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# Assessment and Comparison of Behavior Risk Factor Surveillance Systems for the U.S., Canada, and Italy.

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**CAROLINA ARANA**

Assessment and comparison of Behavior Risk Factor Surveillance Systems for the U.S., Canada, and Italy  
(Under the direction of RUSS TOAL FACULTY MEMBER)

This document describes a comparison and assessment of Behavior Risk Factor Surveillance Systems for the U.S., Canada, and Italy. The aim of this project is to assess and analyze the behavior surveillance systems of U.S., Canada and Italy, compare their strengths and weaknesses and provide recommendations that can be used as a guide for the design of new BRFs systems or the assessment of existing systems.

The key objectives of this study include 1) describe the BRFs systems of three different countries: U.S., Canada, and Italy, 2) assess system attributes and activities of each of the BRFs systems, 3) describe how to enhance capacity to use data to guide disease control and prevention programs, 4) illustrate how to improve implementation and use of the Behavior Risk Factors surveillance systems, and 5) communicate how to improve the Public Health programs that government officials, practitioners, and public health professionals oversee.

Behavior risk factors include health risk factors that increase a person's chances of developing a disease, such as having a high blood pressure, high blood cholesterol, tobacco smoke, physical inactivity, obesity or overweight, diabetes, poor nutrition, lack of sex education and car safety. They can be classified as: Background risk factors, such as age, sex, level of education and genetic compositions; Behavioral risk factors, such as smoking, unhealthy diet and physical inactivity; and Intermediate risk factors, such as serum cholesterol levels, diabetes, hypertension and obesity/overweight.

The purpose of the assessment is to identify ways of improving the respective systems, and also to compare public health BRFSS systems in three different countries: U.S., Canada, and Italy analyzing the magnitude to which the key objectives were met in those systems, documenting the strengths and weaknesses, and providing recommendations for future and existing behavior risk factor surveillance systems.

The attributes used in the evaluation of the systems include simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability. The criteria and standards are based on the CDC Guidelines for Evaluating Surveillance Systems published on 1988 and updated on 2001.

Assessment and Comparison of Behavior Risk Factor Surveillance Systems for  
the U.S., Canada, and Italy.

by

CAROLINA ARANA

D.M.D UNIVERSITY OF VALLE

A Capstone Submitted to the Graduate Faculty  
of Georgia State University in Partial Fulfillment of the  
Requirements for the Degree

MASTER OF PUBLIC HEALTH

ATLANTA, GEORGIA

2009

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<b>ACRONYMS.....</b>	<b>8</b>
<b>CHAPTER I. - INTRODUCTION.....</b>	<b>9</b>
<b>CHAPTER II - BACKGROUND.....</b>	<b>10</b>
A. HISTORY OF PUBLIC HEALTH SURVEILLANCE .....	10
B. PRINCIPLES AND USES OF SURVEILLANCE SYSTEMS .....	16
C. STEPS AND FUNCTIONS OF SURVEILLANCE SYSTEMS.....	21
D. TYPES OF SURVEILLANCE SYSTEMS.....	24
<b>CHAPTER III. - DESCRIPTION OF BEHAVIORAL RISK FACTOR SURVEILLANCE (BRFS)</b>	
<b>SYSTEMS.....</b>	<b>30</b>
A. PUBLIC HEALTH IMPORTANCE OF BEHAVIORAL RISK FACTOR SURVEILLANCE (BRFS) SYSTEMS.....	30
B. PURPOSE AND OPERATIONS OF BEHAVIORAL RISK FACTOR SURVEILLANCE (BRFS) SYSTEMS .....	31
1. <i>Operations</i> .....	32
C. INPUTS FOR BRFS SYSTEMS .....	32
1. <i>CDC's BSB support</i> .....	32
2. <i>Personnel and Managing Staff</i> .....	33
3. <i>Stakeholders</i> .....	33
4. <i>Technology</i> .....	34
5. <i>Security and Privacy</i> .....	35
D. DESCRIPTION AND IMPORTANCE OF SYSTEM ATTRIBUTES IN BRFS SYSTEMS.....	36
1. <i>Simplicity</i> .....	37
2. <i>Flexibility</i> .....	38
3. <i>Data Quality</i> .....	39
4. <i>Acceptability</i> .....	39
5. <i>Sensitivity</i> .....	41
6. <i>Predictive positive value (PVP)</i> .....	43

7.	<i>Representativeness</i> .....	44
8.	<i>Timeliness</i> .....	45
9.	<i>Stability</i> .....	47
<b>CHAPTER IV. - DESCRIPTION OF BEHAVIOR RISK FACTOR SURVEILLANCE SYSTEMS</b>		
<b>IN U.S., CANADA, AND ITALY. ....</b>		<b>48</b>
A.	US BEHAVIOR RISK FACTOR SURVEILLANCE SYSTEM (BRFSS).....	48
1.	<i>Instruments used to collect data</i> .....	48
2.	<i>Data gathering processes</i> .....	60
3.	<i>Implementation of the surveillance system including: Resources, Training, and Funding ...</i>	67
4.	<i>Response rates</i> .....	73
5.	<i>How the data is used</i> .....	78
B.	ITALIAN BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM – PASSI (PROGRESSI DELLE AZIENDE SANITARIE) .....	80
1.	<i>Instruments used to collect data</i> .....	82
2.	<i>Data gathering processes</i> .....	86
3.	<i>Implementation of the surveillance system including: Resources, Training, and Funding ...</i>	92
4.	<i>Response rates</i> .....	95
5.	<i>How the data is used</i> .....	96
C.	THE CANADIAN BEHAVIOR RISK FACTOR SURVEILLANCE SYSTEM .....	98
1.	<i>Instruments used to collect data</i> .....	99
2.	<i>Data gathering processes</i> .....	99
3.	<i>Implementation of the surveillance system including: Resources, Training, and Funding</i>	102
4.	<i>Response rates</i> .....	104
5.	<i>How the data is used</i> .....	104
<b>CHAPTER V. STUDY PURPOSE, FRAMEWORK, AND USE .....</b>		<b>105</b>
A.	PURPOSE OF THE STUDY .....	105

B. FRAMEWORK FOR ANALYSIS AND ASSESSMENT .....	105
C. WHO WILL USE ANALYSIS FINDINGS .....	107
D. HOW ANALYSIS FINDINGS WILL BE USED .....	107
<b>CHAPTER VI. - COMPARISON AND ANALYSIS RESULTS OF BRFS SYSTEMS IN U.S., CANADA, AND ITALY .....</b>	<b>109</b>
<b>CHAPTER VII. – RECOMMENDATIONS AND CONCLUSIONS .....</b>	<b>114</b>
A. RECOMMENDATIONS FOR FUTURE IMPLEMENTATIONS OF BRFS SYSTEMS .....	114
B. PUBLIC HEALTH ACTION .....	119
C. CONCLUSIONS .....	121
<b>CHAPTER VIII. – REFERENCES.....</b>	<b>124</b>

## Acronyms

<b>AERS</b>	Adverse Events Reporting System
<b>BRFS</b>	Behavioral Risk Factor Surveillance
<b>BRFSS</b>	Behavior Risk Factor Surveillance System
<b>BSB</b>	CDC's Behavioral Surveillance Branch
<b>CATI</b>	Computer
<b>CDC</b>	Center for Disease Control and Prevention
<b>CNEPS</b>	
<b>CSTE</b>	Conference of State and Territorial Epidemiologists
<b>DACH</b>	Division of Adult and Community Health
<b>DHSS</b>	Department of Health and Social Services
<b>DPH</b>	Division of Public Health
<b>DSS</b>	Disproportionate Stratified Random Sampling
<b>FDA</b>	Food and Drug Administration
<b>IHR</b>	International Health Regulations
<b>ISS</b>	Italian Surveillance System
<b>LHD</b>	Local health Department
<b>LHU</b>	Local Health Units
<b>MMWR</b>	Morbidity and Mortality Weekly Report
<b>NCCDPHP</b>	CDC's National Center for Chronic Disease Prevention and Health Promotion
<b>NCs</b>	
<b>NETSS</b>	National Electronic Telecommunications System for Surveillance
<b>PASSI</b>	Progressi delle Aziende Sanitarie per la Salute in Italia
<b>PFGW</b>	Pulsed-field gel electrophoresis
<b>PHU</b>	<b>Public Health Units</b>
<b>RDD</b>	Random-digit-dial
<b>STDs</b>	Sexually Transmitted Diseases
<b>WHO</b>	World Health Organization

## **Chapter I. - Introduction**

The purpose of this document is to assess and compare the Behavior Risk Factor Surveillance systems established in U.S., Canada, and Italy; and propose Behavior Risk Factor surveillance recommendations based on the strengths and weaknesses of the examined Behavior Risk Factor Surveillance systems effectiveness. These recommendations can be used as a benchmark for the design of new BRFs systems or the assessment of existing systems.

The document compares the Behavior Risk Factor Surveillance systems in the U.S., Canada, and Italy against the CDC Guidelines for Evaluating Surveillance Systems, and describes the analysis and examination of the each system attribute, surveillance system activity, results, conclusions, and recommendations. This study can be used by government officials seeking improved data collection, and by practitioners and public health professionals looking to improve the Public Health programs they oversee. In addition, this study will provide a baseline that can be used to demonstrate the importance of all behavior risk factor surveillance systems.

## **Chapter II - Background**

### **A. History of Public Health Surveillance**

The concept of public health surveillance has evolved over time. This concept arose in Europe some 600 years ago with the emergence of scientific thought during the Renaissance, and subsequently spread to the Americas with the European settlers (Declich, Carter 1994). Prior to 1950, surveillance meant the close observation of persons exposed to a communicable disease to detect early symptoms and institute prompt isolation and control measures. Over the time differences between “surveillance” and “personal surveillance”, the use of “epidemiological” term to describe surveillance, monitoring and controlling definitions have been distinguished.

Public health surveillance dates back to the time of John Graunt, who published the *Natural and Political Observations Made Upon the Bills of Mortality* in 1662 (Thacker, Berkelman 1988). Graunt, an English statistician generally considered to be the founder of the science of demography, the statistical study of human populations, attempted to define the basic laws of natality and mortality. He developed some fundamental principles of public health surveillance, including death rates, death counts, disease patterns, and disease-specific death counts. Prior to 1662, in 1403 in Republic of Venice and later in 1741 in Rhode Island case surveillance approach was fundamental in public health. This approach was applied to control communicable diseases. In both places, authorities had the power to control communicable diseases by identifying persons with symptoms of plague and preventing from disembarking, or reporting contagious disease to local authorities and control spread of disease, respectively. In U.S reporting of infectious diseases began in 1874 when a postcard

reporting format was developed in Massachusetts. In 1878 Congress authorized the forerunner of the United States Public Health Service to collect morbidity data for use in quarantine measures against “pestilential diseases” such as cholera, smallpox, plague, and yellow fever. In 1881 in Italy reporting of infectious diseases began on a national basis and in other European countries shortly afterwards (MMWR 1996). All these surveillance systems were focused on identifying and reporting cases, and isolating those cases to control infectious disease outbreaks. Smallpox eradication in 1970 is a good example of a successful public health strategic based on an intensive surveillance –based approach. During this time, before the development and widespread availability of antibiotics and vaccines in the twentieth century, control strategies traditionally include monitoring, contact tracing, treatment, and quarantine. These were the most common actions that public health and medicine could do.

Although these days there are few cases of “pestilential diseases”, and the need for quick action to prevent the spread of infectious diseases still remains. One of the main goals of surveillance for diseases such as TB and sexually transmitted diseases (STDs) is to identify infectious individuals before they infect others, thus preventing an exponentially growing epidemic. In this manner, case surveillance has maintained its importance with the increasing interest in emerging infections and bioterrorism since the attacks of September 11, 2001. Indeed, case surveillance was a critical tool in controlling SARS in 2003 (Heymann, Rodier 2004). In 2005 the World Health Organization (WHO) modified the International Health Regulations to require that all countries notify to WHO of all events “which may constitute a public health emergency of international concern” (World Health Organization 2005), and required that countries have the core surveillance and response capacities needed to fulfill the international reporting requirements.

Table 1 gives some of the more important events related to the development of surveillance in the past centuries.

**Table 1: Development of surveillance in the past centuries**

	<b>Year</b>	<b>Event</b>	<b>Country</b>
	<i>Fourteenth and fifteenth centuries</i>		
	1348	The occurrence of the Black Death or pneumonic plague	Venetian Republic
	1377	The detention of travelers from plague-infected areas for 40 days	Marseilles
	1403	The detention of travelers from plague-infected areas for 40 days	Venice
	<i>Sixteenth century</i>		
	1532	The first London Bills of Mortality	London
	<i>Seventeenth century</i>		
	1662	The plague in London in the seventeenth century. John Graunt. He attempted to define the basic laws of natality and mortality. Developed some fundamental principles of public health surveillance, including death rates, death counts, disease patterns, and disease-specific death counts.	London
	1680	Gottfried Wilhelm von Leibniz: establishment of a health council and the application of a numerical analysis in mortality statistics to health planning.	
	<i>Eighteenth century</i>		
	1741	Basic elements of surveillance were developed in some colonies in America; when the colony passed an act requiring tavern keepers to report contagious disease among their patrons, smallpox, yellow fever, and cholera.	Rhode Island
	1766	Surveillance was recognized as an integral part of the provision of population health. Johann Peter Frank created a police medicine system that included school health, injury prevention, maternal and child health, and public water and sewage treatment. And delineated governmental	Germany

		measures to protect public's health.	
	<i>Nineteenth century</i>		
	1800-1890	Sir Edwin Chadwick, Secretary of the Poor Law Commission in England, was the first health administrator to demonstrate, through surveillance, that poverty and disease were closely related.	England
	1850	Lemuel Shattuck's "Report of the Massachusetts Sanitary Commission" landmark publication that related living conditions to rates of deaths, infant and maternal mortality and morbidity, and communicable diseases. He recommended census, collection of health data by age, gender, occupation, SES, and locality. He applied these concepts to preventive medicine.	USA
	1836	Establishment of the General Register Office.	United Kingdom
	1838-1879	William Farr became the first Compiler of Abstract. Created a modern surveillance system. He is recognized as the founder of the modern concept of surveillance.	United Kingdom
	1874	Systematic reporting of disease in the United States, when Massachusetts State Board of Health institutes a voluntary plan for physicians to provide weekly reports on prevalent disease, using a standard postcard-reporting format.	USA
	1878	Congress authorized the forerunner of the United States Public Health Service to collect morbidity data for use in quarantine measures against "pestilential diseases" such as cholera, smallpox, plague, and yellow fever.	USA
	1881-1890	Reporting of infectious diseases Mandatory reporting of eleven communicable diseases and death certificates, in Italy.	Great Britain and Italy Italy

	1888	Michigan became the first U.S. jurisdiction to require reporting of specific infectious diseases (smallpox, TB, and cholera). Publication of international list of causes of death by the International Statistical Institute (founded in London in 1885). Also, law was enacted to provide for the collection of data each week from state and municipal authorities throughout the United States.	USA
	1893		
<b><i>Twentieth Century</i></b>			
	1900	Expansion of the concept of surveillance and the development of many different surveillance systems.	USA
	1911	Use of surveillance data from National Health Insurance, in the United Kingdom.	United Kingdom
	1916	Poliomyelitis epidemic	USA
	1918-1919	Influenza pandemic	
	1925	Increased reporting associated with the severe epidemic and pandemic.	USA
	1935	First national health survey of U.S. citizens	
	1943	First registry, the Danish Cancer Registry, First Sickness Survey, in the United Kingdom.	United Kingdom
	1948-1949	National Office of Vital Statistics assumed the responsibility for reporting morbidity.	USA
	1951	The Conference of State and Territorial Epidemiologists (CSTE) was authorized to determine what disease should be reported by states to the Public Health Service and to develop reporting procedures.	USA

1952	Mortality data were added to the publication that was the forerunner of the Morbidity and Mortality Weekly Report (MMWR).	USA
1955	CSTE officially incorporated, meets annually and in collaboration with CDC recommends appropriate changes in morbidity reporting and surveillance, including what diseases should be reported to CDC and published in the MMWR.	USA
1961	The MMWR publication and its content were transferred to the Communicable Disease Center (now, CDC).	USA
1965	Establishment of an Epidemiological Surveillance Unit in the Division of Communicable Diseases at WHO headquarters, Geneva.	Geneva
1966	First publication of Communicable Disease Surveillance Reports by WHO	
1967	Development of General Practitioners' Sentinel Systems, in the United Kingdom and the Netherlands.	United Kingdom And Netherlands
1968	World Health Organization (WHO) defined surveillance as the “systematic collection and use of epidemiological information for the planning, implementation, and assessment of disease control”.	USA
1970	Eradication of Smallpox	
1990s	Contact tracing helped to quell re-emerging tuberculosis (TB) in the United States in the 1990s and is still a common and effective public health tool.	USA
1990s	Surveillance of occupational morbidity and mortality, and injury surveillance became more common in the 1990s as public health turned its attention to intentional and unintentional violence.	

Over the course of the twentieth century, the primary cause of death shifted from infectious to chronic diseases; as a result the focus of surveillance shifted to populations rather than individuals. Due to this situation, monitoring populations required statistical analysis of data from birth and death certificates, as well as health surveys based on scientifically chosen sample surveys, such as the National Health Interview Survey (NHIS) and Behavioral Risk Factor Surveillance System (BRFSS).

In the early twenty-first century registries as sources of statistical data, health care quality, attendant concerns about medical errors and iatrogenic injuries, and post-marketing surveillance for adverse effects of drugs and vaccines have been growing. At the same time, awareness and recognition of the importance of public health surveillance systems for measuring the health status of a population, emerging health risks and diseases, and for program development has been growing.

In recent years, systematic and timely analysis of health trends has been identified as increasingly important for evidence-based health policy and program development. In addition, behaviors and determinants of health data have become invaluable in the understanding of relationships among human health, risk factors and interventions. It appears that public health surveillance is the focus of health research and can therefore be considered as population-based surveillance system.

## **B. Principles and Uses of Surveillance Systems**

Historically, public health surveillance has combined two different activities: case and statistical surveillances. Case surveillance, which is focuses on individuals, or sometimes

small groups of individuals, has been used for communicable diseases capable of causing great harm to the entire population if allowed to spread. In contrast, statistical surveillance uses populations to identify differentials and trends that can inform public health policymaking, including the allocation of resources (Stoto 2008). Both case and statistical surveillance approaches have roots going back centuries, but it was not until 1963 that Alexander Langmuir of the Communicable Disease Center (now the Centers for Disease Control and Prevention, or CDC) combined them in his classic definition of public health surveillance, the basis for the CDC's definition.

