

# Improving Continuity of Care

by Strengthening  
Health Information  
Systems



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## ABBREVIATIONS

ANC	antenatal care
ART	antiretroviral treatment
CHIS	community health information system(s)
COC	continuity of care
CPIMS	child protection information management system(s)
DCS	Department of Children Services
EHR	electronic health records
EMR	electronic medical records
GAD	Gender Affairs Department
GBV	gender-based violence
HEW	health extension worker
HIS	health information system(s)
HISSM	Health Information System Strengthening Model
ICT	information and communications technology
M&E	monitoring and evaluation
MEval-PIMA	MEASURE Evaluation–PIMA
MOH	ministry of health
MSH	Management Sciences for Health
NGO	nongovernmental organization
RSS	referral system strengthening
SMS	short message service
SOP	standard operating procedure
TA	technical assistance
TOT	training of trainers
USAID	United States Agency for International Development
UNICEF	United Nations International Children’s Fund
WHO	World Health Organization

## BACKGROUND

Health information systems (HIS) represent a significant investment for global, international, and subnational groups and organizations that require evidence for accountability and informed decision making. However, despite such a compelling need for robust evidence of HIS function, these systems have not traditionally been a subject for rigorous study and evaluation. That lack limits learning, sharing, and cultivating best practices that can be shared more widely.

MEASURE Evaluation, a five-year cooperative agreement with the United States Agency for International Development (USAID), helps countries improve HIS management, governance, and performance. In July 2014, USAID asked MEASURE Evaluation to implement activities to justify and build an evidence base for which investments in HIS are effective and useful. In response, we developed an HIS Learning Agenda,<sup>1</sup> to explore what works to strengthen HIS. For the Learning Agenda, we seek to answer questions such as these: What are the factors and stages of progress in HIS performance and how are they measured? And what are the characteristics of a strong HIS? The project is also implementing activities to build the evidence base on HIS strengthening. We hope our efforts will contribute to evidence-informed global work to strengthen HIS and health outcomes.

## INTRODUCTION

One of the many questions that arise in linking improvements to health information systems (HIS) to improved health outcomes is the aspect of coherent client care, or “continuity of care (COC).” COC is the process of providing good-quality healthcare, over time, to a client. Continuity refers to the degree to which care is linked among all providers and made coherent over time. COC is especially important in helping HIV-positive people stay in treatment, therefore contributing to the 90-90-90 goals described by the Joint United Nations Programme on HIV/AIDS (UNAIDS), but it is also important in other health arenas, such as maternal care and childhood immunizations.

An essential element of proper HIS function is that it generates reliable information about population health service needs and individual care needs, the latter so that clients receive COC for their health issues, no matter how many providers are involved. One activity in MEASURE Evaluation’s Learning Agenda is to synthesize what we know so far about how to strengthen HIS and the effects of those efforts. The focus of this synthesis report—which is one of a series—is to document what we are learning about how stronger HIS may improve COC for clients. Here we review what we know now about the effects of HIS strengthening on COC and what areas need research.

## METHODS

We chose COC as a topic for exploration, because it can serve as a proxy for an improved health outcome resulting from HIS strengthening. The lack of a discipline to document how investments in HIS contribute to improved health outcomes means that the peer-reviewed literature offers scant evidence specific to our query.

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<sup>1</sup> MEASURE Evaluation. (2015) Learning agenda. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina at Chapel Hill. Retrieved from <https://www.measureevaluation.org/resources/publications/fs-15-142>

Therefore, to compile evidence for this synthesis, we have blended a review of published literature with evidence from our own work to strengthen HIS. The results are discussed below.

First, we conducted a literature review on the concept of COC to find out what evidence exists for linking strong HIS with improved COC. We searched for peer-reviewed journal articles and gray literature using relevant databases (PubMed, Google scholar, OVID, and Global Health). We used search terms ("continuity of care," "continuity of patient care," "continuity," "care," and "care continuum") to define COC, the impact of HIS on COC, and the impact of COC on health outcomes. Most of the literature focuses on how interventions produce better health outcomes and does not describe the work applied to elements of the HIS that makes up the intervention (e.g., management, training, procedures, etc.).

We also reviewed all MEASURE Evaluation activities, by examining quarterly reports and discussions with activity leads and other staff, to identify which ones addressed COC. Our aim was to explore how each of the HIS activities in each country was contributing to COC. We sought activities that met these criteria: activities being implemented in specific countries (as opposed to global activities), activities that had not experienced significant delays in implementation, and activities that provided examples of different ways that care is defined within the context of MEASURE Evaluation's work.

