Sense Followup: Using Technology to Organize Ebola Outbreak Data and Enable Effective Response

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Overview
In any epidemic outbreak, a country's ability to quell the spread of disease depends directly on how effectively the country can organize people and their health information.

In July 2015, I worked with the US Global Development Lab at USAID to assess and map the flows of data in Ebola-affected West African countries so that we might improve real-time disease response infrastructure in these countries. Technology played a critical role in the fight against Ebola.

As Ebola simmered in West Africa, growing more out of control in Liberia, Sierra Leone and Guinea by the day, neighboring Nigeria, Africa's most populous country, was able to stop Ebola in its tracks. Experts believe that Nigeria's contact tracing organizing system was key to Nigeria's management of Ebola. Contract tracers are responsible for traveling from settlement to settlement looking for and keeping track of everyone who had come into contact with Ebola cases. Initially, these workers were using paper-based forms to keep track of the contacts and follow-ups, but the sheer volume of data soon rendered the system unmanageable.

Nigeria was the first country to partner with eHealth Africa to deploy an app, Sense Followup, that optimized the workflow of contact tracers. Sense Followup, later deployed in Liberia, Sierra Leone, and Guinea played a critical role in strengthening health data organizing systems and defeating Ebola. Apps like Sense Followup are drastically changing the status quo for contact tracing in all epidemiological contexts.

What is being organized?
At the most basic level, contact tracers use Sense Followup to organize contacts during a contact's 21-day risk period. The scope of resources collected by contact tracers is purposely more narrow than the resource's scale. The resource scope is meant to be clear and concise, with only a few resources collected for each contact, so that the protocol may be easily taught to and repeated by a large task force of contact tracers. The scale of resources though, is striking. For example, in Nigeria, one infected individual led to a chain of events where 894 contacts were identified and followed for Ebola symptoms, amounting to a total of 18,500 in-person interviews across Nigeria. With over 28,000 cases of Ebola in West Africa, a robust organizing system is critical.

Sense Followup is an example of an application with a modular architecture that separates the storage of data, the functions of data, and the user interface by which users can interact with the data. Sense Followup organizes digital resources. All data is collected by mobile phone directly through the app. Sense Followup was designed to manage a collection of resources that are continually added and changing. The resources are unique to a particular contact and are not interchangeable among categories or groupings of source contacts. The resources are extracted and aggregated for use across
global health partners combating the disease at different levels of response - WHO, MOH, county hospitals and local-level clinics.

**Why is it being organized?**
The contacts’ health information is organized so that all information from the ground can be made more accessible to all levels of response. As contact tracers collect health information, Sense Followup shares that data with its primary users - international global health partners - who in turn visualize and share that data with both local emergency response centers and national response centers. See attached artifact for a visualization of contact tracing’s data flows.

Sense Followup allows for a number of interactions to support the timely collection and sharing of data:

1. Sense Followup sends local case management teams a notification when any contact is labeled as symptomatic, allowing immediate response
2. Multiple persons can enter data at the same time by different persons, eliminating the time-intensive dependency on a single data entry clerk
3. GPS location coordinates are recorded automatically, allowing contact tracers to meet contacts where they are even if there is no formal addressing system
4. Real-time synchronization of data introduces a sense of accountability into the contact tracer’s workflow, improving data quality and timeliness

These combined interactions allow Sense Followup to reduce the turnaround time between identification of symptomatic contacts and evacuation to the isolation facility from 3 - 6 hours to an hour. With Sense Followup, higher quality data can be collected so that the organizing system’s main institutional goals - responding to disease efficiently and effectively - can be achieved.

**How much is it being organized?**
In an ideal setting, all contact tracers’ reports should be organized uniformly and to the same degree. To enable this, by design, there are only a few granular points of information being collected by contact tracers. Contact tracers record contact demographic information (ex: name, gender, age, county, district), their type of Ebola exposure (ex: direct physical contact, slept or ate in same household, exposure to bodily fluids), and the GPS coordinates of their location. See Figure 1 below. Contact tracers then tag that information with a source-case ID number - a critical step so that all related contacts can then be traced back to the original source case. This level of granularity allows contact data to be collected with very minimal time and effort per case - a key to Sense Followup's scaled success.

Sense Followup's database is driven by organizing principles with the specific functional purpose of identifying which contacts are symptomatic and where they are located.
Organizing Sense Followup's database by the following organizing principles allow for the most efficient contact identification and response:

1. **Source case ID**: Users can easily trace contact records and quickly update the status of infected persons along a contact-chain, minimizing unnecessary follow-up appointments for contact tracers.

2. **Location of most infected persons**: Users can see where the disease spreads and then overlay that data with resource and hospital locations so that response may be better targeted.

3. **The most common mechanism for the spread of disease**: Users can see where community health education can be improved and then target local campaigns to fight the most common spread of disease.

![Figure 1: Screenshots from Sense Followup that display the granularity of the data collected for a contact.](image)

**When is it being organized?**

Sense Followup imposes its organizing principles on resources on the way in - when the contact data is collected initially. There are a number of fields that a contact tracer is required to fill-out upon entry. There is very little flexibility in the app's data collection form.
Sense Followup imposes another set of organizing principles upon a particular set of users’ interaction with the data. Sense Followup has an additional web app, Sense Dashboard, that reorganizes the contact tracing data to provide government users with a summary of all contact tracing activities. For example, the Dashboard allows governments to see the positions of all infected and at-risk persons rendered on maps and thereby get the sense of the spread of disease.

While none of Sense Followup’s organizing is mandated by law, there are global health industry practices that inform the app’s design. For example, tagging all contacts with a source case ID number is a technique practiced across all epidemiological contact tracing contexts.

**How or by whom is it being organized?**

Contact health information is collected by contract tracers, but that data is inherently organized by the designers of the app - eHealth Africa. eHealth Africa is the organizer and a primary user of the data. Because of this, the app’s organizing principles are influenced by eHealth Africa’s bias. In Sense Followup’s design, eHealth Africa has designated different data fields as important for case and disease management. Given this bias, because eHealth Africa is a large US-African NGO, the data collected may then better serve the NGO and global health governmental partners than small, rural or community clinics.

There are other primary users - WHO, country ministries - whose roles govern the organizing activities of Sense Followup’s database. For example, an international governing body like the WHO may be interested in organizing data on the spread of disease across multiple countries who use Sense Followup. A country ministry, on the other hand, may prefer to organize only the information on the spread of disease in their own country.

**Where is it being organized?**

The organization of contact tracing data is constrained by weak connectivity typical of low resource settings. Because of this, Sense Followup is designed to save data locally, at the time of visit. When the app encounters a signal connection strong enough, the local files are then synchronized with Sense Followup’s master database. During this synchronization process, the application also receives any new data from other health workers, making it easier to coordinate contact tracing and followups within large teams.
Sources:

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- Sense Follow-Up, Optimising the workflow of contact tracers in the West Africa Ebola epidemic:
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