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EVALUATION OF THE COLORADO ORAL HEALTH SURVEILLANCE SYSTEM; DATA USES, DATA USERS, AND FUTURE DIRECTIONS

BY

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Abstract

EVALUATION OF THE COLORADO ORAL HEALTH SURVEILLANCE SYSTEM; DATA USES, DATA USERS, AND FUTURE DIRECTIONS

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PURPOSE

Oral health surveillance is a new and different application of traditional disease surveillance that is based in the roots of controlling and preventing population-based infectious diseases. States have identified engaged data as an essential element of the existence and success of oral health programs, thus necessitating the development of oral health surveillance systems. To date, however, the application of surveillance to oral disease and the data's usefulness to public health practitioners has not been evaluated.

To determine how effectively oral health surveillance data are being used for the prevention and control of oral disease in Colorado the present evaluation sought to determine the usefulness of the Colorado Oral Health Surveillance System (COHSS) to inform recommendations for the revision COHSS.

METHODS

Twenty COHSS data users were interviewed to determine basic characteristics of COHSS data users, data uses, and data gaps. Themes within each of the evaluation questions were compared across and among categories of users.

FINDINGS

"Power users" and "critical mass" concepts emerged to describe two groups of data users that have the potential to play a significant role in oral disease prevention and control activities in the state. To date, however, insufficient connections exist between data users and the COHSS, making data less useable for those working directly in prevention and control activities in the state.

RECOMMENDATIONS

The identity of primary data users along with their respective program actions must be clearly understood by the COHSS. Active connections between primary data users and the COHSS must exist for surveillance data to be useful for prevention and control of oral disease. The COHSS should consider collecting bi-annual oral health infrastructure data in the state about primary data users and programs so that COHSS data collection, analyses, and dissemination are guided by concrete end-targets and affecting health outcomes. Tailoring data analysis, data products and strategically addressing data gaps will ensure that oral health surveillance data are useful and fully engaged in oral disease prevention and control activities of public health practitioners in the state.

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CHAPTER I - INTRODUCTION

Introduction and Rationale

The rationale for evaluating the Colorado Oral Health Surveillance System (COHSS) is that the COHSS is a new and different application of traditional disease surveillance that is based in the roots of controlling and preventing population-based infectious diseases over the last four centuries ((Institute of Medicine [IOM], 1988; Declich & Carter, 1994). However, the application of surveillance to oral disease, and the data's ultimate usefulness to public health practitioners has not been evaluated. According to Thacker, Parrish and Trowbridge, a surveillance system's "usefulness" is determined by its ability to generate "a public health response leading to the control and prevention of adverse health events…" (Thacker, Parrish, & Trowbridge, 1988, p. 11). Since the mid 20th century a movement to apply traditional disease surveillance principles has spread to monitoring the prevalence and risk factors of chronic diseases, and more recently the monitoring of oral disease (Thacker & Berkleman,1988; Beltran, Malvitz, Lockwood, Rozier, & Tomar, 2003; IOM, 1988). This was justified by the overall dearth of data to inform national, state, and local public health program actions and policies to control and prevent chronic and oral diseases (IOM, Beltran et al, Malvitz, Barker & Phipps, 2009). Evaluating this new application of traditional disease surveillance to prevent and control oral disease in Colorado will determine how effectively oral health surveillance data are being used for prevention and control of oral disease, which is the essential criteria that made traditional infectious disease surveillance successful in maintaining and improving population health and quality of life for centuries.

The practice and methods of oral and chronic disease surveillance are different than traditional infectious disease surveillance. The application of traditional surveillance methods

cannot be simply duplicated with emerging public health issues, such as chronic diseases. This fact is driven by the etiology of the diseases shown in Figure 1, as described by the epidemiological triad and the foundation of public health surveillance. Whether or not an individual becomes ill or diseased depends on the interaction of three factors in the triad: the host, the agent, and the environment. Dis-equilibrium between any of these three parts presents opportunity for disease to occur.

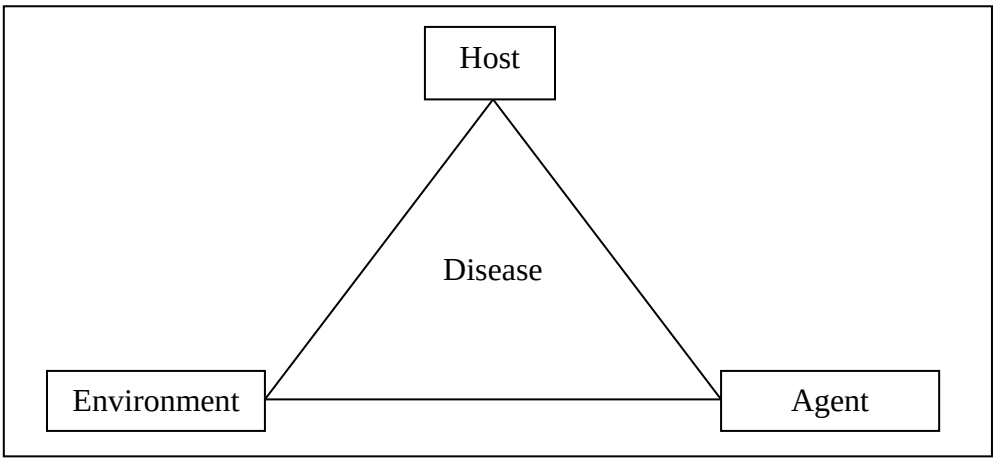

Figure 1. Epidemiological triad. Adapted from Rudolf Virchow.

Within a host (person), genetics, age, and sex play similar roles in the occurrence of both infectious and chronic disease. For example, the susceptibility of a host to an infectious disease like smallpox can be influenced genetically through immunity passed from generation to generation. Likewise, within chronic disease the susceptibility of an individual to hypertension may have also been hardwired into the genes and passed from generation to generation. Environmental factors also can play similar roles in the occurrence of infectious and chronic disease as they act on the host's resistance against or susceptibility to disease. A person's proximity to a healthy or unhealthy environment often influences the likelihood of contracting a disease or not. More recently social determinants of health have become a central focus in public

health due to their influences on infectious and chronic diseases that lead to premature morbidity and mortality. Frieden's (2010) *Health Impact Pyramid* suggests that concentrating disease prevention and control interventions on "the bottom tier of the pyramid" may have a greater impact on health than those interventions higher on the pyramid focusing on individuals (2010, p. e2).

Of the three factors in the triad, the agent differs fundamentally between infectious and chronic diseases. In traditional epidemiology the agent is a single identifiable organism responsible for causing disease. In chronic diseases, however, a single organism is never responsible for causing disease. Instead, it is the interaction between the other two factors in the

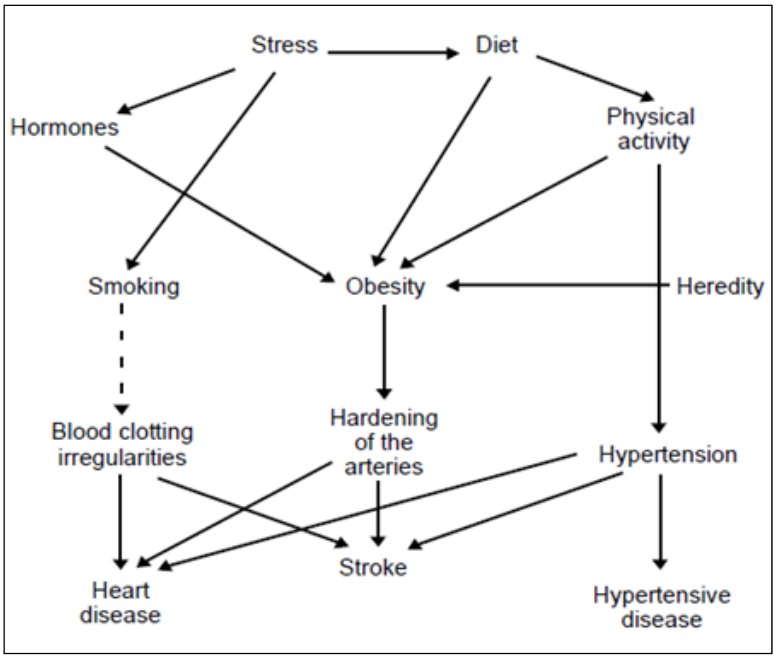

Figure 2. Simplified web of causation applied to cardiovascular disease. Adapted from R.A. Stallones *Public Health Monograph 76* (1966) as cited in Rockett, 1999.

triad. Human behaviors and genetics interact with environmental exposures in complex ways over time to influence the occurrence of chronic disease. The absence of a specific identifiable

agent makes the prevention and control of chronic disease fundamentally different from infectious disease. There is no single source to attack, control and stop. The complex interplay between etiological factors of disease occurrence led to the development of another model of disease etiology termed the web of causation (Rockett, 1999) as shown in Figure 2. Compared to traditional infectious disease etiology that is essentially linear in progression, the complex interconnectedness of the multiple causes of chronic disease complicates the occurrence, as well as control and prevention.

The emerging conceptual framework for oral disease as developed by Fisher-Owens et al. (2007) and shown in Figure 3, illustrates the concepts important for differentiating oral diseases from other infections and chronic diseases. First, the framework incorporates the domains of the social determinants of health such as genetic and biological factors, the social environment, the physical environment, health behaviors, and access to health care. Secondly it recognizes the complex interplay of causal factors important to differentiate oral diseases from other infectious and chronic diseases. Lastly, the conceptual model incorporates time, recognizing the evolution of oral health diseases (eg, caries) and influences on the host over time.

In addition to the multi-factorial etiologies of chronic disease, Thacker and Berkelman (1988) explain that aspects of chronic diseases themselves, such as latency from exposure to disease manifestation, and the need to monitor the various stages of disease progression add to the complexity of using traditional surveillance methods in emerging and relatively new surveillance applications. Therefore, this evaluation of COHSS seeks to better understand the potential and limitations of this new application of surveillance methodology to prevent and control oral disease. Useful evaluation can lead to maximizing the potential and recognizing the limitations of surveillance data used to prevent and control oral diseases.

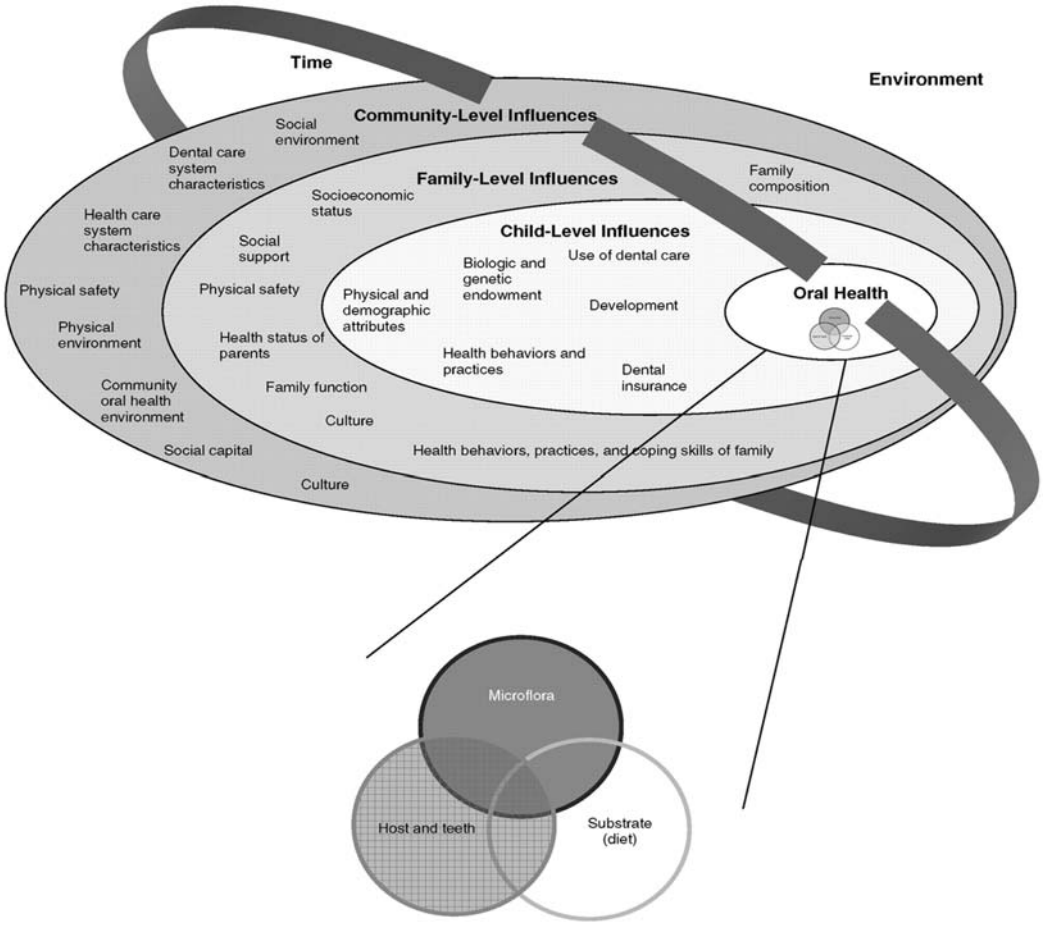

Figure 3. Child, family, and community influences on oral health outcomes of children. Triad adapted from Keyes PH. Int. Dent J. 1962;12:443–464; Concentric oval design adapted from the National Committee on Vital and Health Statistics. Shaping a Health Statistics Vision for the 21st Century. Washington, DC: Department of Health and Human Services Data Council, Centers for Disease Control and Prevention, National Center for Health Statistics; 2002: viii.

Public Health Problem

As the understanding of the cause and transmission of disease in the human population has evolved, the importance of collecting information to protect the public's health has attempted to keep pace, creating need for the surveillance of evolving public health issues. In the 1988 *Future of Public Health*, the Institute of Medicine concluded that the lack of assessment and surveillance data presented a significant barrier to the work of public health in the U.S. The report went on, saying the lack of data represented a significant gap in information needed to plan, implement, and evaluate public health activities. The IOM was not alone in recognizing

need for better public health surveillance. In the 1992 review of progress on Healthy People 2000 objectives, the National Center for Health Statistics stated that important health outcome measures were excluded from the national strategy because sufficient data were not available to characterize the problems confronting public health at the time.

Oral health has similarly lacked surveillance data that could lead to effective prevention and control activities, and policy development. Since the inception of national health objectives, and the Healthy People initiative, there have always been oral health measures. However, in the 1992 progress report on Healthy People 2000 two oral health measures, access to dental care and dental decay in children, were highlighted as two of 16 major national priority data needs. Further, the need for state and local data was also recognized. National dental public health leadership, including the Association of State and Territorial Dental Directors (ASTDD), noted that "...state and local dental programs have been hampered severely in carrying out their programmatic activities to improve health because of a lack of State-specific oral health data" (Lockwood, 1997).

Malvitz, Barker and Phipps (2009) agree there has been a dearth of data to inform state and local oral health improvement initiatives and policy decisions. The early attempts to monitor oral disease in the population occurred in the 1930s when oral health researchers Dean, Klein, Palmer and Knutson collected clinical data on each tooth for national research. These visual and tactile methods utilized dentists and dental instruments to diagnose each tooth surface for severity of disease. In the early 1990s, ASTDD through a survey of its members, concluded that while some state oral health programs attempted to collect surveillance data using the intensive methods pioneered in the 1930s, the development of alternative methods of data collection were necessary that were not so resource intensive. Malvitz et al. (2009) also

concluded that the "absence of state or local data stemmed from primarily methods that have evolved for monitoring diseases of the oral cavity;…[that] used complex sampling protocols, clinical evaluation by a dentist, and multiple detailed measures for each tooth" (p. 2). The solution proposed by the nation's dental public health leaders, including the Centers for Disease Control and Prevention, the Association of State and Territorial Dental Directors and others, was to develop feasible national and state oral health surveillance systems to address the existing data gap.

In November 1999 ASTDD completed a study utilizing the iterative Delphi method to identify state infrastructure and capacity building elements necessary for state oral health programs to meet Healthy People 2010 objectives. Forty-three states responded, representing 93% of the U.S. population. Oral health surveillance was identified as a gap by over 67% of the states reporting on their infrastructure and capacity (ASTDD, 2000). The resulting report and consensus among the nation's dental public health leaders led to funding strategies within the Centers for Disease Control and prevention, and the Health Resources and Services Administration to aid states in developing oral health surveillance systems to address this significant gap.

