HIV/AIDS Core Package: Swaziland

Meeting the Reproductive and Sexual Health Needs of HIV-Positive Women in Swaziland: A Rights-based Approach

June 2003– May 2004

CTO Approval Date: April 2003
Mission Approval: May 2003
Expected End Date: May 2004
I. Purpose

This core package will identify and address some of the prioritized operational policy barriers to improve the Reproductive and Sexual Health Rights (RSHRs) of HIV-positive women in reproductive and sexual health (RSH) care programs, including voluntary counseling and testing (VCT), prevention of maternal-to-child transmission (PMTCT), and antenatal care (ANC). This activity will produce the following results:

- Strategies to address the RSHRs of HIV-positive women will be integrated into national operational and policy guidelines;
- Capacity of organizations serving people living with HIV/AIDS (PLWHA), especially women’s organizations, to advocate for RSHRs will be strengthened; and
- Awareness of the RSHRs of HIV-positive women will increase.

II. Background

The importance of reproductive and sexual health care in the context of PMTCT has been articulated in at least two ways. Access to reproductive health and sexual services in order to prevent unintended pregnancies is one of the three PMTCT program components identified in UNAIDS guidelines. Recent USAID guidelines regarding the integration of family planning and HIV/AIDS similarly identify family planning/reproductive health (FP/RH) as a crucial, yet under-recognized, element of PMTCT. Sexual and reproductive health information and services are also crucial to HIV-positive women’s right to live as full and healthy lives as possible, independent of the goal of preventing maternal-to-child transmission (MTCT). As with MTCT-Plus and its expansion to include access to anti-retroviral (ARV) therapy for the mother’s own health as well as for her child’s, so too should HIV-positive women themselves have the right to comprehensive reproductive and sexual health care.

Yet, research suggests that most HIV-positive women do not receive the information, support, referrals, and related services necessary to meet their sexual and reproductive health needs as HIV-positive women. Instead, HIV-positive women experience stigma and discrimination related to their sexuality and reproductive choices. Historically, HIV-positive women have been viewed as vectors of transmission, with reproductive health information focused on protecting the unborn child. Providers often make implicit and explicit recommendations that HIV-positive women should not engage in sexual relations, nor make choices about childbearing, especially the desire to have a child. Although little data exists specific to HIV-positive young women’s experiences, available information suggests that HIV-positive


young women experience especially harsher sanctions related to their sexuality. As with stigma and discrimination more broadly, fears of coercion regarding reproductive decision-making appear to be a reason why women do not seek out VCT in the first place. In addition, in many cases, health system-level constraints also pose significant barriers to the availability and access to RSH care for HIV-positive women, as well as the capacity to provide counseling about RSH needs and rights.

Through the USAID Regional HIV/AIDS Program (RHAP) in Southern Africa, the POLICY Project has provided extensive support to local NGOs and civil society groups in Swaziland. Specifically, POLICY supports their capability to plan and mobilize resources for reproductive health and HIV/AIDS programs and to carry out advocacy and policy dialogue activities. Through existing NGO networks, POLICY can build on the advocacy and resource mobilization capabilities of these organizations to advocate for the inclusion and funding of interventions for HIV-positive women in larger reproductive health programs. The POLICY Project stands at the vanguard for addressing these key areas. With experience in strengthening advocacy efforts for reproductive health services and addressing the rights and promoting the greater involvement of PLWHA, as well as having partnerships with a well-established network of NGOs and civil society groups in Swaziland, POLICY is poised to make a cutting edge contribution to this critical issue.

