Leveraging ICT Effectively to Strengthen HIV Prevention for Newborns and Monitoring of Maternal and Child Health in Asia-Pacific
Information and Communication Technology (ICT) Assessment

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Information and Communication Technology (ICT) Assessment: Leveraging ICT Effectively to Strengthen HIV Prevention for Newborns and Monitoring of Maternal and Child Health in Asia-Pacific
By Lori Thorell

Cover photographs:
Row 1: from left to right
1. Children from a small primary school near Savannakhet, Lao PDR. Jim Holmes/UNICEF Lao PDR
2. Ain Mazwin Achau, 5 years old in a class at the KEMAS Preschool in Peta Village, Johor, Malaysia. Palani Mohan/UNICEF Malaysia/2007

Row 2: from left to right
1. Hmong ethnic minority children in the northern Bac Ha district of Lao Cai province in Viet Nam having rides on a makeshift see-saw. Doan Bao Chau/UNICEF Viet Nam/2006

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This assessment on Leveraging ICT Effectively to Strengthen HIV Prevention for Newborns and Monitoring of Maternal and Child Health in Asia-Pacific examines the current and potential use of ICT in strengthening the monitoring of PMTCT, primarily by addressing loss of follow-up in advancing the course towards eliminating paediatric HIV by 2015 or beyond in 11 countries. These countries are: Cambodia, Fiji, India, Kiribati, Philippines, Papua New Guinea, Solomon Islands, Thailand, Timor-Leste, Vanuatu and Viet Nam. It is envisaged that the findings and the way forward outlined in this assessment will bring greater clarity in leveraging ICT effectively to strengthen PMTCT, Maternal and Child Health and the health information system.

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## Acronyms

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<th>Description</th>
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<tbody>
<tr>
<td>ADSL</td>
<td>Asymmetric Digital Subscriber Line</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal care</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>AZT</td>
<td>Zidovudine (also known as ZDZ)</td>
</tr>
<tr>
<td>DBMS</td>
<td>Database Management System</td>
</tr>
<tr>
<td>DSL</td>
<td>Digital Subscriber Line</td>
</tr>
<tr>
<td>GPRS</td>
<td>General Packet Radio Service</td>
</tr>
<tr>
<td>GPS</td>
<td>Global Positioning System</td>
</tr>
<tr>
<td>GSM</td>
<td>Global System for Mobile Communications</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-based care</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting drug users</td>
</tr>
<tr>
<td>IEP</td>
<td>Internet Exchange Point</td>
</tr>
<tr>
<td>IMT</td>
<td>International Mobile Telecommunications</td>
</tr>
<tr>
<td>IP</td>
<td>Internet Protocol</td>
</tr>
<tr>
<td>ISDN</td>
<td>Integrated Services Digital Network</td>
</tr>
<tr>
<td>ISP</td>
<td>Internet Service Provider</td>
</tr>
<tr>
<td>Kbps</td>
<td>Kilobytes per second</td>
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<tr>
<td>LAN</td>
<td>Local Area Network</td>
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<tr>
<td>LR</td>
<td>Linked Response</td>
</tr>
<tr>
<td>M&amp;E</td>
<td>Monitoring and evaluation</td>
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<tr>
<td>Mbps</td>
<td>Megabytes per second</td>
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<tr>
<td>MCH</td>
<td>Maternal and Child Health</td>
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<tr>
<td>MDG</td>
<td>Millennium Development Goals (2015)</td>
</tr>
<tr>
<td>MMR</td>
<td>Maternal mortality rate</td>
</tr>
<tr>
<td>MNCH</td>
<td>Maternal, newborn and child health</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
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<tr>
<td>MTCT</td>
<td>Mother-to-child transmission</td>
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<tr>
<td>NVP</td>
<td>Nevirapine</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic infection</td>
</tr>
<tr>
<td>PCR</td>
<td>Polymerase chain reaction</td>
</tr>
<tr>
<td>PLHA</td>
<td>People living with HIV and AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission (of HIV)</td>
</tr>
<tr>
<td>PPTCT</td>
<td>Prevention of parent-to-child transmission (of HIV)</td>
</tr>
<tr>
<td>PWLHA</td>
<td>Pregnant women living with HIV and AIDS</td>
</tr>
<tr>
<td>RDBMS</td>
<td>Relational Database Management System</td>
</tr>
<tr>
<td>RH</td>
<td>Reproductive health</td>
</tr>
<tr>
<td>SRH</td>
<td>Sexual and reproductive health</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually transmitted infections</td>
</tr>
<tr>
<td>SW</td>
<td>Sex workers</td>
</tr>
<tr>
<td>TCP</td>
<td>Transmission Control Protocol</td>
</tr>
<tr>
<td>UPS</td>
<td>Uninterrupted Power Supply</td>
</tr>
<tr>
<td>WLAN</td>
<td>Wireless Local Area Network</td>
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1. EXECUTIVE SUMMARY

The elimination of HIV in newborns by 2015 is an important milestone that contributes to the Millennium Development Goal to halt the spread of HIV. Globally, the increasing coverage of services to prevent mother-to-child transmission (PMTCT) is contributing to a decline in new HIV infections among children. The number of children newly infected with HIV in 2008 was roughly 18 per cent lower than 2001. In Asia-Pacific, PMTCT coverage has increased steadily, albeit slowly, from 9 per cent in 2004 to 32 per cent in 2009, with Thailand surpassing 90 per cent, with other countries ranging from, for example, 3 per cent in Nepal to 55 per cent in Myanmar. Region wide, the impact of PMTCT services on preventing children from acquiring HIV is not yet clearly determined.

In Asia-Pacific, PMTCT services are being scaled up but the monitoring of outcomes – whether newborns are free of HIV or require initiation of antiretroviral treatment – is not yet systematic or comprehensive. Few countries have reported programme-wide results to account for the number of children testing HIV negative or positive after PMTCT interventions, or documented the efficacy of ARV regimens in reducing transmission risk in newborns during pregnancy and delivery. This results in largely unknown outcomes after years of gearing up the health system to prevent mother-to-child transmission. Operationally, the lack of systematic recording and data collection at facilities underpins a high rate of losses of mothers and newborns at various points of the referral chain.

Figure 1: Few countries track results on infants born to HIV-infected women who received an HIV test within the last 12 months


3 Ibid.
PMTCT spans a cross-section of services run by different departments – from HIV counselling and testing to delivery at designated sites and early diagnosis of HIV-exposed infants – it requires management of referral from one service delivery point to another, and contact between health workers. Inadequate operational linkages between these departments lead to weak monitoring.

Health workers, on the other hand, are unable to monitor pregnant women due to inadequate data management across the service continuum (from ANC to laboratory, maternal ward and paediatric services). Beyond the health system, user fees, distance between ANC and HIV test sites, long waiting times for results, transportation costs to the delivery site, denial and fear of stigma and discrimination are common factors that contribute to losses in the service continuum. Many women do not return to designated sites for delivery; neither is their ARV treatment schedule monitored, and many infants are not tested even after their mothers have delivered under ARV interventions. Finally, even when tested, it is common that many do not receive their results or enrol in antiretroviral therapy when tested positive.4

For governments to credibly account for PMTCT results, it is necessary to strengthen data and referral management, and along with this, conceive a new way for health workers in various departments to work together.

Minimizing loss of follow up among pregnant women testing HIV-positive as well as HIV-exposed infants in the postnatal period not only requires better linkage between health departments, but also greater engagement of community organizations and outreach workers. Improved monitoring of HIV-positive pregnancies and outcomes will contribute to improved facility-based delivery and follow up. The latter will have a multiplying effect on strengthening pregnant women’s ANC attendance, the continuum of care for both HIV-positive and general pregnancies, as well as greater capacity for monitoring Maternal and Child Health.

In addition, the initiative will also contribute to a parallel effort to link with reproductive health and family planning services counselling to improve HIV prevention among women through partners, and HIV testing of males with STIs and TB. This will contribute to prevention of HIV among women whose male partners are at high risk of HIV.

**An Information and Communication Technology (ICT) assessment**

An ICT assessment was conducted in 11 countries (Cambodia, Fiji, India, Kiribati, Papua New Guinea, Philippines, Solomon Islands, Thailand, Timor-Leste, Vanuatu and Viet Nam) to explore the potential use of ICT to strengthen the monitoring of PMTCT outcomes, primarily by addressing loss of follow up in advancing toward elimination of paediatric HIV by 2015 or beyond. It draws on criteria from the Health Metrics Network Framework and Standards for Country Health Information Systems, Geneva, World Health Organization, 2008, and the Control Objectives for Information and related Technology (COBIT).

Through key stakeholder consultation the assessment included an investigation of the current ICT services and infrastructure in countries, how data in the health system is gathered and managed, the referral loopholes that result in loss of patients’ follow up, best practices for monitoring and evaluation, and the information pathway for a network of service providers who could be better supported through information technology. The assessment also emphasized the critical need for; ICT to provide a measurable impact on PMTCT health outcomes (especially loss of follow up), fostering government ownership and buy-in; integrating ICT into overall plans for health information system strengthening (especially for Maternal and Child Health); and being sustainable.

**Key findings**

Overall, the ICT assessment confirmed that “programmes for preventing mother-to-child transmission are difficult to monitor and mother and child follow up was often poor with records of interventions and outcomes not linked, resulting in a lack of information on longitudinal follow up after pregnancy, including on final transmission and survival outcomes.”

“In some countries, a considerable number of women deliver at home and sought the services of private health care providers. Mechanisms to collect and report data from these sources are not always available.”

“Double counting across multiple service delivery points in public health system is also a common issue when countries compile national statistics related to preventing mother-to-child transmission of HIV. For example, in settings in which the

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4 Concept Note, 8th Asia-Pacific PPTCT Task Force Meeting, UNICEF, WHO, UNFPA and UNAIDS, 2010
same pregnant woman living with HIV may receive antiretroviral in antenatal care, in a maternity ward during labour and delivery, or in HIV care sites, double counting may happen if data are aggregated across all service delivery points.\(^5\)

In addition, patient logs and registers are often times incomplete or lost resulting in inaccurate aggregation, recording and reporting from the facilities to the sub-national and national levels.

Despite the overall challenges in many countries, Thailand and India have received acclaim for the management and implementation of HIV/PMTCT programmes. Much of this success can be attributed to leadership and a commitment towards effective data management, monitoring and evaluation, effective use of ICT and continuous process improvement. For example, Thailand’s National AIDS Programme has recognized the importance of data management and effective M&E since the inception of its HIV/PMTCT programmes with both manual and computerized data collection and reporting mechanisms (i.e. Perinatal HIV Intervention Monitoring System (PHIMS) and Perinatal HIV Outcome Monitoring System (PHOMS) supporting these critical functions.

Currently Thailand is exploring a data utilization system for PMTCT programme monitoring from the National AIDS Programme (NAP) database. NAP consists of multiple modules (treatment and follow up, authorization (2nd line ARV) and laboratory request and report, VCT, PMTCT, PEP and report) all linked together with a unique identifier (NAP ID). The unique ID will allow for the strengthening of operational linkages through ICT and ultimately will enable more effective tracing of mothers across Maternal and Child Health/Antenatal care and PMTCT service points and the elimination of duplicate records.

As part of continuous process improvement, Thailand has instituted HIVQUAL-T as an integral part of its National Hospital Accreditation process. Using a performance measurement strategy based on a sampling methodology, HIVQUAL-T facilitates data analysis and reporting for key HIV indicators to facilitate quality improvement.

India’s Strategic Information Management System (SIMS), like NAP, is supporting the evolution of M&E and the management of HIV service delivery with the effective use of ICT by moving from the collection and reporting of summary data at the aggregate level to a more comprehensive system supporting a wider range of service delivery, data analysis, strategic information management, interoperability and data dissemination.

SMS/mobile technology was explored extensively during the ICT assessment, especially in the interest of strengthening

referral management and addressing loss of follow up. Through multiple interviews with key stakeholders, it was
determined that SMS texting as a stand-alone intervention would likely not have any measurable impact on addressing
loss of follow up. Most people living with HIV interviewed during the assessment “did not want to receive text messages
related to their HIV status and treatment, even if the messages sent were made to be innocuous, cryptic in nature and
incurred them no cost.”

Healthcare providers, outreach workers and NGO staff all agreed that when follow up was possible (through contact
information and the willingness of beneficiaries) it was already being done by more traditional methods of phone contact
and outreach. Healthcare providers and outreach workers are often already using their own personal mobile phones to
conduct patient follow ups. Subsidies and incentives that compensate and support personal cell phone use are worthy
of consideration. In fact, India is already beginning to develop funding proposals that include compensation for outreach
workers and personal cell phone use.

Beyond stand-alone ICT interventions, mobile technology can have a significant role in strengthening PMTCT monitoring
and evaluation when integrated into the overall strategy to strengthen the health information system. For example, digital
forms could be texted through mobile phones in remote areas where there is no internet for reporting of data. And access
to the internet through existing and expanded broadband capacity could provide e-learning capabilities for the initial and
on-going training necessary to provide quality healthcare services. It could also extend vital education to the community
in the prevention of HIV and addressing stigma and discrimination.

In the long run, the MCH system could utilize technology with greater infrastructure and network capacity to replace its

<table>
<thead>
<tr>
<th>Level of data collection</th>
<th>Quantity of data</th>
<th>Information needs</th>
<th>Information tools</th>
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<tbody>
<tr>
<td>Global/Regional</td>
<td>Less</td>
<td>Summary indicators for global reporting e.g. MDGs, UNGASS</td>
<td>Global/Regional summary reports</td>
</tr>
<tr>
<td>National</td>
<td></td>
<td>Summary indicators for national needs, e.g. strategic planning and resource allocation</td>
<td>National summary reports</td>
</tr>
<tr>
<td>District</td>
<td></td>
<td>Indicators for district and national reporting and planning</td>
<td>District summary reports</td>
</tr>
<tr>
<td>Facility</td>
<td></td>
<td>Facility management, audits, planning, drug procurement</td>
<td>Facility registers, Logbooks</td>
</tr>
<tr>
<td>Patient</td>
<td></td>
<td>Patient care</td>
<td>Patient charts</td>
</tr>
<tr>
<td>Household and community</td>
<td>More</td>
<td>Understanding population burden of disease and risk; Monitoring and evaluation of DBOs</td>
<td>Household surveys, census, civil registration and demographic surveillance</td>
</tr>
</tbody>
</table>

Data and Information Management
Health Information System Standards
MCH/ANC/PMTCT/LAB/Paediatrics

Leadership
E-Strategy, E-Health, M-Health, Health Information System, ICT Strategic Planning and Governance

ICT Mechanisms
Data hub, Data marts, Data warehouses, Dashboards, and GIS mapping tools (i.e. for Trend analysis, What if analysis, etc.)

E-Learning, Digital forms, Electronic health records, DBMS/applications for service delivery tracking and monitoring, SMS for remote data entry, Alerts/appointment reminders, Smart cards

Standard Operating Procedures, Operational Linkages and Service Delivery
Online education for HIV prevention, treatment and care/addressing stigma and discrimination, Social networks (website, blogs), Digital surveys

Infrastructure Technology Standards
Collaboration tools for content management (i.e. Share Point), Metadata dictionary

Sustainability
Leadership, Funding, Infrastructure Capacity (i.e. broadband, mobile), Partnership and Collaboration, Impact on Health Outcomes, Development and Use of Local Content and Expertise, On-going Education and Training, Long-term Government Buy-in and Ownership

Source: UNICEF Asia-Pacific Regional ICT Assessment 2010

Figure 3: Conceptual framework for strengthening PMTCT/MCH in the health information system by leveraging ICT effectively
currently manual, paper-based systems of aggregating and reporting data. The shift toward digital modes of data collection and recording, through a common database – accessible by authorized health workers in different service delivery points – will better facilitate monitoring of pregnant women, HIV-positive mothers at postpartum and HIV-exposed infants. It will eventually carry spin-off to monitoring all pregnancies for subsequent ANC attendance, early detection of danger signs, delivery and birth registration.

In leveraging ICT effectively for PMTCT, immediate attention is needed to improve data and information management in line with an overall health information system strengthening strategy. It will also entail an alignment of data recording, collection and monitoring with modified operating procedures of health workers across the service continuum to buttress referral management. Ultimately, Information Technology could be used to provide the mechanisms for electronic data collection, transmission, storage, reporting, feedback mechanisms, various SMS/automated notifications, training and education all by way of networks, web application and mobile technology.

To build, strengthen and sustain PMTCT throughout Asia-Pacific, establishing a centre of excellence on data management, M&E, strategic information management and leveraging ICT effectively would be the most efficient and effective approach. Drawing on the experiences of Thailand, India and other countries in formulating successful approaches to M&E and integration into MCH/ANC/LAB services for PMTCT and Maternal, Child and Newborn Care, the centre could provide on-going training and support on data management and operational linkages to build the capacity of countries in the region.

Achieving elimination of paediatric HIV by 2015 or beyond is possible with the necessary investments. And with a foundation built on data management, ICT can drive the change, increase the ownership and foster the partnerships and collaboration that are necessary for realizing the “unlimited” potential of Information Technology and the attainment of this goal.

At the XVIII International AIDS Conference in Vienna this year, the prevention of new HIV infections in children took centre stage. In a question and answer session, Elizabeth Glaser Paediatric AIDS Foundation President and CEO Chip Lyons asked Bill Gates what we could do to step up our efforts to prevent new paediatric infections, and how we could move closer to eliminating HIV and AIDS altogether in children.

“It’s outrageous that we haven’t done better on this,” Gates answered. “We need to get countries to set aggressive goals. We need to get political leaders to recognize the tragedy that this is. If we push for a new focus of efficiency in both treatment and prevention and continue innovation with new tools, we can start writing the story of the end of AIDS.”

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* XVIII International AIDS Conference in Vienna, 2010
The regional ICT assessment emanates from a need and a vision for countries in Asia-Pacific to use technology to facilitate a reachable public health goal: freeing children of HIV from mother-to-child transmission. The need for technology is underpinned furthermore by the ubiquitous presence of internet, information and mobile services, and their unquestioned ability to link people, networks and systems together.

The prevention of mother-to-child transmission of HIV has been deemed an area where innovative technology can be explored, especially in Asia-Pacific, where the estimated population affected is relatively small, and ICT is relatively well-developed, but where mother and child exposed to HIV are not always easy to track.