Program Theory and Description

Within public health, surveillance has been defined as "the ongoing systematic collection, analysis and interpretation of health data… used in the planning, implementation, and evaluation of public health interventions and programs" (CDC, 1988, p. 2). A surveillance system provides functional capacity for data collection, analysis, and the timely dissemination of information to persons who can undertake effective prevention and control activities (Thacker & Berkelman, 1988).

In 2002 Colorado began the development of a state oral health surveillance system. Following guidance provided to states from the CDC, Division of Oral Health (CDC/DOH), through the second of three capacity and infrastructure building cooperative agreements the Colorado Oral Health Surveillance System (COHSS) was first conceptualized in a written surveillance plan in 2002. It was updated in 2006 as outlined in the *Surveillance Tool: Guide to Developing a Comprehensive Written Surveillance Plan* (CDC, 2006). The plan defined the purpose, goals and objectives of COHSS, as well as the core measures for data collection, analysis and dissemination strategies meant to benefit dental public health practice in the state. The COHSS Plan is shown in Appendix A.

Colorado's Oral Health Surveillance System monitors the prevalence of oral disease among Coloradans and shows population changes and emerging trends in the state. Additionally, the COHSS supports data collection efforts about specific prevention and intervention programs designed to reduce or control the burden of oral disease in Colorado. These data can be used for program evaluations that lead to more effective and accountable programs to reduce oral disease in the state.

Goals and objectives of the Colorado Oral Health Surveillance System. Goal 1: Develop a system that collects, analyzes, and disseminates data to inform and support oral health decision-makers in Colorado.

Objective 1: Monitor oral health patterns across demographic groups.

Objective 2: Monitor high-risk groups and behaviors to help target programs.

Goal 2: Develop data collection mechanism for evaluation of programs aimed at preventing and controlling oral disease in Colorado

Objective 1: Provide technical assistance in the use of standardized data collection and program evaluation methods.

Objective 2: Build collaborations that promote the development of effective and accountable oral disease prevention and control programs.

Program logic model. A logic model describes the program in the form of "if - then" arguments that form the theory of change; more specifically, the COHSS logic model illustrates how the system will be used to prevent and control oral disease in the state. The logic model developed for the COHSS uses the standard CDC template for logic models, and progresses from left to right showing inputs to long-term or distal outcomes. The entire program logic model is shown in Appendix B. A simplified logic model of the COHSS theory is shown in Figure 4.

Inputs are the resources necessary for a surveillance system to function, and include resources already available, and those needed. Examples of resources include funding, technical expertise in epidemiology, computer technology, such as statistical analysis software. Where resources are needed, but not yet present, a program manager may seek a way to obtain that resource either directly (e.g., obtaining funding through grants to support staffing), or by leveraging the resource through another source (such as sharing a staff person with another program). Without the identified inputs, the system would be under-resourced and unable to achieve its goals and objectives effectively.

Activities in the logic model represent the essential work that needs to be completed to move the system towards the short-term outcomes. Explicit in the theory is that these activities are absolutely necessary to achieve the short-term outcomes, and are often attributed to the

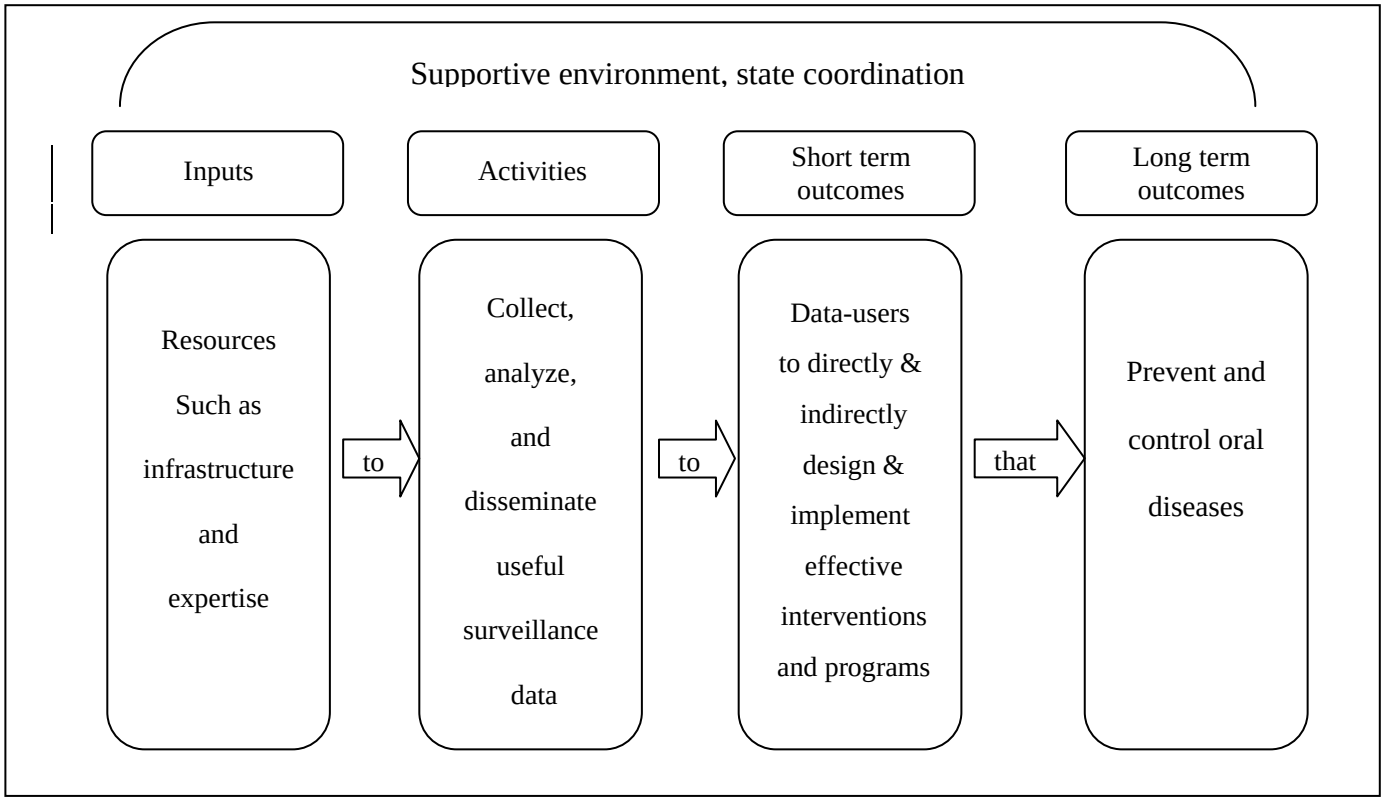

Figure 4. Simplified oral health theory logic model.

achievement of the short-term outcomes. Within the COHSS, collecting the right kind of data, analyzing and interpreting that data in a way that is meaningful to the data-users, and disseminating the data in a manner that supports the users to take action is one point of exploration in the present evaluation.

Prior to the short-term outcomes, the underlying assumption within this logic model is that every component prior to the short-term objectives directly acts upon the component immediately following it, can be traced in a nearly linear fashion from left to right, and can be attributed to the components immediately preceding them. In the case of the COHSS is it is assumed that the data, when given to the appropriate national, state and local organizations will lead those organizations to act, through policy development or program adoption, to change the oral disease in the state. Lavinghouze, et al. (2009) in a presentation at the National Oral Health

Conference (NOHC) and Otteson, et al (2009) in a presentation at the American Public Health Association conference reported that a preliminary evaluation of CDC, Division of Oral Health cooperative agreements for infrastructure development revealed that data, or more accurately, “engaged data” was an identified as an “essential element” of infrastructure development (slide 11). In the presentation NOHC presentation Lavinghouze stated “What makes these elements ‘essential?’ They were mentioned by every state as a component of infrastructure without which the program would not exist. These are not "nice to have" tangential program components; these are "necessary to have" for the program to not only exist, but to evolve and sustain itself. These components serve as building blocks to each other and other aspects of infrastructure. These elements are integrated as core (Lavinghouze, et al., 2009). Therefore, without engaged data a program could not succeed.

It is intuitively logical that the progression from inputs to outcomes occurs, and surveillance systems for infectious diseases can demonstrate their effectiveness by, in some cases, the complete eradication of the disease being surveilled. While the theory behind surveillance systems impact on a public health issue remains constant when applied to oral diseases, there continues a complex interplay among various factors influencing the diseases themselves that limits the amounts of change that can be attributed to by COHSS. This is even more evident when expanding to the most distal outcomes of prevention and control of oral disease.

While the logic model of COHSS illustrates the sequence, an equation if you will, meant to improve oral disease in Colorado, the points that generate the questions of interest in this evaluation fall primarily in theory connecting the activities to the short-term outcomes, and short-term to intermediate (not illustrated in the simplified model above) outcomes.

Evaluation Purpose

The purpose of the present evaluation is to determine the usefulness of the COHSS by understanding who is using data from the system, and determining how the data are being used for public health action and program activity. This evaluation also seeks to identify un-addressed gaps in the system, and develop recommendations for improving the usefulness of the COHSS.

The justification for public health surveillance is that it leads to public health actions that prevent and control disease. This is fundamental criteria, absolute and basic. These actions include planning, implementing, and evaluating public health programs, as well as formulating research hypothesis (CDC, 1988; CDC, 2001; Thacker & Stroup, 1994). According to Romaguera, German and Klaucke (2000), the periodic evaluation of surveillance systems should be completed to "determine whether the system is meeting its objectives, serving a useful public health function, and operating as efficiently as possible" (p. 176). According to CDC such an evaluation: (1) identifies elements of surveillance that should be enhanced to improve the systems attributes, (2) assesses how surveillance findings affect control efforts, and (3) improves the quality of data and interpretations provided by surveillance (CDC, 2001).

Historically, surveillance systems provided evidence and data that could be translated to action to control or eradicate the disease under surveillance (e.g., the eradication of malaria in the United States post World War II). There is less evidence, however, about evaluating the effectiveness of surveillance systems in new applications of disease surveillance such as oral health. Utilizing the CDC Guidelines for Evaluating Public Health Surveillance Systems (2001) the present evaluation seeks to determine how Colorado's recent efforts in developing an oral health surveillance system compares to traditional infectious disease surveillance systems that have been so successful at controlling dangerous diseases.

Evaluation Questions

1. Who are the oral health surveillance data users in Colorado?
2. How are oral health surveillance data being used in Colorado?
3. Are the data sources sufficient to meet the needs of the users, and what are the data gaps?
4. Are current data dissemination strategies effective for getting oral health surveillance data to end-users?
5. Are there any populations or programs where oral diseases have been controlled, prevented, or reduced? And conversely, where has prevention and control proven difficult.

Significance Statement

This evaluation will contribute useful results and recommendations for modifications to the COHSS and may ultimately improve the oral health of Coloradans The findings may also be useful to other states that are similarly conducting oral health surveillance activities under the CDC cooperative agreements, and remaining states that may or may not yet have initiated the development of oral health surveillance systems (Patton, 1997; Patton, 1986; Patton, 2008). More broadly, the present evaluation may prove useful to chronic disease surveillance systems that share surveillance similarities with the COHSS.

Summary

Thacker and Berkelman (1988) propose that prior to the last three decades of the twentieth-century public health surveillance across the globe served, primarily, as an “early warning system… of the unusual occurrence of disease within the population” (p. 185). Following in the tradition of past centuries, surveillance in the United States tracked and

monitored individuals who, because of exposure to a contagious agent, were at risk for developing infectious diseases that had been controlled to protect the public's health. However, in the second half of the twentieth-century, the increasing impact of chronic disease, injury, occupational and environmental hazards to the health and well-being of the population necessitated the application of public health surveillance into these new areas.

Oral health surveillance systems have been one of the most recent applications of surveillance methods to an emerging public health issue, having developed out of need for state and local data for policy development, program planning and evaluation. The development of state oral health surveillance systems, including the COHSS, has had limited evaluation of its effectiveness in prevention and controlling disease.

CHAPTER II - LITERATURE REVIEW

Introduction

Public health surveillance has transformed over the years as it has developed and changed in definition and practice. Expanding from a conventional focus the monitoring of infectious and contagious disease transmission among individuals to monitoring the spread and progression of non-communicable risk and behavior based causes of death in the population, today's public health surveillance covers a broad scope of issues that influence health. The underlying primary purpose of public health surveillance as a basis for public health action, however, remains relatively unchanged from its inception in 14th century Europe. However, newer systems, including those that monitor oral diseases, have yet to be evaluated on their effectiveness to lead to public health action and improve health.

This review of literature will first focus on the history of public health surveillance, and then describe how surveillance has evolved to where it is today. This will include "modern" public health surveillance as it evolved in the 19th and 20th centuries; public health surveillance in the United States; emerging applications of public health surveillance to monitor and control occupational, environmental and chronic disease; and then, surveillance to monitor and control oral disease within the United States. Additionally, this review will touch on the principles, theories and methods used in the present evaluation.

History of Public Health Surveillance

Even without an understanding of the underlying etiology of disease, attempts to prevent and control disease can be traced back to antiquity. Early examples of disease control were religious practices against eating certain foods, such as pork and fish, to protect against diseases caused by inadequate storage and preparation (Schoenbach, 2003).

Throughout the 14th and 15th centuries it became recognized that people, as carriers of a disease, were perhaps responsible for spreading "pestilential diseases." This led to the first explorations of surveillance to monitor individuals to prevent and control the spread of disease. For example, in 16th century Venice, Italy authorities boarded ships to identify individuals with bubonic plague symptoms to prevent them from disembarking and spreading disease in the city (Declich & Carter, 1994). Control activities that resulted from these early surveillance efforts primarily focused on quarantine and isolation of individuals as a means to prevent further infection. Case based surveillance and the monitoring and control of individuals suspected of having the disease remains a standard in public health practice even today (Thacker in Teutsch and Churchill eds., 2d ed. 2000).

It was not until the 17th and 18th centuries, however, when principles more fundamental to public health practice evolved, and governmental responsibility for disease control through monitoring and enforcement measures were established (IOM, 1988). Throughout Europe, Bills of Mortality, weekly reports to authorities of the number of burials and causes of death, provided the basis of data collection to monitor and control disease (Declich & Carter, 1994). In 18th century Germany, Johann Peter Franck's "system of police medicine" provided detailed guidance for public policies about school health, injury prevention, maternal and child health, and public water and sewage treatment. These policies greatly advanced the health of people living in Germany as well as surrounding European countries (Thacker & Berkelman, 1988). In combination these two activities, monitoring and enforcement, significantly reduced the spread of disease in the population. These early and dramatic successes in public health underscored the

importance of having an infrastructure sufficient to act on information provided through surveillance and monitoring to control and prevent disease.

Concepts of Modern Public Health Surveillance

The concept of combining monitoring and control activities, with advancements in statistical methodology in vital records such as births and deaths, brought forth the next leap in evolution of public health surveillance. These early forms of monitoring vital statistics and controlling disease became the foundation of epidemiology and surveillance efforts in the 20th and 21st centuries. In the 19th century, urbanization and institutionalization began to reveal that previous "measures of isolation and quarantine during specific disease outbreaks were clearly inadequate…" to control disease (IOM, 1988, p. 59). Also, advancements in medicine helped to start identifying some of the underlying causes of disease with the re-introduction of the germ theory of Louis Pasteur in 1864. Understanding of the transmission and contagion of disease was advanced through the work of Ignaz Semmelweis's in puerperal fever in Vienna; and by John Snow at the Broad Street pump in London. Effective means to address the causes of disease were emerging through vaccinations and sanitation/hygiene practices.

While the foundation of epidemiology remained solidly immersed in the discipline of medicine, Pierre Charles Alexandre Louis, William Farr, Edwin Chadwick, and others began using "statistical information as a basis for action" (Koplan and Thacker, 2001, p. 982). Farr, considered by many as the "founder of modern concepts of surveillance," collected vital statistics, recorded births and deaths, and analyzed and reported the data to officials to help prevent and control disease outbreaks (Langmuir, 1976). This started the second fundamental surveillance methodology of "statistical surveillance" (Teutsch & Churchill, 2000). The application of statistical analysis and summary to data collected for public health represented a

shift from case surveillance, or monitoring the individuals with the disease, to a comprehensive population approach to disease detection.

