

HANDBOOK

# Introduction to Innovative Disease Surveillance

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IN PARTNERSHIP WITH

# INTRO

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This course is designed to provide a refresher of the basic disease surveillance skills and information you need as a field epidemiologist or health professional.

It also serves to introduce you to newer approaches that can help you improve disease surveillance in your community, country, and globally. In particular, you will learn about innovative disease surveillance methods and tools like EpiCore!

This course is a prequel to the EpiCore Training handbook.

## **Learning objectives for this manual include:**

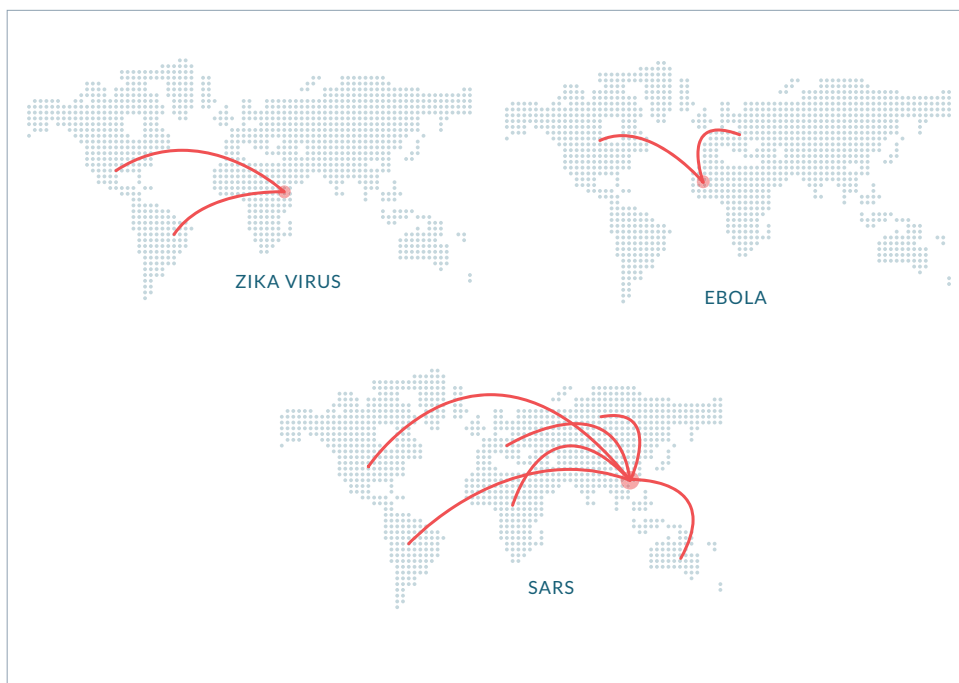
- Recognize the advantages and challenges of traditional disease surveillance.
- Define the meaning of innovative disease surveillance.
- Recognize informal information sources.
- Identify the benefits of using innovative disease surveillance that is complementary to traditional disease surveillance methods.



# WHY DOES DISEASE SURVEILLANCE EXIST?

Disease surveillance exists because of its essential role in disease elimination, as the earlier disease outbreaks can be detected, the more lives can be saved. In addition to serving as an early warning system for public health emergencies, disease surveillance also helps track the impact of an intervention or progress towards specified goals, and help monitor and clarify the epidemiology of health problems, that in turn allows priorities and public health policy and strategies to be set.

As this map shows, outbreaks have the potential to spread across the world.