PMTCT services are delivered through a cross-section of healthcare facilities. The PMTCT pathway – to reduce HIV infection in newborns – spans a range of services, from ANC to laboratory, to maternal wards in hospitals or larger health centres to paediatric services. And to reduce the risk of women themselves getting infected by their husbands and intimate partners, the prevention of parent-to-child transmission is an increasingly recognized strategy. PPTCT spans a larger maze of services from HIV testing and counselling for men with STIs and TB to family planning and reproductive health services. And for parents and children who test positive, the services carry on in a continuum, for opportunistic infections and ARV treatment for life.

In many healthcare settings, these services are not co-located. Distance between the household and ANC clinics, between ANC clinics and HIV test sites, the long waiting time for results, and high transportation costs to ANC clinics, testing and delivery sites are common factors that contribute to losses in the service continuum.

Health workers, on the other hand, are unable to monitor pregnant women as well as track their HIV-exposed newborn due to inadequate data management across the service continuum (from ANC to laboratory, maternal ward and paediatric services). Many women do not return to designated sites for delivery; neither is their ARV treatment schedule monitored, and many infants are not tested even after their mothers delivered under ARV interventions. Finally, even when tested, it is common that many do not receive their results or enrol in ARV therapy when tested positive.

In exploring innovative technology potential, this ICT assessment aims to examine sustainable solutions beyond the often one-off, pilot initiatives. Some of the key underlying causes of poor health outcomes stem from poor data quality and operational bottlenecks that impede the gathering of critical information for decision-making. Up-to-date data is needed, especially in controlling an epidemic, keeping health workers in various service delivery points informed of those testing HIV positive, needing treatment and care, as well as spotlighting inefficiencies in referral management, ARV supplies and placement of human resources.
To improve PMTCT, HIV and maternal health outcomes, it is vital that the health sector begins to standardize patients’ records for follow up, operating procedures for referral across departments and indicators on data to be collected for programme monitoring and evaluation. A simple lack of unique identifiers and vital registration systems throughout the MCH sector, for instance, may result in duplicated or triplicated data. If a woman receives ANC in one town, then relocates to her home village to give birth, as occurs frequently, her records will appear in the health sector’s summary statistics as two unique patients.

In the course of the assessment, it has also been observed that the acute shortage of health workers is compounded by the time needed from the few available in facilities to record data. Paper-based, manually-recorded data is often kept within ANC or health facilities, with few means of tracking patients or verifying data accuracy.

The ICT assessment was conducted between February-July 2010 in 11 countries: Cambodia, Fiji, India, Kiribati, Papua New Guinea, Philippines, Solomon Islands, Thailand, Timor-Leste, Vanuatu and Viet Nam.

It includes an investigation of the current ICT services and infrastructure in these countries, how data in the health system is gathered and managed, the referral loopholes that result in loss of patient follow up, best practices for monitoring and evaluation, and the information pathway for a network of service providers who could be better supported through the use of information technology.

The assessment also comprised a series of consultations with stakeholders and emphasized the critical need for ICT usage to provide a measurable impact on PMTCT health outcomes (especially loss of follow up), foster government ownership and buy-in, be integrated into any overall plans for health information system strengthening (especially for maternal and child health) and be sustainable.

In addition to highlighting the findings, the assessment also puts forth a set of recommendations for UNICEF consideration, in particular by participating country offices in consultation with their government counterparts to develop action plans and associated funding proposals to strengthen PMTCT health outcomes.
3. APPROACH

3.1 Assessment criteria

In evaluating ICT in the context of strengthening PMTCT and Maternal and Child Health, the assessment has drawn criteria from the Health Metrics Network Framework and Standards for Country Health Information Systems, Geneva, World Health Organization, 2008, and the Control Objectives for Information and related Technology (COBIT). Broadly, this has included an exploration of the current ICT services and infrastructure in countries, how data in the health system is gathered, the referral loopholes that result in loss of follow up, the information pathway for a network of service providers – including those from communities who could be supported by web-based or mobile applications and SMS – to bring HIV-positive mothers and their HIV-exposed newborns back for HIV testing, diagnosis and regular treatment, and to have their status recorded for periodic reporting.

More specifically, each criterion provides the necessary insight into where and how ICT could be introduced to strengthen PMTCT and Maternal and Child Health. Often, there is a common notion that leveraging ICT effectively means investing in infrastructure (hardware, software, connectivity, and mobile services). While, of course, this is necessary, it is actually other factors, including data, information and workflow management, leadership commitment to change the way work is done, how and with whom data is shared, and sustainability issues that will ultimately determine whether the unlimited potential of technology is realized.

The paragraphs below describe the high-level criteria used to assess participating countries in their current use and/or future needs in leveraging technology effectively for PMTCT. Appendix A provides the detailed criteria used in the assessment.

Leadership and human resources

Leadership has the greatest impact on the ultimate success of ICT in strengthening health outcomes and health information systems. Ownership at the top level is critical and must be promoted throughout the management chain. All aspects of leveraging technology effectively, from data and information management to promoting standards, interoperability and integration require vision, buy-in, ownership, cooperation and collaboration among all key stakeholders throughout the health system. Without it, the risk of failure becomes almost insurmountable and ICT either does not get implemented in an effective manner or ICT interventions do not help generate meaningful impact on service delivery or health outcomes. The value and role of ICT must be advocated to all stakeholders with knowledge and education providing a new level of awareness about the opportunities and risks of using information technology.
Data and information management

Efforts to improve PMTCT health outcomes and address loss of follow-up are still too often restricted by the lack of needed information or the limited dissemination of the information to people who need it. Data collection for monitoring and reporting is typically a manual process, with data being collated from paper-based registers and referral forms primarily for national and donor reporting without sufficient feedback mechanisms to the people collecting and reporting the data. M&E reports are often confusing to health staff, not user-friendly and are not easily communicated across the health system.

Little or zero data is gathered on the number of HIV-exposed infants. At the same time, information is often collected manually multiple times from different departments, points of service and/or health facilities. The importance of data and information management extends beyond M&E (in this context, most typically the collection of aggregate data and PMTCT indicators for summary reporting at the national level). The health information system, in addition to being essential for M&E, should provide the mechanisms for:

- an alert and early warning capability,
- patient tracking,
- case management,
- health facility management and
- health situation and trend analysis.

Given the current limitations of health information systems in supporting broader information needs, there is a need to review the mechanisms within the health system to manage information and information technology to achieve more consistent results. “ICT can contribute to improving data generation, compilation and sharing, but will require the existence of an information management strategy and data standards to be of optimal value.”

Operational linkages, referral mechanisms and Standard Operating Procedures

There is a need to bridge the physical distance and communication gaps that are vital to ensuring the referral mechanism for PMTCT and improve linkage between departments, between health posts, and all key stakeholders. Loss of follow up is high at every point of the referral chain (often over 50 per cent) and active follow up by health workers is necessary. ICT interventions can either strengthen the current way of operating or offer opportunities to reshape the way work is getting done by promoting integration and interoperability throughout the health information system.

ICT infrastructure, services, systems, support and security

This assessment area explores a wide range of information technology, including infrastructure, services and components; systems (both existing and planned) that could potentially be leveraged for strengthening PMTCT. This area also highlights ICT governance, strategic planning, funding and any best practices or applicable ICT initiatives that could be used to form recommendations for strengthening PMTCT, MCH and ultimately the overall health information system.

Equipped and connected

This assessment area explores the current availability of infrastructure components such as hardware, software, tools and connectivity for use by key stakeholders. This included, but was not limited to: desktop/laptop computers, office productivity software, virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via broadband/DSL/satellite/wireless and mobile service coverage.

ICT systems and mobile initiatives

This area reviews the current systems and applications supporting PMTCT and related health services (i.e. ANC, ART, MCH, lab management, etc.); mobile/SMS initiatives and ICT projects (HIV/MCH) in the planning or piloting stage for future implementation.

The increasing penetration of mobile networks beyond the more urban areas is expanding the opportunity to bring healthcare services to remote areas, even in the vastness of the Asia-Pacific region. Throughout the region, people who have never had regular access to a fixed-phone line or computer are now using mobile phones on a regular basis. Even where other technology and infrastructure are lacking, the demand and increasing access to mobile phones is opening the door to unlimited potential for transforming healthcare services.

Many ICT initiatives, including those involving mobile, SMS and wireless technology were explored in the course of completing this assessment. Most notable were initiatives using remote data entry (to strengthen data collection and reporting); SMS text messages involving alerts and event/appointment reminders; and the mechanisms to promote greater dissemination of data (point-to-multipoint data dissemination).

ICT governance, strategic planning, funding and support

The investment in ICT for HIV and health information system strengthening is growing throughout the region. Almost all countries in Asia-Pacific are building up ICT infrastructures and investing in multiple ICT initiatives in one way or another. While this is positive in many respects, it highlights the increasing need for ICT governance and a broader vision for health information system strategic planning. There is a general view that the ICT landscape is becoming fragmented, with many ICT initiatives being pursued, sometimes without a clear understanding of their purpose in terms of strengthening programmes, health outcomes or the health information system. “After years of experimentation with ICT in often stand-alone, often unsustainable pilot projects, attention is now being drawn to the need to leverage ICT for poverty reduction strategies and the MDGs through a focus on integration, scale and replication.” To achieve integration, economies of scale and replication will require a new vision, enterprise resource and strategic planning, ICT governance and policy formulation at the highest possible levels of government and leadership within the health system.

Security

Security and privacy are ever-growing concerns in the digital world. This is particularly relevant in the protection of personal health information and HIV. Reliability, security, and privacy are reviewed in terms of the policies, procedures and mechanisms that are in place to address access and protection against unauthorized disclosure of information.

Sustainability

The sustainability factors that were considered included:

- Performance measurement (impact on health outcomes and strengthening the health information system)
- Leadership
- Key stakeholder involvement
- Partnership and collaboration
- Infrastructure capacity
- Priority of PMTCT
- Organizational resistance to change
- Development and use of local content and expertise
- On-going education and training
- Financial support and funding and
- Long-term government buy-in and ownership

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8 A 200 Leadershp Imperatve: The Future Built on Broadband, A report by the Broadband Commission, ITU and UNESCO
3.2 The way forward: Leveraging ICT effectively for PMTCT and MCH

The way forward highlights recommendations involving the effective use of ICT that could be used to strengthen PMTCT, the overall health information system and address loss of follow up. Drawing on the findings of each country assessment and best practices, the recommendations intend to provide a foundation for charting an innovative new course in the management, delivery of services and the sharing of data for PMTCT, with the ultimate goal of moving towards virtual elimination of paediatric HIV by 2015 or beyond.

3.3 Country participants

1) Cambodia
2) Fiji
3) India
4) Kiribati
5) Papua New Guinea
6) Philippines
7) Solomon Islands
8) Thailand
9) Timor-Leste
10) Vanuatu
11) Viet Nam

3.4 Detailed tasks

Phase I: Assessment

- Performed a situation analysis to examine infrastructural potential for ICT interventions
- Reviewed relevant mobile and web-based initiatives
- Identified current health system operations for HIV testing, counselling and clinical record management, referral mechanisms, data collection and database management. This included data on HIV testing and counselling of pregnant women, prevention of mother-to-child transmission (PMTCT), testing of newborns and children (number tested HIV positive, negative, died before 18 months or age 5, no. unknown or untraceable), how referrals for treatment are collected and updated, the mechanism for inter-departmental data sharing, and how data is used to track patients.
- Conducted country missions to interview key stakeholders including health system users, healthcare providers, government officials, NGOs and PLHA to examine current standard operating procedures (SOPs) and explore how to leverage ICT effectively
- Presented initial findings to key stakeholders
- Reviewed existing practices to assess ways to adapt SOPs to a mobile telephony or RapidSMS for improved follow ups and accountability of PMTCT results (whether newborns are brought back for a test after ARV interventions, and HIV test results), early infant diagnosis (whether HIV-exposed newborns are placed on Cotrimox and ARV treatment) and ARV treatment (long-term treatment for newborns and mothers testing HIV+)
- Recommended how data and information management and the innovative use of ICT could enhance monitoring of PMTCT outcomes and improve tracking of ARV treatment for newborns and mothers
- Examined types of applications needed and issues of long-term sustainability
- Examined the potential for extending the monitoring of HIV+ pregnancy outcomes to monitoring general pregnancy outcomes
- Prepared Assessment Report

Phase II: Action plan

- Present findings to participating countries, and if a pilot is agreed upon, prepare an action plan
- Assist in preparing a multi-country funding proposal, or components of a Global Fund proposal, depending on country needs
4. Where are countries today: Summary of key findings

The following matrix presents a high-level assessment of each country in relationship to the major assessment areas (Leadership and Human Resources, Data and Information Management, Operational Linkages, Referral Management and Standard Operating Procedures, ICT and Sustainability). The matrix is intended to serve as an overall guide in understanding where countries are and the need to focus attention in developing and maturing ICT capabilities for strengthening PMTCT and health information systems. While the matrix assigns a grade, the grade is not presented for quantitative analysis or even comparison between countries. The formulation of the matrix is subjective and drew from established criteria, observations and consultations with key stakeholders in each country.

Table 1: Summary of findings: Assessing the potential of ICT in 11 Asian countries

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<th>Cambodia</th>
<th>Fiji</th>
<th>India</th>
<th>Kiribati</th>
<th>Papua New Guinea</th>
<th>Philippines</th>
<th>Solomon Islands</th>
<th>Thailand</th>
<th>Timor-Leste</th>
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<th>Viet Nam</th>
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<tbody>
<tr>
<td>A – Developed, matured and continuously improving</td>
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<td>B – Developing and maturing</td>
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<td>C – Needs strengthening</td>
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<td>E – Available (LAB, ART, etc.)</td>
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<td>I – Potential for interoperability and integration</td>
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Table: ICT infrastructure, services, systems, support, tools and security

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<th>Cambodia</th>
<th>Fiji</th>
<th>India</th>
<th>Kiribati</th>
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<tbody>
<tr>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)</td>
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<td>B</td>
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<td>Mobile services (coverage/capacity)</td>
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<td>Existing automated systems supporting PMTCT</td>
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<tr>
<td>On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)</td>
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<td>ICT governance and strategic planning</td>
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<tr>
<td>ICT funding (including Global Fund awards for health system strengthening)</td>
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<td>ICT support</td>
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<td>ICT security</td>
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<td>Sustainability</td>
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The sections below provide a more detailed description of the key findings from each country in relation to the assessment criteria described in section 2. In addition, the key findings below highlight some of the significant factors that have an impact on PMTCT and loss of follow up.

### 4.1 Cambodia

The ICT Assessment for Cambodia highlights many of same opportunities and challenges facing countries in the effective use of ICT to strengthen PMTCT health outcomes. The National Maternal and Child Health Centre (NMCHC) under the Ministry of Health (MoH), in collaboration with the National Centre for HIV/AIDS, Dermatology and STD (NCHADS), is continuing the countrywide scale-up of PMTCT, using the Linked Response approach. Primarily, Linked Response focuses on strengthening referrals and linkages between Reproductive Health and HIV services at the Operational District (OD) level.

While linked response is showing continuous improvement in coverage for key PMTCT indicators, there are opportunities to further strengthen referral management and operational linkages through more effective data and information management. Currently, there are parallel monthly and quarterly monitoring and reporting requirements for NMCHC and NCHADS (with multiple and inconsistent indicators) which are labour-intensive and contribute to inaccurate, incomplete and un-timely reporting of data. In addition, data collection for monitoring and reporting is primarily a manual process, with data being collated from paper-based registers and referral forms into summary tables or Excel spreadsheets for submission. Monitoring reports are said to be confusing, not user-friendly and are not easily communicated across ODs. There is inadequate funding and availability (at OD - LR sites) for Internet and data services which would assist in the timely transmission of data (Excel spreadsheets) to fulfil reporting requirements.

In addition, inadequate communication and tracking between ODs creates issues of follow up and sometimes double counting when mothers move between health facilities and/or ODs for services (especially where no home-based care is available).

In the area of sample submission and the delivery of results for early infant diagnosis PCR testing, there is no standard and systematic process in place to determine if all the samples sent to NIPH are received. In addition, there is no clear path or point of contact for the delivery of test results or an accelerated return process for positive results.

The ICT NGO InSTEDD is currently partnering with NCHADS in Siem Reap Province to automatically generate patient reminders from the electronic patient treatment database. Whenever patients miss an appointment, the reminders are sent via SMS to the mobile phone of the home-based care focal point responsible for following up on that patient. InSTEDD has also developed GEOCHAT which is described more fully in Appendix C.

The MoH’s Health Information System currently collects data for reproductive health; however, there is limited data collected or reported regarding PMTCT through this system. Data for PMTCT is collected and reported through a separate process to both NMCHC and NCHADS involving Excel spreadsheets.

