

Zambia National Prevention of Mother to
Child Transmission (PMTCT)
Communication Strategy:

Mobilising People for Action

April 2004



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ACRONYMS

ABC	Abstinence, Be Faithful, Consistent Condom Use
AED	Academy for Educational Development
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
BCC	Behaviour Change Communication
CBA	Community Based Agent
CBD	Community Based Distributor
CBO	Community Based Organisation
CBOH	Central Board of Health
CDC	Centres for Disease Control
CHP	Community Health Promoter
CHW	Community Health Worker
CIDRZ	Centre for Infectious Disease Research in Zambia
CM	Community Mobiliser
DATF	District AIDS Task Force
DDCC	District Development Co-ordinating Committee
DHMT	District Health Management Team
EHT	Environmental Health Technician
FBO	Faith Based Organisation
FGD	Focus Group Discussion
FP	Family Planning
HIV	Human Immunodeficiency Virus
HW	Health Worker
IEC	Information, Education, Communication
IGA	Income Generating Activity
IPC	Interpersonal Communication
IPT	Intermittent Presumptive Treatment
ITN	Insecticide Treated Net
JHPIEGO	Johns Hopkins Program for International Education in Gynaecology & Obstetrics
M&E	Monitoring and Evaluation
MTCT	Mother to Child Transmission
NAC	National AIDS Council
NFNC	National Food and Nutrition Commission
NGO	Non-Governmental Organisation
NHC	Neighbourhood Health Committee
OIT	Opportunistic Infection Treatment
PLA	Participatory Learning Activity
PLHA	People Living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
STI	Sexually Transmitted Infection
TB	Tuberculosis
TBA	Traditional Birth Attendant
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary Counselling & Testing
ZIHP	Zambia Integrated Health Programme

SECTION A:

National PMTCT Communication Framework

Purpose of PMTCT Communication Strategy

The National PMTCT Communication Strategy was developed as the result of an extensive series of meetings and discussions. A combination of health workers, neighbourhood health committee members, CBOH and DHMT representatives, implementing partners, PMTCT experts and community health communicators developed this strategy through a writing workshop held March 2004.

The purpose of this document is to guide those involved in PMTCT activities throughout Zambia in addressing key issues, which affect the success of PMTCT interventions. This document is meant to be user-friendly and provide a simple framework for guiding communication activities. It is meant for health workers, DHMTs, implementing partners, CBOH and any other interested partner working in PMTCT. It is not meant to be a verbose document which sits on office shelves, instead, it is meant to be a living document which is put to use in each district and community wishing to undertake PMTCT activities.

For further information, please seek out the nearest Health Promotion Focal person in the DHMT or contact CBOH.

Background of PMTCT in Zambia

HIV/AIDS prevalence in Zambia, according to the Zambia Demographic and Health Survey, is 16%. According to UNIADS, mother to child transmission of HIV is the largest source of HIV infection in children under the age of 15. Such statistics result in devastating effects for children undermining the gains made earlier in child survival. The magnitude of the problem requires speedy and decisive action which the CBOH has undertaken through its expansion of PMTCT services throughout Zambia.

PMTCT services were first introduced in Zambia in 1999 through the Ministry of Health in conjunction with UNICEF through a pilot project in Lusaka, Mbala and Monze to ensure both urban and rural sites. The pilot project has expanded since that time into an additional nine sites. In Lusaka and Mongu Districts, CIDRZ is working closely with the DHMT and has expanded into 31 sites. AED/Linkages has also expanded their initial reach in Ndola and Livingstone and are now operating in 25 sites. The CBOH has also begun its expansion plan and is expected that by the end of 2005, all provincial centres and all districts in Zambia will have functioning PMTCT services coupled with strengthened reproductive health services. PMTCT services are currently offered in 10 districts with a combined total of 80 health facilities at the time of this writing (March 2004).

While the expansion is progressing well, there remain a number of issues that have affected the success of PMTCT uptake and have hindered efforts to date.

- ◆ **Women and their partners have limited information on PMTCT.**
PMTCT is still a relatively new concept for many. While some information campaigns have been underway, there are still many people that lack the basic information.

- ◆ **Health Centres and communities are not well informed about PMTCT and need to be supported to engage in providing counselling, care and support, etc.**
While many health centres have still not been well educated about PMTCT, an even greater need remains in supporting those centres and the communities, which contain them through the introduction and implementation of comprehensive PMTCT services. If communities are to provide adequate support for their fellow members, they must be supported and trained in how to do so.
- ◆ **Stigma surrounding HIV remains a problem and limits the success of PMTCT interventions.**
Stigma is a barrier to couples going for VCT since HIV is still largely viewed as a death sentence by many people. HIV is often associated with immoral behaviours which makes many people fear to be tested since they worry they will be seen as bad people and blamed if their result is positive.
- ◆ **Male involvement has been inadequate in PMTCT communication initiatives to date.**
Programmes have largely focused on encouraging women to come for PMTCT services but have often left out men as critical decision-makers. If men are not informed of the benefits of PMTCT and clearly understand the risks to their children, they will not become a supportive force for PMTCT uptake and compliance.
- ◆ **Communities often don't speak openly about sexual matters or HIV/AIDS.**
Cultural norms often do not allow men and women to speak openly about sexual matters which hinders communication about PMTCT and other sexual health topics.
- ◆ **Stigma and cultural practices around *not* breastfeeding make it difficult for many mothers in PMTCT programmes.**
Stigma exists in situations where women may choose not to breastfeed when most people view the practice as culturally acceptable and preferable. Women who therefore do not breastfeed, are sometimes shunned or told they are not good mothers when in fact, the choice not to breastfeed may well be protecting their child. Such stigma makes it difficult for some mothers to adhere to infant feeding practices that can protect their child from HIV.
- ◆ **Pregnant women are unlikely to perform some of the desired PMTCT behaviours if their families and community members do not understand & support them.**
If families and communities do not understand the various components of PMTCT, they will not know how to support women and their partners going through such programmes. For example, if women fear that others will shun them because of their HIV status, then they may be less likely to use drugs that can protect their babies from HIV transmission at the time of delivery.
- ◆ **Limited couple communication in general, and around sexual issues in particular, makes it difficult for women to make decisions about PMTCT, condom use, etc.**
Certain intimate topics are often not discussed between a man and a woman, as it is often not seen as acceptable for a woman to raise such issues. For example, it may be difficult for a married woman to suggest condom use since it might be

viewed as a lack of trust within the marriage. As well, in many cases women do not raise issues around HIV testing for fear their husbands will get upset.

◆ **HIV negative mothers may not be reached with HIV prevention messages where PMTCT services exist.**

Traditionally there has been a predominant focus on HIV positive women within PMTCT service provision for many obvious reasons. But it is also important to see PMTCT as a chance to reach HIV negative women. At present, there is a tendency to ignore HIV negative women instead of making a deliberate effort to get primary prevention messages to them.

◆ **Myths and misconceptions remain problematic.**

Many myths remain around PMTCT programmes as rumours circulate in some communities that devil worship and witchcraft are involved. Such myths and misconceptions must be dispelled immediately so as not to allow them to negatively affect the success of PMTCT interventions.

◆ **Some cultural practices impede the success and health of PMTCT programmes.**

Some cultural practices are counterproductive to the health of men and women in relation to risk of contracting HIV. For example, widow inheritance, sexual cleansing and a tendency towards multiple partners may put men and women at greater risk for HIV infection.

◆ **Communities are often inadequately consulted and involved when PMTCT programmes are initiated in a health centre.**

Lessons have been learned and documented about situations when a health centre is equipped to provide PMTCT services but the community has not been informed or involved in the process. Typically, there is slow uptake of services and other problems when communities are not actively involved in every step of the introduction and implementation.

◆ **Community support structures to follow up on mothers and their families in PMTCT programmes are often lacking or non-existent altogether.**

Many communities lack the training and structures to provide support to women and their families throughout the PMTCT continuum. Post-test clubs, breastfeeding clubs, and the like are often not in place to provide counselling, care and support thereby making it even more difficult for mothers and their families to carry out behaviours which help protect their children from HIV.

◆ **Health workers often have limited skills in communication and working with the community.**

Many health workers have not been trained in basic behaviour change communication skills and are often not well versed in how to work with a community. Without such skills, PMTCT programmes may not be fully successful if the spirit of partnership is not in place with the community.

◆ **Inadequate IEC.**

Information, education and communication are often lacking in PMTCT programmes. Print and other materials are often not available which hinders communication efforts. There is a need to increase IEC throughout PMTCT programmes more widely.

The issues outlined above are the focus of what the national PMTCT communication strategy addresses throughout the following pages. Increasingly, those implementing PMTCT programmes recognise the need for an increased focus on communication activities for PMTCT programmes to be successful and reach as many people as possible.

Guiding Principles

At the onset of designing a national PMTCT communication strategy, it was agreed that a set of guiding principles was necessary to shape discussions and focus the basis of the strategy. The following eight principles are therefore defined below:

1. Research based

Evidence and data form the foundation for the communication strategy, as there is already existing documentation and on-going formative research, which will direct communication interventions around PMTCT.

2. Audience centred approach

Communication activities should focus on specific audiences with specific messages rather than just using generic messages for the entire country. Messages must therefore be tailored to each respective audience.

3. Focus on behaviour change, not merely information giving

While one overarching goal of PMTCT communication is to increase knowledge, that alone is not enough. All communication interventions should therefore focus on encouraging positive and healthy behaviour change rather than just giving information.

4. PMTCT must have an integrated and comprehensive approach

PMTCT does not and cannot stand alone in any health care setting. It must be integrated into maternal and child health, safe motherhood, and care and support among others for it to be successful. PMTCT is not a vertical programme and must be integrated within the globally agreed upon four prong approach (primary prevention of HIV, prevention of unintended pregnancy, prevention of PMTCT, and care and support.) See table below.

5. Community participation, empowerment and ownership

Community participation is central to the full realisation of PMTCT services and the benefits of such programmes. A two-way process between the health centre/DHMT and the community must be in place to ensure that feedback is received from the community and that every community is prepared through on-going consultation at every level of implementation.

6. Use of multiple communication channels

No one channel of communication will be sufficient to ensure that PMTCT information is disseminated widely. A balance must be struck between mass media, community and facility level channels. Each should be complimentary to the others and mutually reinforcing in their messages.

7. Partnership and co-ordination of all players is key

All implementing partners must work in a co-ordinated fashion with the Central Board of Health and one another. Communication goals and

objectives will be similar across all working in the expansion of PMTCT and should therefore be guided by this document and its messages.

8. Dynamic environment

Given that the environment is constantly changing, PMTCT programmes must recognise the need and use of feedback and new information. Successes and challenges must be considered as they arise and inform the future direction of activities on an on-going basis. What works today in PMTCT communication may not necessarily work tomorrow and programme implementers must keep this reality in mind while being flexible to changes.

The four prong approach mentioned above under guiding principle number four, takes into account the comprehensive PMTCT package on which this communication strategy is based. Each of the strategic elements is outlined in greater detail in the table below and encompass a more holistic approach to PMTCT interventions. While PMTCT services at the facility level are central to implementation, there are many other elements that must be in place for comprehensive PMTCT programmes to be fully successful.

