

# Foundations of the Profession and Science of Public Health

History, philosophy, and conceptual foundation of public health in the US

- History of Public Health
- What is Public Health?
- Philosophy and Ethics in Public Health
- Evidence-Based Public Health
- Qualitative Research
- Trends in Morbidity, Mortality and Behaviors in the US

# History of Public Health

Methods of preventing disease go back many centuries. Concepts of disease were crude and often based on anecdote. Some recommendations and practices were ineffective, if not even harmful to health such as bloodletting.

In the mid-1800's there was a hygiene movement, particularly in the UK, with focus of improvements of cleanness and well-being of the poor. Additionally, at the end of the 19th century germ theory became accepted.

## Learning Objectives:

1. Explain the evolution of concepts about cause and prevention of disease
2. Understand the importance of studying the factors associated with outcomes in a systematic way in human populations.
3. Discuss some of the major historical figures and events that played a role in evolution of public health and epidemiology
4. Describe the overall structure of the public health system in the US today

## Early Concepts of Disease

10,000 years ago when humans were hunter-gatherers and lived in small, nomadic groups accumulating waste and contamination wasn't a problem. Early concepts of disease revolved around superstition, myths and religion (bad spirits, Pandora's box, etc).

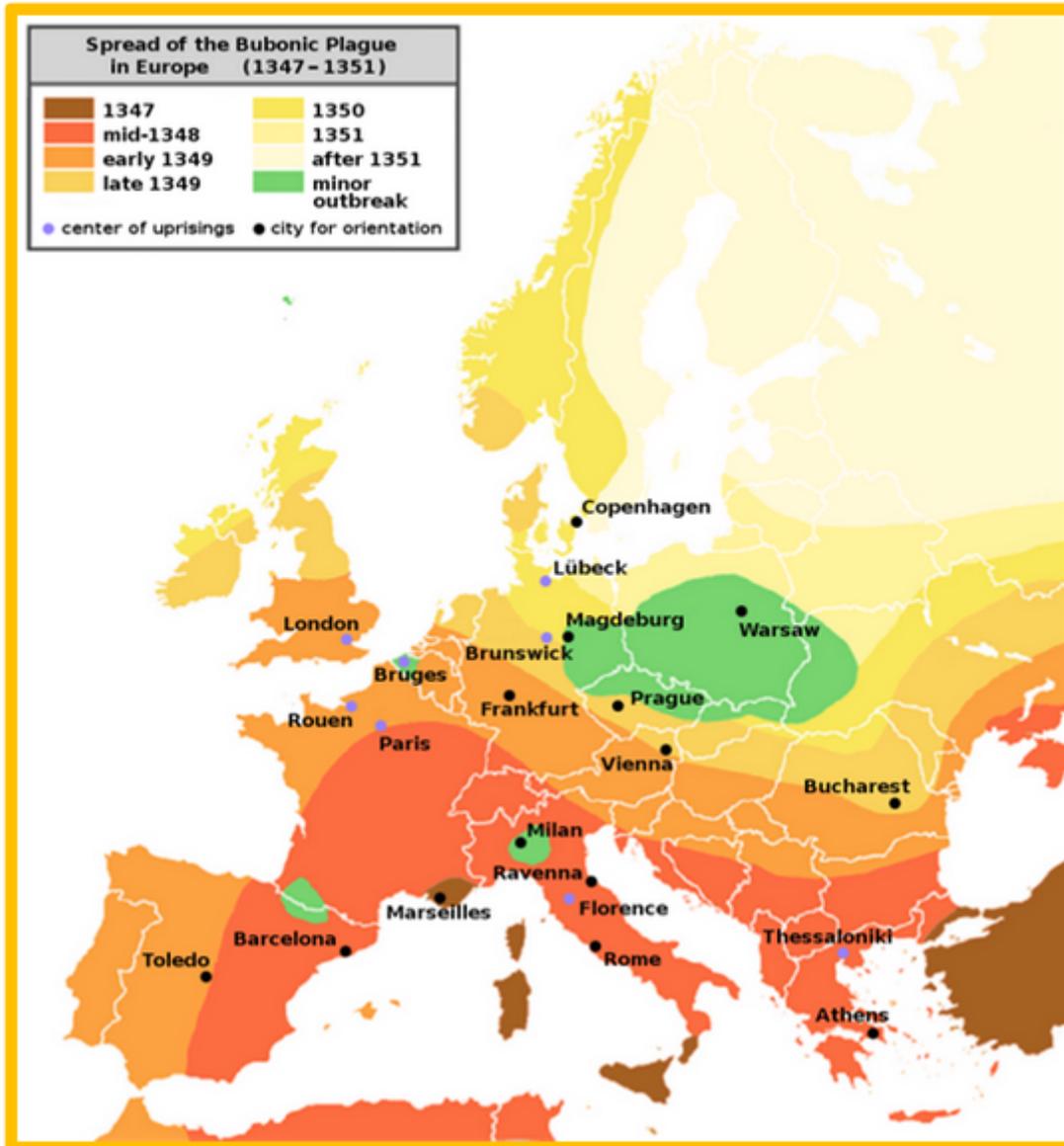
The agricultural revolution provided more secure supply of food and enable expansion of population. People often lived off one or two crops, often lacking protein and vitamins. The domesticated animals provided food and labor, but also carried diseases that could be transmitted to humans. Waste accumulation attracted rodents and insect vectors and with people living in larger groups there was a greater opportunity for transmission of diseases.

The first concept of disease not founded on superstition was the Hippocratic corpus; A Greek concept that disease is caused by an unbalance of the environment or natural forces, and Blood, Bile, Phlegm, and Melancholy must be kept equal within the body. Although the concept clearly incorrect by today's medical standards, Greek doctors would prescribe changes in diet and lifestyle. It also became the rational for bloodletting, which continued for many centuries despite lack of evidence.

# The Bubonic Plague

The bubonic plague caused by a bacteria that lives in the intestines of fleas. Fleas were the vector and rats were a reservoir for the bacteria that could easily transmit the disease. Occasionally, an infected flea could jump to a human and infect them directly. Causing dark, tender, swollen nodules. Symptoms also included headache, and delirium and was fatal in about 60% of cases.

Starting in 1347 Europe experienced waves of the plague which lasted until the late 1700's. It was believed to have originated in Asia and traveled along trade routes to the black sea.



The most popular explanation was that it was caused by miasmas - invisible vapors which emanated from swamps or cesspools and floated around in the air where they could be inhaled. One pope kept fires burning on both sides of the room to counter miasmas. Plague doctors kept herbs and flowers in a beak-like mask to ward off miasmas. Of course these were all ineffective as it was spread by flea bites. In a sense the real cause of transmission was population density and waste stagnation, which attracted rats with the fleas that carried the plague. Later the pneumonic form of the plague caused people to cough up blood and could spread by inhalation.

One might blame the lack of preventative measures and knowledge about transmission on the primitive understanding of medicine, however this wasn't due to a lack of technology but the fact that humans had not come up with a structured way to think about disease. There were theories about how the plague spread and how to prevent it, but no tests were ever done through observation of large groups of people. The idea of studying groups of people to identify risk factors and disease outcomes had not yet evolved. **The lack of a systematic way of testing possible associated between exposures and outcomes was the major factor that prevented advances in understanding the causes of disease and development of effected treatment/prevention.**

The black plague still exists today, and kills a few thousand people every year due to anti-biotic resistant strains. However, when identified early it is curable.

## Quarantine and Isolation

The concept of quarantine dates back to the early 1400's and the black death. In Italian Qaurintina means 40 days. Travelers and merchandise thought to have been exposed would isolate for a set period of time. This practice persisted until the 19th and 20th century. **Isolation** is separating someone who has the disease from the rest of the population, which was useful in cases like SARS where the infected is only contagious when symptoms are present. **Quarantine** is separating someone from the population who might have been exposed, e.g. COVID-19 since one could be contagious without symptoms.

## Public Health in the US

Events in the US paralleled those of the UK as the population moved from an agricultural to an urban and industrial way of living.

