

A Framework for Case-based Community Health Information Systems

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Abstract— There is increasing interest in deploying phone-based tools for community health workers (CHWs) in low-income countries. This work is motivated by numerous studies that have documented the potential for well-run community health programs to substantially improve health outcomes, especially around maternal health and neonatal mortality. However, geographically distributed workers, large volumes of data, and the need for continuous, supportive supervision mean that CHW programs are difficult to run. Community health information systems have the potential to address many of these gaps.

This paper presents the CommCare framework for representing case-management tools for CHWs. This framework has been used to develop and pilot systems for over a dozen different community health programs in eight countries, including programs for HIV, TB, safe motherhood, orphans and vulnerable children, and childhood illness. The open source CommCare codebase allows applications to be defined in a standard XML schema—CaseXML—we have developed around the framework.

We show that the underlying notion of a case can be used to capture elements that are common across diverse health programs. A case can be an episode of malaria, a pregnancy, or a chronic issue, such as HIV. In our framework, different forms can be specified to open, follow, or close cases. The forms allow for decision support, data collection, and educational aids with which CHWs can engage their clients.

By representing different CHW programs in a common framework, we can provide generic tools for tracking referrals and monitoring CHW activity rather than implementing a variety of point solutions that require an unnecessary duplication of effort. Being able to track the number of cases a CHW is currently assigned in real time, along with the percentage of cases overdue for follow-up, has been beneficial for the supervisors of each of the community health programs.

Keywords—CHWs; Community Health Workers; CommCare; mHealth; ICT4CHW; ICTD;

I. INTRODUCTION

Research has shown community health workers (CHWs) to be effective at improving health outcomes in their communities, especially around maternal health and neonatal mortality rates. However, CHW programs are difficult to run and maintain due to geographically distributed workers, large volumes of data, and the need for supervision.

These challenges, combined with increasing ubiquity and decreasing costs of mobile phones has led to recent interest in developing and deploying phone-based tools for CHW programs in a new field, referred to as ICT4CHW (information and communication technology for community health workers) [1][2]. Mobile phone tools have the potential to address the wide range of challenges faced by CHW programs.

CommCare [3][4] is an ICT4CHW tool developed and deployed by the authors and their colleagues to provide mobile phone-based applications for CHWs and their supervisors specifically to strengthen and monitor community health programs. The goals of this paper are to:

- Present the CommCare framework—a generalization of several CommCare applications we have created—and how it supports the development of flexible case-management tools for community health programs.
- Describe CaseXML, the implementation of this framework, and provide evidence that the underlying notion of case-management is widely applicable to a number of diverse community health programs.
- Explore the advantages of using the framework, including: the intervention is not tied to a single technology platform, non-programmers can easily design applications, and standardized metrics and tools can be applied to any well-formed CommCare application, as defined below.

The rest of this paper is organized as follows. First, we describe an example CommCare application. In Section II we present background about CHW programs and related technology to support CHWs. Section III presents the CommCare framework. In Section IV, we present the CaseXML architecture and discuss the deployments that have used it as well as enumerate the benefits of using the framework. Section V concludes by discussing future work.

A. An Example CommCare Application

An example CommCare application is shown in Figure 1. When a user first starts the CommCare application a CHW is presented with a login screen (Figure 1a).