PREVENTION OF HIV IN WOMEN (PRONG 1)	PREVENTION OF UNINTENDED PREGNANCY (PRONG 2)	PREVENTION OF MTCT (PRONG 3)	CARE AND SUPPORT (PRONG 4)
<ul style="list-style-type: none"> • Enhancing community engagement and mobilisation, including male involvement • Integrating VCT information in Adolescent Friendly health Services • Screening and treatment of STIs¹ • Promoting condom use • Providing preventive counselling for HIV negative women and their partners • Encouraging disclosure of HIV status amongst couples • Addressing negative traditional practices that promote the transmission of HIV/AIDS • Empowering women and girls 	<ul style="list-style-type: none"> • Provision of VCT in ANC and family planning units • Provision of family planning information and services to women and their partners in the context of HIV 	<ul style="list-style-type: none"> • Strengthening of MCH services including, malaria prevention (IPT and ITNs), and strategies to reach those missed in ANC and safe delivery practices • Integration of routine counselling and testing (100% counselling with opt out model) in MCH services • Provision of ARVs for PMTCT • Ensuring safe delivery practices including provision and correct use of safe delivery kits • Counselling for optimal and safe infant feeding options as well as maternal nutrition • Condom use • Male involvement and community counselling 	<ul style="list-style-type: none"> • Screening and treatment of opportunistic infections among mothers and their families • Post-partum maternal TB prophylaxis • PCP co-trimoxazole prophylaxis in children from 6 weeks • Establishment of referral linkages for palliative care and support for symptomatic mothers and their families • Provision of nutrition, on- going counselling and psychosocial support for both the mothers and their families • Supporting the creation of peer-support groups for infected mothers and their families • Development of linkages with IMCI, home based care and orphan programs • Empowering women and girls

Communication Framework & Outline

The overall communication framework for Zambia's National Communication Strategy is outlined below which includes the overall PMTCT communication goal, four objectives and each of the more specific strategies. Each objective, its corresponding strategies, audience, communication channels, messages, activities and monitoring indicators are then described in greater detail.

PMTCT Communication Goal:

Empower individuals, families, and communities to make informed choices to prevent HIV transmission, prevent unintended pregnancies, use PMTCT services, and access care and support through effective BCC strategies.

Objective 1: Increase knowledge and awareness of PMTCT.

- Strategy 1: Advocacy on PMTCT at the national, district and community level.
- Strategy 2: Develop and implement PMTCT media campaign nation-wide.
- Strategy 3: Integrate communication interventions throughout the health facility.
- Strategy 4: Integrate communication interventions throughout the health community.
- Strategy 5: Promote communication about PMTCT within the family.

Objective 2: Increase community action, ownership and partnership for PMTCT.

- Strategy 1: Facilitate community dialogue on PMTCT issues.
- Strategy 2: Empower community members to take a leading role in PMTCT programmes.
- Strategy 3: Create/Strengthen community support structures.
- Strategy 4: Strengthen the network/linkages among all actors in HIV and relevant programmes to support activities at the community level.

Objective 3: Encourage male involvement in PMTCT.

- Strategy 1: Increase knowledge around PMTCT for men.
- Strategy 2: Facilitate dialogue around PMTCT by men.
- Strategy 3: Promote couple VCT.

Objective 4: Strengthen Health Workers' ability to promote and provide the PMTCT package.

- Strategy 1: Increase health workers' knowledge and communication skills in PMTCT activities.
- Strategy 2: Enhance partnership between health workers and the community.
- Strategy 3: Strengthen supportive mechanisms between the DHMT and health centres.

Each objective is discussed in greater detail below:

Objective 1: Increase knowledge & awareness of PMTCT.

Strategy 1: Advocacy on PMTCT at the national, district and community level.

- ◆ **Audience:** National (Parliamentarians, Policy Makers, Employers, Faith-based leaders); District (Church leaders, DDCC, DATF, DHMT, etc.); Community (Traditional Leaders, Traditional Healers, Faith-based, NHC, CHW, CBOs, TBAs)
- ◆ **Communication Channels:**
 - Meetings and Workshops
 - Print materials (fact sheet, leaflets, information pack)

Messages:

- ◆ Know the Facts about PMTCT
- ◆ Talk about PMTCT to constituents
- ◆ Promote creation of support systems in your area
- ◆ Use your position of influence/authority to promote PMTCT activities
- ◆ Encourage record keeping/data of PMTCT activities for decision making

◆ **Illustrative Activities:**

-Produce print materials

National Level:

-2 day workshop for parliamentarians (it will be an ongoing activity once a year to: provide feedback, provide updates and address turn over issues)

-CBOH/NAC prepares a quarterly report on PMTCT communication activities and reports to the Co-operating Partners

-Incorporate communication indicators into national PMTCT M&E framework at all levels

-Hold a one day workshop for Policy Makers explaining the 4 prongs of PMTCT

-Faith based one day workshop on PMTCT

-Workshops held with journalists

District level

-Quarterly meetings w/ district leadership

-Quarterly reports on communication activities & share with district partners

Community level

- 3 day PMTCT meeting with local leaders

- Quarterly reports on communication activities & share with local partners

- Solicit input for community entry strategies (stakeholders)

◆ **Indicators:**

- # of people in advocacy target group reached
- # of meetings held by Parliamentarians/Policy Makers, etc on PMTCT
- # of kinds and quantity of advocacy print materials produced and disseminated

Strategy 2: Develop and implement PMTCT media campaign nation-wide.

- ◆ **Audience:** men, women (especially pregnant & lactating women), leaders, youth

- ◆ **Communication Channels:**
 - Mass media-radio (national and local)
 - Television
 - Leaflets (in local languages?) & posters
 - Newspapers (e.g. supplements, regular column)

Messages:

- ◆ Go for VCT to know your HIV status
- ◆ Comply with ARVs
- ◆ Talk with your health care provider about PMTCT
- ◆ Know the benefits of PMTCT

- ◆ **Illustrative Activities:**

- Establish baseline
- Conduct literature review
- Identify target groups, areas of focus and campaign theme
- Plan, develop, pre-test materials
- Produce and disseminate materials (print, radio, television)
- Orientate district teams on the national wide campaign
- Launch campaign

- ◆ **Indicators:**

- Media campaign planned and launched
- # of radio spots produced and aired
- # of print materials produced and distributed
- # of television spots aired
- # of newspaper articles
- # of district teams orientated on nation wide campaign
- % people tested and know their status
- % people compliant with ARV

Strategy 3: Integrate communication interventions throughout the health facility.

- ◆ **Audience:** Anyone who walks into a health facility.

- ◆ **Communication Channels:**
 - Specialised group discussions
 - IPC
 - Print materials
 - Videos
 - Health talks

Messages:

- ◆ Use VCT
- ◆ Practice safe motherhood behaviours
- ◆ Practice healthy child survival behaviours
- ◆ Comply with instructions for taking ART
- ◆ Practice healthier preventive behaviours
- ◆ Adopt an FP method as appropriate
- ◆ Reduce stigma and don't discriminate

◆ **Illustrative Activities:**

- Conduct health talks and specialised group discussions
- Group/Individual motivation (with PLHA)--Use people who have been through the programme (men, women (both young and old))
- Individual/Couple counselling
- Provide leaflets/posters
- Invitation slips for men
- Use videos (with discussion)

◆ **Indicators:**

- # of people who attended group talks
- # of people who attended pre-test counselling sessions
- # of people tested and know their results
- # of people counselled on FP; infant feeding; primary prevention; maternal nutrition; etc.
- # of men/women who accepted a FP method
- # of invitation slips given to men & # that came with them
- # of people attending video discussion
- # of people attended to by a satisfied user
- % people accepting an FP method

Strategy 4: Integrate communication interventions throughout the community.

- ◆ **Audience:** Depends on the message

◆ **Communication Channels:**

Group health talks and meetings
Print materials
Videos
Peer education
Drama

Messages:

- ◆ Go for HIV testing and know your status
- ◆ Know the benefits of VCT
- ◆ Know the benefits of PMTCT
- ◆ Encourage safe motherhood behaviours
- ◆ Encourage child survival behaviours
- ◆ Comply with instructions for taking ART
- ◆ Practice healthier preventive behaviours
- ◆ Adopt an FP method as appropriate
- ◆ Reduce stigma and don't discriminate

◆ **Illustrative Activities:**

- Community forum/dialogue
- Drama/rallies (with PLHA)
- Support Groups (PLHA, women (pregnant, youth, breast feeding), men (fathers, youth))
- Peer education
- Provide leaflets/posters

- Use videos (with discussion)
- ◆ **Indicators:**
 - # of people who attended group talks
 - # of people who attended counselling sessions
 - # of men/women who accepted a FP method
 - # of invitation slips given to men and used
 - # of people attending video discussion
 - # of support groups formed
 - # of drama presentation
 - # of rallies organised and carried out
 - # of meetings held with stakeholders
 - # of peer education meetings
 - # of leaflets/posters distributed

Strategy 5: Promote communication about PMTCT within the family.

- ◆ **Audience:** Adults family members; Children depending on the message
- ◆ **Communication Channels:**
 - Group discussion (schools--all levels; churches; health facility)
 - Print materials
 - Mass media
 - Drama
 - Family gatherings/meetings

Messages:

- ◆ Talk within your family about PMTCT and related topics
- ◆ HIV Testing & Know your status
- ◆ Safe motherhood behaviours
- ◆ Child health behaviours
- ◆ Practice healthier preventive behaviours
- ◆ Adopt an FP method as appropriate
- ◆ Reduce stigma and don't discriminate

- ◆ **Illustrative Activities:**
 - Use school-based initiatives (family life education) with a call to action of "initiate discussion at home"
 - Materials brought home from clinic, school or community event.
 - Use church gatherings, family gatherings, etc to initiate discussion
 - Use information from mass media to talk about PMTCT
- ◆ **Indicators:**
 - # of leaflets distributed
 - # of talks and gatherings held
 - # of school based initiatives (family life education) conducted
 - # of times the call to action of "talk about it" is transmitted

Objective 2: Increase community action, ownership and partnership for PMTCT.

Strategy 1: Facilitate community dialogue on PMTCT issues.

- ◆ **Audience:** Traditional leaders, PLWHA, Mother Support Groups, FBOs, CBAs, NHCs, Traditional Healers, Youth groups, PTAs, farming & fishing co-ops, men, clubs
- ◆ **Communication Channels:**
 - Folk media
 - Community radio/ listening groups
 - Community meetings

Messages:

- ◆ Learn the truth about PMTCT (discuss benefits, address myths and misconceptions)
- ◆ Reduce stigma and don't discriminate (i.e. support people who choose to not breastfeed)
- ◆ Identify harmful cultural practices and seek ways to change them
- ◆ Identify harmful realities/ social norms (poverty, gender inequality) and seek ways to change them
- ◆ Encourage VCT
- ◆ Encourage preventative behaviours (i.e. ABCs, family planning)

- ◆ **Illustrative Activities:**
 - Community meetings (with audiences above)
 - Seek out underrepresented groups and encourage their participation- give voice to the voiceless
 - Radio programming on community stations to initiate community discussion
 - Organising radio listening groups
 - Dramas, song and dance to initiate community discussion
 - Training in facilitation skills for leaders among community groups
- ◆ **Monitoring Indicators**
 - # of community meetings held, groups attending meetings, topics discussed, actions agreed upon
 - # of radio programmes, topics discussed
 - # of radio listening groups organised, # of meetings & discussions held, topics discussed
 - # of drama/song/dance performances
 - # of facilitators trained, # of trained who are active

Strategy 2: Empower community members to take a leading role in PMTCT programmes.

- ◆ **Audience:** Community leaders, traditional leaders, NHC members, church leaders, CBOs, Traditional counsellors, lay counsellors, CBAs (TBAs, CBDs, CHWs, CHPs, etc.), Councillors, Traditional healers, Market leaders
- ◆ **Communication Channels:**
 - Drama
 - Health talks
 - Community radio
 - Group discussions

Messages:

- ◆ The solutions lie in your hands, take a leading role in supporting PMTCT programmes in your community
- ◆ Identify harmful cultural practices and seek ways to change them
- ◆ Identify harmful realities/ social norms (poverty, gender inequality) and seek ways to change them

◆ **Illustrative Activities:**

- Defining roles
- Train community groups in planning and implementation of PMTCT programmes
- Develop participatory action plans based on dialogue
- Training in proposal writing and lobbying for resources
- Initiate IGAs

◆ **Monitoring Indicators:**

- roles defined by type (managerial, care-givers, etc)
- # of community groups trained in planning and implementation (PLA)
- # of action plans developed (%/proportion of activities implemented)
- # of groups trained in proposal writing
- amount of funds sourced by what # of groups, success rate (# of proposals funded/ # of proposals written)
- # of IGAs initiated, # continuing activity, amount of net funds generated per IGA

Strategy 3: Create/Strengthen community support structures.

