MINISTRY OF HEALTH

Improving Completeness and Accuracy of Data for Elimination of Mother-to-child Transmission of HIV

Tested Changes and Guidance from Uganda

OCTOBER 2014

UGANDANS AND AMERICANS IN PARTNERSHIP TO FIGHT HIV/AIDS
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World Health Organization

Foreword

The Ministry of Health with support from the United States President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID), U.S. Centers for Disease Control and Prevention (CDC), USAID Applying Science to Strengthen and Improve Systems (ASSIST), Strengthening Partnerships, Results and Innovations in Nutrition Globally (SPRING), Food and Nutrition Technical Assistance III (FANTA III), the AIDS Support Organization (TASO), Strengthening the Tuberculosis and HIV/AIDS Response South West (STAR SW), and Strengthening the Tuberculosis and HIV/AIDS Response East Central (STAR EC), has been implementing the Partnership for HIV-Free Survival (PHFS) initiative since March 2013, when it was officially launched. The aim of this initiative is to ensure a well-nourished, healthy HIV-free baby, through implementation of eMTCT and nutrition interventions using the quality improvement approach. Among the objectives of this initiative was to generate best practices from implementing sites that can be scaled up to other health facilities in the same district and the country.

Throughout the implementation of the PFHS initiative, a number of learning sessions and harvest meetings have been conducted from which these tested changes and guidance for improving the completeness and accuracy of eMTCT data, improving retention of mother-baby pairs in care, and provision of quality services at routine visits for HIV-positive mothers and their exposed babies have been compiled.

The Ministry of Health extends their appreciation to PEPFAR for providing the financial support to implement this initiative. Sincere gratitude is extended to USAID, CDC, ASSIST, SPRING, FANTA III, TASO, STAR SW, and STAR EC for the technical and financial support which was so essential in generating these best practices.

Special recognition is made of USAID ASSIST for the skilled technical guidance on the quality improvement component of the PHFS initiative, for supporting the regional and district coaches and the health facility improvement teams to apply quality improvement approaches in delivery of eMTCT and nutrition services, and for generating the various change ideas.

The Ministry of Health appreciates all the members listed in Annex 1 for their contribution throughout the process of implementing the initiative. PHFS implementation has been team work, and the compilation of this change package would not have been possible if it were not for the untiring efforts and commitment of these individuals.

This Change Package has been a result of collaborative effort between Ministry of Health, USAID ASSIST, FANTA III, SPRING, TASO, STAR SW, and STAR EC, regional coaches, District Health Officers of 6 focus districts, districts coaches, and health facility improvement teams in the 22 prototype sites.

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Acronyms

ANC	Antenatal care
ART	Antiretroviral therapy
ASSIST	USAID Applying Science to Strengthen and Improve Systems Project
CDC	U.S. Centers for Disease Control and Prevention
DHO	District Health Officer
EID	Exposed infants' diagnosis
eMTCT	Elimination of mother-to-child transmission
FANTA	Food and Nutrition Technical Assistance Project
HC	Health centre
HMIS	Health management information system
HSD	Health sub-district
MCH	Maternal and child health
MoH	Ministry of Health
MUAC	Mid-upper arm circumference
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PHFS	Partnership for HIV-Free Survival
QI	Quality improvement
SPRING	Strengthening Partnerships, Results and Innovations in Nutrition Globally Project
STAR SW	Strengthening the Tuberculosis and HIV/AIDS Response South West
STAR EC	Strengthening the Tuberculosis and HIV/AIDS Response East Central
TASO	The AIDS Support Organisation
URC	University Research Co., LLC
USAID	United States Agency for International Department

I. Introduction

In April 2013, the Partnership for HIV-Free Survival (PHFS) initiative was rolled out in 22 health facilities in six districts of Uganda with support from the Ministry of Health (MoH), the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project, together with other USAID and U.S. Centers for Disease Control and Prevention (CDC) partners—Food and Nutrition Technical Assistance (FANTA), Strengthening Partnerships, Results and Innovations in Nutrition Globally (SPRING), and the AIDS Support Organisation (TASO).

The Partnership for HIV-Free Survival

To achieve the goals of the "Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive," the Ministry of Health, PEPFAR, and other partners in Uganda are supporting national efforts to develop and scale up interventions to provide optimal nutrition for infants and their mothers and to protect infants from HIV infection.

