

Towards Broadening Secondary Prevention Efforts within a State Stroke Registry

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DISSERTATION

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To my wife, Jill Whitney, and our sons, Alex and Tyler Reynen, I hereby dedicate this Dissertation. Were it not for their unwavering support, encouragement, and love, completing this Dissertation would have been impossible. I am blessed beyond measure.

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Holding fast to Philippians 4:13,

DJR

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LIST OF ABBREVIATIONS

AHA/ASA	American Heart Association / American Stroke Association
CASPR	California Acute Stroke Pilot Registry
CCP	California Coverdell Program
CSR	California Stroke Registry
CDC	Centers for Disease Control and Prevention
CDPH	California Department of Public Health
CHDSPP	California Heart Disease and Stroke Prevention Program
EMS	Emergency Medical Services
EMSA	Emergency Medical Services Authority
FOA	Funding Opportunity Announcement
GWTG	Get With The Guidelines
IDP	Integrated Data Platform
IV t-PA	intravenous tissue plasminogen activator
LEMSA	Local Emergency Medical Services Agency
PCNASR	Paul Coverdell National Acute Stroke Registry
TJC	The Joint Commission

SUMMARY

Within the California Stroke Registry/California Coverdell Program (CSR/CCP) – a stroke-care-related quality improvement program, this study was undertaken to achieve the following three objectives: (1) to describe the current secondary prevention efforts of the CSR/CCP; (2) to explore what factors were influential in bringing about this current programmatic state; and (3) to investigate what changes might occur within the registry, in order to usher in a better future state. With respect to data collection, a systematic review of twenty-seven CSR/CCP documents preceded the conduct of fourteen key informant interviews. Subsequently, content and thematic analyses were performed using NVivo, Version 10, and the study findings were vetted and translated into six foundational and six operational recommendations for change.

The study findings are these: First, in terms of the CSR/CCP's current programmatic state, it was revealed that, with respect to recruitment, infrastructure, partnerships, and quality improvement, there is misalignment not only with the program's original guiding vision but also with the prevailing national trends (towards integrating clinical medicine and public health, in order to improve population health). Of special concern, here, is the program's lack of a functional data system – which is a significant and far-reaching liability. To be sure, this liability has hampered the efforts to-date to achieve programmatic objectives.

Second, with regard to those factors that have given rise to the current sub-par programmatic state, this study suggested that certain tangible actions (e.g., historical decisions, staffing patterns, operational constraints) and intangible assets (e.g., held beliefs, a lack of visibility, a lack of programmatic “fit” within the larger organization) have been important. The notion of “fit” (or lack thereof) is rather salient: With its focus on secondary prevention, the

SUMMARY (continued)

CSR/CCP does not really “fit” well within the larger organization in which it resides – given the latter’s focus on primary prevention. Consequently, the CSR/CCP has been deprioritized within, and under-resourced by, the larger organization.

Third, with respect to potential changes that could enable the CSR/CCP to achieve a better future state, two key ideas emerged: First, it was recommended that the CSR/CCP ought to be engaged fully in the practice of knowledge management – i.e., capturing, sharing, and using informational assets. To be sure, heeding this recommendation is contingent upon having a functional data system. Second, it was advised that the CSR/CCP ought to work cross-functionally – i.e., establishing multi-disciplinary teams, intentionally-focused on a particular aspect of the program’s scope of work. Certainly, enabling a bona fide cross-functional approach would be facilitated were the CSR/CCP to have a broader coalition of strategic partners.

Finally, out of this project came a set of six foundational and six operational recommendations for change. The eventual implementation of these twelve recommendations should promote a better future programmatic state, one that (1) is more in line with the CSR/CCP’s original guiding vision; and (2) could serve as a model of clinical medicine and public health coming together in order to improve health at the community level. Accordingly, the CSR/CCP would be more effective in its work to reduce the burden of stroke, in terms of morbidity, mortality, and costs – which is the ultimate goal of those engaged in this very important work.

I.

Chapter 1: Introduction

During the course of their ongoing practice, public health professionals are regularly called upon to deal with what Rittel and Webber (1973) refer to as “wicked” problems – problems which are ill-defined, dependent upon elusive political judgment for resolution, and never truly solved. To appropriately address these “wicked” problems (and “wicked,” as per Rittel and Webber, is akin to “tricky”), public health professionals must be, as Day et al. (2014) suggest, “superheroes” in their work, as they seek to change the problematic situation. Indeed, they must be able to employ an effective combination and intensity of talents to identify, describe, and approach the problems they face – of course, all the while being attentive to the various environments in which their work is occurring.

The overarching goal of the present project is to consider how to approach what appears to be a difficult problem occurring within a State-level public health program – such that there is a sense of (1) the program’s current, seemingly sub-par state of being; (2) the factors that gave rise to this particular state; and (3) the kinds of actions that ought to be undertaken in order to move beyond this particular state. Moreover, it follows that any future movement in the direction of a better future state, motivated by the results from the present project, could align this program well with current national trends in public health, particularly in light of the 2010 passage of the Patient Protection and Affordable Care Act. Achieving success in handling the present problem should bring the program more in line with that which is being called for via the present national healthcare reform efforts – namely better quality and continuity of care.

The present project takes place within the California Stroke Registry / California Coverdell Program (CSR/CCP) – a quality improvement program related to the care of acute stroke patients, in both the pre-hospital and the in-hospital clinical settings. Of note, however, is

that since its inception, the CSR/CCP has concentrated its efforts primarily within the in-hospital clinical setting – contrary to its stated purpose...and out of line with the ongoing national health reform conversation (related to the integration of clinical medicine and public health, for the purpose of improving population health). While the program’s in-hospital efforts have yielded positive results, including those related to how patients are screened, medicated, and educated, the program has not realized the same kinds of successes within the pre-hospital setting. This contrast suggests that there were – and continue to be – missed opportunities within the program, particularly within the pre-hospital setting. Accordingly, there is reason to believe that the program needs to broaden its secondary prevention efforts (i.e., to expand its programmatic “reach,” such that it is “present” earlier on during a stroke event) in order to gain some ground where it had previously failed to get some traction.

The present study has three objectives: First, this project aims to describe what the current secondary prevention efforts are, relative to what they were expected to have been (by the present time). Second, this project aims to explore what factors were influential in bringing about this current programmatic state. Third, this project aims to investigate what changes might occur, such that the current, seemingly sub-par status quo will not persist. Put another way: there appears to be somewhat of a “lost opportunity” (to be more fully engaged in secondary prevention) within the CSR/CCP – and this project endeavors to explore that apparent “lost opportunity.” Ultimately, these findings could be used to inform a meaningful change process within the CSR/CCP. In achieving these overarching study objectives, then, the evidence base for public health practitioners facing similar problems within their own situations may be augmented. Lastly, it merits mention that although the CSR/CCP provides the context for the present work, the implications found herein should serve as valuable “signposts” for approaching

and managing change in various different public health settings in which vital programmatic opportunities are being missed.

In this first chapter, information related to the project's background and context, as a means to introduce and discuss the problem statement, is presented. Additionally, following the discussion of the problem statement, the research questions pursued via this project are posed. Finally, this first chapter concludes with a presentation of the leadership implications and the relevance of this project, given that this investigation seeks not only to address a specific alleged problem of interest but also to contribute to the evidence base of public health.

A. Background and Context

1. The CSR/CCP: An Historical Perspective

a. The Focusing Event

In July, 2000, at the age of sixty-one years, Republican Senator Paul D. Coverdell of Georgia, who championed – among other causes – educational reform and drug prevention, died from a massive cerebral hemorrhage (Schmitt & Alvarez, 2000). As a tribute to the late Senator Coverdell, the Stroke Treatment and Ongoing Prevention Act of 2001, in amending the Public Health Service Act during the first session of the One Hundred Seventh United States Congress, included language to both improve “...the Nation’s capacity to provide effective treatment for stroke...” and create “...the Paul Coverdell Stroke Registry and Clearinghouse...” a repository of data on stroke care (Stroke Treatment and Ongoing Prevention Act of 2001). Additionally, the language of this act mandated the establishment of a federal grant program through which states, participating in the registry, would “...implement systems of stroke care and train health care professionals in the prevention and treatment of stroke.” Indeed, the passing of Senator

Coverdell was a “focusing event” – to invoke the language of Kingdon (1995) – for mounting a national effort aimed at improving the care of stroke.

b. The Resultant Action

i. Academic Medical Center Prototype Stroke Registries

Having thus been charged (and funded) by Congress to implement the Paul Coverdell Stroke Registry, the federal Centers for Disease Control and Prevention (CDC), in consultation with national stroke experts and organizations, initially piloted two “waves” of state-level prototype stroke registries, focused on the following six-part mission: (1) measure, track, and improve the quality of care provided to acute stroke patients across the care continuum; (2) decrease stroke-related morbidity and mortality; (3) eliminate disparities in treatment; (4) support the development of stroke systems of care; (5) improve access to stroke rehabilitation and recovery opportunities; and (6) increase workforce capacity and knowledge of stroke within the stroke systems of care (Centers for Disease Control and Prevention, 2013). Wave I of the CDC’s pilot, which started in 2001, included projects in Georgia, Massachusetts, Michigan, and Ohio, while Wave II of the pilot, which started in 2002, included projects in California, Illinois, North Carolina, and Oregon (George et al., 2009). These eight prototype registries, which focused primarily on pre-hospital and in-hospital care of acute stroke, in order to identify gaps in treatment, were housed in academic medical centers and ran for up to three years (Centers for Disease Control and Prevention, 2013).

At the conclusion of the CDC’s pilot across these eight programs, the pooled patient-level data indicated that large gaps existed between the recommended treatment guidelines and the actual hospital practices (Reeves et al., 2005; George et al., 2009; Reeves et al., 2006). For

example, only a minority of patients received thrombolytic treatment (via IV t-PA [intravenous tissue plasminogen activator]), within the recommended time interval (from arrival at the Emergency Department to t-PA administration, also known as “door-to-needle” time). Further, the data indicated that the administration rates for in-hospital dysphagia screening, lipid testing, and smoking cessation interventions were all considerably below the recommended guidelines. As it is germane to the present project, it is noteworthy that the results from California’s university-based pilot registry, the California Acute Stroke Pilot Registry (CASPR), did not stand out from those observed in the other pilot registries (California Acute Stroke Pilot Registry Investigators, 2005). This seems to suggest that across all prototype registries, the level of care that was being provided to acute stroke patients needed to be improved.

To the CDC, it became apparent in the prototype phase that the performance improvement onus was not to be placed entirely on the clinical providers; rather, the public health system was to play a role in improving stroke outcomes, as well. In fact, one recommendation coming out of CASPR was as follows: “Campaigns that educate patients to seek treatment sooner should be major components of system-wide interventions to increase rates of thrombolysis for acute ischemic stroke” (California Acute Stroke Pilot Registry Investigators, 2005). While new within the context of these eight federally-funded stroke registries, this idea of having a nexus between clinical medicine and public health was not altogether new. A 1997 monograph from the New York Academy of Medicine describes how, because of some (then) dramatic changes within the American health system, the medical and public health sectors were “...becoming increasingly dependent on one another – in achieving their missions, in addressing public health problems, and in responding to economic and performance pressures” (Lasker, 1997). This shared approach to addressing public health

problems has continued since the release of that report, and this integration of clinical medicine and public health has, more and more, become the operational norm (Cashman et al., 1999; Halverson, Mays, and Kaluzny, 2000; Zahner, 2005).

ii. Early State Health Department Stroke Registries

Based upon the above-discussed pilot program results – and given the prevailing trends related to integrating medicine and public health, the CDC made the decision to provide Coverdell funds to state health departments, rather than to academic medical centers. Thus, the Coverdell funding stream, re-directed in mid-2004, for a period of three years, established the federal Paul Coverdell National Acute Stroke Registry (PCNASR), then comprised of state Coverdell programs in Georgia, Illinois, Massachusetts, and North Carolina (Centers for Disease Control and Prevention, 2013). These four state-health-department-based registries were tasked with carrying out the following activities: developing and implementing systems that collect data on the care provided to acute stroke patients, at the patient-level; analyzing those data; and using the results of those analyses to inform quality improvement interventions at the hospital-level. In carrying out the above activities, these programs collectively constituted a public health initiative, as they worked to reduce stroke disparity rates, to address access to care problems, and to improve the quality of care provided (Labarthe, Biggers, LaPier, and George, 2006).

In mid-2007, the CDC expanded the PCNASR by funding six state health departments in Georgia, Massachusetts, Michigan, Minnesota, Ohio, and North Carolina. This second funding cycle for state-health-department-based-registries lasted for five years, and, during that time, the funded states tracked ten performance measures, established jointly in 2008 by the CDC, the American Heart Association / American Stroke Association (AHA/ASA), and The Joint

Commission (TJC), an independent organization that certifies and/or accredits health care programs and organizations (Centers for Disease Control and Prevention, 2013; George, Tong, and Yoon, 2011). These are the ten measures: (1) screening for dysphagia; (2) education on stroke; (3) receipt of IV t-PA; (4) lipid measurement and/or lipid-lowering medication prescribed at discharge; (5) deep venous thrombosis/venous thromboembolism prophylaxis given by the end of hospital day two; (6) assessment for rehabilitation; (7) anticoagulation medication prescribed at discharge for patients with atrial fibrillation; (8) antithrombotic medication administered by the end of hospital day two; (9) antithrombotic medication provided at discharge; and (10) smoking cessation counseling provided for patients and their families. The pooled data indicated that adherence to nine of these ten measures increased significantly during this grant cycle; the one measure that showed no improvement was number nine, antithrombotic medication provided at discharge, which was already at 98% in 2005 (George, Tong, and Yoon, 2011). To be sure, these six state-health-department-based-registries were able to demonstrate that the quality of stroke care could be improved.

iii. The California Department of Public Health Experience

During this same time period (i.e., mid-2007), program staff members within the (then) California Heart Disease and Stroke Prevention Program (CHDSPP) – of the California Department of Public Health (CDPH) –in partnership with the AHA/ASA, were engaged in the development of a stroke registry in California, as an officially-sanctioned CHDSPP activity funded under a federal categorical heart disease and stroke prevention grant¹. Establishing such a registry would accomplish two things: First, building the registry would be part of the larger

¹ Additionally, this work commenced in response to recommendations put forth in *California's Master Plan for Heart Disease and Stroke Prevention and Treatment 2007-2015* (California Heart Disease and Stroke Prevention and Treatment Task Force, 2007).

process to improve the quality of acute stroke care in California – such that there would be reduced morbidity and mortality, lower health care costs, and a higher overall quality of life. Second, the development of a so-called “homegrown registry” that closely resembled the PCNASR would make the CDPH more competitive in the next Coverdell grant cycle – which could mean increasing the state’s organizational capacity to reduce the disease burden (i.e., if the grant application were to be funded). In other words, the idea was that developing this PCNASR-like “homegrown registry” would be of benefit to public health, of course, as the burden of stroke would be lessened...and the CHDSPP/CDPH would position itself to increase its organizational capacity via enhanced federal funding, as well. To these ends, the CHDSPP, along with the AHA/ASA, reached out to a number of hospitals across California, chosen based upon a number of factors – including annual stroke volume, geographic location, and data collection and reporting capacity – and invited them to be a part of the emerging California Stroke Registry (CSR).

Officially launching the CSR in early 2008, the CSR Team (including the CHDSPP staff members and their AHA/ASA partners) established, shared, and set out to follow this comprehensive mission statement:

“To measure, track, and improve the quality of care for acute stroke patients; decrease the rate of premature death and disability from stroke through secondary prevention; reduce disparities in acute stroke care by providing underserved populations with better access to such care; strengthen collaboration between Emergency Medical Services (EMS) Agencies and hospitals to improve stroke systems of care; and increase public awareness of stroke treatment and prevention” (Kamigaki, Reynen, and Chaput, 2008).

Interestingly, one could argue that this mission statement, unchanged in the years since its development and adoption, could be described (e.g., by program stakeholders²) with the use of a number of adjectives, including, perhaps, “noble,” “ambitious,” “important,” “far-reaching,”

² Stakeholders are those individuals or groups who are affected by or can affect the achievement of an organization, as per Freeman (1984).

“forward-thinking”...or, say, even “double-barreled,” given its inclusion of both the pre-hospital and in-hospital settings for carrying out secondary prevention (more on that later).

In working to carry out this mission, the CSR Team, in conjunction with the AHA/ASA, began to target and recruit hospitals to participate in the registry. To be sure, hospital participation in the registry was (and remains) completely voluntary, as there has been no state legislation mandating the establishment and operation of the CSR. As such, the early recruitment strategies were necessarily crafted to make the case (to the hospitals) that joining the registry was a moral imperative. These early recruitment efforts were moderately successful, and the registry slowly expanded with the addition of more and more hospitals. Later, the CSR Team received some invaluable assistance, with respect to recruitment, from a number of LEMSAs (Local Emergency Medical Services Agencies), which were planning to develop and launch local stroke systems of care – to include certain local hospitals as designated stroke patient receiving centers. As the LEMSAs began to design their systems of care and designate their selected hospitals, a number of these LEMSAs either recommended or required that the selected hospitals (which were being included within these planned systems of care) join the CSR – as the registry data could then be assistive in the LEMSAs’ evaluation efforts. That is, from the registry, the LEMSAs could get treatment data on the patients whom their ambulance services transported to these designated hospitals. Thus, over the years 2008 through 2011, the CSR Team, working with its AHA/ASA and LEMSAs partners, was successful in building the state stroke registry to include more than 40 hospitals.

In early 2012, the CDC announced the availability of funding to support a third phase of state-health-department-based-stroke-registries (Centers for Disease Control and Prevention, 2013). Building on their experience with launching their “homegrown registry,” the CSR Team

submitted an application in response to this CDC announcement. The application was favorably reviewed by the CDC, and, on July 1, 2012, California became one of (then) eleven³ funded Coverdell states – the others (as of that date) being Arkansas, Georgia, Iowa, Massachusetts, Michigan, Minnesota, New York, North Carolina, Ohio, and Wisconsin. With this initial three-year federal grant in place – and as a component of the established CSR, the California Coverdell Program (CCP) officially began⁴. Given this history, the newly-launched CCP was staffed by those individuals who had developed and operated the CSR; moreover, for the newly-launched CCP (now the CSR/CCP), the original mission statement of the CSR was adopted, verbatim, (as stated above), as the CSR Team remained firmly committed to reducing the burden of stroke. In short, as of July 1, 2012, the CSR/CCP was established – with the CDC’s granting of the Coverdell funds – essentially to continue the work-to-date (at that time) of the CSR⁵.

Accordingly, since its inception, the CSR/CCP has sought not only to improve the quality of care provided to patients experiencing a stroke, from the onset of stroke symptoms through the discharge of the patient from the hospital, but also to engage in activities focused on stroke prevention.

2. The CSR/CCP: A Narrow Focus on Secondary Prevention

In moving through the CSR/CCP-specific historical events and into the present (especially when contemplating the CDC’s shift from funding academic medical centers to funding state health departments), an important theme emerged, and it bears repeating: It has become evident that the establishment and maintenance of the link between clinical medicine

³ For the 2012-2015 funding cycle, eleven states were funded; in the fourth cycle (i.e., 2015-2020), nine states are funded: California, Georgia, Massachusetts, Michigan, Minnesota, New York, Ohio, Washington, and Wisconsin.

⁴ Hereafter, California’s stroke registry is referred to as the CSR/CCP (i.e., if the timeframe is post-June 30, 2012).

⁵ Upon receiving the federal award, the State registry staff members invited the stroke coordinators at all of the then-CSR hospitals to “upgrade” their memberships to become CCP hospitals. About one quarter of them opted to do so. Additionally, the State registry staff members continued recruiting hospitals across California; some joined the registry as CSR-only hospitals, while others joined as CCP hospitals. Accordingly, the number of CCP hospitals is considerably less than the number of CSR hospitals.

and public health are vital to the success of population-based health promotion and disease prevention efforts. Two recent reports from the Institute of Medicine (2012a, 2012b) explore this integration. The earlier report, entitled, *Primary Care and Public Health: Exploring Integration to Improve Population Health*, called for a number of recommendations, including linking at all levels of government the staffing, funding, and information resources; creating common research and learning networks; developing and training the primary care and public health workforces; coordinating existing and new initiatives at the federal level; and preparing and implementing prudent strategies and investment plans. In like manner, the later report, entitled, *An Integrated Framework for Assessing the Value of Community-Based Prevention*, discussed at length how positive changes in health outcomes at the population level come about when prevention efforts consider and incorporate living and working conditions – to include psychosocial factors, employment status and occupational factors, socioeconomic status, the natural and built environments, public health services, and medical care services.

As is described above, any efforts to improve health at the population level must not occur within one solitary sector; instead, such efforts must be well-integrated across sectors (here, most notably clinical medicine and public health), and this is true for acute stroke, which exacts a heavy burden in terms of morbidity, mortality, and health care (Centers for Disease Control and Prevention, 2011). As is described in the Institute of Medicine’s report on integration (2012a), integration can occur along a continuum, from isolation to merger – via mutual awareness, cooperation, collaboration, and partnership. This report goes on to say that additional opportunities for integration have been opening up, as of late, with the new-found wealth of health information, together with the 2010 passage of the Patient Protection and Affordable Care Act and the increasingly greater potential for forming new partnerships.

The national trend (towards the integration of clinical medicine and public health) was mirrored within the PCNASR, as it called upon state health departments to partner with clinical medical providers in order to optimize the care of acute stroke. Within the context of the CSR/CCP, however, this call to action may be going unrealized, to some extent, as has been alluded to above. This national push towards integration may have become somewhat muted in California, given that the CSR/CCP, right now, appears to have focused its secondary prevention efforts almost entirely within the in-hospital setting, to the near exclusion of the pre-hospital setting. If this is, indeed, the case⁶ (and though it does seem to be apparent, it has not been well-documented), then this seemingly narrow focus would mean several things are occurring: First, the program's current state might well be out of line with its original guiding vision. Second, it also may mean that the program's current state does not align well with the national push towards greater integration of clinical medicine and public health. Finally, the seemingly narrow focus suggests that the CSR/CCP has experienced suboptimization, which, when stated in the contemporary vernacular, is as follows: Suboptimization is the state-of-being that occurs when a process or system fails to yield its best possible outcome. In this case, the narrowing of the secondary prevention efforts within the CSR/CCP (i.e., the suboptimization) has meant lost opportunities –in terms of the efforts that could have been undertaken, the partnerships that could have been formed, and the potential successes that could have been achieved. In short, a sub-par situation with the CSR/CCP may well mean that the noteworthy burden of stroke in California has not been more fully addressed.

This problem within the CSR/CCP not only merits investigation but also demands remediation – via the undertaking of some kind of a well-informed change process. Within the context of the CSR/CCP, working on such a problem could mean a couple of things: First, it

⁶ Data collected and analyzed in the first phase of this project speak to this supposition.

could mean that this important push towards integrating clinical medicine and public health, which may have become somewhat muted as the CSR/CCP has come to be in its present state, could be re-invigorated. Broadening the program's secondary prevention efforts to more fully include the pre-hospital setting would be consistent with the integration and partnerships constructs. Second, working on this problem and expanding the secondary prevention focus could mean that the CSR/CCP's overarching program goals would be more fully achieved, thereby creating better alignment with the original guiding vision and the CDC's intent for its state-level stroke programs. Ultimately, it could lead to a reduced burden of stroke. Thus, in the next several pages, there is discussion not only on what having a narrow focus means, in general, but also how this seems to have manifested itself within the CSR/CCP. Therein the "problem statement" that has given rise to this project is included. Following that presentation and the inclusion of the problem statement is a listing of the questions for which answers are sought within the present project.

B. A Discussion of the Problem

1. Not Achieving the Best Possible Outcome

As indicated above, suboptimization can be described as the state-of-being that occurs when a process or system fails to yield its best possible outcome. In more scholarly circles (e.g., in operations research or in managerial economics), suboptimization actually refers to the series of actions that together give rise to this "second-best" (at best) status (Hitch, 1953). In fact, this "less-than-ideal" state-of-being often comes about when efforts are made to optimize (the outputs of) the individual subsystems (i.e., rather than optimizing the larger system). When this occurs, the state of the larger system can be compromised. Heylighen and Campbell (1995)

present a great illustration of suboptimization, using individual trees and the forest in which these trees are found to represent, respectively, individual subsystems and the larger system which they comprise. The authors write this:

“Trees in a forest are normally competing for access to sunlight. If one tree grows a little bit taller than its neighbours it can capture part of their sunlight. This forces the other trees in turn to grow taller, in order not to be overshadowed. The net effect is that all trees tend to become taller and taller, yet still gather on average just the same amount of sunlight. The competition-induced height increase not only requires more resources (water, nutrients, sunlight, etc.) for its build-up and maintenance, but also makes the tree much more vulnerable to wind, earthquakes, lightning, wood-eating insects, etc. The result is that trees will lose overall fitness while trying to keep up their fitness relative to their competitors. Yet none of the trees can afford not to participate in the race for ever increased height: if one tree would remain at what would be its ideal height without competition, it would be completely overshadowed by its neighbours.”

In this illustration, the “achieved” state of the forest (i.e., the larger system) is less than optimal (particularly when considering the amount of resources that would be consumed to achieve this state – as well as the “risks” that may be faced by the forest [e.g., a loss of trees]), even though the “outcome” for each individual tree (i.e., for each subsystem) allows it to remain competitive, at least with respect to its ability to capture sunlight. As Heylighen and Campbell indicate, this phenomenon of suboptimization was first described by Machol (1965), who stated this principle: “suboptimization – that is, optimizing the outcome for each subsystem (e.g., individual or face-to-face group) – does not generally lead to an optimal outcome for the global system (e.g., organization). In short, focusing on processes that solely involve the component parts of a larger system can negatively impact that larger system.”

With suboptimization, there are interesting dynamics occurring between the subsystems which comprise the larger system and keep it from achieving “full optimization” – or “First Best,” the term most commonly used in economics, as per Trivedi (2002). As Heylighen and Campbell (1995) describe, “...a change in fitness for one subsystem will in general produce a

change in fitness for the other systems.” To be sure, if the subsystem-specific changes all occur in the same direction, then there is a synergetic or cooperative impact on the larger system. More often, however, the subsystem-specific changes occur in different directions, a happenstance which breeds competition between the subsystems for the limited resources found within the larger system. As Hitch (1953) suggests, however, potentially negative impacts on the larger system – as a result of optimizing the subsystems – can be minimized if the subsystem processes are designed to produce outputs that approximate the desired outputs of the larger system. Indeed, this is more easily said than done. According to Crow (1995), the usual scenario, instead, is the one in which leaders (i.e., within an organization) fail to recognize – or can do nothing about – the fact that there is a larger system (in place) and that the various components of that larger system must be appropriately orchestrated.

2. The CSR/CCP: Not Achieving the Best Possible Outcome

As indicated above, the current state of the CSR/CCP is largely unknown – though there is reason to believe that it may in fact be problematic. This is because the CSR/CCP’s secondary prevention activities, since the program’s inception, have been focused primarily within the in-hospital setting, nearly to the complete exclusion of the pre-hospital setting⁷. While much success has been achieved within the in-hospital setting, in having this differential secondary prevention focus, the program efforts have failed to yield comparable results within the pre-hospital setting – to the likely diminishment of the overall program effectiveness. Without prudent programmatic changes, undertaken to more broadly address the secondary prevention of acute stroke, the CSR/CCP likely will

⁷ Excluding the pre-hospital setting means that only a part of the care continuum is addressed; furthermore (and more practically), excluding the pre-hospital setting is not compliant with the grant which funds the CSR/CCP.

remain a suboptimized program. While what has been achieved to-date through the efforts of the CSR/CCP (i.e., particularly within the in-hospital quality improvement arena⁸) is consistent with what was intended via the writing and passage of the Stroke Treatment and Ongoing Prevention Act of 2001, it, nonetheless, seems as though there needs to be a change, such that the ongoing programmatic activities more broadly cover the secondary prevention spectrum – and more consistently align with the national call for improvements in quality and continuity of care. Determining how to approach this is the crux of this study.

C. The Research Questions

As has been discussed above, there appears to be a problem with the current state of the CSR/CCP – as the program’s secondary prevention efforts and resultant accomplishments, to date, have been observed nearly exclusively within the in-hospital setting. Being able to document this current, so-called problematic state is critical; hence, this project seeks first to determine what has been done thus far, with respect to secondary prevention – relative to what was expected to have been done during the same timeframe. In so doing, the “What?” question gets answered. Next, this project seeks to determine what factors have been impactful in determining the program’s current, sub-par operational state, and this aim gets at the “Why?” question. Finally, this project seeks to learn how the program’s current operations could change in order for the program to be working more broadly along the secondary prevention spectrum (in line with the federal grant requirements). Along these lines, answers to the “What next?” question begin to emerge. Accordingly, the research questions, pursued via this project which utilizes multiple methods and is focused on motivating action, are proffered, as follows:

⁸ An example is some work related to improving in-hospital time-to-treatment measures; the concern here is that there are no such examples in the pre-hospital setting.

1. Research Question 1

What work is being done in terms of secondary prevention within the California Stroke Registry/California Coverdell Program? How does that work compare to the program's original vision for secondary prevention?

2. Research Question 2

What factors have contributed to the current state of the program's secondary prevention efforts?⁹

- a. In what way(s) has the program's operational context – including its history, its structure, its culture, and its reach – impacted this current state?
- b. What are the operational challenges which have contributed to this current state?
 - i. (challenges) faced by the program?
 - ii. (challenges) faced by the partners?
- c. How have program stakeholders' beliefs influenced the program's current secondary prevention efforts?

3. Research Question 3

How might change occur within the program, such that the program's secondary prevention efforts can be broadened?

- a. How might the program utilize its present practices and/or resources in new ways?

⁹ The assumption is that the "current state" is undesirable; accordingly, the factors of interest are those which have negatively impacted the program. That stated, it is recognized that some of the factors that will be elucidated are those which have positively impacted the program.

- b. How might the program acquire and utilize new practices and/or resources – and what kinds of new practices and/or resources might these be?
- c. How might a change process be impacted by:
 - i. the program’s operational context?
 - ii. the program stakeholders’ change-related beliefs?

Seeking answers to these research questions should bring about clarity regarding the current and possible future operational states for the CSR/CCP, particularly in regard to the program’s secondary prevention efforts. Moreover, the conduct of this project should enable the knowledge base for public health practice to be enhanced, and with this enhancement come leadership implications. Thus, this first chapter concludes with a discussion of the key leadership implications and the study’s relevance.

D. Leadership Implications and Relevance

Within the context of this project, as well as from the eventual lessons learned via its conduct, various leadership implications are present. First, this project should demonstrate to the CSR/CCP Community that broadening the program’s secondary prevention efforts cannot be achieved via a simple technical change to the program’s current operational model; rather, in order to achieve a paradigm shift such as this one, an enhanced understanding of the various internal and external factors and forces that can exert influence on the program’s operations must be achieved and properly applied. Having had this (eventual) demonstration, a new, better-balanced and more broadly informed perspective from which the CSR/CCP Leadership can begin to consider ongoing and future programmatic efforts related to secondary prevention is

gained. This new perspective, then, is the starting point for the eventual action that, in the long run (i.e., beyond the scope of the present project), improves the CSR/CCP's status quo and reduces the burden of stroke, in terms of morbidity, mortality, and costs – and perhaps gives the CSR/CCP exemplar status with regard to collaborating with clinical medicine to improve population health.

Underlying this first implication (i.e., the informing of the new perspective) is the leadership process of systems thinking – which, as per Senge (1994), is a way of thinking about the forces and interrelationships that shape the behavior of systems. Systems thinking can shed light on how work is influenced and accomplished in the CSR/CCP (including within its various subsystems) – and how that work can impact the overall achievement of the program's secondary prevention scope. Moreover, as change is considered within the CSR/CCP, systems thinking can allow for a more comprehensive understanding of how that change might “behave.” To appreciate this “behavior,” it is vital to develop a perspective that includes not only the “up-close-and-personal” experience but also the “bigger picture” reality – an action that Heifetz and Linsky (2002) metaphorically describe as going (often) from the dance floor to the balcony and back. In other words, within the context of this project – particularly as the results begin to emerge, having an accurate comprehension of the CSR/CCP and how it “exists” – i.e., from the day-to-day operations to the ultimate long-range secondary prevention goals – is paramount to charting a course towards an improved operational state. Of course, the very important process of charting such a course requires not only the right foundational perspective but also prudent, strategic long-range planning and appropriate stakeholder input.

The second key leadership implication from the conduct of this study pertains to the critically-important, firm establishment of how the work of the CSR/CCP going forward – i.e., as

it will occur within the larger system, as has been described above – will happen. Being able to establish this scope of work means that the (“more-well-informed-to-be”) CSR/CCP Leadership will have, by this future time, given consideration to matters such as the following: how much more broadly defined the program’s secondary prevention efforts should be; how this new paradigm and the “larger” context in which these efforts are to be taking place will align; what partnerships and linkages should be enhanced or newly established in this effort to broaden the programmatic scope; what resources should be redirected or newly acquired in order to achieve these ends; how sustainable these efforts, partnerships, and resources will be; and what opportunities and threats might begin to emerge, as this (eventual) workload is described and initiated...and how these opportunities and threats should be managed.¹⁰ In short, this second key leadership implication is the first action step (i.e., as it follows the first implication – which was more of a “cerebral” one) in broadening the secondary prevention efforts of the CSR/CCP.

Central to this second study implication is the leadership skill of visioning. Upon having in mind (collectively within the CSR/CCP Community) an accurate comprehension of the program and how it “exists” in its current state, the ability to craft a clear vision for the program’s future – in which the secondary prevention focus has become more broad –is of utmost importance. What is more is that this leadership skill, prominently included in the work of notable authors like Senge (1994), Kotter (1995), Bryson (1995), and Kouzes and Posner (2007), can bring about a type of mental model (to use the language of Senge [1994]) that can guide the subsequent work potentially motivated by the findings of the present study. Indeed, that mental model of a better future state, wherein the CSR/CCP’s secondary prevention focus has been broadened, can inform the development of a kind of road map (to get “there” – i.e., to

¹⁰ For the scope of this project, the plan for CSR/CCP’s future work will not, in fact, be firmly established, though the stage will have been set for doing this. The implication is presented here to suggest that this project can begin a process which will (eventually) include this kind of planning process for the CSR/CCP.

get away from the unacceptable current state), which considers the types of matters presented above. Within the context of the CSR/CCP, then, given a shared understanding of the current situation – along with a motivated set of stakeholders, a clear vision of the future state of being (i.e., particularly as it concerns the programmatic scope of work) can emerge, as potential interventions are submitted and considered for implementation. In sum, the prudent application of any potential change(s) is predicated upon the ability to craft a well-informed and clear vision.