III. Objectives

The package seeks to achieve the three following objectives:

- Assess the current barriers and gaps to HIV-positive women’s access to RSH information and services in the context of VCT/ PMTCT programs;
- To strengthen the capacity of PLWHA organizations, focusing especially on HIV-positive women run groups, to implement advocacy activities on the RSHRs of HIV-positive women and the reduction of stigma; and
- To strengthen RSH care policies and guidelines, especially in the context of VCT and PMTCT programs, to better meet HIV-positive women’s sexual and reproductive health needs and rights and to reduce stigma

IV. Rationale for the Package

There are several reasons why the current environment in Swaziland favors a successful core package of this nature. Information on the RSHRs of women in the National HIV/AIDS Strategic Plan is not specific and only addresses women in general and policymakers have

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4 Two recent publications highlighting the needs of HIV-positive people noted the absence of young PLWHA views and voices in the assessment of RSH needs. Both ICW’s (2002) Positive Women: Voices and Choices report and the P. Jere’s Qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi. Draft Report, Unpublished. Lilongwe, Malawi: Malawi Network of People Living with HIV/AIDS (MANET+), December 2002 gathered the views of PLWHA through support groups; in both cases the support groups included PLWHA with a mean age of late 20s and early 30, thus not reflecting the perspectives and experiences of young PLWHA.

recognized this issue. This project will support the National Emergency Response Committee
on HIV/AIDS (NERCHA) in Swaziland to continue its work on revising the strategic plan to
include the RSHRs of HIV-positive women. This project is also meant to supplement,
support, and build on existing work outlined in Swaziland’s National HIV/AIDS Strategic
Plan to increase access to RSH services for HIV-positive women and to raise awareness on
stigma and discrimination among RSH service providers.

Women in Swaziland are largely under-represented in formal and informal decision-making
structures, despite the fact they account for 52 percent of the country’s population. This
under-representation results in women’s interests and needs not being expressed and pursued
at the level of decision making. In addition, women’s access to and control over vital
resources is restricted, and according to the Swazi custom of kukhonta, a woman cannot
control the land. HIV/AIDS NGOs supported by POLICY\(^6\) and NERCHA are currently
working with women’s rights organizations already campaigning for better access to land and
property rights, and for the review of inheritance laws and advocacy at the community level,
to take note of the impact these issues have on HIV-positive women.

Women in Swaziland never attain the age of majority\(^7\) and are answerable to a male figure in
the family, such as the father, husband, or brother-in-law. A husband’s consent is needed
before family planning is prescribed. Many women who want to practice family planning are
inhibited by their spouse’s lack of support. For example, the Family Life Association of
Swaziland (FLAS) has found that “many men in rural areas have the attitude that modern
contraception is a foreign intrusion that does not integrate well with traditional practices.
They also believe that it kills.”\(^8\) In addition, women fear seeking medical assistance because
they do not wish to draw attention to themselves, particularly if it involves their spouses or
family members or is seen as challenging traditional custom. Working to increase the
knowledge of men on family planning and HIV/AIDS and the availability of reproductive
health services is an important part of improving the RSHRs of women. Including family
members, particularly mothers-in-law, is also important because they have a lot influence on
the reproductive rights of women in Swaziland. This core package will support activities that
will mobilize their involvement and participation.

In Swaziland, approximately 56 percent of HIV-positive adults are females. In addition, 30
percent of women attending ANC clinics in major urban areas are infected, while 32 percent
of women attending ANC clinics outside of major urban areas are infected.\(^9\) Positive women
who are pregnant are not given the information they need to reduce the risk of infecting their
partner or child. In Swaziland, HIV-positive women who are pregnant also have to cope with
the negative attitude towards them from health workers and others and experience
discrimination once their status is known because they are not expected to be sexually active.
In order to fully realize the intended potential of FP/RH to VCT/PMTCT programs for HIV-
positive women, programs thus need to be able to address the stigma related to HIV-positive
women’s sexuality and reproduction that limits their access to RSH services, as well as
identify other systems-related barriers to the provision of counseling, referrals, and related
services. Adequate pre-test and post-test counseling is also essential, because most women
have little knowledge of HIV transmission or risk before they are diagnosed with HIV.