Public Health Surveillance in the United States

The fundamental principles of public health policies established in 17th century plague-ridden Europe followed settlers across the Atlantic to America. In 1701 Massachusetts passed laws to quarantine individuals and ships (IOM, 1988). Tavern keepers were required to report "contagious diseases" in their patrons (Declich & Carter, 1994). In the mid-18th century Lemuel Shattuck's *Report of the Massachusetts Sanitary Commission,* viewed as primary to the development of public health in the United States, "established the fundamental usefulness of keeping records and vital statistics" (IOM, 1988, p. 61). It was not until the 20th century that significant changes in epidemiology and public health surveillance occurred.

Early 20th century public health surveillance in the United States continued to follow English traditions of using vital statistics for tracking causes of death, and controlling infectious diseases by focusing on identifying and tracking affected individuals (Thacker & Berkelman, 1988). However, issues of national security, and the necessity to control diseases within the theaters of war, spurred significant public health reform such as the formation of the Hygienic Laboratory, the forerunner of the U.S. National Institutes of Health, and the World War II Office of Malaria Control in War Areas, predecessor to the Centers for Disease Control and Prevention (Langmuir, 1963; Langmuir, 1976; Teutsch & Thacker, 1995; Thacker & Stroup, 1996, Declich & Carter, 1994; Thacker, Berkelman & Stroup, 2007). Additionally, rising from social values of the 1930s, the federal government's role in ensuring social welfare obligated increasing federal responsibilities in the areas of public health and welfare.

It was not until the 1950s, however, when significant theoretical changes occurred to public health surveillance practices. Alexander Langmuir, chief epidemiologist at the then Communicable Disease Center, from 1949 to 1970, incorporated elements of the theories and practices from English epidemiological traditions established by John Graunt, Edwin Chadick, William Farr, John Snow and John Simon in the founding of the CDC Epidemic Intelligence Service at CDC (Koplan & Thacker, 2001; Langmuir, 1976; Thacker & Gregg, 1996). Langmuir was also influenced by Wade Hampton Frost, the first professor of epidemiology in the United States at the Johns Hopkins University School of Hygiene and Public Health (Koplan &Thacker, 2001). Frost emphasized the need to build on quantitative foundations for public health, and the need to link data collection with practical application.

Although Frost narrowly restricted his definition and concept of epidemiology to infectious diseases, Langmuir advanced American epidemiology practice to eventually include a full spectrum of issues affecting morbidity and mortality in the United States (Koplan and Thacker, 2001). Langmuir also took a significant departure from the trend of international surveillance, where the disciplines of surveillance, epidemiology, and disease control activities were becoming intermingled. He understood surveillance as having an inexorable link to, but no direct responsibility for, disease control and prevention activities (Declich & Carter, 1994). He defined the discipline of surveillance as "the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation, and evaluation of morbidity and mortality reports and other relevant data" (Langmuir, 1963, pp. 182-183; Declich & Carter, p. 287). However, it took another 60 years for these concepts of surveillance to be universally adopted nationally and internationally (Thacker, 2000), and public health surveillance to emerge as the distinct discipline, separate from epidemiology, it is today.

Emerging Uses of Public Health Surveillance

Over the last four decades public health surveillance has further evolved in its role of monitoring and protecting the public's health as increasing attention has been given to health promotion and disease prevention. Surveillance objectives, data collection, and evaluation methodologies have focused on detecting disease trends in the population rather than tracking, confining, and controlling individuals (Declich & Carter, 1994). Surveillance no longer encompasses just infectious diseases. It now includes chronic diseases and general and environmental health risk factors used to inform policy makers, decision makers, and public health programs working to prevent disease and improve health in the United States.

These new applications of surveillance, however, are complicated by the very nature of the diseases they monitor due to issues such as latency, multi-factorial etiology, and multiple stages of disease progression. To ensure good public health surveillance practice, the CDC and the Council of State and Territorial Epidemiologists published its first comprehensive plan for epidemiologic surveillance in 1986 (Thacker & Berkelman, 1988). This plan served to "explicitly delineate its (CDC's) policies and goals in surveillance, specified plans to establish and evaluate surveillance systems, and describe relevant activities in research and training" (Thacker & Berkelman, 1988, p. 167). As a result a concrete modern definition of public health surveillance in the United States emerged: "Public health surveillance is the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice" (Teutsch & Thacker, 1995, p. 1).

It is important to note, however, that as surveillance has shifted from case surveillance, and the tracking individuals, to statistical surveillance, tracking distribution trends in the population (Langmuir,1963; Declich & Carter, 1994; Thacker & Berkelman, 1988), the

underlying philosophy and purpose of surveillance remains unchanged. Surveillance data should lead to direct public health action, and underlie the planning, implementation, and evaluation of public health practice. The capacity to take action is fundamental when assessing the value of any surveillance data, and further underscores the importance of ensuring the usefulness of the data, not simply seeing surveillance as an end in and of itself, but as a tool in public health practice.

Public Health Surveillance of Oral Disease within the United States

Public health surveillance as a means to describe, understand, and impact *oral diseases* in a population is relatively new, only having emerged over the last two decades of the 20th century. In the report *Oral Health Surveillance: Past, Present, and Future,* Beltrán-Aguilar, Malvitz, Lockwood, Rozier, and Tomar (2003) attribute this emergence, in part, to changes in the prevalence and severity of primary dental diseases namely dental caries and periodontal (gum) disease, and the need to monitor other oral conditions of interest. Additionally, the *Future of Public Health*, and the Healthy People initiatives focused even greater attention on the need for surveillance data to improve the public health system and measure the impact on health outcomes of interest, including those in oral health.

Historically, collection of oral health data was infrequent and relied heavily on resource intensive primary clinical data collection methods pioneered in the 1930s. These data were used to monitor the distributions and trends in oral diseases on the national level, but were empirical research focused (Beltrán-Aguilar et al., 2003). This focus led to data that had limited application for use in national, state and local programming efforts, and the complexity and expense of these intensive data collection methods made replication at the state or local level impractical, as oral health programs did not have the capacity or the sophistication to

complete the methods (Malvitz, Barker & Phipps, 2009). It was not until the 1960s that collection of oral health data for public health purposes emerged.

Between 1960 and 1962 the National Center for Health Statistics (NCHS) included oral health measures as part of a national survey of adults, and followed with a survey of children in 1963 and 1970 (Beltrán-Aguilar et al., 2003). Over the following years, these surveys continued to periodically collect oral health data, and the National Health and Nutrition Examination Survey has continuously collected oral health measures on an annual basis since 1999. In addition to national surveys conducted through NCHS, the National Institute of Dental Research, later renamed the National Institute of Dental and Craniofacial Research (NIDCR), conducted national surveys in various segments of the population including school-children, employed adults, and seniors (Beltrán-Aguilar et al., 2003). These data, primarily collected for the purposes of research, were insufficient for state public health practice. The surveys were cumbersome to reproduce on a state level due to the rigorous scientific research methodology, were time and resources intensive utilizing dentists to perform a comprehensive examination of each individual tooth and tooth surface, and analysis and dissemination were untimely (Beltrán-Aguilar et al., 2003; Malvitz et al., 2009).

Efforts to build national and state oral health surveillance systems can be traced back to dental public health leaders in the early 1990s. The national and state oral health surveillance systems have originated primarily from, the IOM report *The Future of Public Health* (1988); the adoption of national objectives on health, including oral health; from states' demands for more systematic and timely data collection, analysis, and the need for practical data that could be useful in program planning, resources allocation, and evaluation. In the 1990s several agencies and organizations goals for oral health improvement coincided (Beltrán-Aguilar et al.,

2003; Malvitz et al., 2009) including the Health Resources and Services Administration, the Association of State and Territorial Dental Directors (ASTDD), the Centers for Disease Control and Prevention, and the Council of State and Territorial Epidemiologists (CSTE) to establish oral health surveillance systems both on the national and state levels.

The ASTDD was instrumental in many of the efforts related to early oral health surveillance development. In 1992, ASTDD began to standardize oral health questions that would be added on state level Behavioral Risk Factor Surveillance System surveys (BRFSS). As a result, three questions, slightly modified from the original set of four, are now asked on the rotating core (MMWR, 1994). ASTDD also conducted an assessment of state health agency's level of involvement in oral health related activities within the context of the core public health functions as described in the IOM report. State health officials were asked to report on the level and types of health-related assessment activities in their agencies (MMWR). Results showed that only 56% of states participated in some type of assessment activity, and these activities varied greatly. For example, 56% of respondents reported methods using screenings to assess the dental treatment needs of children, whereas 31% reported using state wide dental surveys.

Parallel to ASTDD efforts to assist states in increasing assessment and surveillance activities through standardizing survey questions, the ASTDD and the Division of Oral Health (DOH) at CDC collaborated on two landmark actions that framed oral health surveillance for what it has become today. To address the need of manageable data collection methods for locals and states, in 1997 ASTDD and DOH formed a work group and began developing and testing a simplified prevalence screening data collection protocol that did not require the use of tooth level indices, performed by dentists, but rather data at the level of the individual. In 1998 the Basic Screening Survey was launched and is used today as the standard methodology for surveillance

of oral disease burden in children (Malvitz et al., 2009). A second work group formed in late September, 1998 with the intention of defining the operation of the National Oral Health Surveillance System (NOHSS) (Malvitz et al.). From an initial list of 72 indicators, this workgroup narrowed down to seven the indicators, that the majority of states had the ability to collect, which were then granted approval by the CSTE in 1999. All indicators were related to Healthy People 2010 objectives and served as the basis for the development of the NOHSS which launched in January 2001 (Malvitz et al.).

During the work to build and develop surveillance capacity at the national level, there was recognition that states did not have the funding or the capacity to independently develop their own oral health surveillance systems. The CDC/DOH, in 2001, released its first of three program announcements specifically designed to increase state programs' capacity to fulfill the charge of the core public health functions, and to meet Healthy People 2010 oral health objectives. Recipients of these cooperative agreements were charged with obtaining the technical expertise, an epidemiologist, and developing state level surveillance systems that at a minimum would collect the seven indicators represented in the National Oral Health Surveillance System. Five states were funded in year one, an additional seven states were funded in year two. A total of 16 states have now received funding to meet this program objective. Colorado has received funding since 2002 and remains funded today.

The culmination of these efforts represent the network of oral health surveillance activities that have evolved to inform national, state and local agencies in identifying and acting to control known public health problems (Barker personal communication to author, 2010).

Evaluation Literature

As an “intervention,” surveillance activities should describe a health event, and then measure changes from a baseline, “…in the context of secular influences and public health interventions intended to change the outcome of interest” (Barker, 2010). To ensure the highest value to the authorities responsible for the prevention and control of the health outcome of interest, surveillance systems should “…be periodically reviewed on the basis of their quality as well as their usefulness...” (Thacker, Parrish & Trowbridge, 1988, p. 11). More importantly, however, according to Thacker, Parrish and Trowbridge, a surveillance system's "usefulness" is determined by its ability to generate "a public health response leading to the control and prevention of adverse health events…” (p. 11). Michael Quinn Patton, in *Utilization-focused evaluation: The new century text* (1997) stated that “Program evaluation differs fundamentally from research…(and) is undertaken to inform decisions, clarify options, identify improvements, and provide information about programs and policies within contextual boundaries of time, place, and politics” (p. 24). While the CDC guidelines for evaluating public health surveillance systems focus primarily on the attributes of surveillance systems including simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability (CDC), these attributes are logically more applicable to primary data collection systems. However, the CDC guidelines also suggest that an evaluation of the level of usefulness of a surveillance system may include “…describing the actions taken as a result of analysis and interpretation of the data.” The guidelines go on to suggest “A survey of persons who use data from the system might be helpful in gathering evidence regarding the usefulness of the system” (p. 14).

To date no literature is available on the evaluation of non-traditional applications of surveillance to emerging health outcomes of interest including chronic diseases. The utilization of the CDC guidelines for evaluating public health surveillance provides the best information on how to approach a surveillance system's usefulness related to the goals of oral health surveillance: the prevention and control of oral diseases within the population.

Summary

This chapter has reviewed the literature available on the historical evolution of public health surveillance as a public health practice integral to the prevention and control of a health outcome of interest. Surveillance has progressed from an individual focus, case surveillance, leading to the isolation of individuals to prevent the spread of "pestilential diseases," to "statistical surveillance" and the application of mathematical formulas to extrapolate population effects of disease. Tied closely to both the detection and control of disease has been the evolution of medicine in both diagnosis and intervention measures such as vaccination. The culmination of modern epidemiology was heralded by Alexander Langmuir when he succinctly spanned the boundaries between data and statistics, and the responsibility and authority for disease control became clearly delineated. All of the literature points out the underlying principle that without an infrastructure to take action, surveillance data is only an archival exercise. Further, while the obvious success of infectious disease surveillance can be measured by the eradication of several infectious diseases, the success of surveillance to control and prevent emerging issues, such as oral disease, has less evidence. This underscores the importance of evaluation of oral health surveillance systems.

CHAPTER III - EVALUATION METHODOLOGY

Introduction

The qualitative design of the present evaluation was guided by the need to provide valuable oral health surveillance data to the people and organizations engaged in the work of improving the oral health of Coloradans; and to support programming decisions, resource allocation, and policy development. In-depth interviews with the people taking the actions to improve population oral health were conducted to provide a direct source and gather meaningful evaluation data that can help improve the COHSS for end-users.

Stakeholders and Primary Intended Users

Engaging stakeholders early in the evaluation process of an evaluation design will help ensure that meaningful results are obtained and accepted by "evaluation findings users." This early engagement means that there will be a greater understanding among the stakeholders regarding the purpose the scope of the evaluation; there will be increased acceptance of the evaluation process and findings, and ultimately an increased acceptance and use of the findings from the evaluation (Linnan and Steckler, 2002; Patton, 2008). According to the Centers for Disease Control and Prevention's *Framework for Program Evaluation*, stakeholders are "the persons or organizations having an investment in what will be learned from an evaluation and what will be done with the knowledge" (CDC, 1999, p. 11). Further, key stakeholders and organizations that have a direct, identifiable stake in the evaluation and can be identified as being those involved in program operations or served by the program will most likely be the primary intended users of the evaluation results.

Throughout the present evaluation there were two main classifications of stakeholders. First, those who will directly use the evaluation findings to improve the COHSS defined as the

evaluation findings users (primary intended users of the evaluation findings): and second those who use oral health surveillance data to improve the oral health of Coloradans. The second group is defined as data end-users. Figure 5 illustrates the two groups of stakeholders in the present evaluation process and graphically represents the evaluation process in a manner similar to a logic model.

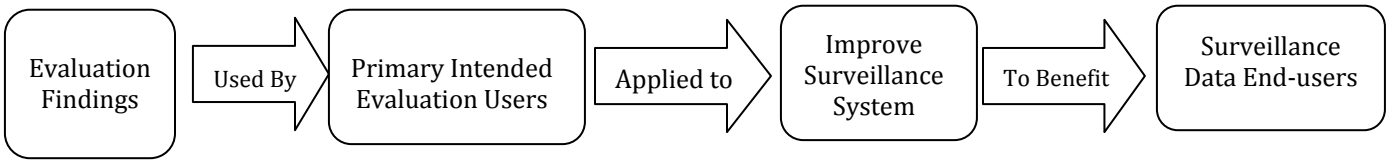

Figure 5. Evaluation process.

For the purposes of the present evaluation, the evaluation findings users were staff in the Oral Health Unit and the Epidemiology, Planning and Evaluation Branch at the Colorado Department of Public Health and Environment. These evaluation stakeholders play a central role in the present evaluation as evaluation findings users provided insight into the design and focus of the evaluation, and being in a position to take findings and make changes needed to improve the COHSS. Consideration has also been given to the fact that while not the direct users of the present evaluation findings, the other evaluation findings users include the sponsors of the development of the Colorado Oral Health Surveillance System including the Centers for Disease Control and Prevention, Division of Oral Health, and potentially other states, either funded by oral health capacity building grants, or similarly developing oral health surveillance systems. Other's developing surveillance systems may utilize the results of the evaluation to help develop evaluations of their own systems, or support the rationale for further development of oral health surveillance systems for improving population oral health in other states.