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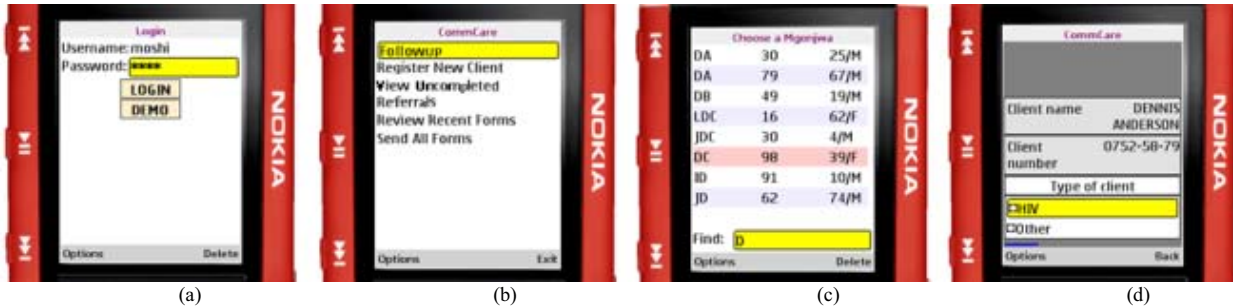


Figure 1. CommCare application screenshots showing (a) login, (b) form selection, (c) client selection and (d) form entry.

After logging into the system, the CHW next chooses what task s/he wishes to perform (Figure 1b). Most likely, this will be to visit a client who has already been registered. This will cause the client selection screen (Figure 1c) to be displayed. This screen shows basic information about all clients registered on the phone.

Selecting a client will take the CHW to the form entry screen (Figure 1d). In our user interface for form entry, the answers to previous questions appear above the current question. Here the first question in the form is shown with some information that was preloaded about the client.

Once the form has been filled out the user is presented with the option to send the data immediately via GPRS, the cellular data network, or to store it on the phone to be sent later using the *Send All Unsent* option on the main menu.

II. BACKGROUND AND RELATED WORK

In this section, we provide additional background on community health programs and describe relevant work around building tools for community health workers.

A. Community Health Workers

Community health workers' broad scope of activities has led to many different labels: village health workers, community health promoters, home-based care providers, lay health workers, community based distributors, community health assistants, to name a few. For simplicity, we will refer to them consistently as community health workers (CHWs).

Rural populations in low-income regions often do not seek care at a facility, even for life-threatening conditions, or do so too late. Community-based approaches allow us to reach people in their homes. CHWs are often in the best position to promote preventive care, encourage safe pregnancy, and refer ill people for diagnosis and treatment at appropriate facilities.

However, there are many challenges in managing such a workforce. Community health workers often receive relatively little medical training [5], have high turnover [6], and have limited opportunities to reinforce their knowledge once they begin working in the field [7]. They typically lack effective tools required to maintain longitudinal records required to provide effective care. Community health workers are difficult to organize and manage for the same reason they are so effective: they live in the community. This means they know the population they serve well, but rarely see their home office or supervisors.

Programs vary greatly in the amount and type of work they expect from CHWs. Some common responsibilities include: assisting nurses and doctors at local health facilities, community health education, routine household visits, scheduling follow-up visits, and tracking patients who miss follow-up appointments. In this paper, we focus on CHW information needs during household visits with individuals.

Home visits from CHWs have been shown to be particularly effective at addressing maternal and newborn mortality. An analysis that looked at outreach, family-community care, and facility-based clinical care predicted that an 18–37% reduction in neonatal mortality could be obtained with substantial improvement in outreach and family-community care alone, without any improvements in facility-based services [8]. A recent study in Bangladesh showed a 34% reduction in neonatal mortality achieved through a newborn-care intervention delivered by CHWs during home visits compared to almost no reduction when the same information was delivered through group community information sessions [9]. A similar study in India showed a 54% reduction in neonatal mortality when CHWs delivered essential newborn-care [10].

B. ICT4CHW

There have been a number of ICT4CHW tools [2] in recent years. The healthline project aims to provide information to CHWs via a simple voice-based interface for illiterate and semi-literate users [11]. Their focus was a tool that could provide health information for CHWs with low literacy rates.

Another group is using an SMS-based application server to set up communication channels between CHWs and other health workers and facilities in Malawi [12] [13].

