COLLECTING RELIABLE DATA

Improving National and Subnational Surveillance Data:
The Models of Bangladesh, Iran and Chile, and the Role of PAHO

C. James Hospedales, Reza Malekzadeh, Daniela Godoy, Andrew Mirelman and Paolo Boffetta

Matlab, Bangladesh, is home to one of the longest-running health and demographic surveys in the developing world. Traveling on foot or by rickshaw, local women regularly visit villages to collect data in this rural subdistrict, where people live in huts topped by corrugated tin roofs and work in the verdant green rice paddies nearby. Going household to household, the surveyors use a small tablet computer to enter basic information on the latest births, deaths, marriages and changes in socioeconomic status as well as health details such as the frequency of prenatal care in expectant mothers, incidence of pneumonia and the prevalence of dysentery among children.

The Matlab survey was started in 1966 to track the lethal, infectious scourge of cholera. Since then, it has amassed nearly a half century of data on more than 200,000 people in 142 villages. But as cholera came under control, the study documented an unsettling new threat.

When the survey’s director, Peter Streatfield, graphed mortality data from 1986 through 2009, the trend became quite obvious. On his color-coded graph, small bars of green, yellow and pink represented maternal and infant deaths, fatal injuries and “miscellaneous” causes of death. Shortening blue columns depicted declining deaths from infectious disease—while a swelling wall of red reflected a rising tide of chronic diseases, such as heart disease, stroke and cancer. The chart “bleeds out red,” said Tracey Koehlmoos, a health systems and policy scientist who worked in Bangladesh from 2006 to 2012. “All of a sudden...more than half of the deaths in Matlab come from noncommunicable diseases,” she said, in particular, cardiovascular problems.

Similar stories are playing out in many of the world’s developing countries. It is a narrative that underscores a need to redirect the focus of many existing health programs. Typically, they focus heavily on infectious childhood killers and maternal health while ignoring the escalating epidemic of heart disease and stroke. In many nations, weak surveillance provides little concrete information, so health authorities cannot gauge the true scope of the problem they face or prioritize efforts to combat it. Nor can they accurately evaluate whether public health interventions are working. They might as well be operating in the dark, and without reliable data it’s difficult for policy makers to meet the needs of their people. The greatest danger is the failure to take action.

In countries with effective health information networks, data is readily available on how often diseases occur, how many lives they take, the disabilities they cause, the risk factors that foster them—and the economic impact. Monitoring programs can reveal new trends, such as rising obesity rates. They can also pinpoint groups whose health may be at risk because of social, economic or environmental factors that may include poverty, poor education or heavy environmental pollution.

The World Health Organization (WHO) and other global health agencies are assisting developing nations to establish surveillance programs that track heart disease,
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stroke and other chronic illness. These agencies are helping translate Western expertise into projects that can be implemented by countries with cash-strapped budgets and few resources. For those that can’t set up a nationwide system—the ideal scenario—a small network of local health registries and surveys collect valuable data. In the end, limited high-quality information is far better than an overambitious system that generates poor data. To generate accurate data, WHO devised a standardized protocol to measure risk factors for chronic diseases. Their “STEPS” framework questionnaire tallies potential health risks such as socioeconomic status, poor diet, tobacco use and exercise habits; physical exams measure weight, height and blood pressure; while blood tests measure glucose levels and cholesterol.

Unreliable information not only drains limited health coffers, but may also prompt misguided policy choices.

**Bangladesh: Small steps toward a sustainable surveillance system**

Aging populations in Bangladesh and across South Asia are increasingly falling prey to noncommunicable diseases. The years of healthy life lost to ischemic heart disease—the type that clogs arteries and triggers heart attacks—soared by more than 200 percent between 1990 and 2010 in Bangladesh, according to a recent estimate from the Global Burden of Disease, Injuries and Risk Factor Study by the Institute for Health Metrics and Evaluation in Seattle.

Most Bangladeshis now develop heart disease about 10 years earlier than in the West, and cardiovascular illnesses account for more than a quarter of all deaths. But there is no formal national program that regularly tracks cardiovascular problems or their risk factors. The current picture has been largely pieced together from disparate, often small or limited ad hoc studies in various locales conducted by various government departments, NGOs and research institutes.

The Matlab surveillance, which is overseen by the International Center for Diarrhoeal Disease Research, Bangladesh, is part of the larger INDEPTH global network of health and demographic surveillance systems. In all, 42 INDEPTH centers observe the life events of millions of people in 20 developing countries in Africa, Asia and Oceania. Four of these sites are in Bangladesh. Although INDEPTH data have mirrored a general trend of escalating chronic disease, specific details of the epidemic are not always the same in different regions.