Population and Sample

Population. In contrast to the evaluation findings users, the oral health surveillance data end-users constitute the study population from whom data will be collected. Unlike the evaluation of a program or intervention where the study population is clearly defined by comparing those receiving treatment to those not receiving treatment, the population in the present evaluation is more elusive because the individuals being interviewed, while a focus, are not what is being evaluated per se. The complexity of identifying a population and selecting a sample for a qualitative evaluation study is described by Patton in the second edition of *Qualitative Evaluation and Research Methods.* Unlike "more practical sampling" in a program evaluation, the evaluator does not need a theory-based definition of the program or intervention being studied as it is usually clearly identified within the constructs of the program itself. "However, to sample a social science phenomenon…one must define the construct to be sampled" (2001 p. 177). Since the inception of the COHSS in 2002, the "population" of oral health data end-users has been, by the very nature of the surveillance system, undefined, given that whoever can access the data can use them. This presented a challenge, however, when attempting to gather information on and from data end-users, to make improvements to a system on behalf those data end-users. Therefore, one question the current evaluation sought to answer was "Who are the primary oral health surveillance data users in Colorado?"

A definition of the data end-users was drafted and agreed upon by the evaluation findings users. It states, " any organization or entity that would potentially use oral health surveillance data for their own individual purpose are the data end-users in Colorado." This definition set an initial boundary, and assists in the development of a general description of the population of data end-users.

Given that the population of users could potentially number in the hundreds, a sampling frame was designed by adapting the "Coalition Framework" provided by the Centers for Disease Control and Prevention, Division of Oral Health. The resulting Data End-users Selection Framework is presented in Figure 6, and describes the types of stakeholders important to oral health programs, and provided a starting point for identifying and selecting a sample of COHSS users.

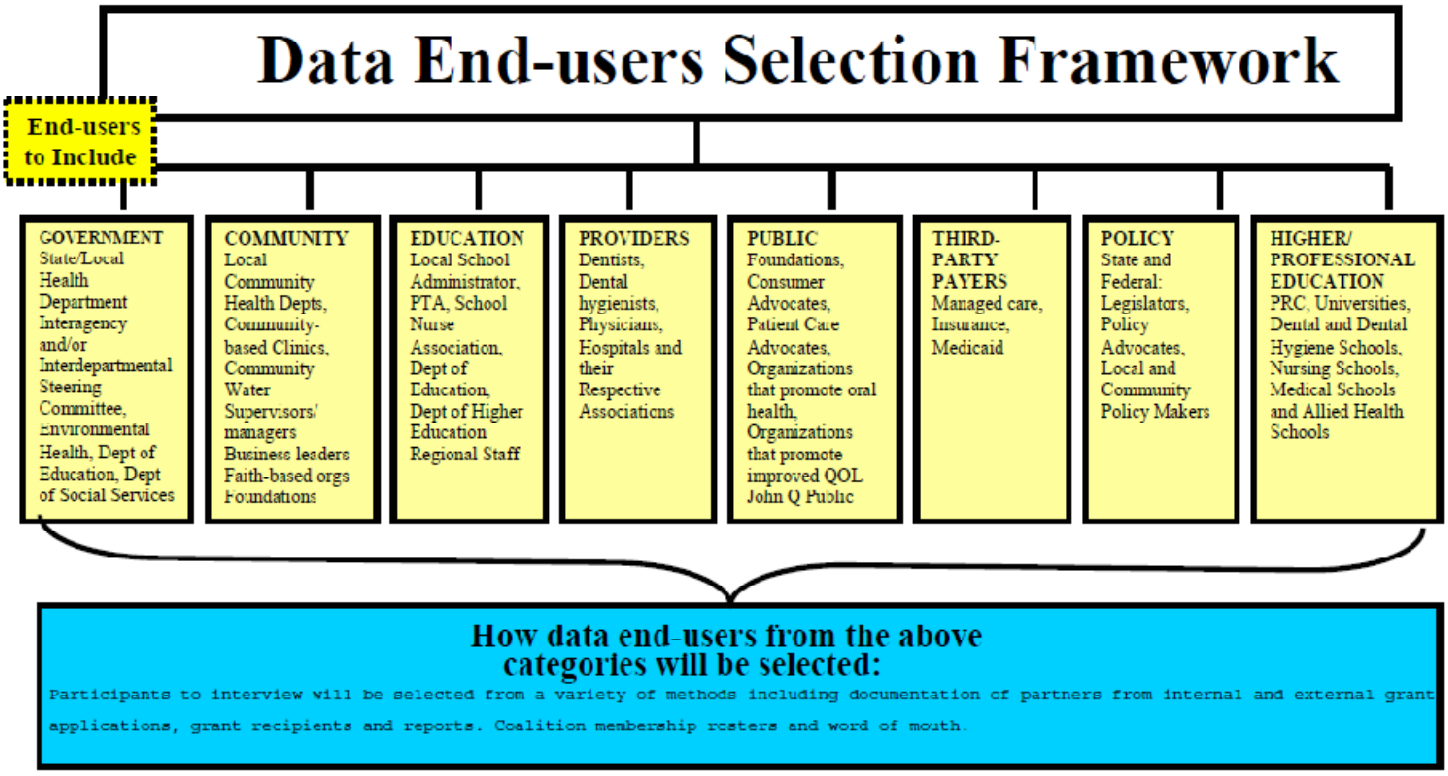

Figure 6. Data End-Users Selection *Framework*.

Reference documents and resources available to the Colorado Oral Health Unit were used to purposefully populate the framework with the names of as many organizations and individuals per category as possible. The framework, once filled as completely as possible, represented the population of potential COHSS users as could be reasonably estimated given the information available. Reference documents included items such as internal grant applications for the school-

based sealant program; oral health grant recipients from several external philanthropic foundations; The Colorado Health Institute's Oral Health Environmental Scan; Oral Health Awareness Colorado! partner membership rosters; and input from stakeholders and the primary evaluation users.

Sampling. Purposeful sampling logic was used to ensure that the selected sample of COHSS users was robust to net valid and reliable information from the interviews, and for its value in obtaining "…information-rich cases… from which one can learn a great deal about issues of central importance to the purpose of the research" (Patton, 2001, p. 169). Additionally, purposeful sampling looks for those cases that can "make a point quite dramatically… and illuminate the questions under study (Patton)." Two strategies within purposeful sampling were employed to gather the most useful information for the present evaluation: critical case and maximum variation.

Critical case strategy, "permits logical generalization and maximum application of information to other cases because if it's true of this one case, it's likely to be true of all other cases" (Patton, 1990, p. 174). Maximum variation sampling, “aims at capturing and describing central themes or principle outcomes that cut across participant or program variation” (Patton, 2001, p. 172).

Once the Data End-users Selection Framework (framework) was populated to collect the requisite interviews and select the sample, a letter briefly explaining the project (Appendix C), and requesting the individual’s participation was sent to each individual within organizations represented on the framework for a total of 55 letters. Individuals were given 15 days to respond, and if a response was not received requesting a time for an interview or declining to participate, a second letter was sent out after the deadline to respond had passed. If no response was received

after the second deadline, a personal email and phone call were made to encourage participation. If, after these three attempts an individual choose not to respond to a request for interview they were considered as "decline to participate." A sample of two to three interviewees per category was determined to be sufficient and feasible for the scope of the current evaluation, so follow-up continued until at least three interviews were scheduled in each category or the strata was exhausted of potential respondents. From the initial mailing, 15 individuals responded and scheduled appointments for an interview. Five remaining interviews were secured after a follow-up letter and a personal phone call.

Evaluation Design

The evaluation design was based on CDC's *Framework for Program Evaluation* (CDC, 1999) and *Updated Guidelines for Evaluating Public Health Surveillance* (CDC, 2001). Recognizing that all activities described within the guidelines might not be appropriate, the evaluation findings users narrowed the focus of the evaluation to evaluating the level of usefulness of the surveillance system through "a survey of persons who use data from the system" (CDC, 2001, p. 14).

Grounded Theory was used as the foundation of the evaluation. To collect data in a manner determined credible to the evaluation findings users, in addition to purposeful sampling, utilization-focused evaluation using qualitative inquiry and an ethnographic perspective was determined to be the best method for answering the evaluation questions of central need.

Procedures

Once an individual agreed to participate in an interview, an appointment was made via telephone. At that time the project was explained in further detail and preliminary consent for recording the interview was obtained, giving the respondent the opportunity to decline. Any

questions regarding the project, the interview process, etc., raised by the respondent were answered. Immediately following the call, a confirmation email and an advanced copy of the interview questions were sent to the respondent. The day prior to the scheduled appointment, a call and/or email were sent to the respondent confirming the date, time and location of the interview.

Interviews were conducted over a three month period from July, 2009 through September, 2009. This time frame was extended exclusively to obtain some interviews from the "Education" category (school nurses) who were not available during the original period of data collection over the summer months.

In-depth interviews were conducted one-on-one, and face-to-face, when possible, and were conducted at the places of employment in the privacy and familiarity of the individuals own offices or at a location suggested by the interviewee. However, other arrangements were made available for completing the questions at the request of the respondent including telephone, and paper and pencil.

Face-to-face interviews were digitally recorded for later verbatim transcription. A total of 15 face-to-face, three phone, and two paper and pencil interviews were completed for a total of 20. Interviews, transcribed and written, were archived in a Microsoft Word format, and uploaded into the ATLAS.ti software for qualitative coding and thematic analyses.

Instruments

An interview tool (Appendix D), including a script, nine open-ended questions, and probes, was developed to collect the necessary information for answering the questions posed in the current evaluation. The tool was pilot-tested with three individuals, and refinements made prior to implementation in the field. Questions included basic identification such as name of

respondent and their organization, the role the respondent had in the organization and how they and/or their organization use data in general. Specific questions were asked about COHSS data use and effective dissemination and evaluation of use strategies.

All respondents received a copy of the questions before to the interview appointment to help them prepare their answers, keep the interviews under 50 minutes, and to collect information from additional parties within their agency if needed. The advance copy contained only the questions, in the same order they would be asked during the interview, and no probes were included so as not to lead the respondent.

In-depth interviews were conducted one-on-one and face-to-face when possible, but in some cases other arrangements were made at the request of the respondent. Due to large distances and time constraints three telephone interviews were completed. Two individuals asked to complete the survey in writing. Interviews were recorded on a Sanyo digital mini-recorder, and on average took between 30 to 45 minutes to complete. Additionally, notes were taken on an individualized version of the instrument that included the date, and name of the respondent being interviewed.

Recorded interviews were transcribed verbatim by a professional transcription agency. Files, recordings and transcribed interviews, were exchanged via a password protected File Transfer Protocol (FTP) software program maintained by the transcription agency. Once interviews were transferred, transcription was completed within five business days.

Data Analysis

According the Michelle Byrne, (2001) “Qualitative data analysis consists of identifying, coding, and categorizing patterns found in the data.” For the current evaluation, cross-case and thematic analyses utilizing ATLAS.ti software was used. As suggested by Patton (1990) the

interview tool was used as a framework for thematic analysis across questions, and the Data End-users Selection Framework (end-user framework) was used as a framework for analysis across categories of users.

Analysis began by using the interview questions and the end-user framework to develop broad categories of deductive codes based on “expected responses” as defined by the evaluation findings users. These initial codes were entered into a code book with the code text, definition and a description of what the code meant (Appendix E). These deductive codes were uploaded into the ATLAS.ti software for later use.

Next the interview questions were categorized into groups by which the evaluation question were answered (Appendix F). This step also created “families” for deeper analysis based on codes already entered in step one (Creswell & Maietta in Miller & Salkind 2002). Finally, the MSWord files were labeled with a naming convention, or shorthand, that includes the last the name of the individual interviewed, and an abbreviation of the category (-ies) from the End-user Framework that the individual/organization represented. This step ensured that analysis could be done across categories or families without having to code the entire transcribed entry multiple times. Once file naming was complete, the interviews were uploaded into the ATLAS.ti software.

Once the initial labeling and larger code families were programmed, interviews were reviewed first individually to code the general responses to the nine interview questions, then again in the family of codes. During this process inductive codes were developed as subtleties of responses are coded to better clarify the variations of the responses within a larger category. According to Patton (1990) inductive analysis reveals “indigenous concepts” or “key phrases or terms used in a program,” or in this case terms used by respondents regarding a single concept.

For example, Question 4 asked “Describe to me how you get your data.” Many respondents reported, in terms of the primary users initial coding, “electronically.” However, to provide more detail and supply the evaluation’s users with richer more useful data, inductive analysis were done to determine what respondents mean by “electronically.” The differences between respondent examples related to “electronically” will be helpful for the evaluation users to know and understand when trying to make decisions about how to disseminate data in a manner that most end-users will find helpful to receive.

Once coding was complete across the questions and then across categories of end-users, the frequency of themes determined the most common, and/or meaningful oral health surveillance issues to find meaning and draw conclusions regarding data end-user characteristics and patterns of data use. Additionally, answers across end-user categories were analyzed to determine meaningful similarities and differences among similar users to draw conclusions about possible strategies for the specific user categories.

Limitations and delimitations

Limitation. The very nature of publically accessible data for the purpose of oral disease prevention and control makes it impossible to truly know COHSS surveillance system users.

Interviews occurred at a time of year when participants for certain categories of user were unavailable, such as “Education.”

Persons who agreed or were put forth by their organization to participate in the study may not be in the position to know the most about data usage for the organization.

Delimitations. The scope of this evaluation is the Colorado Oral Health Surveillance System

- This evaluation is meant to provide recommendations for the improvement of the Oral Health Surveillance System.

CHAPTER IV - RESULTS

Introduction

The results of the current evaluation will be presented in the context question this evaluation was designed to answer.

- Who are the oral health surveillance data users in Colorado?
- How are oral health surveillance data being used in Colorado
- Are data sources sufficient to meet the needs of the users, and what are the data gaps?
- Are current dissemination strategies effective for getting oral health surveillance data to end-users?
- Are there any populations or programs where oral diseases have been controlled, prevented, or reduced?

Findings

Who are the oral health surveillance data users in Colorado? Given that the singular purpose of a surveillance system is to provide data to those in a position to take action, the potential users of a surveillance system are vast. In the present evaluation, the intent was to obtain a sample of organizations assumed to be surveillance data users as defined by the role they play in the public health system within our state as categorized by the Data End-users Selection Framework shown earlier in Figure 6. The selection methodology for the interviews ensured that all eight public health roles/categories had at least one respondent, and the definitions presented in the framework allowed some organization types to qualify for listing in more than one role/category (category). Each respondent organization's name was entered into the category (ies) by meeting the definition of that category. Additionally, if an

organization self-identified additional categories during the interview they were also placed into that category. Interview questions one, two and three were used to determine respondent self-identified additional roles.

Table 1 shows the final distribution of the 20 respondent organizations across categories. Those that had fewer organizations represented in the original sampling framework, for example third-party payers, had fewer organizations to respond to the interviews. Subsequently, those available to participate in the interviews were exhausted more quickly than those with numerous organizations represented. Additionally, organizations agreeing to interviews might have been more likely to recognize the value of participating because they actually used oral health data, whereas in those categories where participation was low, such as education (school nurses, administrators etc.) organizations or individuals may not have had experience using oral health data, so therefore declined to be interviewed, or simply did not respond.

When looking at the overall distribution of users, categories that were populated with a larger number of organizations can be viewed as areas of opportunity for powerful action. This is due, in part, because the categories that are densely populated likely represent organizations that, by definition, play that particular role within public health practice, but also and perhaps more importantly, by self-selection are also playing that role. In these densely populated categories there is also the potential of a critical mass for political will-building in a certain sector of oral health improvement, and this may be beneficial to work going on within the state. Conversely, those roles where few organizations were represented may either indicate little natural opportunity for using surveillance data, or it may indicate a gap resulting in limited or completely missing action for oral disease prevention and control. These gaps, therefore, may

Table 1
Categorical assignment of COHSS data end-users by role

Government Role	Community Role	Education Role	Provider Role	Public Role	Third-party Payer Role	Policy-maker Role	Higher/Profess. Education Role
Colorado Department of Public Health, Oral Health Unit	Howard Dental Center	Denver Public Schools, Health Services	Colorado Dental Association	Caring for Colorado Foundation	Delta Dental Plan of Colorado	Colorado Children's Campaign	University of Colorado, School of Dental Medicine
Colorado Department of Public Health, Vital Statistics	Inner City Health Center	Rocky Mountain SER	University of Colorado, School of Dental Medicine	Colorado Health Foundation	Health Care Policy and Financing	Colorado Rural Health Center	University of Colorado, Native American Health
Eagle County Health Department	Rocky Mountain SER	Denver Great Kids Head Start	Denver Health and Hospitals	Delta Dental of Colorado Foundation		Colorado Department of Public Health, Vital Statistics	
San Juan Basin Health Department	Denver Great Kids Head Start		Colorado Rural Health Center	Colorado Children's Campaign		Eagle County Health Department	
Colorado Department of Public Health, Primary Care Office	Denver Health and Hospitals			Colorado Rural Health Center		San Juan Basin Health Department	
Health District or Northern Larimer County	Kids in Need of Dentistry			Inner City Health Center		Colorado Department of Public Health, Primary Care Office	
Health Care Policy and Financing	University of Colorado, School of Dental Medicine					Health District or Northern Larimer County	
Denver Health and Hospitals	Colorado Health Foundation					Health Care Policy and Financing	
	Caring for Colorado Foundation					Delta Dental of Colorado	
	Colorado Rural Health Center					Delta Dental of Colorado	
	San Juan Basin Health Department					Colorado Department of Public Health, Oral Health Unit	
	Health District or Northern Larimer County						
	Colorado Children's Campaign						
	Eagle County Health Department						

represent areas needing cultivation of data users, as key components necessary for effective prevention and control.

