Slide 1: Introduction
Hello, and welcome to module 7, public health surveillance. My name is Krissy Simeonsson and I’m an assistant professor in the Department of Pediatrics and Public Health at the Brody School of Medicine.

Slide 2: Acknowledgements
This education module is made possible through the Centers for Disease Control and Prevention, and the Association for Prevention Teaching and Research cooperative agreement. APTR wishes to acknowledge the following individuals that developed this module:

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Slide 3: Presentation Objectives
Through the course of this presentation we will start with defining surveillance, then we’ll discuss some of the uses of surveillance, we’ll spend some time reviewing notifiable disease surveillance, and then finally describe some of surveillance’s limitations.
Slide 4: Surveillance – Information for Action

Surveillance is basically information for action. This slide displays the 3 public health core functions, assessment, policy development, and assurance, which you can see on the outside of the circle. The multi-colored pieces in the center represent the 10 Essential Public Health Services. Surveillance activity occurs as part of the assessment pieces; monitoring health, and diagnosing and investigating disease, or health problems. Good surveillance provides data needed to give an accurate assessment of the status of health in a given population. Good surveillance can also provide an early warning of disease problems, so immediate control measures can be put into place. It can also give us information to design and plan public health programs, and also information to plan and conduct research.

Slide 5: Surveillance

We mentioned previously that surveillance is information for action, but on this slide a more formal definition of surveillance is displayed. Surveillance as defined by the Centers for Disease Control and Prevention is the ongoing systematic collection, analysis, and interpretation of health data, essential to planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination to those who need to know.
Where does surveillance data come from? There are many sources of surveillance data available. This slide is only a partial listing of some of the sources. We are going to review notifiable disease surveillance later in the presentation. But some other sources of data that you may be familiar with include vital records, such as birth certificates, and death certificates. Environmental monitoring systems, animal health data, information provided from individuals, information from laboratories, medical records at outpatient healthcare facilities, as well as hospitals. Over the counter medication sales can be a source of data. Registries are sources of data, and finally surveys. Some examples of surveys are population-based surveys such as the National Health Interview Survey, and the National Health & Nutrition Examination Survey, or NHANES. And then there are also provider-based surveys. Some examples of these are the National Ambulatory Medical Care Survey, and also the National Hospital Discharge Survey, which looks at ICD-9 codes.

Let’s turn now to talk about different types of surveillance, and there are three types I would like to discuss in this presentation. Passive surveillance, active surveillance, and also syndromic surveillance.
Passive surveillance is the most common form of surveillance and occurs when laboratories, physicians, or other healthcare providers regularly report cases or disease to the local health department. These reports are based on standard case definitions for a particular disease or condition. Passive surveillance means that the healthcare provider or laboratory initiates the forwarding of the data to the health department.

A second form of surveillance is active surveillance. This occurs when the collection of data from the lab, physician, or other healthcare provider is initiated by the health department. Active surveillance is often used during outbreak investigations or research studies. Active surveillance has an advantage over passive surveillance because it achieves more complete and accurate reporting. However, the draw-back is that it’s more resource intensive for the public health agency that is conducting the active surveillance. It costs more, it takes more personnel, and more time to do active surveillance.

A third type of surveillance is syndromic surveillance. It is defined as the ongoing, systematic collection, analysis, interpretation, and application of real-time indicators for disease that allow for detection before public health authorities would otherwise identify them. Syndromic surveillance data are collected in real time, meaning that the data are automated so that they can be received daily, or even more frequently. The type of data collected is not actual disease, instead we are interested in specific indicators of disease. The definition of syndromic surveillance, you’ve probably noticed is similar in ways to the definition of surveillance in general. It’s on-going and systematic collection, there’s analysis and interpretation of data, however, the time component and type of data collected are different from passive, or even active, surveillance. Some common surveillance syndromes are: gastrointestinal illness,
influenza-like illness, or rash and fever syndrome.

Slide 11: Ideal Surveillance System

What are the key features of an ideal surveillance system? We want the system to be simple, which means it’s easy to participate in and the daily operation of it is not too cumbersome. It also needs to be timely, data that’s not available when we need it, is not helpful for planning or response. It needs to be representative, which means that a surveillance system needs to collect data that’s representative of the population that we’re following. It needs to be flexible, which means at certain times, such as outbreak situations, you need to be able to ramp it up, but then in times when there are not a lot of cases you need to be able to scale back. It needs to be sensitive and have strong predictive value, which we’ll talk about in the next few slides. It certainly needs to be acceptable. Both the public and healthcare providers need to feel like what they’re doing makes sense, and that it’s not too intrusive. And finally, an ideal surveillance system needs to be cost effective.

