



**Fulfilling reproductive rights for women affected by HIV/AIDS
A tool for monitoring
progress toward three Millennium Development Goals**

**Updated version
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PREFACE

In 2004, more than 25 national and international organizations presented a statement to the secretariat of the United Nations (UN) Commission on the Status of Women that highlighted relatively neglected areas in the reproductive health of women affected by HIV/AIDS.¹ In collaboration with the International Community of Women Living with HIV/AIDS (ICW), the Center for Health and Gender Equity (CHANGE) and the Pacific Institute for Women's Health, Ipas used that statement and a literature review² to develop this practical tool to help nongovernmental organizations (NGOs) address those neglected areas of reproductive health. Since the Millennium Development Goals (MDGs) have become a common framework for assessing progress in development,³ the tool links those areas of reproductive health to three of the MDGs related to empowering women, improving maternal health and combating HIV/AIDS.

This document is an updated version of the original resource published in 2004.⁴ Changes were made after the eight partner NGOs listed below piloted the benchmarks in 11 developing countries.⁵⁻⁶ The country reports can be obtained from them (see the appendix for addresses).

- The Federation for Women and Family Planning (hereafter referred to as the Federation), a member association of the International Planned Parenthood Federation (IPPF), works on sexual and reproductive health (SRH) in Poland.⁷
- The Foundation for Studies and Research on Women (FEIM) carries out advocacy and research on SRH in Argentina.⁸⁻⁹
- The Gender AIDS Forum (GAF) is an NGO working on gender and HIV/AIDS issues in South Africa.¹⁰
- The Instituto de Educación y Salud (IES) carries out SRH research and interventions in Peru.¹¹
- ICW, the only international network exclusively representing HIV-positive women and girls, used the benchmarks in Botswana, Lesotho, Namibia and Swaziland.¹²⁻¹⁴
- Planned Parenthood Federation of Nigeria (PPFN), a member association of IPPF, used the benchmarks in data collection in the North-East region of the country.¹⁵
- Punto de Encuentro de la Comunidad, A.C. (PECAC) is the only NGO working on HIV/AIDS in Chetumal, the state capital of Quintana Roo, Mexico.¹⁶
- Women Fighting AIDS in Kenya (WOFAK) is an association that provides counseling, training and material support to women living with and affected by HIV/AIDS.¹⁷

Why develop this tool?

Many NGOs and community-based organizations (CBOs) do not have the capacity and/or human resources to carry out formal or extensive research on SRH issues. They are unable to conduct large-scale baseline and follow-up surveys and therefore are not in a position to measure percentage increases and decreases in various indicators.

Nevertheless, many organizations can collect information that is useful for assessing whether progress has been made in fulfilling complete reproductive rights for women affected by HIV and AIDS. The simple benchmarks and accompanying questions proposed in this document can serve as a tool for such an exercise. Data to answer the questions can be gathered through both qualitative and quantitative means; in some cases, answers can be found simply by reviewing available documents and interviewing staff of organizations involved in HIV/AIDS work.

By linking the questions to three MDGs, we believe somewhat comparable data across countries and time can be collected for presentation at local, national and international venues where HIV/AIDS policies and programs are formulated and reviewed. The benchmarks and questions can be further refined as time goes by.

Organization of the document

This document is organized as follows:

- Section 1 introduces the relevant MDGs and neglected areas of reproductive health.
- Section 2 provides the benchmarks and accompanying sample data-collection questions.
- Section 3 gives some ideas on how the collected data can be used.
- Section 4 lists the organizations that support use of this tool.
- Section 5 provides the text of the Barcelona Bill of Rights, an advocacy tool formulated under the leadership of HIV-positive women at the XIV International AIDS Conference in 2002; this position statement has been endorsed by more than 260 individuals and organizations worldwide.¹⁸

1. INTRODUCTION

Three of the UN-endorsed MDGs are directly pertinent to the reproductive health of women living with HIV.¹⁹ MDG 3 seeks to achieve greater gender equality and empower women; MDG 5 aims to improve maternal health; and MDG 6 focuses on stopping and reversing the spread of HIV infection (as well as malaria and other major diseases). In addition, the UNAIDS Global Coalition on Women and AIDS has recognized that women's and girls' vulnerability to HIV infection and the impact of AIDS are linked to gender inequalities and societal norms that need to be challenged.²⁰

To ensure that all reproductive rights for women affected by HIV/AIDS are fulfilled, policies and programs especially need to challenge inequalities and gender-biased norms regarding relatively neglected areas of women's health. These neglected areas include:

