



SECTION **II**

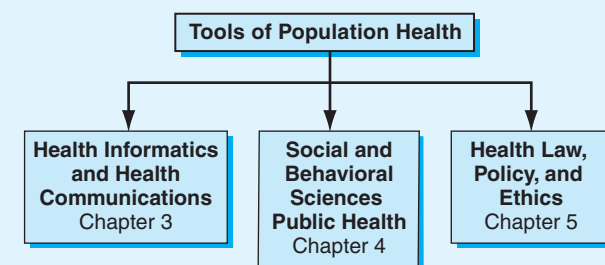
Tools of Population Health

Introduction to Section II

In order to protect and promote health and prevent disease, disability, and death, public health uses an array of tools. In this section, we will examine three of the basic tools of public health: health informatics and health communications; social and behavioral sciences; and health policy, laws, and ethics. Figure 2-A provides a framework for thinking about the tools used in the population health approach and indicates where they are addressed in the book.

In Chapter 3, we will explore how health information is collected, compiled, and presented, as well as how it is perceived, combined, and used to make decisions in the arena of health informatics and health communications. Chapter 4 will examine the contributions of the social and behavioral sciences in helping us to understand the sources of health and disease and strategies available to reduce disease, disability, and death. To do this we will explore how social and economic factors affect health. We will also examine how individual and group behavior can be changed to improve health. Finally, in Chapter 5, we will learn how health policies and laws can be used to improve health, as well as how ethical and philosophical issues limit their use.

FIGURE 2-A Tools of population health framework



CHAPTER 3

Health Informatics and Health Communications

LEARNING OBJECTIVES

By the end of this chapter the student will be able to:

- identify six basic types of public health data.
- explain the meaning, use, and limitations of the infant mortality rate and life expectancy measurements.
- explain the meanings and uses of HALEs and DALYs.
- identify criteria for evaluating the quality of information presented on a Web site.
- explain ways that perceptions affect how people interpret information.
- explain the roles of probabilities, utilities, and the timing of events in combining public health data.
- explain how attitudes, such as risk-taking attitudes, may affect decision making.
- identify three different approaches to clinical decision making and their advantages and disadvantages.

You read that the rate of use of cocaine among teenagers has fallen by 50 percent in the last decade. You wonder where that information might come from?

You hear that life expectancy in the United States is now approximately 80 years. You wonder what that implies about how long you will live and what that means for your grandmother who is 82 and in good health?

You hear on the news the gruesome description of a shark attack on a young boy from another state and decide to keep your son away from the beach. While playing at a friend's house your son nearly drowns after falling into the backyard pool. You ask why so many people think that drowning in a backyard pool is unusual when it is far more common than shark attacks?

Balancing the harms and benefits is essential to making decisions, your clinician says. The treatment you are considering

has an 80 percent chance of working but there is also a 20 percent chance of side effects. What do you need to consider when balancing the harms and the benefits, you ask?

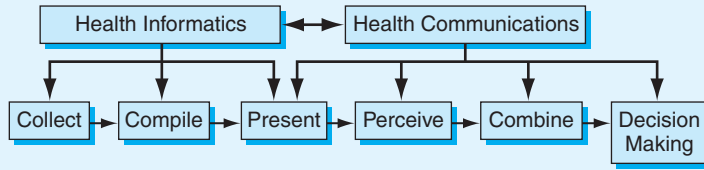
You are faced with a decision to have a medical procedure, One physician tells you there's no other choice and you must undergo the procedure, another tells you about the harms and benefits and advises you to go ahead, and the third lays out the options and tells you it's your decision. Why are there such different approaches to making decisions these days?

These are the types of issues and questions that we will address as we look at health informatics and health communications.

WHAT ARE HEALTH INFORMATICS AND HEALTH COMMUNICATIONS?

The term “**health informatics**” deals with the methods for collecting, compiling, and presenting health information, while the term “**health communications**” deals with how we perceive information, combine information, and use information to make decisions. Thus, together these concepts are about information from its collection to its use. Figure 3-1 displays how these parts of the process fit into a continuous flow of information.

The fields of health informatics and health communications has been growing at the speed of the Internet. These fields have implications for most, if not all, aspects of public health, as well as health care. Therefore, we will focus on key issues in each of the above-mentioned components of this burgeoning field. We will look at the following aspects of health informat-

FIGURE 3-1 Health informatics and health communications and the flow of information

ics and health communications and ask the following questions:

- *Collecting data:* Where does public health data come from?
- *Compiling information:* How is public health information compiled or put together to measure the health of a population?
- *Presenting information:* How can we evaluate the quality of the presentation of public health information?
- *Perceiving information:* What factors affect how we perceive public health information?
- *Combining information:* What types of information need to be combined to make health decisions?
- *Decision making:* How do we utilize information to make health decisions?

We can only highlight key issues in this complex field of health informatics and health communications. To do this, we will use the above questions and provide frameworks and approaches to explore possible answers.

WHERE DOES PUBLIC HEALTH DATA COME FROM?

Public health **data** is collected in a wide variety of ways.^a

These methods are often referred to as **public health surveillance**. Data of this type comes from a growing variety of sources. It is helpful, however, to classify these sources according to the way they are collected. Table 3-1 outlines the most common types of public health data, provides examples of each type, and indicates important uses, as well as the advantages and disadvantages of each type of data.