- ◆ **Audience:** Community leaders, support groups, peer groups, health workers
- ◆ **Communication Channels:**
 - Community meetings
 - Community Radio Programmes (i.e. Sister Evelina & Our Neighbourhood)

Messages:

- ◆ Working together enhances your ability to achieve your PMTCT goals (no man is an island)
- ◆ An informed community on PMTCT is a more supportive community

◆ **Illustrative Activities:**

- Identify the need for selected community groups
- Organise the groups
- Train the groups
- Establish a two way communication system between HC and community groups
- Co-ordinate the groups using the communication system
- Exchange visits among community groups
- Resource mapping
- IGAs, other identification of financial resources for the support groups
- Demonstrations (nutrition, farming, etc.)
- Continuous monitoring and strengthening

◆ **Monitoring Indicators**

- # of groups organised / # of groups identified as needed

- # of groups trained / # of groups organised
- communication system established
- # of reports receiving feedback / # of reports submitted by community groups
- # of exchange visits
- # of groups with a resource map / total # of groups
- # of IGAs, type of IGAs
- Amt. of resources from the outside to support support groups
- # of demonstrations, types of demos, # of different groups attending
- # of reports going from community groups to health centre on a regular basis / # expected
- # of referrals from one group to another

Strategy 4: Strengthen the network/linkages among all actors in HIV and relevant programmes to support activities at the community level.

- ◆ **Audience:** DATF; NGOs; DHMTs; CBOH; District Commissioners; District offices for ministries of Agriculture, Youth, Sport and Child Development, Community Development and Social Welfare; and other partners as appropriate
- ◆ **Communication Channels:**
 - Meetings
 - Face to face conversations
 - Printed reports

Messages:

- ◆ Communities need your support
- ◆ Working together enhances your ability to achieve your PMTCT goals

- ◆ **Illustrative Activities:**
 - Partnership meetings
 - Joint action plans at district and community levels
 - Share reports
- ◆ **Monitoring Indicators**
 - # of actors attending meetings, # of meetings
 - Does a district joint action plan exist?
 - # of community joint action plans / # of communities
 - # of reports shared / # expected
 - # of referrals from one organisation to another

Objective 3: Encourage male involvement in PMTCT.

Strategy 1: Increase knowledge around PMTCT for men.

- ◆ **Audience:** male students (senior secondary and tertiary), men (young and old)
- ◆ **Communication Channels:**
 - Group discussions (Clubs, church groups, schools, anti-AIDS clubs)
 - Radio
 - Traditional ceremonies

Messages:

- ◆ Know the basics of PMTCT
- ◆ Understand the benefits of PMTCT
- ◆ Talk to your HW about PMTCT
- ◆ Go to your nearest health facility for information & services
- ◆ Know about the ABCs & how to protect yourself

◆ **Illustrative Activities:**

- Debates
- Talks
- Training in IPC skills
- Lobby for male friendly environments in health centres

◆ **Monitoring Indicators:**

- # of debates on PMTCT
- # of schools participating in debates
- # of talks on PMTCT
- # of churches holding men's talks
- # of IPC workshops conducted among men
- # of men trained in IPC skills
- # of male-friendly health facilities & men accessing services in them
- % increase in couples presenting for counselling
- % of male knowledge on PMTCT

Strategy 2: Facilitate dialogue around PMTCT by men.

- ◆ **Audience:** community leaders (church, political, traditional), working men (construction, fishing, cross border traders, drivers, uniformed services, etc.), men in recreational places

◆ **Communication Channels:**

- Group discussion
- IPC
- Print materials

Messages:

- ◆ Men should feel free to discuss PMTCT & similar issues with other men (young and old), partners, health workers
- ◆ Review cultural practices and modify those that are harmful (i.e. taboos around sex)
- ◆ Support your partner in PMTCT

◆ **Illustrative Activities:**

- Training in IPC skills
- Conduct FGD/Group talk
- Social mobilisation
- Marriage counselling to include PMTCT
- Recruitment of male volunteers to facilitate dialogue

◆ **Monitoring Indicators:**

- # of IPC workshops held
- # of men trained in IPC skills
- # of men with skills in FGDs
- # of social mobilisation activities held
- # of people attending social mob. events
- # of traditional marriage counsellors trained
- # of male volunteers trained in PMTCT
- % male involvement

Strategy 3: Promote couple VCT.

- ◆ **Audience:** couples, traditional marriage counsellors, church leaders, health workers, circumcisers
- ◆ **Communication Channels:**
 - Group discussions
 - IPC: churches (male fellowship)
 - Radio
 - Print
 - Workshops

Messages:

- ◆ Know the benefits of VCT
- ◆ Go with your partner for VCT--Know your status

- ◆ **Illustrative Activities:**
 - Conduct FGD/Group talk
 - Train traditional & church marriage counsellors in VCT/PMTCT
 - Development of IEC print materials for couple VCT
 - Revise traditional marriage counsellors curriculum, where it exists to include HIV/PMTCT information
 - Forming support groups for men (post-test clubs)
 - Distribution invitation cards for wives to bring husband to clinic for VCT
 - Create & strengthen traditional men's marriage counselling associations
- ◆ **Monitoring Indicators:**
 - # of group talks conducted
 - # of target audience trained in VCT and PMTCT
 - # of support groups for men established
 - # of posters/brochures produced
 - Curriculum revised to include PMTCT
 - # of male partners attending clinics for VCT
 - # of male associations & membership
 - % male involvement at facility level

Objective 4: Strengthen Health Workers' ability to promote and provide the PMTCT package.

Strategy 1: Increase health workers' knowledge and communication skills in PMTCT activities.

- ◆ **Audience:** health workers, DHMT
- ◆ **Communication Channels:**
 - Meetings
 - Lectures
 - Group discussions (question/answer sessions, demonstrations/role play)
 - Field trips
 - Newsletter

Messages:

- ◆ Basic facts of HIV/AIDS: definition, impact/epidemiology, modes of transmission, risk factors, prevention
- ◆ PMTCT: primary prevention of HIV infection, prevention of unintended pregnancies, services, and care and support
- ◆ Services include: ANC, intrapartum, postpartum, VCT, infant feeding options, ARVs
- ◆ HIV therapies
- ◆ Infant and young child feeding: breastfeeding management, replacement feeding techniques, complementary feeding, growth monitoring and promotion
- ◆ Immunisation & malaria prevention
- ◆ Maternal nutrition
- ◆ Counselling/BCC skills: basic counselling skills, health talks, specialised group discussions

- ◆ **Illustrative Activities:**

- Trainings: orientation, basic PMTCT, counselling & communication skills
- Production of quarterly newsletter
- Demonstrations/role plays
- Use counselling tools (i.e. FP Counselling Kit, Maternity Counselling Kit)

- ◆ **Monitoring Indicators:**

- # of health workers trained by course and those active
- # of newsletters produced and circulated
- # of meetings held per quarter
- % of clients accessing PMTCT services

Strategy 2: Enhance partnership between health workers and the community.

- ◆ **Audience:** health workers, NHC leadership, CBOs, CBAs (TBAs, CHWs, CBDs, CM, etc.)
- ◆ **Communication Channels:**
 - Meetings
 - Printed guidelines
 - Work schedule

Messages:

- ◆ Plan and implement with the community
- ◆ Collect and compile community report
- ◆ Provide follow-up and feedback to the community

- ◆ Plan and facilitate exchange visits

◆ **Illustrative Activities:**

- Community entry strategies/formulation of operational guidelines for community work
- Joint planning , implementation and co-ordination with community
- Follow up of PMTCT activities with the community
- Standardise a two-way reporting tool
- Organise regular meetings between health workers and the community
- Exchange visits (community/community, HCs/HCs, HCs/Community)
- Networking with other community organisations
- Facilitate resource mobilisation

◆ **Monitoring Indicators:**

- Availability of guidelines
- # of meetings held per quarter, # of different organisations participating
- # of exchange visits per quarter
- Monthly reports
- Defined action plan
- Resources mobilised

Strategy 3: Strengthen supportive mechanism between the DHMT and health centres.

- ◆ **Audience:** health workers, DHMT

◆ **Communication Channels:**

- Meetings
- Supervisory checklist
- Reports to DHMT
- Self-assessment
- Newsletter
- Leaflets
- Workshops

Messages:

- ◆ Promote team work
- ◆ Promote integration of PMTCT into all health care activities
- ◆ Proper reporting so data can be used for decision making, planning and feedback
- ◆ Offer Interactive support visits

◆ **Illustrative Activities:**

- Update supervisory checklist to incorporate PMTCT (CBOH)
- Regular supportive visits by DHMT that include PMTCT activities
- Refresher courses/updates on PMTCT
- Feedback and follow-up by DHMT
- Resource mobilisation by DHMT/Health Centre Staff
- Produce print materials for HC staff & community (newsletters)

◆ **Monitoring Indicators:**

- # of Departments integrating PMTCT activities

- # of reports submitted to DHMT quarterly
- # of quarterly supportive visits done by DHMT
- # of workshops conducted quarterly
- Clinic level availability of all PMTCT resources

Outstanding Issues

At the time of this writing, a few outstanding questions and issues remain which require further discussion and clarification.

- A question remains as to how to integrate this PMTCT Communication Tool in health centres in a way that does not compromise other health topics being discussed. Given that most health workers have limited time to spend with each client, how can this document ensure that PMTCT is integrated with other health topics?
- Will there be specific training for Health Workers in communication skills or will that training be included within the basic PMTCT and counselling trainings already in existence?
- How will this communication strategy and accompanying tools be shared with communities and in a multi-sectoral manner? Recognising that health workers already have so many demands on their time, it is crucial that communities are able to perform many of the communication activities necessary to spread the word about PMTCT and encourage greater up-take of services.
- A comprehensive tool for PMTCT site preparedness specific to communication is not in existence and needs to be designed.
- A press kit that includes PMTCT information does not currently exist but would be a useful tool in working with the media.

SECTION B: Tools for Implementing PMTCT Communication Activities

The tools found within this section are designed to serve as practical and useful tools for those implementing PMTCT communication programmes at both the facility and community level. Each one can be used alone or in conjunction with the other tools in this document. The following tools are included:

- ◆ Conducting Community Drama
- ◆ Conducting a Group Talk
- ◆ Media Brief
- ◆ Working with Local Radio
- ◆ Message Strategies
- ◆ Conducting Formative Research
- ◆ Formative Research-Sample Question Guide
- ◆ Site Preparedness
- ◆ Site Preparedness—Sample Question Guide
- ◆ Community Entry Protocol
- ◆ Community Dialogue Tool—Sample
- ◆ Monitoring & Evaluation Tools
- ◆ Budgeting Tool

Conducting Community Drama

Community drama is made and acted by people from the community and can be a good way to talk about better health. It can be used to show real life situations and encourage healthy behaviours. Drama can take many forms including stage drama, sketches, role-plays and even acting on radio and television. Drama can be a good way to talk about better health because it:

- Entertains: drama attracts and makes people listen because it entertains them.
- Is real: drama can show a problem that a community thinks is important, in a way that the community can understand easily.
- Informs: drama gives information that community members can use to make their health better. Community drama also shows community members why some behaviours are good for health and others are bad.