The overall infrastructure and ICT maturity and capacity are developing and maturing across the country. Basic digital services (i.e. email and Internet services) and communication services are more readily available. The presence of InSTEDD will foster greater capacity for ICT in the region.
### Cambodia

**A – Developed, matured and continuously improving**

**B – Developing and maturing**

**C – Needs strengthening**

**E – Available (LAB, ART, etc.)**

**I – Potential for interoperability and integration**

* – TBD

<table>
<thead>
<tr>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information</th>
<th>Operational linkages, referral management and SOPs</th>
<th>ICT infrastructure, services, systems, support and security</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PMTCT/MCH</th>
<th>ICT initiatives</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
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</table>

#### Relevant factors impacting PMTCT health outcomes

- Limited reporting on the status of HIV+ exposed infants
- Delays in receiving positive PCR test results
- Awareness and fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided)
- Recently awarded Global Fund grant for Health Systems Strengthening
- Linked Response has resulted in improved health outcomes for PMTCT

#### Stakeholder interviews and site visits

- LY Penh Sun, M.D., MSc, Deputy Director, NCHADS
- NCHADS staff (Data management)
- Prof Kanal, Director, NMCHC
- Dr. Sovanna, NMCHC
- Ms. Vannary, PMTCT Secretariat
- InSTEDD
- NIPH (EID database & results return process)
- Ministry of Health Information System, Representatives
- Svay Rieng, PMTCT/Paediatric care sites at RH and HC centres
- Prey Veng, NL

#### Leadership and human resources

Leadership has a high degree of understanding and promotes the value of:
- M&E, data and information management, process improvement
- Benefits and risks of using technology
- On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT

#### Data and information management

- Data and information management could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection and reporting beyond the standard PMTCT indicators for monitoring and evaluation
- Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to support high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day-to-day programme operations
- Access to relevant external data sources at all levels could be strengthened
- Plans could be developed for reducing or eliminating the collection of the same or similar data multiple times
- Access to relevant sources of data (internal and external) could be strengthened at all levels

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**Table 2: Summary of findings: Assessing the potential of ICT in Cambodia**
<table>
<thead>
<tr>
<th>Operational linkages, referral management and SOPs</th>
<th>Linked Response strengthening PMTCT outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICT infrastructure, services, systems, support, tools and security</strong></td>
<td></td>
</tr>
<tr>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)</td>
<td>Some healthcare providers and key stakeholders are equipped with the hardware, software and connectivity to use ICT. This may include, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband</td>
</tr>
<tr>
<td>Mobile services (coverage/capacity)</td>
<td>Coverage and service is considered to be continuously expanding (over 75%) with competition driving improvements in services and coverage</td>
</tr>
<tr>
<td>Existing automated systems supporting PMTCT and related programmes</td>
<td>• OI/ART • MCH - Health Information System • Extensive use of Excel spreadsheets that serve as database management systems for M&amp;E</td>
</tr>
<tr>
<td>On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)</td>
<td>NCHADS/InSTEDD Patient Reminder SMS – Siem Reap Province</td>
</tr>
<tr>
<td>ICT governance and strategic planning</td>
<td>It would be useful to ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan / Health System Strengthening Strategy</td>
</tr>
<tr>
<td>ICT funding (including Global Fund awards for health system strengthening)</td>
<td>Cambodia received a Global Fund award for Health System Strengthening. It is unknown if any of these funds will be directed toward Health Information System Strengthening. Global Funding is worthy of consideration (Round 11) for Health System Strengthening focused on Health Information System Strengthening that encompasses data and information management, data warehousing and ICT directed towards strengthening PMTCT and interoperability with MCH and ANC</td>
</tr>
<tr>
<td>ICT support</td>
<td>This area would need to be developed more fully to support any ICT initiative</td>
</tr>
<tr>
<td>ICT security</td>
<td>TBD</td>
</tr>
<tr>
<td>Sustainability</td>
<td>The long-term sustainability of any ICT initiative would need to address: • Leadership • Key stakeholder involvement • Partnership and collaboration • Performance measurement (impact on health outcomes and strengthening the health information system) • Infrastructure capacity • Priority of PMTCT • Organizational resistance to change • Development and use of local content and expertise • On-going education and training • Financial support and funding, and • Long-term government buy-in and ownership</td>
</tr>
</tbody>
</table>
4.2 Fiji

Fiji recently received Global Fund awards for health system strengthening focused on lab management and health information systems. Consultations with key stakeholders in Fiji (most notably ICT/lab management) could not be completed given time constraints; therefore, it has not yet been determined what potential impact these funds will have on strengthening health outcomes for PPTCT, if any.

Still, Fiji is facing similar challenges in the area of data and information management, operational linkages, referral management and M&E. Large amounts of data are being collected which is seen as highly fragmented, with the actual quality of the data unknown. Standard operating procedures and operational linkages are newly developed and are not monitored and evaluated in a systematic manner. The significance of this in relation to ICT is that processes need to be repeatable in order to develop and implement ICT effectively.

Like other Pacific countries, the receipt of confirmatory test results (sent to Australia) can often take more than a month and sometimes longer. While enhancing lab management through a more robust database management system could expedite the receipt of lab results, the testing policy which relies on sending blood samples to Australia for the confirmatory test limits the value of any ICT intervention targeted at strengthening the timeliness of information exchange between labs and healthcare providers. As mentioned above, a Global Fund grant for health system strengthening involving lab management has been awarded. It has not been determined whether the current plans involving strengthening lab management will support or benefit HIV/PPTCT testing. As in other Pacific countries, the current testing policy will limit the potential value of any ICT initiative involving health system strengthening.

Follow up discussions with key stakeholders in Fiji are needed to complete the assessment.

Table 3: Summary of findings: Assessing the potential of ICT in Fiji

<table>
<thead>
<tr>
<th>Fiji</th>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information management</th>
<th>Operational linkages, referral management and SOPs</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PPTCT/MCH</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
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<tbody>
<tr>
<td>A – Developed, matured and continuously improving</td>
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<td>B – Developing and maturing</td>
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<td>C – Needs strengthening</td>
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<td>E – Available (LAB, ART, etc.)</td>
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<td>I – Potential for interoperability and integration</td>
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Relevant factors impacting PMTCT health outcomes

- Limited accounting and reporting on the status of HIV+ exposed infants
- Loss of follow up is high at every point of the referral chain and active follow up by health workers is necessary
- Low no. of women referred for PMTCT services (How many more need to be identified, tested and referred for services?)
- Testing policy promotes excessive delays in receiving confirmatory test results (often more than a month, sometimes two or more), confirmatory tests are sent to Australia
- Costs and fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided – no means to follow up)

Stakeholder interviews and site visits

- Dr Ndombi (Fiji Representative) and Tim Sutton (Deputy Representative)
- Partner Meeting with Ministry of Health, FJN+ and Pacific Counselling and Social Services
- Muhamed Turay, UNAIDS, M&E
- Launch of Pacific Commission on AIDS Report
- Vika Waradi, UNICEF Project Officer, Child Protection
| Leadership and human resources | Leadership has a high degree of understanding and promotes the value of:  
• M&E, data and information management, process improvement  
• Benefits and risks of using technology  
• On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT |
| Data and information management | • Data and information management could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection and reporting for PMTCT beyond monitoring and evaluation  
• Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to supporting high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms to more fully support day-to-day programme operations |
| Operational linkages, referral management and SOPs | More comprehensive documentation of the workflow of the services being delivered, including documenting the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future |
| **ICT infrastructure, services, systems, support, tools and security** | **Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)** | TBD |
| | **Mobile services (coverage/capacity)** | Vodafone and Digicel provide mobile services. Coverage and service is considered good with competition driving expanded coverage and the continuous improvement of services |
| | **Existing automated systems supporting PMTCT and related programmes** | • PATIS (National Health Number Register)  
• Public Health Information System (PHIS) – Paper  
• Counselling Database Link – PATIS  
• Rheumatic Heart System |
| | **On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)** | • Digital Doorway  
• Heart Patient SMS Next Clinical Visit in partnership with Vodaphone |
| | **ICT governance and strategic planning** | It would be useful to ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan / Health System Strengthening Strategy |
| | **ICT funding (including Global Fund awards for health system strengthening)** | Fiji has received Global Fund awards for Health Systems Strengthening and Lab Management. It is not known if any of these funds will be directed toward Health Information System Strengthening |
| | **ICT support** | TBD |
| | **ICT security** | Mechanisms would need to be developed to leverage ICT effectively |
| | **Sustainability** | The long-term sustainability of any ICT initiative would need to address:  
• Leadership  
• Key stakeholder involvement  
• Partnership and collaboration  
• Performance measurement (impact on health outcomes and strengthening the health information system)  
• Infrastructure capacity  
• Priority of PMTCT  
• Organizational resistance to change  
• Development and use of local content and expertise  
• On-going education and training  
• Financial support and funding, and  
• Long-term government buy-in and ownership |
4.3 India

The ICT assessment for India primarily covered the PPTCT programme in Tamil Nadu, one of the most successful in the country. Much of its success is attributable to effective leadership (from the top down), the strategic direction of the National AIDS Control Programme, contributions and collaboration by all key stakeholders, the M&E framework/process, the use of Out Reach Workers (ORWs), ICT (SIMS), and availability of strong operational guidelines and SOPs.

“The National AIDS Control Programme is intensifying its efforts to control and reverse the HIV epidemic in India by implementing a comprehensive and responsive Strategic Information Management System (SIMS) to provide an early warning mechanism and support more evidence driven management. SIMS complements and expands on the Computerized Management Information System (CMIS) which has been the heart of the routine monitoring system. The implementation of SIMS supports the countrywide commitment to strengthen the M&E system and address issues related to data collection, compilation, analysis and use. The M&E framework with the implementation of SIMS provides the foundation to integrate all sources of information and provide the strategic information useful for decision-making.

The Strategic Information Management Strategy through SIMS is also simplifying data collection to a set of key indicators, while providing programme managers regular and in-depth information through various reports. The availability of these detailed reports are providing for greater analysis and utilization of the information being collected.

India’s Strategic Information Management Strategy also delineates specific roles and responsibilities for the expanded focus on strategic information and provides extensive training and guidelines for data collection and use.

India is also introducing SMART Cards for all HIV clients and piloting the use of remote data entry for PMTCT.

**Figure 4: National AIDS control programme M&E framework**

Beyond the M&E Framework and the implementation of SIMS, the ORWs are considered essential to the success of the PPTCT programme and addressing loss of follow up as communicated from the ICTC Staff at Tamil Nadu and BSA Hospital Dhararshala. It is anticipated that the success at Tamil Nadu can be replicated throughout the country, especially with the use of ORWs. The Out Reach Workers visited in Tamil Nadu are highly dedicated, continuing to work and follow up with clients, even when incentives and compensation are delayed by contract and funding negotiations. India is building up to funding proposals subsidies for personal cell phone usage by ORWs in the course of follow up. The records kept by ORWs were exceptionally detailed and complete and they take great pride in maintaining the integrity and confidentiality of records.

Costs, fears of stigma and discrimination were cited as the biggest issues with women seeking services and reason for loss of follow up. Also contributing to the issue of loss of follow up are the women (often migrants) who are often lost to the system with no known address or accurate contact information.

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*Operations Manual for Strategic Information Management Unit, National AIDS Control Organization, Ministry of Health and Family Welfare*
In India, a considerable number of PMTCT services are sought and provided by the private sector. Currently, mechanisms to collect and report data from these sources are not always available.

India has a highly developed ICT infrastructure and mature capacity to support and sustain any ICT initiative.

### Table 4: Summary of findings: Assessing the potential of ICT in India

<table>
<thead>
<tr>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information management</th>
<th>Operational linkages, referral management and SOPs</th>
<th>ICT/infrastructure, service, systems, support and security</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PMTCT/MCH</th>
<th>ICT initiatives</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
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</table>

#### Relevant factors impacting PMTCT health outcomes

- Out Reach Workers considered essential to the success of the PPTCT programme and addressing loss of follow up (ICTC staff from Tamil Nadu and BSA Hospital Dhararnshala)
- Fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided or women seek services from private Institutions – often with no means to follow up
- Literacy
- Many women migrant with no permanent address

#### Stakeholder interviews and site visits

- Dr. D. Bachani, Deputy Director General, NACO
- Dr. Suresh Mohammed, NPO (PPTCT), NACO
- Po Lin Chan, WHO
- Tawfique, UNAIDS
- Dr. A.K. Gupta, Project Director, Delhi State AIDS Control Society
- TATA Teleservices, Mobile Service Provider
- TANSACS (PD, ICTC managers, M&E officer, PPTCT consultant)
- Institute of Child Health, Dr. Suresh, Paediatric ART Centre
- Nandivaram, PHC
- Kilpauk ART Centre
- TNNP+, World Vision
- ICTC Centre / BSA Hospital Dhararnshala (ICTC Director and Counsellors)

#### Leadership and human resources

Leadership has a high degree of understanding and promotes the value of:
- M&E, data and information management, process improvement
- Benefits and risks of using technology
- On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT

#### Data and information management

- Strength of India’s PMTCT Programme is the commitment to Strategic Information Management and M&E
- SIMS and M&E Framework focused on simplifying the collection of data providing detailed reporting capabilities for enhanced data analysis and decision-making
### Operational linkages, referral management and SOPs
- Operational linkages and referral mechanisms are well documented and effectively monitored and measured
- SOPs are well developed

### ICT infrastructure, services, systems, support, tools and security

<table>
<thead>
<tr>
<th>Component</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)</td>
<td>Many healthcare providers and key stakeholders are equipped with the hardware, software and connectivity to use ICT. This may include, but is not limited to: desktop/laptop computers; office productivity software, virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband.</td>
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<tr>
<td>Mobile services (coverage/capacity)</td>
<td>Mobile services: Several service providers. TATA growing provider. 55 million subscribers (DOCOMO – more urban/youth; INDICOM – rural). International Social Entrepreneurial Services: well funded, providing coverage and services to rural/remote areas. Currently supporting: Village centres and self-help groups via connectivity, education and vocational training. Fisherman and agriculture community through weather reports and commodity prices. SMS blasts (for campaigns). Mobile tech surveys. Short code SMS (to call centres, to facilitate two-way communication). Providing refurbished handsets. Available for partnership in serving public health goals.</td>
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<tr>
<td>Existing automated systems supporting PMTCT and related programmes</td>
<td>Centralized Management Information System (CMIS) being replaced by SIMS. Exploring remote data entry for PMTCT (in the initial stages).</td>
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<tr>
<td>On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)</td>
<td>SMART Cards being piloted for electronically tracking and updating records for HIV+ clients.</td>
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<tr>
<td>ICT governance and strategic planning</td>
<td>Dedicated to strategic planning and effective use of ICT.</td>
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<tr>
<td>ICT funding (including Global Fund awards for health system strengthening)</td>
<td>Considered to be efficient and effective.</td>
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<td>ICT support</td>
<td>Mechanisms are in place to protect against unauthorized disclosure of information.</td>
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<tr>
<td>Sustainability</td>
<td>The long-term sustainability of any ICT initiative is considered high given the leadership and high level of ICT capacity and maturity within India.</td>
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## 4.4 Kiribati

The country visit to Kiribati revealed that the prospect of strengthening the delivery of health outcomes through innovation and increasing the capacity of ICT (beyond basic digital services) has high appeal to stakeholders.

Data for patient tracking is maintained on paper records that are manually filed and stored. Data for M&E and reporting is collected on paper forms, from paper registers, then transported or mailed to a centralized statistician. These are then manually collated and synthesized for reporting and dissemination, a highly labour-intensive process. In addition, data is seldom collected or disseminated in a timely manner, or at a level to effectively monitor and evaluate the delivery of PMTCT services at an operational level.
The receipt of confirmatory test results (sent to Australia) can often take more than a month and sometimes longer. While enhancing lab management through a more robust database management system could expedite the receipt of lab results, the testing policy which relies on sending blood samples to Australia for the confirmatory test limits the value of any ICT intervention targeted at strengthening the timeliness of information exchange between labs and healthcare providers.

In most cases, summary data provided by health facilities (service delivery points) is reported vertically up the management chain and used for high-level programme status and/or decision-making without feedback mechanisms back to the providers of the data to communicate the effectiveness or quality of the results. The availability of information and database management systems consists primarily of Excel spreadsheets.

It was also revealed that standard operating procedures and operational linkages are newly developed and are not monitored and evaluated in a systematic manner. The significance of this in relation to ICT is that processes need to be repeatable in order to develop and implement ICT effectively.

Mobile service/SMS capacity is growing throughout the Pacific region, but coverage gaps in remote areas still remain. Kiribati has one mobile service provider operating, so the country is not benefitting from competition in the market that is often seen as pushing greater coverage, capacity and quality of service.

The overall infrastructure, ICT maturity and capacity is in the development stage across the country. Basic digital services (i.e. email and Internet services) are not available and there are no known health systems (i.e. ANC, MCH, RH, etc.) to leverage in strengthening PMTCT related outcomes. This, in combination with the low prevalence of HIV, impacts most viable options for investing in ICT to support and strengthen PPTCT.

Table 5: Summary of findings: Assessing the potential of ICT in Kiribati

<table>
<thead>
<tr>
<th>Kiribati</th>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information management</th>
<th>Operational linkages, referral management and SOPs</th>
<th>ICT infrastructure, services, systems, support and security</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PMTCT/MCH</th>
<th>ICT initiatives</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
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<td>A – Developed, matured and continuously improving</td>
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<td>C – Needs strengthening</td>
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Relevant factors impacting PMTCT health outcomes

- Low no. of women referred for PMTCT services (How many more need to be identified, tested and referred for services?)
- Testing policy promotes excessive delays in receiving confirmatory test results (often more than a month, sometimes two or more), confirmatory tests are sent to Australia
- Limited accounting and reporting on the status of HIV+ exposed infants
- Loss of follow up is high at every point of the referral chain and active follow up by health workers is necessary
- Costs and fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided – no means to follow up)

Stakeholder interviews and site visits

- Chief of Kiribati Field Office and HIV Officer
- Maoto Metai, Adolescents Health Development
- TSKL, Officer in Charge
- KGV Youth Friendly Services
- Dr Revite Kirition, Permanent Secretary
- HIV Technical Working Group members
- Visited PMTCT clinic
| Leadership and human resources | Leadership has a high degree of understanding and promotes the value of:  
|                              | • M&E, data and information management, process improvement  
|                              | • Benefits and risks of using technology  
|                              | • On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT |
| Data and information management | • Data and information management could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection and reporting for PMTCT beyond monitoring and evaluation  
|                              | • Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to support high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day-to-day programme operations  
|                              | • Access to relevant external data sources could be strengthened at all levels |
| Operational linkages, referral management and SOPs | More comprehensive documentation of the workflow of the services being delivered, including documenting the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future |

**ICT infrastructure, services, systems, support, tools and security**

| Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.) | Some healthcare providers and key stakeholders (through other initiatives) are equipped with the hardware, software and connectivity to use ICT. This may include, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband |
| Mobile services (coverage/capacity) | TSKL currently the only mobile service provider – coverage is considered to be good in populated areas and is seeing steady improvement |
| Existing automated systems supporting PMTCT and related programmes |  |
| On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.) |  |
| ICT governance and strategic planning | It would be useful to ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan / Health System Strengthening Strategy |
| ICT funding (including Global Fund awards for health system strengthening) | Developing a funding proposal (Round 11) that includes support for Data and Information Management, Monitoring and Evaluation and relevant Information Technology/ICT mechanisms extended to MCH/ANC/LAB could be considered |
| ICT support | This area would need to be developed more fully to leverage ICT effectively |
| ICT security | Mechanisms would need to be developed to leverage ICT effectively |
### Sustainability

The long-term sustainability of any ICT initiative would need to address:
- Leadership
- Key stakeholder involvement
- Partnership and collaboration
- Performance measurement (impact on health outcomes and strengthening the health information system)
- Infrastructure capacity
- Priority of PMTCT
- Organizational resistance to change
- Development and use of local content and expertise
- On-going education and training,
- Financial support and funding, and
- Long-term government buy-in and ownership

### 4.5 Papua New Guinea

The country visit to Papua New Guinea revealed that there are many opportunities and challenges to strengthening PMTCT with the use of ICT. Data for patient tracking is maintained on paper records that are manually filed and stored. The same information is often collected manually multiple times from different departments and/or points of service. Data is fragmented with no standardized indicators and coding system across the PPTCT/health system, and PPTCT data is not systematically linked to MCH services (ANC/VCT).