Data from different sources are increasingly being combined to create integrated health data systems or **databases**

^a Data is usually defined as facts or representation of facts while **information** implies that the data is compiled and/or presented in a way designed for a range of uses. Thus the term data is used here only in the context of collection.

that can be rapidly and flexibly accessed by computers to address a wide range of questions. These systems have great potential to provide useful information to contribute to evidence-based public health. This information can help describe problems, examine etiology, assist with evidence-based recommendations, and examine the options for implementation, as well as help evaluate the outcomes. Despite their great potential, inte-

grated databases also create the potential for abuse of the most intimate health information. Thus, protecting the privacy of data is now of great concern as part of the development of integrated databases.

Data can be used for a wide range of purposes in public health and health care. One particularly important use is the compilation of data to generate summary measurements of the health of a group or population. Let us take a look at how we compile this data.

HOW IS PUBLIC HEALTH INFORMATION COMPILED TO MEASURE THE HEALTH OF A POPULATION?

Measurements that summarize the health of populations are called **population health status measures**. For over a century, public health professionals have focused on how to summarize the health status of large populations, such as countries and large groups within countries—for example, males and females or large racial groups of a particular nation. In the 20th century, two measurements became standard for summarizing the health status of populations—the **infant mortality rate** and **life expectancy**. These measurements rely on death and birth certificate data, as well as census data. Toward the latter part of the 20th century, these sources of data became widely available and quite accurate in most parts of the world.

The infant mortality rate estimates the rate of death in the first year of life. For many years, it has been used as the primary measurement of child health. Life expectancy has been used to measure the overall health of the population using the probability of dying at each year of life.^{1,2} These measures were the mainstay of 20th century population health measurements. Let us look at each of these measures and see why additional health status measurements are needed for the 21st century.

At the turn of the 20th century, infant mortality rates were high even in today's developed countries. It was not usual for

TABLE 3-1 The 6 Ss of Sources of Public Health Data

Type	Examples	Uses	Advantages/Disadvantages
Single case or small series	Case reports of one or a small number of cases, such as SARS, anthrax, mad cow disease and new diseases (e.g., first report of AIDS)	Alert to new disease or resistant disease; alert to potential spread beyond initial area	Useful for dramatic, unusual, and new conditions; requires alert clinicians and rapid ability to disseminate information
Statistics (“Vital Statistics”) and reportable diseases	Vital statistics: birth, death, marriage, divorce; reporting of key communicable and specially-selected noncommunicable diseases (e.g., elevated lead levels, child and spouse abuse, etc.)	Required by law—sometimes penalties imposed for noncompliance; births and deaths key to defining leading causes of disease; reportable disease may be helpful in identifying changes over time	Vital statistics very complete because of social and financial consequences; reportable disease often relies on institutional reporting rather than individual clinicians; frequent delays in reporting data
Surveys—sampling	National Health and Nutrition Examination Survey (NHANES); Behavioral Risk Factor Surveillance System (BRFSS)	Drawing conclusions about overall population and subgroups from representative samples	Well conducted surveys allow inference to be drawn about larger populations; frequent delays in reporting data
Self-reporting	Adverse effect monitoring of drugs and vaccines as reported by those affected	May help identify unrecognized or unusual events	Useful when unusual events closely follow initial use of drug or vaccine; tends to be incomplete; difficult to evaluate meaning because of selective process of reporting
Sentinel monitoring	Influenza monitoring to identify start of outbreak and changes in virus type	Early warnings or warning of previously unrecognized events	Can be used for “real-time” monitoring; requires considerable knowledge of patterns of disease and use of services to develop
Syndromic surveillance	Use of symptom patterns (e.g., headaches, cough/fever or gastrointestinal symptoms, plus increased sales of over-the-counter drugs) to raise alert of possible new or increased disease	May be able to detect unexpected and subtle changes, such as bioterrorism or new epidemic producing commonly occurring symptoms	May be used for early warning even when no disease is diagnosed; does not provide a diagnosis and may have false positives

over 100 of every 1000 newborns to die in the first year of life. In many parts of the world during this time, infant mortality far exceeded the death rate in any later years of childhood. For this reason, the infant mortality rate was often used as a surrogate or substitute measure for overall rates of childhood death. In the first half of the 20th century, however, great improvements in infant mortality occurred in what are today’s developed countries. During the second half of the century, many developing countries also saw greatly reduced infant mortal-

ity rates. Today, many countries have achieved infant mortality rates below 10 per 1000 and a growing number of nations have achieved rates below 5 per 1000.^b

^b The infant mortality rate is measured using the number of deaths among those ages 0–1 in a particular year divided by the total number of live births in the same year. If the number of live births is stable from year to year, then the infant mortality rate is a measure of the rate of deaths. Health status measurements of child health have not sought to incorporate disability on the less-than-completely-accurate assumption that disability is not a major factor among children.

The degree of success in reducing mortality among children aged two to five has not been as great.³ Malnutrition and old and new infectious diseases continue to kill young children. In addition, improvements in the care of severely ill newborns have extended the lives of many children—only to have them die after the first year of life. Children with HIV/AIDS often die not in the first year of life, but in the second, third or fourth year. Once a child survives to age five, they have a very high probability of surviving into adulthood in most countries. Thus, a new measurement known as **under-5 mortality** has now become the standard health status measure used by the World Health Organization (WHO) to summarize the health of children.

