# Lowering the Barriers for Access to Public Health Data *(Kenya, Zambia)*

## Issue: Monitoring Disease in Developing Countries

"It was the late 1990s and I was amazed by the lack of adoption of modern IT [information technology] in collecting health data, whether you were in Haiti or parts of the U.S.," recalls Joel Selanikio, a pediatrician, technologist, epidemiologist, and co-founder of the non-profit DataDyne.org. "Government agencies tend to lag far behind the private sector in pursuing new technologies."

Dr. Selanikio began his public health career working at the Centers for Disease Control and Prevention (CDC), a U.S. government agency. He traveled the globe investigating disease outbreaks. Searching for clues, he collected and analyzed health data, evaluated programs, interviewed patients, and was sometimes able to discern patterns others had overlooked. Yet, as is often the case in addressing public health concerns, his efforts were hindered by a lack of reliable, systematically recorded data. In a number of countries, critical health data was being collected through agonizingly slow paper-based systems–if it was collected at all. These gaps in access to up-to-date public health data made informed public health decision-making extremely difficult.

Having worked earlier in his career as an IT consultant on Wall Street, Selanikio began exploring the use of handheld computers to record field data. He discovered that while the hardware needed to collect data was readily available, the software required was often too complex and costly for use by those in developing countries.

## Response: Collecting Health Data through an Open-Source Mobile Software Tool

In 2002, Selanikio teamed up with computer scientist Rose Donna to form the DataDyne Group, a non-profit dedicated to increasing access to public health data through mobile software solutions. Inspired by an earlier CDC product called Epi Info, Selanikio created EpiSurveyor, a free, open-source, mobile data collection software tool. EpiSurveyor offers health data collection forms that can be downloaded at no cost and modified by anyone with basic computer skills. Selanikio and Donna believed that this technological innovation could empower developing country health officials with the tools needed to gather time-sensitive health data quickly, and without outside assistance.

*Credit: DataDyne*

Health

In many cases when developing countries track public health data, they do so by hiring programming consultants to customize the required IT solutions. This arrangement can strain limited resources, and in some cases also raise questions about health data ownership. Selanikio designed EpiSurveyor to lower the barriers of access to public health data through a user-friendly and easily adaptable health data collection tool. "We wanted to create a tool that the average person who knows how to word process could handle," Selanikio says.

## How It Works

**EpiSurveyor incorporates a Windows-based "Designer" forms-creation application, and a Java-based engine that can run on personal digital assistants (PDAs), smart phones, and soon, common mobile phones. Users start by downloading the software from the DataDyne.org website (*www.datadyne.org*). Then, using a desktop or laptop computer, they enter the health survey questions into the Designer program. The resulting form can then be published to a mobile device. For data that is collected via PDA or smart phone, once data is collected from the field the mobile device is synchronized with the computer. Data from multiple handsets can then be combined into a single data table for analysis.**

### *Piloting the Approach*

Shortly after developing EpiSurveyor, and working with Dr. Mark Grabowsky, then of the American Red Cross, Selanikio entered and won a grant from the World Bank's Development Marketplace Competition. They used the award to develop and test a beta version of the software in Kenya. At the same time, Selanikio and Donna were launching DataDyne, with the goal of creating mobile data products to address public health needs in developing countries.

In 2006, DataDyne entered into a partnership with the United Nations Foundation, The Vodafone Group Foundation, the World Health Organization (WHO), and the Ministries of Health of Kenya and Zambia to launch a pilot program that scaled the beta-tested software at the provincial level. Through the pilot, public health officials in Kenya and Zambia received training and mobile computing devices to support the fight against measles.

"For some time, we had been exploring how to use mobile technology to collect data on the ground that could be used by health officials in making life-saving decisions," says Mitul Shah, senior director of technology partnerships at the United Nations Foundation. "In Zambia and Kenya, for example, health officers traditionally traveled to remote facilities and recorded information, like stock levels, on paper. This information was then transferred manually to an electronic database, which took time. We wanted to systematize how health data was collected."

The pilot sought to contribute to the goals of the Measles Initiative, a partnership aimed at reducing measles deaths worldwide, that counts as its founding partners the American Red Cross, U.S. Centers for Disease Control and Prevention, the United Nations Children's Fund (UNICEF), the WHO, and the United Nations Foundation. From 2000 to 2006, the Initiative succeeded in reducing measles deaths in Africa by more than 90 percent. Still, monitoring measles vaccination rates and disease outbreaks in hard-to-reach areas was a complex and time-consuming task. While the Measles Initiative had worked with DataDyne in using PDAs for this purpose in the past, Selanikio realized that switching from a consultant-based solution to a country-owned process using EpiSurveyor would provide a more sustainable solution.