Communication gaps between departments and points of service create issues with follow up (and sometimes double counting), especially when mothers move between health centres for services.

Monitoring and reporting requirements of National Department of Health (DOH) and National AIDS Council (NAC) with multiple and inconsistent indicators are labour-intensive and contribute to inaccurate, incomplete and untimely reporting of data. Data collection for monitoring and reporting is primarily a manual process with data being collated from paper-based registers and referral forms and registers, then transported or mailed to a centralized statistician. These are then manually collated and synthesized for reporting and dissemination, a highly labour-intensive process. In addition, data is seldom collected or disseminated in a timely manner or at a level to effectively monitor and evaluate the delivery of PMTCT services at an operational level. M&E forms and reports are said to be confusing to health staff, not user-friendly and not easily communicated across the health system. There is little or no data reported on the number of HIV-exposed infants (neither ProMEST for UNGASS nor HBDB for UA reporting). Loss of follow up is an issue throughout the referral chain (over 50 per cent). Data and reports are difficult to obtain for programme planning and monitoring, especially at the national level. The recording of data for facility-based monitoring and for Mother and Child Health Record Book undertaken by ANC staff (15 min to an hour per client) is completed while attending to the demands of clinical services.

Despite some of the challenges in collecting and reporting data, facilities including those run by NGOs and FBOs are providing useful data for PPTCT and paediatric monitoring and follow up.

Mobile phones are used for follow up when possible at the personal expense of healthcare workers. Internet and data services are not readily available for referral management and communication.

NDoH has developed and implemented HBDB which currently captures adult HIV summary data and is moving toward the collection of paediatric and PPTCT summary data for M&E. HBDB has strengthened the HIV programme and M&E, though data is as good as reported. The ART database is consistently maintained and has strengthened the ART programme. The IT department has developed an ICT Strategic Plan and is in the process of developing a data warehouse for the health sector.

Migende Hospital near Mt. Hagan is a PPTCT success story. It is successfully preventing the transmission of HIV to children. Through its effective and inspired leadership, community involvement, dedicated staff and simplified coding system, it is successfully preventing the vertical transmission of HIV.

The overall infrastructure, ICT maturity and capacity is in the development stage across the country. Basic digital services (i.e. email and Internet services) and communication services are becoming more readily available, although limited in the more remote regions. Inadequate funding is available for ICT support, services and data and information management.
Papua New Guinea is to be commended for incorporating ICT into strategic planning and operational plans. The National Health Plan 2011–2020 specifically highlights ICT as a key component and area of work and the draft PPTCT and Paediatric AIDS Operational Plan emphasizes data and information management as well as the use of ICT. Also, an ICT strategic plan has been developed and a data warehouse for health is in the planning and development stage.

Table 6: Summary of findings: Assessing the potential of ICT in Papua New Guinea

<table>
<thead>
<tr>
<th>Papua New Guinea</th>
<th>Leadership</th>
<th>Human resources</th>
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</table>

Relevant factors impacting PMTCT health outcomes
- Limited reporting on the status of HIV+ exposed infants
- Loss of follow up is high at every point of the referral chain (more than 50%)

Stakeholder interviews and site visits
- Dr. Hilda Polume, Principal Advisor, Family Health Services, National Department of Health (NDoH)
- Dr. Esorom Daoni, Technical Advisor, STI/HIV/AIDS, Disease Control, NDoH
- Wep Kanawi, Director, National AIDS Council (NAC)
- Dr. Lahui Geita, MCH Advisor, NDoH
- Appa Parunga, Surveillance Team, NDoH
- Digicel
- Clinton Foundation
- Partners of One UN

Field visits to:
- Port Moresby General Hospital (ANC, Paediatric, ART clinic)
- Migende Regional Hospital (PPTCT/Paediatric care site)
- Susu Mamas (NGO)
- Mount Hagen General Hospital, Tininga Clinic
- Rabiamul ART Centre

Leadership and human resources
- Leadership has a high degree of understanding and promotes the value of:
  - M&E, data and information management, process improvement
  - Benefits and risks of using technology
  - On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT

Data and information management
- Identify and document key indicators, common data elements
- Document information flow vertically from facilities to national departments and horizontally across facilities, including regional referral hospitals and NGOs
- Streamline reporting process
- Standardize the coding system
- Access to relevant external data sources could be strengthened.
<table>
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<tr>
<th>Operational linkages, referral management and SOPs</th>
<th>More comprehensive documentation of the workflow of the services being delivered, the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICT infrastructure, services, systems, support, tools and security</strong></td>
<td>Some healthcare providers and key stakeholders (through other initiatives) are equipped with the hardware, software and connectivity to use ICT. This may include but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband</td>
</tr>
<tr>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)</td>
<td>DIGICEL and B-Mobile provide mobile services. Coverage and service is considered good with competition driving continuous improvement of services and expanded coverage</td>
</tr>
<tr>
<td>Mobile services (coverage/capacity)</td>
<td>DIGICEL and B-Mobile provide mobile services. Coverage and service is considered good with competition driving continuous improvement of services and expanded coverage</td>
</tr>
</tbody>
</table>
| Existing automated systems supporting PMTCT and related programmes | • HBDB (currently captures adult HIV summary data – moving into collecting paediatric and PPTCT summary data for M&E)  
• ProMEST database  
• Susu Mama developing DBMS for client referral and follow up and to support standard and ad hoc reporting.  
• HIVQUAL (being piloted at four sites) |
| On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.) | An ICT strategic plan has been developed. The draft PPTCT and Paediatric AIDS Operational Plan highlights data and information management and the use of ICT. A data warehouse for health is in the planning and development stage. In the PNG National Health Plan 2011–2020 ICT is specifically highlighted as a key component and area of work |
| ICT governance and strategic planning | Global Funding is worthy of consideration (Round 11) for Health System Strengthening focused on Health Information System Strengthening that encompasses data and information management, data warehousing and ICT directed towards strengthening PMTCT and interoperability with MCH and ANC |
| ICT funding (including Global Fund awards for health system strengthening) | • Dedicated support in the use of IT (desktops, systems, DBMS, etc.); although resources are constrained  
• Limited capacity for ICT  
• Limited funding committed to ICT support and data management |
| ICT support | • Dedicated support in the use of IT (desktops, systems, DBMS, etc.); although resources are constrained  
• Limited capacity for ICT  
• Limited funding committed to ICT support and data management |
| ICT security | Mechanisms would need to be developed to leverage ICT effectively |
| Sustainability | The long-term sustainability of any ICT initiative would need to address:  
• Leadership  
• Key stakeholder involvement  
• Partnership and collaboration  
• Performance measurement (impact on health outcomes and strengthening the health information system)  
• Infrastructure capacity  
• Priority of PMTCT  
• Organizational resistance to change  
• Development and use of local content and expertise  
• On-going education and training  
• Financial support and funding, and  
• Long-term government buy-in and ownership |
4.6 Philippines

The ICT assessment for the Philippines highlighted some of the inherent challenges of leveraging technology effectively for PMTCT which has a low number of women being referred for PMTCT services. Data for PMTCT is collected, filed and stored manually although some health centres that make referrals for PMTCT services as well as STI services are beginning to implement the Community Health Information Tracking System (CHITS).

“CHITS was developed as an integrated disease surveillance system in close consultation with village health workers to best identify their needs. The result was an open source application for the village health centre that combined the features of an electronic health record and clinic appointment system while also integrating modules for national health programmes. CHITS was a starting point for the integration of information systems. Through CHITS, community-based health information was made available not only to public health agencies requiring community-level information but also to the community that generated the information. It enabled the community to use this information for local decision-making.

Currently, CHITS is in use in several health centres in the Philippines. It has made the work of village health workers easier, since information is entered only once during a patient consultation and can then be used to generate the different reports that need to be submitted to the Department of Health. Since data is stored electronically, it is now easier to access and consolidate information, and there is less risk of data loss.

Access is limited to authorized personnel, who undergo two-day electronic health record training prior to using the system. In this training programme, the ethics of health information management are taught with special attention given to the responsibility and security required for digital data. All data is owned by the relevant health centre, which also controls access. The data can be extracted using open source software tools.\(^\text{10}\)

In addition to CHITS another ICT initiative involving Maternal and Child Health is in the early stages of development and implementation, Watching Over Women and Babies (WOMB). “The Department of Health (DOH) conceived the WOMB Project as a maternal and neonatal health tracking system (MNHTS). With the creation of the MNHTS, the DOH will have a system accessible through the internet that will enrol expectant mothers, record the provided maternal healthcare services, and monitor their progress and that of their newborn for appropriate management. This is expected to make the monitoring of expectant mothers and their newborns more efficient. The system is intended to aid the collection of quality data to assist in formulation of policy, aid policy and improve service delivery to beneficiaries.”\(^\text{11}\)

Both CHITS and WOMB highlight the potential, given their basic design, to incorporate the tracking and monitoring requirements of PMTCT into future iterations and evolution of the systems.

Currently, there are no standard, systemic mechanisms for monitoring and reporting. There is a need to directly link to and make known the points of contact within service centres for referrals. A one-stop shop for PMTCT services is being highly recommended to address some of the referral issues between service delivery points. Phones are typically used for follow up and health workers often physically escort women to appointments. Manual SMS appointment reminders are being piloted and used at some sites with promising results. PCR testing is done in monthly batches lowering the volume of tests needed.

The overall infrastructure, ICT maturity and capacity are developing and maturing across the country. Basic digital services (i.e. email and internet services) and communication services are readily available.

\(^{10}\) Nivriti G Patel, Richard E Scott, Kendall Ho, Richard Wootton, Telehealth in the Developing World, 2009 Royal Society of Medicine Press Ltd.

\(^{11}\) Watching Over Mothers and Babies – A Maternal and Neonatal Health Tracking System, Commission on Information and Communications Technology, e-Government Project Plan, Draft, February 2010
Table 3: Summary of findings: Assessing the potential of ICT in the Philippines

<table>
<thead>
<tr>
<th>Philippines</th>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information</th>
<th>Operational linkages, referral management and SOPs</th>
<th>ICT infrastructure, services, systems, support and security</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PMTCT/MCH</th>
<th>ICT initiatives</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
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<tbody>
<tr>
<td>A – Developed, matured and continuously improving</td>
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<tr>
<td>B – Developing and maturing</td>
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<td>C – Needs strengthening</td>
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<td>E – Available (LAB, ART, etc.)</td>
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<tr>
<td>I – Potential for interoperability and integration</td>
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</table>

Relevant factors impacting PMTCT health outcomes

- Limited accounting and reporting on the status of HIV + exposed infants
- Very low prevalence of HIV + women
- Low no. of women referred for PMTCT services (How many more need to be identified, tested and referred for services?)
- Awareness and fears of stigma and discrimination often cited as the biggest issues with women seeking services
| Stakeholder interviews and site visits | • Briefing / discussion with Director of Family Health Office, WOMB Management, National AIDS Program, NEC and Babae Plus  
• WOMB Briefing (automated referral management system)  
• Site visits to review PMTCT Referral Management Practices and observe Automated Information Systems  
• Social Hygiene Clinic, Pasay City  
• Cuyegkeng Health Center, Pasay City (SMS)  
• Dr. Elvira Manaloto Lagrosa Health Center, Pasay City (CHITS)  
• San Lazaro Hospital (Treatment Hub), Jointly with PGH OB-IDS and SACCL |
| Leadership and human resources | Leadership has a high degree of understanding and promotes the value of:  
• M&E, data and information management, process improvement  
• Benefits and risks of using technology  
• On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT |
| Data and information management | Data and information management could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection and reporting for PMTCT beyond monitoring and evaluation  
• Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to supporting high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day-to-day programme operations  
• Access to relevant data sources (internal/external) could be strengthened at all levels |
| Operational linkages, referral management and SOPs | More comprehensive documentation of the workflow of services being delivered, the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future |
| **ICT infrastructure, services, systems, support, tools and security** | Some healthcare providers and key stakeholders (through other initiatives) are equipped with the hardware, software and connectivity to use ICT. This may include but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband  
Mobile service/SMS coverage has grown to more than 80%, although, gaps in some remote areas still exist. Competition is seen to be continuously improving services and coverage  
Existing automated systems supporting PMTCT and related programmes  
• Facility Health Services Information System (FHSIS)  
• STI Sentinel and Etiological Surveillance System (SSESS)  
On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)  
• SMS Appointment System for Pregnancy Care  
• Community Health Information and Tracking System (CHITS)  
• Watching Over Mothers and Babies (WOMB)  
ICT governance and strategic planning | It would be useful to ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan / Health System Strengthening Strategy |
ICT funding (including Global Fund awards for health system strengthening) | Developing a funding proposal (Round 11) that includes support for Data and Information Management, Monitoring and Evaluation and relevant Information Technology/ICT mechanisms extended to MCH/ANC/LAB could be considered
---|---
ICT support | This area would need to be developed more fully to leverage ICT effectively
ICT security | Mechanisms would need to be developed to leverage ICT effectively
Sustainability | The long-term sustainability of any ICT initiative would need to address:
- Leadership
- Key stakeholder involvement
- Partnership and collaboration
- Performance measurement (impact on health outcomes and strengthening the health information system)
- Infrastructure capacity
- Priority of PMTCT
- Organizational resistance to change
- Development and use of local content and expertise
- On-going education and training,
- Financial support and funding, and
- Long-term government buy-in and ownership

### 4.7 Solomon Islands

Data for patient tracking is maintained on paper records that are manually filed and stored. Data for M&E and reporting is collected on paper forms, from paper registers, then transported or mailed to a centralized (MoH) statistician who re-enters the data into Excel spreadsheets. In addition, data is seldom collected or disseminated in a timely manner or at a level to effectively monitor and evaluate the delivery of PMTCT services at an operational level.

The receipt of confirmatory test results (sent to Australia) can often take more than a month and sometimes longer. While enhancing lab management through a more robust database management system could expedite the receipt of lab results, the testing policy which relies on sending blood samples to Australia for the confirmatory test limits the value of any ICT intervention targeted at strengthening the timeliness of information exchange between labs and healthcare providers.

In most cases, summary data provided by health facilities (service delivery points) is reported vertically up the management chain and used for high-level programme status and/or decision-making without feedback mechanisms back to the providers of the data to communicate the effectiveness or quality of the results.

It was also revealed that standard operating procedures and operational linkages are newly developed and are not monitored and evaluated in a systematic manner. The significance of this in relation to ICT is that processes need to be repeatable in order to develop and implement ICT effectively.

In the Solomon Islands, the maturity and capacity for ICT is continuing to grow but is constrained by the need for additional resources. A highly dedicated IT staff has more demands than it can currently meet. Priority for technical support, quite naturally, is given to network administration and desktop support. While health information systems are available to potentially leverage in strengthening PPTCT related outcomes, the database management skills necessary to enhance, support and maintain the systems are unavailable. A Global Fund grant for health system strengthening involving lab management has been awarded. It has not been determined whether the current plans involving strengthening lab management will support or benefit HIV/PPTCT testing. As in other Pacific countries, the current testing policy will limit the potential value of any ICT initiative involving health system strengthening.
Table 8: Summary of findings: Assessing the potential of ICT in the Solomon Islands

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Relevant factors impacting PMTCT health outcomes

- Limited accounting and reporting on the status of HIV+ exposed infants
- Loss of follow up is high at every point of the referral chain and active follow up by health workers is necessary
- Low no. of women referred for PMTCT services (How many more need to be identified, tested and referred for services?)
- Testing policy promotes excessive delays in receiving confirmatory test results (often more than a month, sometimes two or more), confirmatory tests are sent to Australia
- Costs and fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided – no means to follow up)

Stakeholder interviews and site visits

- PMTCT clinic visit (Ruve and Kukum Hospitals)
- Youth Friendly Services Centre SIPPA
- Partner Meeting
- McMillian Mede, ICT Director, MoH, Solomon Islands
- Ms. Baakailakoba, Chief Medical Statistician, MoH, Solomon Islands

Leadership and human resources

Leadership has a high degree of understanding and promotes the value of:
- M&E, data and information management, process improvement
- Benefits and risks of using technology
- On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT

Data and information management

- Data and information management could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection and reporting for PMTCT beyond monitoring and evaluation
- Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to supporting high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day to day programme operations
- Access to relevant external data sources could be strengthened at all levels

Operational linkages, referral management and SOPs

More comprehensive documentation of the workflow of the services being delivered, including documenting the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future.
### ICT infrastructure, services, systems, support, tools and security

| Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.) | Some healthcare providers and key stakeholders (through other initiatives) are equipped with the hardware, software and connectivity to use ICT. This may include, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband |
| Mobile services (coverage/capacity) | Solomon Telekom mobile service provider. Coverage and service is considered acceptable; however, the lack of competition slows progress towards greater coverage and improved services |
| Existing automated systems supporting PMTCT and related programmes |  |
| On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.) | • National Referral Health Information System  
• Pharmaceutical Management System  
• Patient Management System  
• Hospital Information Web Services |
| ICT governance and strategic planning | It would be useful to ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan / Health System Strengthening Strategy |
| ICT funding (including Global Fund awards for health system strengthening) | The Solomon Islands received a Global Fund award for Lab System Strengthening. It is not clear if any of these funds will be directed toward Health Information System Strengthening which is a critical success factor for strengthening PMTCT, MCH, ANC Lab Management and the entire health system |
| ICT support | Dedicated support in the use of IT (desktops, systems, DBMS, etc.); although resources are constrained, especially in the area of database administration |
| ICT security | Mechanisms would need to be developed to leverage ICT effectively |
| Sustainability | The long-term sustainability of any ICT initiative would need to address:  
• Leadership  
• Key stakeholder involvement  
• Partnership and collaboration  
• Performance measurement (impact on health outcomes and strengthening the health information system)  
• Infrastructure capacity  
• Priority of PMTCT  
• Organizational resistance to change  
• Development and use of local content and expertise  
• On-going education and training  
• Financial support and funding, and  
• Long-term government buy-in and ownership |

### 4.8 Thailand

Thailand has received worldwide acclaim for the management and implementation of HIV/PMTCT programmes and has reached all of its MDG targets. Much of this success can be attributed to leadership and a commitment towards effective data management, monitoring and evaluation and continuous process improvement. Thailand’s National AIDS Programme has recognized the importance of data management and effective M&E since the inception of its HIV/PMTCT programmes with both manual and computerized data collection and reporting mechanisms (i.e. Perinatal HIV Intervention Monitoring System (PHIMS) and Perinatal HIV Outcome Monitoring System (PHOMS) supporting these critical functions. As a recognized leader in M&E for PMTCT, Thailand offers a PMTCT Programme Management Training course. The course provides the core elements of developing an effective M&E programme for PMTCT.
There are currently a number of key Routine Health Information Systems (RHIS) in Thailand to monitor progress of activities in different programme areas, including the Care and Treatment Monitoring System and the National AIDS Programme (NAP) database introduced by the National Health Security Office (NHSO) in 2007. NAP is a paperless system for monitoring PLHA care and treatment throughout the country. The management framework of the programme consists of two parts: a benefit package and support system. The benefit package includes drugs, laboratory services, counselling and condoms. The support system focuses on personnel training, quality improvement and M&E. The NAP system consists of four core modules – registration, follow up, authorization (2nd line ARV), laboratory requests and reports, and four additional modules – VCT, PMTCT, PEP and reporting systems. Data in each module can be linked together by NAP ID numbers. The NAP system connects all facilities by a web application running in real time on Internet Explorer with a centralized database. All data is sent to the National Health Security Office electronically. The system uses a PID (Personal Identification Number) as a unique identifier. Currently, Thailand is exploring a data utilization system for PMTCT programme monitoring from the National AIDS Programme (NAP) database.

