT programs
- Require modification to better meet the needs of health care workers and clients
- Require follow-up via more intense on-site mentoring, or refresher or advanced training

III.

Using the Toolkit Materials:

Implementation Workshop Trainer Manual

Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

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Implementation Workshop Curriculum for Health Workers

Trainer's Manual
2010

ICAP
International Center for AIDS Care and Treatment Programs
MAILMAN SCHOOL OF PUBLIC HEALTH
Columbia University

Table of Contents

List of Acronyms

ANC	Antenatal care
ART	Antiretroviral therapy/treatment
ARV	Antiretroviral
CD4	Cluster of differentiation 4 cell
CTX	cotrimoxazole
PCR	Polymerase chain reaction
HIV	Human Immunodeficiency Virus
ICAP	International Center for AIDS Care and Treatment Programs
MDT	Multidisciplinary Team
NVP	nevirapine
PLHIV	Person (or people) living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
SMS	Short message service (text message)
WHO	World Health Organization

How to Use This Implementation Workshop Curriculum

This implementation workshop curriculum was designed to provide multidisciplinary team members (doctors, nurses, pharmacists, social workers, counselors, lay counselors, peer educators, etc.) with knowledge and skills to improve retention, adherence, and psychosocial support within PMTCT settings and throughout the spectrum of PMTCT care. The curriculum also provides practical guidance to health workers on using the materials contained within this Toolkit.

Notes on the Training Agenda and Location

The curriculum consists of 5 sequential Modules that build upon one another, as well as a Supplemental Module (Module 6) on counseling and communication skills. This implementation workshop should be conducted at the health facility level, in a series of afternoon sessions. It is best to conduct the training in a meeting room, training room, or other area where distractions from the clinic are minimized. The total training time, including Supplemental Module 6, is approximately 15 hours. Conducting implementation workshops on-site allows time for practical experience and mentoring in the clinic during the mornings, keeps training costs low, and avoids taking health workers away from the clinic for extended periods. In some cases, the implementation workshop may also be conducted at the district or sub-district level with managers, supervisors, and health workers.

General Notes on the Training Methodology

The training curriculum is designed to acknowledge and build upon the existing knowledge and experience of health workers. The training course is highly participatory and based on principles of adult learning. By using the suggested participatory training methodologies, participants will be able to share their thoughts and experiences openly, and will learn from one another as much as they learn from trainers. The training methods used should serve as a model for how participants should communicate with clients in their work. Lectures and trainer-led activities should be minimized, with emphasis instead on participatory activities, with the trainers supplementing information as needed. Some Modules contain a classroom practicum session, whereby participants can apply information and skills learned in the training to real world case studies they may encounter in their daily clinic work.

The key information covered in the training is intended to be practical and interesting to participants. Additionally, all Modules use simple language and participatory activities so that they are accessible to all members of the multidisciplinary team, as well as to trainers with varying experience and comfort with facilitation. The experiences, baseline knowledge, and literacy levels of participants may vary, so trainers should make adaptations as needed.

The participatory training methodologies used in the curriculum include:

- Interactive trainer presentation
- Large group discussion
- Small group work
- Brainstorming
- Cardstorming
- Individual work
- Individual evaluation
- Case studies
- Role play
- Values clarification

Notes on Adapting this Curriculum

Because this was developed as a generic Implementation Workshop curriculum, trainers should allow ample time for adaptation of the materials (Trainer's Manual, slide sets, and Participant's Manual) well in advance of holding workshops. The curriculum, and the content and key information within, should be adapted to reflect national PMTCT and pediatric HIV care and treatment guidelines. The adaptation should also take into account the intended audience and participants of the workshop, their baseline levels of knowledge and experience around PMTCT and adherence and psychosocial support services, as well as the local context in which the curriculum is used. Please see the Toolkit section entitled, "How to Adapt the Toolkit Materials" for more information and guidance on the adaptation process.

More About Supplemental Module 6

This Supplemental Module has been included for settings where all or some participants wish to have more training and practice on specific counseling and communication skills. Trainers may decide to include this Supplemental Module based on the time available and the skills and needs of participants.

The Training Curriculum Design

There are 3 parts to the curriculum—a **Trainer's Manual, a training Slide Set,** and a **Participant's Manual**. Each trainer and participant should also have their own copy of the entire Toolkit, where the various Tools discussed and used during the workshop can be found. Each Module of the Trainer's Manual begins with the following information, followed by step-by-step trainer instructions and key information for each Session:

Duration: The approximate time it will take to facilitate the training Module.

Learning Objectives: The expected knowledge and skills participants will gain by the end of the Module.

Content: A list of the Sessions within the Module.

Methodologies: An overview of the training methods used in the Module.

Materials Needed: A list of materials the trainer should collect and prepare before the training sessions, such as flip chart, markers, tape or Bostik, etc.

Work for the Trainer to Do in Advance: Key preparatory activities for the trainers to do before facilitating the Module.

Key Points: A summary of key points, at the end of each Module.

Step-By-Step Trainer Instructions: Each Session begins with a shaded box, listing the training methodologies used in that Session, followed by suggested step-by-step guidance for trainers. The training is designed to be participant-focused instead of trainer-driven. Adults learn and retain more information when they participate fully, actively, and equally in the learning process. The trainer's main task is to facilitate the learning process and encourage active interaction and learning between participants, recognizing the significant experience that multidisciplinary team members already have working with PMTCT clients. The trainer's role is to draw out these experiences and encourage skills-building, exchange of information, and confidence-building among participants. Additionally, trainers should create an open environment free of hierarchy so that all participants – from all cadres – feel comfortable participating.

Key Information: The key content information for each Session follows the step-by-step trainer instructions. All trainers should be familiar and comfortable with their country's national PMTCT, HIV Counseling and Testing, and Pediatric HIV Care and Treatment Guidelines in advance of the implementation workshop. Trainers should adapt the key information as needed for their particular setting and on the baseline knowledge of participants. Some of the Modules also have Appendices, which contain additional information that will be useful for trainers and participants.

Training Slides: A set of training slides is also included as part of the workshop curriculum. Notes to trainers on which slides to use and when are included in the Trainer's Instructions boxes at the start of each Session. Trainers should review and adapt these slides in advance of the workshop. The slides are meant to reinforce key topics and give guidance to participants on some of the training activities. They should be used as a complement to the participatory methodologies suggested in the workshop curriculum, and not as a stand-alone material.

The Participant's Manual: The Participant's Manual is part of the Toolkit. It contains a simplified version of the Key Information in the Trainer's Manual, as well as relevant Appendices and tools. Trainers should encourage participants to refer to this Manual during the training and to take their own notes as needed. The Participant's Manual also serves as a useful reference for participants after the training and can be used in follow-up mentoring sessions with health workers. The Participant's Manual should be given to each participant, along with other contents of the Toolkit (which contains the counseling cue cards, forms and guides, etc.) as part of an overall package of materials.

Evaluating the Training

A training evaluation form is included at the end of Module 5. Trainers should set aside time to review feedback from participants and make adjustments for subsequent implementation workshops and note where there are key areas for ongoing mentoring and follow-up.

Some Useful Tips for Trainers

How to be an Effective Training Facilitator

Trainers should always keep the following "dos and don'ts" in mind.

DOs:

- Maintain good eye contact
- Prepare in advance
- Involve participants and ask open-ended questions
- Use visual aids
- Speak clearly/ask if clarifications are needed
- Speak loud enough for all participants to hear you
- Encourage questions
- Recap at the end of each Session
- Connect one topic to the next and consecutive Modules with each other
- Encourage everyone to actively participate by asking questions, engaging quiet participants, and affirming contributions
- Discourage domination by one or a handful of participants
- Write clearly and boldly
- Summarize after each Session and Module
- Use logical sequencing of topics
- Use good time management
- K.I.S. (Keep It Simple)
- Give feedback
- Position visuals so everyone can see them
- Avoid distracting mannerisms and distractions in the room
- Be aware of the participants' body language
- Be aware of the participants' energy levels and use energizers as needed
- Keep the group focused on the task
- Provide clear instructions
- Check to see if your instructions are understood
- Evaluate as you go
- Be patient

DON'Ts:

- Talk to the flip chart or the slides
- Block the visual aids
- Stand in one spot—instead, move around the room
- Ignore the participants' comments and feedback (verbal and non-verbal)
- Read from the curriculum or the slides
- Shout at the participants
- Assume everyone has the same level of baseline knowledge
- Assume everyone can read and write at the same level
- Answer your mobile phone during the training

A Note on Confidentiality

The success of this training depends on the active participation and engagement of each participant. Participants should be encouraged and be made to feel "safe" to share their own personal experiences. Trainers should remind participants that what is said in the training sessions is confidential (and they should respect this rule themselves), and that no one will be judged or stigmatized for their comments or questions.

Note: The Dos and Don'ts of training were taken from: Colton, T., Dillow, A., Hainsworth, G., Israel, E. & Kane, M. *Community Home-based Care for People and Communities Affected by HIV/AIDS: A Comprehensive Training Course for Community Health Workers.* Watertown, MA: Pathfinder International, 2006.

MODULE 1:
Introduction and PMTCT Update

DURATION: 90 MINUTES (1 hour, 30 minutes)

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Know more about workshop participants and trainers
- Understand the workshop goal, objectives, and agenda
- Discuss changes and updates to the national PMTCT guidelines

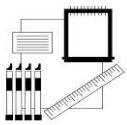
CONTENT:

Session 1.1: Introductions and Overview of the Workshop

Session 1.2: PMTCT Update

METHODOLOGIES:

- **Interactive trainer presentation**
- **Large group discussion**



MATERIALS NEEDED:

- **Nametags**
- **Markers**
- **Tape or Bostik**
- **Slide set for Module 1**
- **Projector/LCD and screen (or white wall)**
- **Toolkit, including Participant's Manual (for each participant)**

WORK FOR THE TRAINER TO DO IN ADVANCE:

- **Set up the training room and gather required materials.**
- **Read through the entire Module and Module 1 slide set and make sure you are familiar with the training methodologies and content.**
- **Plan and update the workshop agenda.**
- **Adapt the PMTCT update information (in Trainer's and Participant's Manuals and slide set) to your national guidelines.**

SESSION 1.1:
Introductions and Overview of the Workshop (40 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion

STEP 1: Welcome all participants to the implementation workshop. Have participants sign in on a registration sheet and make themselves a nametag.

STEP 2: Tell participants that over the course of this 15-hour (less if Module 6 is not included) workshop, they will work as a team to learn more about how to improve retention, adherence, and psychosocial support services within PMTCT, and also learn how to use specific support materials.

STEP 3: Review the Module 1 learning objectives **(Slides 1-1 to 1-2).** Explain that first we will do a quick activity to get to know one another better. Have each participant and trainer state their name, position, and how long they have been working at the clinic (or organization). Then, choose one of the introductory activities below, or use another one that you like.

STEP 4: Discuss why we are doing a workshop on retention, adherence, and psychosocial support in PMTCT services. Review the workshop learning objectives **(Slides 1-3 to 1-4).**

STEP 5: Go over the workshop agenda **(Slide 1-5),** and make sure to mention logistics, such as breaks, start and end times, etc. Remind participants that their attendance and participation throughout the workshop is important to make it a success.

STEP 6: After reviewing the objectives and agenda, ask participants to quickly brainstorm some of their expectations for this workshop by asking:

- *What do you hope to take away from this workshop?*

STEP 7: Introduce the Toolkit, which contains the Participant's Manual as well as tools (cue cards, forms, guides, etc.) and make sure each person has a copy. Explain that the Manual contains the key points for each Module, as well as room for note-taking. The entire Toolkit, including the Participant's Manual should be used as a reference after the training.

STEP 8: Allow participants time to ask questions about the objectives, agenda, logistics, or other concerns.

KEY INFORMATION:

Introductory Activities:

Ask participants to state their name, position, and how long they have been working at the clinic. Then, choose one or more of the below activities:

- Ask participants to state 2 true things about themselves and 1 lie (not necessarily in this order). Encourage participants to be creative and share things that co-workers may not know about them. The other participants should then guess which statement is the lie.

- Ask participants to choose 2 items that they have with them (such as in their bag) or that they are wearing that mean something special to them, and to briefly explain why.

- Ask participants to say 3 things that motivate them—either at home, in the community, or at work.

Implementation Workshop Goal and Objectives

Workshop Goal: This on-site implementation workshop for multidisciplinary team members working in PMTCT settings is intended to improve knowledge, skills, and confidence in improving retention and providing adherence and psychosocial support services throughout the PMTCT spectrum of care.

Workshop Objectives:

By the end of the implementation workshop, participants will be able to:

1. Understand changes to the national PMTCT guidelines and how they should be applied in clinical settings.
2. Define the PMTCT spectrum of care.
3. Define retention, adherence, and psychosocial support in the context of the PMTCT spectrum of care.
4. Understand the importance of retention, adherence, and psychosocial support to meet the needs of women and families enrolled in PMTCT services.
5. Identify strategies to improve retention, adherence, and psychosocial support within PMTCT programs.
6. Use counseling cue cards to conduct ongoing, supportive counseling for pregnant and postpartum women and their family members.
7. Use checklists to improve pre- and post-test counseling services for pregnant women, family members, and children.
8. Conduct a psychosocial assessment and document key points and next steps, as well as make necessary referrals.
9. Use guides to conduct adherence preparation and support sessions with clients and to provide ongoing adherence assessment and follow-up with clients.
10. Develop and use an appointment book and appointment reminder cards in PMTCT settings.

11. Use a patient education video to reinforce key messages on PMTCT with clients and family members.
12. Use improved communication and counseling skills with clients and family members (specific to Supplemental Module 6).

Suggested Implementation Workshop Agenda (adapt as needed):

DAY	SUGGESTED TIME	SUGGESTED ACTIVITY
DAY 1	**12:30-13:00**	LUNCH and WORKSHOP OPENING
	13:00-14:30	Module 1: Introduction and PMTCT Update
	14:30-17:10	Module 2: Retention, Adherence, and Psychosocial Support in PMTCT Programs
DAY 2	**12:30-13:00**	LUNCH
	13:00-15:30	Module 3: Using the PMTCT Counseling Cue Cards
	15:30-17:00	Module 4: Using the PMTCT Checklists, Guides, Forms, and Video
DAY 3	**12:30-13:00**	LUNCH
	13:00-14:15	Module 4: Using the PMTCT Checklists, Guides, Forms, and Video (continued)
	14:15-16:45	Module 5: Monitoring Adherence to PMTCT and Planning the Way Forward
	16:45-17:00	WORKSHOP CLOSING
DAY 4 (OPTIONAL)	**12:30-13:00**	LUNCH
	13:00-16:30	Supplemental Module 6 (optional): Review of Counseling and Communication Skills

SESSION 1.2:
PMTCT Update (50 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion

STEP 1: Introduce the Session by reminding participants that the WHO has made some changes to the recommendations on PMTCT, infant feeding, and pediatric treatment. Based on these recommendations, many countries have also updated their national PMTCT and pediatric care and treatment guidelines.

STEP 2: Present the slides on the new WHO recommendations and country specific adaptations and updates to the PMTCT guidelines using the content below as well as the slide set and accompanying notes **(Slides 1-6 to 1-30).** Allow time for questions.

STEP 3: Facilitate a large group discussion, asking participants:

- *What changes have been made or need to be made at your clinic in order to implement these new guidelines?*
- *What successes have there been implementing the new guidelines? Challenges?*

STEP 4: Conclude the Module by answering any questions and emphasizing the following points **(Slide 1-31):**

- PMTCT does NOT end at delivery! The new guidelines emphasize the entire spectrum of PMTCT care, from pregnancy through the postpartum period, until weaning and knowing the final infection status of the infant.
- A higher CD4 cutoff (<350 cells/mm^3) for ART initiation means that we will have MORE pregnant women who need to initiate ART and who will need ongoing adherence and psychosocial support.
- Earlier initiation of AZT/ART prophylaxis for pregnant women not eligible for treatment means that they will need to be on prophylaxis for approximately 6 months of their pregnancy. They will need ongoing retention, adherence, and psychosocial support.
- The changes to the guidelines also have implications for human and financial resources, drug forecasting, and the organization of services. These implications should be discussed by the entire multidisciplinary team, including lay counselors and peer educators.
- In the postpartum period, the mother and/or baby (if mother is not on treatment) will need prophylaxis for an extended period. This is a challenging period and mothers and babies need ongoing support to ensure that medications are taken the right way, every day, and that they remain engaged in PMTCT care.
- The period of infant feeding, particularly weaning, can be complicated, and mothers need strong support to provide the best nutrition possible to keep their babies healthy and reduce the risks of transmission and malnutrition.
- Caregivers of PCR positive infants need ongoing adherence and psychosocial support, including support to immediately enroll their children in care and immediately initiate ART.

KEY INFORMATION:

Please see the Slide Set for Module 1.

MODULE 2:
Retention, Adherence, and Psychosocial Support in PMTCT Programs

DURATION: 160 MINUTES (2 hours, 40 minutes)

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

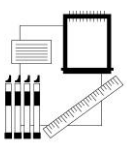
- Define the terms "retention," "adherence," and "psychosocial support"
- Understand the importance of retention, adherence, and psychosocial support in PMTCT programs
- Identify common barriers to retention, adherence, and psychosocial wellbeing among PMTCT clients, including those related to health services
- Identify challenges to providing quality retention, adherence, and psychosocial support services in the PMTCT setting
- Identify strategies to improve retention, adherence, and psychosocial support within the PMTCT program and throughout the PMTCT spectrum of care

CONTENT:

Session 2.1: Retention, Adherence, and Psychosocial Support Basics
Session 2.3: Improving Retention, Adherence, and Psychosocial Support in PMTCT Programs
Session 2.3: Case Studies
Session 2.4: Module Summary

METHODOLOGIES:

- **Interactive trainer presentation**
- **Brainstorming**
- **Large group discussion**
- **Small group work**
- **Cardstorming**
- **Case studies**



MATERIALS NEEDED:

- **Flip chart and stand**
- **Markers**
- **Tape or Bostik**

- **Slide set for Module 2**
- **Projector/LCD and screen (or white wall)**
- **Toolkit, including Participant's Manual**
- **Small sheets of paper or index cards for Session 2.2**

WORK FOR THE TRAINER TO DO IN ADVANCE:

- **Set up the training room and gather required materials.**
- **Read through the entire Module and Module 2 slide set and make sure you are familiar with the training methodologies and content.**
- **Review and adapt the case studies in Session 2.3, as needed.**

SESSION 2.1:
Retention, Adherence, and Psychosocial Support Basics
(40 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion, Small Group Work

STEP 1: Review the Module learning objectives **(Slides 2-1 to 2-2)** and ask if there are any questions.

STEP 2: Ask participants **(Slide 2-3)**:

- *What do we mean by retention?*
- *What do we mean by adherence?*

Allow the group about 5 minutes to brainstorm. Record responses on flip chart.

STEP 3: Present the definitions of retention and adherence and the key concepts about adherence, especially in the context of PMTCT services, using the content below **(Slides 2-4 to 2-5).**

STEP 4: Write "ADHERENCE TO PMTCT and HIV CARE" on one piece of flip chart and "ADHERENCE TO MEDICATIONS" on another. Ask participants to list what we mean by each of these phrases. Record participants' answers on flip chart and fill in using the information below **(Slides 2-6 to 2-7).**

STEP 5: Write "NON-ADHERENCE" on a piece of flip chart and ask participants to discuss what this phrase means. Record participants' responses on the flip chart and fill in using the content below **(Slide 2-8).** Review why adherence is important and what can happen when a client does not adhere to care and medicines **(Slides 2-9 to 2-10).**

STEP 6: Next, ask participants **(Slide 2-11)**:

- *What do we mean by psychosocial support?*
- *Why is it important to providing psychosocial support services to pregnant and postpartum women, including those living with HIV?*

Allow the group about 5 minutes to brainstorm. Record responses on flip chart.

STEP 7: Present the definition of psychosocial support, building on participant responses and using the content below **(Slides 2-12 to 2-13).** Next, discuss why it is important to provide psychosocial support services to pregnant and postpartum women, drawing first on the input of participants and then filling in using the content below**.**

STEP 8: Ask participants to discuss how psychosocial support services are delivered to PMTCT clients (e.g. is it included as a routine part of care or only provided for clients with identified psychosocial issues?). Then, ask participants to discuss specific times when they have provided psychosocial support services to clients in the PMTCT program, including times they have referred clients for other clinical or community services. Record key points on flip chart.

STEP 9: Ask participants to turn to the person seated next to them and spend a few minutes discussing these questions in pairs **(Slide 2-14):**

- *What is the relationship among retention, adherence, and psychosocial support?*
- *Why is it important to offer ongoing retention, adherence, and psychosocial support services to PMTCT clients?*
- *What are the biggest challenges to offering these types of support to PMTCT clients?*
- *How is the referral system working now? What challenges exist with referrals for ongoing adherence and psychosocial support?*

After a few minutes, reconvene the large group and ask participants to share some of their ideas. Fill in using the content below.

STEP 10: Close the session by reminding participants that retention, adherence, and psychosocial support services should be ongoing – not one-time events – and that the entire multidisciplinary team, not just counselors or peer educators, is responsible for providing these services **(Slide 2-15).**

KEY INFORMATION:

Definition of retention:

Retention refers to keeping (or "retaining") clients in the care program, in this case throughout the spectrum of PMTCT care and services. A goal of all PMTCT programs is to retain women and their babies in the full program of care.

- For women who test positive for HIV, this means that they stay in care during pregnancy and throughout the period of breastfeeding. They are also enrolled in HIV care and treatment, with some women starting lifelong ART and others being monitored for eligibility.
- For HIV-exposed babies, this means staying in care until a final HIV infection status is determined, usually once breastfeeding has ended. For babies who become HIV-infected, this also means enrolling in HIV care services and starting ART as quickly as possible.

Definition of adherence:

The standard clinical definition of adherence has been taking at least 95% of medications the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, such as following a care plan, attending scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.

Adherence describes how faithfully a person sticks to and participates in her or his HIV prevention, care, and treatment plan.

Adherence support is an important part of psychosocial support services and PMTCT and HIV clinical care services.

Key concepts of adherence:

Adherence:

- Is not the same as compliance and includes much more than following the doctor's orders
- Includes active participation of the client in her care plan

- Depends on a shared decision-making process between the client and health care providers
- Includes adherence to both care and to medicines
- Impacts the success of PMTCT and HIV care and treatment programs
- Changes over time

Adherence to PMTCT and HIV care includes:

- Entering into and continuing on a care and treatment plan (sometimes this is also called "retention in care")
- Taking medicines to prevent and treat opportunistic infections
- Planning for/having a safe delivery in a health facility
- Practicing safer infant feeding practices
- Bringing the baby back often for checkups and for HIV testing at 6 weeks and then again when the baby is weaned.
- Participating in ongoing education and counseling
- Attending appointments and tests (such as antenatal and postnatal appointments and regular CD4 tests) as scheduled
- Picking up medications for self and the child when scheduled, before running out
- Adopting a healthy lifestyle and understanding and minimizing risk behaviors, as much as is possible
- Recognizing when there is a problem or a change in health and coming to the clinic for care and support

Remember: ALL PREGNANT WOMEN LIVING WITH HIV NEED TO TAKE ARVs, THE RIGHT WAY, EVERY DOSE, EVERY DAY!

Adherence to HIV treatment includes:

- Taking ARVs correctly, as prescribed, even if the person feels healthy
- For women who are eligible for ART, taking ARVs as prescribed for their entire life—every pill, every day, for life
- Taking other medicines, such as cotrimoxazole, as prescribed
- Giving medications, including ARVs and cotrimoxazole, to HIV-exposed and HIV-infected babies and children as prescribed
- Not taking any breaks from treatment

Non-adherence to care and treatment includes:

- Missing one or many appointments at the hospital or health center, lab, or pharmacy – for the client or her baby
- Not following the care plan—of the client or her baby—and not communicating difficulties in following the care plan to health workers
- Missing one or more doses of medicine, or not giving the baby doses on time
- Sharing medicines with other people
- Stopping medicine for a day or many days (taking a treatment "break")
- Taking or giving medicines at different times than recommended by health workers
- Taking or giving medicines without following instructions about food or diet

- Not minimizing risk-taking behavior (for example, not practicing safer sex or not delivering a baby with a trained health care provider). Note that reducing risk-taking often depends on multiple factors and support from others (partner, family), so the ability to do so will depend on the client's specific situation.

Remember: NO ONE IS PERFECT. It is important not to judge clients if they are non-adherent. Instead, we should try to uncover the underlying causes of non-adherence and help find ways to resume good adherence as soon as possible.

Why is near-perfect adherence to PMTCT and ART medications important?

- To reduce the chance of MTCT at all stages (e.g. during pregnancy, during labor and delivery, during breastfeeding)
- To ensure that ART and other medications do their job and keep clients healthy
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid the body becoming resistant to certain medicines
- To make sure the person gets all the benefits that ARVs and other medicines have to offer, such as feeling better, not getting opportunistic infections, etc.
- To monitor the person's health and also to help her find community support resources for herself and her family
- To keep the person looking and feeling good so that she can get back to normal life
- To keep families, communities, and our nation healthy and productive

What happens when a person doesn't adhere to his or her care and treatment plan?

- The levels of drugs in the body drop and HIV keeps multiplying.
- A baby is more likely to acquire HIV from his or her mother during pregnancy, delivery, or breastfeeding.
- The CD4 count will drop and the person will start getting more opportunistic infections.
- Children in particular will become ill very quickly.
- It is more likely that the person will pass HIV to others (during unprotected sex, for example).
- The person might become depressed or de-motivated due to illness or physical deterioration.
- The person can develop resistance to one or all of the drugs, meaning that the drugs will not work anymore even if they are taken correctly again. We can say that HIV is a very "smart" virus—it only takes a couple of missed doses for it to learn how to be stronger than the ARVs, to multiply, and to take over the body again.
- The person may have to start taking a new regimen or second-line ARVs. In many countries, there aren't many kinds of ARVs available, so individuals with poor adherence may run out of medication options.

Definition of psychosocial support:

Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV (PLHIV), their partners, their family, and caregivers of children living with HIV. In the context of PMTCT services, psychosocial support addresses the psychological, social, and adherence needs of pregnant and postpartum women, their partners and families, and children throughout the spectrum of PMTCT care.

Remember: Since pregnancy is a relatively short period of time, it is very important to assess and support pregnant women's psychosocial needs as soon as they are enrolled in ANC and PMTCT services.

It is important to provide psychosocial support to pregnant women and family members because:

- HIV affects all dimensions of a person's life: physical, psychological, social, and spiritual.
- A woman who has just learned her HIV-status during prenatal HIV testing may need support in understanding and adjusting to this information, as well as planning what is going to happen next.
- It can help clients and caregivers cope more effectively with HIV and enhance their own and their children's quality of life.
- It can help facilitate the disclosure process.
- It can create opportunities to provide pregnant women and their families with needed information, specific to their situation.
- It can help clients gain confidence in themselves and their skills (coping with chronic illness, dealing with stigma or discrimination, adhering to the care and treatment plan, dealing with taking/giving medications every day, caring for an HIV-exposed or HIV-infected child, etc.).
- It can help build a trusting relationship between the client and the health worker.
- It can sometimes prevent more serious mental health issues from developing (like anxiety, depression, or withdrawal).
- Psychosocial wellbeing is related to better adherence to PMTCT and HIV care and treatment.
- Mental health is closely linked to physical health and wellbeing.
- It can provide people (or link people) with needed social, housing, and legal services.
- It can help people mentally and practically prepare for difficult circumstances, like ill health, having an HIV-infected baby, etc.
- When people can come together to solve problems and support one another, movements for change, acceptance, and advocacy are born.

Retention, adherence, and psychosocial support are interrelated. A client is more likely to be retained in PMTCT care and adhere to her own and her baby's care and treatment if she receives ongoing information, education, and support at the clinic, in the community, and at home.

SESSION 2.2:
Improving Retention, Adherence, and Psychosocial Support in PMTCT Programs (60 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Cardstorming, Large Group Discussion, Small Group Work

STEP 1: Introduce the Session by reminding participants that retention, adherence, and psychosocial support are multi-dimensional because every person is different, every person's health/life/family situation is different, and people's needs change over time. This is why retention, adherence, and psychosocial support services must be ongoing—and not one-time events—in PMTCT settings.

STEP 2: Pass out 5 small slips of paper or index cards to each participant. Ask participants to "cardstorm" and respond to the following question, writing a single response on each blank card **(Slide 2-16):**

- *Why don't clients stay in care and adhere to PMTCT care and medicines?*

While participants are cardstorming, post 4 pieces of flip chart, each with one of the following labels, around the training room ("HEALTH SERVICES FACTORS," "INDIVIDUAL FACTORS," "COMMUNITY AND CULTURAL FACTORS," "MEDICINE FACTORS").

STEP 3: After about 10 minutes, ask each participant to place their cards under one of the appropriate flip charts pasted around the training room. Facilitate an interactive discussion on the key factors affecting retention, adherence, and psychosocial wellbeing for pregnant and postpartum women, using participant inputs and filling in, as needed, from the content below. Remind participants that most clients do want to adhere to their PMTCT care plan, but there are often barriers that get in the way **(Slide 2-17)**.

STEP 4: Debrief by emphasizing that, while we, as health workers, are not always able to address all of the barriers, there are many factors that we CAN address in order to support clients' retention, adherence, and psychosocial needs. We can start by minimizing health service barriers, which includes improving the quality of counseling for clients **(Slide 2-17)**.

Ask participants to review the cards on the "HEALTH SERVICES FACTORS" flip chart. For each item listed, ask participants to discuss the following question (this can be done in a large group, or in small groups if time allows):

- *How can we address this health services challenge and improve the quality of services for our clients?*

For example, if one of the factors listed is lack of time for adherence counseling, participants can discuss why this is a challenge at their facility and what they can specifically do to allow more time for counseling of PMTCT clients (e.g. using job aides to standardize counseling messages, providing more supervision and mentoring to lay counselors, task shifting, conducting group sessions, spacing client appointments throughout the day, etc.). If one of the factors is long waiting times at the clinic, participants can discuss why this is a challenge and what they can do to decrease wait times and improve client flow.

STEP 5: As a way to remind participants of all of the points where retention, adherence, and psychosocial support can be offered, present the PMTCT spectrums of care **(Slides 2-18 to 2-19).**

STEP 6: Break participants into 4 small groups. Assign each small group one of the following stages: antenatal; labor and delivery; 1-8 weeks postpartum; 2-18 months postpartum. Ask each small group to discuss the following questions for their assigned stage and to record on flip chart **(Slide 2-20):**

- *What retention, adherence, and psychosocial support services do we **currently** offer to clients at this stage of PMTCT care? Who is responsible for offering these services?*
- *What are the **challenges** to offering quality retention, adherence, and psychosocial support services at this stage?*
- *What can we do better at this step in the **future** to improve retention, adherence, and psychosocial support services?*
- *What **tools** could help improve retention, adherence, and psychosocial support at this stage?*

After about 30 minutes, ask each of the small groups to present highlights of their discussions, focusing specifically on what can be done to support clients' retention, adherence, and psychosocial wellbeing and how to overcome specific challenges.

KEY INFORMATION:

Why don't clients stay in care and adhere to care and treatment?

- Most clients want to adhere to their own and their baby's care and treatment, but many times there are barriers that make this a challenge.
- Some of the barriers have to do with the client herself, her family situation, or characteristics of her community.
- Often, the health system itself creates challenges to retention, adherence, and psychosocial wellbeing.
- While the focus of this curriculum is not on these issues per se, they are extremely important and all health workers play a role in trying to make the system better as an individual and as part of a program.
- Retention, adherence, and psychosocial wellbeing can be improved when the client has clear information and practical guidance about her own and her baby's care and medications, as well as other aspects of PMTCT, such as safe infant feeding.
- It is important for health workers to have all of the information and present it to the client and her family using good counseling and communication skills and in ways that are easy to understand.

Factors affecting retention, adherence, and psychosocial wellbeing

Factors about health services (note that as health workers, these are the factors that we have the most control in addressing and minimizing):

- Health worker attitudes
- Health worker language abilities
- Time available for individual counseling
- Space available for individual counseling
- Skills of counselors and other service providers

- Multidisciplinary approach to supporting adherence and psychosocial wellbeing
- Availability of tools to support quality counseling
- Standard procedures to assess and counsel on adherence at every visit
- PLHIV involvement in service delivery
- Drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of health workers
- Youth-friendliness of services
- Waiting times
- Linkages between different services
- Referral systems
- Linkages to community services and support
- Support groups

Factors about individual people:

- How well they think they can adhere
- Acceptance of HIV-status
- Ability to disclose
- Acceptance of HIV-status and level of support from family
- Having a treatment supporter
- Understanding the benefits of HIV care and treatment and PMTCT services
- Quality of life while on treatment
- How sick or well people feel
- Travel and migration
- Health status
- Mental illness, like depression
- Drug or alcohol abuse
- Concern for the family's wellbeing

Factors about our communities and our culture:

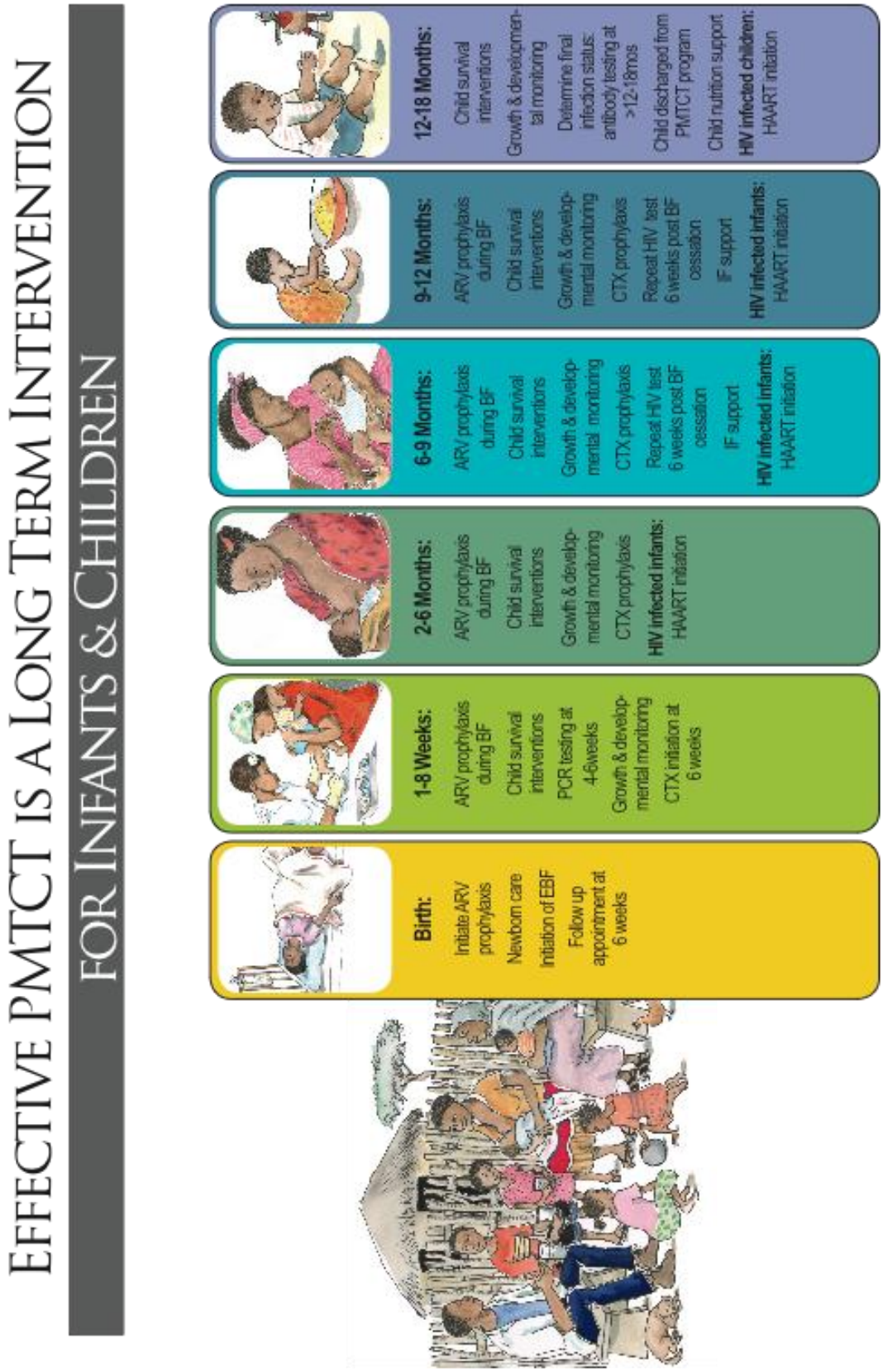
- Poverty
- Lack of food
- Stigma
- Social support at home and in the community
- Access to correct information
- Lack of childcare to attend clinic
- Ability to take time off work to attend clinic
- Family structure and decision-making
- Gender inequality
- Violence
- Forced migration
- Distrust of the clinic/hospital
- Use of traditional medicine
- Political instability or war
- Physical environment, e.g., mountainous, seasonal flooding, etc.

Factors about medicines:

- Side effects
- Number of pills in regimen
- Dose timing
- Need to take with food
- Availability of reminder cues—pill boxes, calendars, alarms, etc.
- Taste
- Changing pediatric doses
- Changes in drug supplier—changes in labeling, pill size, color, formulation
- Portability of medicines, especially syrups

THE PMTCT CARE SPECTRUM FOR WOMEN

THE PMTCT CARE SPECTRUM FOR CHILDREN



SESSION 2.3:
Case Studies (50 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Case Studies, Large Group Discussion

STEP 1: Introduce the Session by explaining that participants will now work through case studies related to retention, adherence, and psychosocial support in PMTCT. Encourage participants to draw upon their own experiences when discussing the case studies and to think about the role of different multidisciplinary team members in the case study. If time allows, participants can also develop their own case studies for discussion **(Slide 2-21)**.

STEP 2: Break participants into multidisciplinary groups of 3 and assign each one of the case studies below. The case studies are also included in the Participant Manual. Ask each group to assign a facilitator and a notetaker. Give the groups 20-30 minutes to discuss their case study, noting key points of the discussion on flip chart.

Reconvene the large group and ask members of each small group to present key points of their case study. Allow time for group discussion.

STEP 3: Summarize and close the session by reminding participants that retention, adherence, and psychosocial support are ongoing processes, throughout the spectrum of PMTCT care for mothers, babies, and families. Emphasize that retention, adherence, and psychosocial support are everyone's job and emphasize the importance of documenting these activities **(Slide 2-22).**

KEY INFORMATION:

Case Studies

Case Study 1:

P___ is 18 years old, pregnant, and tested positive for HIV during her first ANC visit. During your session with P___, she discloses that it will be difficult for her to take medicines because she can't disclose to anybody. She expresses her fears of her boyfriend throwing her out of the house and not supporting her, but she really wants to protect her unborn baby.

Questions:

- ***What are the most important issues for P___ right now?***
- ***What kind of psychosocial support do you think P___ needs?***
- ***What kind of adherence support does P___ need?***
- ***What would your plan be for the current session with P___? What would you discuss?***
- ***How would you document your session and the next steps you agree upon with P___?***

- ***What roles would different members of the multidisciplinary team take in P___'s care and counseling?***
- ***What tools would help you, the health worker, provide quality counseling and care to P___?***
- ***Would you provide any referrals for P___? If yes, describe. How would you document this and find out if she went where she was referred?***

Case Study 2:

N___ is married and has 4 children. She is 5 months pregnant and at her last ANC visit she was referred to the ART clinic because her CD4 count was 200. She missed her next ANC visit, but returns to the clinic a few weeks later. When you meet with her, N___ says that she went to the ART clinic, but left because there was a long queue and people were gossiping about her. She decided she does not want to take any ARV medications and is feeling fine.

Questions:

- ***What are the most important issues for N___ right now?***
- ***What kind of psychosocial support do you think N___ needs?***
- ***What kind of adherence support does N___ need?***
- ***What would your plan be for the current session with N___? What would you discuss?***
- ***How would you document your session and the next steps you agree upon with N___?***
- ***What roles would different members of the multidisciplinary team take in N___'s care and counseling?***
- ***What tools would help you, the health worker, provide quality counseling and care to N___?***
- ***Would you provide any referrals for N___? If yes, describe. How would you document this and find out if she went where she was referred?***

Case Study 3:

M___ delivered her baby, a girl, 9 weeks ago. M___ took ARVs during her pregnancy and delivered at a health facility. She missed her 6-week postpartum visit, but comes to the clinic a couple of weeks later for a well-child visit. The baby was given ARVs at birth, but M___ said she has not been able to give the baby medications at home because she doesn't want her family to be suspicious. Right now, neither the baby nor M___ is taking any medications. The baby doesn't seem to be gaining very much weight even though M___ says she breastfeeds often.

Questions:

- ***What are the most important issues for M___ right now?***
- ***What kind of psychosocial support do you think M___ needs?***
- ***What kind of adherence support does M___ need?***
- ***What would your plan be for the current session with M___? What would you discuss?***
- ***How would you document your session and the next steps you agree upon with M___?***
- ***What roles would different members of the multidisciplinary team take in M___'s care and counseling?***
- ***What tools would help you, the health worker, provide quality counseling and care to M___?***
- ***Would you provide any referrals for M___? If yes, describe. How would you document this and find out if she went where she was referred?***

SESSION 2.4:
Module Summary (10 minutes)

TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

STEP 1: Ask participants what they think the key points are of this Module. What information will they take away from the Module?

STEP 2: Summarize the key points of the Module using participant feedback and the content below **(Slides 2-23 to 2-24).** Review the Module learning objectives **(Slide 2-2)** with participants and make sure all are confident with their skills and knowledge in these areas.

STEP 3: Ask if there are any questions or clarifications **(Slide 2-25).**

STEP 4: Ask each participant to share with the group one thing he or she will do differently in his or her work, based on the information and skills learned in this Module.

KEY INFORMATION:

THE KEY POINTS OF THIS MODULE INCLUDE:

- Retention refers to keeping clients (and their babies) in the care program, throughout the spectrum of PMTCT care.
- Adherence means how faithfully a person sticks to, and participates in, her or his HIV care and treatment plan.
- Adherence to PMTCT and HIV care is important to make sure women and babies stay healthy, get the ongoing care they need, understand how to live positively, know when and how to start ARVs or ART, and get psychosocial support.
- Adherence to medications is important to lower the amount of HIV in the body, to lower the chances that the baby will acquire HIV, and to make sure women and babies get all the benefits that ARVs and other medicines have to offer for their own health.
- Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV, their family, and caregivers of children living with HIV.
- Retention, adherence, and psychosocial support are interrelated. A client is more likely to be retained in PMTCT care and adhere to her own and her baby's care and treatment if she receives ongoing information, education, and support at the clinic, in the community, and in her family.
- There are many barriers and challenges to retention, adherence, and psychosocial wellbeing, including things related to people's lives, to our culture, to the health care program, and to the medicines themselves.

(KEY POINTS, CONTINUED)

- Retention, adherence, and psychosocial support are important services in PMTCT programs and throughout the PMTCT spectrum of care—from the time before a woman gets pregnant, through her pregnancy and delivery, the postpartum period, weaning, and until there is a final infection status for the child.
- The entire multidisciplinary team is responsible for providing retention, adherence, and psychosocial support to pregnant and postpartum women.

MODULE 3:
Using the PMTCT Counseling Cue Cards

DURATION: 150 MINUTES (2 hours, 30 minutes)

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Understand why the PMTCT counseling cue cards were developed and how they can be used by health workers
- Discuss how the PMTCT counseling cue cards could be used in their clinic setting
- Be familiar with the key messages in each of the counseling cue cards
- Use the PMTCT counseling cue cards as an aide/guide when working with clients in various stages of the PMTCT care spectrum

CONTENT:

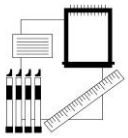
Session 3.1: Overview of the PMTCT Counseling Cue Cards

Session 3.2: Classroom Practicum on Using the PMTCT Counseling Cue Cards

Session 3.3: Module Summary

METHODOLOGIES:

- **Interactive trainer presentation**
- **Individual work**
- **Large group discussion**
- **Small group work**
- **Case studies**
- **Role play**



MATERIALS NEEDED:

- **Flip chart and stand**
- **Markers**
- **Tape or Bostik**
- **Slide set for Module 3**
- **Projector/LCD and screen (or white wall)**
- **Extra copies of the counseling cue cards for each participant**
- **Toolkit, including Participant's Manual and Counseling Cue Cards**

WORK FOR THE TRAINER TO DO IN ADVANCE:

- **Set up the training room and gather required materials.**
- **Read through the entire Module and Module 3 slide set and make sure you are familiar with the training methodologies and content.**
- **Review the set of counseling cue cards in the Toolkit and ensure you are comfortable with each topic area and all of the counseling messages.**
- **Make extra copies of the PMTCT Counseling Cue Cards for each participant.**

SESSION 3.1:
Overview of the PMTCT Counseling Cue Cards (30 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Individual Work, Large Group Discussion

STEP 1: Review the Module learning objectives **(Slides 3-1 to 3-2)** and ask if there are any questions. Explain that, in this Module, we will learn more about the specific counseling messages and the information to discuss in sessions with pregnant women living with HIV. Explain that we will also become more familiar with counseling cue cards—job aides that counselors can use as tools to guide their sessions.

STEP 2: Ask participants to turn to the PMTCT counseling cue cards, which are part of their Toolkit. Explain why the cue cards were developed and how they can be used in the clinic setting **(Slide 3-3).** Remind participants that quality communication and counseling in the PMTCT setting can improve client's retention, adherence, and psychosocial wellbeing.

Tell participants that the cue cards were developed to serve as a job aide and guide to health workers in PMTCT settings. Explain that there are 20 cue cards in total, and that each card focuses on a specific topic important to the care and support of PMTCT clients, their children, and family members, across the spectrum of PMTCT care. Health workers can use these cue cards, based on the individual client's situation and where she is in the PMTCT spectrum.

STEP 3: Review how the cue cards are set up **(Slide 3-4),** including that key questions to ask the client and notes to the health worker are included in italics. References to other, relevant cards are included in the margins.

STEP 4: Give participants about 10-15 minutes to look through the cue cards. Ask participants if there are any questions and, if needed, refer back to the PMTCT Update Session and clarify any questions on the national PMTCT guidelines and cue card content.

STEP 5: Lead a large group discussion, using the following questions as a guide and reminding participants that each facility should develop a plan on how the counseling cue cards will be used **(Slide 3-5):**

- *What are your impressions of the counseling cue cards?*
- *How do you think the counseling cue cards could be used in your clinic?*
- *Who could use the cue cards? When? In what situations?*
- *What next steps would you take to use the cue cards in your clinic?*

KEY INFORMATION:

How to Use the Counseling Cue Cards

The counseling cue cards were developed to support a range of providers who work with pregnant women living with HIV and their families.

Each of the cards focuses on a specific topic important to the care and support of pregnant women living with HIV, their children, and families across the PMTCT continuum of care. Providers may use the cue cards as job aides and reminders of key information to cover during initial post-test and ongoing counseling sessions with pregnant women and newly delivered mothers, their partners, family members, and supporters. The cue cards do not have to be used in sequence, but instead should be used according to the client's specific needs and concerns during the session.

Good counseling and communication skills, such as active listening, being attentive to the client's questions and needs, and avoiding one-way communication, should always be used, no matter what the counseling topic.