In Uganda, the Partnership for HIV-Free Survival (PHFS) Initiative was implemented initially in 22 health facilities in six districts, supported by ASSIST, FANTA, TASO and SPRING.

The PHFS initiative was rolled out in these 22 health facilities using the quality improvement approach. Quality improvement (QI) teams were either formed or reconstituted where they previously existed. These QI teams have been supported through monthly coaching visits to identify gaps in care, prioritize areas for improvement, develop and test change ideas to address the gaps, and implement these changes. To further facilitate the sharing and spreading of change ideas, peer-to-peer learning sessions were organized quarterly so that teams could come together and share their work.

To start improvement work, teams initially focused on two key areas: data quality and the retention of mother and their babies in care. These were the areas with biggest gaps as initial visits to the sites showed that only 2.9% of exposed infants' clinical charts were completely and accurately filled out. Some of the changes introduced, such as assigning a person to be responsible for the data and providing feedback are changes, were already known from previous improvement work.[1] Other change ideas, such as filling out the tools immediately, were obtained through the coaches' experiences with implementing improvement work. These changes were shared with the improvement teams during the initial coaching visits so that they could immediately test and implement them.

Ministry of Health data collection system for eMTCT

The Ministry of Health data management system is managed through the Health Management Information System (HMIS). Data is collected monthly and quarterly at different levels of the system. The steps for collecting and using data for eMTCT in Uganda are:

1. Data is collected at the facility from primary tools like HIV/ART care card and exposed infants' clinical chart by the maternal and child health (MCH) staff, usually midwives and nurses.
2. It is collated and summarized in the registers such as the exposed infants' diagnosis (EID) register and ART register.
3. It is then compiled into the monthly and quarterly report forms by the facility staff in the MCH and in some facilities by the health information assistants. eMTCT data is collected monthly using an addendum report (HMIS 009a) which is a specific tool for eMTCT that has since been integrated into the general monthly report from the facility. HMIS monthly

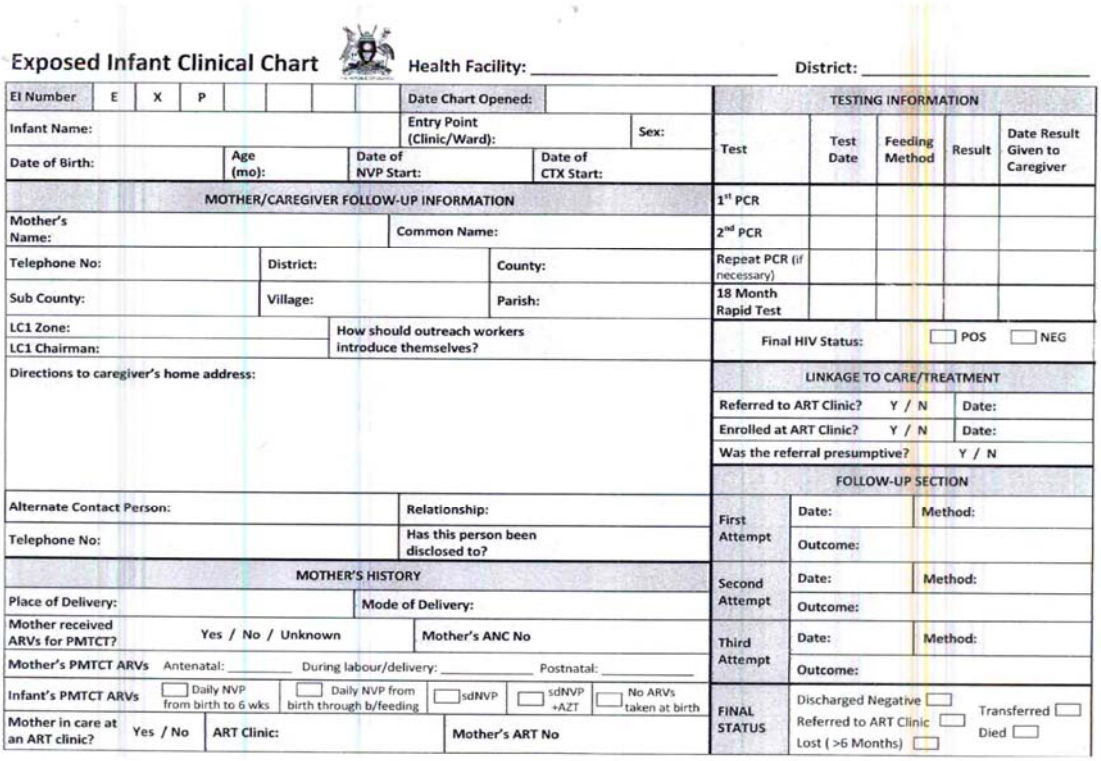
[1] Kyeyagalire R, Southgate R, Broughton E, Livesley N, Karamagi E. 2011. The Data Management Improvement Collaborative in Uganda. Research and Evaluation Report. Published by the USAID Health Care Improvement Project. Bethesda, MD: University Research Co., LLC (URC). Available at: https://www.usaidassist.org/resources/data-management-improvement-collaborative-uganda.