NAP, through ICT and systemic use of a unique identifier (PIN) for the collection and storage of individual records, is supporting the evolution of M&E and programme management from a focus on the collection and reporting of summary data at the aggregate level to a wider range of data analysis, strategic information management, interoperability, integration and data dissemination.

Figure 6: Thailand National AIDS Programme (NAP) system

Besides the implementation and roll out of NAP, the Perinatal HIV Intervention Monitoring System (PHIMS) is continuing to monitor PMTCT activities in many government hospitals, provincial health offices and health promotion centres. The Perinatal HIV Outcome Monitoring System (PHOMS) monitors HIV-infection outcomes in exposed children in 14 provinces and the CHILD monitoring system is used to monitor children infected with HIV from their mother in a few regions.

In addition, the STI programme monitoring system reports key indicators on STI services, including STI screening, STI reported cases and STI treatment, and the TB/HIV monitoring system monitors TB patients and co-infection of TB among PLHA.

As part of continuous process improvement, Thailand has instituted HIVQUAL-T as an integral part of its National Hospital Accreditation process. Using a performance measurement strategy based on a sampling methodology, HIVQUAL-T facilitates data analysis and reporting to improve quality. Data is entered into HIVQUAL-T from hospital records and databases to populate a list of eligible patients to generate random samples. HIVQUAL-T contains multiple indicators including the following:

13 Ibid.
Key Indicators

- CD4 cells and viral loads (HIV status monitoring)
- PCP and Cryptococcosis (Primary OI prophylaxis for PCP and Crypto)
- Antiretroviral therapy medication
- Tuberculosis screening and treatment
- Prevention with Positive
- Pap smear screening
- Supplemental indicators
- OI prophylaxis for Penicillium, MAC
- Treatment adherence to ARV
- STI screening (Syphilis Chlamydia, Gonorrhea, Ulcer)

The Bureau of AIDS, in cooperation with TUC, revised HIV clinical care indicators and developed new software (HIVQUAL-T Version 5) during FY 2009. HIVQUAL-T Version 5 contains five main groups of indicators including the following:

- CD4 Monitoring before ART
- Anti retroviral therapy
  - Access to ART
  - CD4 monitoring
  - Viral load monitoring
  - ARV adherence
  - ARV side effect monitoring
  - ARV resistance and ART failure
- Prophylaxis of opportunistic infection
  - PCP
  - Cryptococcosis
  - Toxoplasmosis
  - Mycobacterium Avium Complex
  - Disease screening
  - Tuberculosis
  - Cervical cancer
  - CMV Retinitis
  - Sexually transmitted infections
  - Hepatitis B
  - Hepatitis C
- Health promotion
  - Assessment of risk behaviour
  - Mental health assessment
  - Health education
  - Safe sex
  - Disclosure to partner
  - Partner testing

“HIVQUAL generates comparative performance reports that offer important insights for improvement. Providers can assess how their performance rates compared with the previous year. These reports offer a powerful stimulus for improving care and targetting areas for improvement. Clinic providers are encouraged to analyze their HIVQUAL data and assess the internal factors that contribute to their performance.”

Quality improvement activities are evaluated by assessing performance on various indicators over time.

In addition to HIVQUAL-T, Paediatric HIVQUAL-T is currently being implemented in Thailand. Paediatric HIVQUAL-T is a similar yet separate quality assurance and improvement process using the same HIVQUAL concept with software that has been modified to support the analysis and reporting of paediatric HIV indicators. Core indicators for Paediatric HIVQUAL-T include HIV status monitoring (clinical and CD4 monitoring, viral load), OI prophylaxis (PCP), antiretroviral therapy, ARV adherence assessment, ARV side effect assessment, TB screening, growth and development, vaccination, and HIV diagnosis disclosure. Optional indicators include MAC prophylaxis, CMV Retinitis screening, dental health and school attendance.

14 www.cqhv.com
15 www.HIVQUAL.org
SMS/mobile technology was explored extensively during the ICT assessment, especially in the interest of strengthening referral management and addressing the loss of follow up of migrants and stateless people. Through multiple interviews with key stakeholders, it was determined that SMS/mobile technology would likely have little impact on addressing the issue of loss of follow up among migrant and stateless people. Healthcare workers, outreach workers and NGO staff all agreed that when follow up was possible (by contact information and the willingness of beneficiaries) it was already being done by more traditional methods of phone contact and outreach.

Cost, fears of stigma and discrimination (including arrest for migrants and stateless people who are undocumented and/or maintain an illegal status) were cited as the biggest issues with women seeking services and reason for loss of follow up. Most people living with HIV interviewed during the assessment “did not want to receive text messages related to their HIV status and treatment, even if the messages sent were made to be innocuous, cryptic in nature and incurred them no cost.”

Also contributing to the issue of loss of follow up is HIV+ stateless people and migrants not being systematically tracked in PHIMS; HIV+ migrants are also often known to send HIV-exposed infants back to their homeland to live with grandparents or relatives without having the HIV status of the child determined.

SMS/mobile text messaging is under consideration to strengthen referral management in the area of PCR testing: when the 1st positive test is reported at the lab for an infant, an SMS text would be sent to healthcare providers to inform them of the due date for the second confirmatory test. In addition, SMS drug adherence reminders are being considered for Paediatric Treatment and Care.
Table 9: Summary of findings: Assessing the potential of ICT in Thailand

<table>
<thead>
<tr>
<th>Leadership</th>
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<th>Data and information management</th>
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</table>

Relevant factors impacting PMTCT health outcomes

- Costs, fears of stigma and discrimination (including arrest for migrant and stateless persons who are undocumented and/or maintain illegal status) cited as the biggest issues with women seeking services and reason for loss of follow up (inaccurate contact information provided or unknown
- HIV+ stateless people and migrants not tracked systematically in PHIMS
- HIV+ migrants known to often send HIV-exposed children back to their homeland without having the HIV status checked
- GFATM grant for stateless people and migrant access to ARV treatment set to expire

Stakeholder interviews and site visits

- Dr. Nipunporn Voramongkol, Chief of MCH Section, Department of Health, Ministry of Public Health
- Ms. Nareeluck Kulrerk, MCH Section, Department of Health, Ministry of Public Health
- Dr. Pachara Sirivongrangson, Director, Bureau of AIDS/TB/STI, Department of Disease Control, Ministry of Public Health
- Dr. Petchsir Sirinirund, Director, National AIDS Management Centre, Department of Disease Control, Ministry of Public Health
- Dr. Sombat Thanprasertsuk, NPO HIV/AIDS, WHO Thailand
- Ms. Thananda Naiwatanakul, Advisor, Global AIDS Programme, Thailand-U.S.CDC Collaboration
- Dr. Achara Teeraratkul, Chief of Surveillance and M&E, Global AIDS Programme, Thailand-U.S.CDC Collaboration
- Dr. Taweesap Siraprapasiri, HIV and AIDS Specialist, UNFPA Thailand
- Dr. Pope Kosaralak, Faculty of Medicine, Khon Kaen University
- Mr. Karl Brown, Rockefeller Foundation
- Ms. Thongphit Pinyosinwat, Chief of Development, M&E Unit, Raks Thai Foundation
- Dr. Khun (Burmese Doctor), migrant drop in centre, Samut Sakhon Province
- Migrant HIV+ married couple, migrant drop in centre, Samut Sakhon Province
- Dr. Wipat Saliddee chaikool, Chiang Dao District Hospital, Chiang Dao District, Chiang Mai
- Ms. Sriphan Thina, PMTCT Focal Point, Doi Saket District Hospital, Doi Saket District, Chiang Mai
- Ms. Lamduan Mahawan, Manager, AIDS Network Development Foundation, Chiang Mai
<table>
<thead>
<tr>
<th>Leadership and human resources</th>
<th>Leadership has a high degree of understanding and promotes the value of:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• M&amp;E, data and information management, process improvement</td>
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<tr>
<td></td>
<td>• Benefits and risks of using technology</td>
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<tr>
<td></td>
<td>• On-going education and training provided to key stakeholders on</td>
</tr>
<tr>
<td></td>
<td>PMTCT, data management, M&amp;E, process improvement and the benefits of ICT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data and information management</th>
<th>• Strength of Thailand's PMTCT programme is the commitment to data and information management and focus on M&amp;E</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Use of technology to support data management and M&amp;E</td>
</tr>
<tr>
<td></td>
<td>• Data management and M&amp;E is evolving from the aggregation of summary data to the collection of individual records to support a wider range of data analysis and sharing by leveraging technology</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Operational linkages, referral management and SOPs</th>
<th>• Operational linkages and referral mechanisms are well-documented and effectively monitored and measured</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• SOPs are well developed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ICT infrastructure, services, systems, support, tools and security</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)</td>
<td>Many healthcare providers and key stakeholders are equipped with the hardware, software and connectivity to perform their roles. This includes, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/ mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband</td>
</tr>
</tbody>
</table>

| Mobile services (coverage/capacity) | Communication services/mobile service providers: AIS and TRUE provide the majority of mobile services. Mobile service/SMS coverage has grown to more than 85%, although gaps in some remote areas still exist. Competition is seen as continuously improving service and coverage |

<table>
<thead>
<tr>
<th>Existing automated systems supporting PMTCT and related programmes</th>
<th>• PHIMS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• PHOMS</td>
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<tr>
<td></td>
<td>• CHILD Monitoring System</td>
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<tr>
<td></td>
<td>• TB/HIV Monitoring System</td>
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<tr>
<td></td>
<td>• STI Program Monitoring System</td>
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<tr>
<td></td>
<td>• HIVQUAL</td>
</tr>
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<td></td>
<td>• NAP</td>
</tr>
</tbody>
</table>

| On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.) | On-going development of data utilization system for NAP, PMTCT-HIV programme monitoring and WHO-EWIs |

| ICT governance and strategic planning | TBD |

| ICT funding (including Global Fund awards for health system strengthening) | Expansion of STI Programme Monitoring System will be implemented in 43 provinces under the GFATM Round 8 in 2010-2011 |

| ICT support | Considered to be efficient and effective |

| ICT security | Mechanisms are in place to protect against unauthorized disclosure of information |

<table>
<thead>
<tr>
<th>Sustainability</th>
<th>The sustainability of any ICT initiative is expected to be high, from pilot to provincial, regional and national roll-out, especially when a measurable impact on health outcomes can be proven.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Potential ICT Pilots being considered – automated SMS system to strengthen: PMTCT PCR testing, 1st positive test reported, due date for the 2nd Drug Adherence Reminder for Paediatric Treatment and Care</td>
</tr>
</tbody>
</table>
4.9 Timor-Leste

Currently in Timor-Leste the formal PMTCT programme is being developed and operationalized. Given its operational infancy, PMTCT is not systematically linked to MCH services (ANC/VCT) which limits communication and tracking and creates issues with follow-up. Whenever possible, health workers use their own phones for follow up because health centre phones are unavailable.

Most referrals come from providers and NGOs (general population) which limits the number of women referred for PMTCT services. Like in many countries, there is little or no data reported on the status of HIV-exposed infants. Data and reports are often delayed, difficult to obtain and are not easily communicated across the health network.

Timor-Leste is in the process of building its ICT infrastructure. Currently, the communications, networks and infrastructure have limited functioning. Pirated software is used with no maintenance agreements and viruses and power outages limit the availability and use of PCs.

Despite many challenges, the Ministry of Health is in the process of developing and implementing web services, SharePoint and planning the implementation of a Centralized Health Information Management Database.

The health system is almost totally reliant on Timor-Telecom (the only licensed operator) for most communication services, although INET is beginning to provide some web/Internet services. While satellites (VSAT) have been explored for remote areas, they have been determined too cost prohibitive.

The IT staff from MoH and Global Fund are aware of and addressing the core issues in the most effective manner possible given available resources and major challenges.

In the immediate future, there is a need to focus on strengthening data and information management, and strengthening the link between MCH ANC/STI services and PMTCT through additional training and clear policy, procedures and SOPs. The use of electronic forms and mobile technology could help streamline the reporting process. As the central HMIS database is planned and developed it would be beneficial to determine if PMTCT requirements for service delivery, referral management and/or reporting could be incorporated into the design.

### Table 10: Summary of findings: Assessing the potential of ICT in Timor-Leste

<table>
<thead>
<tr>
<th>Timor-Leste</th>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information management</th>
<th>Operational linkages, referral management and SOPs</th>
<th>ICT infrastructure, services, systems, support and security</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PMTCT/MCH</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>C</td>
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<td>C</td>
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<td>*</td>
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<td>C</td>
</tr>
</tbody>
</table>

Relevant factors impacting PMTCT health outcomes

- Limited accounting and reporting on the status of HIV+ exposed infants
- Loss of follow up is high at every point of the referral chain and active follow up by health workers is necessary
- Low no. of women referred for PMTCT services (How many more need to be identified, tested and referred for services?)
- Costs and fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided – no means to follow up)
| Stakeholder interviews and site visits | • MoH (CDC, MCH, HIV and AIDS), UNICEF, WHO, UNDP, Global Funds, NAC  
 • NGOs and CBOs involved in PMCTC and home-based care  
 • People living with HIV  
 • Dili National Hospital (Government’s tertiary level referral care hospital) providing PMTCT services  
 • Bairo Pite Clinic (A private clinic offering PMTCT services)  
 • Maliana Hospital (One of the five regional referral care hospitals with PMTCT/VCT provisions)  
 • ICT and Communication specialists from MoH and Global Fund  
 • Timor Telecom |
| Leadership and human resources | Leadership has a high degree of understanding and promotes the value of:  
 • M&E, data and information management, process improvement  
 • Benefits and risks of using technology  
 • On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT |
| Data and information management | • Information management and data quality could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection, data quality and reporting for PMTCT beyond the current indicators for monitoring and evaluation  
 • Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to supporting high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day-to-day programme operations  
 • Access to relevant external data sources could be strengthened at all levels |
| Operational linkages, referral management and SOPs | More comprehensive documentation of the workflow of the services being delivered, the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future |
| **ICT infrastructure, services, systems, support, tools and security** | **Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)**  
 • Barely functioning communications and infrastructure  
 • In the process of developing hardware and communications capacity  
 • Pirated software used (no maintenance agreements; Microsoft Corporation does not recognize Timor-Leste as an independent government and therefore does not offer government pricing)  
 • Implementing SharePoint |
| Mobile services (coverage/capacity) | Timor-Telecom is the sole provider of mobile services (long-standing licensing agreement with government). While coverage is expanding, the lack of competition is seen to limit service and slow the expansion of services and coverage |
| Existing automated systems supporting PMTCT and related programmes | Excel spreadsheets make up most database management systems |
| On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.) | Centralized health system being planned in the next three years |
| ICT governance and strategic planning | The Ministry of Health is establishing policies for ICT governance and strategic planning |
ICT funding (including Global Fund awards for health system strengthening) | Global Funding is worthy of consideration (Round 11) for Health System Strengthening focused on Health Information System Strengthening that encompasses data and information management, data warehousing and ICT directed towards strengthening interoperability and human resources

ICT support | • Dedicated support in the use of IT (desktops, systems, DBMS, etc.); although resources are constrained • Human capacity for IT services and support is low

ICT security | Mechanisms would need to be developed to leverage ICT effectively

Sustainability | The long-term sustainability of any ICT initiative would need to address: • Leadership • Key stakeholder involvement • Partnership and collaboration • Performance measurement (impact on health outcomes and strengthening the health information system) • Infrastructure capacity • Priority of PMTCT • Organizational resistance to change • Development and use of local content and expertise • On-going education and training • Financial support and funding, and • Long-term government buy-in and ownership

4.10 Vanuatu

The country visit to Vanuatu revealed that data for patient tracking is maintained on paper records that are manually filed and stored. Data for M&E and reporting is collected on paper forms, from paper registers, then transported or mailed to a centralized (MoH) statistician who re-enters the data into Excel spreadsheets. These are then manually collated and synthesized for reporting and dissemination, a highly labour-intensive process. In addition, data is seldom collected or disseminated in a timely manner or at a level to effectively monitor and evaluate the delivery of PMTCT services at an operational level.

The receipt of confirmatory test results (sent to Australia) can often take more than a month and sometimes longer. While enhancing lab management through a more robust database management system could expedite the receipt of lab results, the testing policy which relies on sending blood samples to Australia for the confirmatory test limits the value of any ICT intervention targeted at strengthening the timeliness of information exchange between labs and healthcare providers.

In most cases, summary data provided by health facilities (service delivery points) is reported vertically up the management chain and used for high-level programme status and/or decision-making without feedback mechanisms back to the providers of the data to communicate the effectiveness or quality of the results. It was also revealed that standard operating procedures and operational linkages are newly developed and are not monitored and evaluated in a systematic manner. The significance of this in relation to ICT is that processes need to be repeatable in order to develop and implement ICT effectively.