### Timeline 1800s

- 1798: Congress passes the Act for the Relief of Sick and Disabled Seaman and authorizes the formation of US Marine Hospital Service (MHS), a forerunner of the Public Health Service. Seamen were taxed 20 cents per month to fund physicians and support the network of hospitals. The tax was abolished in 1884 and replaced with a levy on merchant ships, then after 1906 funds were allocated by congress.
- 1799: Castle Island in Boston Harbor was chosen as the temporary site for the first marine hospital. Dr. Thomas Welsh was named physician in charge.
- 1799: Boston establishes the first board of health and the first health department in the US. Paul Revere is named as the first health officer.
- 1800: Dr. Ben Waterhouse introduced smallpox vaccination to the US

- 1804: The Boston Marine Hospital is established in Charlestown, Boston. Dr. Ben Waterhouse was appointed physician in charge from 1807-1809
- 1842: MA Legislator Lemuel Shattuck established the first US system for recording births, deaths and marriages. This became the model for states across the Union. Among his contributions were a standard nomenclature for disease; establishment of a system for recording mortality data by age, sex, occupation, socioeconomic level, smoking, and drinking.
- 1849: The MA legislature appointed a Sanitary Commission to prepare a plan for reporting a 'Sanitary Survey of the State' with Shattuck as Chief Commissioner and author. While well-received by the New England Journal of Medicine, the 50 recommendations in the report went ignored. 20 years later the Board of Health based their plans on Shattuck's recommendations.
- 1870: The Marine Hospital Service was reorganized to change the general character of the service. Medical officers, called surgeons, were required to pass entrance examinations and wear uniforms. In 1889 the medical officers were given titles and pay corresponding to the Army and Navy grades. The goal was to create a professional, mobile health corps free from political favoritism to deal with health needs of a growing nation.
- 1874: MA State Board of Health instituted a voluntary plan for weekly reporting of disease by physicians.
- 1884: MA passes legislation requiring the reporting of "diseases dangerous to the public health" and imposes fines for not reporting.
- 1887: A "Hygienic Lab" was established at the marine hospital on Staten Island to aid in the diagnosis of infectious disease among passengers of incoming ships. It eventually moved to Washington DC and became the National Institutes of Health.
- 1891: The Immigration Act of 1891 required all immigrants entering US be given health examination by PHS physicians. All "idiots, insane persons, paupers or people suffering from disease and criminals" were excluded. Ellis island in New York Harbor was the largest inspection site.
- 1894: The first epidemic of polio strikes the US.

## Timeline 1900s

- 1900: Estimates suggest HIV was transmitted from monkeys to humans as early as 1884-1924 but was either unrecognized or failed to initiate human to human transmission.
- 1902: US Congress expanded scientific research at Hygienic Laboratory and gave it a definite budget. Marine Hospital Services were renamed Public Health and Marine Hospital Services (PHMHS).
- 1906: Congress passed the Federal Meat Inspection Act requiring the Department of Agriculture to inspect meat entering interstate commerce. They also passed the Food and Drugs Act that forbade adulteration and misbranding of foods, drinks, and drugs, but contained few requirements to insure compliance.
- 1910-16: The working environment and effect on worker's health became a major area of study for the Public Health Service

- 1918: The influenza pandemic of 1918 is believed to have caused 25-50 million deaths worldwide.
- 1925: All states begin participating in national reporting of disease
- 1938: Congress passes Federal Food, Drug, and Cosmetic Act of 1938, and major changes were made in 1954, 58, and 60. Today the law requires manufacturers to provide scientific proof of a drug's safety and prevents mislabelling of products. Enforcement of these laws is the mission of the FDA.
- 1952: Polio cases surge in the US. Early testing of Jonas Salk's vaccine is encouraging
- 1953: Under President Eisenhower Congress created the Department of Health, Education and Welfare (HEW)
- 1954: A large scale clinical trial of the Salk vaccine begins.
- 1964: Surgeon General Luther Terry concerned a panel of experts to review the impact of smoking on health.
- 1970: The Occupational Safety and Health Act was passed by Congress and OSHA was founded in 1971
- 1970: EPA established
- 1979: HEW's educational tasks were transferred to the new Department of Education and health tasks to the new Department of Health and Human Services (HHS)
- 1979: Smallpox is declared eradicated by the World Health Organization. Last known case was 1977 in Somalia
- 1980: President Jimmy Carter signed the Comprehensive Environmental Response, Compensation and Liability Act (CERCLA or Superfund) to give the EPA authority to clean up hazardous waste spills
- 1981: Dr. Michael Gottlieb and his associates reported on four previously healthy young men who developed Pneumocystis carinii pneumonia. This was monumental in bringing attention to the HIV/AIDS epidemic.

# Ideas About Health

Examples of a few key players who influenced how we think about health and disease and its determinants:

- Girolamo Fracastoro (1546) - Italian physician, poet and astronomer who wrote about "disease seeds" carried by wind. In a way he was proposing germ theory 300 years before its formal discovery, though similar speculation had been made by Roman scholar Marcus Varro had been made in 1st century BC.
- John Graunt (1662) - Around 1592 parish clerks in London began recording deaths. In 1662 Graunt, as a member of the Royal Society of London, summarized the data from the Bills of Mortality in a publication called "Natural and Political Observations Mentioned in a Following Index, and Made Upon the Bills of Mortality". This publication made a variety of observations regarding common causes of death, higher death rates in men, season variation and the fact some diseases had constant death rates. He also estimated population size and growth and was the first to construct a "life table".

- Van Leeuwenhoek (1670s) - In 1665 Robert Hooke devised a compound microscope and discovered plant cells, coining the term "cells" in his book *Micrographia*. Leeuwenhoek of Holland was considered the father of microscopy. While working in a dry goods store and using magnifying glasses to inspect the quality of cloth he discovered new methods to achieve increased magnification up to x270. He was the first to see bacteria (1674), yeast, protozoa, sperm cells, and red blood cells.
- John Pringle (1740s) - A Scot who served as physician general to the British forces during the war of Austrian Succession. In 1752 he published "Observations on the Diseases of the Army" in which he proposed a number of measures to improve health of soldiers such as hospital ventilation and camp sanitation. He wrote extensively on the importance of preventing typhus, which he incorrectly believed was caused by filth (it is caused by bacteria and carried by lice). He also coined the term "Influenza".
- James Lind (1754) - A Scottish navel surgeon who studied Scurvy in sailors and conducted what may have been the first clinical trial in 1754, by treating Scurvy infected sailors with a variety of treatments and correctly finding that citrus fruits cured the illness. Although he was correct in the cure, he was wrong about the cause of the disease, which was caused by vit C deficiency.
- Broussais and Louis (1754) - Broussais was a prominent Parisian physician and a strong proponent of bloodletting. His vigorous use of leeches during a cholera epidemic in Paris substantially contributed to the mortality rate. Louis was a contemporary of Broussais who believed numerical methods to evaluate treatment and discovered bloodletting was ineffective. Since bloodletting was embedded in medical practice his findings were largely dismissed.
- Ignaz Semmelweis (1840s) - Hungarian physician who practiced in the maternity department in Vienna in the 1840s. Post-partum sepsis was a common occurrence nearly always fatal and of unknown cause at this point. There were two different maternity wards, one attended by midwives and one attended by medical students. The medical students often came directly from handling corpses without washing their hands. He was the first to suggest all students wash their hands with chlorinated water and as a result the mortality rate plummeted, though some still ignored the findings.

## John Snow: Father of Epidemiology

In the 1800s there were large outbreaks of Cholera in America and Europe killing thousands of people. John Snow was a physician from London who studied Cholera for many years, and is credited with solving a outbreak in 1854. The theory on Cholera transmission was meassimas or person to person contact. Snow began examining the victims and found symptoms were always related to the gastrointestinal tract and reasoned that if it were spread by bad air there would by pulmonary symptoms so transmission was more likely to occur by food or water consumption.

Many Londoners received their water from hand pump wells that were located throughout the city and two private companies in particular pumped water from the Thames river to the areas primary effected by cholera. Of course, few people believed Snow since he couldn't actually prove there was something in the water. He ended the epidemic in 1854 by removing the handle to the

infected water pump himself. Cholera remains a problem in countries with underdeveloped sanitation and water routes, such as Haiti. In these locations it is more realistic to vaccinate for cholera than fix the entire system.

## The Sanitary Idea

In a way modern public health, i.e. as a function of government, comes from France and Britain around 1850-1875 in the wake of the consequences industrial revolution. However the circumstances that propelled the development of public health as a discipline, such as the importance of the size of a population in measuring the influence and power of a state. This crude notion made the idea of "numbering the people" important. John Graunt's office was the first of it's kind to mandate the recording of births, marriages, deaths. William Farr was the first Chief Statistician. The General Registrar's Office established the importance of surveillance with respect to health.

Another contributing factor was the start of the enlightenment, which embraced democracy, citizenship, reason, rationality and the social value of intelligence. One theme was the reduction of mortality and improvements to health had an economic value to society, healthy workers were able to contribute more. Utilitarianism, or the idea that one can measure the amount of evil by the misery created or relieved by an action, provided underpinnings for public health.

## Health and Class

In 1842 Sir Edwin Chadwick, a social reformer, published a report entitled "Report into the Sanitary Conditions of the Laboring Populations of Great Britain" proving that life expectancy is much lower in towns than in the countryside. He argued that it was possible for government to improve people's lives through reform and a healthier population would work harder and cost less to support. He concluded what was really needed was not more doctors but civil engineers to provide drainage of the streets and more efficient ways of delivering clean water and removing sewage. These ideas contributed to the idea that public health was a legitimate concern of government and led to the creation of legislation and government offices.

# What is Public Health?

The many factors that contribute to disease and health, or *determinants*, are complex and often break down to genetic, environmental and lifestyle factors. In addition Public Health is a multi-disciplinary enterprise that requires expertise in biology, pathology, environmental science, sociology, psychology, government, medicine, statistics, communication, and more to truly understand.