Certain organizations also contribute to more than one role within the state. The results showed that with the exception of three organizations, (i.e., Denver Public Schools, Howard Dental Center, and University of Colorado Native American Health), all respondents represented more than one category. One group of respondents, local public health, represented the most roles at three. Interestingly, the five local public health agencies did not all represent the same three roles. For example Denver Health, the only integrated public health and hospital organization within the state, did not represent itself in a "Policy" role. This may be due, in part, to the position of the person interviewed, and where the individual was situated within the organization. However, another local health agency did report that they used data for "…inform key decision-makers…" on the important health priorities of the county. No organization represented more than three categories. Again, it is important to look at the roles that individual organizations play, and assess if there are certain ones that may have more significant impact due to diversity or concentration of focus. A single organization representing many roles may be able to work across the various roles to impact different systems therefore influencing change at many points, local public health is an example. However, if an organization has a concentrated focus, they may have the reputation and credibility to make certain changes more successfully and impact that area dramatically. Howard Dental Center is one example of an organization with a focused role, treating HIV/AIDS patients exclusively. They are the expert in oral health care for this population, and have great deal of political clout, recognition, and are well respected within the community they serve.

Understanding the concentration and distribution of data-end users across vital public health roles within the state is important in order to develop a surveillance system with enough flexibility to accommodate the different data needs of its end-users at any given time. Perhaps more importantly, understanding where organizations fit within the public health systems may help direct and target resources for public health surveillance in order to achieve the greatest impact. Also, looking at those categories where participation was lacking provides insight into types of organizations that perhaps have not been using COHSS data, but if they could be cultivated to do so might be powerful allies in oral disease control and prevention activities.

How are oral health surveillance data being used in Colorado? Inductive reasoning was used initially to create several broad themes of data. These themes emerged from data usage as defined by the evaluation stakeholders, the Oral Health Unit and the CDC. According to Lavinghouze, et al., (2009) "State programs and coalitions identified three specific types of data used in oral health: surveillance, needs assessments, and evaluation findings." The staff in the Oral Health Unit expanded on these from their own personal uses to include grant writing and funding applications, indicated by "Grants/Funding," and legislative policy, indicated by the title "Policy/Legislation." Additional deductive themes emerged during analysis resulting in the seven categories shown in Table 2 where uses were tallied across category and by user.

Implied in the defined uses of data is that these actions lead to prevention and control activities. No user explicitly stated that they used data to prevent and control disease, but more to inform or direct actions that led to prevention and control of disease. For example, some community clinics report for internal evaluation the number of patients that complete treatment. This measure, defined as a successful intervention by the clinic, is a proxy to preventing and

controlling disease, but note the use is “evaluation” and much more of a proximal measure of intervention, compared to a distal measure of the change in disease status.

Not unexpectedly, a higher the number of organizations represented within in each category in Table 1, correlated with a higher number of positive responses for use of data within a specific theme. This pattern can be seen in the distribution of data uses by user role in Table 2. Every user category had at least one response to each of the uses identified, with the exception of “Education,” which did not have responses in Policy/legislation or Grants/funding.

In the categories titled “Government,” and “Community” over one-half of the respondents indicated that they utilized data in all the ways identified, with the exception of “Policy/legislation” and “Education.” In these categories, only four organizations representing “Community” identified using data in this manner. The category of “Third-party payers” had the most agreement between the respondents with both reporting data use in five of the seven areas. No other category had such agreement. But given that one organization represented was also a government agency, it is evident why grant writing and policy were reported as a use of data. What is not evident from this analysis, however, is whether or not low or no response to a specific type of data use represents an absence of this kind of activity, or simply not an explicit or an inferred reference to these uses. Additionally, as respondents were asked to provide specific examples of data use, but not their exhaustive list of uses, exploration may still be necessary regarding what data users may use data for primarily, rather than generally.

How users describe the data usage varied from organization to organization. For example, data uses in the “Policy/legislation” category implied statutory and regulatory policy. Respondents reported the use of policy using the terms such as “policy decisions,” and

Table 2

Data uses by category of user

Users / Uses	Government Role (8 orgs.)	Community Role (14 orgs.)	Education Role (3 orgs.)	Provider Role (4 orgs).	Public Role (6 orgs.)	Third-party Payer Role (2 orgs.)	Policy-maker Role (11 orgs.)	Higher/Profess. Education Role (2 orgs.)	Total
Policy/ Legislation	4	4		1	2	1	4	1	17
Grants/ Funding	5	9		1	2	1	3	1	22
Program Policy Strategic Plan.	5	9	1	1	4	2	5	1	28
Comm. Needs Assessment	6	7	1	3	3	2	5	2	29
Reporting	5	9	1	2	3	2	3	1	26
Education	3	4			2	2	3	1	15
Monitoring, Evaluation/QI	4	10	1	1	4	2	4	2	28
Total	32	52	4	9	20	12	27	9	

"proposing policy options." While the majority, 15 of the 17 respondents, used the word "policy" to define data use for legislative types of policy work, two respondents did not use the word explicitly. However, when their responses are put into the context of the category they represented, "Community" and "Higher education" their responses "inform key decision-makers" and "educate lobbyists" implied the data were used for regulatory or legislative policy development. The use words implying a type of data use was true across all categories of uses and users.

The data uses mentioned above all represent data from sources external to the organization. Most respondents also reported collecting and using data from within their own organizations. These data often related to evaluation, quality improvement/quality control activities, general demographics, value of service provided, etc. While these data were valuable to help evaluate a particular program or organization for intermediate outcomes, they often did not provide enough information for evaluation of long-term effects and impact on oral disease in the larger population. For example, a local community health center director said "I know how many people I treat, but I don't know if it is making any difference." This type of statement reinforces the importance of data from a variety of perspectives from the individual to the population level, to gain a true picture of prevention and control effects.

Are the data sources sufficient to meet the needs of the users, and what are the data gaps? Prevention and control measures are developed from data indicating the need. If the data available are not sufficient either in the type, detail, or frequency, needed by end-users then activities directed at prevention and control may be more difficult to initiate, or effects of activities being implemented may be harder to evaluate.

Data end-users universally identified federal agencies such as the CDC and HRSA as

reliable sources for data acquisition. Within the state, the Colorado Health Foundation, the Colorado Department of Public Health and Environment (CDPHE), and other state agencies were also seen as reliable places to obtain data. However, most end-users acknowledged that the depth and breadth of data available to them from the COHSS and other state systems was not well understood, "…part of it for me is learning what's out there..." This was evident even more in what gaps users identified. As one community organization stated when looking for specific data "…for us to be able to call and just say 'Do you have this data?' …there's probably just so much data they can't put it all up at the same time" emphasized the need to better publicize what data are actually available. Another respondent stated "if there's poor oral health at this age range, do statistics show that by this age range, they would have these advanced complications" and "how many diabetics are there in the state; or individuals with a concurrent medical condition that would draw on a specific benefit." While this information is available, it is generally not in a single surveillance system, such as COHSS, or in a format useful to the organization.

Additionally, most users that serve specific geographic areas (e.g. a specific county, city or neighborhood), or specific population groups (e.g. people with HIV, or young children in poverty), did not find sufficient data from most federal or state agencies including COHSS. For example, one local public health agency reported when conducting a community needs assessment that they first searched for data from many of the state systems including the Colorado Health Information Data Set and BRFSS, but that data were not specific enough. "We would prefer if there were a way to actually gather the same information very specific to … county." Not finding the level of data they needed the augmented what they did find "… (we) also, did a community survey and we wrote in specific questions around oral health within the

community…" to capture relevant data for their purposes. Another example is a state-wide foundation working in access to care stated that when seeking more specific data "I've always wanted to see just BRFSS as a whole over-sampled for northeast Colorado" due to the challenges of understanding the true need in isolated areas of the state. Yet where and when oversampling did occur in a specific population, African American, she was not aware of the data.

Gaps in data that were reported as inhibiting end-users from meeting their organizational goals are shown in Figure 7. The gap recognized by the most respondents, both state and local organizations, was local level data. When combined with the need for rural data, as stated by one respondent "issues in rural health care" the number of responses was even greater.

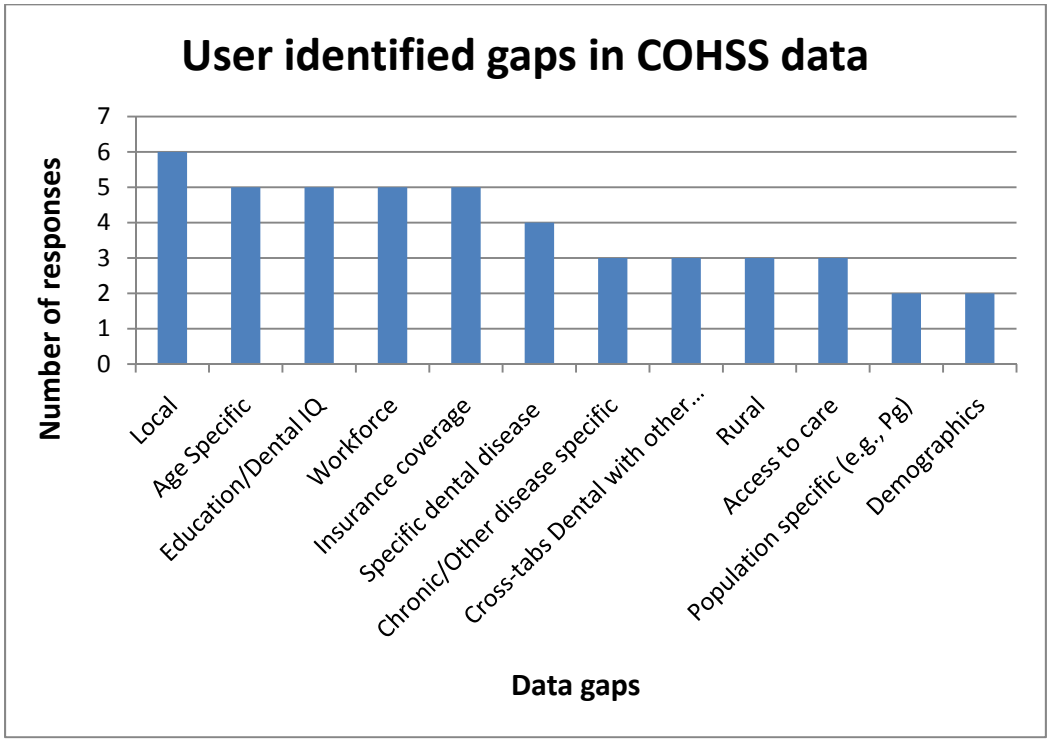

Figure 7. User identified gaps in COHSS data.

Oral health data within specific ages, data on health education effects, health literacy, and individual knowledge regarding oral health (dental IQ), workforce data (data on types distribution and availability of dental professionals), and insurance coverage data were the next

highest reported gaps, as identified by five respondents. Respondents reported these gaps "if there's data that's available to help identify most effective means of educating people, I'd like to know that" or "We're still struggling around the issue of prenatal care and oral health care….I'd like to see something a little more comprehensive, a little more on a larger test population" and "more about the dental field when I hear that there is shortage, …to help meet the need" In total, the distribution of organizations recognizing certain data gaps was dispersed across all categories of data users, with no one category of users identifying a large number of data gaps.

Are current data dissemination strategies effective for getting oral health surveillance data to end-users? End-users seek data from either internal (within their own organization) or external (outside of their own organization) sources. Additionally, they seek, access, and receive these data in different manners. All respondents reported some forms of internal data collection from sources such as electronic health records, and reported actively accessing that data for various purposes, but most frequently for evaluation and monitoring progress on organizational objectives.

For users that represented community organizations and provided direct patient care internal data collection activities often revolved around systems designed for a billing and patient health records. Users reported "chart audits," and other forms of patient record mining as a primary means of capturing evaluation data. Data they report accessing includes "number of patients we see," "Insurance coverage…" "demographics" and the "kinds of services provided." These users also reported internal data were available from pre-defined reports as part of the software package, and fairly easy to access on demand. For example, they could pull reports that illustrated the payer mix for clients seen at defined intervals of time, (e.g., a month, six months, or a year). These systems often reported basic demographics such as race/ethnicity, age, and sex

of clients. However, these systems were often not flexible enough to allow for custom reports, nor did many of the organizations have access to more advanced statistical analyses to take full advantage of the information the software programs could provide.

In addition, the internal data that were primarily record-keeping programs, three categories of users, third-party payer, providers, and government, reported active data collection projects to address identified gaps in existing data. These primary data collection efforts were often in the form of surveys and specific to a project, or activity such as “patient satisfaction,” “member needs,” and challenges faced in providing care. A limitation of these efforts, however, was that these data were often not made available to the public, unless they were collected on behalf of a government agency; did not involve much external stakeholder input for value or utility for bigger prevention and control efforts; and was primarily for internal agency use only.

Universally, users reported accessing data external to their organization, implying that internal data were not sufficient to meet all their data requirements. These data were accessed in either a passive or active manner. Passive data access was reported by the majority of users generally in the form of mailed hard-copy reports, or some form of electronic format. Active data access came in the form of internet searches, or often a personal point of contact within an organization seen as providing credible and reliable data. Figure 8 shows the conceptualized data-seeking patterns of end-users.

It is important to note regarding data seeking and access is that while all respondents reported data in an electronic format was preferable, for in-depth review and reading most users prefer having a printed copy of any documents. Also, the more relevant the data were to organizational goals, the more likely the respondent would utilize the data in some manner, and recall the source of the data in the future.

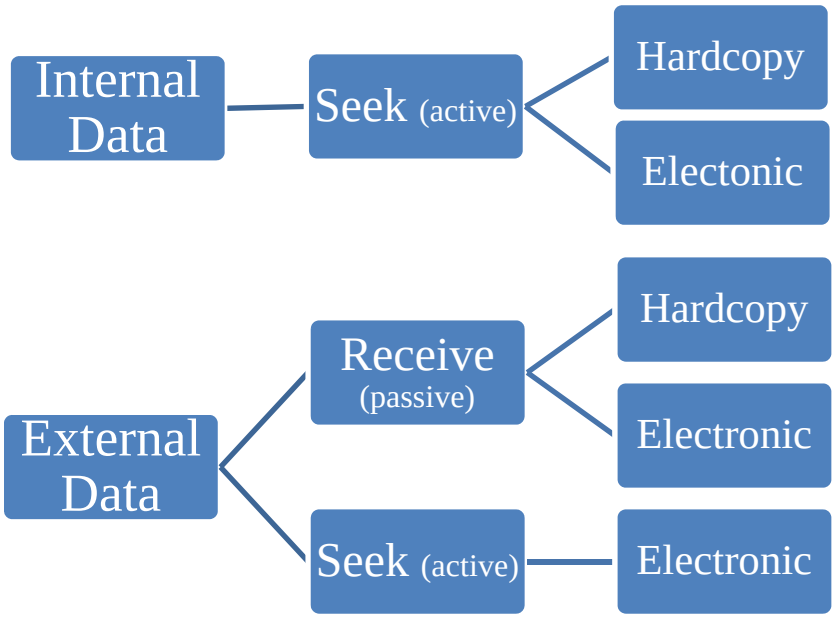

Figure 8. Data seeking and data dissemination patterns of COHSS users.