- Ensuring that HIV-positive women and their networks are involved both in policy-making and implementation of reproductive-health care
- Expanding access to, and ensuring that no woman is coerced into, voluntary HIV counseling and testing, including women receiving postpartum care, emergency contraception and rape crisis services, and abortion-related care
- Expanding access to post-exposure prophylaxis (PEP) following unprotected sex, including sexual assault, as a measure to reduce HIV transmission
- Expanding access to modern contraceptive methods, including emergency contraception, and ensuring that information provision on contraceptive methods is tailored to the needs of women living with HIV
- Ensuring that HIV-positive women have the right to have children when they want to, and should be supported to do so, without judgment and with access to antenatal, perinatal and postnatal care
- Ensuring that sterilization of any HIV-positive woman only occurs when she gives her full, informed and unpressured consent
- Ensuring that reproductive-health programs for HIV-positive women include high-quality postabortion care and measures to enable women to access safe, legal abortions
- Raising the visibility of, and access to, assisted reproduction techniques and possibilities of fostering and adopting children as additional parenting options for people living with HIV.

2. BENCHMARKS AND SAMPLE QUESTIONS FOR DATA COLLECTION

The following 10 benchmarks and sample questions can be useful in fact-finding exercises and collecting data to establish a baseline regarding neglected areas of reproductive health. When they are used to carry out repeat data-collection exercises, NGOs can ascertain whether progressive realization of steps to achieve the MDGs is occurring. The questions can be applied at a local level (for example, a city, district or province/state) or the national level.

The data can be collected in various ways, including:

- Surveys of respondents including policymakers, program managers, NGO and clinic staff, and women living with HIV
- Questionnaire-based interviews with policymakers, program managers, NGO and clinic staff, and women living with HIV
- Focus-group discussions with policymakers, program managers, NGO and clinic staff, and women living with HIV
- Observational site visits (for example, to clinics providing family-planning assistance, prevention of perinatal transmission)
- Mystery client visits to facilities (for example, to clinics providing family-planning assistance, prevention of perinatal transmission)²¹
- Review of laws
- Review of governmental and NGO policies, project and program documents
- Review of locally available training resources and information, education and communication (IEC) materials
- Review of program protocols and consent forms for clients
- Review of treatment record and/or referral record overviews
- Collection of comments through anonymous questionnaires for clients to relevant facilities (for example, a simple form to be left in a drop-box asking: What is your age? Have you undergone counseling for HIV testing (Yes/No)? Have you undergone HIV testing (Yes/No)? Was your participation voluntary (Yes/No)? Did you obtain the HIV test results (Yes/No)? Where did you have the HIV test?)

SAMPLE QUESTIONS BY GOAL

MDG 3: Promoting gender equality and empowering women

1. All agencies serving local HIV-positive women publicly endorse documents listing their sexual and reproductive rights.

- Have staff of NGOs, perinatal transmission prevention programs and health facilities, or women living with HIV/AIDS, heard of sexual and reproductive rights and know what those rights entail?²²⁻²³

- How many NGOs, perinatal transmission prevention programs and health facilities (in your city or district) are familiar with, have endorsed or have adopted as policy guidelines documents that specify the sexual and reproductive rights of women living with HIV/AIDS? (Examples may include the Barcelona Bill of Rights and the guidelines on HIV/AIDS and human rights issued by UNAIDS and the Office of the UN High Commissioner on Human Rights.)^{18, 24}
- How many NGOs, perinatal transmission prevention programs and health facilities have copies of such human rights documents on display or available for clients/patients to read?

Survey or interview questions:

- Are you familiar with any documents describing sexual and reproductive rights of HIV-positive women? If so, do you have copies on display or available for clients?
- Would you be willing to display a copy of the Barcelona Bill of Rights in your facility?

Note for researchers:

- After asking questions related to this benchmark, the interviewer/researcher should give a copy of the Barcelona Bill of Rights to the respondent.

2. *All relevant local government and NGO programs serving HIV-positive women include representatives of these women in policy and program design, monitoring and evaluation.*

How do perinatal transmission prevention and health-care programs for women living with HIV ensure that HIV-positive women's associations are involved in policy and program formulation, implementation and monitoring/evaluation?

Survey or interview questions:

- Does your program require that HIV-positive women's associations are involved in policy and program formulation, implementation and monitoring/evaluation? If so, how are these associations involved?
- If it is not required, does your program receive input from HIV-positive women in some other way? If so, what does this involve?
- How many programs do you know that include HIV-positive women in policy and program design, monitoring and/or evaluation?

