

# Community-Based Health Information Systems in the Global Context

A Review of the Literature

MEASURE Evaluation

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## Background

In developing countries, high disease burden from HIV, malaria, tuberculosis, poor nutrition, and high maternal mortality often intersects with low access to health services (Global Fund, 2014). Community workers (CWs), including community health workers (CHWs), community health extension workers (CHEWs) and community social service providers, have met critical service gaps. Generally, CWs are affiliated with either health facilities or community-based organizations. These providers live in the communities they serve and provide outreach services to people who may otherwise not receive them. The work of community worker providers has helped to improve health, especially maternal, child, and newborn outcomes (Lunsford, 2015; Golding, 2014).

National governments and donors are increasingly emphasizing and supporting the work of CWs to expand health care coverage (de la Torre, 2014). The important role of CWs has been emphasized in recent global health policy, such as USAID's policy for ending preventable child and maternal deaths (EPCMD) (USAID, 2015) and the President's Malaria Initiative. Similarly, there is a recognition that decentralized, community-based approaches to HIV care and support will be required to meet UNAIDS' 90-90-90 target (90% of all people living with HIV will know their status, 90% of people diagnosed with HIV to receive antiretroviral treatment (ART), and 90% of all people receiving ART will be virally suppressed by 2020) (UNAIDS, 2014). Community-based programs implemented by CWs are uniquely suited to help achieve the goals laid out in these policies in the most vulnerable parts of the world. Furthermore, as global health systems move toward universal health coverage, CWs will become even more important to increase health equity (Golding, 2014).

CWs require key health information to do their jobs, and their managers require information to monitor their work. Likewise, Governments and donors require information to better plan community health programs, and to monitor progress against goals. This information, how it is collected, and how it flows, is how we define a community-based health information system(s) (CBHIS). These systems should involve data collection, management, and analysis of health and related services provided to communities outside of facilities (de la Torre, 2014). They should enable information to be shared among community-based services and between community-based services and higher-level health facilities. Moreover, to some extent, they should feed into national health management information system(s) (HMIS). CBHIS have the potential to engage community members, provide them with an avenue to health services, and hold them accountable, contributing to the goals of sustainability (Jeremie, 2014; Sabitu, 2004).

Little is known about how CBHIS are being implemented globally. This literature review seeks to explore the innovations in and different manifestations of CBHIS in developing countries.

## Methods

We conducted a literature search in May 2015 using the following databases: PubMed, POPLINE, and USAID’s Development Experience Clearinghouse. We also searched specific journals, including the Journal of Health Informatics in Developing Countries, International Journal of Medical Informatics, and Electronic Journal of Information Systems in Developing Countries, as well as Google and Google Scholar. We used the following medical subject headings (MeSH) terms: community network; health status indicators; information systems; and information management. Title/abstract search terms were “community-based information” and “community health services” AND “information systems.” Phrase search terms were “community-based information systems” and “community-based health information systems.” We focused on low- and middle-income countries. Ultimately, we found 23 eligible references.

## Results

We grouped results in the following CBHIS functional areas:

- Case management
  - Documenting individual-level needs to support individual care planning
  - Enabling bidirectional referrals
  - Tracking patients lost to follow-up
- Accountability
  - Reporting of inputs and outputs
- Planning, resource allocation, and advocacy
  - Assessing population level needs (outcomes)

### Facilitating Community-Level Case Management

CBHIS can be used for case management, to document individual needs to inform care plans, to enable bidirectional referrals, and to track patients lost to follow-up. Examples from the published literature of each of these are outlined below.

#### *Documenting Individual Needs to Support Care Planning*

The Child Status Index (CSI) collects data on orphans and vulnerable children (OVC) on 12 dimensions of well-being (MEASURE Evaluation, 2012). While data are used for program monitoring and to facilitate planning at higher levels, the individualized approach of the system makes it especially appropriate for case management, allowing child and family services to be tailored to the needs identified at each encounter/presentation. The resulting individualized care plan may also include referral to other agencies and community-based organizations. Sometimes, CSI information is entirely paper-based, and in some instances, programmers have captured data electronically to allow for higher-level planning. The CSI is being used in at least 17 different countries and has been adapted in others to facilitate the same purpose.