When end-users were asked how they would like to learn about new data as they became available, all respondents reported that electronic notifications were preferable. Additional insight was provided through comments pertaining to crafting headlines, or summaries that grabbed the audience's attention immediately, and ensured information was presented in a way that was immediately obvious as relevant to the organizations work.

The theme of "relevance" of the information ran throughout the entire analysis, indicating that it is important to really understand each user's needs when developing specific data tools, reports and analysis to ensure the data is useful.

Are there any populations or programs where oral diseases have been controlled, prevented, or reduced? And conversely, where has control and prevention proven difficult? This section of the analysis will be presented from the standpoint of a single end-user of the

surveillance system, the Oral Health Unit. The trends in disease have been monitored across several indicators in both children and adults. While few indicators have changed in any meaningful manner since the COHSS was developed, modest success has been evident in a few indicators of note within children's oral health.

Kindergarten and third grade children presenting with cavities and/or fillings (decay experience) remained constant over two data collection periods, 2004 and 2007 with 45% of the kindergarten and 57% of the third grade children, compared to 46% and 57% respectively having caries experience. Slight decreases in untreated cavities for both grades were also noted, but were not statistically significant.

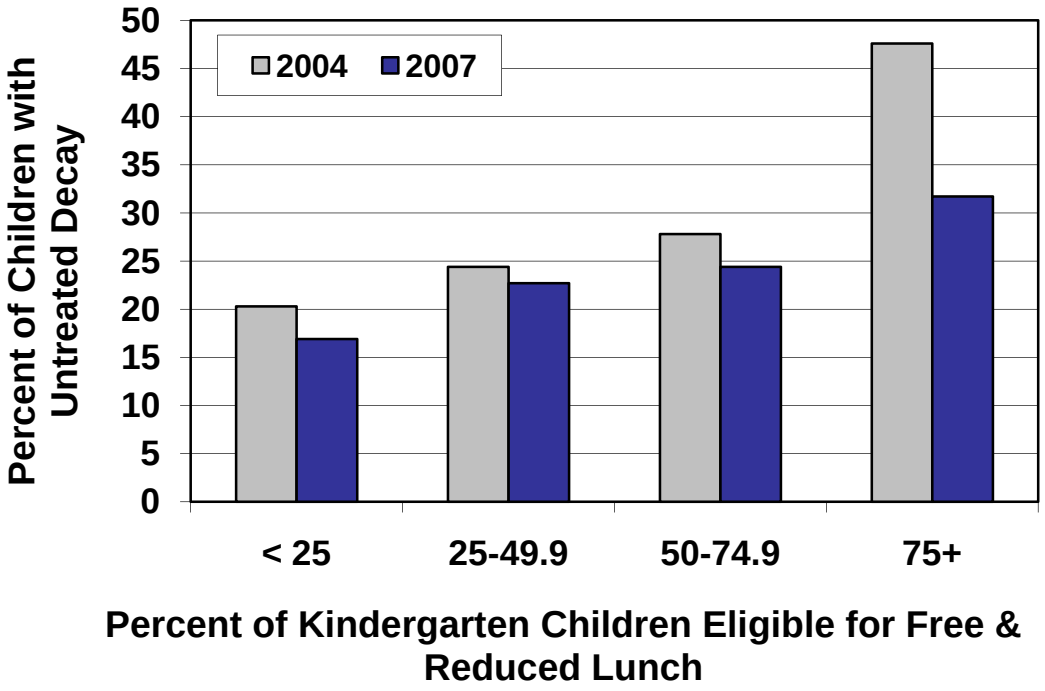

Figure 9. Percent of Colorado kindergarten children with untreated decay by free and reduced lunch status of school, 2004 and 2007.

More importantly, however, was that disparities across most indicators have been reduced. For example, Figure 9 shows that across all socio-economic strata, as determined by

percentage of participation in free and reduced lunch, kindergarteners with untreated decay has gone down. For those children at the highest risk, and with the highest need, represented by 75% or greater participation in free and reduced lunch program, there was a statistically significant decrease in untreated decay from 2004 to 2007.

Another change that, while not statistically significant, was important in the context of surveillance, is the decrease in disparities for preventive dental sealants. Figure 10 shows that between 2004 and 2007 36 percent more students in the lowest socio-economic strata, greater than 50% free and reduced lunch, had dental sealants.

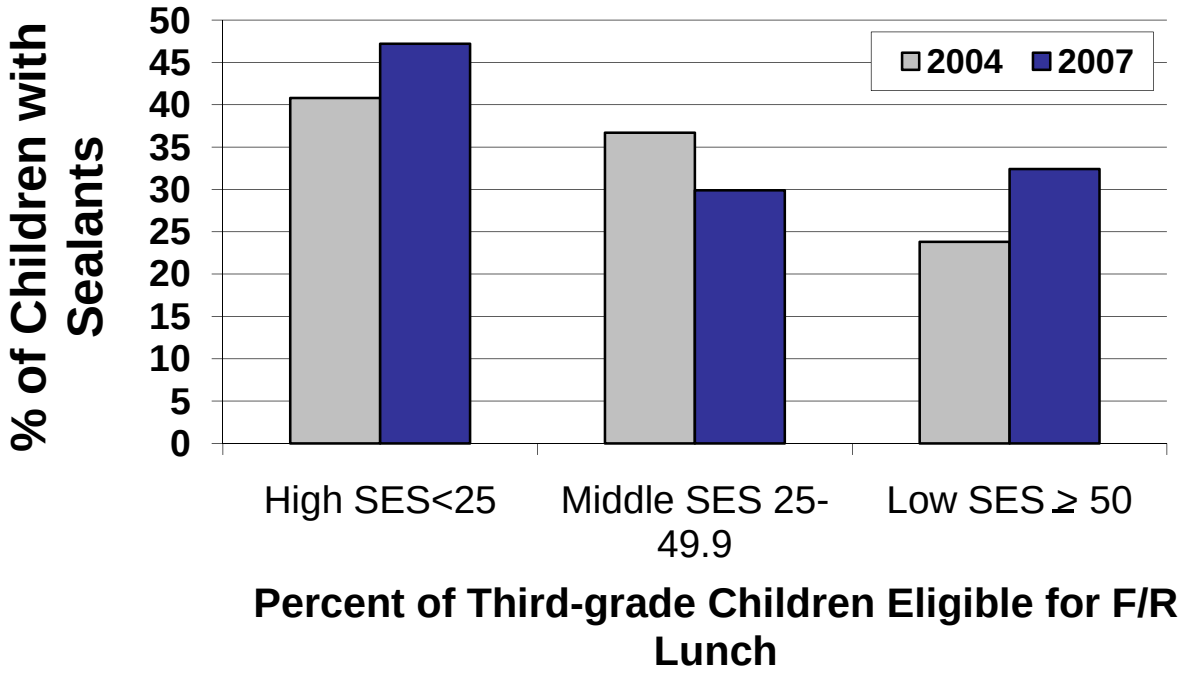

Figure 10. Percent of Colorado third grade children with sealants by free and reduced lunch status of school 2004 to 2007.

Changes reflected in isolation, such as sealants and dental caries comparisons between 2004 and 2007, while interesting, only describe part of the story. When surveillance measures were linked back to prevention and control activities the picture becomes clearer. Case in point,

- Between 2005 and 2007 there was a 32% growth in schools receiving sealant services.

These data were compiled from the annual school eligibility listings and the listings of the schools receiving services as reported by the contractors.

- Between 2005 and 2007 there was a 25% increase in individual students receiving services.

This information is gleaned from contractor reports.

Since the expansion of the sealant programs were specifically aimed at eliminating disparities in access to this effective preventive intervention, sealants, the combination of changes seen in the program, the increasing number of schools served, the increasing number of students receiving services which are program evaluation measures, and the changes seen in the state surveillance measures, increase in the number of sealants in the population, indicated some success. This example of the triangulation of data sources taken in the context of prevention and control activities in the state can demonstrate the contribution of those activities to the changes in surveillance measures and ultimately success of a surveillance system in the prevention and control of disease.

The data presented previously illustrates some improvements have been made, and can highlight where work still needs to be done. More importantly, however, was the recognition that as a user of the data, the Oral Health Unit needed specialized and more detailed analysis, and multiple data sources to show a cohesive story of the impact of its prevention and control activities. This illustrates the need for the data users to be engaged in the development and implementation of the COHSS particularly during planning, data collection, analysis, and probably most importantly, interpretation to make the data as useable as possible for individual

organizations. The input provided during the various phases of surveillance will vary depending on the organizations roles within the public health system in Colorado, and the intended uses for the data. It is important as stewards of this system that the Oral Health Unit utilize the input received to create the most effective and useful system possible.

Summary

The results of the present evaluation illustrate the importance of understanding the intended users of surveillance data. Understanding what role data users play in the public health system can lead to understanding how they might ultimately use data. More importantly may be, however, that categories where there are many data users represent significant opportunity to change oral disease within the state.

Ultimately, understanding when, how and why data users seek data and how they prefer to receive it may increase oral health surveillance data's ultimate use within public health practice.

CHAPTER V - MAJOR FINDINGS AND RECOMMENDATIONS

Introduction

Unlike infectious disease surveillance systems whose users are also those who provide the data (e.g., physicians, laboratories etc.), the identity of oral health surveillance data users is poorly known by state and national organizations that collect, analyze, and report surveillance data results. There is no reason to believe this is different for other chronic disease surveillance users whose primary focus is heart disease and stroke, diabetes, obesity, and cancer control. Furthermore, essential information about how different organizations use surveillance data differently does not exist. Few if any connections exist between the producers of surveillance data and the users of surveillance data. Instead, chronic disease surveillance data are collected, analyzed, and reported without specific users or uses in mind. Therefore, the data are often broad and far removed from any specific purposes and uses. What is known about oral disease surveillance, is summarized by Lavinghouze et al. (2009) “The ability and the responsibility to monitor oral health status in states is core to the oral health program.” However, we must strive make the data useful; to “engage data” directly into public health action.

For oral health surveillance data to be useful they must first be translated into information meaningful to those in a position to act, to implement, or influence disease management and control programs. “Data must be engaged and used as an action and not merely collected and displayed” (Ottoson, 2009). To ensure that data are used to promote some public health action, sometimes an intermediary such as a patient or consumer advocate group, a philanthropic organization, or a community dental clinic is necessary to give data and statistics the voice and the power to influence the decisions of others, such as legislators and funders. Understanding the different characteristics of surveillance users, the uses they put the data to, and their needs for data are fundamental to ground data collection, analyses, and dissemination that can result in

useful information to guide and inform disease control efforts. The users must be known, as well as their work. In turn, the users ideally should feel a reliable connection with and understood by the government agencies charged with the management duties of supplying health surveillance data.

The COHSS has demonstrated a few successes in supporting the prevention and control of oral diseases. However, the COHSS has not fulfilled all its potential as a source of timely and reliable engaged data that is seen as relevant to the oral disease prevention and control organizations in the state. Engaging data users in discussions about COHSS data collection, analyses, and dissemination is the first critical step to building a network of reliable connections between government surveillance and the intended users of surveillance. This will help ensure the utility of the data for those ultimately taking the actions to improve oral health in the state. Gaining a clear understanding of the different types of organizations that use data, the content of their work, and how they prefer to receive or access data could represent the initial data elements of a new data collection and surveillance effort designed to understand the oral disease and prevention infrastructure in the state. These infrastructure data would be used to guide data collection, analyses, and dissemination of the disease and control-related data. The present findings may have potential to help Colorado public health as well as other state governments that collect chronic disease surveillance data.

Key Findings

The present evaluation was designed to answer the fundamental questions important to creating a useful surveillance system to inform public health practice for the prevention and control of oral disease. They key findings of the present evaluation are important when

considering recommendations for improving existing surveillance systems, or planning new ones.

Who are the oral health surveillance data users in Colorado?

- Data users of any surveillance system are virtually unknown.
- Vital roles necessary for public health practice within the state, such as those outlined in the Data End-user Selection Framework, can generate a close approximation of the large categories of potential users.
- Generating a listing of organizations that meet prescribed definitions of public health roles can serve as a basis for beginning to learn more about who is actually using data, who could potentially be using the data, and who one could hope would be using data.

In the present evaluation, by using the Data End-user Selection Framework, a pattern began to emerge about those roles within public health that have the potential to have a significant impact on oral disease prevention and control activities by organizations either being "power users" or forming a "critical mass."

- Power-users are those organizations that play many diverse roles within the public health system in the state, or that have such a concentrated focus in their mission that they have a significant amount of clout, political capital, and are greatly respected in the community.
- Categories within public health practice where a large number of users, or potential users, exist represent an area where there is a critical mass, a tipping point if you will, for action to occur.

- Both power-users and categories where a critical mass for action exists are both areas to best leverage engaged data.

While the present evaluation can only suggest why certain categories of data users had limited response, a lesson to be learned is that the categories as presented in the evaluation of COHSS were deemed vital to public health practice in the state, therefore cultivation of COHSS data users within those under-represented categories is important to the prevention and control of oral disease in Colorado. Further, categories where power-users or a critical mass exists represents an opportunity to leverage engaged data to its fullest potential.

How are oral health surveillance data being used in Colorado?

- Data uses generally followed expected trends as preliminarily defined by Oral Health Unit staff; Grant writing/funding requests, reporting, policy and legislation, and community needs assessments.
- Additional uses emerged that were more explicit for example program policy and strategic planning, education (of patients, advocates, policy makers), and monitoring, evaluation and quality improvement.

Are the data sources sufficient to meet the needs of the users, and what are the data gaps?

- COHSS data users, as defined in the present evaluation find data from well recognized federal and state sources.
- Most data users reported not knowing the depth and breadth of data available in COHSS, and expressed exposure primarily to a single document, the 2005 *The Impact of Oral Disease on the Health of Coloradans.*

- Many users identified data gaps existed in relation to their specific target population, geographic area, or on specific oral health issues, for example health education and health promotion.

Are current data dissemination strategies effective for getting oral health surveillance data to end-users?

- All data users identified seeking data to meet a specific need.
- Data obtained from internal sources, such as chart audits, electronic health records and patient satisfaction surveys met most needs for evaluation and reporting to funders.
- Data obtained from external sources were either sought for a specific purpose, e.g., grant applications, or users were notified by trusted sources for data, for example the Colorado Health Institute.
- Universally, data users reported data notification or dissemination in an electronic format was preferred, namely by email and the internet.
- Users recommended either briefs or summaries as a preferable vehicle for informing them about new data "products."
- Users repeatedly emphasized that to enhance COHSS data utilization, the data must be shown to be relevant to them as targeted users.

Are there any populations or programs where oral diseases have been controlled, prevented, or reduced?

- COHSS has had modest success in preventing and controlling oral disease in the children of Colorado.

- More importantly, perhaps, is the COHSS data shows where work still needs to be done especially in the areas of adult and elderly oral health.

Discussion of Findings

Understanding the role of an organization is important in understanding the influence that specific users have within public health or the health care system. The idea of understanding every organization that may access public health surveillance is daunting. It is not necessary to know absolutely every individual user of a surveillance system. Instead, understanding key organizations that share similar roles within oral disease prevention and control activities can help understand similar users. Moreover, this information can help focus and tailor resources in surveillance to the greatest effect. Ultimately understanding at least a few users within the various roles will help determine how best to collect, analyze and report data for each audience and program role. From the present evaluation two ideas have emerged that are important to reflect on when thinking about data users and their potential to impact oral disease: “power-users,” and “critical mass.”

Power-users are those organizations that represent several different roles within oral disease prevention and control in the state. These agencies are important as they have influence over several aspects of prevention and control roles in the state at any given time. In the present evaluation these organizations were most likely to be local public health agencies, county health departments, such as Eagle County, the Health District of Northern Larimer County, Denver Health, and San Juan Basin Health Department. The roles local health departments play range from providing gap filling direct services, to impact county level policies through the county governance structure.

In Colorado local public health plays an important role in filling health care gaps, in some instances providing direct service, or facilitating health delivery through contracts and agreements. Perhaps most importantly, these agencies understand local dynamics and priorities of the community, and they are positioned to better address those issues. These agencies represent local control, and with the power of county governments can propose local health policy and advocate on behalf of its adoption. Unfortunately, to date organizations with the possibility of being significant, or "power-users" of COHSS data have not been engaged in the system in a meaningful way or with regularity.

The converse of power-user organizations is critical mass organizations. These organizations exist in large numbers and they share in common a single role in oral disease and control and prevention. A large number of organizations saying the same message or implementing the same program can bring to bear a great deal of influence on a certain issue.

