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Kevin Ramos

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Date

BURDEN DOCUMENT REVIEW:  
AN EVALUATION OF USE AND STATE DENTAL DIRECTOR'S PERCEIVED  
USEFULNESS OF ORAL DISEASE BURDEN DOCUMENTS PRODUCED  
THROUGH COOPERATIVE AGREEMENT 3022

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An abstract of  
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Rollins School of Public Health of Emory University  
in partial fulfillment of the requirements for the degree of  
Master of Public Health  
in Behavioral Science  
2011

## **ABSTRACT**

### **BURDEN DOCUMENT REVIEW: AN EVALUATION OF USE AND STATE DENTAL DIRECTOR'S PERCEIVED USEFULNESS OF ORAL DISEASE BURDEN DOCUMENTS PRODUCED THROUGH COOPERATIVE AGREEMENT 3022**

By

Kevin Ramos

The Centers for Disease Control and Prevention (CDC) is the federal agency that is responsible for improving the oral health of the nation and reducing inequalities in oral health (“CDC - Oral Health,” n.d.). Because strong state-based public health programs are critical to the nation’s oral health, CDC invested in the development of a cooperative agreement (Cooperative Agreement 3022) to support the growth of infrastructure and capacity for state oral health programs.

Of the 10 recipient activities outlined in Cooperative Agreement 3022, recipient activity # 2 requires that states develop an oral health burden document to describe the oral disease burden, health disparities and unmet needs of their state. The purpose of this focused utilization evaluation is to examine the use and perceived usefulness of the oral health burden document and to assess *if* and *how* states funded thru CA 3022 utilized the burden document to strengthen their oral health infrastructure within their state oral health programs.

An open-ended interview was developed using a component evaluation approach. Respondents were interviewed by phone about their use and perceived usefulness of the burden document. Additionally, qualitative data were compiled and analyzed using thematic categories and frequency counts.

Findings from this utilization-focused program evaluation may serve as a foundation to guide CDC in evidence-based decision-making and building program infrastructure. Also it may provide guidance for future studies related to the burden document.

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## CHAPTER 1 INTRODUCTION

The Centers for Disease Control and Prevention (CDC) utilizes cooperative agreements as the funding mechanism to assist state oral health programs to strengthen their capacity and oral health infrastructure. In 2003, CDC released funds for a 5-year cooperative agreement program (CA 3022) “Supported States Infrastructure Development and Oral Disease Prevention Programs.” The program addressed the Healthy People 2010 focus areas of Oral Health, Public Health Infrastructure, and Educational and Community-Based Programs (*Healthy people 2010*, 2000).

The purpose of CA 3022 was to establish, strengthen and expand the capacity of states, territories, and tribes to plan, implement, and evaluate oral disease prevention and health promotion programs, targeting populations and disparities, as outlined in the nation’s first ever report on oral health: *Oral Health in America: A Report of the Surgeon General* (U. S. Department of Health and Human Services, 2000). Approximately \$2.9 million was made available to twelve states and one territory. Grantee states were expected to build infrastructure. They were also encouraged to direct and integrate strategies and resources serving as the linking agent for collaboration between the federal, state and local levels, including both the private and public sectors, in support of improved oral health outcomes.

Cooperative Agreement 3022 included ten recipient activities (RA), which were aligned with the public health core functions of assessment, policy development and policy assurance. These activities were designed to help strengthen and build state oral health program capacity and infrastructure (table 1

Table 1: Cooperative Agreement 3022

<b>Cooperative Agreement 3022 Recipient Activities</b>		<b>Core Public Health Function related to CA activity</b>	<b>Performance Measure</b>
RA 1.	Develop oral health program leadership capacity.	Policy Development	Develop leadership
RA 2.	Describe the oral health burden, health disparities and unmet needs of the state.	Assessment	Develop burden document
RA 3.	Develop/update a comprehensive state oral health plan.	Policy Development	Compose state oral health plan
RA 4.	Establish and sustain a diverse statewide oral health coalition.	Policy Development	Develop statewide coalition
RA 5.	Develop/enhance oral health disease surveillance system.	Assessment	Develop surveillance
RA 6.	Identify prevention opportunities for systematic, sociopolitical and/or policy change to improve oral health	Assurance / Policy Development	Promote systems and policy change
RA 7.	Develop/coordinate partnerships to increase state-level and community capacity to address specific oral disease prevention interventions.	Assurance	Develop partnerships with prevention focus
RA 8	Coordinate and implement limited community water fluoridation program management.	Assurance	Manage fluoridation programs
RA 9.	Evaluate, document and share state program accomplishments, best practices, lessons learned, and use of evaluation results.	Assurance	Institutionalize strong evaluation
RA 10.	Community Water Fluoridation: develop/implement a water fluoridation program  School-based/linked sealant program: develop, coordinate and implement limited school-based or school linked dental sealant program	Assurance	Promote water fluoridation  Promote sealant programs

CA 3022 recipient activity RA2 called for grantees to describe the oral disease burden, health disparities and unmet needs of their state through the development of a burden document. This burden of oral disease document, sometimes called the “Burden Document” or BOD, is intended to aid and inform policy makers, the public health community, and all others interested in addressing the burden of oral disease (Centers for Disease Control and Prevention, 2010a). It describes the status of oral diseases (e.g., dental caries, periodontal disease, total tooth loss), including disparities in oral disease status among population groups. It also presents or describes the state’s ability to meet these needs by including a description of existing oral health assets, such as the number of practitioners, professional dental and dental hygiene education programs and any intervention programs that focus on preventing oral diseases (State of Illinois Department of Public Health, 2006).

It is implied that states that complete RA2 would then be able to communicate their state’s burden of oral disease to stakeholders, including policy makers who could then help to affect programmatic and systems changes that would help to reduce the burden of oral disease and disparities within their state.

In 2005, CDC released the burden document tool, a guidance document designed to assist state oral health programs to develop comprehensive burden documents (Centers for Disease Control and Prevention, 2010). The burden document tool incorporated, defined and expounded upon the guidelines. The sections within the burden document tool outlined various key measures that pinpoint priority populations, programmatic focus areas and programmatic strategies.

The burden document tool provided sample language, key national and state health indicators from the National Oral Health Surveillance System (NOHSS) and Healthy People 2010 and references. As an outline for composing the state burden document, the tool brought focus to documenting the prevalence of oral disease, unmet dental needs and disparities in oral health. Although CDC promoted and trained grantees on the use of the tool, grantees were not required to use the tool. The CDC burden document tool was made publicly available on the CDC Division of Oral Health website.

### **PROBLEM STATEMENT**

CDC is currently performing several evaluations of CA 3022. However, none of those evaluations includes an assessment of the use or perceived usefulness of the burden document. It is unknown if and how states funded through CA 3022 utilized their burden documents to strengthen state oral health program infrastructure. The CDC would like to know *if* and *how* the states utilized the oral health burden documents and if the program's success or failure was due to the use or non-use of the burden document. The knowledge gained from this utilization focused program evaluation of Cooperative Agreement 3022, recipient Activity #2 may help state dental directors to plan, set priorities and develop policies. Further, this understanding may inform whether the development of a burden document contributes to system changes that improve infrastructure-building efforts, which may then improve oral health outcomes. Lastly this added knowledge may enable CDC to determine if the activity of developing a burden document was useful; or whether this activity should be omitted from future cooperative agreements.

## PURPOSE STATEMENT

The overarching purpose of this utilization-focused program evaluation is to assess *if* and *how* states funded thru CA 3022 utilized the burden document to strengthen state oral health program infrastructure. In addition the evaluation may serve the following purposes:

- Provide evidence to use the BOD to promote infrastructure development
- Improve the oral health program and decision-making for oral health programs
- Identify intended users and use of the burden document
- Document and share lessons learned
- Market the burden document to stakeholders

*Intended Use:* The results from this evaluation will be used to generate knowledge about the burden document's use and perceived usefulness and its influence on state oral health programs to build infrastructure.

*Users:*

*Primary:* Centers for Disease Control and Prevention (Division of Oral Health Program Services Team, Office of the Director, and Surveillance Investigation and Research Team), CDC Cooperative Agreement 3022 grantees and CDC funded national partners (Children's Dental Project and Association of State and Territorial Dental Directors)

*Secondary:* Centers for Disease Control and Prevention National Center for Chronic Disease Prevention and Health Promotion (CDC/NCCDHP)

management, non-funded states and national partners and those interested in infrastructure and development.

### **EVALAUTION QUESTION**

This evaluation seeks to answer the following overarching question:

1. Did the grantee state oral health programs use the oral health burden document to build infrastructure?

### **PUBLIC HEALTH PROBLEM**

A state oral health program's ability to carry out the core dental public health functions is dependent on having adequate resources and strong infrastructure. Poor infrastructure and the lack of resources can negatively impact a program's ability to implement interventions, thereby potentially causing gaps in care and prevention among the state's most vulnerable populations (Tomar & Reeves, 2009).

The U.S. health care system has been described as being expensive, fragmented, highly decentralized, and poorly organized (Brandies University The Heller School for Social Policy and Management, 2009). In addition, the U.S. public health infrastructure, which protects the Nation against the spread of disease and environmental and occupational hazards, is structurally weak in areas linked to bioterrorism preparedness, developing public health training centers, improving response to emerging infectious diseases, and the development of comprehensive food and safety programs (Centers for Disease Control and Prevention, 1999).

The CDC defines public health infrastructure as the resources needed to deliver the essential public health services to every community (Centers for Disease Control and Prevention, n d). The Association of State and Territorial Dental Directors (ASTDD) defines oral health infrastructure as the systems, people, relationships and the resources that would enable state oral health programs to perform public health functions while capacity is that which enables the development of expertise and competence and implementation of strategies (Association of State and Territorial Dental Directors, 2000).

A strong public health infrastructure is comprised of the workforce, data information systems and public health organizations (Baker et al., 2005). By making significant investments in public health infrastructure the U.S. may stand a better chance at building the capacity needed to prepare for and respond to both acute and chronic threats, whether they are bioterrorism attacks, emerging infections, disparities in health status, or increases in chronic disease or injury rates. Such an infrastructure serves as the foundation for planning, delivering and evaluating public health (Centers for Disease Control and Prevention, n d). It may also allow states to meet the new National Healthy People objectives and improve the oral health for the Nation.