The third key leadership implication that likely should emerge from the present study concerns the translation of the vision, as described above, essentially into a type of ethos...or work ethic. This is a very critical piece. As the secondary prevention efforts are broadened, certain changes should occur – including those related to new and different partnerships, linkages, resources, and opportunities – and it is imperative that these changes do not occur independent of, or without consideration being given to, the guiding vision for the program. Decisions regarding what must be done (or not done) have to be fully consistent with the program's vision – or else the current, sub-par situation (which gave rise to the present project), by and large, will persist. For example, in broadening the secondary prevention efforts of the CSR/CCP, there may be a push towards the enabling of greater information sharing (to inform ongoing and future prevention efforts), particularly with new and different clinical partners. In this case, simply enabling the mechanics of information sharing across these partnerships is insufficient. Instead, it is essential to establish and effectively communicate the purpose for the new (or different) action(s), related to information sharing, and how that action-specific purpose fits within the larger vision for optimizing stroke care. Indeed, a pre-hospital clinical provider, working in partnership with the CSR/CCP, should never wonder why certain information is

being shared; rather, that provider should understand how carrying out that particular action is enabling the ultimate achievement of the overall guiding vision for the program.

For this third study implication, the associated leadership skill is being able to share the well-crafted vision. Again, while this goes beyond the present project, it is something that must be done, as per Kotter (1995), “frequently and powerfully.” Furthermore, according to Kotter (1995), a leader must imbed the vision within everything that she or he does. To be sure, as Quigley (2003) writes, building on the work of W. Edwards Deming, a leader must convey to all the vision for the system or the organization, such that each person can fully appreciate the scope and meaning of it – in a manner that then encourages optimized, collaborative performance. Along these lines, Kouzes and Posner (2007) speak to the act of sharing a vision, as well, in “The Leadership Challenge” framework. In this framework, sharing a vision – which is one of five key practices (the others being modeling the way; challenging the process; enabling others to act; and encouraging the heart) – entails being committed to enlisting others, which, according to the authors, requires one to “appeal to common ideals” and “animate the vision.” In the present context, the common ideals are believed to include having a broader prevention focus – and a better operational situation – and, in the process, generating greater public value, as per Moore (1995). Moreover, the animation of the vision, in this case, entails imparting some sense of inspiration among those with a stake in the program – for example, by motivating them to move beyond a problematic situation. In fact, with well-primed and sufficiently-motivated stakeholders, “crossing the divide” from the CSR/CCP’s current, unacceptable status quo to its future, more well-balanced optimized state does not seem insurmountable.

The next leadership implication, given the broadened perspective and the well-crafted and clearly-articulated vision it has informed, concerns implementation. As has been suggested,

in its history – even leading up to its present operations, the CSR/CCP has not fully implemented its vision, as has been described above. In short, implementation (of the vision) – something that has seems to have been problematic thus far – must not be problematic in the future. Within the present study, certain change ideas will be offered for consideration – and these change ideas will have no value whatsoever (i.e., in terms of guiding future programmatic actions) if appropriate steps and considerations for implementation (at that time) are not clearly articulated as well. For instance, if one of the proposed change ideas entails having existing but previously untapped AHA/ASA human resources assume responsibility for work that heretofore has been handled by CSR/CCP staff members – in order to redirect them in ways that promote a broader secondary prevention focus for the program, then a process to enable this kind of a change must be described. In this example, for both of the partners (i.e., the AHA/ASA and the CSR/CCP), new roles and responsibilities would need to be defined, and processes for training, managing, and appraising employees, as well as for assessing and using their work products, would need to be developed, launched, and evaluated. Certainly, these steps and considerations for implementing this kind of a change would need to be clearly communicated. This notion of communicating the action steps is consistent with the need to clearly and unambiguously share the guiding vision in the first place.

Implementation requires the leadership skill of empowering action. Employing this skill helps change to occur, such that the organization can thrive. Kotter (1995) suggests that the act of empowering entails removing obstacles, changing misaligned systems, and encouraging innovation. Certainly, this last action is particularly consistent with the fourth key practice from the earlier-mentioned work, “The Leadership Challenge” – that is, enabling others to act (Kouzes and Posner, 2007). To be sure, all of these frameworks parallel the lessons found in the seminal

work on employee motivation, written by Herzberg (1968). In his work, Herzberg describes seven principles of vertical job loading – including removing some controls while retaining accountability; increasing the accountability of individuals for their own work; giving an employee a complete natural unit of work (e.g., a division or area); providing job freedom; informing employees directly (rather than via their supervisors); introducing new and more challenging tasks; and enabling employees to develop expertise. These constructs are germane to the implementation of a (potential) future scope of work that emerges from the conduct of the present study, as the process used to clarify and address a seemingly sub-par status quo can only be successful if stakeholders are fully empowered and sufficiently inspired to act, in an environment that is conducive to a high level of performance. In short, leadership in the present study is of utmost importance, as the “value” of study results is fully dependent upon the contributions of some key stakeholders. Only with their contributions can the CSR/CCP more broadly carry out its secondary prevention efforts, more fully work towards achieving the program’s original vision, and more capably address the burden of acute stroke.

The final leadership implication that merits mention is that all of the effort that goes into the CSR/CCP – as follow-up to the actions initiated within the present project, must enable the creation of a culture of “learning.” As has been discussed, the program’s future efforts should allow it to align with the national scene, in terms of secondary prevention – to include key contributions from both clinical and population-based entities. Furthermore, because the national scene is not static, the program’s future operational state must be characterized by this culture of “learning,” or else the program will once again find itself in an unacceptable state. Were this to happen, another concerted and substantial effort to embark upon a change process would have to be initiated – and, given the expectations, as well as the resources, of the

CSR/CCP, this would be very unfortunate. In sum, then, this final implication of this change-focused project means that the CSR/CCP must not only initiate changes – with respect to its current operational state – but also establish a culture, to extend across the program partnerships, in which the idea of continuously learning and appropriately changing is expected, welcomed, and well in hand.

This notion of learning is akin to the team learning discipline about which Senge (1994) writes, in describing how learning organizations are created and function. In team learning, conversational and collective thinking skills are transformed, such that “...groups of people can reliably develop intelligence and ability greater than the sum of the individual members’ talents.” Within the context of the present project, being able to regularly foster this collective learning and enjoy a resultant level of performance that exceeds the sum of the individual contributions, is critical to being able to understand and possibly change the current state, in favor of working towards a better future state. Moreover, even as the steps to achieve a more well-balanced program become clear, it seems that the more fully established and ingrained into the culture the discipline of team learning is, the brighter the future looks.

The bright outlook extends beyond the CSR/CCP, as mentioned above. The lessons learned from the present project can extend beyond its scope, and therein lies the greatest application. In other words, while insights gained herein should initiate changes that will enhance the operations of the CSR/CCP and improve the treatment of acute stroke across the care continuum, what is more is that perspectives will have been enlightened; new partnerships will have been formed; innovative practices will have been identified; and critical alignments will have been achieved. These kinds of results will most certainly extend this project beyond the specific focus of the CSR/CCP. Stated simply, the results of this study should provide

valuable insights regarding approaching and managing change in a variety of other settings in which the status quo should not persist.

E. Chapter Summary

In this first chapter, there was discussion provided on the history of the CSR/CCP, taking the reader into the present day, wherein there appears to be a much too narrow focus in regard to secondary prevention. That is, the CSR/CCP has worked primarily within the in-hospital setting, while ostensibly neglecting the pre-hospital setting. This narrow focus – which leaves the program in a sub-par state – not only merits investigation but also demands remediation. After discussing suboptimization, in general terms, as well as how it seems to characterize the present state of the CSR/CCP's secondary prevention efforts, in specific terms, the study questions that require answers were enumerated. In short, this study aims to determine what the current state is, relative to what it ought to have been (by now); what factors could have contributed to this current state; and what changes ought to be made in order to broaden the program's secondary prevention efforts – thereby creating an improved, better-balanced, and more fully optimized operational state that not only is more in line with the program's original vision, but also is consistent with the national conversation around having better integration of public health and clinical medicine, as outlined within healthcare reform. This first chapter closed with a discussion of some of the key leadership implications of the present study, which has the potential to enrich not only the future work, reach, and impact of the CSR/CCP but also the current knowledge base for the professional practice of public health.

II. Chapter 2: Literature Review and Conceptual Framework

In this second chapter, two narratives are included in succession: the literature review and the conceptual framework. First, the literature review is used to establish the theoretical framework within which answers to the above-listed research questions are sought, found, and then discussed. This theoretical framework begins with a preamble on change. After all, as is indicated above, the crux of this project is to investigate how ongoing programmatic activities within the California Stroke Registry/California Coverdell Program (CSR/CCP) can be changed to more broadly cover the secondary prevention spectrum; accordingly, an opening discussion on change, informed by the academic literature, is fitting.

With the theory of change having set the stage for this project, the discussion next turns to the main constructs captured within the research questions. First, operational context is examined as a contributor to the current state of the CSR/CCP, building primarily on some work by Weiner (2009) and Bolman and Deal (2008). Specifically, the constructs of organizational structure and culture are addressed, with some supporting commentary about the CSR/CCP's history folded into the discussion. Next, the narrative turns to a discussion of operational challenges. In this section, vis-à-vis the work of Trivedi (2002), a number of challenges are presented, in general terms, along with some remarks as to what appears to be occurring within the CSR/CCP. Further, the impact (on the status quo) of stakeholder beliefs regarding change is discussed, in terms of the program's need and ability to change, primarily as per Holt (2007) and Armenakis (2007). Finally, the literature review concludes with some discourse as to what organizational behaviors, if properly instituted and managed, could be effective in broadening the programmatic efforts across the secondary prevention spectrum. The practice of knowledge management and the development and use of teams and communities of practice are two such

ideas that are discussed. Some supplemental remarks regarding how the notion of action research is relevant to the present study are included in this section, as well.

Following the literature review, the conceptual framework is presented, graphically and with accompanying narrative, in order to convey the system of concepts, assumptions, expectations, beliefs, and theories on which the present research is built, to use the language of Maxwell (2013). In other words, the conceptual framework provides a literal picture of the ostensibly key concepts within the present study and the theorized relationships between them. Lastly, it merits mention that although the conceptual framework draws upon existing work, as can be found both in the literature and through experience, it is a new creation within this study.

A. Literature Review

As indicated above, the literature review which follows serves to provide a frame within which the findings of the present study can be considered and discussed. Put another way, the ideas presented within the following sections of the literature review comprise the backdrop against which the results of the present study are assessed – and, given that this project is concerned with the theory of change, it is with this particular construct that the review begins.

1. The Preamble on Change

This first section of the literature review contributes to the theoretical framework by discussing change – again, as a sort of preamble to the project’s main constructs, as captured within the above-listed research questions and depicted graphically within the project’s conceptual framework presented below. After all, if the new understanding of the current state of the CSR/CCP suggests that it is, indeed, problematic, then the next area of interest should

concern the construct of change...and how to achieve it. The initiation of a bona fide change process is predicated upon a positive finding from an assessment of the organization's need for and readiness for change (Weiner, Amick, and Lee; 2008; Weiner, 2009). In other words, it is prudent that before a change process is to commence, those involved in that very process must see a need for and possess a readiness for change. This notion, however, was not well articulated until after a number of change models were introduced and discussed. In the narrative that follows, key constructs and models within change management are discussed, starting from the mid-20th century and continuing into the present.

Using simple terms, Lorenzi and Riley (2000) state that change management is “the process by which an organization gets to its future state, its vision.” Furthermore, they suggest that, contrary to traditional planning processes that delineate what steps ought to be taken to bring about change, change management, instead, seeks to facilitate how those particular steps are taken. Given that as many as 70% of programs designed to usher in a new paradigm fail to achieve their intended outcomes (Balogun and Hope Haily, 2004), it makes sense that careful consideration should be given to managing change. Such management has been discussed in various ways within the academic literature; what follows is a chronological presentation of some of the more well-known scholarly works. Early scholarship from Lewin, writing during the mid-20th century, described a process of unfreezing, changing (or transitioning, as it has been called more recently), and refreezing (as cited in Holt, Armenakis, Feild, Harris, 2007; Weiner, Amick, Lee, 2008; Watkins, Leigh, 2010; Blackman, O’Flynn, Ugyel, 2013; Stevens, 2013). Lewin’s three-part process suggests that existing mindsets first must be “unfrozen,” in order to allow for change. Along with achieving this new “unfrozen” state of consciousness – through the disconfirming of conceptions of the current situation and the stimulating of dissatisfaction

with the status quo, it is critical that a motivation for change be created. Such motivation can come about via the creation of an appealing vision for the future and the fostering of a sense of confidence amongst all of the stakeholders to realize that very vision (Armenakis, Harris, Mossholder, 1993; Kotter, 1996).

Over the course of the next four decades, a number of new change models were introduced, building on the foundational work of Lewin. In fact, Wiebe and Gordon-Biddle (2002) suggest that nearly all of the change models introduced since the mid-20th century have been developed along Lewin's three-part model. One such model, developed by Beckhard and Harris (1977), is a three-part model, comprised of present, transition, and future states¹¹. While this model appears similar to that of Lewin, this latter model further stressed that the middle phase (i.e., transition) is quite distinct from the other two phases; moreover, this model advises that the change leader should expect things to be rather uncertain and fluid – during this middle phase – en route to the eventual future state. Accordingly, Beckhard and Harris stress that the change leader must be an individual capable of adeptly handling this critical middle phase.

Next, Beer (1980) discussed three ingredients of change that he felt must be developed by the change leaders if they expect to be successful in creating change that lasts: Dissatisfaction (D) with the status quo; a Model (M) of the hoped-for future state; and a Process (P) to create D and M, collectively – via the efforts of both the senior management team and the employees. Beer operationalized these three ingredients in suggesting that the amount of change is directly proportional to D, M, and P; as well, Beer suggested that it (i.e., the amount of change) is inversely related to the cost of change – and must be greater than that cost of change.

¹¹ While the Beckhard and Harris model considers three stages (i.e., present, transition, and future), employing it includes taking the following steps: conducting an organizational analysis; asking why change is necessary; conducting a gap analysis; carrying out action planning and transition management; and measuring the change. It is noteworthy that a decade later, Beckhard and Harris departed somewhat from their earlier work, suggesting that "...change management is not a neat, sequential process" (as cited in Leybourne, 2006).

The next innovation came from Kanter (1983), who described another multi-part model that included encouraged departures from tradition, a galvanizing event to signal change, strategic decision-making, empowered individual prime movers (i.e., champions for change), and action vehicles (i.e., mechanisms which enable changes to take root and grow). In Kanter's model, dynamic interrelationships occur across these various "building blocks" for productively managing change (Saffold, 2005). Put another way, there is a recognition that change ought to occur – motivated, in part, by some focusing event (again, to use the language of Kingdon, 1995), along with key plans, people, and procedures, necessary to craft and then implement that needed change.

Additional change models were introduced a few years later by Bridges (1986) and Tichy and Devanna (1986). Bridges, whose model takes into consideration the impact of organizational change on the individuals involved in that change, describes this three-part process – again, from the perspective of the individuals within the organization: (1) letting go of one's old situation and identities; (2) entering a "neutral zone" involving ambiguity and transition, while in search of a new framework and identity for the new, pending environment; and (3) arriving at a "new beginning," once the first two stages are acknowledged, accepted, and resolved. Similarly, Tichy and Devanna developed a model that has an individual-level focus. In this case, however, the focus is on the change leader. Using a theatrical metaphor (i.e., by referring to Act I, Act II, and Act III), Tichy and Devanna describe three acts being directed by the change leader: recognizing the need for revitalization – in which a felt need for change is created and political pressure and cultural resistance are overcome; creating a new vision – in which the problem is diagnosed, the motivation is created, and the collective commitment is mobilized; and institutionalizing the change.

In this same decade, other scholars sought to update the early work of Lewin in order to include some more contemporary constructs. Schein (1987) discussed various kinds of pressures often used to create motivation and a readiness for change, vis-à-vis Lewin's stage of unfreezing. Specifically, Schein suggested pressure could be applied through several modalities, including the disconfirmation of widely-held beliefs, the introduction of anxiety or guilt, and the creation of psychological safety (as cited in Sharma, 2007). While greater detail is noted in this first step for change (i.e., relative to the work of Lewin), Schein's second and third steps for change are akin to Lewin's. Additionally, Beckhard and Harris (1987), in updating their work from ten years earlier, suggested that a transition management team – comprised of wise, highly-respected, well-equipped leaders – should be deployed in order to navigate the organization from its present state into its future state, given that the process is not necessarily neat, nor sequential. Moreover, this team, as per Beckhard and Harris, is strongly encouraged to carry out activity planning as part of its transition-related work. Certainly, these two models from the late-1980's added some more contemporary details to the early change models.

In the mid-1990's, John P. Kotter introduced an eight step model related to change, which, perhaps not surprisingly, follows the general structure described decades earlier by Lewin. Kotter's Eight Step Model is as follows – with the first three steps corresponding with unfreezing; the fourth and fifth steps matching up with movement or transformation; and the final three steps representing refreezing: (1) establish a sense of urgency; (2) form the guiding coalition; (3) create a vision and strategy; (4) communicate the change vision; (5) empower broad-based action; (6) plan for and generate short-term wins; (7) consolidate improvements and produce more change; and (8) institutionalize new approaches (Kotter, 1995). In discussing his model for change (which is part process and part framework, as per Anderson and Anderson

[2010]), Kotter also cautions against committing one or more of eight critical errors, at least one of which, he claims, is often committed by “very capable people.” These eight critical errors, which follow directly from the eight steps above, are the following: (1) not establishing a great enough sense of urgency; (2) not creating a powerful enough guiding coalition; (3) lacking a vision; (4) under-communicating the vision by a factor of ten; (5) not removing obstacles to the new vision; (6) not systematically planning for and creating short-term wins; (7) declaring victory too soon; and (8) not anchoring changes in the organizational culture. The key message, according to Kotter, is that the likelihood of a transformation effort failing is markedly decreased when a realistic change process is envisioned and diligently brought to completion, within its own, natural timeframe. While this lesson might easily be said, one criticism of Kotter’s model suggests that it may not so easily be done, given that little direction is provided in terms of empowering broad-based action and/or generating short-term wins (Biech, 2007). Some more recent models that have attempted to provide more practical steps include Ulrich’s Seven-Step Model (Ulrich, 1998) and Evans’ and Schaefer’s Ten Tasks (2001), both of which emphasize the notion of continuous improvement. Even so, Kotter’s model remains the cornerstone work related to change.

Around this time, other nuances and innovations were introduced into the change management body of knowledge; however, the basic ideas from Lewin continued to stand firm. Kanter, Stein, and Jick (1992), in seeking to provide some greater context to the change process, studied change within some leading business firms and subsequently described the internal and external forces that set in motion the change process; the various kinds of changes that respond to these different forces; and the primary tasks that are involved in managing the changes that are taking place. Around this same time, in addressing the organization’s ability to carry out change,

Nadler and Tushman (1997) developed the congruence model, which essentially is a framework (as opposed to a process) with the following basic elements: Inputs (from both internal and external sources); Strategy (regarding decisions that must be made towards achieving a vision); Outputs (or products and/or services used to fulfill objectives); and Process (by which people convert Inputs to Outputs). This fourth element, the Process, is further comprised of certain components (i.e., the work, the people, the formal organizational constructs, and the informal organizational constructs), and the better these elements “fit” with each other – or the greater the congruence is – the better the organization performs. Orgland (1997) also touches on performance. In discussing change, he suggests that when change is viewed as a continuous or circular process – as opposed to a linear one, then those involved in that change are more proactive and experimental, as well as less risk averse and narrow-minded. As a result, the change process includes problem-solving, knowledge transfer, and enduring outcomes.

Lastly, moving into the current millennium, several recent works merit mention. First, Lueke (2003) published his Seven Steps for managing emergent change. While two of his steps match those of Kotter, as discussed above – including developing a shared vision and institutionalizing successes, Lueke’s model introduces some innovations, including focusing on the results, not on the activities, and starting the change process at the periphery (of the organization) so it can spread to other units, without a push from the top. Lueke believes that these particular innovations, related to perspective, should increase the likelihood of carrying out a successful change process. Next, the latter work of Bridges (2003), whose earlier work was discussed above, further adds to the continuing change management discussion by emphasizing the need to appropriately manage during the transitional phase. Bridges discusses some techniques that can be used in navigating this transitional phase and dealing with endings (in

contrast to Kotter's focus on the pending changes), including compensating for losses; sending a signal (that an ending has, in fact, occurred...and that a change is imminent); and reminding those involved in the ongoing process that change is inevitable. In short, Bridges suggests that the management of the transitions – not the changes – will determine a project's level of success or failure. Like Lueke, Bridges' recent contribution to the understanding of change management emphasizes the psychology more than the situation. Finally, Durlak and DuPre (2008), in systematically reviewing prevention programs geared towards youth and adolescents, described twenty-three critical contextual factors related to the successful implementation of change. These factors span the following five broader constructs: community or societal factors; practitioner characteristics; program characteristics; factors related to the hosting organization; and implementation-related factors. While the importance of these contextual factors is known, how they exert their influences – either as independent factors or in concert with one or more of the other factors – has yet to be clarified. Even so, in terms of understanding change, this recent work suggests that the change agent be cognizant of the larger context in which changes are desired, and this, too, speaks to perspective.

In this first section of the literature review, a preamble on change was presented, moving from the mid-20th century into the present and highlighting some of the key constructs. The works from many scholars were discussed, though, on the whole, the basic premise is that change management consists of recognizing a need for change, determining what that change should be, and implementing that very change. Certainly, important details, considerations, recommendations, innovations, and perspectives were introduced across the decades, but the bottom line remains that change is a process that must be managed appropriately or else there is little hope for ushering in a better, future state of being. Within the context of this project, which

is focused on learning how to achieve such a state, it has been important to lay down this firm theoretical foundation prior to looking more closely at how the CSR/CCP operates in practice (i.e., the focus of the first research question posed in the previous chapter) and what types of influences impact its practice (i.e., the focus of the second research question). To elaborate, the importance of laying down this firm theoretical foundation does two key things for the present project: First, it puts the “why?” component into clear focus. Having this clearly identified from the start of the project serves as a reminder that this project is meant to go beyond the collection and analysis of data. This project is meant to set the stage for real change within the CSR/CCP. Second, laying down this foundation frames the project’s research questions. Put differently, the answers to the above three research questions should be considered within the context of change (and not something else – say, maintenance, for example), since the interest here is learning how to move beyond what appears to be a sub-par status quo.

2. Operational Context

This second section of the literature review contributes to the theoretical framework by discussing how the greater context in which an organization is operating might contribute to its present state of affairs. In presenting this discussion, supporting commentary relevant to the CSR/CCP’s greater context is offered, with the understanding that the CSR/CCP’s present state is one which likely ought to change – hence, the above preamble on change. While this section of the literature review draws primarily on work by Weiner (2009), Weiner, Lewis, and Linnan (2009), and Bolman and Deal (2008), a number of other studies are referenced, as well, in order to present a more complete picture of how an operational context can be influential in determining a program’s current state.

Culture; Policies and Procedures; Experiences; Resources; and Structure

To inform the many promising approaches proposed for improving the delivery of healthcare – which is germane, of course, to the project at hand, Weiner developed a model of organizational readiness for change, which, he states, “...refers to organizational members’ shared resolve to implement a change (change commitment) and shared belief in their collective capability to do so (change efficacy)” (2009). In this model¹² – which has an intermediate outcome (i.e., change readiness) that suggests a current state of being – Weiner has chosen to include *certain contextual factors, including organizational culture, policies and procedures, past experiences, organizational resources, and organizational structure*. In other words, Weiner’s model clearly indicates that certain contextual constructs are impactful upon an organization’s present status – in this case, the time at which (and “space” in which) a change process is (to be) initiated. In fact, he states that content (i.e., the “what”) and context (i.e., what is happening all around the “what”) are of equal importance.

Furthermore, Weiner’s research describes how the influences of these contextual factors may be exerted – that is, through the more proximal causes; this indirect method of influence is in contrast to the what has been described elsewhere (Jones, Jimmieson, and Griffiths, 2005; Ingersoll, Kirsch, Merk, and Lightfoot, 2000). As an example of this indirect method of influence, Weiner suggests that a given contextual factor, like organizational culture, might amplify or dampen a more proximal condition, such as change valence (i.e., the degree to which organizational actors value a proposed change), depending upon whether the anticipated change aligns or conflicts with the culture of the organization. This is an important point, one that speaks to the relationship between the structural and psychological attributes of an organization or program. As Weiner writes, “...resources and other structural attributes of organizations do

¹² Note that this model is presented in Appendix I (as sub-C) and further discussed in Section 4.

not enter directly into the definition of readiness. Instead, they represent an important class of performance determinants that organizational members consider in formulating change efficacy judgments.” Put in more generic terms, contextual (structural) factors may not directly impact a particular (psychological) state of being; rather, they (i.e., the contextual factors) might exert influence on other co-incident and more proximal associated factors.

As it relates to the present project, then, the application of Weiner’s model may well shed some light on how the CSR/CCP’s operational context (including structural factors such as the program’s history, culture, and reach) might bear on other associated factors, such as the operational constraints or stakeholders’ beliefs, in order to impact the present state of the program, particularly with regard to its current narrowly-focused secondary prevention efforts. Within the CSR/CCP, this actually occurs: As has been described above, the CSR/CCP resides within the CDPH, a large governmental organization with a culture of bureaucracy – and it is this hierarchical, rule-bound culture (as discussed in Olsen, 2008) which has led to some of the operational challenges (such as bounded rationality) discussed in the next section. This is consistent with the work of Alvesson (2002) who suggests that “...culture is seen as mediated in actions, language use and arrangements primarily affecting beliefs and understandings, thus having mainly consequences on attitudes and orientations...” (p. 67).

Policies and Practices; Climate; Innovation-Values Fit

Weiner, working in collaboration with Lewis and Linnan (2009), describes how the larger operational context can impact the success of program implementation; this is certainly informative for the current project, which aims to understand how to change its current prevention efforts. In their study, the authors discuss various organizational determinants of effective implementation of comprehensive worksite health promotion programs – after having

observed the implementation of complex innovations in various sectors, including education, manufacturing, and healthcare. They stress that carrying out such a process, which essentially is the transition from decision to action, is not at all straightforward, as such an undertaking often involves collective behavior change by many employees, all of whom are impacted by what Sorenson et al. (2003) refer to as social contextual factors.¹³ As Weiner, Lewis, and Linnan (2009) describe in their study, influences are exerted (on implementation) (1) by *policies and practices* (i.e., "...plans, practices, structure, and strategies...") – which, of course, are impacted by change readiness, as discussed above; (2) by *climate* (i.e., "...a gestalt based upon employees' shared information about, discussions of and experiences with the organization's implementation policies and practices..."); and (3) by *innovation-values fit* (i.e., "...the extent to which targeted employees perceive that innovation use will foster fulfillment of their values..."). In other words, these relationships suggest that certain structural and psychological contextual factors can impact the degree to which a program will achieve its full implementation. Of course, the supposition here is that these factors can exert influence (i.e., too little positive...too much negative...or both), such that the program will fall short of its hoped-for operational state. Again, this appears to be the present situation for the CSR/CCP. Finally, it must be noted that in this particular study, the authors chose to focus on a parsimonious set of organizational constructs; however, they also acknowledge that the addition of other broader social, cultural, and economic factors likely would make the framework more robust and accurate.

Upon consideration of how one could look beyond this parsimonious set of constructs (related to the proverbial "success") – as described in the model from Weiner, Lewis, and Linnan

¹³ Sorenson's conceptual framework (2003), as described within the cancer prevention literature, delineates several types of social contextual factors, including individual factors, interpersonal factors, organizational factors, and neighborhood/community factors – all of which can work, singularly or interactively, to impair or enhance the effectiveness of the intervention of interest.

(2009) – in order to get a better sense of a larger, more realistic operational context, one only need turn to the classic work of Bolman and Deal (2008).¹⁴ In their work with organizations and leadership, the authors identify four “frames,” useful in deepening one’s appreciation for and understanding of organizations and how well they succeed in achieving their visions.

Interestingly, though, in discussing these four “frames,” Bolman and Deal deliberately mix metaphors, choosing to use the words “...windows, maps, tools, lenses, orientations, filters, prisms, and perspectives...” – because all of these terms contribute to one’s understanding of what is really happening. And developing a sense of what is really happening enables one to have “usable knowledge,” to use the words of Bolman and Deal; for a project like the present one, having usable knowledge is critical to being able to eventually achieve a better future state.

Structural, Human Resource, Political, and Symbolic Frames

The four “frames” described by Bolman and Deal (2008) are these: *Structural, Human Resource, Political, and Symbolic*. These frames, which allow (1) for the filtering of “...essence from trivia...” (p. 21), (2) for navigation, (3) for problem-solving, and (4) for getting things done, have their own images of reality, as follows:

Structural Frame

First, for the Structural frame, the metaphor is a factory or machine; this is because this frame is essentially “...a blueprint for officially sanctioned expectations and exchanges among internal players (executives, managers, employees) and external constituents (such as customers and clients).” (p. 50). In other words, much like a machine is built to manufacture a given product, the organizational structure is designed to yield certain results. Moreover, structure certainly will influence outcomes. This is a particularly salient point (related to organizational

¹⁴ The modifier “classic” is used here, even though the date cited is 2008; however, the 2008 date refers to the fourth edition of Bolman’s and Deal’s text, “Reframing Organizations Artistry, Choice, and Leadership,” the first edition of which was published in 1984, as “Modern Approaches to Understanding and Managing Organizations.”

performance) when differentiation (i.e., allocating work) and integration (i.e., coordinating diverse efforts) are the norm. Accordingly, within this first frame, rules, roles, goals, policies, technology, and the environment all are central tenets.

Human Resource Frame

Second, for the Human Resource frame, the metaphor is the family – thereby suggesting that an organization is made up of a group of individuals, each with her or his own needs, feelings, prejudices, talents, and shortcomings. This frame also suggests that organizations need people (to carry out the work) and people need organizations (for the various internal and external rewards they offer), but their respective needs may become misaligned. To the degree that there is misalignment, there is suffering – on one or both parts. As Bolman and Deal describe, “...individuals may feel neglected or oppressed, and organizations sputter because individuals withdraw their efforts or even work against organizational purposes” (p. 137). Perhaps not surprisingly, for this second frame, needs, skills, and relationships are the core concepts.

Political Frame

Third, for the Political frame, the metaphor is the jungle. This particular image conjures up the ideas of self-interest and of fighting for survival, all the while dealing with a harsh environment – one in which power reigns supreme. As Bolman and Deal (2008) write, having this power –or lacking it – is most critical during times of scarce resources. In reviewing the work of others, Bolman and Deal present the following list of sources for power: position power, control of rewards, coercive power, information and expertise, reputation, personal power, alliances and networks, access and control of agendas, and framing (i.e., having control of meaning and symbols). Furthermore, as the authors discuss, any number of these power sources

can be present as an organization exists as a political arena or acts as a political agent. To be sure, within this political frame, there is a milieu in which there is conflict, competition, jockeying for power, and volatile, political, power-based decision-making; these are the central themes. And survival here, within this frame, requires political savvy and effective advocacy.

Symbolic Frame

The fourth frame is the Symbolic frame, and the images Bolman and Deal (2008) use to depict it are these: a carnival, a temple, and a theater. The authors use this frame and these images to emphasize how humans make sense of what is going on all around them – by assigning meaning and value to those things that are a part of the larger experience. In so doing, something can take on meaning that can extend beyond its obvious functional use. Within an organization, this can mean some seemingly inconsequential happenstance can actually mean a great deal more than is obvious on the face of it. Additionally, for those who share an understanding of the symbolic meanings – along with the organizational myths, rituals, and stories – there is a bond that is formed. This bonding can create a cultural context in which constructs like organizational leadership, practices, and performance are established, promoted, and evaluated. As Bolman and Deal (2008) write, this cultural context, then, “...anchors an organization’s identity and sense of self” (p. 278).

The four frames of Bolman and Deal (2008) are helpful in conveying the idea that the operational context in which a program or an organization is working to carry out its vision is one which spans a broad range of constructs (from the roles people have, the rules they follow, and the technology they use...to the skills they possess, the needs they have, and the relationships they form...to the competition they face, the power they exert, and the politics they bear...to the stories they tell, the rituals they create, and the culture they share) – and exercises a

great deal of influence. This influence may be positive or negative – perhaps even preventing employees from “...fully contributing to collective learning and organizational development” (Kira and Frieling, 2007). Consequently, taking into consideration this operational context – to include historical, structural, and cultural influences, both controlled and uncontrolled (Uhl-Bien and Marion, 2009) – is invaluable to understanding a program’s current state of being; moreover, going through this process should facilitate the eventual change process, as well, in order for there to be movement towards a better future state. Within the present project...as well, within the CSR/CCP, that (i.e., understanding how and why something is the way that it is – in order to improve upon it) is the aim.

This second section of the literature review was a discussion of how an organization’s operational context might contribute to its present operational state. This contribution may not be a straightforward, linear one. In fact, the dynamic is often fluid and can occur in either or both directions. Perhaps it may occur first via the so-called “strong-culture” thesis (i.e., a culture of shared values, beliefs, and norms will yield positive results – or the opposite is true and the results are negative). Alternatively, the relationship between the context and the performance may be more complex. The level of performance may lead to the creation of a certain type of culture (e.g., a high level of performance may lead to a strong culture...or the opposite could occur), and that culture is then influential on how things continue. In fact, this dynamic is likely best described as situational or adaptive. In any case, the bottom line is that understanding the operational context is paramount to understanding what exists now and could exist in the future (Alvesson, 2002). In elaborating on this point, a number of scholarly works were discussed. First, work by Weiner (2009) highlighted these influential factors; *organizational culture, policies and procedures, past experiences, organizational resources, and organizational*

structure. Next, research by Weiner, Lewis, and Linnan (2009) included a model for program implementation that included the *impacts from policies and practices, climate, and innovation-values fit*. Finally, scholarship from Bolman and Deal (2008) described these four “frames,” useful in learning about operational context: *Structural, Human Resource, Political, and Symbolic*. In sum, a multitude of factors can emerge and exert influence on an organization’s operations – thereby not only contributing to its current state but also influencing its future possibilities.