In the present evaluation, the role of "community" had the largest number of organizations represented. These organizations included community based health clinics, foundations, and local health agencies. Additionally, the organizations represented some geographic diversity implying that the influence would also have dispersion across the state. The value of a critical mass is that should organizations within a certain role of prevention and control come to agreement that a certain problem exists, they can bring their influence together to address the issue creating a "critical mass" of political will ultimately changing the context or dynamic so improvements can be made.

Schools and school health clinics are another example of critical mass potential. Unfortunately, however, some roles within the oral disease prevention and control arena may lack organizational presence to affect much influence. One vital role was that of education. The

oral health data available for educational institutions is not well developed, nor presented in a manner that is relevant to their priorities. This deficit represents an opportunity to engage the school sector in more conversations about oral health data, and how the use of such information can benefit their students and families.

The COHSS has been less than successful at engaging “power-users” or appealing to the “critical mass” for translating data to action, therefore data is less engaged than it could be in directing public health action. Unless otherwise aware of the data capability of COHSS, for the most part both potential “power-users” and those roles with a “critical mass” haven’t seen the state Oral Health Unit as source of timely, or reliable data that is particularly meaningful to their activities. Additionally, users interviewed identified significant data gaps that still exist in geographic areas, and in certain population groups that would make data more useable. In order to capitalize on these powerful users of oral health data, both power-users and organization roles containing a critical mass must be better engaged, and resources found to address the data gaps.

With a clear idea of how data users are classified in the state, to further hone the value of COHSS data, one must then understand how they intend to use the data. Data users generally seek data to meet a specific need. Commonly, respondents in the present evaluation reported needs assessments and strategic planning, grant and funding applications, and evaluation efforts as primary uses for data. It is incumbent upon the developers of a surveillance system to understand these needs, and therefore understand the ultimate intended use for data to have its greatest impact on prevention and control activities. Further, to have the data presented in a manner that is immediately identifiable as relevant to the user, and easily put into action with little or no additional interpretation or manipulation will increase the ultimate utility of data. As one interviewee put it “data is a continuum. There is data (raw numbers), you analyze it and you

get a statistic, and you interpret it to get information." The COHSS needs to provide information to serve the greatest need of data users.

Using the same classification used for defining the roles of an organization within oral disease prevention and control in the state can also generally categorize an organization's use of data. For example, an organization within the categories of government, public, or policy will likely use data for legislative or regulatory policy development. This activity may come in the form of raising awareness, and educating the public or decision-makers about an issue, or go so far as to present the various legislative or policy solutions to a particular problem and taking a specific position in favor of that policy. In either case, the point remains that the data must go beyond the recitation of pure statistics; it must be engaged. The information should tell the story of the impact of the health issue on the state, county or individuals being affected, prompting action to change that affect.

Identifying users and how they ultimately use data is one link in making COHSS more effective. However, if the means of getting data into the hands of the user are not successful, then the system is also not succeeding. Outside of the data that organizations may collect about themselves, the present evaluation revealed that people have identified reliable and trusted sources for data external to their organizations, and they report returning to these sources again and again. When accessing data in an active manner, users identified both "queryable" and static data as useful. However, this active data seeking is generally in response to a specific need such as completing a grant application, strategic planning and community needs assessments, and evaluation of an intervention.

Passive data seeking, sending information out to data users at regular intervals and in ways that users find helpful; is one way respondents reported that other organizations have built

trust, and become recognized as a reliable source for data. For example, the Colorado Health Institute, a local public health non-partisan data clearing house, often notifies organization of new reports and data tools available on their website through a subscription to an email list serve. On the CHI website, the data are categorized within areas of public interest such as workforce or access to care. This is just one example of a successful dissemination strategy that respondents described, and users find relevant to their work.

Of note when discussing electronic dissemination of data, all users emphasized that with the stimulus overload people are exposed to in the present electronic age the quicker the relevance of a data can be determined the more likely the user is to remember it and put it to use. Additionally, users noted that while quickly previewing data the computer is sufficient, however, for more in depth review documents need to be printable for ease of reading, and graphs and charts in a format compatible for insertion into documents.

Recommendations

The present evaluation focused on findings for improving and enhancing COHSS. The design, interpretation of key findings, and ultimately the following recommendations of how to improve data use from the COHSS were derived from the data user interviews and current body of literature on planning and implementing a surveillance system designed to impact prevention and control activities of the disease under surveillance. These recommendations are presented after careful consideration of what action can be taken given limited resources, requirements of funders, and ultimately meant to provide data of the greatest value to those in a position to take some action with the information.

1. Develop data advisory committee to fully engage data users in the revision of the COHSS.

The results of the present evaluation emphasize that any program developing a surveillance system cannot completely know the users of the data they produce. An effort must be made, however, to engage those organizations and individuals that a program believes are likely to be users, or who, by the nature of the role they play within public health, should benefit from surveillance data, therefore ensuring a system that is flexible and responsive to the users needs.

2. Conduct evaluation and collect periodic oral health infrastructure data in the state about primary data users and programs so that COHSS data collection, analyses, and dissemination are guided by concrete end-targets and affecting health outcomes.

The identity of primary data users along with their respective program actions must be clearly understood by the COHSS. Collecting data on users will enable COHSS to better define its audiences for specific data products, and to evaluate COHSS's effectiveness and usefulness.

3. Convene "power-users" to help define analysis, interpretation and dissemination strategies for specific sets of COHSS data.

Certain organizations have the potential to significantly impact the disease(s) under surveillance. It is important to know who these power-users are so that surveillance resources can be allocated to meet those organizations needs more readily. Ultimately, this inclusion of key power-users in the development of analysis plans, interpretation and dissemination strategies, will provide these organizations with the appropriate information necessary to influence the policies, programs and funding mechanism necessary to conduct effective prevention and control activities.

4. Ensure that data dissemination is targeted, and tailored to specific users and uses.

As a result of continually diminishing resources, strategies that maximize the resources available while delivering the greatest impact are important. Rather than attempting to develop the

majority of data products using broad strokes, and seemingly miss the mark for many data users, tailoring of data products with specific audiences in mind may net greater impacts.

5. Pursue resources and strategies to address user identified gaps in COHSS data.

The present evaluation identified several data gaps. Some, such as disease specific or correlation with other chronic disease etc., are easily manageable with some forethought and planning. Others, however, like geographically specific data are harder to obtain and justify. However, the development of state level oral health surveillance systems grew from the agreed upon need for data more state specific data in order to address oral diseases. Therefore, while the development of local surveillance systems that include oral disease indicators seems challenging, efforts must be made to seek resources to address user identified gaps within COHSS.

Conclusions

Engaged data, which includes all oral health surveillance and evaluation data, was noted in the evaluation of the first CDC cooperative agreement as one of five essential components of infrastructure. All states reported that without engaged data the state oral health program would not exist nor evolve (Lavinghouze, 2009). Information presented in the public health surveillance literature is clear, for a surveillance system to be deemed effective the data must be collected regularly, and analyzed and disseminated in a timely manner. Most importantly, however, the data of a surveillance system must be put to use for the prevention and control of disease by those with the power and authority to do so. Data for traditional infectious disease surveillance is often collected and disseminated to the same source: health providers. Disease is confirmed through laboratory medical tests, and are considered such a high risk to the public's health are required by law to be reported to public health authorities. Data in emerging applications of surveillance, however, are less often laboratory confirmed, may or may not be reportable, and

should be disseminated to individuals outside of the healthcare profession, such as law enforcement, food inspectors and so on.

How do the implementers of COHSS know that data are getting to the right people and impacting the health? Colorado can point to several instances where the COHSS has been used effectively by different programs and organizations in Colorado for oral disease prevention and control activities. For example, fewer children entering kindergarten in 2007 had untreated caries and urgent needs than their counterparts in 2004. Similarly, in 2004 fewer Hispanic third-graders and those in lower socio-economic schools had preventive dental sealants than did students in 2007. The fact that both of these changes can be attributed to intentional efforts of the Oral Health Unit and its state-wide partners illustrates that where oral disease prevention and control efforts have been successful organizations involved in those activities were more aware of and engaged COHSS data with oral disease prevention and control in mind.

Despite modest success of COHSS since its inception in 2003, the system has yet to fulfill its potential in many areas. For example, data users are not aware of the types of data and special analysis available in COHSS. More unfortunate, those organizations that purport using "data driven decision making" do not see COHHS as a source for timely data that is relevant to them.

Traditional disease surveillance systems focus on a single disease or issue. The use of historical methods for surveillance of emerging public health issues, such as chronic diseases, including oral health cannot be treated in the same manner due to the complex interplay of risk and protective factors that may or may not result in disease manifestation. In addition to basic prevalence of specific diseases in the population, the COHSS tracks many of the risk and protective factors relevant to the development or oral disease in the population. This complicates

the analysis and reporting of oral health surveillance information to the users as the amount of potential data is significant. For example, cavities are caused by an imbalance of risk and protective factors. Eating sugary foods, the frequency of consumption, how well the person removes the bacteria that feed on the sugar, and so on are all risk factors for cavity formation. A person's exposure to fluoride, access to dental care, and the good nutrition habits are all protective factors. Depending on where an intervention focuses, there will be different surveillance measures to follow. Additionally, data users report that state level estimates may be less relevant to a county or even to a region within the state due to any number of factors such as geographic isolation, or presence of seasonal workers. These issues all underscore the importance of engaging data users and build functionality into oral disease surveillance to focus surveillance efforts to the most meaningful measures of importance to the interventionists.

For data to be fully engaged in oral disease prevention and control activities it needs to be disseminated to individuals outside of the healthcare profession, such a law enforcement, educational institutions or community organizations. In the article *Future directions for comprehensive public health surveillance and health information systems in the United States* Thacker and Stroup recognize that "Although the core constituents (for a surveillance system) will be public health officials, the expanding roles of private laboratories, clinicians, schools and the public will necessitate that the data needs of these constituents be addressed as the system evolves (Thacker and Stroup, 1994, pg. 389)." Two segments of data users in Colorado have the potential to make the most impact with COHSS data, "Power-users," those groups that play many roles within the public and health care systems in the state, and roles within the public health and health care system that have a "critical mass" of users where impact of data may be multiplied by the number of users in a particular roles using it.

In Colorado these segments of current and potential data users can be put to better use. For example, power-users and roles of public health with a critical mass are areas where with more engagement in COHSS could have an immediate impact. Conversely, those segments that have less representation may need to be cultivated, and therefore, present the opportunity to engage new and valuable data users in the future. Most importantly is the value of understanding how these segments of data users will put the data to use. By knowing the uses and users of COHSS data the resources allocated to surveillance activities may be targeted or further resources sought to ensure data is getting to the key data users in the state.

Implications

By enhancing COHSS from a rote data analysis system to a fully engaged data system that integrally involves those who will ultimately use the data, organizations outside of the Oral Health Unit may find more utility in COHSS data.

"Power-users" and the formation of a critical mass are important facets of user cultivation to consider. With the enactment of the Public Health Revitalization Act (2008), Colorado local public health agencies will soon be defining a set of core functions, disease indicators and programs that all agencies will be responsible for addressing. With the recognition of the importance of good oral health, and the ongoing evolution of COHSS, oral diseases may be one area of focus for these agencies.

A continuing challenge for any oral health surveillance system will be, however, is creating information that is relevant, appeals to, and motivates a broad group of users within the resource constraints currently faced. This necessitates developing data and reporting it in a manner that is targeted and tailored for a specific purpose, and intended use to ultimately help put the data into effective action.

The findings of the current evaluation reveal that data may be accessed in either an active (users will go out and find it) or passive (it will be delivered to them) manner. As long as the data remains relevant to the COHSS user's work, employing successful passive data dissemination strategies may go some way in developing the trust within data users of the reliability of COHSS. This reliability and trust will facilitate COHSS data use, and therefore make the COHSS a more effective system, ultimately leading to better prevention and control of oral diseases in the state.

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APPENDICES

APPENDIX A COHSS PLAN

…how data collection, analysis, and dissemination will support program activity in Colorado

(i.e., used to make program decisions; evaluate progress)

Purpose and Objectives

The purpose of the Colorado Oral Health Surveillance System (COHSS) is to develop a system to monitor and control the burden of oral disease among Coloradans. The system collects, analyzes, and disseminates data to inform and support oral health decision-makers in Colorado. Data collection follows probability-sampling methods guided by the Centers for Disease Control and Prevention (CDC) so that representative samples of the state population are obtained. With these data oral health patterns can be monitored across Colorado's demographic groups. When high-risk groups or behaviors are identified, oral health programs are targeted appropriately to meet the need. Monitoring oral health patterns in the population is able to show any general changes or emerging trends in the state.

In addition to pursuing data collection activities that monitor broad-based and slow moving patterns, the COHSS seeks to support any data collection efforts about specific prevention and intervention programs designed to reduce or control the burden of oral disease in Colorado. For example, data is collected on the fluoridation status of Colorado's drinking water and reported to the national Water Fluoridation Reporting System (WFRS). These data show the proportions and locations of Colorado's drinking waters that still need fluoridation adjustments. Data collection efforts are also underway for the school-based sealant program in Colorado through upgrading to the latest version of Sealant Efficiency Assessment for Locals and States (SEALS): A computer software program created by the CDC to collect all relevant information about sealant prevention and resources. These data show who receives sealants, where disparities are being addressed, and what proportions of students have received them. These

prevention data about water fluoridation and sealant placements will provide opportunity for program evaluations that lead to more effective and accountable programs reducing oral disease in Colorado.

In an effort to promote the collection, analysis, and dissemination of program-level data in Colorado, the COHSS seeks to provide technical assistance that facilitates local program managers in the use of standardized data collection and program evaluation methods. In this way the COHSS can help to build an integrated and sound data based infrastructure among Colorado's oral health stakeholders. These kinds of collaborations promote the development of more effective and accountable programs at the individual-community level.

Measures

A core set of measures describes important oral conditions or behaviors in Colorado and serves as benchmarks for assessing progress in achieving good oral health. Three criteria are used to select items for inclusion into the core set of measures in the COHSS: (1) Ability to monitor salient oral health patterns across Colorado's demographics; (2) Ability to target program resources to gain greatest impact and/or meet greatest need; (3) Ability to compare state oral health patterns with the National Oral Health Surveillance System (NOHSS).

A list of the core set of items tracked by the COHSS is in the Appendix. Items are grouped into one of four categories. (1) Eight important indicators are reported to the NOHSS for national dissemination, comparison, and monitoring. County-level data for these same indicators are monitored by the COHSS as data allow. (2) Fluoridation status of Colorado's drinking water is reported to the national WFRS. (3) The state sealant coordinator manages the school-based sealant database that is populated by contract sites responsible for collecting data with SEALS software. The COHSS monitors the proportions of students receiving sealants. (4)

Statistically significant, and well-established predictors of tooth loss are followed over time using logistic regression modeling to show the changing patterns of association among the predictors of tooth loss (i.e., demographic characteristics, SES, diabetes, smoking, exercise, access to care).

While the main factors that influence tooth loss are well known, the effects of changes in one or more of these factors is relatively unknown and can influence the overall pattern of tooth loss in Colorado. Understanding how these factors associate together over time, and how their continuing effects on tooth loss evolve in Colorado could prove to be crucial information to advance local oral health efforts. This kind of regression modeling allows program staff to identify and target the important local factors that reduce tooth loss the most. In the future the COHSS may be able to identify specific demographic characteristics and lifestyle behaviors that impact tooth loss indirectly through flossing and brushing habits. Once identified these risk groups could be targeted by programs that help individuals to build new oral health habits. Given that 80% of the oral disease burden lies on 25% of the population, local programs will need to start finding reliable ways to identify and target specific groups and behaviors that really need the support.