In 1963 the term surveillance was defined by Alexander Langmuir as "the systematic collection, consolidation, analysis and dissemination of data on specific disease" in public health practice (Langmuir 1963). Prior to that definition, surveillance had been used in public health practice to refer the monitoring of persons who had been exposed to communicable diseases and who might need to be quarantined by public health departments.

In United States a broader, population-based approach of surveillance gained importance following the Francis Field Trial of poliomyelitis vaccine in 1955 (Markel 1955), where having in place the notifiable-disease reporting system to state and local health departments led to an epidemiologic investigation remarkable in the public health field. This evolution of "surveillance" from personal to public health surveillance developed and highlighted what currently are considered its main principles - data collection, data analysis, data interpretation, and dissemination of that data in a timely manner at the lowest possible cost for public health action.

In 1965, the Director General of the World Health Organization (WHO) established the epidemiological surveillance unit in WHO's Division of Communicable Diseases and defined surveillance much more broadly than Langmuir including "the epidemiological study of disease as a dynamic process." In 1968, the 21st World Health Assembly, through the leadership of Alexander Langmuir and Karel Raska, the director of the World Health Organization's Division of Communicable Diseases, affirmed the three main features of surveillance: a) systematic collection of data, b) analysis and evaluation of data, and c) dissemination of data regarding a health-related event for use in public health action to reduce morbidity, mortality and to improve health ( Raska 1966) (World Health Organization 1968).

In recent years, surveillance constitutes a critical part of public health practice. The Center for Disease Control and Prevention (CDC) officially describes public health surveillance as "the ongoing and systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice" (Thacker, Berkelman 1988). By definition, surveillance systems include the capacity for data collection and analysis, as well as the timely dissemination of information to persons or group of persons who can undertake effective prevention and control interventions related to specific health outcomes.

Over the years the concept of surveillance has been changed. However, this system will always have a practical value as it can be used in designing new surveillance systems as well as understanding or evaluating currently operating ones. Current concepts of surveillance systems evolve from public health actions to control disease outbreaks in the population. Nowadays, surveillance extends far beyond the narrow confines of communicable

disease reporting and vital statistics to include surveillance of chronic diseases, environmental factors, behavioral risk factors, health care quality and utilization, adverse events from drugs and medical devices, knowledge, attitudes, and beliefs concerning health, occupational diseases and outcomes of pregnancy and childbirth. Surveillance systems are extending its services to the entire population in a more public health context including collection and analysis of surveillance data to assess public health status, identifying priorities, evaluating and monitoring programs, and conducting research. In addition, surveillance system is being useful in detecting epidemics and changes in health practice, documenting the distribution and spread of a health event, estimating the magnitude of a health problem, and delineating the natural history of disease.

Furthermore, several activities are expected to contribute to the evolution of public health surveillance. For example, the use of technology revolutionized the practice of public health surveillance. In U.S., the National Electronic Telecommunications System for Surveillance (NETSS) connects all the state health departments electronically for collection, analysis, and dissemination of information on notifiable health conditions. States, counties and health-care providers are electronically linked for routine surveillance, using this coordinated, timely, and useful integral multisource of public health surveillance readily developed. Technology, electronic media, and all other communication's tools should facilitate the use of surveillance data for public health action.

In addition to the definition, uses and principles of surveillance systems, it is important to understand some terms related to these systems such as *Indicators* – a measurable factor used to estimate the size of a health event and monitor the processes or the effect of an intervention on the population; *Active surveillance* - dynamic process of

contacting health care providers or population to seek information about health conditions. This is the most accurate and timely information, but it is also expensive; *Passive surveillance*- a system by which a health jurisdiction receives reports submitted from hospitals, clinics, public health units, and other sources. It is a relatively inexpensive strategy to cover large areas, and provides critical information for monitoring a community's health. However, data quality and timeliness are difficult to control ( Losos 1996). Among these surveillance definitions there are also different types of surveillance systems available to specific diseases and health risks such as syndromic surveillance, categorical and integrated surveillance systems, and BRFSS.

It is important to notice that in order to establish and maintain a surveillance system, it is necessary to establish the goals of the system, develop case definitions, select appropriate personnel, and acquire tools and clearances for collection, analysis, and dissemination; then the surveillance system can be implemented and evaluated (Thacker, Stroup 1998). Following these steps will ensure the sustainability and establishing of the systems since they must adapt constantly to changes in the population and the physical and social environment.

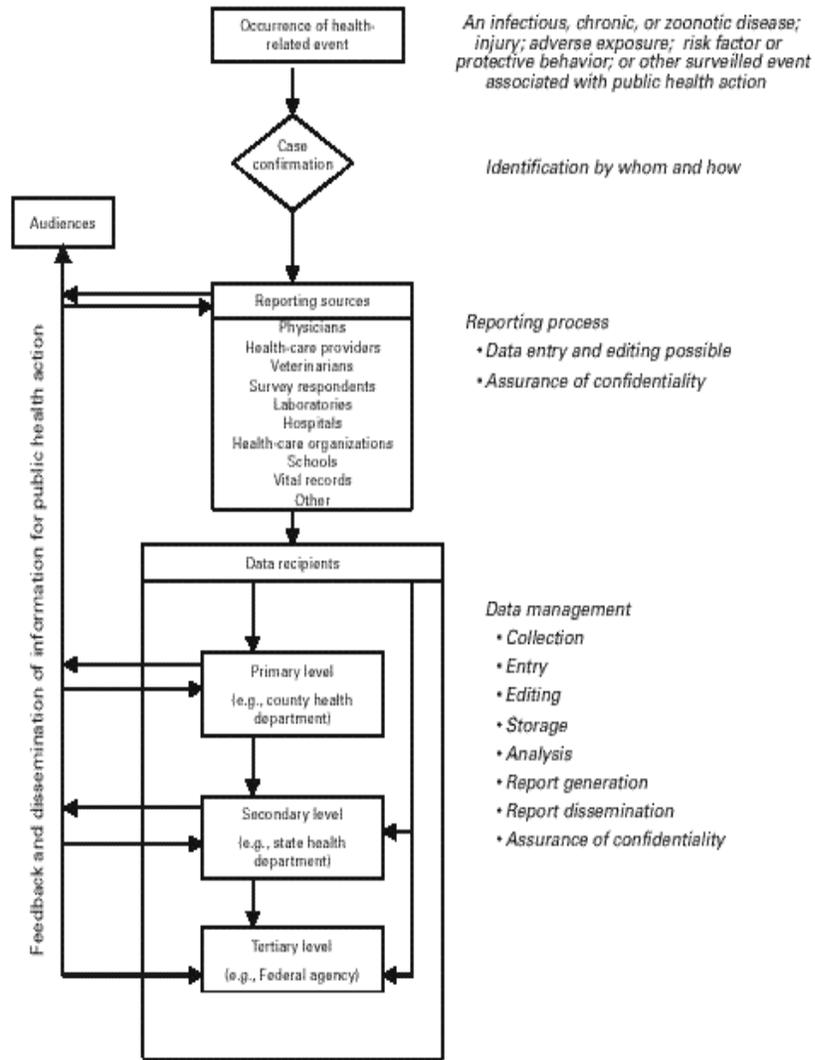
Generally speaking, public health surveillance is considered as the systematic, ongoing assessment of health risks related to the community based on the collection, interpretation, analysis, and dissemination of information. Its purpose is to empower decision makers to lead and manage more effectively by providing timely, useful evidence. Therefore, surveillance data is necessary to guide public health planning, developing, implementing, and decision making. It is crucial not only to improve the quality and effectiveness of collection, analysis, interpretation and display of data, but also to listen to persons who are empowered

to set policy in order to understand and stimulate policymakers' interests and actions. Public health action is based on its majority to an effective, timely and reliable surveillance system.

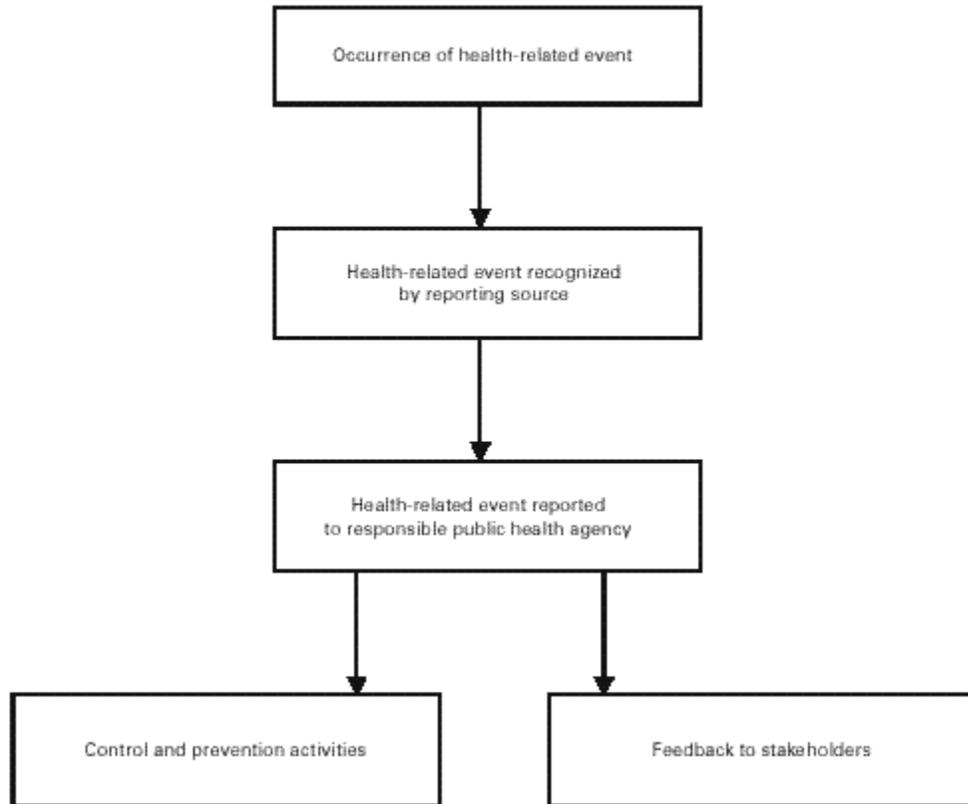
### **C. Steps and functions of Surveillance systems**

Surveillance is undertaken to inform disease prevention and control measures. This systematic and continuous system follows some steps and functions to enable design procedures and methodologies to be developed in order to have effective surveillance systems that support ongoing researches and public health actions. In Figure 1, there is a description of the flow of data and the lines of response in a surveillance system that can help assess the simplicity or complexity of the system, following for Figure 2, which describes the steps of a surveillance system.

**FIGURE 1. Simplified flow chart for a generic surveillance system**



**FIGURE 2. Simplified example of steps in a surveillance system**



*MMWR (2001) Updated Guidelines for Evaluating Public Health Surveillance Systems*

Surveillance is the foundation of all efforts to understand and control and prevent disease . Once a health-related event occurs, such as infectious, chronic or zoonotic disease; injury; adverse exposure; risk factor or protective behavior; or other surveilled events associated with public health, identification and definition of cases will be in placed. During this time cases will be identified and analyzed by place, person, and time. After this period, report generation and dissemination begins including reporting sources as health care providers, physicians, veterinarians, laboratories, health-care organizations, schools, vital records, hospitals, among others, and data recipients at different levels: county and state health department, and federal agencies. At this point management of the data is the key of

the entire surveillance system. Following the collection, entry, editing, storage, analysis, and reporting of data, dissemination and feedback of information is used for public health action to control and prevent disease. In this way, the generic surveillance system can measure the impact of community's health from any health-related event.

On the other hand, it is important to recognize the functions that a surveillance system should perform in order to be effective. These functions include: detection and notification of health events, collection and consolidation of pertinent data, investigation and confirmation (epidemiological, clinical and/or laboratory) of cases or outbreaks, routine analysis and creation of reports, feedback of information to those providing the data, feed-forward of data, and reporting data (MMWR 2004).

Having in place all the steps required to a successful generic surveillance system, public health surveillance will provide the scientific and factual database essential to inform decision making and appropriate public health action. The key objective of this system is to provide information to guide interventions.

#### **D. Types of Surveillance Systems**

Public health departments at local, state, and national levels routinely use different surveillance systems. Here is an overview of some of these systems, including vital statistics, disease reporting, and surveys. There are more specialized surveillance systems, including sentinel surveillance, zoonotic disease surveillance, adverse events surveillance, syndromic surveillance, disease registries, and laboratory surveillance. Some of them are more useful for certain diseases than others, but each fills a specific need. All these systems can be used to monitor disease trends and plan public health programs for a wide variety of conditions.

### ***Vital Statistics***

This surveillance system consists on records of birth and death and it is a critical component for public health practice. Mortality data and infant mortality rate (the number of deaths among infants per 1,000 births) have long been used as indicators of overall population health. Birth data is also used to monitor the incidence of preterm birth, a risk factor for a variety of adverse health outcomes.

In the United States, vital statistics are available from the National Center for Health Statistics and from state vital records offices. The Centers for Disease Control and Prevention (CDC) also operates an online system, CDC WONDER, containing data on births, deaths, and many diseases.

### ***Disease Reporting (Morbidity Data)***

Disease reporting involves the required reporting of certain diseases to public health authorities. It is required internationally by the World Health Organization (WHO), through International Health Regulations (IHR). Under IHR, countries are also required to report any public health emergency of international concern ( WorldHealthAssembly 2005).This surveillance system captures any disease, condition, or event that could represent an international risk. In the United States, disease reporting is mandated by state law, and the list of reportable diseases which is updated regularly by the Council of State and Territorial Epidemiologists and the CDC vary by state. States report nationally notifiable diseases to the CDC on a voluntary basis (MMWR 2008).

### ***Surveys***

Routine surveys are surveillance tools especially useful for monitoring chronic diseases and health-related behaviors. Two of the national surveys conducted in the U.S. are the Youth Risk Behavior Survey (YRBS), and the Behavior Risk Factor Surveillance System (BRFSS). The YRBS and the BRFSS ask high school students and adults respectively, about health-related behaviors such as substance use, nutrition, sexual behavior, and physical activity. Results from these surveillance systems can be used to monitor trends in health behaviors, plan public health programs, and evaluate public health policies at national and state levels. For example, YRBS results have shown a decline in youth smoking from 36% in 1997 to 20% in 2007 (MMWR 2008).

### ***Sentinel Surveillance***

This is a population-based surveillance that involves collecting data from a sample of reporting sites (sometimes called sentinel sites). For example, one of the most common sentinel surveillance systems used in the United States is for influenza. Selected health care providers report the number of cases of influenza-like illness to their state health department on a weekly basis. This surveillance allows states to monitor trends using a relatively small amount of information.

### ***Zoonotic Disease Surveillance***

Zoonotic surveillance system (diseases found in animals that can be transmitted to humans) involves a system for detecting infected animals. For example, in 2001, the Florida health department conducted surveillance for West Nile Virus (WNV) using a variety of strategies such as the provision of a Web site and a telephone hotline for the public to report dead birds. Mosquitoes and blood were collected and tested for WNV in 10 counties. In addition, veterinarians were asked to test horses with neurologic symptoms consistent with

WNV. Health care providers were reminded of reporting and diagnostic criteria for possible human cases of WNV (Blackmore 2003). As a result, detection of WNV led to public health control measures, such as advising the public to protect against mosquito bites and intensifying mosquito abatement efforts.

### ***Adverse Event Surveillance***

Some examples of adverse events surveillance are Adverse Events Reporting System (AERS), the Vaccine Adverse Events Reporting System (VAERS). AERS is a type of surveillance system focusing on patient safety, and it is operated by the Food and Drug Administration (FDA) (FDA 2002). The purpose of this system is to gather information about negative effects experienced by people who have received approved drugs and other therapeutic agents. Reports came from health care providers, including physicians, pharmacists, and nurses, as well as members of the general public, such as patients or lawyers, and manufacturers.

Like AERS, the Vaccine Adverse Events Reporting System (VAERS) is focused on patient safety. This system is operated by the CDC with the FDA, operates like AERS, but focuses on negative effects experienced by people who have received licensed vaccines (Zhou W 2003). Because AERS and VAERS are passive surveillance systems, they may be limited by underreporting or biased reporting, and they cannot be used to determine whether a drug or vaccine caused a specific adverse health event. Instead, these systems are used as early warning signals.

### ***Syndromic Surveillance***

This surveillance system is a relatively new surveillance method that uses clinical information about disease signs and symptoms before a diagnosis is made. It is an active or

passive system that uses case definitions that are based entirely on clinical features without any clinical or laboratory diagnosis (for example collecting cases of diarrhea, rather than cases of cholera). This syndromic surveillance system uses electronic data from hospital emergency rooms, and provides the health department with early notification of the outbreak.

### ***Registries***

Registries are a type of surveillance system used for particular conditions, such as cancer and birth defects. They are often established at a state level to collect information about persons diagnosed with the conditions. This information can be used to improve prevention programs.

### ***Laboratory Data***

Public health laboratory data is another source of surveillance data which routinely conduct tests for viruses, bacteria, and other pathogens. Laboratory serotyping provides information about cases that are likely to be linked to a common source. For this reason, serotypes are useful for detecting local, state, or national outbreaks (Swaminathan 2006). For example, in the US, public health laboratories participate in the National *Salmonella* Surveillance System through electronic reporting of *Salmonella* isolates. In 2006, more than 40,000 isolates from the US were reported through this system (Center of Disease Control and Prevention 2006). Other laboratory system that plays an important role in surveillance is PulseNet, developed by the CDC and the Association of Public Health Laboratories to monitor foodborne illness outbreaks. This system enables public health laboratories across the US to compare pulsed-field gel electrophoresis (PFGE) patterns of bacteria isolated from ill persons and determine whether they are similar. This allows scientists to determine whether an outbreak is occurring, even at geographically distant locations, and can decrease

the time required to identify outbreaks of food borne illness and their causes (Center of Disease Control and Prevention 2008).

Having this variety of surveillance systems, public health practitioners have a broad sources of data ready to be analyzed and distributed at local, state, and national levels for public health action. However, these surveillance systems might increase with the range of health-related events that are associated with public health action and are under surveillance. This issue highlights the importance of having different methods of collecting data and the usefulness that these data means in public health actions including guiding prevention strategies and targeting resources, detecting disease outbreaks of local, national, and international significance, and evaluating public health control measures. Therefore, knowing where to look for different types of data can save valuable time and resources.