Let us take a look at the second traditional measure of population health status—life expectancy. Life expectancy is a snapshot of a population incorporating the probability of dying at each age of life in a particular year. Life expectancy tells us how well a country is doing in terms of deaths in a particular year. As an example, life expectancy at birth in a developed country might be 80 years. Perhaps in 1900, life expectancy at birth in that same country was only 50 years. In 2020, life expectancy might be 85 years. Thus, this metric allows us to make comparisons between countries and within a single country over time.

Despite its name, life expectancy cannot be used to accurately predict the future—that would require assuming that nothing will change. That is, it assumes that the death rates at all ages will remain the same in future years. We have seen increases in life expectancy in most countries over the last century, but declines occurred in Sub-Saharan Africa and countries of the former Soviet Union in the late 20th century.^c

Life expectancy tells us only part of what we want to know. It reflects the impact of dying, but not the impact of disabilities. When considering the health status of a population in the 21st century, we need to consider disability, as well as death.

Today the World Health Organization (WHO) uses a measurement known as the **health-adjusted life expectancy (HALE)** to summarize the health of populations.⁴ The HALE measurement starts with life expectancy and then incorporates measurements of the quality of health. The WHO utilizes survey data to obtain a country's overall measurement of

quality of health. This measurement incorporates key components including:^d

- Mobility—the ability to walk without assistance
- Cognition—mental function including memory
- Self-care—activities of daily living including dressing, eating, bathing, and use of the toilet
- Pain—regular pain that limits function
- Mood—alteration in mood that limits function
- Sensory organ function—impairment in vision or hearing that impairs function

From these measurements, an overall quality of health score is obtained. In most countries, these range from 85 to 90 percent. We might consider a score of less than 85 percent as poor and greater than 90 percent as very good. A quality of health measurement of 90 percent indicates that the average person in the country loses 10 percent of their full health over their lifetime to one or more disabilities.

The quality of health measurement is multiplied by the life expectancy to obtain the HALE. Thus, a country which has achieved a life expectancy of 80 years and an overall quality of health score of 90 percent can claim a HALE of $80.00 \times 0.90 = 72.00$. Table 3-2 displays WHO data on life expectancy and HALEs at birth for a variety of large countries.^e

Thus, today the under-5 mortality and HALEs are used by the WHO as the standard measures reflecting child health and the overall health of a population. An additional measure, known as the **disability-adjusted life year (DALY)**, has been developed and used by the WHO to allow for comparisons and changes based on categories of diseases and conditions.⁵ Box 3-1 describes DALYs and some of the data and conclusions that have come from using this measurement.

Table 3-3 displays DALYs according to these categories of diseases and conditions for the same large countries for which HALEs are displayed in Table 3-2.

^d It can be argued that use of these measurements associate disability primarily with the elderly. Note that these qualities of health do not specifically include measures of the ability to work, engage in social interactions, or have satisfying sexual relationships, all of which may be especially important to younger populations.

^e Not all countries accept the HALE as the method for expressing disabilities. A measurement known as the **health-related quality of life (HRQOL)** has been developed and used in the United States. The HRQOL incorporates a measure of unhealthy days. Unhealthy days are measured by asking a representative sample of individuals the number of days in the last 30 during which the status of either their mental or physical health kept them from their usual activities. It then calculates a measure of the quality of health by adding together the number of unhealthy days due to mental plus physical health. The quality of health is then obtained by dividing the number of healthy days by 30. This measurement is relatively easy to collect and calculate, but unlike the HALE, it does not reflect objective measures of disability and cannot be directly combined with life expectancy to produce an overall measure of health. That is, it does not include the impact of mortality.

^c Life expectancy is greater than you might expect at older ages. For instance, in a country with a life expectancy of 80 years, a 60-year-old may still have a life expectancy of 25 years, not 20 years, because they escaped the risks of death during the early years of life. At age 80, the chances of death are very dependent on an individual's state of health because life expectancy combines the probability of death of those in good health and those in poor health. Healthy 80-year-olds have a very high probability of living to 90 and beyond.

TABLE 3-2 Life Expectancy and Health Adjusted Life Expectancy for a Range of Large Countries

Country	Life expectancy	Health-adjusted life expectancy (HALE)
Nigeria	48.8	41.5
India	62.8	53.5
Russian Federation	66.4	58.4
Brazil	71.7	59.8
China	73.4	64.1
United States	78.0	69.3
United Kingdom	79.2	70.6
Canada	80.6	72.0
Japan	82.6	75.0

Source: Data from World Health Organization. World Health Report 2004 Statistical Appendix 4; Geneva: World Health Organization; 2004.

The Global Burden of Disease (GBD) project has produced a number of important conclusions using DALYs including:

- Depression is a major contributor to most nation's DALY and may become the number one contributor in the next few decades in developing, as well as developed countries.
- Chronic disabling diseases, including hookworm, malaria, and HIV, affect the young and working-age population and are the greatest contributors to the burden of disease in many developing countries.
- Cancers—such as breast cancer, hepatomas (primary liver cancer), and colon cancer—which affect the working-age population and are common in many developing countries—have an important impact on the burden of disease as expressed in DALYs.
- Motor vehicle, occupational, and other forms of unintentional injuries have a disproportionate impact on the burden of disease compared to merely measuring deaths

BOX 3-1 DALYs.