Counseling Cue Card Topics:

1. PMTCT Basics
2. Staying Healthy During Your Pregnancy
3. Adhering to Your PMTCT Care Plan
4. Preparing to Start and Adhere to Lifelong ART
5. Continuing and Adhering to ART During Pregnancy
6. Preparing to Start and Adhere to AZT Prophylaxis
7. Preparing to Start and Adhere to ART Prophylaxis
8. HIV Testing for Your Partner and Family Members
9. Disclosing Your HIV-Status
10. Being Part of a Discordant Couple
11. Having a Safe Labor and Delivery
12. Taking Care of Yourself After Your Baby is Born
13. Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines
14. Safely Feeding Your Baby
15. Exclusively Breastfeeding Your Baby
16. Exclusively Replacement Feeding Your Baby
17. Introducing Complementary Foods to Your Child at 6 Months
18. Making Decisions About Future Childbearing and Family Planning
19. Testing your Baby or Child for HIV
20. Caring for Your HIV-Infected Baby or Child and Adhering Care and Medicines

Please note:

- **Key questions** are included in *italics*, and may be used to initiate discussions, learn more about what the client already knows and her specific concerns, and to gauge understanding and elicit follow-up questions.
- **Notes to guide counselors** are also included in *italics*.
- The margins of each card contain **cross-references** to other cards on related topics (for example, if infant feeding is mentioned, there will be a cross-reference to the specific cue cards addressing infant feeding to which the provider may want to refer).

SESSION 3.2:
Classroom Practicum on Using the PMTCT Counseling Cue Cards (80 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Case Studies, Role Play

STEP 1: Introduce the Session by telling participants that they will now learn more about the key counseling messages for PMTCT clients at different stages in the PMTCT care spectrum, and that they will get practical experience using the counseling cue cards.

STEP 2: Break participants into small groups of 4. Refer to the case studies written below and in the Participant's Manual. Explain that each small group will go through at least 2 of the case studies (assign at least 2 case studies to each small group), with group members shifting roles so that each person has the chance to play the role of the "health worker."

STEP 3: Once participants are in their small groups and have been assigned case studies, give each group flip chart paper and markers. Ask each group to discuss the following questions for each of their 2 case studies **(Slide 3-6):**

- *What are some of the retention, adherence, and psychosocial issues and challenges you think this client is facing?*
- *What are the key issues and messages you would focus on with this client?*
- *Which of the cue cards do you think would be helpful to guide your session with this client?*

STEP 4: Next, ask the groups to assign one person to play the role of a "health worker," one the role of the "client," and two the role of "observer." Have the small groups role play each of their case studies, switching roles after about 10 minutes.

Encourage participants to use the counseling cue cards to help guide the session and their key messages when they are playing the role of the "health worker." The "observers" should use the extra copies of the counseling cue cards as a checklist to ensure that all key messages are covered.

Continue until all of the small groups have worked through both case studies, and each has had the chance to play the role of the "health worker."

STEP 5: Bring the large group back together. Ask each small group to role play one of their case studies in front of the large group. Go over the key points and considerations of each case study as a large group and be sure to answer any questions. Allow participants time to give feedback and debrief the activity using these questions **(Slide 3-7):**

- *What were the key issues for the client in this case study? Key retention and adherence issues? Key psychosocial issues? Other issues?*
- *What did the "health worker" do well in the session?*
- *What other points do you think the "health worker" could have discussed with the client?*

- *How did the "health worker" use the counseling cue cards during the role play? Which cue cards did he or she use?*
- *For the "health worker:" What were your experiences using the counseling cue cards? What was easy? Challenging?*

STEP 6: Debrief the activity by reminding participants that all health workers should be comfortable discussing key counseling messages and providing necessary information during sessions with PMTCT clients, caregivers, and family members. The counseling cue cards can serve as a useful reminder of these key messages.

KEY INFORMATION:

Case Studies:

Case Study 1:

N___ is 14 weeks pregnant and just came to the antenatal clinic for her first visit. You deliver the news that her HIV test was positive and provide post-test counseling. After talking with her, you sense that she does not have very much information on PMTCT. Counsel N___ on the key things she needs to know about PMTCT and having a healthy pregnancy.
(see PMTCT Basics, Staying Healthy During Your Pregnancy, HIV Testing for Your Partner and Family Members, and Adhering to Your PMTCT Care Plan cue cards)

Case Study 2:

J___ is enrolled in the PMTCT program and will begin prophylaxis now that she is 14 weeks pregnant (and her CD4 count is 500). Counsel her on adherence to her PMTCT care plan and her prophylaxis regimen. Also talk with her about planning to have a safe labor and delivery.
(see Adhering to Your PMTCT Care Plan, Preparing to Start and Adhere to AZT or ART Prophylaxis [depending on national guidelines], and Having a Safe Labor and Delivery cue cards)

Case Study 3:

L___ is enrolled in the PMTCT program. She began taking ART about one month ago, but complains that she is not feeling well and says that she wants to stop taking the medicine. Counsel L___ on having a healthy pregnancy, on why ART is important, and on how she can adhere to her care plan and ART.
(see Adhering to Your PMTCT Care Plan, Preparing to Start and Adhere to Lifelong ART, and Staying Healthy During Your Pregnancy cue cards)

Case Study 4:

T___ has been on ART for about 3 years and her CD4 count is high. You meet her at the ANC clinic, where she is enrolled in the PMTCT program. She is worried that the ART she has been taking will hurt her baby. Counsel T___ on adherence to her PMTCT care plan and ART, and also on how she can safely breastfeed her baby once he or she is born.
(see Adhering to Your PMTCT Care Plan, Continuing and Adhering to Your ART During Pregnancy, and Safely Feeding Your Baby – Breastfeeding cue cards)

Case Study 5:

A___ tests positive for HIV at her first antenatal visit. She is shocked and says she's only ever had sex with her husband. She has 2 other young children at home, but A___ says she has never thought about testing them for HIV since they are healthy. She is afraid to talk to her husband about her test result and says she will just keep it to herself. Counsel A___ on PMTCT basics, as well as on HIV testing for her husband and children, and disclosure to someone she trusts.
(see PMTCT Basics, HIV Testing for Your Partner and Family Members, and Disclosing Your HIV-Status cue cards)

Case Study 6:

M___ found out that she is HIV-infected 7 months ago, while she was pregnant. She just gave birth to a baby girl and doesn't think it's safe for her to breastfeed the baby. She is willing to do anything to make sure her daughter remains HIV-uninfected. However, she also has to return to work soon and has 2 other children to support. M___ has not told her boyfriend about her or the baby's HIV-status. Counsel M___ on taking care of herself, talking with her partner, and caring for her HIV-exposed daughter.
(see HIV Testing for Your Partner and Family Members, Disclosing Your HIV-Status, Taking Care of Yourself After Your Baby is Born; Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

Case Study 7:

B___ is a client in the PMTCT program. She gave birth to her son about 2 months ago. She missed the baby's 6-week follow-up appointment, but returns to the clinic 2 weeks later. B___ is breastfeeding her son, but complains that her nipples are very sore. B___'s family does not know she is HIV-infected and she is having trouble remembering to give her baby nevirapine. Counsel B___ on disclosure, adherence to care and medicines for her HIV-exposed baby, HIV testing for the baby, and also on safely feeding her baby.
(see Disclosing Your HIV-Status, Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

Case Study 8:

P___ returns for her 8-week old baby's HIV test results. The results show that the baby is HIV-uninfected. P___ is exclusively breastfeeding her baby and taking lifelong ART. P___ is very happy about the results and says she thinks she should stop breastfeeding immediately since her baby is negative. Counsel P___ on caring for her HIV-exposed baby, safe breastfeeding and when to retest the baby, and on being part of a discordant couple.
(see Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

Case Study 9:

C___ is a client in the PMTCT program and is taking lifelong ART. She recently delivered a healthy baby boy, who tested HIV-negative at 6 weeks. C___ comes back to the clinic for a checkup. She says she really wants to have another child in a couple of years, but that her husband does not think it's worth the risk of the baby being HIV-infected. C___'s husband is HIV-uninfected. Counsel C___ on how she can make safe decisions about having children in the future, how she can prevent or space pregnancies now, and about being part of a discordant couple.
(see Making Decisions About Future Childbearing and Family Planning and Being Part of a Discordant Couple cue cards)

Case Study 10:

V___ is the primary caregiver of her 8-month old nephew, who has been sick a lot and is not gaining weight. She is shocked to learn that the baby is HIV-infected and had no idea that her sister was HIV-infected. She feels frustrated because she already is caring for her own children and doesn't have much money or time to keep bringing her nephew to the clinic. Counsel V___ on caring for her HIV-infected nephew, including on adherence to care and medicines.
(see Caring for Your HIV-infected Child and Adhering to Care and Medicines cue card)

SESSION 3.3:
Module Summary (10 minutes)

TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

STEP 1: Ask participants what they think the key points are of this Module. What information will they take away from the Module?

STEP 2: Summarize the key points of the Module using participant feedback and the content below **(Slides 3-8 to 3-9).** Review the Module learning objectives **(Slide 3-2)** with participants and make sure all are confident with their skills and knowledge in these areas.

STEP 3: Ask if there are any questions or clarifications **(Slide 3-10).**

STEP 4: Ask each participant to share with the group one thing he or she will do to use the counseling cue cards at his or her clinic and in his or her work with PMTCT clients.

KEY INFORMATION:

THE KEY POINTS OF THIS MODULE INCLUDE:

- All health workers should be up-to-date and knowledgeable about their national PMTCT guidelines.
- Pregnant and postpartum women and caregivers of HIV-exposed and HIV-infected babies and children often have a number of retention, adherence, and psychosocial support needs that may change over time.
- Quality communication and counseling in the PMTCT setting can lead to increased retention, adherence, and psychosocial wellbeing among clients.
- Health workers can use counseling cue cards to help explain the basics of PMTCT care and remember key counseling messages for clients in different places along the PMTCT care spectrum.
- Each clinic should have a specific plan on how the counseling cue cards are used (who, when, where, how, etc.).
- Counseling is a part of everyone's job and all multidisciplinary team members should be familiar with and have copies of the counseling cue cards.
- When talking with clients, it is always important to use the 7 key counseling and communication skills (discussed in Supplemental Module 6).

MODULE 4:
Using the PMTCT Checklists, Guides, Forms, and Video

DURATION: 150 MINUTES (2 hours, 30 minutes)

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

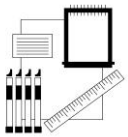
- Discuss the importance and relevance of each of the PMTCT Tools within the Toolkit
- Conduct pre-test and post-test education and counseling sessions with clients, using structured checklists
- Conduct a psychosocial assessment and fill in the psychosocial assessment reporting form
- Conduct and document adherence preparation and support counseling with clients, using a guide and reporting form
- Conduct and document adherence assessments and follow-up counseling with clients, using a guide and reporting form
- Discuss the importance of having an appointment system in PMTCT settings and how to use an appointment book and appointment reminder cards
- Describe how each PMTCT Tool might be applied in their specific clinic setting
- Discuss how to use the PMTCT video in their clinic and/or community settings

CONTENT:

Session 4.1: Overview of the PMTCT Checklists, Guides, and Forms
Session 4.2: Practical Session on Using the PMTCT Forms and Guides
Session 4.3: Orientation to the PMTCT Video
Session 4.4: Module Summary

METHODOLOGIES:

- **Interactive trainer presentation**
- **Large group discussion**
- **Individual work**
- **Small group work**
- **Case studies**
- **Role play**



MATERIALS NEEDED:

- **Flip chart and stand**
- **Markers**
- **Tape or Bostik**
- **Slide set for Module 4**
- **Projector/LCD and screen (or white wall)**
- **VCD player or computer to play video**
- **Extra copies of all of the PMTCT Tools in the Toolkit for each participant**
- **Toolkit, including Participant's Manual and All Sample Checklists Guides, and Forms, as well as the PMTCT Video**

WORK FOR THE TRAINER TO DO IN ADVANCE:

- **Set up the training room and gather required materials.**
- **Read through the entire Module and Module 4 slide set and make sure you are familiar with the training methodologies and content.**
- **Review all of the PMTCT Tools and the PMTCT Video in the Toolkit and ensure you are comfortable with each Tool and the content within.**
- **Make extra copies of all of the PMTCT Tools in the Toolkit so that each participant has at least one extra copy to take notes on and use during role plays.**
- **Test the video player to make sure it is working and that the video can be projected and heard clearly by participants.**
- **Make sure there are at least 2 extra chairs in the front of the room that can be used during role plays.**

SESSION 4.1:
Overview of the PMTCT Checklists, Guides, and Forms
(45 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Individual Work

STEP 1: Review the Module learning objectives **(Slides 4-1 to 4-3)** and ask if there are any questions. Explain that, in this Module, we will learn more about helpful tools (including checklists, guides, forms, etc.) that health workers can adapt and use to support their work with PMTCT clients.

STEP 2: Ask participants to turn to the PMTCT checklists, guides, and forms, which are part of their Toolkit. Explain that, here, there are 5 helpful tools for health workers to adapt and use **(Slide 4-4)**:

1. Counseling checklists for HIV testing in antenatal care settings
2. Psychosocial assessment guide and recording form
3. Adherence preparation and support guides
4. Adherence assessment and follow-up guides
5. Appointment book and appointment reminder card templates

STEP 3: For each of the 5 tools listed above, discuss the following and encourage participants to follow along in their Toolkit **(Slide 4-5):**

- *Why was the tool developed?*
- *How can the tool contribute to improved PMTCT services and improved adherence and psychosocial support for PMTCT clients?*
- *What are the major components of the tool?*
- *How do you think the tool could be used in your clinic?*

Give participants about 5 minutes to look through each tool on their own after it is discussed. Ask participants if there are any questions and, if needed, refer back to the PMTCT Update Session and clarify any questions on the national PMTCT guidelines or on the specific tools.

KEY INFORMATION:

Please see the "How to Use…" sections and individual tools in the Toolkit for more information.

There are 5 sets of forms and guides in the Toolkit:

- **PMTCT Pre- and Post- HIV Test Counseling Checklists** to be used by health workers when providing pre- and post- test counseling to PMTCT clients

Pre-test information and education sessions and individual post-test counseling should be conducted with clients.

- **A PMTCT Psychosocial Assessment Guide and Reporting Form** to be used by health workers when conducting initial and follow-up psychosocial assessments with PMTCT clients

It is recommended that a psychosocial assessment be conducted with all clients upon entry into the PMTCT program.

- **Adherence Preparation and Support Guides** to be used by health workers to help clients prepare to adhere to their own (and their baby's) care and treatment plans and when providing ongoing adherence support

Initiation of ARVs or ART among pregnant women should NOT be delayed for any reason. Basic adherence preparation should be conducted in 1 visit (if possible) and follow-up adherence counseling provided at each subsequent clinic visit.

- **Adherence Assessment and Follow-up Guides** to be used by health workers to assess adherence and learn more about adherence challenges the client may be facing, as well as to provide ongoing adherence support

Adherence should be assessed at each clinic visit and ongoing counseling and support provided throughout the PMTCT spectrum of care.

- **Appointment Book and Appointment Reminder Card Templates** to be adapted and implemented at the clinic level in order to help keep track of appointments and to help trace clients lost to follow-up, as well as to help clients keep track of upcoming appointments

Functional appointment systems are the cornerstone of retention and adherence to PMTCT care. All clinics should have an appointment system, including systematic follow-up of clients who miss appointments.

SESSION 4.2:
Practical Session on Using the PMTCT Forms and Guides (65 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Case Studies, Role Play

STEP 1: Introduce the Session by telling participants that they will now learn more about each of the 5 tools and have an opportunity to practice using them.

STEP 2: Break participants into 5 small, multidisciplinary groups. Assign a station in the room for each of the 5 tools, and then assign each small group to one of the 5 stations. Make sure there is flip chart paper and markers at each station, as well as extra copies of the Tools. Ideally, a trainer or other facilitator should be at each station. The 5 stations include **(Slide 4-6)**:

1. Counseling checklists for HIV testing in antenatal care settings
2. Psychosocial assessment guide and recording form
3. Adherence preparation and support guides
4. Adherence assessment and follow-up guides
5. Appointment book and appointment reminder card templates

Ask each small group to move to its assigned station.

STEP 3: At each of the 5 stations, the small groups should carefully review their assigned Tool from the Toolkit and discuss the following questions, taking notes on flip chart **(Slide 4-7):**

- *How can the tool improve retention, adherence, and/or psychosocial support for PMTCT clients?*
- *Who at your clinic could use the tool? When? In what situations?*
- *Where would the Tool/forms be stored?*
- *Are there challenges (now or anticipated) in using this tool? Are there solutions to these challenges?*
- *What next steps would you take to use the tool in your clinic?*

STEP 4: Next, small group members should take turns using their assigned Tool as part of the case studies written below and in the Participant's Manual. As time allows, each member of the small group should role play the role of the "health worker" and use the Tool, including filling in forms, as applicable.

STEP 5: If small groups complete their role plays, they can move as a group to another station and conduct the same activities with a new Tool.

STEP 6: After about 45 minutes have passed, bring the large group back together. Ask each small group to present a brief summary of their assigned tool, based on the discussion questions. As time allows, ask some of the small groups to perform a role play on using their Tool in front of the large group. Open up the discussion of each Tool to the large group.

STEP 7: Summarize by explaining to participants that Tools can help health workers provide clients with retention, adherence, and psychosocial support services; however, we should remember that it is important that the tools are used in combination with good counseling and within a supportive, welcoming, and client-friendly environment at the health facility. Remind participants that they will be supported and mentored on using the tools over time **(Slide 4-8)**.

KEY INFORMATION:

Case Studies for Each of the 5 Tools:

1. Counseling checklists for HIV testing in antenatal care settings

Part A:
You are leading a group pre-test information session for pregnant women at the clinic. What would you say in the session? Use the checklist as a guide.

Part B:
O___ is a pregnant woman coming for her first antenatal appointment. She received HIV testing and her results are negative. Provide O___ with post-test counseling. Use the checklist as a guide.

Part C:
F___ is a pregnant woman who decided to be tested for HIV at her second antenatal visit. Her test results are positive. Provide F___ with post-test counseling. Use the checklist as a guide.

2. Psychosocial assessment guide and recording form

Part A:
G___ is a newly enrolled PMTCT client. Conduct a psychosocial assessment with G___. Be sure to complete the psychosocial assessment recording form.

Part B:
W___ is a client in the PMTCT program. She delivered a baby girl 6 weeks ago and has returned to the clinic for the 6-week checkup. Conduct a psychosocial assessment with W___. Be sure to complete the psychosocial assessment recording form.

3. Adherence preparation and support guides

Part A:
F___ is 14 weeks pregnant and her CD4 count is 650, so she will be starting PMTCT prophylaxis. Counsel and prepare F___ on adherence to her care and the ARVs that she will be given today. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

Part B:
S___ is pregnant and just started taking lifelong ART 2 weeks ago. Counsel and prepare S___ on adherence to her care and ART. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

Part C:
P___ goes for her first visit at the antenatal clinic. She has been taking ART for the last 3 years and is excited to have a baby. Counsel her on adherence to ART during her pregnancy and for life. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

Part D:
X___ is the primary caregiver of her sister's 1-month old baby. The baby, named C___ is HIV-exposed. Counsel X___ on adherence to the baby's care and medicines. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

4. Adherence assessment and follow-up guides

Part A:
R___ returns for her monthly antenatal visit and ARV refill. Assess R___'s adherence and provide follow-up adherence counseling and support.

Part B:
H___ is caring for her 3-month old baby, who is HIV-exposed and breastfeeding. The baby's 6 week PCR test was negative. They return for a checkup and medication refill. Assess H___ and the baby's adherence and provide follow-up adherence counseling and support.

5. Appointment book and appointment reminder card templates

Part A:
B___ is a PMTCT client. She needs to make a follow-up appointment for an ARV refill and checkup. Make a follow-up appointment with B___ being sure to fill in the appointment book and to give her an appointment reminder card to take home.

Part B:
I___ is a PMTCT client that was scheduled to come in for a checkup and refill on Monday. It is now Friday and I___ has not come to the clinic. How would you complete the appointment book and what next steps would you take?

SESSION 4.3:
Orientation to the PMTCT Video (30 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion

STEP 1: Introduce the Session by explaining that a PMTCT video was created to reinforce key messages with PMTCT clients, family members, and caregivers of HIV-exposed and HIV-infected children. Remind participants that the video was created for use in many countries and settings, so while it may not completely reflect the situation in their clinic or setting, it still can be used to promote key PMTCT messages **(Slide 4-9)**.

STEP 2: Play the PMTCT video for participants.

STEP 3: After watching the video, lead a large group discussion using the following questions as a guide **(Slide 4-10):**

- *What are your impressions of the video?*
- *How do you think the video could help reinforce key PMTCT messages with clients?*
- *How do you think the video could be used in your clinic?*
- *Who could use the video? When? Where? In what situations?*
- *How could health workers (especially nurses, counselors, and peer educators) facilitate the video to help clients get the most out of it?*
- *What next steps would you take to distribute and use the video in your clinic?*
- *Do you think there are additional uses for the video in a community setting? If yes, explain.*

KEY INFORMATION:

How to Use the PMTCT Patient Education Video:

"Saving Two Lives: A Patient Education Video on Adherence to PMTCT" was created to reinforce key PMTCT messages with clients, their family members, caregivers, and community members. The video was filmed in Port Elizabeth, South Africa and most of the actors are actual nurses, peer educators, mother mentors, and community members from the area.

The video was developed as a generic product, so while it may not completely reflect the specifics of PMTCT care in all countries, it is still useful in promoting the key concepts of PMTCT, including retention, adherence, and the importance of psychosocial support. The video is in English, so careful facilitation is especially required in settings where viewers do not use English as a first language.

The video is divided into specific scenes. It may be played in its entirety, or by section, depending on the time available and the audience.

- In the first scene, the viewer is introduced to Hope, a young woman who lives with her husband and mother-in-law. Hope goes to the clinic for her first ANC visit (despite her mother-in-law's insistence that this is a waste of time), where she is tested for HIV, and learns that she is HIV-infected. The nurse at the clinic gives Hope information on the meaning of her test results and how she can prevent MTCT. Afterwards, Hope meets an experienced mother and PMTCT client, Janet, who gives her information and support on what she needs to do to prevent MTCT.
- In the second scene, Janet returns to the clinic with Hope one week after they met. Hope picks up her CD4 test results and prepares to start taking ARVs. The nurse and Janet give Hope practical advice on how she can lower the chances that her baby will be HIV-infected, including the importance of adherence to her PMTCT care plan and medicines.
- In the third scene, we see Hope and her newborn baby attend a mother's support group meeting in the community. Hope shares some of her experiences caring for her HIV-exposed baby and learns more from other support group members and the Peer Educator who is facilitating the meeting.
- Each scene is separated by "commercials" that reiterate key messages on PMTCT.

The video may be used in a number of settings, including:

- In the ANC waiting area, if there is a TV and DVD/VCD player
- As part of group education sessions with PMTCT clients
- As part of individual counseling and education sessions with PMTCT clients
- As part of training and mentoring activities for lay counselors, peer educators, mother mentors, etc.
- In support group meetings
- In the community, for example at community meetings, religious gatherings, workplaces, marketplaces, and other venues where people come together
- In women's and youth group activities
- In PLHIV association activities
- As part of a public service announcement (PSA) on television

The video will be most effective if a health worker (nurse, peer educator, counselor, etc.) facilitates the video with viewers.

- Once programs decide on how and where the video will be used, it is recommended that tailored facilitation guides, including prompts and questions, be developed and implemented.
- For example, if the video is used as part of a group education session with PMTCT clients, the facilitator could stop the video at regular intervals and ask clients what they think is happening, what they think the characters are feeling, and how the situation shown in the video relates to their own PMTCT care and medicines. Similar questions can be asked at the end of the video in cases where the entire video is shown at once.
- Facilitation and guided discussion will also allow for more in-depth discussion of PMTCT care and medicines, for example discussing which specific ARVs pregnant women and HIV-exposed children take and for how long, specific examples of adherence challenges and reminders, and ways to safely feed and care for HIV-exposed infants.
- As mentioned above, guided facilitation will also help viewers understand what is happening in the video, especially if they do not speak/understand English as a first language.

SESSION 4.4:
Module Summary (10 minutes)

TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

STEP 1: Ask participants what they think the key points are of this Module. What information will they take away from the Module?

STEP 2: Summarize the key points of the Module using participant feedback and the content below **(Slides 4-11 to 4-12).** Review the Module learning objectives **(Slides 4-2 to 4-3)** with participants and make sure all are confident with their skills and knowledge in these areas.

STEP 3: Ask if there are any questions or clarifications **(Slide 4-13).**

STEP 4: Ask each participant to share with the group one thing he or she will do to use one or more of the Tools discussed in this Module in his or her work.

KEY INFORMATION:

THE KEY POINTS OF THIS MODULE INCLUDE:

- All health workers should be up-to-date and knowledgeable about their national PMTCT guidelines.
- Pregnant and postpartum women and caregivers of HIV-exposed and HIV-infected babies and children often have a number of retention, adherence, and psychosocial support needs. Their needs will depend on their specific situation and may also change over time and as they move along the PMTCT spectrum of care.
- Pre-test information, educational sessions, and individual post-test counseling are key to delivering basic information on the importance of HIV testing, the meaning of test results, and PMTCT basics to all women. Health workers can use the *pre- and post-test counseling checklists* as a guide when working with clients.
- It is recommended that a psychosocial assessment be conducted with all women upon entry into the PMTCT program and when there are any major changes in a client's life situation. Health workers can use the *Psychosocial Assessment Guide and Reporting Form* to guide this process. It is important to note key issues on the form and to retain these in the client's file to allow for follow-up and continuation of counseling at return visits.

(KEY POINTS, CONTINUED)

- Initiation of ARVs or ART among pregnant women should NOT be delayed for any reason. Basic adherence preparation should be conducted in 1 session if possible and follow-up adherence counseling and support provided at each subsequent clinic visit. Health workers can use the *Adherence Preparation and Support Guides* as reminder of the key messages to cover and key questions to ask clients.
- Adherence should be assessed at each clinic visit and ongoing counseling and support provided throughout the PMTCT spectrum of care. Health workers can use the *Adherence Assessment and Follow-up Guides* to assist in this process.
- Remember, adherence will change over time and as clients move through the PMTCT spectrum of care so it is important to provide ongoing adherence assessment, counseling, and support at every visit.
- Functional appointment systems are the cornerstone of retention and adherence to PMTCT care. All clinics should institute an *appointment system*, including systematic follow-up of clients who miss appointments.
- The *PMTCT Video* may be used to reinforce key PMTCT messages with clients at the clinic or in the community.
- Each clinic should have a specific plan on how the Tools discussed in this Module are used (who, when, where, how, etc.).
- Remember, retention, adherence, and psychosocial support are a part of everyone's job and all multidisciplinary team members should be familiar with and have copies of the counseling cue cards.
- When talking with clients, it is always important to use the 7 key counseling and communication skills (discussed in Supplemental Module 6).

MODULE 5:
Monitoring Retention and Adherence to PMTCT and Planning the Way Forward

DURATION: 150 MINUTES (2 hours, 30 minutes)

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

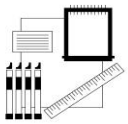
- Discuss the importance of documentation, record keeping, and routine monitoring and evaluation in PMTCT services
- Understand the differences between program- and client-level monitoring of retention and adherence
- Describe available data that could be used to monitor retention and adherence at a program level
- Describe available data that could be used to monitor retention and adherence at an individual client level
- Discuss which PMTCT materials will be prioritized for implementation at the clinic
- Develop a site-specific action plan to improve retention, adherence, and psychosocial support services, including roll out of the Toolkit materials
- Evaluate the implementation workshop

CONTENT:

Session 5.1: Monitoring and Evaluating Retention and Adherence to PMTCT
Session 5.2: Developing an Action Plan to Roll Out the PMTCT Materials
Session 5.3: Workshop Evaluation and Closure

METHODOLOGIES:

- **Interactive trainer presentation**
- **Large group discussion**
- **Individual evaluation**



MATERIALS NEEDED:

- **Flip chart and stand**
- **Markers**
- **Tape or Bostik**
- **Slide set for Module 5**
- **Projector/LCD and screen (or white wall)**
- **Extra copies of Appendix 5A and 5B for each participant**
- **Toolkit, including Participant's Manual**

WORK FOR THE TRAINER TO DO IN ADVANCE:

- **Set up the training room and gather required materials.**
- **Read through the entire Module and Module 5 slide set and make sure you are familiar with the training methodologies and content.**
- **Make extra copies of Appendix 5A and 5B for each participant.**
- **Invite additional facility or district-based mangers and supervisors for these Sessions, as is feasible and appropriate.**

SESSION 5.1:
Monitoring and Evaluating Retention and Adherence to PMTCT (45 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion

STEP 1: **NOTE:** If possible, invite facility- or district-level managers and supervisors to participate in discussions around monitoring, evaluation, and action planning. The activities can by modified if the workshop is being conducted at the district- instead of the facility-level. For example, district-level participants could discuss: the types of data that are collected at the district level; how these data are used and fed back to improve clinical services; how retention, adherence, and psychosocial support activities are documented and reported; and how this process can be improved at health facilities within the district.

Review the Module learning objectives **(Slides 5-1 to 5-2)** and introduce the Session by telling participants that we will spend some time talking about documentation, monitoring, and evaluation of retention and adherence in PMTCT. Ask participants **(Slide 5-3)**:

- *Why is monitoring retention and adherence important?*
- *What are the differences between program-level monitoring and individual client-level monitoring related to retention and adherence?*
- *What could routine monitoring tell us about the overall program's progress in terms of retention and adherence?*
- *What could routine monitoring tell us about an individual client's retention and adherence?*

Fill in the discussion using the content below **(Slides 5-4 to 5-6)**.

STEP 2: Lead a discussion on the different ways that we can monitor and evaluate retention and adherence to PMTCT and the quality of services that are provided to clients. Discuss the differences between individual patient-level monitoring of adherence and program- or clinic-level monitoring of retention, adherence, and psychosocial support.

Ask participants to start with what is feasible to measure with the current information available. Ask participants the following questions and record answers on flip chart **(Slide 5-7)**:

- *What type of program-level information do we currently have (e.g. in registers, pharmacy records, or the appointment system)? How can this be used to measure retention and adherence?*
- *What type of client-level information do we currently have on mothers and babies in the PMTCT program (e.g. in patient records)? How can this be used to measure retention and adherence?*
- *How could we improve monitoring and evaluation of adherence to PMTCT services and medicines in the future? At the program level? At the client level?*

STEP 3: Lead a large group discussion on client records using the following questions. Be sure to acknowledge that many programs do not maintain individual client files in antenatal care **(Slide 5-8).**

- *Why is it important to keep records on each client?*
- *How are client records kept in your clinic? If there are no client records kept at the clinic, why not? What are the challenges?*
- *Are client retention and adherence and psychosocial services recorded and kept on file for PMTCT clients at your clinic? Why or why not? What are the challenges?*
- *How could we improve record keeping and ensure that each client has a file at your clinic?*
- *How could we improve record keeping and ensure that data are used for service strengthening at your clinic?*

STEP 4: Close the Session by reminding participants that monitoring and evaluation of retention and adherence in PMTCT is important at both the program and individual client level, and that systems need to be in place to support both. This can help ensure that clients get the support that they need, that the work done by health workers is documented, and that program level data are used for service strengthening **(Slide 5-9)**.

KEY INFORMATION:

Monitoring and evaluation at the individual client and program levels:

Routine monitoring and evaluation are necessary to gather information on both individual outcomes (are clients being retained in care, are clients adhering to care, are clients adhering to medicines/treatment?) as well as PMTCT program outcomes (is the program retaining clients overall, are mothers and babies completing the spectrum of PMTCT care?). Program outcomes are usually the cumulative tally of individual outcomes and can give insight into strengths and areas needing improvement within the PMTCT program—at an individual facility or in a district, province, etc.

Systems need to be developed and strengthened to monitor BOTH individual clients' retention and adherence, as well as the program's ability to retain clients in care and support adherence and psychosocial wellbeing.

Why monitoring and evaluation are important at the *facility* or *program* level:

- To tell us if clients are being retained in care across the PMTCT spectrum
- To tell us how many and which types of PMTCT clients are receiving adherence support
- To show us the successes and gaps in our PMTCT retention, adherence, and psychosocial support services
- To give us a sense of the number of clients discontinuing PMTCT care and/or treatment or prophylaxis, and the trends in these numbers over time
- To help us understand what is working and what isn't working and to plan improvements in PMTCT retention, adherence, and psychosocial support activities to best meet the needs of clients

At the *individual* level, record keeping and monitoring of retention, adherence, and psychosocial support is useful:

- To tell us whether or not individual clients and their babies are retained in care
- To tell us whether or not individual clients are adhering to their own and their baby's PMTCT care plan and medications
- To help us follow adherence and psychosocial support issues of individual clients over time

Measuring retention and adherence support activities in PMTCT settings:

Retention and adherence are a reflection of the ultimate quality of the PMTCT services we provide. It is important to look at what can actually be measured using existing data instead of creating new, parallel systems. Sometimes data to measure these indicators can be obtained as routine data from client registers, but others may need to be measured through the reviewing of individual client files or through client interviews.

Depending on the information available, we may be able to measure the following:

- The #/% of PMTCT clients and babies who are retained in care at specific service delivery points (ANC, under-5 clinic, etc.) and across the entire spectrum of care
- The #/% of PMTCT clients who return on time for clinic appointments
- The #/% of PMTCT clients who return on time for pharmacy appointments/refills
- The #/% of HIV-exposed and HIV-infected babies who return on time for clinic appointments (including follow-up appointments, early infant diagnosis, etc.)
- The #/% of HIV-exposed and HIV-infected babies who come back for pharmacy appointments/refills
- The #/% of PMTCT clients who are followed up after a missed appointment, and of these, the #/% who return to care
- The #/% of PMTCT clients who receive adherence preparation counseling
- The #/% of PMTCT clients who receive adherence assessment and follow-up counseling on return visits
- The #/% of PMTCT clients who have "near perfect" adherence to medicines
- The #/% of PMTCT clients for whom a psychosocial assessment has been conducted and documented
- The #/% of PMTCT clients given referrals to community support services, and, if possible the #/% of these that were "successful" referrals

A note about patient files in ANC:

Many ANC clinics do not have individual patient files, so each program/site will have to develop their own way of documenting the monitoring and evaluation of PMTCT retention and adherence. Some options to consider are:

- Using existing records, registers, and appointment books to gather and summarize information about retention and adherence at the program level. Pharmacy records are also a good source of information on retention and adherence.
- Starting an adherence register in PMTCT where each client's adherence is noted at each visit.
- Opening an adherence and psychosocial support file for each client, where there is the possibility to do so.

SESSION 5.2:
Developing an Action Plan to Roll Out the PMTCT Materials (75 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Discussion, Large Group Discussion

STEP 1: Tell participants that we have learned a great deal about how we can improve retention, adherence, and psychosocial support activities for pregnant and postpartum women and their children over the past few days, as well as how we can apply updates to the PMTCT guidelines. A number of PMTCT Tools have also been introduced.

Explain that, in this Session, we will create a site-specific action plan to implement and improve retention, adherence, and psychosocial support activities over the coming 6 months (or, use a shorter time frame if preferred). **(Slide 5-10).**

NOTE: This action planning activity can by modified if the workshop is being conducted at the district instead of the facility level. For example, district-level participants could plan how they will improve retention, adherence, and psychosocial support activities within the PMTCT sites they support and plan/prioritize rollout of the various Tools at different types of sites.

STEP 2: Note that implementing/technical assistance partners and district and regional mentors and supervisors can use this action plan to guide their support to multidisciplinary PMTCT teams. The multidisciplinary team can also use the action plan to prioritize activities and measure progress.

STEP 3: Discuss with participants that, before we think about specific action planning, we need to ensure that we follow the national PMTCT guidelines, as well as certain standards, no matter what the prioritization of activities. Use the content below **(Slide 5-11)** to review these standards.

STEP 4: Explain that implementing the entire package at once would be difficult, so we need to prioritize as we develop the action plan. Ask **(Slide 5-12)**:

- *How would you prioritize rollout of the Tools at your site, given the current level of resources?*
- *What is your basis for this prioritization (e.g. monitoring data about certain aspects of the program or retention in care along the different phases of the PMTCT spectrum of care, etc.)?*
- *List the items in the Toolkit in order of priority for implementation at the site.*

STEP 5: Facilitate a large group discussion to complete the action plan **(Slide 5-13)**. Refer participants to Appendix 5A, which provides a template for the action plan. Distribute extra copies of the action plan template to each participant. One of the trainers should project the action plan on the screen and take notes as participants contribute items. Encourage participants to take notes as well.

For each action, type into the Action Planning Matrix:

- *The specific action*
- *Who is responsible*

- *What information or resources are needed*
- *When the action will happen*
- *How progress on the action will be measured*

NOTE: Participants should not feel pressure to list action items for each and every objective and Tool, and should only list actions that are realistic and achievable given staff's high workload and other challenges. Participants should be guided to focus on concrete actions that can be achieved in the timeframe.

STEP 6: After the group has gone through each of the objectives and Tools and made an action plan, ask participants to prioritize which of the actions can be realistically implemented in the next 2-3 months. Star these items in the action plan matrix **(Slide 5-14)**.

STEP 7: Summarize the priority actions for the next 2-3 months. Conclude the Session by thanking participants for their hard work to create an action plan. Remind participants that this plan will be typed and distributed to all participants in the coming days and that ongoing mentoring and assistance will be provided to complete these actions within the timeframe given.

NOTE: After the workshop, the trainers should provide printed copies to all participants and facility managers and supervisors within 1 week of the training. Site Action Plans should be revisited throughout the year (for example, during multidisciplinary team meetings) to determine the progress made and to make adjustments as needed.

KEY INFORMATION:

Implementing all of the Toolkit materials at the same time and at multiple sites is likely not feasible. The MDT (with support from hospital administrators and managers, if possible) at each site will need to prioritize activities and materials according to its capacity and needs.

When thinking about how to prioritize the activities, managers and health workers should keep 3 key standards in mind:

- All pregnant and postpartum women living with HIV need ongoing retention, adherence, and psychosocial support throughout the PMTCT care spectrum.
- All pregnant and postpartum women living with HIV need to have clear and correct information about their own and their baby's PMTCT care plan, as well as ongoing support for adherence to care and medicines.
- Every PMTCT site, to the best of its ability, should have systems in place to retain pregnant and postpartum women living with HIV and their infants in care.

SESSION 5.3:
Workshop Evaluation and Closure (30 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Individual Evaluation

STEP 1: Congratulate participants on a job well done throughout the workshop and thank them for their active participation.

Review the overall Workshop learning objectives **(Slides 5-15 to 5-16)**. After each objective, ask participants if they feel they have achieved it, and if not, what additional information or training is needed.

STEP 2: Go around the room and ask each participant to say **(Slide 5-17):**

- *One thing they have learned about retention, adherence, and psychosocial support for PMTCT clients during the workshop*
- *One thing that they will prioritize in their work to improve retention, adherence, and psychosocial support services for pregnant and postpartum women living with HIV and their families*

STEP 3: The trainers should give a brief summary of how they will assist the site to move their Action Plan forward in the coming weeks and months **(Slide 5-18)**.

STEP 4: Give each participant a copy of the Workshop Evaluation Form (Appendix 6B).

STEP 5: Ask that participants take 10 minutes to give their honest feedback about the workshop. Remind participants that they do not have to write their name on the evaluation form and that the trainers appreciate constructive feedback so that the workshop can be improved in the future.

STEP 6: Ask that participants put their evaluation forms face down in a pile in the front of the room when they are finished.

Thank participants again for their active participation in the workshop and dedication to improving services for women, children, and families **(Slide 5-19)**.

STEP 7: Give participants their workshop completion certificates and formally close the workshop.

KEY INFORMATION:

Reminder of Workshop Objectives:

By the end of the implementation workshop, participants will be able to:

1. Understand changes to the national PMTCT guidelines and how they should be applied in clinical settings.
2. Define the PMTCT spectrum of care.
3. Define retention, adherence, and psychosocial support in the context of the PMTCT spectrum of care.

4. Understand the importance of retention, adherence, and psychosocial support to meet the needs of women and families enrolled in PMTCT services.
5. Identify strategies to improve retention, adherence, and psychosocial support within PMTCT programs.
6. Use counseling cue cards to conduct ongoing, supportive counseling for pregnant and postpartum women and their family members.
7. Use checklists to improve pre- and post-test counseling services for pregnant women, family members, and children.
8. Conduct a psychosocial assessment and document key points and next steps, as well as make necessary referrals.
9. Use guides to conduct adherence preparation and support sessions with clients and to provide ongoing adherence assessment and follow-up with clients.
10. Develop and use an appointment book and appointment reminder cards in PMTCT settings.
11. Use a patient education video to reinforce key messages on PMTCT with clients and family members.
12. Use improved communication and counseling skills with clients and family members (specific to Supplemental Module 6).

Appendix 5A:

Action Plan for Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

Clinic Name: _____ PMTCT Point Person's Name/Title: _____ Date:_____

OBJECTIVE 1: *All pregnant and postpartum women living with HIV will receive ongoing retention, adherence, and psychosocial support throughout the PMTCT care spectrum.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

OBJECTIVE 2: *All pregnant and postpartum women living with HIV will have clear and correct information about their own and their baby's PMTCT care plan and ongoing support for adherence to care and medicines.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

OBJECTIVE 3: *Every PMTCT site will have systems in place to retain pregnant and postpartum women living with HIV and their infants in care.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

PMTCT Counseling Cue Cards

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Counseling Checklists for HIV Testing in Antenatal Care Settings

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Psychosocial Assessment Guide and Recording Form

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Adherence Preparation and Support Guides

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Adherence Assessment and Follow-up Guides

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Appointment Book and Appointment Reminder Card

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

PMTCT Video

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Additional Notes:

_____

_____

_____

_____

_____

_____

Appendix 5B:

Workshop Evaluation Form

Name (optional): _____ Health Facility: _____ Position: _____

Please rate the following statements on a scale of 1 to 5.

	☹ Strongly Disagree	Disagree	Neither agree nor disagree	Agree	☺ Strongly Agree
1. The workshop objectives were clear.	**1**	**2**	**3**	**4**	**5**
2. This workshop met my expectations.	**1**	**2**	**3**	**4**	**5**
3. The technical level of this workshop was appropriate.	**1**	**2**	**3**	**4**	**5**
4. The pace or speed of this workshop was appropriate.	**1**	**2**	**3**	**4**	**5**
5. The facilitators were engaging and informative.	**1**	**2**	**3**	**4**	**5**
6. The information I learned in this workshop will be useful to my work.	**1**	**2**	**3**	**4**	**5**

How helpful were each of the workshop Modules to you and your work? You can write extra comments on the back.

	☹ Not helpful				☺ Very helpful
Introduction and PMTCT Update	**1**	**2**	**3**	**4**	**5**
Retention, Adherence, and Psychosocial Support in PMTCT Programs	**1**	**2**	**3**	**4**	**5**
Using the PMTCT Counseling Cue Cards	**1**	**2**	**3**	**4**	**5**
Using the PMTCT Checklists, Guides, Forms, and Video	**1**	**2**	**3**	**4**	**5**
Monitoring Retention and Adherence to PMTCT and Planning the Way Forward	**1**	**2**	**3**	**4**	**5**
Review of Counseling and Communication Skills *(optional)*	**1**	**2**	**3**	**4**	**5**

What was the BEST THING about this workshop?

What was NOT USEFUL about this workshop?

Do you have other comments (use the back of the page if needed)?

NOTE: THIS MODULE IS OPTIONAL AND MAY BE PARTICULARLY USEFUL FOR LAY AND PROFESSIONAL COUNSELORS, SOCIAL WORKERS, PEER EDUCATORS, MOTHER MENTORS, AND OTHER MEMBERS OF THE MULTIDISCIPLINARY TEAM WHO DEVOTE MUCH OF THEIR TIME TO COUNSELING IN PMTCT.

SUPPLEMENTAL MODULE 6: Review of Counseling & Communication Skills

DURATION: 210 MINUTES (3 hours, 30 minutes)

LEARNING OBJECTIVES:

By the end of this Supplemental Module, participants will be able to:

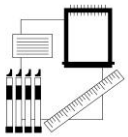
- Describe the importance of effective communication and counseling skills in PMTCT care and treatment settings
- Discuss the basic principles of counseling and challenges to putting these principles into practice
- Discuss what is meant by shared confidentiality and why it is important
- Reflect on their own attitudes, values, and beliefs, and discuss how these may affect the quality of counseling
- Demonstrate the 7 key counseling and communication skills
- Understand the main components of a counseling session

CONTENT:

Session 6.1: Counseling Basics
Session 6.2: Key Counseling and Communication Skills
Session 6.3: Classroom Practicum
Session 6.4: Module Summary

METHODOLOGIES:

- **Interactive trainer presentation**
- **Large group discussion**
- **Values clarification**
- **Role play**
- **Small group work**
- **Case studies**



MATERIALS NEEDED:

- **Flip chart and stand**
- **Markers**
- **Tape or Bostik**
- **Slide set for Module 6**
- **Projector/LCD and screen (or white wall)**
- **Extra copies of Appendix 6A for each participant**
- **Toolkit, including Participant's Manual**

WORK FOR THE TRAINER TO DO IN ADVANCE:

- **Set up the training room and gather required materials.**
- **Read through the entire Module and Module 6 slide set and make sure you are familiar with the training methodologies and content.**
- **Make large "AGREE" and "DISAGREE" signs on flip chart.**
- **Review the counseling and communication skills checklist (Appendix 6A).**
- **Make extra copies of Appendix 6A for each participant. Review and practice the role plays in Sessions 6.2 with a co-trainer or training participant(s).**
- **Make sure there are at least 2 extra chairs in the front of the room that can be used during role plays.**

Note: Portions of this Module were adapted from: WHO & CDC *Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual,* 2008.

SESSION 6.1:
Counseling Basics (50 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Values Clarification

STEP 1: Review the Supplemental Module learning objectives **(Slides 6-1 to 6-2)** and ask if there are any questions.

STEP 2: Start by asking participants to reflect on a time when they received good counseling—from a friend, a colleague, a counselor, etc. Ask some participants to share their experiences.

STEP 3: Write "WHAT IS COUNSELING?" on top of flip chart. Ask participants to brainstorm possible answers. Write participants' responses on flip chart. Fill in using the content below **(Slides 6-3 to 6-5).**

STEP 4: Write "WHY DO WE DO COUNSELING?" on top of flip chart. Ask participants to brainstorm possible answers. Write participants' responses on flip chart. Fill in using the content below **(Slide 6-6).**

STEP 5: Write "CONFIDENTIALITY AND SHARED CONFIDENTIALITY" on top of flip chart. Ask participants to brainstorm what is meant by these terms. Write participants' responses on flip chart. Fill in using the content below **(Slide 6-7).**

STEP 6: Ask participants to think about and discuss the challenges to providing good counseling. Ask **(Slide 6-8)**:

- *Even though we know what good counseling is, why don't we always provide good counseling?*

Record answers on flip chart.

STEP 7: Introduce the next activity by asking participants to discuss the meanings of the term "self-awareness" and why it is important for health workers to be aware of their own values, attitudes, and prejudices **(Slide 6-9)**.

STEP 8: Post the pre-prepared flip chart papers that say, "AGREE" and "DISAGREE" on opposite sides of the training room.

Ask participants to stand up and move to the open space in the room where the "AGREE" and "DISAGREE" signs are posted. Tell participants that you will read some statements out loud and that, after each statement, they should move to the "AGREE" or the "DISAGREE" sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the 2 signs.

STEP 9: Read each of the sentences listed below ("Statements for Values Clarification") out loud. Allow participants a few seconds to move to the side of the room that reflects their opinion. Ask a few participants to tell the group why they "AGREE" or "DISAGREE" with the statement.

Once you have read all of the statements below, or 15-20 minutes have passed, ask participants to return to their seats.

Step 10: Debrief the activity by discussing why it is important for health workers to be self-aware, reminding participants that although we ALL bring certain values and attitudes to our work, we must not let these values and attitudes affect the quality of counseling we provide to clients **(Slide 6-10).** By striving to be self-aware, counselors can make sure they are equally supportive of all of their clients.