Someone who is overweight and smokes might require a expensive heart surgery to prolong their life. However, public health is about the interventions that prevent disease from occurring in the first place, so the benefits tend to be less obvious. The prevention of disease not only prolongs life, but improves the quality of life. In a sense public health is the epidemic that didn't happen, or the heart disease that didn't developed. Successful public health is the sum of the adverse health outcomes that never occurred.

## Learning Objectives:

1. List and describe the three core functions of public health
2. Expand on the three core functions of public health and discuss how they relate to the 10 essential functions of public health
3. Define and give examples of primary, secondary, and tertiary prevention of disease
4. Discuss modern concepts of population health
5. Briefly explain how "Public Health 3.0" differs from earlier approaches.
6. Explain the rationale and approach of Health Impact in 5 Years (HI-5)
7. Outline the overall structure of global public health
8. Outline the overall structure of US public health

## Primary, Secondary, and Tertiary Prevention

The goal of primary prevention is to prevent healthy people from becoming ill. While that sounds easy, it often creates ethical conflicts when healthy people are asked to take additional steps to prevent developing disease (i.e. vaccination, exercise, smoking).

Secondary prevention consists of screening for disease in order to find sub-clinical disease and treat it in the hope that earlier treatment will provide reduced harm or cure (e.i. cancer screening, blood pressure test for hypertension, routine urine and blood analysis).

Once an individual has been diagnosed and treated for a disease, subsequent efforts to reduce effects are regarded as tertiary prevention (i.e. cardiac rehabilitation after a heart attack, exercise and weight loss for people who developed type 2 diabetes).

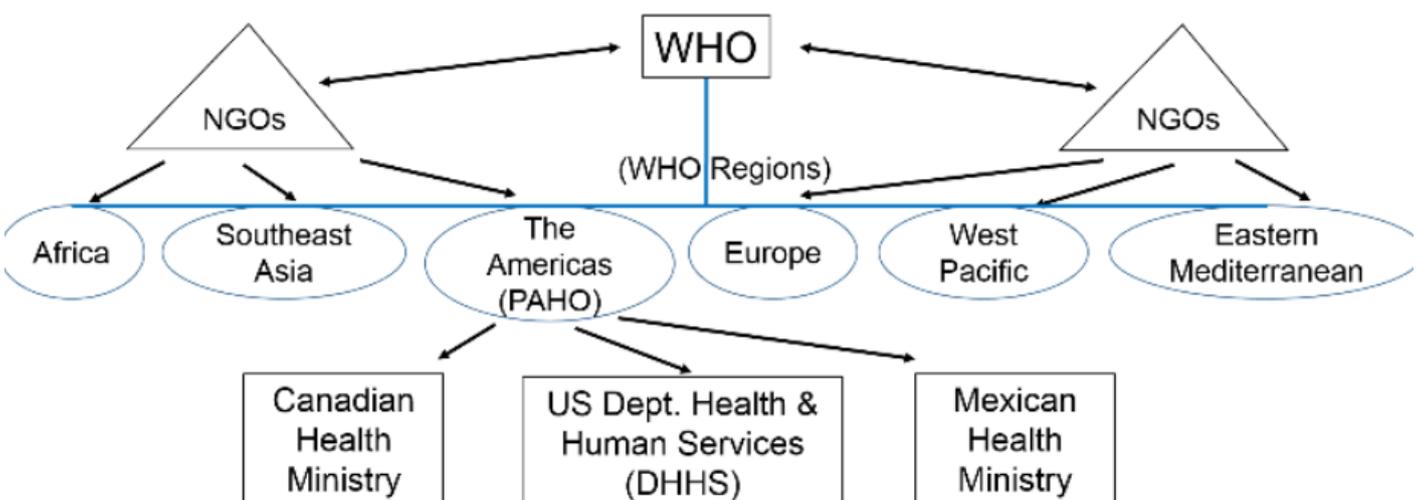
# International Public Health Organizations

The World Health Organization (WHO) was created in 1948 by the UN as the global health authority that would coordinate and guide health policy, practice, research, and surveillance in participating countries. The headquarters is located in Geneva, Switzerland. The director general is appointed by the World Health assembly which consists of representatives from participating countries.

The core functions of the World Health Organization are:

1. Providing leadership on matters critical to health and engaging in partnerships where joint action is needed.
2. Shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge.
3. Setting norms and standards and promoting and monitoring their implementation.
4. Articulating ethical and evidence-based policy options
5. Providing technical support, catalyzing change, and building sustainable institutional capacity.
6. Monitoring the health situation and assessing health needs.

The WHO oversees 6 region and each of these interacts with the national public health agencies of it's member nations.



# Non-Governmental Organizations (NGOs)

NGOs are private organizations that are not part of a particular government, though they often partner with governmental or inter-governmental organizations. They can be supported by public or private funding, and thus may be supported by government but not governed by them. NGOs are important to countries to provide programs to countries that do not have them such as HIV prevention, clean water allocation, and disaster relief. Ex. Red Cross, CARE for Europe.

## Public Health in the US

In some respect Winslow's definition of public health is still correct today but in the US the focus has shifted over the last several decades.

In 1988 The institute of Medicine issued a report entitled "The Future of Public Health" which concluded the US public health system needed refocusing because there was a lack of clarity regarding its roles and responsibilities. The report introduced the concept of three core functions:

1. Assessment - Assessing needs of communities by collecting statistics and information related to the community's health needs. Assessment also means identifying the sources of health problems and the determinants of health and disease.
2. Policy Development - Prioritizing public health needs, advocating for public health, building constituencies and coalitions and pursuing the enactment of policies and laws that promote health.
3. Assurance - Establishing and maintaining an infrastructure for public health and implementing programs to monitor the effectiveness of public health interventions. Assurance also requires effective communication of public health information to the general public.

In 1994 the CDC expanded the 3 core functions and identified 10 essential services which should be undertaken in all communities, regardless of size:

1. Monitor health status to identify and solve community health problems
2. Diagnose and investigate health problems and health hazards in the community
3. Inform, educate, and empower people about health issues
4. Mobilize community partnerships and action to identify and solve health problems
5. Develop policies and plans that support individual and community health efforts
6. Enforce laws and regulations that protect health and ensure safety
7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable

8. Assure competent public and personal health care workers
9. Evaluate effectiveness, accessibility and quality of personal and population-based health services
10. Research for new insights and innovative solutions to health problems

In 2002 the Institute of Medicine titled "Who Will Keep the Public Healthy?", which concluded public health professionals must have a framework for action and an understanding of the forces that impact health.

## Population Health

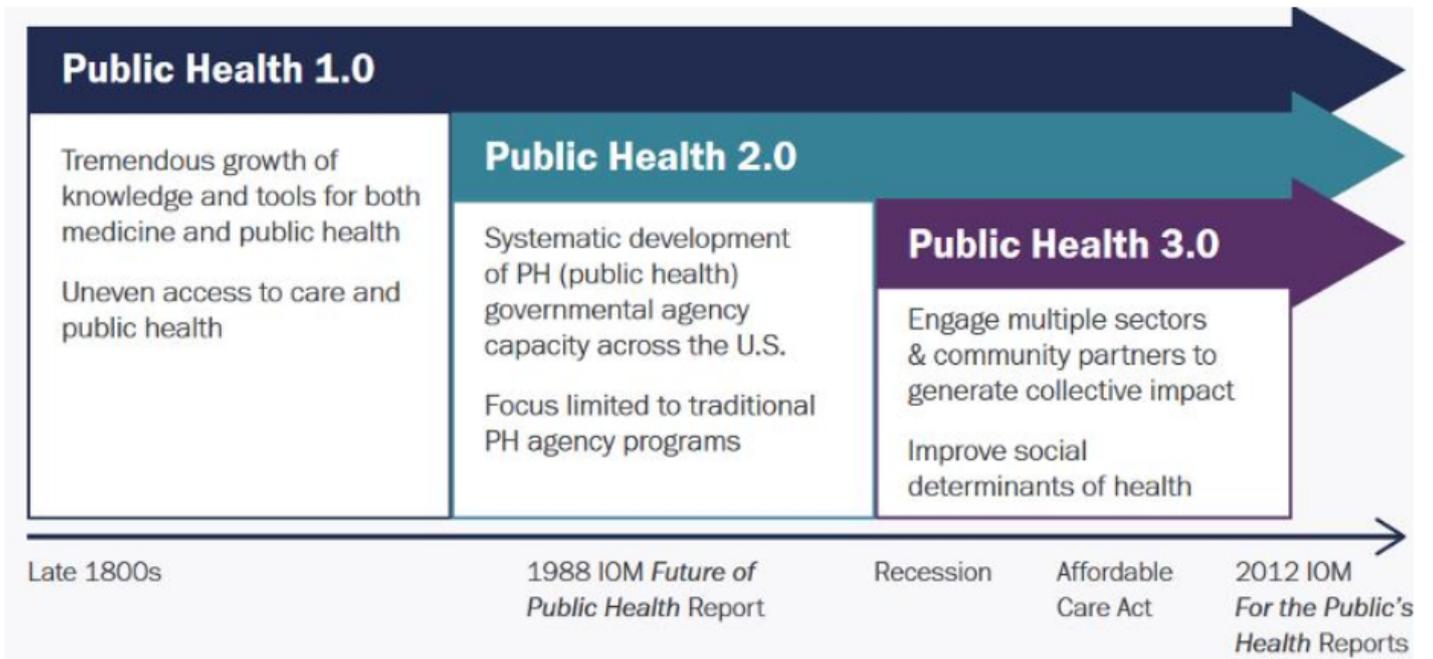
The final decades of the 20th century placed heavy emphasis on individual responsibility for health and behavior modification. The newer definition by the CDC reflects a shift to population health. This shift was brought on by the recognition of the social determinants of health and acknowledgement of effective strategies to make communities safer and healthier. Other factors were threat of bio-terrorism, disparities in healthcare. During the 20th century, Winslow's definition of public health focused mainly on physical health of a geographical region, but this has been redefined in the 21st century to conciser mental health and envision populations not only geographically but by needs (the mentally ill, poor, those with HIV, etc).