3. Operational Challenges

In Theory

This third section of the literature review presents a number of operational challenges that can impact an organization’s ability to succeed – and these are presented, for the most part, in the negative, which is appropriate, given the earlier suppositions about the CSR/CCP and the preamble on change; these challenges tend to be more “intrinsic” (i.e., to the program) than “extrinsic” (as were the contextual factors discussed above). Trivedi (2002) discusses five of these challenges. Each is presented in succession.

Disjointed Incrementalism Challenge

The first operational challenge that can impact operations is “*disjointed incrementalism*,” a concept discussed by Baybrooke and Lindblom (1963) and used by Van Gigch (1978) in his work related to decision-making. Disjointed incrementalism is a practice whereby numerous, small, often externally-compelled changes are made over time, as needed – a process which is largely antithetical to the process of developing and implementing a comprehensive long-term strategic plan. To be sure, this incremental approach often occurs with information asymmetry

or a need to “fire fight” or an inability to embark upon a larger, more resource-intensive planning process. In short, a sub-par situation can materialize when the modus operandi is to simply make small adjustments, as needed (i.e., in how a given workload is handled), with no real consideration being given to any long-range strategic plan.

Subsystem Application Challenge

Another reason for failing to achieve that “First Best” global outcome, according to Trivedi (2002), is *the application of a “Philosophy of Improvement” within a single subsystem*. The problem is that if improvements are made in just one subsystem, then there is going to be some level of neglect of the potential interactions with – and effects of – the other subsystems. The result of this isolated improvement is a suboptimal state-of-being for the larger system of which the newly-improved subsystem is a part. Crow (1995) concurs. In discussing works by W. Edwards Deming and Peter Senge, he describes how a lack of positive interdependence (which is what this “selected improvement” situation is) can lead to breakdowns within the larger system. In these kinds of situations, organizations fail to recognize how having a special emphasis in one sector causes there to be neglect of the other sectors – to the detriment of the overall functioning of the organization.

Selection Process Challenge

Next, Trivedi (2002) discusses how *the process of selecting performance-related objectives* (within an organization) can pose some operational challenges, thereby leading to a suboptimal organizational state. If, by chance or design, the selected objectives pertain only to a particular subsystem, without any regard to the total system, then there is a high likelihood of success in one sector with concomitant failure in another sector. According to Trivedi, “The linkages, externalities, and dis-economies of interrelated subsystems are not taken into

consideration. This leads to suboptimization of the system.” It is for this reason that Hitch (1953) counsels a leader to study and bear in mind “...the characteristics of the optimization at the appropriate higher level, and the relation to it of his optimizing criteria.” Surely, measuring results in just one program area (i.e., that one area for which the performance-related objectives have been established) can result in unbalanced efforts across the spectrum of program areas.

Limitations Challenge

Further, a sub-par status quo may be realized as a result of *certain limitations and constraints* that individuals and/or organizations may have or experience (Trivedi, 2002). This concept has been termed bounded rationality (Simon, 1991), and it can greatly impact one’s (i.e., an individual’s or an organization’s) ability and/or motivation to identify and/or achieve the ideal situation for the larger system. Indeed, with bounded rationality, there are going to be certain variables, parameters, and assumptions that cannot be well-defined and/or controlled. As these limitations and constraints grow in magnitude, the likelihood of achieving a suboptimal state escalates. According to Wall (1993), building on Simon’s work, bounded rationality, as a cause of suboptimization, extends beyond the actual resource constraints (e.g., constraints related to information, finances, and workforce). As Wall suggests, bounded rationality can alter the decision-making process, independent of these resources, as it can compel the decision-makers to simply construct new paradigms from old ones or just settle for the first available option (for change) that is deemed “good-enough,” rather than continue searching for a more optimal one. Without doubt, bounded rationality is a critical factor leading to a sub-par state.

Criteria Problem Challenge

Finally, Trivedi (2002) describes the operational challenge known as *the criteria problem*. Essentially, this occurs as the criteria, which are to be used to develop and then

evaluate simultaneously all potential alternatives up for consideration (i.e., for initiating change), are such that the process is hampered, and the end result is less than optimal. For example, if the criteria employed in a process are geared only to the short-run and not the long-run as well, then every considered alternative is going to fall short in some way. Another example of a criterion problem impacting an eventual outcome is having a lack of a feasibility construct in the evaluation process. In this case, it would be possible to find an optimal solution or alternative that is simply not feasible. Adopting and attempting to implement such a solution or alternative guarantees failure. Indeed, the end result in this example would be a suboptimized system.

In Practice (Potentially)

Transitioning from the theoretical to the practical, the purported sub-par status quo of the CSR/CCP (i.e., with its narrow secondary prevention focus) can be considered – within the context of these somewhat abstract constructs. The same considerations are made again (later), using the actual results yielded within the present study. That stated, the alleged problem (of the program’s all-too-narrow focus) likely has a multi-factorial model of causation, to paraphrase Morgan (1991). Moreover, it might be expected that the various causative factors (of the CSR/CCP’s apparent problem) align well with those identified by Trivedi (2002).

In the narrative that follows, three potential causative factors are suggested. The first potential factor which merits discussion, then, is the practice of incrementalism. As discussed at length in Chapter 1, the history of the CSR/CCP is characterized, for the most part, by a series of program changes and enhancements, all building on the original CSR “platform,” depending on how various internal and external forces acted upon the (then) ongoing business operations. For example, when a given LEMSA began to collaborate with the CSR/CCP staff members, with regard, say, to hospital recruitment, decisions would be made to accommodate the needs of that

LEMSA. In other words, in order to enjoy the benefits of having this particular LEMSA on board as a partner, the developing registry had to be flexible (in order to make adjustments, as the needs would arise) – and having that flexibility precluded following a prescribed formalized plan. Thus, while the vision to create a stroke registry in order to inform clinical decision-making in the pre-hospital and in-hospital settings was clear, for the most part, the process for getting to that point unfolded incrementally as was needed.

The second possibly causative factor of the CSR/CCP's sub-par state – again following Trivedi (2002) – is the application of a “Philosophy of Improvement” within a single subsystem...namely, in this case, the in-hospital subsystem. This singularly-based, improvement-focused philosophy is evident upon consideration of the ten Coverdell performance measures, developed via a collaborative process involving TJC, the CDC, the AHA/ASA, a number of hospital associations, and various stakeholder groups (The Joint Commission, 2008). Achieving improvements within these ten performance measures, which are abbreviated as PM1 through PM10 and presented in Table I below, certainly can contribute to a reduced burden of disease for acute stroke, as patient outcomes improve over time and across the affected populations; however, such improvements are really only optimizing the subsystem of in-hospital clinical care. The CSR/CCP, which tracks these ten performance measures, also seeks to reduce the stroke burden by effecting positive changes beyond the in-hospital setting, as discussed in Chapter 1. In fact, the CSR/CCP aims not only to improve care within the pre-hospital setting (in addition to the in-hospital-setting) but also to inform those who are at-risk of stroke as to how to prevent – or at least delay – the onset of stroke. In other words, the CSR/CCP, as a “larger system,” seeks to be impactful more broadly in its prevention efforts, yet

these ten performance measures (in Table I) only pertain to the in-hospital setting – i.e., to just a narrow part of the secondary prevention spectrum.

Table I: The Ten Coverdell Performance Measures

Measure	Description
PM1	Patients received deep venous thrombosis prophylaxis (now venous thromboembolism [VTE], not Deep Venous Thrombosis).
PM2	Patients received antithrombotic therapy at discharge.
PM3	Patients received anticoagulation therapy for atrial fibrillation.
PM4	Patients received tPA (tissue plasminogen activator) (i.e., among eligible patients).
PM5	Patients received antithrombotic therapy within 48 hours of admission or by the end of the second hospital day.
PM6	Patients discharged on statin medication (cholesterol reducing therapy).
PM7	Patients received dysphagia screening.
PM8	Patients received stroke education.
PM9	Patients received smoking cessation counseling.
PM10	Patients received assessment for rehabilitation services.

As the CSR/CCP tracks these measures and works to optimize the in-hospital performance¹⁵ – perhaps to the exclusion of other program facets (i.e., particularly those from the pre-hospital setting), it could well be suboptimizing its overall efforts. The end result may be a failure to achieve that “First Best” global outcome. Perhaps one could make the case that this suboptimization problem is borne, in part, out of the arguably double-barreled mission statement that calls for achievement in both the pre-hospital and in-hospital clinical settings, as described above. What is more is that this problem seems to have been “enabled,” to some extent, by

¹⁵ Note that the program data were analyzed in March, 2014, yielding the following: (1) For eight of the performance measures (i.e., PM2, PM3, PM4, PM5, PM6, PM7, PM8, and PM10), the (then) most recent data (i.e., data from the fourth quarter of 2013) showed significant improvements from the baseline data (i.e., data from the fourth quarter of 2007). (2) The comparison could not be made for PM1, as the measure has been changed from baseline. (3) For PM9, there has been little change from baseline, as both measures are in the mid-90’s (when expressed as percentages).

certain other external factors, including the CDC grant funding amount and the there-to-attached “strings,” as discussed further below. As Jacobson (2012) writes about suboptimizing: “Choosing one side comes with costs...” Further, he states: “Well-intentioned choices sow the seeds of further dissatisfaction, suboptimize the chance of finding a range of options, and limit the ability to respond effectively.” Indeed, the present program focus on improving the in-hospital care is not a bad thing, per se; however, it likely means that other areas (ripe for intervention) are not being addressed as they might otherwise be. On the whole, then, the result can be a status quo that falls short of what it ought to be.

With respect to the CSR/CCP’s efforts-to-date, the third potentially impactful factor that aligns with the work of Trivedi (2002) is bounded rationality. As suggested above, bounded rationality can impair one’s (i.e., an individual’s or an organization’s) ability to achieve a higher-level or global optimum – as certain limitations or constraints can prove to be too much to overcome. In the case of the CSR/CCP – which is California’s sole state-level program focused on stroke, one key limitation (to achieving a more optimal state) is the program’s funding. Specifically, the CSR/CCP has been funded in its entirety via one funding source, and that source (i.e., the CDC) provided just \$1,039,500 in total for the registry’s first three fiscal years (i.e., \$350,000 in the first fiscal year; \$339,500 in the second fiscal year [i.e., a 3% reduction from the first year, because of budget sequestration]; and \$350,000 in the third fiscal year). While that amount for California’s program was close to the average Coverdell award across the (then) eleven funded states during those first three fiscal years (i.e., the average Coverdell award for the 2012 fiscal year was \$356,000 [Centers for Disease Control and Prevention, 2014a]), it was relatively low, in comparison to other state-specific CDC chronic-disease-prevention-and-health-promotion-related awards. To illustrate this comparison, average state awards (from the

CDC) for this same time period, for similar programmatic efforts, are shown below in Table II.

As is evident from the table, the funding allocated for state stroke registries (and, again, in California, this is the only dedicated funding for state-level stroke-related prevention efforts) was quite a bit less than was the funding for other chronic disease initiatives during that same time frame. In fact, the amount allocated for stroke registries (at this time) is less than one-third of the amount allocated for tobacco control programming.

Table II: Average Annual Federal Awards for Chronic Disease Programs

Amount	Type of Programming
\$1,181,000	Tobacco Control Programming
\$852,000	WISEWOMAN (Well-Integrated Screening and Evaluation for WOMen Across the Nation) Programs
\$714,000	Nutrition, Physical Activity, and Obesity Prevention Programming
\$577,000	Prevention Research Centers
\$565,000	Cardiovascular Disease Prevention
\$514,000	Diabetes Prevention
\$356,000	Paul Coverdell National Acute Stroke Registries

In short, the CSR/CCP has a funding constraint that has been rather impactful; it may have even contributed to the program's limited secondary prevention focus. Moreover, this particular limitation has persisted (within the CSR/CCP), as there has been no influx of supplemental funding sources, despite the efforts of the CSR/CCP staff. Of note is that supplemental funding has been secured by several other states, including Ohio (D. Nutter, personal communication, March 6, 2014), North Carolina (S. Coleman, personal communication, March 6, 2014), and Arkansas (D. Vrudny, personal communication, June 27, 2014).

Beyond the fiscal constraints, the CSR/CCP has experienced additional limitations, particularly related to its utilization of certain human resources. Two noteworthy examples are

these: First, early in its grant cycle, the program lost an in-kind fiscal manager (due to external forces beyond the program's control). As a result, the fiscal management function has fallen on program staff members whose scopes of work do not include that kind of work¹⁶, and this creates inefficiencies in how the program operates.

Second, before the CDC grant was in place, the program sought the assistance of a programmer to develop its data system; however, during the development of that system, the programmer position has turned over multiple times, resulting in a number of starts and stops in the development of the data system. Of course, these kinds of inefficiencies consume time and money and limit the program's ability to optimally carry out its scope of work. To be sure, the CSR/CCP has had to make certain hard choices related to its staffing and work plan, given its current funding situation, and these choices arguably represent a departure from that "First Best" global outcome. In sum, if there is indeed a suboptimization problem within the CSR/CCP, a likely contributing cause is bounded rationality, and dealing with this situation has clear leadership implications.

In this third section of the literature review, a discussion of a number of operational challenges was presented, following the work of Trivedi (2002). These challenges, which tend to be intrinsic – in contrast to the largely extrinsic nature of the contextual factors as discussed earlier, tend to lead to a sub-par state. As has been discussed, this seems to be the case for the CSR/CCP, which has dealt with certain limitations, a perhaps skewed focus, and an arguably necessarily incremental approach to carrying out its workload. While the contextual factors and the programmatic challenges are impactful, there are other determinants of present and future

¹⁶ More recently, the CSR/CCP has lost both an in-kind scientific consultant and an in-kind medical consultant (again, due to external forces beyond the program's control). Continuing staff members have had to take on some of the duties these consultants carried out previously.

program performance. These particular determinants lie with the stakeholders, and, collectively, they are the focus of the next section of this literature review.

4. Stakeholder Beliefs

In this fourth section of the literature review, the impact (on a program's current state) of stakeholder beliefs regarding change is discussed, in terms of a program's need and ability to change. Though this construct was mentioned briefly in the second section of the literature review while discussing operational context and referencing the work of Weiner (2009), the topic gets much more attention here (as does Weiner's model, along with a number of other well-known models). The logic for including this particular discussion is this: Even if the operational context is conducive to goal achievement – and even if the operational challenges are being handled adeptly and are, therefore, of little consequence...if the key program stakeholders believe that the program does not need to change – or believe that it simply cannot change – then the program's status quo (and a sub-par status quo is under discussion here) will persist.

Foundational studies by Burke and Litwin (1982), Phillips (1983), and Van de Ven and Poole (1995) began the discussion on change-related beliefs, and subsequent work by Lehman, Greener, and Simpson (2002) suggested that the different types of change-related beliefs typically fall into the following four domains: motivation for change (including perceptions of current functioning and consequent need for change); beliefs regarding institutional resources of the program (including human resources, technology, and training opportunities); personality attributes of the staff (such as growth potential, efficacy, influence, and adaptability); and perceived organizational climate of the program (as it relates to the mission clarity, staff cohesiveness, staff autonomy, communication practices, stress management, and management

flexibility). In sum, Lehman and colleagues suggested that the stakeholder beliefs regarding change are rather cross-cutting with respect to the program, its staff members, and the environment in which the program exists.

These earlier studies set the stage for a host of other scholarly works on the subject of stakeholder beliefs regarding change; some notable examples follow: Saka (2003), after conducting fieldwork in both an engineering firm and a training organization, found that the perceptions of managers – that is, “...those actors who generally determine organisational priorities and make crucial resource allocation decisions” – can limit organizational change. Examples of detrimental beliefs include the feeling that an initiative is poorly-defined and the sense that the organization is already overextended. Bronn and Bronn (2003) concur; additionally, they suggest that unfavorable beliefs around suspicion, self-interest, and gamesmanship can come into play as well.

Next, in working on change within the US Department of Veterans Affairs, Sharp, Sales, and Pinerios (2003) suggested that within the collection of stakeholder beliefs, there should be an assessment of facilitation (for change) as well. In other words, beliefs not only about the change itself, but also how it actually could occur, are important. Similarly, Patterson et al. (2004), who worked within the context of manufacturing businesses, highlighted the impact of appropriate beliefs and responses, on a variety of levels, when change readiness seems apparent. In fact, the authors were able to correlate the employee perceptions and the organizational outcomes, across various levels of employment, including managers and their direct reports.

White (2004), studying change in Thailand, went even further, developing a multi-level process model that includes the interactions of stakeholders (in terms of their interests and power), cognitive structure (to include values, beliefs, and assumptions), and external structure

(comprised of organizational structure, regulations, laws, and procedures). Also taking a multi-level approach, Simmons and Lovegrove (2005), conducting a case study of performance appraisal in United Kingdom academic institutions, discussed how stakeholder perceptions (and these include the perceptions of employees-as-stakeholders) can influence the viability of strategic initiatives. Such influence can come across as the exertion of power, the intimation of legitimacy, or the presentment of urgency. To the extent that these kinds of perceptions are included in the emerging mental change models of the organization, the change capabilities may be strengthened or weakened (Karp, 2005). Along these lines, Kenny (2006) developed a so-called "...maturity model for the formation of strategy..." which stresses the inclusion of stakeholder beliefs in the initiation phase of the strategic planning process. Put another way, a failure to include the stakeholder beliefs would result in a flawed process, the results of which would likely be quite poor. This supposition was validated by Fuller et al. (2007) whose multi-level regression model indicated that drug abuse treatment innovations were influenced by the perceptions and beliefs of internal program stakeholders.

While the above studies are helpful in describing the influential nature of some key change-related beliefs, even greater insight is provided by reviewing the conceptual models put forth in several of the better-known works on this topic. The inclusion of these works within the scope of this project underscores the thinking that change-related beliefs among the program stakeholders not only may have influenced the CSR/CCP's present state of being but also could impact its ability to move past this present state. Turning to these works, then: First, Holt, Armenakis, Feild, and Harris (2007) describe a change-related model that includes not only the change process (i.e., the steps followed during implementation of the change), the change content (i.e., the particular change being implemented and its attributes), and the change context

(i.e., the conditions and environment within which employees function), but also the individual attributes of the employees. The importance of this inclusion is evident in the following statement by the authors: “Because of the differences between individuals, some employees are more inclined to favor organizational changes than others may be.” To the extent that the favor is held by those employees in positions of power or influence, the greater the likelihood of change. The authors further describe how these four areas of influence (i.e., process, content, context, and employees’ individual attributes) then interact with each other and give rise to certain change-related beliefs that impact readiness and subsequent behaviors. In other words, the authors contend that these change-related beliefs impart a cognitive and emotional inclination to “...accept, embrace, and adopt a particular plan to purposefully alter the status quo...” – or not. The resultant actions, then, are adoptive or resistive behaviors, and these actions exert influence on both the current and future states of being. This model from Holt, Armenakis, Feild, and Harris (2007) is shown graphically in Appendix I (as sub-A).

The second better-known work which models how beliefs can impact change-related behaviors (which are, of course, influential in giving rise to a particular status quo...and in predicting a likely future state, as well) comes from Bouckenooghe, Devos, and Van den Broeck (2009). In this article, the authors describe an approach for studying a change process by looking at certain process-of-change dimensions (i.e., quality of change communication, support by supervisors, attitude of top management towards organizational change, and participation); climate-of-change dimensions (i.e., trust in leadership, politicking, and cohesion); and readiness for change dimensions (i.e., emotional, cognitive, and intentional readiness for change). These dimensions, shown graphically in the model presented in Appendix I (as sub-B), come from what the authors describe as “...the human relations perspective...” thereby suggesting that the

thoughts and beliefs of individuals who have a stake in the operations of a particular organization are key components to making or breaking a change process. Indeed, the authors suggest that both management's and employees' perceptions of, and beliefs about, the internal circumstances under which some change process might occur (or not) can determine, in part, the degree to which an organization's climate motivates its actions.

Third, the work of Weiner (2009), addressed earlier in the section on operational context, highlights the importance of stakeholder beliefs, as well. In Weiner's model, presented in Appendix I (as sub-C), contextual factors – as mentioned earlier – exert influences on organizational readiness for change, via the mediating constructs of change valence and informational assessment, and these two mediating constructs are fully steeped in values and beliefs; change valence (defined above) is the degree to which organizational actors value a proposed change, and informational assessments are shaped, in large part, by these individuals' beliefs. Moreover, the model from Weiner indicates that this operational readiness for change (which includes change commitment and change efficacy – both of which are belief-based ideas) will promote or impede the subsequent change-related effort put forth by the organizational actors, thereby predicting the effectiveness of the change implementation. In other words, across nearly every aspect of this model, stakeholder beliefs come into play in determining how an organization will act (and, essentially, exist). As Weiner notes, any overestimation or underestimation of the organization's ability to act will result in hardship – because the organization either acted and failed...or chose not to act and settle for the (“lesser”) status quo.

The fourth better-known work comes from Rafferty, Jimmieson, and Armenakis (2013), whose multilevel model, presented in Appendix I (as sub-D), includes antecedents, change readiness factors, and outcomes of interest – at both the individual and organizational levels.

This model, in contrast to some of the earlier models that build on the work of Armenakis et al. (1993), deemphasizes behavioral intentions, while promoting cognitive and affective factors in the so-called causal pathway (i.e., the one which can lead to change readiness and, eventually, some outcome of interest) – again at both the individual and organizational level. With respect to the former level, the authors suggest that influence (on some outcome of interest) is exerted by an individual's beliefs and feelings that such an outcome can and should occur; that she or he has the capacity to somehow impact that occurrence; and that that outcome will be desirable for her or his well-being now and in the future. Regarding the latter level (i.e., the organizational level), the authors contend that additional impact (again, on some outcome of interest) is felt because of shared beliefs and feelings concerning this particular outcome – and these shared beliefs and feelings can emerge via common exposures to stimuli, leaders, events, processes, and rumors. In other words, the “thoughts” and “feelings” of individuals and of groups of individuals within an organization can be powerful determinants of how that organization operates. In a similar vein, Blackman, O'Flynn, and Ugyel (2013), discuss adoptive or resistive practices, by highlighting individual- and organizational-level enablers for, and barriers to, change; notably, these authors suggest that “...even where there are individuals ready for change, there can be macro level organisational elements that prevent the adoption of the change” (p. 11). Similarly, Khan et al. (2014) identify the need to consider both individual and organizational factors. These authors suggest that the critical constructs germane to change can be organized and considered as individual psychological factors, individual structural factors, organizational psychological factors, and organizational structural factors.

The fifth and final better-known work related to the impact of stakeholder beliefs on an organization's operational state – and, here, again, the state of particular interest is the state of

readiness for change – comes from the work of Stevens (2013)¹⁷. In this model, presented in Appendix I (as sub-E), the author builds on the cognitive and affective factors, discussed by Rafferty, Jimmieson, and Armenakis in their multilevel model (2013), by incorporating the “...influence of context and environment...” on these particular factors. Additionally, Stevens explains in his model that readiness (which is a state of being) is the culmination of evaluations and responses occurring amidst various conditions and factors, to include the individual and collective factors discussed above, along with influential contextual factors. Finally, Stevens suggests that this process is a recursive one as the various factors can change and interact over time. In other words, at any given point in time, a particular state of being is, according to this model, the result of the ongoing relationships and interactions of these various individual, collective, and contextual factors as they occurred in the timeframe leading up to the time of interest.

In this fourth section of the literature review, a discussion of the importance of stakeholder beliefs (as they impact the organization’s operational state) was presented. Five better-known models were introduced and highlighted in support of this notion. Within the context of the present project, these five models suggest that the current state of the CSR/CCP is what it is, in part, because of the influences of individual and collective cognitions and affectations present within and around the program. Moreover, these five models suggest that the potential future state of the CSR/CCP is also partially predicated upon these factors. Of course, the potential future state of the CSR/CCP is also predicated, in part, upon other factors, to include intentional action steps focused on change – in this case, change which would broaden

¹⁷ It is appropriate to use the general term, operational state, and the specific terms, change readiness, more-or-less interchangeably; as Stevens (2013) indicates, the term change readiness has been conceptualized in a variety of ways, including as a change message, as stages of change, as commitment to change, as openness to change, as capacity, as a multidimensional state, and, finally, as a process.

the CSR/CCP's secondary prevention efforts. These sorts of (potential) action steps are discussed in this next section of the literature review.

5. Potential Action Steps

This fifth and final section of the literature review briefly explores the “so what?” and “what next?” kinds of questions, more from a theoretical perspective than from an applied perspective – given that the latter perspective is informed with the actual conduct of the present study. Accordingly, with an emphasis on action, this section cursorily presents a high-level overview of some organizational behaviors, which, if properly instituted and managed, potentially could be effective in broadening the CSR/CCP's programmatic efforts across the secondary prevention spectrum; this overview aligns with the third research question posed in the previous chapter. In this overview, the practice of knowledge management and the development and use of cross-functional teams and communities of practice are discussed first as separate strategies (as each one is often used independent of the other) and then as an integrated effort (which can promote synergy), as per Mohamed, Stankosky, and Murray (2004). Additionally in this fifth section of the literature review, following the work of Zuber-Skerritt and Perry (2002), Zuber-Skerritt and Fletcher (2007), and Coughlan (2007), some supplemental remarks regarding the use of an action research approach, within the context of the present study, are included; these closing remarks begin to get at that applied perspective mentioned above.

Knowledge Management

The first strategy of interest is employing knowledge management. Knowledge management, as defined by Davenport and Prusak (1998, as cited in Ponzi and Koenig, 2002), “...is the process of capturing, distributing, and effectively using knowledge.” This definition,

while simply stated, conveys the more complex message that this operational component concerns both the data systems in place within an organization and the individuals who work with the data that come from those systems. In other words, having systems to collect data is certainly important; however, if no one is able to make good use of the data, then the data collection systems are of little to no value. Similarly, Shipley (1999), in looking at how to create and sustain a culture of organizational improvement and high performance (within the realm of primary and secondary education), stresses how the proper management of knowledge means employing strategies designed to “...get the right information at the right time in order to take action and create value.” And, as discussed earlier, the creation of value (as per Moore, 1995) is consistent with moving in the direction of achieving that “First Best” state. In short, then, optimizing an organization’s operations is predicated, in part, upon continually getting good data into the hands of strong leaders who can employ effective strategies designed to make judicious use of those data. Within the context of the present project, perhaps being able to more effectively process and share information that is already (or could be) available from within the CSR/CCP could facilitate any action steps taken in order to broaden the program’s secondary prevention focus.

Cross-functional Teams

A second effective measure for achieving an optimal level of performance is the establishment of cross-functional teams – and weaving these teams into larger communities of practice (Kochan and Useem, 1992; Proehl, 1996; McDermott, 1999; Wegner and Snyder, 2000). The first step here is to build within an organization a team that is comprised of individuals (or small groups), each of whom (or which) has the functional expertise that is necessary for the achievement of a common goal. Next, on a grander scale – perhaps across organizations,

multiple cross-functional teams can come together, in pursuit of a larger, shared vision, and form a purposeful community of practice that can promote high-level learning and create common practices – in free-flowing and creative ways (Wegner and Snyder, 2000). Through these different organizational systems, these teams and communities are able to “...build understanding, problem-solving capabilities, coordination, communication, and, ultimately, improved quality and productivity” (Proehl, 1996). Of course, these efforts must be well coordinated, nurtured, and monitored or else there is risk for certain performance problems, including isolation, myopia, and short-sightedness, which could stifle progress (McDermott, 1999). Within the context of the present project, perhaps the CSR/CCP could not only draw on some of the currently untapped functional expertise from the CDPH Division or Branch in which the program resides, but also work to create a larger community of practice, possibly along with the AHA/ASA and other stakeholder groups. After all, as Kochan and Useem (p. 5) write: “Achieving effective cooperation and coordination across traditional boundaries is critical to organizational effectiveness.” This perspective could certainly inform the eventual process undertaken in order to broaden the program’s efforts across the secondary prevention spectrum.

The Potential for Synergy

While each of these above two measures (i.e., managing knowledge and building cooperative teams) stands on its own, Mohamed, Stankosky, and Murray (2004) suggest that the potential for synergy of these two practices is great, and for the present project, this synergy seems to hold a certain appeal. On this topic, the authors write: “The successful application of knowledge management necessitates interaction among multi-disciplinary groups of people as a basic requirement. Cross-functionality cannot be effective without sharing knowledge among team members” (p. 127). In other words, having one or the other practice is good – and having

them both and fostering synergy is exponentially better, in part because of the resulting advances in creativity and innovation (Stebbins and Shani, 1995), as well as the reduction in redundancies and inefficiencies (Proehl, 1996).

To achieve and maintain this synergy, Mohamed, Stankosky, and Murray (2004) contend that four “pillars” (first described in an earlier work by Stankosky [2000]) must be in-place: leadership, organization, technology, and learning. First, the leadership pillar suggests that senior managers within an organization must be intentional about bringing different teams of people and groups together and rewarding them for their successful collaborations. Moreover, they must create environments conducive to sharing both information and practices and to experimenting with new methods. Next, the organizational pillar is critical here as the particular amalgamation of the various separate functional entities will drive thought processes, interactions, and workloads. Rigid functional silos and compartmentalized operations must be avoided. Further, the technology pillar, in this synergetic model, functions as an enabler, not an end-solution. In other words, the technology is used in a way that facilitates the sharing of information across the various linked communities. Finally, the learning pillar mandates that all of those involved in a particular collaborative project must pool their skills and knowledge to drive decision-making across “usual” boundaries. Doing so should result in better decisions, made in shorter periods of time. Additionally, as per Mohamed, Stankosky, and Murray (2004), learning can alleviate problems with morale and job satisfaction. As Proehl (1996) cautions, however, achieving this state of learning can be challenging, given the changes in human resources, reporting relationships, and assigned tasks. Within the context of the present project, the synergy of managing knowledge and creating teams might position the CSR/CCP to more effectively carry out its secondary prevention workload. Of course, in working to achieve that

synergy, it would be prudent for the program staff members and stakeholders to be aware of the four pillars of leadership, organization, technology, and learning.

Action Research (or “Pre-Action” Research)

While the above-discussed operational practices are presented from a theoretical perspective, it is true that the present project utilizes an action research approach (or perhaps a “pre-action” approach¹⁸) in seeking to change the status quo. Put another way, the present project goes beyond the theoretical discussion of addressing the problem-at-hand, by utilizing research methods designed to uncover real-world action steps that should likely lead to its solution. Zuber-Skerritt and Perry (2002) discuss action research, describing it as collaborative, participatory research conducted in the field, in order to motivate practical improvement within a learning organization and add to a particular body of knowledge. Furthermore, they suggest that it is “...more appropriate than traditional research for improving practice, and professional and organisational learning.” Action research, therefore, can be of benefit to both the organization (which serves as the setting for a given project) and the body of scholarly work to which the project’s write-up belongs. This capacity to contribute rather broadly is enabled because action research, unlike traditional research, has a “soft” boundary in place between the researcher and the system under study. Of course, when action researchers cross that “soft” boundary, they must adhere to a number of so-called requirements, as per Zuber-Skerritt and Fletcher (2007): (1) they must seek to improve practice; (2) their research must be participative and include all relevant parties; (3) they must be cognizant of issues that are significant in a much broader sense (i.e., not just germane to their particular research interests); (4) their research must employ multiple perspectives of knowing, as well as strong connections to what is found in the current,

¹⁸ Using the term “pre-action” is more appropriate, here, since the scope of this project does not include certain action-oriented steps, such as organizational readiness assessment, stakeholder management, resource acquisition, or strategic planning.

relevant literature; (5) they must employ rigor in their methods; (6) their assumptions must be explicit so that the results can be appropriately interpreted and used; and (7) they must be reflective, critical, and ethical in their work. Within the context of this project and with these requirements in mind, the workload should unfold in four phases: planning the research; acting in the field; evaluating the field work; and reflecting on the results, in light of the earlier research. This reflection should motivate the ability to provide real contributions to what Coughlin (2007) refers to as actionable knowledge. In this project, these types of contributions should enable the CSR/CCP to broaden its secondary prevention efforts, thereby aligning them with the program's original vision, as well as the current national prevention agenda.

This fifth section of the literature review presented some proven organizational behaviors¹⁹, which, when properly implemented and judiciously managed, have produced meaningful, sustained changes. Again, moving from theory to practice, organizational behaviors such as those discussed above could well be effective in broadening the CSR/CCP's programmatic efforts across the secondary prevention spectrum. This final section of the literature review concluded with some commentary on the use of an action research approach (or "pre-action" research approach, as it were) within the present study, as this type of approach is more likely to produce actionable knowledge than is the traditional research approach.

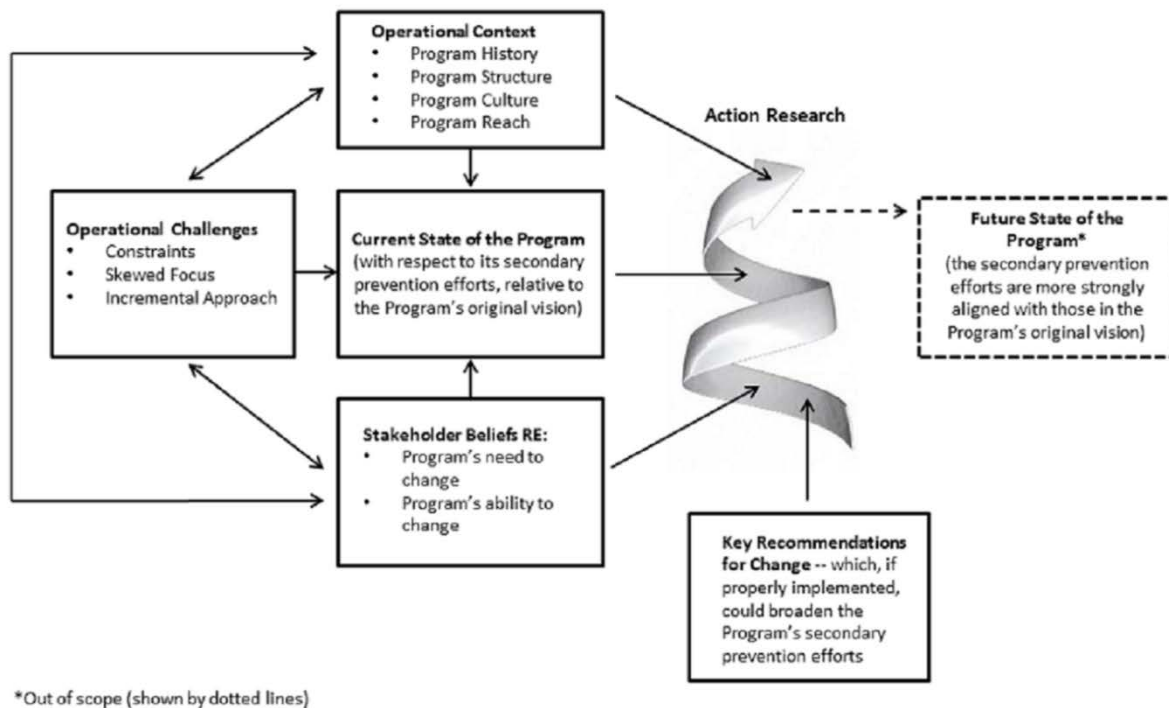
B. Conceptual Framework

Having described the theoretical framework, as found in the academic literature, the conceptual framework is now presented. This framework shown in Figure 1 below provides a literal picture of the key concepts within the present study and the theorized relationships

¹⁹ Specifically, the practice of knowledge management and the development and use of cross-functional teams and communities of practice were discussed – first as individual practices and then as components of an integrated approach.

between them. Moreover, as mentioned above, although the conceptual framework draws upon both theory and practice, it is a new creation within this study.