Elements of a drama include:

- subject or theme; example: importance of couple VCT
- plot or story line--how the drama will progress from beginning to end
- few messages (1 or 2)
- short dramas--not too lengthy
- elements of fun to keep the audience interested
- main and supporting characters; characters should show the different opinions in the community and must be believable
- conflict/ problem behaviour; example: couples fear going for VCT since there may be stigma around being tested
- resolution, desired behaviour change or solution; example: couples go for VCT
- call to action; example: Go for VCT with your partner
- Encourage discussion with a question and answer session after to make sure that all the messages are clear to the audience

As listed under the elements of drama above, good community drama must be clear and talk about one issue or problem. The topic of the drama must be decided upon before the drama begins and the actors should practice in advance of the performance(s). The information should be acted in a way that everyone understands and clearly shows why it is good to behave in a certain way. It must also please the audience and not make the people watching angry or upset. This may be achieved by using local customs, songs, etc. The drama should suggest answers or actions that people can actually do while also making the story interesting to watch.

It must present all sides of a problem, show why problems happen, and show the different ways people deal with these problems. Engaging or involving as many local leaders or organisations as possible also helps convey the message with authority. The best way to promote healthy behaviours in a positive way is by showing the benefits of that behaviour. By giving the good behaviours to a character that is liked or respected, people will be more likely to adopt that behaviour. Those same good characters that people like should also be the ones that solve the health problem in

the drama. Bad behaviours, therefore, should not be given to well liked and respected characters in the drama script.

If an issue is raised in the drama, the drama script must include answers to those issues and not leave any questions unanswered. The discussion period after the drama is another opportunity to make sure that people understand what is being said. It is important to leave enough time for it. People watching the drama should be clear about the problems that were discussed and the answers the drama suggests. A health worker or NHC member can lead the discussion about what they can do to help solve the problem, and to make sure people got correct information before they leave the drama. It is very important for everyone watching to have a chance to discuss what he or she saw and learned. There should also be a follow up plan to support individuals or collective decisions made as a result of the performance. For example, the health worker might need to help the community set up a support group or help an individual go for VCT.

As stated above, dramas should begin and end on time since most people don't have a lot of free time in their day. Community drama groups must get their points across in a short time to be effective. Drama group members must understand the health problem or issue, in this case it is PMTCT, and how the problem or issue can be solved by working with local stakeholders (community leaders, politicians, NHC members, religious leaders, etc.). For example, they should be clear on:

- What causes this problem?
- Does this problem affect everyone as badly, or does it affect some people more than other people?
- What can be done to solve this problem?
- Who can help solve the problem?

Understanding the different opinions that community members have about the health problem affecting them, and realistic solutions for those problems, is very important. It is important to know if everyone in the community believes it is a problem, if everyone would try to solve the problem in the same way, and whether or not the community will think it's worth their effort to solve the problem in the way being presented. The play should not stigmatise or present any bad behaviours in a way that will make people laugh, such as a husband beating his wife.

Tips on working with drama groups:

- Present drama group with a message strategy so they can use it when developing a script (with background, facts, etc.)
- Set objective for the event: example 1. Raise awareness on PMTCT, 2. Motivate members of the community to go for VCT
- Review script for technical content, accuracy and cultural acceptability
- Ensure there is no misinformation and no undesirable characters
- Ensure there is a call to action
- Watch the drama before the community sees it and work with the actors to make changes if needed. This can be done with colleagues and a small group from the target audience
- Revise script based on feedback from preview

- Engage stakeholders to mobilise members of the community to attend the performance(s).
- Watch drama with audience to be able to encourage discussion, answer questions and clarify points

Conducting a Group Talk

A group talk is a way of communicating with members of a community about health topics such as PMTCT. They serve to increase awareness and information about a topic or issue, provide an opportunity for giving basic facts, and show that the topic is important. In addition, group health talks ensure that messages reach many people at the same time while also reinforcing messages that people may have heard elsewhere and correcting misinformation.

Group talks are a common way to share information and people can learn more if group talks are combined with stories, dramas and pictures. They are important because they allow people to support and encourage each other in healthy behaviours if they are all discussing it together. They also allow people to share similar experiences, learn from each other, and understand the value of the whole group in coming up with ideas.

What should be done to prepare for a group talk?

- Select a topic of interest with the community.
- Set objectives for the discussion; example: To identify the root cause of why people don't want to go for VCT; or To educate the community on the benefits of PMTCT
- Identify the target audience
- Involve local leaders or other stakeholders
- Have clear up-to-date information and decide ahead of time what is to be discussed.
- Practice the talk before the actual meeting time.
- Try to include familiar examples, stories, songs and drama to make the talk more interesting for the group.
- Think of ways to involve community members in the discussion.
- Make arrangements on where and when the talk will be given.
- Gather people together.
- Arrive on time

How is a group talk conducted?

- Introduce yourself to the audience.
- Introduce the importance and benefits of the subject clearly and simply and ask the group for ideas on how to discuss it.
- Ask participants about the concerns they may have about the topic under discussion
- Use questions to get people to participate.
- Explain the need for everyone to have a chance to talk.
- Show concern for the group members and value their opinions.
- Encourage the quieter ones to also have their say.
- Encourage the group to speak freely; do not stop, interrupt or argue with them.
- Listen respectfully to members in the group when they offer comments or ask questions and respond nicely. Respect everyone's ideas and try not to judge.
- Help make points clearer to the group.
- If participants have questions, ask other participants if they can help to answer those questions as a way to stimulate discussion.

- Give correct information and gently correct any misinformation people have. Clarify what is unclear to the group to make sure that everyone understands the topic well.
- Try to resolve disagreements and avoid taking sides; you are there to assist, not to get in the way with your own opinion.
- Help identify specific problems and solutions by recommending concrete actions/behaviours that participants might consider taking.
- Reinforce what participants are already doing well.
- Answer all questions and, if you don't know the answer, find it and get back to the group and/or person who asked it.
- Summarise important points.
- Ask participants about the behaviours that they think they can try for themselves. Encourage them to try these behaviours and to share their experiences and fears.
- If the service being discussed is within the health centre and can be given right away on the same day, (example: VCT), encourage them to go for the service after the discussion.
- Before ending a meeting, ask members if they are happy with the group talk, if they have learned something, and if they have any suggestions for making the talk better.
- Be sure to tell people that they are welcome to meet you after the meeting if they have things to discuss in private.
- Thank everyone for participating.

Media Brief

Media briefs can be used when subcontracting an agency to design materials or when sharing information on PMTCT more generally with journalists and other members of the press. They help narrow the scope of the information one wants to be shared and in making sure that information is technically accurate and appropriate.

When subcontracting an agency to produce print or broadcast materials, one has control over the messages that are to be given. In this case, a media brief provides information to a media company with specifications on what information and messages are to be conveyed in the materials. The agency and its creative experts then use the message brief for developing creative ideas on how best to convey the messages. The media brief outlines what the messages need to say and the agency or creative experts determine how the messages will be designed. It should include:

- Purpose of the messages and what one hopes to accomplish
- Description of target audience
- Overall objectives describing the desired behaviour change
- Key facts and messages around PMTCT
- Benefits to the audience to motivate their behaviour change
- Describing competition for the message, i.e. social norms which may get in the way of the desired behaviour change
- Call to action
- Communication channel, i.e. radio, newsletter, television
- Budget

When finding and reviewing an agency to assist with creative aspects of message delivery in the media, there are several steps one can take in finding and choosing the right agency:

1. Define your communication needs.
2. Identify the agencies in the area.
3. Request information about the agencies or individual's capabilities.
4. Review those capabilities against your needs.
5. Develop a short-list of qualified individuals or agencies and meet with them to determine if they would make a good fit.
6. Hire an agency.

When sharing information with journalists, on the other hand, one does not necessarily have control over what members of the media write in the end. At the very least though, journalists can be given a media brief that has accurate information from which they can generate their own stories. Press releases are often used and are basically a news story with essential information about PMTCT. Sometimes press releases are just given to journalists on paper, and other times one might choose to hold a press conference to share the press release. The elements of a press release are listed below:

- Release date from which the information can be shared.
An example might be that VCT services will be available at a particular centre from June 1st. When putting together the press release then, one might want to only release the information shortly before the VCT services are available to

make sure that people don't come too early to the health centre when it is not yet available.

- **Headline**
This should summarise the main findings in a striking way that gets the attention of a potential reader.
- **Lead**
This is the first part of the story, which should capture the attention of the reader with the most important points of the story. Additional paragraphs that follow should include other details that build on the main point.
- **Quotations**
The first part of a press release should include quotations from key people that are willing to comment on the topic of the story. Make sure that you get approval of the person you are quoting before you include their words in the press release.

A media brief may also be expanded to be included in a press kit. A press kit might contain:

- press release
- sample speeches
- fact sheets
- list of experts to interview, with their contact details
- photographs or other visuals
- websites and other references

Working with Local Radio

Radio reaches a lot of people and is a good way of communicating information. If there is a local or community radio station in the area, it's a good idea to get in touch with them to discuss ways of working together to raise awareness about HIV in general and PMTCT more specifically.

Start by going to the local radio station and discussing ideas and topics around PMTCT that might be aired locally. Negotiate when the messages will air and how much they will cost, if anything. Some ideas are listed below that may help with reaching as many people as possible with information about PMTCT.

- **Announcements**
Once a District has decided on its PMTCT activities, share the details with the local/community radio station so that they can place announcements on their station. This may help to encourage greater turn out and generate interest in PMTCT.
- **Talk Shows**
Hold a series of talk shows with invited guests, which might include some of the following:
 1. If there is a voluntary counselling and testing site in the area, ask one of the counsellors to explain the process of going for an HIV test and encourage community members to come for one by discussing the benefits of knowing your status.
 2. Invite people working in home based care projects to explain how to care for someone living with the virus and that there is nothing to fear. Maybe they can discuss how good care and attention can help those living with HIV.
 3. Invite people living with HIV and AIDS to talk openly about their status and what it is like to live with the virus. Women and their families that have used PMTCT services and have been happy with the results can help ease the fears of others that might be considering it. They can explain first hand what is involved and use their own experience to highlight the benefits of PMTCT. This may also help in reducing stigma and discrimination around issues like infant feeding options other than breastfeeding, and so on. When an HIV positive person explains situations where they have been discriminated against, it can also help others realise their own stigmatising behaviours.
 4. Invite the relatives and close friends of those living with HIV and those that have used PMTCT services to talk about how one can be supportive of a relative that has HIV.
 5. A compassionate church leader that accepts everyone into the church, regardless of HIV status, may also want to speak about how God's word can serve as an example that we should love one another and treat each other nicely. HIV is not a punishment from God, but is an illness like any other.

Message Strategies

A message strategy consists of a message statement, description of the audience, discussion points and facts, a key message with benefits, and a call to action. These strategies are useful in guiding communication activities and ensuring that there is a focused message

The messages need to be attention getting, relevant to the audience, focused, memorable, motivational, and include a call to action. One way to make sure all elements of a good message strategy are in place is to follow the 7 C's which stand for:

- Command Attention.
- Cater to the heart and head.
- Clarify the message.
- Create trust.
- Communicate a benefit.
- Call to action.
- Consistency counts.

Sample message strategies are included on the following pages but are not to be taken as a comprehensive list; they are merely examples that may be of use in PMTCT communication programmes.