Disability-adjusted life years (DALYs) are designed to examine the impacts that specific diseases and risk factors have on populations, as well as provide an overall measure of population health status. They allow comparisons between countries or within countries over time, based not only on overall summary numbers, such as life expectancy and HALEs, but based on specific diseases and risk factors. The DALY compares a country's performance to the country with the longest life expectancy, which is currently Japan. Japan has a life expectancy that is approximately 83 years. In a country with zero DALYs, the average person would live approximately 83 years without any disability and would then die suddenly. Of course, this does not occur even in Japan, so all countries have DALYs of greater than zero. The measurement is usually presented as DALYs per 1000 population in a particular country.^f

Calculations of DALYs require much more data on specific diseases and disability than other measurements, such as life expectancy or HALEs. However, the WHO's Global Burden of Disease (GBD) project has made considerable progress in obtaining worldwide data collected using a consistent approach.⁵ Data is often not available on the disability produced by a disease. The WHO then uses expert opinion to estimate the impact.

The GBD project presents data on DALYs divided into the following categories. Data is also available on specific diseases and risk factors.

- Communicable disease, maternal, neonatal and nutritional conditions
- Noncommunicable diseases
- Injuries

^fThe DALY is a complex and technical measurement. If, in a country with zero DALYs, 1000 newborns suddenly died, there would be a loss of as much as 83,000 DALYs from the death of these 1000 newborns. Thus, the total DALYs a country can lose in a particular year can range from zero to approximately 83,000 per 1000 persons. This somewhat overstates the possible loss due to the discounting and weighing that occurs in the calculation of DALYs. Nonetheless when interpreting a country's total DALYs, it may be useful to compare the number of DALYs to this maximum possible loss. It is also important to recognize that DALYs require a number of policy decisions that are hidden in the numbers. For instance, it was decided to emphasize the importance of death and disability among those of working age by giving them greater weight or importance in the calculation of this measurement. Working age was defined as age 16–60, which reflects a concept of working age more often used in developing countries. Death and disability at ages greater than the approximately 83 years of life expectancies of Japan do not add to the DALYs. In calculating DALYs, separate maximum life expectancies are used for males (~80 years) and females (>85 years), implying that loss of life among females is given slightly greater importance. These issues illustrate that in order to understand quantitative measures such as DALYs, you need to recognize that policy decisions are often subtly integrated into quantitative measurements. We need to appreciate the policy and sometimes the ethical decisions that are part of what appears to be objective measurements.

Source: Author created.

TABLE 3-3 DALYs Lost by Disease Categories and Total of All Categories Per 1,000 Population

Country	DALYs lost due to communicable diseases; maternal, neonatal, and nutritional conditions	DALYs lost due to noncommunicable diseases	DALYs lost due to injuries (unintentional + intentional)	Total DALYs lost
Nigeria	41,251	10,279	4,815	56,345
India	12,958	11,824	3,793	28,575
Russian Federation	2,189	18,752	6,411	27,352
Brazil	4,361	13,113	3,247	20,721
China	2,847	10,217	2,314	15,378
United States	941	11,939	1,387	14,267
United Kingdom	855	11,192	744	12,791
Canada	585	10,256	967	11,808
Japan	588	8,791	1,051	10,430

Source: Reprinted from World Health Organization. Global Burden of Disease Project 2004. Geneva: World Health Organization; 2004.

because these injuries produce long-term disabilities, as well as death at young ages.

- Obesity is rapidly overtaking malnutrition as a burden of disease in developing countries as early onset diabetes, heart disease, and strokes become major causes of death and disabilities among younger populations.

We have now looked at important sources of public health data and examined one key way that data is compiled to generate population health status measurements. Now, let us look at a third issue—the presentation of public health information.

HOW CAN WE EVALUATE THE QUALITY OF THE PRESENTATION OF HEALTH INFORMATION?

Having information is not enough. A key role and essential tool of public health is to effectively present the information in ways that serve as a basis for understanding and decision making. Issues of information presentation are increasingly important and increasingly complex. They require the study of a range of disciplines from mass media, to computer graphics, to statistics.⁸ Public health information is often presented as graphics. Graphics create a picture in our mind of what is going on and a picture is truly worth a thousand words. Graphical presentations can accurately inform, but they can also mislead us in a

wide variety of ways. The accurate presentation of visual information has become an art, as well as a science that deserves attention from all those who use information.⁶

Issues of quality are key to the presentation of information. The Internet is increasingly the primary source of public health information for the user. Thus, when we address issues of quality, we need to have a set of criteria for judging the quality of information presented on the Internet. Before relying on a Web site for health information, you should ask yourself key questions.⁷ These questions are summarized in Table 3-4. Try these out the next time that you view a health information Web site.

The presentation of data may be viewed as the end of health informatics, but also the beginning of health communications. Even the most accurate data presentation does not tell us how the data will be perceived by the user. Let us take a look at the rapidly-growing component of health communications that deals with how we perceive information.

WHAT FACTORS AFFECT HOW WE PERCEIVE PUBLIC HEALTH INFORMATION?

Regardless of how accurately information is presented, communication also needs to consider how the information is perceived by the recipient. Therefore, we also need to look at factors known to affect the perception of information or the subjective interpretation of what the information means for an individual.

At least three types of effects can greatly influence our perceptions of potential harms and benefits.⁸ We will call them

⁸ The use of statistics is one approach to data presentation. It asks questions, such as: what are the strengths of the relationships between risk factors and diseases? This is known as **estimation**. Statistical analysis also draws conclusions from data on small groups (**samples**) about larger groups or populations—this is called **inference** or **statistical significance testing**.