Figure 1: The Conceptual Framework



Properly navigating the above conceptual framework requires one to first focus on the box labelled “Current State of the Program” (which is just left of center). The purpose of including and starting with this box is to illustrate that understanding the status quo (as per the first research question posed in the previous chapter) is essential to knowing if – and perhaps in what areas – programmatic change should occur. Before getting to the process of change, though (which “happens” in the framework by moving to the right²⁰), one should remain within

²⁰ In other words, the real process of going through a change is conveyed in the conceptual framework by rightward movement, depicted by the three arrows “entering” into the Action Research Spiral, just to the right of center, as well as by the Action Research Spiral itself; continued rightward movement means approaching the sought-after future operational state – though that particular movement...all the way to the right, as shown by the dotted line, is out of the scope of the present project.

the area of the “Current State of the Program” box and consider the three boxes in closest proximity to this starting point (i.e., above it, below it, and to the left of it). These three boxes depict those constructs which are impactful on the current state, as well as on each other. These different influences have been categorized in this framework as one of three types: operational context, operational challenges, and stakeholder beliefs, consistent with the earlier discussion in this second chapter and associated with the second research question as posed in the first chapter.

Operational context, the category which includes the history, structure, culture, and reach of the CSR/CCP, along with operational challenges, the category which includes constraints, a skewed focus, and an incremental approach, both relate to how the organization has existed over time and sought to carry out its operations. The former (i.e., operational context) tends to have been constructed as a result of internal forces (e.g., the structure of the CSR/CCP is what it is, in part, because of the bureaucratic structure of the public health agency in which it resides), while the latter (i.e., operational challenges) tends to reflect external forces (e.g., the incremental approach of the CSR/CCP has come about, in part, due to the “ebb and flow” of the external funding streams). The third box in this proximal collection is there to represent the impact of the stakeholders’ beliefs regarding change, and this category of influence relates to the people within the organization – the “human factor” (Horak, 2001), rather than the “nuts and bolts” of the organization (as did the other two categorical influences). Accordingly, perhaps more than these other two categories of influence, this particular category of influence is significant not only when contemplating the present state of being, but also when considering the possibility of moving away from it. In sum, then, the conceptual framework posits that the current state of affairs (here, the current state of the CSR/CCP) is as it is because of the impacts of the operational context, the operational challenges, and the stakeholders’ beliefs.

Moving from the current operation state – which, as has been suggested, is not optimal with respect to its secondary prevention work, relative to the program’s original vision – to a better, future state means starting to move rightward in the graphical framework in Figure 1. Such movement means that one enters into an Action Research Spiral (discussed above), into which some key recommendations for change are brought²¹. The graphical depiction of this part of the framework is a spiral (to indicate a non-linear process)²² which “accepts contributions” (in this case, not only some of the earlier-discussed influences on the current status quo, but also some key recommendations for change) as it (the spiral) works to usher in a new status quo.

With respect to the research questions posed in the previous chapter, this part of the conceptual framework corresponds to the third question. The idea is that during data collection, information would be gathered regarding ideas for change, and these ideas would be translated into a set of recommendations which enter into the action research process²³. As these recommendations enter into the process, they are turned into action taken and resultant movement in the direction of a better future state. This better future state is one in which the secondary prevention efforts of the CSR/CCP are broadened and in line not only with the program’s original vision but also the national trends and conversations on prevention. This better future state, as illustrated in the framework by the box furthest to the right, is not to be thought of as theoretical – since it represents a more optimal organizational state²⁴; however, as indicated by the dotted lines of the arrow shaft and the box itself, achieving this state is out of scope for the present project.

²¹ The recommendations are developed by an ad hoc advisory group which vets the data, as described in Chapter 3.

²² It must be noted that the spiral is an upward spiral, thereby suggesting that the action research process leads to something positive (as “up” is conventionally positive – as opposed to “down,” which is conventionally negative).

²³ Entry into the Action Research Spiral is beyond the scope of this project.

²⁴ It also represents the eventual outcome of the action research process initiated in the present project.

C. Chapter Summary

In this second chapter, the literature was reviewed and a conceptual framework was presented. In reviewing the literature, the importance of several key ideas emerged. First, change is a process – wherein the current operational status (of a program or an organization) is assessed and found to be unacceptable; a better future state is envisioned and described; and a thoughtful, intentional process for achieving that vision is developed. Next, in order to understand the status quo, as well as how it could potentially change (i.e., improve), it is critical to understand those factors that exert some influence – either individually or in concert with one or more of the other factors – on how things are...and/or on how they could be. Three categories of influence were discussed: operational context; operational challenges; and stakeholders’ beliefs, with the first two categories being more relevant to the “infrastructure” and the third category being more relevant to the “people.” The final theme that emerged from the review of the literature is that there are certain steps that can be taken in order to begin moving away from that unacceptable current state – towards the better future one. The steps discussed related to how information and human resources can be used, as well as how to ensure that the steps are actionable – so that progress can be made. Following the literature review, there was the presentation of the conceptual framework – which enables a graphical presentation of all of the key concepts within the present study (as discussed in the literature review), as well as the theorized relationships between them. As indicated above, while it covers what is found in the literature, the conceptual framework, itself, is not from the literature; instead, it is a “new creation” specific to the present project.

III.

Chapter 3: Study Design, Data, and Methods

As stated in the first chapter and discussed in the second chapter, the present project seeks to accomplish three things: to describe what the current secondary prevention efforts of the California Stroke Registry/California Coverdell Program (CSR/CCP) are – particularly in relation to what they were expected to have been, according to the program’s original vision; to explore what factors were influential in bringing about this current operational state; and to investigate what kinds of changes might occur, such that the current, seemingly sub-par status quo will not persist. In line with these objectives, three research questions were posed in the first chapter then referenced during the two narratives in the second chapter. In this third chapter, the methodology used to answer these three research questions is presented. What follows are descriptions of the study setting; the study design and study methods; the data management process; the data analysis process; and the validity considerations.

A. The Study Setting

For the present project, the study setting is the CSR/CCP, a CDC-funded²⁵ quality improvement program for acute stroke, administratively located within the CDPH and run in collaboration with the AHA/ASA, as described above. In carrying out its mission of optimizing the care of stroke and, thereby, reducing the burden of stroke, as stated in Chapter 1, the CSR/CCP has formed and maintained a number of relationships with clinical partners working in both the pre-hospital and in-hospital settings – though the number of partners in the former

²⁵ Dedicated funding for the CSR/CCP has been in place since July 1, 2012, via the CDC’s Paul Coverdell National Acute Stroke Registry (more recently known as the Paul Coverdell National Acute Stroke Program); prior (partial) support came from the CDC’s categorical funding, earmarked for state-based heart disease and stroke prevention programming.

setting pales in comparison to the number of partners in the latter setting (on the order of about 1 to 12). Given this setting and the partnerships found therein (to include the partnership with the funding agency), there exists a wealth of resources (including both work products and key personnel) available to provide critical information, as answers to the above three research questions are sought. Furthermore, there is a truly “soft” boundary in place between the researcher (DJR) and the system under study, to use the language of Zuber-Skerritt and Fletcher (2007). Finally, because the CSR/CCP is one of a number of such programs in the country (i.e., one of eleven during the third funding cycle; one of nine during the fourth and current funding cycle) – and not one of the longer-standing programs, having only been “in place” since early 2008 and part of the national program since 2012 – there is a unique opportunity during the conduct of this project to gain some helpful insights from program staff working in other state stroke programs, among others.

B. The Study Design and Study Methods

This project, which has utilized a multi-methods design²⁶ and taken an action research (or “pre-action” research) approach (as discussed in the previous chapter), was conducted in three phases; each phase corresponds primarily to one of the three research questions posed in Chapter 1, and the third phase has begun the action research approach. (It is of note that each of the three phases does provide insight, with respect to all three of the research questions.) Below, within the context of each of the corresponding research questions, each of the three phase is discussed (in terms of “why,” “what,” and “how”). Within this three-part discussion, the various question-specific measures of interest are presented.

²⁶ Here, the term multi-method refers to the use of multiple methods. Alternatively, the term mixed methods could apply here, even with the project’s dominant emphasis on qualitative data, as per Johnson, Onwuegbuzie, and Turner (2007).

1. Research Question 1 – and Phase I

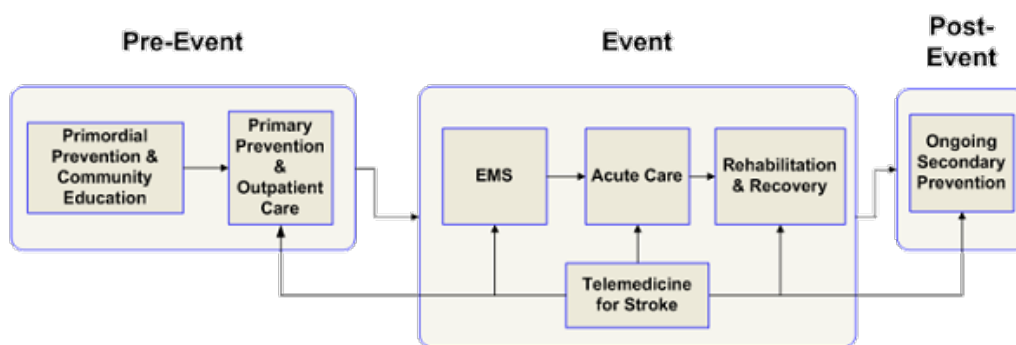
a. The “Why?”

The first research question is posited in order to determine what work is being done in terms of secondary prevention within the CSR/CCP and how that work compares to the program’s original vision for secondary prevention. Put differently, the answer to this first question reveals the extent to which the program’s prevention efforts are what they ought to be...with the implication that things should change if these efforts are out of alignment with what has been envisioned. Figure 2 below, which displays the components of a stroke system of care (to include pre-event, event, and post-event components), is helpful to put the stroke event (i.e., the central part of the diagram and the focus of this project) into its proper context, as well as to illustrate its elements. As shown in the figure, during the stroke event, both EMS and Acute Care resources²⁷ must be marshalled to provide appropriate patient care. Accordingly, and per the original guiding vision for the registry, the work of the CSR/CCP should connect with both of these components – and this first question seeks to explore whether this is happening.

Figure 2: The Components of a Stroke System of Care²⁸

²⁷ This figure shows that during the stroke event, rehabilitation and recovery resources can be at play, too; however, for the present project, the post-discharge component is beyond the project’s scope.

²⁸ This figure was retrieved from http://www.cdc.gov/dhdsp/programs/stroke_registry.htm. It was adapted by the CDC from Schwamm LH, et al. (2005). Recommendations for the Establishment of Stroke Systems of Care: Recommendations from the American Stroke Association’s Task Force on the Development of Stroke Systems. *Stroke*, 36: 690-703.



b. **The “What?”**

i. **Systematic Document Reviews: The Documents**

Phase I of this project is designed to produce the majority of the information used in answering this first research question. The primary method of generating data in this first phase comes from a systematic review of a collection of CSR/CCP-related documents. As Bowen (2009) states, document reviews can be used to “...elicit meaning, gain understanding, and develop empirical knowledge” (p. 27).

While documents used in qualitative research can take a variety of forms, the collection of documents reviewed during this first phase of the project is rather narrowly defined – as it has been generated as part of the ongoing CSR/CCP-CDC cooperative agreement. This collection of documents includes the following: (1) the original Funding Opportunity Announcement (FOA) from the CDC; (2) California’s application in response to this FOA; (3) California’s every-other-month written state updates (16 in total); (4) California’s two annual reports/reapplications for continued funding²⁹ (4 documents in total); (5) slide presentations (4 in total), prepared by CSR/CCP staff for California’s annual site visits (with the CDC); and (6) the CDC’s follow-up report on the annual site visits (to California). In sum, this collection is comprised of 27 documents, numbering 595 pages of material.

²⁹ The annual report/reapplication for continued funding, completed during the first year of the grant, required both an evaluation plan and a quality improvement plan; thus, as part of that document, these plans are included in the systematic document review conducted in Phase I.

There are several advantages to using this narrowly-defined set of documents in working to answer the first research question. Following the work of Wood (2011, as cited in Taylor and Francis, 2013), the first advantage is that the provenance of the various documents is known. In other words, the authorship of these primary data sources is not in question, nor is the timing of the documents' creation. Next, the purposes for creating the documents are clear – as are the intended audiences for the documents. Further, the contexts of the documents, in terms of their temporal, geographic, and professional perspectives, are evident. Finally, while the veracity of the writing is not in dispute, certain biases could be present in the documents, and this possibility is kept in-mind during the systematic document review. As Taylor and Francis (2013) indicate, a careful review of research documents – when combined with other forms of data collection and analysis – leads to a set of beliefs about the subject matter under investigation. In this first phase of the present study, the key documents identified above are invaluable in revealing what is happening with respect to the CSR/CCP's secondary prevention efforts and how that revelation compares to what was intended.

ii. **Systematic Document Reviews: The General Approach**

a. **Content and Thematic Analyses**

The general idea, here, is that from this above-described collection of documents, selected excerpts, quotations, and passages are systematically organized into categories and then combined into major themes, based upon content (Labuschagne, 2003). These results, then, when used in conjunction with other sources of information (e.g., reflections by the researcher), begin to converge on a set of facts that promote understanding (of the program's current status, in relation to what it ought to have been) and guide the continuing research, going into the project's subsequent phases. This review process, discussed further below, is aided by NVivo,

Version 10, a software package designed specifically for qualitative analyses (QSR International Pty Ltd., 2012).

The document review – which entails taking on a holistic perspective, searching for underlying themes or patterns, and using non-standardized instrumentation (Miles and Huberman, 1994) – is comprised of two processes, as per Bowen (2009): First, a document is analyzed, and this analysis involves superficial skimming, thorough reading, and appropriate interpretation, such that content analysis and thematic analysis occur in an iterative fashion. The former, which “...entails a first-pass document review, in which meaningful and relevant passages of text or other data are identified (p. 32),” results in the production of organized information, while the latter, which includes “...coding and category construction, based on the data’s characteristics, to uncover themes pertinent to a phenomenon (p. 32),” results in the identification of emerging themes – to guide the analysis. In short, via what Bowen refers to as a “back-and-forth interplay with the data,” critical content is organized and categorized, allowing for the emergence of key themes. As Miles and Huberman (1994) describe, this process is facilitated via memoing.

b. Evaluation of the Evidence

Second, after the documents are analyzed (i.e., both content analysis and thematic analysis have occurred), the evidence is evaluated. This is a process of establishing the meaning of what has been reviewed and how it contributes to the questions and issues under exploration. While the provenance, purpose, context, and veracity of each document are known in the present case (as suggested above), in evaluating this kind of evidence, it is imperative to assess both completeness and balance. The suggestion or finding of any omission or skewing should give a researcher pause, and that can be a finding in and of itself.

In the present study, given that one of the research questions explores a potential imbalance (i.e., regarding the CSR/CCP's efforts-to-date across the secondary prevention spectrum), the evaluation of evidence gathered via the systematic review of the above-listed program-related documents is critical to promoting understanding; moreover, being able to appropriately assemble and interpret the evidence allows for the conceptual framework to be evaluated. In other words, in working through the data from the systematic document review, a particular understanding emerges...and with that understanding in mind, the original conceptual framework is revisited and assessed.

c. **The “How?”**

Operationally, the systematic document review (which includes the content and thematic analyses) is accomplished in the present study via the use of (1) a document review guide (presented in Appendix II, along with the Interview Guides, discussed below); (2) a code book, for coding the data (presented in Appendix III); and (3) NVivo, Version 10, as mentioned above.

First of all, the document review guide helps to organize the 27 Phase I documents, by tracking each one's type, title, date, authorship, and purpose – and whether the information contained therein, on the whole, refers to what is anticipated or realized; moreover, this guide leads the coding process through the above-mentioned four main constructs, germane to the first research question, as well as through those constructs relevant to the other two research questions – as some of these documents address contextual factors, programmatic challenges, and change-related beliefs (i.e., what is elicited from the second question) and/or speak to ideas for change (i.e., what is sought in response to the third question). Next, the guide directs the coding process within the two clinical settings of interest in the present study: the pre-hospital and in-hospital settings. In short, the guide enables the process to be systematic, across the three

research questions. Finally, with respect to the constructs – and, as appropriate, for the specific clinical settings – the code book provides the instructions for coding the Phase I documents (and, later, the interview transcripts), in NVivo, Version 10. Thus, coding of the source materials utilizes 4 main codes and 30 sub-codes for Phase I (as well as 9 main codes and 26 sub-codes for Phase II and 8 main codes and 18 sub-codes for Phase III). For Research Question 1/Phase I, the approach for working through the study’s source materials is shown in Table III below.

Table III: The Approach for Phase I

<p>Research Question 1:</p> <p>What work is being done in terms of secondary prevention within the California Stroke Registry/California Coverdell Program? (<i>e.g., related to recruitment, infrastructure, partnerships, and QI</i>) How does that work compare to the program's original vision for secondary prevention?</p> <p>(As is appropriate, select a setting and a state – e.g., <i>Pre-hospital</i> and <i>Actual</i>; note that there are four combinations)</p>						
Clinical Setting	State of Being	Construct	Indicator	Measure	Data Source	Analysis
<input type="checkbox"/> Pre-hospital <input type="checkbox"/> In-hospital	<input type="checkbox"/> Actual <input type="checkbox"/> Anticipated	Recruitment – this refers to the action of recruiting clinical providers	As a result of the recruitment efforts, clinical providers joined the program	Numbers of clinical providers: <ul style="list-style-type: none"> ▪ Hospitals ▪ LEMSs 	Program documents <ul style="list-style-type: none"> ▪ FOA / Response ▪ Reports to CDC ▪ Site Visit docs ▪ Key Informants 	Qualitative, via document reviews
		Infrastructure – this refers to the use of the data system, the establishment of performance measures; and the use of human resources	<ul style="list-style-type: none"> ▪ Data system built and launched; ▪ Performance measures established ▪ Human resources dedicated and used 	Statements as to the data system's functionality; data; the number/use of performance measures; and the number/use of program staff	Program documents <ul style="list-style-type: none"> ▪ FOA / Response ▪ Reports to CDC ▪ Site Visit docs ▪ Key Informants 	Qualitative, via document reviews
		Partnerships – this refers to the ways in which the program has formed and used partnerships	Evidence of having formed and used partnerships	Number of program partners; Number of shared efforts (i.e., with partners)	Program documents <ul style="list-style-type: none"> ▪ FOA / Response ▪ Reports to CDC ▪ Site Visit docs ▪ Key Informants 	Qualitative, via document reviews
		QI Initiatives – this refers to Quality Improvement work, jointly undertaken by the program and the providers	Some number of unique QI efforts jointly undertaken within a given clinical setting	Number of joint QI efforts	Program documents <ul style="list-style-type: none"> ▪ FOA / Response ▪ Reports to CDC ▪ Site Visit docs ▪ Key Informants 	Qualitative, via document reviews

In sum, in seeking to answer the first research question, the primary method is a systematic document review of the 27 programmatic documents; this process (i.e., to include coding³⁰ and memoing³¹, conducted June 2015 through August 2015) is carried out in NVivo, Version 10, using a document review guide and a code book, via the approach outlined above. It merits mention that data collected from the 14 key informant interviews (conducted September 2015 through January 2016, primarily to answer the second and third research questions) are also informative with respect to the first research question³². Indeed, all of the findings related to the CSR/CCP's current operational state (with respect to secondary prevention) are used to further the investigation and to establish opportunities for triangulation of the data (Maxwell, 2013).

2. Research Question 2 – and Phase II

a. The “Why?”

The second research question, which is focused on understanding what types of factors have been influential on the emergence of the current operational state of the CSR/CCP, marks the beginning, in earnest, of the second phase of this project. Put differently, the purpose in asking this second question – i.e., for conducting Phase II – is to learn how various kinds of contextual factors, operational challenges, and strongly-held beliefs have been impactful on the secondary prevention efforts of the CSR/CCP. While the systematic document reviews conducted during Phase I do provide some insights as to these factors of interest, the primary method used to ascertain this information in Phase II is the conduct of key informant interviews.

³⁰ To assure quality, double-coding was performed in NVivo, Version 10. The results indicate high intercoder reliability (therefore, high quality). Appendix IV provides detailed information on this process.

³¹ Memoing was performed in NVivo, Version 10. Twelve memos were written and reviewed in seeking an answer to the first research question.

³² For the first research question, a total of 3,017 references were captured and coded in NVivo, Version 10. Of this total, 88.4% (2,666 references) came from the 27 Phase I documents; 10.6% (319 references) came from the Phase II interviews; and 1.1% (32 references) came from the Phase III interviews.

The methodology employed to answer this second research question follows what is known as the constructivist research paradigm, which “holds that multiple realities exist to be studied and understood” – in contrast to the positivist and post-positivist research paradigms, which suggest that a single reality on how things truly are can be fully captured (Israel, Eng, Shultz, and Parker, 2013). In other words, via key informant interviews, an understanding is constructed, based upon information provided via a number of sources, all of which could be considered “informed,” at the very least, if not “true.” The aim of this approach, therefore, is to generate a “consensus construction of reality” (Israel et al., p. 141) that is more informed than any prior understanding.

b. **The “What?”**

i. **Key Informant Interviews: The Interviewees**

As described by LeCompte and Schensul (2010), in-depth interviews are conducted with selected individuals who have been in an organization or community for a sufficient duration to acquire special knowledge, develop key relationships, and gain access to observations that would be unavailable to others. Given this capacity, key informants are able to not only articulate important issues, but also explain how and why those particular issues are important (Israel et al., 2013). As described by DiCicco and Crabtree (2006), the interviewees are encouraged to share “rich descriptions of phenomena while leaving the interpretation or analysis to the investigators.” These authors go on to describe various types of interviews, including unstructured, semi-structured, and structured. In the present study, selected informants³³ completed interviews which were semi-structured; that is, they were “generally organized around a set of pre-determined open-ended questions, with other questions emerging from the dialogue...” (p. 315).

³³ A total of 14 informants were interviewed, 7 in Phase II and 7 in Phase III; the process for selecting these key informants (for both the second and third phases) is discussed later in this chapter, in detail.

ii. **Key Informant Interviews: A Practical Guide**

A practical guide, available from the Center for Health Policy Research at the University of California Los Angeles (UCLA) (n.d.), provides a step-by-step process for planning and conducting a key-informant interview. This process includes ten steps: review existing data; decide what information is needed; brainstorm possible key informants; choose informants; choose interview type; develop an interview tool; determine a documentation method; choose interviewer(s); conduct interviews³⁴; and compile and organize informant interview data.

In the present study, carrying out these first two steps from the UCLA document entails not only building on the literature review and engaging in systematic reflection, but also utilizing findings from the first phase (i.e., the systematic document review). Continuing with the UCLA list, then, the pool of potential informants for this second phase is known and relatively small (as is the pool of potential informants for the third phase of this project), given the historical and current staffing compositions of the CSR/CCP, the size of the greater community in which it operates, and its “outside reach” – both horizontally (i.e., out to other state stroke registries) and vertically (i.e., down into the state’s different clinical settings). Of course, the actual informants (as per UCLA’s fourth step), then, comprise a sub-set of the pool from which they were drawn. Next, the interview type is known (i.e., semi-structured), and the interview materials³⁵ (for both Phases II and III) are presented in Appendix II. Further, as in the first phase of the study, NVivo, Version 10 is, again, the method for documenting information. Finally, for the present project, there is one person (i.e., the researcher) to conduct the interviews and compile all of the resultant information – mostly following a structured process DiCicco and Crabtree (2006) refer to as a

³⁴ It must be stated that informed consent, which was not mentioned in the list from the University of California Los Angeles, was obtained from the all of the informants interviewed in the present study.

³⁵ In addition to the Systematic Document Review Guide mentioned earlier, Appendix II contains an introductory e-mail, a follow-up phone call script, and some consent language, for use in both Phases II and III. Additionally, there are two sets of questions for use in guiding the semi-structured interviews: one for Phase II; the other for Phase III.

template approach, in which the data are organized into a kind of template that reflects prior research and perspectives.

c. **The “How?”**

As indicated above, there was a defined process utilized to select the key informants for this second phase, as well as those for the third phase (which is discussed later). For this second phase (looking “inside” – as opposed to “outside”), the list of potential informants included all former and/or current staff members of the CSR/CCP (n=7, not counting the researcher), as well as all former and/or current AHA/ASA representatives assigned to work with the CSR/CCP (n=3). The first group (i.e., the seven) is comprised of five former staff members (i.e., LC, the original Principal Investigator (PI); TH, a scientific consultant; DR, a data analyst; EW, a fiscal manager; and SK, a program assistant) and two current staff members (i.e., JB, the current PI; and AK, the evaluation lead). The second group (i.e., the three) is comprised of two former representatives (SO and LK-H) and one current representative (MS). All of these individuals were identified as potential informants, with regard to the second research question.

Once identified, the researcher sought to acquire contact information for all of these individuals – as the five former CSR/CCP staff members and the two former AHA/ASA representatives had transitioned into new situations, including, in some cases, in new states. Of the ten potential informants for this second phase, contact information was acquired for nine of these individuals. (All but one former AHA/ASA representative, LK-H, was able to be located; she was lost to follow-up.) Next, these nine individuals were listed by “perceived likelihood of providing useful information” (primarily for Phase II), based upon each individual’s role and tenure in that role³⁶. This prioritized list then served as the order for asking each potential key

³⁶ For example, a principal investigator would likely have more to contribute than a data analyst, and someone with a long tenure would likely be more well-informed than someone with a short tenure.

informant for an interview, as it was decided that all potential Phase II key informants would receive such an invitation. Extending the invitation for an interview included an initial email, with follow-up contact, as needed, via telephone calls and/or additional emails; as well, comprehensive information on consent was sent via email to each potential informant, as part of this follow-up process (Appendix II).

Finally, each potential informant who agreed to be interviewed was scheduled for either an in-person interview or a telephone interview; based upon the informant's preferences. As shown in Figure 3 below, of the nine potential Phase II key informants, one (DR) refused and one (LC) initially consented but then backed out later. Thus, a total of seven Phase II interviews were conducted; three were in-person interviews (JB, AK, MS), and four were conducted via telephone (TH, EW, SK, and SO).

Figure 3: The Phase II Key Informants



After each interview guide³⁷ was pilot-tested and finalized – and a given informant provided informed consent, the process to collect and use information from the interview³⁸ proceeded as follows: First, using the phase-specific interview guide, a semi-structured interview was conducted and digitally audio-recorded. In this second phase, during each interview, the informant was asked what she or he knows about how various contextual factors, programmatic challenges, and change-related beliefs were influential in shaping the registry’s current operational state – in line with the two narratives presented in the previous chapter. Then, while the researcher reflected on the interview and memoed his reflections, the digital audio-recording was professionally transcribed, verbatim, and a transcript was provided to the researcher³⁹. Next, member checking was conducted by the researcher in order to ensure validity of the data collected during the interview (Creswell and Miller, 2000), via informal follow-up conversations with the informant. Finally, the interview transcript was coded in NVivo, Version 10. Coding of the Phase II interview transcripts meant utilizing primarily the aforementioned 9 main codes and 26 sub-codes; however, as was the case with the systematic document review, the source materials gathered in this particular phase (here, the Phase II interview transcripts) did tend to be informative in the other two phases as well⁴⁰. For Research Question 2/Phase II, the approach for working through the key informant interview transcripts is shown over the next three pages in Table IV. This table includes the main constructs related to the operational context, the operational challenges, and the stakeholders’ beliefs – following closely what was laid out in the conceptual framework presented in Chapter 2.

³⁷ There is one guide for the Phase II interviews and a second guide for the Phase III interviews.

³⁸ This applies to each interview, whether it was conducted primarily for Phase II or Phase III.

³⁹ Professional transcription services were provided by Conejo Loco Transcription in Sante Fe, New Mexico.

⁴⁰ For the second research question, a total of 1,970 references were captured and coded in NVivo, Version 10. Of this total, 56.3% (1,109 references) came from the Phase II interviews, 39.6% (780 references) came from the 27 Phase I documents; and 4.1% (81 references) came from the Phase III interviews.

Table IV: The Approach for Phase II

Research Question 2:					
Q2: What factors have contributed to the current state of the program's secondary prevention efforts?					
a. In what way(s) has the program's operational context – including its history, its structure, its culture, and its reach – impacted this state?					
b. What are the operational challenges which have contributed to this state? (<i>e.g., a set of constraints, a skewed focus, an certain approach</i>)					
i. (challenges) faced by the program?					
ii. (challenges) faced by the partners?					
c. How have program stakeholders' beliefs, related to change, influenced the program's current secondary prevention efforts?					
Part a Operational Context	Construct	Indicator	Measure	Data Source	Analysis
	History – this refers to those events/actions in the program's past which, in part, have brought about the current operational state	History may include: ▪ Dedicated staff ▪ Instability ▪ Compartmentalization ▪ Differential view of prevention (i.e., primary v. secondary)	Interviewee mentions: ▪ Changes in staffing ▪ Rates of change ▪ Position within the organization ▪ Secondary v. primary prevention	Key Informant Interviews; program documents (for corroboration)	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review
	Structure – this refers to the program make-up/its "environs" and how it functions (as a result of these traits)	Structure may include traits such as: ▪ Hierarchical ▪ Inefficient ▪ Rule-bound	Examples may include: ▪ Hierarchical stalls ▪ Inefficient decision-making ▪ Prohibitive rules	Key Informant Interviews; program documents (for corroboration)	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review
	Culture – this refers to values and behaviors which describe the working environment	Culture may include: ▪ Approach to planning ▪ Decision-making processes/politics ▪ Innovative practices	Measures such as: ▪ Having a long- or short-term approach ▪ Top-down decisions ▪ Having a successful innovation	Key Informant Interviews	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review
	Reach – this refers to the extent to which the program is in operation with its clinical partners across the state (i.e., how far reaching it is...)	Reach may include: ▪ Hospital volume ▪ LEMSA volume ▪ Geographic coverage ▪ Population served	Measures may include: ▪ Proportion of state hospitals signed up ▪ Proportion of LEMSAs signed up ▪ Gaps in geography ▪ Proportion of state population served	Key Informant Interviews; program documents (for corroboration)	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review

(Table IV: The Approach for Phase II continued)

Part b Operational Challenges (select one) <input type="checkbox"/> Program <input type="checkbox"/> Partners	Construct	Indicator	Measure	Data Source	Analysis
	Constraints – this refers to those things within the program that hamper its ability to achieve its mission	Constraints may be related to the following: <ul style="list-style-type: none"> ▪ Budget ▪ Staffing ▪ Locus of control (e.g., a small locus) 	Measures may include: <ul style="list-style-type: none"> ▪ Fiscal constraints ▪ Loss of staff ▪ Imposed restrictions on setting work plan, forming partnerships 	Key Informant Interviews; program documents (for corroboration)	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review
	Focus – this refers to the program’s emphasis a particular aspect of its workload (in this case, having a differential focus, relative to the two clinical settings)	Focus may include: <ul style="list-style-type: none"> ▪ Uneven recruiting of clinical partners (i.e., across settings) ▪ Collecting data in just one setting ▪ Gauging performance in just one setting 	Measures may include: <ul style="list-style-type: none"> ▪ History/evidence of narrow recruitment (e.g., in one setting) ▪ Proportion of data elements, by setting ▪ Setting-specific performance measures 	Key Informant Interviews; program documents (for corroboration)	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review
	Approach – this refers to the processes that are utilized in order to bring about change or move forward in some aspect of the program (e.g., incrementalism)	Approach may include: <ul style="list-style-type: none"> ▪ Working from a long-term strategic plan (proactive) ▪ Using an incremental approach (reactive) 	Measures may include: <ul style="list-style-type: none"> ▪ Having a long-term strategic plan in place (or not) ▪ (In the absence of a strategic plan), using a defined process 	Key Informant Interviews; program documents (for corroboration)	Qualitative via review of interview transcripts; possible triangulation with reflections, data from document review, literature review

(Table IV: The Approach for Phase II continued)

	Construct	Indicator	Measure	Data Source	Analysis
Part c Stakeholders' Beliefs	Need to Change – this refers to the beliefs of the stakeholders with regard to the program's need to change (i.e., their thoughts as to whether change is even necessary...)	Need to change may include recognition: <ul style="list-style-type: none"> ▪ That the program has not met its goals ▪ That the status quo is not acceptable 	Measures may include: <ul style="list-style-type: none"> ▪ Evidence of goals not being met (or even addressed) ▪ Perceptions that the current functioning is not acceptable ▪ Suggestions that change must occur 	Key Informant Interviews	Qualitative via review of interview transcripts; possible triangulation with reflections, themes from the literature
	Ability to Change – this refers to the beliefs of the stakeholders with regard to the program's ability to change (given a belief that change should occur)	Ability to change may include: <ul style="list-style-type: none"> ▪ A readiness to make change happen (i.e., a motivation to make change happen) ▪ A process designed to make change happen ▪ Sufficient resources to enable change ▪ A climate conducive to change 	Measures may include: <ul style="list-style-type: none"> ▪ A dissatisfaction with the status quo; motivation to make change happen ▪ A plan for change ▪ Resources available for such a plan (e.g., technology, staff resources) ▪ Support for change to occur 	Key Informant Interviews	Qualitative via review of interview transcripts; possible triangulation with reflections, themes from the literature

To conclude, in working to answer the second research question, the primary method utilized is the conduct of seven semi-structured key informant interviews, a process which also includes (a) the subsequent coding of the verbatim transcripts – as per the approach outlined in the table above – as well as (b) the memoing of the researcher’s reflections. Via the use of this methodology, key information is captured with respect to those factors that have given rise to the program’s current operational state – including contextual elements, operational challenges, and change-related beliefs. As was true for the Phase I findings, these results, too, are used to advance the analysis and to generate opportunities for triangulation of the data (Maxwell, 2013).