Currently, the U.S. is served by 3,000 county and city health departments, more than 3,000 local boards of health, 59 State and territorial health departments and tribal health departments, and more than 160,000 public and private laboratories (“23 Public Health Infrastructure,” n d). Additionally, a series of Federal health and environmental agencies set national standards and provide funding, training, guidance and technical support (Centers for Disease Control and Prevention, 1999). This complex web of practices and organizations has been characterized as being in “disarray” (Centers for



Disease Control and Prevention, n d). Achieving structural soundness in the nation's public health infrastructure across the board will require a more comprehensive, sustainable effort from the Federal, State and local governments as well as the private sector (Centers for Disease Control and Prevention, 1999).

The complexity of the nation's current system and the lack of resources prompted CDC to respond to a Senate Appropriations Committee report (Senate Report 106-166, 1999) with a status report on the nation's public health infrastructure. The report outlined a major national initiative to link partners at the local, state and Federal levels to address gaps in workforce capacity and competency; information data systems, and organizational capacities of local and state health departments and laboratories (Centers for Disease Control and Prevention, 1999).

The nation has seen great improvements in oral health (U. S. Department of Health and Human Services, 2000). These improvements are attributed to community water fluoridation and fluoride products, advancements in dental technologies and treatment modalities, changing patient and provider attitudes and treatment preferences, improved oral hygiene, and regular use of dental services (Gooch, Eke, & D. Malvitz, 2003). However, despite these improvements, 100 million persons in the U.S. still do not have access to optimally fluoridated water and only 18 percent of children have dental sealants (Association of State and Territorial Dental Directors, 2000). In addition, significant dental disease and oral health disparities still exists among racial and ethnic groups (Centers for Diseases Control, n.d.)

Oral diseases are among the most widespread of all chronic diseases ("CDC - Chronic disease - oral health - at a glance," n d). In fact dental caries are identified as the

most common chronic disease of childhood and is five times more common than asthma, with lower socio-economic children experiencing twice as much disease as affluent children (U. S. Department of Health and Human Services, 2000).

Oral diseases also have a negative impact on the economy. They lower productivity in both adults and children. In 1995, dental visits and dental problems accounted for the loss of ~\$3.7 billion from hours missed from work and about \$1.8 billion from restricted activity (Centers for Disease Control and Prevention, 1992) and in 1996, U.S. schoolchildren missed a total of 1.6 million days of school as a result of acute dental conditions, which is more than 3 days for every 100 students (Centers for Disease Control and Prevention, 2010).

Oral health may be substantially improved for U.S. children and adults by investing in oral health public infrastructure and capacity (Surgeon General, 2000). The Surgeon General's report, *Oral Health in America: A Report of the Surgeon General*, declared that the Nation's dental public health infrastructure was insufficient to address the needs of disadvantaged groups (U. S. Department of Health and Human Services, 2000). The Association of State and Territorial Dental Directors further noted in their assessment of 43 state oral health programs that several states did not have an oral health program or adequate resources (e.g. staff, funds, and local support) to address oral health needs (Centers for Disease Control and Prevention, n d), (Association of State and Territorial Dental Directors, 2000).

In a state oral health program, epidemiologists are essential for the monitoring of chronic conditions and diseases and the rapid detection and reporting of infectious diseases (Centers for Disease Control and Prevention, 2005). The Institute of Medicine

(IOM) recommended in 1988 and again in 2002 that every public health department regularly and systematically collect, assemble, analyze, and make available information regarding the health of the community. In 2001, the Council of State and Territorial Epidemiologists (CSTE) conducted a survey of state and territorial health departments to assess their core epidemiologic capacity and found that states had inadequate capacity to fully perform the essential public health services most dependent on epidemiology (“Assessment of epidemiologic capacity in state and territorial health departments-- United States, 2004,” 2005). According to ASTDD 40.5 percent of states reported a high need for additional staff expertise in epidemiology (Association of State and Territorial Dental Directors, 2000).

## **DESCRIPTION OF THE PROGRAM LOGIC MODEL**

Focusing on the coordination and activities of community water fluoridation and dental sealant programs, the program (CA 3022) logic model (Appendix A) was developed to emphasize that state oral health programs can build a solid foundation through planning, partnerships/coalitions, surveillance, evaluation, policy and staffing. The program logic model theorizes that by building infrastructure and capacity the oral disease burden could be reduced.

The CA 3022 logic model illustrates the resources (inputs), activities and outcomes of the program. The following section is a walkthrough of CA 3022’s logic model.

### **Program Inputs**

CA 3022 was a five-year cooperative agreement funded by CDC. Cooperative agreements, unlike grants, stipulate that there will be a substantial level of programmatic

involvement between the executive agency and the state, local government or other recipient when carrying out the activities in the agreement (“Cooperative Agreement Law & Legal Definition,” 1995). Traditionally cooperative agreements are the mechanisms that have allowed CDC to partner with state and local health departments and other partners for the sole purpose of providing guidance, strategic direction and oversight for the investment of CDC resources and assets (Richmond, Hostler, Leeman, & King, 2010). As a result, CDC integrated funding, technical assistance and training, and access to national partners as major components, and important inputs, of the program.

**Funding:** Twelve state oral health programs and one territory received performance based funding between \$250,000-\$450,000 per fiscal year to support the implementation of program activities. Funding increases for the grantees were based on the availability of CDC funds at the end of the year.

**Technical Assistance:** Building the competency level of state oral health staff through technical assistance was identified as a key element to success of the program. Grantees received technical assistance in several ways. Each year, grantees and their staff participated in at least one Grantee Workshop. The Grantee Workshops served as a base for CDC and its national partners to provide technical and assistance and guidance. CDC national partner relationships benefitted grantees by providing them with technical assistance from national experts in various program areas. CA3022 also required state oral health program staff to attend a grantee meeting at the National Oral Health Conference. This annual conference provided grantees with additional training and networking opportunities. State oral health programs also received one on one, tailored support and technical assistance from an assigned CDC project officer. Project officers

conducted site visits and scheduled monthly conference calls with their assigned states to discuss and document the state's progress with cooperative agreement recipient activities.

**National Partners:** CDC partnered with the Association of State and Territorial Dental Directors, Oral Health America and the Children's Dental Health Project to provide additional support for state oral health programs. The national partners provided technical assistance and guidance directly related to the cooperative agreement such as coalition building, policy development, and evaluation.

### **Program Activities**

Program activities, also known as recipient activities (RA) were the core of the cooperative agreement and were designed to build infrastructure and capacity of the state oral health programs. Recipient activities were aligned with the core public health functions (assessment, policy development and assurance) and promoted the development and maintenance of leadership and staffing, surveillance capabilities, partnerships and coalitions, statewide oral health planning, policy planning, evaluation and evidence-based interventions (Table 1).

### **Performance Measures**

Performance measures, like program activities, were aligned with the core public health functions and were linked to a specific activity. For example, describing the burden of oral disease (RA2) was measured by the development of a burden document. Developing or enhancing an oral disease surveillance system including community level indicators (RA5) was measured by the development of a surveillance system (Table 1).

## **Program Outcomes**

Short term and long term outcomes are missing from the program logic model. During the development of the program's logic model CDC had limited knowledge and understanding of the effects of infrastructure and capacity on state oral health programs. Before the short-term and intermediate outcomes could be articulated, CDC oral health staff needed to learn more about the effects of the infrastructure and capacity development program and its impact on state oral health programs. This knowledge would be gained through program monitoring and evaluation. CDC is currently conducting a national evaluation of Cooperative Agreement 3022 that will determine the short-term and intermediate outcomes. The program's distal outcomes were based upon national goals presented in HP2010 and the Surgeon General's report on oral health. The theory is that building infrastructure will lead to proximal outcomes which in turn will lead to meeting health achievements, and thereby will allow the program to experience the following distal outcomes:

1. reduce prevalence of caries,
2. reduce prevalence of oral cancer,
3. reduce prevalence of periodontal disease,
4. universal adoption and implementation of infection control methods in dental settings, and
5. reduce health disparities.

## THEORETICAL FRAMEWORK

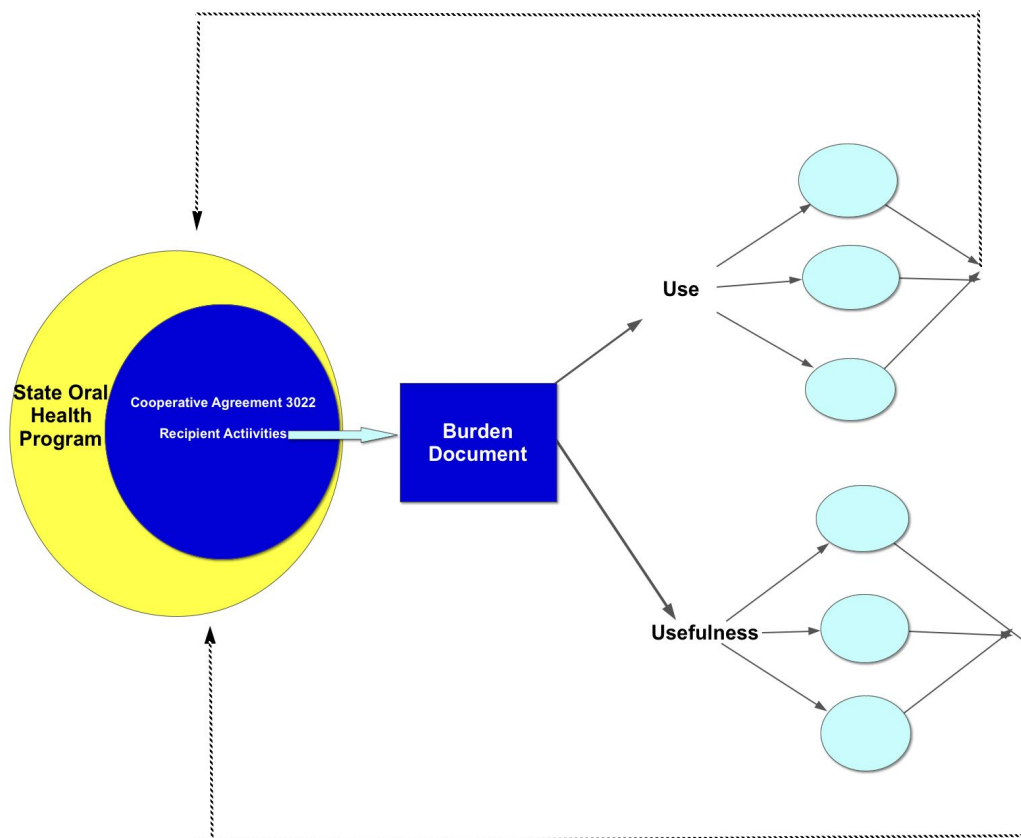


Figure 1: Theoretical Framework

The theoretical framework of this evaluation is grounded in utilization-focused evaluation. Because utilization-focused evaluation focuses on the intended *use* by intended users, the recommendation is for evaluators to design their utilization evaluations *from beginning to end* on the premise of utility and actual use (Patton, 1996). Utilization focused evaluation does not advocate any particular evaluation content, model, theory, or use. It is defined as a process for helping primary intended users to select the most appropriate content, model, methods, theory and uses for the most particular situation (Patton, 1996).