TABLE 3-4 Quality Standards for Health Information on the Internet

Criteria	Questions to Ask
Overall site quality	<ul style="list-style-type: none"> • Is the purpose of the site clear? • Is the site easy to navigate? • Are the site's sponsors clearly identified? • Are advertising and sales separated from health information?
Authors	<ul style="list-style-type: none"> • Are the authors of the information clearly identified? • Do the authors have health credentials? • Is contact information provided?
Information	<ul style="list-style-type: none"> • Does the site get its information from reliable sources? • Is the information useful and easy to understand? • Is it easy to tell the difference between fact and opinion?
Relevance	<ul style="list-style-type: none"> • Are there answers to your specific questions?
Timeliness	<ul style="list-style-type: none"> • Can you tell when the information was written? • Is it current?
Links	<ul style="list-style-type: none"> • Do the internal links work? • Are there links to related sites for more information?
Privacy	<ul style="list-style-type: none"> • Is your privacy protected? • Can you search for information without providing information about yourself?

Source: Data from American Public Health Association. Criteria for Assessing the Quality of Health Information on the Internet. Available at: <http://www.apha.org/NR/rdonlyres/36630D3D-D50E-4215-8835-4B80298B0685/0/November152000.pdf>. Accessed November 13, 2008.

the **dread effect**, the **unfamiliarity effect**, and the **uncontrollability effect**. The dread effect is present with hazards that easily produce very visualizable and feared consequences. It explains why we often fear shark attacks more than drowning in a swimming pool. The dread effect may also be elicited by the potential for catastrophic events, ranging from nuclear meltdowns to a poisoning of the water supply. Our degree of familiarity with a potential harm or a potential benefit can greatly influence how we perceive data and translate it for our own situation. Knowing a friend or relative who died of lung cancer may influence how we perceive the information on the hazards of smoking or the presence of radon. It also may explain why we often see the danger of sun exposure as low and food irradiation as high, despite the fact that the data indicates that the degree of harm is the other way around.

Finally, the uncontrollability effect may have a major impact on our perceptions and actions. We often consider hazards that we perceive as in our control as less threatening than ones that we perceive as out of our control. Automobile collisions, for instance, are often seen as less hazardous than airplane crashes, despite the fact that statistics show that commercial air travel is far safer than travel by automobile.

Perception of bad outcomes (or harms) and good outcomes (or benefits) needs to be considered along with the numbers if

we are going to understand the ways information is used to make decisions. Not everyone perceives harms and benefits the same way. The selection of accurate and effective methods for conveying data is key to health communications.^h

One approach to addressing differing perceptions of information is the use of a method known as **decision analysis**. Decision analysis relies on the vast information-processing ability of computers to formally combine information on benefits and harms to reach quantitative decisions. It provides us with insight into the types of information that need to be combined. Let us look at how we combine information—the next question in our flow of health information.

WHAT TYPE OF INFORMATION NEEDS TO BE COMBINED TO MAKE HEALTH DECISIONS?

Decision analysis focuses on three key types of information that need to be combined as the basis for making decisions. We can better understand these types of information by asking the following questions:

- *How likely?*—what is the probability or chance that the particular outcome will occur?
- *How important?*—what is the value or importance we place on a good or a bad outcome?
- *How soon?*—when, on average, will the particular outcome happen if it is going to happen?

When expressing the chances that an outcome will occur, we often express the results as a percentage from 0 to 100.

^h For instance, we generally have difficulty distinguishing between small and very small numbers. The difference between 1 in 10,000 and 1 in 100,000 is difficult for most of us to grasp and incorporate into our decisions. When comparing these types of probabilities it is tempting to compare the outcomes to ones that are better known, such as those with similar emotional impacts. We might compare the chances of dying from a motorcycle accident with that of a truck or automobile accident. Comparison of different types of outcomes, such as between being struck by lightning compared to dying from a chronic exposure to chemicals or radiation, is far less informative.

Probabilities, on the other hand, range from 0 to 1. Percentages and probabilities are often used interchangeably—the probability of 0.10 can be converted to 10 percent and vice versa. When faced with a percentage or probability we need to ask: what period of time is being considered? For instance, if you hear that the chances of developing a blood clot while taking high-dose estrogen birth control pills is 5 percent, what does that mean? Does it mean 5 percent per cycle, 5 percent per year, or 5 percent over the time period that the average user is on the pill?

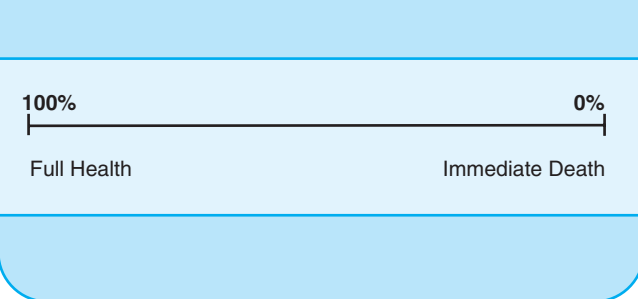
Outcomes vary from death to disabilities. Some outcomes greatly affect our function and limit our future, while we can learn to live with some outcomes despite the limitations they impose. When dealing with a quantitative approach, we are forced to place numbers on the value or importance of specific outcomes. A scale known as a **utility scale** is one method to measure and compare the value or importance that different people place on different outcomes.⁹ This scale is intended to parallel the scale of probabilities, that is, it extends from 0 to 1 or from 0 to 100 percent. It defines 1 or 100 percent as the state of health in which there are no health-related limitations. Zero is defined as immediate death. On the utility scale there is nothing worse than immediate death. Figure 3-2 displays the utility scale.¹ Box 3-2 illustrates how we can use the utility scale to assign numbers to specific outcomes.