(105A) and quarterly (106A) have information on eMTCT in antenatal care (ANC), maternity, and postnatal care.

4. At HC IIIs, the copy of the report form is sent to the Health Sub-district (HSD). The HSD then aggregates and sends one report to the district. Hospitals, HSDs, and HCIVs submit their reports to the district HMIS focal person who works with a biostatistician to aggregate all district data.
5. At district level the data is entered online into DHIS2, a national level electronic data system managed by the MoH Resource Center. Some facilities that have capacity, especially the hospitals and the HCIV, can enter an electronic version of their report directly to the DHIS2. Once the data is in the DHIS2, it is then accessible at the national level and can be used by other implementing partners.
6. This data is used at the quarterly performance review meeting held at the district, for all the facilities providing PMTCT services.

PHFS data follows this pathway from the patient to DHIS2. MoH partners access this data at any point in this pathway. For PHFS, the clients' care cards (HIV/ART care card and the exposed infants' clinical chart) are the primary sources of data; information from these charts is recorded in a register—either the ART register or the EID register. The main data tools used for the PHFS work are the exposed infant's clinical chart, the mother's HIV/ART card, the ANC and ART registers, and the EID register.

Exposed Infant Clinical Chart



Exposed Infant Clinical Chart Health Facility: _____ District: _____

EI Number	E	X	P					Date Chart Opened:	
Infant Name:								Entry Point (Clinic/Ward):	Sex:
Date of Birth:			Age (mo):		Date of NVP Start:			Date of CTX Start:	

MOTHER/CAREGIVER FOLLOW-UP INFORMATION		
Mother's Name:		Common Name:
Telephone No:	District:	County:
Sub County:	Village:	Parish:
LC1 Zone:	How should outreach workers introduce themselves?	
LC1 Chairman:		
Directions to caregiver's home address:		
Alternate Contact Person:		Relationship:
Telephone No:		Has this person been disclosed to?

MOTHER'S HISTORY					
Place of Delivery:		Mode of Delivery:			
Mother received ARVs for PMTCT?	Yes / No / Unknown	Mother's ANC No			
Mother's PMTCT ARVs	Antenatal: _____	During labour/delivery: _____	Postnatal: _____		
Infant's PMTCT ARVs	☐ Daily NVP from birth to 6 wks	☐ Daily NVP from birth through b/feeding	☐ sdNVP	☐ sdNVP +AZT	☐ No ARVs taken at birth
Mother in care at an ART clinic?	Yes / No	ART Clinic:	Mother's ART No		

TESTING INFORMATION				
Test	Test Date	Feeding Method	Result	Date Result Given to Caregiver
1st PCR				
2nd PCR				
Repeat PCR (if necessary)				
18 Month Rapid Test				
Final HIV Status:	☐ POS	☐ NEG		

LINKAGE TO CARE/TREATMENT		
Referred to ART Clinic?	Y / N	Date:
Enrolled at ART Clinic?	Y / N	Date:
Was the referral presumptive?	Y / N	

FOLLOW-UP SECTION		
First Attempt	Date:	Method:
	Outcome:	
Second Attempt	Date:	Method:
	Outcome:	
Third Attempt	Date:	Method:
	Outcome:	
FINAL STATUS	Discharged Negative ☐ Referred to ART Clinic ☐ Lost (>6 Months) ☐	Transferred ☐ Died ☐

Why focus on data quality?