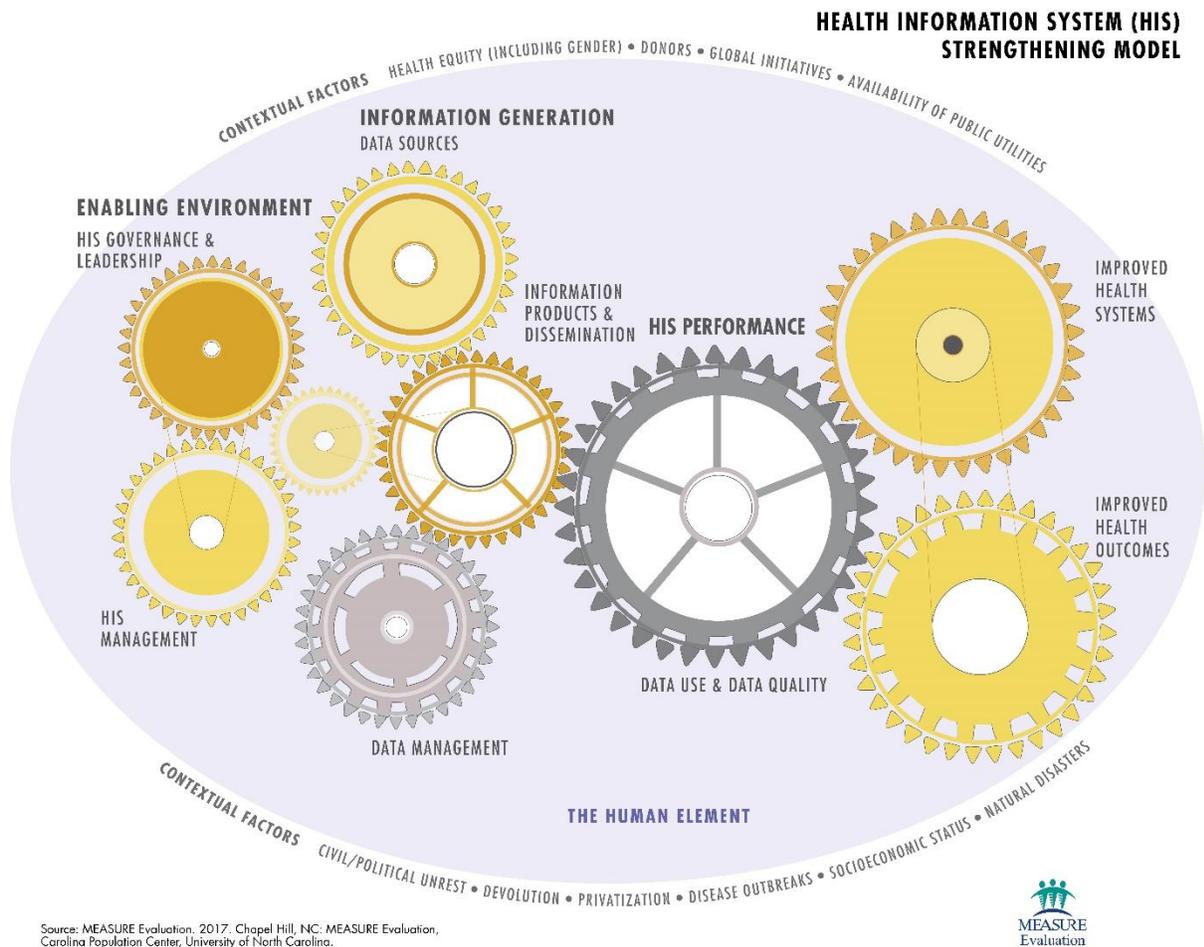
We chose to highlight four activities in three countries.

1. Gender-based violence (GBV) referral system, in Botswana
2. Referral strengthening, in Kenya
3. Child-protection information system, in Kenya
4. Family folder program, in Ethiopia

## **Mapping to the HIS Strengthening Model**

Part of MEASURE Evaluation's HIS Learning Agenda has been to develop a health information system strengthening model (HISSM) (Figure 1). The model illustrates the logical progression of the effects of HIS strengthening activities to improve management, data, and data use to improve health systems and health outcomes for people. One of the questions we are asking is what types of HIS investment—in which components of the model—are most effective for better outcomes.

**Figure 1. HIS Strengthening Model (HISSM)**



Source: MEASURE Evaluation, 2017. Chapel Hill, NC: MEASURE Evaluation, Carolina Population Center, University of North Carolina.



This model is divided into several areas: the human element and contextual factors (both of which affect everything), the enabling environment (HIS leadership and governance and HIS management), information generation (data sources, data management, and information products and dissemination), and HIS performance (data quality and use). It is a starting point for framing how an HIS works, what we know now about contributions to improved outcomes, and where in the framework are the opportunities to learn more about strengthening the HIS. This model also helps us map MEASURE Evaluation’s activities to assess what part of HIS strengthening we are addressing. One of the premises of the model is that the HIS is a tool that serves the larger health system and it can only be as strong as the system it supports.

# WHAT WE LEARNED FROM THE LITERATURE REVIEW

## How Is COC Defined?

The concept of COC emerged in reaction to concerns about how client care models had evolved from a single provider (who takes care of a client over time) to team medical practices, plus a new emphasis on COC as a pillar of primary care (Starfield, Shi, & Macinko 2005). COC also became a concern regarding clients without medical homes who are seeing new providers for every disease or injury and for clients with comorbidities that ought to be managed by multiple providers (Haggerty, et al., 2003).<sup>2</sup> COC is important in the areas of prenatal, postnatal, and early childhood care. Attending first and fourth antenatal care appointments are indicators of continuity that are tracked in low- and middle-income countries. Early childhood immunizations often require multiple doses to be effective and are another health-seeking behavior that good COC can facilitate.

In defining what constitutes good COC, the assumption was that the best care is provided by a single physician who manages all aspects of care and is familiar with the entire health history of a client. From the client side, COC means constancy of a single clinician to manage care, having a usual source or place of care, and keeping follow-up appointments. From the clinician's point of view, good COC means the availability of client information in a medical record, providing seamless and coordinated care during transitions among providers, and having an ongoing commitment to the client (van Walraven, Oake, Jennings, & Forster, 2010).

Three categories of COC have emerged from this thinking: *provider* continuity, *information* continuity, and *management* continuity (Haggerty, et al., 2003). According to van Walraven, Oake, Jennings, and Forster (2010), *provider* continuity is defined as a relationship between a client and one provider over time. MEASURE Evaluation does not work at that level, so our focus was on the other two categories. *Information* continuity means the facilitation of ongoing healthcare through the availability and use of data from past health encounters during treatment for current health-related events (Keenan & Aquilino, 1998; Sparbel & Anderson, 2000; Rusch, 1986). *Management* continuity (sometimes referred to as “care coordination”) means the coordinated delivery of care from different providers (Haggerty, et al., 2003; Keenan & Aquilino, 1998; Sparbel & Anderson, 2000).

Other definitions blend two or all three categories. According to Cabana and Jee (2004), continuity refers to “care over time by a single individual or team of healthcare professionals and to effective and timely communication of health information.” Shortell (1976) defines continuity of medical care “as the extent to which services are received as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of clients.”

## How Does COC Improve Health Outcomes?

While there is quite a bit of information on how COC may improve health outcomes, the direct evidence for this effect is more limited. A substantial portion of the evidence available uses outcome indicators that are intermediary outcomes (missed appointments, adherence to treatment, immunization, health service use, etc.) and not actual health outcomes, such as the presence or absence of diabetes, hypertension, etc. (O'Malley, 2004). COC is especially important to people who suffer from chronic diseases and require close follow-up (Breslau, 1982; Guthrie, Saultz, Freeman, & Haggerty, 2008; Laerum, 1992; Weyrauch, 1996). For these

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<sup>2</sup> The main subspecialties that are concerned with promoting continuity of care are primary healthcare specialists and mental health professionals. This is largely because the illnesses presented in these subspecialties are typically associated with other comorbidities that make it imperative for coordination and continuity of care if clients are to receive effective holistic treatment.

people, all three types of COC are important in securing better health outcomes, because they all support efficiency and effectiveness. In South Korea, a study by Nam, et al., (2016) based on national health insurance claims, found that greater COC was associated with a lower risk of readmission of hypertensive clients. The authors suggested that the mechanism of impact was that COC improved treatment adherence, which facilitated the reduction in likelihood of readmissions.