Other groups are building mobile tools for CHWs similar to CommCare. ClickDiagnostics is equipping CHWs with camera phones, allowing them to take pictures of skin conditions to be sent to medical experts [14]. The CA:SH project [15] was a tool for CHWs in India to collect data and run automated clinical protocols during home visits. Grisedale, et al. [16] also implemented a mobile application allowing CHWs in India to collect data during home visits. In Kenya, AMPATH is using ODK to support HIV counselors [17].

Other previous work looked at decision support for health workers with limited training in facility-based settings. Using a standard World Health Organization (WHO) clinical protocol [18] on a PDA, the e-IMCI project showed that electronic devices lead to improved adherence to the protocol, while maintaining a similar patient throughput [19]. Finally, our work

builds on a larger effort intended to support mobile data collection and decision support in low-income countries.

C. Form-based Data Collection and Decision Support

There has been significant prior work investigating the use of mobile devices, primarily PDAs, to collect data in low-income countries. In rural Tanzania, enumerators equipped with PDAs surveyed 21,600 households (83,346 individuals) over a seven-week period [20]. Some studies have confirmed that PDAs allow for faster data collection than paper, are generally preferred by users, and can be cost-effective for organizations [21]. However, others have shown a slight decrease in accuracy when compared with paper forms [22]. Mobile tools are not a panacea, but do offer advantages for data collection.

Similar to PDAs, collecting data using mobile phones has the potential to improve both the quality and timeliness of data. The CAM framework has been used for automating data collection in microfinance and agriculture by providing a link between paper and [23].

The OpenROSA consortium [24] includes CAM; JavaRosa [25], a pure J2ME application; ODK, an Android-based toolkit [26]; EpiSurveyor [27]; and EpiHandy [28]. It started when a large number of groups developing open source data collection tools decided to combine resources and use the XForm standard [29] as their representation of mobile data collection forms. XForms allow a user to specify the set of questions, branching logic and translations for any particular form.

Because of the framework-approach described below, CommCare applications can be built either on J2ME or Android—the latter providing a richer user experience, GPS, barcode scanning, and other important features.

III. COMM CARE FRAMEWORK

In this section, we present a conceptual framework that encompasses the CommCare applications we have deployed with partnering community health organizations.

A. Background of CommCare Framework

We originally started working on CommCare with three different organizations in East Africa. The community health workers at each organization all performed slightly different duties. At one organization, they were primarily data collectors. At another the primary responsibility was health education in the community. And at the third organization the CHWs were primarily providing social support for HIV positive clients.

During our initial development, we followed the same methodology with all of the organizations. We started with focus groups, then followed the CHWs during their home visits, and finally engaged in rapid iterative design to develop a CommCare application. Based on that experience, and building on the work done by Winch et al. [30], we can list the generalized responsibilities for community health workers:

- **Visit households:** Some CHWs visit every household, while others visit specific demographics (e.g., newborns or HIV positive individuals). Some visits are routine, while others are targeted visits (e.g., following-up with the results of a test).

- **Assessment/Treatment:** Some CHWs are trained to assess illness and distribute medications, while others are trained to recognize danger signs.
- **Data Collection:** Every program collects data during visits to provide longitudinal care, track client health, and fulfill monitoring and reporting requirements.
- **Advice:** In all programs, CHWs are delivering preventative health messages to the community.
- **Referral/Follow-up:** All programs involve referral to the next level of the health system and most involve follow-up to ensure that the client completed the referral.

B. Definition of the CommCare Framework

The CommCare Framework provides scaffolding for designing, discussing and building CommCare applications.

1) Components

A *case* is the most basic building block in our framework. It represents the entity that a CHW is tracking and monitoring in the community. Each case has the following properties:

- **Type:** The entity that is being tracked (e.g. malaria, newborn, pregnancy, sickness referral).
- **Status:** A binary property: open or closed.
- **Deadline:** The date by which the case requires further action.
- **Parent:** The case from which this case was created.
- **Data:** Set of longitudinal information for the case.