Sample Message Strategy 1:

- Message statement: Know the facts about PMTCT
- Audience: Policy Makers
- Discussion Points/facts
 - What MTCT is
 - How MTCT of HIV occurs
 - Statistics: HIV in Zambia, MTCT rates
 - Services available in Zambia
- Key message with benefits: By knowing about PMTCT you can generate better plans for your constituency
- Call to action: Learn more about PMTCT

Sample Message Strategy 2:

- Message statement: Talk about PMTCT with constituents
- Audience: Policy Makers
- Discussion Points/facts
 - Facts about why it is important that people know about MTCT
 - Ideas of what to talk about
- Key message with benefits: Talking to your constituents can bring about behaviour change and reduce stigma and discrimination
- Call to action: Talk about PMTCT with constituents

Sample Message Strategy 3:

- Message statement: Promote the creation of support systems in your area
- Audience: Policy Makers
- Discussion Points/facts
 - What community support systems are like: roles, functions, membership, etc.
 - Advantages/benefits of community support systems

- Key message with benefits: Communities with support systems can better support PLHA, fight stigma and discrimination and promote healthier behaviours
- Call to action: Promote the creation of support systems in your area

Sample Message Strategy 4:

- Message statement: Use your position of influence and authority to promote PMTCT activities
- Audience: Leaders
- Discussion Points/facts
 - What are the potential community PMTCT activities
 - What you can do to help (advocacy type activities)
- Key message with benefits: You will see the changes and health improvement in your community if you use your position of influence and authority to promote PMTCT activities
- Call to action: Use your position of influence and authority to talk about and promote PMTCT activities

Sample Message Strategy 5:

- Message statement: Go for VCT to know your HIV status
- Audience: adults of reproductive age
- Discussion Points/facts
 - HIV prevalence, risky behaviours
 - What is VCT
 - Where services are to be found
 - Why it is important/benefits
- Key message with benefits: Knowing your status will help you to know how to live a longer, healthier life. Sample slogan: "VCT promotes life- go for it!"
- Call to action: Go for VCT to know your HIV status

Sample Message Strategy 6:

- Message Statement: Practice safe motherhood behaviours
- Audience: Men & Pregnant Women
- Discussion Points/Facts:
 - Deliver with a skilled attendant
 - Who is a skilled attendant
 - Benefits
 - Importance of early antenatal care
 - Safe motherhood behaviours
- Key message with benefits: Practising safe motherhood behaviours will help you to prevent HIV transmission to your baby
- Call to Action: Talk to your health care provider about safe motherhood

Sample Message Strategy 7:

- Message Statement: Practice child survival behaviours
- Audience: Parents and caretakers
- Discussion Points/Facts:
 - List the healthy child survival behaviours: immunisation, infant and young child feeding, growth monitoring and promotion, malaria prevention, good health seeking behaviours, etc.
- Key Message with benefits: Practising healthy child behaviours leads to a strong and happy child
- Call to Action: Talk to your HW; Practice those behaviours; Take your child to the nearest health centre regularly

Formative Research

Formative research is a general term describing an investigation conducted for programme design and planning. It helps programme planners and implementers to capture information about knowledge, attitude and practices within a given community.

Formative research often follows a step by step approach by: defining the problems or issues around PMTCT; identifying simple and effective actions within a community or family that will improve the success of PMTCT interventions; testing those practices or behaviours to determine if they are feasible and culturally acceptable; and then develop an effective strategy to promote PMTCT within the community.

Formative research can be done through qualitative and quantitative research methods. Qualitative research includes information gathering and exploratory research through open-ended questions. This type of research is based on techniques that try to get at the basis for people's behaviours and current norms and practices in a community. Since this document is focusing on PMTCT, questions might relate to how men and woman feel about going for VCT, their attitudes on breastfeeding practices and what is seen as the cultural norm, community views about delivering babies with a skilled birth attendant, and so on. While there are other methods to conduct qualitative research, focus group discussions and in-depth individual interviews are often used in gathering information. Each of these methods is described in more detail below.

Focus Group Discussions (FGDs):

A skilled moderator must conduct FGDs with a small group of participants with similar characteristics. As the name states, an FGD is a guided discussion with a small group of people ranging in size from about 6-15 people to explore insights into a focused and narrow topic area. The method relies on group dynamics and the ability of people to participate fully and share their opinions.

In-depth Interviews:

These interviews are one-to-one discussions between a person and an interviewer with a set of questions. The interviewer is responsible for asking the questions and, after the person being interviewed answers, for probing the person further to gain insights into what the person provided. Often the interviewer is able to get further detailed information and explanations in a one-to-one interview than in a FGDs since the interview is only with one person at a time. Sometimes when a person is answering questions in a private way, they are able to say more on certain sensitive topics than they could otherwise do within a FGDs.

Quantitative data collection is based on surveys with structured questionnaires or estimates to quantify conditions. It is usually based on random sampling and analysis involving statistical tests. For the purpose of this document, qualitative research is the primary focus for learning about a community's knowledge, attitudes and practices as they relate to PMTCT.

The following five pages includes part of a sample question guide which may serve as a basis for thinking about conducting formative research in your area. It is only one example, there are many others available, but at least it may serve as a starting point for designing your own question guide.

Formative Research—Sample Question Guide¹

Focus Group Discussion Guide

Group composition:

- Women of child bearing age (with children <2 years)
- HIV positive women (if possible)
- Men of unknown status
- HIV positive men (if possible)
- Community (neighbourhood Health Committee, etc.)

Topics:

1.0 Infant feeding practices.

- 1.1 Infant feeding practices
- 1.2 Alternatives to breastfeeding
- 1.3 Other infant feeding options

2.0 HIV and related issues:

- 2.1 General issues related to HIV
- 2.2 General issues related to HIV counselling and testing
- 2.3 General issues related to transmission of HIV from mother to-child

3.0 Optional Discussion Topic

6-8 members per group. Two groups per segment, if possible.

Format

Introduce the moderator and note-taker. Explain that we are here to learn more about infant feeding and HIV. We want to learn from them to better develop a program to improve the quality of care in health and community services in relation to infant nutrition and prevention of mother– to- child transmission of HIV, as well as for the general population. Explain the ground rules for the meeting (***These are covered during training and role-plays***) - that the discussion will last 1 to 1.30 hours; that everything they say will remain confidential and their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the discussion.

Trials:

Discussion guides, notepads, pens, tape recorder, tapes, batteries, beans, bottle tops.

¹ Sample provided by Kabwe District Health Management Board & AED/Linkages

Topic 1: Infant Feeding

1.1 Breastfeeding practices

- a. How long do mothers usually exclusively breastfeed their babies in this community?
- b. What would help mothers to exclusively breastfeed?
- c. At what age do women stop breastfeeding in this community?
- d. What other reasons are given for stopping breastfeeding early.
- e. Are there any reasons for weaning a baby (earlier than usual)?
PROBE for illness in the mother, HIV.
- f. Do you think that women who are infected with HIV should breastfeed their babies? Why? Why not?
- g. How would a woman make this decision? Who/what would influence her?
- h. What is the correct time to introduce complementary foods?

1.2 Alternatives to breastfeeding

- i. Now let us talk about alternatives to breastfeeding.
 - a. Are there women in this community who do **not** breastfeed? Why not? (*Is HIV/AIDS mentioned*)?
 - b. How do these women feed their babies? (**PROBE for wet-nursing practices, use of formula, or non-human milks**)
 - c. Are there babies in this community that were not ever breastfed? Why not? **PROBE to see if orphans are mentioned; mothers with HIV/AIDS.**
 - d. What has happened to these non-breastfed babies? Are they healthy? Do they survive, grow and develop like other children? **PROBE about psychological as well as health/nutritional needs of non-breastfed babies.**
- ii. Now let's talk about what happens in this community if a baby cannot be breastfed for various reasons
 - a. What are the reasons a mother would not breastfeed her baby? **PROBE about illness, separation, and other reasons.**
 - b. What does the baby feed on to replace breastfeeding?
 - c. Who feeds and cares for the baby?
 - d. What services, if any, are available in the community to help families with this problem/decision of feeding the baby?
 - e. What do people say or think about a woman who does not breastfeed (by choice or other necessity as mentioned above)?
- iii. Now let's talk about babies whose mothers have died.
 - a. Are there many young infants (< 1 year old) whose mothers have died in this community?
 - b. What happens to them? Who cares for them?
 - c. Who is responsible for providing them with food? What/how are they fed?
 - d. What happens to the baby if its father dies?
 - e. What services are available to help care for orphans in this community?

1.3 Other feeding options

- i. Introducing liquids and solid foods
 - a. At what age do women (not necessarily HIV-infected) typically introduce other liquids to their babies?

- b. What liquids are given?
 - c. Do mothers give water to babies who are below 6 months of age? Why?
 - d. How often during the day/evening?
 - e. How are these liquids given? How often? And how are they given? (in cup, for example)
 - f. Why are liquids introduced?
 - g. Are there any dangers in introducing liquids and solids early?
 - h. How do you know that a baby is ready for solid foods? PROBE for cues and milestones that are recognised (e.g., specific ages, teeth, sitting, crying, reaching for food, etc.)
 - i. At what age are semi-solid foods first introduced to babies?
 - j. What are the first foods typically given to young babies? PROBE for name, ingredients, and consistency.
 - k. How are these foods fed? PROBE for use of separate plate, cups, by hands, other utensils.
 - l. During the day, how often do you prepare foods for your children (< 2 years old)?
 - m. How often do you give them food? PROBE about main meals, other times.
- ii. Feeding Style and active feeding issues:
- a. How do mothers/care givers know how much food to give a baby (or how much a baby can eat at one sitting)? **PROBE for how a mother knows that the baby has eaten enough; are specific quantities recognised).**
 - b. How does a mother encourage her baby to eat more?
 - c. What does it mean to you when a baby does not want to eat?
 - d. What can be done in this circumstance? PROBE to see if they would go to the health clinic, participate in monitoring growth, consult others about the problem/who; suspect illness/give multivitamins.
 - e. What are the signs of a healthy baby? PROBE for descriptions related to growth, size, and activity.
 - f. What can a woman do to ensure that she has a healthy baby (what are practices, things within her control)?

Topic 2: HIV /AIDS and related issues:

2.1 General issues related to HIV/AIDS

- i. We would like to begin our discussion with the disease known as HIV/AIDS.
 - a. What do we know about HIV?
 - b. What do we know about AIDS?
 - c. Who is affected by it?
 - d. What is AIDS called in this community? (Record names, relevant characteristics)
- ii. Now let's talk about how the disease is spread.
 - a. Who can tell us about how is HIV transmitted (in this community)? **PROBE and note if mother-to-child transmission is mentioned.**
 - b. What do people do here to prevent getting infected with HIV?
 - c. How likely is a woman contracting HIV from her husband/partner in this community?
 - d. How likely is a man contracting HIV from wife/partner?
- iii. Sources of information on HIV/AIDS

- a. Where have you heard about HIV transmission? **PROBE on all sources:**
 - Media (which, what said)
 - Family members (who, what said)
 - Health system (who, what said)
 - Community HIV/AIDS organisations (who, what)
 - Other infected family members/friends
- b. What do these sources say about HIV and how to prevent transmission of the virus?

2.2 General issues related to HIV counselling and testing

- i. Familiarity with the HIV test.
 - a. How can people tell if someone is infected with HIV? **PROBE** and note if testing is mentioned.
 - b. If testing not mentioned, ask if anyone has heard of testing for the HIV?
 - c. Do you know anyone who has ever been tested for HIV?
 - d. How did you come to know?
- ii. Willingness to get tested and find out about personal status.
 - a. Where HIV testing can be done in this community?
 - b. If available would you have an HIV test? Ask why/why not.
 - c. How would you decide on whether to be tested?
 - d. Whom would you consult before testing? What factors would influence this decision?
 - e. If you got an HIV test, would you come back to find out about the results of the test? Ask why/why not. **PROBE about factors that would facilitate or hinder getting this information.**
 - f. Once you found out the results, would you tell anyone? Who? Who would you not tell?
 - g. Do you know anyone who has received any counselling about HIV prevention and/or treatment? Where? From whom?
- iii. Imagine that you have been tested and the results were positive.
 - a. What would you do?
 - b. Who would you turn to for advice and assistance? Who would you NOT turn to?
 - c. Would others in your family want to get tested too?
 - d. When someone finds out that he/she is infected with HIV, how would his/her family react? Would his/her family support him/her? Would the family treat him/her differently? What about the spouse (husband, wife)?
 - e. Is one's HIV status a private or public issue - something that is well known or guarded information? Why?