### *Enabling Bidirectional Referrals*

Originally designed for the SIDALE (“AIDS Go Away”) project in Haiti, IQReferrals is a tool used to track clients who have been referred to and from multiple programs and link them across the continuum of care. IQReferrals provides a communication portal for major hospitals, supporting satellites and community service clinics to capture referral and counter-referral information, so that the overall healthcare ecosystem serves clients efficiently and effectively. IQReferrals facilitates tracking and easy provision of feedback between a site or program that has referred a client and the one that has received the client. IQReferrals can be used to track clients who are referred among various program areas—for example, tuberculosis, voluntary counseling and testing, and the prevention of mother-to-child transmission of HIV—as well as those transferred to other sites within one or several programs and/or catchment areas. IQReferrals can produce automated reports both at the facility and central levels as well as across multiple databases, thereby improving data quality and feedback.

The USAID-funded Linkages across the Continuum of HIV Services for Key Populations Affected by HIV Project (LINKAGES) is applying a similar approach to facilitate real-time tracking of clinic referrals among key populations in Papua New Guinea, Laos, and Thailand. Through the mobile application, built on Dimagi's CommCare platform, outreach workers enter clients' responses to HIV risk questions onto a smartphone. Based on the answers given to early questions, the outreach workers are prompted to ask additional questions. When a client's answers indicate that they should be referred for HIV testing or other clinical services, the referral is automatically created by the application and sent to an application on a smartphone at the clinic's receiving desk. The clinician can then confirm through the app that the client appeared for the referral, thus providing direct and immediate statistics about follow-up. After a period of time, if a client has not appeared for a referral, the system will send an SMS message to the client's mobile phone, providing a reminder of the appointment and offering further assistance.

### *Tracking Patients Lost to Follow-Up*

One key innovation was keeping a family folder for every family in the catchment area of a health post as part of CBHIS (MEASURE Evaluation, 2012; Chewitha and Azim, 2013). Along with the family folders was a simple tickler system, whereby wooden boxes were used to organize health cards according to the month in which follow-up services were needed for family members. If a health card had been left in a previous month's box, health workers could see when a service had not been provided and then reach out to the family to provide care. Health extension workers also used the boxes/health cards to plan follow-up with pregnant women, family planning clients, and children for immunization. For example, in one zone, the family folder system showed that not many children were getting vaccinated. Health workers were able to identify children who had dropped out or who had missed an immunization service, initiate contact, and provide the vaccinations.

Now, family folders connected with HMIS and CBHIS enable health workers to build trust with client households, and thus clients return for critical health services and have more confidence in service quality. With family folders as a tool for identifying pregnant women who have missed services, workers are able to reach more women for continuity of services and provide better antenatal care.

A program in India deployed informal educators to collect data on child immunization dropout rates, community health needs, and resources (Singh, 1997). Computer-generated immunization dropout lists were given to CHWs and auxiliary nurse midwives for outreach targeting. Follow-up data showed increases in “fully immunized children” for the diphtheria, pertussis, and tetanus vaccination.

## Accountability

Perhaps the most familiar functional aspect of a CBHIS is to enable reporting both to the government and donors. The following examples are illustrative of systems that aggregate and report community data to higher levels.

The family folder program in Ethiopia not only facilitates service provision at the community level through its referral and follow-up reminder system but also is integrated in the national HMIS (Mutale, 2013; Damtew, 2013). HEWs report the data they collect to the nearest health centers monthly; in turn, district health offices as well as other partners receive reports monthly, quarterly, and in emergencies. The districts then compile these reports and send them to zonal health offices, which forward them to regional and national offices quarterly.

The Connect Project, in Tanzania, links community data collected by community health agents (CHAs) with the district and national HMIS through its aggregate data from community registers (Mutale, 2013). CHA supervisors at the facility level are responsible for meeting with CHAs to create action plans, and for reporting data collected by CHAs to the district level. There, a council health management team develops comprehensive council health management plans and reports to the national level.

