Why Does Prevalence Matter?

It is important to know about prevalence for many reasons.

It helps with planning for the needs of the people who have a certain diagnosis or disease.
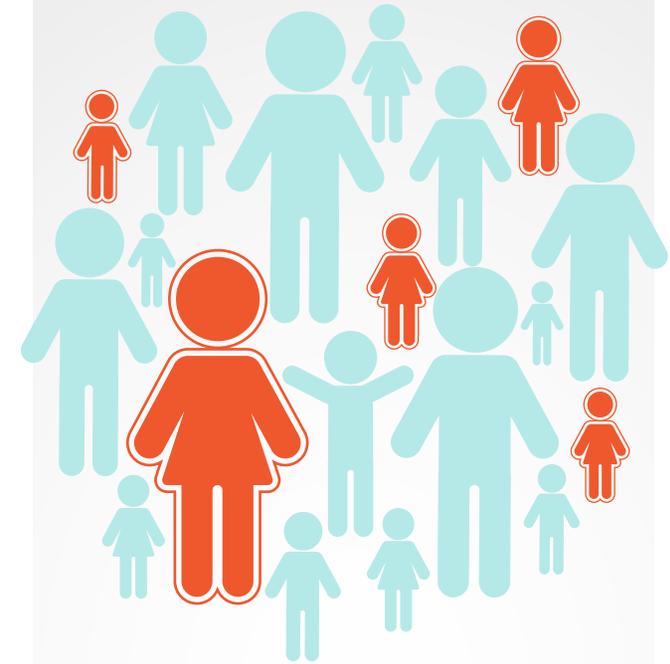
Policymakers, administrators, doctors, and service providers need to know how many people need services and treatments so they can plan for the needs right now and the needs in the future.

Knowing the prevalence also helps researchers who are trying to learn more about certain diagnoses and diseases to see how the population has changed over time.

What is Prevalence?

Prevalence is the proportion of people with a diagnosis or disease at a given time. Prevalence is an estimate.

Types of Prevalence

Point prevalence
prevalence at a given point in time

Period prevalence
prevalence covering a period of time *(like a year)*

Prevalence is calculated by comparing the number of people with a certain diagnosis or disease to the number of people in an entire population.

How Can Prevalence be Measured?

Prevalence estimates can be different depending on how people with certain diagnoses and diseases are counted. Here are several ways that prevalence can be measured. Each way has pros and cons.

REGISTRY

Clinical screening and comprehensive clinical evaluation is the best way to confirm a diagnosis. Professionals, like doctors or clinicians, look at patient records to confirm if a person has a certain diagnosis or disease. Results from clinical evaluation can be reported to the state or city for what's called a "registry". Like a census, a registry is a count of the number of people with a diagnosis or disease, not an estimate.

👍 Pros
- Information is confirmed by a professional like a researcher or a doctor, not just from a patient or family
- Very accurate

👎 Cons
- Requires a lot of people (clinicians, researchers, or doctors) to look at the information and confirm a diagnosis
- Expensive
- Time-consuming
- People must be willing to share their personal information
- Does not count people who are not added to the registry or seeking services

CENSUS

A census is a count of everyone in a certain population. A census can use different ways to count people, including phone calls, going to houses, or counting people in a database. A census is meant to be a full count of everyone in a certain population or group, not an estimate.

[Note: The Pennsylvania Autism Census, conducted by the ASERT Collaborative is an "administrative census" which means that it doesn't count everyone in the population. The PA Autism Census counts only people receiving publicly-funded autism services. For more information visit: paautism.org/census]

👍 Pros
- Counts everyone in a population
- Most accurate count

👎 Cons
- Very expensive
- Very difficult to count everyone in a population

ADMINISTRATIVE DATABASES

Federal, state, and local institutions collect a lot of data about health and health services that people use. This information is stored in administrative databases. This method uses data that is already collected to give information about certain diagnoses and diseases.

👍 Pros
- Relatively inexpensive
- Data already exists, new collection is not needed
- Large sample sizes
- Long-term observations

👎 Cons
- Captures only those people receiving services for specific procedures and diagnoses. It may miss some people
- Information is collected differently, quality may vary

❌ NOTHING

Sometimes, nothing is done to try to know the prevalence of certain diseases and diagnoses

👍 Pros
- No cost

👎 Cons
- Impossible to understand the impact a diagnosis or disease has on the population or show the current and future needs
- No guide for future research
- Results in uninformed policy decisions

SURVEILLANCE

Surveillance is the continuous collection, analysis, and interpretation of health data used to help plan, implement, and evaluate needs of a population based on estimates. This is specifically designed to track diseases over time to help inform public health action, with the goal of balancing accuracy and cost.

👍 Pros
- Accurate
- Design can be flexible depending on the disease or diagnosis
- Primary purpose is to track the disease for which surveillance is constructed

👎 Cons
- Time consuming
- Expensive

SURVEYS

Surveys ask people questions about their health or diagnoses, and usually are not paired with any other data collection method. Surveys can be an interview, or they can be a paper or electronic form that someone completes on their own. The results of a survey are used to estimate the prevalence of a disease or condition.

👍 Pros
- Cost-effective
- It can be widely spread out to a large amount of people
- There are many ways that surveys can be given (online, in person, by phone, etc.)

👎 Cons
- Surveys that rely on individual or family report may not confirm a diagnosis
- How a survey is given may affect who takes a survey (by phone, online, in person, etc.)
- Surveys do not include everyone in the population