2.3 Mother-to-child transmission of HIV issues

- i. Now let's talk about one way that HIV can be transmitted, from an infected mother to her child. *Please make reference to 2.1.ii: Remember the discussion on how the disease is spread.*
 - a. Has anyone ever heard of transmission of HIV from mother to child?
 - b. How does this happen?
 - c. In general, do you think **all children from HIV** infected mothers will be infected by the virus?

d. If not how many children do you think will be infected out of 10 born of these mothers (then show 10 beans) explain that all these women have been tested and are HIV positive, How many children will be infected during:

- 1. Pregnancy.....out of 10**
- 2. Laborout of 10**
- 3. Through breastfeeding.....out of 10**

- e. Do you think that HIV transmission through breastfeeding is common in this community?
- f. Consider a time when you are/were pregnant. If you got tested for HIV and found out that you were HIV-positive (infected), what would you do about infant feeding?
- g. Would you breastfeed your baby?
- h. **If yes why** would you breastfeed? (Explain)
- i. **If no**, why not?
- j. How would you feed your baby?
 1. With what?
 2. Who would assist?
 3. How would this decision be reached?
- k. If a mother is not breastfeeding what would be the reaction of the husband, family, community?
- l. Imagine you are infected with HIV, would you want to have more children? If yes, why?

ii. Mention all interventions that can be used to reduce mother to child transmission of HIV

Are Antiretroviral drugs mentioned? If No ask:

1. Have you heard about the use of drugs to reduce transmission of HIV from an infected mother to her child? If yes, mention two.

2. Are there any cultural-traditional beliefs that will influence women not to take these drugs during:

- 1. Pregnancy**
- 2. Labour and delivery**

3.0 Optional Discussion Topic:

What are the common causes of death among children in this community (Rank Them)

- A baby dying from diarrhoea
- A baby dying from malaria
- A baby dying from tuberculosis
- A baby dying from **not** being breastfed
- A baby become malnourished

Site Preparedness

The process of site preparedness begins either through a bottom up approach when a DHMT makes a request to the Government and/or an implementing partner or through a top down approach when CBOH chooses to expand into a particular district.

A district implementing partner or representative from CBOH will make joint visits to health facilities to arrive at consensus by conducting assessments to determine how and when the introduction of PMTCT may take place. A checklist is often used for this assessment. A sample checklist for communication activities is attached on the next page. Items often taken into consideration in a checklist include:

- Size of catchment area population and number of zones
- Functionality of Health Centre & services being provided: VCT, ANC, Labour & delivery, Postnatal Care, Child Health follow up including immunisation, Outpatient and Curative services, Youth Friendly services, etc
- Health Education registers
- Community groups available; location, number, availability of TBAs, NHCs, CHWs; activities; level of involvement
- Staffing & Training within health centre: trained nurses, NHCs, EHTs, counsellors, etc.
- Structure of health centre: number of rooms, location for deliveries, counselling, waiting rooms, laboratory facilities, etc.
- Materials available for communication activities
- HIV/AIDS Activities: sensitisation, health talks, promotion of VCT, etc.
- Existence of PMTCT programme; communication component; activities around PMTCT; Needs assessment & formative research completed

The DHMT will propose sites to the implementing partner after discussion and assessments including social mapping exercises and the like. Communication is central to site preparedness as any PMTCT programme cannot be fully successful without ongoing communication with the community in which PMTCT activities are introduced and ongoing.

A communication group should be established that includes a focal point person based at the DHMT. This person is often the health promotional specialist. There should also be a person at the health centre to act as a link with ties into the community. The “site co-ordinator” should also be a member of this group, working closely with the focal point person at the DHMT and the focal point person at the health centre. The DHMT focal point person, the site co-ordinator and the health facility focal point person will also belong to a subcommittee on PMTCT for the District HIV/AIDS Task Force.

A sample tool is provided on the following pages that may be of use. This example can serve as a sample from which to design something similar or use the parts that are relevant to communication questions in your community.

Site Preparedness—Sample Question Guide²

1. Do you have a PMTCT programme?
2. Does the PMTCT programme/strategy integrate a communication component?
3. Is there a PMTCT Communication working group? Who participates in it? What skills do the members have?
4. How is the implementation of the communication component of the PMTCT monitored?
5. Who has accountability for the implementation and monitoring of the communication component of the PMTCT strategy?
6. What indicators are utilised to monitor PMTCT communication activities?
7. What are the main communication activities for PMTCT?
8. Have the activities, messages, materials been developed on the basis of research data? Which data? What research?
9. Are health education registers kept?
10. What are the main barriers/obstacles to the uptake of the different components of PMTCT services by pregnant women?
11. How do women, couples, families, communities receive information on the risk of MTCT and on the availability of MTCT preventive services?
12. Are the communities involved in PMTCT programmes? How?
13. Are there community-based mechanisms for sharing information, stimulating discussion around PMTCT?
14. Are the local leaders (religious, traditional, NHCs, TBAs, political) involved in PMTCT promotion / information sharing / facilitation of discussion? How?
15. Are there community-based mechanisms to support women, couples/families chosen infant feeding options?
16. What follow-up support, counselling, OIT is available at community level for HIV-positive women who have enrolled in the programme and their partner/family? How is this organised?
17. Is the mass media (television, radio, newspaper etc.) involved in sharing accurate information and motivating women/couples to enrol in the programme? How?

² Adapted from the UNICEF Baseline Assessment Tool for PMTCT Communication Planning

18. Are organisations within the civil society (NGOs, CBOs, private sector, trade unions, youth organisations, women organisations, religious organisations, etc.) involved in providing services, information, facilitating debate, providing counselling, funds on PMTCT?
19. What materials have been developed? For whom? How are they disseminated and utilised? Have they been pre-tested? Has their impact been monitored/evaluated?
20. What are the main successes/strengths of the PMTCT communication programme? What lessons have you learned so far?

Community Entry Protocol

There are several steps one might take in working with communities in the introduction of PMTCT services. The following outline may serve as a guide for community activities and buy-in for the promotion and use of PMTCT services. The overall aims are to empower and promote partnership with the community while also creating awareness among the entire community. The following may improve co-operation between health workers and community members:

- _____The DHMT shares information on the introduction of PMTCT services with the in-charge at the health facility.
- _____DHMT together with the in-charge then meet the health centre committee.
- _____The health centre committee calls for a meeting with all the Neighbourhood health committees.
- _____The meeting should include representation from all zones including CBOs, CBAs, etc.
- _____Explain the PMTCT programme: what it is, how it will be done (health education/counselling), importance and benefits, etc.
- _____Discuss the different roles that can be played among those community leaders at the meeting.
- _____Choose a day to hold a meeting for all stakeholders.
- _____Identify other influential leaders to work with to form a stakeholders meeting. Be sure to capture every organisation in the catchment area.
- _____Brief the leaders about the programme as was done in the meetings with NHCs, CBOs, CBAs and enlist their support. Once they are supportive, agree on the roles and responsibilities for each.
- _____Identify gatherings and groups such as schools, churches and markets with traditional leadership roles to begin to promote the idea of PMTCT.
- _____Identify groups that can play a pivotal role in sharing information and be trained in PMTCT awareness creation, i.e. drama groups, youth groups, anti-AIDS clubs, men's groups, church groups, etc. and integrate PMTCT and infant feeding content in the activities of those selected groups wherever possible.
- _____Develop the capacity among these groups and leaders to conduct meetings in the community.
- _____Work with the various groups to identify and train trainers and supervisors to facilitate PMTCT and infant feeding activities in the various groups. Stimulate formation of groups to work with, where suitable ones do not exist.

- _____ Orient them on:
 - What is the whole PMTCT package
 - Services that will be provided
 - What are the benefits
 - How to encourage care & support for those using PMTCT services
 - How to encourage male involvement
 - How to work with and orient the community

- _____ Work with leaders to develop procedures and processes of working together.

- _____ Strengthen cross referral between health facilities and the community.

- _____ Conduct awareness talks in the community while also watching for myths and misconceptions that may appear in the community surrounding PMTCT. It is important then to give correct information and dispel myths as they arise.

- _____ Maintain frequent and on-going contact with the community to discuss successes within PMTCT programmes as well as to share problems and issues as they arise.

A sample tool is provided in the next few pages that may of use in working with communities.

Community Dialogue Tool—Sample₃

DIRECTIONS FOR USE

This Community Dialogue tool was designed to support the development of a community engagement/ behavioural change strategy for these programmes. It can also be adapted to address any community-based issue that requires a local solution.

The Community Dialogue tool can help programmes to achieve several aims: 1) to stimulate dialogue about local HIV/AIDS-related issues that may be difficult to discuss at first; 2) to help communities to identify local sources of risk and vulnerability to HIV; 3) to help communities to discuss how HIV affects local people's lives; and 4) to assist communities to define realistic ways to create more supportive environments to prevent HIV infection and to care for HIV-affected families.

Community Dialogue is a powerful tool to help communities to identify existing community-based mechanisms that have previously been successful in problem solving. Using those mechanisms, communities can overcome stigma and discrimination towards people living with HIV/AIDS and begin to create support systems for HIV-affected families.

Finally, this latest version of the tool adds exercises from field experiences in India. The exercises should be easy to adapt to make them relevant to local communities. *For maximum participation, these exercises should be conducted with groups of 8-to-15 persons, not more.*

OPENING ICE BREAKER

INTRODUCTION OF COMMUNITY PARTICIPANTS & OPENING REMARKS

Objective: Icebreaker for participants and facilitators to get to know each other; brief overview of the day from lead facilitator

Time: 30 minutes

Method: Participatory session using paper chits

Materials: Container (hat, large can or bowl for holding the pieces of paper)
Pieces of paper (1 per person) – write on each piece of paper, half of a famous film or song title on it (e.g.: 1 piece of paper says “Hari Rama” and another piece says “Hari Krishna” for the film “Hari Rama, Hari Krishna”)

INTRODUCTION:

Put the paper chits into the container and mix well. Pass the container around the room and ask each participant to take one piece of paper out of the container.

Tell the participants that they have 5 minutes to get up and go around the room quickly until they find the person who has the other half of their film or song title.

³ Communication for Prevention of HIV in Pregnant Women, Mothers and Children (UNICEF)

When they find the person they should pair off and learn three things about each other:

1. Name
2. What they do (home-maker, teacher, carpenter, etc.)
3. Their favourite food or pass time or one good thing about themselves

After 5 minutes, have each person around the room introduce his/her partner to the group.

Facilitators can also play if desired.

SESSION 1

DEFINING EXISTING COMMUNITY CHANNELS THAT LEAD TO SUCCESSFUL OUTCOMES

Objective: The community will identify and define the existing community-based channels that lead to successful outcomes.

Time: 1.0 – 1.5 hours

Method: Open discussion

Materials: None.

But facilitators can prepare to use VIPP cards if participants are shy or not responding. VIPP cards provide a flexible way to organise participants' different points of view on a wall for participatory presentation, discussion and summaries. (See Annex 2) If groups have low literacy skills or mixed literacy, then participants can rely on the literate members of the group or make drawings or simply work without visuals.

INTRODUCTION:

Explain to the group that you will now be taking them through some group exercises.

Begin the discussion by explaining that you would like to spend the day listening to the community talk about their experiences in addressing social issues and learning from them how they successfully support various community-based activities.