In a study on coordination of maternal and infant HIV services conducted in Malawi, the authors found that the delivery of antenatal care (ANC), prevention of mother-to-child transmission programs, and early infant diagnosis in separate facilities is associated with delays in antiretroviral therapy (ART) treatment initiation, loss-to-follow-up, high mortality in infants with HIV, and increased transit costs. The authors proposed that *information* continuity, through use of a unique client ID, would link clients to their medical records and ensure that—irrespective of where they seek care—their medical history would be complete across a continuum of services and that fact would decrease the number of missed opportunities and save lives (Braun, et al., 2011). *Information* continuity helps prevent medical errors and safeguards client safety. It accomplishes these two goals by ensuring that up-to-date client health information is available at every clinical encounter and that the provider is aware of key details in a client’s history; previous medications; and possible adverse effects of newly prescribed medication, especially in emergencies (Burton, Anderson, & Kues, 2004).

A study by Buescher, et al. (1991) in North Carolina evaluated the impact of care coordination (the *management* continuity category) on birth outcomes for pregnant women on Medicaid. The program assigned maternity care coordinators to eligible women to assist them in accessing services that addressed medical needs plus nutritional, psychosocial, and financial resource needs. Using a retrospective cohort study design, health program data files were linked to certificates of live births to compare birth outcomes. Study results showed that negative birth outcomes (low birth weight and infant mortality rate) were more prevalent among women on Medicaid who did not receive maternity care coordination.

## **Health Information Systems and Continuity of Care**

COC requires certain data sources: a system to collect and record client information (whether paper-based or electronic), a system to make this information available to providers within and outside of the originating practice, and a system to follow up with clients who have been referred to other providers and with those who have missed appointments. All this information is dependent on investments in an HIS.

Individual medical records are a component of a strong HIS and are important, because they provide information summarizing a client’s history and previous care. Both electronic medical records (EMR) and electronic health records (EHR) can improve efficiencies, availability, and readability of health information and improve *information* continuity. EHRs can also improve *management* continuity, because the information can be shared more easily among providers outside the originating practice. Some electronic systems can also provide prompts to providers, which can minimize medical errors and encourage providers to be proactive in healthcare provision (e.g., a reminder to offer a flu vaccine to a client). Many of these types of investments have been shown to be associated with improved COC.

For example, outside of the United States, providers are using client-held cards (sometimes referred to as logbooks, client travelling records, or shared care diaries) that contain the clients’ individual medical information. These are kept by the client, who presents the card to each provider visited. The provider then documents the services provided and other medical information on the card (Ko, Turner, Jones, & Hill, 2010). These cards have been used for family planning and ANC as well as chronic health conditions (Ko, Turner, Jones, & Hill, 2010; Schoevers, van den Muijsenbergh, & Lagro-Janssen, 2009; Turner & Fuller, 2009).

A few studies have been published that assess the impact of a powerful HIS tool—such as an HER—on COC in general or specifically on the three categories of COC.<sup>3</sup> The available studies use robust research designs—randomized control trial, quasi-experimental design, and a qualitative framework approach. The studies were conducted in developed and developing countries. Each study examined a different tool in a clinical setting but researchers were not focused on how the tool fit into the context of the larger HIS.

Using the HIS strengthening model (HISSM) would have been useful in that regard. The HISSM highlights the main areas to be strengthened in the HIS: the enabling environment (HIS leadership and governance and HIS management) and information generation (data sources, data management, and information products and dissemination). The studies we reviewed focused solely on the tool, which is a type of data source. We are able to infer that an effective HIS improves COC, but the findings from the studies do not say that explicitly.

In rural Kenya, Haskew, et al. (2015) assessed the impact of a cloud-based EMR system on the reduction of treatment gaps in the HIV treatment continuum. Using a pre- and post-intervention study design, the authors found that with the implementation of the EMR-based clinical decision support, the percentage of clients who were eligible for ART but were missed decreased significantly (30% pre-intervention versus 6% post-intervention).

In the U.S., an evaluation of a computerized system to facilitate end-of-rotation handover and sign-out procedures for medical residents found that the system improved COC, by decreasing the number of clients missed during the following morning rounds because of oversights in handover (Van Eaton, Horvath, Lober, Rossini, & Pellegrini, 2005). A study that evaluated a care coordination-enhanced tele-home care<sup>4</sup> program for elderly veterans with chronic heart failure found improvements in weight, in shortness of breath rating, and in blood pressure (Schofield, et al., 2005). Another intervention assessed the impact of tele-monitoring on COC. This study was a qualitative assessment of clients with chronic obstructive pulmonary disease (COPD), their healthcare professionals, and the managers of those providers. Based on a thematic framework analysis of the data gathered from interviews, the study authors found that provider relationship continuity was associated with client satisfaction (Fairbrother, et al., 2012). One meta-analysis of client-held cards found evidence that these cards can help improve health outcomes and preventive behaviors but that the evidence is stronger for maternal and child health than for other health conditions (Turner & Fuller, 2011).

## **WHAT WE HAVE LEARNED FROM MEASURE EVALUATION'S WORK ON HIS AND COC**

We reviewed all of MEASURE Evaluation's activities, including USAID associate awards, to determine how many address COC and HIS. We found several that address COC, even though it was not the explicit objective of the activity. MEASURE Evaluation's work spans the entirety of the HISSM: developing core documents for data quality, national strategies, and training curriculum (enabling environment); developing ways to integrate data collection and referral tracking in DHIS 2 and developing and implementing electronic data collection tools (information generation); and assessing data quality and use for programs (HIS performance).

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<sup>3</sup> Haskew, Rø, Turner, Kimanga, Sirengo, & Sharif, 2015; Casey, et al., 2013; Fairbrother, Pinnock, Hanley, McCloughan, Sheikh, Pagliari, & McKinstry on behalf of the TELESCOT program team, 2012; Van Eaton, Horvath, Lober, Rossini, & Pellegrini, 2005; Schofield, et al., 2005.