"The long-term goal [of the pilot] was to strengthen systems–to make clinics more responsive and train health surveillance officers to be able to report more accurately and on a more timely basis about measles and other priority diseases," says Andrea Gay, executive director of Children's Health for the United Nations Foundation and senior advisor to the Measles Initiative.

*Credit: DataDyne*

## Outcome: Improved Public Health Response to Disease Outbreaks

Through the pilot, thirty provincial health supervisors in each country were trained in how to use EpiSurveyor on Palm Zire™ handheld computers. The health officers then used EpiSurveyor to collect management data about public health clinics–such as medical supply quantities and levels of staff training. In both countries, officers went beyond the purpose of the pilot to gather additional health data as new needs arose. In Zambia, for example, the supplied PDAs and EpiSurveyor software were used by health officers to conduct a post-measles vaccination campaign coverage survey–the very first time that such a survey had been independently conducted by in-country staff using PDAs.

Another instance in which local health officials modified the open source software to meet new health needs as they arose occurred in Kenya, when political unrest and fighting in neighboring Somalia brought in waves of unvaccinated refugees–some of whom carried the polio virus. Despite the fact that the last native case of polio in Kenya had been seen more than two decades ago, the human migration introduced a new threat of disease outbreak.

Titus Kolongie, who works with the Kenya Expanded Programme on Immunizations (KEPI), was part of a cadre of health workers trained on EpiSurveyor who responded to the crisis. Using a PDA loaded with EpiSurveyor, he evaluated an emergency polio vaccination campaign that targeted individuals who may have come into contact with the virus as it entered Kenya. In total, KEPI was targeting almost two million children for vaccination, giving the polio virus fewer places to hide, and preventing life-long infections from a debilitating disease. Says Kolongie, "EpiSurveyor made things work efficiently, allowing us to collect information and conduct analyses quickly."

Even more remarkably, the pilot officers in Zambia learned of the outbreak investigation form created by the Kenyan team, downloaded it from the project website, and put it into use in Zambia with minor modifications. This adaptation of the software and forms came as great news to Selanikio.

"First, you had health professionals using the software–on their own initiative–to meet a pressing need," he explains. "Next,

*Credit: DataDyne*

you had health professionals in a different country sharing forms leading to the standardization of data. This is a potentially revolutionary change in the way we collect data." If comparable health data were available across countries, it would be easier to share best practices and implement more widespread interventions, he adds.

## Challenges: Overcoming In-Country Logistical Constraints

Selanikio points out the challenge of measuring the effectiveness of a tool like EpiSurveyor in the face of independent variables that users have no control over. In some communities in Kenya, for example, lack of fuel and bad weather made it difficult for those trained to use EpiSurveyor to travel to clinics.

An abundance of new data is also generating a demand in government ministries of health for back-end data aggregation and analysis tools. This means that in some cases, until aggregation and analysis are embedded in the system, this new data may not be acted upon as quickly as one might hope. Still, this offers a real opportunity for further research and development to bring to fruition complete front- and back-end solutions.

## Next Steps: Adapting the Application, and Bringing It to Scale

Despite these challenges, the results of the pilot have paved the way for wider applications of EpiSurveyor. "The results are very encouraging in that they demonstrate the potential for using mobile devices for widespread data collection," says Shah. "The Millennium Development Goals have underscored the need for better data–data that can help prevent the spread of disease, monitor child nutrition, and determine people's access to clean water. Tools like EpiSurveyor offer great potential for helping to monitor these needs."

Based on the results of the pilot program, WHO is considering plans to implement EpiSurveyor in all sub-Saharan African countries. Starting in 2008, health professionals in ten countries will be trained to use the software in their work, particularly in the area of disease surveillance.

DataDyne is also working with Cell-Life (see Case Study 1), a non-profit developer in South Africa, to adapt EpiSurveyor to run on Java-enabled mobile phones. This will allow users of the software to transmit data wirelessly, thereby saving time and improving efficiency.

Because the software is open source and can be easily downloaded for free, hundreds of people and organizations have accessed EpiSurveyor and are using it–formally and informally–in their work. Among these are the Harvard and Johns Hopkins schools of public health. Those who seek to modify the EpiSurveyor code to create new functionality, rather than simply using it as provided, are required by the licensing agreement to make their source code open to others, thereby stimulating new innovations and the sharing of valuable tools.

For its part, DataDyne is focused on refining and adapting the software to address a wide variety of needs. "By adding functionality, we can use the platform to provide clinical updates, patient tracking and management, reference materials, and other tools," says Selanikio.

By the year 2010, DataDyne estimates that more than 1,000 public health professionals will be using EpiSurveyor for data collection and analysis. "We've just put our toe into the pool," says Selanikio. "Imagine where this could be ten years from now." ■