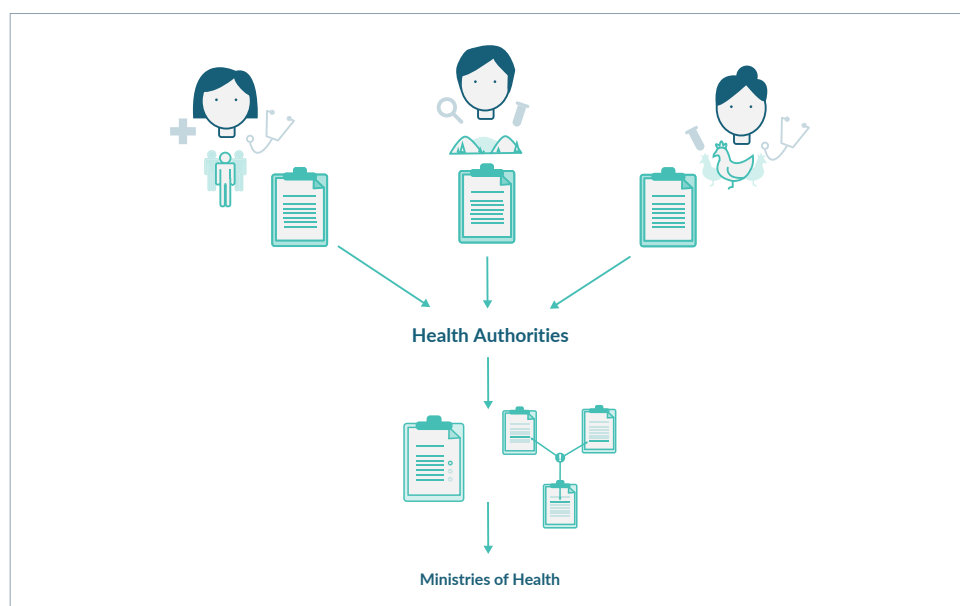


# TRADITIONAL SURVEILLANCE

Conventionally, health professionals have used what is referred to as “traditional disease surveillance techniques”. Traditional disease surveillance is the continuous systematic collection, analysis and evaluation of health information from formal sources.



Traditional healthcare-based surveillance systems often rely on healthcare professionals to report information on the illnesses they see in their clinical practice, in what is referred to as “passive disease surveillance”. This information is often collected, analyzed, and disseminated by local health authorities who report to centralized Ministries of Health.



## Pros and Cons of Traditional Surveillance

There are many advantages to using traditional disease surveillance techniques; two of those advantages are:

- The information received is often highly reliable and easily verified;
- There are standards in place that provide incentives and a uniform structure for reporting.

However, certain challenges with using traditional disease surveillance techniques are:

- Missing information from populations who do not access healthcare or do so through informal channels, for example, people who choose not to see a doctor when they are sick, or may see a doctor who works at a facility that is not part of the official reporting system; or go to a pharmacist for medications, or go to a traditional healer.
- Not suited to detect new, often high-impact outbreaks, such as SARS, Avian Influenza, MERS and other emerging and unknown diseases.
- Delays in reporting due to laboratory confirmation waiting periods or difficulty obtaining specimens for laboratory confirmation.

### QUESTIONS

Can you think of anything being missed by the official reporting system?

Can you think of ways the system might be able to capture outbreak information earlier?

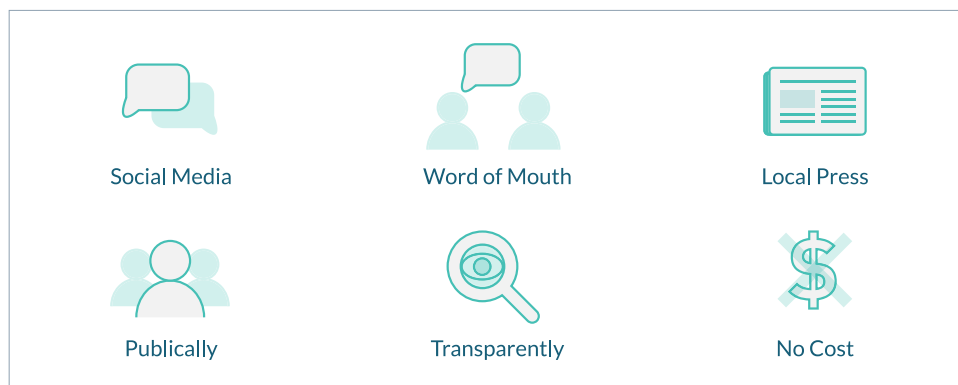
# INNOVATIVE DISEASE SURVEILLANCE

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As we discussed earlier, some of the gaps resulting from only using traditional disease surveillance are:

- Delays in official reporting
- May miss novel diseases or those with vague case definitions
- Limited reach of traditional systems

To help fill in some of these gaps, health professionals have started using what are referred to as “innovative disease surveillance methods” as a complementary addition to traditional disease surveillance.