<sup>4</sup> Tele-home care uses telecommunications—combining voice, video, and health data—to deliver healthcare services to clients in their homes.

COC in MEASURE Evaluation’s work goes beyond the clinical setting and includes types of social care provided to individuals. For example, several of our activities focus on community-based information systems and community HIS that incorporate a wide range of data (including HIV testing and treatment and data on other services offered). Some activities pursue the dual purposes of improving HIS to improve case management and to collect information for monitoring and evaluation (M&E) reporting. MEASURE Evaluation is also working on global activities that focus on understanding how ART retention can be improved and how software platforms such as DHIS 2 can be used for referrals.

The examples that follow are organized to include the rationale for the activity and how each one maps to the components of the HISSM.

## **Gender-Based Violence Referral System in Botswana**

### **Overview**

This activity focuses on COC for survivors of gender-based violence (GBV) and falls in the “information generation” area of the HISSM, because it developed a mobile phone-based data repository to facilitate referrals. This activity supports the government of Botswana through the Gender Affairs Department (GAD) in the Ministry of Nationality, Immigration, and Gender Affairs to implement a multisectoral GBV referral system. The objective of the activity is to ensure that GBV survivors have access to all the services and care they need. A survivor may access services from a health facility, the police, a nongovernmental organization (NGO) clinic, the department of social protection, the educational system, or the traditional justice system. Thus, the mobile referral system would connect providers who serve survivors to provide them with COC and to reduce the burden on the survivor to tell their story multiple times. This information system is not only a tool of the HIS but also a tool for other sectors that deal with GBV.

The referral system was piloted August 1, 2016–July 31, 2017, in two urban and two rural areas. All service providers were identified through a provider survey and were trained to use the system. Another implementing partner conducted community mobilization around GBV in the pilot areas.

### **The Need that the MEASURE Evaluation Activity Meets in Botswana**

There is currently no national system to gather information on GBV. Fewer than half of all providers collect some information; and these providers use forms they created themselves. Therefore, care for GBV survivors is scattered and uncoordinated, and the system has created a heavy burden on survivors, on service agencies, and on national programs. For example, standard operating procedures (SOPs) for dealing with GBV in a multisectoral way beyond clinical care do not exist. Management Sciences for Health (MSH) is currently developing an SOP for GBV in Botswana, and MEASURE Evaluation will finalize it in 2017. Findings on the informal referral system gathered from local and national stakeholder meetings showed that providers were losing clients who were traumatized from having to retell their stories multiple times. It also showed that client referral forms were not used consistently or correctly and that tracking clients or referrals was not easy, because it required service providers to maintain a register and required motivated staff to do the follow-ups that are important in these cases. This situation meant that generating national statistics about GBV was a challenge and the country often relied on special studies to generate estimates.

### **HISSM: Enabling Environment**

MEASURE Evaluation has worked with key stakeholders (the GAD, Ministry of Health [MOH], Department of Social Protection, Botswana Police Service, Department of Education, Tribal Administration, and relevant national and local NGOs and civil society organizations) and brokered partnerships with private partners,

such as mobile phone companies, to develop and implement the referral system. The GBV referral system will collect uniform information across providers. Mantra Solutions developed the mobile and web-based application and the data dashboards and databases for accessing and reporting data. MEASURE Evaluation developed and implemented the first four user trainings with the assistance of the GAD. To ensure sustainability, a training of trainers was conducted for the GAD and for two in-country subcontractors (Stepping Stones International and Women Against Rape). Training was then standardized so that consistent materials would be used for all future trainings on the system, including SOPs and GBV awareness assessments.

## HISSM: Information Generation

The GBV referral system is a data source used to collect data at service points, but it also generates information for stakeholders. The system produces regular reports on standard, agreed-on indicators made available to stakeholders at the national and community levels, as well as to providers at site-level service delivery points. When the electronic system is successfully implemented, it will reduce the burden of manual data entry for the workforce and will provide real-time data on referrals. Furthermore, it will provide a unique ID to each client that will facilitate tracking and monitoring services received by each client per incident. An automated system also allows providers to follow up on cases they have referred. For example, once an incident is entered into the system, both the referring and receiving providers will get a short message service (SMS) alert after 24 hours if the referral is incomplete.

## HISSM: Expected Effects on HIS Performance

Data quality and data use are indicators of HIS performance. The referral system is designed to produce high-quality data that can be used by service providers and for national monitoring. Data entry has been designed to use pop-up menus and pre-populated fields for client and service identification, which improves accuracy in data entry. Data use is expected to improve both at the provider level and at the national level. Providers can use the referral system to follow up on referrals they started and record information on services provided. Dashboards were built to let the GAD see data as graphs and charts.

This activity has an operations research component to assess its overall utility, its effectiveness at achieving stated objectives, and the viability of the eventual rollout of the system after the pilot stage. Ongoing monitoring uses both quantitative and qualitative data. Monthly user support meetings with service providers are conducted to gather feedback and information in a focus group-like setting on technical, logistical, and training challenges and to facilitate discussion on other challenges in using the system and handling GBV cases within their institutions. This information is used to understand additional technical assistance and training needs and to facilitate updates or corrections to the pilot for better implementation. Site visits with service providers occur regularly on a rotating basis to investigate any challenges, questions, or concerns and to provide ad hoc training or TA when needed. Additionally, any anomalies in referral system reporting (such as referrals that are not completed, or unusual trends in the data) trigger a provider site visit or follow-up to examine problems so they can be fixed. Monitoring also involves analyzing raw data from the referral system to discover general trends that may illuminate any additional areas of need or assistance. These data also help the GAD understand general challenges in GBV service delivery and potential areas of concern for specific types of services, all of which improve HIS performance. The data also can be used for advocacy.

## HISSM: Expected Effects on Health Outcomes

The referral system is expected to improve the coordination of care for GBV survivors in the country and, therefore, their health outcomes. The GBV referral system is a tool that spans the health system to offer protection to survivors but the tool will only be as strong as the system it supports.

Because GBV reporting and services encompass several agencies and stakeholders, the referral system will help providers identify what care any GBV survivor needs to access. It will reduce the burden on survivors by sparing them from repeating details of the incident to every provider, but it will also help each survivor seek all the necessary care. Raising awareness of GBV among both survivors and service providers is, therefore, the first step toward a strong GBV referral system.