Slide 12: Ideal Surveillance System

So in the next few slides we’re going to spend a little bit more time talking about these two characteristics (Sensitive and Strong Predictive Value) of an ideal surveillance system.
For an ideal surveillance system to be sensitive, we want it to not miss many cases. We want to have few, if any, missed cases of the disease we’re trying to track. We increase the sensitivity of a surveillance system by having very broad case definitions, which means that we capture cases that may not actually be cases by only having a few characteristics that we’re looking for, for each disease. Clearly, the problem with that is there will be cases counted that might not actually be true cases of disease. But if you really are trying to catch every case out there, and not miss any then we have to have a sensitive surveillance system.

The flip side of that is positive predictive value of a surveillance system. All case reports that we are receiving for a disease or illness meet the case definition; we can feel fairly certain that any cases we’re capturing in our system truly represent cases. We can increase the positive predictive value of a surveillance system by adopting a more restrictive case definition: individuals have to match more characteristics of a disease to be counted as a case. There is a balance, or a trade-off, between sensitivity and predictive value of a surveillance system.

Next we’re going to talk a little bit about the uses of public health surveillance. Public health surveillance can be used to estimate the magnitude of a health problem; it can help us determine the geographic distribution of an illness. It helps to portray the natural history of a disease, is it on the rise, is it on the decline? It helps us detect epidemics, or define problems in the community. It can help us generate hypotheses, and stimulate research. It helps us evaluate our control measures. We can monitor changes in infectious agents, for example whether certain bacteria are becoming more resistant to some of the antibiotics that are in use. Surveillance helps us detect changes in health practices; are more people getting screened in a community, or are less people, and what are the barriers? Finally, surveillance can help us facilitate planning.
Slide 13: Uses of Public Health Surveillance

Let’s follow with a few examples. The first example is going to illustrate how surveillance helps us estimate the magnitude of a problem, and also at the same time determine the geographic distribution of illness.

Slide 14: Incidence of Chlamydia

This data is looking at the incidence of chlamydia among women in the United States in the year 2009. It gives us incidence by state and shows us right away the magnitude of the problem, in the sense that chlamydia is very common. We have geographic distribution as well, by showing the states that are highlighted or shaded in dark blue clearly have, a higher incidence of chlamydia than other states.

Slide 15: Uses of Public Health Surveillance

The next example is the use of public health surveillance to detect epidemics.
Slide 16: Botulism

This is data from the CDC from 2002, looking at botulism that was responsible for foodborne outbreaks over a 20-year period, from 1982 to 2002. There are definite peaks in the number of cases of botulism, and there are labels showing which ones were related to foodborne outbreaks.

Slide 17: Uses of Public Health Surveillance

Finally, the last example is how public health surveillance can help us evaluate our control measures.

Slide 18: Cases of Varicella or Chicken Pox

This figure is a line graph that is showing the number of cases of varicella or chicken pox in 4 states from 1993 to 2009. On the y-axis we have the number of cases in thousands of chicken pox. On the x-axis we have the period of time from 1993 to 2009. What you see overall is a steady decline in the number of cases of chicken pox, but this data also shows us that licensing of varicella vaccine in the mid-90s was followed by a steady decline in the number of cases of chicken pox. Then in 2006 a second dose of varicella vaccine was recommended, and you can see from 2006 to 2009 there was a decline in the number of cases.
Slide 19: Notifiable Disease Surveillance

We are going to turn now to notifiable disease reporting. It has been said that no health department can effectively prevent or control disease without knowledge of when, where, and under what conditions cases are occurring. Public health agencies monitor diseases and conditions of importance by designating them as notifiable. The foundation of notifiable disease surveillance is the state and local application of the National Notifiable Disease Surveillance System. A list of nationally notifiable diseases is available at the Centers for Disease Control and Prevention website. You will find that most of the diseases are infectious in nature, but there are some that are non-infectious, and I’ve listed some of the examples here. Cancer, elevated blood lead levels, and pesticide-related illness are just some examples of conditions that are reportable, but are non-infectious.