Innovative Disease Surveillance is defined as gathering health information from informal information sources such as social media, word of mouth, local press, etc. and to share that information publically, transparently, and at no cost.

## “Informal” Information Sources

Across the world, different terminologies are used when talking about innovative disease surveillance, but they are all synonymous.

Innovative disease surveillance includes using “informal” information sources, a term that may also be referred to as non-traditional, non-governmental, unofficial, off-the-record, unconfirmed, unstructured, rumored, and event-based surveillance.

Informal information sources can come from articles in the local press or media, reports from individual clinicians or field-based NGO staff, and Internet-based media such as discussion forums, blogs, and social networking sites.



This graphic illustrates how connected the world has become:



Global Data Snapshot (January 2015), August 2014 Global Digital Statistics, WeAreSocial.sg ,  
Sources: US Census Bureau, InternetLive Stats, Facebook, Tencent, GSMA Intelligence

Innovative disease surveillance methods seek to utilize this connectivity to increase the flow of information between health professionals, as well as communities, in order to increase the speed at which an outbreak is detected.

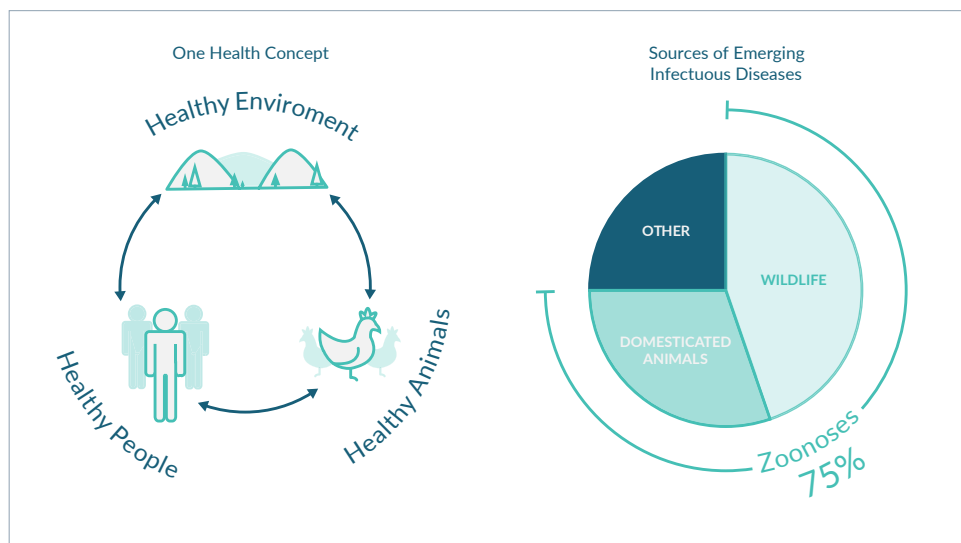
The World Health Organization’s International Health Regulation supports the use of innovative disease surveillance sources, referred to as event-based surveillance, and informal information sources to rapidly detect outbreaks. Indeed, more than 60% of the initial outbreak reports of the WHO Epidemic & Pandemic Alert & Response come from these unofficial and informal sources.