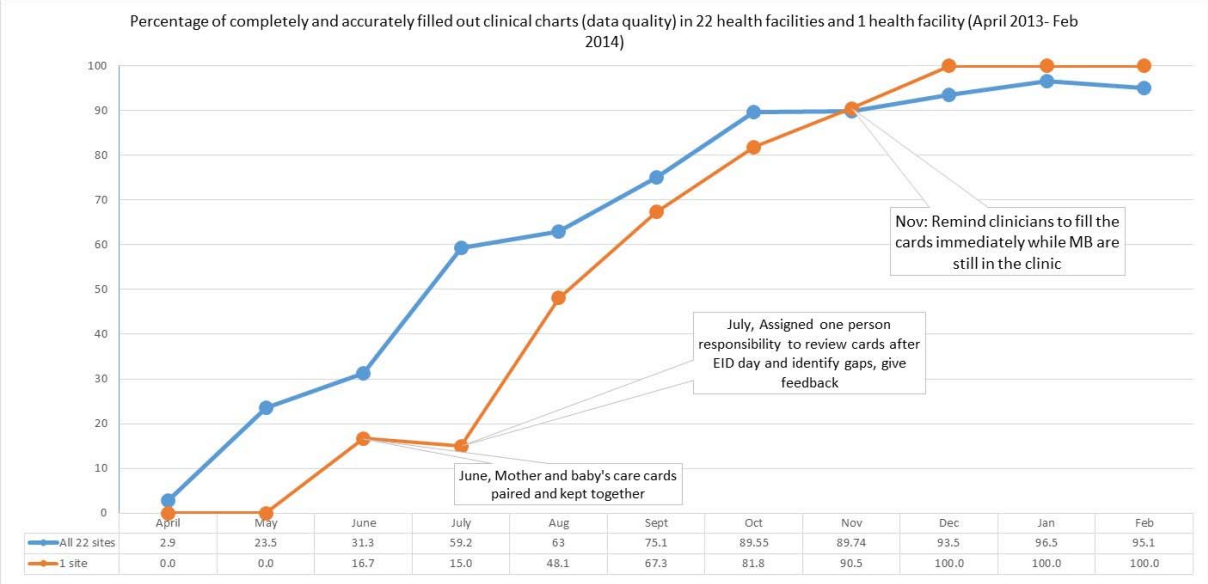
The primary data sources, the exposed infants' diagnosis (EID) register and the EID clinical charts, were not completely filled out, and coaches and teams were unable to determine whether infants were still in care and receiving services. In some cases the information filled out in these tools was inaccurate, codes were wrongly used, and instructions for filling out the cards were not followed. Only 2.9% of the patient records at baseline had complete and accurate data. As a result of these findings, teams were supported to focus on improving data quality of these primary tools, and therefore improve the accuracy of data entering the data system.

The use of data to support decision making is fundamental to quality improvement; teams can only improve what they can measure. It is therefore important that all data tools are completely and accurately filled out so that teams can identify the gaps in their services and processes and address these gaps.

What results did these teams achieve?

By February 2014, the 22 sites had all achieved marked improvement in the proportion of EID registers that were completely and accurately filled out, from 2.9% of records to 95%, as seen in Figure 1 below. The upward trend in the chart implies that we can be certain that the improvement shown was a result of the changes which the sites tested and implemented.

Figure 1: Percentage of EID registers filled out completely and accurately, 22 sites (blue line), April 2013-February 2014



The sites that participated in the demonstration phase of PHFS and that contributed to this change package are listed below.

District	Sites	Supporting implementing partner
Ntungamo district	Itojo General Hospital, Kitwe HCIV, Rubaare HCIV, Ruhaama HCIII	SPRING, STAR-SW
Kisoro district	Kisoro General Hospital, Busanza HCIV, Rubuguri HCIV, Muramba HCIII	SPRING, STAR-SW
Manafwa district	Magale HCIV, Bugobero HCIV, Bubutu HCIII, Bubulo HCIV	TASO
Tororo district	Tororo General Hospital, Nagongera HCIV, Mukujju HCIV, Malaba HCIII	TASO
Jinja district	Mpumudde HCIV, Bugembe HCIV, Buwenge HCIV	TASO
Namutumba district	Namutumba HCIII, Ivukula HCIII, Magada HCIII	SPRING, STAR-EC

II. Harvest Meeting

After approximately 10 months of work, representatives from the 22 teams gathered at a harvest meeting held in conjunction with the third learning session in February 2014 to reflect on their results, discuss both the successful and unsuccessful changes and related evidence which had led to the results, and develop their "best advice" based on their experience that could guide other facility teams to improve data quality.