3. Research Question 3 – and Phase III

a. The “Why?”

The third research question, with its focus on looking to the future, formally initiates the project’s final phase. This final phase is designed to provide some key insights as to what kinds of changes might be made within the registry, such that its eventual efforts lie more broadly along the secondary prevention spectrum – that is, so that there is greater engagement within the pre-hospital setting (than what has been the case thus far). Additionally, the lessons learned from this final phase of the project feed directly into the Action Research Spiral shown in the conceptual framework presented in Chapter 2. The reasoning here is that once the “lay of the land” is established via the first two phases in this project, some action-oriented information is then solicited during this final phase – so that these new ideas might inform the (eventual) process to take the program to a better future operational state.⁴¹ Thus, this final phase of the project includes not only a method to solicit the information but also a structured way to consider how to make prudent use of that information.

⁴¹ As mentioned previously, getting to this better future operational state is beyond the scope of the present project.

b. The “What?”

Seeking an answer to the third research question invokes two complementary processes: generating findings (from collected data) and translating those findings into recommendations for action. First, as in Phase II, the primary method to collect the data in Phase III is the conduct of key informant interviews, and the above-discussed rationale for using informants, as well as the earlier-described interview process (as per the practical guide from UCLA), remain relevant in this final phase. Second, the method for translating the findings into action – again, represented by the Action Research Spiral – is a stepwise one which is designed to enable action and forward movement (Zuber-Skerritt and Fletcher, 2007). While an action research project usually entails a series of steps within a cycle – including planning, taking action, observing, reflecting, revising, and taking action again, as per Zuber-Skerritt (2002), the present project only begins this process; as such, this project is more of a “pre-action” research project, as suggested above. In short, actually moving the project fully to a better future state is beyond the scope of this project. What is “in scope,” though, is this: the information gleaned from the Phase III key informant interviews is translated into key recommendations that are then (eventually) vetted by the staff members of the CSR/CCP. It is this set of key recommendations that informs the program’s future work plan, in terms of goals, objectives, activities, responsible parties (to include partners), and timeframes.

c. The “How?”

i. The Key Informant Interviews

For Phase III (i.e., looking “outside”⁴²), there was a defined process utilized in order to select the key informants, as was true for the second phase (which looked “inside”). For this

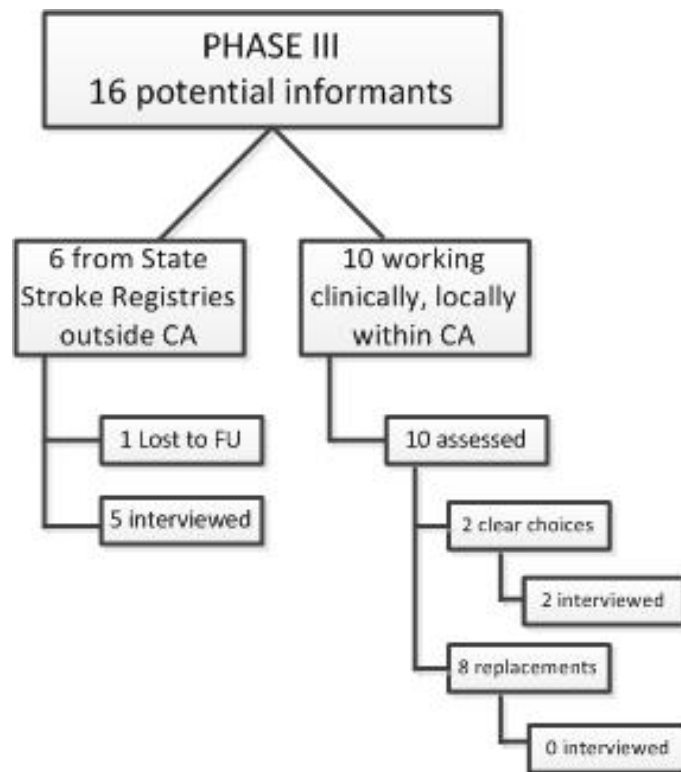
⁴² As per DiCicco and Crabtree (2006), utilizing this “outside” look for Phase III reduces the likelihood of hearing biased recommendations from informants, the kind that could potentially come from utilizing an “inside” look.

third phase, the list of potential informants included individuals from two different groups – one group that represents a “horizontal” look (from the registry) and a second group that represents “vertical” look (from the registry). The former group is comprised of six individuals, each one employed within a federally-funded state stroke registry outside of California (which has the same scope of work as has California’s registry). This group includes the following individuals: DV from Arkansas; JL from Georgia; BS from Iowa; AT from Minnesota; SC from North Carolina; and JB from Wisconsin. Given that these six individuals have been engaged in the same kind of work as is the CSR/CCP Team, it was decided that the researcher would attempt to contact each one and invite her or him to serve as a key informant; these attempts resulted in five interviews, as BS, who had transitioned out of the Iowa program, could not be located.

The latter group is comprised of ten individuals, each one employed in a local California agency or organization that is charged with the provision of clinical care for stroke and is in an active partnership with the CSR/CCP. This group includes these people: PF from the Contra Costa County LEMSAs; LW from the Riverside County LEMSAs; JP from the Sierra-Sacramento Valley LEMSAs; KD from Corona Regional Medical Center; SW from Enloe Medical Center; DM from Hoag Hospital; JCB from John Muir Medical Center; LB from Kaiser Permanente;; VW from San Ramon Regional Medical Center; and FC from Sutter East Bay Medical Center. Notably, some of these potential informants are more well-informed than are others – perhaps because of a particularly specialized scope of work and/or a long tenure in active partnership with the CSR/CCP. Accordingly, these ten individuals were prioritized into a list. On that list, there were two individuals (LW and JCB) who, because of their professional positions and long-standing relationships with the CSR/CCP, rose to the top of the list. It was then decided that the researcher would schedule and conduct interviews until there was saturation (Baker and

Edwards, n.d). With five “horizontal” interviews already conducted, saturation was achieved after the first two “vertical” interviews were conducted (i.e., with LW and JCB, the so-called “clear choices” who rose to the top of the prioritized list). Figure 4 below shows how Phase III resulted in seven key informant interviews.

Figure 4: The Phase III Key Informants



To ascertain information on the types of changes that should occur within the CSR/CCP, in order to begin to usher in a new more fully optimized operational state, Phase III key informants were asked during the semi-structured interviews – conducted in the same fashion as were the Phase II interview – to share and discuss what they know about the kinds of programmatic changes that might accomplish this objective. For Research Question 3/Phase III, the approach to collect and process this information is shown below in Table V.

Table V: The Approach for Phase III

Research Question 3:					
Q3: How might change occur within the program, such that its secondary prevention efforts can be broadened?					
a. How might the program utilize its present practices and/or resources in new ways (<i>e.g., vis-à-vis technology, staffing, and partnerships</i>)?					
b. How might the program acquire and utilize new practices and/or resources – and what kinds of new practices and/or resources might these be? (<i>Maybe knowledge management, cross-functional teams, synergy?</i>)					
c. How might a change process be impacted by:					
i. the program's operational state?					
ii. the program stakeholders' change-related beliefs?					
Present Resources, Used in New Ways	Construct	Indicator	Measure	Data Source	Analysis
	Technology –using the existing technology to create efficiencies (e.g., using technology to free up already-dedicated staff resources)	Technology used in new ways may include: ▪ automating reporting ▪ creating list-serves	Measures may include: ▪ mentions of new uses of technology ▪ innovative ideas	Key Informant Interviews	Qualitative via review of interview transcripts
	Staff Resources – redirecting staff, e.g., to fill in existing gaps	Redirection may mean: ▪ redefining roles	Measures may include: ▪ staffing changes	Key Informant Interviews	Qualitative via review of interview transcripts
New Practices, New Resources	Partnerships – utilizing the program partners to achieve program goals	Partners could be: ▪ assuming workloads from program staff	Measures may include: ▪ suggested transfers of work to partners	Key Informant Interviews	Qualitative via review of interview transcripts
	Knowledge Management – being able to capture/manage/use data to facilitate goal and objective achievement	This may involve: ▪ the data system(s) ▪ how data are used (and by whom)	Measures may include: ▪ suggestions for more broadly using/sharing data	Key Informant Interviews	Qualitative via review of interview transcripts, triangulation with the literature
	Cross-functional Teams – along with partners, creating/using teams focused on particular shared goals and objectives (G&O)	This may include: ▪ G&O being identified ▪ roles being identified ▪ roles being filled	Measures may include: ▪ suggestions to create and use such teams ▪ such teams at work	Key Informant Interviews	Qualitative via review of interview transcripts, triangulation with the literature
Impact of Operational State, Stakeholders' Beliefs	The Potential for Synergy – within and across teams, sharing data	This may include: ▪ data sharing in teams	Measures may include: ▪ examples of synergy	Key Informant Interviews	Qualitative via review of interview transcripts
	Operational State Impact – feeling the impact (of the current state) on a possible change process	Evidence would include feelings about the program's current state	Measures may include: ▪ examples of past changes attempts	Key Informant Interviews	Qualitative via review of interview transcripts
	Stakeholders' Beliefs Impact – feeling the impact (of the beliefs of the stakeholders) on a possible change process	Evidence would include giving credence to the stakeholders' beliefs and their impact	Measures may include: ▪ examples in which an expressed opinion affected progress	Key Informant Interviews	Qualitative via review of interview transcripts

ii. **The Action Research Spiral**

Following the conduct of the seven “outside looking” key informant interviews, Phase III concluded with the experience of the Action Research Spiral, as shown in the conceptual framework in Chapter 2. Methodologically, the spiral included the following steps. First, the information gathered via the Phase III key informant interviews was systematically organized within NVivo, Version 10, into brief topical summaries. Next, these summaries were shared and discussed with CSR/CCP staff members and key partners – in some cases, individually...in some cases, within a group. Further, these staff members and key partners were asked to provide feedback on this information, in terms of the feasibility of adopting what was proposed, in order to take the CSR/CCP to a better future state. Finally, based upon this advice, a set of recommendations was generated, with the shared understanding that these emergent recommendations ought to be pursued (by the CSR/CCP) so that the secondary prevention efforts of the registry would be broadened and be better aligned with the guiding vision as originally stated; again, as previously mentioned, the full implementation and evaluation of these recommendations extend beyond the scope of the present project.

In summary, in working to answer the third research question, the primary method utilized is the conduct of seven semi-structured key informant interviews⁴³, following the same approach taken in Phase II. In these interviews, key information was shared with respect to using present resources (e.g., technology, staff resources, and partnerships) in new ways; utilizing new practices and resources (e.g., knowledge management, cross-functional teams); finding opportunities for synergy; and handling the impacts of ongoing programmatic operations. Phase III also included an entry into the Action Research Spiral, wherein the key findings from

⁴³ A total of 1,619 references were noted for the third research question. The document reviews from Phase I provided 2.0% (32) of these; the Phase II interviews provided 9.8% (159) of these; and the Phase III interviews provided 88.2% (1,428) of these.

the interviews were shared with an ad hoc group of advisors who helped shape a final set of recommendations for moving the project towards a better future state. As was true for the Phase I and Phase II findings, these results, as well, provide opportunities for triangulation of the data (Maxwell, 2013). In triangulating the data, they are shown to be valid; as a result, the emergent recommendations are known to be well-founded, thereby enabling the eventual action to occur.

C. The Data Management Process

For the three phases of this project, a data management plan was carried out as follows: First, for Phase I, an inventory was developed in Excel (as per the University of Michigan, n.d.), in which each of the 27 program documents was listed, by name, date, type, and source. This inventory, which also noted the length of each document, facilitated the loading of, and the coding of, these 27 documents in NVivo, Version 10. Loading was made easier with the documents sorted chronologically (in the inventory), and coding was expedited as the information on document length helped dictate the coding workload within NVivo, Version 10, wherein all of the systematic review data were held.

Next, for Phases II and III, a key informant tracker was developed in Excel. For each of the 14 key informants⁴⁴, it was noted when contact was made, when informed consent was received, when the interview was scheduled, when the audio-file was sent for transcription, when the transcript was received, and when the transcript was coded. Additionally, both the duration of the interview and the length of the transcript were noted, again, to help dictate the workload, once the transcripts were loaded into NVivo, Version 10, again, wherein all of the key informant interview data were held. Certainly, this detailed tracking process enabled the status of each key

⁴⁴ The demographics of the 14 key informants are as follows: 9 females, 5 males; 9 whites, 5 Asians; 3 aged 30-39, 5 aged 40-49, 4 aged 50-59, and 2 aged 60-69; 14 with some post-secondary education, 9 with graduate-level training; 9 from California, 5 from outside of California (i.e., Arkansas, Georgia, Minnesota, North Carolina, and Wisconsin).

informant to be known at any time during the conduct of the second and third phases; furthermore, this tracking process ensured that only informants who had already provided informed consent were interviewed.

Finally, the data management plan included certain provisions related to data security, as follows: First, all data were stored with no personal identifiers. For the 27 Phase I documents, this meant that authors' names were not made known (in the document naming convention), nor could the names be reasonably ascertained upon visual inspection. Similarly, for the interviews conducted in Phases II and III, maintaining security meant that the 14 key informants were assigned codes which were used instead of names. Furthermore, though clearly stated in the audio-recordings, informants' names were not included in the interview transcripts; further, in the reporting of the findings, no reference culled from any of the transcripts was given an exact attribution as to source. These particular security measures were applied both for general storage and in NVivo, Version 10, as appropriate. Next, along with all of the original data, all of the supporting documentation (e.g., each informant's informed consent) was stored securely, with appropriate, separate back-up copies also stored securely "off site." This safeguard (i.e., the "off-site" storage) also included the secure storing of the project file (i.e., the project database and the loaded documents), created and used within NVivo, Version 10.

D. The Data Analysis Process

In this fourth section of Chapter 3, the process for analyzing the data, collected in order to answer the three research questions posed above, is presented. This process for analysis – which is carried out within NVivo, Version 10, and enables the interpretation of the data – includes

steps informed by the work of Onwuegbuzie and Leech (2006). The steps in the process were as follows: First, the data were reduced. As Miles and Huberman (1994, p. 11) write:

“Data reduction is not something separate from analysis. It is *part* of analysis. The researcher’s decisions – which data chunks to code and which to pull out, which patterns best summarize a number of chunks, which evolving story to tell – *are all analytic choices*. Data reduction is a form of analysis that sharpens, sorts, focuses, discards, and organizes data in such a way that “final” conclusions can be drawn and verified.”

In Guest and MacQueen (2007), a number of data reduction techniques are presented, and, for the data collected in this project, three data reduction techniques were utilized (in NVivo, Version 10): (1) structural coding – in which references from the source documents (i.e., the 27 programmatic documents and the 14 key informant interview transcripts) were assigned (in an iterative process, with the use of the codebook presented in Appendix III) to specific deductive codes, which are simply words or short phrases that signify the “spirit” of those references and that are based on the research questions; (2); frequency counts – in which coded references were counted, as a means to identify some of the most prevalent constructs mentioned within the source documents⁴⁵; and (3) code co-occurrence – in which notations were made (usually via memoing) when two or more deductive codes were used for the same reference.

Following the data reduction, the next step was data display. As Miles and Huberman (1994) define it, data display is “an organized, compressed assembly of information that permits conclusion drawing and action.” Put differently, organizing the data in this way simply allows the researcher to look at them and, in so doing, make sense of them; it is, then, inductive. Straightforward data display techniques include drawing diagrams and making organized lists (Onwuegbuzie and Leech, 2006). Again, quoting Miles and Huberman (1994, p. 11):

“...the creation and use of displays is not separate from analysis, it is *part* of analysis. Designing a display – deciding on the rows and columns of a matrix for qualitative data

⁴⁵ Performing frequency counts is a way of “quantitizing” the qualitative data, as per Tashakkori and Teddlie (1998).

and deciding which data, in which form, should be entered into the cells – are analytic activities.”

In the present project, data display was carried out via two main techniques using NVivo, Version 10, after the deductive coding was performed: (1) Selected data were displayed via a word cloud, which is a graphical presentation of word frequency, in which the most often mentioned words are featured most prominently. Via the use of a word cloud, particular emphases within a given construct were made known; moreover, when all of the construct-specific emphases were considered as a collection, key themes emerged. (2) Certain related sets of data were included in cluster analyses, which are designed to gather like observations together into distinct groupings in order to reveal trends and patterns. Cluster analyses demonstrate similarities graphically, by drawing distinct groups, and numerically, by providing similarity coefficients. In the present study, similarities (between certain groups of observations) were known via the use of Jaccard’s coefficient, which is defined as the intersection of at least two groups divided by the union of those same groups (Deng, Siersdorfer, and Zerr, 2012). To be sure, after the data were reduced (primarily via coding) and then displayed (via word clouds and cluster analyses), the content began to reveal some key themes.

The final step in the data analysis process was data integration, in which all of the data are brought together to inform the interpretation. Miles and Huberman (1994) suggest that the integration of the data – i.e., enabling “ever and ever greater linkage among variables, expressed at a more and more powerful level” (p. 254) – is a key method of generating meaning...of drawing conclusions. In this project, integration of the data was initiated and informed early on by the conceptual framework presented in Chapter 2, and, later, by the processes of reducing the data, displaying the data, and writing memos in NVivo, Version 10. Indeed, the data from

Phases I and II (mostly) facilitated the understanding of the current operational state of the CSR/CCP, as well as those factors which worked to bring about that state; additionally, data from Phase III (mostly) enabled the development of key recommendations which were then entered into the Action Research Spiral – so that there could be (eventual) movement towards broadening the secondary prevention efforts of the state stroke registry.

Finally, these steps described above presented opportunities for triangulation in this study. Triangulation occurs when data from a variety of sources begin to converge on a fact or a set of facts, such that a researcher's comprehension of a phenomenon of interest is increased (Yin, 2009). Furthermore, as this occurs, there is, as May (2002) states, "...good reason to conclude that a persuasive case can be made" (p. 211). In the present study, because the phase-specific data across the three phases were informative for all three of the research questions, triangulation did occur, opportunities for learning did appear, and an evidence-based set of recommendations did emerge. Thus, moving forward (i.e., after this study is concluded), the CSR/CCP is equipped to begin a change process in order to move beyond its alleged sub-par current status quo towards a better, more fully optimized future state in which the program's secondary prevention efforts are being implemented more broadly (than before).

E. Validity Considerations⁴⁶

Once the data were analyzed, the researcher gave consideration to the validity of the conclusions being drawn. To this end, the following four "standard tests" were passed in this project: construct validity, internal validity, external validity, and reliability (Yin, 2009; pp. 40-45). First, construct validity – which relates to not only stipulating the concepts under investigation but also how they are properly operationalized – can be achieved via the use of

⁴⁶ These are considerations beyond the validity of the coding process, which is discussed in Appendix IV.

multiple sources of evidence, during data collection. As this project collected and used data from a number of document reviews and two phases of key informant interviews, construct validity is assured in this project.

Second, internal validity – which seeks to describe a causal relationship for the phenomenon under investigation – can be accomplished via the use of pattern matching, during data analysis. Since patterns did, indeed, emerge (both within and between the project phases – e.g., as the phase-specific findings were found to be germane to all three of the research questions), internal validity, as well, is present in this project. Another method known to ensure internal validity is to have a second person code (a subset of) the data, and this was done in the present study, as noted previously and further described in Appendix IV; hence, this is further evidence of this present study's internal validity.

Third, external validity – which concerns defining the broader realm in which a study's findings can be applied – can be realized via the use of theory within a study; this is analytical generalization, and it is achieved in the study design. Given that this project has clear theoretical underpinnings which bolstered the study design process (and which were discussed in the literature review), the use-of-theory tactic is being employed to meet this standard for external validity.

Finally, reliability – which requires that the study protocols can be repeated with the same results – can be ensured through the development of a clear study protocol and documentation, during the data collection phase. As has been described above, this tactic is in use in the present project, thereby ensuring its reliability. Indeed, through the use of these various tactics within this project, the overall quality of the study is high – and the validity of the conclusions drawn is clear.

F. Chapter Summary

In this third chapter, the methodology for the present study – which was granted an exemption from the Institutional Review Board of the University of Illinois at Chicago (Appendix V) – was presented. Descriptions of the study setting; the study design and study methods; the data management process; the data analysis process; and the validity considerations were provided. By following these methods, this project has been able to accomplish its stated aims – that is, it has done the following: describe what the CSR/CCP’s current secondary prevention efforts are, relative to what they were expected to have been (by the present time); identify the various factors that were influential in bringing about this current programmatic state; and investigate what changes might occur, such that the current, seemingly sub-par status quo will not persist. In the next chapter, the study findings are presented.

IV.

Chapter 4: Study Results

Introduction

The purpose of this fourth chapter is to present the project results, by research question. Question one examines the current operational state of the California Stroke Registry/California Coverdell Program (CSR/CCP), while question two seeks to describe those factors which gave rise to this current state. Finally, question three considers what kinds of changes might be necessary to move the CSR/CCP beyond this current state, given an interest in doing so. While these results, generated via content and thematic analyses conducted in NVivo, Version 10, are discussed in detail later in this fourth chapter and interpreted in the next chapter, they are first summarized here in order to give some context to what follows. By research question, the types of findings, in general terms⁴⁷, are shown in Table VI. Of note is that the findings are based on all of the data collected via the systematic document review and the 14 key informant interviews.

Table VI: Types of Findings by Research Question

Research Question	Findings
1 (The Registry's Current State?)	The current state of the stroke registry is characterized by unmet recruitment goals – as considerably fewer hospitals and LEMSAs (than anticipated) have joined the registry; infrastructure-related concerns – including experiencing a data system development process which has failed thus far to deliver a functional system; a challenging partnership – that is, with the data system development team; and very little Quality Improvement – as registry staff members have had to spend additional time on other aspects of the program.
2 (The Influential Factors?)	The influences (on the registry's current state) include contextual factors (such as changes in staffing patterns that have reduced the program's capacity, unilateral management decisions that have removed programmatic assets, and the registry's "lack-of-fit" within the larger organization because of its secondary prevention focus); operational challenges (including budgets that are insufficient to carry out the registry's scope of work, and an external locus of control which limits the registry's planning processes); and held beliefs (i.e., by registry stakeholders, vis-à-vis change – both the need for change and the ability to change).
3 (Recommendations for Change?)	A number of recommendations, both foundational (e.g., discussing change in terms of improvement, increasing visibility, and improving communication/coordination) and operational (e.g., reworking/replacing the data system, changing recruitment practices, sharing data/information more widely, and utilizing cross-functional teams), are proffered as means for moving the registry towards a better future state.

⁴⁷ This presentation of results, stated in very general terms, is not comprehensive.

As shown above, (1) the current state of the CSR/CCP is known through findings related to the program's four main areas of activity: Recruitment, Infrastructure, Partnerships, and Quality Improvement; (2) numerous factors have been identified and are considered to have been influential in shaping the program's current state; and (3) certain foundational and operational changes have been suggested in order to effect change in the program's current state. In this fourth chapter, the specific findings germane to these three overarching ideas, which correspond to the three research questions posed in the first chapter, are explored in depth.

The Format for Sharing the Results

In sharing these results, the following 5-part format is utilized: First, a key concept or issue is raised as a frame for what follows. The inclusion of this frame allows the reader to have a sense of what piqued the interest of the researcher and what specifically he sought to learn – in other words, why this idea is important (i.e., “Why It Matters”). Second, the main constructs, which have been used to more clearly define the issue in question as well as to explore how it can be answered, are enumerated⁴⁸. This enumeration provides further insight into the research question of interest. Third, when appropriate, for each enumerated construct, a short statement is made as to what specific steps were taken in order to produce a particular finding or set of findings. Fourth, the particular finding or set of findings is shared as a way to build a particular case, using a variety of presentation methods, including counts, lists, word clouds, clusters, tables, narratives, quotations, and summary statements, as appropriate (i.e., “Building a Case”). Finally, before moving to the next enumerated question-specific construct and then to the next research question, an explanatory or “take home” statement is presented in order to impart to the

⁴⁸ These research-question-and-phase-specific constructs appear in Tables III, IV, and V in Chapter 3.

reader the significance of the finding of interest and to tell more of the story that is unfolding. Below are the results, presented by research question, using this format.

A. Research Question 1: Findings

What work is being done in terms of secondary prevention within the California Stroke Registry/California Coverdell Program? How does that work compare to the program's original vision for secondary prevention?

This first research question is designed to ascertain the CSR/CCP's current operational state and then to assess whether that observed state is in line with the program's original vision (i.e., that which was expected)⁴⁹. Because the notion of an operational state can be rather broad, a certain structure was created and imposed in order to more concretely understand and discuss this particular idea. Thus, the current operational state is viewed and assessed across four main constructs, each of which is elaborated upon further and shared within the framework outlined above. For the first research question, these four main constructs (i.e., Recruitment; Infrastructure; Partnerships; and Quality Improvement) are discussed below, in succession.

1. Recruitment

Why It Matters

First, in assessing the current operational state, it is important to know the degree to which the CSR/CCP has been able to recruit local clinical partners – that is, LEMSAs (i.e., local EMS agencies) and hospitals – into registry membership. The importance is two-fold: First, recruitment is one of the program's main areas of activity in working to optimize clinical care for

⁴⁹ What was planned in terms of recruitment was to have enrolled (1) enough hospitals into the registry that 50% of the State's annual stroke volume is captured; and (2) 100% of the LEMSAs in which the enrolled hospitals operate.

stroke in California; if the output of this activity is contrary to that which was expected (and it is less than expected), then that may be an indication that there is a problem operationally, as was suggested in the first chapter. Second, this construct provides information on the registry's scope and its reach across the state into the local provider communities; to wit, it tells a part of the story about the registry's current operational state, for better or for worse – as the scope and reach, to some degree, dictate how programmatic resources are employed. In short, if the recruitment-efforts-to-date have, in fact, failed to yield the expected results (e.g., how many participants, from what geographic area), then the CSR/CCP on the whole is likely to be in a sub-par state.

Accordingly, data on the actual results of the recruitment efforts are compared to data on the expected results of the recruitment efforts in order to determine if the registry's current operations, in this area, align with the planned operations; moreover, this alignment (or misalignment) is assessed across the two clinical settings (i.e., the pre-hospital setting and the in-hospital setting) in order to have a sense of whether that finding is differential. If there is misalignment, first of all, and, secondly, if it is observed to be differential across these clinical settings, then these findings support the claims (in this regard) made by the problem statement presented in Chapter 1. Furthermore, were this the case, it would support the underlying premise, here, that the registry efforts ought to be broadened so that it operates more fully across the care continuum – particularly in the pre-hospital setting.

Building a Case

Hereafter, for this first construct, a case is built⁵⁰. In building this case – i.e., that the efforts of the CSR/CCP were insufficient to enable the recruitment goals to be met, thereby

⁵⁰ Note that across the different constructs, cases are built. Collectively, these cases may lend support to claims made in Chapter 1; furthermore, they might suggest that the registry's ongoing and future operations ought to be occurring more broadly along the care continuum, particularly within the pre-hospital setting.

causing, to some degree, misalignment with the program’s original vision – results of the content analyses (e.g., counts of contributing sources and references, similarity comparisons) are provided first. Following the presentation of these results, exemplar qualitative data are shared, and the emergent themes are discussed.

Results of the Content Analyses

Three sets of descriptive results (i.e., from the content analysis) are presented in building this particular case: (1) code-specific counts of contributing sources⁵¹ and references; (2) a Word Cloud (which graphically displays the most frequently used words within a given selection of text); and (3) similarity indices generated in comparing content from two codes of interest.

First, in NVivo, Version 10, four distinct codes⁵² were used to investigate the planned and the actual recruitment of hospitals and LEMSAs. In coding the content of the documents from the systematic document review, as well as the content of the transcripts from the key informant interviews, selected information was categorized within each of the four distinct codes shown in Table VII below, thereby producing four code-specific bodies of knowledge. For each code, **counts** are given for (1) the number of sources making mention of the construct (out of 41 total sources) and (2) the number of references made to the construct.

Table VII: Recruitment-specific Codes: Sources and References

Code ⁵³	Contributing Sources	References
“planned hospital recruitment” (PI_1s_Recruit_Hosp_Plan)	21	73
“actual hospital recruitment” (PI_1s_Recruit_Hosp_Real)	27	119
“planned LEMSA recruitment” (PI_1s_Recruit_LEMSA_Plan)	12	42
“actual LEMSA recruitment” (PI_1s_Recruit_LEMSA_Real)	23	70

⁵¹ The data sources total 41 (27 documents and 14 interview transcripts). For a given construct, not all 41 sources contributed information.

⁵² All of the codes are presented as part of the Code Book, which is included in Appendix III.

⁵³ The parenthetical codes are those which were used in NVivo, Version 10.

To elaborate, the “planned hospital recruitment” code (shown in the first row) captures all mentions (73 of them) of the registry’s plans to bring hospitals into membership. Certainly, this code-specific body of knowledge has value on its own; however, even greater insight is gained when considering it in relation to other code-specific bodies of knowledge. For example, recruitment of hospitals (i.e., both “planned” and “actual,” with 192 total references [i.e., 73+119], as shown in the first two rows above) can be considered in relation to recruitment of LEMSAs (i.e., both “planned” and “actual,” with 112 total references [i.e., 42+70], as shown in the second two rows above). From these counts, it is clear that hospital recruitment got “more press” (71.4% more) than did LEMSAs recruitment – a curious finding which might suggest skewing. This is noteworthy, as a finding of differential efforts might be partially explanatory with regard to the purported sub-par state of the registry. Even so, this quantitative information, while informative, represents an incomplete look at the data (Morgan, 1993)⁵⁴. Simply counting contributing sources and captured references provides no insight as to what these data of interest reveal. Thus, the actual content of these references is assessed next.

With respect to the actual content, several key findings merit mention: First, an analysis of the content of the references found within these four recruitment-related codes supports the earlier suggestion (based solely on counts) that hospital recruitment was featured much more prominently (in the source documents) than was LEMSAs recruitment. This finding is also evident in the **word cloud** shown below in Figure 5. In this figure, the words “hospital” and “hospitals” stand out quite visibly; in contrast, the words “EMS,” LEMSAs,” and “LEMSAs” are rather less obvious, thereby supporting the idea that there has been less attention paid to recruitment in the pre-hospital setting. Again, following the suggestion that recruitment on the

⁵⁴ Morgan suggests that counting references can be of value in qualitative data analyses; however, he advises that counting references should be one of many steps performed in such analyses.

whole was “less than” expected, this differential finding here (i.e., that hospital recruitment received more attention than did LEMSA recruitment) is important because it suggests that the registry’s efforts going forward may need to be re-doubled within the pre-hospital setting.

Figure 5: Word Cloud related to Recruitment



Finally with respect to the actual content, a **cluster analysis** of these codes shows how similar the code-specific contents are. As shown in Table VIII below, the contents describing what was planned for hospital recruitment and what actually occurred in terms of hospital recruitment are moderately dissimilar (Row 1), with a Jaccard’s coefficient (which quantifies how similar two “objects” are) of 0.56⁵⁵. Likewise, the plans for LEMSA recruitment and the actual LEMSA recruitment were fairly dissimilar (Row 2), with a Jaccard’s coefficient of 0.52.

Table VIII: Cluster Analysis related to Recruitment

Code 1	Code 2	Jaccard's coefficient
"planned hospital recruitment"	"actual hospital recruitment"	0.56
"planned LEMSA recruitment"	"actual LEMSA recruitment"	0.52

⁵⁵ A Jaccard coefficient of 1.00 would indicate that the items being compared are identical, given that this measure is defined as the intersection of at least two groups divided by the union of those same groups. With coefficients of 0.56 and 0.52, the findings here suggest that the code-specific contents being compared are rather dissimilar. See Deng, Siersdorfer, and Zerr (2012) for more information.

The message here – as evidenced by the observed dissimilarities – is twofold: First, recruitment into the registry, in actuality, seems rather different than that which was expected (based upon what was planned, which is noted above); more information on this observed difference is included later. Second, across the two clinical settings, the observed difference seems somewhat more pronounced within the pre-hospital setting than it does within the in-hospital setting. On the face of it, this two-fold message, as it relates to recruitment, seems to support the supposition that the program is failing to achieve its best possible outcome; moreover, this message may well fit with the suggestion that change should take place, such that the registry’s prevention efforts are occurring to a greater extent within the pre-hospital clinical setting (than has been the case historically). Of course, a more thorough understanding of what has been observed requires delving into the actual content of the references (i.e., going beyond making comparisons regarding similarity). Accordingly, what follows are descriptions of the emergent themes, as per the thematic analysis.

The Emergent Themes

Related to recruitment, the references, as captured by the content analysis, came together and enabled key ideas to emerge in the thematic analysis. These key themes – which speak not only to various recruitment-related concerns but also to potential leverage points for positive change (which, of course, are pivotal within Phase III of this project) – are discussed in the narratives below. Furthermore, these key themes are elaborated upon later, along with themes related to Infrastructure, Partnerships, and Quality Improvement, via the presentation of some exemplars from the project’s source documents. These quotations are presented in summary in Table XVII, immediately preceding the Phase II results; as above, all 41 data sources were used to cull out these quotations.

*Falling Short: "...it's limited, limited recruitment..."*⁵⁶

The first emergent theme related to recruitment is that there were reasonable goals set when the CSR/CCP was envisioned circa 2007, and these goals have since gone unrealized (thus far); this is a "planned" versus "actual" look at the data. To reiterate, the original goals related to recruitment are these: First, the CSR/CCP planned to recruit enough hospitals into the registry to enable the capture of data on 50% of the state's annual total stroke volume (by mid-year 2015). Second, the expectation was that every LEMSA in which a partner hospital was operating would be brought into the registry. Thus, the goal for this care setting was 100% of the LEMSAs of interest, as dictated by the hospital partners being enrolled into the registry. However, what was planned is not what was achieved, as has been mentioned above.