The group will then identify ways in which they can actively participate in providing or creating a supportive environment for PMTCT & HIV/AIDS prevention, care and support activities within their community for families affected by HIV.

Begin the process by asking the group to identify some of the best things about their community. Then ask the following questions in the exact order below.

NOTE: *Please note that these questions are designed to build a story so if they are asked out of order it is possible you will wind up with a lot of pieces of community information, but no story.*

WRITE QUESTIONS & ANSWERS ON FLIPCHART.

Let's talk about how you feel about your community. What are the best things about living in this community?

For example, it's close to the marketplace, has good medical facilities, people pull together for common causes, etc.

What have been some successful community-based activities in this community?

For example, have they had any events that have been particularly successful (sanitation competitions, immunisation days campaigns, religious/spiritual gatherings, etc.)? Which ones? What results did they see?

What are the reasons those activities were successful?

Explore the specific causes for these initiatives, campaigns, and competitions being successful.

Who were the organisations, committees, community groups and/or individuals that made these activities successful?

Explore and identify who participated in these activities – Was it local NGO/CBOs, PTA, Teachers, extension committees, local religious leaders, multi-sector groups, traditional leaders (chiefs, headmen, healers...), community-based health workers, etc.?

Why were these groups and/or individuals able to pull the community together?

What is it about these people that they can mobilise the community when others may not be able to? What qualities do they have? What process do they use to get people mobilised?

What are some of the most pressing problems in your community? Have you dealt with any of them successfully? If yes, how?

EXAMPLE: *How does the community deal with alcoholism? Does the community provide assistance to families of alcoholics? Explore what are the factors that drive a person to drink too much. Then, if HIV/AIDS is identified as a pressing problem, explore with the group the factors that might lead a person to have sex outside his/her primary relationship. Are they similar to the factors that cause someone to drink too much? Why is it that the community is supportive of alcoholics but not of those people affected by HIV/AIDS?*

SESSION 2A

QUESTION AND ANSWER SESSION ON HIV/AIDS

Objective: To enable community members to clarify their knowledge and increase their correct understanding of basic issues related to HIV/AIDS

Time: 1.0 hour

Method: Group discussion, group work & case studies & VIPP (if needed)

Materials: *Flipchart paper, markers (red, blue, green & black), VIPP cards.*

VIPP provides a flexible way to organise participants' questions into similar categories that everyone can see. (See Annex 2)

Note: You can first try to do this in an informal open discussion group without VIPP. If you find that the participants are too shy to ask questions in front of others, you can pass out VIPP cards and have every person write one question they have about HIV/AIDS on the cards. Then you can answer them in front of the group.

INTRODUCTION:

- A. Ask the community members the following questions:
“Have you heard about HIV and AIDS? What have you heard?”
Clarify any misunderstandings, myths or misconceptions.**
- B. Usually you will get enough of a discussion going with those two questions, that you won't need any special games or exercises. However, if the group is not participating or, if the facilitators feel participants are uncomfortable asking questions in a group setting, you can revert to using VIPP cards. Simply pass out cards (all cards should be the same size, shape and colour) and black markers to everyone and use one of the two options:**

- 1. Ask them to write down one question they have about HIV and/or AIDS.**
- 2. Finish the sentence “HIV/AIDS makes me feel _____.”**

Then collect the cards and begin discussing each question or feeling. Usually there will be similar questions and once the discussion gets going people usually tend to be more comfortable asking additional questions.

NOTE: If some participants are illiterate, you can assign small working groups (2-4 people per group) to compile questions and have one literate person write the questions or feelings on cards.

SESSION 2B

WHAT IS PREVENTION OF HIV TRANSMISSION IN PREGNANT WOMEN, MOTHERS AND THEIR CHILDREN (PMTCT)?

Objective: To enable community members to clarify their knowledge and increase their correct understanding of basic issues related to PMTCT.

Time: 1.5 hours

Method: Group discussion, group work & case studies & VIPP (if needed)

Materials: Flipchart paper, markers (red, blue, green & black), VIPP cards (enough for working groups of 5+ people, depending on number of participants).

VIPP cards provide a flexible way to organise participants' different points of view on a wall for participatory presentation, discussion and summaries. (See Annex 2) If groups have low literacy skills or mixed literacy, then participants can rely on the literate members of the group or make drawings or simply work without visuals.

PROCESS:

Part I

A. Give each working group one case study scenario from the box below. Ask them to discuss in a group and write down their thoughts, ideas and suggestions on how each case would/should be handled. After 30 minutes, each working group will present its ideas to the entire group.

Suggested Case Studies:

1. Newly married couple, both HIV-positive, would like a child. What should they do?
2. HIV-positive husband, HIV-negative wife, 2 year old daughter with unknown HIV status. Would like to have a boy child. What should they do?
3. Pregnant woman goes to the ANC and receives counselling on HIV and decides she must go home and consult with her family on whether or not she should take an HIV test. What does the family do? What should the family do?
4. HIV-positive husband is dying, HIV-positive wife is pregnant and in-laws are throwing her out of the house. What will the family do? What should the family do?
5. An HIV-positive woman is unmarried and 2.5 months pregnant. What should she do?

Suggested Time: 30 minutes for group work on case studies
30 minutes for group presentations and group discussion

Part II

B. After the group has finished discussing the case studies, a qualified counsellor for the program to prevent HIV transmission in pregnant women, mothers and their children should be available to give an overview of the program, including the service components and the benefits. After briefing the group on these issues, open the discussion up for general Q&A on preventing HIV transmission in pregnant women, mothers and their children.

NOTE: Usually the group will have many questions (including on HIV/AIDS generally). You will have to decide when to end the discussion because typically an entire day could be devoted to just Q&A on HIV/AIDS and preventing HIV transmission in pregnant women, mothers and their children. If the group appears to have many more questions, the facilitators can offer to schedule a follow up meeting to continue the Q&A session.

Suggested Time: 30 minutes (more time is suggested, if schedules will allow)

SUGGESTED BRIEFING POINTS FOR COMMUNITY DIALOGUE MEETINGS:

Based on their level of correct knowledge and awareness, give a brief description of the basic components of the services to prevent HIV transmission in pregnant women, mothers and their children, from beginning to end including:

1. The services begin at the ANC clinic where pregnant women are provided with pretest counselling. If the woman chooses, she can receive an HIV test. The benefits of knowing one's HIV status are quite important, especially if a woman is pregnant. If she is negative, the woman will receive counselling on how to remain negative, including couples counselling and testing for both her and her partner, if they want it. Condoms will be offered to support the couple to remain negative. If a woman tests HIV-positive, she will be offered services to prevent transmission to her child.
2. These services include:
 - ◆ Voluntary CONFIDENTIAL counselling & testing (*make sure people understand what 'confidential' means*), including condoms to prevent re-infection.
 - ◆ Special drugs for the mother, to reduce the chances of spreading the HIV to her baby before birth. And special drugs for the baby immediately after birth, to further reduce the chances of becoming infected with HIV.
 - ◆ There are also special procedures that are followed during delivery to further reduce the chances of the HIV virus passing from mother to baby during birth.
 - ◆ Counselling is also provided to HIV-positive mothers so that they can determine the best type of infant feeding method for their particular situation. For some HIV-positive women exclusive breastfeeding will be the best option for infant feeding, and for other HIV-positive women exclusive replacement feeding will be the best option. Only counselling by a trained PMTCT counsellor will be able to help a woman (and her family) decide which method is best for her individual situation.
 - ◆ Drugs for opportunistic infections are provided for mother and baby. Sometimes these drugs are also provided for the father if he is HIV-positive. Although special anti-AIDS drugs are not yet available for the mother and father, there are plans to bring those drugs into the program as they become available and affordable.
- Follow up services for the mother and baby.

ENERGIZER

THE FOX & THE LAMB

Objective: To enable community members to experience feelings of community protection and commitment to one cause.

Time: 15 minutes

Method: Group activity

Materials: None

PROCESS:

- A.** The lead facilitator will ask for volunteers – one to play the fox and one to play the lamb.
- B.** Send the “fox” to wait outside the room for a moment. Meanwhile, the “lamb” stands in the centre of the room, while all the participants join hands in a circle surrounding the lamb. When the group is ready, call the fox back into the room.

The objective is for the group to protect the lamb by not allowing the fox to enter the circle. If the fox gets into the circle the group should let the lamb out of the circle, thus trapping the fox in the middle. At this point, the game is finished.

The facilitator should end the game by creating parallels between the game and HIV/AIDS.

MORAL 1: The lamb symbolises the community and the fox symbolises stigma and discrimination. The moral is that we must protect our community from stigma and discrimination by coming together for one common goal – creating a more supportive environment for those affected by HIV and AIDS and protecting them from stigma and discrimination.

MORAL 2: Another moral that can be used is that the lamb represents the community and the fox represents HIV/AIDS. Only by joining hands and coming together can the community keep HIV/AIDS out of their community.

SESSION 3

CREATING A MORE CARING & SUPPORTIVE ENVIRONMENT FOR HIV-AFFECTED FAMILIES

Objective: To enable community members to brainstorm on realistic, sustainable ways in which they can begin creating a more caring and supportive environment for HIV-affected families.

Time: 1.5 hours

Method: Group discussion, group work & VIPP (if needed)

Materials: Flipchart paper, markers (red, blue, green & black), VIPP cards.

VIPP cards provide a flexible way to organise participants' different wishes on a wall for participatory presentation, discussion and summaries. (See Annex 2)

Preparation: Draw a house or a map, or use an actual map of the community you are working with. Fold up the drawing or map into a medium or small sized square. Then wrap it with another piece of paper so that you cannot see the map at all. Draw a lamp or other magic talisman on the paper square.

PROCESS:

Part 1: The Magic Lamp Suggested Time: 20-30 minutes

Tell participants that the paper square represents a magic lamp. Ask each participant (facilitators can participate if they want to) to make one wish out loud as they hold the magic square:

They should be wishing on what they would like to do – or what they would like their community to do – to create a more supportive and caring environment for HIV-affected families in their community.

Pass the magic square around the room and as each person makes their wish, a facilitator should be writing all the wishes down on VIPP cards or on flipchart paper.

After everyone has made their wishes, ask the participants “to whom do they think they are making their wishes?” Then ask one participant to open up the magic square, revealing that the participants are wishing for the community to make these things happen.

Part 2: Creating solutions to improve community support for HIV-affected families

Suggested Time: 1.0 – 1.5 hours total
(30 - 60 minutes to brainstorm
30 minutes to present to entire group)

PROCESS:

- A. Ask participants to break into their working groups and continue brainstorming on how they can make their wishes for a more caring and supportive environment come to life. Remind them to be realistic and to assume there is no external money for these activities so they must come up with creative solutions based on the capacity and resources they have already in their community.
- B. Remind the groups that they should refer back to the morning session where they identified successful channels within their community and try to utilise those channels for their plans to address stigma and discrimination within the community. Suggest that they consider if there are ways to link these activities to the program to prevent HIV transmission in pregnant women, mothers and their children – without jeopardising the woman's right to confidentiality.
- C. If there is some type of training or skills enhancement that they would need to enhance their proposed activities, they should make note of that so that the

facilitating NGO can determine how to assist the community in meeting those needs.

The emphasis should be on existing resources within the community, to ensure sustainability and community ownership.

Ideas and plans should begin with “We will”, not with “Agencies should...”

NOTE: If solutions cannot be developed because further community dialogue & community consensus must take place, then skip to Session 4 and ask the groups to draft a series of “NEXT STEPS” so that they can move towards developing concrete activity plans during a series of future meetings.