MDG 5: Improving maternal health

1. *All HIV-positive women have access to family planning information that addresses contraception in relation to HIV/AIDS.*

- How many organizations have created or have available materials on contraceptives that address issues of concern to people living with HIV (for example, methods that offer dual protection against pregnancy and HIV/STIs, use of emergency contraception, breakthrough bleeding or spotting with some

methods, sterilization, possible interactions between hormonal contraceptives and drugs used to treat HIV and opportunistic infections)? What kinds of materials are available?

- How many organizations address HIV and AIDS in counseling on contraceptives? What kinds of information regarding HIV and AIDS do they include?

Survey or interview questions:

- Which contraceptive methods does your organization discuss in information, counseling and printed materials for HIV-positive women?
- Does your organization/program have available information and education materials on contraceptives that address which methods offer dual protection against pregnancy and HIV infection or reinfection?
- Does your organization/program have available IEC materials on contraceptives that address possible interactions between hormonal contraceptives and drugs used to treat HIV and opportunistic infections? If you don't have such materials available, why not?
- In your opinion, do providers tend to recommend certain contraceptive methods to HIV-positive women? If so, which ones and why?
- Do you know of cases in which HIV-positive women were pressured to use a certain contraceptive method? If so, which method and why?

2. *Women's choices on how to regulate their fertility do not prevent them from accessing antiretroviral therapy.*

- Do antiretroviral treatment programs require women to use a particular contraceptive method in order to be able to enroll (for example, condoms, an IUD, injectables)?
- What reasons are given for requiring women to use particular contraceptive methods?

Survey or interview questions

- Does your antiretroviral treatment program require women to use a particular contraceptive method?
- If so, which methods and why?

3. *Information is available to people living with HIV about methods to improve the safety of conception and childbirth (for example, sperm washing, artificial insemination, in vitro fertilization as methods of assisted conception, and antiretroviral therapy and cesarean section for childbirth).*

- Are any IEC materials available locally that address assisted conception methods?
- Have women living with HIV heard about or used assisted conception methods?
- What options do local programs to prevent perinatal transmission offer to HIV-positive women at childbirth?

Survey or interview questions

- Are any measures available and accessible locally to help HIV-positive men and women conceive safely (for example, sperm washing, in vitro fertilization, artificial insemination)?
- What measures are available locally to help HIV-positive women give birth safely?

4. *HIV-positive women and men are informed about all their legal options for parenting children.*

- Do national/local regulations or laws place restrictions on foster parenting or adoption by people living with HIV/AIDS? If so, what restrictions are there?
- How many NGOs and AIDS-related organizations have included the options of fostering/adopting by HIV-positive people in their advocacy materials and actions?
- Have associations of people living with HIV/AIDS discussed these options for parenting with their members?

Survey or interview questions

- Does your organization address the possibility of people living with HIV/AIDS becoming legal foster or adoptive parents? Why or why not?
- Do you know of any people living with HIV/AIDS who have legally adopted children?

5. *All local organizations serving HIV-positive women address all legal options for dealing with unwanted pregnancy.*

- How many organizations have created materials specifically for women living with HIV that discuss options for dealing with unwanted pregnancies, including emergency contraception, safe legal abortion and adoption? What kinds of materials are available?
- How many organizations, facilities or programs to prevent perinatal transmission discuss contraceptive failure, unwanted pregnancy and measures to deal with this with their clients?
- How many local health or other facilities (for example, pharmacies, NGOs) offer emergency contraception without a prescription or as a prophylactic measure?
- How many women known to be living with HIV have been able to access emergency contraception or safe, legal abortions within the last year?

Survey or interview questions

- Does your organization/program have available IEC materials that address use of emergency contraception?
- Does your program/facility offer emergency contraception without a prescription or as a prophylactic measure?
- If not, do you offer referrals on where women can get emergency contraception?

- Does your organization/program have available IEC or counseling materials specifically for women living with HIV that discuss safe legal abortion for unwanted pregnancies?
- If so, what kinds of materials are available?

Note for researchers:

- It is important to determine in advance whether there are legal restrictions on the availability of emergency contraception and abortion. Even in countries with restrictive abortion laws, there is usually at least one reason for which abortion is legally permitted, such as rape/incest and/or to protect a woman's health and life. When abortion is restricted and stigmatized, you may find that both women and health-care providers believe it is always illegal.

MDG 6: Combating HIV/AIDS

1. Voluntary HIV counseling and testing (VCT) is available to women through health-care services other than antenatal and delivery care, as well as other venues.