\(^6\) Through the U.S. Ambassador’s Initiative Small Grants Program, grants were awarded to The AIDS Information
Support Centre (TASC), the Family Life Association of Swaziland (FLAS), Women’s Resource Centre, Women
and the Law Southern Africa (WLSA) and the Good Shepherd Hospital.

\(^7\) Women remain minors, even after the age of 18. Unmarried women remain in the “custody” of their fathers,
while married women remain in the “custody” of their husbands according to Swazi Customs and Tradition &
Swazi Law.


\(^9\) World Bank, Swaziland Summary Gender Profile.
Gender guidelines for PMTCT are currently being drafted for the World Health Organization (WHO), following an expert consultation held in June 2002, and should be ready for dissemination by the end of 2002.\(^\text{10}\) These may provide some overall model guidance. However, even with the guidance these may offer, national and operational policies and guidelines are needed to implement these guidelines in a particular context—and will still need to be developed.\(^\text{11}\)

A core package aimed at developing concrete national and operational policies in Swaziland that promote these rights in order to better meet the RSH needs of HIV-positive women would thus contribute to the effective realization of PMTCT’s potential, and offer further guidance on how to translate emerging guidelines on PMTCT into practice.

V. Approach and Activities

An important and structural element of this package is the meaningful involvement of PLWHA. This project grounds itself in participatory processes designed to identify, prioritize, advocate for, and develop policy solutions. It particularly embraces the approach of the Greater Involvement of People Living with HIV/AIDS (GIPA) Principle by building the capacity of HIV-positive women to centrally engage in and assume leadership roles in all phases of the core package (see Box 1 for a list of partners). Within this broader approach, the project proposes to use a number of key POLICY approaches to influence policy change, including applied research and analysis for policy development, policy dialogue and advocacy, and the strengthening of PMTCT endeavors. Proposed approaches and activities are outlined below.

A. Identification of partners, establishment of task team, needs assessment analysis

- **Identification, collaborative planning, and sensitization of key stakeholders.**
  - Identify key stakeholders, including the Ministry of Health (MOH) and NGO/PLWHA partner organizations;
  - Carry out collaborative planning and consensus building activities with key stakeholders to achieve commitment/ownership and develop plan of work; and
  - Conduct needs assessment analysis for development of activities.

B. Conduct research, analysis, and survey activities and identify existing gaps and barriers in addressing RSHRs of HIV-positive women in the VCT/PMTCT programs

- **Conduct in-depth analysis of the current situation of the RSHRs of HIV-positive women and their links to other components of VCT/PMTCT/RH programs.**
  - Analyze existing programs;
  - Interview positive women to assess their experiences and needs related to RSH services in VCT/PMTCT/RH programs;
  - Conduct focus groups with men and mothers-in-law to assess current knowledge, awareness, and support for RSHRs of positive women;

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\(^\text{10}\) Personal communication. International Center for Research on Women (ICRW), September 2002.

Interview VCT/PMTCT/RH service providers who serve HIV-positive women. (For example: What do they do? What do they wish they could do? Do they feel adequately skilled and empowered to meet the RSH needs of HIV-positive women?).

• Assess the existing programmatic environment (e.g., international agencies, NGOs, public sector) and their capacity (have/can be trained) to address the RSH needs of HIV-positive women, both from a prevention and care perspective.

• Identify the additional inputs and cost additional key RSH care services to existing VCT/PMTCT/RH service delivery points (if needed based on consensus meetings, see below).

C. Policy dialogue and advocacy

• Organize workshops and work sessions with local counterparts.
  o Review and discuss the information collected through DHS analysis, interviews, and assessment of current service availability and effectiveness;
  o Discuss and agree on the types and scope of interventions necessary to have a direct impact on positive women’s RSH lives;
  o Identify gaps and barriers to the availability of essential RSH prevention/care services; and
  o Prioritize interventions that need to be included in VCT/PMTCT/RH programs in the HIV/AIDS strategic plan.