The data bear out this theme: In the CDPH's response to the original FOA, in terms of hospital recruitment, it was stated (page 11 of the Project Narrative):

"Our goal is to include 50 percent of all stroke cases annually in California (approximately 100 hospitals). Consideration will also be given to ensuring that the sample of participating hospitals represents both rural and urban hospitals, as well as public and private hospitals."

Moreover, in a State Update from September 2012, a targeted recruitment strategy was described, and this prediction was made: "If we are successful in securing commitments from all of these targeted hospitals, we will exceed our goal of having 50% of the state's strokes (based on an annual total) included in the registry." However, as early as the Site Visit during Year 2, it was evident that this goal would not be achieved. From the Year 2 Site Visit materials (in a November 18, 2013 Memorandum written by AV [initials] from the CDC), it was stated:

"...a goal was to have 50% of stroke cases in the registry by the end of year 3. However, at the end of year 1, there were only 5% of stroke cases which is not a sufficient amount to expect to have 50% in two years."

⁵⁶ From the interview with Phase II, Key Informant #2.

A key informant⁵⁷ corroborated this information, stating:

“Our goal, originally, when we wrote this grant, was we would be able to collect stroke data from fifty-percent of the hospitals in California, which, in California, is over two hundred hospitals. And, you know, we’re nowhere near that goal.”

This finding of “falling short” is true for the recruitment of hospitals (as revealed by 24 of 27 Phase I documents and 6 of 14 key informants [all 6 are from Phase II]) and LEMSAs (as revealed by 18 of 27 Phase I documents and 7 of 14 key informants [6 of 7 are from Phase II]). Indeed, the registry has secured considerably fewer clinical partners (i.e., hospitals and LEMSAs) than anticipated. As stated above (in quoting the Memorandum from AV), the realized numbers for annual stroke hospitalizations, captured by the hospitals enrolled in the registry, are in the 5% range. This proportion is about one-tenth of what was originally planned and about one-twentieth of the annual total stroke hospitalizations in California. Additionally, only 3 LEMSAs (out of the 15 LEMSAs in which the registry’s partner hospitals are operating and out of the 33 total LEMSAs in California) have chosen to partner with the CSR/CCP⁵⁸.

From the Reapplication for Year 3 (page 5 of the Project Narrative):

“As has previously been described, California has 33 individual LEMSAs (at present), each with the independent authority to implement and monitor a stroke system of care. This structure requires the Coverdell Program to cultivate, establish, and maintain relationships with each LEMSA. To-date, we have partnered with three LEMSAs (Contra Costa EMS, Sierra- Sacramento Valley EMS, and Riverside EMS)...”

Thus, actual recruitment in both settings has fallen short of what was expected, based upon what was planned. The data from the Phase I documents indicate further that the CSR/CCP staff members decided to abandon these *a priori* numeric recruitment goals, after not realizing them,

⁵⁷ Phase II, Key Informant #1.

⁵⁸ Of note is that the 3 partner LEMSAs serve 4.5 million California residents, while the other 12 LEMSAs (i.e., those which chose not to join the registry) serve 26.5 million California residents; taken together, the potential reach is 31.0 million of California’s 38.1 million residents. Indeed, the actual reach, in terms of the LEMSAs, indicates that the CSR/CCP fell rather short of achieving its LEMSA-specific recruitment goal, just as it did with its hospital-specific recruitment goal.

and, instead, chose to focus on the retention of existing clinical partners, especially given the circumstances under which they were working and the events which they were experiencing. As stated in the Reapplication for Year 3 (page 17 of the Project Narrative):

“At the time of the writing of our response to the FOA, we felt, based on work already underway, that growing our registry to include 50% of the strokes in California was a reasonable goal... However, the Program staff have come to realize during Y1 and Y2 that these two goals are out of reach... Hence, the Program is planning to maintain its current efforts related to recruitment/retention, given its goals around pre-hospital data acquisition and linkage, as well as ongoing QI, and measure reach and impact without having a specific numeric goal in mind...”

As these statements indicate, the program’s recruitment goals, set before the federal award was made, went unrealized. What is more is that these goals were ultimately discarded, and the CSR/CCP simply maintained its recruitment efforts as they were.

Challenges: Certain circumstances and events precluded these goals from being realized

The next developing theme is that the program’s efforts to realize the recruitment-related goals were hampered. While this idea is discussed more fully later – in presenting the results related to the second research question, one particular circumstance is especially salient here: too few dedicated human resources. The original recruitment efforts, mounted in response to the above-listed goals, entailed having two individuals (one within the CSR/CCP [AK] and a second within AHA/ASA) who, together, carried out the activities required to recruit, enroll, and retain clinical partners; however, some source documents and key informants described two changes (for the worse) which caused these activities to be curtailed. First, it was unilaterally decided by Senior Management within the Branch wherein the CSR/CCP resides that (1) the CSR/CCP’s fiscal manager (EW) would be reassigned to work elsewhere within the Branch and (2) that person’s duties would have to be assumed by the one of the remaining CSR/CCP staff members. Ultimately, these duties were assumed by AK, the CSR/CCP staff member who was the lead on

recruitment. This meant that she could not do as much in terms of recruitment as she had planned. From the November 2013 State Update (names have been replaced with initials):

“EW, our fiscal manager for Coverdell, was assigned (by our Branch’s senior management) to other duties in the Branch. As a result...AK, a Research Scientist who works half-time, is now...handling the program’s fiscal responsibilities.”

Second, within AHA/ASA, the representative (LK-H) who was assisting AK with recruitment, left her position, which remained unfilled for nearly one year (until MS was hired).

As stated in the Reapplication for Year 3 (page 8 of the Project Narrative):

“...within our local AHA/ASA affiliate, the Regional Director for QI Initiatives position has been vacant, and this has meant that we have not been able to be as active in our recruitment- and QI-related activities as we had hoped to have been.”

These two changes – AK having to assume EW’s workload and the AHA/ASA vacancy – were impactful on the program’s ability to recruit hospital and LEMSA partners. This was stated explicitly within the Year 2 Annual Report (page 25 of the Project Narrative), as follows: “...in terms of recruitment, given changes in staffing (both within the CSR/CCP and within AHA/ASA), during Year 2, hospital recruitment, out of necessity, became essentially ‘passive’...” While other circumstances and events impacted the program’s recruitment efforts (e.g., the stalled process to develop the data system, as discussed below), the reduced workforce capacity is likely the most notable one.

2. Infrastructure

Why It Matters

The current operational state is also assessed in terms of the registry’s infrastructure, to include the development of its data system, the establishment of performance measures, and the availability of human resources, which was touched on briefly above. The central issue for this

construct concerns the adequacy of these different elements of the infrastructure; any suggestion that the infrastructure is problematic is also a suggestion for needing improvement, which is the philosophy that undergirds this project, of course. It is of interest, therefore, within the context of the first research question, to know: (1) whether the data system has been developed and enabled to facilitate data collection and reporting in both the pre-hospital and in-hospital settings as planned⁵⁹; (2) the extent to which setting-specific performance measures have been established and used; and (3) the adequacy of staffing in the program, as per its scope of work. The findings germane to each of these key issues are presented below.

Building a Case

As with Recruitment, for this second construct, case building is utilized; however, in this narrative, this process is undertaken for each component of Infrastructure (i.e., the data system, the performance measures, and the staffing). In building this case⁶⁰ (by component), the results of the content analyses (e.g., counts of references, similarity comparisons) are provided first, again, as with Recruitment. After the presentation of these results, the qualitative data are shared, and the emergent themes are discussed.

a. Data System Development

Results of the Content Analyses

In the same way the recruitment efforts are evaluated, the data system development process, as one component of the Infrastructure construct, is assessed – specifically by observing what was planned (which is noted above) and what was realized for both the pre-hospital and in-

⁵⁹ The data system, by design, is supposed to collect, standardize, and link, at the patient-level, clinical data from the pre-hospital setting and the in-hospital setting – in order to enable a continuous patient record (i.e., across the care continuum) which can be used to inform local-level quality improvement initiatives.

⁶⁰ The case here is that the infrastructure of the CSR/CCP is, in some way(s), problematic and perhaps out of alignment with the program's original vision.

hospital components of the data system. This assessment process entails: counting (and comparing counts of) code-specific references captured during the coding process; performing a cluster analysis to determine the similarity of the contents of selected codes; and studying the themes that emerge when the code-specific contents come together in the thematic analyses.

First, through a number of comparisons (e.g., data-system-related plans versus data-system-related accomplishments; the data system’s capacity in the pre-hospital setting versus its capacity in the in-hospital setting), more about the CSR/CCP’s current operational state is known. As well, any discrepancy between the pre-hospital and in-hospital clinical settings, with regard to the data collection and reporting, is highlighted. The logic behind making these comparisons is this: If the data system development has fallen short of what was intended and/or if there is a marked difference in capacity across the two clinical settings, then this may be an indication that the registry’s current operational state is sub-par, given that the data system development process is one of the program’s major foci.

As with recruitment, via NVivo, Version 10, four code-specific bodies of knowledge were generated via the coding of the documents from Phase I and the interview transcripts from Phases II and III. They are as follows: “planned” hospital component of the data system; “actual” hospital component of the data system; “planned” LEMSA component of the data system; and “actual” LEMSA component of the data system. The **counts** of contributing sources (out of 41) and references captured for these constructs are shown in Table IX.

Table IX: Data-system-specific Codes: Sources and References

Code	Contributing Sources	References
“planned hospital component of the data system” (PI_2s_Infrast_DataSys_Hosp_Plan)	39	294
“actual hospital component of the data system” (PI_2s_Infrast_DataSys_Hosp_Real)	23	110
“planned LEMSA component of the data system” (PI_2s_Infrast_DataSys_LEMSA_Plan)	37	281
“actual LEMSA component of the data system” (PI_2s_Infrast_DataSys_LEMSA_Real)	20	111

The table above shows the following: (1) The references related to what was planned for the data system greatly outnumber the references related to what was actually realized – nearly three to one (i.e., 294 + 281 and 110+111). This discrepant finding supports the idea that the data system plans may have gone unrealized; in other words, seemingly much more was made of the plans than of their execution. This notion is discussed further, later. (2) This phenomenon appears to be occurring cross the two setting-specific components of the data system – which suggests that the efforts of the data system development team were not successful in even one aspect of the system. Again, more information is provided based upon a review of the actual content, not just the counts, and this is presented later.

Next, a **cluster analysis** of the actual content captured within each of these four data-system-related codes reveals certain dissimilarities. First, as shown in Table X below, the code-specific content describing what was planned for the hospital component of the data system (discussed above) and the code-specific content describing what was realized for that part of the data system are dissimilar, with a Jaccard’s coefficient of 0.45. As a coefficient of 1.00 means the content of the two groups under comparison is exactly the same, this finding of 0.45 suggests considerable differences. In fact, this degree of dissimilarity means that more than half of the total content (from both codes) was found in just one code or just the other – and not in both. The same is true for the LEMSA-specific comparison (Jaccard’s coefficient = 0.45); in short, the development of the LEMSA component of the data system was also “less than” expected.

Table X: Cluster Analysis related to Data System Development

Code 1	Code 2	Jaccard’s coefficient
“planned hospital component of the data system”	“actual hospital component of the data system”	0.45
“planned LEMSA component of the data system”	“actual LEMSA component of the data system”	0.45

Within the context of this construct, these comparison-specific similarity metrics suggest that the actual development of the data system, across both the hospital and LEMSA components, does not seem to match with the plans for its development. As with recruitment discussed above, this similarity comparison seems to indicate that the CSR/CCP is falling short of its goals. It follows that if this is, indeed, the case, then a change process may need to be initiated. Again, though, the actual content of the captured references lends more insight into the program's current operational state, as per Morgan (1993). Thus, via thematic analysis in NVivo, Version 10, key themes were identified. These themes are discussed below, and some summary exemplars related to these themes are included in Table XVII presented later in the chapter.

The Emergent Themes

The data system development has been problematic

In terms of the data system development process, the first finding to emerge from the thematic analysis is as follows: The data system development process has not gone smoothly; in fact, the process has experienced multiple considerable delays. As early as November 2012, it appeared that the system was close to development (from the State Update): "Our Integrated Data Platform/Report Generator is continuing to undergo some enhancements before it is made available for use by our participating hospitals. It is anticipated that these enhancements will be completed by the beginning of 2013." About four months later (i.e., in March 2013), in the Reapplication for Year 2, it is stated: "At the time of this writing, the integrated data platform is in its final stages of completion..." But completion was not imminent at that time, as evidenced by this statement from the July 2013 State Update: "Our Integrated Data Platform/Report Generator is in the QA (Quality Assurance) testing phase before it is made available for use by our participating hospitals. We expect to have this testing phase completed soon." It was around

this time that the system fell out of the testing phase and went back into the development phase.

In the Year 2 Site Visit materials (from October 2013), it is noted that, “Activities of the Integrated Data Platform (IDP) are continuing.” Additionally, in the Reapplication packet for Year 3 (submitted in February 2014), this activity is proposed (for Year 3): “Continuing development of the Coverdell Program’s integrated data platform/reporting system...” This comment is noted, as well: “...the development of the integrated data platform (Eureka-CSR) has taken longer than anticipated.” Then, perhaps not surprisingly, the already-delayed development plan is pushed further into the future (i.e., to mid-2015), with this statement (from the Reapplication packet for Year 3, page 18 of the Project Narrative):

“By the end of Y3, the program intends to have the capacity to receive, store, and link pre-hospital data with in-hospital data, consistent with what was outlined in our response to the FOA, in order to inform QI efforts across the stroke care continuum.”

However, just two months later, in the May 2014 State Update, in discussing the data system in terms of the Software Development Cycle (SDL), this was noted: “...we are now facing some down-time in the SDL, and we need to develop a plan for getting back on track.” Five months later, in the Year 3 Site Visit materials, is this: “The IDP remains under development, with no pre-hospital functionality yet.” This same sentiment was again expressed in the January 2015 State Update, and, to-date, the Eureka Team has not delivered a functional data system. This fact is true for both the pre-hospital and in-hospital components of the system, which speaks to both the Infrastructure construct as well as to the registry current operational state. To sum up this theme, as one key informant⁶¹ described: “...we’ve had some bad luck with a contractor who was working with us on the development of the system and, you know, because of that, we, still, years later, were left with nothing really useful.”

⁶¹ Phase II, Key Informant #1.

Next, while the delay in the development of the data system has been problematic in and of itself – as the collection and reporting of data across the care continuum⁶² has been impeded, the ramifications extend out to other aspects of the program. As described in the program’s response to the original Funding Opportunity Announcement (page 2 of the Abstract), the data system is designed to “...allow LEMSAs and hospitals to link patient data, so that the continuity of care, from the time of symptom onset to the time of hospital discharge, can be monitored, tracked, and evaluated.” This source document continues (page 2): “A linked data system will improve the quality of care provided to acute stroke patients and will reduce costly hospital readmissions.” Since the data system plans have not been realized, critical activities, which are data-driven and undertaken in order to meet these particular ends, have been curtailed. In short, this problem has had a ripple effect. With an incomplete data system, it is more challenging to initiate and nurture key partnerships as well as to implement and evaluate quality improvement initiatives. One key informant⁶³ said it this way:

“...in the case of the database creation, the resources, perhaps, were [pause] were stuck to some extent in that effort, which wasn’t very productive, and that meant that there was [pause] little effort going in some of the other areas that, perhaps, needed some attention.”

In sum, the data system development process has been problematic, and this situation has had spill-over effects into other aspects of the program, including recruitment, discussed previously, and quality improvement initiatives, discussed later. Indeed, this problem and its consequences speak to the registry’s current operational state.

Too many resources have been consumed in developing the data system

The data sources – particularly those developed or acquired more recently – suggest that the data system development process consumed too many program resources, especially when

⁶² This refers to the collection of patient-level data in both the pre-hospital and in-hospital clinical settings.

⁶³ Phase II, Key Informant #6.

the process began to languish, as described above. Moreover, these sources suggest that this occurred because the development team (i.e., the Eureka Team from the California Cancer Registry), under contract with the CSR/CCP, made numerous promises that were not honored. As one key informant⁶⁴ stated, they (i.e., the contractors) “...were going to deliver the world [laughter] for the registry, uh, the Stroke Registry and that didn’t happen and so many changes within that also affected the progress and the movement forward on that scale.” Another informant⁶⁵ had this to say about the investment of resources into the development of the data system (or IDP, Integrated Data Platform, as it has been called): “it has dictated everyone’s time and how it’s being spent, because [pause] you know, your time [laughter in voice] like has been spent having to work on this IDP...” She continued, saying: “Many staff hours were dedicated from our side in working with them and helping them [pause] get a, something developed. And, in the end, nothing was developed.” To be sure, with respect to the Infrastructure construct, the poorly executed data system development process not only precluded the program from carrying out its planned activities but also consumed too many resources.

b. **Performance Measures**

Results of the Content Analyses

The second part of the Infrastructure construct (from Phase I – which, in total, includes Recruitment, Infrastructure, Partnerships and Quality Improvement) addresses performance measures. Within this context, any evidence related to planning for, establishing, or using one or more performance measures is of interest. Moreover, given that the supposition is that there is a differential emphasis placed on the in-hospital clinical setting, relative to the pre-hospital clinical setting, assessing whether there is skewing across the two clinical settings, with respect to the

⁶⁴ Phase II, Key Informant #4.

⁶⁵ Phase II, Key Informant #1.

use of performance measures, is revealing. Indeed, more about the CSR/CCP's current operational state is revealed via the exploration of the performance measures.

In coding the source documents in NVivo, Version 10, four codes were used to capture the references related to planned and actual performance measures, within each of the two clinical settings: “planned” hospital performance measures; “actual” hospital performance measures; “planned” LEMSA performance measures; and “actual” LEMSA performance measures. The **counts** of the contributing sources and the captured references across these four codes (within NVivo, Version 10) are shown in Table XI below:

Table XI: Performance-Measures-specific Codes: Sources and References

Code	Contributing Sources	References
“planned hospital performance measures” (PI_2s_Infrast_PerfMeas_Hosp_Plan)	5	16
“actual hospital performance measures” (PI_2s_Infrast_PerfMeas_Hosp_Real)	4	5
“planned LEMSA performance measures” (PI_2s_Infrast_PerfMeas_LEMSA_Plan)	3	13
“actual LEMSA performance measures” (PI_2s_Infrast_PerfMeas_LEMSA_Real)	1	1

The data in Table XI indicate the following: (1) The total number of references (n=35) is relatively small, in comparison to the references captured by the constructs discussed above; this paucity suggests that having information about the performance measures may not be as explanatory as is having information about the data system or the staffing, in terms of the Infrastructure construct and, therefore, the program's current operational state. (2) Though the amount of information related to the performance measures is relatively scant, what is there speaks much more to the in-hospital setting (21 references) than to the pre-hospital setting (14 references). In other words, in terms of performance measures, it seems that more time and energy has been devoted to the in-hospital setting than to the pre-hospital setting. In building this case – that there is a sub-par operational state overall as well as a differential emphasis

across the two settings – this can be shown graphically. Thus, Figure 6 is a **word cloud** related to Performance Measures.



The Emergent Theme

Upon considering the actual content captured by these four performance-measures-related codes, the following was observed. For both clinical settings, performance measures

exist (and are more-or-less standardized). The in-hospital performance measures (which are first discussed in Chapter 1 and later enumerated Chapter 2 [in Table I]) are standardized, well-documented, and endorsed by multiple agencies, including The Joint Commission, AHA/ASA, the CDC, the National Quality Forum, and the Centers for Medicare and Medicaid Services (Poisson and Josephson, 2011). These in-hospital measures are the ones tracked by the CSR/CCP. For the pre-hospital clinical setting, in contrast, there is not one clear set of consensus measures, as several measures have been proposed⁶⁷ (Oostema, Nasiri, Chassee, and Reeves, 2014).

The in-hospital/pre-hospital contrast related to performance measurement was evident not only in the counts of the references (as suggested above), but also in the content of those references. In the original Funding Opportunity Announcement (page 6), there was language related to measuring performance; however, this language was specific to the in-hospital setting:

“Improve the quality of acute and subacute hospital stroke care through adherence to established guidelines and endorsed quality measures (e.g., Brain Attack Coalition recommendations for Primary Stroke Centers and Comprehensive Stroke Centers, National Quality Forum (NQF) endorsed stroke measures, American Heart Association’s Get With The Guidelines – Stroke measures and goals, CDC and CMS patient safety goals and priorities).”

The State, in responding to this announcement, stated the following – again making reference only to the in-hospital setting (p. 18):

“By looking at individual measures across hospitals, it is possible to gauge how well each hospital reports its data and design an intervention, if needed. For example, if a particular measure is relatively poorly reported by one hospital but well reported by another hospital, the former can implement the best practices from the latter to improve reporting.”

Later, (once funded) the CSR/CCP reported on its efforts to measure performance – so as to improve it, starting with an assessment of the quality of the in-hospital data. (Note that data

⁶⁷ A partial list of these measures includes the following: a glucose test, a stroke screen, an on-scene time maximum, an activation call (to the hospital), and an appropriate hospital destination plan.

quality has been identified by the registry as the first of the three “settings” in which quality improvement efforts must take place – the other two being the in-hospital and pre-hospital clinical settings). In the Year 1 Annual Report (on page 8 of the Project Narrative), this was written:

“The Program’s approach in this area has been to start with the data, in order to have some sense of where the leverage points for change may exist. Accordingly, the Program not only looked at the data across all participating hospitals in order to identify any problematic data elements, but also the Program focused on certain patient outcomes at the hospital level.”

Following an assessment of the data, the CSR/CCP concentrated on the established performance measures. In the Year 2 Annual Report (page 14 of the Project Narrative), the following was reported:

“...the Team looked at the ten in-hospital stroke performance measures, overall and by hospital, and identified just one negative hospital-specific stand-out performance measure, Doctors San Pablo Hospital’s smoking cessation counseling measure, which came in at just 76.5% (while nearly all of the other hospital-specific measures were at least 90%).”

Based on these findings, the CSR/CCP came to realize that further information gathering (on performance) was required. From the Year 2 Annual Report (page 15 of the Project Narrative):

“...inquiries were made of the other 10 Coverdell states, as to what measures were being investigated. The answer, in many cases, was ‘Door-to-Needle’ (D2N) time, in minutes, and ‘Door-to-CT’ (D2CT) time, expressed as a percentage of cases getting to the scanner in 25 minutes or less.”

While not included in the set of the ten performance measures from Table I, the CSR/CCP chose, nonetheless, to focus on D2N and D2CT; this choice reinforces the contention that the CSR/CCP’s focus has tended to be on the in-hospital setting.

Content related to performance measurement within the pre-hospital setting speaks to this in-hospital/pre-hospital contrast – wherein the in-hospital setting is given considerably more emphasis than is the pre-hospital setting. The data indicate that, early on, some pre-hospital

measures were referenced⁶⁸; however, as this statement from the Year 2 Annual Report indicates, no decisions were made with respect to the establishment of pre-hospital measures (page 10 of the Project Narrative): “Given that the Program collected no primary pre-hospital data during Year 2, no EMS performance measures were implemented.” Even so, in that same report, there was information about the CSR/CCP’s efforts in this regard – including the co-opting, for a time, of some pre-hospital measures that the California Emergency Medical Services Authority has promoted:

“In discussing the information from the State’s EMS Authority..., the Program has considered how to establish quality improvement indicators for the pre-hospital setting. Perhaps glucose testing, total scene time, and direct transport to a stroke center will prove to be worthwhile quality indicators (for Year 3) – and this could well be the case...certainly (at least) until the IDP is able to receive (and process) pre-hospital data.”

In other words, within the pre-hospital setting, the CSR/CCP’s efforts to measure performance were quite limited, in part because the data system was unable to receive and process the pre-hospital data. Even so, the CSR/CCP did look to other sources for information that might enable performance measurement within the pre-hospital setting. Finally, with respect to performance measures and the in-hospital/pre-hospital contrast, additional exemplars are included in Table XVII, presented at the end of the Phase I results.

c. **Staffing**

Results of the Content Analyses

The third topic of interest related to the Infrastructure construct is staffing. While this topic has been discussed briefly above, it is given attention here as a means to assess, in part, the current operational state of the CSR/CCP. The value in looking at this third topic as part of the Infrastructure construct is that it provides insight with regard to the utilization of human

⁶⁸ These pre-hospital performance measures were noted in the State’s Stroke Plan, “Recommendations for The Establishment of an Optimal System of Acute Stroke Care for Adults,” which was included as an appendix in the State’s response to the federal FOA. Thus, it was included in the systematic document review.

resources. Any suggestion that staffing is inadequate to carry out the activities of the CSR/CCP speaks to potential problems with the infrastructure – which lends credence to the idea that there may be problems occurring within the registry. Using NVivo, Version 10, four codes were used to capture information (from the 41 data sources) on planned and actual staffing assignments as per the program’s in-hospital and pre-hospital operations: “planned” staffing for hospitals; “actual” staffing for hospitals; “planned” staffing for LEMSAs; and “actual” staffing for LEMSAs. In Table XII below, the **counts** of contributing sources and captured references for these four staffing-related codes are listed, as a first look⁶⁹ at this component of the program’s infrastructure.

Table XII: Staffing-specific Codes: Sources and References

Code	Contributing Sources	References
“planned staffing for hospitals” (PI_2s_Infrast_Staffing_Hosp_Plan)	12	30
“actual staffing for hospitals” (PI_2s_Infrast_Staffing_Hosp_Real)	20	65
“planned staffing for LEMSAs” (PI_2s_Infrast_Staffing_LEMSA_Plan)	13	25
“actual staffing for LEMSAs” (PI_2s_Infrast_Staffing_LEMSA_Real)	18	51

From the data in Table XII come two ideas that merit mention: First, less information was provided about the planned staffing patterns than the actual staffing patterns (55 total references for planned versus 116 total references for actual), thereby suggesting that changes and/or adjustments may have been necessary once the work plan was being executed. Second, across the two clinical settings (i.e., the in-hospital and pre-hospital settings), no real differences are observed, with respect to staffing. In other words, it appears based upon these counts that the setting-specific workloads did not differ in terms of how they were staffed (i.e., Row 1 is like Row 3 and Row 2 is like Row 4).

⁶⁹ This first look approach was taken in presenting the findings for both the data system and the performance measures, as parts of the infrastructure construct.

More insight as to how similar or different staffing patterns are across the clinical settings is gained via a **cluster analysis** – in which two comparisons are made. As shown in Table XIII, the code-specific content is very similar for both (a) what was planned with respect to staffing the in-hospital scope of work versus what was planned with respect to staffing the pre-hospital scope of work (Jaccard’s coefficient is 0.93) and (b) what really happened in terms of staffing the in-hospital scope of work versus what really happened in terms of staffing the pre-hospital scope of work (Jaccard’s coefficient is 0.89).

Table XIII: Cluster Analysis related to Staffing

Code 1	Code 2	Jaccard’s coefficient
“planned staffing for hospitals”	“planned staffing for LEMSAs”	0.93
“actual staffing for hospitals”	“actual staffing for LEMSAs”	0.89

As these two similarity coefficients are close to 1 (which means the code-specific contents are nearly the same), there is further evidence that the staffing patterns did not differ across the settings; however, what cannot be known from this cluster analysis (or from the counts shown in Table XII) is whether this “sameness” is in line with an optimal level of functioning or a sub-optimal level of functioning. Thus, the content captured by these four performance-measures-related codes was studied, and, from this content, a critical theme emerged.

The Emergent Theme

“...we just don’t have, you know, the, the staff resources...”⁷⁰

Initially, the CSR/CCP Team was comprised of those individuals who were present and active during the early planning stages (of the registry), as described in Chapter 1. These individuals worked to complete the various programmatic activities, though it became apparent

⁷⁰ From the interview with Phase III, Key Informant #2.

early on that additional staffing resources were necessary. In fact, in the Year 1 Annual Report, the following was stated (page 21 of the Project Narrative): “Dedicated QI staff is needed for future years to implement QI activities...” Even so, the program was unable to bring on any dedicated QI staff.

Then, during the second year of the grant (i.e., 2013-14), the staffing situation worsened, as reported in several State Updates and in the Year 2 Annual Report, as certain dedicated staff members were redirected (away from the CSR/CCP) or laid off, based on unilateral decisions made by Senior Management within the Branch in which the registry resides⁷¹. The impact of this was stated during one of the key informant interviews⁷²: “...the capacity was less, but the workload was the same...” From the Year 3 Site Visit (reporting on Year 2) comes this corroborating statement (names have been replaced with initials): “With the loss of EW, TH, LC, and LS, the current staff members were stretched pretty thinly...” Losing staff members also interrupts continuity, which can negatively impact operations. About continuity, one key informant⁷³ had this to say:

“...I think having a consistency, you know, in terms of staffing volumes, but, also, familiar relationships... I think from a, from a statewide registry standpoint, the value in having consistent faces who have the ability to kind of [pause] you know, effectively [pause] be involved in that process of them getting engaged in the registry.”

To be sure, changes in staffing can impact how the workload is handled in a number of ways.

Finally, with regard to staffing, it merits mention that one key informant⁷⁴ suggested that the program has experienced fiscal constraints as it has looked to acquire additional staff resources: “...there was also less money for staffing, and so even if we thought maybe we could

⁷¹ This was described earlier in presenting the findings related to Recruitment; it is revisited later when presenting the findings related to the second research question.

⁷² From the interview with Phase II, Key Informant #1.

⁷³ Phase II, Key Informant #4.

⁷⁴ Phase II, Key Informant #1.

hire another staff person to help with fiscal or administrative duties, that was no longer an option.” These statements above reinforce the claim that the staffing of the CSR/CCP is inadequate to carry out its present scope of work; additional statements to this effect are presented in Table XVII below. Also, many of these ideas are revisited later when discussing various contextual factors and operational challenges that have been instrumental in determining the CSR/CCP’s current operational state.

In sum, the Infrastructure construct (to include its three component parts) is very informative with respect to the current operational state of the CSR/CCP, and this particular construct – as did the Recruitment construct discussed earlier – supports the contention that the registry may not be achieving its best possible outcome. Indeed, in the infrastructure-related areas of the data system, the performance measures, and the staffing, the CSR/CCP has fallen out of alignment with its original vision.

3. **Partnerships**

Why It Matters

Third, in describing the registry’s current operational state, it is helpful to evaluate the registry’s work with its strategic partners⁷⁵, a key focus for CDC-funded state stroke registries as evidenced by this language from the FOA (page 16):

“State health departments have effective collaborations in place with strategic public and private partners at the national, regional, and state level, state hospital associations, state physician associations, quality improvement organizations, emergency medical services agencies, and others.”

Indeed, utilizing partnerships to meet program objectives is an important part of the registry’s operations. If a partnership is positive overall, then it can facilitate programmatic operations;

⁷⁵ These are not the clinical partners (i.e., not the hospitals and LEMSAs).

however, if it is negative overall, then it can impede programmatic operations. In assessing the data related to this third construct (of four Phase I constructs), four different partnerships are included: the Eureka Team of the California Cancer Registry (CCR); the AHA/ASA; the CDC; and “Other,” which is a category that includes various ad hoc relationships with external entities for specific purposes (e.g., consultancy). For each of these four partnerships two codes were established and used in NVivo, Version 10 – one indicating something positive (that was reported); the other, something negative.

Within the context of the first research question (i.e., determining the registry’s current operational state), the data from this construct on partnerships is used in a two-fold manner, which is somewhat of a departure from how Recruitment and Infrastructure were presented above. First, each of these four partnerships is evaluated in terms of its impact on the operational state of the program – that is, whether positive, negative, or both. Second, the “whole” of these four partnerships is considered, with interest as to whether (a) the registry has been affected in a positive or negative way, overall; and (b) the registry might benefit from having new and/or different partners. As above, first, a case is built; second, the emergent themes are discussed.

Building a Case

As with Recruitment and Infrastructure above, a case is built – here, it is built with respect to the influence of Partnerships on the registry’s operations. The case begins with findings from the content analyses, before presenting the results of the thematic analyses.

Results of the Content Analyses

In coding the source documents, to include the twenty-seven Phase I documents and the fourteen key informant interview transcripts, for the four partners, a total of 736 references were captured; of these, 511 references were categorized as positive and 225 were categorized as

negative. For each of the eight partnership codes⁷⁶, the **counts** of contributing sources and captured references are shown in Table XIV below.

Table XIV: Partnership-specific Codes: Sources and References

Code	Contributing Sources	References
“positive experience with CCR” (PI_3s_Partner_CCR_Pos)	19	62
“negative experience with CCR” (PI_3s_Partner_CCR_Neg)	21	167
“positive experience with AHA/ASA” (PI_3s_Partner_AHAASA_Pos)	31	164
“negative experience with AHA/ASA” (PI_3s_Partner_AHAASA_Neg)	10	38
“positive experience with Other” (PI_3s_Partner_Other_Pos)	20	135
“negative experience with Other” (PI_3s_Partner_Other_Neg)	11	19
“positive experience with CDC” (PI_3s_Partner_CDC_Pos)	28	150
“negative experience with CDC” (PI_3s_Partner_CDC_Neg)	1	1

From these data on partnerships, there are several key findings. First, in terms of the numbers of captured references (regardless of whether positive or negative), the most references were recorded for the CCR (229), followed by AHA/ASA (202), “Other” (154), and the CDC (151). This suggests that, operationally, the CSR/CCP has worked most closely with the CCR; as the CCR is the contractor for the development of the registry’s data system (discussed above), this makes sense. Hence, it may be the case that this partnership with the CCR was instrumental in bringing about the registry’s current operational state.