Population health might include:

1. Healthcare - Delivery of 1 on 1 screening, prevention, cure and rehabilitation
2. Traditional public health - Surveillance, control of infection of disease and environmental hazards, food and drug safety, education to public, and behavior modification
3. Social intervention - improvements to the environment, better access to healthy food, community safety and reduction in disparities.

## Public Health 3.0

The birth and evolution of public health during the enlightenment is identified by the US Health and Human services separates into 3 eras:



Public Health 1.0 - Modernized by the invention of vaccine, antibiotics, development of epidemiology, and advances in biological sciences. Led to advances in sanitation in safety.

Public Health 2.0 - Spurred by 1988 and 2002 report by National Institute of Medicine papers regarding the governments inability to act on mental health issues and HIV. The ability to cope with these problems were made worse during the budget cuts in the great recession (2008)

Public Health 3.0 - Innovative ideas on improving environmental factors in communities. Requires collective action and inter-organizational cooperation. In many communities the local health officer will take the role of Chief Health Strategist who guides community efforts and analyzes data mathematically to determine if best response has been enacted.

## Health Impact in 5 Years

Achieving lasting impact on health outcomes requires a focus on community wide approaches to improve population health. Programs that address the conditions where we work and live. By changing the context that make healthy choices easier we can improve the health for everyone. The health impact in 5 years initiative highlights non-clinical community-wide approaches that have evidence reporting:

1. Positive health impacts
2. Results within 5 years
3. Cost effectiveness or cost savings

The public health impact pyramid shows the potential impact of public health interventions.



The base of the pyramid has the interventions that have the greatest potential for impact on public health. They reach entire populations at once and require less individual effort. The HI-5 initiative maps to the bottom 2 tiers of the pyramid with greatest potential which are often hardest to implement, and the most obvious aspect at the top.

Social determinants have an enormous impact on health across the globe, solving problems like poverty, ignorance, nutrition, housing and sanitation. But these are complicated problems with no meaningful solution. Although counseling people on their behaviors tend to have the smallest impact, however it is the easiest to accomplish.

## Public Health Structure

Unlike some countries, the US constitution does not explicitly establish a structure for provision of public health. However Congress has the power to levy funds to public health services. On a federal level, the US Department of Health and Human Services is responsible for protecting the health and well-being of all Americans by providing effective health and human services, and fostering advances in medicine and public health.

His Strategic Plan describes HHS's efforts within the context of five broad strategic goals:

Strategic Goal 1: Protect and Strengthen Equitable Access to High Quality and Affordable Healthcare

Strategic Goal 2: Safeguard and Improve National and Global Health Conditions and Outcomes

Strategic Goal 3: Strengthen Social Well-being, Equity, and Economic Resilience

Strategic Goal 4: Restore Trust and Accelerate Advancements in Science and Research for All

Strategic Goal 5: Advance Strategic Management to Build Trust, Transparency, and Accountability

## Healthy People

Healthy People provides science-based 10-year national objectives for improving the health of all Americans. For 3 decades, Healthy People has established benchmarks and monitored progress over time in order to:

- Encourage collaborations across communities and sectors
- Empower individuals toward making informed health decisions
- Measure the impact of prevention activities

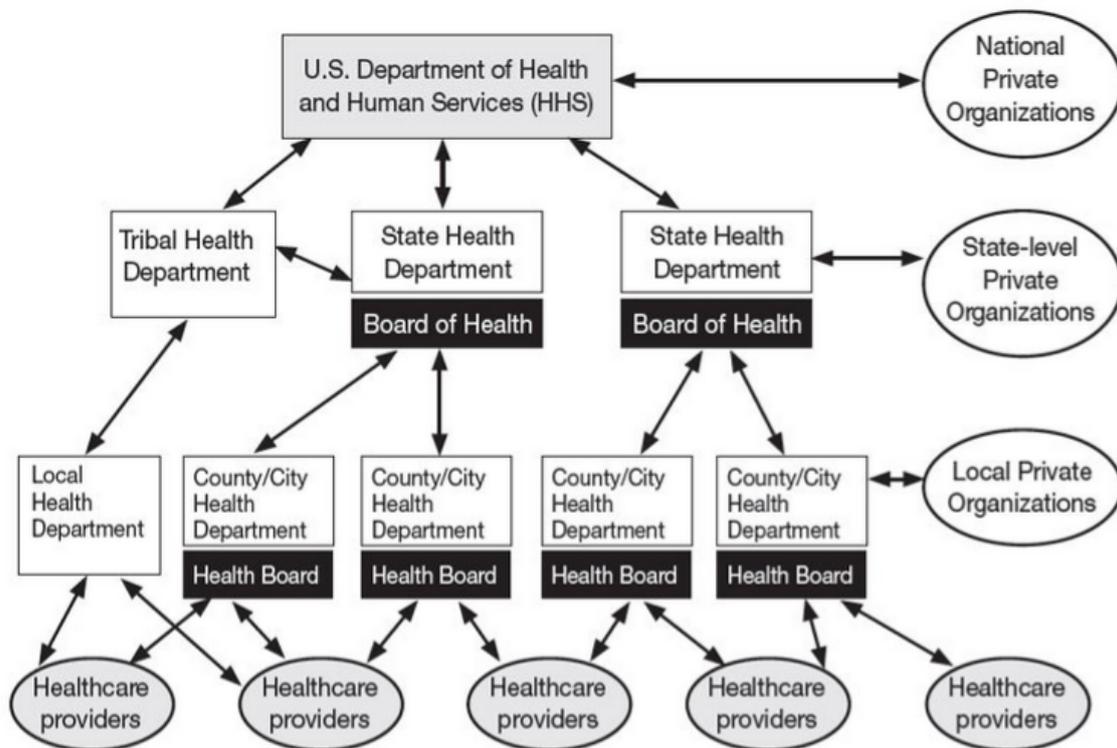
Healthy People periodically sets 10 year agenda of goals for improving health in the US. Healthy People 2020 strives to:

- Identify nationwide health improvement priorities
- Increase public awareness and understanding of the determinants of health disease and disability and opportunity for progress

- Provide measurable objectives and goals that are applicable at the national, state, and local levels.
- Engage multiple sectors to take actions to strengthen policies and improve practices that are driven by the best available evidence and knowledge
- Identify critical research, evaluation and data collection needs

# Police Power

Powers that are not specifically given to the federal government are retained by the states and referred to as *police power*. It allows each state to enact laws for the welfare to its citizens. Federal health laws supersede state laws, but in absence of federal law, states enact their own. Similarly, state laws take precedent over local laws. There is still significant interaction between HHS and state departments as well as national and state level organizations.



# Philosophy and Ethics in Public Health

There are many definitions of public health, but the simplest is that public health is the constellation of actions that a society takes to enable people to enjoy good health and remain free of disease.

The goal of achieving a healthy society is intrinsically good, since it reduces disease, suffering and enables people to live longer, happier lives. These benefits have tangible benefits such as greater productivity and reduced spending on medical care.

While these goals are unarguably good, there is still debate as to how much money should be directed to public health when there is competition for limited resources, or whether the cost of a particular public health intervention justify the benefits.

Other considerations:

- What freedoms may be in conflict with the intervention?
- Do the benefits of interventions outweigh the potential for unknown risks?

**Public health ethics involves the principals that guide us as a society in making decisions about public health that conform to our morals and standards while resolving or minimizing conflicts.**

## Learning Objectives:

1. Discuss the philosophical justifications for public health
2. Discuss the moral considerations for public health
3. Discuss the justifications for overriding interests such as freedom of action privacy and confidentiality in order to achieve public health goals
4. Explain the key questions that should be addressed when analyzing an ethical issue in public health
5. Define the "police power" and discuss the major precedents set by *Jacobson v. Massachusetts*

## Philosophical Justification

Several theories had significant impact on shaping public health ethics.