• Produce a report of findings from the analysis and consensus workshops identifying existing policy barriers to reproductive and sexual health services for HIV-positive women, as well as costing of additional services (if needed), for advocacy purposes to promote policy reform in Swaziland.

• Work with existing NGO/PLWHA partner organizations to develop and implement a multi-level advocacy and training strategy to mobilize support for RSHRs of HIV-positive women. This work would include the awarding of small empowerment grants to NGOs/PLWHA organizations to carry out relevant issue-based advocacy and training work and would be focused as follows:
  o At the family and community level, among men and mothers-in-law;
  o At the provider level, among health care workers; and
  o At the policy level, among the decision makers involved in the RH strategic plan advisory committee.

• Work with an RH strategic plan advisory committee to incorporate RSHRs issues, specifically those pertaining to HIV-positive women, and identified RSH prevention/care interventions into the strategic plan.

• Document and disseminate a final report describing the process results achieved and lessons learned, as well as the methodology, implementation, and documented outcomes.
VI. Relationship of the Core Package to RHAP Objectives

Because there is no USAID Mission in Swaziland, dedicated USAID in-country HIV/AIDS activities are supported through the Southern Africa Regional HIV/AIDS Program (RHAP). After numerous consultations with USAID Mission Directors, PHN officers, and American Ambassadors in the region, this program was launched in February 2000. The program has three main objectives:

1. Work with high-risk cross border population groups;
2. Support the development of national policies; and
3. Expand access to the information generated through the program.

POLICY’s existing working relationship with the RHAP program in general and more specifically in Swaziland through the U.S. Ambassador’s Initiative meets the goal of providing tailor-made technical support in areas of identified need. In 2002 Ambassador Mcgee, the U.S. Ambassador in Swaziland, explained that “RHAP’s greatest strength lies in its ability and willingness to fund programs aimed at specific needs.” POLICY/RHAP currently provides extensive technical assistance to various nongovernmental agencies through the provision of comprehensive capacity-building programs, strategic planning facilitation and expertise, and reviews of current legislation so as to accommodate the development of appropriate national policy and program responses. The proposed core package would build on the strength of this existing relationship with the range of nongovernmental agencies and organizations and government departments in Swaziland.

This core package will simultaneously address a need that has been articulated by all the relevant in-country stakeholders and complement much of the NGO policy and advocacy networking support that is taking place under the auspices of the U.S. Ambassador’s program. It will further strengthen the work done by POLICY to challenge the stigmatization of PLWHA (reported as one of the achievements in the 2002 RHAP, Southern Africa Report). Developing an understanding of the issues highlighted within the scope of this core package and addressing some of the operational policy gaps in relation to the RSH needs of all women, and HIV-positive women in particular, offers concrete synergies with existing POLICY Project work in Swaziland, the broader RHAP, and global POLICY initiatives.

VII. Rapid Achievements Anticipated

At the end of the year, it is anticipated that the core package in Swaziland will result in:
National and operational policy guidelines that address the RSHRs and reduce the stigma faced by HIV-positive women;

- Strengthened ability and advocacy capacity of PLWHA organizations, especially HIV-positive women’s groups;

- Increased awareness of the RSHRs of positive women among women, family and community members, providers, and policymakers; and

- Identified examples of best practice that will illustrate how the RSHRs of HIV-positive women can be effectively incorporated and addressed within existing RSH care programs.

**VIII. Potential for Wider Impact and Leveraging Resources**

The core package will strengthen the development and implementation of RSHRs operational policies and guidelines and will improve provision and access to VCT/PMTCT/RH services, especially for HIV-positive women. This package is intended to showcase a multi-pronged approach to show that simultaneously directing interventions at different levels (family and community, service delivery, and policy) is an effective means of addressing the needs of HIV-positive women in VCT/PMTCT interventions. Through the development of a more responsive PMTCT structure, HIV-positive women will also have improved access to other RSH services. The lessons learned through implementing this project in Swaziland will inform the modification of the methodology for application in other settings, as well as possible replication of all or parts of the program by the MOH. Such lessons might include whether the interventions at all levels are necessary, whether there is a preferred sequence to the implementation of the interventions, and whether there are any specific programmatic recommendations about tailoring the interventions to subpopulations.