Service providers must be able to assess the extent of GBV when they encounter survivors. Every service provider, including the police, should have a GBV focal person who fully understands the scope of GBV and how to appropriately deal with a survivor.

The improvement of the GBV referral system can be measured in outcomes for survivors but also can be measured through other indicators, such as knowledge among providers about referrals, about other providers in the network, and about where to refer; provider understanding of the use of the referral system application, dashboard, and other technical requirements; sufficient resources allocated to the GBV referral system from the health ministry; regular provider use of the referral system; regular completion of referrals; harmony between case management records and referral system information; and formalization of the system by relevant ministries.

## Challenges

Potential barriers to the success of the GBV referral system are the lack of SOPs and lack of awareness and understanding of GBV by all providers. Even if SOPs are developed, providers still will need to be trained. Lack of stakeholder buy-in would be the most significant barrier to the successful implementation of the GBV referral system. Stakeholders at all levels have a role in the implementation and success of the system by ensuring the compliance of their service providers, as well as cultivating an understanding of the utility of the system. Additionally, devoting resources of staff, time, and money will help ensure success. Lack of buy-in by the ministry responsible for GBV (in Botswana, the Ministry of Nationality, Immigration, and Gender Affairs) and insufficient dedication of human and financial resources for this activity has heretofore been a barrier to implementing the system. Technical barriers also have thwarted successful implementation. Although the actual operation of the mobile application has been shown to be easy and efficient, other mobile technical requirements have posed challenges, such as making sure the data allowance is not used up by nonapproved use of phones, that the phones are reloaded with data and SMS allowances every month, and that all phones are consistently charged and in working order.

## Referral Strengthening in Kenya

### Overview

This activity centers on referral strengthening in Kenya through the associate award to MEASURE Evaluation–PIMA (MEval-PIMA). Referral strengthening is an example of an activity that spans the health system’s core functions of service delivery and health information. This associate award illustrates the importance of working within the enabling environment of the HISSM. MEval-PIMA’s referral strengthening efforts have evolved since 2012, when the focus was on supporting health sector referral performance *monitoring*. This focus first shifted to providing more support for health-sector referral systems *strengthening*

and, subsequently, strengthening efforts were more specifically aimed at HIV referral systems and linkage to care for HIV-positive clients. MEval-PIMA has worked at the national level and in 10 target counties to strengthen structures for policy and coordination of referral systems, build the capacity of health workers to manage and monitor referral systems and provide linkage to care, and improve performance monitoring and data use for decision making. MEval-PIMA has engaged in this work alongside public, private, and faith-based providers.

Referral system strengthening (RSS) is one part of MEval-PIMA's larger mandate in Kenya to improve the availability of good-quality health information at national and subnational levels.<sup>5</sup> As the first step, MEval-PIMA assessed HIS systems at all levels to determine the strategy for improvement. For RSS, it was determined that a strong referral system should (1) be documented well, meaning it can be described the same way by different people; (2) run by itself, meaning that all players are aware of their responsibilities and comply with their roles; (3) have a feedback loop for learning and improvement; (4) be measurable or trackable; and (5) be diverse and allow for multiple approaches and innovations. MEval-PIMA has worked in each of these five domains with the government of Kenya and other development partners.

## The Need that the MEASURE Evaluation Activity Meets in Kenya

The RSS initiative is a response to system weaknesses, such as a high proportion of clients receiving care at secondary and tertiary facilities when care at a primary health center would be appropriate and less expensive. A pilot implementation of a global toolkit for the Rapid Monitoring of AIDS Referral System<sup>6</sup> in two districts in Nyandarua County found a lack of quality data to measure the completion of referrals among clients at all levels of the health system, including the community level. The lack of data was attributed to a lack of referral performance monitoring systems, lack of data ownership and data use, and lack of a data management system. Additionally, an assessment undertaken in eight counties in 2013 showed that mechanisms to collect referral data were weak, that documentation of referrals was poor, tracking a referred client through the system was difficult, referral data were never analyzed or used systematically in decision making, referral coordination structures did not exist, and processes for referrals varied across facilities. MEval-PIMA has supported several initiatives to support referrals tracking, including defining priority indicators for referral performance monitoring, revising Kenya Ministry of Health (MOH) routine registers and DHIS 2 to include referral data elements and support for data collection on key indicators, and analyzing and using data for decision making.

## HISSM: Enabling Environment

MEval-PIMA has worked to improve the enabling environment for strengthening referrals in Kenya. First, it aimed to improve the availability of policy and coordination structures to guide RSS. Through MEval-PIMA's advocacy at the national level, a Referrals Unit was formed at the MOH to oversee referral strengthening and to monitor referrals nationally. MEval-PIMA supported the development of a national referral strategy, referral guidelines, formation of a referral systems technical working group (TWG), establishment of referral coordination structures at the subnational level, and customization of the referral strategy for county-level implementation. The National Referral Guidelines are the basis for clear documentation of referral standards in Kenya and are an important piece of the enabling environment component of the national HIS. The guidelines outline the structure and organization of the referral system; roles and responsibilities at each level, from the MOH to the referring and receiving facilities; management of referrals; coordination of referral services; and monitoring of the referral system. In addition to the referral TWG, stakeholder forums were

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<sup>5</sup> Other systems that are being supported are the community HIS and civil registration/vital statistics.

<sup>6</sup> <https://www.measureevaluation.org/our-work/hiv-aids/rapid-monitoring-of-aids-referrals-tested>

conducted in selected counties to enhance coordination in the county referral system, provide a setting to discuss referral data and challenges in the referral process, and to review progress on the RSS action plans. Some counties established referral units, and MEval-PIMA provided technical support to establish the roles and responsibilities of these units and to build their capacity.

The second step was to build the capacity of health workers to manage and monitor referral system performance. MEval-PIMA supported development of a training curriculum on referral systems, which has been used to train more than 2,000 health workers in 10 counties, supported by MEval-PIMA. The World Health Organization (WHO) and the United Nations International Children's Fund (UNICEF) are using the curriculum to train staff in 11 more counties. MEval-PIMA also supported the development of an abridged curriculum on HIV referrals and linkage to care that has been used to train county-level mentors. These mentors guide health workers at the facility level on the management and performance monitoring of HIV referrals and linkage to care.