- How many NGOs, businesses and health-care facilities offering postpartum care, rape-crisis services, postabortion care and induced abortions offer VCT or referrals for VCT?
- Do health-care facilities offering postpartum care, rape-crisis services, postabortion care and induced abortion make and record referrals for VCT?
- How many women who use maternal health services have undergone VCT and where?
- Are women pressured into HIV testing or given incentives to have HIV tests at any local health-care facilities or other venues?

Survey or interview questions

- Does your facility provide voluntary HIV counseling and testing services (VCT) or referrals to VCT?
- Do you know women who say they were pressured into having an HIV test? If so, what form did the pressure take?

2. Measures have been taken to minimize chances of HIV infection for women who have been subjected to coerced or forced sex, both within and outside marriage.

- How many local health facilities offer post-exposure prophylaxis (PEP) for unprotected nonconsensual sex?
- How many women have received PEP within the last year?

Survey or interview questions

- Does your facility provide post-exposure prophylaxis (PEP) for survivors of rape, marital rape and incest or referrals for PEP in such cases?
- How many rape/incest survivors have received PEP at your facility within the last year?

Note for researchers:

- Explain what PEP is if respondents are unfamiliar with this.

3. *Stigma and discrimination in relation to HIV/AIDS have been successfully eradicated in the health-care sector.*

- How many instances of stigmatization and discrimination against women living with HIV/AIDS by personnel in the health-care sector have been reported locally (for example, to hospital ethics committees, ombudspersons, human rights commissions, NGOs)?
- In which areas of health care have stigma and discrimination been documented (for example, family planning, gynecological care, antenatal care, childbirth, postpartum care, abortion-related care)?

Survey or interview question

- Do you know of women living with HIV who suffered discrimination within the health-care system?
- If so, what did this discrimination involve?
- Were these cases reported to any agencies, and if so, which ones? Do you know how the cases were handled?

Additional questions

The above-mentioned benchmarks can, of course, be supplemented with other progress markers. Examples might include:

- HIV-positive women have easy and affordable access to health-care services such as Pap smears and breast examinations.
- HIV-positive women receive results from Pap smears within three weeks and are offered follow-up when necessary.
- Programs to prevent perinatal transmission address issues of stigma or involvement of other caregivers in relation to exclusive replacement or breastfeeding of babies.
- Research is being done in the country regarding the effects of antiretroviral therapy in relation to fertility and/or menopause.
- HIV-positive women are not required to fulfill unreasonable conditions in order to receive certain health-care services (for example, obligatory participation in clinic-based support groups as a condition for receiving antiretroviral therapy; agreement to sterilization; or placement of an IUD or contraceptive implant as a condition for receiving an abortion).
- HIV-positive women who are injecting drug users are not excluded from antiretroviral therapy programs.

3. IDEAS FOR USING THE BENCHMARKS AND FINDINGS

Global and regional levels

This monitoring tool can be presented to key actors for endorsement (and to encourage its eventual use) at international meetings, such as AIDS conferences and technical consultations on various aspects of HIV and reproductive health. For example, information about the tool was shared with NGOs from various regions at a meeting organized by UNFPA in June 2006 and resulted in several requests for the tool.

The document can also be used for advocacy and monitoring purposes in conjunction with regional agencies that are considering the MDGs, such as the New Partnership for Africa's Development (NEPAD) or with governmental agencies entrusted with reporting on the country's fulfillment of the MDGs.

Findings from data-collection exercises using the benchmarks can be shared through presentations (both oral and written, such as posters) at conferences and meetings on the MDGs, sexual and reproductive health and HIV/AIDS. Reports on the pilot studies using the tool were given at the 12th Priorities in Reproductive Health and HIV Conference, held in South Africa in October 2005,²⁵ and the XVI International AIDS Conference in Canada in August 2006.²⁶ The first overall project report posted on the Ipas website was downloaded more than 13,000 times between September 2005 and April 2006.

The national level

At the national level, the monitoring tool can also be presented for endorsement and use at meetings such as national AIDS program reviews. Other possible uses:

- NGOs can invite key actors within a specified geographical area to a meeting at which the benchmarks and the Barcelona Bill of Rights are introduced, for example, as part of feedback sessions on use of the tool or perhaps a report on the most recent international AIDS conference.
- At this meeting, participating organizations can decide which benchmark indicators will be useful for monitoring work in their geographical area. Individual participants can be asked to collect baseline data using specific questions; the findings can be collated by one central body (for example, an AIDS network office).
- Plans can be made to organize a follow-up meeting within six months or one year where follow-up data are reviewed to assess the extent to which progress has been achieved.
- Findings can be used to prepare project proposals for donors. Punto de Encuentro de la Comunidad, A.C., in Mexico received funding from a government agency for a

yearlong project to address the needs of HIV-positive women based on their research using the monitoring tool benchmarks.