Dissemination

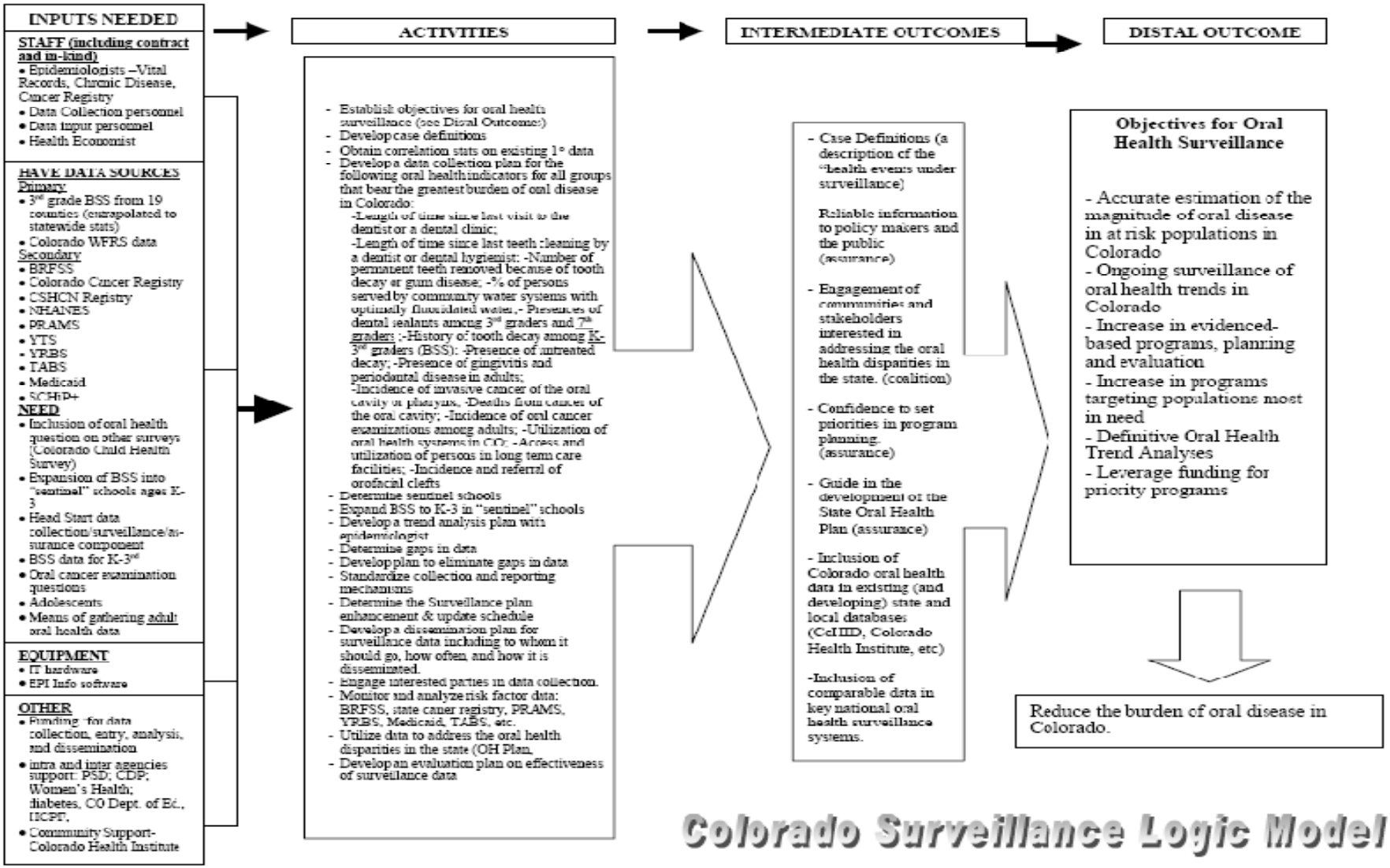
COHSS data analysis and dissemination activities are designed to meet the information needs that lead to effective and accountable oral health programs in Colorado. Not only are statistical analyses disseminated, but also instruction about areas of need, and how those needs might be met. Feedback from oral health stakeholders is also solicited to guide and support COHSS dissemination efforts. The COHSS is a flexible system that adjusts data collection and dissemination activities to address the evolving needs of oral health in Colorado.

Analyzing oral health trends in Colorado is a priority when time data are available. Trends provide more usable information for guiding programs than presenting many different indicators that reflect on only one point in time. Similarly, regression modeling of tooth loss rather than simple descriptive analyses about frequency distributions provides the most useful and accurate conclusion. Understanding how the predictors of oral health influence each other, as well as the oral health outcome, is the most effective use of technology to reduce oral health disparities across race, age, and socio-economic groups.

The format of data dissemination depends partially on the data structure and partially on the intended audience. For example, the NOHSS is a web-based tool designed to compare states on significant oral health indicators and across relevant demographic characteristics. Monograph summaries, on the other hand, are local state mailings prepared to meet more specific needs about the programs of oral health stakeholders. The Colorado Oral Health Burden Document is unique because it intends to be the comprehensive state document that describes in detail the oral health status and issues in Colorado every five years. The Colorado Oral Health Program also supports an online website where COHSS information can be obtained.

The COHSS is beginning to build cooperative relationships with local oral health stakeholders. As integration with stakeholders continues the COHSS should become an objective resource for reliable information to guide the development of prevention and intervention programs that reduce the burden of Coloradans' oral disease.

APPENDIX B COHSS LOGIC MODEL



APPENDIX C INVITATION LETTER

STATE OF COLORADO

Bill Ritter, Jr., Governor
James B. Martin, Executive Director

Dedicated to protecting and improving the health and environment of the people of Colorado

4300 Cherry Creek Dr. S.
Denver, Colorado 80246-1530
Phone (303) 692-2000
TDD Line (303) 691-7700
Located in Glendale, Colorado

http://www.cdphe.state.co.us

Laboratory Services Division
8100 Lowry Blvd.
Denver, Colorado 80230-6928
(303) 692-3090

Colorado Department
of Public Health
and Environment

July 8, 2008

The Colorado Department of Public Health and Environment, Oral Health Unit, is conducting an evaluation of the Colorado Oral Health Surveillance System and we would like your input.

The Oral Health Unit, through a cooperative agreement with the Centers for Disease Control and Prevention, has invested in the development of the Colorado Surveillance System (COHSS). We need feedback from organizations such as yours as to how your organization routinely uses oral health data, the usefulness of the data from the COHSS, and what improvements or modifications would make the COHSS a more valuable tool to your organization.

If you are interested in helping in this evaluation, please contact me by July 18, 2008 to set up an interview. The interview should take between 20 to 30 minutes, and can be schedule at a time and place that is convenient for you.

Sincerely,

Theresa M Anselmo, RDH, BS

Oral Health Program Manager
Oral Health Unit
303-692-2569
theresa.anselmo@state.co.us

APPENDIX D INTERVIEW GUIDE

The Oral Health Unit at the Colorado Department of Public Health and Environment is evaluating its oral health surveillance system. The Oral Health Unit would like to know how programs/agencies are using data, and more specifically how they are using data from the Colorado Oral Health Surveillance System. Do they use data for evaluation, are data used for programmatic decision making? Do they use data for funding proposals, for planning and prioritization of interventions and activities? Where do they normally look for oral health data? What format do they like to receive data in? Finally, how would organizations that use oral health data from the COHSS like to be notified and sent information when new data from COHSSS becomes available?

A sample of interviewees will be drawn from the list of stakeholders and members of the Oral Health Awareness Colorado! coalition and from those organizations inventoried in the Colorado Health Institute Environmental Scan document.

Interview Guide:

Thank you for agreeing to speak with me about your program and how you use data. As I explained to you when we spoke to set up this meeting I will be recording this interview for transcription. Would you please state, out-loud, that you agree to have this interview recorded.

Thank you.

Let me tell you about why the Oral Health Program is interested in how your organization uses data and how the information you provide will be used. The Colorado Oral Health Surveillance System is at a stage of development that a format for the presentation and accessibility of the data to stakeholders, such as yourself, needs to be evaluated. The Oral Health Program evaluation and epidemiology staff will compile the information from these interviews and look for themes and trends in how stakeholders currently use data; assess how the Oral Health Program can best provide you with oral health data in the future.

For the purpose of this interview if I ask a question with "you" I am referring to your organization unless I specify I am asking you personally. When I say data I am referring to any kind of data (oral health, demographic, health, etc). I will use the terms "oral health surveillance data and oral health data synonymously. I will try to specify when I am discussing Colorado Oral Health Surveillance System Data (which will be synonymous with Oral Health Program data) but if I don't and you wonder, please interrupt me for clarification. Does that make sense? Please feel free to interrupt me at any time for any reason.

Any comments on these broads ideas before we get into specifics?

QUESTIONS:

First let's begin by having you…**tell me a little bit about your agency.**

Probes: What is the purpose, mission, and vision of your organization/program?
Probes: What types of or describe the interventions/services you provide?
Probes: How many programs would you say you have? (I need to know this specific quantitative answer for the evaluation we are conducting.)
Probes: What are some of your organization's or program/intervention goals and objectives.

Now, thinking in global terms about your organization. What do you use data/oral health data for?

Probes: Describe some ways you have used data or types of data you have used for program activities, funding requests, advocacy efforts, program evaluations etc??

Can you share with me any of the documents or materials that you produced that use or contain oral health data?

Describe to me how you get your data.

Probes: Where do you search, obtain, receive the data you use, how do you do a search for data, what sources (name some) do you go to for reliable data?

I want to get a little more detail on a couple things (you said) if they did:
(You said that) you serve(d) _____ population(s), how did you decide to target that (these) population(s)?

You provided me with some examples of your organization or program/intervention goals and objectives.

Thinking about those examples, explain ways in which data has helped in the development of those goals and objectives.

What types of data do your programs collect about themselves ?

Probe: (evaluation data)

Describe to me what your other oral health surveillance data needs might be?

Probes: What are the "critical" issues for your program/organization, that would help you be more effective in addressing your programmatic goals an (i.e., income, improved OH, etc…)

This next question gets back to how you access your data,

What do you feel is the best way for you to learn about oral health program surveillance data?

Probes: How could the Oral Health Program make it easier for you to access oral health data?

We want to know how organizations such as yours are using our data.

How do you suggest the Oral Health Unit find out how such as yours use the data we provide?

Probes: If data is available on the website how could we determine how you used it, what type/amount of usage reporting would inhibit your use of the data.

Can you state your name, organization and title/position for the record?

Do you have any final thoughts you would like to share with me about our interview topic today?

Well, _____ thank you so much for your time and we will be letting you know what we found out from this evaluation.

APPENDIX E CODE BOOK

Code	Text	Definition	Code type
Interview Questions	Q		
	Q1	Your Name	Supercode
	Q1	Name of your agency	Supercode
	Q2	Tell me about your agency	Supercode
	Q3	What do you use data/oral health data for?	Supercode
	Q4	How do you get your data?	Supercode
	Q5	How does the agency define their target population?	Supercode
	Q6	How does data help the organization define its programs?	Supercode
	Q7	What data does the organization collect about itself	Supercode
	Q8	What data is needed to help programs achieve goals?	Supercode
	Q9	What is the best way to learn about new data?	Supercode
	Q10	How can we find out if you are using our data?	Supercode

Users	User	A "family" of codes used to describe the characteristics of the users of COHSS data	Family Supercode
Organization Category	Orgcategory	The category on the “framework” this individual’s agency, experience etc. represents by my perception.	Supercode or Family and/or autocode
Government	govt		Supercode or Family
Community	comm		Supercode or Family
Education	ed		Supercode or Family
Providers	provider		Supercode or Family
Public	public		Supercode or Family
3rd party payer	3payer		Supercode or Family
Policy	policy		Supercode or Family
Higher-ed	hied		Supercode or Family
Name of interviewer	TA	The name of the interviewer for sorting out words used by her.	
Name of individual	Name	The name of the person being interviewed	
Name of organization	Orgname	The name of the organization the interviewee represents	
Position in Organization	Position	What is the position the individual holds in the organization	
Multiple categories	Multicat	Does organization represent more than 1 category on the FW	
Public sector	Pubsector	Organizations that are in the public sector, includes all Gov't agencies (both local and state)	
Non-profit sector	Nonprof	Organizations that represent NGO's and the non-profit sector	
Program or intervention	Program	The intervention, service, activity the agency, organization or individual is involved in generally	Supercode or Family

Program intervention oral health focus	ProOH	Intervention, service, activity the agency, organization or individual is involved in related to oral health	
Target population	Targetpop	What is the target population that the agency, organization or individual targets generally	Supercode or Family
Target population oral health focus	TargetpopOH	What is the target population that the agency, organization or individual targets related to oral health	

Use of data	Datause	Examples of how data is used	Supercode or Family
Policy decisions, development, recommendations (eg. Big "P" government agencies, legislation, guidance for program implementation)	Policy	Data used for policy decisions, development, recommendations	Autocode
Grant writing, funding requests	Grant	Data used for documenting need and helping support needs for programming. Include in grants and funding requests.	Autocode
Planning (eg. little "p" deciding program priorities, evidence based practices, resource allocation)	Planning	Data used to directly plan a program, define a population to target, to allocate resources, prioritize populations/interventions/ geographic areas etc	Autocode
Community Needs Assess	CNA		Autocode
Strategic Planning	SP		Autocode
Evaluation	Eval	Data used for evaluation of program activities, documenting success and justifying continuation of program	Autocode
Reporting	Report	Reporting to funders or other interested parties.	Autocode
Education	Ed	Creating of fact sheets, presentationsor other forms of information to inform and educate audiences	Autocode

Source of Data	Datasource	Specific data sources referenced	Supercode or Family
Program data	Progdata	Program data such as dental charts, encounters etc.	Autocode
Demographics	Democensus Demoother	Demographics including census and DOLA info or geographic information	Autocode
Federal data	Fed	Federal data (HPSA's or CDC, NIH data etc)	Autocode
Colorado Health Institute	CHI	Reports and information fro Colorado Health Institute	Autocode
Department of Education	CDE	CO Dept. of Ed such as Free and reduced lunch	Autocode
Commissioned reprots	Comm	Reports or data collected through a specific project	Autocode
			Autocode
			Autocode

Data access	Dataaccess	Where, how or in what format data is accessed	Supercode or Family
Electronically	Electronic	Electronically search or review data (relates to dissemination)	Autocode
Search	Search	Search for data electronically (literature review, abstracts etc)	Autocode
Read	Read	For in depth reading prefers paper version, or will print out themselves (relates to dissemination)	Autocode
Query and self-explore	Query	Will access interactive and query-able websites and/or explores data on own (relates to dissemination)	Autocode

Code	Text	Definition	Code type
Dissemination preferences	Dissem	What dissemination seems to work best?	Supercode or Family
From CDPHE-OHU		How best to find out about (new) data from OHU	
Electronic post-card	Emailpostcard		
Electronic full document	Emaildoc		
Mail post-card	Mailpostcard		
Mail full document	Maildoc		
Other	Dissemother		
Types of data programs collect about themselves	Selfdata	What types of data do programs collect about themselves	Supercode or Family
Primary data	Primary	Do they have tools themselves (eg chart audits, client files, provider profiles, surveys etc)	
Secondary data	Secondary	Do they use other's data about them? (SEALS)	
Types of data	Typeofdata	Demographic, service area (geographic), utilization	
Critical issues	Critissue	Imperatives to advancing the work of the organization	Supercode or Family
Data gaps	Gaps	Is there data that could help address this critical issue	
Data use evaluation	Evaldatause	How do you suggest the Oral Health Unit find out how your organization uses data CDPHE-OHU provides?	Supercode or Family
Survey	Survey	Conduct an survey	Supercode or Family
Manual	Surveyman	Survey manually through mail	
Electronic	Surveyelec	Survey electronically through email, survey monkey etc.	
Combination	Surveycombo	A combination of methods	
Interview	Interview	Conduct phone interviews	
Other	Other	Some other method or a combination of methods	
Combination	Combo	A combination of methods	
Timing	Freqeval	At what interval, frequency etc would data best be collected	
Annual	Freqevalann	At "end" of year or once a year	
Defined frequency	Freqevaldefine	At specified intervals after the initial release of the data (e.g., (1-month, 3-month, …)	

APPENDIX F ANALYSIS PLAN

1. Who are the oral health surveillance data users in Colorado?

Data to answer: "User" "Orgcategory" "Orgname" "Q1" "Q2" "Q3"

2. How are oral health surveillance data being used?

"Datause" "Q3"

3. What are the data sources "Q3" "Q4" "ProgData" "Democensus" Demoother" "Fed" "CHI" "CDE" "Comm" "Selfdata", are they sufficient to meet the needs of the users and what are the gaps "Q8"

4. Are current data dissemination strategies effective for getting oral health surveillance data to end-users?

"Q9" "Electronic" "Search" "Read" Query" "Emailpostcard" "Emaildoc" "Mailpostcard" "Maildoc" "Dissemother"