KEY INFORMATION:

What is counseling?

- Counseling is a two-way communication process that helps people look at their personal issues, make decisions, and plan how to take action.

Counseling includes:

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening carefully
- Helping people tell their stories without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognize and build on their strengths
- Helping people to develop a positive attitude toward life and to become more confident
- Respecting everyone's needs, values, culture, religion, and lifestyle

Counseling does NOT include:

- Solving another person's problems
- Telling another person what to do
- Making decisions for another person
- Blaming another person
- Interrogating or questioning another person
- Judging another person
- Preaching to, or lecturing, another person
- Making promises that cannot be kept
- Imposing one's own beliefs on another person
- Providing inaccurate information

Why do we do counseling?

- To help people talk about, explore, and understand their thoughts and feelings
- To help people work out for themselves what they want to do and how they will do it

Confidentiality:

In order for clients to trust health workers with their feelings and problems, it is important for them to know that anything they say will be kept confidential. This means that members of the multidisciplinary care team will not tell other people any information about the client, including what the client says or that the client is living with HIV. Confidentiality is especially important in HIV programs because of the stigma surrounding HIV and discrimination against PLHIV in the home, at work, at school, and in the community.

Because multidisciplinary teams take care of clients, sometimes they need to discuss a client's needs and health status with one another to provide the best care possible.

Statements for Values Clarification Exercise:

1. I expect clients to do everything in their power to protect their health.
2. I feel comfortable discussing sex and sexuality with clients.
3. A woman who knows she has HIV and gets pregnant is irresponsible.
4. Health workers should always know which services exist for pregnant women in the community.
5. It is usually a waste of time to provide counseling to our clients—they rarely listen.
6. The biggest reason pregnant women do not adhere to their ARVs is because they are forgetful.
7. If I see that a client is acting irresponsibly, it's my job to correct her behavior.
8. Many people living with HIV have made irresponsible decisions in their lives.
9. HIV-infected children are victims.
10. Some clients do now know enough to make good decisions for themselves.

Self-Awareness:

Listening and counseling require that the counselor be aware of his or her strengths and weaknesses, as well as his or her fears or anxiety about HIV. All health workers should strive to be self-aware and to understand how others affect them as well as how they affect others.

Being self-aware means knowing yourself, how other people view you, and how you affect other people.

Attitudes and values are feelings, beliefs, and emotions about a fact, thing, behavior, or person.

- For example, some people believe that having multiple sexual partners is okay as long as you practice safer sex, while other people believe that this is wrong.

Prejudices are negative opinions or judgments made about a person or group of people before knowing the facts.

- For example, when a health worker assumes that a person with HIV must be promiscuous or that a miner is probably sleeping around when he is away from home, the health worker is being prejudicial.

Health Workers should always:

- Think about the issues related to their own attitudes, values, and prejudices, and how these can affect their ability to help provide effective counseling and support services to pregnant and postpartum women, families, and children
- Be sensitive to the culture, values, and attitudes of their clients, even if they are different from their own

- Learn as much as they can about the main culture, values, and attitudes of the clients at the facility
- Examine their own values and beliefs in order to avoid prejudice and bias, and make all people feel comfortable and that it is "safe" to talk with them openly and honestly.

Remember: Prejudice, stigma, and negative attitudes drive the HIV epidemic, so we all need to work hard to provide quality, fair, equal, and non-judgmental services to all of our clients!

SESSION 6.2:
Key Counseling and Communication Skills (90 minutes)

TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Role Play, Small Group Work

STEP 1: Tell participants that, in this session, we will learn more about key counseling and communication skills needed to provide PMTCT (and all) clients with quality care and psychosocial support **(Slide 6-11)**.

STEP 2: Refer participants to Appendix 6A and explain that this is an observation checklist of the key counseling and communication skills that they are about to learn and practice. Participants should refer back to the checklist as each skill is introduced so they start to become familiar with it. Following the training, the checklist can be used for self-assessment and mentoring.

STEP 3: Ask participants to turn to the person sitting next to them. One person will talk about the best day of her or his life and the other will just listen without saying anything at all.

After 3 minutes, ask the pairs to switch roles. Debrief by asking participants how it felt to be the speaker and how it felt to be the listener.

STEP 4: Write **"Skill 1: Use helpful non-verbal communication"** on flip chart and ask participants to brainstorm what this means, thinking about the last activity. Record responses on flip chart and fill in using the content below **(Slide 6-12).**

With a co-trainer (or participant), perform the role plays under Skill 1 below. Then ask:

- *What were some examples of unhelpful non-verbal communication?*
- *What were some examples of helpful non-verbal communication?*

Ask participants to turn to the person sitting next to them again. This time, one person will talk about one of the hardest days of her or his life and the other will just listen, without saying anything, but applying helpful non-verbal communication skills.

After 3 minutes, ask the pairs to switch roles. Debrief by discussing what types of non-verbal communication were used and what was most effective.

STEP 5: Write **"Skill 2: Actively listen and show interest in the client"** on flip chart and ask participants to brainstorm what this means. Record answers on flip chart and fill in using the content below **(Slide 6-13).**

With a co-trainer (or participant), perform the role play under Skill 2 below. Ask:

- *What did the counselor do to show she or he was actively listening to the client?*
- *Why was it important that the counselor apply active listening skills in this example?*

Ask participants to turn to the person sitting next to them again. This time, one person will talk about their favorite family traditions and the other will use active listening skills.

After 3 minutes, ask the pairs to switch roles. Debrief by discussing how the listener practiced active listening and what was most effective.

STEP 6: Write **"Skill 3: Ask open-ended questions"** on flip chart and ask participants to brainstorm what this means, using examples. Record answers on flip chart and fill in using the content below **(Slide 6-14).**

With a co-trainer (or participant), perform the role plays under Skill 3 below. Ask:

- *What were the differences in the ways the counselor asked questions?*
- *Why was it important to use open-ended questions in this example?*

Ask participants to change close-ended questions into open-ended questions, using the examples below **(Slide 6-15).**

STEP 7: Write **"Skill 4: Reflect back what the client is saying"** on flip chart and ask participants to brainstorm what this means, using examples of how to reflect feelings and paraphrase content. Record responses and fill in using the content below **(Slide 6-16).** Go over the different formulas for reflection (e.g. "you feel _____ because _____", and others**) (Slide 6-17).**

With a co-trainer (or participant), perform the role plays under Skill 4 below. Ask:

- *How did the counselor use reflection in this session?*
- *Why was it important for the counselor to use reflection?*

Ask participants to reflect back the statements a client might say below **(Slide 6-18).**

STEP 8: Write **"Skill 5: Empathize—show that you understand how the client feels"** on flip chart and ask participants to brainstorm what this means, and how empathy is different from sympathy. Record responses on flip chart and fill in using the content below **(Slide 6-19).**

With a co-trainer (or participant), perform the role plays under Skill 5 below. Ask:

- *In which role play was the health worker sympathizing? Empathizing?*
- *How did the health worker show empathy for the client?*
- *Why was it important for the health worker to show empathy?*
- *How can you, as a health worker, better empathize with clients, and avoid sympathizing?*

Step 9: Write **"Skill 6: Avoid words that sound judging"** on flip chart and ask participants to brainstorm what this means, and to brainstorm examples of judging words in the local language(s). Record responses on flip chart and fill in using the content below **(Slide 6-20).**

With a co-trainer (or participant), perform the role plays under Skill 6 below. Ask:

- *Which words did you think were judging?*
- *How might these words make a client feel?*

STEP 10: Write **"Skill 7: Help your client set goals and summarize each counseling session"** on flip chart and ask participants to brainstorm what this means. Discuss why it is important to work with clients to set goals and plan next steps, and why it is important to summarize the session. Record responses on flip chart and fill in using the content below **(Slides 6-21 to 6-22).**

Break participants into pairs. One person should begin by telling the other (the "counselor") their plans to incorporate these 7 listening and learning skills into their work with clients.

After about 5 minutes, the "counselor" should help his or her partner set goals and summarize the session. Then participants should switch roles so each has a chance to practice goal setting and summarizing.

STEP 11: Tell participants that they should be aware of the different phases of a counseling session. Ask participants:

- *How do you normally structure your counseling sessions?*

Review the 4 main phases of a counseling session using the content below **(Slides 6-23 to 6-26).** Ask participants if they have any questions.

STEP 12: Summarize by asking participants to recall the key counseling and communication skills, and the phases of a counseling session.

KEY INFORMATION:

Counseling and Communication Skills

There are 7 essential skills that health workers should practice and use in their work:

Skill 1: Use helpful non-verbal communication.
Skill 2: Actively listen and show interest in the client.
Skill 3: Ask open-ended questions.
Skill 4: Reflect back what the client is saying.
Skill 5: Empathize—show that you understand how the client feels.
Skill 6: Avoid words that sound judging.
Skill 7: Help the client set goals and summarize each counseling session.

Skill 1: Use Helpful Non-verbal Communication

- Make eye contact.
- Face the person.
- Be relaxed and open with your posture.
- Sit squarely facing the person. Do not sit behind a desk!
- Dress neatly and respectfully.
- Use good body language—nod your head and lean forward.
- Smile.
- Make the client feel that you have time, greeting the client warmly, and wait for the client to talk when she is ready.
- Do not look at your watch, the clock, or anything other than the person you are counseling.
- Try not to write during a counseling session, unless you are recording key information for the client to take home or for your records. Turn your mobile phone off and never take calls during a counseling session.

Role play: Non-verbal communication

WHAT NOT TO DO Unhelpful non-verbal communication	WHAT TO DO Helpful non-verbal communication
Client walks in	Client walks in
Health Worker: Hello. My name is ___. *(Health worker is filling in the register from behind a desk, does not look at client)*	**Health Worker:** Hello. My name is ___. *(Health worker is filling in the register from behind a desk and looks up at client)*
Client: I have some questions about my baby getting HIV.	**Client:** I have some questions about my baby getting HIV.
Health Worker: Please sit down *(speaking in a hurried fashion)*. What were your questions? *(Health Worker still looking at the register)*	**Health Worker:** *(Looks at client, stops writing in the register, and moves chair so that it is not behind the desk)* Please sit down. What were your questions? *(Leans forward, open posture)*
Client: Well, I want to do everything I can to prevent my baby from getting HIV. But I'm not sure what I can do.	**Client:** Well, I want to do everything I can to prevent my baby from getting HIV. But I'm not sure what I can do.
Health Worker: Mm-Hmm. *(Does not look up and still filling in the register)*	**Health Worker:** I'm glad you are here. Let's talk about the ways you can lower the chances that your baby will be HIV-infected. *(Looks warmly, yet with concern, at client. Optional: demonstrate appropriate touch)*
Client: *(Clears throat to get counselor's attention)*	**Client:** Ok.
Health Worker: Oh sorry *(she finally stops writing and looks at watch)*. Yes, go ahead, you said that you are concerned about your medicines? *(Health Worker's hands are folded, legs crossed and facing away from client, looking across the room with expression suggesting disinterest)*	**Health Worker:** There are many things we can do to protect your baby and make sure you stay healthy. Why don't you tell me a bit more about how things have been going for you and what you have heard about mother-to-child transmission of HIV. *(Health Worker looks at client, leaning forward and not crossing legs)*
Client: Well not exactly, I want to know more about how I can protect my baby...Don't worry, sorry to have bothered you.	**Client:** *(Proceeds to tell her story)*

Skill 2: Actively Listen and Show Interest in the Client

It is important for the client to know that she has the counselor's full attention. Feeling that the counselor is actively listening will encourage the client to share more about her situation.

Active listening skills:

- Listen in a way that shows respect, interest, and empathy.
- Show the client you are listening by saying *"mm-hmm"* or *"aha."*
- Use a calm tone of voice.
- Listen to what the client is saying—do you notice any themes?
- Listen to how client is saying it—does she seem worried, angry, etc.?
- Allow the client to express her emotions. For example, if she is crying, allow her time to do so.
- Never judge or impose your own values on a client.
- Find a private place to talk and keep distractions, such as phone calls or visitors, to a minimum.
- Do not do other tasks while counseling a client.
- Do not interrupt the client.
- Ask questions or gently probe if you need more information. For example, if a client says, *"I can't exclusively breastfeed my baby,"* you could ask, *"In what way is exclusive breastfeeding a concern for you?"*
- Use open-ended questions that can't be answered with *"yes"* or *"no."* For example, *"Can you tell me a bit more about that?"*
- Summarize key points as you go along during the counseling session.

Role play: Active listening

WHAT TO DO Gestures and responses that show interest
Health Worker: How do you think your partner will react if you tell him your HIV test results?
Client: Actually, I'm really very worried about it. I was hoping you wouldn't ask, to tell you the truth.
Health Worker: Mm-hmm. *(nods sympathetically)*
Client: I think my husband will accuse me of being unfaithful if he knows I have HIV.
Health Worker: He'll accuse you of being unfaithful then?
Client: Well, mostly he'll be angry that I went ahead and agreed to be tested without telling him first. And then he will probably say I was unfaithful.
Health Worker: Mm-hmm.
Client: Last time I was sick and went to the clinic without asking him, he got angry with me for spending the money to see the doctor and get some tests done. I think he's going to react the same way.
Health Worker: I'm hearing that he may get upset that you got tested without consulting with him first. So, how do you feel about bringing him to the clinic and then one of the counselors he talk with him about how HIV testing is a routine part of care for all pregnant women? And also that HIV testing is important to get the care you and the baby need and why he should you think about that?

Skill 3: Ask Open-ended Questions

Closed-ended questions:

Closed-ended questions can be answered with a one-word or short answer. Examples of closed-ended questions are, *"How old are you?" "What is your CD4 count?"* and *"Do you have children?"*

Closed-ended questions are good for gathering basic information at the start of a counseling or group education session. They should not be used too much because they can make it seem like the counselor is being too direct. They are not helpful in getting at how the client is really feeling.

Open-ended questions:

Open-ended questions cannot be answered in one word. People answer open-ended questions with more of an explanation. Examples of open-ended questions are, *"Can you tell me more about your relationship with your partner?"* or *"How does that make you feel?"*

Open-ended questions are the best kind to ask during counseling and group education sessions because they encourage the client to talk openly and they lead to further discussion. They help clients explain their feelings and concerns, and also help counselors get the information they need to help clients make decisions.

Role play: Open-ended questions

WHAT NOT TO DO Closed-ended questions	WHAT TO DO Open-ended questions
Client walks in	Client walks in
Health Worker: Hi, how are you? I'm ___. I am a nurse. Today, as part of your visit, I will be discussing with you the medicines you need to take to stay healthy and lower the chance that your baby will be infected.	**Health Worker:** Hi, how are you? I'm ___. I am a nurse. Today, as part of your visit, I will be discussing with you the medicines you need to take to stay healthy and lower the chance that your baby will be infected.
Client: OK	**Client:** OK
Health Worker: Do you know what ARVs are?	**Health Worker:** Tell me, what have you heard about ARV medicines?
Client: Yes, I think so.	**Client:** Well, I'm not sure, but I heard they can make people with HIV feel better. But I also heard they are dangerous for babies.
Health Worker: OK. And do you know that you have to take them at the same time every day?	**Health Worker:** You are right that ARVs are medicines that can help people with HIV feel better and stay healthy. They can also lower the chance that your baby will be HIV-infected. ARVs are safe for pregnant women and babies. How do you feel about taking ARVs during your pregnancy?
Client: Um, yes, I guess so.	**Client:** Well, I guess I will do anything to protect my baby. But, how long will I have to take them?

Health Worker: OK, good. So, here are the medicines you need to take every day. Don't miss any doses, OK?	**Health Worker:** Well, we recommend that you start taking ARVs now and every day during your pregnancy and your labor and delivery. You can stop taking them one week after you deliver, but you will need to give your baby ARV syrup every day as long as you are breastfeeding. This will protect your baby from HIV. Tell me, what support do you have at home to take medicines every day and care for your baby?
Client: OK.	**Client:** Well, my sister helps me and she knows that I have HIV.
Health Worker: See you at your next visit then.	**Health Worker:** That's great. What are some of the ways that you think will help you to remember to come back for all of your appointments and to take your medicine every day?
	Client: Well…(*client continues to discuss with health worker)*

Additional practice on closed- and open-ended questions:

Closed-ended question	Open-ended question
Do you have safe sex?	How do you negotiate safe sex with your partner?
Do you have more than one sex partner?	There are a lot of ways to reduce risk for HIV—like not having sex, being faithful to your partner, and using condoms. Which would work best for you based on your situation?
Do you use condoms?	What challenges do you have using condoms with your partner?
Do you drink alcohol when you are upset?	What are some of the ways you cope with stress or anger?
Did your partner get tested?	How would you feel about asking your partner to get tested so you can both be as healthy as possible?
Do you want to have children in the future?	How do you feel about having a bigger family? What concerns to do you have?
Do you have someone you can talk with about taking your medicines the right way?	Tell me more about the people you have disclosed to and how they could help you remember to take your medicines.
Do you know how to prevent transmission of HIV to your baby?	I want to make sure that I have explained everything well to you – can you tell me what you understand about ways you can protect your baby from HIV?
Do you exclusively breastfeed your baby?	Can you tell me more about how you feed your baby?

Skill 4: Reflect Back What the Client is Saying

Reflecting skills:

The counselor repeats back to the client the main feelings and themes that the client has just expressed.

Reflecting:

- Provides feedback to the client and lets her know that she has been listened to, understood, and accepted
- Encourages the client to say more
- Shows that the counselor has understood the client's story
- Helps the counselor check that he or she has understood the client's story
- Provides a good alternative to always answering with another question
- Can reflect the client's feelings and include a summary of the content of what the client has said (sometimes called paraphrasing)
- For example, the counselor can use the following formulas for reflecting:
    - *"You feel _____ because _____."*
    - *"You seem to feel that _____ because _____."*
    - *"You think that _____ because _____."*
    - *"So I sense that you feel _____ because _____."*
    - *"I'm hearing that when _____ happened, you didn't know what to do."*
- When reflecting back, try to say it in a slightly different way. Do not just repeat what the client said. For example, if a client says, *"I can't tell my partner about my HIV test result,"* the counselor could say, *"Talking to your partner about your result sounds like something that you are not comfortable doing."* Then say, *"Let's talk about that".*

Role play: Reflecting skills

WHAT TO DO Reflecting back
Health Worker: I'm hearing that you are having some challenges remembering to take your medicines every day. What do you think about telling your partner about your HIV-status? Maybe he could be your treatment supporter?
Client: Well, I honestly don't think I could ever bring up the subject to him. I think he'd get really angry and say that I have been sleeping around.
Health Worker: It sounds like you could use some extra support, but that disclosing to your husband is something that you would actually be hesitant, maybe even afraid, to do right now.
Client: Yes, that's right…

Additional Practice on Reflecting:

Reflect back to the following statements:

- I missed a lot of my pills this month and I feel hopeless.
- My boyfriend does not know my test results—I'm scared to tell him.
- I feel like a bad mother because my baby does not want to suckle from me.
- My husband would just get angry if I asked him to use a condom, so I am not going to ask.
- My husband thinks it's dangerous to give the baby medicines and I am afraid of disobeying him.
- I am worried because my mother-in-law will assume I am living with HIV if I don't give the baby herbs.
- I feel so happy that my baby is growing well.

Skill 5: Empathize—Show That You Understand How the Client Feels

Empathy or empathizing:

- Is a skill used in response to an emotional statement
- Shows an understanding of how the client feels and encourages the client to discuss the issue further
- Is different than sympathy. When you sympathize, you feel sorry for a person and look at the situation from your own point of view. For example, if the client says: *"My baby wants to feed very often and it makes me feel so tired,"* the counselor can show empathy by saying: *"You are feeling very tired all the time then?"* However, if the counselor responds by saying, *"I know how you feel. My baby also wanted to feed often and I was exhausted!,"* this is sympathizing because the attention is on the counselor and her experiences instead of on the client.

Role play: Showing empathy vs. sympathy

WHAT NOT TO DO Sympathizing	WHAT TO DO Empathizing
Health Worker: What do you think about asking your partner to use condoms while you are breastfeeding?	**Health Worker:** What do you think about asking your partner to use condoms while you are breastfeeding?
Client: I'd be really afraid that he might hit me, or even worse.	**Client:** I'd be really afraid that he might hit me, or even worse.
Health Worker: Yes, I know what you mean, that happened to my sister. She actually did ask her husband to use condoms after the baby and you know what? He hit her then he made her leave the house. He didn't let her come back for two full days.	**Health Worker:** It sounds like you're afraid of your husband's response.
Client: So did your sister go back?	**Client:** Yes, I am. It's not just about asking him to use condoms. I'm also scared that he'll be upset if dinner is late, if the house isn't tidy, if the children aren't behaving well, and for a lot of other reasons.

Skill 6: Avoid Words That Sound Judging

Judging words are words that can include:

- "*right":* You should do the right thing.
- *"wrong":* That is the wrong way to feel.
- *"badly":* Why are you behaving badly and missing appointments?
- *"good":* Be a good girl and tell your boyfriend to use condoms.
- *"properly*": Why don't you take your medicine properly?
- *"these people"* or *"those people"* (referring to people living with HIV for example): Those people are irresponsible and should not have children.

If a counselor uses these words when asking questions, the client may feel that she is wrong, or that there is something wrong with her actions or feelings. Sometimes, however, counselors need to use the "good" judging words to build a client's confidence.

Role Play: Avoiding judging words

WHAT NOT TO DO Using judging words	WHAT TO DO Avoid words that sound judging
Health Worker: What do you think about asking your partner to use condoms during your pregnancy?	**Health Worker:** What do you think about asking your partner to use condoms during your pregnancy?
Client: Honestly I don't feel comfortable with it.	**Client:** Honestly I don't feel comfortable with it.
Health Worker: *(Surprised)* Really? That's the wrong way to feel! Have you had a conversation about condoms?	**Health Worker:** Mm-hmm.
Client: No, not really.	**Client:** It came up once many years ago before we got married. He said that condoms were uncomfortable and will give him kidney problems.
Health Worker: He's stupid, isn't he? I guess he doesn't care about you or the baby. Typical man. Be a good, responsible woman and talk with him about condoms—he should care more about his baby.	**Health Worker:** I've heard other women say that as well. Maybe, now that you are pregnant, you could try talking to him again—about using condoms to protect the baby's and your health? Also, condoms definitely won't cause any kidney problems, that is a myth.
Client: Yes, I will.	**Client:** That's a good idea, maybe I'll try that.

Skill 7: Help the Client Set Goals and Summarize Each Counseling Session

Goal-setting:

Toward the end of a counseling session, the counselor should work with the client to come up with "next steps" to solve her issues in the short and long term.

Next steps and goals:

- Should be developed by the counselor and client together
- Can empower the client to achieve what she wants by agreeing to realistic short- and long-term goals and actions
- Provide direction and must be results-oriented
- Must be clear enough to help the client measure her own progress (people feel good when they achieve something they have set out to do)
- To start, the counselor could say, *"Okay, now let's think about the things you will do this week based on what we talked about."*

Summarizing:

The counselor summarizes what has been said during a counseling session and clarifies the major ideas and next steps.

Summarizing:

- Can be useful in an ongoing counseling session or in making sure you are clear on important issues raised during a counseling session
- Is best when both the counselor and client participate and agree with the summary
- Provides an opportunity for the counselor to encourage the client to examine her feelings about the session
- The counselor could say, *"I think we've talked about a lot of important things today.* (List main points.) *We agreed that the best next steps are to _____. Does that sound right? Let's plan a time to talk again soon."*

The Phases of a Counseling Session

4 PHASES OF A COUNSELING SESSION

1. Establishing the Relationship
2. Understanding the Problem
3. Supporting Decision-Making
4. Ending the Session

1. Establishing the Relationship

- The room should be quiet with doors that close and where there are no interruptions.
- **Introduce yourself:** Say your name and explain your role and the length of time you have together (i.e. half an hour).
- **Ask the client to introduce herself or himself.**
- **Explain that what is discussed will be kept confidential.**
- Ways to begin a counseling session:
    - *Can you tell me why you came here today?*
    - *Where would you like to start?*

2. Understanding the Problem

- Let the client talk about the thoughts, feelings, and actions around her or his issues or problems.
- Use the 7 essential counseling and communication skills.
- Help the client decide which issues or problems are the most important to talk about in the session.

3. Supporting Decision-Making

- Support the client to make her or his own decisions on next steps and focus for the future.
- The health worker can help the client explore the options, but it is ultimately the client's decision to make.

4. Ending the Session

- Summarize what was discussed during the session.
- Review the client's next steps.
- Give the client a chance to ask questions.
- Make referrals, if needed.
- Discuss when the client will return and make sure she or he has an appointment.

SESSION 6.3:
Classroom Practicum (60 minutes)

TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Case Studies, Role Play, Large Group Discussion

STEP 1: Break participants into small groups of 4 **(Slide 6-27)**. Ask each group to read through all of the case studies in the Participant's Manual. Encourage participants to add detail to the case studies, based on their own experiences and those of clients they see in the clinic. Ask the groups to select one person who will first play the role of the "health worker," another who will play the role of the "client", and 2 people who will act as "observers."

STEP 2: Refer participants back to the communication and counseling skills checklist, and provide extra copies for each participant. Ask the observers to use the checklist to observe and record the different skills used during the role plays.

Ask the groups to start a role play for Case Study 1. The "client" should spend 5-10 minutes talking to the "health worker" about her concerns. The "health worker" will practice as many of the counseling and communication skills possible in the time given.

After 5-10 minutes, stop the exercise and ask the "observers" to provide feedback on each of the skills and techniques observed, using the checklist as a guide.

As time allows, have the small groups go through all of the 4 case studies until everyone has had an opportunity to practice each role in at least one of the case studies. The trainers should participate in the small groups if possible.

STEP 3: Bring participants back to the large group and ask the groups to report on the things they saw the "health worker" doing to improve their counseling. If time allows, ask some of the small groups to present their role play.

STEP 4: Summarize by pointing out strengths observed and possible ways to improve counseling and communication skills. Remind participants that improving counseling skills takes practice, as well as continuous self-exploration.

KEY INFORMATION:

Case Studies:

Case Study 1:

M___ is at the ANC clinic for the first time. She is 16 and lives with her aunt. M___ is still in school, and just found out that she is pregnant and HIV-infected. She is concerned that being pregnant and having HIV will mean giving up her dream of becoming a nurse.

Case Study 2:
P___ is pregnant with her first baby and has found out she has HIV. P___'s husband is the boss of the house. She says she is so frightened that her husband might find out when he sees the medicines from the clinic.

Case Study 3:

D___ is enrolled in the PMTCT program and started taking ART about 4 months ago. She starts crying because she was not able to get enough money to pay for the bus to the clinic last month, so she has stopped taking her ARVs. D___ is very worried because she has no job, no money, and now she is feeling unwell.

Case Study 4:

L___ is living with HIV. She is enrolled in the PMTCT program and had her second child about 7 weeks ago. Her first child is HIV-uninfected. She comes to the clinic today to get her new baby tested for HIV. She is very worried that the baby is HIV-infected because he is sick a lot of the time.

SESSION 6.4:
Module Summary (10 minutes)

TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

STEP 1: Ask participants what they think the key points are of this Module. What information will they take away from the Module?

STEP 2: Summarize the key points of the Module using participant feedback and the content below **(Slides 6-28 to 6-29).** Review the Module learning objectives **(Slide 6-2)** with participants and make sure all are confident with their skills and knowledge in these areas.

STEP 3: Ask if there are any questions or clarifications **(Slide 6-30).** Refer participants to Appendix 3B, which is an optional review/practice exercise on the information contained in this Module. Give instructions to participants on how and when they should complete this review exercise (could be assigned as homework, or could be part of ongoing mentoring sessions after the workshop, etc.).

STEP 4: Ask each participant to share with the group one thing he or she will do differently in his or her work, based on the information and skills learned in this Module.

KEY INFORMATION:

THE KEY POINTS OF THIS MODULE INCLUDE:

- Counseling is a way of working with people to understand how they feel and help them decide what they think is best to do in their situation.
- Health workers are not responsible for solving all of the client's problems.
- The role of health workers is to support and assist the client's decision-making process.
- It is important for clients to know that what they say will be kept private. All health workers should practice shared confidentiality.
- The multidisciplinary care team should work to ensure that there is private counseling space available and that counseling sessions are not interrupted for any reason.
- Our own attitudes, values, and prejudices should not be a part of communication and counseling with clients and other community members.
- These are the 7 key counseling and communication skills health workers should use:
  - Use helpful non-verbal communication.
  - Actively listen and show interest in the client.
  - Ask open-ended questions.
  - Reflect back what the client is saying.

(KEY POINTS, CONTINUED)

- Empathize—show that you understand how the client feels.
- Avoid words that sound judging.
- Help the client set goals and summarize each counseling session.

- There are 4 main phases of a counseling session:
  - Establishing the relationship
  - Understanding the problem
  - Supporting decision-making
  - Ending the session
- There can be many challenges to providing quality counseling in PMTCT and ART clinics, including lack of time and lack of private counseling space.
- Improving counseling skills takes practice, as well as continuous self-exploration of our own values and attitudes.

Appendix 6A:
Counseling and Communication Skills Checklist

COUNSELING AND COMMUNICATION SKILLS CHECKLIST		
Skill	**Specific Strategies, Statements, Behaviors**	**(√)**
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality.	
	• Start the session with an open-ended question (*"Where would you like to start?"* or *"Tell me more about why you came today."*)	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as *"yes," "okay"* and *"mm-hmm"*).	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as *"bad," "proper," "right," "wrong,"* etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counseling session	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counseling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

Note: This checklist was adapted from: WHO & CDC. *Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual.* 2008.

Appendix 6B:
Optional Homework/Review of Counseling and Communication Skills

INSTRUCTIONS:
Please answer the following questions. Refer to the Key Information from Supplemental Module 6 if you need additional help or a refresher.

1. **Why is non-verbal communication important? What are some ways to show good non-verbal communication?**

2. **Why is active listening important? What are some ways a counselor can show she or he is actively listening to the client?**

3. **What is the difference between closed- and open-ended questions?**

4. **Change the following into open-ended questions:**
    - Do you use condoms?
    - Did you take all of your medicines?
    - Did you tell someone about your HIV test results?
    - Do you have support at home to give the baby medicines?
    - Are you having any side effects?
    - Do you know you need to come back to the clinic in 4 weeks time?
    - Did you get your CD4 test results?
    - Are you breastfeeding?

5. Why is reflection important? What are some of the formulas for reflection?

6. Reflect back the following statements:

- I missed a lot of my pills this month and I feel hopeless.
- My boyfriend does not know my test results—I'm scared to tell him.
- I feel like a bad mother because my baby does not want to suckle from me.
- My husband would just get angry if I asked him to use a condom, so I am not going to ask.
- My husband thinks it's dangerous to give the baby medicines and I am afraid of disobeying him.
- I am worried because my mother-in-law will assume I am living with HIV if I don't give the baby herbs.
- I feel so happy that my baby is growing well.

7. What is the difference between showing empathy and showing sympathy?

8. How would you use reflection and show empathy if your client said the following:

- I am so dizzy and weak since I started taking these pills. I am going to stop.
- My milk looks so thin. I am worried it isn't enough for the baby.
- I am really scared to tell my boyfriend I have HIV.
- I will be so sad if my baby has HIV.
- I have to hide my medicines so it is hard for me to remember to take them at the right times.

9. What are the key parts or phases of a counselling session? Why is each phase important?

Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

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Implementation Workshop Curriculum for Health Workers

Thank you for participating!

Improving Retention, Adherence, and Psychosocial Support within PMTCT Services:

Implementation Workshop for Health Workers

ICAP International Center for AIDS Care and Treatment Programs

All slide illustrations by Petra Röhr-Rouendaal, *2010*

Module 1: Introduction and PMTCT Update

Module 1: Learning Objectives

- Know more about workshop participants and trainers
- Understand the workshop goal, objectives, and agenda
- Discuss changes and updates to the national PMTCT and infant feeding guidelines

Workshop Learning Objectives - 1

By the end of this workshop, participants will be able to:

1. Understand the changes to the national PMTCT guidelines and how they should be applied in clinical settings
2. Define the PMTCT spectrum of care
3. Define psychosocial and adherence support in the context of PMTCT services
4. Understand the importance of psychosocial and adherence support to meet the needs of women and families enrolled in PMTCT
5. Identify strategies to improve psychosocial and adherence support within PMTCT programs
6. Use counseling cue cards to conduct ongoing, supportive counseling for pregnant and postpartum women

Workshop Learning Objectives - 2

7. Use checklists to improve pre- and post-test counseling in PMTCT settings
8. Conduct a psychosocial assessment and document key points and next steps, as well as make referrals
9. Use guides to conduct adherence preparation and support sessions with clients and to provide ongoing adherence assessment and follow-up
10. Develop and use an appointment system
11. Use a patient education video to reinforce key PMTCT messages
12. Use improved communication and counseling skills with clients

Workshop Agenda

DAY	SUGGESTED TIME	SUGGESTED ACTIVITY
DAY 1	**12:30-13:00**	LUNCH and WORKSHOP OPENING
	13:00-14:30	Module 1: Introduction and PMTCT Update
	14:30-17:10	Module 2: Retention, Adherence, and Psychosocial Support in PMTCT Programs
DAY 2	**12:30-13:00**	LUNCH
	13:00-15:30	Module 3: Using the PMTCT Counseling Cue Cards
	15:30-17:00	Module 4: Using the PMTCT Checklists, Guides, Forms, and Video
DAY 3	**12:30-13:00**	LUNCH
	13:00-14:15	Module 4: Using the PMTCT Checklists, Guides, Forms, and Video (continued)
	14:15-16:45	Module 5: Monitoring Adherence to PMTCT and Planning the Way Forward
	16:45-17:00	WORKSHOP CLOSING
DAY 4 (OPTIONAL)	**12:30-13:00**	LUNCH
	13:00-16:30	Supplemental Module 6 (optional): Review of Counseling and Communication Skills

PMTCT Update

1-6

Newly Released WHO Guidelines for HIV Prevention, Care & Treatment, 2009 (and adapted at country level)

- **Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants ('PMTCT guidelines')**
- Infant feeding in the context of HIV
- Antiretroviral therapy for HIV infection in adults and adolescents
- Antiretroviral therapy for HIV infection in infants and children

1-7

Principle Objectives of the PMTCT Guidelines

- Maximally reduce the risk of MTCT
- Improve maternal and infant survival
- Maximize effectiveness of PMTCT, minimize side effects for mothers and infants, and preserve future HIV care and treatment options

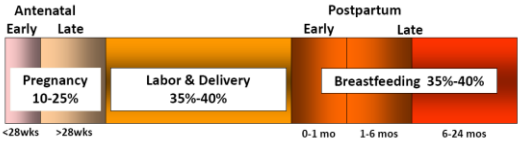
1-8

Rationale Underlying PMTCT Guidelines Changes

- Recognizes the importance of addressing maternal health status and ensuring ART for women eligible for treatment
- Extends the duration of prophylaxis throughout most of the period of exposure
- Emphasizes the importance of using multidrug regimens
- Recommends a single approach for ART prophylaxis (Option A or Option B) on national or sub-national level

1-9

Two Key Approaches for PMTCT



Maternal lifelong ART

Lifelong ART for HIV-infected women in need of treatment for their own health*, which is also safe and effective in reducing MTCT
Highlights importance of CD4 testing to determine ART eligibility

Maternal/Infant ART prophylaxis

ARV prophylaxis to prevent HIV transmission from mother to child during pregnancy, delivery and breastfeeding for HIV-infected women not in need of treatment

1-10

Key WHO Recommendations

1. **Lifelong Antiretroviral Treatment for Pregnant Women who Qualify:**

   Earlier ART initiation to improve maternal health and infant outcomes

2. **Maternal-Infant Antiretroviral Prophylaxis:**

   Earlier initiation and longer provision of ARV prophylaxis for HIV-infected pregnant women who do not need ART for their own health, with continued (maternal/infant) prophylaxis during breastfeeding

3. **Infant Feeding:**

   Improve HIV-free survival of HIV-exposed Infants (HEI) by **supporting safer breastfeeding practices** in the presence of ARVs (elimination of AFASS criteria)

1-11

I. Maternal Lifelong Antiretroviral Treatment

1-12

Immunologic and Clinical Criteria for Lifelong ART

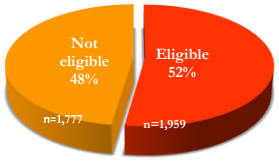
WHO clinical stage	CD4 <350 cells/mm³	CD4 >350 cells/mm³
Stage I	ART	*ARV prophylaxis*
Stage 2	ART	*ARV prophylaxis*
Stage 3	ART	ART
Stage 4	ART	ART

1-13

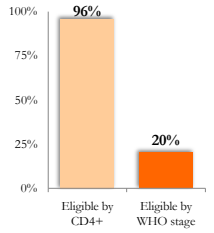
WHO 2009

CD4 Testing Critical to Identify Pregnant Women Eligible for ART

% pregnant women eligible for ART, n=3,736, The MTCT-Plus Initiative, 2003-2008



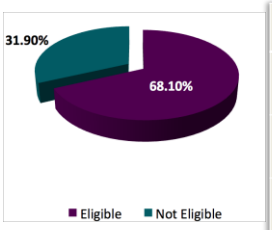
Eligibility by CD4+ and WHO stage (n=1,959)



1-14

Dugan , Carter, JAIDS 2010

Women Eligible for ART Are at High Risk for MTCT and Mortality



Pregnant women in Zambia, 2002, eligible for ART by current WHO criteria (n=1,025)

	Eligible for ART	Not eligible for ART
Proportion of MTCT by 6 weeks	87.5%	12.5%
Proportion of MTCT after 6 weeks	87.5%	12.5%
Maternal mortality 24 months after delivery	92%	8%

1-15

Kuhn, AIDS 2010

Recommended Regimens for ART Eligible Pregnant Women & Their Infants

MATERNAL TREATMENT

Start ART *as soon as possible* for women with CD4 < 350 or WHO Clinical Stage 3 or 4
Initiate ART at any gestational age

REGIMENS

Preferred Regimen	Alternative Regimen
AZT + 3TC + NVP	TDF + 3TC(FTC) + NVP
AZT + 3TC + EFV*	TDF + 3TC(FTC) + EFV*

*EFV to be avoided in 1st trimester

INFANT ARV Prophylaxis

Infants (breast feeding and formula feeding): Once daily NVP or twice daily AZT from birth until 4 - 6 weeks of age

1-17

WHO 2009

Regimen Choice for ART Eligible Women (adapt to national guidelines)

- Recommended regimens parallel WHO adult ART guidelines
  - AZT + 3TC backbone 'preferred' for PMTCT
    - Demonstrated safety and efficacy of AZT + 3TC
  - EFV more acceptable for PMTCT
    - Initiate **after** first trimester
    - Effective contraception required postpartum
  - Each regimen carries drug specific risks and toxicities
    - Overall low risk of severe toxicities
      - Neural tube defects associated with EFV during first trimester (very rare event)
      - Hepatotoxicity/hypersensitivity associated with NVP particularly in women with liver dysfunction/hepatitis
      - TDF contraindicated with renal dysfunction
    - Balance in favor of protecting maternal health and preventing infant infections

1-18

Considerations for Choice of Infant Prophylaxis Regimen When Eligible Mother Receives ART

AZT

- Twice daily
- Toxicity rare: anemia, neutropenia
- Recommended in 2006 guidelines and currently in use in the field
- Resistance mutations rare
- Not effective for prevention of BF transmission

NVP

- Once daily
- Toxicity rare: rash
- Efficacious for prevention of BF transmission
  - May be especially useful if maternal ART is initiated late
- High rate of NNRTI resistance in babies who become infected
- Not studied in context of maternal ART during BF
  - Risk of toxicity if mom and baby both on NVP

1-19

II. Maternal-Infant Antiretroviral Prophylaxis

Option A -or- Option B

1-20

Immunologic and Clinical Criteria for PMTCT Antiretroviral Prophylaxis (Option A or Option B)

WHO clinical stage	CD4 <350 cells/mm³	CD4 >350 cells/mm³
Stage I	ART	*ARV prophylaxis*
Stage 2	ART	*ARV prophylaxis*
Stage 3	ART	ART
Stage 4	ART	ART

1-21

WHO 2009

Option A

1-22

Prophylaxis Regimens for Pregnant Women & Their Infants - Option A

MATERNAL ANTIRETROVIRAL PROPHYLAXIS

Initiate as early as 14 weeks gestation through delivery

REGIMENS

Antepartum	Intrapartum	Postpartum
Daily AZT from 14wks	sd-NVP, AZT + 3TC*	AZT + 3TC for 7 days*

*sd-NVP and AZT+3TC intra- and post-partum can be omitted if mother receives > 4 wks AZT during pregnancy

INFANT ANTIRETROVIRAL PROPHYLAXIS

Breastfeeding Infant: Once daily NVP from birth through duration of breastfeeding until one week after last exposure to breast milk**

Non-breastfeeding Infant: Once daily NVP or sd-NVP + twice daily AZT from birth to 4-6 weeks of age

* **Infant feeding guidelines recommend breast feeding up to 12 months of age

1-23

WHO 2009

Option B

1-24

Prophylaxis Regimens for Pregnant Women & Their Infants - Option B

MATERNAL ANTIRETROVIRAL PROPHYLAXIS

- Initiate as early as 14 weeks gestation through delivery
- If breast feeding , continue until 1 week after weaning

RECOMMENDED PROPHYLAXIS REGIMENS

AZT + 3TC + LPV/r
AZT + 3TC + ABC
AZT + 3TC + EFV
TDF + ETC (FTC) + EFV

INFANT ANTIRETROVIRAL PROPHYLAXIS

Breastfeeding and Non-breastfeeding Infants: Daily NVP or twice daily AZT from birth until 4-6 weeks of age

1-25

WHO 2009

III. Infant Feeding

1-27

Infant Feeding Recommendations, 2010

ONE NATIONAL infant feeding strategy

BREASTFEEDING IN THE PRESENCE OF ARV INTERVENTIONS

- Exclusive breastfeeding for the first 6 months of life
- Introduce complementary foods at 6 months
- Continued breastfeeding up to 12 months of life (Breastfeeding should then only stop once a nutritionally adequate and safe diet, without breastmilk, can be provided

OR

AVOID ALL BREASTFEEDING

- Formula provision at national level – NO AFASS Assessment

1-28

PMTCT Update Summary

- **Earlier diagnosis and treatment of HIV with ART**
  CD4 ≤ 350cells/mm^3 , Stage III, IV*
- **Prophylaxis started earlier and longer duration**
  Regimens initiated at 14 weeks gestation and continued throughout duration of breastfeeding
- **Safer infant feeding practices to maximize HIV-free survival**
  Exclusive breastfeeding for 6 months, with breastfeeding continued through 12 months in the presence of maternal/infant prophylaxis

*critical importance of CD4 testing during pregnancy to determine ART eligibility

1-29

Implications for Adherence Support?

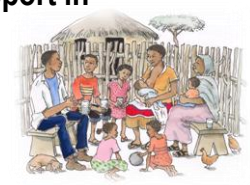
- PMTCT does not end at delivery – need to support adherence throughout the entire duration of PMTCT care and interventions
- Higher CD4 (≤350 cells/mm^3) means that there will be MORE pregnant women who need to initiate ART and who will need ongoing adherence support
- Earlier initiation of prophylaxis for women not eligible for ART means greater need for adherence support during pregnancy
- Extended prophylaxis during breastfeeding means greater need for adherence support postpartum
- Mothers need compassionate, consistent and ongoing support to adhere to safe infant feeding practices

1-30

Any Questions?

1-31

Module 2:
Retention, Adherence, and Psychosocial Support in PMTCT Programs



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International Center for AIDS Care and Treatment Programs
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Module 2: Learning Objectives

- Define the terms "retention," "adherence," and "psychosocial support"
- Understand the importance of retention, adherence, and psychosocial support in PMTCT Programs
- Identify common barriers to retention, adherence, and psychosocial wellbeing among PMTCT clients, including those related to health services
- Identify challenges to providing quality retention, adherence, and psychosocial support services in the PMTCT setting
- Identify strategies to improve retention, adherence, and psychosocial support within the PMTCT program and throughout the PMTCT spectrum of care

2-2

Discussion Questions

- What do we mean by retention?
- What do we mean by adherence?

2-3

Definition of Retention

- Retention refers to keeping (or "retaining") clients in the care program, in this case throughout the spectrum of PMTCT care and services.
  - For pregnant women, this means that they stay in care during pregnancy and throughout the duration of breastfeeding, and that they enroll in HIV care and treatment.
  - For HIV-exposed babies, this means staying in care until a final infection status is determined, and enrolling in HIV care and treatment if HIV-infected.

2-4

Definition of Adherence

- Adherence describes how faithfully a person sticks to and participates in her or his HIV prevention, care, and treatment plan.
- Adherence:
  - Is not the same as compliance
  - Includes active participation of the client in her care plan
  - Depends on a shared decision-making process
  - Includes adherence to both care and medicines
  - Impacts the success of PMTCT and HIV care and treatment programs

2-5

Adherence to PMTCT and HIV Care Includes:

- Entering into and continuing on a care and treatment plan
- Taking medicines to prevent and treat OIs
- Having a safe delivery in a health facility
- Practicing safer infant feeding practices
- Bringing the baby back often for checkups and for HIV testing at 6 weeks, and then again after weaning
- Participating in ongoing education and counseling
- Attending appointments and tests as scheduled
- Picking up medications before running out
- Adopting a healthy lifestyle (as is possible)
- Recognizing when there is a problem and coming to the clinic right away

2-6

Adherence to Medications Includes:

- Taking ARVs correctly, as prescribed, even if the person feels healthy
- For women who are eligible for ART, taking ARVs as prescribed for their entire life
- Taking other medicines as prescribed
- Giving medications to HIV-exposed and HIV-infected babies and children as prescribed
- Not taking any breaks from treatment

Remember: All pregnant women living with HIV need to take ARVs, the right way, every dose, every day!

2-7

Non-adherence Includes:

- Missing one or many appointments
- Not following the care plan and not communicating difficulties in following the care plan to health workers
- Missing one or more doses of medicine, or not giving the baby doses on time
- Sharing medicines with other people
- Stopping medicines for a day or many days
- Taking or giving medicines at different times than recommended by health workers
- Taking or giving medicines without following instructions about food or diet
- Not minimizing risk-taking behavior (as much as is possible given the client's circumstances)

Remember: No one is perfect!

2-8

Why is Adherence Important?

- To reduce the chance of MTCT at all stages
- To ensure that ART and other medicines do their job
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid resistance
- To monitor the client's health and link her to community support services
- To keep the person feeling well
- To keep families and communities healthy and productive.

2-9

What Happens When a Client Doesn't Adhere?

- The HIV keeps multiplying
- There is a greater chance of MTCT
- The CD4 count will drop; more OIs
- Children in particular will become ill very quickly
- There is a greater chance of passing HIV to others
- The client may become depressed or de-motivated due to illness
- Resistance can develop and the ARVs will stop working

2-10

Discussion Questions

- What do we mean by psychosocial support?
- Why is it important to provide psychosocial support services to pregnant and postpartum women, including those living with HIV?

2-11

Psychosocial Support

- Psychosocial support addresses the ongoing psychological and social concerns and needs of PLHIV, their partners, their family, and caregivers of children living with HIV.
- In the context of PMTCT services, psychosocial support addresses the psychological, social, and adherence needs of pregnant and postpartum women, their partners and families, and children throughout the spectrum of PMTCT care.

2-12

Remember:

- Since pregnancy is a relatively short period of time, it is important to assess and support pregnant women's psychosocial needs as soon as they are enrolled in ANC and PMTCT services.
- Retention, adherence, and psychosocial support are interrelated.
  - A client is more likely to be retained in care and adhere to her own and her baby's care and medicines if she receives ongoing information, education, and support at the clinic, in her community, and at home.