Jeremy Bentham was a proponent of utilitarianism, evaluating actions based on their consequences in producing happiness and contributing toward the greater good. His philosophy was "the greatest good for the greatest number".

John Stuart Mill was also a utilitarian but refined his views to distinguish higher and lower pleasures. "The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others." He was not absolute on this, as he acknowledged that no system of ethics requires the sole motive of all we do be based on duty. 99% of all our actions are done from other motives, and rightfully so if the rule of duty does not condemn them.

"Public Health draws its foundational legitimacy from the essential and direct role that health plays in human flourishing... However, the general justification is sometimes too broad to provide sufficient moral warrant for specific public health policies which are implemented by the state and affect the liberty or privacy or corporate or individual persons." -JSM

## Overall Benefit

All individual population members benefit from public health agencies and interventions, even if they don't benefit from all interventions. Agencies such as the CDC and FDA are charged with improving health within the population. While public health regulations may pose restrictions and inconvenience to some of us, the overall effect is an improvement in the quality of our lives.

## Collective Action and Efficiency

Public health operates at the population level, and many of its benefits could not be achieved without regulation and coordinated efforts of many trained people with special expertise. For example, food safety at the level we currently enjoy could not be achieved without extensive, coordinated effort by many agencies.

## Fairness in the Distributions of Burdens

A basic premise is that burdens and benefits should be distributed fairly. For example the requirement for childhood vaccinations encourage high levels of population immunity and provides a distribution of both the benefit of protection and the burden of having to get vaccinations.

## The Harm Principal

John Stuart Mill established what we now know as the harm principal, which states power can be exercised over members of a society when the purpose is to prevent harm to others. This principle provides justification for limiting individual freedom through isolation or quarantine to control the spread of disease, and even for mandatory treatment in some instances.

This was also an important justification for banning smoking in public places once there was evidence of harm from secondhand smoke. This brings up the question regarding the extent of harm and weighing in on the curtailment of personal liberty. Mill recognized by separating lesser freedoms and fundamental freedoms that should not be interfered with in the absence of compelling justifications.

## Paternalism

Paternalism generally has a negative connotation implying unwanted interference. However, the notion of paternalism as a justifications comes into play in the context of protecting vulnerable people such as those with cognitive disability or immaturity (situations where autonomy is already compromised and protection is needed).

## Moral Considerations

The United States, constitution recognizes that police power is needed to enforce laws to promote health, safety and general welfare. This led to the concept of "strict scrutiny" whenever the use of police power threatens fundamental freedoms. Ex:

- Is there justification for the state to require citizens to use seat belts while driving or helmets while riding a bike?
- Is there justification for quarantining citizens with active tuberculosis to ensure they take their medications?

## Ethical essentials of public health:

1. Producing benefits
2. Avoiding, preventing and removing harms
3. Distributive justice - distributing benefits and burdens fairly - and procedural justice - meaning ensuring public participation
4. Autonomy - respect for autonomous choices and actions
5. Protecting privacy and confidentiality
6. Keeping promises and commitments\
7. Transparency - disclosing information honestly
8. Building and maintaining trust

## Justification for Infringing Interests

### Effectiveness

One important question is whether there is reason to believe that a proposed public health intervention, such as quarantine, would be effective. If not, it would not be ethically justified to restrict individual liberty.

## Necessity

Even if forced quarantine might be effective, it might not be necessary. For example, Tuberculosis (TB) is one of the great killers of all time, especially in recent years due to the emergence of a multiple-drug resistant TB. The CDC recommends Directly Observed Therapy (DOT) in which the patient is required to meet with a health care worker every day or several times a day to ensure the medications are taken. New York City uses a tiered system of DOT. Most patients are observed taking their medications via smart phone. However the city may impose quarantine on TB patients at Bellevue Hospital, but these extreme measures are only used in extreme measures when infectious people habitually fail to take their medication. Every alternative must be exhausted before infringing on personal liberties.

## Least Infringement of Presumptive Value

In any given circumstance the least restrictive infringement that enables the goals to be achieved is the one that should be utilized. NYC's tiered DOT system is a good example. Similarly, if it were justifiable to breach privacy or confidentiality, the breach should limit the information disclosed as much as possible.

## Proportionality

Even after satisfying the previous three justifications, one must also consider whether the likely benefits justify the cost, both financially and in terms of personal interest. Here is a list of interventions from the most restrictive to the least restrictive:

- Eliminate choice
- Restrict choice
- Guide choice by incentives
- Guide choice by changing the default policy
- Enable choice
- Provide information
- Do nothing

## Impartiality

There have been a number of instances when coercive measures such as quarantine were applied more rigorous to certain categories of citizens. For example, coercive measures were applied disproportionately against the Chinese during the SARS outbreak in 2003.

Involvement of the public in deliberations about public health is essential, since community members are the most important stakeholders. Public health activities and interventions should be carefully explained to community members honestly and transparently.

# Analyzing Ethical Issues

There are several key questions public health policymakers should address when analyzing ethical issues:

1. What public health problems, needs, or concerns are at issue?
2. What are appropriate public health goals in this context?
3. What is the source and scope of legal authority, if any, and which laws and regulations are relevant?
4. What are the relevant norms and claims of stakeholders in the situation and how strong or weighty are they?
5. Are there relevant precedent legal and ethical cases?
6. Which features of the social-cultural-historical context are relevant?
7. Do professional codes of conducts provide guidance?

# Public Health Law

## Jacobson V. Massachusetts

In 1900 smallpox was still a significant issue. In 1900 there were 100 cases of smallpox in MA. By 1902 there were over 2300 infections. The board of health became concerned and mandated all citizens should get a smallpox vaccine if they had not been vaccinated since 1897. It was within the board's power to do so and had already been proven that vaccines were an effective measure for prevention. Many citizens were opposed to vaccines for various religious, political, and philosophical arguments as well as concerns about safety. Jacobson was a Swedish Reverend in MA who refused vaccination and was fined \$5. He sued, and lower courts upheld the fine and eventually it went to the SCOTUS where the court ruled in favor of the state. In essence, their decision ruled that public health laws have to be rational and reasonable noting that there are times we must give up our personal liberties for the common good. This case has been used as precedent on many following lawsuits, such as those regarding quarantine or mandating helmets on motorcycles.

## Police Power

While the power to create public health law exists in all levels of government. One could argue most the power of public health authority lies at the state and local level where police powers exist, the ability to enforce policy to help guide the health and welfare of the citizens. The 10th amendment of the Bill of Rights specifically reserves police power to the states and sometimes local authorities. The federal government can collect funds from taxes and distribute them to programs, or regulate commerce to stop the spread of disease. State and local health departments are responsible for the public health of their communities, rather than the CDC.

**Legal Epidemiology** refers to the study of law as a factor in the cause, distribution, and prevention of disease and injury. It applies rigorous, scientific methods to translate complex **legal** language into data that can be used to evaluate how laws affect population health. The idea that

law is a major determinant of health is only just starting to evolve, we are still studying the most effective interventions on smaller populations before introducing it to a larger population.

# Principals for Public Health Professionals

In 2010 a CDC sponsored project published a **code of ethics** for public health. Public health should:

1. Address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes
2. Achieve community health in a way that respects the rights of individuals in a community
3. Develop policies programs and priorities that are evaluated through processes that ensure an opportunity for input from community members
4. Advocate for, or work for the empowerment of, disenfranchised community members, ensuring that the basic resources and conditions necessary for health are accessible to all people in the community
5. Seek the information needed to implement effective policies and programs that protect and promote health
6. Provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation
7. Act on a timely manner on the information they have within the resources and the mandate given to them by the public
8. Incorporate a variety of approaches to programs and policies that anticipate and respect diverse values, beliefs, and cultures in the community
9. Be implemented in a manner that most enhances the physical and social environment
10. Protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.
11. Ensure the professional competence of their employees
12. Engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness

# Evidence-Based Public Health

Maximizing the health of a population is largely achieved through three core functions of public health; Assessment, policy development, and assurance. Within each core function lies a subset of the 10 essential functions of public health:



As mentioned in the the previous module on ethics, it is essential to consider alternative courses of action to maximize benefit, minimize adverse consequences and make the most efficient use of scarce resources. As a result decisions on how to address public health must be evidence-based, meaning they are based on accurate and complete data which have been rigorously analyzed.

Two broad types of evidence are essential to the practice of public health:

1. The Evidence regarding the efficacy and adverse consequences of interventions
2. Evidence regarding the determinants of health and disease

In addition, it is useful to have evidence regarding how a disease spreads across a population, including social and political factors. Ex. are there members of the population at higher risk due to behavior, age, preexisting conditions or geography?

Even though most research depends on quantitative data, a fine understanding usually requires qualitative data.