### **Chapter III. - Description of Behavioral Risk Factor Surveillance (BRFS) systems**

#### **A. Public health importance of Behavioral Risk Factor Surveillance (BRFS) systems**

The Behavioral Risk Factor Surveillance systems are telephone health surveys that collect information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury (BRFSS Website). The importance of these systems resides on different valuable points involving all public health fields. First of all, these systems are available sources of timely and accurate data on health-related behaviors very useful for many state health agencies that have the primary and critical role of targeting resources to reduce behavioral risks and their consequent illnesses. BRFS data is provided on a state-specific basis. However, state and local agency participation is critical to achieve national health goals and BRFS systems provide surveillance data necessary to cover national and in some instances international needs.

Second, in recent years chronic diseases have emerged as a critical health concerns all around the world. “Chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading cause of mortality in the world, representing 60% of all deaths. Out of the 35 million people who died from chronic disease in 2005, half were under 70 and half were women” (World health Organization Website). With this in mind, personal health behaviors are receiving wider recognition in relation to chronic diseases morbidity and mortality. BRFS systems are an acceptable method for determining the prevalence of several health risk behaviors among populations, in order to planning, analyzing, and implementing effective and accurate interventions based on the data provided by these systems.

Prevalence estimates are of particular importance for major chronic illnesses such as diabetes, stroke, cardiovascular and respiratory diseases, among others. Allocations of health funds are an important part for this process and should be distributed according to local need. At this point estimates of disease prevalence for small areas are increasingly required and necessary for this action. Here is where BRFS system plays a crucial role in order to estimate the information related to the local need, to compile the individual and geographic risk factors relevant to explain prevalence variations and needs.

In synthesis, BRFS systems can provide systematic and continuous collection of information on a state-specific basis useful not only to understand and monitor lifestyles and behaviors related to the leading causes of mortality and morbidity, but also to estimate prevalence of specific diseases in small areas that will contribute to achieving the disease prevention goal at the local and national level.

## **B. Purpose and Operations of Behavioral Risk Factor Surveillance (BRFS) systems**

The Behavioral Risk Factor Surveillance systems are on-going telephone health survey systems tracking health conditions and risk behaviors in different countries. The purpose of the BRFS systems is to provide valid data to the states and decision makers in a timely manner at the lowest possible cost in order to identify emerging health problems, establish and track health objectives, develop and evaluate public health policies and programs, and also to support health-related legislative efforts (Nsubuga, Eseko, and others 2002).

A number of BRFS systems are used routinely by public health departments at local, state, and national levels. Among others, these systems provide information of vital statistics,

disease reporting, and prevalence of health risks and diseases that can be used to monitor disease trends and plan public health programs for a wide variety of conditions. This surveillance data will also help to detect outbreaks, provide information to plan public health interventions, and stimulate research.

## **1. Operations**

Operations of BRFSS systems include a random telephone survey of state residents aged 18 and older in households with telephones. Through BRFSS systems, information is collected in a routine, standardized manner at the state level on a variety of health behaviors and preventive health practices related to the leading causes of death and disability such as cardiovascular disease, cancer, diabetes, and injuries. At the same time, BRFSS system interviews are conducted monthly and data are analyzed annually (on a calendar-year basis). Having all that data, state health agencies can have estimates and trends of selected specific diseases getting a broad perspective of the health status of the nation, also many states can have access to a valuable data ready to be used for public health actions to improve, reduce, monitor, and control risk health behaviors and illnesses related to the population.

## **C. Inputs for BRFSS systems**

### **1. CDC's BSB support**

Behavioral Risk Factor Surveillance systems are state-based programs that gathers information on risk factors among adults 18 years of age and older through monthly telephone surveys. These systems provide a state-based telephone survey which is conducted through a collaborative effort among the Behavioral Surveillance Branch (BSB) of the

Centers for Disease Control and Prevention (CDC), local health departments, Universities and Institutes of Public Health. In U.S., state health departments conduct the annual BRFSS surveys with technical and methodological assistance provided by the expertise of CDC's BSB staff in matters of training, technical assistance, and data management. The same situation happens when BRFS systems established in different countries take the BRFSS of U.S. as a basis of their BRFS systems having continuous support from the CDC's BSB. That is the case of the Italian BRFS system called Progressi delle Aziende Sanitarie per la Salute in Italia (PASSI). CDC's BSB support is a key element to the development and adequate performance of the system in order to obtain expected results.

## **2. Personnel and Managing Staff**

BRFS data is collected via telephone through standardized surveys. Construction and distribution of questionnaires, data collection, sampling methodology, and implementation of BRFS systems are possible to the cooperation and performance of managing staff and personnel including coordinators, interviewers, supervisors, local health departments, statistical analysts, epidemiologist, and informational technology (IT) group. The efficiency, continuing education and professionalism of each person involved in BRFS system team will ensure an accurate data collection and analysis that will result in a timely and valid (true) data ready to be used for public health professionals and organizations to address health-related events.

## **3. Stakeholders**

Stakeholders include public health practitioners, health-care providers, data providers and users, representatives of affected communities, governments at the local, state, and

federal levels, and professional or private nonprofit organizations (MMWR 2001). They are considered as the persons or organizations that will use the data for the promotion of healthy lifestyles and the prevention and control of diseases, injuries, and adverse exposures. They provide input to surveillance systems to ensure that these systems address appropriate questions and assess pertinent attributes to provide acceptable and useful findings necessary for the development and implementation of programs and interventions.

#### **4. Technology**

Applying modern information technology and automation to all the steps of a surveillance system will facilitate the adaptation process of public health surveillance to changing health practice. Increasing automation, which means increasing techniques and equipment to achieve automatic operation and control of surveillance systems, will improve the procedures of storing and sharing rich sources of data stored in hospitals, clinical laboratories, health departments, and pharmacies. As a result of this modern information technology, sources of data will be more organized and accessible for public health practitioners. Dissemination of valid data will be faster making the surveillance system more effective and efficient for action.

On the other hand, components of the public health surveillance system include public health informatics concerns such as comparable hardware and software, standard user interface, standard data format and coding to facilitate efficient data exchange, appropriate quality checks, and adherence to confidentiality and security standards. All these factors are crucial for effectively matching data within the system or to other systems, and technology plays an important role in their operations and performances.

Many aspects of collection, organization, summary, description and interpretation of data have long been addressed in the mathematics curriculum. However, technological changes have influenced the techniques of data collection, retrieval, manipulation, analysis and communication, and have increased the capacity to pursue investigations with large quantities of real and simulated data. The introduction of and involvement of technology to public health will facilitate the creation of a complete integrated technical computing environment with well-defined applications and systems that will make procedures not only easier to execute but also more accurate and confident with the results. Real and valid data should reflect these changes.

## **5. Security and Privacy**

Public health system has been working to adopt needed standards for security and privacy related to surveillance systems. Privacy issues include both information technology and policy considerations. For example, security can be addressed by encryption techniques and policies that strongly discourage sharing of passwords. Early detection of biological events, electronic reporting of laboratory test results, efficient exchange of case reports across jurisdictions, and timely alerting of health threats are critical components of effective health protection. Essential to public health surveillance is the timely availability of information relating to individuals' healthcare behaviors and clinical conditions posing a threat to personal privacy. Therefore, security and privacy elements of surveillance systems should maintain the delicate balance between personal privacy and population safety.

#### **D. Description and Importance of System Attributes in BRFS Systems**

Development of efficient and effective public health surveillance systems provide the best use of public health resources, facilitating not only the response of public health to emerging health threats (e.g., new diseases), but also allowing the public health community to respond more quickly to public health threats (e.g., outbreaks of emerging infectious diseases and bioterrorism) (MMWR 1988).

As the targets of public health actions have expanded beyond infectious diseases to include chronic diseases, violence, emerging pathogens, threats of bioterrorism, and the social contexts that influence health disparities, the task of evaluation those systems has become more complex. CDC has developed a framework for program evaluation to ensure that amidst the complex transition in public health, it will remain accountable and committed to achieving measurable health outcomes. This CDC's Framework for Program Evaluation in Public Health has been updated in 2001 as a CDC's guidelines for evaluating public health surveillance systems.

The purpose of evaluating public health surveillance systems is to ensure that problems of public health importance are being monitored efficiently and effectively, and that surveillance systems operate to meet their purpose and objectives. The evaluation of public health surveillance systems should involve an assessment of nine critical system attributes including simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability (MMWR 2001). These attributes are analyzed during the evaluation process of public health surveillance systems in order to

ensure quality, efficiency, and usefulness of data which will be applied to the development, and implementation of public health programs.

## **1. Simplicity**

The simplicity of a public health surveillance system refers to both its structure and ease of operation. Surveillance systems should be as simple as possible while still meeting their objectives (MMWR 2001). Describing the flow of data and the lines of response in a surveillance system can help assess the simplicity or complexity of a surveillance system. For example, a surveillance system with a case definition that is easy to apply would be considered a simple surveillance system. The person identifying the case will also be the one analyzing and using the information. In contrast, a more complex system might involve follow-up laboratories test, investigation of the case, and multiple levels of reporting. In accordance to CDC's Guidelines for Evaluating Public Health Surveillance systems, in order to get a simple surveillance system it is necessary to consider the following measures:

- Amount and type of data necessary to establish that the health-related event has occurred.
- Amount and type of other data on cases (e.g., demographic, behavioral, and exposure information for the health-related event).
- Number of organizations involved in receiving case reports.
- Level of integration with other systems.
- Method of collecting the data, including number and types of reporting sources, and time spent on collecting data.
- Amount of follow-up that is necessary to update data on the case.

- Method of managing the data, including time spent on transferring, entering, editing, storing, and backing up data.
- Methods for analyzing and disseminating the data, including time spent on preparing the data for dissemination.
- Staff training requirements.
- Time spent on maintaining the system.

Acceptance and timeliness of the system as the amount of resources required to operate the surveillance systems are influenced by how simple or complex the system's design is.

## **2. Flexibility**

A flexible public health surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds (MMWR 1999). This is applied to new health-related events, changes in definitions or technology, and variations in funding or reporting sources. The use of standard data formats (electronic data) influences the flexibility of the system in terms of its ability to be integrated with other systems and allows changes easier. Simpler systems might be more flexible in the case of fewer components needing to be modified when adapting the system for a change in information needs or operating conditions (MMWR 2001). The flexibility of a system is probably best evaluated retrospectively by observing how a system has responded to a new demand.

### **3. Data Quality**

Data quality reflects the completeness and validity of the data such as demographic characteristics, details about the health-related event, and the presence or absence of potential risk factors, that is recorded in the public health surveillance system. Examination of the percentage of "unknown" or "blank" responses to items on surveillance is a straightforward measure of data quality. Higher data of high quality will have lower percentages of such responses. In order to measure data quality, the data values recorded in the surveillance system can be compared to "true" values through, for example, a review of sampled data (Klebens, Fleming, Neal 1999), a special record linkage (Fox 1998), or patient interview (Phillips-Howard 1990). In addition, other factors that might be useful in assessing data quality are the calculation of sensitivity and predictive value positive. Based on the CDC's Guidelines for Evaluating Public Health Surveillance systems, quality of data is influenced by factors that provide an indirect measure of the data such as performance of the screening and diagnostic tests for the health-related event; clarity of surveillance forms; quality of training and supervision of persons who complete surveillance forms; and care exercised in data management. Acceptability and representativeness of a public health surveillance system are also factors that could influence the quality of data. For example, data of high quality might be accepted by those who participate in it, and at the same time, the system can accurately represent the health-related event under surveillance.

### **4. Acceptability**

Acceptability reflects the willingness of people that operate and use the system, as the organizations to participate in the surveillance system. To assess acceptability, the points of

interaction between the system and its participants must be considered, including persons with the health-related event and those reporting cases (MMWR 2001).

Based on the CDC's Guidelines for Evaluating Public Health Surveillance systems the quantitative measures of acceptability can include:

- Subject or agency participation rate.
- Interview completion rates and question refusal rates.
- Completeness of report forms.
- Physician, laboratory, or hospital/facility reporting rate.
- Timeliness of data reporting.

Some of these measures might be obtained from a review of surveillance report forms, whereas others would require special studies or surveys. On the other hand, acceptability is influenced by some factors including:

- The public health importance of the health-related event.
- Acknowledgment by the system of the person's contribution.
- Dissemination of aggregate data back to reporting sources and interested parties.
- Responsiveness of the system to suggestions or comments.
- Burden on time relative to available time.
- Ease and cost of data reporting.
- Federal and state statutory assurance of privacy and confidentiality.
- The ability of the system to protect privacy and confidentiality.
- Federal and state statute requirements for data collection and case reporting.
- Participation from the community in which the system operates.

Assessing acceptability in a surveillance system will ensure accuracy, consistency, completeness, and timely data.

## **5. Sensitivity**

The sensitivity of a surveillance system can be considered on two levels. First of all, at the level of case reporting sensitivity refers to the proportion of cases of a disease (or other health-related event) detected by the surveillance system (Weinstein, Fineberg 1980). The second level consists on the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time (MMWR 2001).

Sensitivity of a public health surveillance system is affected by the likelihood that certain diseases or other health-related events are occurring in the population under surveillance. For example, cases of certain health-related events might be under medical care, which means that those cases will be diagnosed and identified receiving laboratory testing, reflecting the skill of health-care providers and the sensitivity of screening and diagnostic tests. Once diagnosis is completed the case will be reported to the system (MMWR 2001).

It is important to consider that the extent to which these situations are explored depends on the system and on the resources available for assessing sensitivity. The primary emphasis in assessing sensitivity is to estimate the proportion of the total number of cases in the population under surveillance being detected by the system, represented by  $A/(A+C)$  in Table 2.

Table 2: Calculation of sensitivity and predictive value positive for a surveillance system.

**TABLE 3. Calculation of sensitivity\* and predictive value positive† for a surveillance system**

Detected by surveillance	Condition present		
	Yes	No	
Yes	True positive A	False positive B	A+B
No	False negative C	True negative D	C+D
	A+C	B+D	Total

\* Sensitivity =  $A/(A+C)$

† Predictive value positive (PVP) =  $A/(A+B)$

*MMWR (2001) Updated Guidelines for Evaluating Public Health Surveillance Systems*

Based on the CDC's Guidelines for Evaluating Public Health Surveillance systems, sensitivity of a system might be improved by:

- Conducting active surveillance (i.e., contacting all providers and institutions responsible for reporting cases).
- Using external standards (or other surveillance indicators) to monitor the quality of case reporting.
- Identifying imported cases.
- Tracking the number of cases of suspected disease that are reported, investigated, and ruled out as cases.
- Monitoring the diagnostic effort (e.g., tracking submission of laboratory requests for diagnostic testing).
- Monitoring the circulation of the agent (e.g., virus or bacterium) that causes the disease.

The measurement of the sensitivity of a surveillance system requires access to data usually external to the system to determine the true frequency of the condition in the population under surveillance (Chandra Sekar, Deming 1949), and also requires validation of the data collected by the system. Furthermore, sensitivity can be assessed through estimations of the total cases in the population under surveillance by using capture-recapture techniques (Van Tuinen, Crosby 1998) (Hook, Regal 1992). The assessment of the sensitivity of each data source including combinations of data sources can determine if the elimination of a current data source or if the addition of a new data source would affect the overall surveillance results (Johnson 1997). It is known that a public health surveillance system that does not have high sensitivity can still be useful in monitoring trends as long as the sensitivity remains reasonably constant over time. Changes in sensitivity can be precipitated by introduction of new diagnostic tests, and changes in the method of conducting surveillance.

## **6. Predictive positive value (PVP)**

Predictive positive value (PVP) is the proportion of reported cases that actually have the health-related event under surveillance (Weinstein, Fineberg 1980) and is represented by  $A/(A+B)$  as shown in Table 2. The assessment of sensitivity and PVP provides different perspectives regarding how well the system is operating. Depending on the objectives of the public health surveillance system, assessing PVP whenever sensitivity has been assessed might be necessary (Gazarian 1999).

In assessing PVP, primary emphasis is placed on the confirmation of cases reported through the surveillance system. The effect of PVP on the use of public health resources can be considered on two levels:

- Case detection: PVP affects the amount of resources used for case investigations. A record of the number of case investigations completed and the proportion of reported persons who actually had the health-related event under surveillance would allow the calculation of the PVP.
- Outbreak (or epidemic) detection: a high rate of erroneous case reports might trigger an inappropriate outbreak investigation. Therefore, the proportion of epidemics identified by the surveillance system that are true epidemics can be used to assess this attribute. The review of personnel activity reports, travel records, and telephone logbooks might enable the assessment of PVP.

The PVP reflects the sensitivity and specificity of the case definition (i.e., the screening and diagnostic tests for the health-related event) and the prevalence of the health-related event in the population under surveillance. This PVP can improve with increasing specificity of the case definition, and also having a good communication between the persons who report cases and the receiving agency.

In case of having a low PVP noncases might be investigated, and outbreaks might be identified that are not true but are instead artifacts of the public health surveillance system. False positive reports can lead to unnecessary interventions, and falsely detected outbreaks can lead to costly investigations and undue concern in the population under surveillance. A public health surveillance system with a high PVP will lead to fewer misdirected resources.

## **7. Representativeness**

A public health surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place

and person. Representativeness is assessed by comparing the characteristics of reported events to all such actual events. Based on the CDC's Evaluating Public Health Surveillance systems, some judgment of the representativeness of surveillance data is possible, based on knowledge of:

- Characteristics of the population, including, age, socioeconomic status, access to health care, and geographic location.
- Clinical course of the disease or other health-related event (e.g., latency period, mode of transmission, and outcome [e.g., death, hospitalization, or disability]).
- Prevailing medical practices (e.g., sites performing diagnostic tests and physician referral patterns).
- Multiple sources of data (e.g., mortality rates for comparison with incidence data and laboratory reports for comparison with physician reports).

For many health-related events under surveillance, the proper analysis and interpretation of the data require the calculation of rates. The choice of an appropriate denominator for the rate calculation should be given careful consideration to ensure an accurate representation of the health-related event over time and by place and person. To generalize findings from surveillance data to the population at large, the data from a public health surveillance system should accurately reflect the characteristics of the health-related event under surveillance relate to time, place, and person.

## **8. Timeliness**

Based on the CDC's Evaluating Public Health Surveillance systems timeliness reflects the speed between steps in a public health surveillance system. The interval usually considered first is the amount of time between the onset of a health-related event and the

reporting of that event to the public health agency responsible for instituting control and prevention measures. There are some factors affecting the time involved during this interval including the patient's recognition of symptoms and acquisition of medical care, the attending physician's diagnosis or submission of a laboratory test, the laboratory reporting test results back to the physician and/or to a public health agency, and the physician reporting the event to a public health agency (MMWR 2001). Also the time required for the identification of trends, outbreaks, or the effect of control and prevention measures are other aspects of timeliness. Some factors that influence the identification process include the severity and communicability of the health-related event, staffing of the responsible public health agency, and communication among involved health agencies and organizations (MMWR 2001).