2-13

Discussion Questions

- What is the relationship among retention, adherence, and psychosocial support?
- Why is it important to offer ongoing retention, adherence, and psychosocial support services to PMTCT clients?
- What are the biggest challenges to offering these types of support to PMTCT clients?
- How is the referral system working now? What challenges exist with referrals for ongoing adherence and psychosocial support?

2-14

Remember:

- Retention, adherence, and psychosocial support are multi-dimensional
  - Every person is different
  - Every person's health, life, and family situation is different
  - People's needs change over time
- This is why retention, adherence, and psychosocial support services must be ongoing in PMTCT settings; not one time events
- The entire multidisciplinary team is responsible for providing these services

2-15

"Cardstorming" Activity

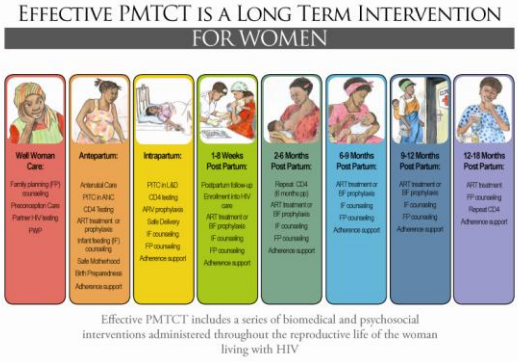
- Why don't clients stay in care and adhere to PMTCT care and medicines?

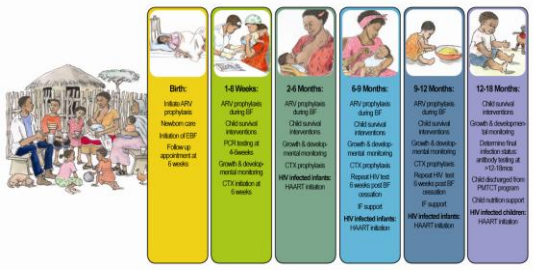
2-16

Factors Affecting Adherence

- Most clients want to adhere, but there are many challenges
- Some of the barriers have to do with the client herself, her family or her community situation
- Medicines themselves may also create barriers (e.g. side effects, pill burden)
- BUT…often the **health system** creates barriers to retention, adherence, and psychosocial wellbeing – as health workers, these are the barriers we can minimize
  - How can we address health system challenges and improve the quality of services for our clients?

2-17





Discussion Questions in Small Groups

- What retention, adherence, and psychosocial support services do we **currently** offer to clients at this stage of PMTCT care? Who is responsible for offering these services?
- What are the **challenges** to offering quality retention, adherence, and psychosocial support services at this stage?
- What can we do better at this step in the **future** to improve retention, adherence, and psychosocial support services?
- What **tools** could help improve retention, adherence, and psychosocial support at this stage?

2-20

Case Studies in Small Groups

2-21

Remember:

Retention, adherence, and psychosocial support are ongoing processes, throughout the spectrum of PMTCT care for mothers, babies, and families. Providing them is everyone's job!

2-22

Module 2: Key Points

- Retention refers to keeping women (and babies) in the care program, throughout the spectrum of PMTCT care.
- Adherence means how faithfully a person sticks to, and participates in her or his HIV care and treatment plan.
- Adherence to PMTCT and HIV care and medications is important to make sure women and babies stay healthy and get the ongoing care they need, lower the chances of MTCT, know when and how to start ARVs or ART, and get psychosocial support.
- Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV, their family, and caregivers of children living with HIV.

2-23

Module 2: Key Points, con't.

- Retention, adherence, and psychosocial support are interrelated.
- There are many barriers and challenges to retention, adherence, and psychosocial wellbeing.
- Retention, adherence, and psychosocial support are important services in PMTCT programs and throughout the spectrum of care.
- The entire multidisciplinary team is responsible for providing these services and supports.

2-24

Any Questions?

2-25

Module 3:Using the PMTCT Counseling Cue Cards

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Module 3: Learning Objectives

- Understand why the PMTCT counseling cue cards were developed and how they can be used by health workers
- Discuss how the PMTCT counseling cue cards could be used in your clinic setting
- Be familiar with the key messages in each of the counseling cue cards
- Use the PMTCT counseling cue cards as an aide/guide when working with clients in various stages of the PMTCT care spectrum

3-2

How to Use the Counseling Cue Cards

- Developed to support providers who work with pregnant women living with HIV and their families
- There are 20 cue cards. Each card focuses on a specific topic important to the care and support of pregnant women living with HIV, across the PMTCT continuum of care
- Providers may use the cue cards as job aides and reminders of key information to cover during clinic visits and counseling sessions
- The cue cards do not have to be used in sequence, but instead should be used according to the client's specific situation, needs, and concerns

3-3

How the Cue Cards are Set Up

- **Key questions** are included in *italics*, and may be used to initiate discussions, learn more about what the client already knows and her specific concerns, and to gauge understanding and elicit follow-up questions
- **Notes to guide counselors** are also included in *italics*
- The margins of each card contain **cross-references** to other cards on related topics

3-4

Discussion Questions

- What are your impressions of the counseling cue cards?
- How do you think the counseling cue cards could be used in your clinic?
- Who could use the cue cards? When? In what situations?
- What next steps would you take to use the cue cards in your clinic?

3-5

Discussion Questions for Case Studies in Small Groups

- What are some of the retention, adherence, and psychosocial issues and challenges you think this client is facing?
- What are the key issues and messages you would focus on with this client?
- Which of the cue cards do you think would be helpful to guide your session with this client?

3-6

Discussion Questions for Role Plays

- What were the key issues for the client in this case study? Key retention and adherence issues? Key psychosocial issues? Other issues?
- What did the health worker do well in the session?
- What other points do you think the health worker could have discussed with the client?
- How did the health worker use the counseling cue cards during the role play? Which cue cards did he or she use?
- For the health worker: What were your experiences using the counseling cue cards? What was easy? Challenging?

3-7

Module 3: Key Points

- All health workers should be up-to-date and knowledgeable about their national PMTCT guidelines.
- Pregnant and postpartum women and caregivers of HIV-exposed and HIV-infected babies and children often have a number of retention, adherence, and psychosocial support needs that may change over time.
- Quality communication and counseling in the PMTCT setting can lead to increased retention, adherence, and psychosocial wellbeing among clients.
- Health workers can use counseling cue cards to help explain the basics of PMTCT care and remember key counseling messages for clients in different places along the PMTCT care spectrum.

3-8

Module 3: Key Points, con't.

- Each clinic should have a specific plan on how the counseling cue cards are used (who, when, where, how, etc.).
- Counseling is a part of everyone's job and all multidisciplinary team members should be familiar with and have copies of the counseling cue cards.
- When talking with clients, it is always important to use the 7 key counseling and communication skills (discussed in Supplemental Module 6).

3-9

Any Questions?

3-10

Module 4:
Using the PMTCT Checklists, Guides, Forms, and Video

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Module 4: Learning Objectives

- Discuss the importance and relevance of each of the PMTCT Tools within the Toolkit
- Conduct the pre-test and post-test education and counseling sessions with clients, using structured checklists
- Conduct a psychosocial assessment and fill in the psychosocial assessment reporting form
- Conduct and document adherence and preparation and support counseling with clients, using a guide and reporting form
- Identify strategies to improve retention, adherence, and psychosocial support within the PMTCT program and throughout the PMTCT spectrum of care

4-2

Module 4: Learning Objectives, cont'd

- Conduct and document adherence assessments and follow-up counseling with clients, using a guide and reporting form
- Discuss the importance of having an appointment system in PMTCT settings and how to use an appointment book and appointment reminder cards
- Describe how each PMTCT Tool might be applied in their specific clinic setting
- Discuss how to use the PMTCT video in their clinic and/or community settings

4-3

There are 5 Helpful Tools for Health Workers to Adapt and Use

1. Counseling checklists for HIV testing in ANC settings
2. Psychosocial assessment guide and reporting form
3. Adherence preparation and support guides
4. Adherence assessment and follow-up guides
5. Appointment book and appointment reminder card templates

4-4

Discussion Questions for Each of the 5 Tools

- Why was the tool developed?
- How can the tool contribute to improved PMTCT services and improved adherence and psychosocial support for PMTCT clients?
- What are the major components of the tool?
- How do you think the tool could be used in your clinic?

4-5

Orientation to the Tools in Small Groups

4-6

Discussion Questions in Small Groups

- How can the tool improve retention, adherence, and/or psychosocial support for PMTCT clients?
- Who at your clinic could use the tool? When? In what situations?
- Where would the tool/forms be stored?
- Are there challenges (now or anticipated) in using this tool? Are there solutions to these challenges?
- What next steps would you take to use the tool in your clinic?

4-7

Remember:

- Tools can help health workers provide clients with retention, adherence, and psychosocial support
- It is important that the tools are used in combination with good counseling and within a supportive, welcoming, and client-friendly environment
- You will be supported and mentored on using the tools over time

4-8

"Saving 2 Lives" – A PMTCT Patient Education Video

- Created to reinforce key PMTCT messages with PMTCT clients, family members, and caregivers in an interesting, narrative format
- 3 distinct sections in the video (can be played all at once or one section at a time)
- Can be used in multiple settings (waiting room, group sessions, support group meetings, community meetings, etc.)
- Is most effective when discussion of the video is facilitated by a health worker, such as a peer educator, counselor, nurse, or support group leader

4-9

Video Discussion Questions

- What are your impressions of the video?
- How do you think the video could help reinforce key PMTCT messages with clients?
- How do you think the video could be used in your clinic?
- Who could use the video? When? Where? In what situations?
- How could health workers (especially nurses, counselors, and peer educators) facilitate the video to help clients get the most out of it?
- What next steps would you take to distribute and use the video in your clinic?
- Do you think there are additional uses for the video in a community setting? If yes, explain.

4-10

Module 4: Key Points

- All health workers should be up-to-date and knowledgeable about their national PMTCT guidelines.
- PMTCT clients, family members, and caregivers often have a number of retention, adherence, and psychosocial support needs that change over time and across the spectrum of care.
- Health workers can use the *pre- and post-test counseling checklists* as a guide when counseling and testing clients for HIV.
- Initiation of ARVs or ART among pregnant women should NOT be delayed for any reasons. Use the *Adherence Preparation and Support Guides* as a reminder of the key messages.
- Adherence should be assessed at each clinic visit and ongoing counseling and support provided throughout the PMTCT spectrum of care. Use the *Adherence Assessment and Follow-up Guides* to assist in this process.

4-11

Module 4: Key Points, con't.

- Adherence will change as clients move through the PMTCT spectrum of care so it is important to provide ongoing adherence assessment, counseling, and support at every visit.
- All clinics should institute an *appointment system*, including systematic follow-up of clients who miss appointments.
- The *PMTCT Video* may be used to reinforce key PMTCT messages with clients at the clinic or in the community.
- Each clinic should have a specific plan on how the Tools discussed in this Module are used.
- Retention, adherence, and psychosocial support are a part of everyone's job.
- When talking with clients, it is always important to use the 7 key counseling and communication skills (discussed in Supplemental Module 6).

4-12

Any Questions?

4-13

Module 5: Monitoring Retention and Adherence to PMTCT and Planning the Way Forward

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Module 5: Learning Objectives

- Discuss the importance of documentation, record keeping, and routing monitoring and evaluation in PMTCT services
- Understand the differences between program- and client-level monitoring of retention and adherence
- Describe available data that could be used to monitor retention and adherence at a program level
- Describe available data that could be used to monitor retention and adherence at an individual level
- Discuss which PMTCT materials will be prioritized for implementation at the clinic
- Develop a site-specific action plan to improve retention, adherence, and psychosocial support services, including roll out of the Toolkit materials
- Evaluate the implementation workshop

5-2

Discussion Questions

- Why is monitoring retention and adherence important?
- What are the differences between program-level monitoring and individual, client-level monitoring related to retention and adherence?
- What could routine monitoring tell us about the overall program's progress in terms of retention and adherence?
- What could routine monitoring tell us about an individual client's retention and adherence?

5-3

Monitoring and Evaluation (M&E) at Different Levels

- Necessary to gather and use information on:
  - Individual outcomes (are clients being retained in care, are clients adhering to care, are clients adhering to medicines?)
  - PMTCT program outcomes (is the program retaining clients overall, are mothers and babies completing the spectrum of PMTCT care?)
- Program outcomes are usually the cumulative tally of individual outcomes and can give insight into strengths and areas needing improvement within the program

Remember: Systems need to be developed and strengthened to monitor BOTH individual clients' retention and adherence, as well as the program's ability to retain clients in care and support adherence and psychosocial wellbeing.

5-4

Why M&E are Important at the *Facility* or *Program* Level

- To tell us if clients are being retained in care across the PMTCT spectrum
- To tell us how many and which types of PMTCT clients are receiving adherence support
- To show us the successes and gaps in our PMTCT retention, adherence, and psychosocial support services
- To give us a sense of the number of clients discontinuing PMTCT care and/or treatment or prophylaxis, and the trends in these numbers over time
- To help us understand what is and isn't working and to plan improvements to best meet the needs of clients

5-5

Why Record Keeping and M&E are Important at the *Individual* Level

- To tell us whether or not individual clients and their babies are retained in care
- To tell us whether or not individual clients are adhering to their own and their baby's PMTCT care plan and medications
- To help us follow adherence and psychosocial support issues of individual clients over time

5-6

Discussion Questions

- What type of program-level information do we currently have (e.g. in registers, pharmacy records, or the appointment system)? How can this be used to measure retention and adherence?
- What type of client-level information do we currently have on mothers and babies in the PMTCT program (e.g. in patient records)? How can this be used to measure retention and adherence?
- How could we improve monitoring and evaluation of adherence to PMTCT services and medicines in the future? At the program level? At the client level?

5-7

Discussion Questions

- Why is it important to keep records on each client?
- How are client records kept in your clinic? If there are no client records kept at the clinic, why not? What are the challenges?
- Are client retention and adherence and psychosocial services recorded and kept on file for PMTCT clients at your clinic? Why or why not? What are the challenges?
- How could we improve record keeping and ensure that each client has a file at your clinic?
- How could we improve record keeping and ensure that data are used for service strengthening at your clinic?

5-8

Remember:

- Documentation, monitoring, and evaluation of retention and adherence in PMTCT are important at BOTH the program and individual levels
- Systems need to be in place to support documentation, monitoring, and evaluation
- This can help ensure that clients get the support they need, that our work is documented, and that program data are used to strengthen services

5-9

Site-Specific Action Planning

- Implementing the entire Toolkit contents at the same time would be difficult, so we need to prioritize
- We are going to create a 6-month, site-specific action plan on improving retention, adherence, and psychosocial support activities – including use of the Tools
- The action plan will be used to prioritize site-support and mentoring of multidisciplinary teams

5-10

Keep These Standards in Mind

- We always need to follow the national PMTCT guidelines
- All pregnant and postpartum women living with HIV need ongoing retention, adherence, and psychosocial support throughout the PMTCT care spectrum
- All pregnant and postpartum women living with HIV need to have clear and correct information about their own and their baby's PMTCT care plan, as well as ongoing support for adherence to care and medicines
- Every PMTCT site, to the best of its ability, should have systems in place to retain pregnant and postpartum women living with HIV and their infants in care

5-11

Discussion Questions

- How would you prioritize rollout of the Tools at your site, given the current level of resources?
- What is your basis for prioritization?
- List the items in the Toolkit in order of priority for implementation and your site.

5-12

Let's Fill in the Action Planning Matrix
(see Appendix 5A)

Appendix 5A:
Action Plan for Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

Clinic Name: _____ **PMTCT Point Person's Name/Title:** _____ **Date:** _____

OBJECTIVE 1: *All pregnant and postpartum women living with HIV will receive ongoing retention, adherence, and psychosocial support throughout the PMTCT care spectrum.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

OBJECTIVE 2: *All pregnant and postpartum women living with HIV will have clear and correct information about their own and their baby's PMTCT care plan and ongoing support for adherence to care and medicines.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

5-13

Discussion Question

- From the list of activities in the action planning matrix, what are the immediate priorities (to be accomplished in the next 2-3 months)?
- What support, mentoring, and assistance are needed to ensure that these activities take place?

Note: Typed and printed copies of the action plan will be distributed to all participants and managers within 1 week

5-14

Reflection on Workshop Learning Objectives - 1

We agreed that, by the end of this workshop, participants would be able to:

1. Understand the changes to the national PMTCT guidelines and how they should be applied in clinical settings
2. Define the PMTCT spectrum of care
3. Define psychosocial and adherence support in the context of PMTCT services
4. Understand the importance of psychosocial and adherence support to meet the needs of women and families enrolled in PMTCT
5. Identify strategies to improve psychosocial and adherence support within PMTCT programs

5-15

Reflection on Workshop Learning Objectives - 2

6. Use counseling cue cards to conduct ongoing, supportive counseling for pregnant and postpartum women
7. Use checklists to improve pre- and post-test counseling in PMTCT settings
8. Conduct a psychosocial assessment and document key points and next steps, as well as make referrals
9. Use guides to conduct adherence preparation and support sessions with clients and to provide ongoing adherence assessment and follow-up
10. Develop and use an appointment system
11. Use a patient education video to reinforce key PMTCT messages
12. Use improved communication and counseling skills with clients

5-16

Please Share With the Group:

- One thing you have learned about retention, adherence, and psychosocial support for PMTCT clients during the workshop
- One thing that you will prioritize in your work to improve retention, adherence, and psychosocial support services for pregnant and postpartum women living with HIV and their families

5-17

Discussion of Next Steps

Workshop Evaluation

5-18

Thank you for your dedication, participation, and hard work to improve services for women, children, and families!

5-19

Supplemental Module 6: Review of Counseling & Communication Skills

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Module 6: Learning Objectives

- Describe the importance of effective communication and counseling skills in PMTCT care and treatment settings
- Discuss the basic principles of counseling and challenges to putting these principles into practice
- Discuss what is meant by shared confidentiality and why it is important
- Reflect on your own attitudes, values, and beliefs, and discuss how these may affect the quality of counseling
- Demonstrate the 7 key counseling and communication skills
- Understand the main components of a counseling session

6-2

What is counseling?

- Counseling is a two-way communication process that helps people look at their personal issues, make decisions, and plan how to take action

6-3

Counseling Includes:

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening carefully
- Helping people tell their stories without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognize and build on their strengths
- Helping people to develop a positive attitude toward life and to become more confident
- Respecting everyone's needs, values, culture, religion, and lifestyle

6-4

Counseling Does NOT Include:

- Solving another person's problems
- Telling another person what to do
- Making decisions for another person
- Blaming another person
- Interrogating or questioning another person
- Judging another person
- Preaching to, or lecturing, another person
- Making promises that cannot be kept
- Imposing one's own beliefs on another person
- Providing inaccurate information

6-5

Why Do We Do Counseling?

- To help people talk about, explore, and understand their thoughts and feelings
- To help people work out for themselves what they want to do and how they will do it

6-6

Confidentiality

- In order for clients to trust health workers with their feelings and problems, it is important for them to know that anything they say will be kept confidential
- This means that members of the multidisciplinary care team will not tell other people any information about the client
- Confidentiality is especially important in HIV programs because of the stigma surrounding HIV and discrimination against PLHIV
- Because multidisciplinary teams take care of clients, sometimes they need to discuss a client's needs and health status with one another to provide the best care possible. This is called **SHARED CONFIDENTIALITY.**

6-7

Discussion Question:

- Even though we know what good counseling is, why don't we always provide good counseling?

6-8

Values Clarification Activity

- What do we mean when we say "self awareness?"
- Why is it important for health workers to be aware of their own values, attitudes, and prejudices?

6-9

Remember:

- Although we ALL bring certain values and attitudes to our work, we must not let these values and attitudes affect the quality of counseling we provide to clients
- By striving to be self-aware, counselors can make sure they are equally supportive of all of their clients

6-10

7 Key Counseling and Communication Skills

1. Use helpful non-verbal communication
2. Actively listen and show interest in the client
3. Ask open-ended questions
4. Reflect back what the client is saying
5. Empathize – show that you understand how the client feels
6. Avoid words that sound judging
7. Help the client set goals and summarize each counseling session

See Appendix 6A: Counseling and Communication Skills Checklist

6-11

Skill 1: Use Helpful Non-verbal Communication

- Make eye contact
- Face the person
- Be relaxed and open with your posture
- Sit squarely facing the person. Do not sit behind a desk.
- Use good body language—nod your head and lean forward
- Smile
- Make the client feel that you have time
- Do not look at your watch, the clock, or anything other than the person you are counseling
- Try not to write during a counseling session
- Turn your mobile phone off

6-12

Skill 2: Actively Listen and Show Interest

- Listen in a way that shows respect, interest, and empathy.
- Show the client you are listening by saying *"mm-hmm"* or *"aha."*
- Use a calm tone of voice.
- Listen to what the client is saying—do you notice any themes?
- Listen to how the client is saying it--do they seem worried, angry, etc?
- Allow the client to express her emotions
- Never judge or impose your own values on a client
- Find a private place to talk and keep distractions to a minimum
- Do not do other tasks while counseling a client
- Do not interrupt the client
- Ask questions or gently probe if you need more information
- Use open-ended questions
- Summarize key points during the counseling session

6-13

Skill 3: Ask Open-ended Questions

- Open-ended questions cannot be answered in one word. People answer open-ended questions with more of an explanation. Examples of open-ended questions are, *"Can you tell me more about your relationship with your partner?"* or *"How does that make you feel?"*
- Open-ended questions are the best kind to ask during counseling and group education sessions because they encourage the client to talk openly and they lead to further discussion
- They help clients explain their feelings and concerns, and also help counselors get the information they need to help clients make decisions

6-14

Change into Open-ended Questions:

- Do you have safe sex?
- Do you have more than one sex partner?
- Do you use condoms?
- Do you drink alcohol when you are upset?
- Did your partner get tested?
- Do you want to have children in the future?
- Do you have someone you can talk with about taking your medicines the right way?
- Do you know how to prevent transmission of HIV to your baby?
- Do you exclusively breastfeed your baby?

6-15

Skill 4: Reflect Back What the Client is Saying

- Provides feedback to the client and lets her know that she has been listened to, understood, and accepted
- Encourages the client to say more
- Shows that the counselor has understood the client's story
- Helps the counselor check that he or she has understood the client's story
- Provides a good alternative to always answering with another question
- Can reflect the client's feelings and include a summary of the content of what the client has said (sometimes called paraphrasing)
- When reflecting back, try to say it in a slightly different way

6-16

Formulas for Reflecting

- "You feel _____ because _____."
- "You seem to feel that _____ because _____."
- "You think that _____ because _____."
- "So I sense that you feel _____ because _____."
- "I'm hearing that when _____ happened, you didn't know what to do."

6-17

Reflect Back to these Statements:

- I missed a lot of my pills this month and I feel hopeless.
- My boyfriend does not know my test results—I'm scared to tell him.
- I feel like a bad mother because my baby does not want to suckle from me.
- My husband would just get angry if I asked him to use a condom, so I am not going to ask.
- My husband thinks it's dangerous to give the baby medicines and I am afraid of disobeying him.
- I am worried because my mother-in-law will assume I am living with HIV if I don't give the baby herbs.
- I feel so happy that my baby is growing well.

6-18

Skill 5: Empathize—Show That You Understand How the Client Feels

Empathy or empathizing:

- Is a skill used in response to an emotional statement
- Shows an understanding of how the client feels and encourages the client to discuss the issue further
- Is different than sympathy. When you sympathize, you feel sorry for a person and look at the situation from your own point of view.

6-19

Skill 6: Avoid Words That Sound Judging

Judging words include**:**

- *"right"*: You should do the right thing.
- *"wrong"*: That is the wrong way to feel.
- *"badly"*: Why are you behaving badly and missing appointments?
- *"good"*: Be a good girl and tell your boyfriend to use condoms.
- *"properly"*: Why don't you take your medicine properly?
- *"these people"* or *"those people"*: Those people are irresponsible and should not have children.

- If a counselor uses these words when asking questions, the client may feel that she is wrong, or that there is something wrong with her actions or feelings.
- Sometimes, however, counselors need to use the "good" judging words to build a client's confidence.

6-20

Skill 7: Help the Client Set Goals and Summarize Each Session

Next steps and goals:

- Should be developed by the counselor and client together
- Can empower the client to achieve what she wants by agreeing to realistic short- and long-term goals and actions
- Should provide direction and must be results-oriented
- Must be clear enough to help the client measure her own progress (people feel good when they achieve something they have set out to do)
- To start, the counselor could say, *"Okay, now let's think about the things you will do this week based on what we talked about."*

6-21

Summarizing:

- The counselor summarizes what has been said during a counseling session and clarifies the major ideas and next steps.
- Can be useful in an ongoing counseling session or in making sure you are clear on important issues raised during a counseling session
- Is best when both the counselor and client participate and agree with the summary
- Provides an opportunity for the counselor to encourage the client to examine her feelings about the session
- The counselor could say, *"I think we've talked about a lot of important things today.* (List main points.) *We agreed that the best next steps are to* _____. *Does that sound right? Let's plan a time to talk again soon."*

6-22

The 4 Phases of a Counseling Session

1. Establishing the relationship
2. Understanding the problem
3. Supporting decision-making
4. Ending the session

6-23

1. Establishing the Relationship

- The room should be quiet with doors that close and where there are no interruptions
- **Introduce yourself:** Say your name and explain your role and the length of time you have together
- **Ask the client to introduce herself or himself**
- **Explain that what is discussed will be kept confidential**
- Ways to begin a counseling session:
  - *Can you tell me why you came here today?*
  - *Where would you like to start?*

6-24

2. Understanding the Problem

- Let the client talk about the thoughts, feelings, and actions around her or his issues or problems
- Use the 7 essential counseling and communication skills
- Help the client decide which issues or problems are the most important to talk about in the session

3. Support Decision-Making

- Support the client to make her or his own decisions on next steps and focus for the future
- The health worker can help the client explore the options, but it is ultimately the client's decision to make

6-25

4. Ending the Session

- Summarize what was discussed during session
- Review the client's next steps
- Give the client a chance to ask questions
- Make referrals, if needed
- Discuss when the client will return and make sure she or he has an appointment

6-26

Case Studies and Role Plays in Small Groups

6-27

Module 6: Key Points

- Counseling is a way of working with people to understand how they feel and help them decide what they think is best.
- Health workers are not responsible for solving all of their client's problems.
- The role of health workers is to support and assist the client's decision-making process.
- It is important for clients to know that what they say will be kept private. Practice shared confidentiality.
- Ensure that there is private counseling space available and that counseling sessions are not interrupted for any reason.

6-28

Module 6: Key Points, con't.

- Our own attitudes, values, and prejudices should not be a part of communication and counseling with clients and other communities.
- There are the 7 key counseling and communication skills health workers should use.
- There are 4 main phases of a counseling session.
- There can be many challenges to providing quality counseling in PMTCT and ART clinics, including lack of time and lack of private counseling space.
- Improving counseling skills takes practice, as well as continuous self-exploration of our own values and attitudes.

6-29

Any Questions?

6-30

III.

Using the Toolkit Materials:

Implementation Workshop Participant Manual

ICAP International Center for AIDS Care and Treatment • Mailman School of Public Health • Columbia University

Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

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Implementation Workshop Curriculum for Health Workers

Participant's Manual
2010

ICAP
International Center for AIDS Care and Treatment Programs
MAILMAN SCHOOL OF PUBLIC HEALTH
Columbia University

Table of Contents

List of Acronyms

ANC	Antenatal care
ART	Antiretroviral therapy/treatment
ARV	Antiretroviral
CD4	Cluster of differentiation 4 cell
CTX	cotrimoxazole
PCR	Polymerase chain reaction
HIV	Human Immunodeficiency Virus
ICAP	International Center for AIDS Care and Treatment Programs
MDT	Multidisciplinary Team
NVP	nevirapine
PLHIV	Person (or people) living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
SMS	Short message service (text message)
WHO	World Health Organization

MODULE 1:
Introduction and PMTCT Update

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Know more about workshop participants and trainers
- Understand the workshop goal, objectives, and agenda
- Discuss changes and updates to the national PMTCT guidelines

CONTENT:

Session 1.1: Introductions and Overview of the Workshop

Session 1.2: PMTCT Update

SESSION 1.1:
Introductions and Overview of the Workshop

Implementation Workshop Goal and Objectives

Workshop Goal: This on-site implementation workshop for multidisciplinary team members working in PMTCT settings is intended to improve knowledge, skills, and confidence in improving retention and providing adherence and psychosocial support services throughout the PMTCT spectrum of care.

Workshop Objectives:

By the end of the implementation workshop, participants will be able to:

1. Understand changes to the national PMTCT guidelines and how they should be applied in clinical settings.
2. Define the PMTCT spectrum of care.
3. Define retention, adherence, and psychosocial support in the context of the PMTCT spectrum of care.
4. Understand the importance of retention, adherence, and psychosocial support to meet the needs of women and families enrolled in PMTCT services.
5. Identify strategies to improve retention, adherence, and psychosocial support within PMTCT programs.
6. Use counseling cue cards to conduct ongoing, supportive counseling for pregnant and postpartum women and their family members.
7. Use checklists to improve pre- and post-test counseling services for pregnant women, family members, and children.
8. Conduct a psychosocial assessment and document key points and next steps, as well as make necessary referrals.
9. Use guides to conduct adherence preparation and support sessions with clients and to provide ongoing adherence assessment and follow-up with clients.
10. Develop and use an appointment book and appointment reminder cards in PMTCT settings.
11. Use a patient education video to reinforce key messages on PMTCT with clients and family members.
12. Use improved communication and counseling skills with clients and family members (specific to Supplemental Module 6).

SESSION 1.2:
PMTCT Update

Please see the Slide Set for Module 1.

MODULE 2:
Retention, Adherence, and Psychosocial Support in PMTCT Programs

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Define the terms "retention," "adherence," and "psychosocial support"
- Understand the importance of retention, adherence, and psychosocial support in PMTCT programs
- Identify common barriers to retention, adherence, and psychosocial wellbeing among PMTCT clients, including those related to health services
- Identify challenges to providing quality retention, adherence, and psychosocial support services in the PMTCT setting
- Identify strategies to improve retention, adherence, and psychosocial support within the PMTCT program and throughout the PMTCT spectrum of care

CONTENT:

SESSION 2.1:
Retention, Adherence, and Psychosocial Support Basics

Definition of retention:

Retention refers to keeping (or "retaining") clients in the care program, in this case throughout the spectrum of PMTCT care and services. A goal of all PMTCT programs is to retain women and their babies in the full program of care.

- For women who test positive for HIV, this means that they stay in care during pregnancy and throughout the period of breastfeeding. They are also enrolled in HIV care and treatment, with some women starting lifelong ART and others being monitored for eligibility.
- For HIV-exposed babies, this means staying in care until a final HIV infection status is determined, usually once breastfeeding has ended. For babies who become HIV-infected, this also means enrolling in HIV care services and starting ART as quickly as possible.

Definition of adherence:

The standard clinical definition of adherence has been taking at least 95% of medications the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, such as following a care plan, attending scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.

Adherence describes how faithfully a person sticks to and participates in her or his HIV prevention, care, and treatment plan.

Adherence support is an important part of psychosocial support services and PMTCT and HIV clinical care services.

Key concepts of adherence:

Adherence:

- Is not the same as compliance and includes much more than following the doctor's orders
- Includes active participation of the client in her care plan
- Depends on a shared decision-making process between the client and health care providers
- Includes adherence to both care and to medicines
- Impacts the success of PMTCT and HIV care and treatment programs
- Changes over time

Adherence to PMTCT and HIV care includes:

- Entering into and continuing on a care and treatment plan (sometimes this is also called "retention in care")
- Taking medicines to prevent and treat opportunistic infections
- Planning for/having a safe delivery in a health facility
- Practicing safer infant feeding practices
- Bringing the baby back often for checkups and for HIV testing at 6 weeks and then again when the baby is weaned.
- Participating in ongoing education and counseling

- Attending appointments and tests (such as antenatal and postnatal appointments and regular CD4 tests) as scheduled
- Picking up medications for self and the child when scheduled, before running out
- Adopting a healthy lifestyle and understanding and minimizing risk behaviors, as much as is possible
- Recognizing when there is a problem or a change in health and coming to the clinic for care and support

Remember: ALL PREGNANT WOMEN LIVING WITH HIV NEED TO TAKE ARVs, THE RIGHT WAY, EVERY DOSE, EVERY DAY!

Adherence to HIV treatment includes:

- Taking ARVs correctly, as prescribed, even if the person feels healthy
- For women who are eligible for ART, taking ARVs as prescribed for their entire life—every pill, every day, for life
- Taking other medicines, such as cotrimoxazole, as prescribed
- Giving medications, including ARVs and cotrimoxazole, to HIV-exposed and HIV-infected babies and children as prescribed
- Not taking any breaks from treatment

Non-adherence to care and treatment includes:

- Missing one or many appointments at the hospital or health center, lab, or pharmacy – for the client or her baby
- Not following the care plan—of the client or her baby—and not communicating difficulties in following the care plan to health workers
- Missing one or more doses of medicine, or not giving the baby doses on time
- Sharing medicines with other people
- Stopping medicine for a day or many days (taking a treatment "break")
- Taking or giving medicines at different times than recommended by health workers
- Taking or giving medicines without following instructions about food or diet
- Not minimizing risk-taking behavior (for example, not practicing safer sex or not delivering a baby with a trained health care provider). Note that reducing risk-taking often depends on multiple factors and support from others (partner, family), so the ability to do so will depend on the client's specific situation.

Remember: NO ONE IS PERFECT. It is important not to judge clients if they are non-adherent. Instead, we should try to uncover the underlying causes of non-adherence and help find ways to resume good adherence as soon as possible.

Why is near-perfect adherence to PMTCT and ART medications important?

- To reduce the chance of MTCT at all stages (e.g. during pregnancy, during labor and delivery, during breastfeeding)
- To ensure that ART and other medications do their job and keep clients healthy
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid the body becoming resistant to certain medicines
- To make sure the person gets all the benefits that ARVs and other medicines have to offer, such as feeling better, not getting opportunistic infections, etc.
- To monitor the person's health and also to help her find community support resources for herself and her family
- To keep the person looking and feeling good so that she can get back to normal life
- To keep families, communities, and our nation healthy and productive

What happens when a person doesn't adhere to his or her care and treatment plan?

- The levels of drugs in the body drop and HIV keeps multiplying.
- A baby is more likely to acquire HIV from his or her mother during pregnancy, delivery, or breastfeeding.
- The CD4 count will drop and the person will start getting more opportunistic infections.
- Children in particular will become ill very quickly.
- It is more likely that the person will pass HIV to others (during unprotected sex, for example).
- The person might become depressed or de-motivated due to illness or physical deterioration.
- The person can develop resistance to one or all of the drugs, meaning that the drugs will not work anymore even if they are taken correctly again. We can say that HIV is a very "smart" virus—it only takes a couple of missed doses for it to learn how to be stronger than the ARVs, to multiply, and to take over the body again.
- The person may have to start taking a new regimen or second-line ARVs. In many countries, there aren't many kinds of ARVs available, so individuals with poor adherence may run out of medication options.

Definition of psychosocial support:

Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV (PLHIV), their partners, their family, and caregivers of children living with HIV. In the context of PMTCT services, psychosocial support addresses the psychological, social, and adherence needs of pregnant and postpartum women, their partners and families, and children throughout the spectrum of PMTCT care.

Remember: Since pregnancy is a relatively short period of time, it is very important to assess and support pregnant women's psychosocial support needs as soon as they are enrolled in ANC and PMTCT services.

It is important to provide psychosocial support to pregnant women and family members because:

- HIV affects all dimensions of a person's life: physical, psychological, social, and spiritual.
- A woman who has just learned her HIV-status during prenatal HIV testing may need support in understanding and adjusting to this information, as well as planning what is going to happen next.
- It can help clients and caregivers cope more effectively with HIV and enhance their own and their children's quality of life.
- It can help facilitate the disclosure process.
- It can create opportunities to provide pregnant women and their families with needed information, specific to their situation.
- It can help clients gain confidence in themselves and their skills (coping with chronic illness, dealing with stigma or discrimination, adhering to the care and treatment plan, dealing with taking/giving medications every day, caring for an HIV-exposed or HIV-infected child, etc.).
- It can help build a trusting relationship between the client and the health worker.
- It can sometimes prevent more serious mental health issues from developing (like anxiety, depression, or withdrawal).
- Psychosocial wellbeing is related to better adherence to PMTCT and HIV care and treatment.
- Mental health is closely linked to physical health and wellbeing.
- It can provide people (or link people) with needed social, housing, and legal services.
- It can help people mentally and practically prepare for difficult circumstances, like ill health, having an HIV-infected baby, etc.
- When people can come together to solve problems and support one another, movements for change, acceptance, and advocacy are born.

Retention, adherence, and psychosocial support are interrelated. A client is more likely to be retained in PMTCT care and adhere to her own and her baby's care and treatment if she receives ongoing information, education, and support at the clinic, in the community, and at home.

SESSION 2.2:
Improving Retention, Adherence, and Psychosocial Support in PMTCT Programs

Why don't clients stay in care and adhere to care and treatment?

- Most clients want to adhere to their own and their baby's care and treatment, but many times there are barriers that make this a challenge.
- Some of the barriers have to do with the client herself, her family situation, or characteristics of her community.
- Often, the health system itself creates challenges to retention, adherence, and psychosocial wellbeing.
- While the focus of this curriculum is not on these issues per se, they are extremely important and all health workers play a role in trying to make the system better as an individual and as part of a program.
- Retention, adherence, and psychosocial wellbeing can be improved when the client has clear information and practical guidance about her own and her baby's care and medications, as well as other aspects of PMTCT, such as safe infant feeding.
- It is important for health workers to have all of the information and present it to the client and her family using good counseling and communication skills and in ways that are easy to understand.

Factors affecting retention, adherence, and psychosocial wellbeing

Factors about health services (note that as health workers, these are the factors that we have the most control in addressing and minimizing):

- Health worker attitudes
- Health worker language abilities
- Time available for individual counseling
- Space available for individual counseling
- Skills of counselors and other service providers
- Multidisciplinary approach to supporting adherence and psychosocial wellbeing
- Availability of tools to support quality counseling
- Standard procedures to assess and counsel on adherence at every visit
- PLHIV involvement in service delivery
- Drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of health workers
- Youth-friendliness of services
- Waiting times
- Linkages between different services
- Referral systems
- Linkages to community services and support
- Support groups

Factors about individual people:

- How well they think they can adhere
- Acceptance of HIV-status
- Ability to disclose
- Acceptance of HIV-status and level of support from family
- Having a treatment supporter
- Understanding the benefits of HIV care and treatment and PMTCT services
- Quality of life while on treatment
- How sick or well people feel
- Travel and migration
- Health status
- Mental illness, like depression
- Drug or alcohol abuse
- Concern for the family's wellbeing

Factors about our communities and our culture:

- Poverty
- Lack of food
- Stigma
- Social support at home and in the community
- Access to correct information
- Lack of childcare to attend clinic
- Ability to take time off work to attend clinic
- Family structure and decision-making
- Gender inequality
- Violence
- Forced migration
- Distrust of the clinic/hospital
- Use of traditional medicine
- Political instability or war
- Physical environment, e.g., mountainous, seasonal flooding, etc.

Factors about medicines:

- Side effects
- Number of pills in regimen
- Dose timing
- Need to take with food
- Availability of reminder cues—pill boxes, calendars, alarms, etc.
- Taste
- Changing pediatric doses
- Changes in drug supplier—changes in labeling, pill size, color, formulation
- Portability of medicines, especially syrups

THE PMTCT CARE SPECTRUM FOR WOMEN

THE PMTCT CARE SPECTRUM FOR CHILDREN

SESSION 2.3:
Case Studies

Case Studies

Case Study 1:

P___ is 18 years old, pregnant, and tested positive for HIV during her first ANC visit. During your session with P___, she discloses that it will be difficult for her to take medicines because she can't disclose to anybody. She expresses her fears of her boyfriend throwing her out of the house and not supporting her, but she really wants to protect her unborn baby.

Questions:

- ***What are the most important issues for P___ right now?***
- ***What kind of psychosocial support do you think P___ needs?***
- ***What kind of adherence support does P___ need?***
- ***What would your plan be for the current session with P___? What would you discuss?***
- ***How would you document your session and the next steps you agree upon with P___?***
- ***What roles would different members of the multidisciplinary team take in P___'s care and counseling?***
- ***What tools would help you, the health worker, provide quality counseling and care to P___?***
- ***Would you provide any referrals for P___? If yes, describe. How would you document this and find out if she went where she was referred?***

Case Study 2:

N___ is married and has 4 children. She is 5 months pregnant and at her last ANC visit she was referred to the ART clinic because her CD4 count was 200. She missed her next ANC visit, but returns to the clinic a few weeks later. When you meet with her, N___ says that she went to the ART clinic, but left because there was a long queue and people were gossiping about her. She decided she does not want to take any ARV medications and is feeling fine.

Questions:

- ***What are the most important issues for N___ right now?***
- ***What kind of psychosocial support do you think N___ needs?***
- ***What kind of adherence support does N___ need?***
- ***What would your plan be for the current session with N___? What would you discuss?***
- ***How would you document your session and the next steps you agree upon with N___?***
- ***What roles would different members of the multidisciplinary team take in N___'s care and counseling?***
- ***What tools would help you, the health worker, provide quality counseling and care to N___?***
- ***Would you provide any referrals for N___? If yes, describe. How would you document this and find out if she went where she was referred?***

Case Study 3:

M___ delivered her baby, a girl, 9 weeks ago. M___ took ARVs during her pregnancy and delivered at a health facility. She missed her 6-week postpartum visit, but comes to the clinic a couple of weeks later for a well-child visit. The baby was given ARVs at birth, but M___ said she has not been able to give the baby medications at home because she doesn't want her family to be suspicious. Right now, neither the baby nor M___ is taking any medications. The baby doesn't seem to be gaining very much weight even though M___ says she breastfeeds often.

Questions:

- ***What are the most important issues for M___ right now?***
- ***What kind of psychosocial support do you think M___ needs?***
- ***What kind of adherence support does M___ need?***
- ***What would your plan be for the current session with M___? What would you discuss?***
- ***How would you document your session and the next steps you agree upon with M___?***
- ***What roles would different members of the multidisciplinary team take in M___'s care and counseling?***
- ***What tools would help you, the health worker, provide quality counseling and care to M___?***
- ***Would you provide any referrals for M___? If yes, describe. How would you document this and find out if she went where she was referred?***

SESSION 2.4:
Module Summary

THE KEY POINTS OF THIS MODULE INCLUDE:

- Retention refers to keeping clients (and their babies) in the care program, throughout the spectrum of PMTCT care.
- Adherence means how faithfully a person sticks to, and participates in, her or his HIV care and treatment plan.
- Adherence to PMTCT and HIV care is important to make sure women and babies stay healthy, get the ongoing care they need, understand how to live positively, know when and how to start ARVs or ART, and get psychosocial support.
- Adherence to medications is important to lower the amount of HIV in the body, to lower the chances that the baby will acquire HIV, and to make sure women and babies get all the benefits that ARVs and other medicines have to offer for their own health.
- Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV, their family, and caregivers of children living with HIV.
- Retention, adherence, and psychosocial support are interrelated. A client is more likely to be retained in PMTCT care and adhere to her own and her baby's care and treatment if she receives ongoing information, education, and support at the clinic, in the community, and in her family.
- There are many barriers and challenges to retention, adherence, and psychosocial wellbeing, including things related to people's lives, to our culture, to the health care program, and to the medicines themselves.
- Retention, adherence, and psychosocial support are important services in PMTCT programs and throughout the PMTCT spectrum of care—from the time before a woman gets pregnant, through her pregnancy and delivery, the postpartum period, weaning, and until there is a final infection status for the child.
- The entire multidisciplinary team is responsible for providing retention, adherence, and psychosocial support to pregnant and postpartum women.

MODULE 3:
Using the PMTCT Counseling Cue Cards

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Understand why the PMTCT counseling cue cards were developed and how they can be used by health workers
- Discuss how the PMTCT counseling cue cards could be used in their clinic setting
- Be familiar with the key messages in each of the counseling cue cards
- Use the PMTCT counseling cue cards as an aide/guide when working with clients in various stages of the PMTCT care spectrum

CONTENT:

SESSION 3.1:
Overview of the PMTCT Counseling Cue Cards

How to Use the Counseling Cue Cards

The counseling cue cards were developed to support a range of providers who work with pregnant women living with HIV and their families.

Each of the cards focuses on a specific topic important to the care and support of pregnant women living with HIV, their children, and families across the PMTCT continuum of care. Providers may use the cue cards as job aides and reminders of key information to cover during initial post-test and ongoing counseling sessions with pregnant women and newly delivered mothers, their partners, family members, and supporters. The cue cards do not have to be used in sequence, but instead should be used according to the client's specific needs and concerns during the session.

Good counseling and communication skills, such as active listening, being attentive to the client's questions and needs, and avoiding one-way communication, should always be used, no matter what the counseling topic.

Counseling Cue Card Topics:

1. PMTCT Basics
2. Staying Healthy During Your Pregnancy
3. Adhering to Your PMTCT Care Plan
4. Preparing to Start and Adhere to Lifelong ART
5. Continuing and Adhering to ART During Pregnancy
6. Preparing to Start and Adhere to AZT Prophylaxis
7. Preparing to Start and Adhere to ART Prophylaxis
8. HIV Testing for Your Partner and Family Members
9. Disclosing Your HIV-Status
10. Being Part of a Discordant Couple
11. Having a Safe Labor and Delivery
12. Taking Care of Yourself After Your Baby is Born
13. Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines
14. Safely Feeding Your Baby
15. Exclusively Breastfeeding Your Baby
16. Exclusively Replacement Feeding Your Baby
17. Introducing Complementary Foods to Your Child at 6 Months
18. Making Decisions About Future Childbearing and Family Planning
19. Testing your Baby or Child for HIV
20. Caring for Your HIV-Infected Baby or Child and Adhering Care and Medicines

Please note:

- **Key questions** are included in *italics*, and may be used to initiate discussions, learn more about what the client already knows and her specific concerns, and to gauge understanding and elicit follow-up questions.
- **Notes to guide counselors** are also included in *italics*.
- The margins of each card contain **cross-references** to other cards on relevant topics (for example, if infant feeding is mentioned, there will be a cross-reference to the specific cue cards addressing infant feeding to which the provider may want to refer).