Mobile technology can facilitate the reporting of community data. The Nigeria Evidence-based Health System Initiative (NEHSI) used CommCare to connect its CBHIS with the provincial and national HMIS for planning (Asangansi, 2013). Community field workers were given Android mobile devices, which they used to register 5,600 people and link that data to the larger information systems. Benefits of the mHealth system were ease of use as expressed by field workers; savings both in material and human resources, because fewer man-hours were needed to collect, manage, and synchronize data; and improved data quality.

## Planning, Resource Allocation, and Advocacy

CBHIS are used to identify health needs in communities to inform planning and resource allocation decisions at the local, sub-national and national levels. These data also enable advocacy for most-in-need populations. Sahay and Braa (2012) distinguish data collection to support action planning at the facility and systems level, with data collection and management to support high level planning. For the purposes of this review, we have wrapped these together. There are diverse examples from the literature of instances where community data are routinely collected and documented to influence change.

For example, in Nyanza Province, Kenya, CHEWs and CHWs were trained to facilitate community dialogue and maintain the CBHIS and the village register (Kaseje, 2010). Health status data from each household were routinely collected and maintained by CHWs through the village register, and then analyzed by community members and committees and at the health center. Data-driven participatory action planning by the community and health centers helped to improve services. Reports are sent to the district-level, where they are processed electronically. The districts saw statistically significant improvements in immunization coverage, health-facility childbirth, use of insecticide-treated bednets, and treated drinking water in comparison with control sites. In another example, under the Kenya Essential Health Package, CHEWs inform community health committees on key community health indicators, whereupon data collection is planned (Jeremie, 2014). Data collected are then fed back to the facility to identify health utilization gaps and outbreaks, and ultimately to improve services.

In the Community-Level Nutrition Information System for Action (COLNISA) project in northern Nigeria, supported by the United Nations Children's Fund (UNICEF), volunteers collected maternal and child health data and analyzed them with the COLNISA committee; then together they created a workplan to address areas of need (Sabitu, 2004). These data informed several community interventions: community-based growth monitoring and promotion, outreach antenatal and immunization services, exclusive breastfeeding promotion, and education about oral rehydration therapy and complementary feeding. Follow-up data collected by CHWs showed statistically significant improvements on all indicators except under-five nutritional indices.

In a family-focused program in the Philippines, CHWs visited households and completed family profiles, assessing child health, family planning practices, and desire to space births (Management Sciences for Health, 2001). CHWs then used a geographic information system to create a "spot map" of communities with high child health and family planning needs, which were then targeted by additional CHW intervention.

The Sustainability through Economic Strengthening, Prevention and Support for OVC and Other Vulnerable Populations Project (STEPS OVC) is the largest USAID-funded project supporting OVC in Zambia. STEPS OVC has a fully-functional monitoring and evaluation system that helps to fulfill reporting requirements, as well as facilitate service provision by subgrantees through community caregivers. Data regarding services received and referrals made are collected during

routine household visits by community caregivers. Data are then transferred to subgrantee M&E officers, who enter data in the project-specific Community Prevention Information System database for analysis at the project level. Data are also reported to the District AIDS Task Forces using government forms to enable planning. Similarly, the AIDS, Population and Health Integrated Assistance (APHIAplus) project, in Kenya, as well as Pamoja Tuwalee, in Tanzania, use CHWs to collect data on child well-being, shelter, water and sanitation conditions, food security, and household income, and use those data to inform services provided by CHWs based on children's needs (MEASURE Evaluation, 2014; MEASURE Evaluation, 2014).

## Challenges

As with any system, CBHIS are not without challenges. A common challenge experienced was lack of technical capacity of CWs (Chewicha, 2013; Jeremie, 2014; MEASURE Evaluation, 2009). An evaluation of a CBHIS in Kenya highlights the need for intensive training with periodic refresher courses for CHWs involved in data collection (Jeremie, 2014). Another challenge regarding the CWs or volunteers is the added workload of data collection and associated activities (Byrne, 2004; MEASURE Evaluation, 2009; MEASURE Evaluation, 2014; MEASURE Evaluation, 2014; MEASURE Evaluation, 2014). The added responsibilities may or may not be feasible for CWs, depending on such factors as whether or not community-level staff earn a salary.