The timeliness of a public health surveillance system should be evaluated in terms of availability of information for control of a health-related event, including immediate control efforts, prevention of continued exposure, or program planning. The need for rapidity of response in a surveillance system depends on the nature of the health-related event under surveillance and the objectives of that system. With acute or infectious diseases, for example, the interval from the onset of symptoms or the date of exposure might be used. With chronic diseases, it might be more useful to look at elapsed time from diagnosis rather than from the date of symptom onset.

Increasing use of electronic data collection from reporting sources (e.g., an electronic laboratory-based surveillance system) and via the Internet (a web-based system), as well as the increasing use of electronic data interchange by surveillance systems, might promote timeliness of the surveillance system (Effler 1999) (Yokoe 1999)

## 9. Stability

Stability of a public health surveillance system refers to the reliability, the ability to collect, manage, and provide data properly without failure; and availability, the ability to be operational when it is needed. Based on CDC's Evaluating Public Health Surveillance systems, measures of the system's stability include:

- The number of unscheduled outages and down times for the system's computer.
- The costs involved with any repair of the system's computer, including parts, service, and amount of time required for the repair.
- The percentage of time the system is operating fully.
- The desired and actual amount of time required for the system to collect or receive data.
- The desired and actual amount of time required for the system to manage the data, including transfer, entry, editing, storage, and back-up of data.
- The desired and actual amount of time required for the system to release data.

A lack of dedicated resources might affect the stability of a public health surveillance system. Assessing stability based on the purpose and objectives of the system would be a more useful approach.

Because public health surveillance systems vary in methods, scope, purpose, and objectives, attributes that are important to one system might be less important to another. A public health surveillance system should emphasize those attributes that are most important for the objectives of the system.

## **Chapter IV. - Description of Behavior Risk Factor Surveillance systems in U.S., Canada, and Italy.**

The BRFSS of U.S., Canada and Italy use routine telephone surveys that help the states survey adults to gather information about a wide range of behaviors that affect their health. The primary focus of these surveys has been on chronic diseases and health-related behaviors such as not using seat belts; using tobacco and alcohol; not being active, or getting enough physical activity; having unhealthy eating habits and being overweight; and not having preventive medical care services, such as vaccination, screening and laboratory tests. All these behaviors are linked with the leading causes of death—heart disease, cancer, stroke, diabetes, and injury—and other important health issues. Through these questionnaires and interviews data is collected and analyzed, and is disseminated for developing effective health education and intervention programs, and policies to prevent morbidity and mortality from chronic diseases.

### **A. US Behavior Risk factor Surveillance System (BRFSS)**

#### **1. Instruments used to collect data.**

In 1984, the Centers for Disease Control and Prevention (CDC) initiated the state-based Behavioral Risk Factor Surveillance System (BRFSS) to collect prevalence data on risk behaviors and preventive health practices that affect health status. By this time, 15 states participated in monthly data collection. In 1994, all states, the District of Columbia, and the three territories were participating in the BRFSS. Actually, the BRFSS, administered and supported by the Division of Adult and Community Health, National Center for Chronic

Disease Prevention and Health Promotion, CDC, is a state-based system used to gather information through a telephone surveys conducted by the health departments of all 50 states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam, with technical and methodological assistance provided by CDC. Approximately 430,000 interviews of adults were completed in 2007, making BRFSS the largest health survey conducted by telephone in the world.

### **Questionnaire Construction and Distribution**

The BRFSS questionnaire was developed jointly by CDC's Behavioral Surveillance Branch (BSB) and the states. Annually at the BRFSS Working Group meeting in February, program representatives from National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and other parts of CDC have the opportunity to propose to BSB additional and emerging BRFSS questions for consideration, and provide inputs and feedback on the proposed content of the core components and optional modules. After the conference, taking into consideration state priorities, potential funding and other practical aspects, BSB designs core components and optional modules, produces data processing layouts and sends them to the states. States add questions that they have designed or acquired (BRFSS Web site). The purpose of the conference is to improve the BRFSS data collection process and help to develop the BRFSS questionnaire. The following statements form the rationale used in the design of the BRFSS questionnaire:

- The core questionnaire is brief enough to allow the states to add their own questions at the end.
- Questions are designed to yield information about the personal behaviors of respondents rather than those of other household members.

- Questions relate to health behaviors. Non-behavioral question items, such as those about demographic characteristics, knowledge, attitudes, and opinions, should explain, enhance, or otherwise provide more in-depth understanding of health-related behaviors.
- Questions should relate to the leading causes of premature death and disability in the United States.
- The subject matter of the questions is not so sensitive as to seriously distort responses.
- Questions are relevant to the *Healthy People 2010* objectives.
- Questions are chosen based on need for state-specific measurement of questionnaire items.
- Questions are chosen based on need to measure questionnaire items over time.

In order to keep the questionnaire at a reasonable length and highly representative of the state population, states must be judicious when selecting optional modules and state-added questions, to avoid long questionnaires that may result in loss of data for questions placed later in the survey if respondents discontinue before the end. For example, in Delaware, the coordinator restricts the length of the average interview to 15 minutes or less.

### **BRFSS Questionnaire Components**

The BRFSS uses a standardized questionnaire which is divided in three parts:

1. Core component, asked by all states:

- **Fixed core:** Fixed core questions must be asked by all states. It includes queries about current behaviors that affect health (e.g., tobacco use, women's health) and questions on demographic characteristics.
- **Rotating core:** Rotating core questions are asked every other year. It is made up of two different sets of questions, each asks in alternating years by all states, addressing different topics. In the year that rotating questions are not used in the core, they are supported as optional modules.
- **Emerging issues:** Emerging core is a set of up to five questions that are added to the fixed and rotating cores. These questions typically focus on "late breaking" health issues. They are evaluated each year to determine their potential value in future surveys. After one year, these questions are either discontinued or incorporated into the fixed core, rotating core, or optional modules. There are up to 10 emerging issues questions included within the core component.

2. Optional modules, chosen by the states.

3. State-added questions developed or acquired by the states

All health departments must ask the core component questions without modification in wording, however, the modules are optional.

### ***1. Core component***

The core component has core questions which are considered and discussed during the Annual BRFSS Conference. Organizations within the states can submit core questions, and

new questions can be proposed for inclusion in the fixed core, the rotating core, or the emerging issues section. The proposed questions must be formatted for the BRFSS questionnaire using the current questionnaire as a model, and each submission also requires a proposal that includes new questions that meet all question requirements, funding available to support the proposed questions, and rationale supporting the questions. This is the rationale to should follow to support the questions:

1. A statement of funding that will be provided to support BRFSS operations.
2. The origin of the question.
3. History of prior cognitive and validity testing.
4. History of prior use.
5. An analytical plan, in other words, specific prevalence estimates that can be derived from the data.
6. Extent to which the proposed questions satisfy primary and secondary question criteria, as described in the following table:

Criteria	Question Requirements
<b>Primary</b>	<ol style="list-style-type: none"> <li>1. What is the relationship of the variable to personal behaviors linked to promoting health, preventing disease, and reducing health risks?</li> <li>2. Is the question suitable for telephone interviewing?</li> <li>3. What is the pertinence of the variable to <i>Healthy People 2010</i> objectives or priority health issues?</li> <li>4. What is the need to measure the variable over time?</li> <li>5. What is the need to have state-specific data?</li> <li>6. What is the degree to which alternative data sources are unsatisfactory?</li> <li>7. What is the degree to which the prevalence of the variable will be adequate for planned analyses?</li> <li>8. What is the relationship of the variable to other questionnaire topics?</li> <li>9. What is the expected validity of the question?</li> </ol>
<b>Secondary</b>	<ol style="list-style-type: none"> <li>1. Are financial and technical resources available for support of the question?</li> <li>2. How will the question affect questionnaire length?</li> <li>3. Will data benefit the states?</li> <li>4. How widely will the data benefit CDC?</li> </ol>

The contented topics in the core component consist on questions related to health status, health care access, sleep, exercise, diabetes, oral health, cardiovascular disease prevalence, asthma, disability, tobacco use, demographics, alcohol consumption, immunization, falls, seatbelt use, drinking and driving, women’s health, HIV/AIDS, prostate cancer screening, colorectal cancer screening, and emotional support and life satisfaction.

Here are some examples of those questions:

**Section: Health Status**

Would you say that in general your health is \_\_\_\_.

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- Or
- 5 Poor

**Section: Health Care Access**

Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

**Section: Disability**

Are you limited in any way in any activities because of physical, mental, or emotional problems?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

**Section: Tobacco Use**

Have you smoked at least 100 cigarettes in your entire life?

**NOTE: 5 packs = 100 cigarettes**

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

**Section: Diabetes**

**DIABEDU** Have you ever taken a course or class in how to manage your diabetes yourself? [M2.10]

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

## ***2. Optional modules***

The optional modules are sets on specific topics (e.g., smokeless tobacco, oral health, cardiovascular disease, and firearms) chosen by the states. A list of supported optional modules is sent to the states and they must report their optional module selection to BSB by the deadline given for that year. Once chosen, optional modules must be used in their entirety and asked of all respondents. If for any reason the optional modules are modified in any way (for example, if a question is omitted) then they are treated as state-added questions.

### Criteria for Selecting Modules

- Is the module or set of questions necessary to provide baseline data or track progress toward achievement of a *Healthy Delaware 2010* objective or objectives of another established state plan?
- Is the module necessary for collecting baseline data for development of a new program?
- How much length (in terms of number of questions and time to ask them) will the questions add to the survey?
- How much the questions will cost, and is funding available to support the addition? (The estimated cost is approximately \$1,000 per question).
- Are other sources available for the data, or is there a more appropriate resource for collecting it?
- What is the feasibility of collecting an adequate sample size for the desired use?
- How will the data be used? Will the data be used effectively?
- Does the request originate within the Department of Health and Social Services, and will the data benefit the Division and Department?

Below are some examples of optional modules that were added to the 2008 BRFSS questionnaire of Florida:

### **Module 5: High Risk / Health Care Worker**

The next few questions ask about health care work and chronic illness.

**M5.1** Do you currently volunteer or work in a hospital, medical clinic, doctor's office, dentist's office, nursing home or some other health-care facility? This includes part-time and unpaid work in a health-care facility as well as professional nursing care provided in the home.

**INTERVIEWER NOTE:** If necessary say: "This includes non-health care professionals, such as administrative staff, who work in a health-care facility.

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

### **Module 7: Other Tobacco Products**

Now, I would like to ask you questions about your use of tobacco products other than cigarettes.

**M7.1** Have you ever used or tried any smokeless tobacco products such as chewing tobacco, snuff, or snus? (Snus rhymes with goose).

**NOTE:** Snus (Swedish for snuff) is a moist smokeless tobacco, usually sold in small pouches, that is placed under the lip against the gum.

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

### ***3. State-added questions***

States are encouraged to gather data on additional topics related to their specific health priorities through the use of state-added questions. They should identify health data

needs within the state; develop, identify, or solicit appropriate questions; and being aware of limitations on the number of questions that they can use. All proposed state-added questions should be carefully evaluated, and must be adhered to the BRFSS question layout and restricted to the columns reserved for state-added questions. States must notify BSB to discuss the impact of modifications before making any changes to the questionnaire during the year.

BRFSS has a significant amount of flexibility to meet state needs. CDC annually provides the states with a set of approved modules which can be added to the core questionnaire. If any of these modules are used, CDC staff provides basic analysis and data entry, as they do for the core questionnaire. In addition, states have the opportunity to add local questions, which can provide data to meet state-specific needs. Locally added questions, however, will not be analyzed by CDC. In order to add local questions, the DPH or the requesting program must provide resources for cognitive and field testing, and data analysis. Below there are two examples of State-Added questions from the 2008 BRFSS questionnaire of Florida.

### **State-Added 1: Diabetes**

**CATI note: Ask question FL1.1 if question DIABEDU = 1 (Yes). Otherwise, go to question FL1.2.**

**FL1.1** About how long did the course or class you took in how to manage your diabetes yourself last? The total time you spent in course or class may have been spread out over days or weeks.

- 1 Less than one hour
- 2 More than 1 hour but less than 4 hours
- 3 More than 4 hours but less than 8 hours
- 4 8 to 10 hours
- 5 Over 10 hours
- 7 Don't know
- 9 Refused

**FL1.2** Has anyone in your household under the age of 18 ever been told by a doctor that he/she has diabetes?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

### **Requesting Added Data Items**

Requesting for inclusion of additional data items, whether local questions or CDC-supported modules, will be reviewed and acted on by the BRFSS coordinator, in consultation with the BRFSS Advisory Committee, and the Behavioral Surveillance Branch of CDC. If necessary to determine priorities, the advice of the Committee and the Coordinator may be referred to the Division Director for final recommendation. Decisions regarding which questions or modules will be included in the survey will be made by September 1 of the year preceding the survey. Surveillance is done on a calendar year basis.

Requests for additional data items should be made to the BRFSS state coordinator during the spring and summer of the year preceding the survey. All requests must be received by July 1 to be considered for the coming year. Late requests will be considered only for the Division's high-priority issues or for questions relating to timely or emergency issues, and must have the approval of the Division Director.

### **Emergency or Critical Health Issues**

The flexibility of the BRFSS allows questions to be added for a portion of a year under certain circumstances. If a critical health issue or a statewide emergency develops about which the Division needs behavioral or attitudinal data, questions can be added to the

BRFSS at any time during the year. Requests for emergency or critical health issue questions must be reviewed by the BRFSS Advisory Committee, and approved by Director of the Division of Public Health as “critical” or “emergency” questions.

Requests for Added Data Items Must Contain the Following Information for Review:

1. Reason for the request, with a statement of its relationship to the *Healthy Delaware 2010* objectives or other appropriate strategic plan.
2. How the data will be used by the program or agency, and who will benefit.
3. What other sources have been considered for obtaining the data, and reasons for choosing BRFSS.
4. Estimated prevalence of the behavior or risk factor to be measured, based on other national or state surveys, or best available evidence. [Due to sample size issues, we do not recommend BRFSS as the system for gathering data about behaviors with less than 5% prevalence in the general adult population.]
5. If the request is *not* for a CDC-approved module, the number of questions to be asked and a draft of the proposed questions.
6. Amount and source of available funds to cover the request.
7. How frequently would the questions need to be asked (every year, every other year, every five years, etc.) and justification. This should be based primarily on expectations for change in the prevalence.
8. Type of additional analysis the requesting program will conduct, and data needed for that analysis.
9. Prior use of the questions (have they been used in other states, other surveys? have they been field tested?).

For locally developed questions, once accepted, the BRFSS coordinator will work with the requester on question wording, question placement and order, and cognitive and field testing.

The data derived from BRFSS questionnaires provide health departments, public health officials, and policymakers with necessary behavioral information. When these data is combined with mortality and morbidity statistics enable public health officials to establish policies and priorities to initiate and assess health promotion and prevention strategies.

## **2. Data gathering processes.**

States conduct monthly telephone surveillance using a standardized questionnaire to determine the distribution of risk behaviors and health practices among adults. They collect the data through the monthly telephone interviews with no institutionalized adults aged 18 years and older. BRFSS interviewers ask questions related to behaviors associated with preventable chronic diseases, injuries, and infectious diseases, providing state-specific benchmarks for prevention (tobacco use, nutrition, physical activity, and weight gain as measured by obesity) and early detection of disease (mammograms, Pap tests, and colorectal and prostate cancer screening tests). Responses from surveillance questionnaires are forwarded to CDC, where the monthly data are aggregated for each state, returned with standard tabulations, and published at the year's end by each state.

## Sampling Selection and Screening

States obtain samples of telephone numbers from BSB. They review sampling methodology with a state statistician and BSB to make sure data collection procedures are in place to follow the methodology. If any change in sampling methodology is considered, states **MUST** consult with BSB before making changes (BRFSS Website).

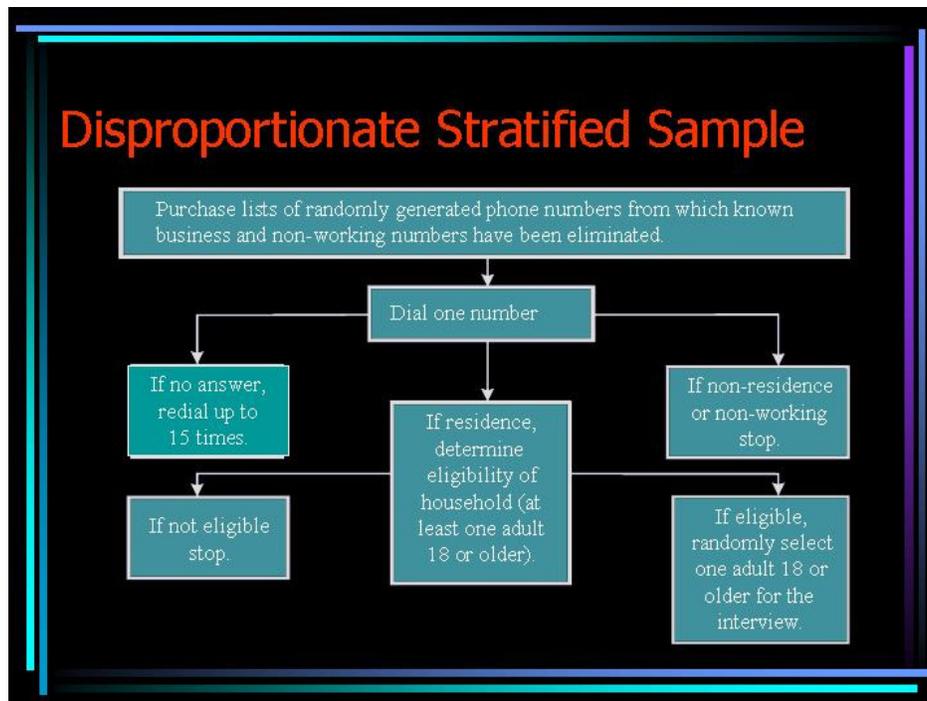
Data are collected from a representative sample in each state, and the sampling is designed to provide national estimates when all state data are combined (Iachan, Schulman, Powell-Griner, Nelson, Mariolis, Stanwyck 2001).

The sampling design or method used to select respondents to interview is known as sampling method or sampling strategy. This method of choosing telephone numbers must be statistically valid, which means, that the resulting sample must be a probability sample, in which all households with telephones have a known, nonzero chance of inclusion, so information obtained from the sample can be used to generalize results to the total population in the state as well as to the nation as a whole.