SESSION 3.2:
Classroom Practicum on Using the PMTCT Counseling Cue Cards

Case Studies:

Case Study 1:

N___ is 14 weeks pregnant and just came to the antenatal clinic for her first visit. You deliver the news that her HIV test was positive and provide post-test counseling. After talking with her, you sense that she does not have very much information on PMTCT. Counsel N___ on the key things she needs to know about PMTCT and having a healthy pregnancy.
(see PMTCT Basics, Staying Healthy During Your Pregnancy, HIV Testing for Your Partner and Family Members, and Adhering to Your PMTCT Care Plan cue cards)

Case Study 2:

J___ is enrolled in the PMTCT program and will begin prophylaxis now that she is 14 weeks pregnant (and her CD4 count is 500). Counsel her on adherence to her PMTCT care plan and her prophylaxis regimen. Also talk with her about planning to have a safe labor and delivery.
(see Adhering to Your PMTCT Care Plan, Preparing to Start and Adhere to AZT or ART Prophylaxis [depending on national guidelines], and Having a Safe Labor and Delivery cue cards)

Case Study 3:

L___ is enrolled in the PMTCT program. She began taking ART about one month ago, but complains that she is not feeling well and says that she wants to stop taking the medicine. Counsel L___ on having a healthy pregnancy, on why ART is important, and on how she can adhere to her care plan and ART.
(see Adhering to Your PMTCT Care Plan, Preparing to Start and Adhere to Lifelong ART, and Staying Healthy During Your Pregnancy cue cards)

Case Study 4:

T___ has been on ART for about 3 years and her CD4 count is high. You meet her at the ANC clinic, where she is enrolled in the PMTCT program. She is worried that the ART she has been taking will hurt her baby. Counsel T___ on adherence to her PMTCT care plan and ART, and also on how she can safely breastfeed her baby once he or she is born.
(see Adhering to Your PMTCT Care Plan, Continuing and Adhering to Your ART During Pregnancy, and Safely Feeding Your Baby – Breastfeeding cue cards)

Case Study 5:

A___ tests positive for HIV at her first antenatal visit. She is shocked and says she's only ever had sex with her husband. She has 2 other young children at home, but A___ says she has never thought about testing them for HIV since they are healthy. She is afraid to talk to her husband about her test result and says she will just keep it to herself. Counsel A___ on PMTCT basics, as well as on HIV testing for her husband and children, and disclosure to someone she trusts.
(see PMTCT Basics, HIV Testing for Your Partner and Family Members, and Disclosing Your HIV-Status cue cards)

Case Study 6:

M___ found out that she is HIV-infected 7 months ago, while she was pregnant. She just gave birth to a baby girl and doesn't think it's safe for her to breastfeed the baby. She is willing to do anything to make sure her daughter remains HIV-uninfected. However, she also has to return to work soon and has 2 other children to support. M___ has not told her boyfriend about her or the baby's HIV-status. Counsel M___ on taking care of herself, talking with her partner, and caring for her HIV-exposed daughter.

(see HIV Testing for Your Partner and Family Members, Disclosing Your HIV-Status, Taking Care of Yourself After Your Baby is Born; Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

Case Study 7:

B___ is a client in the PMTCT program. She gave birth to her son about 2 months ago. She missed the baby's 6-week follow-up appointment, but returns to the clinic 2 weeks later. B___ is breastfeeding her son, but complains that her nipples are very sore. B___'s family does not know she is HIV-infected and she is having trouble remembering to give her baby nevirapine. Counsel B___ on disclosure, adherence to care and medicines for her HIV-exposed baby, HIV testing for the baby, and also on safely feeding her baby.

(see Disclosing Your HIV-Status, Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

Case Study 8:

P___ returns for her 8-week old baby's HIV test results. The results show that the baby is HIV-uninfected. P___ is exclusively breastfeeding her baby and taking lifelong ART. P___ is very happy about the results and says she thinks she should stop breastfeeding immediately since her baby is negative. Counsel P___ on caring for her HIV-exposed baby, safe breastfeeding and when to retest the baby, and on being part of a discordant couple.

(see Caring for Your HIV-Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

Case Study 9:

C___ is a client in the PMTCT program and is taking lifelong ART. She recently delivered a healthy baby boy, who tested HIV-negative at 6 weeks. C___ comes back to the clinic for a checkup. She says she really wants to have another child in a couple of years, but that her husband does not think it's worth the risk of the baby being HIV-infected. C___'s husband is HIV-uninfected. Counsel C___ on how she can make safe decisions about having children in the future, how she can prevent or space pregnancies now, and about being part of a discordant couple.

(see Making Decisions About Future Childbearing and Family Planning and Being Part of a Discordant Couple cue cards)

Case Study 10:

V___ is the primary caregiver of her 8-month old nephew, who has been sick a lot and is not gaining weight. She is shocked to learn that the baby is HIV-infected and had no idea that her sister was HIV-infected. She feels frustrated because she already is caring for her own children and doesn't have much money or time to keep bringing her nephew to the clinic. Counsel V___ on caring for her HIV-infected nephew, including on adherence to care and medicines.

(see Caring for Your HIV-infected Child and Adhering to Care and Medicines cue card)

SESSION 3.3:
Module Summary

THE KEY POINTS OF THIS MODULE INCLUDE:

- All health workers should be up-to-date and knowledgeable about their national PMTCT guidelines.
- Pregnant and postpartum women and caregivers of HIV-exposed and HIV-infected babies and children often have a number of retention, adherence, and psychosocial support needs that may change over time.
- Quality communication and counseling in the PMTCT setting can lead to increased retention, adherence, and psychosocial wellbeing among clients.
- Health workers can use counseling cue cards to help explain the basics of PMTCT care and remember key counseling messages for clients in different places along the PMTCT care spectrum.
- Each clinic should have a specific plan on how the counseling cue cards are used (who, when, where, how, etc.).
- Counseling is a part of everyone's job and all multidisciplinary team members should be familiar with and have copies of the counseling cue cards.
- When talking with clients, it is always important to use the 7 key counseling and communication skills (discussed in Supplemental Module 6).

MODULE 4:
Using the PMTCT Checklists, Guides, Forms, and Video

LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Discuss the importance and relevance of each of the PMTCT Tools within the Toolkit
- Conduct pre-test and post-test education and counseling sessions with clients, using structured checklists
- Conduct a psychosocial assessment and fill in the psychosocial assessment reporting form
- Conduct and document adherence preparation and support counseling with clients, using a guide and reporting form
- Conduct and document adherence assessments and follow-up counseling with clients, using a guide and reporting form
- Discuss the importance of having an appointment system in PMTCT settings and how to use an appointment book and appointment reminder cards
- Describe how each PMTCT Tool might be applied in their specific clinic setting
- Discuss how to use the PMTCT video in their clinic and/or community settings

CONTENT:

SESSION 4.1:
Overview of the PMTCT Checklists, Guides, and Forms

Please see the "How to Use…" sections and individual tools in the Toolkit for more information.

There are 5 sets of forms and guides in the Toolkit:

- **PMTCT Pre- and Post- HIV Test Counseling Checklists** to be used by health workers when providing pre- and post- test counseling to PMTCT clients

Pre-test information and education sessions and individual post-test counseling should be conducted with clients.

- **A PMTCT Psychosocial Assessment Guide and Reporting Form** to be used by health workers when conducting initial and follow-up psychosocial assessments with PMTCT clients

It is recommended that a psychosocial assessment be conducted with all clients upon entry into the PMTCT program.

- **Adherence Preparation and Support Guides** to be used by health workers to help clients prepare to adhere to their own (and their baby's) care and treatment plans and when providing ongoing adherence support

Initiation of ARVs or ART among pregnant women should NOT be delayed for any reason. Basic adherence preparation should be conducted in 1 visit (if possible) and follow-up adherence counseling provided at each subsequent clinic visit.

- **Adherence Assessment and Follow-up Guides** to be used by health workers to assess adherence and learn more about adherence challenges the client may be facing, as well as to provide ongoing adherence support

Adherence should be assessed at each clinic visit and ongoing counseling and support provided throughout the PMTCT spectrum of care.

- **Appointment Book and Appointment Reminder Card Templates** to be adapted and implemented at the clinic level in order to help keep track of appointments and to help trace clients lost to follow-up, as well as to help clients keep track of upcoming appointments

Functional appointment systems are the cornerstone of retention and adherence to PMTCT care. All clinics should have an appointment system, including systematic follow-up of clients who miss appointments.

SESSION 4.2:
Practical Session on Using the PMTCT Forms and Guides

Case Studies for Each of the 5 Tools:

1. Counseling checklists for HIV testing in antenatal care settings

Part A:
You are leading a group pre-test information session for pregnant women at the clinic. What would you say in the session? Use the checklist as a guide.

Part B:
O___ is a pregnant woman coming for her first antenatal appointment. She received HIV testing and her results are negative. Provide O___ with post-test counseling. Use the checklist as a guide.

Part C:
F___ is a pregnant woman who decided to be tested for HIV at her second antenatal visit. Her test results are positive. Provide F___ with post-test counseling. Use the checklist as a guide.

2. Psychosocial assessment guide and recording form

Part A:
G___ is a newly enrolled PMTCT client. Conduct a psychosocial assessment with G___. Be sure to complete the psychosocial assessment recording form.

Part B:
W___ is a client in the PMTCT program. She delivered a baby girl 6 weeks ago and has returned to the clinic for the 6-week checkup. Conduct a psychosocial assessment with W___. Be sure to complete the psychosocial assessment recording form.

3. Adherence preparation and support guides

Part A:
F___ is 14 weeks pregnant and her CD4 count is 650, so she will be starting PMTCT prophylaxis. Counsel and prepare F___ on adherence to her care and the ARVs that she will be given today. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

Part B:
S___ is pregnant and just started taking lifelong ART 2 weeks ago. Counsel and prepare S___ on adherence to her care and ART. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

Part C:
P___ goes for her first visit at the antenatal clinic. She has been taking ART for the last 3 years and is excited to have a baby. Counsel her on adherence to ART during her pregnancy and for life. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

Part D:
X___ is the primary caregiver of her sister's 1-month old baby. The baby, named C___ is HIV-exposed. Counsel X___ on adherence to the baby's care and medicines. Use the appropriate Adherence Preparation and Support Guide, being sure to take notes on the form.

4. Adherence assessment and follow-up guides

Part A:
R___ returns for her monthly antenatal visit and ARV refill. Assess R___'s adherence and provide follow-up adherence counseling and support.

Part B:
H___ is caring for her 3-month old baby, who is HIV-exposed and breastfeeding. The baby's 6 week PCR test was negative. They return for a checkup and medication refill. Assess H___ and the baby's adherence and provide follow-up adherence counseling and support.

5. Appointment book and appointment reminder card templates

Part A:
B___ is a PMTCT client. She needs to make a follow-up appointment for an ARV refill and checkup. Make a follow-up appointment with B___ being sure to fill in the appointment book and to give her an appointment reminder card to take home.

Part B:
I___ is a PMTCT client that was scheduled to come in for a checkup and refill on Monday. It is now Friday and I___ has not come to the clinic. How would you complete the appointment book and what next steps would you take?

SESSION 4.3:
Orientation to the PMTCT Video

How to Use the PMTCT Patient Education Video:

"Saving Two Lives: A Patient Education Video on Adherence to PMTCT" was created to reinforce key PMTCT messages with clients, their family members, caregivers, and community members. The video was filmed in Port Elizabeth, South Africa and most of the actors are actual nurses, peer educators, mother mentors, and community members from the area.

The video was developed as a generic product, so while it may not completely reflect the specifics of PMTCT care in all countries, it is still useful in promoting the key concepts of PMTCT, including retention, adherence, and the importance of psychosocial support. The video is in English, so careful facilitation is especially required in settings where viewers do not use English as a first language.

The video is divided into specific scenes. It may be played in its entirety, or by section, depending on the time available and the audience.

- In the first scene, the viewer is introduced to Hope, a young woman who lives with her husband and mother-in-law. Hope goes to the clinic for her first ANC visit (despite her mother-in-law's insistence that this is a waste of time), where she is tested for HIV, and learns that she is HIV-infected. The nurse at the clinic gives Hope information on the meaning of her test results and how she can prevent MTCT. Afterwards, Hope meets an experienced mother and PMTCT client, Janet, who gives her information and support on what she needs to do to prevent MTCT.
- In the second scene, Janet returns to the clinic with Hope one week after they met. Hope picks up her CD4 test results and prepares to start taking ARVs. The nurse and Janet give Hope practical advice on how she can lower the chances that her baby will be HIV-infected, including the importance of adherence to her PMTCT care plan and medicines.
- In the third scene, we see Hope and her newborn baby attend a mother's support group meeting in the community. Hope shares some of her experiences caring for her HIV-exposed baby and learns more from other support group members and the Peer Educator who is facilitating the meeting.
- Each scene is separated by "commercials" that reiterate key messages on PMTCT.

The video may be used in a number of settings, including:

- In the ANC waiting area, if there is a TV and DVD/VCD player
- As part of group education sessions with PMTCT clients
- As part of individual counseling and education sessions with PMTCT clients
- As part of training and mentoring activities for lay counselors, peer educators, mother mentors, etc.
- In support group meetings
- In the community, for example at community meetings, religious gatherings, workplaces, marketplaces, and other venues where people come together
- In women's and youth group activities
- In PLHIV association activities
- As part of a public service announcement (PSA) on television

The video will be most effective if a health worker (nurse, peer educator, counselor, etc.) facilitates the video with viewers.

- Once programs decide on how and where the video will be used, it is recommended that tailored facilitation guides, including prompts and questions, be developed and implemented.
- For example, if the video is used as part of a group education session with PMTCT clients, the facilitator could stop the video at regular intervals and ask clients what they think is happening, what they think the characters are feeling, and how the situation shown in the video relates to their own PMTCT care and medicines. Similar questions can be asked at the end of the video in cases where the entire video is shown at once.
- Facilitation and guided discussion will also allow for more in-depth discussion of PMTCT care and medicines, for example discussing which specific ARVs pregnant women and HIV-exposed children take and for how long, specific examples of adherence challenges and reminders, and ways to safely feed and care for HIV-exposed infants.
- As mentioned above, guided facilitation will also help viewers understand what is happening in the video, especially if they do not speak/understand English as a first language.

SESSION 4.4:
Module Summary

THE KEY POINTS OF THIS MODULE INCLUDE:

- All health workers should be up-to-date and knowledgeable about their national PMTCT guidelines.
- Pregnant and postpartum women and caregivers of HIV-exposed and HIV-infected babies and children often have a number of retention, adherence, and psychosocial support needs. Their needs will depend on their specific situation and may also change over time and as they move along the PMTCT spectrum of care.
- Pre-test information, educational sessions, and individual post-test counseling are key to delivering basic information on the importance of HIV testing, the meaning of test results, and PMTCT basics to all women. Health workers can use the *pre- and post-test counseling checklists* as a guide when working with clients.
- It is recommended that a psychosocial assessment be conducted with all women upon entry into the PMTCT program and when there are any major changes in a client's life situation. Health workers can use the *Psychosocial Assessment Guide and Reporting Form* to guide this process. It is important to note key issues on the form and to retain these in the client's file to allow for follow-up and continuation of counseling at return visits.
- Initiation of ARVs or ART among pregnant women should NOT be delayed for any reason. Basic adherence preparation should be conducted in 1 session if possible and follow-up adherence counseling and support provided at each subsequent clinic visit. Health workers can use the *Adherence Preparation and Support Guides* as reminder of the key messages to cover and key questions to ask clients.
- Adherence should be assessed at each clinic visit and ongoing counseling and support provided throughout the PMTCT spectrum of care. Health workers can use the *Adherence Assessment and Follow-up Guides* to assist in this process.
- Remember, adherence will change over time and as clients move through the PMTCT spectrum of care so it is important to provide ongoing adherence assessment, counseling, and support at every visit.
- Functional appointment systems are the cornerstone of retention and adherence to PMTCT care. All clinics should institute an *appointment system*, including systematic follow-up of clients who miss appointments.
- The *PMTCT Video* may be used to reinforce key PMTCT messages with clients at the clinic or in the community.
- Each clinic should have a specific plan on how the Tools discussed in this Module are used (who, when, where, how, etc.).
- Remember, retention, adherence, and psychosocial support are a part of everyone's job and all multidisciplinary team members should be familiar with and have copies of the counseling cue cards.
- When talking with clients, it is always important to use the 7 key counseling and communication skills (discussed in Supplemental Module 6).

MODULE 5:
Monitoring Retention and Adherence to PMTCT and Planning the Way Forward

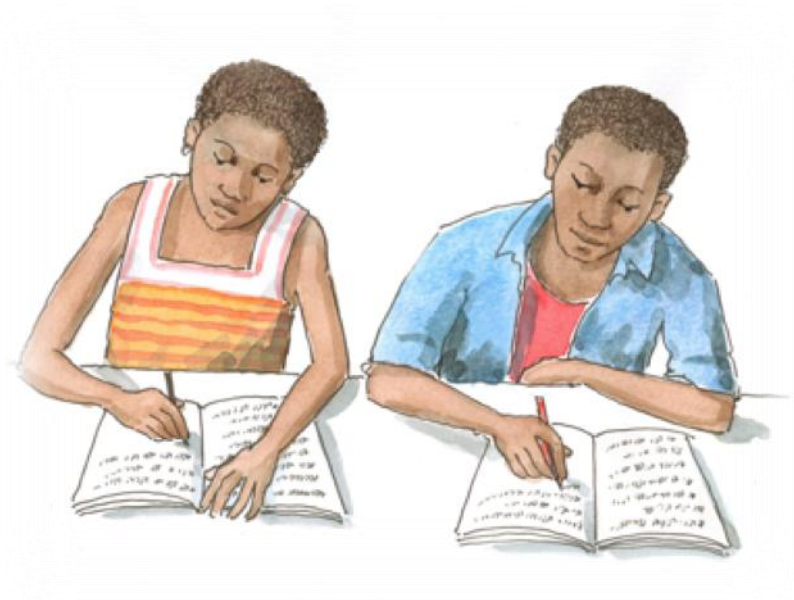
LEARNING OBJECTIVES:

By the end of this Module, participants will be able to:

- Discuss the importance of documentation, record keeping, and routine monitoring and evaluation in PMTCT services
- Understand the differences between program- and client-level monitoring of retention and adherence
- Describe available data that could be used to monitor retention and adherence at a program level
- Describe available data that could be used to monitor retention and adherence at an individual client level
- Discuss which PMTCT materials will be prioritized for implementation at the clinic
- Develop a site-specific action plan to improve retention, adherence, and psychosocial support services, including roll out of the Toolkit materials
- Evaluate the implementation workshop

CONTENT:

Session 5.1: Monitoring and Evaluating Retention and Adherence to PMTCT
Session 5.2: Developing an Action Plan to Roll Out the PMTCT Materials
Session 5.3: Workshop Evaluation and Closure



SESSION 5.1:
Monitoring and Evaluating Retention and Adherence to PMTCT

Monitoring and evaluation at the individual client and program levels:

Systems need to be developed and strengthened to monitor BOTH individual clients' retention and adherence, as well as the program's ability to retain clients in care and support adherence and psychosocial wellbeing.

Routine monitoring and evaluation are necessary to gather information on both individual outcomes (are clients being retained in care, are clients adhering to care, are clients adhering to medicines/treatment?) as well as PMTCT program outcomes (is the program retaining clients overall, are mothers and babies completing the spectrum of PMTCT care?). Program outcomes are usually the cumulative tally of individual outcomes and can give insight into strengths and areas needing improvement within the PMTCT program—at an individual facility or in a district, province, etc.

Why monitoring and evaluation are important at the *facility* or *program* level:

- To tell us if clients are being retained in care across the PMTCT spectrum
- To tell us how many and which types of PMTCT clients are receiving adherence support
- To show us the successes and gaps in our PMTCT retention, adherence, and psychosocial support services
- To give us a sense of the number of clients discontinuing PMTCT care and/or treatment or prophylaxis, and the trends in these numbers over time
- To help us understand what is working and what isn't working and to plan improvements in PMTCT retention, adherence, and psychosocial support activities to best meet the needs of clients

At the *individual* level, record keeping and monitoring of retention, adherence, and psychosocial support is useful:

- To tell us whether or not individual clients and their babies are retained in care
- To tell us whether or not individual clients are adhering to their own and their baby's PMTCT care plan and medications
- To help us follow adherence and psychosocial support issues of individual clients over time

Measuring retention and adherence support activities in PMTCT settings:

Retention and adherence are a reflection of the ultimate quality of the PMTCT services we provide. It is important to look at what can actually be measured using existing data instead of creating new, parallel systems. Sometimes data to measure these indicators can be obtained as routine data from client registers, but others may need to be measured through the reviewing of individual client files or through client interviews.

Depending on the information available, we may be able to measure the following:

- The #/% of PMTCT clients and babies who are retained in care at specific service delivery points (ANC, under-5 clinic, etc.) and across the entire spectrum of care
- The #/% of PMTCT clients who return on time for clinic appointments
- The #/% of PMTCT clients who return on time for pharmacy appointments/refills
- The #/% of HIV-exposed and HIV-infected babies who return on time for clinic appointments (including follow-up appointments, early infant diagnosis, etc.)
- The #/% of HIV-exposed and HIV-infected babies who come back for pharmacy appointments/refills
- The #/% of PMTCT clients who are followed up after a missed appointment, and of these, the #/% who return to care
- The #/% of PMTCT clients who receive adherence preparation counseling
- The #/% of PMTCT clients who receive adherence assessment and follow-up counseling on return visits
- The #/% of PMTCT clients who have "near perfect" adherence to medicines
- The #/% of PMTCT clients for whom a psychosocial assessment has been conducted and documented
- The #/% of PMTCT clients given referrals to community support services, and, if possible the #/% of these that were "successful" referrals

A note about patient files in ANC:

Many ANC clinics do not have individual patient files, so each program/site will have to develop their own way of documenting the monitoring and evaluation of PMTCT retention and adherence. Some options to consider are:

- Using existing records, registers, and appointment books to gather and summarize information about retention and adherence at the program level. Pharmacy records are also a good source of information on retention and adherence.
- Starting an adherence register in PMTCT where each client's adherence is noted at each visit.
- Opening an adherence and psychosocial support file for each client, where there is the possibility to do so.

SESSION 5.2:
Developing an Action Plan to Roll Out the PMTCT Materials

Implementing all of the Toolkit materials at the same time and at multiple sites is likely not feasible. The MDT (with support from hospital administrators and managers, if possible) at each site will need to prioritize activities and materials according to its capacity and needs.

When thinking about how to prioritize the activities, managers and health workers should keep 3 key standards in mind:

- All pregnant and postpartum women living with HIV need ongoing retention, adherence, and psychosocial support throughout the PMTCT care spectrum.
- All pregnant and postpartum women living with HIV need to have clear and correct information about their own and their baby's PMTCT care plan, as well as ongoing support for adherence to care and medicines.
- Every PMTCT site, to the best of its ability, should have systems in place to retain pregnant and postpartum women living with HIV and their infants in care.

SESSION 5.3:
Workshop Evaluation and Closure

Reminder of Workshop Objectives:

By the end of the implementation workshop, participants will be able to:

1. Understand changes to the national PMTCT guidelines and how they should be applied in clinical settings.
2. Define the PMTCT spectrum of care.
3. Define retention, adherence, and psychosocial support in the context of the PMTCT spectrum of care.
4. Understand the importance of retention, adherence, and psychosocial support to meet the needs of women and families enrolled in PMTCT services.
5. Identify strategies to improve retention, adherence, and psychosocial support within PMTCT programs.
6. Use counseling cue cards to conduct ongoing, supportive counseling for pregnant and postpartum women and their family members.
7. Use checklists to improve pre- and post-test counseling services for pregnant women, family members, and children.
8. Conduct a psychosocial assessment and document key points and next steps, as well as make necessary referrals.
9. Use guides to conduct adherence preparation and support sessions with clients and to provide ongoing adherence assessment and follow-up with clients.
10. Develop and use an appointment book and appointment reminder cards in PMTCT settings.
11. Use a patient education video to reinforce key messages on PMTCT with clients and family members.
12. Use improved communication and counseling skills with clients and family members (specific to Supplemental Module 6).

Appendix 5A:

Action Plan for Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

Clinic Name: _____ PMTCT Point Person's Name/Title: _____ Date:_____

OBJECTIVE 1: *All pregnant and postpartum women living with HIV will receive ongoing retention, adherence, and psychosocial support throughout the PMTCT care spectrum.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

OBJECTIVE 2: *All pregnant and postpartum women living with HIV will have clear and correct information about their own and their baby's PMTCT care plan and ongoing support for adherence to care and medicines.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

OBJECTIVE 3: *Every PMTCT site will have systems in place to retain pregnant and postpartum women living with HIV and their infants in care.*

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

PMTCT Counseling Cue Cards

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Counseling Checklists for HIV Testing in Antenatal Care Settings

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Psychosocial Assessment Guide and Recording Form

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Adherence Preparation and Support Guides

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Adherence Assessment and Follow-up Guides

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Appointment Book and Appointment Reminder Card

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

PMTCT Video

What is the specific action?	Who is responsible?	What information or resources are needed?	When will the action happen?	How will we measure progress on this action?

Additional Notes:

_____

_____

_____

_____

_____

_____

Appendix 5B:
Workshop Evaluation Form

Name (optional): _____ Health Facility: _____ Position: _____

Please rate the following statements on a scale of 1 to 5.

	☹ Strongly Disagree	Disagree	Neither agree nor disagree	Agree	☺ Strongly Agree
1. The workshop objectives were clear.	**1**	**2**	**3**	**4**	**5**
2. This workshop met my expectations.	**1**	**2**	**3**	**4**	**5**
3. The technical level of this workshop was appropriate.	**1**	**2**	**3**	**4**	**5**
4. The pace or speed of this workshop was appropriate.	**1**	**2**	**3**	**4**	**5**
5. The facilitators were engaging and informative.	**1**	**2**	**3**	**4**	**5**
6. The information I learned in this workshop will be useful to my work.	**1**	**2**	**3**	**4**	**5**

How helpful were each of the workshop Modules to you and your work? You can write extra comments on the back.

	☹ Not helpful				☺ Very helpful
Introduction and PMTCT Update	**1**	**2**	**3**	**4**	**5**
Retention, Adherence, and Psychosocial Support in PMTCT Programs	**1**	**2**	**3**	**4**	**5**
Using the PMTCT Counseling Cue Cards	**1**	**2**	**3**	**4**	**5**
Using the PMTCT Checklists, Guides, Forms, and Video	**1**	**2**	**3**	**4**	**5**
Monitoring Retention and Adherence to PMTCT and Planning the Way Forward	**1**	**2**	**3**	**4**	**5**
Review of Counseling and Communication Skills *(optional)*	**1**	**2**	**3**	**4**	**5**

What was the BEST THING about this workshop?

What was NOT USEFUL about this workshop?

Do you have other comments (use the back of the page if needed)?

SUPPLEMENTAL MODULE 6:
Review of Counseling & Communication Skills

LEARNING OBJECTIVES:

By the end of this Supplemental Module, participants will be able to:

- Describe the importance of effective communication and counseling skills in PMTCT care and treatment settings
- Discuss the basic principles of counseling and challenges to putting these principles into practice
- Discuss what is meant by shared confidentiality and why it is important
- Reflect on their own attitudes, values, and beliefs, and discuss how these may affect the quality of counseling
- Demonstrate the 7 key counseling and communication skills
- Understand the main components of a counseling session

CONTENT:

Note: Portions of this Module were adapted from: WHO & CDC *Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual,* 2008.

SESSION 6.1:
Counseling Basics

What is counseling?

- Counseling is a two-way communication process that helps people look at their personal issues, make decisions, and plan how to take action.

Counseling includes:

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening carefully
- Helping people tell their stories without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognize and build on their strengths
- Helping people to develop a positive attitude toward life and to become more confident
- Respecting everyone's needs, values, culture, religion, and lifestyle

Counseling does NOT include:

- Solving another person's problems
- Telling another person what to do
- Making decisions for another person
- Blaming another person
- Interrogating or questioning another person
- Judging another person
- Preaching to, or lecturing, another person
- Making promises that cannot be kept
- Imposing one's own beliefs on another person
- Providing inaccurate information

Why do we do counseling?

- To help people talk about, explore, and understand their thoughts and feelings
- To help people work out for themselves what they want to do and how they will do it

Confidentiality:

In order for clients to trust health workers with their feelings and problems, it is important for them to know that anything they say will be kept confidential. This means that members of the multidisciplinary care team will not tell other people any information about the client, including what the client says or that the client is living with HIV. Confidentiality is especially important in HIV programs because of the stigma surrounding HIV and discrimination against PLHIV in the home, at work, at school, and in the community.

Because multidisciplinary teams take care of clients, sometimes they need to discuss a client's needs and health status with one another to provide the best care possible.

Statements for Values Clarification Exercise:

1. I expect clients to do everything in their power to protect their health.
2. I feel comfortable discussing sex and sexuality with clients.
3. A woman who knows she has HIV and gets pregnant is irresponsible.
4. Health workers should always know which services exist for pregnant women in the community.
5. It is usually a waste of time to provide counseling to our clients—they rarely listen.
6. The biggest reason pregnant women do not adhere to their ARVs is because they are forgetful.
7. If I see that a client is acting irresponsibly, it's my job to correct her behavior.
8. Many people living with HIV have made irresponsible decisions in their lives.
9. HIV-infected children are victims.
10. Some clients do now know enough to make good decisions for themselves.

Self-Awareness:

Listening and counseling require that the counselor be aware of his or her strengths and weaknesses, as well as his or her fears or anxiety about HIV. All health workers should strive to be self-aware and to understand how others affect them as well as how they affect others.

Being self-aware means knowing yourself, how other people view you, and how you affect other people.

Attitudes and values are feelings, beliefs, and emotions about a fact, thing, behavior, or person.

- For example, some people believe that having multiple sexual partners is okay as long as you practice safer sex, while other people believe that this is wrong.

Prejudices are negative opinions or judgments made about a person or group of people before knowing the facts.

- For example, when a health worker assumes that a person with HIV must be promiscuous or that a miner is probably sleeping around when he is away from home, the health worker is being prejudicial.

Health Workers should always:

- Think about the issues related to their own attitudes, values, and prejudices, and how these can affect their ability to help provide effective counseling and support services to pregnant and postpartum women, families, and children
- Be sensitive to the culture, values, and attitudes of their clients, even if they are different from their own
- Learn as much as they can about the main culture, values, and attitudes of the clients at the facility
- Examine their own values and beliefs in order to avoid prejudice and bias, and make all people feel comfortable and that it is "safe" to talk with them openly and honestly.

Remember: Prejudice, stigma, and negative attitudes drive the HIV epidemic, so we all need to work hard to provide quality, fair, equal, and non-judgmental services to all of our clients!

SESSION 6.2:
Key Counseling and Communication Skills

Skill 1: Use Helpful Non-verbal Communication

- Make eye contact.
- Face the person.
- Be relaxed and open with your posture.
- Sit squarely facing the person. Do not sit behind a desk!
- Dress neatly and respectfully.
- Use good body language—nod your head and lean forward.
- Smile.
- Make the client feel that you have time, greeting the client warmly, and wait for the client to talk when she is ready.
- Do not look at your watch, the clock, or anything other than the person you are counseling.
- Try not to write during a counseling session, unless you are recording key information for the client to take home or for your records. Turn your mobile phone off and never take calls during a counseling session.

Role play: Non-verbal communication

WHAT NOT TO DO Unhelpful non-verbal communication	WHAT TO DO Helpful non-verbal communication
Client walks in	Client walks in
Health Worker: Hello. My name is ___. *(Health worker is filling in the register from behind a desk, does not look at client)*	**Health Worker:** Hello. My name is ___. *(Health worker is filling in the register from behind a desk and looks up at client)*
Client: I have some questions about my baby getting HIV.	**Client:** I have some questions about my baby getting HIV.
Health Worker: Please sit down *(speaking in a hurried fashion)*. What were your questions? *(Health Worker still looking at the register)*	**Health Worker:** *(Looks at client, stops writing in the register, and moves chair so that it is not behind the desk)* Please sit down. What were your questions? *(Leans forward, open posture)*
Client: Well, I want to do everything I can to prevent my baby from getting HIV. But I'm not sure what I can do.	**Client:** Well, I want to do everything I can to prevent my baby from getting HIV. But I'm not sure what I can do.
Health Worker: Mm-Hmm. *(Does not look up and still filling in the register)*	**Health Worker:** I'm glad you are here. Let's talk about the ways you can lower the chances that your baby will be HIV-infected. *(Looks warmly, yet with concern, at client. Optional: demonstrate appropriate touch)*
Client: *(Clears throat to get counselor's attention)*	**Client:** Ok.
Health Worker: Oh sorry *(she finally stops writing and looks at watch)*. Yes, go ahead, you said that you are concerned about your medicines? *(Health Worker's hands are folded, legs crossed and facing away from client, looking across the room with expression suggesting disinterest)*	**Health Worker:** There are many things we can do to protect your baby and make sure you stay healthy. Why don't you tell me a bit more about how things have been going for you and what you have heard about mother-to-child transmission of HIV. *(Health Worker looks at client, leaning forward and not crossing legs)*
Client: Well not exactly, I want to know more about how I can protect my baby...Don't worry, sorry to have bothered you.	**Client:** *(Proceeds to tell her story)*

Skill 2: Actively Listen and Show Interest in the Client

It is important for the client to know that she has the counselor's full attention. Feeling that the counselor is actively listening will encourage the client to share more about her situation.

Active listening skills:

- Listen in a way that shows respect, interest, and empathy.
- Show the client you are listening by saying *"mm-hmm"* or *"aha."*
- Use a calm tone of voice.
- Listen to what the client is saying—do you notice any themes?
- Listen to how client is saying it—do she seem worried, angry, etc.?
- Allow the client to express her emotions. For example, if she is crying, allow her time to do so.
- Never judge or impose your own values on a client.
- Find a private place to talk and keep distractions, such as phone calls or visitors, to a minimum.
- Do not do other tasks while counseling a client.
- Do not interrupt the client.
- Ask questions or gently probe if you need more information. For example, if a client says, *"I can't exclusively breastfeed my baby,"* you could ask, *"In what way is exclusive breastfeeding a concern for you?"*
- Use open-ended questions that can't be answered with *"yes"* or *"no."* For example, *"Can you tell me a bit more about that?"*
- Summarize key points as you go during the counseling session.

Role play: Active listening

WHAT TO DO Gestures and responses that show interest
Health Worker: How do you think your partner will react if you tell him your HIV test results?
Client: Actually, I'm really very worried about it. I was hoping you wouldn't ask, to tell you the truth.
Health Worker: Mm-hmm. *(nods sympathetically)*
Client: I think my husband will accuse me of being unfaithful if he knows I have HIV.
Health Worker: He'll accuse you of being unfaithful then?
Client: Well, mostly he'll be angry that I went ahead and agreed to be tested without telling him first. And then he will probably say I was unfaithful.
Health Worker: Mm-hmm.
Client: Last time I was sick and went to the clinic without asking him, he got angry with me for spending the money to see the doctor and get some tests done. I think he's going to react the same way.
Health Worker: I'm hearing that he may get upset that you got tested without consulting with him first. So, how do you feel about bringing him to the clinic and then one of the counselors he talk with him about how HIV testing is a routine part of care for all pregnant women? And also that HIV testing is important to get the care you and the baby need and why he should you think about that?

Skill 3: Ask Open-ended Questions

Closed-ended questions:

Closed-ended questions can be answered with a one-word or short answer. Examples of closed-ended questions are, *"How old are you?" "What is your CD4 count?"* and *"Do you have children?"*

Closed-ended questions are good for gathering basic information at the start of a counseling or group education session. They should not be used too much because they can make it seem like the counselor is being too direct. They are not helpful in getting at how the client is really feeling.

Open-ended questions:

Open-ended questions cannot be answered in one word. People answer open-ended questions with more of an explanation. Examples of open-ended questions are, *"Can you tell me more about your relationship with your partner?"* or *"How does that make you feel?"*

Open-ended questions are the best kind to ask during counseling and group education sessions because they encourage the client to talk openly and they lead to further discussion. They help clients explain their feelings and concerns, and also help counselors get the information they need to help clients make decisions.

Role play: Open-ended questions

WHAT NOT TO DO Closed-ended questions	WHAT TO DO Open-ended questions
Client walks in	Client walks in
Health Worker: Hi, how are you? I'm ___. I am a nurse. Today, as part of your visit, I will be discussing with you the medicines you need to take to stay healthy and lower the chance that your baby will be infected.	**Health Worker:** Hi, how are you? I'm ___. I am a nurse. Today, as part of your visit, I will be discussing with you the medicines you need to take to stay healthy and lower the chance that your baby will be infected.
Client: OK	**Client:** OK
Health Worker: Do you know what ARVs are?	**Health Worker:** Tell me, what have you heard about ARV medicines?
Client: Yes, I think so.	**Client:** Well, I'm not sure, but I heard they can make people with HIV feel better. But I also heard they are dangerous for babies.
Health Worker: OK. And do you know that you have to take them at the same time every day?	**Health Worker:** You are right that ARVs are medicines that can help people with HIV feel better and stay healthy. They can also lower the chance that your baby will be HIV-infected. ARVs are safe for pregnant women and babies. How do you feel about taking ARVs during your pregnancy?
Client: Um, yes, I guess so.	**Client:** Well, I guess I will do anything to protect my baby. But, how long will I have to take them?

Health Worker: OK, good. So, here are the medicines you need to take every day. Don't miss any doses, OK?	**Health Worker:** Well, we recommend that you start taking ARVs now and every day during your pregnancy and your labor and delivery. You can stop taking them one week after you deliver, but you will need to give your baby ARV syrup every day as long as you are breastfeeding. This will protect your baby from HIV. Tell me, what support do you have at home to take medicines every day and care for your baby?
Client: OK.	**Client:** Well, my sister helps me and she knows that I have HIV.
Health Worker: See you at your next visit then.	**Health Worker:** That's great. What are some of the ways that you think will help you to remember to come back for all of your appointments and to take your medicine every day?
	Client: Well…(*client continues to discuss with health worker)*

Additional practice on closed- and open-ended questions:

Closed-ended question	Open-ended question
Do you have safe sex?	How do you negotiate safe sex with your partner?
Do you have more than one sex partner?	There are a lot of ways to reduce risk for HIV—like not having sex, being faithful to your partner, and using condoms. Which would work best for you based on your situation?
Do you use condoms?	What challenges do you have using condoms with your partner?
Do you drink alcohol when you are upset?	What are some of the ways you cope with stress or anger?
Did your partner get tested?	How would you feel about asking your partner to get tested so you can both be as healthy as possible?
Do you want to have children in the future?	How do you feel about having a bigger family? What concerns to do you have?
Do you have someone you can talk with about taking your medicines the right way?	Tell me more about the people you have disclosed to and how they could help you remember to take your medicines.
Do you know how to prevent transmission of HIV to your baby?	I want to make sure that I have explained everything well to you – can you tell me what you understand about ways you can protect your baby from HIV?
Do you exclusively breastfeed your baby?	Can you tell me more about how you feed your baby?

Skill 4: Reflect Back What the Client is Saying

Reflecting skills:

The counselor repeats back to the client the main feelings and themes that the client has just expressed.

Reflecting:

- Provides feedback to the client and lets her know that she has been listened to, understood, and accepted
- Encourages the client to say more
- Shows that the counselor has understood the client's story
- Helps the counselor check that he or she has understood the client's story
- Provides a good alternative to always answering with another question
- Can reflect the client's feelings and include a summary of the content of what the client has said (sometimes called paraphrasing)
- For example, the counselor can use the following formulas for reflecting:
    - *"You feel _____ because _____."*
    - *"You seem to feel that _____ because _____."*
    - *"You think that _____ because _____."*
    - *"So I sense that you feel _____ because _____."*
    - *"I'm hearing that when _____ happened, you didn't know what to do."*
- When reflecting back, try to say it in a slightly different way. Do not just repeat what the client said. For example, if a client says, *"I can't tell my partner about my HIV test result,"* the counselor could say, *"Talking to your partner about your result sounds like something that you are not comfortable doing."* Then say, *"Let's talk about that".*

Role play: Reflecting skills

WHAT TO DO Reflecting back
Health Worker: I'm hearing that you are having some challenges remembering to take your medicines every day. What do you think about telling your partner about your HIV-status? Maybe he could be your treatment supporter?
Client: Well, I honestly don't think I could ever bring up the subject to him. I think he'd get really angry and say that I have been sleeping around.
Health Worker: It sounds like you could use some extra support, but that disclosing to your husband is something that you would actually be hesitant, maybe even afraid, to do right now.
Client: Yes, that's right…

Additional Practice on Reflecting:

Reflect back to the following statements:

- I missed a lot of my pills this month and I feel hopeless.
- My boyfriend does not know my test results—I'm scared to tell him.
- I feel like a bad mother because my baby does not want to suckle from me.
- My husband would just get angry if I asked him to use a condom, so I am not going to ask.
- My husband thinks it's dangerous to give the baby medicines and I am afraid of disobeying him.
- I am worried because my mother-in-law will assume I am living with HIV if I don't give the baby herbs.
- I feel so happy that my baby is growing well.

Skill 5: Empathize—Show That You Understand How the Client Feels

Empathy or empathizing:

- Is a skill used in response to an emotional statement
- Shows an understanding of how the client feels and encourages the client to discuss the issue further
- Is different than sympathy. When you sympathize, you feel sorry for a person and look at the situation from your own point of view. For example, if the client says: *"My baby wants to feed very often and it makes me feel so tired,"* the counselor can show empathy by saying: *"You are feeling very tired all the time then?"* However, if the counselor responds by saying, *"I know how you feel. My baby also wanted to feed often and I was exhausted!,"* this is sympathizing because the attention is on the counselor and her experiences instead of on the client.

Role play: Showing empathy vs. sympathy

WHAT NOT TO DO Sympathizing	WHAT TO DO Empathizing
Health Worker: What do you think about asking your partner to use condoms while you are breastfeeding?	**Health Worker:** What do you think about asking your partner to use condoms while you are breastfeeding?
Client: I'd be really afraid that he might hit me, or even worse.	**Client:** I'd be really afraid that he might hit me, or even worse.
Health Worker: Yes, I know what you mean, that happened to my sister. She actually did ask her husband to use condoms after the baby and you know what? He hit her then he made her leave the house. He didn't let her come back for two full days.	**Health Worker:** It sounds like you're afraid of your husband's response.
Client: So did your sister go back?	**Client:** Yes, I am. It's not just about asking him to use condoms. I'm also scared that he'll be upset if dinner is late, if the house isn't tidy, if the children aren't behaving well, and for a lot of other reasons.

Skill 6: Avoid Words That Sound Judging

Judging words are words that can include:

- "*right":* You should do the right thing.
- *"wrong":* That is the wrong way to feel.
- *"badly":* Why are you behaving badly and missing appointments?
- *"good":* Be a good girl and tell your boyfriend to use condoms.
- *"properly*": Why don't you take your medicine properly?
- *"these people"* or *"those people"* (referring to people living with HIV for example): Those people are irresponsible and should not have children.

If a counselor uses these words when asking questions, the client may feel that she is wrong, or that there is something wrong with her actions or feelings. Sometimes, however, counselors need to use the "good" judging words to build a client's confidence.

Role Play: Avoiding judging words

WHAT NOT TO DO Using judging words	WHAT TO DO Avoid words that sound judging
Health Worker: What do you think about asking your partner to use condoms during your pregnancy?	**Health Worker:** What do you think about asking your partner to use condoms during your pregnancy?
Client: Honestly I don't feel comfortable with it.	**Client:** Honestly I don't feel comfortable with it.
Health Worker: *(Surprised)* Really? That's the wrong way to feel! Have you had a conversation about condoms?	**Health Worker:** Mm-hmm.
Client: No, not really.	**Client:** It came up once many years ago before we got married. He said that condoms were uncomfortable and will give him kidney problems.
Health Worker: He's stupid, isn't he? I guess he doesn't care about you or the baby. Typical man. Be a good, responsible woman and talk with him about condoms—he should care more about his baby.	**Health Worker:** I've heard other women say that as well. Maybe, now that you are pregnant, you could try talking to him again—about using condoms to protect the baby's and your health? Also, condoms definitely won't cause any kidney problems, that is a myth.
Client: Yes, I will.	**Client:** That's a good idea, maybe I'll try that.

Skill 7: Help the Client Set Goals and Summarize Each Counseling Session

Goal-setting:

Toward the end of a counseling session, the counselor should work with the client to come up with "next steps" to solve her issues in the short and long term.

Next steps and goals:

- Should be developed by the counselor and client together
- Can empower the client to achieve what she wants by agreeing to realistic short- and long-term goals and actions
- Provide direction and must be results-oriented
- Must be clear enough to help the client measure her own progress (people feel good when they achieve something they have set out to do)
- To start, the counselor could say, *"Okay, now let's think about the things you will do this week based on what we talked about."*

Summarizing:

The counselor summarizes what has been said during a counseling session and clarifies the major ideas and next steps.

Summarizing:

- Can be useful in an ongoing counseling session or in making sure you are clear on important issues raised during a counseling session
- Is best when both the counselor and client participate and agree with the summary
- Provides an opportunity for the counselor to encourage the client to examine her feelings about the session
- The counselor could say, *"I think we've talked about a lot of important things today.* (List main points.) *We agreed that the best next steps are to _____. Does that sound right? Let's plan a time to talk again soon."*

The Phases of a Counseling Session

4 PHASES OF A COUNSELING SESSION

1. Establishing the Relationship
2. Understanding the Problem
3. Supporting Decision-Making
4. Ending the Session

1. Establishing the Relationship

- The room should be quiet with doors that close and where there are no interruptions.
- **Introduce yourself:** Say your name and explain your role and the length of time you have together (i.e. half an hour).
- **Ask the client to introduce herself or himself.**
- **Explain that what is discussed will be kept confidential.**
- Ways to begin a counseling session:
    - *Can you tell me why you came here today?*
    - *Where would you like to start?*

2. Understanding the Problem

- Let the client talk about the thoughts, feelings, and actions around her or his issues or problems.
- Use the 7 essential counseling and communication skills.
- Help the client decide which issues or problems are the most important to talk about in the session.

3. Supporting Decision-Making

- Support the client to make her or his own decisions on next steps and focus for the future.
- The health worker can help the client explore the options, but it is ultimately the client's decision to make.

4. Ending the Session

- Summarize what was discussed during the session.
- Review the client's next steps.
- Give the client a chance to ask questions.
- Make referrals, if needed.
- Discuss when the client will return and make sure she or he has an appointment.

SESSION 6.3:
Classroom Practicum

Case Studies:

Case Study 1:

M___ is at the ANC clinic for the first time. She is 16 and lives with her aunt. M___ is still in school, and just found out that she is pregnant and HIV-infected. She is concerned that being pregnant and having HIV will mean giving up her dream of becoming a nurse.

Case Study 2:

P___ is pregnant with her first baby and has found out she has HIV. P___'s husband is the boss of the house. She says she is so frightened that her husband might find out when he sees the medicines from the clinic.

Case Study 3:

D___ is enrolled in the PMTCT program and started taking ART about 4 months ago. She starts crying because she was not able to get enough money to pay for the bus to the clinic last month, so she has stopped taking her ARVs. D___ is very worried because she has no job, no money, and now she is feeling unwell.

Case Study 4:

L___ is living with HIV. She is enrolled in the PMTCT program and had her second child about 7 weeks ago. Her first child is HIV-uninfected. She comes to the clinic today to get her new baby tested for HIV. She is very worried that the baby is HIV-infected because he is sick a lot of the time.

SESSION 6.4:
Module Summary

THE KEY POINTS OF THIS MODULE INCLUDE:

- Counseling is a way of working with people to understand how they feel and help them decide what they think is best to do in their situation.
- Health workers are not responsible for solving all of the client's problems.
- The role of health workers is to support and assist the client's decision-making process.
- It is important for clients to know that what they say will be kept private. All health workers should practice shared confidentiality.
- The multidisciplinary care team should work to ensure that there is private counseling space available and that counseling sessions are not interrupted for any reason.
- Our own attitudes, values, and prejudices should not be a part of communication and counseling with clients and other community members.
- These are the 7 key counseling and communication skills health workers should use:
  - Use helpful non-verbal communication.
  - Actively listen and show interest in the client.
  - Ask open-ended questions.
  - Reflect back what the client is saying.
  - Empathize—show that you understand how the client feels.
  - Avoid words that sound judging.
  - Help the client set goals and summarize each counseling session.
- There are 4 main phases of a counseling session:
  - Establishing the relationship
  - Understanding the problem
  - Supporting decision-making
  - Ending the session
- There can be many challenges to providing quality counseling in PMTCT and ART clinics, including lack of time and lack of private counseling space.
- Improving counseling skills takes practice, as well as continuous self-exploration of our own values and attitudes.