### QUESTION

Identify which of the following can be considered an outbreak information source:

- A. Health Centers official reports
- B. Social Media
- C. Rumors (gossip)
- D. Blogs and online discussion groups
- E. Local news and media
- F. All of the above

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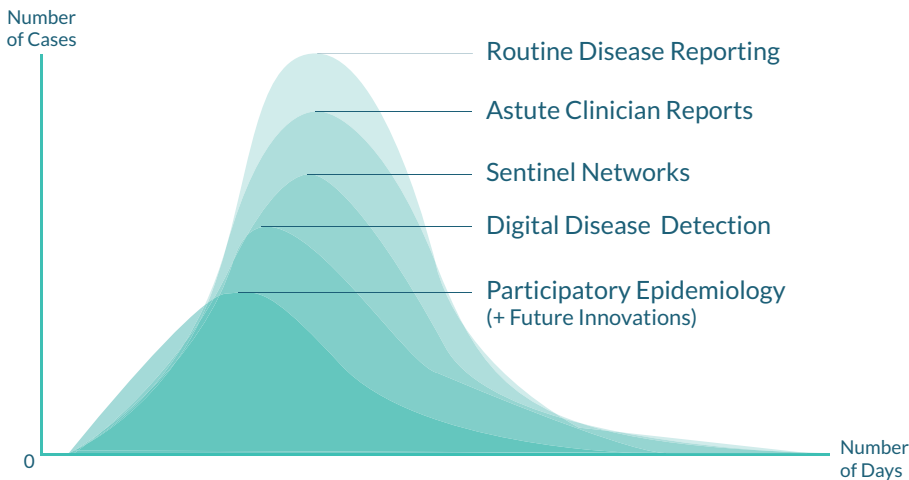
The “diseases” covered under the umbrella of “innovative disease surveillance” embrace the “One Health Concept”, which recognizes the important links between human, animal and environmental health.

To understand the links between human, animal, and environmental health, it is important to note that approximately 75% of emerging infectious diseases in humans are zoonoses, and that more than 70% of these zoonoses originate from wildlife<sup>1</sup>, as opposed to domesticated animals. Therefore, continued surveillance of both domesticated animal and wildlife health is critical for early detection of new diseases that will jump species, and it is very important that excellent communication is maintained between professionals working in human, animal, and environmental health.

<sup>1</sup> Taylor LH, Latham SM, Woolhouse ME. Risk factors for human disease emergence. *Philosophical Transactions of the Royal Society B: Biological Sciences*. 2001;356(1411):983-989. doi:10.1098/rstb.2001.0888



So how exactly has using innovative disease surveillance impacted time to detecting outbreaks? This chart depicts the impact of surveillance improvements over time.



This chart shows that the time to detect an outbreak has decreased substantially over the past 20 years. Some data measuring median days to outbreak detection indicate a reduction of more than 50%, from an average of 29.5 days in 1996 to 13.5 days in 2009 <sup>2</sup>. This is thought to be due to the adoption of the innovative surveillance methods that increased the speed of outbreak detection around the world

## Online Tools and Information Sources for Rapid Disease Detection and Reporting

As we discussed earlier, innovative disease surveillance methods, when used together with traditional disease surveillance, can increase the speed of outbreak detection and reporting!



Next, we would like to introduce several available online tools and information sources for rapid disease detection and reporting.

### QUESTIONS

1. \_\_\_\_\_% of emerging infectious diseases in humans are zoonoses.  
A. 25%  
B. 15%  
C. 90%  
D. 75%  
E. 10%
2. \_\_\_\_\_% of zoonotic diseases originate from wildlife?  
A. 70%  
B. 25%  
C. 50%  
D. 85%  
E. 30%

1. D, 2. A

<sup>2</sup>Chan EH, Brewer TF, Madoff LC, et al. Global capacity for emerging infectious disease detection. Proc Natl Acad Sci USA 2010; 107: 21701–06.

## Industry Pioneers and Available Tools

We will begin with the industry pioneers. Early innovative global surveillance initiatives are included.

**1994: ProMED-mail**, or ProMED, is a moderated electronic outbreak and event reporting system. ProMED monitors emerging and re-emerging infectious diseases and toxic events globally. It emphasizes the One Health approach, as it reports on plant, animal, and human diseases.