A *form* defines the set of steps that should be taken during a visit. Similar to a case, a *form* has a set of properties:

- **Prompts:** The set of questions or informational prompts displayed to a user when the form is used.
- **Operations:** The set of operations that a form can perform. Valid operations are: *open*, *update*, or *close*.
- **Types:** The set of types of cases that this form can perform an operation upon.
- **ApplyForm(*c*):** A function with an optional parameter *c*, which is a *case*. This function returns a set of cases after applying the operations of this form.

A *module* is a collection of one or more *forms* that guide a CHW during a home visit. Similarly, an *application* is defined as a set of one or more *modules* that the CHV can use.

2) Convention

Here we provide definitions for consistent convention used throughout the rest of this section. We present two parts: sets and predicates.

a) Sets

For a given application defined by the CommCare framework, we have the following sets:

- **homeVisits:** The set of all home visits done for this CHW organization.
- **cases:** The set of all possible case entities.
- **forms:** The set of all forms.
- **modules:** The set of all modules.
- **LateCases:** $\{c \in cases: Late(c)\}$

- **Cases_T**: $\{c \in \text{cases}: c.type = T\}$
- **Operations**: $\{\text{open}, \text{update}, \text{close}\}$

b) *Predicates*

We define *now* as the current date, $c \in \text{cases}$, $f \in \text{forms}$, $t \in \text{modules.types}$, and $v \in \text{homeVisits}$.

- **Late(*c*)**: $c.deadline < now$
- **Applicable(*v*, *f*)**: True if *f* is filled out during *v*

Next, we define the notion of an *application* being *well-formed*. In order to be *well-formed*, the following properties must hold for an *application*:

- $\forall f \in \text{forms}, \forall c \in \text{cases}: c.type \in f.types \rightarrow f.ApplyForm(c) \neq \emptyset \wedge f.ApplyForm(c) \neq \{c\}$
- $\forall c_1, c_2 \in \text{cases}, \exists f \in \text{forms}: c_2.parent = c_1 \rightarrow c_2 \in f.ApplyForm(c_1)$
- $\forall f \in \text{forms}: f.operations \neq \emptyset$
- $\forall v \in \text{homeVisits}, \exists f \in \text{forms}: Applicable(v, f)$
- $\forall c \in \text{cases}: c.type = \text{referral} \rightarrow c.parent \neq \emptyset$
- $\forall c \in \text{cases}: c.status.open \leftrightarrow c.deadline \neq \emptyset$
- $\forall c \in \text{cases}: c.status.closed \leftrightarrow c.deadline = \emptyset$

3) *Referrals*

Cases can have associated referrals, which note that further action is required for that particular case. For example, a pregnant woman would be referred to the health facility if it were determined that the pregnancy was high risk.

A referral is simply a *case* that is guaranteed to have a parent *case*. That parent represents the entity being referred.

4) *Common Metrics*

There are many broadly useful queries that can be generically applied to any well-formed application. For example, we can identify which cases are late or are due tomorrow. Additionally, we can define the percentage of cases that are on time for a given type *T* as:

$$\frac{|\text{cases}_T| - |\text{LateCases}_T|}{|\text{cases}_T|} \quad (1)$$

As we discuss below, this serves as a powerful indicator of how well CHWs are performing in order to target supportive supervision or re-training.

C. *Example use of the CommCare Framework*

To better illustrate how the CommCare framework is used, we present the description of an application to be used by CHWs for monitoring and supporting pregnant women.

1) *Components*

The example application contains a single safe pregnancy module. The *module* contains two different types of cases: a pregnant woman and pregnancy referral. These cases are manipulated by 4 forms, which are listed below:

1. **Registration**: Registers a new pregnant woman.
 - a. **Prompts**: The form collects demographic information about the pregnant woman and determines if the pregnancy is high-risk.

- b. **ApplyForm()**:
 - i. Creates a new pregnancy case.
 - ii. (Optional) Creates a new pregnancy referral if the pregnancy is high risk.