With the disproportionate stratified random sampling (DSS) design, implemented in the BRFSS in 2003, telephone numbers are drawn from two strata (lists) that are based on the presumed density of known telephone household numbers. In this design, telephone numbers are classified into strata that are either high density (**listed 1+ block** telephone numbers) or medium density (**not listed 1+ block** telephone numbers) to yield residential telephone numbers. Telephone numbers in the high density stratum are sampled at the highest rate. The rate at which each stratum is sampled is called the *sampling rate*. The ratio of the sampling rate of one stratum to sampling rate of a reference stratum is called the *sampling ratio* (BRFSS 2006). In this way, sampling telephone numbers is more efficient compared to simple random sampling. Interviewers call **listed 1+ block** numbers at a higher rate than **not**

**listed 1+ block** numbers, achieving a high hit rate (compared to simple random sampling) and still achieve a statistically representative sample. In Figure 3 there is a graphic explanation of DSS.

**Figure 3: Disproportionate Stratified Sample (DSS).**



### Sample Size

Sample size refers to the number of telephone numbers that must be called within a given period of time. There are some factors influencing sample size such as, cost of collecting and processing survey data, number and size of subpopulations — for example racial or ethnic minority groups, or persons aged 65 years or older — for which estimates are desired, and desired level of confidence in estimates. BSB's goal is to support at least 4,000 interviews per state.

## **Selection Criteria**

First, interviews must identify if the number they have dialed is a household. A household is eligible if it is a housing unit with a separate entrance where occupants eat separately from other persons on the property and is occupied by its members as their principal or secondary place of residence. In case of finding vacation homes not occupied by household members for more than 30 days per year, group homes, or institutions, those would be considered as noneligible households for interviewing.

Once a telephone number is determined to be a household, a random selection procedure must be used to select the appropriate household member to interview. At this point is important to recognize that household members include all related adults 18 years old or older, unrelated adults, roomers and domestic workers who consider the household their home, even though they may not be home at the time of the call. Does not include adult family members who are currently living elsewhere, such as at college, a military base, a nursing home or a correctional facility (VAhealth.org).

The first question on the BRFSS questionnaire regarding household selection asks how many members in the household are 18 years of age or older:

- If the answer is one and the person answering the telephone is that adult, the interviewer proceeds to the first question on the questionnaire.
- If the response indicates that there are five or more adults, the interviewer should probe to ensure that they all are 18 years of age or older, that all are currently living in the household and that the household is not a group home or institution.

The next question would ask how many of the adults are men and how many are women. The interviewer enters the appropriate answers. If there is only one adult in the household, the interviewer enters "1" and leaves the other box blank. If there are more than one adults living in the household, the interviewer asks to speak to the adult with the most recent birthday. This adult is then selected to complete the BRFSS.

### **Monthly Data Collection**

During the monthly collecting data process all the states must follow a survey protocol that consists on:

- All states must ask the core component questions without modification. They may choose to add any, all, or none of the optional modules and state-added questions after the core component. Deviation from protocol will be addressed by the chief, survey operations, or the branch chief.
- Systematic electronic monitoring should be a routine part of the monthly survey procedures for all interviewers.
- Understanding the definitions of eligible and non-eligible household unit, as well as of a household member.
- Individual respondents are randomly selected from all adults' aged 18 years and older living in a household and are interviewed in accordance with this protocol.
- An interview is considered complete if data are collected for age, race, and sex. If values on age or race are not entered, imputed values will be generated and used only to assign post-stratification weights.
- Unless electronic monitoring of interviewers is being routinely conducted, a 5% random sample of each month's interviews must be called back to verify selected responses for quality assurance.

- With the exception of verbally abusive respondents, eligible persons who initially refuse to be interviewed will be contacted at least one additional time and given the opportunity to be interviewed. Preferably, this second contact will be made by a supervisor or a different interviewer.
- Call attempts on all sample pieces should be completed during the calendar month of the sample selection.

BRFSS surveys will provide monthly behavioral information that will help public health professionals determine health conditions prevalence in the states. For example, on the 2009 BRFSS survey, every respondent will be asked at least one of the following four questions:

1. Have you ever been told by a doctor, nurse, or other health care professional that you had cancer?
2. *[If yes]* At what age were you told that you had cancer?
3. How many different types of cancer have you had?
4. *[If one]* What type of cancer was it?  
*[Or if more than one]* With your most recent diagnosis of cancer, what type of cancer was it?

In addition to this information, states could choose asking questions to measure follow-up care (who is providing the care and where), treatment plans, and pain management.

During this data collection process, states will conduct interviews during each month in accordance with a prescribed protocol, and incorporate surveillance results into computer-assisted telephone interviewing (CATI) computer files. They will also edit and correct completed interviews each month. Collecting data from the BRFSS surveys convert this surveillance system as the primary source of data for local health entities reflecting the health-related behaviors of populations and providing an abroad view of the health status of the nation.

Following the annual questionnaire construction and distribution, sample selection and screening, and the monthly data collection; data management and reporting continue the data collecting process. These steps consist on:

- Submission of data from each state.
- BSB weights data annually according to state-specific population estimates provided for each state.
- BSB produces and distributes yearly, state-specific, standard cross-tabulations of responses and risk-factor prevalence estimates for statewide core and optional module data, nationwide summaries of state-specific risk-factor prevalence estimates, and nationwide summaries of state-specific response rates.
- BSB and states publish analyses of data.

Data collected will allow states identifying emerging health problems, establishing health objectives and tracking their progress toward meeting them. Also states might use data to plan, conduct, and evaluate public health polices and programs to address identified health problems.

### **3. Implementation of the surveillance system including: Resources, Training, and Funding**

#### **Resources**

Description of the system's resources should consider all levels of the public health system, from the local healthcare provider to municipal, county, state, and federal health agencies. Resources directly required to operate a public health surveillance system are sometimes referred to as "direct costs" and include the personnel and financial resources expended in operating the system. The assessment of these resources could also include the estimation of indirect costs, and costs of secondary data sources such as follow-up laboratory tests and vital statistics or survey data respectively.

#### **Personnel**

BRFSS resources include managing, recruiting, and training staff.

#### **Coordinator Responsibilities**

The BRFSS coordinator is responsible for the overall administration of the BRFSS questionnaire and ensuring data integrity through all steps of the BRFSS process. These responsibilities are divided in six groups:

1. **Management and Staffing:** Coordinator selects appropriate staff to perform all necessary roles; monitor performance of in-house staff and contractors; and ensure adequate training and retraining for all BRFSS staff.

2. **Questionnaire Development:** Develop or acquire state-added questions and oversee selection of optional modules that meet the needs of the state.
3. **Survey Methodology:** Ensure that survey design and implementation follow BRFSS guidelines and BSB requirements.
4. **Data Collection:** Ensure that telephone interviews are conducted according to protocol; that data are properly edited, corrected, and submitted on time; and that quality assurance statistics are monitored and quality assurance procedures are followed.
5. **Funding:** Manage the budget, and identify and secure sources of additional funding. This the most difficult responsibility as a BRFSS coordinator: securing enough funding to support the BRFSS unit each year ( BRFSS 2006).
6. **Data Analysis, Use, and Promotion:** Promote the use of BRFSS DATA among Public Health Programs.

Coordinator needs to have good management skills necessary to manage and solve annual funding problems as well as analysis skills. Both are necessary to ensure that the BRFSS data are used to the fullest extent. Ones of the most important responsibilities of a coordinator are to make sure the BRFSS activities meet the needs of the health department in monitoring both the health status of the citizens in the state and the state's overall progress toward the Healthy People 2010 objectives, and also to find time to devote to the analyses of the data once they are collected in order to get the data used. It is vital that the BRFSS unit collects and provides the data needed by the various programs within the health department.

### **Primary Supervisor Responsibility: In-house Data Collection**

Supervisor's responsibility resides on the day-to-day operations of survey administration. Basically, supervisors are responsible for sample management, which refers to controlling the release of telephone numbers to interviewers, tracking appointments made to complete the survey, and assigning proper disposition codes to interviews. Also, supervisors are responsible for survey supervision, quality assurance, and procedure adherence. Mainly, supervisors oversee daily data collection activities and are responsible for ensuring quality interviews and adherence to protocol. They are usually recruited from among interviewers. Most states will need more than one supervisor. Most of them will need one supervisor in charge of the overall BRFSS operation; a few supervisors to monitor interviews for consistency and accuracy; and normally both a day and a night supervisor are necessary.

### **Interviewers: Gathering the Data**

The core of the BRFSS staff is the interviewers, an essential part of survey research. They are the only link between the persons being surveyed and the public health officials who will use that data. Competent interviewers help insure the integrity of the data; and their job is to follow protocol and complete interviews honestly and accurately. Interviewing is part-time or temporary work, usually 10 to 30 hours a month, primarily nights and weekends. They are trained to:

- Understand the nature and content of the questions
- Ensure respondent confidentiality.
- Perform respondent selection procedures.
- Record responses properly.

- Ensure that the correct respondents are interviewed.
- Make quality a priority in all aspects of interviewing. Follow BRFSS protocol.
- Appropriately deal with interview problems.
- Attempt to convert refusals into complete interviews.

### **Data Processing: Making the Data Usable**

CATI manager usually processes the data collected before submission to BSB, in addition to keeping the CATI system running. CATI manager edits and corrects monthly data, submit data to BSB, and generates monthly quality assurance and data reports. CATI managers need to have strong computer and programming skills, and supervisors often fill this role. CATI management is a part-time or temporary work that requires more hours at the beginning and at the end of the monthly data collection cycle.

### **Statistical Support**

Health departments should enlist the aid of their own statisticians for analysis of state data. However, BSB may provide some support when staffing is available and warranted. They provide assistance with both sampling design and the data collection process. Statistical consultation is strongly recommended throughout the surveillance process, particularly during data analysis.

### **Recruiting**

BRFSS staff (interviewers, supervisors, and CATI managers) can be recruited from a variety of sources, such as:

- Job placement services in community organizations
- Temporary service agencies

- Local marketing research firms that subcontract
- Health department personnel working for extra pay
- College students
- Retired persons

## **Training**

Training is an important part of the BRFSS process and includes an overview of:

- BRFSS background, elements of a surveillance system, surveillance procedures, BRFSS roles and interviewer, coordinator, supervisor, or CATI manager responsibilities.
- Review of survey questions, pronunciation of medical terms, disposition codes, CATI training, respondent selection process, and refusal conversion.
- Quality control procedures, BRFSS protocol.
- Work scheduling, refusals and appointment assignments, and legitimacy verification calls.

Topics for the on-going monthly training depend on needs. Coordinators developed policies and trainings to address related issues of:

- Respondents in crisis (suicide).
- Bias of respondents during conversations with interviewers.
- Respondents that assume that interviewers are trained public health professionals, and will sometimes confide highly sensitive information.
- Refusal conversations.
- Situations when a respondent began to share his political or religious views after the interview is over

- Situations of some verbal abuse from someone she hoped would be a potential respondent.

In addition, an important issue addressed during training is the interviewers' comfort with the questions. Unfamiliar terms, sexual assault questions, and intimidating question wording, are reasons for discomfort that are addressed during the training in order to provide solutions to these type of situations and teach the best way to deal with them.

### **Refresher Training**

BRFSS offers refresher training for interviewers as an ongoing process. After initial training, refresher training occurs yearly for each new questionnaire; monthly for state-added questions that have changed or been added; and also as indicated by the interviewer monitoring or by interviewer statistics. Training is a critical part of the BRFSS process and is refreshing on-ongoing time.

### **Funding**

In the United States, public health surveillance often results from collaboration among federal, state, and local governments. Funding received from CDC does not come close to covering the costs of operating the program so each year there is a struggle to find funding to supplement the federal funds. BRFSS is supported in part by funds from Cooperative Agreement No. U 58 between the CDC and the states' Department of Health. As part of those agreements, CDC requires that a specified core questionnaire be used each year.

#### **4. Response rates**

The literature provides evidence that the median BRFSS response rate increased from 51.1 percent in 2001 to 58.3 percent in 2002. However, in 2006 “The Race, ethnicity, and linguistic isolation as determinants of participation in public health surveillance surveys” study, found that “participation rates were significantly lower in counties with higher percentages of black people and people who did not speak English. Response rates decreased by 4.6% in counties with the highest concentration of black residents compared with counties with few black residents. Likewise, response rates decreased by approximately 7% in counties in which a larger percentage of the population spoke only Spanish or another Indo-European language compared with counties in which all residents spoke English ( Link MW, Mokdad AH, Stackhouse HF, and Flowers NT 2006). They concluded: “The negative relationship between the percentage of Spanish-only-speaking households and participation rates is troubling given that the BRFSS is conducted in both Spanish and English. The findings also indicate that more needs to be done to improve participation among other minorities. Researchers are investigating several ways of addressing disparities in participation rates, such as using post-survey adjustments, developing more culturally appropriate data-collection procedures, and offering surveys in multiple languages” ( Link MW, Mokdad AH, Stackhouse HF, and Flowers NT 2006).

Response rate is influenced by multiple factors such as rapid changes in telecommunication, increases in the required level of effort and associated costs, characteristics of each type of questionnaire such as physical characteristics, content, and administration methods. That rate of return is also influenced by some aspects such as clarity and brevity of interviews and questionnaires; familiar but not overly personal subject matters;

and use of convenient methods of completion and return of questionnaires. People wished to know the purpose of the research and sometimes they would like to know about the researchers, and also to be assured of confidentiality. All these factors should be recognized in surveillance systems, and analyzed in order to obtain better response rates.

Based in part on recommendations from the Expert Panel Meetings, BRFSS has undertaken a number of innovative and informative pilot studies and analyses to improve the BRFSS response rate, including the following:

### **Use of pre-notification letters and messages on answering machines**

In telephone surveys, advance letters can improve participation. When tested in a number of states, letters improved response rates, on average, 6 percentage points. The letters were also cost efficient in that the cost of obtaining a fixed number of completed surveys using advance letters was lower than the cost without letters. As a result, advance letters are recommended for use with the BRFSS in all states. Messages left on the answering machines of potential respondents did not, however, improve response rates significantly. This is likely due to the relatively small percentage of sample members who remembered hearing the message and who found the message to be effective in persuading them to participate in the survey.

### **Assessing the impact of the Do Not Call Registry**

More than 100 million telephone numbers have been listed on the National Do Not Call Registry since it began in 2003. To assess the potential impact of the registry on participation rates in BRFSS, case outcomes were examined from nearly 4.5 million telephone numbers called between January 1, 2002, and June 30, 2005. Using trend analyses

and time series modeling, the findings indicated that once pre-DNC Registry trends in response rates and other potential covariates were accounted for, the do-not-call rules appeared to have had no significant impact on state-level response rates in either a positive or negative direction.

### **Use of real-time telephone survey interpreters**

Real-time interpretation during a survey can expand the number of languages in which surveys are offered. A detailed assessment of the quality of this approach was conducted as part of the BRFSS in California using behavior coding of interviews conducted with respondents who otherwise would have been finalized as “language barrier nonrespondents.” Interviews were recorded and behavior coded, quantifying for each question (1) the accuracy of the question interpretation, (2) the accuracy of the interpreted response, (3) the degree of difficulty administering the question, (4) the number of times the question was repeated, and (5) the number of times the interpreter and respondent engaged in conversation that was not relayed to the interviewer. The approach produced favorable results, with less than a 4% error rate for interpretation of the questions and a 1% error rate in interpretation of survey responses.

### **Use of Web and mail questionnaires**

Web and mail versions of the BRFSS questionnaire were administered to potential respondents drawn from the standard BRFSS telephone sampling frame and reverse-matched to identify valid mailing addresses. Telephone survey follow-up was conducted with Web and mail survey nonrespondents. The findings suggest that self-administered modes, when used in conjunction with telephone follow-up, can improve levels of participation, but may

also increase differences between respondents and nonrespondents on certain measures of interest such as respondent demographic characteristics and key health and risk measures.

### **Use of Address-Based Sampling (ABS)**

Advances in electronic record keeping have allowed researchers to develop and sample from a frame of addresses, which appears to provide coverage that rivals that obtained through RDD sampling methods. A pilot study conducted in 2005 compared use of traditional RDD telephone survey methodology to an approach using a mail version of the questionnaire completed by a random sample of households drawn from an address-based frame. The findings indicate that the mail survey approach can achieve higher response rates in low-response-rate states (< 40%) than RDD (particularly when two mailings are sent). Additionally, the address frame with mail survey design provides access to households with cellular telephones only and offers cost savings over the telephone approach.

### **Improving the current BRFSS weighting methodology**

Post-survey adjustments are becoming an increasingly important means of maintaining the representativeness of survey data. Using statistical raking techniques, the approach to weighting BRFSS data is being re-evaluated. The new approach adjusts the data not only in terms of respondents' sex and age, but also race (in a more consistent manner), education, and telephone coverage—variables all found to be significantly related to key health and risk outcomes on BRFSS.

Table 3, represents an example of sample size and response rate obtained from the BRFSS of the state of Florida. As the response rate varies over time, we could assume some factors should influence more than others on those rates.

**Table 3: Sample Size and Response Rate, Florida BRFSS**

Year of survey	Sample Size	CASRO**
1986	1,162	
1987	1,238	53.0%
1988	1,483	66.0%
1989	1,683	66.0%
1990	2,143	64.8%
1991	2,240	37.7%
1992	2,719	64.6%
1993	3,087	66.0%
1994	3,573	66.7%
1995	3,335	54.8%
1996	3,575	55.8%
1997	3,495	49.4%
1998	4,724	32.5%
1999	5,177	37.0%
2000	5,202	41.5%
2001	4,683	34.53%
2002 (State)	6,150	44.4%
2002 (County)	34,551	51.0%
2003	5,038	43.2%

2004	7,153	42.6%
2005	8,190	N/A

\*\*The response formula used in BRFSS is developed by Council of American Statistics Research Organizations

## **5. How the data is used**

Once the data is collected and analyzed, it should be available to be used for public health action. Health departments use the data for different purposes, including to identify demographic variations in health-related behaviors, target services, address emergent and critical health issues, propose legislation for health initiatives, measure progress toward state and national health objectives, and design program and policy evaluations. All collected information is also useful for policy development, program planning, program evaluation, priority setting, intervention design, trend assessment, and risk group identification.

One of the global examples of the usefulness of data is the monitoring progress toward the eradication of poliomyelitis. Surveillance data allowed to see the dramatic decrease in paralytic poliomyelitis in the United States in the decades following the licensure of inactivated polio vaccine in 1955 and the oral polio vaccine in 1961 (MMWR 1998). Based on that surveillance information, the World Health Organization (WHO) has implemented intensive vaccination programs in areas where the decline of polio has not been as significant, using the similar data from countries around the world.