Utilities are important especially when we need to combine potential harms with potential benefits. Probabilities alone often do not give us the answers we need when addressing issues of hazards ranging from environmental toxins to unhealthy behaviors. Utilities are also critical when looking at particular interventions, such as prevention or treatment options that include positive benefits, but also involve side effects or harms. Thus, whenever we need to combine or balance benefits and harms, we need to consider the utility of the outcomes along with the chances or probabilities of the outcomes.

The expected timing of the occurrence of good and bad outcomes can also affect how we view the outcome. Most people view the occurrence of a bad outcome as worse if it occurs in the immediate future compared to its occurrence years from now. Conversely, we usually view a good outcome as more valuable if it occurs in the immediate future. Thus, whenever we consider harms and benefits and try to combine them, we need to ask: when are the outcomes expected to occur?⁹ When both the good and the bad outcomes occur in the immediate future, the timing is not an issue. In public health and medi-

¹ Many people consider prolonged incapacity or vegetative states as worse than death. The utility scale does not generally take this into account. This is a specific example of the more general limitation of quantitative decision making—that it focuses on the outcome and not on the process of getting there.

FIGURE 3-2 Scale used to measure utilities



cine, however, this is rarely the case. When dealing with many treatments the benefits come first while the harms may occur at a later time. When dealing with vaccines and surgery, the pain and side effects often precedes the potential gain. The timing of the benefits is rarely the same as the timing of the harms. Thus, we need to take this into account. This process is known as **discounting**. Discounting is a quantitative process in which we give greater emphasis or weight to events which are expected to occur in the immediate future compared to events which are expected to occur in the distant future.^k

We have seen that probabilities, utilities, and timing are key components of health communications that need to be combined when making public health and healthcare decisions.¹ However, there are other factors that are characteristic not of the data itself, but of the **decision maker**. A decision maker may be an individual, a health professional, or it may be an organization like a nonprofit, a corporation, or a government agency. Let

^k The exact amount of discounting that should occur is controversial, but there is agreement that we should place less importance on outcomes that occur in the distant future than those which occur in the immediate future. There is also agreement that the rate of discounting for harms and for benefits should be the same. The concept of discounting comes from economics and can be most easily understood with a financial example. Let us imagine that we want to discount at 5 percent per year. A discount rate of 5 percent implies that I am willing to give you \$95 today if you are willing to give me \$100 one year from now.⁹ Discounting is above and beyond inflation, so the actual return might be \$100 plus the rate of inflation. Note that economists try to set the rate based on the average real return on money invested over a large number of years. In the past, this has been about 3 percent in most developed countries. When making decisions on a subjective basis, we often discount the future at a much higher rate. This is especially true of those who are very sick and are often focused heavily on the immediate future.

¹ Decision analysis is not the usual method used to combine information. Because the task of combining information is so complex and the ability of our minds to handle large quantities of information is so limited, we often use rules of thumb known as **heuristics**.⁸ Heuristics allow us to make decisions more rapidly and often with less information. For instance, we often prefer to structure decisions to allow only one of two choices, rather than choosing from a large number of options presented to us at the same time. Thus, we often narrow the field of candidates in primary elections to allow side-by-side comparisons in the general elections. The one-on-one comparisons allow manipulation of the results by getting rid of candidates in the primaries who might have fared better in the general election.

BOX 3-2 Obtaining a Utility Score.

Let us see how we can use the utility scale to put numbers on a specific outcome—complete and permanent blindness. Using the scale in Figure 3–2, place a number on the importance or value that you give to complete and permanent blindness.

In large groups of individuals, the average utility placed on blindness is quite predictable—about 50 percent. However, the range of values among a group is generally quite wide ranging from 20 to 80 percent and sometimes even wider. Predicting an individual's utility is quite difficult since gender, socioeconomic group, and other predictors have little impact.^j

Individuals who place a high utility on complete and permanent blindness usually indicate that they can learn to live with blindness and it will not greatly affect their enjoyment of life. Those who place a low utility on blindness generally say just the opposite. Thus, we need to understand that a utility of 50 percent is an average including some with a much higher and some with a much lower utility. Therefore the best way to know the value or utility that an individual places on a particular outcome such as blindness is to ask them.

^j There are at least two predictors that are of some value. Those who have experienced an outcome usually find that they can adapt to it to a certain extent and usually rate its utility as somewhat higher than those who have not experienced the outcome. Second, age does have an impact on the scoring of utility. Younger people generally rate the utility of an outcome as somewhat worse or lower than older people, perhaps due to the longer-term impact the disability has on their future options. The average utility placed on blindness by college students, for instance, is often closer to 40 percent. Neither of these impacts is large on average, nor can they be used to successfully predict the utility of any one individual.

us turn our attention to decision makers and ask about how we can go about making decisions. To do this we need to address issues beyond probability, utility, and timing.

HOW DO WE UTILIZE INFORMATION TO MAKE HEALTH DECISIONS?

There are two key questions that we can ask to gain an understanding of how we use information to make health decisions:

- How do our risk-taking attitudes affect the way we make decisions?
- How do we incorporate information into our decisions?