**1997: GPHIN**, or the Global Public Health Intelligence Network, is a secure Internet-based multilingual early-warning tool, monitoring the internet for reports on disease outbreaks and other public health events including chemical, biological, radiological and nuclear threats in 9 languages.



**2005: MedISys** or the European Media Monitor – Medical Intelligence System, monitors reports on human and animal infectious diseases, chemical, biological, radiological and nuclear threats, and food & feed contamination, scanning reports in 45 languages.



**2006: HealthMap** brings together disparate data sources in real-time, including online news-media, eyewitness reports, expert-curated discussions and validated official reports on human, animal and plant diseases in 15 languages.



All of these tools have helped shape global disease surveillance and reduce the time to detection over the past two decades. These tools are still making an impact today and are used by hundreds of thousands of health professionals around the world.

## Recent Innovative Disease Surveillance Tools

During the past few years, several smaller scale localized innovative disease surveillance tools were created. These include:

**DOCTOR ME**, the first and most downloaded mobile application for health in Thailand, with approximately 400,000 visitors per month. DoctorMe is a web- and mobile-based application that provides users in Thailand with free health-related advice. Dr. Me has a function that can locate the nearest hospital, and a service that can send for an ambulance in the case of emergency. The tool also allows user to self-report their symptoms and receive advice on how to treat those symptoms.



**Flu Near You** is an online participatory surveillance tool administered by HealthMap of Boston Children's Hospital in partnership with the Skoll Global Threats Fund. On this site, any individual living in the United States, whose 13 years of age or older, can register to complete brief weekly surveys and report their flu symptoms. This helps to map influenza and provides collective understanding of the flu. Flu Near You provides data on influenza-like illness (ILI) at local, state and national levels and creates a map of the ILI spread within the U.S. It also provides the user with a number of public health resources and connections to public health links.



### QUESTION

Some data indicate a more than \_\_\_\_\_% reduction in time to detect an outbreak due to using innovative disease surveillance methods in conjunction with traditional disease surveillance methods.

- A. 45
- B. 50
- C. 15
- D. 30
- E. 90

B. 50

## Case Studies

Here are some examples of how innovative surveillance, used to complement traditional surveillance, has helped to identify disease outbreaks faster than relying on traditional surveillance alone.



This case study looks at a Meningococcal Meningitis Outbreak in western Kenya. It illustrates some of the challenges associated with traditional surveillance. As you go through this case study, consider how the use of innovative surveillance in conjunction with traditional surveillance may have increased the speed at which this outbreak was recognized and reported.

On January 23rd 2006, a leading national newspaper reported that people in a remote area of the district were sick and were dying from an unknown illness. Symptoms being reported were fever and neck stiffness. Local health officials could not be reached for comment. The information in the article was from an interview with a local religious leader.

When district health officials were contacted, they said that they had seen some cases but had not yet reported them because they were still waiting for laboratory confirmation. When they did receive preliminary lab results, they were negative.

A national disease investigation team was called in and they arrived in the scene on January 30th of 2006, a week following the newspaper report. Their investigation established that the outbreak had been ongoing since December of 2005, and that the majority of the cases in the district were

being treated in a neighboring district in Uganda, where a similar outbreak was occurring. By the end of the outbreak, there were 82 cases and 16 deaths.

This case clearly illustrates some of the challenges of relying entirely on traditional disease surveillance, and the gaps that can sometimes result. Paying attention to informal information sources in this case, as well as increasing the communication between the Ugandan and Kenyan health officials, would have significantly increased the recognition of this outbreak with earlier intervention and control measures (such as vaccination) and may well have saved more lives.



This next case study looks at Chikungunya cases in Mauritius and Reunion Islands. It illustrates how innovative surveillance methods used in conjunction with traditional surveillance helped to rapidly identify an outbreak. As you review the key facts of the case, think about how innovative surveillance techniques influenced the outcomes.