Other example is how the BRFSS data is been used in the state of Georgia. Georgia has used the system to:

- Report physical activity levels in each of Georgia's 159 counties and estimate the overall burden of inactive and irregularly active lifestyles on deaths, hospitalizations, and hospital charges for related health conditions.
- Highlight the public health burden of arthritis in the state, address disease awareness, and compare Georgians with and without arthritis in terms of health status, employment, inactivity, and weight.
- Provide a scientific basis for collaboration among public and private medical providers to reduce cancer-related illness and death through behavioral change and improved screening and detection.
- Collect baseline information on the prevalence of disease and screening in support of the state's osteoporosis prevention initiative.
- Support behavioral risk factor surveillance in health districts in the state that have initiated their own population surveys.

On the other hand, it is important to recognize that data collected from BRFS systems are not only used to program planning, implementation, and evaluation, but also to formulating research hypotheses and for immediate public health action. For example data from public health system can be used to measure burden of a disease, monitor trends in burden of a disease, detect changes in health practices, prioritize the allocation of resources for public health purposes, and provide basis of epidemiologic research.

## **B. Italian Behavioral Risk Factor Surveillance System – PASSI (Progressi delle Aziende Sanitarie)**

In 2006, the Center for Disease Control and Prevention at the Italian Ministry of Health (MoH) entrusted the Italian National Health Institute (Istituto Superiore di Sanità, ISS) with the task of developing a system for continuous surveillance over the adult population (Rapporti ISTISAN 2007). In that year, the Italian Ministry of Health (MoH) in order to improve and support the public health of the country, funded the National Center for Epidemiology, Surveillance and Health Promotion (CNESPS) to develop ongoing surveillance of behavioral risk factors and preventive measures included in the National Prevention Plan over the adult population in Italy (Baldissera 2007).

The National Center for Epidemiology, Surveillance and Health Promotion (CNESPS) is one of the seven National Centers of the Istituto Superiore di Sanità (ISS), and is organized in 9 Units (e.g., the Communicable Disease Epidemiology Unit) plus the Statistics, Training, and Communication Offices (EpiSouth 2008).

The Istituto Superiore di Sanità (ISS) is the leading technical and scientific public body of the Italian National Health Service. Its activities include research, control, training and consultation in the interest of public health protection. This Institute is divided in seven Departments and seven National Centers (NCs). The NCs are technical scientific structures which carry on research, control, training activities and consultation, also involving different departments within the ISS, and play a coordinating role with institutions outside the ISS (EpiSouth 2008).

In 2006, the National Center for Disease Prevention and Control (CCM) funded the ISS to develop an ongoing surveillance system to collect, analyze, and disseminate data related to behavior risk factors and prevention health measures over the Italian population. This project was called PASSI (Progressi delle Aziende Sanitarie) the Italian Behavior Risk Factor Surveillance system.

Prior to PASSI, in 2005-2006 the National Institute of Health (Istituto Superiore di Sanità - ISS) in cooperation with the Italian regions conducted two cross-sectional pilot surveys to demonstrate the feasibility of having an ongoing telephone survey surveillance system that provide local and regional data for public health interventions in the Italian Health System. They tested surveillance questionnaires, sampling methods and design, protocols for gathering data, data analysis, and implementation; for the future implementation of a surveillance system. Based on results obtained from these pilot studies and the necessity to promote healthy lifestyles and implementation of preventive measures in Italy, in 2006 PASSI, the Italian Behavior Risk Factor Surveillance system, was launched as an experimental approach useful in the behavioral risk factor surveillance, and monitoring of programs for the prevention of chronic diseases.

The main objective of PASSI is to estimate the frequency and evolution of behavioral risk factors for health and the diffusion of preventative measures, over-time. Production and dissemination of information relevant to public health professionals and community are PASSI's priority goals (Massimo 2007). This surveillance system was adopted on all the 21 administrative Italian regions where they were agreed to participate. The Italian regions comprises one or up to 22 local health units (LHU) which offer preventive medical services

for populations ranging from 40,000 to over a million. Actually, PASSI is focused on Italy's 180 Local Health Units (LHU) being a national system with a local implementation.

#### **1. Instruments used to collect data.**

PASSI is a cross-sectional telephone survey conducted by local health units with technical and methodological assistance provided by the Istituto Superiore di Sanità (ISS) and CDC's Behavioral Surveillance Branch (BSB). It is designed to produce appropriate and timely results for assisting local decision makers and public health professionals. Through this surveillance system behavior risk factors and preventive health practices data are collected and provided for public health action.

#### **Questionnaire construction and distribution**

The construction of PASSI questionnaires was mainly based on the US BRFSS's protocol (CDC) in agreement with the Regions and the Ministry of Health. Similar international surveillance surveys, in particular the BRFSS in U.S., were taken as a references to follow in the construction and distribution of questionnaires, however, the questionnaire and the PASSI's protocol were rewritten, adapting them to the Italian context. Some questions from international surveillance systems have already been tested for validity and comparability providing valuable information to PASSI.

Steps, ISTAT, Cindi, and most BRFSS's surveys were adapted to the Italian populations based on the economic, demographic, and epidemiological characteristics of this country. The adaptation process was carried out by the PASSI national group, personnel of the ISS,

and Regional representatives. Basically, questionnaires consist on close-ended and multiple choice type of questions and provide 114 questions, many administered to specific subpopulations (e.g. cancer screening) or categories (e.g. present smokers). Topics included in the questionnaires and also priorities of the National Health Plan are:

- Quality of life
- Smoking habits
- Physical activity
- Diet
- Alcohol consumption
- Driving behavior
- Cardiovascular risk factors
- Cancer screening
- Vaccinations
- Mental health
- Domestic accidents
- Socio-demographic aspects

### **PASSI Questionnaire Components**

PASSI questionnaire is divided in four parts:

1) **Fixed core component:** standard set of questions, asked by all participating Regions, intended to remain unchanged for many years.

2) **Rotating Core component:** sets of questions, asked in alternating years by all participating LHUs and address different topics.

3) **Optional Modules:** questions that Regions elect to use on their questionnaires to satisfy specific information needs.

4) **Emerging Modules:** consisting of a few questions administered for brief periods of time, to gather timely information on important issues of a "late breaking" nature.

The core questionnaire consists of 114 questions distributed in 12 modules. Fixed core components are represented by 14 sections. Table 4, shows the specific topics contented in the Fixed Core component and the Optional Modules respectively.

**Table 4: Topics of PASSI's questionnaire**

<b>Fixed core modules (at June 2009)</b>	<b>Target population</b>
Self perceived health and quality of life	All
Smoking habits	All
Alcohol consumption	All
Screening for tumors	
- uterine cervical cancer	Women, 25-69 years
- breast cancer	Women, 40-69 years
- colon-rectal cancer	Women and Men, 50-69 years
Diet and nutritional status	All
Physical activity	All
Mental health	All
Cardiovascular risk factors	All
Adult vaccinations	
- influenza	All
- rubella	Women, 18-49 years

Prevention of traffic accidents	All
Prevention of domestic accidents	All
Socio-demographic aspects	All
<b>Regional optional modules (since June 2008)</b>	<b>Target population</b>
Prevention of traffic accidents (supplement)	All
Hormone replacement therapy	Women, 45-60 years
Children health promotion campaign	All

Annually revisions are scheduled in order to adapt new questions at the questionnaires in a more adequate format related to the Italian culture and behaviors. Those changes and improvements following the needs of the public health policies and the evidence gained about the issues addressed in the surveillance.

During the first two years of PASSI data collection, the fixed core has had two minor revisions, and three optional modules have been added. In this fall 2009, the pandemic FLU A-H1N1 emerging module is being implemented. “Rotating modules will be adopted in 2010 however the ISS will probably transform some fixed components, like “domestic accidents”, in rotating ones.” (Ferrante 2009).

### **Criteria of Selecting Modules**

A single region or a LHU may propose a topic to investigate on the base of their specific needs. Then a work group is created to develop and analyze the following aspects:

How the module will provide baseline data or track progress toward achievement of the National Health Plan; How much length will the questions add to the survey; How is the feasibility of collecting an adequate sample size for the desired use; How will the data be used; and how much the questions will cost in order to add either optional or emergency modules. Once the modules are ready to be added, other regions can decide to administer the modules based on their particular needs.

### **Requesting Added Data Items**

Requesting for inclusion of additional data items, must be at least six months before implementing the questionnaire. The requesting proposal must be evaluated by the coordinating group; and an operative version must be released and tested through a pilot in selected LHUs to identify changes. In case that not changes need to be performed the final version will be ready for the regions who want to administer those data items; otherwise changes are need to be made, evaluated, and approved by the coordinating group before data items been added to the questionnaire.

## **2. Data gathering processes.**

The Italian behavior risk factor surveillance system - PASSI is an ongoing telephone survey that collects information on health risk behaviors and preventive health practices related to chronic disease and disability. For many regions, PASSI is an available source of timely, accurate data on health –related behaviors useful for public health action.

In Italy, the National Health Service was introduced in 1979 to guarantee health care as a fundamental right of the individual. Since that date, residents at the Local Health Units must register with a local general practitioner, and they are free to choose their doctors. Each doctor is in charge of no more than 1,500 patients. General physicians are funded by the Local Health Unit (LHU) with a fixed allowance per patient registered, regardless of the number of consultations, prescriptions, or any other medical provisions of care. The system enforces patients to visit the practitioner before seeing the specialist or attending hospital or community departments. However, special rules exist for patients attending psychiatrists, dentists, and optometrists, and they may refer themselves directly (Cooper B and Eastwood M.R 1992). Based on this Health System, in Italy, LHUs have access to all residents' demographic data including gender, age, race, name, address, and in some cases telephone numbers; keeping and updating those databases for public health surveillance.

“To ensure the comparability of the results among Regions and LHUs and in different years, it was decided to utilize the same questionnaire nationwide, to share a common information system and database, and to provide a central supervision and support for training, data analysis and communications activities.” (Baldissera 2009).

PASSI staff at the public health departments of each participating LHU performs:

- Telephone interviews and collection of data.
- Entry and analysis of data.
- Dissemination and communication of results.
- Promotion of data use for public health planning, implementation and evaluation of programs.

LHUs' teams receive assistance from Regional coordinating groups, while the national coordinating committee, based at the CNESPS, supervises the functioning of the system to ensure a valid collected data, accurate interpretation and analysis of the data, and an effective channel of communication for that data being used.

LHUs conduct monthly telephone surveillance using a standardized questionnaire to determine the distribution of risk behaviors and health practices among adults. Specially trained LHU staff conducts telephone interviews, after briefly explaining the objectives of the surveillance and obtaining an oral consent. They collect the data over local health unit residents aged 18 and older, and entry that data either using a computer or computer assisted telephone interviewing (CATI). “Collected data are entered through a client on a personal computer, encrypted and transmitted through the Internet to a common national server. No personal identifiers appear in the database.” (Baldissera 2009). PASSI practitioners have protected access to the server through a dedicated web portal (<http://www.passidati.it/>), with individual user-names and passwords and differentiated access profiles. Uploaded records are accessible to the local coordinators and any input error can be corrected on-line. When collection and entry the data is finished in a calendar year, data are edited at central level, and appropriate data weights are added to account for the demographic composition of the adult population in each participating LHU. After that the datasets of Regions and LHUs are made available for downloading.

PASSI administers telephone interviews by trained local health personnel to minimum 25 persons per month in each LHU, using either paper or CATI questionnaires. Interviewers should complete at least 275 persons per year per LHU. For example, in 2007:

21,489 interviews were executed with 85% response rate (Pirous 2009). The interview duration is approximately 20 minutes. However, not duration limits are imposed.

In some cases, many questions are administered only to specific population subgroups, which mean that most people receive just one part of the questionnaire. Telephones numbers for each selected person are obtained from the enrollment LHU lists, telephone directories, physicians, or by the persons themselves calling to establish an appointment to collaborate with PASSI surveillance. Letters are sent in advance to selected individuals and families explaining the purpose of the system and informing that they will be contacted shortly; associate general practitioner and their physicians are also informed about PASSI and its process. Interviewers don't have the possibility to know when the letter is delivered. Usually they give the first call ten day after sending the letter.

At least six attempts are made to call on different days of the week (including weekends) and at different times during the day; if the selected person cannot be reached, a substitute from the same sex and age group is randomly selected. This procedure is aimed to ensure the representativeness of the sample at the LHU level.

LHUs and Regions have full autonomy in the preparation of data and communication of results. Regional coordinating groups give assistance to and support the working teams of LHUs. The national coordinating group, CNESPS of the ISS supervises the application of methods and standards of the process to ensure quality data collection, reliability of results and comparability of information, obtained in different geographical areas and periods of time. In particular, the National Technical Group (GT) presides over the process of verification and correction of the interviews and makes available the dataset after appropriate quality controls to programs to perform the main analysis.

As a result of this collection data process, valid (true) data is available, providing evidence based prevention information useful to decision makers and public health professionals interested in the wellness of the community. Additionally, through all this collecting process, PASSI encourage collaboration, participation and integration of different departments and services in order to obtain a valid data ready to be disseminated and used to make public action. Once the data is collected, analyzed, and reported by the LHUs, it is forwarded to a central server. Here the main monitoring indicators are calculated (response rate, refusal rate, etc.) and published on the [passidati.it](http://passidati.it) website. “Once in a year, after appropriate quality controls, ISS release datasets aggregated per LHUs, regions or pool. Each LHU is responsible for analyzing and disseminating its own results; and the ISS analyzes and disseminates the results at the pool level.” (Ferrante 2009).

and the ISS analyzes and disseminates the results at the pool level; data is disseminate to all the regions and exposed to public health professionals for conducting, planning, implementing and evaluating public health programs.

### **Sampling Design**

PASSI uses Stratified Random Sampling method, stratifying by sex and age. There is a random systematic sampling in each stratum, which is defined by age groups and sex, such as females vs. males, and 18-34 vs. 35-49 vs. 40-59 years. Each sample is representative of the 6 strata of investigated population. One sample is monthly collected either once or twice times a year, depending on the taking time used to update the list of residents in the LHU. The minimum sample for each LHU is 25 interviews a month for LHU sampling having at

least 275 per year per LHU. The minimum sample for each region is 600 interviews a year for regional sampling. Through this sampling strategy is intended to constitute a statistically representative sample of the variables under investigation.

### **Sample Size**

For the purposes of PASSI a sample is extracted from the list of enrolled residents at each LHU selecting a monthly random sample of persons between 18-69 aged, posteriorly stratified it by six sex-and-age groups ( 18-34, 35-49, 50-69 years) based on the proportion of local population obtained for each of these strata. This sample size allows obtaining annual estimates of main variables presented at the LHU with an acceptable precision. On the other hand, regional and national pool estimates are calculating aggregating the data from the different LHUs. At this point, since the LHUs differ considerably in terms of population size and por consiguiente in sample size, data need to be weighted. This weight is calculated for each LHU, taking into account the number of interviews performed in each of the six strata of the unit's sample and the size of the corresponding strata of the LHU's population.

### **Selection Criteria**

The inclusion criteria used to select individuals to participate in the PASSI surveillance system include:

- Range of Age from 18 through 69 years.
- Reside in the LHU area.
- Have the availability of a telephone number (mobile or land-line, obtained through various sources).

- Be able to hold a conversation in Italian, or in some cases in other official language of their regions,
- Being present during the time of the investigations, which means not being hospitalized or institutionalized (Pirous 2009) (Baldissera 2009).

### **3. Implementation of the surveillance system including: Resources, Training, and Funding**

#### **Resources**

##### *Personnel*

Include all Regional Working Group: coordinators, interviewers and public health experts.

##### **Coordinators Responsibilities**

PASSI coordinators are responsible for the overall administration and managing of PASSI surveillance system. Some of their responsibilities consist on questionnaire construction and distribution, survey methodology, data collection, funding, data analysis, used and promotion. They manage all the surveillance process from contracts and supervision of equipment until data use and promotion. They also in charge of selecting appropriated personnel and contractors necessary for the developing of the system; and ensure training for all PASSI staff.

##### **Interviewers: Gathering the Data**

They are a key element in the system. They contribute to the integrity of the data

following protocols in order to make interview process a more efficient and effective way to obtain a confident and accurate data.

### **Statistical Support**

Each Local Health Unit (LHU) has their own statistical support team integrated by epidemiologists and statisticians who provide input and perform data collection, analysis and interpretation processes. In addition, the ISS and the Regions provide support and training to the system.

### **Recruiting**

At LHU level, PASSI's operators are selected among the personnel already working in the LHU. There's one coordinator and some interviewers (the number depends on the size of the LHU). Generally the coordinator is a MD, while the interviewers are nurses, but this is not a rule. At regional level there are two figures who manage the PASSI system: the regional referent and the regional coordinator. Both are nominated by the regional health prevention department. Generally they are MDs or executives. At central level (ISS) PASSI is directed by a group of experts: MDs, epidemiologists and statisticians. Some of them are recruited through public concourse and some others are consultants.

### **Training**

Training is offered to all the operators at the enrolment. So far, there's not a structured calendar of these sessions. However, when being necessary, Regional coordinators

organize further training sessions. PASSI operators are specifically trained for working on the project, according to the role they have to cover.

On the other hand, the ISS offers continuing education courses to all members of PASSI team including interviewers, coordinators, supervisors, and statisticians; in order to maintain new approaches related to the development and understanding of surveillance systems, among others.

### ***Training plan***

This plan promotes professional development of local and regional staff as one of the main objectives of the project.

### ***Training activities***

#### 1) Short courses for the start-up of the system

–Stepwise process involving regional and local coordinators and interviewers already completed in 19/21 Regions.

2) Two year cycle of courses and supervised activities on surveillance systems, communication, and public health interventions leading to a Master's degree in Epidemiology and Surveillance (in cooperation with Tor Vergata University, Rome)

### **Funding**

In 2006, funding was made available by the Ministry and a national committee consisting of staff from the National Centre for Epidemiology, Surveillance and Health Promotion (CNESPS) at the National Institute of Health (Istituto Superiore di Sanità-ISS),

graduates of the training program who had participated in the pilot studies and outside experts was established. Regarding the costs for running the system, the National Centre for Disease Prevention and Control (CCM) of the Italian Ministry of Health funded the CNESPS with one million Euro, used for financing the national coordinating activities and for supporting the Regions in the first 3 years of the project. The participating Regions and local health units (LHUs) offered personnel part time to the project (Baldissera 2009).

#### **4. Response rates**

Starting from a base of 275 interviews per year per LHU, the population of LHUs is very well informed and involved in participation in the survey. This is demonstrated by some indicators, such as a response rate of 97.1%, a replacement rate of 2.9% and a refusal rate of 2.4%. However, there is a problem with respect to the receipt of letters of warning (only 83% of participants received it, while communication has reached by physicians in almost all cases).