The theoretical framework focuses on the burden document, an output produced by RA2, which called for 3022 CA grantees to describe the oral disease burden, health

disparities and unmet needs within the state. The burden document is a concrete tangible product that is defined in the program logic model as a performance measure, and is aligned to the core public health function of *assessment*.

Patton suggests that evaluation findings can serve three purposes: rendering judgements, facilitating improvements and/or generating knowledge (Patton, 1996). The review of the burden document's *use* may facilitate judgements about the burden documents intrinsic worth, facilitate programmatic improvements and guidance with technical assistance on developing a burden document. In addition it may generate knowledge to determine if the document was used by state dental directors or program managers and other stakeholders to affect programmatic or systems changes within their oral health programs.

The *uses* and perceived *usefulness* findings will be evaluated to assess whether the actual use of the burden document by intended users helped to build infrastructure.

## **SIGNIFICANCE STATEMENT**

The ability to identify, understand and interpret the burden of oral disease within the state is critical for the success of a state oral health program. Knowing how state oral health programs utilize that data to plan, set priorities and/or implement policies may be even more important because it may help other state, territorial and community health programs build infrastructure, achieve Healthy People 2010 Oral Health Objectives and to meet the National Call to Action to Promote Oral Health (Association of State and Territorial Dental Directors, 2008). The generated knowledge from this utilization-focused evaluation may inform CDC staff, state dental directors, policy makers and other stakeholders how to best use the burden document to reduce oral diseases and eliminate



disparities.

## **DEFINITION OF TERMS**

**Burden Document:** The written text that can be used as a communication tool to describe the status of oral diseases (e.g., dental caries, periodontal disease, total tooth loss), including any disparities in oral disease status among population groups. It also includes a description of existing oral health assets, such as professional dental and dental hygiene education programs and any intervention programs that focus on preventing oral diseases (Association of State and Territorial Dental Directors, 2000).

**Burden Document Tool:** a CDC reference tool that provides background information and graphic templates for building a comprehensive state burden of oral disease document (Centers for Disease Control and Prevention, 2010)

**Capacity:** Enables the development of expertise and competence and implementation strategies (Association of State and Territorial Dental Directors, 2000).

**Cooperative Agreement:** An agreement between the federal government and a recipient whenever (1) the principle purpose of the relationship is the transfer of money, property, services, or anything of value to the state or local government or other recipient in order to accomplish a public purpose of support or stimulation authorized by a federal statute, rather than acquisition, by purchase, lease, or barter, of property or services for the direct benefit or use of the federal government; and (2) substantial involvement is anticipated between the executive agency, acting for the federal government, and the state or local

government or other recipient during performance of the contemplated activity

<http://www.ors.hawaii.edu/award-definition-types.asp>.

**Infrastructure:** The systems, people, relationships and the resources that would enable state oral health programs to perform public health functions (Association of State and Territorial Dental Directors, 2000).

**Recipient Activity (RA):** An activity that must be completed by states that received funding through Cooperative Agreement 3022.

## CHAPTER II REVIEW OF THE LITERATURE

Burden of Disease (BOD) is a specialized area of research that quantifies ill health by measuring and analyzing the extent and causes of health problems (Kapiriri, Norheim, & Heggenhougen, 2003). Virtually absent from abstracts of medical literature in PubMed until 1978, the terms “burden of disease” or “disease burden” grew in use and by 1980 were found in 43 abstracts. By 1990, that number rose to 651 and then to 5,241 by 2010. The rise in the term “burden of disease” appears to be related to work first published in the early 1990’s by the World Health Organization <http://www.globalburden.org/>. The original Global Burden of Disease Study (GBD 1990 Study) created a common metric to estimate the health loss associated with morbidity and mortality associated with the burden of 107 diseases which included oral health and injuries and ten selected risk factors for the world and eight major regions (Alan D. Lopez, Mathers, Ezzati, Jamison, & C. J. L. Murray, 2006).

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 (D. M. Malvitz, Barker, & Phipps, 2009). The US Department of Health and Human Services reports that epidemiologic and surveillance data are essential in conducting health services research, generating research hypotheses, planning and evaluating programs, and identifying emerging public health problems (U. S. Department of Health and Human Services, 2000). Authors have stated that scientific evidence is key to improving global public health, because national and international health policies

should be based on accurate and meaningful health information that meets the needs of stakeholders [http://www.who.int/foodsafety/foodborne\\_disease/Q%26A.pdf](http://www.who.int/foodsafety/foodborne_disease/Q%26A.pdf)

Governments and non-governmental agencies have used the Global Burden of Disease study findings to inform priorities for research, development, policies and funding (Alan D. Lopez et al., 2006). Rudan et al. (2005) suggest that there is a need for credible estimates for the burden of disease in children which could lead to the development of health policy that then leads to the implementation of interventions for the prevention of childhood disease, especially in less developed countries where most child deaths occur. Health officials in Tanzania used surveillance data to show politicians and government officials that a high number of malaria deaths occurred outside the health sector, prompting officials to invest in promoting insecticide-treated bed nets (Ulin & Robinson, 2005). Kafiriri et al. (2003) used the burden of disease (BOD) in Uganda to measure health planners' perception and usefulness of the BOD in priority setting and found that politicians appreciated the quantification and ranking of disease burden when setting priorities and strategic planning. This is reflected in the following statement:

following statement can qualify this:

*“Politicians like figures; with the BOD results we are able to show them, in figures, the health problems. This has helped us advocate for more resources for the health sector (National respondent. We were allocating our resources haphazardly assuming we knew where the biggest problems were, but now we have revised our budgets to reflect the actual burden...” (District respondent) (Kafiriri et al., 2003)*

One mechanism in which the burden of disease data is disseminated to stakeholders and the general public is a burden of disease document. One example is Health, *United States*. Prepared annually by the US Department of Health and Human

Services for the President and the Congress, *Health, United States* documents trends in health status, health care utilization, resources and expenditures for the nation. It also identifies variations in health status, modifiable risk factors, and health care utilization among people by age, race and ethnicity, gender, education and income level, and geographic location (National Center for Health Statistics, 2010). Stakeholders and decision-makers have used *Health, United States* data to set and make health policies and to set research and program priorities (National Center for Health Statistics, 2009).

Burden-type documents and reports have also been used by policy-makers to guide decision making towards the adoption and implementation of effective tobacco control policies (World Health Organization, 2010), (“Smoking and Tobacco Use: Global Adult Tobacco Survey (GATS): Office on Smoking and Health (OSH): CDC. Documents such as the Global Adult Tobacco Survey (GATS) Report, WHO Report on Global Tobacco Epidemic, 2008; and GATS Country Fact Sheets (World Health Organization, 2010) utilized GATS data to project tobacco-related problems using quantifiable evidence of the patterns of tobacco use within adult populations (World Health Organization, 2010). These data inform stakeholders about the nature, magnitude and distribution of tobacco use and tobacco related illnesses in a country as well as the knowledge, attitudes and perceptions that influence tobacco use.

According to (Ulin & Robinson, 2005) stakeholders have various information needs. If the health information does not meet the audience’s needs, it may be deemed inaccessible and thus not used by decision-makers. Additionally, state health problems without vocal advocates appear unimportant, and as a result, are frequently ignored by policy-makers (C. J. Murray & A D Lopez, 1996). Lindsay et al. (2002) argue that the

Nation's ability to alter trends in health problems such as obesity is dependent on the ultimate utility of surveillance in public health and on the end users' ability to understand and utilize data to meet the needs of stakeholders in a timely and efficient manner. Health information should be *available, accessible relevant, and useful*, and tailored to the needs of the stakeholders (Ulin & Robinson, 2005). One example is lead exposure. Before 1999, the Miami Dade County (MDC) Health Department screened only a few of the state's children for lead poisoning. In addition, they did not disseminate lead poisoning surveillance data or screening recommendations to stakeholders (Trepka, 2005). However in 2003 after the development and dissemination of local screening recommendations screening rates increased from 4.1% in 1998 to 20.3% (Trepka 2005). The success was attributed to the MDC Health Department's ability to recognize that an effective surveillance system should not only include data collection and analysis but should also be effective at communicating data to those involved in prevention and control (Trepka 2005).

Lindsay et al. (2008) conducted in-depth interviews with 17 respondents from state and federal agencies to gain their perspective on health related surveillance and data use and found differing opinions about flexibility timeliness, accessibility and use. The lack of understanding of surveillance data use suggests that there is a need for increased communication and partnerships between state and federal agencies (Ulin & Robinson, 2005). Effective data dissemination requires partnerships with organizations and individuals that can broaden the reach to larger audiences to improve the overall effectiveness of communication efforts (World Health Organization, 2010). Overall, respondents from state and federal agencies interviewed by Lindsay et al. reported the

main uses of surveillance data were raising awareness of a health problem, conducting needs assessments and monitoring trends over time. State level respondents noted that another major use of surveillance data was the incorporation into presentation and grant applications to foster and strengthen communications with community members and decision-makers (Lindsay et al., 2008).

The burden of oral disease has been well established in the published literature (U. S. Department of Health and Human Services, 2000), however, a critical problem cited by the Department of Health and Human Services is that epidemiologic and surveillance databases for oral health and disease, health services, utilization of care, and expenditures are limited or lacking at the national, state, and local levels (U. S. Department of Health and Human Services, 2000). Moreover, there is a need to develop new techniques to build up surveillance systems for oral diseases, conditions and behaviors at the national, state and local level (Beltrán-Aguilar, D. M. Malvitz, Lockwood, Rozier, & Tomar, 2003).