## Learning Objectives:

1. Describe the general steps involved in identifying and addressing public health problems
2. Describe and give examples of the role of surveillance systems in public health
3. Explain what is meant by the term "notifiable/reportable disease"
4. Describe the breadth of modern public health surveillance systems and give specific examples
5. Define "syndromic surveillance" and explain how it can be advantageous over regular surveillance
6. Explain how the characteristics of person, place, and time are used to formulate hypotheses in acute disease outbreaks and in studies of chronic diseases
7. Distinguish among case reports, case series, cross-sectional surveys, and ecological studies and explain their importance
8. Explain the concept of ecologic fallacy
9. Describe the difference between descriptive and analytic epidemiologic studies
10. Define and explain the distinguish between retrospective and retrospective cohort studies
11. Define and explain features of a case-control study
12. Explain and distinguish features of of an intervention study (clinical trial)
13. List and define 3 major threats to validity in analytical studies
14. Describe the contribution of quantitative and qualitative research to public health

## Four Steps

Rothman summarized the four steps to public health approach as followed:

### 1. Identifying the Problem

In the US there are number of ways in which public health problems are identified:

- Surveillance systems monitor and record occurrences of specific infectious diseases, and information is communicated from municipalities or counties to state health departments and then federal agencies
- States maintain cancer registries
- Computerized registries are increasingly used for diseases like diabetes, kidney failure, and a variety of other problems
- Vital statistics regarding births, deaths, marriages, and divorces are collected by each state and other jurisdictions and through co-op agreements that data is shared with the US National Vital Statistics System
- Many federal agencies periodically conduct surveys to monitor health status of the population

- Health care providers report new or unusual problems to health departments and disseminate findings in the form of case reports or case series
- Local and federal organizations and systems are in place to inspect food and monitor water quality

## 2. Identifying Contributory Causes

Epidemiology is a discipline that studies the distribution of health outcomes and its possible determinants in populations in order to identify casual associations. Epidemiology is described as the basic science of public health, because it is based in scientific method and identifies factors associated with health states by systematically collecting, analyzing and interpreting quantitative data.

## 3. Identifying What Works

This is also largely achieved through quantitative methods that evaluate the efficacy of interventions through clinical trials and program evaluation.

## 4. Identifying the Means

This may rely on quantitative methods, but increasingly relies on qualitative research which aims at understanding people's perceptions and developing an understanding of why they believe what they do. Ex interviewing a key informant to see why a particular intervention did or did not work in order to improve future programs.

# Surveillance Systems

Surveillance for public health is based on a variety of data sources that track health status and health-related behaviors in a population over time in order to identify new problems, such as infectious disease outbreaks. In addition to monitoring trends these data help identify new health problems and provide clues about the causes of new issues in a population. Surveillance data enables us to:

- Monitor and report on the health status and health related behaviors in a population
- Identify emerging health problems
- Alert us to potential threats
- Establish public health priorities for a population
- Evaluate the effectiveness of intervention programs
- Explore potential associations between risk factors and health outcomes in order to generate hypotheses about the determinants of disease

## Passive Surveillance

Routine reporting of health data. Can create a full picture when combined but is limited by under-reporting.

- Hospital Data
- Disease registries
- Notifiable diseases - Some countries have laws which list diseases which are required to report

## Active Surveillance

Actively sought out information:

- Active case finding
- Testing blood markers
- Community Surveys

## Sentinel Surveillance

A group of selected institutions or groups pool health data together on a certain disease. This can be used to monitor disease outbreaks and trends, but is unable to detect cases outside sites/groups making it ineffective for rare diseases.

## Rumor Surveillance

Relies on unofficial sources of information (blogs, social media, hearsay, etc.). It might alert authorities to investigate further for signs of an outbreak.

## Syndromic Surveillance

Monitors for non-specific illness syndromes recorded at medical clinics, along with tells like medicine purchases or absenteeism from school or work. Allows for early identification and can rely on automatic reporting methods. A "syndrome" is a cluster of signs and symptoms.

## Other Types

- ProMED - Web-based
- GPHIN - Early warning tool to monitor significant health events

## Characteristics of a Good Surveillance System (from CDC)

- An integrative approach uses all available information and provides the best overall picture of health
- It has simple, clearly defined objectives
- The data should be complete and accurate
- The plan should be flexible without incurring additional costs
- Accepted by people and organizations involved in public health surveillance

- Sensitive and Positive Predictive Value (PPV), it should pick up most if not all cases of the disease in the population
- It accurately measures what it intends to measure
- Timeliness to leave room for action
- Stable and available when needed

And all surveillance systems should be evaluated on their effectiveness and if they meet public health functions

## Data Sources

There are many sources of data that are useful for monitoring health of the populations and exploring disease frequency over time. Ex:

- Census and Records - US Census and US National Vital Statistics System and the Massachusetts Registry of Vital Statistics and Records
- Disease registries - Massachusetts Cancer Registry, ALS Registry
- Hospital Discharge Registries
- Community Health Information - In MA the Community Health Information Profile (MassCHIP) provides a dynamic, user-friendly service for obtaining free online access to many health and social indicators. One can obtain community-level data to assess health needs, monitor health status indicators and evaluate health programs.
- Infectious Disease Surveillance - Division of Emerging Infections and Surveillance Services (DEISS)
- Commercial Data - Sale of tobacco, drugs, etc

## Reportable Diseases

Each US state designates a specified list of diseases that are required to report by law. The MA Department of Public Health provides a Reportable Diseases web site as an online resource for all public health organizations. This data is fed into the National Notifiable Disease Surveillance System (NNDSS).

Data for selected nationally notifiable diseases reported by the 50 states and D.C. and the US territories are collated and published weekly in the Morbidity and Mortality Weekly Report (MMWR).

# Descriptive Epidemiology

Descriptive epidemiology is defined as epidemiological studies and activities with descriptive components that are much stronger than their analytic components or that fall within the descriptive area of the descriptive-analytic spectrum.

When new health problems arise, health practitioners need to find details on the determinants. The most basic starting point is to collect detailed information about a single case (case-report) and

search for additional persons with similar cases and gather information from a series of similar cases (case series). The most fundamental information focuses on three key aspects: **Person, place, and time**. These fundamental elements enable us to look for suggestive patterns.

- Person - all relevant characteristics including age, diet, behaviors, exposures, etc.
- Place - Spatial distribution of the problem.
- Time - Whether the frequency of disease varies over time.
- Differences - Factors may cause the frequency of disease to differ in circumstances
- Similarities - A high frequency of disease found in several different circumstances with a common factor
- Correlations - If the frequency of disease varies in relation to some factor

# Epidemiological Studies

A study is a scientific process of answering a question using data from a population. The first step is having a question to study, then decide a study type, collect and analyze data (ethically), interpret results, and reporting findings.

## Types of studies

### Ecological Study

Disease rates and information about exposures are made on a group of people. Could be a household or an entire country. Results apply to groups and not individuals, meaning these studies are better at comparing health between populations and generating questions.

### Case Series

Describes characteristics of people with the same disease or exposure.

### Cross-Sectional/Prevalence Study

Health information of a selected population at a given point in time. Usually involves a questionnaire or survey and are relatively inexpensive, but it cannot determine if exposure caused a disease because the data is collected from a single point in time (i.e. which came first) and also tend to favor cases with a longer duration and overlook cases which recovered quickly.

### Case Control Study

People with a disease, called cases, and people without the disease but with similar characteristics, called controls, are asked about past exposures to certain risk factors. For each risk factor the odds of being exposed as a case is compared to the odds of being exposed if they were control, giving us the Odds Ratio (OR).

	Cases (Have Disease)	Controls (No Disease)
Exposed	a	b
Unexposed	c	d

Odds Ratio (OR) =  $(a/c) / (b/d) = a*d / b*c$  = Odds that a Case was Exposed / Odds that a Control was Exposed

Relative Risk (RR) =  $(a / (a + b)) / (c / (c + d))$  = Risk of Disease of Exposed / Risk of Disease Unexposed

If the OR is greater than 1 than the risk factor is associated with disease, less than 1 suggests its a protective factor and =1 suggests no association.

This is often used when searching for food-borne illnesses. They are quick and cheap, and can be used for uncommon disease. It falls short when finding rare exposures, and it can be difficult to find a representative control selection who can accurately recall if they were exposed.

## Cohort Study

A group of people are followed over a period of time to collect data on risk factors and then compare occurrences of similar outcomes of those who were exposed and those who were not.

The main measurement used in cohort studies is called the Relative Risk (RR), which is the risk of disease for those exposed to a risk factor over the risk of disease in the unexposed group.

RR > 1 is increased risk, RR < 1 is lower risk, RR = 1 is same risk

Advantages are that time sequence can be determine causality and info on various outcomes/risk factors can be collected at the same time. Disadvantages are the fact that many people have to be followed over a long period of time make them costly and not good for rare diseases, also if too many people drop out it will interfere with the results of the study.

## Interventional Study

Intervention is done on a group and outcomes are measured. This could be medicine, vaccine, health advise, etc.

The best design for an interventional study is a randomized controlled trial, where people are randomly selected from the population to either receive the intervention or take part in the control group. Ideally the experiment would be double blind, where neither the participant or investigator know who is the control group.

These studies can provide good evidence of causality, and randomization provides equal chance that groups are similar. Disadvantages are the cost of finding participants.