There are a large number of attitudes that can affect the way we make decisions. One of the most important is known as our **risk-taking attitudes**.^m

Let us examine what we mean by this term and see what type of risk-taking attitude you use in making decisions. Attitudes toward risk greatly influence the choices that we all make in the prevention and treatment of disease.⁹ Box 3-3 illustrates how you can understand your own attitudes toward risk taking by making some choices. We will assume that you understand what we mean by utilities and that you have thought through what a wide range of utilities means to you personally.

^m In addition to a risk-taking attitude, there are other attitudes that affect our decision making. For instance, decision making may depend on whether we regard an error of omission as equal to an error of commission. Decision analysis and most ethicists regard them as equal, but many people see errors of omission as more acceptable than errors of commission. That is, most people consider a bad outcome resulting from inaction as more tolerable than a bad outcome resulting from their own actions.

Understanding attitudes toward risk is important for analyzing how individuals make decisions about their own lives. It is also key when trying to understand how group decisions are made that require society to balance harms and benefits. Perhaps the most common health decisions that you will make are the decisions related to your health care and that of your family. Therefore, let us complete our examination of health communications by looking at three different approaches that can be used to make clinical healthcare decisions.

There are three basic approaches to clinical decision making. We will call these approaches **inform of decision**, **informed consent**, and **shared decision making**. Preferences for these types of approaches have changed over time, yet all three are currently part of clinical practice.

The inform of decision approach implies that the clinician has all the essential information and can make decisions that are in the patient's best interest. The role of the clinician is then merely to inform the patient of what needs to be done, to prescribe the treatment, or write the orders. At one point in time, this type of decision-making approach was standard for practicing clinicians. In the not-too-distant past, clinicians rarely told patients that they had cancer—justifying their silence by arguments that the knowledge might make the patient depressed, which could interfere with their response to the disease and to the treatment. The decision to have many tests and receive a range of medications is still often done using the inform of decision approach.

A second type of decision-making approach is called informed consent. It rests on the principle that ultimately patients need to give their permission or consent before major

BOX 3-3 Risk-Taking Attitudes.

Review the following situations and write down your decisions.

Situation A

Imagine that you have coronary artery disease and have a reduced quality of life with a utility of 0.80 compared to your previous state of full health with a utility of 1.00. You are offered the pair of options below. You can select only one option. Which of the following two options do you prefer?

OPTION #1: A treatment with the following possible outcomes:

50% chance of raising the quality of your health (your utility) from 0.80 to 1.00

50% chance of reducing the quality of your health (your utility) from 0.80 to 0.60

OPTION #2: Refuse the above treatment and accept a quality of your health (your utility) of 0.80

Situation B

Imagine that you have coronary artery disease and have a reduced quality of life that has a utility of 0.20 compared to your previous state of full health that had a utility of 1.00. You are offered the pair of options below. You can select only one option. Which of the following two options do you prefer?

OPTION #1: A treatment with the following possible outcomes:

10% chance of raising the quality of your health (your utility) from 0.20 to 1.00

90% chance of reducing the quality of your health (your utility) from 0.20 to 0.11

OPTION #2: Refuse the above treatment and accept a quality of your health (your utility) of 0.20

What was your answer in Situation A? Situation B? To understand the meaning of your answers you need to appreciate that in terms of the probabilities and utilities presented in each situation, these options are a “toss-up.” That is, taking into account the probabilities and the utilities, there is no difference between these options.⁸

Thus, the information does not determine your choice; it must be your attitude toward taking chances, which is your attitude toward risk taking.

Did you choose Option #2 in Situation A and Option #1 in Situation B? Most, but not all, people make these choices. In Situation A, we begin with a utility of 0.80. For many people, this is a tolerable situation and they do not want to take any chances of being reduced to a lower, perhaps intolerable utility. Thus, they want to guarantee a tolerable level of health. We can call this the certainty effect. In Situation B, we begin with a utility of 0.20. For many people, this is an intolerable situation. Thus people are usually willing to take their chances of getting even worse in the hopes of a major improvement in their health. When the quality of life is bad enough, most, if not all, people are willing to take their chances or “go for it.” This risk-taking behavior can be called the long-shot effect. Thus, risk-taking and risk-avoiding choices are both common, defensible, and reasonably predictable. Most of us are risk takers when conditions are intolerable and risk avoiders when conditions are tolerable.

A few people will choose Option #1 in both Situation A and B. These individuals are willing to take their chances in a range of situations in order to improve their outcome. We call them risk takers. Are you one of them? The only way to know is to ask yourself. Similarly, a few people will choose Option #2 in both situations. These individuals seek to avoid taking chances in a range of situations in order to preserve their current state of health. We call them risk avoiders. Are you one of them? Only you can answer that question.⁹

⁸ Notice that the outcomes occur in the immediate future so there is no issue of timing or need to discount the benefits or the harms.

⁹ There is a fourth option, which is to choose Option #2 in Situation A and Option #1 in Situation B. The small number of individuals who make this choice usually have a very different perception of what utilities mean to them. For instance, they might perceive little difference between a 0.80 and a 0.20 utility.

interventions, such as surgery, radiation, or chemotherapy, can be undertaken. Informed consent may be written, spoken, or implied. Clinically, informed consent implies that individuals have the right to know what will be done, why it will be done, and what the known benefits and harms are. Patients have the

right to ask questions, including inquiring about the availability of other options. Informed consent does not mean that all possible options are presented to the patient, but it does imply that a clinician has made a recommendation for a specific intervention.