### HISSM: Information Generation

This activity did not focus on creating or managing specific data sources, but it supported forums and mentorship that focused on the collection, analysis, and use of referral data, which have the effect of improving information products. The goal was to enhance collaboration among service providers, promote ownership of activities to improve referrals in the target counties, and discuss data and challenges. The main objective of mentorship visits, which were conducted in collaboration with the county and subcounty management, was to enhance referral performance monitoring through technical support for facility personnel on how to improve collection, analysis, and utilization of quality referral data—all important components of an HIS.

### HISSM: Expected Effects on HIS Performance

These activities would be expected to lead to increased data quality and use, which is how the HISSM defines HIS performance. Baseline data were collected in 2012, and follow-up data in 2014. Findings at key sites show that many issues remain regarding the quality of data entry in registers using the referral indicator columns, but monitoring has identified solutions. As part of its work to strengthen the HIV referral network, MEval-PIMA worked with partners to select sentinel facilities in the target counties and conducted baseline assessments of those—involving data abstraction, questionnaires for staff, and focus group discussions—to determine the state of the referral system. Referral directories were created and validated in selected counties. Once the revised RSS was introduced, mentorship visits to high-volume health facilities were conducted to strengthen health workers' capacity to initiate and manage referrals and monitor performance. Data on key referral indicators were collected during the mentorship visits, and data analyzed and displayed at the facility so performance on all indicators could be discussed and action plans for improvement developed.

### HISSM: Expected Effects on Health Outcomes

A strong RSS is expected to have positive effects on providing HIV services—and therefore improved health outcomes for HIV-positive clients. A strong referral system allows healthcare workers to correctly link clients to needed care and allows facilities to track referrals to ensure follow-up. These improvements help ensure that clients receive services in the appropriate service delivery level. These outcomes are possible because all health workers have standard forms, have guidelines to follow, know the network of providers to refer to, and have been trained to analyze and use data to make decisions. Linking clients and keeping them in care contributes to achieving 90-90-90 goals, especially if all health programs adopt this model of a strong RSS for HIV services.

## Challenges

The overall weakness of a health system would be the main barrier to successful implementation of RSS. The functioning of a referral system reflects the performance of the health system overall and affects the quality of care it delivers. While RSS is important, it is only one element of providing good-quality services. Clinical staff who are trained and motivated, facilities that are clean and well maintained, access to laboratory services, and availability of required medical commodities are necessary elements, as well.

## The Child Protection Information Management System in Kenya

### Overview

The development of a child protection information-management system (CPIMS) in Kenya—an electronic system used to capture and share information on child protection data—is another example of MEASURE Evaluation’s work in COC that goes beyond the clinical setting. MEval-PIMA supported the Department of Children Services (DCS) to establish an electronic national child protection database that would be sustainable. This activity required work in the enabling environment, information generation, and HIS performance areas of the HISSM. The framework for Kenya’s national child protection system was designed to promote the welfare and well-being of children, by helping to prevent violence, abuse, neglect, and exploitation and addressing instances that occur. The child protection system is meant to ensure prompt and coordinated action to prevent further harm and to refer threatened children to the services they need. The activity has the following components: systems and stakeholder assessments, system upgrades, user training, participation in and strengthening of a stakeholder coordination forum, and enhancement of the child protection data from CPIMS.

### The Need that the MEASURE Evaluation Activity Meets in Kenya

This activity was proposed to help coordinate the collection and transfer of information about individual vulnerable children to all actors in child protection. Child protection falls under certain line ministries within the Kenyan government (health, interior, justice), each of which have their own systems to track child protection, none of them interoperable. A paper-based system produced low-quality data because of duplication of records and could not quickly aggregate data for sharing among stakeholders.

### HISSM: Enabling Environment

Two national child protection systems had been tried before in Kenya and had failed. Reviews of these two systems concluded that they failed because of the following factors: (1) the inadequate involvement of local stakeholders in the design and implementation of the database to ensure sustainability past the duration of the initial project; (2) minimal levels of acceptance among users; (3) limited human resource capacity, especially in information and communications technology (ICT) to manage the system; and (4) a rollout strategy that was not comprehensive. This information was used to help develop the new CPIMS, with one of the first steps being to develop a system design roadmap and sustainability plan. This was followed by an ICT audit. Once the first version of the system was developed, a user acceptance test was conducted to inform system changes.

Given the challenges encountered by the two previous attempts, it was decided that a key to CPIMS success was wide stakeholder engagement to identify information needs to inform system development. The DCS did not have an M&E unit or M&E plan for child protection, which fact made it a challenge to determine what information should be collected. Therefore, an M&E unit was created to help oversee CPIMS, and MEval-PIMA helped develop an M&E plan using CPIMS as a data source. It is expected that DCS should own the

process, taking the lead role in managing the system while working with other partners for continuous support. MEval-PIMA also supported the development of system security and data quality guidelines.

Several governance structures were established to inform the process of setting up the CPIMS: the ICT taskforce meets monthly, made up of the information technology staff from the stakeholders who manage the day-to-day development and implementation of the system; the CPIMS TWG meets every two months; and a steering committee chaired by the DCS meets every six months.

Creating a training curriculum and training implementation are important components of a successful rollout of any information system within an HIS. For the CPIMS, user trainings take five days. The first three of 10 counties were trained by the government of Kenya and MEval-PIMA and CPIMS launched in those counties in August 2016. Seven more counties were launched by the end of October 2016.

### HISSM: Information Generation

The CPIMS is a data source with its own management structure to disseminate information. It includes modules for registries (organization and personnel), forms, and reports. As envisioned, the CPIMS will be a gateway for all who engage in child protection services in Kenya to share relevant information, reducing duplication and delays in data sharing. It will also enable the DCS and the National Coalition of Children's Rights and Child Protection to handle some of their data collection and M&E needs for child programs.

### HISSM: Expected Effects on HIS Performance

A functional CPIMS is expected to improve data quality and use—and, therefore, HIS performance—because it can collect and aggregate data from all relevant actors in child protection in a timely manner. This means the data will be more complete and available earlier for decision making at all levels of child protection—from the field, when dealing with an individual case, to the national level. This expectation relies on the CPIMS being properly used. MEval-PIMA put several mechanisms in place to ensure this. Monthly site visits are conducted to assess how CPIMS use is progressing and to address any challenges. CPIMS allows supervisors to see what sites have not logged in so they can address this in site visits. Technical support is provided by the ICT authority and the DCS. A community of practice at the county level can help sites to resolve issues among themselves. Each county established a “WhatsApp” group for posting questions or issues they encounter. CPIMS champions have been identified to take the lead in resolving questions, and, during the pilot, it was found that the group can usually resolve the issues encountered or can seek help from the technical team (one person from the government and one from MEval-PIMA) with any unresolved questions. Data are monitored as they come in and data audits and reviews monitor data quality. The redundancy of parallel electronic and paper systems will aid in monitoring data quality. This, however, bespeaks hesitation to rely solely on an electronic system.