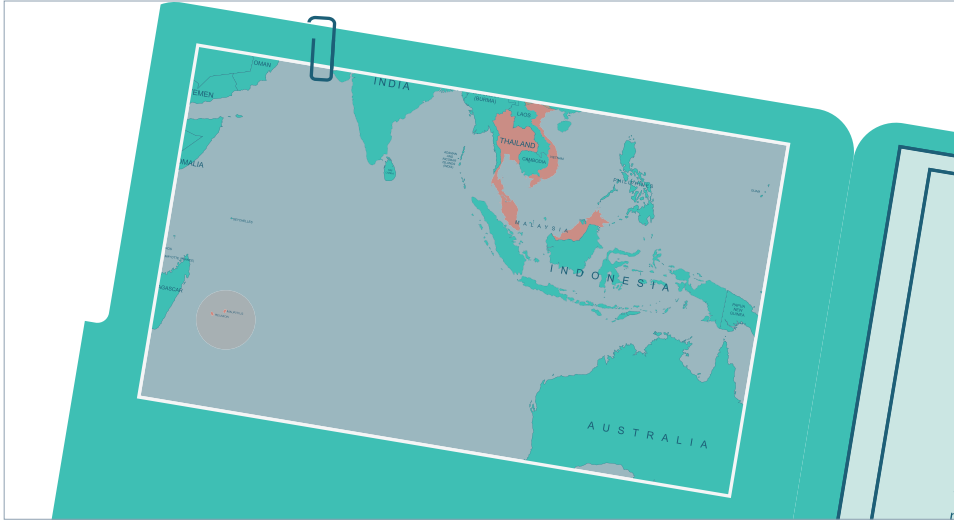
On May 18 2005, a health professional reported on ProMED that, “In Mauritius, since early April 2005, several people have been attending the hospital and health centres of the capital city, Port-Louis, with fever and arthralgia of hands and feet... a rash was also noted.”

Chikungunya virus was suspected based on the clinical presentation, the self-limiting course, and the recent report on ProMED-mail of a Chikungunya epidemic in the Comoros Islands.

The diagnosis was confirmed on blood samples sent to Erasmus University in Rotterdam, and Marseilles-Armies Laboratory in France.

The outbreak started in an area of the capital where there is a hostel often used by visitors from the Comoros Islands.

According to newspaper articles, not long after this report, the first cases of Chikungunya were reported on the Island of Reunion (230 km from Mauritius) and the cases increased rapidly.



This is a Map of the Indian Ocean Region showing migration of Chikungunya from the various Indian Ocean Islands to other regions including Thailand, Vietnam and Malaysia.

Chikungunya spread through Asia, then appeared in the Americas region and spread across the Caribbean, and into Central and South America.

This case shows us again why it is so important for health professionals to be aware of what is going on in terms of disease surveillance in other parts of the world, and why it is so important to create and participate in a global surveillance network.

The EpiCore platform, which you will have an opportunity to learn more about later, will enable you to do this.

## Challenges of Innovative Surveillance

As you saw in the case studies, innovative surveillance can be a valuable tool, but it is not without its challenges.

Some challenges of innovative disease surveillance include:

- Low specificity and false alarms as there are likely to be reports about events of no risk to public health
- Potential inaccuracy, and as such the need to validate the information received
- Sources may present biased information for secondary gains

### QUESTION

Can you think of any other challenges to using innovative disease surveillance?

# CONCLUSION

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## Disease Surveillance Methods Strengths and Weaknesses

Let us summarize what we just discussed by comparing the traditional disease surveillance methods with innovative disease surveillance methods as shown in the below tables.