## Summaries

Summaries are studies made with other studies. Systematic review finds all relevant studies to a topic, assesses and interprets the results and creates an unbiased, impartial summary of the evidence. A meta-analysis uses data from studies which asked the same question and had a similar design, then uses that data to combine analysis and produce a single summary result.

# Examples of Descriptive Epidemiology

## Case Report

A detailed description of disease occurrence in a single person.

Ex. April 1983, it was not yet known AIDS could be transmitted by blood. An infant born with a blood disorder required transfusion from 18 donors over 8 weeks and later developed a low T cell count suggesting AIDS. It was later found one of the donors died of AIDS.

## Case Series

A report on the characteristics of a group of subjects who all have a particular disease or condition. Cannot be used to infer causality because there is no comparison group, but can be used to hypothesize questions for a study.

Ex. 1981 Pneumonia study on previously healthy young men, which was an important milestone in the AIDS epidemic. Case studies cannot establish a valid association but in this case laid the groundwork for subsequent case-control and cohort studies.

## Cross Sectional Surveys

Surveys which assess the prevalence of disease and risk factors at the same point in time.

Ex. US government agencies sent surveys to random samples of the US population asking about health status and behaviors. There was a heart disease survey given to farmers asking only if they were physically active. Because the participants were not followed, we can't tell if the cases developed heart disease because they were inactive, or if they are inactive because they developed heart disease.

However, in some circumstances the temporal relationship is clear. Ex. a study which measures salary between male and female employees could be regarded as analytical because gender was already established because the outcome (salary). In a sense, cross sectional and ecological studies are an intermediate category between descriptive and analytic studies.

## Ecological Studies

These studies are distinguished by the fact the unit of observation is not a person but an entire population.

Ex. Comparing the rate of colon cancer based on meat consumption in different countries. The issue is the study assumes everyone in each country has the same exposure, or ate the same amount of meat. There is no information about individual people, thus there is no way of knowing if the people who ate the most meat are the ones who developed colon cancer. This is referred to as ecological bias or ecological fallacy.

# Analytical Studies

Descriptive epidemiology is useful for generating hypotheses about determinants of health, but they have a number of limitations that do not allow them to firmly establish a valid association between a given factor and a health outcome. Analytic studies are more formal comparisons that enable investigators to test specific hypotheses. Samples of subjects are identified and information about exposure status and outcome is collected and analyzed in order to estimate the magnitude of association.

## Prospective Cohort Studies

A cohort is an identified individual who does not have the outcome of interest initially, but have potential to develop the outcome of interest.

Ex. Framingham Heart Study enrolled residents who did not have cardiovascular disease when enrolled and followed them to see if and when they developed cardiovascular issues.

## Retrospective Cohort Studies

In contrast to prospective cohort studies, retrospective cohort studies are conceived after some subjects have already developed the outcome of interest. Investigators jump back in time to identify a cohort of individuals at a point in time before they developed an outcome and try to establish exposure.

Ex. studying employee health records at a chemical plant after multiple employees die. The preexisting data was data may not be acquired in a predetermined way or may be incomplete.

## Intervention Studies

Experimental research studies that compare the effectiveness of public health interventions or medical treatments. The design is similar to prospective cohort studies, except that the exposure is assigned by investigators. Exposure status is assigned randomly to produce equal effects of confounding variables.

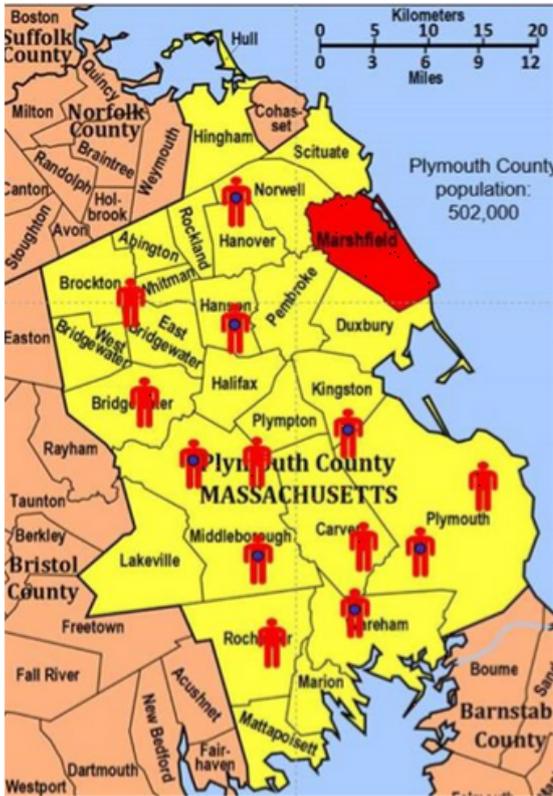
Ex. A drug treatment trial with a placebo group.

## Case Control Studies

Cohort studies fall short when the outcome being investigated is rare, or there is a long period of time between exposure and outcome. In a case control study, investigators start by finding an adequate number of cases who already have the outcome and a comparison group without the outcome and all are sorted into an exposed or unexposed categories.

## Rare Disease in Plymouth County

In this hypothetical situation Plymouth County has a total population of 6647.



	DISEASED	NON-DISEASED	TOTAL
EXPOSED	7	1,000	1,007
NOT EXPOSED	6	5,634	5,640

	DISEASED	NON-DISEASED	TOTAL
EXPOSED	7	10	UNKNOWN
NOT EXPOSED	6	56	UNKNOWN

If we somehow had all the exposure and outcome information in the source population we could calculate the incidence of exposed and non-exposed individuals and calculate the risk ratio.

$$I_e = 7 / (1000 + 7) = .70\%$$

$$I_u = 6 / (6 + 5634) = .11\%$$

$$RR = .7 / .11 = 6.5$$

Meaning those exposure to the risk factor had 6.5 times the risk of getting the disease.

However, in practice we rarely have the resources to get data on all subjects in a population. In the lower table we take a sample of 1% of the non-diseased population. We can't predict the Risk Ratio because we don't know the denominator, but we can compute the odds of disease in each group

$$O_e = 7:10$$

$$O_u = 6:56$$

$$\text{Odds Ratio} = (7/10) / (6/56) = 6.65$$

This is very close to the risk ratio and thus is a reasonable estimate.

## Which Study is best?

- If the outcome is uncommon a case control study would be best
- If the exposure is uncommon a cohort study is best
- Consider ethics: if studying the association between smoking and cancer it wouldn't be ethical to conduct a clinical trial in which you randomly assign half the subject to smoking
- Resources: If you have limited time, money and personnel to gather data it is unlikely that you will can conduct a prospective cohort study. A case-control study or retrospective cohort study would be better options, depending on if the outcome or exposure was more rare

## Sources of Error

Random error (Sampling Error) - Samples may provide estimates of relationships in the population that are inaccurate, particularly if the population size is small

Bias - Estimates of parameters in the population may be distorted by errors in the data collection (**information bias**) and if the selection or retention of subjects into our samples is somehow dependent on the exposure-outcome relationship (**selection bias**)

Confounding - a particular type of bias that occurs when other determinants of the outcome are unevenly distributed in the groups being compared

# Program Evaluations

To know if programs and interventions are effective one needs to answer several critical questions:

1. Is the program meeting its objectives? Why or why not?
2. What are the strengths of the program?
3. How might the program be improved?
4. What can be learned from current or past programs to improve future programs?

## Types of Program Evaluation

Formative

The goal is to obtain feedback on strengths and areas of improvement for the program and explore overall applicability and feasibility of the project. Typically takes place early in the inception to determine whether the program is applicable or makes sense.

Ex. Focus groups at a community center, pen and paper surveys, one-on-one interviews with members of the target community

## Process

Addresses whether the program was implemented as intended and why it did or did not meet its main objectives.

Ex. Access what percent of a online education model was completed, interview program coordinators

## Outcome/Impact

Measure the overall effectiveness of the program in meeting its objective.

Ex. Observing teen pregnancy rates 5 years after a sex education course.

# Framework for Program Evaluation

## CDC Framework



## Engage Stakeholders

An accurate, valid evaluation is a major goal for evaluators, but ultimately the strongest evaluation is the one used to beget action. In order to do so, a critical step is to consider the evaluation audience (stakeholders) and who is most invested.

## Describe the Program

Elucidate and explore the program's theory of cause and effect, outline and agree upon program objectives, and create focused and measurable evaluation questions.

## Focus Evaluation Design

Consider your hypothesis and available resources and weigh different design options to understand advantages and limitations of design options.

## Gather Credible Evidence

Data collection is essential to support evaluation conclusions and recommendations. What you collect and how directly impacts the quality and credibility of findings.

## Justify Conclusions

Use the evidence and data analysis to answer the main research questions and create conclusions and recommendations.

## Use and Share Lesson Learned

The primary goal of an evaluation should be useful and this requires communicating and sharing results. Stakeholders should be aware of the study process, findings, and efforts should be made to ensure results are incorporated into program decisions.