Currently, there is no data available on oral health status, prevention services or infrastructure at the county or local levels (Tomar & Reeves, 2009). Baker et al. (2005) argue that the present public health infrastructure for information and data systems is inconsistent and information and communication systems do not operate seamlessly across the federal, state and local levels (Baker et al., 2005). One recommendation in the *National Call to Action to Promote Oral Health* is to elevate the general public's awareness and understanding of oral health so that people can make informed decisions and articulate their expectations regarding their individual and community's oral health needs (Surgeon General, 2000). Documenting data use is important for researchers and

other stakeholders because it illustrates the results of dissemination efforts and assesses whether communication objectives were achieved and how research findings were used (Ulin & Robinson, 2005). Since 2003, CDC has encouraged the creation of burden documents that focus on oral diseases. Although several state health departments have published burden of oral disease documents (Alaska Oral Health Department, 2008), (Colorado Department of Public Health and Environment Oral Health Program, 2005), (Mouden, Philips, Sledge, & Evans, 2007), (State of Illinois Department of Public Health, 2006), (Michigan Department of Community Health, 2006), (Bureau of Family Health Services Nevada State Health Division Department of Health and Human Services, 2006), (New York State of Department of Health Bureau of Dental Health, 2006), there are no studies in the scientific literature that indicate whether these documents are useful to state health departments in addressing oral disease burden or building infrastructure.

Because stakeholders have different health information needs, research findings should be tailored to audience needs and should be user-friendly and actionable (Ulin & Robinson, 2005). Additionally there is a need to close the communication gap between researchers and stakeholders. Communication tools should be transparent and developed with inclusion from users from various levels within public health and the community (Ulin & Robinson, 2005). Baker et al. (2005) suggest that public health officials should continue to strive to communicate effectively with stakeholders, including policy makers and the general public about what public health is and what it does. In theory, burden documents could achieve this in part, but evidence to demonstrate their effectiveness is lacking. Research is needed to explore the utility of burden documents for addressing



oral diseases and related issues and for laying out the groundwork for improving state oral health program infrastructure.

## **CHAPTER III METHODOLOGY**

### **INTRODUCTION**

This utilization-focused program evaluation was designed to evaluate the use and perceived usefulness of oral disease burden documents among recipients of Cooperative Agreement 3022. The findings of this study may be used to inform CDC staff and other stakeholders how the burden documents developed through CA 3022 were used to strengthen the infrastructure of state oral health programs. It may also be used to drive future analysis of the burden of oral disease.

The utilization-focused program evaluation was combined with a component approach. A component approach is an assessment of the distinct parts of a program (Patton, 2008). As defined by Patton, a component approach has the potential for greater generalizability of findings and is more appropriate for cross-program comparison (Patton, 1996).

The goal of the evaluation is to describe, through retrospective interviews with primary authors of the burden document, how the state oral health programs used their oral health burden document to build infrastructure. This chapter will further describe the survey population, selection criteria, research design, data collection instruments, procedures, and data handling, analysis and study limitations.

## **POPULATION**

The population of interest was comprised of state dental directors or program managers from states that successfully competed for grant funding through CA 3022. Participants competed for funding by demonstrating a need to improve state oral health infrastructure and presenting clear and reasonable plans to build the state's oral health program's infrastructure and capacity. CDC maintains current information on state dental directors and program managers to ensure continued communication between CDC and state health departments.

## **SURVEY SAMPLE**

Because this study was designed to gather retrospective information about whether the burden document was used to build infrastructure within a state oral health program, the study population was identified from states with documented receipt of 3022 funding with dental directors or program managers who were present throughout the lifecycle of CA 3022 and were responsible for, or had knowledge about recipient activity 2.

### **Inclusion/exclusion criteria**

1. Participants must be from a U.S. State health department. U.S. territories were excluded because their health department infrastructure was perceived to be different from the states.
2. Participants must have produced a fully developed burden document by the end of the five-year funding cycle that was:

- a. made publicly available
- b. had burden of oral disease data less than five years old

## **RESEARCH DESIGN**

The study design for this utilization-focused program evaluation was a descriptive study. Due to the relatively small, finite target population, random selection was not performed. The purpose of a descriptive study is to provide an in-depth description of a phenomenon or relationships between two or more phenomenon (Project Star, 2006). Descriptive study designs help to show whether a program is producing the desired types of outputs and outcomes and help to clarify program processes, goals and objectives (Project Star, 2006).

## **PROCEDURES**

After identification of the study population, potential interviewees were contacted by telephone or email, given a brief description about the design and purpose of the study, and invited to participate (Appendix B). All were informed that participation was voluntary and that refusal would not impact their program. Verbal informed consent was obtained over the phone (Appendix C).

Interviews were scheduled at the convenience of the participant. The primary investigator conducted the interviews by phone, and with the consent of the participant, recorded the interview with a digital recorder for reference during data review and analysis.

The interview style was conversational and the primary investigator clearly stated the goals and objectives at the beginning of the interview. To ensure standardization, the primary investigator used a script to administer the interview (Appendix D).

## INSTRUMENTS

The primary investigator with the guidance of a CDC subject matter expert (SME) developed the data collection instrument, which included the script and evaluation questions (Appendix E). The SME was a CDC Health Scientist Evaluator who conducted several previous evaluations of CDC oral health cooperative agreements and who is knowledgeable about CA 3022. The questionnaire, which was also developed using a component evaluation approach (Patton, 1996), consisted of 7 open-ended questions, divided among 3 categories: background, knowledge and values/opinions. Each evaluation question with rationale is summarized below:

1. How was your burden document used to strengthen the state's oral health infrastructure?

**Rationale:** This question was designed to elicit discussion of infrastructure improvement resulting from data presented in a state's burden document.

2. How was the burden document used to influence policy?

**Rationale:** This question was designed to engage respondents in discussion on how the data contained in the burden document influenced policies

3. How did your state oral health program use the burden document to affect programmatic change?

**Rationale:** this question was designed to generate discussion about whether data contained in the burden document was used to make changes to any programs. Programmatic examples were not provided with the question to avoid leading the responses.

4. How do you plan to utilize your burden document in the future to strengthen your state's oral health program?

**Rationale:** this question was asked to explore respondent's views on use of their burden document data as a tool for program planning.

5. Based on your experience, what would you say were the strengths of your burden document?

**Rationale:** this question was asked to learn what elements or sections of the respondent's burden document were perceived to be the strongest.

6. Based on your experience, what would you say were the weaknesses of your burden document?

**Rationale:** this question is asked to explore what aspects of the burden document were perceived to have little use or did not meet the goals of the burden of disease exercise.

7. How valuable of an exercise was the development of the burden document?

**Rationale:** this question was asked to determine whether respondents actually found value in the exercise of locating data and describing the burden of oral disease for their state.

The CDC subject matter expert provided guidance on the development of the questionnaire and the types of questions to be asked. All data was stored in a locked file cabinet and on password protected computer. Only the Principle Investigator (PI) had access to these data.

## **DATA ANALYSIS**

Qualitative survey analysis was conducted. The responses collected from open-ended questions were derived inductively and categorized by themes. A randomly assigned alphanumeric identifier (r1, r2, r3 etc.) was assigned to the participants. Data were assembled in narrative and tabular form. Matrix tables were developed to facilitate program summarization and comparability.

## **HUMAN SUBJECTS PROTECTION**

The protocol for this evaluation was submitted to the Emory University Institutional Review Board (IRB) on February 3, 2011 and included a cover letter describing the study purpose, the protection of confidentiality of participants, and name and contact information of the principle investigator (PI). The project was found to be research exempt under 45CFR46 on February 9, 2011 (Appendix F). This project also met Office of Management and Budget (OMB) regulations for OMB clearance (“CDC -

Clearance of Information - Policies - Overview - Advancing Excellence & Integrity of CDC Science,” n d).

## **LIMITATIONS AND DELIMITATIONS**

The study design presented several possible limitations:

- Recall bias: respondents were expected to recall CA 3022 events that occurred five years ago.
- Social desirability: because the PI for this study is also a CDC Project Officer, participants may have felt pressured to provide social desirable responses and avoid responses that may indicate dissatisfaction with or criticism of CDC or the burden document activity.
- Generalizability: because the study was limited to funded states only, results were not generalizable to U.S. state health departments as a whole.

## **SUMMARY**

This utilization-focused evaluation seeks to gather information about states funded through Cooperative Agreement 3022. Cognitive interviews were conducted with dental directors or program managers to gather information rich examples of how state oral health programs used the oral disease burden document, and whether these examples illustrated infrastructure building. Findings from the cognitive interviews may be used to develop further evaluations of the use of oral disease burden documents by state health departments.



## **CHAPTER IV RESULTS**

### **INTRODUCTION**

This chapter presents the findings from oral disease burden document interviews that were conducted with state dental directors or program managers who were identified as the administrators over the life cycle of Cooperative Agreement 3022. The results from the interviews are discussed in the order of the evaluation questions. Themes that emerged from the interviews are categorized and are discussed and illustrated through quotes from interviewees.

### **RESULTS**

Seven states had documented receipt of 3022 funding with dental directors or program managers who were present throughout the lifecycle of CA 3022 and were responsible for, and had knowledge about, recipient activity 2. Of these, representatives from five states participated in the study and two were unavailable. Of the five participants, 3 were state dental directors and 2 were program managers. All respondents participated in the recipient activities of CA 3022, including the preparation of a state-based oral disease burden document. However because the questions were open ended, responses often included several replies or examples. Several themes emerged upon analysis of the replies, such as program development, planning, communication, collaboration, awareness, leveraging, education, comprehensiveness, utility, and functionality.

*Evaluation Question 1: How was your burden document used to strengthen the state oral health program's infrastructure?*

The three most common themes that emerged from this evaluation question were program development, planning and communication (table 2).

Respondents who cited program development used the burden document to develop their surveillance and state oral health plans. The following statement from a respondent supports this:

“The development of the burden document strengthens the infrastructure of the program by giving you data and surveillance data in epidemiology — incidence — prevalence so you can allocate resources within your program so you can prioritize.”

Another one said:

“It helped us to identify data that was available and wasn't available when developing our surveillance system.”

Planning was another theme for this evaluation question. Several respondents used it to set priorities, to identify gaps and allocate resources within their state oral health programs. One respondent even used it for grant writing.

Communication was another theme that respondents felt strongly about. Respondents stated that the burden document was used to disseminate data, inform policy-makers and educate partners and the coalition.

One respondent said:

“We used data from the burden document with our Medicaid agency to inform policy-makers.”

Two respondents said that the burden document was used to promote awareness for the state oral health program. One respondent said:

“I think the surveillance information and the burden document has served to make the oral health program more visible.”

Another one said:

“It elevated the oral health program and the department as something we need to pay more attention to.”