Appendix 6A:
Counseling and Communication Skills Checklist

COUNSELING AND COMMUNICATION SKILLS CHECKLIST		
Skill	**Specific Strategies, Statements, Behaviors**	**(√)**
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality.	
	• Start the session with an open-ended question (*"Where would you like to start?"* or *"Tell me more about why you came today."*)	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as *"yes," "okay"* and *"mm-hmm"*).	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as *"bad," "proper," "right," "wrong,"* etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counseling session	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counseling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

Note: This checklist was adapted from: WHO & CDC. *Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual.* 2008.

Appendix 6B:
Optional Homework/Review of Counseling and Communication Skills

INSTRUCTIONS:
Please answer the following questions. Refer to the Key Information from Supplemental Module 6 if you need additional help or a refresher.

1. **Why is non-verbal communication important? What are some ways to show good non-verbal communication?**

2. **Why is active listening important? What are some ways a counselor can show she or he is actively listening to the client?**

3. **What is the difference between closed- and open-ended questions?**

4. **Change the following into open-ended questions:**
    - Do you use condoms?
    - Did you take all of your medicines?
    - Did you tell someone about your HIV test results?
    - Do you have support at home to give the baby medicines?
    - Are you having any side effects?
    - Do you know you need to come back to the clinic in 4 weeks time?
    - Did you get your CD4 test results?
    - Are you breastfeeding?

5. Why is reflection important? What are some of the formulas for reflection?

6. Reflect back the following statements:

- I missed a lot of my pills this month and I feel hopeless.
- My boyfriend does not know my test results—I'm scared to tell him.
- I feel like a bad mother because my baby does not want to suckle from me.
- My husband would just get angry if I asked him to use a condom, so I am not going to ask.
- My husband thinks it's dangerous to give the baby medicines and I am afraid of disobeying him.
- I am worried because my mother-in-law will assume I am living with HIV if I don't give the baby herbs.
- I feel so happy that my baby is growing well.

7. What is the difference between showing empathy and showing sympathy?

8. How would you use reflection and show empathy if your client said the following:

- I am so dizzy and weak since I started taking these pills. I am going to stop.
- My milk looks so thin. I am worried it isn't enough for the baby.
- I am really scared to tell my boyfriend I have HIV.
- I will be so sad if my baby has HIV.
- I have to hide my medicines so it is hard for me to remember to take them at the right times.

9. What are the key parts or phases of a counselling session? Why is each phase important?

Improving Retention, Adherence, and Psychosocial Support within PMTCT Services

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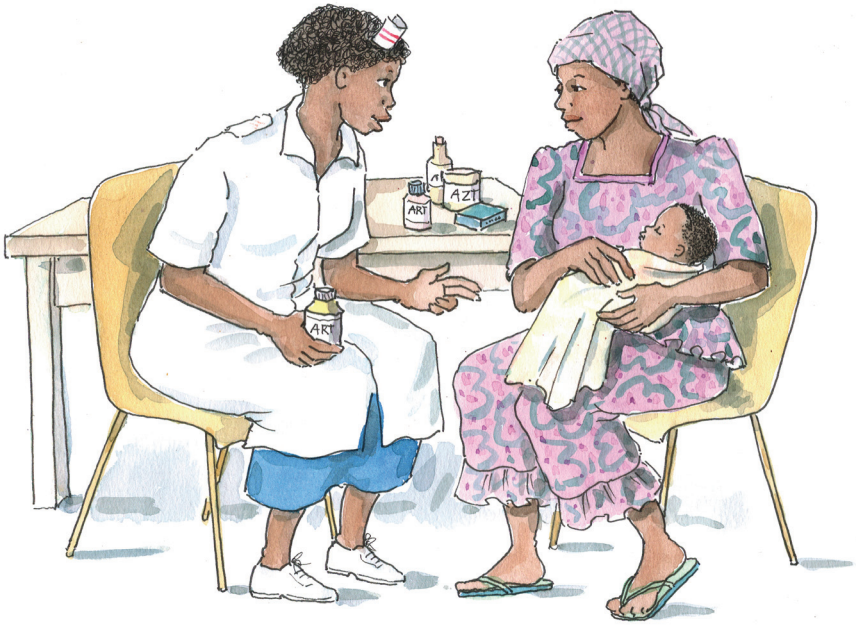
Implementation Workshop Curriculum for Health Workers

Thank you for participating!

IV.



Counseling Cue Cards

How to Use These Counseling Cue Cards

ABOUT THE CUE CARDS

This set of counseling cue cards was developed to support a range of providers (trained counselors, lay counselors, peer educators, expert clients, mother mentors, doctors, nurses, pharmacists, community health workers, and others) who work with pregnant women living with HIV and their families. The cue cards should be adapted to reflect national PMTCT and pediatric care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used. It may be helpful to translate the cards into the local language.

Each of the cards focuses on a specific topic important to the care and support of pregnant women living with HIV, their children, and families across the PMTCT continuum of care. Providers may use the cue cards as job aides and reminders of key information to cover during initial post-test and ongoing counseling sessions with pregnant women and newly delivered mothers, their partners, family members, and supporters. The cue cards do not have to be used in sequence, but instead should be used according to the client's specific needs and concerns during the particular session. Good counseling and communication skills, such as active listening, being attentive to the client's questions and specific needs, and avoiding lecturing and one-way communication, should always be used, no matter what the counseling topic.

NOTES:

- Key questions are included in italics, and may be used to initiate discussions, learn more about what the client already knows and her specific concerns, and to gauge understanding and elicit follow-up questions.
- Notes to guide counselors are also included in italics.
- The margins of each card contain cross-references to other cards on specific topics (for example, if infant feeding is mentioned, there will be a cross-reference to the specific cue cards addressing infant feeding to which the provider may want to refer). The topics are color coded.

Counseling Cue Card
Topics

1. PMTCT BASICS
2. STAYING HEALTHY DURING YOUR PREGNANCY
3. ADHERING TO YOUR PMTCT PLAN
4. PREPARING TO START AND ADHERE TO LIFELONG ART
5. CONTINUING AND ADHERING TO YOUR ART DURING PREGNANCY
6. PREPARING TO START AND ADHERE TO AZT PROPHYLAXIS
7. PREPARING TO START AND ADHERE TO ART PROPHYLAXIS
8. HIV TESTING FOR YOUR FAMILY MEMBERS & PARTNER
9. DISCLOSING YOUR HIV-STATUS
10. BEING PART OF A DISCORDANT COUPLE
11. HAVING A SAFE LABOR & DELIVERY
12. TAKING CARE OF YOURSELF AFTER YOUR BABY IS BORN
13. CARING FOR YOUR HIV-EXPOSED BABY & ADHERING TO CARE & MEDICINES
14. SAFELY FEEDING YOUR BABY
15. EXCLUSIVELY BREASTFEEDING YOUR BABY
16. EXCLUSIVELY REPLACEMENT FEEDING YOUR BABY
17. INTRODUCING COMPLEMENTARY FOODS TO YOUR CHILD AT 6 MONTHS
18. MAKING DECISIONS ABOUT FUTURE CHILDBEARING AND FAMILY PLANNING
19. TESTING YOUR BABY OR CHILD FOR HIV
20. CARING FOR YOUR HIV-INFECTED BABY OR CHILD AND ADHERING TO CARE & MEDICINES

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General Tips

WHEN COUNSELING CLIENTS, IT IS IMPORTANT TO:

- Examine your own attitudes, values, and prejudices and how they affect your ability to provide effective, client-centered counseling services.
- Be sensitive to the culture, values, and attitudes of your clients, even if they are different from your own.
- Avoid prejudice and bias and make all people feel comfortable. Make them feel that it is "safe" to talk with you openly and honestly.
- Allow time for each client to share his or her story and feelings, even though you see many clients each day.
- Remember that even though your clients may all be people living with HIV or pregnant women, each person has a unique situation, their own story to tell, and diverse psychosocial support challenges and needs.
- Know your limitations as a counselor and know when and where to refer clients for more support —either in the health facility or in the community.
- Use an up-to-date referral directory to provide clients with ongoing support, including resources in the communities where clients live.
- Practice shared confidentiality so your clients trust you. This means that information about a client can, when necessary, be disclosed to another person involved in the client's care (with the client's consent).
- Ensure privacy. Even though finding space can be a challenge, it is important to create private areas where other people cannot see or hear counseling sessions. Also make sure counseling sessions are not interrupted for any reason.

REMEMBER THE GOALS OF COUNSELING:

- Counseling is a supportive, two-way communication process that helps people look at their personal issues, make informed decisions, and plan how to take action.
- Counseling helps people talk about, explore, and understand their feelings. It helps them work out what they want to do and how they will do it.

General Tips
CONTINUED

COUNSELING INCLUDES	COUNSELING DOES NOT INCLUDE
Establishing supportive relationships	Solving another person's problems
Having conversations with a purpose	Telling another person what to do
Listening attentively	Making decisions for another person
Helping people tell their stories without fear of stigma or judgment	Blaming another person
Giving correct and appropriate information	Interrogating another person
Helping people to make informed decisions	Judging another person
Exploring options and alternatives	Preaching or lecturing to another person
Helping people to recognize and build on their strengths	Making promises that cannot be kept
Helping people to develop a positive attitude	Imposing one's own beliefs on another person
Respecting everyone's needs, values, culture, religion, and lifestyle	

PRACTICE THE 7 ESSENTIAL COUNSELING AND COMMUNICATION SKILLS DURING EACH SESSION WITH CLIENTS:

SKILL	SPECIFIC STRATEGIES, STATEMENTS & BEHAVIORS
1. Use helpful non-verbal communication	Make eye contact. Face the person (sit next to her or him) and be relaxed and open with your posture. Use good body language (nod, lean forward, etc.). Smile. Do not look at your watch, the clock, or anything other than the client. Do not write during the session.
2. Ask open-ended questions.	Use open-ended questions to get more information. Ask questions that show interest, care, and concern.
3. Actively listen and show interest.	Nod, smile, and use encouraging responses (such as "yes," "okay," "mmm-hmmm"). Use a calm tone of voice that is not directive. Allow the client to express emotions. Do not interrupt.
4. Reflect back what the client says.	Use reflection to show understanding of the client's emotions, e.g., "It sounds like you are feeling _____ because _____."
5. Show empathy.	Show an understanding of how the client feels. Avoid sympathy.
6. Avoid judging words.	Avoid judging words such as "good," "bad," "correct," "proper," "right," "wrong," etc. Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).
7. Assess needs and provide referrals, help set goals, and summarize the session.	Assess the client's need for other clinical and community- and home-based services; provide referrals. Ensure that there are no emergency situations requiring immediate action. Work with the client to come up with realistic next steps. Summarize the main points of the counseling session. Ask the client if she or he has any questions. Make a follow-up counseling appointment.

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *I would like to talk with you about how you can keep yourself and your baby healthy. You are probably feeling a lot of different emotions right now. Can you tell me how you are feeling? What concerns do you have for your baby? What concerns do you have for your own health and wellbeing?*

IT IS IMPORTANT FOR YOU TO KNOW THAT:

- Not all babies born to women living with HIV will become HIV-infected.
- If you, your partner, and your baby all get the care and medicines that are needed, you can lower the chances that your baby will become HIV-infected.
- **You can save 2 lives—your own and your baby's—if you get services and take medicines to help you stay healthy and to help prevent passing HIV to your baby.**

THERE ARE MANY THINGS YOU CAN DO TO KEEP YOURSELF AND YOUR BABY HEALTHY AND TO KEEP YOUR BODY STRONG:

- **All pregnant women living with HIV need to take medicines called ARVs**—even if they do not look or feel sick. Starting ARVs early in your pregnancy and taking them throughout your pregnancy will lower the chances that your baby will become HIV-infected. They can also improve your health. 4 5 6 7
- **All babies born to mothers living with HIV also need to take ARVs.** ARVs will help lower the chances that your baby will become HIV-infected. 13
- It is important that you **come back to the clinic for all of your appointments**—both during your pregnancy and after your baby is born. 3 12 13
- It is important that you plan to **have a safe delivery** at a health facility. 11
- We can plan how you will **feed your baby safely** to lower the chance that your baby will become HIV-infected after he or she is born. 14 15 16 17
- You also need **emotional support**—from your partner, family, and friends. 9
- **Tell people you trust about your HIV-status** so they can help you care for yourself and your baby. 9

TOGETHER, WE CAN LOWER THE CHANCES THAT YOUR BABY WILL BECOME HIV-INFECTED:

- There are many things you can do to lower the chances of passing HIV to your baby. We can help you learn more about the steps you can take during your pregnancy, labor, and delivery, as well as after your baby is born.
- If you come back to the clinic for all appointments and make sure you and your baby take medicines the right way, it will help you stay healthy and lower the chances that your baby will become HIV-infected.
- If your baby is HIV-infected, there is a lot we can do to keep him or her healthy. By coming to the clinic and following your own and your baby's care plan, you can make sure your baby has the chance to grow up to be a healthy child and adult. 20

ASK: *I want to make sure I explained everything well. How do you think you can stay healthy during your pregnancy and lower the chances that your baby will be HIV-infected? How do you feel about talking to someone you trust about your HIV-status and your care plan? What questions do you have?*

Let's set up a time for your next appointment. *(explain to the client why it is important for her to return)*

1

STAYING HEALTHY
DURING YOUR PREGNANCY

2

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Many people living with HIV are healthy and able to live productive and fulfilling lives. Many pregnant women living with HIV are also able to stay healthy and prevent HIV infection in their babies. What are some of the things you think you can do to stay healthy during your pregnancy and lower the chances that your baby will be HIV-infected?*

COME TO THE CLINIC FOR ALL APPOINTMENTS DURING YOUR PREGNANCY AND AFTER YOU DELIVER:

3 12 13

- You should come to the clinic for **at least 4 antenatal care visits**. *(review what the client should expect to happen at each of these visits)*
- After the baby is born, you should come back to the clinic **within 3–7 days of birth**.
- The next visit for you and your baby will be at **4–6 weeks after birth**.

TRY AND FIND THE EMOTIONAL SUPPORT YOU NEED:

9

- It is important that you have support to take care of yourself and your baby—this support could come from a relative, your partner, or a friend.
- Having people who can give you emotional support is important because there may be times you feel very down. Try to remember that you are not alone and that there are people who can support you.
- If you are feeling very anxious or like you have too much stress, or if you feel very down or depressed, it is important that you speak with a counselor, nurse, or other health care provider.
- You may want to join a mother's support group to talk with other women going through the same situation. We can link you to a support group if you are interested.

MAKE SURE YOU GET A CD4 TEST AND COME BACK TO LEARN YOUR CD4 TEST RESULTS:

3

- The CD4 cells are the soldiers in our bodies that help us fight infections.
- HIV attacks the CD4 cells and it becomes more and more difficult for our bodies to fight infections.
- To know how many CD4 cells you have, the nurse will take a sample of blood from your arm and send it to the lab. It is very important that you pick up your CD4 test results.
- The higher your CD4 count, the better. If your CD4 count is high, there is a lower chance your baby will have HIV than if your CD4 count is low.

TAKE MEDICINES CALLED ARVs AND GIVE YOUR BABY ARVs:

4 5 6 7 13

- All pregnant women living with HIV need to take medicines called ARVs.
- ARVs are safe for you and your baby.
- The type of ARVs that you take, and for how long, depends on your CD4 count and how advanced your HIV is. It is important to start taking ARVs early in pregnancy.
- All babies born to women living with HIV also need to take ARVs.
- The type of ARVs your baby will take, and for how long, depends on your CD4 count, how advanced your HIV is, and which ARVs you take during pregnancy.
- ARVs do not cure HIV. There is no cure for HIV.
- You will also need to take a medicine called cotrimoxazole every day to prevent infections. *(show CTX and describe how to take it)*
- It is important that you always take your medicines at the same time, every day. Never share your medicines with other people.

CONTINUED ON BACK

8

ASK YOUR PARTNER TO GET AN HIV TEST TOO:

- Sometimes it can be hard to talk to your partner about getting tested. If you want, we can talk about ways to get your partner to come for an HIV test.

18

PRACTICE SAFER SEX:

- Always use a new male or female condom every time you have sex. *(demonstrate)*
- Even though it can be hard, it is good to talk to your partner about using condoms.

PREVENT AND TREAT SEXUALLY TRANSMITTED INFECTIONS (STIs):

- If you or your partner has signs of STIs, like itching, a rash, strange discharge, or sores around the genitals, come to the clinic right away. Many times women do not have any of these signs, so it is important that we test you for STIs to know for sure.
- If either you or your partner has an STI, both of you need to get treatment. Otherwise, you will just keep giving the infection to each other.

PREVENT AND TREAT TUBERCULOSIS (TB):

- Make sure you have a lot of fresh air in your home.
- Cover your mouth when you cough or sneeze, and ask others do the same.
- TB spreads very easily. If you live with someone who has TB, try to avoid very close contact, protect yourself, and support that person to get treatment at the clinic.
- If you have signs of TB, like coughing, night sweats, fever, or a lot of weight loss, come to the clinic right away. Tell the doctor or nurse so they can check you for TB.

EAT ENOUGH NUTRITIOUS FOODS AND GET ENOUGH REST:

- Pregnant and breastfeeding women need to eat more healthy foods than normal to stay healthy and to have healthy babies. Not eating enough or not eating healthy foods can make you unwell and lead to problems for your baby.
- Drink lots of fluids. Avoid alcohol.
- Take the vitamin and iron tablets that you get at the clinic.
- Try and get plenty of rest, especially in the last months of pregnancy.

11

PLAN TO DELIVER YOUR BABY SAFELY:

- Plan on having a safe delivery in the hospital.
- Talk with your partner and family members about how you will get to the hospital and why it is important to deliver your baby there.

STAY AWAY FROM SMOKING, ALCOHOL, AND DRUGS:

- Smoking, alcohol, and drugs, even in small amounts, will only hurt your own health and your baby's health and development.
- If you are having trouble quitting smoking, drinking alcohol, or taking drugs, we can help you or refer you for professional help to quit.

ASK: *I want to make sure I explained everything well. Can you tell me what you think are the most important things you can do to have a safe pregnancy—for yourself and your baby? How often will you come back to the clinic during your pregnancy? After you deliver? How is your pregnancy going so far? What questions do you have?*

ADHERING
TO YOUR PMTCT PLAN

ASK: *It is very important that you come back to the clinic for all of your appointments—during the pregnancy and after your baby is born. How do you think coming back to the clinic often during and after your pregnancy will help you and the baby stay healthy?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR CARE PLAN DURING AND AFTER YOUR PREGNANCY. THIS INCLUDES:

- Coming to all of your clinic, lab, and pharmacy appointments
- Taking all of your medications and giving your baby medications the right way, at the right time, every day
- Following the advice of the nurses and doctors about how to take care of yourself and your baby during pregnancy and after the baby is born

IT IS IMPORTANT THAT YOU COME TO ALL OF YOUR OWN AND YOUR BABY'S APPOINTMENTS:

- You should come to the clinic for **at least 4 antenatal care visits**.
- After the baby is born, you should come back to the clinic **within 3–7 days of birth**.
- The next visit for you and your baby will be **at 4–6 weeks after birth**.
- After that, your baby should be seen **every month** until we know for sure if he or she is HIV-infected or not.

ALL OF THESE CLINIC VISITS ARE IMPORTANT BECAUSE:

- The nurse will give you a checkup and may also take blood. This is to make sure that you are healthy and that your baby is doing well.
- If something is wrong, the doctors and nurses will be able to quickly get you (or your baby) the treatment that is needed.
- During these appointments, you will get the medicines and vaccinations that you and your baby need. *(give an overview of which medicines and vaccinations will be needed)*
- You will have a chance to have one-on-one counseling during your visits.
- Always remember that if you are feeling sick or have questions, you should come to the clinic even if you do not have an appointment.

IT IS IMPORTANT TO MAKE AN ADHERENCE PLAN THAT FITS WITH YOUR LIFE:

- Get support from people you trust. They can help you remember your appointments, take care of things at home when you are away, or come to the clinic with you.
- If you cannot keep an appointment, call the clinic and then come as soon as possible. *(explain appointment card and give clinic contact information)*
- Be sure to come back to the clinic before your or your baby's medicines run out. If you are planning to be away, we can give you extra medicines.
- Plan ahead if you will need money for transport to the clinic.
- Write down the dates of your appointments and ask someone to help remind you.
- Join a mothers' support group *(give specific information about local support groups).* Counselors at the clinic are also here to support and help you.

ASK: *I want to make sure I explained everything well. Can you tell me why you think it is important to come back to the clinic for all of your appointments? What will help you remember to come back for appointments? What challenges do you think there will be? What questions do you have?*

PREPARING TO START AND ADHERE TO LIFELONG ART

4

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Because your CD4 count is below 350 (or your exam showed that you have advanced HIV or AIDS), we recommend that you start taking ART now, and keep taking it during your pregnancy and for your whole life. Starting ART now and taking ART for your whole life will help lower the chances that your baby will be HIV-infected and will help you live longer and stay well. How do you feel about taking ART every day during your pregnancy? For your whole life?*

WE RECOMMEND THAT YOU START TAKING MEDICINES CALLED ART: *(show ARVs)*

- ARVs are medicines that help lower the amount of HIV in the body. When we take different ARVs at the same time (usually 3 kinds), we call this antiretroviral therapy, or ART.
- These medicines are **safe** for you and for your baby.
- People with HIV can live long, healthy lives. ART does not cure HIV, but it can make you stay healthy and live a long life.
- It is important to start ART early in pregnancy. We will give you ART to take during your pregnancy and for the rest of your life. Taking these medicines for your whole life will lower the chance that your baby will be HIV-infected and will help keep you healthy.
- You should take your ART 2 times every day. This usually means taking pills in the morning and in the evening for your whole life. *(adapt according to regimen)*
- It is important to keep taking your ART during your labor and delivery. Be sure to bring your medicines with you wherever you deliver. Tell the nurse or doctor that you are taking ART when you are admitted. 11
- Your baby will also need to take ARV syrup for 6 weeks after he or she is born to lower the chances that he or she will become HIV-infected. 13

ASK: *What do we mean by "adherence?" Why is adherence to ART so important?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR CARE AND TREATMENT PLAN. THIS INCLUDES:

- Coming to all of your clinic, lab, and pharmacy appointments—during and after the pregnancy—and ongoing for your whole life
- Taking medicines to prevent and treat infections, like cotrimoxazole
- Taking your ART the right way, every day, during pregnancy and for your whole life

WHY ADHERENCE TO YOUR CARE AND YOUR ART ARE IMPORTANT:

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need, and will give you a chance to ask questions and get support.
- Very good adherence is needed for ART to work. If you take your ART the right way, every day, for your whole life, you will feel better and not get sick as often. Taking ART will lower the chance that your baby will become HIV-infected.
- If you do not take your ART the right way, every day, the HIV in your body will grow stronger. Your CD4 count will go down and you will likely get more infections and illnesses. There will be a higher chance that your baby will become HIV-infected.
- Stopping your medicines or missing many doses can lead to "drug resistance." This means that the medicines will no longer work (even if you start again).

CONTINUED ON BACK

ASK: *What do you think are some things that will help you remember to come back to the clinic and to take your ART every day for your whole life? Who is closest to you in your family? How do you feel about talking to him or her about your care and medicines?*

IT IS IMPORTANT FOR YOU TO MAKE AN ADHERENCE PLAN THAT FITS WITH YOUR LIFE:

- Try to talk with someone you trust so you have support to come back to the clinic and to take your medicines.
- Make sure you understand your care and treatment plan. If there is something you do not understand, make sure to ask at the clinic. *(review client's specific care and treatment plan)*
- Come to all of your scheduled appointments at the clinic. If you cannot keep an appointment, try to call the clinic, and then go as soon as possible.
- Take your ART the right way, at the same time, every day. *(discuss client's medication schedule)*
- Try to make your medicine part of everyday life by fitting it in with things you normally do. *(give examples)*
- Use reminders, such as a mobile phone, health card, watch, pill box, or medicine calendar. *(discuss specific reminder options that the client would like to use)*
- Pick up your medicines on time and before they run out.
- Plan ahead if you will need to take your ART when you are away from home, including for your labor and delivery. Some people like to store their medicine in a pill box or a small bag when they travel.
- Join a support group *(give specific information about local support groups).* Counselors at the clinic are also here to help you.

WHAT YOU CAN DO ABOUT ARV SIDE EFFECTS:

- Side effects from ARVs are usually not serious and most go away after a couple of weeks.
- It is important to keep taking your medicines, even if you have some side effects at first.
- Some side effects caused by ARVs are nausea, vomiting, headache, and diarrhea. These are usually not serious. *(discuss how to manage at home)*
- **You should come to the clinic right away** if you have: a rash, high fever, problems breathing, a bad headache, numbness in the hands or feet, or very bad vomiting or diarrhea.
- It is important to keep taking your iron pills while you take ART to prevent anemia.
- Never make the decision alone to stop taking ART. Instead, come to the clinic right away to talk with the nurse or doctor.

WHAT YOU SHOULD DO IF YOU MISS DOSES OF YOUR ART:

- If you miss a dose of ARVs, take the missed dose if your next dose is scheduled for more than 6 hours away. Do not take the missed dose if the next dose is less than 6 hours away. *(give example)*
- Never take 2 doses at the same time. If you are not sure how to take your medicines, call or come to the clinic to ask.

ASK: *I want to make sure I explained everything well. Why is it important to take your ART 2 times every day throughout your pregnancy and for your whole life? Who/what will help you remember to take your ART every day and to come back to the clinic for appointments? What challenges do you think you will face with taking your medicines every day during your pregnancy? For your whole life? What will you do if you have side effects? What questions do you have about your care and treatment plan?*

(Note: This may be a good time to use the adherence preparation and support guide with the client.)

CONTINUING AND ADHERING TO YOUR ART DURING PREGNANCY

5

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *How long have you been taking ART? Which ARVs do you take? Now that you are pregnant, we will review some of the basics about ART and why it is important to continue taking ART while you are pregnant, after the baby is born, and for your whole life. How have you felt taking ART so far? How do you feel about taking ART every day during your pregnancy?*

TAKING ART HELPS LOWER THE CHANCES THAT YOUR BABY WILL BE HIV-INFECTED AND HELPS YOU LIVE LONGER AND STAY WELL:

- ARVs are medicines that help lower the amount of HIV in the body. When we take different ARVs at the same time (usually 3 kinds), we call this antiretroviral therapy, or ART.
- These medicines are **safe** for you and for your baby.
- People with HIV can live long, healthy lives. ART does not cure HIV, but it can make you stay healthy and live a long life.
- You should continue to take ART during your pregnancy and for the rest of your life to lower the chance that your baby will be HIV-infected and to help keep yourself healthy.
- You will take the same ARVs during your pregnancy that you were taking before, unless you were taking a drug called **efavirenz.** *(show new ARVs if regimen will change)*
- You should continue to take your ART at the same times every day. This usually means taking pills in the morning and in the evening for your whole life. *(review dosing)*
- It is important to keep taking your ART during your labor and delivery. Be sure to bring your medicines with you wherever you deliver. 11
- Your baby will also need to take ARV syrup for 6 weeks after he or she is born. 13

ASK: *What do we mean by "adherence?" Why is adherence to your care and ART so important?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR CARE AND TREATMENT PLAN. THIS INCLUDES:

- Coming to all of your clinic, lab, and pharmacy appointments—during and after the pregnancy—and ongoing for your whole life
- Taking medicines to prevent and treat infections
- Taking your ART the right way, every day, during pregnancy and for your whole life

WHY ADHERENCE TO YOUR CARE AND ART IS IMPORTANT:

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need, and will give you a chance to ask questions and get support.
- If you take your ART the right way, every day, you will feel better and not get sick as often. Adherence is very important during pregnancy because taking your ART correctly will help lower the chance that your baby will become HIV-infected.
- If you do not take your ART the right way, every day, the HIV in your body will grow stronger. Your CD4 count will go down and you will likely get more infections and illnesses. There will also be a higher chance that your baby will become HIV-infected.
- Stopping ART or missing many doses can lead to "drug resistance." This means that the medicines will no longer work (even if you start again).

CONTINUED ON BACK

ASK: *Can you tell me about any adherence challenges you have had? Do you think there will be new challenges now that you are pregnant? What helps you remember to come to the clinic and to take your medications? Do you have support to take care of yourself and to adhere to your care and medicines?*

IT IS IMPORTANT FOR YOU TO MAKE AN ADHERENCE PLAN THAT FITS WITH YOUR LIFE:

9

- Try to talk with someone you trust so you have support to come back to the clinic and to take your medicines.
- Make sure you understand your care and treatment plan. If there is something you do not understand, make sure to ask at the clinic. *(review client's specific care and treatment plan)*
- Come to all of your scheduled appointments at the clinic. If you cannot keep an appointment, try to call the clinic, and then go as soon as possible.
- Take your ART the right way, at the same time, every day. *(discuss medication schedule)*
- Try to make your medicine part of everyday life by fitting it in with things you normally do. *(give examples)*
- Use reminders, such as a mobile phone, health card, watch, pill box, or medicine calendar. *(discuss specific reminder options that the client would like to use)*
- Pick up your medicines on time and before they run out.
- Plan ahead if you will need to take your ART when you are away from home, including for your labor and delivery. Some people like to store their medicine in a pill box or a small bag when they travel.
- Join a support group *(give specific information about local support groups).* Counselors at the clinic are also here to help you.

ASK: *Have you had any side effects from your ART? How did you treat or manage those side effects?*

WHAT YOU CAN DO ABOUT ARV SIDE EFFECTS:

- Side effects from ARVs are usually not serious and most go away after a couple of weeks.
- It is important to keep taking your medicines, even if you have some side effects at first.
- Some side effects caused by ARVs are nausea, vomiting, headache, and diarrhea. These are usually not serious. *(discuss how to manage at home)*
- **You should come to the clinic right away** if you have: a rash, high fever, problems breathing, a bad headache, numbness in the hands or feet, or very bad vomiting or diarrhea.
- It is important to keep taking your iron pills while you take ART to prevent anemia.
- Never make the decision alone to stop taking ART. Instead, come to the clinic right away to talk with the nurse or doctor.

WHAT YOU SHOULD DO IF YOU MISS DOSES OF YOUR ART:

- If you miss a dose of ARVs, take the missed dose if your next dose is scheduled for more than 6 hours away. Do not take the missed dose if the next dose is less than 6 hours away. *(give example)*
- Never take 2 doses at the same time. If you are not sure how to take your medicines, call or come to the clinic to ask.

ASK: *I want to make sure I explained everything well. Why is it important to continue taking your ART the right way, every day, throughout your pregnancy and for your whole life? Who/what will help you remember to take your ART and to come back to the clinic? What challenges do you think you will face taking your medicines every day? What will you do if you have side effects? What questions do you have about continuing your care and treatment plan?*

(Note: This may be a good time to use the adherence preparation and support guide with the client.)

PREPARING TO START AND ADHERE TO AZT PROPHYLAXIS

6

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Because your CD4 count is over 350 and you do not have advanced HIV or AIDS, we would like you to start taking AZT 2 times every day (starting at 14 weeks of pregnancy) and to continue taking it throughout your pregnancy to help lower the chances that your baby will be HIV-infected. How do you feel about taking AZT every day during your pregnancy?*

WE RECOMMEND THAT YOU START TAKING A MEDICINE CALLED AZT AT 14 WEEKS OF PREGNANCY (or anytime after 14 weeks if you are further along in your pregnancy): *(show AZT)*

- AZT is a kind of antiretroviral medicine. Antiretrovirals, or ARVs, are medicines that help lower the amount of HIV in the body.
- This medicine is **safe** for you and your baby.
- We will give you AZT during your pregnancy to help protect your baby from HIV.
- You should take AZT 2 times every day. Usually this means one pill in the morning and one pill in the evening, until you give birth. *(review AZT dosing)*
- It is important to keep taking your AZT during your labor and delivery. Be sure to bring your medicines with you wherever you deliver. The doctor may also give you other ARVs during your labor and delivery and during the 7 days after you deliver your baby. 11
- Your baby will also need to take ARV syrup once every day until you stop breastfeeding to lower the chances that he or she will be HIV-infected (or for 6 weeks if not breastfed). 13
- After your baby is born, the doctor will examine you and do tests to see if you need to start taking ART (3 kinds of ARVs) for your own health, which you would then need to continue for your whole life. 12

ASK: *What do we mean by "adherence?" Why is adherence to AZT so important?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR CARE AND TREATMENT PLAN. THIS INCLUDES:

- Coming to all of your clinic, lab, and pharmacy appointments—during and after the pregnancy—and ongoing
- Taking medicines to prevent and treat infections
- Taking your ARVs the right way, every day, for as much time as the doctor says. For AZT, this means taking your doses every morning and every evening, every day during your pregnancy

WHY ADHERENCE TO YOUR CARE AND AZT IS IMPORTANT:

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need, and will give you a chance to ask questions and get support.
- Very good adherence is needed for AZT to work. If you take your AZT the right way, every day, there is a much lower chance that your baby will become HIV-infected.
- AZT protects your baby from HIV. If you do not take your AZT the right way, every day, there will be a higher chance that your baby will become HIV-infected.

CONTINUED ON BACK

ASK: *What do you think are some things that will help you remember to come back to the clinic and to take your AZT every day? Who is closest to you in your family? How do you feel about talking to him or her about your care and medicines?*

IT IS IMPORTANT TO MAKE AN ADHERENCE PLAN THAT FITS WITH YOUR LIFE:

9

- Try to talk with someone you trust so you have support to come back to the clinic and to take your medicines.
- Make sure you understand your care and treatment plan. If there is something you do not understand, make sure to ask at the clinic. *(review client's specific care and treatment plan)*
- Come to all of your scheduled appointments at the clinic. If you cannot keep an appointment, try to call the clinic, and then go as soon as possible.
- Take your AZT the right way, at the same time, every day. *(discuss client's medication schedule)*
- Try to make your medicine part of everyday life by fitting it in with things you normally do. *(give examples)*
- Use reminders, such as a mobile phone, health card, watch, pill box, or medicine calendar. *(discuss specific reminder options that the client would like to use)*
- Pick up your medicines on time and before they run out.
- Plan ahead if you will need to take your AZT when you are away from home, including for your labor and delivery. Some people like to store their medicine in a pill box or a small bag when they travel.
- Join a support group *(give specific information about local support groups).* Counselors at the clinic are also here to help you.

WHAT TO DO ABOUT AZT SIDE EFFECTS:

- Side effects from AZT are usually not serious and most go away after a couple of weeks.
- It is important to keep taking your AZT, even if you have some side effects at first.
- Some side effects caused by AZT are nausea, vomiting, headache, and diarrhea. These are usually not serious. *(discuss how to manage at home)*
- **You should come to the clinic right away** if you have: a rash, high fever, problems breathing, a bad headache, numbness in the hands or feet, or very bad vomiting or diarrhea.
- It is important to keep taking your iron pills while you take AZT to prevent anemia.
- Never make the decision alone to stop taking your AZT. Instead, come to the clinic right away to talk with the nurse or doctor.

WHAT TO DO ABOUT MISSED AZT DOSES:

- If you miss a dose of AZT, take the missed dose if your next dose is scheduled for more than 6 hours away. Do not take the missed dose if the next dose is less than 6 hours away. *(give example)*
- Never take 2 doses at the same time. If you are not sure how to take your medicines, call or come to the clinic to ask.

ASK: *I want to make sure I explained everything well. Why is it important to take your AZT 2 times every day throughout your pregnancy? Who/what will help you remember to take your AZT every day and to come back to the clinic for appointments? What challenges do you think you will face taking your medicines every day? What will you do if you have side effects? What questions do you have about your care and treatment plan?*

(Note: This may be a good time to use the adherence preparation and support guide with the client.)

PREPARING TO START AND ADHERE TO ART PROPHYLAXIS

7

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Because your CD4 count is over 350 and you do not have advanced HIV or AIDS, we recommend that you start taking ART 2 times every day (starting at 14 weeks of pregnancy and until one week after you stop breastfeeding your baby) to help lower the chances that your baby will be HIV-infected. How do you feel about taking ART every day during your pregnancy and while you breastfeed?*

WE RECOMMEND THAT YOU START TAKING MEDICINES CALLED ART AT 14 WEEKS OF PREGNANCY: *(show ARVs)*

- ARVs are medicines that help lower the amount of HIV in the body. When we take different ARVs at the same time (usually 3 kinds), we call this antiretroviral therapy, or ART.
- These medicines are **safe** for you and for your baby.
- We will give you ART to take during your pregnancy and until one week after you stop breastfeeding to lower the amount of HIV in your body. Taking these medicines will lower the chance that your baby will be HIV-infected.
- You should take your ART 2 times every day. This usually means taking pills in the morning and in the evening, until one week after you stop breastfeeding your baby. *(adapt according to regimen)*
- It is important to keep taking your ART during your labor and delivery. Be sure to bring your medicines with you wherever you deliver. 11
- Your baby will also need to take ARV syrup for 6 weeks after he or she is born to lower the chances that he or she will become HIV-infected. 13
- After your baby is born, the doctor will examine you and do tests to see if you need to keep taking ART for your own health, which you would then need to continue for your whole life. 12

ASK: *What do we mean by "adherence?" Why is adherence to ART so important?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR CARE AND TREATMENT PLAN. THIS INCLUDES:

- Coming to all of your clinic, lab, and pharmacy appointments—during and after the pregnancy—and ongoing
- Taking medicines to prevent and treat infections
- Taking your ART the right way, every day, during your pregnancy and until one week after you stop breastfeeding your baby

WHY ADHERENCE TO YOUR CARE AND ART IS IMPORTANT:

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need, and will give you a chance to ask questions and get support.
- Very good adherence is needed for ART to work. If you take your ART the right way, every day, you will feel better and not get sick as often. There is also a much lower chance that your baby will become HIV-infected.
- If you do not take your ART the right way, every day, there will be a higher chance that your baby will become HIV-infected.
- Stopping your medicines or missing many doses can lead to "drug resistance." This means that the medicines will no longer work (even if you start again).

CONTINUED ON BACK

ASK: *What do you think are some things that will help you remember to come back to the clinic and to take your ART every day? Who is closest to you in your family? How do you feel about talking to him or her about your care and medicines?*

IT IS IMPORTANT FOR YOU TO MAKE AN ADHERENCE PLAN THAT FITS WITH YOUR LIFE:

- Try to talk with someone you trust so you have support to come back to the clinic and to take your medicines.
- Make sure you understand your care and treatment plan. If there is something you do not understand, make sure to ask at the clinic. *(review client's specific care and treatment plan)*
- Come to all of your scheduled appointments at the clinic. If you cannot keep an appointment, try to call the clinic, and then go as soon as possible.
- Take your ART the right way, at the same time, every day. *(discuss client's medication schedule)*
- Try to make your medicine part of everyday life by fitting it in with things you normally do. *(give examples)*
- Use reminders, such as a mobile phone, health card, watch, pill box, or medicine calendar. *(discuss specific reminder options that the client would like to use)*
- Pick up your medicines on time and before they run out.
- Plan ahead if you will need to take your ART when you are away from home, including for your labor and delivery. Some people like to store their medicine in a pill box or a small bag when they travel.
- Join a support group *(give specific information about local support groups).* Counselors at the clinic are also here to help you.

WHAT YOU CAN DO ABOUT ARV SIDE EFFECTS:

- Side effects from ARVs are usually not serious and most go away after a couple of weeks.
- It is important to keep taking your medicines, even if you have some side effects at first.
- Some side effects caused by ARVs are nausea, vomiting, headache, and diarrhea. These are usually not serious. *(discuss how to manage at home)*
- **You should come to the clinic right away** if you have: a rash, high fever, problems breathing, a bad headache, numbness in the hands or feet, or very bad vomiting or diarrhea.
- It is important to keep taking your iron pills while you take ART to prevent anemia.
- Never make the decision alone to stop taking ART. Instead, come to the clinic right away to talk with the nurse or doctor.

WHAT YOU SHOULD DO IF YOU MISS DOSES OF YOUR ART:

- If you miss a dose of ARVs, take the missed dose if your next dose is scheduled for more than 6 hours away. Do not take the missed dose if the next dose is less than 6 hours away. *(give example)*
- Never take 2 doses at the same time. If you are not sure how to take your medicines, call or come to the clinic to ask.

ASK: *I want to make sure I explained everything well. Why is it important to take your ART 2 times every day throughout your pregnancy and until one week after you stop breastfeeding your baby? Who/what will help you remember to take your ART every day and to come back to the clinic for appointments? What challenges do you think you will face taking your medicines every day? What will you do if you have side effects? What questions do you have about your care and treatment plan?*

(Note: This may be a good time to use the adherence preparation and support guide with the client.)

HIV Testing
FOR YOUR FAMILY MEMBERS & PARTNER

8

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *I would like to talk to you more about the children who live with you at home—both your own children and children you help take care of.*

FOR EACH CHILD, ASK: *How old is the child? How is his/her health? Has he/she been tested for HIV? Do you know his/her HIV-status?*

IF A CHILD IS HIV-INFECTED, ASK: *Can you tell me more about the care and medicines the child gets?*

IT IS IMPORTANT FOR ALL OF YOUR CHILDREN TO GET TESTED FOR HIV: 19

- Even though you are living with HIV, this does not necessarily mean that your children are also HIV-infected. To find out for sure, we need to do an HIV test.
- Even if your children do not seem sick, they may be HIV-infected.
- Children living with HIV need care and treatment, which is available for free.
- HIV develops much faster in children than it does in adults, so it is important to test children as early as possible (as early as 4–6 weeks of age).
- Without treatment, many children living with HIV will become very sick and die.
- HIV care and treatment, including ARVs, can help save your child's life and help him or her grow and become a healthy adult. 20

ASK: *What questions do you have about getting your children tested for HIV? Would you like to make an appointment to bring your children to the clinic for an HIV test?*

ASK: *Now I would like to talk about your sexual partner(s). Do you know if your partner(s) has been tested for HIV recently? Do you know his or her HIV-status? Have you tried talking with your partner about getting an HIV test? How did you do so?*

IT IS IMPORTANT FOR YOUR PARTNER(S) TO GET TESTED FOR HIV:

- Your test result does not tell us whether or not your partner has HIV. The only way to know your partner's HIV-status is for him or her to get an HIV test.
- The sooner your partner knows his or her HIV-status, the sooner we can take steps to keep your partner negative or to get your partner started on care and treatment.
- If your partner is living with HIV, he or she will also need HIV care and treatment to stay healthy.
- If your partner is HIV-negative, we can help you learn what steps to take in order to keep him or her negative. 10

HOW TO TALK WITH YOUR PARTNER ABOUT GETTING AN HIV TEST: 9

- Sometimes it can be hard to talk to your partner about getting an HIV test.
- You could tell your partner you want to talk about HIV testing so that the two of you can be closer, make decisions together, and keep your family healthy.
- Ask your partner to come to this clinic—or another clinic that is convenient—to learn more about HIV testing and counseling. All test results are kept confidential.
- We can also help by talking to your partner about getting an HIV test.

ASK: *What concerns do you have about asking your partner to get an HIV test? Would you like to make an appointment to come back with your partner so we can talk more about HIV testing together?*

DISCLOSING YOUR HIV-STATUS

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Who have you told about your HIV-status, if anyone? Can you tell me more about your concerns and your experiences talking with others about your HIV-status?*

IF THE CLIENT HAS NOT YET DISCLOSED TO HER PARTNER, ASK: *How do you think your partner would react if you told him or her your HIV-status?*

- We recommend that you talk to your partner about your HIV-status if you feel safe doing so.
- You could say that HIV testing is a routine part of care for all pregnant women, and that this is why you were tested. HIV testing helps protect the baby.
- It is possible that your partner will be supportive of you, help you protect your baby from HIV, and help you stay healthy.
- It may be hard for you to adhere to your and your baby's care and medicines if your partner does not know your HIV-status. Your partner may ask questions about your clinic visits or medicines.
- Your partner should also have an HIV test and, if positive, enroll in care and treatment. We can provide information, services, and support to your whole family so you can all get the care you need. …….. 8
- If you want, we can help you talk to your partner about your HIV-status.

ASK: *What good things do you think could result from telling someone your HIV-status? What bad things do you think could result from telling someone your HIV-status?*

POSSIBLE BENEFITS OF TELLING SOMEONE YOU TRUST ABOUT YOUR HIV-STATUS:

- You will not have to keep your HIV-status a secret anymore.
- You will not have to worry about the person finding out your HIV-status accidentally.
- You might be able to talk to the person about your concerns and get his or her support.
- The person might be able to help you with your own and your baby's care and treatment.

ASK: *Who do you think you could tell about your HIV-status? When do you think would be a good time and place to tell this person? How will you tell him or her? How do you think the person will react?*

DISCLOSING YOUR HIV-STATUS IS A PROCESS:

- Many people prefer to disclose to one person they trust at a time, instead of disclosing to many people at once.
- Here are some ways that you could start the conversation: *(practice by role playing)*
  - — "I wanted to talk to you about something because I know you can help and support me."
  - — "I went to the clinic today for a checkup and they talked to me about how it is important for everyone to get an HIV test because you can't tell if someone is positive just by looking at them."
  - — "I need to talk to you about something difficult. It is important for our family that I be able to tell you even the hard things. We need to support each other."

ASK: *We are here to support you during your disclosure process. Would you like to set up another appointment to continue talking about this—either alone or with your partner, a friend, or a family member?*

BEING PART OF A DISCORDANT COUPLE

10

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *It can be hard for couples to learn that one partner is HIV-positive and the other is HIV-negative. Can you tell me about your concerns? What do you think you can do to lower the chances of passing HIV to your partner if he or she is HIV-negative?*

TALK TO YOUR PARTNER:

- It is good to talk to your partner about your HIV-status if you feel safe doing so.
- We can help you both understand the ways you can keep each other safe and healthy.
- Encourage your partner to go for regular HIV tests. 8
- Bring your partner to the clinic for couples counseling. We can help you both understand the ways to prevent HIV from spreading. This will also give you and your partner a chance to talk about your concerns and how you plan to keep each other healthy.

TAKE YOUR ARVs THE RIGHT WAY, EVERY DAY: 4 5 6 7

- Taking your ARVs the right way, every day, lowers the amount of HIV in your body.
- The less HIV there is in your body, the lower the chance you will pass HIV to your partner during sex, or to your baby during pregnancy and breastfeeding.

PRACTICE SAFER SEX:

- Not having sex at all is one way to be completely safe, but this is not practical for many people.
- Using condoms is one reliable way to practice safer sex. Even though it can be hard, it is important to talk to your partner about using condoms—both with you and with other partners, including during pregnancy and breastfeeding. *(demonstrate and give condoms)*

PREVENT AND TREAT SEXUALLY TRANSMITTED INFECTIONS (STIs):

- If you or your partner has signs of STIs, like itching, a rash, strange discharge, or sores around the genitals, come to the clinic right away. Many times women do not have any of these signs, so it is important that we test you for STIs to know for sure.
- If either you or your partner has an STI, both of you need to get treatment. Otherwise, you will just keep giving the infection to each other.

PLAN FOR, OR PREVENT, FUTURE PREGNANCIES (DEPENDING ON YOUR DESIRES): 18

- Use family planning if you do not want to become pregnant ever again or if you want to wait before becoming pregnant again. *(give examples of methods and referrals, if needed)*
- Using condoms can help prevent HIV, STIs, and pregnancy. *(discuss dual protection)*
- If you want to have another baby, the safest time to get pregnant is when your CD4 count is over 350; you do not have any opportunistic infections, including TB, or advanced AIDS; and you are taking and adhering to ART (if the doctor prescribes it).
- If you decide you want to have another baby in the future, come to the clinic with your partner and we can help you decide the safest times and ways to get pregnant.