Other projects have also helped fill the information gaps. One of those, the 2006 Bangladesh Urban Health Survey, interviewed more than 12,000 households in Dhaka, Chittagong and four other cities, discovering that more people living in slums were overweight than those living in higher income neighborhoods.

In 2007, the government made noncommunicable diseases an official priority. That year, the Ministry of Health and Family Welfare developed a three-year strategic plan to monitor and prevent chronic illnesses. They started by calling for government hospital cooperation in reporting chronic disease cases to a central records database, though progress has been slow.

Three years later, the health ministry and the Bangladesh Society of Medicine incorporated the STEPS protocol to gain a country-wide perspective on the cardiovascular health problem. Researchers discovered that 99 percent of the population had at least one heart disease risk factor, while many Bangladeshis had multiple strikes against them: about 77 percent had two risk factors, while 28 percent had three. The most common problems were a poor diet lacking sufficient fruits and vegetables, not enough exercise—and smoking was rampant among men.

Bangladesh has a strong tradition of health research. An updated plan for 2011–2015 aims to establish strict data collection standards and better linking of various monitoring projects through the Bangladesh Network for NCD Surveillance and Prevention. By taking formal policy steps toward better surveillance of heart health, they are setting an example for other countries in South Asia.
with major health or economic repercussions. Without sound data on how often people seek or follow medical treatments, for example, a program that provides free hypertension drugs might well fail because patients don’t sign up or don’t take their medication regularly.

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Iran: Lessons from Golestan Province

Over the past quarter century, dramatic economic growth has ushered in a higher standard of living across Iran. Today this middle-income nation is in the intermediate phases of a growing chronic disease epidemic. Monitoring by both government and university research groups has provided a reasonably good assessment of the problem: Heart attack and stroke are the culprits in close to half of all deaths.

Twelve years ago, the Center for Disease Control in Iran’s Ministry of Health and Medical Education began implementing large-scale projects to monitor heart health. But academic research centers such as Tehran University, Shiraz University and the Isfahan Cardiovascular Research Institute have helped drive nationwide health surveillance projects, where local health registries gather data on patients with heart disease or other noncommunicable illnesses.

One such program, a long-term study of 50,000 adults in the northeastern province of Golestan, was launched in 2004 by Reza Malekzadeh, Paolo Boffetta and their colleagues in a broad collaboration between the International Agency for Research on Cancer, WHO, the U.S. National Cancer Institute, Tehran University of Medical Sciences and Isfahan School of Medicine at Mount Sinai. Perched on the Caspian Sea, Golestan is dominated by wheat and rice fields that are tended by descendants of Turkmen nomads.

Collecting data there is relatively straightforward because of a fairly well developed rural public health network, which employs behvarz—community health workers.

With their help, field research teams invited all 40- to 75-year-old residents in 326 villages to come to their local health center to answer health questionnaires and give blood, hair and urine samples. They also surveyed urban residents in the provincial capital of Gonbad. This cohort has now been followed for a decade, including careful documentation of deaths using verbal autopsies and hospital records.

Although the investigators originally went into Golestan to study esophageal cancer, they were shocked to discover the large numbers of residents, especially women, who were overweight or obese. Their survey revealed alarming impacts from cardiovascular illnesses. Amongst every 100,000 women, 435 died from heart attack and stroke each year; 614 out of every 100,000 men met the same fate.

The reasons are clear. With rapid modern progress, Iranians are eating more. Everyone drives to work or school rather than walking. Farming machinery has replaced manual labor.

Several studies have estimated that more than half of all Iranian men are overweight or obese and about 25 percent have hypertension. About one third have high cholesterol and triglyceride levels; 10 percent suffer from diabetes.

Motivated by such statistics, several public health initiatives have promoted heart-healthy habits, such as eating less salt and exercising more. Unfortunately, changing people’s lifestyles and daily habits is not easy.

Malekzadeh and Boffetta realized that the Golestan project was the perfect venue for testing an alternative strategy.

The “polypill” was first proposed in 2003 by U.K. preventive medicine specialists Nicholas Wald and Malcolm Law: A way of preempting heart attacks and strokes by treating all older adults with a single, inexpensive daily pill that combines low-dose aspirin, a cholesterol-lowering statin drug and blood pressure–lowering medications. Iran’s rural community health workers were trained at little cost to deliver the polypill in a way that adhered to strict guidelines. In 2011, the research team launched a five-year clinical trial in 7,000 older adults in Golestan using a domestically manufactured experimental polypill. The investigators expect preliminary trial results in 2014. Their projections: This preemptive treatment could prevent half of premature cardiovascular disease cases and extend the average adult life span by 10 years in Iran.