### HISSM: Expected Effects on Health Outcomes

A strong CPIMS is expected to improve case management and services provided to individual children, thereby improving their health outcomes. It also is expected to improve the capacity of the national program to monitor and report on achievements and gaps in child protection, thereby contributing to the robustness of the HIS. A strong CPIMS should have the following attributes: the ability to monitor all services provided to a child by any provider (educational, psychosocial support, health, shelter, legal and protection, and food and nutrition); capacity for data visualization; flexibility in its web-based platform for batch uploading of data to optimize Internet connectivity; the capability of collecting longitudinal records; full interoperability with other systems in child protection; and the ability to link with other phone and mobile applications.

## Challenges

Some challenges and barriers to effectively implementing CPIMS are the potential to rush to enact an electronic solution before having an adequate enabling environment, such as a child protection M&E plan that describes the information that needs to be collected. Setting realistic timelines and adjusting the expectations of stakeholders has been a challenge. Stakeholder involvement is critical, and it is important that all staff involved with the CPIMS see its usefulness. The field staff must be transformed into users of the system and not just producers of data, so promoting data use will be an important challenge. Access to power and Internet remain a challenge at the county level, as does staff capacity. Continuous reinforcement of training is necessary to ensure people use the system correctly.

## Family Folders in Ethiopia

### Overview

This activity was accomplished during 2008–2014 of the MEASURE Evaluation project and is an example of the use of a paper-based system to improve COC in a resource-poor setting. It is another activity that worked in several areas of the HISSM: enabling environment, information generation, and HIS performance. MEASURE Evaluation supported Ethiopia to transform its national health management information system (HMIS), which receives data from a robust community health information system (CHIS). The centerpiece of this CHIS is the “family folder.” The family folder, which covers every household in the community, is a client filing system used at rural health posts that provides data for the CHIS. Two health extension workers (HEWs) per health post serve roughly 5,000 people. In what is called the “enumeration” phase, HEWs assess the households in their catchment area to collect information such as the age and sex of household members, health behaviors, and the availability of water and sanitation. Once the initial family folder is completed, the HEW updates the health card when family members come to the health post for services or after the HEW visits the home.

### The Need that the MEASURE Evaluation Activity Meets in Ethiopia

Prior to the family folder, no standard information system existed for HEWs to use in their work with their communities. HEWs relied on registers provided by local health offices or NGOs and were expected to carry notebooks to record services when they visited households and then transfer their notes to the registers in the health post. The entire national HMIS suffered from a lack of standard definitions for data elements and basic indicators.

### HISSM: Enabling Environment

Commitment from the government of Ethiopia was critical in the uniform implementation of the family folder system rollout throughout the country. Uniform implementation also involved effective coordination and collaboration among health sector actors to support the CHIS. Partnering with local networks was especially critical during the enumeration phase. The Kebele (village-level administrative unit) and the Health Development Army (a term used in Ethiopia for a cadre of health workers) were actively involved in this process, which was a massive undertaking. The community valued the effort, which helped in the motivation and mobilization to accomplish the task.

MEASURE Evaluation assisted the Federal Ministry of Health, Ethiopia (FMOH) to roll out the CHIS family folder system nationwide. The main components of this activity were (a) developing and field-testing the operational guidelines for the use of family folders at the health posts, (b) developing a national training manual on family folders for HEWs, (c) training providers on a family-folder-centered CHIS, (d) establishing

a supportive environment, by building the mentoring capacity of the HEW supervisors, and (e) telling the success stories of the family folders at national and international forums. One of the innovations that MEASURE Evaluation introduced was the tickler file system, which organizes client records according to the future date that a follow-up visit will be required. After each client visit, the HEW records a date for the next expected visit for the specific household member. The health card is removed from the family folder at the health post and placed in a box corresponding to the month of the next appointment. At the beginning of each month, the HEW reviews the cards in the box and prepares appointment reminders or conducts household visits.

The family folder system was implemented in stages. The design phase involved the FMOH working with implementing partners to determine what information the family folder would collect and what the folder would look like. This design was reviewed by technical experts. However, because not all implementers were involved in the design, there was confusion about how to implement the system and so operational guidelines were devised to ensure uniform implementation at the community level. The FMOH formed a TWG that came up with options for using the system. These options were pilot-tested, the most feasible option was selected, and operational guidelines and training manuals were developed. This pilot was important, because it gathered feedback from HEWs, who would be the users of this system. National scale-up was the last step.

### HISSM: Information Generation

The family folder has five parts: (1) identification, (2) household description, (3) household characteristics, (4) documentation of health-education trainings of household members conducted by HEWs and household status, and (5) documentation of a household's implementation of the lessons from the trainings. The outside of the folder contains information on drinking water sources, number of insecticide-treated bed nets, and latrine characteristics. Inside the family folder, a health card for each household member has information on health services, including immunizations, family planning, and tuberculosis treatment. The family folder offers the HEW a one-stop source for review of all the services received by everyone in the family.

### HISSM: Expected Effects on HIS Performance

A successful family folder should compile data that is easy for HEWs to use and understand. It should provide them with information as they provide services to the community. The family folder can also be used by supervisors for data quality checks and assessment of the quality of care provided, which improves the HIS and promotes objective mentoring of the HEWs. Data generated by family folders is transferred to the national HMIS for analysis of how the health system is performing at the community level.

The family folder system has improved the quality of data produced and facilitated data use at the client and community levels and beyond. The standard forms help HEWs collect data uniformly and completely for each household and the tickler file system helps them identify people who need follow-up services, especially for pregnancy care, immunization, and family planning. This information reminds HEWs of follow-up visits to clients and helps them identify service defaulters—which contributes to improvements in COC for these people. The additional information about household characteristics also helps HEWs tailor health training topics to the needs of a specific household.