PASSI implement different mechanisms of communication with the community including:

- Mailing of letter homes, to inform, invite and alert the community about PASSI and its ongoing surveillance. The letters content pertinent information about the PASSI surveys, and are supported by the signature of the President of ISTAT (The Italian Institute of Statistics), adding more confidence and trust to the process. In addition, it will be included a toll free-phone number where people can get any information available about the PASSI surveys.

- Other channel of information is the personal visit, or call to their physicians. By this way members of the community will be informed by their physicians about this surveillance receiving this information from 2 different channels influencing their participation to the program.
- The last and less individualized method is the media. It plays an important role in dissemination of information but is more superficial, unserious and mass approaching. However, it will be an additional way to reinforce or catch more people to the program.

Letters sent to families and members are distributed a few days before the interview. They receive a letter signed by the President of ISTAT, with all the information about the PASSI survey and purposes, and also it is provided a free-phone number to which people can get information about the survey process, or any other concerns about PASSI surveillance.

With this PASSI ensure a high response rate from the community participating with PASSI, the BRFS system.

## **5. How the data is used**

The relationship between determinants of health, risk behaviors, medical conditions, disability and in general health has been extensively explored in Italy. Thanks to the data collected from PASSI it has been possible to detect and analyzed these inverse associations, as for example, socioeconomic position (SEP) and health. However few studies have been carried out on the relationship between inequalities and health status or health services utilization, particularly at a local level. Though PASSI the analysis of all that collected data

has been possible not only to evaluate the possible 'signal alarms' due to individual behaviors that could develop life threatening diseases and disability among community, but also, has been contributed to the planning, implementation, monitoring, and evaluation of public health program and interventions.

To promote the utilization of the surveillance data, communications activities are conducted emphasizing the system's usefulness, promoting cooperation and appropriate use of results. The structured design and implementation of this communication channels are at different levels (national, local), different targets (decision makers, health professionals, the lay public), and different means (posters, leaflets, press kits, internet, media). Some communication tools are already in place and are available to the community, including:

1. The PASSI web site which offers news, documentation and other services for the network and the public health community (forums, material for training activities, etc.)

[www.epicentro.iss.it/passi](http://www.epicentro.iss.it/passi)

2. PASSI-one: a monthly newsletter for the surveillance network. Is created in a electronic format and freely downloadable from the web site.

3. PASSI reports which highlight how active behaviors can also be responsible for medical conditions such as stroke, hypertension, cardiovascular diseases, depression, and obesity, among others.

Dissemination, promotion and use of data is the way how all this PASSI collected data is applied to the wellness of the community preventing and controlling chronic diseases and leading causes of death.

### **C. The Canadian Behavior Risk Factor Surveillance System**

The Rapid Risk Factor Surveillance System (RRFSS) is an ongoing telephone survey used to gather surveillance data, monitor public opinion on key public health issues, and collect information on emerging issues of importance to public health. The purpose of RRFSS is to provide timely data relevant to local public health needs in participating Public health Units (PHUs). RRFSS is used to monitor key public health issues and to collect information on emerging issues (PHAC).

The Rapid Risk Factor Surveillance System (RRFSS) began in 1999 as a pilot telephone survey of adults aged 18 years and older in Durham Region. The pilot project was a joint partnership between Health Canada, the Ontario Ministry of Health and Long-Term Care, Cancer Care Ontario and the Durham Region Health Department. The idea was to pilot test a risk factor survey based on the Behavioral Risk Factor Surveillance System (BRFSS) used in each state in the U.S.A. (RRFSS 2007).

The survey is conducted by the Institute for Social Research (ISR) at York University on behalf of all the RRFSS-participating health units. From June to October 1999, a random sample of approximately 200 Durham Region residents was surveyed each month. Respondents were asked about various lifestyle behaviors associated with chronic diseases and disability, such as cancer, heart disease, diabetes, and injuries, in particular behaviors such as smoking use, sun safety, fruit and vegetable consumption, physical activity, among others, that are targeted by public health programs.

Following the successful pilot project, the Durham Region Health Department decided to continue with RRFSS and was soon joined by the Haliburton, Kawartha, Pine

Ridge District Health Unit and the Simcoe County District Health Unit. These three health units formed the RRFSS Working Group. In 2000, the RRFSS Working Group reviewed and revised the questionnaire. By the end of 2000, 3 more health units had joined the RRFSS Working Group; Region of Peel Health Services, Middlesex-London Health Unit and Niagara Regional Public Health Department. In January 2001, the next cycle of RRFSS began. Interest in RRFSS continued to grow and in 2007, there were 21 RRFSS-participating health units.

## **1. Instruments used to collect data.**

### **RRFSS Questionnaire Components**

Core component: Core questions are asked by all RRFSS-participating health units.

Optional modules: Each health unit decides which optional modules to ask.

## **2. Data gathering processes.**

RRFSS uses computer assisted telephone interviewing (CATI) technology, with sampling based on random digit dialing. Interviews are conducted by the Institute for Social Research (ISR) at York University on behalf of all RRFSS participating health units. This cross-sectional telephone survey provides estimates of risk factors for participating public health units (PHUs), and its target is individuals aged 18 years and older living in dwellings representing all participating public health units (PHUs). Each month, a random sample of 100 adults aged 18 years and older is interviewed regarding risk behaviors and knowledge, attitudes, and awareness of health-related topics of importance to public health.

Interviews should no more than 20 minutes in length, on average. The survey cycle begins each January. In a typical cycle, 100 interviews are completed in each of the following 12 months, for a total of 1,200 interviews per year in each participating health unit. Health units receive the data in SPSS format from ISR approximately two months after each month of data collection.

### **RRFSS Sample Size and Design**

RRFSS is a series of ongoing monthly telephone surveys designed to monitor community trends in behavior risk factors within the service area of participating public health units (PHUs). The sample has been designed to represent the adult population 18 years and over, who speak either English or French and who reside in private households (e.g., sex, age group: 18-44, 45-64, 65+). The sample size is approximately 100 per PHU per month.

Choosing individuals in RRFSS basically follows a two-stage probability selection process. The first stage involves the selection of households by randomly selecting residential telephone numbers. A Random Digit Dialing (RDD) approach is used to select the phone numbers by randomly selecting from commercially available list of telephone numbers as well as using telephone numbers of either side of the listed numbers (to cater for numbers that might be unlisted or new). The second stage, which is the disproportionate selection of an adult from a cluster of adult respondents in the household, is made by choosing the person with the most recent birthday. Overall RRFSS can be considered as a disproportionate sample design within each public health unit.

## **RRFSS Survey Analysis**

Unweighted data in RRFSS are the actual responses of each participant. Unweighted data represent results before any adjustment is made either for variation in respondents probability of selection, for disproportionate selection of population groups or subgroups relative to the overall population distribution, or for non-response. In this manner, weighted RRFSS data will represent results that have been adjusted to compensate for such differences.

As long as the sample weight has been computed, generating a point estimate (a single number that is the best estimate of the indicator) becomes a simple process of applying the appropriate sample design formula to the data. Statistics can also be computed to assess the precision levels of the estimates, including the standard error (also referred to by 'se' and defined as the square root of sample variance), confidence intervals (range of values that describes the uncertainty around a point estimate) and the coefficient of variation (which measures the relative variability around a point estimate and is defined as the standard error divided by the point estimate).

Although standard data analysis software can be used to compute RRFSS point estimates, unless the survey design is a simple random sample (SRS), accurate generation of precision statistics requires appropriate survey analysis software that can accommodate complex survey designs. In the absence of the survey analysis tools analysts can assume a simpler survey design or compute proxy measures for estimating the precision statistics.

When RRFSS commenced in 2001, the majority of data analysts did not have access to the survey analysis tools to compute accurate precision measures associated with the point

estimates. By assuming that the sample of respondents was representative of a random sample of 18+ individuals in the PHU, analysts applied standard formula for estimating the variance and other precision statistics.

More recently most of the popular statistical analysis programs, including SPSS which is the standard analysis tool for RRFSS analysts, have incorporated functionality for handling complex survey designs. As a result some analysts have begun to apply this methodology for generating point estimates.

### **3. Implementation of the surveillance system including: Resources, Training, and Funding**

#### **Resources**

Personnel involved in the RRFSS include: coordinators, interviewers, epidemiologists, public health professionals, and administrative staff.

#### ***Coordinator***

To assist in coordinating activities required by RRFSS, each participating health unit identifies a RRFSS representative, often the epidemiologist or data analyst involved in analysis and reporting of RRFSS results. An additional position of provincial RRFSS coordinator has existed since June 2003. Participating health units share the cost of the RRFSS coordinator. The coordinator works with the RRFSS Steering Group to facilitate the planning, organization, coordination and maintenance of RRFSS, and represents and acts on behalf of all RRFSS members and seeks new opportunities to promote RRFSS (RRFSS Web site). RRFSS representatives meet in Regional Working Groups, of which there are four.

### ***The Analysis Group***

This group sets out analysis guidelines, reviews data dictionaries and responds to analysis issues.

### ***The Website Group***

This group manages the RRFSS website.

### ***The Workshop Planning Group***

Plans and implements the annual RRFSS Workshop. Other ad hoc committees, such as the Website

### ***Evaluation Advisory Group***

This group is responsible for the monitoring and evaluation of this project. It is created as needed.

## **Training**

This ensures that knowledge and capacity is improved and maintained. Training covers all aspects of the planning, implementation, analysis and reporting and dissemination of the results of a RRFSS survey in the context of an integrated surveillance system.

## **Funding**

Each health unit contracts directly with ISR for each cycle of RRFSS. The Ontario Ministry of Health and Long-Term Care funded the Durham Region Health Department and the RRFSS Working Group to document additional aspects of RRFSS in the context of all Ontario health units. The Central East Health Information Partnership (CEHIP) supported RRFSS by developing the prototype for the automated web-based reporting of RRFSS results.

#### **4. Response rates**

The overall response rate was 69%.

#### **5. How the data is used**

The results from RRFSS are used to support program planning and evaluation, to advocate for public policy development, and to improve community awareness regarding the risks for chronic diseases, infectious disease and injuries.

## **Chapter V. Study Purpose, Framework, and Use**

### **A. Purpose of the Study**

The purpose of this study is to conduct a systematic and objective review of Behavior Risk Factor Surveillance systems in U.S., Canada, and Italy, and to assess the extent to which the system attributes were met. In addition, this study aims to compare and contrast the experiences among the countries, to document the strengths and weaknesses in the context of their different environments and to propose recommendations based on the strengths of the examined BRFS systems effectiveness that can be used as benchmarks for the design of new BRFS systems or the assessment of existing systems.

### **B. Framework for Analysis and Assessment**

This study provides a comparison and assessment of BRFS systems based on the strengths of the examined BRFS systems effectiveness. The analysis describes many tasks and related activities that can be applied to public health BRFS systems, also includes discussion of concerns, and comments related to public health BRFS systems from the public health professionals and community.

The framework used for analysis and assessment is presented in an analysis design model in Figure 4. It involves all aspects of the BRFS systems starting with describing on each system the specific instruments and methods used to collect data; identifying data gathering processes; explaining the process of implementation (resources, training, and funding); establishing response rates; and considering the actions that will be taken with the

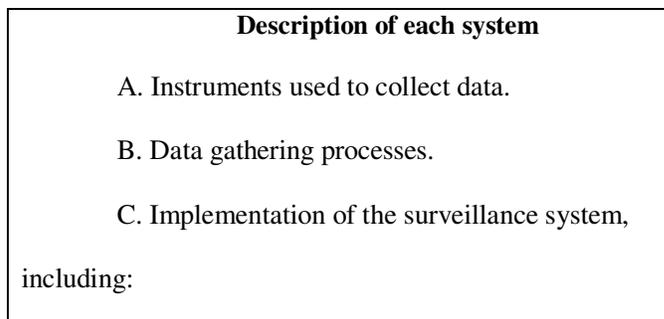
collected data. After that, the performance of each surveillance systems will be compared among the others describing and analyzing each system attribute (e.g., simplicity, acceptability, timeliness, etc) and activities illustrating level of usefulness of the data ( e.g., reviewing of the objectives of the system and considering the system's effect on policy decisions and disease-control programs).

The final step of the study illustrates the outputs which are assumed to occur as a result of the activities and system attributes involved on each BRFS system. For example, having an adequate structure and ease operation of the surveillance system follows the attribute of simplicity; and identifying strengths and weaknesses of the surveillance system follows from monitoring and evaluating activities. And provides recommendations based on the strengths of the examined BRFS systems effectiveness that can be used as benchmarks for the design of new BRFS systems or the assessment of existing systems.

All indicators were adapted from the Updated Guidelines for Evaluating Public Health Surveillance Systems (MMWR 2001).

**Figure 4:** Analysis Framework

**Assessment and Analysis Design**



<ul style="list-style-type: none"> <li>a. Resources</li> <li>b. Training</li> <li>c. Funding</li> <li>D. Response rates</li> <li>E. How the data is used</li> </ul>
<p><b>Analysis of Performance</b></p> <ul style="list-style-type: none"> <li>A. System Attributes</li> <li>B. Activities</li> </ul>
<p><b>Outputs</b></p> <ul style="list-style-type: none"> <li>From activities</li> <li>From system attributes</li> </ul>

**C. Who will use analysis findings**

The findings of this study will be used by government officials seeking improved data collection, and by practitioners and public health professionals looking to improve the Public Health programs they oversee. It includes local and state surveillance and medical professionals, program managers and officers, stakeholders, community-leaders, health programs coordinators, non-profit and for-profit organizations, and partners at the regional, state, federal and global level.

**D. How analysis findings will be used**

This report can be used in many ways. First, the assessment and comparison will serve as the final report to document the use of BRFS system in each country. Second, and perhaps most importantly, this report will intent to propose an analysis based on the assessment and comparison of BRFS systems based on the strengths of the examined BRFS

systems effectiveness. In addition, this study will be available to all partners at the local, regional, state and international level for its use in guiding planning, assessment, implementation, monitoring and evaluation of their BRFS system activities. Finally, recommendation from this study can be considered as benchmarks for the design of new BRFS systems or the assessment of existing ones not only in U.S., Canada, and Italy but also in other countries.

## **Chapter VI. - Comparison and Analysis Results of BRFSS systems in U.S., Canada, and Italy**

This section will compare and analyzed the Behavior Risk Factor Surveillance systems in U.S., Canada, and Italy, based on the magnitude to which the system attributes were met in those systems, and also on the assessment and the strengths and weaknesses of the systems. The attributes used in the analysis of these systems include simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability.

- In Italy, the utilization of pre-notification letters has been very successful in the response rate obtained for the system: The lowest response rate is from the US BRFSS having 50-55 %, compare with 69% of Canadian BRFS and 97.1% of the Italian BRFS (PASSI). They send a pre-notification letter 10 days before the interview, providing information about the surveillance system (PASSI), and the survey that will be administrated. This will enhance participation of the community in the survey.
- General physicians play an important role in the Italian BRFS system, they are considered almost part of the Italian families, therefore they reinforce families participation on health survey and other health events.
- All the three surveillance systems collect demographic, behavioral, and exposure information for the health-related event through ongoing telephone surveys.
- In Italy based on its National Health System all individuals living in a local health unit have access to health care. Most of the time people maintain their physicians for

a long time, in some cases for 30 years or more. This situation build a relationship of trust between patient and doctor, that will enhance the type and detailed data reported from LHU medical facilities, and will enhance the support and trust of individuals to participate with the BRFS survey. In contrast, in U.S., the health system is completely different, most people either have not access to doctors or they change their doctors all the time depending on their insurance plans and coverage. This situation makes more difficult the collection of reported data from physicians, and is more difficult to create a vinculum of trust between patient and doctor that could be useful to encourage participation in health surveys.

- Italian and Canadian BRFS present similar levels of integration with other systems and number of organizations involved in receiving case reports. They integrate regional departments (LHUs and PHUS), with state department and federal level at the end. LHUs and PHUs have autonomy for the development of collection, analysis, and dissemination of data. They conduct their own questionnaires and reports; they send those reports to the state departments to aggregate all LHUs and PHUs data, to finally produce a national data report ready to be exposed to stakeholders and public health professionals for public health action.
- In Italy: collection of data is carried out by people living in the same LHU where the survey is distributed. That helps the interviewer to understand better the questions and answers of the LHU community, recognized weakness and strength in the design of questionnaires, and most important identify factors that could influence response rates. In contrast, in U.S., the interviewers can be located in different states from the interviewed. Not being familiar with the area and their function limits the interview to

formulate questions only and data entry, instead of having an additional understanding of possible factors that could influence decline of response rates.

- In Canada and U.S., in some situations a special or follow-up laboratory tests to confirm cases is necessary. Adding complexity to the surveillance systems.
- In Italy, it is more common to conduct home visits by public health personnel to collect detailed information, due to interviewers live in the same local unit and have contact with providers and doctors, facilitating the easy access to the community to visit and collect detailed information.
- US BRFSS permits states to add questions of their own design to the BRFSS questionnaire but is uniform enough to allow state-to-state comparisons for certain questions. These state-specific questions can address emergent and locally important health concerns. In addition, states can stratify their BRFSS samples to estimate prevalence data for regions or counties within their respective states. This flexibility of the system is also characteristic in the Italian and Canadian surveillance systems. They adapt and add questions to specific regional needs (LHUs and PHUS), and maintain the core components in the questionnaire. This characteristic allow getting data from particular areas and regions, necessary to implement intervention to target risk health behavior and prevent and control disease.
- In Italy sensitivity of the system is high. This is due to continued information about the Italian surveillance system provided not only on regular medical check-up visits, but also through the media and form the interview is administrated. These elements contribute to the willingness of respondents to report their status, and the ability of the persons to understand the questions and correctly identify their status.

- In U.S., in some states, reported cases of a particular disease are promptly investigated by a public health nurse, and contacts at risk are referred for prophylactic treatment. This in order to reduce false positives and low PVP.
- All three surveillance systems conduct monitoring methods to identify population subgroups that might be systematically excluded from the reporting system. Construction of questionnaires of all three systems include questions that facilitate the measurement of risk factor behaviors (e.g., tobacco use) enable the monitoring of important aspects in the development of a disease or other health-related event. These factors affect the representativeness of the systems to identify groups at high risk and to target and evaluate interventions.
- US BRFSS has developed electronic data collection from reporting sources and via the Internet, as well as the use of electronic data interchange by surveillance systems. This promotes availability of information and access to data. However, this aspect is still in development.
- All three surveillance systems have established their own purpose and objectives. They conduct continuous evaluation of results analyzing fulfillment of their purpose and objectives. Supervision of this surveillance by the departments of health contributes with this attribute.
- All three surveillance systems are exposed to lack of resources that might affect the stability of the system.
- The Italian Behavior Risk Factor Surveillance provides a high point of interaction between the system and its participants including persons with the health related event and those reporting the cases.
- The ability of the systems to protect privacy and confidentiality is equally present in all three systems.