Good health data sparked this prevention trial, illustrating how health monitoring research can spur public health measures that may reverse the trends of rising cardiovascular disease.

All photos by Edward Bell

Promoting Cardiovascular Health Worldwide
wasting resources and losing an opportunity to improve health. And without surveillance data, governments can simply choose not to act against disease threats.

Amassing valid information on the leading causes of death is crucial for public health policy makers. That's not easy in many countries, where a death certified by a doctor can be a rare thing. But those data can be gathered by trained fieldworkers who interview family members or neighbors about the symptoms that led up to a loved one's death. Physicians or other health personnel can then review these “verbal autopsies” and categorize each case within broad groups, distinguishing, for example, a heart attack from a respiratory ailment.

The heart disease epidemic in Chile, an upper middle-income country, is much akin to that of western Europe where cardiovascular disease is the biggest killer. From 1960 to 2009, the number of overall deaths induced by cardiovascular and related diseases more than tripled, jumping from 8.7 to 27 percent, according to the Chilean Department for Health Statistics and Information. But with earlier diagnosis and treatment, the numbers are looking better than they did a decade ago. In 1997, 162 out of every 100,000 Chileans died of heart-related problems, but by 2007, that number had dropped to 137, Ministry of Health statistics showed. While risk factors continue to rise, the Chilean government has generated the information needed to build comprehensive health policy and intervention efforts.

Since 2000, the Ministry of Health has used a new countrywide health surveillance system dedicated to noncommunicable diseases. It built on previous efforts that had assessed lifestyle habits, diseases and health risk factors, most importantly, the Encuesta Nacional de Salud, (National Health Survey) that was launched in 2003. When it was repeated in 2009–2010, fieldworkers interviewed 5,434 people aged 15 and older in a random, representative sampling of Chilean residents. The surveyors used PDAs to gather data about participants’ health status and living conditions; they also measured height, weight and blood pressure. Another survey found that nearly one third of Chileans tend to be sedentary, overweight and have elevated blood pressure. Yet another found that nearly one third of girls under age seven who lived in extreme poverty were overweight or obese, compared with 5 percent of girls from wealthy families.

With substantial information in hand, the next step was to craft comprehensive public policies to both lower health risks and address the inequities associated with them. In 2011, then-First Lady Cecilia Morel launched Elige Vivir Sano (Choose to Live Healthy). It’s an initiative that weaves together policies and programs developed by various ministries and public agencies that influence behaviors and reduce risk factors associated with cardiovascular diseases. It promotes healthy habits, like nutritious eating, exercise and spending more time outdoors with family, and improves access to healthy lifestyles and habits among disadvantaged populations.

This policy was signed into law in 2013 to better coordinate initiatives from across government ministries, with support from the private sector. School physical education classes were increased from three to four hours per week for seven- to 10-year-olds. Over 270 new playgrounds were built across 172 districts. Hundreds of healthy lifestyle workshops and sporting events were held across the country, financed with help from private companies. From 2009 to 2012, participation in sports and other physical activity increased significantly while those who remained sedentary fell by 3.7 percent, according to data from Universidad de Concepción. However, the challenge of whether Elige Vivir Sano is improving the health of the Chilean population can only be answered with long-term data.

Emerging technologies are changing surveillance systems, making it possible to now capture and transmit data with cell phones, pinpoint locations with GPS devices and maintain electronic health records. Matlab stands as a model. For decades, field staff recorded their data within big books of color-coded forms. In 2008, they began using handheld personal digital assistant (PDA)

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devices, and have recently switched to computer tablets. Digitizing data not only saves time and reduces errors, but allows researchers to map village and household coordinates, making it simple to analyze spatial patterns of death and disease. Across the globe, both poor and middle-income nations are mounting varied responses to the cardiovascular disease epidemic. Programs in Bangladesh, Iran and Chile offer snapshots into various initiatives to improve surveillance data from countries that are at very different stages of development, with very different health resources—thus offering examples across the spectrum of developing countries. Their efforts are guided by WHO’s regional arms that share both research and practices from richer nations.

There are many ways to embed good surveillance programs for heart disease and other chronic diseases within national health systems. But reliable monitoring data is, of course, just the starting point for making informed plans and establishing policies to improve public health. Ultimately, it is what we do with the information that matters most.

**About the Authors**

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