2. **Follow up**: Requires a pregnancy case.
 - a. **Prompts**: The form collects information on a set of health actions that need to be taken by the woman before she gives birth (e.g. test for HIV, establish a birth plan etc.). The state of the actions is saved within the pregnancy case in the *data* property.
 - b. **ApplyForm(*c*)**:
 - i. Updates the pregnancy case *c* deadline to be due in one month.
 - ii. (Optional) Creates a new pregnancy referral when the woman needs to go for an antenatal visit at the clinic.
3. **Close**: Requires a pregnancy case.
 - a. **Prompts**: The form asks questions about the result of the pregnancy, where the birth occurred and who was present.
 - b. **ApplyForm(*c*)**: Unconditionally sets the status of *c* to closed.
4. **Follow up referral**: This form requires a referral case.
 - a. **Prompts**: The form asks if the client went to the health facility and what the results were.
 - b. **ApplyForm(*c*)**: Sets the status of *c* to closed if the client went to the health facility. Otherwise, updates the deadline for *c*.

2) *Next Steps*

A natural next module to build for this example application would be a neonatal module. In the *Close* form of the pregnancy module, a new neonatal case would be created if the birth was successful.

IV. IMPLEMENTATION AND RESULTS

A. *Framework Implementation: CaseXML*

The above framework has been implemented to allow a well-formed CommCare application to be specified in XML, and used to create the mobile phone application. The specification is comprised of two elements external to the software. One is a set of specification files, which describe the XForms (XML representation of a form) [29], views, and operations that are available to the CHW. The other is the specification of the cases that will be created or modified by each operation (*open*, *update*, and *close*). These specifications (existing as XML documents) are collectively known as the *CaseXML* for an application.

Since these files are externally specified, a CommCare application can be executed in a number of different environments, behaving identically on each. CommCare is currently available on J2ME powered mobile phones (including many Nokia, Sony Ericson, and Samsung models), as well as on Android devices where the CommCare application utilizes Open Data Kit Collect [17] for rendering XForms and collecting data. Support for executing a CommCare application in a browser-based session on a tablet or traditional computer is under development.

CaseXML provides a clear mechanism for not only the specification of an application, but also the way interface for data exchange. Each operation executed on a *case* is defined as an atomic transaction whose structure is specified inside of an XForm. The advantage is that these atomic transactions can be utilized in other contexts as well. For example, if a CHW's phone is lost, their list of open cases, referrals, and other data are transmitted back to a new phone as a set of atomic transactions in order to restore the phone state. Additionally, this system allows CHWs to share cases between one another by merging together the transactions for each shared *case* and allowing the resulting data to be synchronized between users.

Defining an applications behavior through the *CaseXML* files provides a large degree of freedom for implementing organizations. In addition to not being locked in to a specific software implementation (each component is part of an open specification), each organization can use the best resources available to create their CommCare application. Straightforward deployments can be created using simple GUI tools and cloud data hosting services, while more sophisticated deployments can hand write (or modify) *CaseXML* files and can create a custom backend to communicate with CommCare clients directly. This is particularly helpful if the organization needs to integrate CommCare with an existing service or data store.

B. CommCare Deployments

The *CaseXML* architecture is already powering CommCare applications in over a dozen different community health programs in eight countries. These deployments are primarily

supported by Dimagi, Inc. and D-tree International. The following categories of modules are currently being deployed:

- **Safe Motherhood:** As described above, this module supports many aspects of Maternal and Newborn Care.
- **Tuberculosis:** The TB module supports prevention and case-detection. A complimentary module supports nurses doing outreach for multi drug resistant TB.
- **Orphans and Vulnerable Children:** This module supports monitoring and delivering health and educational services to vulnerable populations.
- **HIV Support:** This module supports collecting data about the well-being of HIV-positive clients.