The proposed core package will also make important contributions to addressing the RSHRs of women. It also might promote better targeting of VCT/PMTCT/RH funds from international donor organizations and others. Finally, the package will provide a strong leadership development component that will enhance the capabilities of PLWHA organizations and also health professionals involved in VCT/PMTCT/RH policy, services, and systems.

We expect to achieve several specific results through the implementation of this proposed core package. Expected results and data sources are show in the table below.
### IX. Expected Results

<table>
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<tr>
<th>POLICY Results</th>
<th>Country Core Package Result</th>
<th>Data Sources</th>
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| **SO:** Policies and plans to promote and sustain access to quality reproductive health services, including family planning and HIV/AIDS services. | RSHRs issues integrated into national operational and policy guidelines | Policy documents  
Official MOH documents |
| | New and/or revised policies aimed at HIV and AIDS preventative and care measures within selected government and private departments are adopted/approved | |
| | Guidelines for protecting and promoting the RSHRs of HIV-positive women adopted for testing by MOH | |
| **IR1:** Increased institutional and organizational response to HIV/AIDS in key sectors. Political and popular support broadened and strengthened for increasing access to family planning services and protecting the RSHRs for HIV-positive women. | NGOs participate in the formulation of an action plan to incorporate RSHRs into reproductive health programs | Minutes of meetings, speeches, agendas, and lists of participants  
Workshops reports and proceedings  
NGO reports  
Qualitative assessments  
Key informant interviews  
Published statements of public sector officials or NGO leaders |
| | Increased support of advocacy efforts among public and private sector stakeholders to promote policy change | |
| | MOH policymakers express support for testing and implementing new guidelines | |
| | Increased involvement of PLWHA organizations in PMTCT and advocacy activities targeting PMTCT | |
| **IR3:** POLICY-supported data informs planning and policy development | Data from POLICY-supported RSHRs analyses, program assessments, and health surveys used in development of national operational and policy guidelines | Project documents  
Official documents, including the National Strategic Plan |
| | Data used in the development the Reproductive Health Strategic Plan | |
| | Recommendations for improved PMTCT practice incorporated into health sector guidelines | |
| **IR4:** In-country capacity to guide advocacy and strategic planning process enhanced | PLWHA organizations demonstrate enhanced skills in planning and implementing advocacy activities and in participating in strategic planning activities | Project documents  
Meeting and workshop rosters |
This core package will be carried out for a period of 12 months beginning June 2003 through May 2004.

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<th>Activities</th>
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<td><strong>A. Identification of partners, establishment of task team, needs assessment analysis</strong></td>
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<td>3) Carry out collaborative planning and consensus building activities with key stakeholders to achieve commitment/ownership and develop plan of work;</td>
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<td>4) Conduct needs assessment analysis for development of activities</td>
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<td>5) Establish focus groups, which include men, HIV-positive women, and mothers-in-law, to assess current knowledge and awareness, and support for RSHRS of HIV-positive women. The focus groups will meet at the very least on a monthly basis. The focus groups will review interview questionnaires developed and “pilot them”. Additionally, while conducting interviews initial feedback will be shared with the focus groups.</td>
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<td>6) Development of a Monitoring and Evaluation Tool for the Core Package program activities.</td>
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<td>B. Conduct research, analysis, and survey activities and identify existing gaps and barriers in addressing RSHRS of HIV-positive women in the VCT/PMTCT programs.</td>
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<td>7)</td>
<td>Identification of an organization to conduct analysis</td>
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<td>8)</td>
<td>Conduct in-depth analysis of the current situation of the RSHRS of HIV-positive women and their links to other components of VCT/PMTCT/RH programs and analyze existing programs</td>
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<td>9)</td>
<td>Development of the research design (incl. The establishment of clear aims and objectives, assessment tool, interview guides, questionnaire and the identification of the interviewees) Research design to be reviewed by the task team, POLICY, key stakeholders, and focus groups</td>
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<td>10)</td>
<td>Piloting of the Questionnaire, Carry out a working session to review feedback from the pilot phase and to develop a final questionnaire/finalize the research design</td>
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<td>11)</td>
<td>Interview HIV-positive women to assess their experiences and needs related to RSH services in VCT/PMTCT/RH programs; Conduct interviews (with men, women, mother-in-laws) to assess current knowledge and awareness, and support for RSHRS of HIV-positive women</td>
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### 12) Development of Questionnaire to Interview VCT/PMTCT/RH Service Providers who serve HIV-Positive women.