- Participation from the community in which the system operates is high in the Italian and Canadian systems. They are more focused in LHU and PHU instead of a broader approach as states.
- Completeness and validity of data is reached on all systems. The type of data they commonly collect include the demographic characteristics of affected persons, details about the health related event, and the presence or absence of potential risk factors.
- In US there is an interaction dynamic process between CDC and states. In Italy and Canada is between local units and ISS, and public health units and ISR, respectively.

## **Chapter VII. – Recommendations and Conclusions**

The following recommendations have been developed after broad consultation across three countries: U.S., Canada, and Italy; and through discussion with individuals directly involved in the behavior risk factor surveillance systems. Enhancing BRFS systems require of an integrated approach, including consideration and implementation of not only one of the recommendations below, but also including the variety of them that will probably produce the big impact in the surveillance system that it is expected to have.

### **A. Recommendations for future implementations of BRFS systems**

#### **1. Interviewers**

Having interviewers that belong to the community allows the identification of mistakes in the design of questionnaires, barriers in communication with individuals, issues related to participation of the survey, and they will have the ability to better understand the community being interviewed.

#### **2. Providers' involvement**

Physicians, nurses, and health workers could play an important role in the participation of health surveys. They might provide trust and confidence in the program for the community. They know their communities and the best way to reach them becoming keys in promoting the participation of individuals in the surveillance system.

### 3. Community involvement

Participation of the community and community organizations will likely produce higher response rate of surveys and greater collection of data. Increased response rates can likely promote the implementation more public health programs to target specific needs for certain community.

### 4. Collecting Local data versus State data

Enabling the surveillance at the local level can have several benefits such as:

- Identification of local detailed needs versus state general needs that should be collected, analyzed, and used for planning, implementation, and evaluation of public health programs. The needs assessed by state-level surveillance could not be able to identify those local needs in order to target them with effective interventions reducing prevalence of diseases and disability.
- Effective allocation of resources for specific needs belonging to the local community. This can avoid the waste of resources at a regional or state level implementation of a health program, when smaller scale interventions at the community level could have similar results for less cost.

### 5. Inspection of special reported cases

That will reduce false positives and low PVP in the surveillance system.

### 6. Involvement of technology

Development of electronic data collection from reporting sources and via the Internet, as well as the use of electronic data interchange by surveillance systems will promote availability of information and access to data.

#### 7. Performance of monitoring methods

These methods can provide identification of population subgroups that might be systematically excluded from the reporting system. Construction of questionnaires of surveillance systems should include questions that facilitate the measurement of risk factor behaviors (e.g., tobacco use), enable the monitoring of important aspects in the development of a disease, or other health-related event. These factors affect the representativeness of the systems to identify groups at high risk and to target and evaluate interventions.

#### 8. Training

It is important to have a training program that accounts for local or regional cultural differences. Subtle cultural differences can affect the value of the data collected, if the interviewers cannot recognize those differences.

A program should have training sessions during its lifetime to reinforce concepts, methodologies, and strategies, or to communicate lessons learned.

#### 9. Establishment of surveillance support systems

Training can provide the establishment of surveillance support systems with universities, institutes and others for the analysis, interpretation, and use of data of existing surveys and databases to build local and regional public health unit capacity. Also, reviewing

existing surveillances and other data collection efforts that have a surveillance component, and comparing with the needs required for new BRF surveillance systems can contribute to make decisions of new efforts and changes in existing ones.

#### 10. Continuing education for BRFS systems staff

Providing of learning conferences, courses, webinars, forums, and workshops can increase knowledge and skills to people involved in the surveillance systems and enhance their capacity of analysis and interpretation of data. This can be useful not only for the development of each participant of the system but also can influence the effectiveness and efficacy of the system. Also, this continuing education can improve the implementation of methods and strategies to the system making it a more useful and effective in its development and performance.

#### 11. Interaction between the surveillance system and its participants

The high point of interaction between the system and its participants, including persons with the health related event and those reporting the cases can ensure a dynamic participation of the community to the survey, adequate collection of data and allocation of resources, and effective target of community needs with implementation of effective programs. Promoting some ownership of the program with the community can raise their interest in the outcomes of the programs and promote the quality of the data produced.

#### 12. Reporting of data

The reporting of data should be done using standards that allow the sharing and access of data from multiple systems. The data should be accessible and communicated not

only to stakeholders, but also to the community which will reinforce the advocating and participation of the community in the surveillance systems

13. Continuous health education provided to the community based on their needs and prevalence of diseases.

This can provide a better understanding of risk factors and prevalent diseases in the community which can help to control and prevent disease, injuries, and disabilities.

14. Continuous education to provider sector

This education is based on prevalent diseases and disability in the communities. This can provide information and awareness of disease and risk factors that the provider sector and population should be prepared to address.

15. Simplicity of the surveillance system

A simple structure and ease of operation can help that the surveillance system to be more effective while meeting its objectives.

16. Establishment of clear and realistic objectives and goals of the surveillance system.

This can ensure effectiveness of the program and clarity in its purpose and operation.

17. Brief description of the surveillance system

Having a brief description and operation of the programs can facilitate readiness and understanding of it for people interested in research and implementation of those programs as a guide to others.

#### 18. Privacy and confidentiality of the surveillance system

The ability of the systems to protect privacy and confidentiality should be equally present in all surveillance systems. However, it is not only the real ability to protect the privacy and confidentiality of the data, but the perception by the community and the subjects that plays a significant role. The involvement of trusted local leaders or health workers is very important to ensure that the perception meets the reality. The lack of the real and perceived privacy and confidentiality protection compromises the effectiveness of the system.

### **B. Public Health Action**

Surveillance systems provide the foundations on which to build successful control and prevention programs. The analysis and comparison of surveillance systems can help ensuring that these systems are collecting the right data and following appropriate procedures to obtain good data and support quality planning, dissemination of data, and implementation of population-based interventions.

Much of public health data comes from hospitals, laboratories and private providers and public health has considerable data that has health policy, research and clinical value.

This study can provide the stakeholders of those surveillance systems with an important resource to benchmark their systems and learn from the insights obtained from the three BRFS systems reviewed in this work.

The demand for a more efficient and responsive public health system that uses its data as a resource to improve community health and public health practice, the increasing need to exchange data across public health information systems in order to create more complete and integrated profiles of individuals, families, and communities, and the increasing need to exchange data with hospitals, private providers, jails, state agencies, and other local health departments, requires a critical analysis of existing and new BRFS systems. This study can provide those systems that require improvement or that are under development, with guidance on the importance of elements like data resources, technology, methods, tools, and strategies implemented and how major systems are applying them.

Data obtained from these BRFS systems can support quality care/services and improvements in public health practice, and also make comprehensive community assessments of needs, a successful step to control and prevent disease and disability. It is important to raise awareness among and involve public health partners in quality data improvement, since public health is more than what happens in the health department. Data from these BRFS systems will provide a detailed and a general scope of the population needs, which should be targeted for the different programs and interventions resulting in prevention and control of risk health behaviors and diseases.

In this study the analyses and comparisons of different BRFS systems is also critical because we cannot improve what we do not measure. Comparisons from state-to-state and to national data can be important to identify not only local but also national health status that at the same time could be compared among countries. This will help to evaluate and develop interventions related to the population needs assessment and programs' rationales. The more valid the data obtained from surveillance systems the more realistic and effective the population based interventions to control and prevent diseases and disability will be.

Other important aspect as a result of the analysis and comparison of these BRFS systems is the fact that public health communities are transforming how they manage and use health information. Therefore, it is crucial to be informed about the different methods of collecting, analyzing, and disseminating data presented in other systems, in order to improve existing surveillance systems and create new ones that ensure more valid and timely data at the lowest possible cost to public health action. It is learned that effective and realistic population based interventions are based on valid and timely data obtained from surveillance systems and disseminated among decision-makers in order to make public health action.

### **C. Conclusions**

The success of BRFS systems resides on participation of providers and community in the surveillance process.

Participation of community and provider sector will likely increase the response rate of the system. The Italian surveillance system presents higher response rate than US' and Canada's most likely due to the involvement of the community and physicians in the

surveillance system. The U.S and Canada BRFSS systems should improve participation of these sectors in order to increase the response rate of their systems.

Government health offices should allocate more resources for local health departments to obtain detailed local data from LHUs, PHUs, and counties rather than exclusively focusing in state/regional implementation.

Including optional modules and state-added questions increases the flexibility of the surveillance systems. Canada and Italy should continue developing their optional and state-added questionnaire components in order to increase the flexibility of their surveys.

A country that wants to start the implementation of a surveillance system should base the new system on the nine attributes defined by the CDC's Guidelines for Evaluating Public Health Surveillance Systems and can use as basis existing programs like US' BRFSS. It is effective to use an existing system and adapted rather than creating one from scratch.

Studies should be completed to validate the Internet and other technologies as a valid alternate medium to distribute and complete the surveys.

The BRFSS systems should produce valid data in a timely manner at the lower cost possible to decision makers and community, so funds can be secured for continuing and creating new programs and obtaining the benefits of the surveillance.

The BRFSS systems are essential knowledge tools to guide government and public health officials with decisions related to behavior risk factors, need of intervention, and public health policy; they provide information about what is happening with the population.

Public action is the best result of any surveillance systems, looking for improving the wellness of the community based in the assessment of their needs and implementation of adequate programs.

More studies could be performed that compare surveillance systems in other countries that extend this study.

## Chapter VIII. – References

Armstrong, G. L., Conn, L. A., Pinner, R. W (1999). “Trends in infectious disease mortality in the United States during the 20th century.” *JAMA* **281**(1):61-66.

Baldissera, S (2007). “The Italian Behavioral Risk Factor Surveillance System -PASSI: an account of the first year of activity.” 5th International Conference on Surveillance Systems

Blackmore, C. G. M., Stark, L. M., Jeter, W. C., Oliveri, R. L., Brooks, R. G., Conti, L. A., Wiersma, S. T (2003). “Surveillance results from the first west Nile virus transmission season in Florida.” *American Journal Tropical Medical Hygiene* **69**(2):141-150.

Campostrini, S., McQueen, D.V., Evans, L (2009). “ Health Promotion and Surveillance: The establishment of an IUHPE global working group.” Global Public Health.

Chandra, S . C., Deming, W. E (1949). “On a method of estimating birth and death rates and the extent of registration.” *Journal of the American Statistical Association* **44**:101-15.

Centers for Disease Control and Prevention. (2008) *HIV/AIDS Surveillance Report, 2006*. Vol. 18

Chronic Disease Sub-Group (2001). National surveillance networks for chronic disease in Canada: Charting a path forward. Health Canada internal publication.

Chronic Disease Sub-Group (2002). Situational analysis for chronic disease surveillance systems and networks in Canada. Health Canada internal publication.

Declich, S., Carter, A. O (1994). “Public Health Surveillance: historical origins, methods and evaluation.” *Bulletin of the World Health Organization* **72**(2): 285-304.

Foege, W. H., Hogan, R. C., Newton, L. H (1976). “Surveillance Projects for Selected Diseases.” *International Journal of Epidemiology* **5**(1): 29–37.

Effler, P., Ching-Lee, M., Bogard, A., Jeong, M. C., Nekomoto, T., Jernigan, D (1999). “Statewide system of electronic notifiable disease reporting from clinical laboratories: comparing automated reporting with conventional methods.” *JAMA* **282**:1845-50.

EpiSouth (2008). “ Questionnaire about Institutions partners”. Network for Communicable Disease Control in Southern Europe and Mediterranean Countries.

Food and Drug Administration (2002). Center for Drug Evaluation and Research Adverse Event Reporting System (AERS) <http://www.fda.gov/cder/aers/default.htm>.

Fox, J., Stahlsmith, L., Remington, P., Tymus, T., Hargarten, S (1998). "The Wisconsin firearm-related injury surveillance system." American Journal of Preventive Medicine **15**:101-8.

F/P/T Advisory Committee on Health Infostructure (2001). Tactical plan for a pan-Canadian health Info structure.

Gazarian M, Williams K, Elliott E, et al. (1999). Evaluation of a national surveillance unit. Archives of Disease in Childhood **80**:21-7.

Health Canada, Office of National Health Surveillance (1999). Partnering for quality, timely surveillance leading to action for better health

Health Surveillance Working Group, Canadian Health Infostructure (2001). Health Surveillance Blue Print and Tactical Plan.

Heymann, D. L (2004) Control of Communicable Diseases Manual. Washington, DC: American Public Health Association.

Heymann, D. L., Rodier, G (2004). "Global Surveillance, National Surveillance, and SARS." Emerging Infectious Diseases **10**(2): 173-175

Hook EB, Regal RR. The value of capture-recapture methods even for apparent exhaustive surveys. Am J Epidemiol 1992;135:1060--7.

Iachan, R., Schulman, J., Powell-Griner, E., Nelson, D. E., Mariolis, P., Stanwyck, C (2001). Pooling state telephone survey health data for national estimates: the CDC Behavioral Risk Factor Surveillance System.

Italian Ministry of Health (2009). "Guadagnare salute – Rendere facili le scelte salutary." Publicazioni **605**.

Johnson, R. L., Gabella, B. A., Gerhart, K. A., McCray, J., Menconi, J. C., Whiteneck, G. G (1997). Evaluating sources of traumatic spinal cord injury surveillance data in Colorado. American Journal of Epidemiology **146**:266--72

Klevens, R. M., Fleming, P. L., Neal, J.J (1999) Mode of Transmission Validation Study Group. American Journal of Epidemiology **149**:75--84.

Langmuir, A. D (1963). "The surveillance of communicable diseases of national importance." New England Journal Medicine **268**:182-92.

Losos, J. Z (1996). "Routine and Sentinel Surveillance Methods." Eastern Mediterranean Health Journal **2**(1):46-50.

Markel, H (1955). "Tommy Francis and the Salk Vaccine." The New England Journal of Medicine **352**:1408-1410.

MMWR (1988) "Guidelines for evaluating surveillance systems." **37** (Suppl No. S-5): 1-20.

MMWR (1996). "Historical Perspectives Notifiable Disease Surveillance and Notifiable Disease Statistics." **45**(RR25): 530-536.

MMWR (1998) "Summary of notifiable diseases, United States, 1997." **46** (54):1-87.

MMWR (1999) "Framework for program evaluation in public health." **48**(RR-11).

MMWR (2001). "Updated guidelines for evaluating public health surveillance systems." **50**(RR13): 1-35.

MMWR (2003). "Public Health Surveillance for Behavior Risk Factors in a Changing Environment. Recommendations from the Behavior Risk Factor Surveillance Team." **52**(RR09) 1-12

MMWR (2004). "Framework for Evaluating Public Health Surveillance Systems for Early Detection of Outbreaks." **53**(RR05):1-11.

MMWR (2008) "Summary of notifiable diseases – United States, 2006." **55**(53):1-84.

MMWR (2008) "Cigarette use among high school students – United States, 1991-2007." **57** (25):689-691.

Mokdad, A (2009) The Behavior Risk Factor Surveillance System: Past, Present, and Future. Annual Review of Public Health **30**: 43-54

Nsubuga, P., McDonnell, S. M., Perkins, B., Sutter, R., Quick, L., White, M. E. et al. (2002) Polio Eradication Initiative in Africa: Influence on Other Infectious Disease Surveillance Development. BMC Public Health **2**(1): 27.

Phillips-Howard, P.A., Mitchell, J., Bradley, D.J (1990). Validation of malaria surveillance case reports: implications for studies of malaria risk. Journal of Epidemiology and Community Health **44**:155--61.

Pirous, F. M (2009). "The collection of data on physical activity by the Italiana Behavioral Risk Factor Surveillance System-PASSI (and other sources)." WHO-Workshop on integration of physical activity data.

Raporti ISTISAN (2007). PASSI (Progressi delle Aziende Sanitarie per la Salute in Italia): an Italian behavioral risk factor system. Edited Coordinating technical group of the behavioral risk factor system viii 228 p. (in Italian)

Raska, K (1966). "National and international surveillance of communicable diseases." WHO Chronicle **20**:315-21.

Sistema di Sorveglianza PASSI. Progressi delle Aziende Sanitarie per la Salute in Italia. ISS (2007). Gruppo Tecnico di Coordinamento del Progetto di sperimentazione del “Sistema de Sorveglianza PASSI.” Rapporti ISTISAN.

Smith, J (1999) The History and Future of Record Linkage in the ONS Longitudinal Statistical Office of the European Communities (EUROSTAT).

Stoto, M. A (2008). “Public Health Surveillance in the Twenty-First Century: Achieving Population Health Goals While Protecting Individuals’ Privacy and Confidentiality”. The Georgetown Law Journal **96**:703.

Swaminathan, B., Barrett, T.J., Fields, P (2006). Surveillance for human *salmonella* infections in the United States. Journal of AOAC International **89**(2):553-559.

Teutsch, S. M. and R. E. Churchill (2000). Principles and practice of public health surveillance. New York, Oxford University Press.

Thacker, S. B., Stroup, D. F., Parris, h R. G., Anderson, H. A (1996). Surveillance in Environmental Public Health: Issues, Systems, and Sources. American Journal of Public Health **86**(5): 633–38.

Thacker, S. B., Berkelman, R.L (1988). “Public health surveillance in the United States.” Epidemiologic Reviews **10**:164-90.

Van Tuinen, M., Crosby, A (1998). Missouri firearm-related injury surveillance system. American Journal of Preventive Medicine **15**:67--74.

Weinstein, M.C., Fineberg, H.V (1980). Clinical decision analysis. Philadelphia, PA: W.B. Saunders **84**-94.

World Health Organization (2003). WHO-recommended standards for surveillance of selected vaccine-preventable diseases, Vaccines and Biologicals, World Health Organization.

World health Organization (2005). “Preventing chronic diseases:a vital investment.” WHO Global Report.

World Health Assembly (2005). "Revision of the International Health Regulations." Fifty-eighth World Health Assembly 58.3.

Yokoe, D.S., Subramanyan, G.S., Nardell, E., Sharnprapai, S., McCray, E., Platt, R(1999). Supplementing tuberculosis surveillance with automated data from health maintenance organizations. Emerging Infectious Diseases **5**:779--87.

Zhou, W., Pool, V., Iskander, J.K., et al.(2003) Surveillance for safety after immunization: vaccine adverse events reporting system (VAERS) – United States, 1991-2001. **52**(SS-1):1-11.