Feedback provided immediately by the focal person to the staff who filled out EID register on a clinic day. *Photo by Tamara Nsubuga-Nyombi, URC.*

In small groups, teams discussed the changes which they had tested, whether these changes had been successful or not, and related these changes to the results they had for each of the focus areas. These changes were discussed further in plenary to exhaust the list generated. The groups then evaluated these changes and scored them on the basis of evidence from pilot tests, relative importance, level of simplicity, and how scalable these changes were. The proceedings of the harvest meeting have been described in greater detail in the companion change package, *Improving Retention of Mother-Baby Pairs: Tested Changes and Guidance from Uganda*.

The teams participating in the harvest meeting also reflected on their high-level advice to other teams who wanted to improve data quality. They recommended:

1) Fill in the primary data tools before the mother and baby leave. The information on these cards will be used to fill out the registers.
2) Keep the mothers' and babies' cards together, preferably paired and in one place. This will help the health workers to not only link the mother-baby pairs but fill out the infants' cards, since some of the information to be filled out (e.g., the mother's ART number) is on the mother's card.

III. Change Package for Improving Data Quality

Intended use

This change package is intended to provide other quality improvement teams that will be starting on improvement work in PHFS a general idea of areas that have to be considered when improving data quality. The change package identifies the main gaps or problems with data quality identified by the initial 22 PHFS teams, some changes that were successful in those areas, the number of sites that tested the change, results that may be attributed to the changes, and whether the change was successful or not. The detailed table also provides guidance on how these changes were tested and implemented. Teams may not necessarily replicate these change ideas; rather, they should adapt them to suit their clinics.

During the harvest meeting, teams were divided into four groups and asked to evaluate and score each change on a scale of 1-5 (1 being the lowest score and 5 the highest) according to: evidence from pilot tests (from sites implementing the particular change), relative importance, how simple or complex the change was, and how scalable the change was. Table 1 summarises how the participants in the harvest meeting evaluated the changes to improve data quality and lists the key changes implemented in order of ranking, beginning with the highest-rated change. Table 2 provides a comprehensive list of all the change ideas tested, with notes on the number of sites that implemented the change, the results, and specific steps to implement the change.

Table 1: Rank-ordered changes to improve data quality

Changes to improve data quality	Evidence from pilot tests	Relative importance	Simplicity (not difficult or complex)	Scalability	Total rating
Assign QI/data focal person to demonstrate how to fill all the data tools	4.5	5	4.3	4.8	18.6
Train peer educators on job how to fill out some of the data tools on ART clinic days	4	4.5	4.3	4.3	17.1
Assigning EID focal person/supervisor to check all charts for completeness and accuracy and provide feedback to the clinicians	4.3	5	3	4.3	16.6
Updating registers and clients' cards before the mother and baby leave the facility	4	5	3.3	3	15.3

Challenges in implementing some of the changes to improve data quality

In the course of implementing the changes to improve data quality, some sites faced challenges including:

- Absence of the staff assigned to fill out the registers: To address this, teams oriented more staff to be able to fill out the registers
- Staff transfers: The teams made sure that most of the staff and some mentor mothers were able to fill out and check the tools to address this gap

Getting started

Teams seeking to improve data quality might start off by reviewing the prioritised list of changes to implement in Table 1. Teams should refer to Table 2 to identify change ideas that respond to specific barriers to data quality that they have identified and then use the suggestions for implementing the change in the last column.

Finally, we recommend that health facilities aiming to improve completeness and accuracy of data should implement changes in each of the following areas:

1. Changes that improve the skills and competencies of staff to fill out data tools
2. Changes that will ensure primary tools are filled out before the patient leaves the facility
3. Changes that provide for at least one round of checking by another person for accuracy and completion of primary data tools.

These changes are recommended because all the health facilities that tested and implemented these changes reported significant improvement in their data quality.

Improvement work in any of the areas of the PHFS work such as retention of mother-baby pairs, care provided at routine visits, and care at special visits, should be preceded by review and improvements in data quality. Improvement teams need to know and understand the gap in the care provided before they can begin to improve the process of care—this cannot be done unless data is complete and accurate.