SESSION 4

COMMUNITY DIALOGUE MEETING WRAP UP

Objective: To enable community members to have a clear action plan for simple “Next Steps”

Time: 1 hour

Method: Group discussion, VIPP (if needed)

Materials: Flipchart paper, markers (red, blue, green & black), VIPP cards. VIPP cards provide a flexible way to organise different participants’ next steps on a wall for participatory presentation, discussion and summaries. (See Annex 2)

PROCESS:

A. Based on the presentations by the community in Session 3, ask the group to draft a list of “Next Steps” to move their ideas forward. Try to get a confirmed date for a follow-up meeting, and ask the group to set realistic, achievable goals between now and then.

E.g.: Does the group need to have a larger community meeting to gain consensus from all community members? Does the group require any technical assistance or training? Can each participant commit to bring more community members to the next meeting?

B. Facilitators should close the meeting and allow the participants to make closing remarks if desired. In some meetings, it has been common for the group to conclude the meeting with a group oath to work towards a common goal of reducing stigma within their community. Try to encourage the participants to make a commitment to a common goal before they depart to foster ownership and team building.

Annex 1. Community Dialogue Meeting

Sample Agenda Outline

8:30 – 9:00	Introduction of Participants & Facilitators	
9:00 – 10:30	SESSION 1: CHANNELS THAT	DEFINING EXISTING COMMUNITY LEAD TO SUCCESSFUL OUTCOMES
10:30 – 10:45	<i>TEA BREAK</i>	
10:45 – 11:45 HIV/AIDS	SESSION 2A:	QUESTION & ANSWER SESSION ON
11:45 – 1:15PM	SESSION 2B:	WHAT IS PMTCT?
1:15 – 2:00PM	<i>LUNCH BREAK</i>	
2:00 – 2:15PM	ENERGIZER :	THE FOX & THE LAMB
2:15 – 3:45PM	SESSION 3:	Creating A More Caring & Supportive Environment For HIV-Affected Families
3:45 – 4:45PM	SESSION 4:	COMMUNITY DIALOGUE WRAP UP - NEXT STEPS

Annex 1. Visualisation in Participatory Programmes (VIPP)

Basic principle: Use (coloured) cards to visualise ideas.

VIPP Rules:

- ✓ Write one single idea per card so that ideas can later be grouped
- ✓ Write a maximum of 3 lines per card
- ✓ Use key words instead of complete sentences
- ✓ Write in large letters, beginning each word with a CAPITAL letter and completing it with small letters so that words can be read from a distance of 10 metres
- ✓ Write legibly using the thick part of the marker, not the point
- ✓ If we establish a colour code for different categories of ideas, use it

Advantages of VIPP:

- ◆ Lots of good ideas in a short time
- ◆ Allows rapid display of concepts for all participants through visualisation
- ◆ Ensures the anonymity of participants
- ◆ Allows democracy: each and every participant can contribute his/her ideas resulting in -more consensus, sharing-less arguing and misunderstanding
- ◆ One idea per card allows grouping of ideas according to the needs of the task: nothing is fixed in stone

Uses of VIPP:

- Development of problem trees
- Country programme planning
- Planning for community mobilisation

- Development of a training curriculum
- Design of print or audio-visual materials to support communication
- Planning of a research study
- Use of results of a study for planning messages and strategies

Monitoring & Evaluation Tools

Monitoring

Monitoring is a very important activity in measuring the ongoing success of any PMTCT intervention. Plans for monitoring activities must be planned for at the beginning and must focus attention on process, performance and outcomes. It is important for:

- Tracking the implementation of planned activities and outputs;
- Assessing how messages, education materials and other inputs are being received and how acceptable they are;
- Measuring whether your inputs are achieving your programme objectives; and
- Collecting information to help advocate for continued support

Listed below are some of the elements one should consider for monitoring:

- Programme inputs (resources, messages, materials)
 - Number of staff trained in communication
 - Support communication materials available and how they are used
 - Job aids
 - Radio and television broadcast
 - Quality of IPC
 - Content of traditional/folk and local media
 - Number of NGOs, CBOs, CBAs etc engaged in activities that support PMTCT (degree of community involvement & ownership)
- Implementation of planned communication activities
- Support structures
- Data collection and reporting
- Interim effects of the implementation
- Effectiveness of messages
- Reactions of the communities to the communication strategies

It is important to know how to conduct and use monitoring information. One must make sure to set aside time and money for monitoring; produce simple reports which capture progress and issues in the implementation of the comprehensive PMTCT package; share the reports with stakeholders as a management and motivation tool; and use the information to build on programmes and make adjustments as needed.

Evaluation

Evaluation helps a PMTCT programme measure its effectiveness and impact. It is extremely important and must be introduced, understood, and planned from the start of a programme. Funds must be set aside in advance and it is necessary to have baseline data before the introduction of PMTCT programmes to compare the data to during the evaluation process. Evaluation should be guided by established indicators (refer to indicators compiled under Section A) and is important because it measures inputs/activities actually carried out, helps identify successes and shortcomings in implementation, and determines if positive health impact was made from a PMTCT programme.

There are three main types of evaluation: process, impact and outcome. Process evaluation provides feedback on activities and processes used to implement

activities and focuses on short-term achievements of a programme. It asks questions such as: were activities implemented as planned; how efficiently; and how well did administrative arrangements work?

Impact evaluation focuses on medium-term effects of a program and often uses quantitative research methods such as structured surveys that try to capture the extent to which programme objectives have been achieved. For example, one could try to determine if a PMTCT communication programme was increasing uptake of PMTCT services within a health centre.

Outcome evaluation provides information on the long-term effects of communication interventions and their impact on improved health status. In many ways outcome evaluation is similar to impact evaluation except that it measures long-term effects.

Below is an example of possible monitoring and evaluation indicators based on information provided under Section A above. It is not a complete set of indicators for an evaluation but can provide an outline for the basis of how an evaluation might be conducted.

Objective 1: Increase knowledge & awareness of PMTCT.		
Strategy 3: Integrate communication interventions throughout the health facility.		
Process Indicators	Impact Indicators	Outcome Indicators
# of people attending health talks on PMTCT	% of people tested and know their status	Reduced number of HIV infected babies born to HIV positive women.
# of invitation slips given to men	% of men/women who accepted a family planning method	
# of people that attended pre-test counselling sessions after the health talk	% change in male involvement at HC level	
# of people counselled on family planning, infant feeding, primary prevention, maternal nutrition		
# of men that came to HC with invitation slip		

Budgeting Tool

Developing a budget ensures the availability of financial resources that are needed to carry out communication activities in promoting the comprehensive PMTCT package. When the amount of funds is fixed, the team must allocate funds across activities for the period the funds are available and justify the allocations. It is important to know what the costs are for basic inputs such as stationary, training, etc. to provide accurate numbers in the budget.

Below is an example of a budgeting worksheet that may be of use in the planning process for the implementation of PMTCT communication activities. It is only meant to be used as a rough guide, since each programme is likely to have somewhat different budget lines specific to its programme.

Labour & Direct Costs	Estimated Cost (Year 1) in Zambian Kwacha
ADMINISTRATION	K
Project manager	
Programme Officer	
In-charge	
Health Workers	
Telephone service	
Mailing costs	
Meeting materials	
Fuel costs	
RESEARCH & EVALUATION	
Formative research	
Monitoring	
Evaluation	
PROMOTIONAL MATERIALS	
Pre-testing	
Press conferences	
Printing of IEC materials	
Community radio airtime	
COMMUNITY ACTIVITIES	
Contracting drama groups	
Holding meetings with stakeholders	
TRAINING	
Training of Health Centre staff and NHCs	
Training of community leaders/peer educators	
Exchange visits	
Total Estimated Cost	K

WHO Infant Feeding Guidelines

Group 1: Pregnant women whose HIV status is unknown or who have been tested and are HIV negative:

- ◆ Promote exclusive breastfeeding 0-6 months
- ◆ Introduce complementary foods at 6 months
- ◆ Continue breastfeeding to 24 months or more
- ◆ Promote maternal nutrition and health:
 - Breastfeeding mothers should consume an extra 650 kcal/day (one extra meal)
- ◆ Practice safe sex to avoid becoming HIV infected (transmission rates with new infections during breastfeeding as high as 29%)

Group 2: Pregnant women who have been tested and are HIV positive:

- ◆ Counsel on optimal infant feeding practices (informed choice for mother to choose replacement feeding or exclusive breastfeeding)

WHO recommendations on infant feeding for HIV+ women

“When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life.

To minimise HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks of replacement feeding (including infections other than HIV and malnutrition).”

New Data on the Prevention of Mother-to-Child Transmission of HIV and their Policy Implications: Conclusions and Recommendations (WHO 2001)

Replacement Feeding:

What does acceptable, feasible, affordable, sustainable and safe (AFASS) mean?

What is meant by ACCEPTABLE?

- ◆ The mother perceives no barrier to choosing the option for social and cultural reasons or for fear of stigma and discrimination

What is meant by AFFORDABLE?

- ◆ The mother and family (with available community and/or health system support), can pay for the costs for the purchase/production, preparation, and use of the feeding option, including all ingredients, fuel, and clean water

What is meant by SUSTAINABLE?

- ◆ Replacement Feeding option must be practiced every day & night throughout infancy (Feeds must be made fresh each time (every 3 hours))

I. When AFASS conditions DO exist: Replacement Feeding Options for HIV+ mothers

- ◆ Practice exclusive replacement feeding from birth

- ◆ What do we know about the feasibility of commercial or homemade infant formula?
 1. Stigma associated with its use widely reported in Africa
 2. Access to safe water, adequate hygiene, and health care very important
 3. Proper instruction on safe preparation and feeding very important
 4. Costs can be high for many low-income families

II. When AFASS conditions DO NOT exist:

Option 1: Exclusive breastfeeding

Option 2: Treated breastmilk

Option 3: Wet nursing by HIV negative woman

- ◆ Practice exclusive breastfeeding from birth
- ◆ Avoid becoming re-infected with HIV during breastfeeding (counsel on safe sex)
- ◆ Aim is to shorten duration of exposure to HIV virus in breastmilk
- ◆ Stop breastfeeding as soon as exclusive replacement feeding is AFASS
- ◆ Key words are affordable and safe
- ◆ Early cessation could happen at 6 months, but this is dependant on AFASS circumstances of mother and family
- ◆ May take from 2 weeks to 2 months to transition from breastfeeding to replacement feeding

Feasibility of early cessation of breastfeeding:

<p>Potential risks for infant</p> <p>Dehydration Anorexia Later behavior problems Malnutrition Illness or death</p>	<p>Potential risks for mother</p> <p>Engorgement Mastitis Increased risks of pregnancy Depression Stigma Possible reversion to breastfeeding (mixed feeding)</p>
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- ◆ Breast milk contributes > 50% of the nutrient intake of children > 6 months in developing countries
- ◆ Replacing breast milk nutrients and energy will be a challenge
- ◆ From 6 months of age, infants can be given undiluted animal milk or commercial formula to replace breast milk
- ◆ Express milk from breast into clean container
- ◆ Heating breast milk for 20-30 minutes at 54-56 degrees Celsius in order to kill the virus
- ◆ Feed heat treated milk to infant
- ◆ Use a cup (always avoid bottle)
- ◆ Ensure wet-nurse is HIV negative and remains negative (counsel on safe sex)
- ◆ Exclusive breastfeeding until 6 months
- ◆ HIV+ baby transmission to wet-nurse: no evidence

Questionnaire

On a scale of 1-10, how useful has this National PMTCT Communication Strategy been? (Please circle one)

1 2 3 4 5 6 7 8 9 10

What was the most useful part?

What would you like to see added?

Were the objectives and strategies clear and easy to understand?

Have you used any of the tools in Section B?
If yes, which did you use and how?

Do you feel like this document helped you in your work?

What would you like to see added or changed in Section B: Tools?

Please return to:

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