C. Advantages of the CommCare Framework

While there is fundamentally nothing the CommCare framework does that could not be done with free-form programming, there are several benefits.

Having an external, explicit specification of CommCare applications, such as *CaseXML*, is useful for several reasons. First, as previously mentioned, it enables easier deployment on multiple technology platforms. The same CommCare application can be generated for both J2ME and Android. This means that organizations can decouple the design of their application from the platform they choose. If they want to switch between the platforms, it can be done without any custom programming, just the procurement of new devices.

Additionally, *CaseXML* as an external specification makes it easier to design and develop new CommCare applications. We are able to mix and match different modules easily. For

TABLE 1. DEPLOYMENTS OF COMM CARE

Implementing Org.	Country	Technical Org.	Topic	Status
World Vision	Afghanistan, Mozambique	Dimagi	Safe Motherhood	Launching
CARE	India	D-Tree	Safe Motherhood	Launching
CRS ^a	India	Dimagi	Safe Motherhood	Launching
IntraHealth	India	Dimagi	Safe Motherhood	Launching
CRS	Malawi	D-Tree	OVC ^d	Launching
Univ. Michigan	South Africa	Self	MDR-TB ^e	Launching
JHIPEGO	Tanzania	D-Tree	Safe Motherhood	Launching
UNICEF	Tanzania	D-Tree	Safe Motherhood	Launching
PACT/PIH	USA	Dimagi	HIV	Launching
Grameen-Intel	Bangladesh	Dimagi	Safe Motherhood	Ongoing
NEEDS	India	Dimagi	Safe Motherhood	Ongoing
PIH ^b	Mexico	Self	Drug dosing	Ongoing
ITIDO	Tanzania	Dimagi, UW ^c	Routine care, safe motherhood	Ongoing
Pathfinder	Tanzania	D-Tree	HIV support	Ongoing
CIDRZ	Zambia	Dimagi	Safe Motherhood	Ongoing
BRAC	Tanzania	UW	Routine Care	Completed
CRS	Tanzania	D-Tree	OVC	Completed
Millennium Villages Project	Tanzania	D-Tree	Safe Motherhood	Completed
PATH	Tanzania	D-Tree	TB ^f	Completed

a. Catholic Relief Services. b. Partners in Health c. University of Washington d. Orphans and Vulnerable Children e. Multi drug resistant tuberculosis f. Tuberculosis

example, we originally created a safe pregnancy module with one organization, and ported it for another organization in just hours. Similarly, when designing a new module, the majority of the work is now designing the new forms, which take hours, not a mobile application, which can take months. Furthermore, subject experts can focus on creating the content of the CommCare modules, rather than how to program that content.

Using well-formed CommCare modules allow for the sharing of several standardized tools. We have begun experimenting with sending automated SMS reminders to CHWs using CommCare who have late cases. We can easily extend this service to any well-formed CommCare application. Similarly, we have found that the metric defined above for percentage of cases that are on time is an extremely useful indicator of CHW performance and participation. Most ICT4CHW programs—including ours initially—track the number of forms that the CHW submits per day. This gives some sense of how active the CHW is, but not how many visits a CHW still needs to perform.

Finally, using the framework allows easier comparison and sharing between different modules and different organizations. For example, we can compare the number of open pregnancy cases to different programs—even if they have different forms for what to do during each visit. We can also easily compare the percentage of late cases, to assess CHW performance.

V. CONCLUSION

The CommCare framework presented in this paper plays an important role in our goal to provide mobile phone-based applications to strengthen a range of community health programs. The CommCare deployments are all from a single code base and we are continually developing standard metrics and services that can be applied to all these deployments.

Furthermore, the framework has provided an easy way to interact with non-technical content experts. In developing new applications, we have found it effective to circulate the English versions of our forms for the different operations and have the content experts iterate upon those forms. In this way, we can begin to leverage the work of different organizations to improve upon similar interventions.

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