Leveraging was discussed the following manner:

“It has assisted us with maintaining in-kind epidemiology support from the MCH Epidemiology unit e.g. inclusion of oral health questions in PRAMS and reporting (without cost to the oral health program), inclusion of oral health question in an infant/toddler survey (again without cost to the program) and periodic information from the Birth Defects registry on oral clefts.

Table 2: Question 1: How was your burden document used to strengthen the state oral health program's infrastructure?

Theme	Responses
Program Development	Helped to develop surveillance plan [r1, r4, r5] Helped to drive work groups [r2] Used to develop the state oral health plan [r1, r3] Used to implement the state oral health plan [r5] Used to address workforce issues [r3, r5]
Planning	Impetus for moving program forward [r5] Used to set context for priority setting [r5] Used to allocate resources [r2] Helped to identify gaps [r1, r5] Helped to identify data that was or was not available [r1] Helped health departments in conducting their needs assessment and planning process [r3,] Used in grant writing [r2]
Communication	Used to inform our policy makers [r2] Used to educate legislators, partners and the coalition [r2] Used to disseminate data [r4]
Awareness	Made the oral health program more visible [r5] Helped to elevate the status of the program [r4]
Leverage	Assisted in maintaining in-kind epidemiology support [r5]

Respondents used the burden document to strengthen state oral health programs through program development, planning, communication, awareness and leveraging. The most common themes: program development, planning and communication were identified as essential elements in building infrastructure and as a result respondents were able to develop surveillance and state oral health plans, identify gaps, allocate resources, address workforce issues, and inform policy-makers.

Respondents who used the burden document for awareness and leveraging elevated the status of the program, made the oral health program more visible and maintained in-kind support for an epidemiologist. For example, the one respondent that

used the burden document to elevate program status was also successful with using the burden document to implement a school based sealant policy to expand adult Medicaid coverage (table 3).

A closer look at the results suggests that all of the respondents used the burden document for program development and four respondents used it for planning. Two respondents used the burden document for communication and awareness; another used it to inform policy-makers and to educate legislators, partners and the coalition.

*Evaluation Question 2: How was the burden document used to influence policy?*

The most common theme that emerged for this evaluation question was state based policies. Several respondents used the burden document to influence policy change to establish school based dental sealant programs and another discussed how it was used to put forth a Medicaid benefit, while another used it to expand adult Medicaid coverage (table 3).

One respondent had this to say about sealants:

“One significant policy change in our state was to formalize school based dental sealant programs in the state. In other words, although we have had school based dental sealant programs in the state for a long time, there was no authority in the state law to implement school based dental sealant programs. So the state legislature introduced a bill and authorized the establishment of school based dental sealant programs.”

Another respondent said:

“...I think we were able to document the benefit of school based dental sealant programs and so policy decisions that occurred was a significant funding increase for our school based sealant program.”

The respondent that used the burden document to put forth a Medicaid benefit said:

“We used the data to see where we can make some big system changes. And one the major ones was putting forth a Medicaid benefit.”

Reinforcement and programmatic policy development also emerged as themes.

One respondent had this to say about reinforcement:

“We have used the burden document to reinforce good policy. We forget that it is not always about policy change but about reinforcing already established “good” policies.”

Another had this to say about programmatic policy development:

“Within the oral health program we developed a policy that said when we found new data sets, oral health would be included.”

The second most common theme that emerged was non-use.” Two respondents, r2 and r5, stated that the burden document was not used to influence policy. Respondent r5 said that the burden document was not the influencing factor for policy change. Here is what was said:

“The burden document in itself was not solely responsible for policy changes for adults enrolled in Medicaid but was a factor of the Behavioral Risk Factor Surveillance information. “

The other said:

“We have not had a lot of state level policy change in this state.”

Table 3: Question 2: How was the burden document used to influence policy?

Theme	Responses
State based policies	<p style="text-align: center;"><b>Sealants</b></p> <p>Used to formalize school based sealant programs in the state [r3]  Used to increase funding for school based sealant programs [r4]  Used by state legislators to authorize the establishment of school based sealant programs [r3]</p> <p style="text-align: center;"><b>Medicaid</b></p> <p>Used it to put forth a Medicaid benefit [r4]  Used to expand Medicaid coverage for adults [r5]</p>
Reinforcement	Used the burden document to reinforce good policy [r2]
Programmatic policy development	Within the oral health program we developed a policy that said when we found new data sets, oral health would be included [r1]
Non-use	<p>We have not had a lot of state level policy change in this state [r2]  The burden document was not the influencing factor in policy development in our state but was a factor of the behavioral risk factor surveillance information [r5]</p>

Respondents r3 and r4 used the burden document to implement state based policies. One used it to formalize school based sealant programs and to engage stakeholders to authorize the establishment of school based sealant programs. Another used it to increase funding for school based sealant programs. The respondent that used the burden document to expand Medicaid coverage for adults also said that the burden document was not the influencing factor in policy development, but was a factor of the behavioral risk factor surveillance information. Only one respondent discussed utilizing the burden document to establish programmatic policies within the oral health program.

Respondent r2 used to communicate with policy-makers and to educate legislators, partners and the coalition (table 2). According to the respondent r2, policy development was not a favorable activity of the state so the burden document was used to reinforce already established “good policies.”

Here is what respondent r2 had to say about reinforcement:

“We tend to forget about good policy. Its not always about setting new policies.”

*Evaluations Question 3: How did your state oral health program use the burden document to affect programmatic change?*

Planning was another dominant theme that emerged for this evaluation question. Four respondents reported that the burden document was used for planning activities to affect programmatic change (table 4).

Here is what one respondent had to say about planning:

“It really made us hone in on our programmatic objectives and look at the core functions for public health—public dental health.”

Leveraging also emerged as a theme.

One respondent discussed leveraging in the following way:

“...we were able to start the discussion of having an epidemiologist on staff and more specifically to the burden document being able to have someone on staff who knew the data more intimately.”

Another respondent had this to say about leveraging:

“It basically allowed the Bureau of Dental Health to take over the management of school based dental sealant programs.”



Management and functionality were themes that were discussed by two respondents.

One respondent had this to say about management:

“There was a clear impact in terms of time management.”

One respondent said that in terms of functionality, the burden document became the program’s one-stop-shop for data.

Table 4: Question 3: How did your state oral health program use the burden document to affect programmatic change?

<b>Theme</b>	<b>Responses</b>
Planning	It gave us a better focus on the needs of the program [r1] It was the tool we used in the program planning process [r2] It helped us to hone in on programmatic areas that we wanted to concentrate on [r4] It helped us to be more strategic on programs we wanted to focus on [r4] It helped us with workforce development and loan repayment programs. [r4] It showed us the value in investing in surveillance [r4] Identify priorities for implementation of sealant programs [r5]
Leveraging	We were able to start discussion of having an epidemiologist on staff [r1] It allowed a state agency to take over the management of school based sealant programs [r3]
Management	There was a clear impact in terms of time management [r5]
Functionality	It became our one stop shop for data [r2]

Overall the respondents, with the exception of r3, discussed using the burden document for planning to affect programmatic change within a state oral health program.

Respondent r3 used the burden document for leveraging and as a result were able to have a state agency take over the management of school based sealant programs in the state.

The number of examples that R4 provided during the interview suggests that planning to affect program change was important. Respondent r4 was also successful with influencing policies that increased funding for school based sealant programs and for putting forth a Medicaid benefit (table 3). Respondents who used the burden document for planning to build infrastructure (table 2) also use it for planning purposes to affect programmatic change.

*Evaluation Question 4: How do you plan to utilize your burden document in the future to strengthen your state's oral health program?*

The most common themes that emerged for this evaluation question were: planning, collaboration, and communication (table 5).

One respondent had this to say about planning:

“In 2006 when we were developing the oral health burden document we were concurrently developing the state plan so it was hard to utilize the information to inform the state plan. In developing the next state plan the burden document will be used to inform the direction that the state plan will go.”

Another respondent said:

“...one of the things we are trying to do is ... traditionally our program focuses on children. So now we are trying to expand... to include other vulnerable populations groups, for example pregnant women.”

Respondents who said that the burden document was used for collaboration offered these comments:

“So we are kind of using it as the starting point for discussions about how to improve data documents in the future.”

“We have developed several documents assessing the needs and the link between diabetes and tooth loss and diabetes and dental visits. So we are now working with chronic disease programs to improve the health of diabetic populations.”

Respondents answering this question also said that the burden document would be used for communication with stakeholders and legislators. The following statement supports this:

“In the future.... if we can finagle this differently I would like to see both the burden document and the state oral health plan in getting more exposure within our legislative body. We have had opportunities to share it with specific legislators upon request.”

Another said:

“Additionally, I am working to catalog all past data collection efforts and develop summary tables so the information is readily available to other program staff and/or predecessors (part of succession planning).”

Two respondents discussed evaluation and informing. One respondent had this to say about evaluation:

“It will be used as a tool to measure program growth.”

“As more data has been collected we will begin showing more trend information on oral disease, dental access and workforce (e.g., aging of the dentist workforce...).”

Table 5: Question 4: How do you plan to utilize your burden document in the future to strengthen your state's oral health program?

Theme	Responses
Planning	Will use it to inform the direction of the next state plan [r1] We will use it to expand/include other populations [r3]
Collaboration	We will use it with other chronic disease programs [r3] Will use it as the starting point for discussions about how to improve data documents [r4]
Communication	Use it in getting more exposure with legislators [r5], [r2]
Evaluation	Use as a tool to measure program growth [r4]
Informing	Will show more trend information on oral disease, dental access and workforce [r5]

Respondent (r1) used the burden document to develop the state plan (table 2), which was used to help build oral health infrastructure. To build infrastructure in the future, r1 will also use the burden document to direct the next state plan (table 5).

Development was a common theme for building program infrastructure (table 2). Respondents will also use the burden document in the future for planning, collaboration, and communication to strengthen state oral health program infrastructure. For example, respondent r3 will use the burden document to collaborate with other disease programs and respondent r4 will use it as a starting point for discussions with collaborators and partners on how to improve data documents. Respondents r5 and r2 will use it to communicate with legislators and r4 will use it for evaluation to measure program growth.

For planning purposes, respondent r3 used the burden document to help the state health departments develop needs assessments.