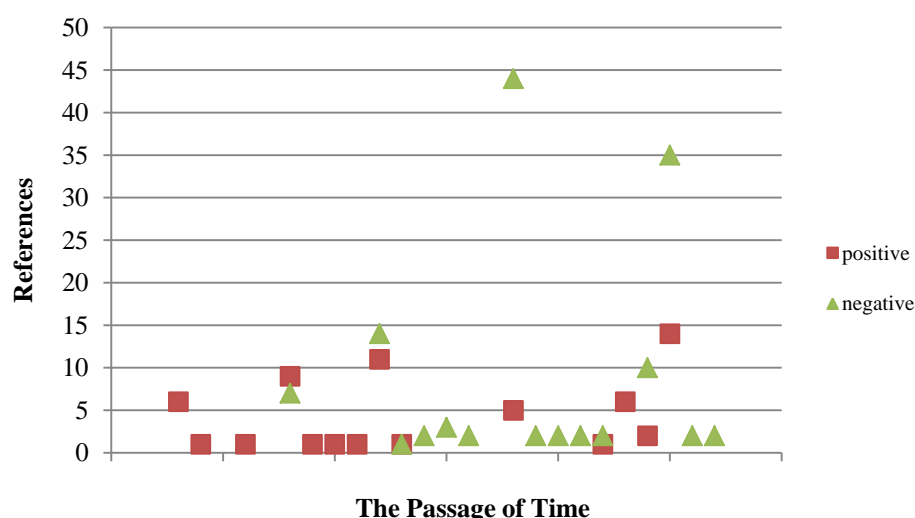
Next, this partner with which the CSR/CCP worked most closely (i.e., the CCR) recorded more negative findings than did the other partners. In fact, the CCR recorded 2.7 times as many negative references as positive ones; moreover, it was the only partner which was negative overall. In contrast, data for the other three partners indicated overall positive experiences: For the AHA/ASA, there were 4.3 times more positive references than negative references. For the

⁷⁶ The naming convention includes an abbreviation of the name of the partner and either “Neg” for negative or “Pos” for positive (e.g., the code “PI_3s_Partner_CDC_Pos” is for all positive references about the registry’s partnership with the CDC).

“Other” partnership, the positive to negative ratio was 7.1 to 1, and for the CDC, of 151 references, only 1 was negative. In short, though a primary partner’s impact has been negative, three other key relationships have been quite positive – especially the one with the CDC.

Finally, for three of these partners (i.e., all but the CDC, which has just one negative reference – which was more about funding), it is of value to note when the various positive and negative references were captured (i.e., over time)⁷⁷. Determining these **time-specific reporting trends** may provide insight as to each partner’s contributions to the registry’s operation. First, in looking at the references captured for the CCR, the data indicate that earlier on, the captured references were categorized as overwhelmingly positive; in fact, near the beginning of the reporting period, the positive references for the CCR outnumbered the negative ones by about three to one. Over time, this shifted dramatically; by the end of the reporting period, the negative references outnumbered the positive ones by nearly four to one. This shift from positive reporting to negative reporting for the CCR is shown graphically in Figure 7 below.

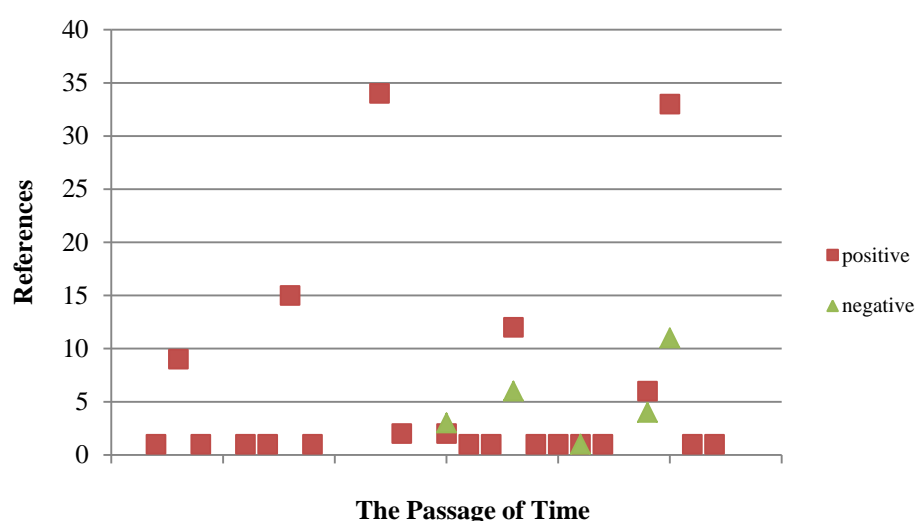
Figure 7: For the CCR: Positive and Negative Reporting over Time



⁷⁷ Note that only the 27 Phase I documents are used here, as the interviews are not specific to one point in time.

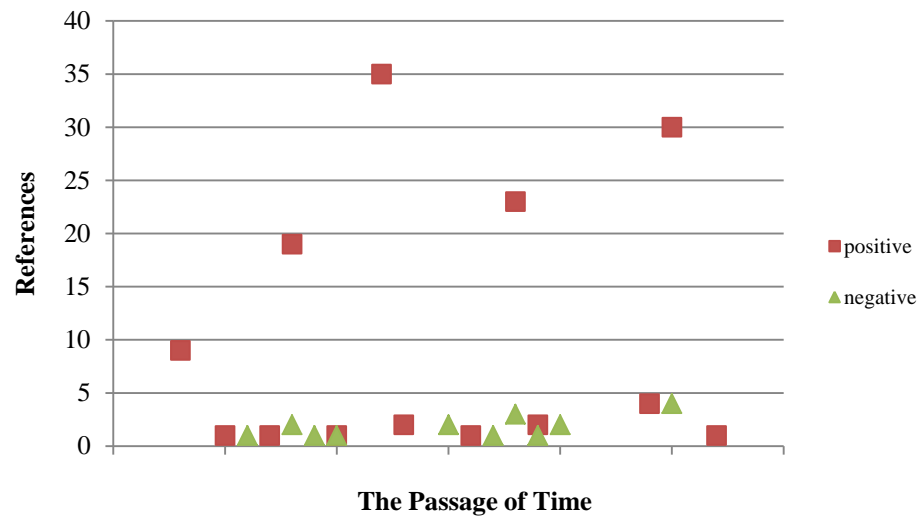
Next, in looking at the references describing the CSR/CCP's relationship with the AHA/ASA over time, there is a suggestion that the quality of this partnership changed somewhat. While positive references were captured all along the study period, there were a few negative ones captured starting near the middle of the study period. Of note is that this timeframe is consistent with the information presented earlier about the AHA/ASA vacancy that impeded the registry's recruitment efforts. Even so, the references are overwhelmingly positive over time – which suggests that the partnership is, too. Figure 8 below shows the timing of the positive and negative reports about the AHA/ASA partnership.

Figure 8: For the AHA/ASA: Positive and Negative Reporting over Time



Finally, in assessing the captured references describing the “Other” partnership – which, as mentioned above was in place to provide ad hoc resources to the registry (e.g., consultancy) – the data indicate that there were no clear trends as to when the positive and negative references were captured. Regularly, over time, reports of both types were made, though, as indicated above, the positive reports outnumbered the negative reports by a factor of 7.1 to 1. This is evident in Figure 9 below.

Figure 9: For the “Others”: Positive and Negative Reporting over Time



In sum, in building this case related to partnerships, the counts of the code-specific references suggest the following: (1) Of the four partners, the CSR/CCP has worked most closely with the CCR. (2) The CSR/CCP’s partnership with the CCR, on the whole, is characterized as negative, while the CSR/CCP’s partnerships with the AHA/ASA, “Others,” and the CDC have been quite positive. (3) For two of the partnerships, there were noticeable trends (over time), as the CCR relationship worsened with time, and the AHA/ASA relationship was challenging for a time but then recovered. More insights on all of these Partnerships are provided by the assessing the actual content of these references. In so doing, key themes related to the Partnerships construct emerge.

The Emergent Themes

“...keeping the relationships going that we, we have [pause] you know...”⁷⁸

As suggested above, the CSR/CCP has continued to maintain its original partnerships, and, for the most part, it has derived benefits from working with these partners. In the Year 1

⁷⁸ From the interview with Phase II, Key Informant #6.

Annual Report (page 18 of the Project Narrative), it was written: “Program records, key informant interviews, direct observation, and personal communications indicate a positive outcome from partnerships.” With that assessment, it makes sense that in that same document, there is a call for “...increased collaboration amongst partners and stakeholders...” (Appendix E of that document). As was suggested above, however, the CSR/CCP’s experiences with its partners were somewhat varied. These partnerships are discussed below in succession.

The California Cancer Registry

First, the data germane to the CSR/CCP’s partnership with the CCR – in place for the development of the registry’s data system – reveal an inconsistent relationship: Initially, this partnership and its purpose were described in this way (in the State’s response to the federal funding announcement, page 2):

“Early in this process it was recognized that a new data system would require the expertise and leadership of the staff within CDPH’s California Cancer Registry (CCR), so a CSR-CCR partnership was formed. The CCR has over 25 years of experience in collecting data from multiple data systems and has designed a system (Eureka) that is used by the CCR to collect and manage cancer data. The features and functionality of Eureka parallel those required by the CSR. The newly developed platform (Eureka-CSR) allows for data submission, standardization, storage, download, and report generation.”

Further, once the grant was underway, the CSR/CCP staff reported favorably on the status of this partnership (in the State Update from July, 2012):

“The collaboration between the California Stroke Registry and the California Cancer Registry is ongoing. This includes the development of an integrated data platform for GWTG-S and non-GWTG-S hospital data. This data platform will eventually support the integration of pre-hospital (Emergency Medical Services) data and will enable the linkage of pre-hospital data with hospital data.”

From the Reapplication for Year 2 (on page 18 of the Project Narrative) comes the following positive statement about how the anticipated data system might help promote the program’s sustainability:

“With the guidance of our advisory committee and through the efforts of our leadership team, the program activities can be sustained, using ongoing partnerships, particularly with the hospitals and the LEMSAs, supported by the data collection and reporting features of Eureka-CSR.”

Into the second year, however, things began to change in this partnership, and the reporting reflected that change, consistent with the reporting trends shown above in Figure 7. Materials from the Year 2 Site Visit (to discuss the activities from the first year) indicate this concern: “The California Cancer Registry is transitioning and this has impacted the IDP development...” That same year, it was reported in the Reapplication for Year 3 (on page 8) that the CCR’s transitioning has been problematic: “...in working with the CCR, we have encountered situations in which there was a lack of clarity regarding certain roles and responsibilities.” Several other data sources from this same time period make mention of the delays in the development of the data system and what those changes have meant for the CSR/CCP’s ongoing work, as well (as discussed earlier, as per the Infrastructure construct). To be sure, these data suggest that, at this time, the relationship with the CCR’s Eureka Team was changing (for the worse) as the data system development process was languishing.

Late in the second year of the federal grant (i.e., 2013-14), there is a hint that things may be improving. From the Reapplication for Year 3 (on page 8 of the Project Narrative), comes this statement: “...we have reinvigorated our partnership with the California Cancer Registry (CCR) as we look forward not only to launching the data system but also to enhancing it during Y3.” Later, in the same document (page 25), more is written about this reinvigorated partnership: “...the Program intends to refocus its efforts on getting the data system fully functional, such that data – across the continuum of care – can be used to inform collaborative, successful QI initiatives.” To be sure, this was the sentiment heading into the third year of the federal grant (i.e., 2014-15).

Since that information was reported, optimism has faded (again), as the data system development process has waned, as has been described in detail earlier in this chapter. As one key informant⁷⁹, external to the CSR/CCP, stated about the CCR and its efforts over the years to develop the anticipated data system: “...we thought we had the right partner and even with multiple times and multiple chances, the partner just did not end up delivering what’s needed.” In short, given this evidence, the registry’s up-and-down relationship with the CCR has not fared that well overall. To be sure, this particular situation has been rather impactful, in a negative way, on the ongoing operations of the CSR/CCP.

The American Heart Association/American Stroke Association

Second, with respect to the CSR/CCP’s partnership with the AHA/ASA, the data suggest that this has been a very positive, long-standing relationship, one with just a single, relatively short-lived challenge – i.e., the nine-month vacancy created when LK-H left her position (in August of 2013), as described above under the Recruitment construct. This challenge (represented by the collection of small green triangles shown in Figure 8 above) was described as follows, during one of the key informant interviews⁸⁰:

“...we’ve worked with the American Heart, American Stroke Association for many years and we’ve had a strong relationship with them, and we still do, but there was a few years where things weren’t, we didn’t have as [pause] strong of a relationship. It was still a good relationship, but given their staffing changes and then there was, um, vacancies, temporarily, that severely impacted us.”

Again, even with this challenge – which did impact the registry’s ability to interact with both current and potential clinical partners (i.e., hospitals and LEMSAs)⁸¹, having the AHA/ASA as a

⁷⁹ Phase II, Key Informant #5.

⁸⁰ Phase II, Key Informant #1.

⁸¹ The interaction here refers primarily to recruitment-and-retention-related activities. Quality-improvement-related activities were also hampered somewhat with the AHA/ASA’s nine-month vacancy. From the Year 3 Reapplication (page 7): “Our two staffs communicate frequently to coordinate recruitment efforts and to monitor QI activities (even as the AHA/ASA has had a vacancy in their Regional Director for QI Initiatives position since August, 2013).” Of note is that both the in-hospital and pre-hospital clinical settings were impacted.

partner has been a very good thing. Indeed, the historical connection to the AHA/ASA – which, in and of itself, was a component of the process undertaken to launch the registry (as described in the first chapter) – is one which has continued to be of vital importance (for the registry), given that the AHA/ASA and the registry have shared objectives. As one informant⁸² (from the AHA/ASA) put it: “...the American Heart Association and [pause] the Stroke Association and the Department of Public Health, we have some very common interests and we can look to each other to see, you know, the overlap and the strengths.” He continued this theme, saying this:

“...because we have common interests – your organization and mine – it works well for us to partner and we can get some of the capacity that [pause] you have here and some of the connections you have here to help us, you know, as we collaboratively work on this...”

Further, this positive working relationship is evident in the following excerpt (from the Reapplication for Year 2, on page 5 of the Project Narrative⁸³), which describes the partners’ collaborative effort to recruit hospitals into the registry:

“We continue to build upon our longstanding relationship with AHA/ASA by working together to develop and implement hospital recruitment strategies and activities. Our two staffs communicate frequently to facilitate recruitment activities and to keep both organizations apprised of the status of each hospital in the recruitment pipeline. In addition to regular emails and individual phone calls, conference calls and in-person meetings with AHA/ASA staff are regularly scheduled to coordinate recruitment efforts.”

To be sure, all of these data suggest a positive working-relationship between the two organizations and, therefore, a positive impact on the registry’s ongoing operations. Finally, the future outlook for this long-standing CSR/CCP – AHA/ASA partnership looks positive, too, as evidenced by the closing comments made by the informant from the AHA/ASA⁸⁴. He said this: “Yeah, I, I just think it’s... I’m, I’m excited about the direction things are going...”

⁸² Phase II, Key Informant #4.

⁸³ Note that this excerpt comes from a report that pre-dates the AHA/ASA vacancy; however, this is an apt description, as well, of how the partnership has functioned since that vacancy was filled.

⁸⁴ Phase II, Key Informant #4.

The “Other” Partnerships

Third, the CSR/CCP has at times relied on “Other” partnerships, for the purpose of availing itself of specific services that were unavailable through the usual channels within the organization. Collectively, this has been mostly positive for the CSR/CCP, as the following examples illustrate: First, some of the early human resources were provided through a partnership with the University of California (UC), as described in the State’s response to the federal funding announcement (page 5):

“CDPH and the UC have been partners in public health and prevention of disease for over 20 years, with UC providing much of the professional staff support for CDPH. To facilitate timely implementation of the proposed project, some CSR staff will be employed through the longstanding contract with the UC.”

Indeed, among others, the original Principal Investigator for the registry, LC (who was called “visionary” by one key informant⁸⁵), was a UC employee; she served in this role until the Branch management began to make staffing decisions, as reported above, under Infrastructure. In short, the Branch management essentially voided this partnership.

Next, much of the advisory role has been provided via partnerships. Not only has the CSR/CCP had an Advisory Committee, but also it has sought guidance from a Leadership Team. The former has provided “...guidance regarding hospital recruitment, data collection and reporting, QI activities, and overall project direction...” while the latter has provided general guidance with respect to “...the development of the CSR, including hospital recruitment, data integrity, evaluation measures, and the dissemination of findings...” (page 8 of the State’s response to the federal funding announcement). While both of these groups have made this “Other” partnership positive overall, in both cases, members were lost – which has impacted the work of the CSR/CCP. As reported in the Reapplication for Year 2 (on page 3 of the Project

⁸⁵ Phase II, Key Informant #2.

Narrative): “The 9-member Leadership Team and the 13-member Advisory Committee from Y1 each lost members (respectively, one and four) due to job transitions.” Thus, this “Other” partnership is not as strong as it once was.

Further, an “Other” partnership has provided consultancy services related to the data system development process. With this process being led by the CCR’s Eureka Team as has been described above, it was important for the CSR/CCP to bring on someone with technical expertise who could liaise with that team during this process. In the Year 1 Annual Report, the role of this consultant is described this way: “...to provide the technical and scientific expertise necessary for successful development, implementation, and maintenance of the IDP.” For a time, this consultant helped to move the previously-described decelerated process forward; however, the consultant resigned⁸⁶. While this was in place, there was benefit to the registry; however, once it was gone, the CSR/CCP’s technical capacity was diminished.

Finally, the CSR/CCP has had a partnership with the State’s Emergency Medical Services Authority (EMSA), as reported in the Reapplication for Year 2 (page 10 of the Project Narrative): “We have also been working with the state Emergency Medical Services Agency (EMSA) on the adoption of regulations for stroke systems of care in California.” As part of this “Other” partnership, the CSR/CCP, early on, contributed to (then) ongoing discussions related to the collection and reporting of patient-level data on stroke treatment; however, those discussions stagnated somewhat as there was a lack of consensus related to the data elements. As a result, the CSR/CCP became somewhat less engaged. One key informant⁸⁷ described the partnership like this: “I think the way [pause] that the registry partnered with EMSA at the beginning of the program was based on EMSA’s capabilities at that time and I think we kind of looked away from

⁸⁶ This was reported in the State Update from May 2014.

⁸⁷ Phase II, Key Informant #6.

EMSA as a partner.” Even so, this “Other” partnership has been of benefit to the CSR/CCP and could well be of additional benefit moving forward; in fact, this same informant noted how things have changed, potentially for the better: “In the meantime, they changed within their own organization and once we became aware of that change, it, it changed the way that we thought about what might happen and the possibilities...” In sum, these various “Other” partnerships have provided the CSR/CCP with some needed assistance over the years; however, in all cases, the support was not sustained.

The Centers for Disease Control and Prevention (CDC)

Finally, the CSR/CCP has had an overwhelmingly positive relationship with the CDC. In fact, the one and only negative reference about this partnership came from a key informant⁸⁸ who expressed her opinion that the amount of Coverdell funding provided by the CDC (for the registry) “...was not enough to do the activities that were being required to be done.” This one negative comment is outweighed by all (i.e., 150 in total) of the positive references about the CSR/CCP – CDC partnership, captured from the contributing data sources.

For this partnership, the positive tone was established right away, as the original funding opportunity announcement stated (on page 14): “CDC staff is substantially involved in the program activities, above and beyond routine grant monitoring.” Following this statement, such activities were enumerated, including the provision of technical assistance on all operational aspects of the program; guidance with respect to data standards, data collection, data linkage, and data-driven quality improvement initiatives; and evaluation support. This offer was recognized by those preparing the State’s response to the announcement, as evidenced by the stated objective to “...collaborate with the CDC to develop a comprehensive stroke data program” (page 10). Indeed, the nature of the partnership was clear from the beginning.

⁸⁸ Phase II, Key Informant #6.

Over the years, the collaborative effort of the partners has accomplished many things. One area in which the CDC assisted the CSR/CCP was in hospital recruitment. As described in the State Update for September 2012, the CSR/CCP inventoried "...the more than 300 general acute care hospitals in California not participating in the registry (by geographic location, annual volume of stroke discharges, and use of GWTG-S)..." and then "...developed several possible recruitment strategies..." which were shared with the CDC during the August 2012 Site Visit. Hearing these proposed strategies, the CDC Team members provided guidance related to stroke volume but also advised the CSR/CCP to "...take into account the needs (of potential hospitals) related to quality improvement." Based on this guidance, the CSR/CCP was able to move forward with its recruitment efforts. Next, the CDC provided support related to the development of the program's logic model and evaluation plan. The development is described in the Reapplication for Year 2 (page 8):

"Consistent with what was outlined in our response to the FOA, the methodology for program evaluation is being based on the framework of the logic model. This model was developed in partnership with the CDC during the current report period and includes a balance of process and short, intermediate, and long-term outcome measures."

The final products (i.e., the logic model and the evaluation plan) are included in the Annual Report for Year 1 (page 15):

"A logic model was developed (and used) by the Program during Year 1. Resources provided by the CDC were utilized to provide guidance in its development. As well, the Leadership Team met and provided input into the development process. The final logic model was submitted to CDC in December 2012. To be sure, this model was invaluable in the development of the Program's Evaluation Plan."

Finally, the CSR/CCP-CDC partnership has facilitated the CSR/CCP's efforts to meet all of the requirements of the federal grant including "...submitting the quarterly data and handling regular State updates along with other ad hoc correspondence and requests..." (Reapplication for Year 3, page 20); sending in the required reports, including "...year-end reports, chart audits, the hospital

inventory, the federal financial reports, and other requirements of the grant...” (page 21); submitting and updating, as necessary, a State Stroke Plan⁸⁹ and a Quality Improvement Plan⁹⁰ (in addition to the Logic Model and Evaluation Plan discussed above); and participating in “...all CDC-sponsored trainings and/or meetings...” (page 15). To conclude, this CSR/CCP-CDC partnership has been a positive influence on the ongoing work of the registry.

“I think in partnerships, again, it’s an evolving thing...”⁹¹

The second emergent theme related to partnerships concerns the number of key strategic partners the registry has...or perhaps should have. As well, the identities of these key strategic partners (including the potential future partners) are important to consider. As discussed above, the registry has had four such partners: the CCR, the AHA/ASA, “Other” partners, and the CDC. On the whole, this collection has been positive for the registry – though with one partner (i.e., the CCR), the relationship has soured. Given this overall positive experience for the registry, it stands to reason that perhaps more strategic partnerships should be in place. On this topic, one key informant⁹² had this to say: “...as far as broad-based prevention work, I think it’s critical to partner, partner, and partner some more.” Certainly, this is her recommendation. (Though recommendations such as this one are discussed at length later in this chapter, this idea of having additional partners merits an early mention here.)

Seven key informants (whose participation in this study was secured while looking “outside” the CSR/CCP⁹³) were asked to provide the CSR/CCCP with recommendations for change, and six of them spoke about partnerships. All of these informants encouraged utilizing

⁸⁹ As per the Reapplication for Year 3 (page 4): “California’s State Stroke Care Plan, *Recommendations for the Establishment of an Optimal System of Acute Stroke Care for Adults: A Statewide Plan for California*, was published in 2009 and is on file with the CDC.”

⁹⁰ As per the Reapplication for Year 3 (page 10): “Early in Y2, we finalized our Coverdell Quality Improvement Plan, begun in Y1, and submitted it as part of our Y1 Annual Report...”

⁹¹ From the interview with Phase II, Key Informant #4.

⁹² Phase III, Key Informant #4.

⁹³ See Chapter 3, Section B.

partners in carrying out all aspects of the program – to include assisting with recruitment and retention; providing data systems support; contributing human (and other) resources; conducting training and quality improvement activities; and promoting the program’s visibility. Moreover, multiple potential partners were suggested by these informants: the State’s emergency medical services agency; the State’s hospital association; universities and medical centers; healthcare systems and networks; advocacy organizations; quality improvement organizations; and other related public health entities. In sum, these informants unequivocally recommended utilizing a broad consortium of partners.

A number of potential benefits were cited, too, during these interviews. One such benefit is that the various programmatic strategies and plans can be vetted through the partners. One informant⁹⁴ described her experience with this as follows:

“...we had lot of partners around the table that we could bounce ideas off of and strategize about how we wanted to accomplish [pause] our work, and get some volunteerism, too, ‘cause as you well know, there’s never enough financial resources to do everything you wanna do, so I think that was really helpful.”

Yet, this informant did offer a word of caution as well:

“I mean you really have to learn – not only do you have to partner, you have to know your partners. You have to know the politics of each of your partners and who can help you and who you can trust. So I should have said that like in the very beginning. For me, one of the most important [pause] pieces is, is just [pause] building the relationships that you need to help you get to where you need to go, because you might not be able to get there yourself...”

Certainly, as this informant suggests, there is some risk associated with partnering. If one partner has an agenda of its own that does not comport with agenda of the other partner, there is a potential for problems. One example of this was brought up by another key informant⁹⁵ who suggested that the financial interests of the AHA/ASA (i.e., selling the Get With The

⁹⁴ Phase III, Key Informant #4.

⁹⁵ Phase III, Key Informant #1.

Guidelines®-Stroke) have tended to drive outreach efforts toward the hospital providers...and away from the pre-hospital providers⁹⁶. Beyond the opportunities to strategize, partnerships also bring more passion and drive to the ongoing efforts, according to another key informant⁹⁷. She said this:

“Well, we looked at, you know, what, what we had to go on was the passion of these [pause] different partners and, and, again, looking at how we could [pause] get their, their partnerships and, and build on the goodwill of different organizations wanting to [pause] work together in, in change management.”

She continued with this:

“...it, it’s no longer my vision or our team’s vision, but we have partners who really believe this is possible, and we’ve talked through sustainability, and [pause] they have a framework for really seeing what they need to do. So then it’s no longer like the state, trying to, you know, like Sisyphus, roll the stone up the hill, which it often feels like working at the state.”

In sum, though there may be some risk, the message is clear: The CSR/CCP, which has already benefitted from its short list of key strategic partners, should look to (vet and) take on new partners, in order to impact in a positive way its current operational state. Lastly, some additional exemplars related to partnerships are presented in Table XVII, which follows this next section of findings.

4. **Quality Improvement**

Why It Matters

Fourth and finally, in assessing the CSR/CCP’s current operational state, as per the first research question, it is important to have a sense of the quality improvement activities that were carried out in conjunction with the program’s local clinical partners – since improving quality is central to the program’s mission as stated in the first chapter. In general, if the data reveal any

⁹⁶ This idea is revisited later, when discussing the differential reach of the CSR/CCP.

⁹⁷ Phase III, Key Informant #3.

problems associated with the CSR/CCP's achievements related to quality improvement, then there is further support for the contention that things are not as they should be. More specifically, in studying this construct, two lines of inquiry were pursued: First, to evaluate the activity itself, information was collected with respect to the process to facilitate local quality improvement initiatives: (a) the provision of baseline data; (b) the design of an intervention; and (c) the execution of the intervention. Second, to determine the efforts' reach, an assessment was made as to the specific settings for the initiatives – i.e., the in-hospital setting or the pre-hospital setting. Again, any shortcomings (e.g., having incomplete activities or a skewed focus) suggest that the registry's operations are sub-par. As with earlier constructs, content is analyzed first, before the emergent themes are presented.

Building a Case

As with Recruitment, Infrastructure, and Partnerships above, a case is built – this time, it is built to explore the quality-improvement-related activities of the CSR/CCP and what they might mean in terms of the program's current operational state. In other words, as this case builds, whether the program's current operations reflect its original guiding vision begins to be revealed. As before, the case starts off with results of the content analyses, before presenting the findings from the thematic analyses.

Results of the Content Analyses

Related to Quality Improvement (QI), six codes were used in NVivo, Version 10, to analyze the content of the 41 source documents (i.e., 27 Phase I documents and 14 key informant interview transcripts). From 32 of these 41 source documents⁹⁸, a total of 642 references were captured across these six codes. These code-specific **counts** are shown in Table XV below.

⁹⁸ These 32 documents include 26 of 27 Phase I documents and 6 of 14 key informant interview transcripts.

Table XV: Quality-Improvement-specific Codes: Sources and References

Code	Contributing Sources	References
“baseline data provided to in-hospital” (PI_4s_QI_BaselineData_Hosp)	32	149
“baseline data provided to pre-hospital” (PI_4s_QI_BaselineData_LEMSA)	30	112
“QI activity designed for in-hospital” (PI_4s_QI_Design_Hosp)	27	154
“QI activity designed for pre-hospital” (PI_4s_QI_Design_LEMSA)	22	116
“QI activity executed in in-hospital” (PI_4s_QI_Initiative_Hosp)	18	75
“QI activity executed in pre-hospital” (PI_4s_QI_Initiative_LEMSA)	15	36

From these data on Quality Improvement activities, the following merits mention: First, in terms of the three-part quality improvement process described above, it appears that perhaps there have been problems with execution, given the tallies shown above – i.e., 261 total (149+112) for the provision of baseline data; 270 total (154+116) for the planning of the initiative; and only 111 total (75+36) for the execution of the initiative. In short, it seems that the process (to conduct a local quality improvement activity) has come to completion less than half of the time. Second, with respect to the two clinical settings, it appears that the in-hospital setting has been favored over the pre-hospital setting, as 149, 154, and 75, respectively, are greater than 112, 116, and 36⁹⁹. These setting-specific counts add further support to the suggestion that the registry’s shortfalls are more marked in the pre-hospital setting than in the in-hospital setting.

In continuing to build this case, more information with regard to these setting-specific data on executing initiatives is provided via a **cluster analysis** – wherein the code-specific contents from two codes are compared¹⁰⁰. The data in Table XVI below reveal that: (1) what was designed, related to quality improvement within the in-hospital setting, and what was

⁹⁹ That is, the three process-specific counts for the in-hospital setting are greater than the corresponding three process-specific counts for the pre-hospital setting.

¹⁰⁰ In this case, the cluster analysis is done twice – once for each of the two settings.

actually executed therein are rather dissimilar (Jaccard's coefficient is 0.58); and what was designed, related to quality improvement within the pre-hospital setting, and what was actually executed therein are quite dissimilar (Jaccard's coefficient is 0.28).

Table XVI: Cluster Analysis related to Quality Improvement

Code 1	Code 2	Jaccard's coefficient
"QI activity designed for in-hospital"	"QI activity executed in in-hospital"	0.58
"QI activity designed for pre-hospital"	"QI activity executed in pre-hospital"	0.28

Given that these two similarity coefficients are not close to 1 (which means the code-specific contents under comparison are really not the same), it appears that there may be a disconnect between what was planned and what actually occurred; moreover, it seems that this disconnect is more pronounced within the pre-hospital setting than it is in the in-hospital setting, since the similarity coefficient for the former (0.28) is much smaller than that for the latter (0.58).

The content analysis – including the counts in Table XV and the similarity indices in Table XVI – seems to suggest that the execution component of the quality-improvement-related work has been a problem for the registry, particularly within the pre-hospital setting; however, this suggestion is based only upon the logging and comparing of references – not what they actually convey. Via a thematic analysis, the key concepts conveyed by the captured references are made known. As before, these concepts are presented as emergent themes.

The Emergent Themes

*"...to help systems of care for strokes reach a better, a better outcome..."*¹⁰¹

This excerpt above, from one of the key informant interview transcripts, makes it clear that the ultimate goal of the CSR/CCP is to enable stroke systems to achieve better patient

¹⁰¹ From the interview with Phase II, Key Informant #2.

outcomes. To be sure, this message is stated within the source documents rather explicitly, starting with this language from the federal funding announcement (on page 3):

“This program announcement provides support for the development of strategic partnerships for improving stroke care at the state level and thus encourages implementation of quality improvement activities with EMS, hospitals, stroke specialists, and rehabilitation facilities.”

Certainly, this message has been embraced, as evidenced (early on) by the State’s response to this announcement. On page 1 of the response, this is written: “The overall goals of this project are to improve the quality of care provided, thereby improving health outcomes and reducing hospital readmission, and to demonstrate how the exchange of health information can produce measurable improvements in health care.” Further, it was clear that these improvements were to occur across the care continuum. Again, in the State’s response (on page 2), the (then-developing) registry was described as being “...designed to promote quality improvement for stroke treatment in California hospitals and the pre-hospital (EMS) setting.” And later (on page 16), this idea was repeated – this time with more specificity in terms of the care continuum:

“Over the next three years, with this funding award, the CSR will work to improve disease management including: (1) the quality of EMS; (2) the quality of transitions between EMS and hospitals; and (3) the quality of acute stroke care in hospitals.”

This first emergent theme – that the CSR/CCP strives to improve stroke treatment across the care continuum – speaks to the very mandate which gave rise to the registry’s activities related to quality improvement. In reviewing the data related to those activities, other themes emerge.

*“...we just didn’t quite have the data collection piece with stroke systems of care...”*¹⁰²

As has been discussed earlier, the quality improvement initiatives are to be data-driven; this was the first emergent theme (here). This means that the data must be available; however, as has been presented above (under the Infrastructure construct), the data system development

¹⁰² From the interview with Phase II, Key Informant #5.

process has not produced a functional data system as expected. (This is the second theme.) Via this long expected (and still anticipated) data system, in-hospital and pre-hospital data were to have been collected, standardized, linked (at the patient-level), and made available for informing programmatic activities. This expectation was described in the State’s response to the federal funding announcement (on page 18):

“Data linkages will better describe the stroke continuum of care, from pre-hospitalization through hospital discharge. Having this continuum of patient-level information will (1) optimize decision-making by LEMSAs regarding the field treatment, transport, and destination of suspected stroke patients and (2) inform clinical treatment within the hospital setting, as both EMS personnel and hospital-based clinical staff can determine what transpired during an event for a given patient. Further, this kind of information will not only help inform QI efforts in the field (e.g., over/under-triage) and in the hospital (e.g., time-to-treatment), but will also inform the development of local and regional Stroke Systems of Care.”

Even without the expected data system in place, the CSR/CCP did work to provide some baseline data to its clinical partners, in order to inform local-level quality improvement initiatives. In the Year 1 Annual Report (page 8), the following is reported:

“For Year 1, the Program’s focus was on infrastructure development and program implementation – to include establishing/nurturing partnerships, recruiting/enrolling hospitals, forming connections with the LEMSAs, building the IDP, and collecting/reporting in-hospital data. This reporting included summary data tables for the hospitals and LEMSAs.”

More information on the registry’s provision of these summary data tables comes from the Reapplication for Year 2 (on page 10):

“These summary data tables, which were produced according to the expressed needs of the LEMSAs, included hospital-specific data on patient demographics and outcomes. The frequency of the reporting (e.g., quarterly, twice annually, ad hoc, depending on the needs of a given LEMSAs) was determined by the LEMSAs.”

This practice of providing summary data tables to hospitals and LEMSAs – though originally meant to be a stopgap measure – has continued in the absence of a functional data system¹⁰³.

¹⁰³ This is revisited later, when discussing programmatic constraints, under the Operational Challenges construct.

While this practice has been moderately successful, given the continuing interest expressed by the registry's clinical partners, one shortcoming is that the shared data come exclusively from the in-hospital setting. Again, this suggests somewhat of a skewed focus across the two clinical settings.