Another challenge in adding to new CW responsibilities is the lack, or early stages, of integration of CBHIS in formal HMIS. Without complete integration, there are duplicative efforts in data collection, analysis, and reporting. The family folder system in Ethiopia, for example, faced the challenge of redundant data elements in registers within and across health posts and districts (Damtew, 2013). A report on the uThukela District Child Survival Project also cited nonoverlapping data sets as a major challenge (Byrne, 2004). Because CHW catchment areas are not the same as that of the Department of Health, reporting to higher levels is difficult. Time spent collecting and harmonizing redundant or nontransferable data is time that could otherwise be spent serving the community (Damtew, 2013).

In two separate CBHIS efforts in Ethiopia, the need for a streamlined physical system is highlighted (Chewicha, 2013; Damtew, 2013). The family folders were bulky and vulnerable to damage from rain when carried from house to house, so HEWs ended up recording in registers instead and transferring the data to folders later on (Damtew, 2013). In the Southern Nations, Nationalities and People's Region (SNNPR) of Ethiopia, each health post generated a large amount of data, which became manually unmanageable (Chewicha, 2013).

Other challenges mentioned are: data collection tools often not in a language CWs are most comfortable using (Chewicha, 2013); weak data quality (MEASURE Evaluation, 2009); high turnover or vacant district-level positions (Byrne, 2004); and lack of data collection supplies in remote areas (Chewicha, 2013). Asangansi (2013) addresses challenges unique to those CBHIS using mobile technology, including the potential for lost or stolen phones and lack of existing policy



around electronic data privacy and security. Some CWs have reported that community members at times express frustration when they provide information during data collection, complaining that they often don't see the improvements in programming or services that are needed (MEASURE Evaluation, 2014; MEASURE Evaluation, 2014).

## Discussion & Conclusion

As this review demonstrates, CBHIS come in various structures and cover diverse health areas, with different uses of technology and integration in formal HMIS. COLNISA, in northern Nigeria, is community-focused, with all data collected and used for interventions by CWs and volunteers and no integration in facility or formal HMIS (Sabitu, 2004), whereas NEHSI, also in Nigeria, automatically synchronizes data with the national HMIS (Asangansi, 2013). CBHIS can be used for different goals, including identifying people in need of specific services, facilitating access to community health services, and reporting to higher HMIS for program planning.

Some common challenges are low technical capacity of community staff (Chewicha, 2013; Jeremie, 2014; MEASURE Evaluation, 2009); burden of new data collection responsibilities on CHWs (Byrne, 2004; MEASURE Evaluation, 2009); redundant data collection (Damtew, 2013; Byrne, 2004); and cumbersome paper-based data (Chewicha, 2013; Damtew, 2013). Duplicative data may be reduced if key indicators from CBHIS are harmonized with and integrated in national HMIS. Similarly, USAID/Kenya has identified ways to streamline reporting systems across implementing partners, which paves the way for standardized country-level data (MEASURE Evaluation, 2014). One potential solution to cumbersome physical data is use of electronic data collection systems, but this is not always possible in lower-resource settings, and priority should be placed on collecting the right data.

Low technical capacity and the burden of new job responsibilities of CHWs and other CWs are challenges potentially connected to that of integration in the national HMIS. If CBHIS become integrated, governments would likely need to consider employing more CWs, as well as providing training courses and livable wages. Some CWs, such as CHEWs and HEWs, are already employed by health ministries; others, including volunteers, may not be able to dedicate as much time and effort to CBHIS, if the work can't support their livelihoods.

This review is not without limitations. Its primary weakness is that only published articles and gray literature were included. It is likely that other CBHIS exist that have not yet been discussed in the literature or presented on a website. Therefore, the practices, strengths, and challenges outlined here are not comprehensive. Thorough documentation and publication of CBHIS experiences is encouraged to provide a fuller picture.

While CBHIS are relatively nascent and few comprehensive systems have been well-documented, this review has shown some promising practices. CBHIS have the potential to shed light on unique health issues and their causes in communities, as well as aid in improving case management, health

programming, and outcomes. As increased healthcare coverage and health equity become more important to governments and other donors, the role of community health systems and their information systems will continue to increase (Golding, 2014). Integration in national HMIS and putting resources into the training and support of CWs will strengthen CBHIS.

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