*Evaluation Question 5: Based on your experience, what would you say were the strengths of your burden document?*

All of respondents said that the burden document was comprehensive and cited various reasons. One respondent said the burden document was good at describing disparities related to oral disease and dental access and another said the burden document's focus on the burden i.e. financial, societal and economics of the state made the document comprehensive. The following statement supports this:

“The biggest strength I think our burden document shared was truly the burden—the financial burden—the societal burden. It's not just a repetition of data sets with a lot more text and pretty graphics. It really gets into what is this costing our state. And I think at that time we were the only state that had done anything with financial or economic analysis and it was pretty powerful and I think it continued to be powerful to continue to make statements about that.”

Another respondent had this to say about comprehensiveness:

“Where we were able to have had state level data. Obviously that is a no brainer. We had a comprehensive review of national data and the strongest part was we were able to drill down to a state level on BRFSS, PRAMS, and our oral health needs assessment, and our cancer data. Those are the pieces, the key factors of the burden document – being able to look at your state level data.”

Utility emerged as a theme and was discussed by several respondents” One respondent said the burden document was easy to read and another had this to say about its utility:

“The information helped coalition members and stakeholders understand the context for policy development and recommendations in the state plan.”

Table 6: Question 5: Based on your experience, what would you say were the strengths of your burden document?

Theme	Responses
Comprehensiveness	Comprehensive nature of the information that it included [r1] Where we were able to have state level data [r2] Focused on the burden i.e. financial, societal and economic [r3, r4] Included lifespan [r3] Followed the CDC template [r1, r2, r3, r4, r5] It was good at describing disparities related to oral disease and dental access [r5]
Utility	It was easy to read [r5] The information helped coalition members and stakeholders understand the context for policy development and recommendations in the state plan [r5]

All of the respondents cited comprehensiveness as a major theme. Of the respondents that identified comprehensiveness as a theme, two respondents (r3 and r4) used it for policy development. In addition to using the CDC burden document tool, respondents' r3 and r4 were the only respondents to include an economic analysis within the burden document. The addition of an economic analysis plan was not a requirement of the cooperative agreement; nor was this built into the burden document tool. Respondent r5 wanted to include an economic analysis but cited time management and resources as a barrier for such a major undertaking.

While respondent r5 said the burden document was easy to read as well as being functional, the document in itself was not the influencing factor for policy change within the state. However r5 was able to use the burden document to put forth a Medicaid benefit.

*Evaluation Question 6: Based on your experience, what would you say were the weaknesses of your burden document?*

The themes that emerged around this evaluation question were lack of comprehensiveness, lack of utility and lack of knowledge. Several participants felt that the burden document lacked comprehensiveness. One respondent said that it was not organized according to topics of public interest. Another one said that it was only a snapshot in time. Because time and staff were identified as factors for developing a comprehensive burden document, one respondent said:

“...and other audiences would have looked at it if we had the time and staff to do an economic impact of oral disease in the state.”

Utility also emerged as theme for one respondent. Here is what the respondents had to said:

“You have to know or you have to have some idea of who your users are. You just can’t expect them to know that you have this information. We continue to raise that challenge with all of our data not just with our burden document. And so I would really like to see how we can improve on this the next time because we do have a better idea of who are data users are— what people interested in this information.”

One respondent said the burden document was too lengthy and was not user friendly.

Another respondent claimed not to have heard any negative feedback on the burden document.

One respondent said that the oral health program’s strategies, changes or accomplishments were not discussed in the burden document. Additionally, another respondent said that the lack of evaluation of the dissemination of the burden document was a weakness:

“The second weakness of the document is evaluating that dissemination. Did people use it? How soon do you follow up to make sure that they’ve used it?”

Those are all very big challenges when you're investing in resources trying to get it done and not so much in --ok--- well now it's done now what? So I think it will be really important for us to evaluate those dissemination strategies to make sure people really getting it in their hands and are finding it valuable and documenting the things you are asking about. How did this influence policy? How did this influence programmatic change? —Not just within our agency but within people on the ground trying to make changes in the system.”

Table 7: Question 6: Based on your experience, what would you say were the weaknesses of your burden document?

Theme	Responses
Lack of Comprehensiveness	Burden document was not organized according to topics that were easily accessible based on people's interest [r1] It was a snapshot—a point in time [r2] We did not have staff or time to conduct economic impact [r5] Did not have data on caries for adults and seniors [r5]
Lack of Utility	It was a lengthy document—not user friendly [r3]
Lack of Knowledge	We did not know who our users of our burden document were at that time [r4]

The respondents who stated utility (r3) and lack of knowledge (r4) as noted weaknesses with the burden document were still able to utilize it to influence policy. And one respondent, who did not know who the users of the burden document, used the burden to establish school based sealant policies.

*Evaluation Question 7: How valuable of an exercise was the development of the burden document?*

All of the respondents answering this evaluation question indicated that the development of a burden document was a valuable exercise (table 8). The most common themes that emerged were program development and utility. The respondents who said



the value of developing a burden document was high in respect to program development made the following comments:

“Without CDC funding we wouldn’t have had the impetus to move our program forward.”

Another said:

“For an emerging program we were certainly in the formation stage and thinking of the oral health unit as a system in and of itself was fairly new. The exercise allowed us to look at our program and how we want to collect, use and present data.”

One said that it was the backdrop for the state plan. Here is what was said:

“I think it was not only valuable but necessary to set the backdrop for the state plan.”

Several respondents also discussed utility as a value.

One respondent said:

“It was very valuable to go through the exercise of looking at all of these things, asking the hard questions about this data— more important than this data? How do you present this data? What are people going to want? So I think it was a valuable exercise in that way. I would caution that to publish a burden document every five years just for the sake of publishing a burden document is probably less valuable for us is what we are finding.”

Another said:

“When you talk about burden in terms of cost to society like hospitalization, or overall costs that makes much more impact than talking about the fee levels. SO this burden document brings together all those other topics.”

Policy development, collaboration, knowledge and informing also emerged as themes for this evaluation question. The respondent who said the value was related to policy development said:

“I think that it is valuable in setting the context for what policy actions that need to be taken to address oral disease. From that perspective, it was valuable.”

Here is what one respondent said about collaboration:

“It is valuable because it encouraged us to collaborate with other programs for data collection.”

One respondent said that the development of the burden was a valuable exercise because it helped the oral health program to become aware of what was not known and what the oral health staff needed to work on.

Another respondent said that the development of the burden document was a valuable exercise because the burden document was used to inform stakeholders and policy-makers.

Table 8: Question 7: How valuable of an exercise was the development of the burden document?

Theme	Responses
Program Development	We use it for grant writing on a monthly basis [r1] Our program was in the formation stage and the development of the burden document pulled all the elements of our program together [r4] It was the backdrop for the state plan [r5]
Utility	It was the impetus for moving our program forward [r1] The value is high in terms of utility [r2] It is valuable because when you talk about burden in terms of cost to society it makes more of an impact with policy-makers [r3] It is a one-stop-shop for data [r5]
Policy Development	It was valuable in setting the context for what policy actions that needed to be taken to address oral health [r5]
Collaboration	It encouraged collaboration with other programs for data collection [r5]
Knowledge	It helped us to become aware of what we did not know and what we needed to work on [r1]
Informing	It is valuable because it was used to inform stakeholders [r5]

Several respondents found value in the burden document exercise and found the burden document to be useful for developing the infrastructure of an oral health program. The respondents provided examples of using the burden documents for grant writing, bringing all the elements of the program together, and developing the state plan.

Several respondents also discussed utility as a function to move the program forward and having a document on-hand that was a one-stop-shop for data.

## **OTHER FINDINGS**

Another finding shows respondents that incorporated an economic analysis within the burden document were successful with implementing policies for school based sealant programs and for putting forth or expanding Medicaid benefits for adults. Economic analyses according to one respondent are valuable because the burden of oral disease is discussed in terms of societal costs, which are more impactful for policy-makers.

The CDC burden document tool may have influenced many of the responses. For example several respondents stated the comprehensiveness and organization of the burden document by topics of interest were weaknesses of the document. Another respondent said that the burden document was lengthy and not user friendly. These comments suggest dissatisfaction with the CDC burden document tool. One respondent even suggested that the burden document tool should be revised to reflect more accurate and current data.

## SUMMARY

Overall, respondents say that the burden document is an important tool for developing state oral health program infrastructure. Responses suggest that the use of the burden document for program development, planning and collaboration may be important for building oral health program infrastructure.

Below is a discussion on the findings that emerged from each of the evaluation questions.

### **How was your burden document used to strengthen the state oral health program's infrastructure?**

Responses suggest that respondents use the burden document for program development, planning, communication, awareness and education to strengthen state oral health program infrastructure.

- **Program Development**

Respondents who use the burden document for program development developed surveillance and state oral health plans. Respondents also use the burden document as the impetus to move an oral health program forward and to address workforce issues.

- **Planning**

Respondents use the burden document for planning activities such as setting priorities, allocating resources, identifying gaps and conducting needs assessments.

- **Communication**

To strengthen a state oral health program respondents use the burden document to communicate with policy-makers and to disseminate data.

- **Education**

Respondents use the burden document to educate legislators, partners and coalitions.

- **Leveraging**

Respondents use the burden document to leverage for positions within the oral health program. For example one respondent leveraged the burden document to maintain in-kind epidemiology support.

### **How was the burden document used to influence policy?**

Respondents use the burden document to influence state based and programmatic policies. Respondent also use the burden document to reinforce already established “good” policies.

- **Sealants**

Respondents use the burden document to influence policies for school based sealant programs (i.e. formalize school based sealant programs, increase funding for school based sealant programs and to authorize the establishment of school based sealant programs).

- **Medicaid**

Respondents use the burden document to influence policies for the expansion of adult Medicaid benefits.

- **Reinforcement**

Respondents use the burden document to reinforce already established “good” policies.

- **Programmatic Policy Development**

Respondents use the burden document to develop programmatic policies. One respondent developed a policy for data collection.

- **Non-use**

One respondent does not attribute the burden document as the influencing factor for policy change, but gives credit to the behavioral risk factor system. Another respondent’s state was not favorable towards policy change and the burden document is therefore used to reinforce already established “good” policies.

**How did your state oral health program use the burden document to affect programmatic change?**

To affect programmatic change, respondents use the burden document for planning, leveraging and management. Respondents also say the burden document is a functional and resourceful tool.

- **Planning**

Respondents use the burden document to focus on the needs of the program, identify priorities for the implementation of sealant programs, and develop loan repayment programs and to show the importance of investing in surveillance.

- **Leveraging**

Respondents leverage the burden document to bargain for positions and to provide management over sealant programs.

- **Management**

Respondents say that time management is a factor for using the burden document to affect programmatic change.

- **Functionality**

Respondents view the burden document as resourceful tool. For one respondent it is a one-stop-shop for data.