ASK: *I want to make sure I explained everything well. Can you tell me what you think are the most important things about being part of a discordant couple? What concerns do you have about talking with your partner? Would you like to come back with your partner for more counseling?*

HAVING A SAFE LABOR & DELIVERY

11

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *There is a chance that HIV will be passed from a mother living with HIV to her baby during labor and delivery. What are some of the things you think you can do to lower this chance? Can you tell me more about your plans for your baby's birth, such as where you plan to deliver? Are there any traditional customs you will follow during or after your baby's birth?*

HAVE A SAFE DELIVERY IN A HEALTH CARE FACILITY:

- Deliver your baby in a hospital. Any woman can have complications during delivery, and health care workers know how to take care of you in case of these complications.
- Plan where you want to give birth to your baby, and how you will get there. You may want to plan to stay with family or friends near the clinic if you live far away.
- Find someone you trust who can give you emotional support during labor and delivery.
- Bring your health card and ARVs to the hospital. Be sure to inform the health care worker of your HIV-status and any medicines, such as ARVs, you have taken.

YOU WILL NEED TO TAKE ARVs DURING LABOR AND DELIVERY: *(counsel based on the client's regimen)*

4 5 6 7

- If the nurse gave you a **single dose of nevirapine** during an antenatal visit, take it as soon as you go into labor. *(show NVP tablet)*
- If you are taking **ART (3 or more ARVs)** during your pregnancy, be sure to bring your medicines to the hospital and keep taking them at the same times every day.
- If you are taking **AZT during your pregnancy,** continue taking the AZT during labor. You may also be given one other medicine to take at delivery.
- If you haven't taken any ARVs during your pregnancy, the doctor or nurse will give you ARVs to take when you are in labor and during the delivery.

YOUR BABY NEEDS TO TAKE ARVs RIGHT AFTER BIRTH, AND FOR SOME TIME AFTER THAT: .....

13

- ARVs are **safe** for your baby and will help protect him or her from HIV.
- Your baby needs to take **nevirapine syrup as soon as possible after birth—within 72 hours (3 days) of delivery**. If the nurse gave you the baby's dose during an antenatal visit:
  - — Bring the baby's dose to the hospital and tell the health care worker you have been given nevirapine. *(show NVP and how to measure)*
  - — Bring the baby to the hospital as soon as possible after birth, and make sure that the baby takes nevirapine syrup within 3 days of birth.
- Your baby will also need to take **ARVs for some time after he or she is born.** We will help you understand which ARVs your baby needs to take and for how long.

TAKING CARE OF YOURSELF AND YOUR BABY AFTER THE DELIVERY: .....

12 13

- What babies need most after delivery is to be loved and to bond. Spend as much time as you can with the baby skin-to-skin on your chest. Cuddle, sing, and talk to the baby.
- Your baby will need to eat within one hour of being born. He or she will naturally want to breastfeed once lying on your chest. .....

14 15 16

- Be sure to rest (with your baby, if possible), drink lots of fluids, and eat healthy foods.

ASK: *I want to make sure I explained everything well. Can you tell me how you plan to have a safe labor and delivery? What questions do you have?*

Taking Care of Yourself
after your baby is born

12

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Delivering a baby is hard but rewarding work. Like their babies, mothers also need care after giving birth. Taking care of yourself after delivery and ongoing is important for you to feel strong and healthy and will help you have the energy you need to care for your baby. What do you think you can do to take care of your own health after your baby is born?*

TAKING CARE OF YOURSELF AFTER THE DELIVERY:

- Spend as much time as you can with the baby skin-to-skin on your chest or resting together. Cuddle, sing, and talk to the baby. Babies love this and it helps with their development.
- Try to get help and emotional support from friends or family. Try not to do too much physical labor.
- If you have heavy bleeding, problems breathing, fever, pain in your belly, or bad-smelling discharge, come to the clinic right away.
- As a new mother, you need to eat and drink more than usual, especially if you are breastfeeding. Try to eat at least one extra meal each day.
- You should wash often and try to keep your genitals very clean—but only use clean water with no soap. Wait a couple of weeks before you sit in water.

COME BACK TO THE CLINIC WITHIN 1 WEEK AND THEN AGAIN 6 WEEKS AFTER YOU DELIVER: 3

- You will need a postnatal checkup during the first week after you have your baby. At this appointment, we will check to make sure you are healing properly and that you are not bleeding too much.
- You will need a second checkup 6 weeks after the baby is born to make sure you are still healing properly. We will also check your baby and give him or her an HIV test. 19
- You need to continue your own HIV care and treatment for your whole life. This is true for all women living with HIV—whether or not they have started taking ART.
- You will need to get another CD4 test done 6 months after you deliver your baby.
- If you feel unwell, or have questions about your own or your baby's health, remember that you can always come to the clinic.

PRACTICE SAFER SEX WITH YOUR PARTNER(S): 18

- In order to prevent infection, wait at least 6 weeks after delivery to have sex again.
- Talk with your partner about using condoms while you are breastfeeding and afterwards. Condoms will protect against STIs and another pregnancy. If your partner is HIV-negative, using condoms will protect him from becoming HIV-infected. *(provide condoms and demonstrate their use)* 10 18
- Using water-based lubricants can make sex less painful and more pleasurable. *(provide lubricants)*
- Although it may be difficult, talk to your partner about being faithful or always using condoms with other partners.
- Encourage your partner(s) to come for an HIV test. We can also talk to your partner if he or she comes to the clinic with you. 8
- If you or your partner has itching, a rash, strange discharge, or sores around the genitals, come to the clinic right away. If diagnosed with an STI, you will both need treatment.

ASK: *I want to make sure I explained everything well. Can you tell me some of the ways you will take care of yourself after you have your baby? How do you think you will talk with your partner about safer sex?*

CARING FOR YOUR HIV-EXPOSED BABY & ADHERING TO CARE & MEDICINES

13

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Caring for yourself and your baby after birth is very important. Your baby will need a lot of attention in the first few months of life. Who can help you care for your baby? What have you heard about caring for babies born to mothers living with HIV?*

YOUR BABY NEEDS ARVs AND SHOULD COME BACK TO THE CLINIC EVERY MONTH:

- The medicines that you and your baby take during this period can lower the chance that your baby will become HIV-infected.
- The medicines work by protecting your baby from HIV; they do not treat HIV.
- Your baby needs to take **nevirapine** syrup as soon as possible after birth—within 72 hours (3 days).
- ***For breastfeeding mothers on AZT prophylaxis:*** Your baby will continue to take nevirapine syrup once every day, until one week after you stop breastfeeding. *(show how to measure)*
- ***For breastfeeding mothers on ART prophylaxis or lifelong ART for their own health:*** Your baby will continue to take nevirapine syrup once every day until he or she is 6 weeks old. The ART you are taking also helps to protect your baby from HIV. *(show how to measure)*
- ***For mothers who are NOT breastfeeding:*** Your baby will take nevirapine or AZT syrup once every day from birth until he or she is 6 weeks old. *(show how to measure)*
- When your baby is 6 weeks old, he or she will also need to start taking a medicine called **cotrimoxazole** to prevent infections. How much cotrimoxazole syrup you will give your baby depends on his or her age. *(show CTX syrup and how to measure)*
- It is important that you and your baby come back to the clinic every month so we can make sure everything is going well with your and your baby's health.

ASK: *Breast milk is the healthiest food for all babies. There is HIV in breast milk, but mothers living with HIV can safely breastfeed when they/the baby take ARVs. Can you tell me how you plan to feed your baby?*

IT IS IMPORTANT TO FEED YOUR BABY SAFELY: 14 15 16 17

- **Exclusive breastfeeding for the first 6 months of life (with ARVs)** is the safest way to breastfeed, and lowers the chance that your baby will be HIV-infected. 15
  - — Breast milk is the only food your baby needs until he or she is 6 months old.
  - — Exclusive breastfeeding means giving your baby ONLY breast milk and no other liquids or foods, like water, herbal mixtures, juice, porridge, or cow's milk. It is okay to give the baby medicines that you get from the doctor or nurse.
- **Exclusive formula feeding** for the first 6 months of life is an option for some women. 16
  - — Formula feeding is only safe if you have support, time to prepare the formula up to 12 times each day, money to buy formula and supplies, access to clean water, and a way to boil it.
  - — Exclusive formula feeding means giving your baby ONLY formula and no other liquids or foods, like herbal mixtures, juice, porridge, or cow's milk. It is okay to give the baby medicines that you get from the doctor or nurse.
  - — If you use formula, do not breastfeed your baby—not even once. Giving your baby both formula and breast milk increases the chance your baby will become HIV-infected.
  - — It is important to prepare the formula safely, every time.
- After 6 months, the baby will need other foods in addition to breast milk/formula. 17

CONTINUED ON BACK

ASK: *We talked about adherence to the medicines that you take during and after pregnancy. It is also important that your baby gets his or her medicines the right way, every day, and that you bring the baby back to the clinic often, including for an HIV test at 6 weeks. What will help you do these things for yourself and your baby?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR OWN AND YOUR BABY'S CARE AND TREATMENT PLAN. THIS INCLUDES:

- Bringing your baby for all appointments at the clinic for checkups, lab tests, pharmacy refills, immunizations, if the baby gets sick, and for other care
- Giving your baby cotrimoxazole every day once the baby is 6 weeks old
- Giving your baby his or her ARVs the right way, every day, for as long as the doctor says. For your baby, this means giving the proper dose of ARVs every day, for 6 weeks or until one week after you stop breastfeeding. *(remind client of the baby's medication plan)*
- Giving the right dose of medicines to your baby. Remember, the amount of medicine will change when he or she gains weight and ages. *(check understanding of changing doses)*

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- Making sure the baby gets an HIV test at 6 weeks, and picking up the results
- Taking your own ART the right way, every day, so you will feel better and lower the chances that your baby will become HIV-infected *(review client's medication plan)*

IT IS IMPORTANT TO MAKE AN ADHERENCE PLAN FOR YOUR BABY:

- If you are taking medicines, give your child medicines at the same time you take yours.
- Try to schedule your own and your baby's appointments on the same day.

9

- Get support from someone you trust.
- **Here are some tips on giving your baby syrups:** *(demonstrate)*
  - Look at the colored tape on the syringe to make sure you are giving the right dose.
  - You can reuse syringes until the markings begin to wear off or the plunger is hard to use. Wash the syringes with warm, soapy water, rinse, and let them air dry.
  - If the medicine is too sticky, add a little breast milk or formula to the syringe.
  - DO NOT add medicines to a baby bottle or cup of milk.
- **If your baby does not want to take his or her medicine,** here are some tips: *(demonstrate)*
  - Wrap your baby in a blanket and hold him or her in the bend of your arm.
  - Place the dropper in the corner of the baby's mouth and slowly give the medicine. Aim for the inside of the baby's cheek instead of the back of the tongue.
  - Blow gently into your baby's face, which should make him or her swallow.
  - Do not give medicine when your baby is crying or by pinching his or her mouth open.
- If your baby vomits medicine within 30 minutes of giving it, give the dose again.

19

YOU SHOULD BRING YOUR BABY FOR AN HIV TEST WHEN HE OR SHE IS 6 WEEKS OLD:

- It is important that all of your children get an HIV test. The sooner we know each child's HIV-status, the more quickly he or she can get care and treatment.
- The nurse will take a small amount of blood from your baby's foot and put it on a piece of paper that will be sent to the lab. It usually takes about 2–3 weeks to get the results.
- It is very important to come back to the clinic to get your baby's test results.
- If your baby tests HIV-negative and you are breastfeeding, he or she will need to get another HIV test when you stop breastfeeding to know his or her HIV-status for sure.

ASK: *I want to make sure that I explained things well. Can you tell me the most important things about caring for your baby? Why is adherence to your baby's care and medicines important? What questions do you have about caring for your baby?*

SAFELY FEEDING YOUR BABY

14

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Breast milk is the best food for all babies. There are many things you can do to safely feed your baby. Can you tell me how you plan to feed your baby?*

FOR COUNTRIES WHERE BREASTFEEDING IS THE RECOMMENDATION AND/OR WHERE WOMEN CHOOSE TO BREASTFEED

IT IS IMPORTANT FOR YOU TO EXCLUSIVELY BREASTFEED YOUR BABY FOR AS LONG AS POSSIBLE, UP TO 6 MONTHS: 15

- Exclusive breastfeeding means giving your baby **ONLY** breast milk and no other liquids or foods, like water, herbal mixtures, juice, porridge, or cow's milk. It is okay to give the baby medicines that you get from the doctor or nurse.
- Breast milk is the only food your baby needs until he or she is 6 months old.
- Breast milk is healthy, free, and prevents your baby from being exposed to serious diseases.
- Babies should start breastfeeding within one hour of birth—this is when they will be most awake. Babies should breastfeed at least 8 times every day (per 24 hours, this means about every 3 hours).
- It is important that your baby has a good latch onto your breast so that you are comfortable and so that he or she gets enough milk. *(demonstrate how to hold and latch the baby)*

YOU CAN LOWER THE CHANCES OF PASSING HIV TO YOUR BABY THROUGH BREAST MILK: 15

- If you are on ART while you are breastfeeding, take your medicines every day at the same time. This will lower the chance of passing HIV to your baby. 4 5 7
- If you are not on ART while you are breastfeeding, your baby needs to take ARVs every day for protection against HIV. Give your baby nevirapine syrup once every day for as long as you are breastfeeding. *(show NVP syrup and how to measure)* 13
- While breastfeeding for the first 6 months, make sure your baby does not have any other liquids or foods other than breast milk and medicines. 17
- If you have cracked, sore, or painful nipples, come to the clinic right away.
- If you see thrush (white spots) in the baby's mouth, come to the clinic right away.

YOUR BABY WILL NEED FOODS IN addition TO BREAST MILK AFTER 6 MONTHS: 17

- Once your baby is 6 months old, he or she will need to have other foods in addition to breast milk to get the nutrition he or she needs to grow and develop.
- Your baby can have both breast milk and other foods until he or she is 1-2 years old. It is important for your baby to continue taking ARVs as long as you are breastfeeding.
- You should only stop breastfeeding if you have enough healthy foods and milk to feed your baby.
- If your baby is HIV-infected, breast milk will help keep him or her healthy. 20
- When you want to stop breastfeeding, slowly wean your baby. Stopping quickly can be painful for you and bad for the baby.

ASK: *I want to make sure I explained everything well. Can you tell me how you plan to safely breastfeed your baby? What challenges do you think you will face with exclusive breastfeeding (for example, time away from the baby, family pressure, and traditional customs)? What questions do you have about safely breastfeeding your baby?*

CONTINUED ON BACK

FOR COUNTRIES WHERE AVOIDANCE OF ALL BREASTFEEDING IS THE RECOMMENDATION AND/OR WHERE WOMEN CHOOSE TO FORMULA FEED

16 **FORMULA FEEDING IS ONLY SAFE FOR YOU AND YOUR BABY IF:**

- You and your family will accept that the baby is formula fed
- You have the time to prepare the formula and feed your baby as many as 12 times in 24 hours
- You can afford everything that you need to prepare the formula for as long as your baby needs it *(give examples—bottles/cups, formula, way to boil water, brushes to clean bottles/cups)*
- You will have access to all that you need to safely prepare the formula for as long as your baby needs it
- AND you have access to clean water and a way to boil it

16 **IT IS IMPORTANT FOR YOU TO EXCLUSIVELY FORMULA FEED YOUR BABY UP TO 6 MONTHS:**

- Exclusive formula feeding means giving your baby ONLY formula and no other liquids or foods, like herbal mixtures, juice, porridge, or cow's milk. It is okay to give the baby medicines you get from the doctor or nurse.
- It is important that you do not breastfeed your baby—not even one time. Giving the baby both formula and breast milk increases the chance that your baby will become HIV-infected.

16 **IT IS IMPORTANT TO PREPARE THE FORMULA SAFELY EVERY TIME TO PREVENT YOUR BABY FROM GETTING SICK:** *(demonstrate safe preparation of formula)*

- Always get the water from a safe source, like a faucet.
- Always boil the water and allow it to cool before mixing the formula.
- Always put the cooled water in a clean bottle or cup first, and then add the formula powder.
- To add the powder, use the scoop that comes inside the tin. Make sure you use the correct amount of formula powder for each feeding. Using too little formula is harmful to your baby's growth and development.
- In order to completely clean the bottle and teat or feeding cup so you can use them again, first use soap and a cleaning brush. Then put the bottles in a pot of water and boil them for at least 5 minutes. Then cover and store the bottles in a clean place so they do not get dirty before using them again.

17 **AFTER 6 MONTHS, YOUR BABY NEEDS FOODS IN ADDITION TO FORMULA:**

- Once your baby is 6 months old, he or she will need to have other foods in addition to formula to get the nutrition he or she needs.
- Your baby can have both formula and other foods until 1–2 years old.
- You should only stop giving formula if you have enough other healthy foods and milk to feed your baby. You can discuss this with the nurse.

ASK: *I want to make sure I explained everything well. Can you tell me how you plan to safely feed your baby with formula? What challenges do you think you will face exclusively formula feeding your baby (for example, time away from the baby, family pressure, and traditional customs)? How do you think you will deal with these challenges? What questions do you have about safely feeding your baby with formula?*

EXCLUSIVELY BREASTFEEDING YOUR BABY

15

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Now that your baby is here, I would like to talk with you about some of the challenges women face with exclusive breastfeeding and how you can overcome them. Remember: it is very important to give your baby ONLY breast milk (and any medicines given by the health care worker) for as long as possible, up to 6 months.*

Exclusive breastfeeding, taking your ARVs, giving your baby ARVs, and coming to all clinic appointments can lower the chance that your baby will be HIV-infected and will help keep your baby healthy. What questions or concerns do you have about exclusively breastfeeding your baby?

REMEMBER:

IT IS IMPORTANT THAT YOU OR YOUR BABY ARE TAKING ARVs THE RIGHT WAY, EVERY DAY, THE WHOLE TIME YOU ARE BREASTFEEDING. THESE MEDICINES WILL MAKE BREASTFEEDING SAFER FOR YOUR BABY AND LOWER THE CHANCE THAT THE BABY WILL BECOME HIV-INFECTED.

14

HOW DO YOU KNOW YOUR BABY IS GETTING ENOUGH TO EAT?

- During the first 1–2 days after your baby is born, you will make a small amount of milk. This is fine because at this time your baby's stomach can only hold a little bit of milk.
- About 3–5 days after your baby is born, your full milk will "come in" and you will be making more milk. By this time, your baby's stomach will be able to hold more milk.
- It is important to breastfeed your baby often during the first few days—this will help your milk come in and give the baby important nutrients.
- You should feed your baby between 8 and 12 times each day, with each feeding time lasting about 30 minutes total. You should try and feed from both breasts at each feeding (about 10-15 minutes per breast).
- Your baby should have around 3 bowel movements per day—some days it will be more and some days less.
- Most of the time, your baby will let you know when he or she is hungry. Common cues that a baby is hungry include sucking hands, smacking lips, and acting fussy.

SOME WOMEN FACE CHALLENGES WITH EXCLUSIVE BREASTFEEDING.

IF YOU HAVE SORE NIPPLES:

- You may have some discomfort during the first week of breastfeeding. Usually this goes away over time, but if you keep having a lot of pain, you should come to the clinic.
- **One cause could be poor positioning:** The baby should take your whole nipple in his or her mouth each time. *(demonstrate good positioning and latch)*
- **Another cause could be cracked nipples:** Expose your nipples to air and sunlight as much as possible and put a bit of breast milk on them between feedings. Do not use soap on your nipples.
- **Another cause could be thrush:** If you have a burning feeling on your nipples or pain for many days, and you see white spots or redness on your nipples and in the baby's mouth, you and the baby may have thrush. Come to the clinic right away for medicines.

CONTINUED ON BACK

IF YOUR BABY WILL NOT LATCH, THE REASON MAY BE THAT:

- **Your baby is sleepy:** If your baby falls asleep while breastfeeding, keep offering your breast and try to feed whenever the baby wakes up. You can wake the baby up by tickling its feet, wiping its face with a cool cloth, or undressing the baby.
- **Your baby is fussy:** Try to calm your baby by putting him or her on your skin naked, rocking the baby, offering a finger to suck on before switching to the breast, or squeezing your nipple and putting some milk on your baby's lips.

IF YOU HAVE ENGORGED BREASTS:

- If your breasts feel hard and firm for a few days; if you feel swelling, tenderness, warmth, and throbbing; or if your nipples are flat, you may have engorged breasts/nipples.
- **Common reasons why women have engorged breasts:**
  - — Your milk just came in.
  - — Your baby is not feeding enough or you waited some time to breastfeed.
  - — Your baby is not positioned the right way or is not latching well. *(demonstrate good positioning and latch)*
- **If you have engorged breasts, here are some tips:**
  - — Use your hand to express as much milk from the breast as possible. *(demonstrate how to hand express)*
  - — Put both of your breasts into a sink or dishpan filled with warm water.
  - — Put the baby to your breast often. After the feeding, apply fresh cabbage leaves or cool wet cloths to your breasts.

IF YOUR FAMILY WANTS TO FEED YOUR BABY FOODS OR LIQUIDS OTHER THAN BREAST MILK:

- Family members and friends might want to give your baby food other than breast milk. Remember, breast milk is the only food your baby needs for the first 6 months.
- Some things you could say to your family and friends: *(discuss client's specific situation)*
  - — "Breast milk is the only food my baby needs for the first 6 months of life."
  - — "I do not want my baby to get diarrhea from the water/tea/food."
  - — "I am trying to keep my baby healthy and prevent HIV so I am exclusively breastfeeding."
- If you think it would be helpful, someone from the clinic can talk to your family about the importance of exclusive breastfeeding, either at the clinic or at your home.

YOU NEED ENOUGH FOODS AND LIQUIDS WHILE YOU ARE BREASTFEEDING:

- You should eat nutritious foods while breastfeeding, including foods with lots of proteins and fats, and lots of fruit and vegetables.
- If possible, eat more than normal while you are breastfeeding—eat one extra full meal per day.
- Drink plenty of fluids like clean water, milk, or tea.
- No matter how much or how little a woman eats, her body will make good breast milk.

BREASTFEEDING IF YOU ARE SICK OR UNWELL:

- Even if you are not feeling well, it is still good to continue breastfeeding your baby.
- Drink plenty of fluids and breastfeed often.
- Always take your medicines the right way, every day, including ARVs.

ASK: *I want to make sure I explained everything well. What questions or concerns do you have about exclusively breastfeeding your baby for as long as possible, up to 6 months?*

EXCLUSIVELY REPLACEMENT FEEDING YOUR BABY

16

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Now that your baby is here and you will be using formula, I would like to talk with you about how to safely prepare formula and some of the challenges women face with exclusive formula feeding. Remember: it is very important to give your baby ONLY formula for the first 6 months.*

Exclusive formula feeding, taking your ARVs, giving your baby ARVs, and coming to all clinic appointments can lower the chance that your baby will become HIV-infected. What questions or concerns do you have about giving your baby formula?

IT IS IMPORTANT TO PREPARE FORMULA SAFELY EVERY TIME SO YOUR BABY DOES NOT GET SICK: *(If possible, demonstrate and ask for a return demonstration)* 14

- Wash your hands with soap and dry them on a clean cloth before making formula.
- Be sure to have clean utensils to make the formula each time.
  - — Prepare the formula on a clean table or mat. Clean it each time you make formula.
  - — Rinse utensils with cold water right away after each use to remove milk before it dries on them, and then wash with hot water and soap. If you can, use a soft brush to reach all the corners.
  - — Make sure the utensils are covered to keep off insects and dust.
  - — Use a clean cup and spoon to give formula to your baby. Wash them well each time.
- Use safe water to make your baby's formula.
  - — Boil water for at least 5 minutes before using it to make formula.
  - — Always keep water in a clean, covered container.

STORE THE FORMULA SAFELY:

- Keep the formula powder in a tightly covered tin. Make sure no insects or dirt can get into the tin. Use a clean scoop to get the powder out of the tin.
- Use prepared formula within one hour of making it.
- If a baby does not finish the feed, you can give it to an older child or use it for cooking. Do not give it to your baby for the next feed.
- If you have a refrigerator, all the formula for one day can be made at once and stored in the refrigerator in a sterilized container with a tight lid.
- If you do not have a refrigerator, you will have to make feeds freshly each time the baby needs to be fed.

MAKE SURE YOU ARE GIVING YOUR BABY ENOUGH FORMULA:

- Babies do not need any foods or drinks other than formula until about 6 months of age.
- Your baby will need to drink small amounts of formula often—at least 8 times each day at first (about every 3 hours). You will need to give your baby more formula more often as he or she grows.
- The amount of formula you give depends on your baby's age and weight. *(give instructions on how much formula and how many feeds to give the baby)*
- Your baby may eat a bit more or less formula at each feed. When your baby is feeding by cup, offer a little extra but let the baby decide when to stop.
- If your baby takes a very small feed, offer extra at the next feed, or give the next feed earlier.
- If your baby is not gaining enough weight, he or she may need to be fed more often or be given larger amounts at each feed.
- Always bring your baby to the clinic if he or she is not gaining weight or is sick.

CONTINUED ON BACK

FEED YOUR BABY FROM A CUP AND MAKE SURE YOU HAVE SKIN-TO-SKIN CONTACT DURING THE FEEDINGS: *(demonstrate feeding with clean cup and spoon)*

- Cup feeding is safer and healthier than bottle-feeding.
- Cups are easier to clean than bottles.
- Cup feeding can help you and your baby bond more than bottle-feeding.
- It is important to have skin-to-skin contact when you are feeding your baby.

ASK: *There are some common challenges that many women face when exclusively formula feeding their babies. What challenges do you think you might face?*

14 **LET'S PLAN AHEAD FOR SOME OF THE CHALLENGES YOU MAY FACE WITH EXCLUSIVE FORMULA FEEDING:**

- Some people in your family or community may wonder why you are giving the baby formula. It is important to plan what you will say. *(discuss what client will say)*
- It is important to plan ahead if you and the baby are going to be away from home during feeding times. *(discuss what client will do if she's away from home)*
- It is important to plan ahead if you are going to leave the baby with someone else during feeding times. *(discuss how client will make sure other caregivers prepare formula safely)*
- If you see you are running low on formula, be sure to get more before you run out. What would you do if there was no formula available at the clinic? *(discuss how often and where client can get formula as well as planning for transport costs)*
- Many women want to put the baby on the breast when he or she is crying. You will need to think of other ways to comfort your baby during these times, since there is a higher chance your baby will become HIV-infected if you give him or her breast milk AND formula. *(discuss what client can do to comfort the baby)*
- Feeding your baby at night can be difficult if you are tired and have to make formula often and in the dark. It is important to get support to make these night feeds safely. *(discuss how client will prepare feeds at night)*

ASK: *I want to make sure I explained everything well. Can you tell me how you will prepare your baby's formula? How often? How much? What will you say to people if they ask you about the formula? What questions or concerns do you have about exclusively formula feeding your baby for the first 6 months?*

INTRODUCING COMPLEMENTARY FOODS TO YOUR CHILD AT 6 MONTHS

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Now that your baby is getting close to 6 months old, he or she will need foods other than breast milk/formula (Note: adjust according to woman's feeding choice). What have you heard about starting to give your baby other foods? Why do you think it is important to start giving other foods to your baby at 6 months?*

YOUR BABY NEEDS TO START EATING FOODS OTHER THAN BREAST MILK/FORMULA AT 6 MONTHS OF AGE:

- Complementary foods are foods you feed your baby in addition to breast milk/formula.
- Breast milk/formula alone is not enough to meet your growing baby's nutritional needs after 6 months. This is why you should start giving your baby other foods when he or she is 6 months old.
- It is important that you or your baby take ARVs the whole time you are breastfeeding to lower the chances that your baby will be HIV-infected.

ASK: *What kinds of food do you think will be good to give your baby? What kinds of food do you have at home that you can give your baby?*

YOU SHOULD START GIVING YOUR BABY DIFFERENT KINDS OF FOODS STARTING AT 6 MONTHS:

- Continue to breastfeed/formula feed as frequently as the baby wants, about 8 times throughout the day and night.
- Give your baby other foods 2–3 times a day at first, about half a cup (1–2 large palmfuls) at a time. Then increase this amount over time.
- Your baby's first foods other than breast milk/formula should be soft and mild in taste, such as cereal or porridge. Introduce different foods one at a time so your baby can get used to them.
- You can add some protein to your baby's food. You can give the baby ground meats, beans, ground nuts, or eggs. *(give examples of locally available foods and how to prepare them)*
- You can also add colorful foods to porridge, such as orange and green vegetables or fruits. Be sure to mash them well. *(give examples of locally available foods and how to prepare them)*
- You can add some butter, oil, or milk to porridge to provide some fat. If you are giving the baby animal milk, you should always boil it first.
- All foods should be cooked until soft and mushy, or combined with thick porridge to make it easier for your baby to chew and swallow.
- Always use a clean cup or bowl and a clean spoon to feed your baby.

HOW OFTEN TO FEED YOUR BABY:

- You will need to give the baby complementary feeds more often over time, while also continuing to breastfeed/formula feed.
- When your baby is 6–9 months old, you should give him or her about half a cup (1–2 large palmfuls) of other foods 2–3 times a day. Remember to also keep giving the baby breast milk/formula.
- Then, for the next 3 months (when your baby is 9–12 months old), you can increase the number of complementary feeds to 3–4 times a day.
- After that, you can give your baby 4–5 complementary feeds every day until he or she is 2 years old—or until you have completely stopped breastfeeding/formula feeding.

CONTINUED ON BACK

IF YOUR BABY IS SICK, HE OR SHE MAY NOT BE HUNGRY:

- If your baby is sick, bring the baby to the clinic right away.
- When your baby is sick, try to breastfeed or formula feed him or her more often. If your baby has diarrhea, he or she will need more liquids.
- Be patient and encourage your baby to eat while he or she is sick.
- If your baby is more than 6 months old and gets sick, give your baby an extra meal of enriched porridge every day for 2 weeks afterwards.

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- It is important to always give your baby any medicines (like ARVs) prescribed by the doctor, even when he or she is sick.

ASK: *If you are breastfeeding, when do you think you will stop breastfeeding? What questions do you have about weaning your baby off of breast milk?*

WHEN YOU DO DECIDE TO STOP BREASTFEEDING, IT IS IMPORTANT TO DO IT IN A SAFE WAY:

- Do not try to stop breastfeeding quickly.
- Instead, stop breastfeeding over the span of a couple of weeks or one month, slowly decreasing the number of times you breastfeed per day, and increasing the amount and number of times you give your baby other foods. This will help prevent engorgement, breast pain, and other problems.
- If you have questions about how to stop breastfeeding safely and comfortably, you can always talk with us here at the clinic.

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BREASTFEEDING AND YOUR BABY'S HIV TEST RESULTS:

- If your baby has a negative HIV test, you should start thinking about weaning when he or she is 1 year old. In most cases, it is not safe to wean the baby earlier than that. Talk to your health care worker about what is best for you and your child. Remember that you or your baby should be taking ARVs the whole time you are breastfeeding to lower the chances that your baby will become HIV-infected.

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- If your child is HIV-infected, you can continue breastfeeding while also feeding your baby other foods until your baby is 2 years old (or even older). Breast milk helps keep HIV-infected babies healthy.
- You should only stop breastfeeding if you have enough healthy foods and clean water to feed your baby.

ASK: *I want to make sure I explained everything well. Why do you need to start giving your baby food other than breast milk/formula when he or she is 6 months old? What kinds of foods do you have at home that you can give your baby? Will you need to buy other kinds of foods? How often do you need to feed your baby other foods?*

If you are breastfeeding, when and how will you stop? What questions do you have about feeding your baby?

ASK: *Would you like to have more children? If yes, would you like to have another child soon, or would you like to wait some time before having another child? Have you talked to your partner about family planning? Are you using a family planning method now? Would you like to use one in the future?*

ALL WOMEN AND COUPLES, INCLUDING PEOPLE LIVING WITH HIV, HAVE A RIGHT TO MAKE INFORMED DECISIONS ABOUT THEIR REPRODUCTIVE LIVES AND THE NUMBER AND SPACING OF THEIR CHILDREN.

IF YOU AND YOUR PARTNER WISH TO HAVE MORE CHILDREN, THERE ARE TIMES WHEN IT IS SAFEST TO GET PREGNANT AND HAVE A BABY:

- It is healthiest for you and your children if you wait at least 2 years between pregnancies.
- If you want to have another baby, the safest time to get pregnant is when:
  - Your CD4 count is over 350
  - You do not have any opportunistic infections (including TB) or advanced AIDS
  - You are taking and adhering to ART (if the doctor prescribes it)
- If you decide you want to have another baby in the future, come to the clinic with your partner and we can help you decide the safest times and ways to get pregnant.

THERE ARE MANY SAFE FAMILY PLANNING OPTIONS FOR YOU AND YOUR PARTNER IF YOU WANT TO PREVENT PREGNANCY OR IF YOU WANT TO WAIT BEFORE BECOMING PREGNANT AGAIN:

- People living with HIV can usually use all methods of contraception safely.
- **Dual protection:** Dual protection means that the method prevents unintended pregnancy, HIV, and other STIs. Male and female condoms give dual protection.
- **Dual method use:** Another way to have dual protection is by using two methods at the same time, such as oral contraceptive pills and condoms—this is called dual method use.
- There are many things to think about when you choose a family planning method. For example: how easy is it to use the method? how well does it work? how long does the protection last? does your partner need to be involved or accepting of the method? *(discuss different family planning options and provide methods or referrals if the client would like to start using a method)*
  - **Barrier methods**, including male and female condoms, are the only methods that protect against pregnancy, HIV, and other STIs. *(discuss male and female condom use)*
  - **Hormonal methods**, including oral contraceptives, injectables, implants, and emergency contraceptive pills, are generally easy to use, are good for short- and long-term use, and are safe and effective for women living with HIV and those on ART. They protect against pregnancy but not HIV or other STIs. It is important to adhere to hormonal contraceptive methods for them to be effective. For example, if taking oral contraceptive pills, make sure to take one at the same time, every day. *(discuss hormonal contraceptive options. Note: oral contraceptives are not recommended for women taking some protease inhibitors, rifampicin for TB treatment, or certain anti-convulsants)*

CONTINUED ON BACK

  - — **Long-term and permanent methods**, such as IUDs (long-term) and male and female sterilization (permanent), offer a lot of protection against pregnancy, but do not protect against HIV or other STIs. *(discuss long-term and permanent methods. Note: IUDs are not recommended for women with untreated STIs, clinical AIDS, or those not responding to ART)*
  - — **Natural methods,** including lactational amenorrhea method (LAM), fertility awareness methods (like cycle beads), and withdrawal, are not as effective as other methods but do give limited protection against unintended pregnancy. They do not protect against HIV or other STIs. *(discuss natural methods, especially LAM if breastfeeding)*
  - — **Abortion,** where legal in all cases or to save the life of a woman, is another option. However, it is best to use other methods to prevent an unintended pregnancy in the first place. *(discuss abortion options in countries where it is legal or can be used to save a woman's life)*
- There are safe family planning methods to use while you are breastfeeding, including condoms, some kinds of oral contraceptives, implants, injectables, IUDs, and sterilization. *(discuss specific methods that are safe to use during breastfeeding and when the client can start using them)*
- Just like with ARVs, it is important that you adhere to whatever method you choose. *(discuss adherence to oral contraceptives, injectables, or whatever method the client is interested in)*

ASK: *I want to make sure I explained everything well. What are your plans for having more children or preventing future pregnancies? Would you like to talk more about preventing or planning future pregnancies? Would you like to talk more about starting on a family planning method today? (provide or give referrals as needed) What questions do you have?*

TESTING YOUR BABY OR CHILD FOR HIV

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *Not all children born to women living with HIV are HIV-infected, but some babies will become infected. In order to know if your child is HIV-infected or not, we need to do an HIV test. Babies should be tested for HIV at 6 weeks of age, or as soon as possible after that, since HIV can make infants very sick very quickly. In order to prevent this, it's important to know their status as soon as possible. What have you heard about HIV testing in children? What plans do you have to test your child/children for HIV?*

THERE IS A CHANCE THAT BABIES BORN TO MOTHERS LIVING WITH HIV WILL ALSO BE HIV-INFECTED: 8 13

- Babies can get HIV during pregnancy, during labor and delivery, or during breastfeeding.
- The medicines that you and your baby took or are taking help lower the chance that your baby will be HIV-infected, but you will only know for sure if the child is tested and you receive the results.

IT IS IMPORTANT FOR YOUR BABY AND ALL OF YOUR CHILDREN TO GET TESTED FOR HIV: 8

- Even though you are living with HIV, this does not mean that your children are also HIV-infected. We need to do an HIV test to find out for sure.
- Even if your children do not seem sick, they still might be HIV-infected.
- HIV develops much faster in children than it does in adults. It is very important that we identify HIV infection in children as early as possible so that the child can be protected and treated.
- HIV testing is strongly recommended because it allows children with HIV to access life-saving treatment as early as possible.
- Children living with HIV need care and treatment, which is available for free. Without treatment, many children living with HIV will become very sick and die. 20
- HIV care and treatment, including ARVs, can help save your child's life and help him or her grow and become a healthy adult. 20
- You have the right to say no to testing. If you say that you don't want your child tested, we will talk with you more and still take care of you and your child.
- The result of your child's HIV test is confidential; it is only shared with those health care workers who need this information in order to care for your child.
- Knowing your child's HIV-status for sure can help you and your family plan for the child's care and make sure the child gets the care and treatment he or she needs as early as possible.

IF YOUR CHILD IS 6 WEEKS–18 MONTHS OLD:

- Children born to mothers who know they are living with HIV should be enrolled in follow-up care. 13
- All babies who are born to mothers living with HIV should have an HIV test when they are 6 weeks old. This is a PCR test and it tests for the virus in the baby's blood.
- For HIV tests in babies and children 6 weeks to 18 months of age, we will do a Dried Blood Spot sample, also called a DBS.
  - — To get a DBS sample, we will prick your child's heel with a small needle and put some drops of blood on a piece of paper.
  - — The paper will then be sent to a lab, and we will get the results back in about 2–3 weeks.

CONTINUED ON BACK

- It is very important to come back for your child's test results. What do the results mean?
  - — If the results are negative and you are breastfeeding now or have breastfed in the last 3 months, the virus can't be detected in your child's blood right now, but it is still possible for your child to become HIV-infected. It is important to repeat the HIV test 6 weeks after you stop breastfeeding completely.
  - — If the results are negative and you are NOT breastfeeding now and have not breastfed in the last 6 weeks, your child is not HIV-infected. We will do a confirmation test when the baby is 18 months old to be sure.
  - — If the results are positive, this means your baby is HIV-infected and should start care and treatment right away. 20
  - — HIV-infected children less than 24 months of age will start taking medicines called ART right away to keep them healthy.
  - — We will help you learn about HIV treatment and ways to care for yourself and your child at home. We will help you with a follow-up plan and give ongoing support to you, your family, and your child.

IF YOUR CHILD IS OVER 18 MONTHS OLD:

- For children older than 18 months, we can use a rapid HIV test and you will get the result the same day. This is the same test we use for adults.
- For this test, the nurse will take a small blood sample from your child's heel or finger and you will get the results within 30 minutes.
- What do the results mean?
  - — If the results are negative and you are breastfeeding now or have breastfed in the last 3 months, the virus can't be detected in your child's blood right now, but it is still possible for your child to become HIV-infected. It is important to repeat the HIV test 6 weeks after you stop breastfeeding completely.
  - — If the results are negative and you are NOT breastfeeding now and have not breastfed in the last 3 months, your child is not HIV-infected.
  - — If the results are positive, this means your child is HIV-infected and should start care and be evaluated for treatment right away. 20
  - — We will help you learn about HIV treatment and ways to care for yourself and your child at home. We will help you with a follow-up plan and give ongoing support to you, your family, and your child.

ASK: *What questions do you have about testing your children for HIV? (If the client is with her child and the child is more than 6 weeks old): Would you like us to test your child for HIV now?*

Would you like to make an appointment to bring your baby or the other children that live with you to the clinic for an HIV test?

CARING FOR YOUR HIV-INFECTED BABY OR CHILD AND ADHERING TO CARE & MEDICINES

REFER TO CARD NUMBER(S) INDICATED BELOW

ASK: *I would like to talk with you about the important care and medicines your child will need to be well and to become a healthy adult. What have you heard about caring for an HIV-infected baby or child? What questions or concerns do you have now that you know your child is HIV-infected?*

IMPORTANT THINGS TO REMEMBER IF YOUR CHILD IS HIV-INFECTED:

- There is a lot we can do to keep your child healthy.
- Children living with HIV need the same things that all children need—immunizations and other child health services; healthy food; safe water; to play, laugh, and learn; and to be loved and protected.
- HIV develops much faster in children than it does in adults.
- All children living with HIV need care and treatment, which is available for free.
- Without treatment, many children living with HIV will become very sick and die.
- HIV care and treatment, including ARVs, can help save your child's life and help him or her grow to become a healthy adult.

FEEDING YOUR CHILD:

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- If you are exclusively breastfeeding your baby, continue until your baby is 6 months old.
- Your baby needs other foods after he or she is 6 months old, but continue breastfeeding as well (up to or beyond 2 years of age). Breast milk will help keep your baby healthy.
- HIV-infected children need more food each day to stay healthy. Try and give your child at least 3–5 meals every day so he or she gets enough nutrition and gains weight.

BRING YOUR CHILD FOR REGULAR CARE AT THE CLINIC:

- Your child needs to come to the clinic often and for all appointments.
- When your child starts ART, it is important to come back to the clinic every 2 weeks for the first month.
- After your child has adjusted to the medicines, bring him or her to the clinic every month.
- If your child is not taking ART, it is important to bring him or her to the clinic every month for a checkup and lab tests.
- Children with HIV can get sick very quickly, so it is important to bring your child for all clinic appointments and whenever he or she seems sick or has a fever.

GIVING YOUR CHILD MEDICINES:

(show the mom or caregiver the syrups and/or tablets the child will take, the dosing, and how to give them to the child. Allow time for practice and questions.)

- Antiretrovirals, or ARVs, are medicines that help lower the amount of HIV in the body. When a child takes different ARVs at the same time (usually 3 different medicines), we call this antiretroviral therapy, or ART.
- ART does not cure HIV, but it can help your child become a healthy adult.
- All HIV-infected children **under age 2** need to start taking ART. The doctor will do a checkup and tests to see when older children need to start taking ART.
- Usually babies and young children take syrups, or else tablets may be crushed and dissolved.
- Once your child starts ART, he or she will need to take it every day, at the same times, for his or her whole life.
- Your child will also need to take a medicine called cotrimoxazole to prevent infections.

CONTINUED ON BACK

ASK: *It is very important that your baby gets his or her medicines the right way, every day, and that you bring the baby back to the clinic often. What things do you think will help you and your child stick to the care and treatment plan?*

ADHERENCE MEANS HOW FAITHFULLY YOU STICK TO AND PARTICIPATE IN YOUR OWN AND YOUR BABY'S CARE AND TREATMENT PLAN. THIS INCLUDES:

- Bringing your baby for all appointments at the clinic for checkups, lab tests, pharmacy refills, immunizations, if the baby gets sick, and for other care
- Giving your baby cotrimoxazole every day once the baby is 6 weeks old
- Giving your baby his or her ARVs the right way, every day, for his or her whole life *(remind the client of her baby's medication plan)*
- Giving the right dose of medicines to your baby. Remember, the amount of medicine will change when he or she gains weight. *(check understanding of changing doses)*

IT IS IMPORTANT TO MAKE AN ADHERENCE PLAN THAT FITS WITH YOUR LIFE:

- If you are taking medicines, give your child medicines at the same time you take yours.
- Try to schedule your own and your baby's appointments on the same day.
- Taking care of a child living with HIV can be hard work. You need emotional support.
- You may also need support from family or friends to help give your child medicines, to bring him or her to the clinic for all appointments, and to make sure he or she is fed safely.

HERE ARE SOME TIPS ON GIVING YOUR BABY SYRUPS: *(demonstrate)*

- Look at the colored tape on the syringe to make sure you are giving the right dose.
- You can reuse syringes until the markings begin to wear off or the plunger is hard to use. Wash the syringes with warm, soapy water, rinse, and let them air dry.
- If the medicine is too sticky, add a little breast milk or formula to the syringe.
- DO NOT add medicines to a baby bottle or feeding cup.

YOU MAY ALSO NEED TO CRUSH AND DISSOLVE TABLETS:

- If syrups are not available or if your child prefers it, you can also crush pills and mix them with some expressed breast milk or formula. *(demonstrate how to crush and dissolve pills)*

IF YOUR CHILD DOES NOT WANT TO TAKE HIS OR HER MEDICINE, HERE ARE SOME TIPS: *(demonstrate)*

- Talk or sing to the child to help him or her stay calm.
- Wrap your child in a blanket and hold him or her in the bend of your arm—this will help keep the baby still.
- Place the dropper in the corner of the baby's mouth and slowly give the medicine. Aim for the inside of the baby's cheek instead of the back of the tongue.
- Blow gently into your baby's face, which should make him or her swallow.
- Do not give medicine when your baby is crying or by pinching his or her mouth open.
- If your baby vomits medicine within 30 minutes of taking it, give the dose again.
- If the problem doesn't get better, you should talk to your doctor. You may be able to change medications or change the form of the medication that you are giving the child.

ASK: *I want to make sure that I explained things well. Can you tell me the most important things about caring for your child? Can you tell me why adherence to your child's care and treatment plan is important? What do you think can help you adhere to your own and your child's care and treatment plan? What questions do you have about caring for your child?*

V.

Forms & Guides

Counseling Checklists for HIV Testing in Antenatal Care Settings

ICAP International Center for AIDS Care and Treatment • Mailman School of Public Health • Columbia University

How to Use the Pre- and Post- HIV Test Counseling Checklists

These pre- and post-test counseling checklists were developed to support a range of providers (trained counselors, lay counselors, peer educators, expert clients, mother mentors, doctors, nurses, pharmacists, community health workers, and others) who work with pregnant women living with HIV and their families. Pre- and post-HIV test counseling can help clients understand the importance of HIV testing, the HIV testing process, the meaning of their test results, and key steps to ensure their own and their baby's health. The pre- and post-test counseling checklists should be adapted to reflect national HIV testing and counseling and PMTCT guidelines, as well as the specific clinic, community, and cultural contexts in which they are used. It may be helpful to translate the checklists into the local language.

There are 3 checklists: one on pre-test counseling, one on post-test counseling for HIV-negative women, and one on post-test counseling for HIV-positive women. Pre-test counseling may be conducted individually or in group sessions, depending on national and clinic protocols. Post-test counseling should always be conducted in an individual setting, ensuring the client's privacy and confidentiality.

Key information from pre- and post-test sessions should be recorded on the checklists and kept in the client's file. While many ANC and PMTCT programs do not keep client files, such information from pre- and post-test sessions is a very important part of quality, continuous care and client-centered counseling. If individual client files are not maintained at the clinic, these checklists can also be used as job aides to guide providers when conducting pre- and post-test counseling.

Basic information: Write down the client's name and file number. Be sure to sign and date the form at the end of each session and then put the completed form in the client's file.

Key topics: Lists of key topics to cover during pre- and post-test counseling, and a suggested flow of topics, are provided. These topic lists should be used as a guide to pre- and post-test counseling sessions, and adapted as needed according to the client's specific situation and needs. Once a specific topic is covered and discussed with the client, place a tick mark in the appropriate column. It is important to allow time for the client to react and to ask questions throughout the pre- and post-test sessions. Never rush sessions. Clients should always be made to feel comfortable expressing emotions and questions and should never be judged or punished. Clients' rights should always be respected and upheld, including their right to decline testing or to return at a later date for testing and counseling.

Notes: Write any additional notes about the post-test session, the client's needs, or next steps in the space provided.

Date of next counseling session/clinic appointment: Schedule a follow-up counseling appointment with the client and record this date, as well as any clinic appointments, in the space provided.