Currently, Vanuatu is also at an early stage of maturity in developing its ICT capacity and has no known health systems to leverage in strengthening PMTCT related outcomes. Yet Child Protection has developed an innovative approach to birth registration notification through the use of SMS/mobile technology. From remote areas, birth records are being sent via SMS/mobile phone to the central birth registry for early notification. The central birth registry then follows up with the official birth certificate and has a much more accurate account of births in Vanuatu. In addition, an e-Government initiative is underway, which is providing digital services (i.e. email and Internet/web access and telecommunication capabilities). This will expand opportunities to explore ICT interventions in the future.

Vanuatu, like Kiribati, has a very low prevalence of HIV; this, combined with the benefits of strengthening data and information management, operational linkages and referral management, limits the short-term options of leveraging ICT effectively for PPTCT at this time. In the future, the Birth Registration Notification initiative could serve as potential model for reporting RH/STI/HIV related data from remote areas.
### Table 6: Summary of findings: Assessing the potential of ICT in Vanuatu

<table>
<thead>
<tr>
<th>Vanuatu</th>
<th>A – Developed, matured and continuously improving</th>
<th>B – Developing and maturing</th>
<th>C – Needs strengthening</th>
<th>E – Available (LAB, ART, etc.)</th>
<th>I – Potential for interoperability and integration</th>
<th>* – TBD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leadership</td>
<td>Human resources</td>
<td>Data and information management</td>
<td>Operational linkages, referral management and SOPs</td>
<td>ICT infrastructure, services, systems, support and security</td>
<td>Equipped and connected</td>
<td>Mobile services</td>
</tr>
<tr>
<td>B</td>
<td>C</td>
<td>C</td>
<td>C</td>
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<td>C</td>
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</table>

**Relevant factors impacting PMTCT health outcomes**

- No HIV+ test results in the last 3 years
- Low no. of women referred for PMTCT services (How many more need to be identified, tested and referred for services?)
- Testing policy promotes excessive delays in receiving confirmatory test results (often more than a month, sometimes two or more), confirmatory tests are sent to Australia
- Costs and fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided – no means to follow up)

**Stakeholder interviews and site visits**

- Dr. Len Tarivonda, Permanent Secretary, Ministry of Health
- Visit to PMTCT clinic, Vila Central Hospital
- NGO, Won Smol Bag
- Partner Meeting
- Brenda Mutumba – UNICEF Project Officer, Child Protection / Johannes Gambo, ICT Specialist, Developer, SMS Birth Registry Notification System

**Leadership and human resources**

Leadership has a high degree of understanding and promotes the value of:

- M&E, data and information management, process improvement
- Benefits and risks of using technology
- On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT

**Data and information management**

- Data and information management could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection, data quality and reporting for PMTCT beyond monitoring and evaluation
- Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to supporting high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day-to-day programme operations
- Develop and adopt an Information Management and Data Quality guideline
- Provide greater access to relevant data sources (internal/external) at all levels

**Operational linkages, referral management and SOPs**

More comprehensive documentation of the workflow of the services being delivered, including documenting the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future
**ICT infrastructure, services, systems, support, tools and security**

| Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.) | e-Government initiative is equipping and connecting many healthcare providers and key stakeholders with the hardware, software and connectivity to use ICT. This may include, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband |
| Mobile services (coverage/capacity) | TELECOM Vanuatu (SMILE) and Digicel Mobile provide mobile services. Coverage and service are considered good with competition continuously driving expanded coverage and improved services. Digicel is providing a toll-free number for Child Protection Birth Notification System. SMS coverage is supporting some of the most remote areas in Vanuatu |
| Existing automated systems supporting PMTCT and related programmes | • SMS for Birth Registration Notification – SMS application written to paste essential elements of a birth record into multiple SMS messages that are sent to the centralized Birth Registry for early notification and follow up. Uses basic cell phone with GSM coverage  
• e-Government: linking government department to digital services including email and access to web/Internet  
• Digicel toll-free hotline (a landline) for Youth (Family Planning Centre)  
• (See Appendix B for more information)  
• Won Small Bag: provides computer training as part of youth services |
| On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.) | ICT governance and strategic planning: It would be useful to ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan / Health System Strengthening Strategy |
| ICT funding (including Global Fund awards for health system strengthening) | Developing a funding proposal (Round 11) that includes support for Data and Information Management, Monitoring and Evaluation and Relevant Information Technology/ICT mechanisms extended to MCH/ANC/LAB could be considered |
| ICT support | This area would need to be developed more fully to leverage ICT effectively |
| ICT security | Mechanisms would need to be developed to leverage ICT effectively |
| Sustainability | The long-term sustainability of any ICT initiative would need to address:  
• Leadership  
• Key stakeholder involvement  
• Partnership and collaboration  
• Performance measurement (impact on health outcomes and strengthening the health information system)  
• Infrastructure capacity  
• Priority of PMTCT  
• Organizational resistance to change  
• Development and use of local content and expertise  
• On-going education and training,  
• Financial support and funding, and  
• Long-term government buy-in and ownership |
4.11 Viet Nam

The ICT Assessment for Viet Nam also highlights the potential for data and information management to be strengthened and extend beyond M&E and routine reporting for PMTCT. “Viet Nam’s National Monitoring and Evaluation Framework for HIV Prevention and Control Programmes was strengthened over the past two years by developing a single reporting form and database of HIV routine monitoring (Decision 28/QD-BYT) to harmonize donor reporting. This, along with training workshops on the implementation of the HIV routine reporting system, data management and data use, is improving the quality of data. In addition, Viet Nam is further reinforcing collaboration between HIV, STI and reproductive health programmes in a cost-effective manner by developing a national agenda.”16 Other efforts are focused on strengthening M&E and data dissemination and use; however, they are still in their infancy.

Still, some stakeholders stated that monitoring and reporting requirements continue to be labour-intensive and the multiple and sometimes inconsistent indicators continue to be confusing to health staff and not easily communicated across the health system. There is little or no data reported on the number of HIV-exposed infants.

Communication gaps between departments and points of service are said to create issues of follow up. In most cases, summary data provided by health facilities (service delivery points) is reported vertically up the management chain and used for high-level programme status and/or decision-making without timely feedback mechanisms to the providers of the data to communicate the effectiveness or quality of the results. District health centre staff would like to have greater accessibility to the systems (Decision 28, HIV Info) and have enhanced functionality to support more effective monitoring and reporting at their level. In addition, numerous stakeholders expressed the need for greater access to information (through a data warehouse) and enhanced reporting capabilities.

The overall infrastructure and ICT capacity are developing and maturing across the country. Basic digital services (i.e. email and Internet services) and communication services (mobile) are readily available throughout much of the country.

Table 12: Summary of findings: Assessing the potential of ICT in Viet Nam

<table>
<thead>
<tr>
<th>Viet Nam</th>
<th>Leadership</th>
<th>Human resources</th>
<th>Data and information management</th>
<th>Operational linkages, referral management and SOPs</th>
<th>ICT infrastructure, services, systems, support and security</th>
<th>Equipped and connected</th>
<th>Mobile services</th>
<th>Existing systems that support PMTCT/MCH</th>
<th>ICT initiatives</th>
<th>ICT governance and strategic planning</th>
<th>ICT funding (including GF awards for health system strengthening)</th>
<th>ICT support and security</th>
<th>Sustainability</th>
</tr>
</thead>
<tbody>
<tr>
<td>A – Developed, matured and continuously improving</td>
<td>A</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>B</td>
<td>B</td>
<td>B</td>
<td>B</td>
<td>A</td>
<td>*</td>
<td>C</td>
<td>A</td>
<td></td>
</tr>
</tbody>
</table>

Relevant factors impacting PMTCT health outcomes

- Fears of stigma and discrimination often cited as the biggest issues with women seeking services (incorrect contact information provided)

Stakeholder interviews and site visits

- Chief of CSD
- HIV TWG, Communications Officer
- Mr. Nguyen Mac Ha, IT Specialist
- Viet Nam Administration of HIV and AIDS Control (VAAC-MoH)
- Chief of Information Education, Communication and Community Mobilization Unit
- Chief of Care and Treatment Unit (VAAC)
- Chief of M&E Unit (VAAC)
- Leader of MCH DPT, MoH
- WHO, UNFPA, UNAIDS Representative
- Clinton Foundation
- Madame Bihn, CDC/PEPFAR, PMTCT Specialist

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- Hai Phong Provincial AIDS Centre
- Hai Phong Provincial Hospital (Obstetric and Paediatric Wards)
- Thuy Nguyen Hospital, District Health Centre (Director/Deputy Director)
- Commune Health Station
- OPC at Hai Phong City

### Leadership and human resources
Leadership has a high degree of understanding and promotes the value of:
- M&E, data and information management, process improvement
- Benefits and risks of using technology
- On-going education and training provided to key stakeholders on PMTCT, data management, M&E, process improvement and the benefits of ICT

### Data and information management
- Information management and data quality could be strengthened by adopting a more formalized/systematic approach that involves all key stakeholders and looks at data collection, data quality and reporting for PMTCT beyond the current indicators for monitoring and evaluation
- Reporting mechanisms could be strengthened by moving beyond vertical reporting lines and dissemination of data from point to point (from the aggregation of summary data to supporting high-level reporting requirements) into adopting new reporting mechanisms that provide sufficient feedback mechanisms and more fully support day-to-day programme operations

### Operational linkages, referral management and SOPs
More comprehensive documentation of the workflow of the services being delivered, the flow of information vertically and horizontally and more systematic measurement of how referral mechanisms are working could strengthen PMTCT in the short-run and better align the programme to leverage ICT in the future

### ICT infrastructure, services, systems, support, tools and security
- **Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)**
  Some healthcare providers and key stakeholders are equipped with the hardware, software and connectivity to perform their roles. This includes, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband

- **Mobile services (coverage/capacity)**
  Coverage and service is considered to be expanding with competition driving continuous improvement (multiple service providers)

- **Existing automated systems supporting PMTCT and related programmes**
  - Decision 28
  - HIV Info

- **On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)**

- **ICT governance and strategic planning**
  It is beneficial to establish ICT governance policies and strategic plans specifically for Health Information System Strengthening that incorporate ICT mechanisms (including data and information management) for strengthening PMTCT/MCH/ANC health outcomes

- **ICT funding (including Global Fund awards for health system strengthening)**
  Global Funding is worthy of consideration (Round 11) for Health System Strengthening focused on Health Information System Strengthening that encompasses data and information management, data warehousing and ICT directed towards strengthening PMTCT and interoperability with MCH and ANC

- **ICT support**
  Limited support and capacity for ICT dedicated to PMTCT
<table>
<thead>
<tr>
<th>ICT security</th>
<th>Mechanisms would need to be developed to leverage ICT effectively</th>
</tr>
</thead>
</table>
| Sustainability | The long-term sustainability of any ICT initiative would need to address:  
• Leadership  
• Key stakeholder involvement  
• Partnership and collaboration  
• Performance measurement (impact on health outcomes and strengthening the health information system)  
• Infrastructure capacity  
• Priority of PMTCT  
• Organizational resistance to change  
• Development and use of local content and expertise  
• On-going education and training  
• Financial support and funding, and  
• Long-term government buy-in and ownership |
5. THE WAY FORWARD – LEVERAGING TECHNOLOGY EFFECTIVELY TO STRENGTHEN PMTCT AND MCH

The way forward in leveraging technology effectively for PMTCT for many countries involves leadership and information management in line with the overall health information system strategy and ICT strategic plan.

Data and information contained in forms, health records, lab results, treatment orders, referrals, clinical protocols and treatment outcomes is the lifeline of PMTCT and the entire health information system. Strengthening the processes of creating, processing, storing, retrieving analyzing and communicating information requires immediate attention to data management and also entails an alignment of data recording, collection and monitoring with modified operating procedures of health workers across the service continuum to buttress referral management. Investment in ICT infrastructure, components and services will ultimately strengthen PMTCT, MCH and the entire health system. Conceptually, the ICT mechanisms to strengthen PMTCT and help address loss of follow up would include:

- Use of collaboration and data management tools (metadata repository, content/document management such MS SharePoint, etc.)
- Use of digital forms and mobile technology (i.e. to strengthen M&E and provide more effective mechanisms for the reporting and feedback of summary and aggregate data), especially when Internet is not available
- Implementing a PMTCT subsystem (DBMS) for referral and tracking (using an existing open source platform and currently available infrastructure/network) that would provide the capability to:
  - Digitally capture and store patient records that are accessible from multiple locations through the Internet/mobile
  - Record ANC, PMTCT, LAB, ARV healthcare services with automated referrals (and feedback mechanisms upon receipt) to manage the delivery of services among various departments and health facilities (monitoring an HIV+ mother’s treatment/pregnancy/on-going health status and that of her newborn) for the appropriate follow up
  - Integrate SMS into the system to automate notices and alerts
  - Interface with other systems and networks where patients can be tracked
  - Produce standard, ad hoc reports and extracts to data marts/data warehouses
- E-learning for healthcare providers
- Online education and social networks for HIV prevention/addressing stigma and discrimination within the community where Internet is available
- Strategic planning for the expansion of Internet access and infrastructure/network capabilities (in line with government’s e-strategy) to support long-term strengthening of ICT for PMTCT, MCH and Health Information Systems

Appendix C provides the major activities involved in the delivery of PMTCT services and the potential role of ICT in strengthening those activities.
5.1 Information and data management: The essential foundation

Information Management is a complex discipline that encompasses everything from strategies, governance, policies, data management, data quality, metadata, indicators, standardization, data profiling, data cleansing, information and data models, conceptual models, reference architecture, process models, knowledge management and beyond.

"In the context of health sector reform and decentralization, health systems are managed as closely as possible to the level of service delivery. This shift in function between the central and peripheral levels generates new information needs, and calls for the restructuring of information systems to collect and use information for decision-making at local, district, provincial and national levels. Health sector reforms also present major challenges in achieving standardization and ensuring the quality of information – challenges which must be addressed at the central level."

The Health Metrics Network Framework for information management describes the components and standards of a health information system including the system resources, indicators, data sources, data management, and information products for dissemination and use.

Effectively tracking patients across the service continuum and eliminating duplicate records – standards and unique identifiers

The key to tracking people across the PMTCT referral chain requires the development and/or use of a unique ID to easily identify the same person across multiple departments and points of service. Lab records should also document a person’s...
unique ID to directly link to a person’s collected blood samples and test results. A person’s health records should carry
the lab test result codes and identifiers too. The two-way documentation enables cross-checking between multiple points
of service. In addition, to maintain an effective linkage between mothers and newborns, a mother’s record should carry
the unique ID of her own newborn and the newborn’s records should contain the unique ID of the mother. Finally, a
universal coding system and standards are highly beneficial for commonly used data (i.e. personal health information
(name, address, telephone number, etc.) and for reproductive health data that is captured and used for PMTCT as well as
MCH and ANC (i.e. gestation, labour/delivery information, etc.).

Figure 9: Health metrics network framework for information management

Components and Standards of a Health Information System

- HIS resources
- Indicators
- Data sources
- Data management
- Information products
- Dissemination and use

Strengthening Health Information Systems

- Principles
- Processes
  - Leadership, coordination and assessment
  - Priority-setting and planning
  - Implementation of health information system strengthening activities
- Tools

HMN Goal
Increase the availability, accessibility, quality and use of health information vital for decision-making at country and global levels.

Figure 10: Horizontal flow of information across the PMTCT referral chain – sample data needed for effective tracking

- Unique ID (personal ID, patient ID, etc.): to uniquely identify the same person across the service continuum
- Personal data: name, address, phone no., DOB, etc.
- Lab results: blood sample no., test results (HIV status, CD4 count, etc.)
- Lab records should maintain unique personal ID for each blood sample
- ANC/MCH data (gestation, etc.)*
- ARV/ART treatment schedule/results
- Labour/delivery data (scheduled delivery date, delivery date, etc.)
- Child ID (for mother records to carry the unique ID of all children born)
- Mother ID (for baby records to carry the unique ID of birth mother)
- Referred from
- Referred to
  *mother records only
In addition to being vital for tracking patients throughout the PMTCT referral chain, standard and unique identifiers are necessary for interoperability and the development of relational database management systems (DBMS). A well-designed DBMS is the most effective mechanism to eliminate the duplication of records and improve the management of data.

**Defining “metadata” and developing a “metadata” repository: An essential step towards effective data management and quality data**

Within the context of strengthening PMTCT and the health information system, it is necessary to identify, define and document all the indicators, data sources and information products for dissemination and use. It is also necessary to document the horizontal flow of information (as described above) to service delivery points (referrals) and the pathways for feedback mechanisms and the generation of reports. Typically this process is an integral part of data management and provides the foundation for defining “metadata”. Metadata is data that specifies its definition and use. This includes information about physical data representations, technical and operational processes, rules and constraints and data structures.

Metadata management is the practice that enables information to become more accurate, accessible, complete, consistent, timely, valid and relevant. All information management metadata should be documented and published in a metadata repository made available to key stakeholders. When developing a metadata repository, the metadata that needs to be defined includes, but is not limited to, the following:

**PMTCT indicators: Challenges for data and information management**

A number of core indicators are collected and calculated for PMTCT and currently serve as the foundation for M&E and summary reporting. Because the core indicators for PMTCT consist primarily of derived values (percentages calculated from nominators and denominators), they represent unique challenges for data quality and information management. Typically derived data is not standardized and requires special attention when developing the mechanisms for its collection and calculation to ensure consistent and quality reporting. Therefore, it is critical to clearly define and document all PMTCT indicators. The Regional Initiative for the Elimination of Mother-to-Child Transmission of HIV and Congenital Syphilis in Latin America and the Caribbean: Regional Monitoring Strategy documents the definition and use of key indicators.