- Findings can be discussed with human rights commissions or ombudspersons to devise ways in which violations of rights can be addressed at the local or national level.

The local level

The data-collection exercise itself can be used to educate respondents about the issues addressed in the monitoring tool. For example, in Botswana, many of the HIV-positive women who participated in the pilot study did not know what reproductive rights entailed. After this was explained to them and they understood more about reproductive health services to which they should have access, some of the women began asking for services such as breast examinations and Pap smears.

When the researchers distribute copies of the Barcelona Bill of Rights and local or national documents on HIV/AIDS and human rights to respondents, they also contribute to awareness-raising and increases in knowledge.

Respondents in studies can further be encouraged to raise the issues addressed in the monitoring tool in relation to their institutional policies and programs.

4. ORGANIZATIONS AND INDIVIDUALS ENDORSING THIS MONITORING TOOL

- Action Canada for Population and Development (ACPD)
- Australian Reproductive Health Alliance
- Center for Health and Gender Equity (CHANGE)
- CHOICE for youth and sexuality, The Netherlands
- Equilibres & Populations, France
- Federation for Women and Family Planning, Poland
- FEIM, Argentina
- Flora Tristán, Peru
- Gender AIDS Forum, South Africa
- Jashodhara Dasgupta, KRITI Resource Centre, India
- Instituto de Educación y Salud, Peru
- International Women and AIDS Caucus, International AIDS Society
- International Community of Women Living with HIV/AIDS (ICW)
- Ipas
- Pacific Institute for Women's Health, USA
- Planned Parenthood Federation of Nigeria, North-East Region
- Punto de Encuentro de la Comunidad, A.C., Mexico
- Susan Paxton, consultant, Asia-Pacific Network of People Living with HIV/AIDS (APN+)
- Women Fighting AIDS in Kenya (WOFAK)
- Women for Women's Human Rights – NEW WAYS, Turkey
- World Population Foundation, The Netherlands

5. BARCELONA BILL OF RIGHTS

A global effort initiated by Women at Barcelona and Mujeres Adelante with lead involvement by the International Women's AIDS Caucus of the International AIDS Society and the International Community of Women Living with HIV/AIDS

As we enter the third decade of HIV/AIDS, women, especially the young and the poor, are the most affected. Because gender inequality fuels the HIV/AIDS pandemic, it is imperative that women and girls speak out, set priorities for action and lead the global response to the crisis. Therefore, women and girls from around the world unite and urge all governments, organizations, agencies, donors, communities and individuals to make our rights a reality.

Women and girls have the right:

To live with dignity and equality

To bodily integrity

To health and healthcare, including treatment

To safety, security and freedom from fear of physical and sexual violence throughout their lives

To be free from stigma, discrimination, blame and denial

To their human rights regardless of sexual orientation

To sexual autonomy and sexual pleasure

To equity in their families

To education and information

To economic independence

These fundamental rights shall include, but not be limited to the right:

To support and care which meets their particular needs

To access acceptable, affordable and quality comprehensive healthcare including antiretroviral therapies

To sexual and reproductive health services, including access to safe abortion without coercion

To a broader array of preventive and therapeutic technologies that respond to the needs of all women and girls regardless of age, HIV status or sexual orientation

To access user-friendly and affordable prevention technologies such as female condoms and microbicides with skills building training on negotiation and use

To testing after informed consent and protection of the confidentiality of their status

To choose to disclose their status in circumstances of safety and security without the threat of violence, discrimination or stigma

To live their sexuality in safety and with pleasure irrespective of age, HIV status or sexual orientation

To choose to be mothers and have children irrespective of their HIV status or sexual orientation
To safe and healthy motherhood for all, including the safety and health of their children
To choose marriage, form partnerships or divorce, irrespective of age, HIV status or sexual orientation
To gender equity in education and lifetime education for all
To formal and informal sexual education throughout their lives
To information, especially about HIV/AIDS, with an emphasis on women and girls' special vulnerability due to biological differences, gender roles and inequality
To employment, equal pay, recognition of all forms of work including sex work and compensation for care and support
To economic independence such as to own and inherit property, and to access financial resources
To food security, safe water and shelter
To freedom of movement and travel irrespective of HIV status
To express their religious, cultural and social identities
To associate freely and be leaders within religious, social and cultural institutions
To lead and participate in all aspects of politics, governance, decision-making, policy development and program implementation

XIV International AIDS Conference, Barcelona, Spain, 11 July 2002

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APPENDIX: CONTACT INFORMATION FOR PROJECT PARTNERS

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