Health post staff conduct a regular data quality self-assessment using a lot quality assurance sampling survey (LQAS), which is a rapid and inexpensive approach to data collection primarily used for M&E of a specific area or facility of interest. The government also has conducted data quality assessments using MEASURE Evaluation's Routine Data Quality Assessment Tool.

## HISSM: Expected Effects on Health Outcomes

This activity has had many successes and was selected by USAID as one of the top 10 case studies of health system strengthening activities.<sup>7</sup> No formal evaluation has been done on the effects of the family folder system on health outcomes, but there is anecdotal evidence that the effects are beneficial. In just one example of how the family folder helped improve health outcomes in Ethiopia, HEWs in one locale realized that mothers were not bringing their children in for follow-up immunizations. This realization led to a house-to-house canvass to encourage mothers to complete immunizations. Because of this effort, more children were immunized in one month alone than had been immunized in the three months before.

## Challenges

Ensuring that a continuous supply of CHIS materials is available in a timely manner at health posts is a challenge. Often, shortfalls in supply result from distribution challenges or a lack of understanding of how many materials to distribute. There is still some confusion about who is responsible for the production, distribution, and costs of CHIS materials for the family folders at health posts. Also, the continued use of parallel information systems within the FMOH and systems promoted by implementing partners creates more work for HEWs and is a threat to the continued viability of the CHIS. In some places, the CHIS is used only for specific services (such as family planning, immunizations, or ANC). At the initial stage, there was variation in how well the HEWs understood the CHIS and how it works—both in terms of the quality of understanding by any one person and the consistency of understanding among people across the levels of the health system. Targeted training for HEWs and their supervisors (who also were found to misunderstand the CHIS), along with strong supportive supervision, helped minimize these effects. High turnover among HEWs and supervisors means training is a continuous process. One significant change for the CHIS currently is a shift from a paper-based to an electronic system.

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<sup>7</sup> <https://hssglobalcall.hsaccess.org/top-cases>

# DISCUSSION

## Conclusions from the Literature Review

In this synthesis, we have compiled evidence from the literature suggesting that improved COC positively affects health outcomes. The documents and activities reviewed provide plausible evidence that investments in HIS improve COC and that the tools discussed here (electronic health records, patient-held cards, etc.) also strengthen the HIS. However, we cannot find *direct* evidence in the peer-reviewed literature about how the COC interventions are (or are not) strengthening components of the HIS. Still missing is documentation of effective packages of HIS strengthening that will improve COC. For example, the GBV referral system is a data source that facilitates better outcomes for survivors and generates information for stakeholders and decision makers—a result that can be said to strengthen HIS. But the connection is not explicitly made in the analysis described in the literature.

## Conclusions from MEASURE Evaluation's Experience

Our review of MEASURE Evaluation's activities have shown effects on multiple components of HIS strengthening, as mapped to the HISSM, in areas such as leadership, governance, management, and information generation. They also have been shown to improve COC. For example, RSS improvements in Kenya were supported with mentorship visits, the main objectives of which were to enhance referral performance and monitoring through technical support. This support, in turn, improved referrals and strengthened the HIS through better data collection, analysis, and use of good-quality referral data—all important components of an HIS.

Evidence from MEASURE Evaluation's work in the four activities discussed have several themes in common that highlight what we are learning as these activities are implemented. The activities concern the implementation of two electronic information systems, a paper-based system, and an activity that focused on referral strengthening in general. Activity reports indicate that specific program-data needs have been identified and mechanisms to improve data quality and use have been implemented. However, questions remain about whether these interventions also improve HIS functioning and health systems overall. We still can't be certain if the interventions result in better care and health outcomes, because—even though the activities were designed to achieve this objective—the necessary empirical studies have not been conducted.

Moreover, all the activities are operating in dynamic environments with many stakeholders and engage multiple areas of the HISSM. Even when the focus of an activity was to create a data source, many other components of the enabling environment may not have been specifically addressed, such as governance, finance, and clear identification of information needs. Therefore, the creation of a data source, for example, cannot be isolated from other important components of an enabling environment. And these components will influence the activity—either negatively or positively—whether or not they are taken into account. The inability to isolate parts when implementing an activity makes the work in health systems complex and underscores the challenge of working in a system in which one activity does not exist in a vacuum and is impacted by other core functions.

Another theme the highlighted activities have in common is that they are all designed to meet two primary needs of stakeholders: (a) a system that is easy to use and that will contribute to COC in the provision of health services and case management, and (b) a system that collects information that can be aggregated to meet M&E requirements and reporting for decision making. These needs are a difficult balance of service provision and data collection that is reliable for decision making. An HIS must not interfere with the primary

need to provide care. Managing an HIS requires careful consideration of how much information providers are asked to collect, how easy or difficult the system is to use, how much training is required, and what kind of support can be provided. Shortcomings in these areas can lead to the underuse, incorrect use, or complete user abandonment of the HIS system. The possibility of abandonment was highlighted in the CPIMS example, which was the third attempt to develop a system for child protection in Kenya.

These examples also underscore the importance of vigorous stakeholder engagement for the success of an activity. Effective stakeholder engagement requires not only assessing different information needs of each stakeholder but also gathering input from the system's future users during its design. Pilot-testing new systems can reveal inefficiencies and areas for improvement. It can also help determine how people will be trained on the system once it is revised. System users must be comfortable with their roles and have a clear understanding of the purpose. Users must have supportive supervision when new systems are implemented, to ensure they use the system correctly and to answer their questions or concerns. For COC to be achieved, M&E goals to be met, services to be provided, and data quality assured, frontline users must be comfortable with the system.

This focus on the people associated with the system is part of the common theme of the human element in the HISSM, which includes not only the people involved in designing and using information systems but also the clients, or consumers, themselves. As already discussed, users of the system play an important role in success but, in many cases, consumers in need of COC also should have their needs considered in design. No system will work if clients are not aware of it or don't follow up with the services provided. For example, in Botswana, community mobilization around GBV is essential to the success of the referral system, because GBV survivors and people close to them need to be aware that (a) GBV is a problem, and (b) there is a system in place to provide assistance. Anything that can be done to improve consumer engagement will improve COC.

Finally, a limitation of this synthesis is that three of MEASURE Evaluation's four activities are in the pilot phase or are ongoing, so we are unable to assess success or any long-term effect on providing COC. It would be advisable to return to these activities to update what has been learned about the HIS and improving COC.

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