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Defining metadata – Better quality data for dissemination and use

<table>
<thead>
<tr>
<th>Who / What / Where</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who</td>
<td>Owns the data (i.e. MCH, HIV, Health, Paediatrics). The owner establishes metrics for the accuracy, timeliness, relevancy, consistency and validity</td>
</tr>
<tr>
<td>Maintains the data (i.e. data steward)</td>
<td></td>
</tr>
<tr>
<td>Has authorized access to the data</td>
<td></td>
</tr>
<tr>
<td>What</td>
<td>Definition, what the data means (i.e. entity, attribute definitions, valid values and sample data)</td>
</tr>
<tr>
<td>Where</td>
<td>The data comes from, is collected and stored (i.e. registers, logs, forms, application systems)</td>
</tr>
<tr>
<td>When</td>
<td>Data is collected (i.e. monthly, quarterly)</td>
</tr>
<tr>
<td>How</td>
<td>Is the data used (e.g. summary reports, management information, marketing analytics)</td>
</tr>
</tbody>
</table>

Additional metadata for application systems

<table>
<thead>
<tr>
<th>Who / What / Where</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who</td>
<td>Maintains the application i.e. IT owner</td>
</tr>
<tr>
<td>Maintains the database (i.e. production DBA; other IT staff)</td>
<td></td>
</tr>
<tr>
<td>Is responsible for change control</td>
<td></td>
</tr>
<tr>
<td>What</td>
<td>The data looks like e.g. logical/physical data models</td>
</tr>
<tr>
<td>The data means e.g. table/column definition, and sample data</td>
<td></td>
</tr>
<tr>
<td>The data profile looks like (e.g. for each table and column, the number of rows, min/max values, distinct values)</td>
<td></td>
</tr>
<tr>
<td>Interfaces feed into and feed out of the application</td>
<td></td>
</tr>
<tr>
<td>Where</td>
<td>Data originates from</td>
</tr>
<tr>
<td>Data is stored</td>
<td></td>
</tr>
<tr>
<td>Server</td>
<td></td>
</tr>
<tr>
<td>Database name</td>
<td></td>
</tr>
<tr>
<td>IP address</td>
<td></td>
</tr>
<tr>
<td>Archived including near and offsite storage</td>
<td></td>
</tr>
<tr>
<td>When</td>
<td>Updated, backed-up, archived, stored offsite, extracted for “Extract, Transform and Load” (ETL) processes</td>
</tr>
<tr>
<td>How</td>
<td>Data is moved between applications (e.g. transfer mechanisms, ETL processes)</td>
</tr>
</tbody>
</table>

PMTCT indicators as the foundation of its regional monitoring strategy. It defines the rationale, numerator, denominator, frequency of reporting, data sources, measurement tools, strengths and weakness of each core indicator used for PMTCT. This is representative of the some of the “metadata” that is essential to capture indicators for effective data management.

5.2 Information Technology (IT) standards: Key to interoperability and the development and use of open source technology

IT standards are the telecommunication, network, application and security, etc. protocols that allow for interoperability and the sharing of information among networks and systems. Where data and information standards are concerned, with defining a common understanding of “what is being communicated and shared”, IT standards are more focused on “how”. IT standards also play a significant role in the development of open source technology. In the future, Information Technology standards will hinge on an open source development underscored by the need to understand clinical goals in building products or services. The development of standards for healthcare IT will largely depend on the creation of new open source technology and will replicate the success of other technologies currently on the market, such as open source web servers and browsers.
The primary benefit of the open source development is that the technology typically uses current industry standards. The community of stakeholders, providers and governments must drive the development of key health IT products and services that meet operational needs. Appendix D provides a sample of some open source software and tools that could be leveraged to strengthen PMTCT and health information systems.

5.3 Mobile technology: Focus on strengthening the health information system and supporting healthcare workers

Mobile phones are being viewed as an almost perfect solution to many of the communication challenges inherent in the developing world. And while mobile technology is showing great promise and providing greater avenues for “education, awareness, remote data collection, remote monitoring, training, disease and epidemic outbreak tracking, diagnostics and treatment and disaster relief support” [19], there is yet another reality. Expecting to effectively reach the most disadvantaged through mobile phones, especially women and children (let alone when HIV is involved), may be an unrealistic goal at this time. In her case study “Mobile Cell Phones and Poverty Reduction: Technology Spending Patterns and Poverty Level Change among Households in Uganda” (Diga, 2008) Kathleen Diga writes:

> The findings also reveal continuous gender imbalance of mobile phone usage and spending through unequal partner control of the mobile phone and reduced well-being from unprofitable phone calls. Some households suffer under the exacerbated control of assets by the family’s income earner or household head... In these situations, access to mobile phones neither changed traditional gender roles nor offered a marked improvement in the women’s quality of life. In theory, the greatest benefit of a mobile phone is that they give the user access to a much broader circle of communication than before. The problem with this theory is that it assumes that mobile phones are a solution in and of themselves – that the presence of a mobile phone immediately offers unlimited access to the outside world. Yet many poor women in developing countries are unable to access this technology...

ICT interventions directed at health information system strengthening and providing appropriate subsidies and incentives to healthcare providers in using mobile technology may be the most effective way to reach the most disadvantaged at this time.

5.4 Broadband: Accelerating progress towards MDGs and the transformation of health service delivery

During the recent convening of the Broadband Commission for Digital Development “it was stated that the new realities and opportunities for digital development must be fixed without delay in the minds of world leaders as a leadership and development imperative.” [20] For many in the international development community, the key to meeting the “interlinked MDGs agenda of poverty, education, gender, health and environment are “scalability” and “replicability”. It is generally believed that progress towards achieving MDGs can be accelerated with ICT in general and broadband in particular.” [21]

In addition, combining increased broadband capacity with mobile technology has the potential to promote transformation in health service delivery. “The digitization of vital patient medical records offers key advantages in the recording, preservation and availability of patients’ medical history and risk factors for maximum information disclosure in diagnosis and treatment. Electronic health records can help treat patients along complex referral chains, speeding up treatment and potentially improving health outcomes.” [22]

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[21] Ibid.
5.5 Health information system strengthening: A vital component of health system strengthening

As country leaders grapple with the nature and extent of healthcare reform and the direction of health system strengthening, one thing is becoming increasingly clear – no matter how far reform measures go, it is unlikely that health systems can see a significant transformation in healthcare without the successful implementation of advanced technology to reduce costs and improve the delivery of healthcare services.

Momentum is growing toward future Global Fund proposals focused on Health Information System Strengthening aligned with Health System Strategic Planning and overall clinical goals and service delivery. Leveraging technology effectively to strengthening PMTCT is an ideal avenue to advance this growing momentum and move toward virtual elimination of paediatric HIV, and in the process contribute to the attainment of other MDGs related to maternal and child health.

Figure 12: The Global Fund framework for health system strengthening highlights information systems and technology

Global Fund - HSS Framework

Global Fund East Asia and the Pacific Regional Meeting, 14-17 September 2010
## 5.6 Summary of recommendations

**Table 13: Summary of findings and conclusions: Assessing the potential of 11 Asian countries**

<table>
<thead>
<tr>
<th>Summary of Findings</th>
<th>Cambodia</th>
<th>Fiji</th>
<th>India</th>
<th>Kiribati</th>
<th>Papua New Guinea</th>
<th>Philippines</th>
<th>Solomon Islands</th>
<th>Thailand</th>
<th>Timor-Leste</th>
<th>Vanuatu</th>
<th>Viet Nam</th>
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<tr>
<td>A – Developed, matured and continuously improving</td>
<td>B</td>
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<td>B</td>
<td>B</td>
<td>B</td>
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<td>B</td>
<td>B</td>
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<tr>
<td>B – Developing and maturing</td>
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<tr>
<td>C – Needs strengthening</td>
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<tr>
<td>E – Available (LAB, ART, etc.)</td>
<td>C</td>
<td>C</td>
<td>C</td>
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<td>C</td>
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<tr>
<td>I – Potential for interoperability and integration</td>
<td>*</td>
<td>C</td>
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<td>*</td>
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<td><strong>Operational linkages, referral management and SOPs</strong></td>
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<td>B</td>
<td>C</td>
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<td>C</td>
<td>C</td>
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<tr>
<td><strong>ICT infrastructure, services, systems, support, tools and security</strong></td>
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<tr>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.)</td>
<td>B</td>
<td>C</td>
<td>C</td>
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<td>C</td>
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<td>C</td>
<td>C</td>
<td>B</td>
<td>B</td>
<td>C</td>
</tr>
<tr>
<td>Mobile services (coverage/capacity)</td>
<td>B</td>
<td>B</td>
<td>B</td>
<td>C</td>
<td>B</td>
<td>B</td>
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<td>C</td>
<td>B</td>
<td>B</td>
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</tr>
<tr>
<td>Existing automated systems supporting PMTCT</td>
<td>E</td>
<td>E</td>
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<td>E</td>
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</tr>
<tr>
<td>On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)</td>
<td>I</td>
<td>I</td>
<td>*</td>
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<tr>
<td>ICT governance and strategic planning</td>
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</tr>
<tr>
<td>ICT funding (including Global Fund awards for health system strengthening)</td>
<td>*</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>B</td>
<td>C</td>
<td>*</td>
<td>C</td>
<td>*</td>
</tr>
<tr>
<td>ICT support</td>
<td>B</td>
<td>C</td>
<td>C</td>
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<td>C</td>
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<td>*</td>
<td>C</td>
<td>C</td>
<td>B</td>
<td>C</td>
</tr>
<tr>
<td>ICT security</td>
<td>B</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>*</td>
<td>C</td>
<td>C</td>
<td>B</td>
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<td>B</td>
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<tr>
<td><strong>Sustainability</strong></td>
<td>B</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>C</td>
<td>*</td>
<td>C</td>
<td>C</td>
<td>B</td>
<td>B</td>
<td>C</td>
</tr>
</tbody>
</table>

**Summary of recommendations**

**Leadership and human resources**
- Promote Information Management and Health Information System Strengthening
- Dedicate more full-time resources to data and information management
- Provide initial and on-going training for data collection, data and information management and data quality
- E-Learning

**Data and information management**
- Develop and implement Information Management and Data Quality Strategy in line with the overall Health Information System Strategy
- Come up with a data and information profile/inventory
- Define “metadata” for all data, indicators, information products (for all departments) that span across the PMTCT referral chain
- Invest in collaboration/content management tools and build a “metadata” repository
- Document information flow vertically from facilities to national departments and horizontally across facilities, including regional referral hospitals and NGOs
<table>
<thead>
<tr>
<th>Operational linkages, referral management and SOPs</th>
<th>Review existing SOPs and referral mechanisms to ensure that effective linkages and feedback mechanisms are in place between MCH/ANC/STI services and PMTCT – incorporate data quality mechanisms. Update policy, procedures, and standard operating procedures and continuously assess the prospective use of ICT</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICT Infrastructure, services, systems, support, tools and security</td>
<td>Equipped and connected (i.e. hardware, software, connectivity, collaboration tools, etc.) Ensure that healthcare providers and key stakeholders are equipped with the hardware, software and connectivity to perform their roles. This includes, but is not limited to: desktop/laptop computers; office productivity software; virus protection; printers, scanners; phones (landline and cell/mobile); teleconferencing; electricity/UPS; connectivity to the Internet via wireless/DSL/broadband</td>
</tr>
<tr>
<td>Mobile services (coverage/capacity)</td>
<td>Provide incentives and subsidies to healthcare, outreach and home-based care workers for personal cell phones used for PMTCT follow up Seek to leverage applicable data about subscribers (i.e. age, sex, location, that could help target communications to relevant populations through SMS text messaging Toll-free numbers for health workers and clients</td>
</tr>
<tr>
<td>Existing automated systems supporting PMTCT</td>
<td>Define “metadata” for existing systems</td>
</tr>
<tr>
<td>On-going and planned ICT initiatives for health information systems (i.e. LAB, MCH, ANC systems, data marts/warehouses, etc.)</td>
<td>Proactively engage IT department to consider interoperability requirements for integrating PMTCT/ANC/MCH/LAB into ICT strategies for strengthening health information system</td>
</tr>
<tr>
<td>ICT governance and strategic planning</td>
<td>Ensure that on-going ICT governance and strategic planning is in place and in alignment with the overall Health Information Strategic Plan Health System Strengthening Strategy.</td>
</tr>
<tr>
<td>ICT funding (including Global Fund awards for health system strengthening)</td>
<td>Develop funding proposals (Round 11) that include support for Data and Information Management, Monitoring and Evaluation and relevant Information Technology and ICT mechanisms</td>
</tr>
<tr>
<td>ICT support</td>
<td>Build ICT support into programme plans and funding proposals. Budget for ICT support and develop cost-effective models to sustain and build its operation</td>
</tr>
<tr>
<td>ICT security</td>
<td>Identify and address security requirements early in the development of ICT (i.e. security models and mechanisms). Use Information Technology (IT) standards.</td>
</tr>
<tr>
<td>Sustainability</td>
<td>The long-term sustainability of any ICT initiative would need to address: • Leadership • Key stakeholder involvement • Partnership and collaboration • Performance measurement (impact on health outcomes and strengthening the health information system) • Infrastructure capacity • Priority of PMTCT • Organizational resistance to change • Development and use of local content and expertise • On-going education and training • Financial support and funding, and • Long-term government buy-in and ownership</td>
</tr>
</tbody>
</table>
6. **CONCLUSIONS**

At the XVIII International AIDS Conference in Vienna this year, the prevention of new HIV infections in children took centre stage. In a session moderated by Elizabeth Glaser Paediatric AIDS Foundation President and CEO Chip Lyons, Bill Gates praised the foundation’s global efforts, and spoke about the urgent need to expand the reach of services to prevent mother-to-child transmission of HIV.

In a question and answer session with audience members, Lyons asked Gates what we could do to step up our efforts to prevent new paediatric infections, and how we could move closer to eliminating altogether HIV and AIDS in children.

“It’s outrageous that we haven’t done better on this,” Gates answered. “We need to get countries to set aggressive goals. We need to get the political leaders to recognize the tragedy that this is.”

He added that he was “horrified” that only 45 percent of women currently had access to PMTCT services. “In terms of cost of intervention, the impact on the lives involved, that should be something that we have above 90 percent. This is one where, even in the next year, I’d like to see a big change. If we push for a new focus of efficiency in both treatment and prevention and continue to innovate new tools we can start writing the story of the end of AIDS.”

**Investments are necessary to reasonably move toward elimination of paediatric HIV by 2015 in the Asia-Pacific region**

Despite the progress made in rolling out PMTCT in Asia-Pacific, it is evident for most countries that significant investment is needed to strengthen the mechanisms within PMTCT and maternal and child healthcare to manage information and leverage Information Technology effectively.

“To make a systemic impact that enables health systems to support healthier mothers and babies, we must understand the key gaps in health information flows throughout health systems. This will enable health planners and health technologists to adopt innovations and policies to address failures and help save lives.”

Without a commitment to health information system strengthening and leveraging ICT effectively, the referral gaps within PMTCT will most likely remain. Programme risks will continue and unique opportunities for improvement will remain unrealized. Many low-value, high-risk information systems projects will continue to be developed unimpeded and poorly managed as technology promoters blindly respond by pushing technology in narrowly defined pilot projects.

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23 XVIII International AIDS Conference in Vienna, 200
24 Ibid.
25 Health Information is Health Aid: How Data Can Revolutionize Health Care, October 6, 2010 www.mhealthafrica.com
Furthermore, most PMTCT managers will continue to operate without the information they need to truly improve health outcomes. Many health workers will struggle unsuccessfully, under increasing workloads, to do their jobs better as they are hampered with information systems that simply add on another automated layer of work.

Given these risks, sustained attention is vital to reinforce the link between accountability for returns on information-related investments and the realization of improved health outcomes for PMTCT, as well as maternal and child survival.

In a number of countries, investments over the next five years (2011-2015) directed at data and information management, standardization, monitoring and evaluation, strategic planning, human resources and ICT are required to accelerate the scale-up of PMTCT services towards achieving the virtual elimination of HIV among children by 2015 or beyond.

To build, strengthen and sustain PMTCT throughout Asia-Pacific, establishing a centre of excellence on data management, M&E, strategic information management and leveraging ICT effectively would be the most efficient and effective approach. Drawing on experiences of Thailand, India and other countries in formulating successful approaches to M&E and integration into MCH/ANC/LAB services for PMTCT and maternal, child and newborn care, the centre could provide on-going training and support on data management and operational linkages to build the capacity of countries in the region.

With greater recognition of data management as vital to MCH and health system strengthening, ICT can be leveraged more fully to strengthen health outcomes by providing the mechanisms to move away from paper-based systems into the digital world. In the long run, this will not only strengthen MCH capacity for monitoring pregnancies, but also bridge the digital divide between urban centres and peripheral health services.
APPENDICES
APPENDIX A
DETAILED ASSESSMENT CRITERIA

Leadership, human resources, education and training

a) Leadership has an understanding of the value of:
   • Data and information management, documented workflow, process improvement
   • Benefits and risks of using technology
b) Are healthcare workers overworked and often burdened by the demands of the data collection, administrative and reporting processes?
c) Initial and on-going education and training provided to key stakeholders on PMTCT: data/information management, referral management, process improvement, ICT

Data and information management

a) Is a Health Information System Strategy available?
b) Is a formal data quality and information management programme in place?
c) Are dedicated roles and responsibilities for data and information management beyond the vertical reporting done for M&E defined and funded?
d) Are policies established for defining data, naming the data, established domains, business rules?
e) Has a metadata repository been developed?
f) Have guidelines been developed for capturing and reporting data, edit checking, validating and auditing of data, and correcting data errors?
g) Is data collected, filed and reported manually?
h) Is the same information collected manually multiple times from different departments and/or points of service?
i) Are indicators and the coding system standardized across the PMTCT/health system?
j) Common understanding among all stakeholders about the data collected for PMTCT and related ANC/MCH/Lab/Paediatric referral services
k) Data reported on the status of HIV-exposed infants
l) Data collected for PMTCT is timely, accurate and complete/incomplete and inaccurate
m) Data and reports are easily obtained and communicated across the health network
n) Plans for reducing or eliminating the collection of the same or similar data multiple times
o) All key stakeholders have access to the relevant information that is needed to fulfil their role
p) Relevant information is shared among authorized stakeholders and the shared information is aggregated to support PMTCT, HIV, MCH, public health, disease management and health system surveillance
q) Health service providers, health system managers, planners and researchers have access to tools that provide access to knowledge and information supporting collaboration and the remote delivery of healthcare
r) Opportunities to strengthen the health system and linkages between the points of service/department are being pursued (developing standards, fostering interoperability and integration)
Operational linkages, referral mechanisms and Standard Operating Procedures

a) SOPs are documented?
b) The information pathway for services being delivered is documented, including the flow of information vertically and horizontally with feedback loops to measure how referral mechanisms are working

ICT services, support, systems and security

COBIT is a framework that suggests an approach to Information Technology management with the objective of ensuring that the technology delivers the information that meets the business needs of an organization and stakeholders.

COBIT (Control Objectives for Information and related Technology) is designed to be an information technology governance (IT governance) aid to management in their understanding and managing of the risks and benefits associated with information and related technology. It is intended that COBIT provide clear policy and good practice for IT governance throughout the organization. COBIT provides a tool to assist management with better IT governance so that the information that an entity needs to achieve its objectives can be managed by the four broad domains.