Table 2: Detailed change package for improving data quality

Change Concepts	Specific problem being addressed	Change tested and number of sites which tested/ implemented the change	Change successful? Yes/No? Evidence of successful change	How exactly was change tested/ implemented (where, who, how, when, resources required, etc.)?
Competence building	Knowledge gap; some staff, especially new ones, do not know how to fill out data tools completely and accurately	Assigning QI or data focal person to demonstrate to staff how to fill all data tools after the weekly meetings and orient new staff members. **Number of sites tested and implemented change: 10**	**Yes: All 10 health facilities which tested this change reported improvement; e.g.,** Kisoro: before orientation (May 2013) 29.6%; by Aug 2013 83% Manafwa: June 2013 20%; August 2013 90%; and Sept. onwards 100% Muramba: April 2013 0%; June 2013 41%; and August onwards 100% Bugembe: April 2013 47%; by Jan 2014 98% Mpumude HCIV: April 2013 0%; Aug 2013 90%; and Jan 2014 98%	• ART clinic leader /QI leader gathers new staff for a meeting to teach them about data collection and filling registers, emphasizing proper documentation. • The data focal person is asked to continue with hands-on orientation on clinic days. • Whenever there are new staff, orientation meetings are held to orient them. • Action plans are developed after the data person has demonstrated use of data tools. • Charts are checked during the week in all the contact points, including maternity
	Low staffing so not enough time for staff to completely fill out all the tools	On-the-job training of peer educators on how to fill out data tools on ART clinic days **Number of sites tested and implemented change: 6**	The 6 sites which tested this change registered improvement in data quality: e.g., Busanza HCIV: Sept. 2013 63%; Oct 2013 onwards 100%	• On-the-job training done by the peer educator/supervisor before the next client/patient comes in the clinic on topics such as where to indicate weight, MUAC, CD4 etc. In other units, mentor mothers and expert clients help with filling out the cards. These peers, mentor mothers and expert clients are all members of the QI team. • Peers educators are allowed to fill charts in presence of the supervisor to ensure it is done well-only one peer at a time is engaged. • After the clinic, the supervisor meets with the peer to counter check the filled cards.

Change Concepts	Specific problem being addressed	Change tested and number of sites which tested/ implemented the change	Change successful? Yes/No? Evidence of successful change	How exactly was change tested/ implemented (where, who, how, when, resources required, etc.)?
Checking records	EID clinical charts were not filled well, only treatment given was filled out in the card and all other parameters were left blank	Assigning different people (e.g., the EID focal person, supervisor or records person) to check through all charts and provide feedback to the team **Number of sites tested and implemented change: 7**	All 7 health facilities that rolled out this change registered improvement in data quality	• A staff who has undergone training in data, or a records person who a member of the QI team, was assigned as supervisor with the responsibility to check all cards and provide feedback. • In 2 sites, the supervisor or focal person checks charts at the end of the clinic day; in 2 sites, the supervisor checks the cards weekly. • In one HCIV, linkage facilitators trained to identify babies and have them registered in care and mentor mothers look at the charts for *no gaps left* and take them back to the clinicians if they have not filled out completely • On a clinic day with a lighter patient load, some sites ask the clinicians to fill all the parameters by taking back the card to the responsible staff that did not completely or correctly fill the card. • EID focal person orients on data tools during weekly meetings • In one HCIV, checking is done at the end of the clinic by the data focal person on the QI team who informs the health workers about gaps noted during the scheduled QI meetings. • QI team leader carries the incomplete EID clinical charts to the monthly QI meetings to demonstrate any documentation issue • In one health facility, the dispenser checks the mothers' and babies' cards before the mother leaves the facility to ensure that all parameters are filled out; the dispenser then sends the card back to the clinician to complete it. • In one hospital, the data focal person and clinicians review the cards before they are shelved.

Change Concepts	Specific problem being addressed	Change tested and number of sites which tested/ implemented the change	Change successful? Yes/No? Evidence of successful change	How exactly was change tested/ implemented (where, who, how, when, resources required, etc.)?
Update records	There was a tendency to postpone filling out of the cards and doing this at a later date, after mothers and their babies have left the facility	Update the registers before the mother and baby leave the clinic ***Number of sites tested and implemented change: 5***	All the 5 sites which rolled out this change reported improvement: e.g., Kisoro Hospital: Aug 2013 83%; Jan 2014 97%	• During the meeting, QI team leaders asks the clinician and peer mothers who are part of the QI team to fill the cards on the same day in order to accurately record some parameter such as if pregnant or breastfeeding. • One of the hospital QI teams decided to put up a message as a reminder to the clinicians. These reminders are pinned up in the clinical, dispensing and EID rooms to help remind the team to fill in the cards. • At the end of the clinic day, a data person checks to ensure the right parameters have been filled in completely and accurately • 4 sites make sure that the cards are filled in the mother's presence

Annex 1: List of Contributors

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