Slide 20: National Notifiable Disease Surveillance System (NNDSS)

The National Notifiable Disease Surveillance System is a system for passing reports from local and state public health agencies through to the CDC. There is a role for the Council and State and Territorial Epidemiologists (CSTE) who work closely with the CDC in revising the list of nationally notifiable disease every year. The CDC keeps a list of disease and laboratory findings of public health interest, and also with support from the CSTE, maintains case definitions for their surveillance. The CDC also works to disseminate surveillance data back to healthcare providers. They do this through the Morbidity and Mortality Weekly Report (MMWR). They also publish an Annual summary of Notifiable Diseases.
Slide 21: Case Definitions

This is an example of a case definition that you can find at the CDC website. This is the 2011 case definition for hepatitis A, which is a nationally notifiable disease. The case definition includes a clinical component, a laboratory component, and an epidemiologic component, (often used during outbreak investigations).

Slide 22: MMWR Annual Summary of Notifiable Diseases

The CDC disseminates surveillance data back to providers. More detailed information is published in the MMWR Annual Summary of Notifiable Diseases. In this publication, data for all reportable or notifiable diseases are published, along with a brief summary of the year’s activity and information on recent case definitions. At the end of the report are summary tables and maps. This is an example of a map showing the rate of newly reported AIDS cases per 100,000 people in the United States in 2002. The information from the CDC is invaluable source for learning about and understanding the broad scope of disease surveillance around the country. It also allows healthcare professionals and public health officials to see what’s going on in their own state, as well as other states around them. Finally, the publication of these reports shows the collaborative nature of surveillance. Without the work of healthcare providers and local health departments these data would not be available.
State participation in the National Notifiable Disease Surveillance System is voluntary. There is not a legal requirement that states have to participate in this system; however, all states choose to participate. Reporting of notifiable disease is mandated at the state level and the list of diseases varies by state. Reportable conditions are determined by laws and regulations of each state and jurisdiction. Some conditions deemed nationally notifiable might not be reportable in certain states or jurisdictions. It’s important as a healthcare provider to know what the list of diseases that are notifiable, are in the states that you’re practicing in.

The next few slides are going to highlight examples of healthcare providers who did their part in surveillance and reported a notifiable disease to their local health department. The first is an example of a physician who reported a case of hepatitis B to the local health department. This case of acute hepatitis B was in a resident of a long-term care facility, who was admitted to the hospital with hepatitis B. After the physician made the report for this one case, the health department nurse remembered that there were several other cases of acute hepatitis B that had occurred recently at the same long-term care facility. An investigation was begun, and an unsuspected outbreak was discovered at the long-term care facility.

These cases ended up being part of a larger study that looked at the transmission of hepatitis B virus among people undergoing blood glucose monitoring in long-term care facilities.
Another example is a health care provider who reported a case of listeriosis to their local health department. This was a pediatrician who attended a delivery of a stillborn infant. The physician reported this case to the local health department and because of this case report and further investigation, the health department discovered an outbreak of listeriosis, identified among Hispanic females with 12 cases identified over four months. There were five stillbirths associated with this outbreak, three premature births and two newborns who were infected with listeriosis. A case control study was performed to discover what the source of the exposure was for all of these cases.

Investigators found that the source of the outbreak of listeriosis was associated with homemade Mexican style cheese or queso fresco.

This is one of the samples that was tested during this outbreak investigation. Again this outbreak was initially identified because a healthcare provider had reported the disease to the local health department.
Slide 29: Limitations of Surveillance

With all systems and programs there are limitations. Some of the limitations of surveillance systems are listed here. We’re always dealing with incomplete data. There’s overwhelming volumes of data sometimes coming in from a variety of sources which makes the organization and management of all that data complicated. With the continuing advancement of information technology, there’s uneven application of surveillance. Some jurisdictions still have paper-based reporting, where case reports are completed on paper and mailed in or faxed. There is a transition over to electronic reporting or internet-based reporting. So we’re in a period of transition with an uneven application of the information technology; two systems trying to merge together. Timeliness is an issue, how fast can we get the data that we need? Completeness of the data that’s being reported is another issue. Sometimes cases aren’t reported at all and sometimes the cases that are reported have data that’s missing. Trying to improve all of these areas are challenges that public health agencies face on a daily basis.