# Qualitative Research

Quantitative research are designed to precisely measure the association between biological, social, environmental, and behavioral factors and health conditions.

Qualitative research methods focus on understanding why and how individual life experience and the context of community life influence health and wellness. Such contextual information is difficult to capture through traditional quantitative surveys. Methods that rely on rapport and trust between researcher and participant that include open-ended questions enable participants to talk about their perceptions and experiences. Qualitative methods may be employed in combination with quantitative methods during the research process.

## Mixed Methods Research

When qualitative and quantitative methods are blended in the context of a research study, we refer to it as a "mixed methods research." In such cases it is common to employ qualitative methods to:

1. Generate hypotheses which may be applied to intervention design and evaluation
2. Enrich Understanding about a research topic that may be inaccessible using quantitative methods
3. Provide insights that specialists and researchers may not considered beforehand
4. Facilitate partnership between researcher and community members affected by the health issue under study

## Comparison of Research Methods

	QUANTITATIVE	QUALITATIVE
<b>GENERAL FRAMEWORK</b>	Test hypotheses, data collection is rigid relying on structured methods, such as questionnaires, surveys, record reviews.	Explore phenomena using more flexible methods that categorize responses to semi-structured methods such as in-depth interviews, focus groups, and participant observation
<b>ANALYTIC OBJECTIVES</b>	Describe populations and quantify exposure-outcome associations	Describe and explain variations and relationships
<b>QUESTION FORMAT</b>	Close-ended	Open-ended
<b>DATA FORMAT</b>	Numeric or categorical	Textual (based on audiotapes, videotapes, and field notes)
<b>FLEXIBILITY IN STUDY DESIGN</b>	Study design is stable throughout a study. Participant responses do not influence or determine how and which questions researchers ask next.	Study design is more flexible. Participant responses affect how and which questions researchers ask next. Study design is iterative, i.e., data collection and research questions can be adjusted according to what is learned.

The product of qualitative research can be recurrent themes or hypotheses by identifying salient factors and informing predictions about relationships. Themes are unifying concepts that identify and characterize a pattern of behaviors, group interactions, or individual perceptions.

## Learning Objectives

1. Articulate the purpose and significance of qualitative research methods
2. Determine when it is appropriate to use qualitative methods to address research
3. Illustrate ethical considerations in the conduct of qualitative methods
4. Define the major qualitative research techniques, their strengths and limitations and contexts in which they are best used
5. Define and illustrate the importance of "Community-based Participatory Research" (CBPR) as a research design often involving qualitative methods

## Common Qualitative Methods

### Participant Observation

Collecting data on behaviors in natural settings; study cultural aspects of a particular setting. Usually conducted early in a study but can be used to follow up as well. The role of the participant/observer is to carefully observe all details with a wide angle lens.

- **Non-participation:** No involvement with the people or activities studied (ex. studying television programs)

- **Passive Participation:** Present at the scene where activities take place, but does not participate in them or interact with other people. (Ex. Court or clinic waiting room observer)
- **Moderate Participation:** Balance between insider and outsider / participant and observer. (Ex. Participating in a town meeting)
- **Active Participation:** Active involvement in what your subjects are doing. (taking a minimum wage job to see how poor people manage expenses)
- **Complete Participation:** Some who is already involved in a particular activity or part of a particular group to specifically record systematic observations.

## In-Depth Interviews

These are the best way of collecting in-depth information on personal histories, opinions, and life experiences. These can be unstructured, semi-structured, or structured interviews. The idea is to have a guided discussion reflecting the individual's perspectives and experiences. The researcher might read questions from a prewritten guide which are open-ended in order to have the participant lead the discussion. These are great for sensitive topics when surveys or focus groups are ineffective.

## Focus Group Discussion (FGD)

These provide a means of collecting data on cultural perspectives and norms of a group. Usually about 5-10 people, with 3-5 groups per strata, discussing a set of predetermined topics. Stratification is the breakdown of groups based on how similar or different members of the group should be. These strata could be characteristics such as age, wealth, race, etc. These are useful for characterizing social and cultural norms or exploring how people talk about a sensitive topic. Keep discussion open-ended and avoid asking why or for examples. The group is the unit of analysis, not the individuals within it.

# Community-Based Participatory Research (CBPR)

Over the past 25 years it has become increasingly apparent that there is a health disparity in people living in disadvantaged communities, which is why it is crucial to move beyond traditional approaches which have previously led to breaches of trust and deep divides between researchers and the community.

Minkler and Wallerstein state: "CBPR begins with an issue of real importance to the community and involves the stakeholders and community members throughout the research process, including its culmination in education and action for social change." CBPR is not a method but an orientation; subjects are not objects of research but active participants. It's like a potluck with everyone bringing knowledge and expertise to the table. Note there are several names given to such approaches.



CBPR can...

- ... support the development of research questions that reflect issues of real concern
- ... improve our ability to achieve informed consent and address "cost and benefits" at the community level
- ... improve cultural sensitivity and reliability and validity of measurement tools
- ... uncover knowledge critical to enhancing understanding sensitive health issues
- ... improve recruitment and retention efforts by increasing community trust
- ... increase the relevance of intervention studies, and thus the likelihood of success

## Qualitative Data Analysis

Qualitative data analysis is the process of organizing, coding and examining raw data and finding patterns in order to interpret or understand behavior and social phenomena.

Data could be in the form of texts, audio-recordings, images, and artifacts. Software programs such as NVivo are useful for managing qualitative data. In such programs the analyst does the coding of the data himself, which allows them to identify major themes. There are two type of coding; **Inductive**, which is often done at the formative stage of research and relies on "open" coding to allow meaning to emerge from the data, and **deductive**, which is usually done at the confirmatory

stage and starts with a hypothesis before starting to code.

Using a qualitative research approach means:

- Focusing on social, economic, and political context of behavior
- Looking at ourselves as well as objects of our study
- Examining things we take for granted
- Recognizing the inadequacy of judging solely with our own norms
- Understanding the importance of obtaining an insider's perspective
- Being open to expect the unexpected
- Being willing to admit we may not know all the questions, let alone all the answers
- Realizing there is no "value-free" science

## Criticisms of Qualitative Research

- Lacks reproductability
- Lacks generalizability
- Researcher bias

Qualitative Articles Should Report:

- Relevance of question and rationale for approach
- Sampling strategy (selection, saturation)
- Data collection (interview guide, depth of data)
- Analysis (number of coders, training, code structure, systematic process, software, divergent cases, participant confirmation, audit trail)

# Trends in Morbidity, Mortality and Behaviors in the US

To follow trends in the causes of disease and death, the two measure of incidence that are always of interest are mortality and morbidity rates.

**Mortality Rate:** The incidence of fatal cases of a disease in a population during a specific time period.

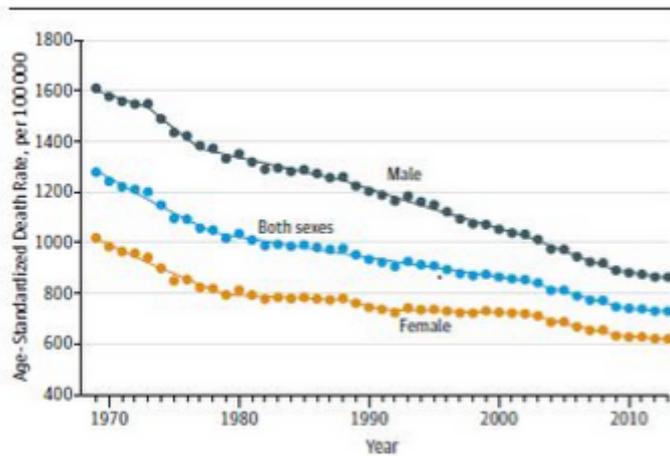
**Morbidity Rate:** The Incidence of non-fatal cases of a disease in a population during a specific time period.

## Learning Objectives

1. Define and calculate mortality and morbidity rates
2. Identify major causes of mortality and morbidity
3. Discuss gender and racial differences in overall mortality trends
4. Discuss trends in the major causes of mortality and morbidity
5. Discuss the temporal relationship among per capita cigarette consumption
6. Discuss where the US ranks among nations in regard to infant mortality rates

## Trends in Mortality

In order to adjust for differences in age distribution of the population over time researchers computed age-adjusted death rates per 100,000 population per year, finding that from 1969 to 2013 mortality rates decreased by almost 50%. Mortality rates in males were greater than females across the entire period.



One size does not fit all in the US. A breakdown of reasons for death revealed a variety of trends in different parts of the country. I.e. violence related deaths are more common on the West Coast, while heart disease related deaths are increasingly common in the Southeast. While death by heart diseases are slowly declining overall due to declining smoking rates, while in comparison the rate of COPD has been increasing since the 80's. This is because it takes many years for COPD to manifest. Heart disease is still the leading cause of death in US.

Years of Potential Life Lost (YPLL) is an estimate of the average number of years a person would have lived had they not died prematurely, it is a measure of premature mortality. To calculate YPLL one must establish a reference age for the population.