<table>
<thead>
<tr>
<th>Plan and Organize (PO)</th>
<th>Deliver and Support (DS)</th>
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<tr>
<td>PO1 Define a strategic IT plan</td>
<td>DS1 Define and manage service levels</td>
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<td>PO2 Define the information architecture</td>
<td>DS2 Manage third-party services</td>
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<td>PO3 Determine technological direction</td>
<td>DS3 Manage performance and capacity</td>
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<td>PO4 Define the IT processes, organization and relationships</td>
<td>DS4 Ensure continuous service</td>
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<td>PO5 Manage the IT investment</td>
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<td>PO6 Communication management aims and direction</td>
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<td>PO7 Manage IT human resources</td>
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<td>PO8 Manage quality</td>
<td>DS8 Manage service desk and incidents</td>
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<td>PO9 Assess manage IT risks</td>
<td>DS9 Manage the configuration</td>
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<td>PO10 Manage project</td>
<td>DS10 Manage problems</td>
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</table>

<table>
<thead>
<tr>
<th>Acquire and Implement (AI)</th>
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</thead>
<tbody>
<tr>
<td>AI1 Identify automated solutions</td>
<td>ME1 Monitor and evaluate IT performance</td>
</tr>
<tr>
<td>AI2 Acquire and maintain application software</td>
<td>ME2 Monitor and evaluate internal control</td>
</tr>
<tr>
<td>AI3 Acquire and maintain technology infrastructure</td>
<td>ME3 Ensure regulatory compliance</td>
</tr>
<tr>
<td>AI4 Enable operation and use</td>
<td>ME4 Provide IT governance</td>
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<tr>
<td>AI5 Procure IT resources</td>
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<tr>
<td>AI6 Manage changes</td>
<td></td>
</tr>
<tr>
<td>AI7 Install and accredit solutions and changes</td>
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</tbody>
</table>

Sustainability

The sustainability factors to be considered in promoting a potential pilot to strengthen health outcomes for PMTCT include:

- Leadership
- Key stakeholder involvement
- Partnership and collaboration
- Performance measurement (impact on health outcomes and strengthening the health information system)
- Infrastructure capacity
- Priority of PMTCT
- Organizational resistance to change
- Development and use of local content and expertise
- On-going education and training
- Financial support and funding, and
- Long-term government buy-in and ownership
# Appendix B
## Major Activities of PMTCT and the Potential Use of ICT

<table>
<thead>
<tr>
<th>Major PMTCT Activity</th>
<th>The Potential Role of ICT (i.e. PMTCT subsystem and automated alerts and appointment reminders and enhanced reporting)</th>
</tr>
</thead>
</table>
| Attended ANC and Referred (or self-access at HIV clinic) | - Electronic health records, remote data entry  
- Register, retrieve, validate and update records online  
- Remote data entry, Smart Cards |
| Offered and Agreed to HIV Test | - Order lab test (electronic referral)  
- Receive confirmation of receipt of lab test request (electronic receipt)  
- Schedule visit to receive results and counselling (if not immediately provided) online  
- SMS appointment reminder sent to healthcare providers, home-based care and/or Out Reach Workers / NGOs  
- Lab sends lab test results back to referring HF (automated alert for positive results) |
| Got Results and Counselling | - Update online record with results  
- Schedule safe delivery with ANC/MCH |
| Offered and Accepted ARV treatment | - Referral to ART (CD4 count below 250) or other MCH services as needed  
- Schedule treatment for ARV/to receive results and counselling (if not immediately provided)  
- Receive confirmation of AR treatment referral  
- ARV/ART records treatment, notice sent to the referring HF |
| Safe Birth at Health Facility (ARV) and Dispensed Medication to Baby, Safe feeding | - SMS delivery reminder sent to healthcare providers, home-based care and/or NGOs  
- Update record following safe delivery  
- Schedule next visits for mother (ARV/ART), mother/baby or baby/caretaker |
| Continued ARV Treatment for Mothers’ Health | - SMS delivery reminder sent to healthcare providers, home-based care and/or NGOs  
- Update record following safe delivery  
- Schedule next visits for mother (ARV/ART), mother/baby or baby/caretaker  
- Send back service results  
- Update record |
| DNA PCR at 6 Weeks | - Order lab test (electronic referral)  
- Receive confirmation of receipt of lab request  
- Healthcare workers/home-based carer receives SMS appointment of scheduled PCR test  
- Lab sends test results back to referring HF (automated notice sent for positive results)  
- Schedule next test for 7.5 months or >
| DNA PCR at 7.5 months | • Order lab test (electronic referral)  
| | • Receive confirmation of receipt of lab request  
| | • Healthcare workers/ home-based carer receives SMS alert for scheduled PCR test  
| Positive Child Referred to Paediatrics Department | • Electronic referral to Paediatrics for services as needed  
| | • Schedule appointment  
| | • Receive confirmation alert of ARV treatment referral  
| | • ARV/ART records treatment, alert sent to the referring HF  
| | • Treatment adherence reminders for children  
| Negative Child Discharged from PMTCT | • Update record with discharge notice |
GeoChat – InSTEDD

GeoChat is a flexible open source group communications technology that lets team members interact to maintain shared geospatial awareness of who is doing what where – over any device, on any platform, over any network. GeoChat allows you and your team to stay in touch with one another in a variety of ways: through SMS, email and on the surface of a map in a web browser. Whether you are sitting at a computer with a high-speed Internet connection, or on the go with your mobile phone, GeoChat lets you react to events on the ground with maximum agility, forming cross-organizational virtual teams on the fly, linking field to headquarters, and keeping everyone on your team connected, in sync, and aware of who is doing what, and where. www.instedd.org

FrontlineSMS

FrontlineSMS is award-winning free, open source software that turns a laptop and a mobile phone into a central communications hub. Once installed, the programme enables users to send and receive text messages with groups of people through mobile phones. What you communicate is up to you, making FrontlineSMS useful in many different ways:
- No Internet connection required
- Attach a phone and SIM card, and pay your local operator per SMS as usual
- Store all phone numbers and records, all incoming and outgoing messages
- All data lives on your computer, not on servers controlled by someone else
- You can send messages to individuals or large groups, and reply individually – useful for fieldwork or during surveys
- Easy to install and requires little or no training to use
- Developers can freely take the source code and add their own features
- Can be used anywhere in the world simply by switching the SIM

Frontline Forms

Frontline Forms is used in conjunction with FrontlineSMS and allows the creation of simple paper forms on your computer, which can then be sent to a Java-enabled mobile phone through a text message. Information is collected directly on the phone and once data input is complete, the information collected can be sent back to FrontlineSMS as a compressed text message. There is no need for a mobile phone network, special device or PDA. www.FrontlineSMS.com

RapidSMS

RapidSMS is a SMS-based (text message) framework that manages data collection, complex workflows, and group coordination using basic mobile phones – and can present information on the Internet as soon as it is received. So far, RapidSMS has been customized and deployed with diverse functionality: remote health diagnostics, nutrition surveillance, supply chain tracking, registering children in public health campaigns and community discussion. RapidSMS was designed to be customized for the challenges of governments,
multilateral, international and non-government organizations and development practitioners: working effectively in spite of geographical remoteness of constituents, limited infrastructure (roads, electricity), and slow data collection (due to paper-based records, slow courier systems, etc). www.rapidsms.org

OpenMRS

OpenMRS is an (open source) software platform and a reference application which enables design of a customized medical records system with no programming knowledge (although medical and systems analysis knowledge is required). It is a common platform upon which medical informatics efforts in developing countries can be built. The system is based on a conceptual database structure which is not dependent on the actual types of medical information required to be collected or on particular data collection forms and so can be customized for different uses.

OpenMRS is based on the principle that information should be stored in a way which makes it easy to summarize and analyze, i.e. minimal use of free text and maximum use of coded information. At its core is a concept dictionary which stores all diagnoses, tests, procedures, drugs and other general questions and potential answers. OpenMRS is a client-server application, which means it is designed to work in an environment with many client computers.

projectUNITE – Strengthening health outcomes for HIV

projectUNITE has taken the OpenMRS concept along with mobile technology and is extending it to a high-level platform to improve health outcomes for HIV in India.

Within the scope of projectUNITE the following services are available:

For patients:
- **A Pill Reminder** service dials out to patients at patient-specified “pill times”, and reminds them to take their dose of medication.
- **A Self-reported Adherence** service dials out to patients and inquires about their adherence to their medication, using standard self-reported adherence questionnaires.
- **An Appointment Reminder** service dials out to the patient several days prior to their next scheduled clinic visit, to remind the patient to schedule their next appointment at the HIV clinic.
- **The Symptoms** module allows patient to dial into the system and report symptoms they are struggling with. Based on the individual medical status of the patient, as well as the standard treatment guidelines as published (in this case) by NACO, TAMA will then advise the patient what to do: the system can conclude that the patient may self-medicate the symptom, e.g. when it concludes that it must be a side effect of the recently prescribed HIV medication. Alternatively, the system may conclude that the patient should visit the HIV clinic, e.g. when it suspects that the symptoms are due to progressing disease status. Also, if the system cannot come to a reliable conclusion either way, it will advise the patient to visit their family doctor, and recommend that the family doctor may contact the HIV clinic for consultation, to thus strengthen the overall continuum of care extended to the patient.
- **The Health Tips** service dials out to the patient and provides health tips targeted by the patient's individual medical status as well as environmental factors such as holiday seasons, e.g. a patient may provide practical tips about good food practices prior to a holiday season.
- **The Socialization** service allows the patient to dial in and alert TAMA that they would like to talk to someone. HIV patients often find themselves isolated, in large extent due to the stigmatization of the disease. The positive effects of social networking amongst HIV patients are well known in clinical practice. The TAMA system helps patients connect to such social networks upon their request.

For clinics:
- **The Alerts** service sends an alert to the HIV clinic if one of their patients meets specific conditions that would require the attention of the clinic. This could be, e.g. when TAMA concludes the patient has not been adhering to their medication (through the Pill Reminder service or the Self-reported Adherence service), when the patient reports particular symptoms, or when a patient fails to schedule their next appointment.
- **The Reports** service provides the clinic with a comprehensive view on all interaction between TAMA and the patient since the patient's last visit. A typical consultation at the HIV clinic always starts with the question “how have you been in the past 3 months?” – and it is difficult to get an accurate image of the patient’s well-being based solely on the patient’s response. This TAMA report helps complement that picture, and thereby allows the clinic to better target their intervention based on the individual patient's history.
- **The Patient Admin** service allows clinics to maintain patient health record data in TAMA, thus enabling the TAMA platform to personalize its interventions based on that record.
Leveraging ICT Effectively to Strengthen HIV Prevention for Newborns and Monitoring of Maternal and Child Health in Asia-Pacific

Project UNITE high-level platform architecture

**Specialized Clinic**
- Local EMR
- No local EMR
- Internet
- Upload
- Data entry

**Community HIT Platform**
- Patient History DB
- Clinical Knowledge DB
- Open MRD Health Records
- Diagnostic
- Events/Alerts
- Messaging (Cell Phone/IVR)

**3rd parties**

**Source:** projectUNITE

**Funded by Bill and Melinda Gates Foundation, developed by Grameen Foundation**

**Founded by J&J Development Grant**

**Provided by Robertson Research Institute**

**Future Developments**

**Project Introduction**

**Patients and Patient Support**

**Primary Healthcare**

**Outreach Workers**

**Patients**

25/10/2010

**Project Introduction**

Patients and Patient Support

Source: projectUNITE
APPENDIX D
GLOSSARY OF TERMS

Asymmetric Digital Subscriber Line (ADSL) – a high-speed digital telephone connection that operates over an existing telephone line, allowing the same line to be used for voice calls. ADSL offers transmission speeds that are usually in the range of 2Mbps to 8Mbps, and are used mainly for Internet access. The term *asymmetric* is used because the data flows more quickly from the telephone exchange to the user than from the user to the exchange – because most web users are more interested in receiving data quickly from websites rather than uploading it to websites. The term *symmetric* is used for connections where the data flows at the same speed in both directions, which is essential for accessing websites where there is a high degree of interactivity.

Broadband/Bandwidth – refers to a signalling method that includes or handles a relatively wide range (or band) of frequencies. The wider the bandwidth, the greater its information-carrying capacity.

Data Cleansing – the act of detecting and correcting (or removing) corrupt or inaccurate records from a record set, table or database. Used mainly in databases, the term refers to identifying incomplete, incorrect, inaccurate, irrelevant, etc. parts of the data and then replacing, modifying or deleting this dirty data.

Data Governance – an emerging discipline involving the convergence of data quality, data management, data policies, business process management and risk management surrounding the handling of data in an organization. Through data governance, organizations are looking to exercise positive control over the processes and methods used to collect, define report and manage data. Data governance is a set of processes that ensures that important data assets are formally managed throughout the enterprise.

Database Management System (DBMS) – a set of software programmes that controls the organization, storage, management and retrieval of data in a database. DBMS are categorized according to their data structures or types. The DBMS accepts requests for data from an application programme and instructs the operating system to transfer the appropriate data. The queries and responses must be submitted and received according to a format that conforms to one or more applicable protocols. When a DBMS is used, information systems can be managed more easily as the organization’s information requirements change. New categories of data can be added to the database without disruption to the existing system.

Data Management – a set of procedures to collect, store, analyze and distribute data. Once data is collected, a sound management approach is essential. Firstly, a metadata dictionary is necessary to accurately describe the data elements. Next, effective data storage procedures require a well-designed logical structure to permit data retrieval and analysis. Data analysis and presentation include calculating indicators and preparing tables and graphs. Finally, the data should be made available to all those who can use and act upon them.
Data Profiling – the process of examining the data available in an existing data source (e.g. a database or a file) and collecting information and statistics about the data. The purpose of these statistics may be to:

1. Find out whether existing data can easily be used for other purposes
2. Improve the ability to search the data by tagging it with keywords, descriptions, or assigning it to a category
3. Give metrics on data quality, including whether the data conforms to particular standards or patterns
4. Assess the risk involved in integrating data for new applications, including the challenges of joins
5. Assess whether metadata accurately describes the actual values in the source database
6. Understand data challenges early in any data-intensive project, so that late project surprises are avoided. Finding data problems late in the project can lead to delays and cost overruns
7. Have an enterprise view of all data, for uses such as master data management where key data is needed, or data governance for improving data quality.

Data Warehouse – an integrated information-storage area that consists of a data repository bringing together multiple databases from various data sources, and a report generating facility.

Data Over Cable Service Interface Specification (DOCSIS) – an international telecommunications standard that permits the addition of high-speed data transfer to an existing Cable TV (CATV) system. It is employed by many cable television operators to provide Internet access over their existing hybrid fibre coaxial (HFC) infrastructure.

Digital Subscriber Line (DSL) – a family of technologies that provides digital data transmission over the wires of a local telephone network. DSL originally stood for digital subscriber loop. In telecommunications marketing, the term Digital Subscriber Line is widely understood to mean Asymmetric Digital Subscriber Line (ADSL), the most commonly installed technical variety of DSL. DSL service is delivered simultaneously with regular telephone on the same telephone line.

E-Learning – comprises all forms of electronically supported learning and teaching. It includes all computer- and network-enabled transfer of skills and knowledge. E-learning applications and processes include web-based learning, computer-based learning, virtual classroom opportunities and digital collaboration. Content is delivered via the Internet, intranet/ extranet, audio or videotape, satellite TV and CD-ROM. It can be self-paced or instructor-led and includes media in the form of text, image, animation, streaming video and audio.

General Packet Radio Service (GPRS) – a packet-oriented mobile data service for GSM including 2G and 3G cellular communications.

Geographic Information Systems (GIS) or geospatial information systems – a set of tools that captures, stores, analyzes, manages, and presents data that are linked to location(s). In the simplest terms, GIS is the merging of cartography, statistical analysis and database technology.

Global Positioning System (GPS) – a space-based global navigation satellite system that provides reliable location and time information in all weather conditions and at all times and anywhere on or near the earth when and where there is an unobstructed line of sight to four or more GPS satellites.

Global System for Mobile Communications (GSM) – a cellular network or digital mobile telephony system that is widely used in Asia, Europe and other parts of the world. GSM uses a variation of time division multiple access (TDMA) and is the most widely used of the three digital wireless telephony technologies (TDMA, GSM, and CDMA). GSM digitizes and compresses data, then sends it down a channel with two other streams of user data, each in its own time slot. It operates at either the 900 MHz or 1800 MHz frequency band.

Information and Communications Technology (ICT) – includes the computers, software, data-capture devices, wireless communication devices, and local and wide area networks that move information, and the people that are required to design, implement and support these systems.

ICT Governance – a subset discipline of Enterprise Governance focused on Information Technology (IT) systems and their performance and risk management. The rising interest in IT governance is partly due to the need for greater accountability for decision-making around the use of IT in the best interest of all stakeholders. ICT governance promotes making IT related investments in line with strategic priorities.

Internet Protocol (IP) – the principal communications protocol used for relaying and routing packets across one or more networks.
Internet Service Provider (ISP) – a company that provides a subscription service to enable you to access the Internet. An ISP typically has a network of computers permanently linked to the Internet. When you take out a subscription with an ISP they link your computer to their network, usually via an existing telephone line, but dedicated lines are also provided by some ISPs. ISPs also give you an email address and space on the World Wide Web for setting up your own website.

Metadata (dictionary) – metadata is “data about data”. To relate data from multiple sources, it is essential to develop common definitions and understand the characteristics of each data element. The tool for achieving this is the metadata dictionary. It covers definitions of data elements/variables, their use in indicators, data-collection method, time period of data-collection, analysis techniques used, estimation methods and possible data biases.

Transmission Control Protocol (TCP) – provides the service of exchanging data directly between two network hosts, whereas IP handles addressing and routing messages across one or more networks. In particular, TCP provides reliable, ordered delivery of a stream of bytes from a programme on one computer to another programme on another computer. TCP is the protocol that major Internet applications rely on, applications such as the World Wide Web, email and file transfer.

Wireless Local Area Network (WLAN) – links two or more devices using some wireless distribution method (typically spread spectrum or OFDM radio), and usually providing a connection through an access point to the wider Internet. This gives users the mobility to move around within a local coverage area and still be connected to the network.
Leveraging ICT Effectively to Strengthen HIV Prevention for Newborns and Monitoring of Maternal and Child Health in Asia-Pacific