### Traditional Disease Surveillance



- + Information received is often highly reliable and easily verified
- + Standards in place that provide incentives and a uniform structure for reporting



- Slow detection
- May miss novel diseases or those with vague case definitions
- Uses only confirmed information, from a limited number of sources

### Innovative Disease Surveillance



- + Fast detection and reporting
- + Not limited to pre-determined events
- + Multiple sources of information (e.g. clinicians, labs, media reports, internet blogs)
- + Leverages publicly available information increasing transparency



- Information captured might not be accurate or significant
- Sources may present biased information
- Doesn't use pre-defined case definitions
- No standard data format, and takes additional time to synthesize



## So, what have we learned?

We live in a global village. Diseases travel as rapidly as humans, animals, and vectors can in a world that is continuously growing smaller. This is why creating a global network for disease surveillance is so important. It is also why it is critical that we adopt innovative surveillance methods that, when used in addition to traditional disease surveillance, can help us increase the speed of disease detection.

Non-traditional information sources may be the first indication of an unusual health event occurring in a remote area. Early sharing of information on emerging and re-emerging infectious diseases through non-traditional reporting channels could lead to:

- More rapid official confirmation of ongoing outbreaks, and
- More rapid recognition of cases in other geographic areas

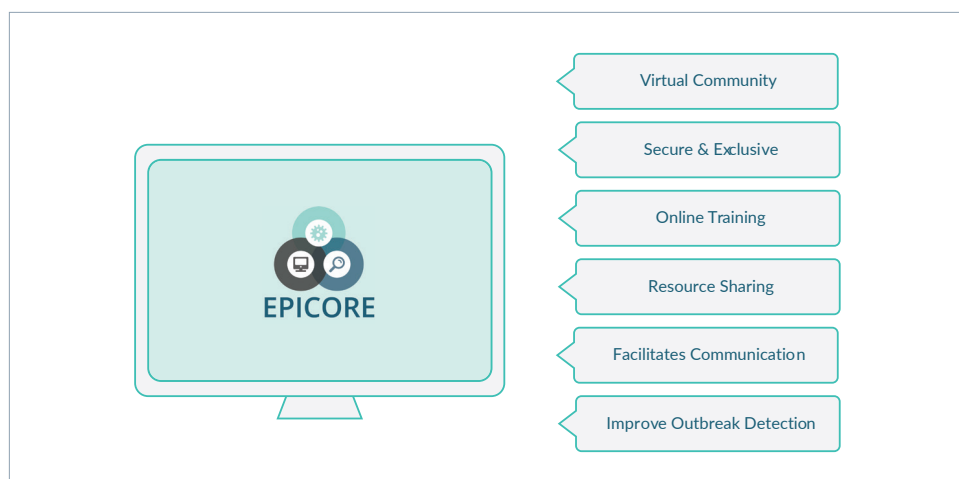
Innovative disease surveillance methods continue to demonstrate an ever-increasing potential to help us detect outbreaks faster and with greater sensitivity.

For these reasons, we created a project called EpiCore, which uses innovative surveillance methods by leveraging non-traditional information sources and drawing on the knowledge and skills of trained health professionals around the world, like yourself, to help the world verify outbreaks faster using participatory epidemiology.

# EPICORE

## So what exactly is EpiCore?

EpiCore is a new system that finds and reports outbreaks faster than traditional disease surveillance methods alone. A virtual community with a secure and exclusive digital platform that provides online training, EpiCore allows resource sharing and facilitates communication between EpiCore members and health experts in order to improve global outbreak detection and reporting.



Systems like EpiCore need the participation of human, animal, and environmental health professionals on the ground to validate informal surveillance data and to harness the full potential of innovative surveillance systems.

By now, we hope you are excited about incorporating innovative disease surveillance into the traditional surveillance methods you may already



EpiCore is a partnership between the Skoll Global Threats Fund, HealthMap, ProMED-mail, and TEPHINET.

be using. An easy way to do this is to become a member of an innovative disease surveillance network, such as EpiCore. Next, you will be directed to take the EpiCore platform training that should answer any questions you have on EpiCore and provide you with the necessary training to use the platform.

Your membership in EpiCore will not only help you improve the health of your community and region, but will help all of us improve health globally.