**How do you plan to utilize your burden document in the future to strengthen your state's oral health program?**

To strengthen state oral health programs, respondents will use the burden document to plan, collaborate, communicate, evaluate and inform.

- **Planning**

Respondents will use the burden document in the future to plan the direction of the next state plan and to expand or include other populations.

- **Collaboration**

Respondents will use the burden document to collaborate with other chronic disease programs in the future. Respondents will also use it as a starting point for discussion about how to improve data documents.

- **Communications**

Respondents will use the burden document in the future to communicate with legislators.

- **Evaluation**

Respondents will evaluate the burden document in the future to measure the growth of the oral health program.

- **Informing**

Respondents will use the burden document in the future to show more trend information on oral disease, dental access and workforce.

**Based on your experience, what would you say were the strengths of your burden document?**

Answering this evaluation question respondents say that comprehensiveness and utility are strengths of the burden document.

- **Comprehensiveness**

Respondents say that the burden document is comprehensive because it describes oral health disparities, discusses dental access and focuses on financial, economic and societal costs. Respondents also say that the burden document is comprehensive because it follows the CDC burden document tool.

- **Utility**

Respondents say that the burden document is easy to read and that the information contained in the document helps coalition members and stakeholders understand the context for policy development and recommendations in the state plan.



**Based on your experience, what would you say were the weaknesses of your burden document?**

Respondents cite lack of comprehensiveness, lack of utility and lack of knowledge as weaknesses of the burden document.

- **Lack of Comprehensiveness**

Respondents who cite lack of comprehensiveness as a weakness state that the burden document is not organized according to topics that are easily accessible and based on people's interests. Respondents also say that the burden document is only a snap shot in time, does not have data on caries for adults or seniors and does not include an economic analysis.

- **Lack of Utility.**

One respondent says that the burden document is lengthy and not user friendly.

- **Lack of Knowledge**

One respondent does not know who the users are of the burden document.

**How valuable of an exercise was the development of the burden document?**

Respondents say that developing a burden document is a valuable exercise and cite 7 themes that resulted from answering this evaluation question: program development, utility, policy development, collaboration, knowledge, and informing.

- **Program Development**

Respondents use of the burden document for developing a state plan and grant writing makes it a valuable exercise.

- **Utility**

Respondents equate value with use. The burden document is valuable to respondents because it discusses economic and societal costs and therefore makes an impact with policy-makers. It is also a one-stop-shop for data.

- **Policy Development**

Respondents say that the burden document exercise is valuable because it sets the context for what policy actions need to be taken to address oral health.

- **Collaboration**

Respondents say the burden document is used to collaborate with other (internal) programs for data collection.

- **Knowledge**

The development of a burden document helps respondents become aware of the program's knowledge limitations and what needs to be improved.

- **Inform**

Respondents value the burden document exercise, because the document is used to inform stakeholders.

## **CHAPTER V CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS**

### **INTRODUCTION**

This chapter presents the conclusions drawn from the results and the implications of those results. Next there is a presentation of recommendations on how the oral disease burden document should be used to maximize its full benefit. And lastly this section will discuss how to strengthen this study for future evaluations of the burden document.

#### **Conclusion**

The evaluation of oral disease burden documents produced through cooperative agreement 3022 is a first attempt at documenting and assessing the use and perceived usefulness of the burden document. The interview data suggests that the burden document may be a useful tool for building infrastructure when used for program development, planning, collaboration, communication, informing, awareness, evaluation, leveraging, and policy development. Additionally, the data suggests that the burden document may also be used to support the three core public health functions of assessment, policy development and assurance.

Many of the respondent's responses appear to be directed at the CDC burden document tool. For example, when respondents were asked about the burden document's comprehensiveness it is described as not being user friendly, not organized according to topics of interest, and too comprehensive. The burden document, according to several respondents, is also lengthy and not user friendly. Because all of the respondents followed the CDC burden document tool template, these responses may be expressions of

dissatisfaction with the tool itself and not the burden document. And according to one respondent, the CDC burden document tool should be revised.

While respondents say that they use the burden document to collaborate with internal chronic disease programs and partners, there is not enough data to suggest that state oral health programs do not use the burden document to collaborate with external partners. Also, while the common themes such as program development and planning are easily identifiable, not all themes are so apparent. Some themes such as informing and communication are closely related.

## **IMPLICATIONS**

Prior to cooperative agreement 3022, state oral health programs did not develop an oral disease burden document. The published burden documents produced through CA 3022 were the states' first such document. The oral health burden document may be a useful tool for building oral health infrastructure. If respondents are provided with proper resources such as an updated CDC burden document tool and technical assistance and guidance on how to use the burden document to help build infrastructure, state oral health programs may then be able to maximize its use. With current data a burden document may then be used to better inform and influence legislators for policymaking decisions. Obtaining meaningful data and using such data to correctly influence policy and build oral health program infrastructure will be a challenge to both the state oral health programs, CDC and its partners because as the demand for data grows, financial and logistical challenges may increase in return

## **RECOMMENDATIONS**

Based on the findings from the data, there are several recommendations this study offers. Efforts should be aimed at providing technical assistance and guidance on the burden document, revising the CDC burden document tool, developing an economic analysis template and training module as well as making suggestions for making this study stronger.

### **Retain the burden document as a recipient activity**

Because the data suggests that the development of a burden document is a valuable exercise and that oral health burden documents produced through Cooperative Agreement 3022 may be a useful tool for building infrastructure, the burden document should therefore be included as a cooperative agreement recipient activity for future agreements.

### **Technical assistance and guidance**

Technical assistance and guidance should be aimed at CDC funded and non-funded states and should focus on how to utilize and maximize the benefits of the burden document to its fullest potential when building and strengthening state oral health program infrastructure. Technical assistance and guidance should focus the 11 major themes that emerged from this evaluation.

Below is a list of the technical assistance and guidance focus areas. State oral health programs may be more successful using the burden document to building infrastructure when technical assistance and guidance efforts focus on utilizing the burden for:

1. program development (i.e. developing surveillance and state plans);
2. planning (i.e. for setting priorities, identifying gaps, and allocating resources);
3. communicating with internal and external partners;
4. informing policy makers about the burden of oral disease and disparities in oral health within a state;
5. informing the general public (non-oral health professionals);
6. engaging external partners, including influencing policy;
7. leveraging for resources;
8. creating awareness of the program;
9. collaborating with internal and external partners; and
10. reinforcing already established “good” policies

Other technical assistance and guidance should focus on how to conduct and utilize data collected from economic analyses.

### **CDCC Burden Document Tool**

- **Revise the CDC burden document tool**

There are several concerns about the functionality of the burden document. While it is considered easy to read, it is cited as being lengthy and not user friendly.

These types of comments speak directly to the use of the CDC burden document

tool. Based on these findings the burden document tool should be revised to meet user's needs in terms of comprehensiveness and functionality.

- **Update the CDC burden document tool**

To include accurate and current data from reliable data sources, efforts should be aimed at updating the CDC burden document tool. Additionally, efforts should be aimed at developing a standardized process for updating the burden document tool periodically.

- **Technical assistance**

Efforts should be aimed at providing technical assistance and guidance to states on how to use the CDC burden document tool. Additionally, a training module, including template with instructions on how to construct an economic analysis should also be developed.

### **Economic Analysis**

Respondents including an economic analysis in the burden document were successful at engaging policymakers and influencing policy. Future cooperative agreements should include an economic analysis as a recipient activity. Additionally, efforts should also include the development of an economic analysis template which should be posted on the CDC oral health website.

### **Conduct further evaluations**

To further understand how the burden document can be used to build program infrastructure, efforts should be aimed at conducting additional studies of the burden

document to understand how the burden document can be used to help build infrastructure.

### **Change the study design**

- **Restructure the evaluation questions**

This study design employs open-ended interviewing techniques to gather information-rich data from state dental directors or program managers. This study design proved to be challenging; respondents required a great deal of prompting by the investigator. Closed-ended questions should be included in the questionnaire. Adding closed-ended questions will provide a more specific response and will thus elevate any confusion with responses having similar meanings.

- **Inclusion criteria**

Interviewees for this study are dental directors or program managers. To provide a richer discussion on the burden document and to gain a better understanding of how the CDC burden document tool impacts the use of the burden document, the state oral health program's epidemiologist should also be included as an interviewee in future studies.



## SUMMARY OF STUDY

The purpose of this study was to evaluate state dental directors' use and perceived usefulness of the oral health burden document. Five of 12 states funded through the CDC Cooperative Agreement 3022 participated in this study. State dental directors and program managers were asked several open-ended questions about their use and perceived usefulness of the burden document. Responses were tape-recorded and categorized by themes by the researcher. The most common reoccurring themes were program development and planning.

Respondents used the burden document to meet the public health core functions and to build oral health program infrastructure. Several respondents, after incorporating an economic analysis within the burden documents were successful at influencing state based policies for school based sealant programs and for expanding adult Medicaid benefits.

The recommendations based on the findings are aimed at technical assistance and guidance on how to utilize and maximize the burden document's full potential to build infrastructure based on the themes that emerged from this study. Other recommendations include revising the CDC burden document tool, including an economic analysis as a recipient activity for future cooperative agreements and making changes to the study design to make it more generalizable to all U.S. state health departments.