Slide 30: Burden of Illness Pyramid

The burden of illness pyramid depicted here is a model for understanding foodborne disease reporting. This illustrates steps that must occur for an episode of illness in the population to be registered in a surveillance database. Starting from the bottom of the pyramid, the areas in yellow, shows that some members of the general population can be exposed to an organism, but not all of them will become ill. The next line of the pyramid represents people who do become ill. In the pink portion of the pyramid, a percentage of people who become ill will seek care, and of those that do seek care, in a proportion of them a specimen will be obtained. Then in the purple portion of the pyramid some of those lab tests will be submitted for the organism of interest and the laboratory will confirm a case. Only a small proportion of those will be reported to the health department, which represents that very small section at the top of the pyramid in green. You can get data on foodborne illnesses in other ways; surveillance is really just the tip of the iceberg in terms of diseases that are reported to the health department. There are surveys that are done at the laboratory level to look at what lab tests are positive. Active surveillance can involve a physician survey targeting that pink portion of the pyramid, where you can actually ask healthcare providers if they’ve seen a
certain number of people with a constellation of signs and symptoms. And finally at the bottom of the pyramid you can perform common population surveys, were you interview a whole group of people to find out about common exposures and also what group of people became ill even if they didn’t seek care. So the surveillance data, the Notifiable Disease Surveillance really is the top of the pyramid or the tip of iceberg. And that’s the take home point when you’re reviewing surveillance data, to realize that the number of cases reported for any specific condition is always going to be an underestimation of the actual number of cases out there.

Slide 31: Limitations of Surveillance – Shigella

This is a similar example of the pyramid. This was from a 1977 article by Rosenberg, which talked about cases of shigella. He found in his study that for every 100 people infected with shigella about 3/4 of them or 76 would be symptomatic. 28 would go to a healthcare provider for evaluation, only nine of those 28 would have stool cultures submitted for testing, seven would have positive results, six of the cases of confirmed shigella would be reported to the local health department, and only five would actually be reported to the CDC. So out of 100 people infected with shigella, it’s estimated that only five are reported to the CDC.

Slide 32: Reasons for Failure to Report

In a 2002 study by Doyle et. al, the authors looked at some of the reasons why healthcare providers fail to report. Oftentimes it’s a lack of awareness or knowledge of what conditions need to be reported. A lot of providers don’t know that it’s a legal requirement for them to report. They may not understand the process if they have a disease they need to report: who do they report it to? Oftentimes there's an assumption that someone else will take care of it, it’s someone else's job to report. Occasionally providers don’t report on purpose or intentionally because they want to protect patient privacy. Finally it's been found that insufficient reward or insufficient penalty are reasons why providers wouldn't report.
I wanted to mention limitations of syndromic surveillance as well. We’ve mentioned that syndromic surveillance certainly has advantages over passive surveillance because it’s real time data, it’s automated, it’s coming in quickly. But syndromic surveillance systems are costly and they require resources to bring together all of the different syndromic data from hospitals, ambulance transport, poison control centers, and even school absenteeism as part of the syndromic surveillance system. They require significant staff expertise and dedicated time. We talked early on about an ideal surveillance system would be simple, but certainly syndromic surveillance requires staff expertise. Finally formal evaluations of existing syndromic surveillance systems are incomplete, so the data still out on how well these work in terms of how cost effective they are. It’s important to keep in mind that syndromic surveillance systems are not meant to replace regular surveillance systems but rather to enhance the data that we are already getting from a passive surveillance system.

Other limitations of syndromic surveillance are false alarms and failure to detect outbreaks. False alarms can occur because of non-specific case definitions. Syndromic surveillance systems are run off software that recognizes keywords as part of the syndrome’s case definition (e.g. fever and rash). This results in many more cases being picked up that aren’t representative; these are considered false alarms. There can also be inadequate sensitivity meaning syndromic surveillance is not detecting all outbreaks or bioterrorism events. This can occur if the outbreak is too small to raise a red flag that the number of cases has gone beyond a set threshold. Also, if this syndromic surveillance data are coming from a number of different healthcare facilities across a state or region, an outbreak can be missed. If a group of people is exposed in one location but disperses after the event, the cluster may not be evident via syndromic surveillance.
In summary, surveillance data has many practical uses and is the crux of the public health core function assessment. Notifiable disease surveillance is fundamental to prevention and control efforts in public health. Regardless of where you practice the list of notifiable diseases is going to vary by state. Finally we've talked about limitations in surveillance, but significant improvements are being made in advancing surveillance and reporting, so stay tuned and make sure you understand your role in this vital public health function.