Pre-HIV Test Counseling Checklist for Pregnant Women (group or individual session)

Client's Name: _____ **Client's File#:** _____

TOPIC	TICK
1. Introduce yourself and give an overview of the counseling session	
2. Review HIV basics, transmission, and prevention	
- Review HIV basics and answer questions	
- Modes of HIV transmission, including from mother to baby	
- Ways to prevent HIV transmission, including PMTCT	
3. Counsel on benefits of HIV testing	
- You cannot tell from looking at a person if he or she has HIV	
- Everyone should learn their HIV-status, especially pregnant women	
- HIV testing is a part of routine antenatal care and is offered to all pregnant women	
- If a pregnant woman has HIV, she can pass it to her baby	
- Benefits of knowing one's HIV-status, including PMTCT	
3. Explain HIV testing process	
- Confidentiality	
- Client's right to refuse or get tested at a later time	
- Method of HIV testing	
- Meaning of test results	
4. Counsel on discordance and partner testing	
- One partner can be living with HIV while the other is HIV-negative	
- Encourage partner testing and couples counseling	
5. Counsel on HIV prevention and HIV/STI risk reduction	
- High risk of MTCT if she becomes HIV-infected during pregnancy or breastfeeding	
- Practice safer sex (e.g., mutual faithfulness, always using condoms, abstinence)	
- Condoms, challenges to using condoms	
- STI screening, prevention, signs, and treatment	
6. Counsel on PMTCT and having a safe pregnancy	
- Ways to reduce MTCT, including ARVs for mom and baby	
- HIV testing and early treatment for herself, the baby, partner, and family members	
- Attend all antenatal care appointments	
- Deliver baby at a health facility	
- Exclusive breastfeeding (or exclusive formula feeding) for 6 months or as long as possible up to 6 months. Then introducing complementary foods at 6 months.	
- Bring the baby back to the clinic for appointments (immunization, weighing, checkups)	
- Family planning to prevent or space future pregnancies	
7. Offer the client an HIV test	
- If she gives consent (written or verbal, depending on your guidelines), perform HIV test	
- If she refuses, encourage her to think about why and to come back if she has more questions or changes her mind; set up a return visit date	
8. Provide referrals for ongoing counseling or other support, as needed	
9. Ask if she has any questions or concerns	
10. Summarize the session and next steps	

Post-HIV Test Counseling Checklist for HIV-NEGATIVE Pregnant Women

Client's Name: _____ **Client's File#:** _____

TOPIC	TICK
1. Provide test results and give client time to react, give emotional support	
2. Explain window period and encourage retesting	
- Retesting in 6 weeks if there was possible exposure to HIV in past 6 weeks	
- Encourage repeat testing after 34-36 weeks gestation or during labor and delivery	
3. Counsel on disclosure, discordance, and partner testing	
- Who will she share the results with?	
- Her test does not tell us if her partner has HIV	
- Encourage partner testing and couples counseling	
4. Counsel on HIV prevention and HIV/STI risk reduction	
- High risk of MTCT if she becomes HIV-infected during pregnancy or breastfeeding	
- Practice safer sex (e.g., mutual faithfulness, always using condoms, abstinence)	
- Condoms, challenges to using condoms	
- STI screening, prevention, signs, and treatment	
5. Counsel on plans to keep herself and family healthy	
- Attend all antenatal care appointments	
- Deliver baby at a health facility	
- Exclusive breastfeeding for 6 months or as long as possible up to 6 months	
- Bring the baby back to the clinic for appointments (immunization, weighing, checkups)	
- Family planning	
6. Provide appropriate referrals and take-home information, if needed	
7. Ask if she has any questions or concerns	
8. Summarize the session and next steps, including the next clinic appointment date	

Notes:

_____

_____

_____

_____

_____

Date of next counseling session/clinic appointment: _____

Counselor's signature: _____ **Date:** _____

Post-HIV Test Counseling Checklist for HIV-POSITIVE Pregnant Women

Client's Name: _____ **Client's File#:** _____

TOPIC	TICK
1. Provide test results and give client time to react, give emotional support	
2. Discuss any concerns the woman has about her own and her baby's health	
3. Discuss PMTCT basics	
- Not all babies will become HIV-infected	
- Can lower the chances that baby will be HIV-infected by getting care at the clinic, taking ARVs, and safely feeding the baby	
4. Counsel on staying healthy and PMTCT during the pregnancy	
- Come back to the clinic for all appointments during pregnancy and after delivery	
- Importance of emotional support from family and friends	
- CD4 testing and meaning of results	
- ARVs or ART and importance of starting early and adherence	
- Disclosure - who will she share the results with?	
- Partner testing, testing other children	
- Safer sex (e.g., mutual faithfulness, always using condoms, abstinence)	
- Preventing and early treatment of opportunistic infections	
- Nutrition and hygiene	
5. Counsel on safe delivery	
- Plan to deliver at a health facility	
- Tell the health worker your HIV-status and medicines you are taking	
- ARVs for mom and baby during labor and delivery	
6. Counsel on infant feeding and help her choose an appropriate feeding method	
- Exclusive breastfeeding for 6 months, or as long as possible up to 6 months	
- Exclusive formula feeding for 6 months	
- Dangers of mixed feeding in the first 6 months	
- Avoiding early weaning	
- Add complementary foods at 6 months, continue breastfeeding	
7. Counsel on plans for her own and baby's care	
- Mom needs lifelong HIV care	
- Importance of getting support from someone she trusts	
- Family planning and safe childbearing in the future	
- Bring the baby back to the clinic for appointments (immunization, weighing, checkups)	
- ARVs and CTX for baby	
- Early infant diagnosis at 6 weeks	
- Care and treatment if the baby is HIV-infected	
8. Provide appropriate referrals and take-home information	
9. Ask if she has any questions or concerns she wants to discuss now	
10. Summarize the session and next steps, including the next clinic appointment	

Notes:

_____

_____

_____

Date of next counseling session/clinic appointment: _____

Counselor's signature: _____ **Date:** _____

Psychosocial Assessment Guide for use in PMTCT Settings

ICAP International Center for AIDS Care and Treatment • Mailman School of Public Health • Columbia University

How to Use the Psychosocial Assessment Guide

This psychosocial assessment guide was developed to support a range of providers (trained counselors, lay counselors, peer educators, expert clients, mother mentors, doctors, nurses, pharmacists, community health workers, and others) who work with pregnant women living with HIV and their families, as well as caregivers of HIV-exposed and HIV-infected children. Conducting a psychosocial assessment with each client helps to learn more about his or her specific situation, to prioritize needs, and to give direction to ongoing counseling and psychosocial support. This includes referrals for needed community and home-based services. The psychosocial assessment guide should be adapted to reflect national PMTCT and pediatric care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used. It may be helpful to translate the guide into the local language.

A psychosocial assessment should be conducted with **each client after enrollment in PMTCT services.** Health workers may want to conduct another psychosocial assessment or revisit specific psychosocial issues when a client's situation changes in a significant way, such as after a client gives birth. Always respect client confidentiality and conduct sessions in a space that offers visual and auditory privacy. Key information from the psychosocial assessment should be recorded on the form and kept in the client's file. A template to record follow-up counseling notes is also included.

Completed psychosocial assessment forms should be kept in the client's file and referred to during follow-up visits. While many ANC and PMTCT programs do not keep client files, psychosocial assessments and documentation of psychosocial issues are very important parts of quality, continuous care and client-centered counseling. If individual client files are not maintained at the clinic, this guide can also be used as a job aide to help providers assess psychosocial needs and provide follow-up counseling and referrals.

Basic information: Write down the client's name and file number. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver: The questions in these sections allow the health worker to discuss and assess the client's psychosocial issues and needs. Different questions are suggested for different topic areas, including: coping, support system, and disclosure; plans for the mother's and baby's care; and partner and family testing. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing psychosocial challenges and should never be judged or punished. Write down any important information from their responses, as this will help decide on effective next steps, important areas for follow-up, and in supporting the client's psychosocial wellbeing over the long term.

Questions, summary, and next steps: Ensure that the client has time to ask questions and that the health worker has time to summarize the session and agreed upon next steps. Record key next steps in the space provided.

Additional notes: Write any additional notes about the session, the client's psychosocial needs, or next steps in the space provided.

Referrals made: Linkages and referrals to psychosocial support services are important elements of quality PMTCT programs and the ongoing support of clients and their families. Each clinic should have an up-to-date list of community support services (such as mother's support groups, home-based care programs, adherence supporters, PLHIV associations, food support, legal support, etc.) and formal two-way referral systems to these organizations and services. Clients with severe psychosocial and psychological issues (such as depression, use of drugs and alcohol, feeling suicidal) will require careful follow-up and immediate referrals and linkages to ongoing professional counseling and other services. Record any referrals made to the client in the space provided. At the next session, follow up to determine if the client accessed these referral services.

Date of next counseling session/clinic appointment: Schedule a follow-up counseling appointment with the client and record this date, as well as any clinic appointments, in the space provided.

PMTCT Psychosocial Assessment Guide and Recording Form

Client's Name: _____ **Client's File#:** _____

Coping, Support System, and Disclosure

1. Now that you know your HIV-status, what feelings or concerns do you have?	
2. Can you tell me how things have been going since you learned your HIV-status? How are you coping? *Explore and discuss client's coping strategies*	
3. Who can you go to for emotional support? *Counsel on importance of social support*	
4. How often in the last week have you used cigarettes, alcohol, or other drugs to help you cope? *Assess for harmful coping strategies, such as drug/ alcohol use, and provide counseling/ referrals*	
5. Have you disclosed your HIV-status to anyone? *Counsel on full and partial disclosure*	Yes No
5a. If yes, to whom? What was their reaction?	
5b. If no, how do you feel about disclosing to someone you trust? What support do you need?	
6. Do you belong to a community organization, support group, or religious group that gives you the support you need?	Yes No Name/location of organization or group:
6a. Would you be willing to join a support group at this clinic or in the community? *Give information about support groups*	Yes No
7. Have you experienced or do you fear stigma, discrimination, or violence because of your HIV-status or other reasons? *Counsel and discuss available support services*	Yes No Details:
7a. If you experience stigma, discrimination, or violence, or are afraid you will, what do you think you will do? *Counsel on available support services*	
8. Do you have a regular source of income or do you receive help, such as social grants, food parcels, or anything else? *Counsel and refer to social worker and community-level support*	Yes No Sources of income/support: Receiving social grant? Yes No

Plans for Her Own and Baby's Care

9. What are you going to do to stay well during and after your pregnancy, and to reduce the chance that your baby will be HIV-infected? *Counsel on ANC and PMTCT services, including ARVs*	
10. Other than coming to this clinic, do you go to other places for health services (e.g. other clinics, TBA, traditional healers, etc.)?	
11. How will you remember to take your medications every day? How will you remember when to come back to the clinic? Is there someone who can help you? *Counsel on adherence to care and medicines*	

12. What do you think are the most important things you can do to care for your new baby? *Counsel on care for HIV-exposed infants and bringing the baby back for all clinic appointments*	
13. How do you plan to feed your baby? Do you have any questions or concerns? *Counsel on safe infant feeding per national guidelines*	Exclusive breastfeeding Exclusive formula Not sure Final infant feeding choice:
14. Who will help you take care of the baby and give the baby medicines? *Counsel on importance of bringing baby back often and having all caregivers understand the care plan*	Name(s) and relationship(s):
14a. If you cannot bring the baby back to the clinic, who else will be able to bring the baby? Have you disclosed to this person?	Name and relationship: Disclosed? Yes No
15. Would it be ok if we called you (or someone you trust) if you miss an appointment at the clinic? Would it be ok if we visited you at home?	Consent for phone call: Yes No Phone number (own/other's?): Consent for home visit: Yes No Detailed address:

Partner and Family Testing

16. Can you tell me who lives with you at home? *Counsel on family-testing, care, and treatment*	Name:_____ Age:_____Relationship:_____ Name:_____ Age:_____Relationship:_____ Name:_____ Age:_____Relationship:_____ Name:_____ Age:_____Relationship:_____
17. For the children who live with you, can you tell me if each has been tested for HIV and what the test result was? *Counsel on HIV testing for all children, even if they seem well, and importance of early care and treatment for HIV-infected children*	Name:_____ Age:_____Tested: Yes No *Result:* pos neg *If positive, in care and tx*: Yes No Name:_____ Age:_____Tested: Yes No *Result:* pos neg *If positive, in care and tx*: Yes No Name:_____ Age:_____Tested: Yes No *Result:* pos neg *If positive, in care and tx*: Yes No
18. Do you have a sexual partner(s) now?	Yes No
18a. If yes, has your partner been tested for HIV? What was the result? *Counsel on partner testing and discordance*	Partner tested? Yes No Don't know Partner's test result? Positive Negative Don't know If positive, in care and tx? Yes No Don't know
18b. If no, do you think your partner would be willing to come for an HIV test?	Yes No Don't know
18c. If yes, can you tell me how you and your partner(s) practice safer sex?	

Questions, Summary, and Next Steps

19. What other questions or concerns do you want to discuss today?	
20. *Summarize the session and review immediate plans and next steps, including the next clinic visit date*	Note next steps here and in the space below:

Notes:

_____

_____

_____

Referrals made:

_____

_____

Date of next counseling session/clinic appointment: _____

Counselor's signature: _____ **Date:** _____

PMTCT Counseling Follow-up Notes

(photocopy additional forms for client's file, as needed)

Client's Name: _____ **Client's File#:** _____

Date of counseling session: _____

Key issues and concerns discussed:

_____

_____

_____

_____

_____

Next steps and areas for follow-up:

_____

_____

_____

_____

_____

Counselor's signature: _____

Date of counseling session: _____

Key issues and concerns discussed:

_____

_____

_____

_____

_____

Next steps and areas for follow-up:

_____

_____

_____

_____

_____

Counselor's signature: _____

Adherence Preparation & Support Guides for use in PMTCT Settings

ICAP International Center for AIDS Care and Treatment • Mailman School of Public Health • Columbia University

How to Use the Adherence Preparation and Support Guides

These adherence preparation and support guides were developed to assist a range of providers (trained counselors, lay counselors, peer educators, expert clients, mother mentors, doctors, nurses, pharmacists, community health workers, and others) who work with pregnant women living with HIV and their families, as well as caregivers of HIV-exposed and HIV-infected children. These guides can help providers work with their clients to understand the importance of adherence throughout the spectrum of PMTCT care and throughout life; to ensure understanding of the care and medications plan; to identify potential adherence challenges; and to come up with practical solutions. The adherence guides should be adapted to reflect national PMTCT and pediatric care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used. It may be helpful to translate the guides into the local language.

Often, adherence preparation is not tailored to the specific needs and concerns of pregnant and postpartum women and, in some cases, pregnant women are referred to general ART clinics for adherence counseling and preparation. Many programs stipulate that clients participate in a series of group and individual counseling and preparation sessions before starting ART. **However, given the importance of early and timely initiation for PMTCT, it is critical that barriers to immediate ARV/ART initiation are removed for pregnant women and HIV-exposed infants.** Adherence preparation should be conducted in a way that encourages immediate ARV/ART initiation and that supports focused adherence preparation within ANC and PMTCT settings. This preparation should be coupled with intensive ongoing adherence support. To avoid delays, initial adherence preparation counseling can be conducted on the same day the client initiates ARVs/ART. In most cases, when ample time is dedicated to client-centered, individual counseling, clients will be able to understand the basics of their own and their baby's care and medication plan as well as the importance of adherence, and can develop an adherence plan with providers all on the same day.

Included are 4 adherence preparation and support guides: one for pregnant women starting ARV or ART prophylaxis, one for pregnant women starting lifelong ART, one for women on ART who become pregnant, and one for caregivers of HIV-exposed infants. The appropriate form should be used during adherence counseling sessions, according to the client's needs and situation. Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits. While many ANC and PMTCT programs do not keep client files, such adherence assessments are a very important part of quality, continuous care and client-centered counseling. If individual client files are not maintained at the clinic, these guides can also be used as job aides to help providers conduct adherence counseling with clients.

Basic information: Write the client's name and file number at the top of the form. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver: The questions in this section allow the health worker to discuss specific care, medication, and adherence issues with the client. The questions should be used to identify areas where the client may need additional information and support, but should not be used to "score" a client's knowledge and readiness to take ARVs. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on effective next steps, important areas for follow-up, and in supporting the client's adherence over the long term.

Client requires more counseling and support in these areas (LIST): Write down specific areas in which the client needs ongoing adherence counseling and support. Refer to this section of the form during follow-up counseling appointments and clinic visits. Even if a client has questions about her own or her child's care and medicines, or is facing specific adherence challenges, this is usually not a reason to delay initiation of ARVs/ART. Instead, these issues should be viewed as important areas for ongoing counseling and support.

Adherence Preparation/Support Guide for Pregnant Women Starting ARV/ART Prophylaxis

Client's Name: _____ Client's File#: _____

1. Can you tell me what group or one-on-one counseling sessions you have attended here at the clinic?	
2. Can you explain why you need to take ARVs during your pregnancy?	
3. What do you expect from taking ARVs?	
4. How confident do you feel about taking medicines every day during your pregnancy?	
5. Can you tell me the names of the ARVs you will be taking and when you will take them (how many pills, what times of day)?	
6. Can you tell me how many weeks (or months) into your pregnancy you are? Do you know when you will start taking ARVs?	
7. For how long after your baby is born will you keep taking ARVs or ART?	
8. Can you tell me some possible side effects of your ARVs? What will you do if you have side effects?	
9. Can you explain what happens if you do not take all of your ARVs every day, at the same time?	
10. Is there someone who can help you come to the clinic for appointments and help you take your medicine every day? What is their contact information?	
10a. Has he/she been to the clinic with you?	
11. Do you think you will have any problems coming to this clinic for your appointments?	
12. How will you remember to come for your clinic appointments?	
12a. How will you remember to take your medicines the right way, at the same time, every day?	
13. Are you taking any medicines - other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
14. Where will you store your medicines?	
15. What will you do if you are about to run out of your medicine(s)? What about if you are going to be away from home?	
16. What will you do if you miss a dose of your medicine?	
17. Do you have any questions about the plan for your care or your medicines?	

Client requires more counseling and support in these areas (LIST):

Signature of person completing assessment: _____Date: _____

Adherence Preparation/Support Guide for Pregnant Women Starting Lifelong ART

Client's Name: _____ Client's File#: _____

1. Can you tell me about the group or one-on-one counseling sessions you have had here at the clinic?	
2. Can you explain why you need to take ART during your pregnancy and for your entire life?	
3. What do you expect from taking ART?	
4. How confident do you feel about taking medicines every day during your pregnancy and for your entire life?	
5. Can you tell me the names of the ARVs you will be taking and when you will take them (how many pills, what times of day)?	
6. Can you tell me some possible side effects of your ARVs? What will you do if you have side effects?	
7. Can you explain what happens if you do not take all of your ARVs every day, at the same time, during your pregnancy and for your entire life?	
8. Is there someone who can help you come to the clinic for appointments and help you take your medicine every day? What is their contact information?	
8a. Has he/she been to the clinic with you?	
9. Do you think you will have any problems coming to this clinic for your appointments?	
10. How will you remember to come for your clinic appointments?	
11. How will you remember to take your medicines the right way, at the same time, every day?	
12. How will you take your ART when you are in labor? If you are breastfeeding?	
13. Are you taking any medicines - other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
14. Where will you store your medicines?	
15. What will you do if you are about to run out of your medicine(s)? What about if you will be away from home?	
16. What will you do if you miss a dose of your medicine?	
17. Do you have any questions about the plan for your care or your medicines?	

Client requires more counseling and support in these areas (LIST):

Signature of person completing assessment: _____Date: _____

Adherence Support Guide for Pregnant Women Already on ART

Client's Name: _____ Client's File#: _____

1. Can you tell me about the group or one-on-one counseling sessions you have had at this clinic or at the ART clinic?	
2. Can you explain why you need to take ART for your entire life?	
3. What have been your experiences taking ART?	
4. Can you tell me about any challenges you have had taking your ART?	
5. How confident do you feel about continuing to take ART every day during your pregnancy and for your entire life?	
6. Can you tell me the names of the ARVs you take and how and when you take them (how many pills, what times of day)?	
7. Have you had any side effects from your ARVs? What did you do about them?	
8. Can you explain what will happen if you do not take all of your ARVs every day, at the same time, now during your pregnancy and for your entire life?	
9. Is there someone who helps you come to the clinic for appointments and helps you take your medicine every day? What is their contact information?	
9a. Has he/she been to the clinic with you?	
10. Do you think you will have any problems coming to this clinic or the ART clinic for your appointments?	
11. How do you remember to come for your clinic appointments?	
12. How do you remember to take your medicines the right way, at the same time, every day?	
13. How will you take your ART when you are in labor? If you are breastfeeding?	
14. Are you taking any medicines - other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
15. Where do you store your medicines?	
16. What do you do if you are about to run out of your medicine(s)? What about if you will be away from home?	
17. What do you do if you miss a dose of your medicine?	
18. Do you have any questions about your care and treatment plan – now while you are pregnant or for your entire life?	

Client requires more counseling and support in these areas (LIST):

Signature of person completing assessment: _____Date: _____

Adherence Preparation/Support Guide for Caregivers of HIV-Exposed Infants

Client's Name: _____ Client's File#: _____

1. Can you tell me about the group or one-on-one counseling sessions you have had here at the clinic?	
2. Can you explain why your baby needs to take ARVs?	
3. How long will your baby need to take ARVs?	
4. What concerns do you have about giving your baby ARVs?	
5. Who helps you take care of your baby? Do they know your baby has been exposed to HIV? Do they understand how to feed your baby and how to give your baby medicines?	
6. How will you remember to give the baby medicines the right way, at the same time, every day?	
7. How will you remember to come for your baby's clinic appointments?	
8. Can you tell me the names of the ARVs you will give to your baby and how and when you will give them (how much, how to give syrup, what times of day)?	
9. What will you do if your baby does not want to take medicine? Or spits up the medicine?	
10. Can you tell me some possible side effects of ARVs? What will you do if your baby has side effects?	
11. Are you giving the baby medicines other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
12. Where will you store the baby's medicines?	
13. What will you do if you are about to run out of medicine(s)? What about if you will be away from home? Or away from the baby?	
14. What will you do if you or your baby misses a dose of medicine?	
15. Can you tell me how you plan to feed your baby in the first 6 months? What will you say if people want to give your baby something other than breast milk (or formula)?	
16. What tests and medicines does your baby need at 6 weeks of age? After 6 weeks of age?	
17. *For mothers:* Can you tell me how you plan to continue your own care and treatment now that you are also taking care of the baby?	
18. Do you have any questions about your own or your baby's care and treatment plan?	

Client requires more counseling and support in these areas (LIST):

Signature of person completing assessment: _____Date: _____

Adherence Assessment & Follow Up Guide for use in PMTCT Settings

ICAP International Center for AIDS Care and Treatment • Mailman School of Public Health • Columbia University

How to Use the Adherence Assessment Guides

These adherence assessment guides were developed to support a range of providers (trained counselors, lay counselors, peer educators, expert clients, mother mentors, doctors, nurses, pharmacists, community health workers, and others) who work with pregnant women living with HIV and their families, as well as caregivers of HIV-exposed and HIV-infected children. Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. The adherence assessment guides should be adapted to reflect national PMTCT and pediatric care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used. It may be helpful to translate the guides into the local language.

Included are 2 adherence assessment guides: one for pregnant/postpartum women and one for caregivers of children enrolled in HIV care and treatment. The appropriate form should be used at every follow-up and refill visit to ensure that the client understands the care and medication plan and is taking his or her medicines the correct way, every day and/or giving the child his or her medicines the correct way, every day. Completed adherence assessment forms should be kept in the client's file and referred to at follow-up visits. If individual client files are not maintained at the clinic, these guides can be used as job aides to help providers when counseling pregnant/postpartum women and caregivers. The completed assessments can then be given to clients to keep with their health card, which is brought to each clinic visit.

Basic information: Write the client's name and file number at the top of the form. If the client is a child, write down the name of the caregiver attending the clinic visit. Then, tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session, and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver: The questions in this section allow the health worker to discuss and assess adherence. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on effective next steps, know important areas for follow-up, and support the clients' adherence over the long term.

Other assessment measures and next steps:
This is the section where health workers will plan with the client to ensure that he or she keeps up good adherence or develops strategies to improve adherence.

- **Other adherence assessment measures:** Depending on standard procedures at the clinic, the health worker may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- **Specific adherence challenges identified by client and health worker:** Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made:** If there is an outside organization, such as a support group or a home-based care program, that could help support the client to overcome his or her challenges to adherence, refer the client to that organization or service and indicate the name and specific service in this part of the form. In some cases, the client may need to be referred for other facility-based services, such as an appointment with a trained counselor or a session with the pharmacist to explain dosing.
- **Next steps and follow-up plan:** Together with the client, identify which solutions and next steps he or she thinks are feasible and manageable. For each solution, list the necessary steps the client or health worker will need to take and a time line for each. Also, make an appointment for a follow-up visit and record the date on the form. This section of the form can be used as a starting point for the adherence assessment during follow-up visits.

Adherence Assessment for Pregnant and Postpartum Women Taking ARVs or ART

Client's Name: _____ **Client's File#:** _____

Tick one: ☐ **2-week follow-up visit** ☐ **1-month follow-up visit** ☐ **monthly refill** ☐ **3-month refill**

Questions to ask the client:

1. Can you tell me more about how you took your medications this past month (or 2 weeks)? (Do you know the names of the medicines? How many pills do you take? At what time of day do you take them?)	
2. I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late?	
3. How many pills did you miss in the last 7 days? What were the main reasons you missed them?	
4. Which of these pictures best shows how many of your doses you took in the last month (or 2 weeks)? *(circle one)*	
5. How did the medicines make you feel?	
6. Can you tell me about any changes you noticed (such as in your health) or challenges you had with your medicines?	
7. What support or reminders do you have to help you take your medicines at the same time, every day?	
8. What questions do you have about your care or your medicines?	

Other assessment measures and next steps:

Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by client and health worker: *(discuss possible solutions to each)*	
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

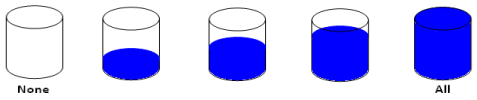
Signature of person completing assessment: _____ **Date:** _____

Adherence Assessment for Caregivers of HIV-Exposed and HIV-Infected Infants and Children

Client's Name: _____ **Client's File#:** _____

Tick one: ☐ **2-week follow-up visit** ☐ **1-month follow-up visit** ☐ **monthly refill** ☐ **3-month refill**

Questions to ask the caregiver:

1. Can you tell me more about how you gave your child his or her medicines this past month (or 2 weeks)? (Do you know the names of the medicines? How much medicine do you give? At what time of day do you give them?)	
2. Can you show me how you give your child his or her medicines? *(give praise and provide additional training and support, as needed)*	
3. I would like you to think about the last 7 days. How many doses did your child take late in the last 7 days? What were the main reasons the doses were late?	
4. How many doses did your child miss in the last 7 days? What were the main reasons the doses were missed?	
5. Which of these pictures best shows how many doses you gave to your child in the last month (or 2 weeks)? *(circle one)*	
6. Can you tell me about any changes you noticed (such as in your child's health) or challenges you or your child had with the medicines?	
7. What support or reminders do you have to give your child medicines at the same time, every day?	
8. What questions do you have about your child's care or medicines?	

Other assessment measures and next steps:

Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by client and health worker: *(discuss possible solutions to each)*	
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment: _____ **Date:** _____

Clinic Appointment Book & Appointment Card Templates

ICAP International Center for AIDS Care and Treatment • Mailman School of Public Health • Columbia University

How to Use the Clinic Appointment Book Template

Appointment systems are an important part of quality ANC, PMTCT, ART, and under-5 services. An appointment book is an important foundation for a functioning appointment system. Appointment books can help clinic staff manage client flow, plan for each day, and identify clients who have missed appointments so they can be followed up, according to the facility protocol, and brought back into care. Each clinic (e.g. ANC, ART, under-5, etc.) should have its own appointment book. **It is best if one person at each clinic is designated as responsible for making and keeping track of daily appointments and follow-up to make sure that no one is missed.**

Making an Appointment Book:

- Use the template on the following pages as a guide to create an appointment book.
- Decide on the needed columns in the appointment book. At minimum, the appointment book should include spaces to write: the client's name, the client's unique clinic number, the client's contact information, the reason for the appointment, whether or not the client attended the appointment, actions taken to follow up on a missed appointment, the outcome of follow-up attempts, and comments. Clinic teams should decide which column headings and response choices are most appropriate for their clinical setting.
- Decide the date range for the appointment book. The appointment book should cover at least one full year from the current date (but can cover more). You should "X" national holidays, weekends, and other days the clinic will be closed in the yearly calendar and on the daily calendar pages to avoid scheduling appointments on these days.
- Decide how many appointment slots and pages the clinic will need for each day. Each working day should have at least one full page in the appointment book, and maybe more, depending on how many clients are seen at the clinic on an average day. For example, a clinic that sees an average of 30 or fewer clients per day will likely only need 1 page allocated for each working calendar day; a clinic that sees between 30-60 clients per day will need 2 pages for each working day; and a clinic that sees more than 60 clients per day will need 3 (or more) pages for each working day.
- Once all the necessary pages of the appointment book have been printed, spiral bind the appointment book with a thick, hard, and/or plastic cover to prevent wear and damage.
- Create a Standard Operating Procedure (SOP) on the clinic appointment system, including how the appointment book will be used. The SOP should be detailed and specific to the clinical setting. Include who will be responsible for scheduling and following up on appointments, where the appointment book will be housed, how the appointment book will be used, and how missed appointments will be followed up.
- Train all of the clinic staff on the rationale for, and use of, the appointment book.

Daily Activities *(adapt these activities to the specific clinical setting and outline in detail in the SOP)*
Making appointments:

- Before each client leaves the clinic, she or he should schedule a follow-up appointment.
- Use the yearly calendar at the start of the appointment book to determine which day the person should return (for example, in 6 months for a CD4 test and follow-up, in 2 months for a routine ANC visit, in 1 week for lab results, in 3 days for an adherence counseling session, or in 2 weeks for a follow-up appointment with the doctor).
- Find the daily appointment sheet for the return date. Each day, Monday-Friday, has its own page (front and back).
- When you find the correct daily appointment sheet, and confirm that this date is convenient for the client, write the Client's Name, Client Number (ANC or ART number on file), and the Phone Number where the person can be reached.
- Using the codes given, write the Reason for Visit (FU=Routine Follow-up, HP = Health Problem, C=Counseling, Rx=Refill, LT=Lab Test, LR=Lab Results, or O=Other [list]).
- Make sure to tell the client when to return to the clinic and why she or he needs to return. Write the appointment date on the small take-away reminder slip (this can be stapled to any existing client-held health card).
- Give the client instructions on what to do if she or he will not be able to come back to the clinic on the date of the appointment (for example, if there is a phone at the clinic, make sure the client has this number so she can call and reschedule the appointment if necessary).

Keeping track of daily clinic attendance:

- Each morning, pull the client files for all of the people with an appointment, and put them in a convenient location.
- Each morning, draw a thick line on the daily appointment sheet under the last person with a scheduled appointment.
- When a client arrives at the clinic, check to see if she or he is scheduled for an appointment that day.
- If you see the name on the daily appointment sheet, tick Yes under the column that says Attended?
- If you do not see the name, DO NOT SEND THE CLIENT AWAY! Record the name under the line on the daily appointment sheet and fill in the client's information as above. Every day, it is important to record each person who comes to the clinic, whether or not they have an appointment. Make sure the client understands why it is important to have an appointment.
- Try to prioritize clients who have scheduled appointments to decrease their waiting time and reinforce the importance of making and keeping appointments.
- At the end of each day, go through each entry above the line you drew on the daily appointment sheet. For each person that had a scheduled appointment for that day (above the line you drew), make sure Yes or No is ticked in the Attended? column.
- Then, in the Total row at the bottom of the last page for that day, enter how many people attended the clinic for scheduled appointments and how many did not show up for their scheduled appointments.

Weekly Activities ***(adapt these activities to the specific clinical setting and outline in detail in the SOP)***

- Every Monday morning, review the daily attendance of the previous week (5 working days).
- It is important to give a couple of days leeway for clients who miss appointments, before conducting follow-up. Clients may come to the clinic during the couple of days following their scheduled appointment.
- Implement the standard clinic protocol for following up with clients who miss appointments each week (this will depend on the site). Clients need to give specific consent to get a phone call, SMS, or home visit. This should be noted on their individual client record.
- For each person who missed an appointment in the previous week, tick the appropriate Action Taken. This could be more than one action and could include sending an SMS, calling the person, conducting a home visit, or linking with a community health worker to conduct a home visit. Remember, this should only be done if the client has given consent.
- Record the Outcome of follow-up activities. If the client comes back to the clinic within two weeks of the missed appointment, tick Came back. If the client does not return, tick Did not come back.
- Write any Comments about attempts to contact specific clients or the outcomes of these contacts. For example, record when a client has died, moved away, transferred to another health facility, or other information. You can also record when you were unable to reach the person or if there is a wrong phone number on file.

Monthly or Quarterly Activities ***(adapt these activities to the specific clinical setting and outline in detail in the SOP)***

- Each month, the person responsible should review the previous month's appointments and ensure that follow-up has been conducted with all clients who missed appointments during that month, and that the type of follow-up attempt(s) and outcomes have been documented in the appropriate columns.
- In some cases, clients may require multiple follow-up attempts, which should be recorded.
- Monthly and quarterly totals of the number of attended and missed appointments, as well as the number of follow-up attempts and results of these attempts, should be calculated.
- These data can be presented for discussion at multidisciplinary team meetings, and used to track trends in attended and missed appointments over time. Program strategies for follow-up can be discussed and modified based on trends in follow-up success or failure over time. These data can also be used to advocate for more human and financial resources to ensure adequate and timely follow-up of clients who have missed appointments.
- Data and trends in attended and missed appointments, as well as follow-up, should be discussed with local partners, including community-based organizations and community health workers who are responsible for home-based follow-up and encouraging clients who have missed appointments to return to care.

2010 Yearly Calendar

("X" out holidays and weekends)

January 2010 (1)

S	M	T	W	Th	F	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

February 2010 (2)

S	M	T	W	Th	F	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28						

March 2010 (3)

S	M	T	W	Th	F	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

April 2010 (4)

S	M	T	W	Th	F	Sa
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

May 2010 (5)

S	M	T	W	Th	F	Sa
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

June 2010 (6)

S	M	T	W	Th	F	Sa
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

July 2010 (7)

S	M	T	W	Th	F	Sa
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

August 2010 (8)

S	M	T	W	Th	F	Sa
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

September 2010 (9)

S	M	T	W	Th	F	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

October 2010 (10)

S	M	T	W	Th	F	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

November 2010 (11)

S	M	T	W	Th	F	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

December 2010 (12)

S	M	T	W	Th	F	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

NOTES:

2011 Yearly Calendar

("X" out holidays and weekends)

January 2011 1

S	M	T	W	Th	F	Sa
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

February 2011 2

S	M	T	W	Th	F	Sa
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28					

March 2011 3

S	M	T	W	Th	F	Sa
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

April 2011 4

S	M	T	W	Th	F	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

May 2011 5

S	M	T	W	Th	F	Sa
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

June 2011 6

S	M	T	W	Th	F	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

July 2011 7

S	M	T	W	Th	F	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

August 2011 8

S	M	T	W	Th	F	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

September 2011 9

S	M	T	W	Th	F	Sa
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

October 2011 10

S	M	T	W	Th	F	Sa
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

November 2011 11

S	M	T	W	Th	F	Sa
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

December 2011 12

S	M	T	W	Th	F	Sa
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

NOTES:

Date: _____

	CLIENT NAME	CLIENT NUMBER (ANC or ART)	PHONE NUMBER	REASON FOR VISIT*	ATTENDED ?		IF NO, ACTIONS TAKEN			OUTCOME		COMMENTS (client refused to return, died, moved, transferred, no contact information, etc.)
					YES	NO	Call	SMS	Visit	Came back	Did not come back	
1												
2												
3												
4												
5												
6												
7												
8												
9												
10												
11												
12												
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15												
16												
17												
18												
19												
20												
21												
22												
23												
24												
25												
	TOTALS (from all pages)											

***REASONS FOR VISIT**: **FU**=Routine Follow-up • **HP**=Health Problem • **C**=Counseling • **Rx**=Refill • **LT**=Lab Test • **LR**=Lab Results • **O**=Other (explain)

Date: _____

	CLIENT NAME	CLIENT NUMBER (ANC or ART)	PHONE NUMBER	REASON FOR VISIT*	ATTENDED ?		IF NO, ACTIONS TAKEN			OUTCOME		COMMENTS (client refused to return, died, moved, transferred, no contact information, etc.)
					YES	NO	Call	SMS	Visit	Came back	Did not come back	
26												
27												
28												
29												
30												
31												
32												
33												
34												
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43												
44												
45												
46												
47												
48												
49												
50												
	TOTALS (from all pages)											

*REASONS FOR VISIT: **FU**=Routine Follow-up • **HP**=Health Problem • **C**=Counseling • **Rx**=Refill • **LT**=Lab Test • **LR**=Lab Results • **O**=Other (explain)

How to Use the Appointment Card Template

Appointment systems are an important part of quality ANC, PMTCT, ART, and under-5 services. Appointment reminder cards for clients are an important component of functioning appointment systems, along with appointment books and active and timely follow-up of missed appointments. Appointment reminder cards can help clients remember their return appointment dates and the reasons for their appointments.

- **Adapt the appointment reminder card template below**, according to the clinic's and the client's specific needs, including translating the card into local languages, as needed.
- **Prepare many, blank copies of the appointment cards** to have readily available at the clinic.
- **Each client should have an appointment reminder card.** In some cases, it may be useful to staple the appointment card onto existing client-held records or booklets.
- **When an appointment is made, the person responsible for appointments should clearly write the appointment date** in the 1st column and briefly describe the reason for the appointment in the 2nd column. Always use language that is understandable to the client – for example, write "Refill" instead of "Rx" or "Lab test" instead of "LFT."
- **Be sure to discuss the appointment date and reason** with the client to ensure that it is on a convenient date and that the client understands the importance of returning to the clinic for all scheduled appointments. Ask the client if there are other appointments that she, he, or the baby has at the clinic in order to organize both visits on the same day (for example, an infant EPI visit).
- **Encourage the client to inform the clinic**, for example by calling, if she or he will not be able to make the scheduled appointment.
- **When the client returns for her or his appointment on the correct day, place a tick (√) in the 3rd column**. Thank the client for being responsible and coming in on the appointment day.
- **This template has space to include 10 separate appointments**—use more cards for each client as necessary.

CLINIC APPOINTMENTS

Client's Name: _____ **Health Facility:** _____

APPOINTMENT DATE	REASON	ATTENDED (√)
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

PLEASE COME TO ALL OF YOUR APPOINTMENTS!

If you cannot come, please call: _____

VI.

PMTCT Patient Education Video

How to Use the PMTCT Patient Education Video

"Saving Two Lives: A Patient Education Video on Adherence to PMTCT" was created to reinforce key PMTCT messages with clients, their family members, caregivers, and community members. The video was filmed in Port Elizabeth, South Africa and most of the actors are actual nurses, peer educators, mother mentors, and community members from the area.

The video was developed as a generic product, so while it may not completely reflect the specifics of PMTCT care in all countries, it remains useful in promoting the key concepts of PMTCT, including retention, adherence, and the importance of psychosocial support. The video is in English, so careful facilitation is especially required in settings where viewers do not use English as a first language.

The video is divided into specific scenes. It may be played in its entirety, or by section, depending on the time available and the audience.

- In the first scene, the viewer is introduced to Hope, a young woman who lives with her husband and mother-in-law. Hope goes to the clinic for her first ANC visit (despite her mother-in-law's insistence that this is a waste of time), where she is tested for HIV and learns that she is HIV-infected. The nurse at the clinic gives Hope information on the meaning of her test results and how she can prevent MTCT. Afterwards, Hope meets an experienced mother and PMTCT client, Janet, who gives her information and support on what she needs to do to prevent MTCT.
- In the second scene, one week has passed and Janet returns to the clinic with Hope. Hope picks up her CD4 test results and prepares to start taking ARVs. The nurse and Janet give Hope practical advice on how she can lower the chances that her baby will be HIV-infected, including the importance of adherence to her PMTCT care plan and medicines.
- In the third scene, we see Hope and her newborn baby attend a mother's support group meeting in the community. Hope shares some of her experiences caring for her HIV-exposed baby and learns more from other support group members and the Peer Educator who is facilitating the meeting.
- Each scene is separated by "commercials" that reiterate key messages on PMTCT.

The video may be used in a number of settings, including:

- In the ANC waiting area, if there is a TV and DVD/VCD player
- As part of group education sessions with PMTCT clients
- As part of individual counseling and education sessions with PMTCT clients
- As part of training and mentoring activities for lay counselors, peer educators, mother mentors, etc.
- In support group meetings
- In the community, for example, at community meetings, religious gatherings, workplaces, marketplaces, and other venues where people come together
- During women's and youth group activities
- During PLHIV association activities
- As part of a public service announcement (PSA) on television

The video will be most effective if a health worker (nurse, peer educator, counselor, etc.) facilitates the video with viewers.

- Once programs decide on how and where the video will be used, it is recommended that tailored facilitation guides, including prompts and questions, be developed and implemented (see next pages for a sample).
- For example, if the video is used as part of a group education session with PMTCT clients, the facilitator could stop the video at regular intervals and ask clients what they think is happening, what they think the characters are feeling, and how the situation shown in the video relates to their own PMTCT care and medicines. Similar questions can be asked at the end of the video in cases where the entire video is shown at once.
- Facilitation and guided discussion will also allow for more in-depth discussion of PMTCT care and medicines, for example, discussing which specific ARVs pregnant women and HIV-exposed children take and for how long, specific examples of adherence challenges and reminders, and ways to safely feed and care for HIV-exposed infants.
- As mentioned above, guided facilitation will also help viewers understand what is happening in the video, especially if they do not speak English as a first language.

Sample PMTCT Video Discussion Guide
(adapt to your setting)

Scene 1: Hope goes to the clinic for her first antenatal care visit, where she is tested for HIV and meets Janet in the waiting area

- What challenges does Hope face in going to the clinic for antenatal care?
- How do you, or people you know, get support from partners and family members?
- What do you think of Hope's concerns about getting an HIV test as part of her antenatal care?
- What do you think Hope was thinking and feeling when she got the results of her HIV test from the nurse? How did you feel when you got your test results?
- Why do you think it's important for pregnant women to be tested for HIV?
- What does a CD4 count tell us? Why is it important for pregnant women living with HIV to know their CD4 count? What is your CD4 count, and what do you think the number means?
- What do you think Janet means when she tells Hope that she is "very lucky" and had "the good sense to come to the clinic?"
- What are the most important things Hope learns from Janet about PMTCT?
- What steps has Janet taken in the past, and what steps is she taking now, to lower the chances that her children will become HIV-infected?
- What do you think Janet means when she tells Hope, "no one can do this on their own?"
- What do you think Hope said to her husband after returning from the clinic? What have been your experiences talking to your partner and family members about HIV and PMTCT?
- How do Hope's experiences relate to your own experiences with antenatal care and PMTCT services?
- How do you think Hope can lower the chances that her baby will become HIV-infected? What steps do you think you can take to lower the chances that your baby will become HIV-infected?

Scene 2: Hope and Janet return to the clinic for Hope's CD4 test results and Hope starts taking ARVs

- Hope learns that her CD4 count is 450, and that she will have to start taking ARVs. Why does she need to take ARVs during pregnancy and not start ART for life?
- What if Hope's CD4 count was 350 or below? How would her care and treatment be different?
- What is your CD4 count and what medicines are you taking?
- Why is it important that Hope take ARVs during her pregnancy? Why is it important that you take ARVs during your pregnancy?
- What concerns does Hope have about taking ARVs during pregnancy? What concerns do you have?
- Why does Hope's baby need to take ARVs after he is born and until she stops breastfeeding? What ARVs does your baby need to take and why?
- What do you think Hope and the adherence counselor talk about during their session (which we don't see in the video)? What do you think pregnant women need to know when they start taking ARVs or ART?
- How would you answer Hope's question to Janet, "Will ARVs cure the HIV?"

- What ways does Janet suggest to Hope to remember to take her medicines the right way, at the same time, every day? How do you remember to take your medicines every day?
- What ways does Janet suggest to Hope to remember to come back to the clinic for all of her appointments? How do you remember to come back to the clinic for your appointments?
- Janet tells Hope that she will need support to adhere to her own and her baby's care and medicines and refers Hope to a support group. How do you get the support that you need? What have been your experiences with mother's support groups?
- Hope's mother doesn't think she needs to deliver the baby at a hospital. Do you think it's important that all women deliver their babies at a clinic or hospital? Why?
- What does Janet tell Hope to do during her labor and delivery? What plans do you have for your labor and delivery?
- What do you think are the key messages about PMTCT during pregnancy, labor, and delivery?

Scene 3: Hope and her one-month old baby attend a mother's support group meeting in the community, facilitated by a Peer Educator

- What do you think happened to Hope between the time we saw her with Janet at the clinic and when we see her with her baby at the mother's support group meeting?
- What challenges does Hope have with exclusive breastfeeding? What challenges do you have or think you will have? Why is exclusive breastfeeding and taking ARVs or giving your baby ARVs important to lower the chances that your baby will be HIV-infected? How do you plan to feed your baby?
- The mothers talk about their own 6-week checkup. Why is it important for mothers to go back to the clinic for their own checkups within 1 week and 6 weeks after they deliver? What do you think happens at these visits?
- The mothers talk about taking their babies for a 6-week checkup. Why is it important for babies to go back to the clinic when they are 6-weeks old? What do you think will happen when Hope takes her son for his 6-week visit?
- When can a baby be tested for HIV? Why is it important to test your baby for HIV and to pick up the results?
- What is cotrimoxazole? Why do babies exposed to HIV need to take it?
- One woman in the support group is taking ART for life. Hope took ARVs during her pregnancy, labor, and delivery only. Why do some pregnant women need to take ART for life, and others need to take ARVs/ART only during pregnancy, labor, and delivery? Are you taking ART for life or only during pregnancy, labor, and delivery?
- Why do women living with HIV need to continue their own care for life? How often do you go back to the clinic? What happens when you go back to the clinic?
- Why do all babies exposed to HIV need to take ARVs? How long do they need to take ARVs?
- Hope says she has some challenges giving her baby ARV syrups. What kinds of challenges do you have? What are some of the solutions to giving your baby ARVs every day?
- Why do you think the nurse asks her client who else takes care of her baby at home? Who else takes care of your baby at home? How do you help them learn about the care and medicines the baby needs?

- The support group members want to talk about sex. What does the Peer Educator tell the women about having sex after delivering a baby? What about condoms and family planning? What do you and your partner do to protect each other and prevent unintended pregnancies?
- The Peer Educator reminds the support group members that, "Adherence equals life" and that, "Adherence is the key to you and your baby staying healthy." What do the support group members do to adhere to their own and their babies' care and medicines? What do you do to adhere to your own care and medicines? Your baby's care and medicines?
- Why do you think Hope goes to the support group meeting, even though she has a lot to do at home? How do you think the support group helps her? What mother's support groups are there in your community? What are your experiences with these groups?
- What do you think are the key messages about PMTCT after the baby is born?

Interstitials (breaks between scenes, these are key PMTCT messages):
Discuss each statement, including the meaning, the "how," and the "why":

- Not all babies born to mothers living with HIV will become HIV-infected.
- There's a lot you can do to lower the chance that your baby will be infected.
- All pregnant women living with HIV need to take medicines called ARVs.
- All babies exposed to HIV need to take medicines called ARVs.
- Never miss an appointment.
- Take your medicines the right way, at the same time, every day.
- Give your baby his or her medicines the right way, at the same time, every day.
- Adherence equals life.
- PMTCT can help you save 2 lives—your own and your baby's.
- We need to accept and support each other.
- There are 12 million women living with HIV in Africa. You are not alone.