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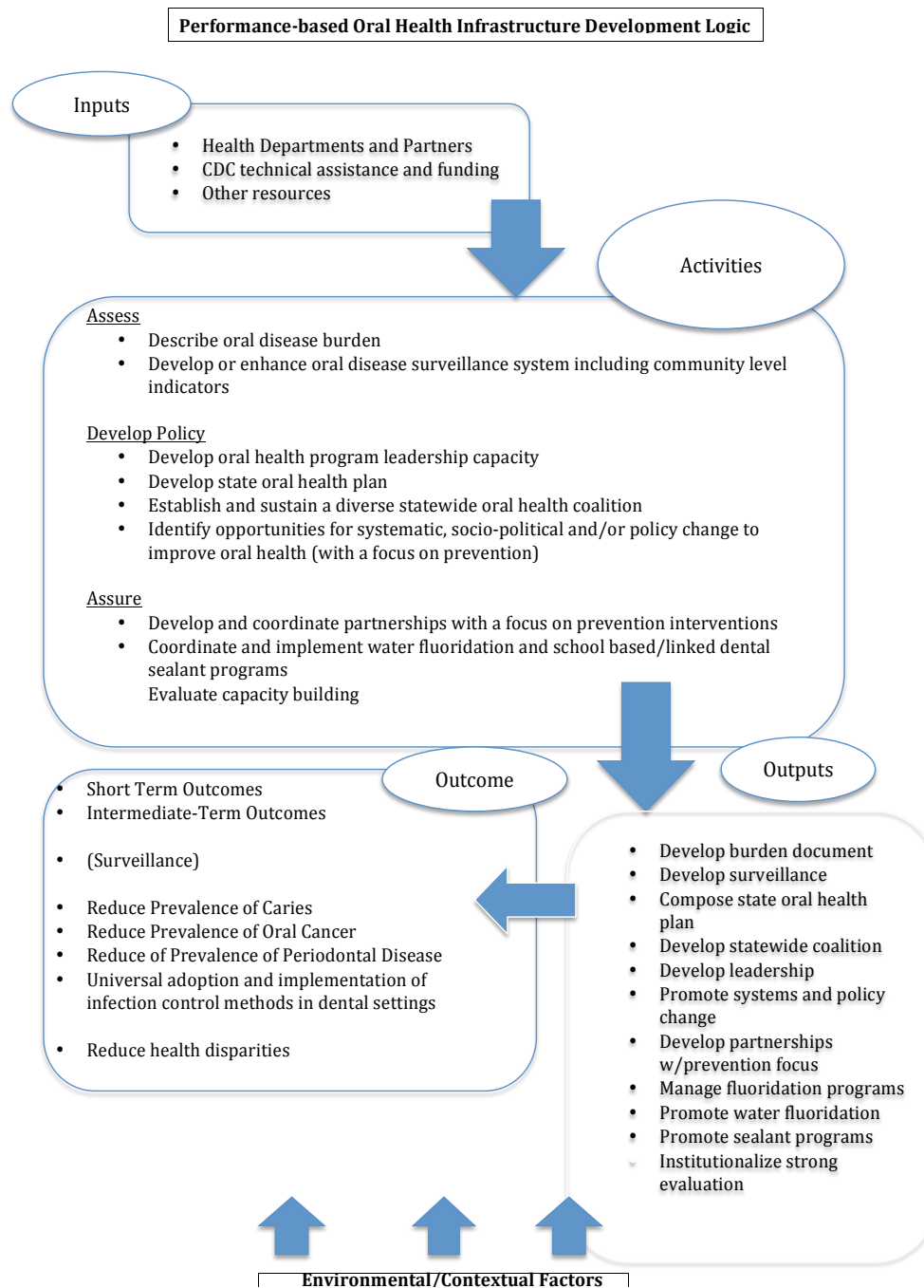
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## Appendix A: Program Logic Model





## Appendix B: Introduction and Recruitment Letter

**Dear (Name)**

You may or may not know that I am completing my Masters in Public Health at Emory University. A requirement for completion of the program is to complete a Special Studies Project (SSP). For my project I am conducting an evaluation of state dental director's *use* and *perceived usefulness* of the oral health burden document produced through Cooperative Agreement 3022. Over the next two weeks, I will be conducting in-depth interviews with state dental directors or program managers over the life cycle of CA 3022 and who are familiar, specifically with recipient activity #2.

I anticipate that the interviews will last 45 minutes. I would like to include you as a study subject for the evaluation and interview you to gain your perspective about your state's *use* and *perceived usefulness* of the oral health burden document. Please let me know if you agree to participate in this study. Your participation is voluntary. The information you share with me will be kept confidential and will not be shared with anyone outside of the study. If you have any questions, about the study, you can reach me at the number listed below or on my cell phone at 404-606-3156.

Thank you

Sincerely,

Kevin Ramos, MPH candidate

## **Appendix B: Verbal Consent Form**

### **Oral Consent To Be A Research Subject**

**Title:** Burden Document Review: An evaluation of use and state dental director's perceived usefulness of oral health burden documents produced through Cooperative Agreement 3022

**Principal Investigator:** Kevin Ramos

**Co-Investigator:** Iris Smith, PhD

Dear \_\_\_\_\_,

#### **INTRODUCTION AND PURPOSE**

You are being invited to participate in a research study because you were identified as being the state dental director who was responsible for the Centers for Disease Control Cooperative Agreement DP 3022 deliverables and outcomes. I am interested in learning if or how the oral health burden document produced by your state was used to strengthen your state oral health program's infrastructure. Approximately 4 other state dental directors will be interviewed for this research study. This study is being conducted for my masters' special study project under the direction of Dr. Iris Smith.

#### **PROCEDURE**

If you agree to participate, I will interview you for about an hour over the phone. The questions will be about your perceptions of the usefulness of the oral health burden document. With your consent, I will tape record the interview. These voice recordings will be transcribed by me and will be immediately destroyed thereafter.

#### **RISKS**

There are no foreseeable political or social risks associated with participation in this interview.

#### **BENEFITS**

Taking part in this research study may not benefit you personally. The information you provide, however, will add to our knowledge about the use of the oral health burden document

#### **CONFIDENTIALITY**

I will not include your name in study results, but your position in the organization might be included. If you feel uncomfortable, quotations or narratives can be left out of the analysis at your discretion. You will never be asked for any personal information beyond your perceptions of the oral health burden document. All research records and recorded interviews will be kept in a locked secure location. People other than those doing the research may look at the study records. Agencies and Emory departments and committees that make rules and policy about how research is done have the right to review these records. We will keep all records that we produce private to the extent we are required to

do so by law.

**CONTACT PERSONS**

If you have any questions, I invite you to ask them now. If you have any questions about

the study later, you may contact me at [ilr8@cdc.gov](mailto:ilr8@cdc.gov) or 770-488-5630. You may also contact my advisor, Dr. Iris Smith, at [ismith@emory.edu](mailto:ismith@emory.edu) or 404-727-2925.

Do you have any questions? Do you agree to participate in this study?

## Appendix D: Interview Script

### Interview Script

#### Introduction

(Name), thank you for agreeing to participate in this interview. As you know, I am conducting an evaluation of Cooperative Agreement 3022 for my masters' Special Studies Project for the Emory University Career MPH program. Several weeks ago I mailed an introductory letter to you outlining the goals and objectives of the evaluation. Hopefully you had a chance to look over the letter and familiarize yourself with the goals and objectives of the program evaluation. For the sake of time, please allow me to review them with you again. I will be brief as I am aware that your time is important.

The overarching purpose of this evaluation is to assess *if* and *how* states funded thru CA 3022 utilized the burden document to strengthen their oral health infrastructure within the their state oral health programs. In addition the evaluation will:

- Provide evidence to promote infrastructure development
- Improve the program and decision-making
- Identify intended users and use of the burden document
- Document and share lessons learned
- Market the burden document to stakeholders

DOH evaluated CA 3022. The evaluation did uncover the use of the burden document and found that the burden document was pivotal to the program and was instrumental in strengthening infrastructure. However, the evaluation did not ask pointed questions strictly about the burden document. It is unknown to CDC DOH at this time if

and how states funded through CA 3022 utilized their burden documents to strengthen their states' oral health infrastructure. Understanding the *use* and perceived usefulness of the burden document, may inform DOH whether RA2 contributes to system changes that improves the infrastructure building efforts, which may improve oral health outcomes. Lastly this added knowledge might enable DOH to determine if RA2 was a useful activity or not.

I anticipate that the interview should last no longer than 45 minutes. I will ask you a several open-ended questions to gather some background information. Because I will be collecting a lot of information from you, I am asking your permission to tape record this interview. The tape will remain in my possession and will not be shared with anyone not associated with this study and will be destroyed at the end of this study. Do I have your permission to record this session? Before we begin do you have any questions? Okay, let's begin.

## **Appendix E: Interview Questions**

### **Interview Questions**

#### **Background Information**

1. For the record, please state your name, title and state that you are from.
2. Were you the dental director at the time (from 2003-2008) Cooperative Agreement 3022 was in place?
  - a. If no:
    - i. Were you on staff at the time CA 3022 was in place? If so, what was your role?
    - ii. How familiar are you with Cooperative Agreement 3022, specifically the development of the burden document?

#### **Knowledge**

3. How was your burden document used to strengthen the state oral health program's infrastructure?
4. How was the burden document used to influence policy change?
  - a. What oral health policies were implemented in your state as a result of using the burden document?
5. How did your state oral health program use the burden document to affect programmatic change?
  - a. What impact did it have on the state oral health program?
6. How do you plan to utilize your burden document in the future to strengthen your state's oral health program?

**Opinion**

7. Based on your experience what would you say were the strengths of your burden document?
8. Based on your experiences what would you say were your weaknesses of your burden document?

**Value**

9. How valuable of an exercise was the development of the burden document?

**Conclusion**

That concludes the survey for this evaluation. Again, I would like to reiterate: your comments will be kept confidential. I would like to thank you for your taking the time to participate in this study. If you have any questions about this evaluation or feel the need to provide additional information, I can be reached at [ilr8@cdc.gov](mailto:ilr8@cdc.gov) or by phone at 770-488-5630.

## Appendix F: Emory University Institutional Review Board Exemption Letter



EMORY  
UNIVERSITY

Institutional Review Board

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February 9, 2011

Kevin Ramos  
Emory University  
Rollins School of Public Health  
1518 Clifton Road  
Atlanta, GA 30322

**RE: Determination: No IRB Review Required**  
**IRB00048814 – Burden Document Review: An evaluation of use and state dental director's perceived usefulness of oral health burden documents produced through Cooperative Agreement 3022**  
**PI: Kevin Ramos**

Dear Mr. Ramos:

Thank you for requesting a determination from our office about the above-referenced project. Based on our review of the materials you provided, we have determined that it does not require IRB review because it does not meet the definition(s) of "research" involving "human subjects" or the definition of "clinical investigation" as set forth in Emory policies and procedures and federal rules, if applicable.

45 CFR Section 46.102(f) defines "Human Subjects" as follows:

Human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains: (1) Data through intervention or interaction with the individual, or (2) Identifiable private information.

Based on the information included in the submission, you intend to speak with several state dental directors to evaluate the use of a health burden documentation requirement by the Centers for Disease Control. Since the interviews will principally be about the documentation, and not the subjects themselves, the IRB has determined that this study does not constitute research on "human subjects" under the foregoing definition.

This determination could be affected by substantive changes in the study design, subject populations, or identifiability of data. If the project changes in any substantive way, please contact our office for clarification.

Thank you for consulting the IRB.

Sincerely,

Tom Penna  
IRB Analyst Assistant  
*This letter has been digitally signed*