- What do they do? What do they wish they could do? Do they feel adequately skilled and empowered to meet the RSH needs of HIV-positive women?
- Pilot and review Questionnaire

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### 13) Assess the existing programmatic environment (e.g., international agencies, NGOs, public sector) and their capacity (have/can be trained) to address the RSH needs of HIV-positive women, both from a prevention and care perspective.

### 14) Identify the additional inputs and cost additional key RSH care services to existing VCT/PMTCT/RH service delivery points

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### 15) Organize a workshop for presentation of findings from the in-depth analysis

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### 16) Development of an Implementation Plan and Activities and Identification of Priority Areas for Monitoring

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### C. Policy Dialogue and Advocacy

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<th>Jun</th>
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<td>17)</td>
<td>Organize workshops and work sessions with Local Counterparts (themes to be guided from the findings of research)</td>
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<td>18)</td>
<td>Review and discuss the information collected through DHS analysis, interviews, and assessment of current service availability and effectiveness and review/discuss the policy implications of research findings and develop recommendations for policy review</td>
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<td>19)</td>
<td>Discuss and agree on the types and scopes of interventions necessary to have a direct impact on positive women’s RSH lives; Develop recommendations for appropriate interventions for Swaziland</td>
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20) Identify gaps and barriers to the availability of RSH prevention/care services; and prioritize interventions that need to be included in the in the HIV/AIDS Strategic Plan (Utilizing e recommendations for interventions as a guide)

21) Produce a Final Report on the findings from the analysis and consensus workshops identifying existing policy barriers to reproductive and sexual health services for HIV-positive women, as well as costing of additional services (if needed), for advocacy purposes to promote policy reform in Swaziland.

22) Work with existing NGO/PLWHA partner organizations to develop and implement a multi-level advocacy and training strategy to mobilize support for RSHRs of HIV-positive women. This work would include the awarding of small grants to NGO/PLWHA organizations to carry out relevant issue-based advocacy and training work and would be focused at: the family and community level, the provider level, and the policy level

23) Incorporate RSHRs issues, specifically those pertaining to HIV-positive women, and identified RSH prevention/care interventions into the strategic plan by working with RH Strategic Plan Advisory Committee

24) Disseminate a final report describing the process and results achieved and lessons learned as well as the methodology, implementation, and documented outcomes of the project.

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<tr>
<th>Activities</th>
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### XI. Budget

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<thead>
<tr>
<th>Deliverable</th>
<th>Estimated Total Cost (USD)</th>
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<tbody>
<tr>
<td>A. Identification of partners, establishment of task team, needs assessment analysis.</td>
<td>$15,000</td>
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<td>B. Conduct research, analysis, and survey activities and identify existing gaps and barriers in addressing RSHS of HIV-positive women in the VCT/PMTCT strategies</td>
<td>$20,000</td>
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<td>C. Policy dialogue and advocacy <em>including Grants and subcontracts to partners/NGOs</em></td>
<td>$70,000</td>
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<td>D) Management of core package</td>
<td>$20,000</td>
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<tr>
<td><strong>Grand Total</strong></td>
<td><strong>$125,000</strong></td>
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