The third type of decision-making is called shared decision making. In this approach, the clinician's job is to provide information to the patient with which he or she can make a decision. This might include directly giving information to the patient, providing consultations, or referring patients to sources of information often on the Internet. Shared decision making places a far greater burden on the patient to seek out, understand, and use information. Using this approach, clinicians are not required to provide recommendations on specific interventions, though patients are free to ask for a clinician's opinion.

All three types of decision-making approaches are currently in use today. Table 3-5 outlines the process and roles

implied by each of these approaches, as well as some of the potential advantages and disadvantages of each approach.

Health informatics and health communications are key tools for population health. We have taken a look at important issues related to each of them. We have asked questions about how public health data and information is collected, compiled, presented, perceived, combined, and used in decision making. Data and information are key public health tools for guiding our decision making. We will find ourselves coming back again and again to these principles as we study the population health approach. Now, let us turn our attention to Chapter 4, which discusses a second key tool—utilization of the social and behavioral sciences.

TABLE 3-5 Types of Individual Decision Making

Type of decision making	Process/Roles	Advantages	Disadvantages
Inform of decision	<p>Clinician has all the essential information to make a decision that is in the patient's best interest</p> <p>Clinician aims to convey their decision as a clear and unambiguous action or order</p> <p>Patients accept the clinician's recommendation without necessarily understanding or agreeing with the underlying reasoning</p>	<p>May be efficient and effective when patients seek clear direction provided by an authoritative and trusted source</p> <p>Patient may favor if they do not seek out or feel they cannot handle independent decision-making responsibilities</p>	<p>Patient may not gain information and understanding of the nature of the problem or the nature of the treatment</p> <p>Patient may not be prepared to participate in the implementation of the decision</p> <p>Patient may not accept responsibility for the outcome of the treatment</p>
Informed consent	<p>Clinician has the responsibility to convey a recommendation to the patient</p> <p>Harms and benefits of treatment are weighed by the clinician in making a recommendation</p> <p>Clinician has a responsibility to provide information on the aim of the recommendation, the potential benefits, the known harms, and the process that will occur. The patient has the right to ask additional questions about the treatment and the availability of other alternatives</p>	<p>Patient gains information and understanding of the nature of the problem or the nature of the treatment</p> <p>Patient may be prepared to participate in the implementation of the decision</p> <p>Patient may accept responsibility for the outcome of the treatment</p>	<p>Time consuming compared to informing of the decision</p> <p>May require elaborate paperwork to implement formal informed consent process</p> <p>May increase emphasis on legal documents and malpractice law</p>
Shared decision making	<p>Clinicians serve as a source of information for patients including providing it directly or identifying means of obtaining information</p>	<p>May increase the control of the patients over their own lives</p> <p>May increase the types of information considered in decision making</p>	<p>May be time consuming for patients and clinicians</p> <p>May increase the costs of health care</p>

continues

TABLE 3-5 Types of Individual Decision Making (continued)

Type of decision making	Process/Roles	Advantages	Disadvantages
	<p>Patients can expect to be informed of the existence of a range of accepted options and be assisted in their efforts to obtain information</p> <p>Patients may seek information on experimental or alternative approaches and can discuss the advantages and disadvantages of these approaches with a clinician</p> <p>Considerations besides benefits and harms are part of the decision-making process, including such considerations as cost, risk-taking attitudes, and the distress/discomforts associated with the treatment</p> <p>Patients are often directly involved in the implementation of care</p>	<p>May reduce the adversarial nature of the relationship between clinicians and patients</p> <p>May improve the outcome of care by increasing the patient's understanding and commitment to the chosen course of care</p>	<p>May increase the stress/anxiety for patients</p> <p>May shift the responsibility for bad outcomes from the clinician to the patient, i.e., takes the clinician off the hook/clinician does not need to do the hard work of thinking through the decision and making a recommendation</p>

Key Words

- Health informatics
- Health communications
- Data
- Public health surveillance
- Databases
- Population health status measures
- Infant mortality rate
- Life expectancy
- Under-5 mortality
- Health-adjusted life expectancy (HALE)
- Disability-adjusted live year (DALY)
- Decision analysis
- Utility scale
- Discounting
- Decision maker
- Risk-taking attitude
- Dread effect
- Unfamiliarity effect
- Uncontrollability effect
- Inform of decision
- Informed consent
- Shared decision making
- Certainty effect
- Long-shot effect
- Risk takers
- Risk avoiders



Discussion Questions

Take a look at the questions posed in the following scenarios which were presented at the beginning of this chapter. See whether you can now answer these questions.

1. You read that the rate of use of cocaine among teenagers has fallen by 50 percent in the last decade. You wonder where that information might come from?
2. You hear that life expectancy in the United States is now approximately 80 years. You wonder what that implies about how long you will live and what that means for your grandmother who is 82 and in good health?
3. You hear on the news the gruesome description of a shark attack on a young boy from another state and decide to keep your son away from the beach. While playing at a friend's house your son nearly drowns after falling into the backyard pool. You ask why so many people think that drowning in a backyard pool is unusual when it is far more common than shark attacks?
4. Balancing the harms and benefits is essential to making decisions, your clinician says. The treatment you are considering has an 80 percent chance of working but there is also a 20 percent chance of side effects. What do you need to consider when balancing the harms and the benefits, you ask?
5. You are faced with a decision to have a medical procedure. One physician tells you there's no other choice and you must undergo the procedure, another tells you about the harms and benefits and advises you to go ahead, and the third lays out the options and tells you it's your decision. Why are there such different approaches to making decisions these days?

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