"...we can maybe help many hospitals by improving that situation" ¹⁰⁴

The third emergent theme is that some quality improvement initiatives have taken place, even with the data-related limitations discussed above; however, these initiatives have occurred within the in-hospital setting only. In the Year 2 Annual Report, a couple of these interventions are described (starting on page 17):

"...during Year 2, interventions took place in the data setting (in order to improve data completeness for Hoag Hospital) and in the in-hospital setting (in order to improve time-to-treatment numbers in two KP¹⁰⁵ hospitals – using lessons learned from a third hospital, SEB¹⁰⁶)."

Via these interventions, there were improvements, as noted in this same report. First, after jointly studying Hoag Hospital's data collection and reporting process (which had yielded 53.3% incomplete records during 2013), some changes were made (during the first quarter of 2014), such that over the first 6 months of 2014, the following was observed, with respect to the completeness of the data: "...January, 0% complete; February, 0% complete; March, 3.8% complete; April, 3.1% complete; May, 44% complete; June, 100% complete." In a matter of months, the data quality was greatly improved.

Second, after working with two Kaiser Permanente Hospitals – each with room-for-improvement, in terms of time-to-treatment – it was discovered that a "bottle neck" to rapid

¹⁰⁴ From the interview with Phase II, Key Informant #2.

¹⁰⁵ KP is Kaiser Permanente.

¹⁰⁶ SEB is Sutter East Bay.

treatment was occurring because of the late entry (into the case) by the neurologist¹⁰⁷. After some sharing of best practices by the stroke coordinator at Sutter East Bay, additional conversations took place with the Kaiser Permanente hospitals' corporate offices. Based on these conversations, a decision was made to utilize tele-neurology as a means to reduce time-to-treatment. Again, as documented in the Year 2 Annual Report: "By using tele-neurology, a neurologist is present immediately in the process, for each stroke case..." As a result, "...the time-to-treatment numbers are better – and this is exactly what the KP Stroke Coordinators have reported." Certainly, this intervention resulted in improved time-to-treatment numbers, a change which has been shown to improve patient outcomes (Ido et al., 2016).

Finally, a summary statement about conducting quality improvement initiatives within a challenging environment (e.g., one without a comprehensive dataset) comes from one key informant, who said this:

"...we're able to maybe [pause] look at one issue and know that we can maybe help many hospitals by improving that situation or finding a hospital that's a, a, you know, has a, could model a really good system they've put into place and how we, they can share that, then, with others. They're all kind of reaching for the same thing and they face very similar issues."

To be sure, as illustrated by these interventions, the CSR/CCP has been able to work with a number of its local clinical partners in order to help improve how data are collected and reported and how patient care is delivered. In Table XVII, additional references about quality improvement are presented.

In this first section of Chapter 4, the findings related to the CSR/CCP's current operational state have been presented. These findings, which come from both content and

¹⁰⁷ As described in the Year 2 Annual Report: Late entry by the neurologist meant (1) more minutes were consumed by the emergency department physician, whose own handling of the case was usually less efficient than that of a neurologist; and (2) more time was spent in shared decision-making processes, since patients' families usually felt they needed to talk directly with the specialist (i.e., the neurologist), not the generalist (i.e., the emergency department physician), and those kinds of conversations ended up occurring relatively late in the process.

thematic analyses, can be summarized as follows: First, the registry's recruitment efforts have yielded fewer clinical partners than anticipated, particularly within the pre-hospital setting. Next, the infrastructure of the registry – to include the data system, the performance measures, and the staffing patterns – has been problematic: The data system development process has failed...the pre-hospital performance measures continue to lack clarity...and the staffing patterns have been inefficient over the years. Further, the registry's key strategic partnerships, on the whole, have been quite positive – though the registry's relationship with the California Cancer Registry (under contract to develop the data system) has turned rather negative. Finally, the registry's quality improvement initiatives have been somewhat successful – though the reach has been fairly small and existent primarily within the in-hospital setting. To be sure, these findings comprise the CSR/CCP's current operational state. Again, in Table XVII below, more information on this state is presented, before exploring those factors that have given rise to this state.

Table XVII: Representative Statements Germane to Phase I

<p>Research Question 1:</p> <p>What work is being done in terms of secondary prevention within the California Stroke Registry/California Coverdell Program? (<i>e.g., related to recruitment, infrastructure, partnerships, and QI</i>) How does that work compare to the program’s original vision for secondary prevention?</p>			
Construct	Themes	Data Sources	Representative Statements
<p>Recruitment – this refers to the action of recruiting clinical providers</p> <p>(260 total references; 3.9% of grand total of 6606)</p>	<ul style="list-style-type: none"> • Falling Short: Reasonable Goals went unrealized • Challenges: Certain factors precluded goal achievement 	<ul style="list-style-type: none"> • Reapplication for Year 3 • Year 2 CDC Site Visit • Reapplication for Year 3 • Reapplication for Year 3 • Year 2 Annual Report 	<p>“...At the time of the writing of our response to the FOA, we felt, based on work already underway, that growing our registry to include 50% of the strokes in California was a reasonable goal...and so capturing 35% of strokes by the end of Y2 seemed reasonable, as well. However, the Program staff have come to realize during Y1 and Y2 that these two goals are out of reach.”</p> <p>“...a goal was to have 50% of stroke cases in the registry by the end of year 3. However, at the end of year 1, there were only 5% of stroke cases which is not a sufficient amount to expect to have 50% in two years.”</p> <p>“Hence, the Program is planning to maintain its current efforts related to recruitment/retention... without having a specific numeric goal in mind.”</p> <p>“...within our local AHA/ASA affiliate, the Regional Director for QI Initiatives position has been vacant, and this has meant that we have not been able to be as active in our recruitment- and QI-related activities as we had hoped to have been.”</p> <p>“In planning for Year 2, the Program had anticipated partnering with AHA/ASA to reach out to LEMSAs about joining the registry; however, AHA/ASA had a vacancy for nearly all of Year 2...and our “enticement” (i.e., the IDP¹⁰⁸), for appealing to the LEMSAs, has remained under development, as described above (so it has not been much of an “enticement”). As a result, LEMSAs recruitment was essentially tabled. Some “off- the-cuff” inroads were attempted with two LEMSAs (Los Angeles and San Diego), but nothing developed from those attempts during Year 2.”</p>

¹⁰⁸ IDP stands for “Integrated Data Platform,” the CSR/CCP data system under development since 2009.

(Table XVII: Representative Statements Germane to Phase I continued)

Construct	Themes	Data Sources	Representative Statements
<p>Infrastructure – this refers to the use of the data system, the establishment of performance measures; and the use of human resources</p> <p>(1012 total references; 15.3% of grand total)</p>	<ul style="list-style-type: none"> Data system development is problematic Resources have been redirected In-hospital measures used EMS measures not standard EMS measures not really used Staffing is inadequate 	<ul style="list-style-type: none"> Year 2 Annual Report Phase II, Key Informant #1 Phase II, Key Informant #1 Year 2 Annual Report Phase II, Key Informant #1 Year 2 Annual Report Year 1 Annual Report Reapplication for Year 3 	<p>The "...IDP remains under development, as previously reported, due to several factors, including personnel problems, fiscal constraints, and a lack of clarity (on the part of the developers) with respect to the Program needs for the IDP."</p> <p>"We set forth, you know, working on this data platform years ago, and faced some challenges and [pause] along the way, we've had staff changes, we've had some [pause] – how to, how do I say it? [laugh] – we've had some bad luck with a contractor who was working with us on the development of the system and, you know, because of that, we, still, years later, were left with nothing really useful."</p> <p>"We received many promises that this time things would be better, they would [pause] definitely deliver a solid product to us, and we worked [pause] with them very closely. Many staff hours were dedicated from our side in working with them and helping them [pause] get a, something developed. And, in the end, nothing was developed, and we [pause] in a way, we feel like we wasted a year [pause] again, working with this partner and [pause] receiving nothing at the end."</p> <p>The "...Team looked at the ten in-hospital stroke performance measures, overall and by hospital, and identified just one negative hospital-specific stand-out performance measure, Doctors San Pablo Hospital's smoking cessation counseling measure, which came in at just 76.5% (while nearly all of the other hospital-specific measures were at least 90%).</p> <p>"They don't exist as much on a consistent, you know, basis across all the local EMS agencies. The local EMS agencies have their own sets..."</p> <p>"Given that the Program collected no primary pre-hospital data during Year 2, no EMS performance measures were implemented."</p> <p>"Explore options to hire dedicated QI staff, perhaps via a part time or limited term position to establish QI activities."</p> <p>"During Y2, some organizational changes occurred within the Branch in which the Coverdell Program resides. EW¹⁰⁹ (a state employee who had provided part- time fiscal/administrative support for Coverdell, on budget) was redirected to work on California's 1305¹¹⁰ efforts, starting in November, 2013, and Dr. TH (a contractor who had provided part-time scientific and technical consulting related to the development of the data system, off budget) was laid off in early December, 2013. These duties have been taken on by the two funded state employees."</p>

¹⁰⁹ Names have been replaced with initials.

¹¹⁰ The number 1305 refers to a federal grant related to diabetes, heart disease, obesity, and their associated risk factors, as well as school health.

(Table XVII: Representative Statements Germane to Phase I continued)

Construct	Themes	Data Sources	Representative Statements
<p>Partnerships – this refers to the ways in which the program has formed and used partnerships</p> <p>(794 total references; 12.0% of grand total)</p>	<ul style="list-style-type: none"> We kept all of our partnerships going, for better or worse... Should there be more partners? 	<ul style="list-style-type: none"> Phase II, Key Informant #1 (talking about the CCR) Phase II, Key Informant #5 (talking about the AHA/ASA) Phase II, Key Informant #2 (talking about the AHA/ASA) Phase II, Key Informant #2 (talking about “Others”) State Update from May 2014 (regarding “Others”) Year 2 Annual Report (regarding the CDC) Phase II, Key Informant #2 (talking about the CDC) Phase III, Key Informant #4 (talking about partners) Phase III, Key Informant #3 (talking about partners) Phase III, Key Informant #2 (talking about partners) 	<p>“I think if the opportunity arises that we could find someone else who could help us develop a system that we need, I think if we can afford to work with that per...that person or group, that we should do that.”</p> <p>“...it was just a perfect team and combination [pause] that helped move it along...”</p> <p>“...we are known in California for kind of trying new things, or at least having partners, like yourself¹¹¹, to be willing to do or try new things and figure out a way to make something work...”</p> <p>“...the American Heart, American Stoke Association was a key resource that enabled us to get into the hospitals... They were able to [pause] lay a lot of the groundwork, because we had, in our program, limited resources.”</p> <p>“...we were working with [pause] people that had a lot of experience. I’m thinking of the UC [pause] UCSF partners we had – or [pause] the contractors that we had – that were able to [pause] help us...’</p> <p>“...Given that LS¹¹² has resigned, we are now facing some down-time in the SDL¹¹³, and we need to develop a plan for getting back on track.”</p> <p>“The CDC-CSR/CCP partnership presents an opportunity for partner hospitals to be included in a national quality improvement effort – which tends to be very helpful in (recruitment) and retention.”</p> <p>“And be in compliance with the, the CDC and their [pause] their, their greater vision for the entire nation, actually...”</p> <p>“...we learned pretty quickly that we needed other partners at the table...”</p> <p>“...we looked at where is the self-interest of these partners, where do we have common ground?” “...again, it’s looking at how can we engage people where they’re, where they already have a self-interest and [pause] they already have, perhaps, a, you know, initiative that could line up?”</p> <p>“So our work is based on the notion that the health department cannot and should not do anything alone. Partnerships and collaborations with outside organizations is absolutely essential...”</p>

¹¹¹ Note that the work “yourself” refers to the CSR/CCP, not the interviewer (DJR).

¹¹² His name has been replaced with his initials.

¹¹³ SDL is the Software Development Cycle.

(Table XVII: Representative Statements Germane to Phase I continued)

Construct	Themes	Data Sources	Representative Statements
<p>QI Initiatives – this refers to Quality Improvement work, jointly undertaken by the program and the providers</p> <p>(881 total references; 13.3% of grand total)</p>	<ul style="list-style-type: none"> • Goal is better patient outcomes • Initiatives must be data-driven • Some initiatives have taken place 	<ul style="list-style-type: none"> • Reapplication for Year 2 • Phase II, Key Informant #3 • Phase II, Key Informant #4 • Year 2 Annual Report • Year 3 Site Visit Materials 	<p>“As was described in our response to the FOA, we will carry out the QI activities both in the pre-hospital and hospital settings. These pre- hospital and hospital QI activities will be data-driven and will include ongoing evaluation and feedback to the providers.”</p> <p>“...the registry, of course, was not just for the data collection and storage, but also what we would do with the data...”</p> <p>“...we also [pause] are struggling with our ability to share data effectively in order to promote our, you know, our ongoing work with quality improvement...”</p> <p>“The summary data tables continue to be a stopgap method to provide data to the LEMSAs; the IDP will later meet this need.”</p> <p>“During Y2, data QI and time-to-treatment QI activities were undertaken, by first assessing capacity (with AHA/ASA), then using the data (PM¹¹⁴, T2Tx¹¹⁵), and finally engaging with the hospitals.”</p> <p>“During Y2, no pre-hospital QI activities were conducted; however, information was obtained from State EMS Authority for Y3 planning (as a “temporary” QI measure, until the IDP can support QI).”</p>

¹¹⁴ PM is Percent Missing – which is a misnomer, as the actual indicator, here, is Percent Incomplete.

¹¹⁵ T2Tx is time-to-treatment (in this case, within the in-hospital setting).

B. Research Question 2: Findings

What factors have contributed to the current state of the program's secondary prevention efforts?

This second research question is designed to investigate what factors have been influential in giving rise to the program's current operational state, as discussed above. In seeking to answer this question, the primary method of data collection used was the conduct of the Phase II key informant interviews¹¹⁶; however, the final data set analyzed is comprised of all of the data from all 41 sources (i.e., both program documents and key informant interview transcripts), as stated earlier. For this second research question, three main areas of inquiry were pursued: (1) contextual factors (to include historical events, structural factors, organizational culture, and programmatic reach); (2) operational challenges (to include various programmatic constraints and sharpness of focus); and (3) held beliefs (to include those related to a need for change and those related to an ability to change). Each of these areas is discussed in succession.

In discussing these results, a narrative approach is used, rather than case-building – which was one of the models¹¹⁷ appropriate for presenting the above-discussed results (i.e., per the first research question). The narrative approach is favored here because there are no “planned versus actual” comparisons being made (as was the case above); moreover, the data collected in this second phase do not lend themselves to being “quantitized” (as per Tashakkori and Teddlie [1998]), as did the data discussed above. For these reasons, the presentation methods of tallying references and sharing similarity indices are not utilized here. Hence, in the three results sections that follow, the data within the narratives reveal key insights about those factors that have given rise to the current operational state of the CSR/CCP.

¹¹⁶ Note that there were 14 total key informant interviews; 7 primarily for Phase II and 7 primarily for Phase III.

¹¹⁷ In presenting the data for Phase I, case building was the first model used; providing narrative was the second.

1. **Contextual Factors**

Why These Factors Matters

First, in determining how the current operational state of the registry came about, it is important to look at what sorts of things are enmeshed the landscape of the registry, as they may have shaped its experiences, both past and present. Furthermore, these factors may be important considerations in some future change process, as they could potentially exert some influence on such a process; this notion is revisited later, in presenting the results per the third research question. As mentioned above, the contextual factors of interest within this project, as discussed in the literature review and presented in the conceptual framework (both found in Chapter 2), include these four: historical events, structural factors, organizational culture, and programmatic reach. Below, the findings for each factor are presented, before turning to the second area, operational challenges, and, later, the third area, held beliefs.

The Four Contextual Factors

a. Historical Events

In Chapter 1, an historical account of the registry's development was given, going back to *California's Master Plan for Heart Disease and Stroke Prevention and Treatment 2007-2015*; while that account adds to the overall understanding of what the stroke registry is and what it seeks to do, what was sought here, in terms of history, is something more granular. Specifically, the inquiry into history as an instrumental factor (in terms of the CSR/CCP's operations) concerns certain decisions that were made, various staffing patterns that were in place, and particular notions of prevention that were prevailing. Across these areas, via the thematic analyses conducted in NVivo, Version 10, key themes became apparent.

Decisions made external to the CSR/CCP have greatly affected the CSR/CCP

As has been described, the CSR/CCP is administratively housed within the Chronic Disease Control Branch of the California Department of Public Health. Thus, the registry, though federally funded and run in partnership with the AHA/ASA, is subject to decisions made at the Branch and/or Department level. The data suggest that some of these decisions have been impactful on the operational state of the registry. As one CDC staff member (AV) stated in the Year 2 Site Visit materials (about the 2012-13 fiscal year): “The Branch Chief is making lots of changes to the Branch which are out of their control and much of this is related to the Consolidated FOA (1305)¹¹⁸ and reallocation of the Block Grant¹¹⁹ funds.” Specifically, these decisions concerned the allocation of resources within the Branch, including those previously made available to the CSR/CCP, as is evident in this statement (also from these Site Visit materials): “...the environment has changed and has negatively impacted the resources available to the CSR; their Branch has not discussed how the CSR fits into the chronic disease program.” While this particular statement refers to human resources, another statement from these materials concerns the budgetary resources:

“They have some concerns about continuing funding for the IDP and for the ongoing maintenance of it. All budgets are controlled at the Branch level and they have stressed the importance of this to the Branch Chief but this is out of their control. CSR staff are not involved in decisions being made about the budget.”

To be sure, external decisions that impede the work of the registry have direct impacts on its operational state. Finally, from the Site Visit materials, this statement captures this situation well: “The changing environment in their department and the additional administrative responsibilities that they have been assigned has impacted their program operations.”

¹¹⁸ This is the federal State Public Health Actions to Prevent and Control Diabetes, Heart Disease, Obesity and Associated Risk Factors and Promote School Health Grant.

¹¹⁹ This is the federal Preventive Health and Health Services Block Grant.

Key informants shared these sentiments, too. One key informant¹²⁰, while talking about staffing, in general, and the loss of the original Principal Investigator and the Senior Scientific Consultant, in particular¹²¹, noted the following: “...certain decisions made by upper management related to the staffing and leadership of this program, over the course of its history, have impacted how it operates currently.” This informant also discussed the Branch-level decisions related to how the various chronic disease control programs were organized and prioritized...and how those decisions impacted the operations of the registry. She stated:

“...even though the CDC, I think, was trying to erase some of that silo effect, they [pause] in essence, here, created just one giant silo and we weren’t part of it anymore, at all. And at least before, we were still seen as part of the cardiovascular disease silo in the past and [pause] we were, you know, we were and we still are part of the same division at CDC, but [pause] we are no longer looked as a program connected to [pause] the Heart Disease and Stroke Program, and we are no longer seen as connected even to this – you know, we currently are not seen as connected to the new grant, either, and we’re looked at very separately.”

She continued:

“...they have structured things in a way that [pause] I think has left us as [pause] well, I think as I’ve mentioned, like a step-child, and they haven’t given us importance in this hierarchy, so we’ve sort of have been left to function on our own, and we are not given the support that we feel like we need and deserve.”

The data here indicate that the CSR/CCP was impacted negatively as resources were being redirected (i.e., within the Branch, away from the CSR/CCP) based upon how programs within the Branch were prioritized. (Here, other Branch programs were prioritized ahead of the CSR/CCP; more discussion on this point is provided later.) Additionally, this informant’s comments speak to the idea of visibility – which is an area that is addressed later, in presenting the results from the third phase of this project.

¹²⁰ Phase II, Key Informant #1.

¹²¹ These two CSR/CCP staff members (LC and TH) were laid off when the Branch Chief, citing budgetary concerns at the Branch-level, cut their positions via a contract amendment; LC found employment elsewhere, while TH took an early retirement.

Similar sentiments were shared by another informant¹²²: In talking about the various decisions made at the Branch level regarding budgets, other chronic-disease-related programs, and Branch-level staffing patterns, she noted:

“...the Branch leadership was [pause] creating a culture in which [pause] she chose to spend limited resources on creating new positions and filling those positions in the state civil service, rather than using those funds to support programs so that they could [pause] move forward with their objectives.”

She went on to say:

“...there’s a, a culture there that [pause] isn’t conducive to the program achieving its goals, because that culture is more focused on [pause] spending money to grow the civil service than spending money to carry out the objectives of the program.”¹²³

A concluding statement sums it up: “...decisions that were made...impacted the budget which then impacted the staff which, ultimately, led to the program’s inability to achieve its vision [pause] as originally stated.” Indeed, these statements support the contention that decisions made at the Branch-level were detrimental to the ongoing operations of the CSR/CCP.

A third key informant¹²⁴ described impactful decisions, but his area of focus was on the data system development process, rather than on the fiscal- and human-resources-related decisions made by the Branch’s senior management, as discussed above. This informant noted how significant changes within the working environment of the CCR’s Eureka Team (under contract with the CSR/CCP to develop the data system) impacted the CSR/CCP’s operational state. In discussing these personnel- and system-changes, he stated that they:

“...took more than a year and during the...that time we were just [pause] not able to make any progress because of the personality...personnel change, um, because [pause] of the system change, you know, computer system change [pause] and that killed [pause] um [pause] the momentum of the project.”

¹²² Phase II, Key Informant #2.

¹²³ This speaks to the priorities of the Branch’s upper management.

¹²⁴ Phase II, Key Informant #3.

Again, these data-system-development-related changes were made external to the registry; however, they were very impactful to its operations as they killed the momentum of the project.

Further, it was stated during that interview:

“I believe that [pause] through the program’s history up to [pause] you know, the recent [pause] times, there have been decisions made that have been [pause] out of our control and those decisions have impacted our registry and our, and our ability to [pause] you know, expand it, ability to, to do some of the things that we had [pause] wanted to do from the beginning.”

In sum, various decisions were made that impacted the CSR/CCP, in terms of its budget, its staffing, its data system and, therefore, its current operational state.

The data above tend towards the negative; however, there are a few positives of note, too. In a key informant interview with an individual employed with a partner organization, there was talk of decisions made related to collaboration between the two organizations. These kinds of decisions have shaped the registry’s ongoing efforts, positively, by enabling the pooling of resources. As this informant¹²⁵ noted:

“...we have common interests – your organization and mine – it works well for us to partner and we can get some of the capacity that [pause] you have here and some of the connections you have here to help us, you know, as we collaboratively work on this, shared objectives.”

This positive sentiment on collaborative decision-making was echoed by another informant¹²⁶ employed within that same partner organization. In reflecting on the partnership and its impact on the registry, she noted that, were it not for the partnership, “...we wouldn’t have come that...this far.” These data reinforce the idea that, for better or worse (and, here, the preponderance of the evidence seems to suggest worse), certain decisions made external to the registry have been impactful on its operational state – in terms of budgets, staffing, technology, and collaboration.

¹²⁵ Phase II, Key Informant #4.

¹²⁶ Phase II, Key Informant #5.

Staffing patterns within the CSR/CCP have been impactful on its operational state

Staffing patterns have been mentioned multiple times, in relation to other key themes. The data from twenty-two of the source documents suggest that, on its own, staffing is a key factor in shaping the registry's current operational state. Within the CSR/CCP over the years, a number of staff changes have taken place: Of the eight individuals ever employed within the program (including the researcher), two left for other jobs (i.e., SK, DR); one was reassigned within the Branch (i.e., EW); and two were let go via the amendment of a contract (i.e., LC, TH). Similarly, within the AHA/ASA over time, there have been staff changes. Most notably, the position which liaises with the registry has changed over twice, as the first incumbent was reassigned and the second left for another job.

The source documents revealed several important findings related to staffing: First, there is some diminishment of institutional memory, which can impact the program going forward. As one informant¹²⁷ stated:

“...we've lost some of that historical context because we don't have the same leadership and [pause] you know, with... I feel like, since we don't have the history, we don't have the same leadership, it's, it's sort of [pause] thrown us for a loop, so to speak, in terms of [pause] you know, the staff that are still here and know the history, we still strive to reach those end goals that we've always had in mind over the years, and with new upper management and, and new [pause] overall leadership for this program, who do not have the same – they don't have the same history.”

This comment, made in reference to the loss of the original principal investigator (LC) and others, suggests that the program staff members who have continued with the registry have had to deal with somewhat of a disconnect between what was set in place early on and what is in place at present. On this subject of losing the original leadership because of a Branch-level decision, the informant continued: “...we [pause] you know, you still need a good leader, and I feel like [pause] you know, we've been lacking that and we've been feeling the loss of a really

¹²⁷ Phase II, Key Informant #1.

good leader and are trying to recover from it.” This informant commented not only on staff changes within the program’s leadership, but also on staff changes within its administrative support structure. Again, referring to the changes made by the Branch, she stated this:

“...staffing changed so much and it impacted us so negatively that we were no longer left with administrative support, and, in fact, some support that did exist before were actually taken away from us and [pause] you know, and we’ve, only have one and a half fulltime, or FTEs, working on this program and we were charged with handling all of the fiscal and administrative duties, which [pause] you know, around here, those can be very burdensome given just the bureaucracy of state government and all of the paperwork that needs to be completed to do anything.”

She continued to discuss these staffing changes and the administrative burden and the inefficiencies that they created within the program, saying this:

“...unfortunately, it takes away from my time as well as others’ time, because we’re all involved in some degree with this now and [pause] and so we just can’t spend as much time on what we want to and what we should be doing which is the true program activities of the registry – especially the quality improvement activities, some of the newer things we envisioned happening in this funding cycle. And we still have not been able to do that, which is really frustrating for us.”

Another key informant¹²⁸ spoke about these inefficiencies, as well. In talking about the new principal investigator, she felt that the Branch, in staffing that position, did so “...at a higher level than originally anticipated and planned for, and that really impacted the budget and I think put some constraints on it.” She remarked, as well, on how other CSR/CCP staff members were spending their time. She described how, because of staffing changes, one of the scientists “...had to assume administrative duties, which really isn’t an efficient use of staff time or grant money.” Moreover, this staffing situation meant that the daily operations of the registry were not what they should have been. As this interview concluded, this was noted about the program: “...we had existing program staff having to do things that were, maybe, outside of their scopes or

¹²⁸ Phase II, Key Informant #7.

outside of their skill sets and that could introduce inefficiencies.” Surely, as evidenced by these data, the staffing patterns, in part, have dictated how the CSR/CCP has operated over the years.

The registry’s notion of prevention: A unique perspective

This third theme under the historical events component of the contextual factors construct concerns the registry’s notion of prevention. Of note is that the registry’s scope deals primarily with secondary prevention – as it seeks to reduce the impact of an event (i.e., a stroke) that has already occurred through immediate appropriate treatment; in contrast, the focus of nearly every other public health program within the CDPH is on primary prevention – to prevent disease before it ever occurs. Given this contrast, there is somewhat of a “lack-of-fit” (within the larger organization) for the registry, and this situation has been impactful on its operational state. Statements made by one of the key informants¹²⁹ speak to this situation. First, she stated: “The direction tends to be more primary prevention and secondary prevention is usually, is sort of left off the table or it’s thought of after the fact, or it’s a back-burner issue.” Then she continued:

“...I don’t think we are [pause] elevated to a level of importance within the [pause] structure here, or in the view of all of upper management. I think they’d like to see us succeed, of course, and they’re happy when we’re successful in getting funding and [pause] and... But I don’t feel that they [pause], you know, are focused on us and they don’t truly understand everything that we do and what we’re trying to do.”

This belief that the ongoing efforts of the CSR/CCP have not been well understood by upper management was expressed during another interview. According to this informant¹³⁰, who spoke about the how the registry fared within an environment in which the prevailing notion of prevention was different (than that of the registry): “...maybe it’s not understanding what it was, how it functioned, why it was important, wh...how it fit in – with all the changes that happened, I think it got kind of lost a little.” This key informant then posed the following hypothetical

¹²⁹ Phase II, Key Informant #1.

¹³⁰ Phase II, Key Informant #5.

question – which underscores this idea that the fit of the registry, within the larger organization, is not ideal, given the differing historical notions of prevention:

“Can the senior leadership within the organization value the registry as much as, perhaps, those who are working in it do, if the philosophy, you know, at that higher level isn’t exactly consistent with the philosophy of those who are, you know, working right in the registry itself?”

This idea was discussed further when another informant¹³¹ stated this about the registry’s focus on secondary prevention:

“I think that is consistent with [pause] you know, the, the focus on public health, but because those activities occur in a clinical setting, in a hospital setting, I think it becomes an arena that public health is not as comfortable in – at least this department as it’s organized, I think it’s an area that is probably more foreign.”

Moreover, she commented on the ramifications of this misalignment situation, in terms of the amount of support given to the registry by the organization’s senior leadership, saying: “...it’s been so different from other traditional public health programs, I think it hasn’t gotten recognition from leadership. It certainly hasn’t gotten any additional financial support or resources.” That stated, she did suggest that perhaps things might change (for the better) in the future, in terms of how the registry’s notion of prevention might be viewed by the CDPH. She commented this way:

“I think it’s, it’s coming, but I think, my impression about the history of [pause] this program when it started in the context of public health, I think it [pause] my sense is that it was probably not in alignment with traditional public health notions of prevention.”

For this third theme under the historical events component of the contextual factors construct, it appears that the CSR/CCP has been hampered in its ability to meet its objectives. This inability may a consequence of deprioritization because of the disconnect between the CSR/CCP’s notion of prevention (i.e., having a focus on secondary prevention) and that of the larger organization in which it resides (which has a focus on primary prevention).

¹³¹ Phase II, Key Informant #6.

b. Structural Factors

In terms of context, the second line of inquiry concerns the impact of structural factors on the CSR/CCP's operations. Of particular interest are these topics: the hierarchical nature of the organization in which the registry resides; that organization's processes in place for carrying out programmatic activities; and that organization's rules established for guiding the program staff. Again, in analyzing the source documents in NVivo, Version 10, a number of key themes emerged across these topic areas; they are discussed below.

Working within the hierarchy has introduced inefficiencies

As has been discussed previously, the capacity of the CSR/CCP has been diminished, at times, due to various organizational influences. This has been shown in terms of (mostly unfavorable) decisions being made, human resources being cut, and prevention ideas being misunderstood. Now, in assessing the impact of the larger organization's hierarchical structure, there is evidence to suggest detriment on the operations of the CSR/CCP. One example, which was reported in the Reapplication for Year 2 (on page 7 of the Narrative) and concerns the impact the CDPH's Office of Legal Services had on the registry during the first year of Coverdell funding (i.e., 2012-13), is this: "In Y1, we experienced a significant delay in our recruitment efforts due to barriers posed by our department's Office of Legal Services regarding the authority to run the Coverdell Registry in California." In this case, a certain part of the bureaucracy (separate from the registry) got involved in – and negatively impacted – the ongoing business of the registry.

Another example of the problematic nature of the hierarchy was voiced by a key informant¹³². In describing the hierarchy of the Branch in which the registry resides, she said:

¹³² Phase II, Key Informant #1.

“I feel like we’re top-heavy in terms of certain [laugh] positions in the management level, and then we have a lot of admin type of people, and [pause] and there’s not enough program activities going on, in general, in the Branch, and it’s, it’s definitely impacted our program.”

In other words, the hierarchical nature of the Branch is such that some of the programmatic activities have been impeded. Another informant¹³³ spoke to this concern, as well, stating (about the registry): “I think it should be within the department, but I don’t necessarily think it should be within the Branch. Or maybe it should be its own [pause] maybe its own program not underneath, buried underneath so many other layers.” She continued:

“...if it were out from under different layers, it would [pause] be able to...the program would be able to focus on its vision specifically...it would be able to achieve its, its goals quicker and faster, ‘cause it could stay focused.”

Even an informant¹³⁴ external to the program (and the larger organization) was aware of the impact of the hierarchy on the registry, as he stated:

“...it’s gotta be a pretty massive organization, right, so in terms of allocating funding and resources, I think any of the challenges with big organizations is really trying to optimize, you know, the flow of, the work flow and, and how things structurally are gonna work.”

Further insight was provided by another external informant¹³⁵, who, in discussing the registry’s need to work with local clinical providers in the pre-hospital setting, had this to say about how structure can impact operations:

“...anytime they decide they’re gonna make a change, they have thousands and thousands of EMS providers, so now they also have to think about things like, ‘How do we get...how do we let them know, how do we let those field folks know?’”

In sum, ongoing programmatic efforts can be impeded not only by the layers that exist internally but also by the layers that exist externally. For the CSR/CCP Team and its partners, this has been the case, given all of the challenges they have faced.

¹³³ Phase II, Key Informant #2.

¹³⁴ Phase II, Key Informant #4.

¹³⁵ Phase III, Key Informant #6.

Processes can sometimes get in the way

The second theme related to structure (which is the second contextual factor of interest) is that organizational processes can, at times, get in the way of progress. For the registry, these processes have tended to be internal ones, put in place by the larger organization in which the registry resides. On the subject of these internal processes, one informant¹³⁶ shared this:

“There’s a lot of procedures that have been put in place in terms of how forms are handled and how anything can get done around here, which sometimes has been maybe a little helpful, and made things a little better around here in terms of just maybe helping us set up a computer or something, but it, in terms of most procedures, it just seems like additional work that has to be done, or more control that’s been put in place.”

The concern over burdensome processes was expressed by another informant¹³⁷ who felt that they (i.e., the processes) can be rather stifling. She made the following remarks:

“I think we are [pause] constrained by the environment that we work in, so we can have a lot of innovative ideas, but actually being able to implement those ideas [pause]...there are a lot of structural, organizational constraints around that.”

A third key informant¹³⁸ spoke about how these organizational processes have been detrimental, as they have not only caused delays but also, perhaps, engendered some mistrust (of the organizational leadership) by the program staff. She had this to say about the senior management structure within the Branch in which the CSR/CCP resides: “...Branch management was [sigh] – I don’t know – kind of secretive, in a sense, about plans for different programs and very [pause] late in getting information to the programs and late in getting budgets to the programs.” The implication here is that processes can take time; however, when they are not well run – as this informant suggests has been the case, they take even more time, which can be devastating to a program. This particular statement also speaks to the organizational culture, another key contextual factor of interest discussed later in this chapter.

¹³⁶ Phase II, Key Informant #1.

¹³⁷ Phase II, Key Informant #6.

¹³⁸ Phase II, Key Informant #7.

Rules can also get in the way

Following this discussion on processes, the third theme related to structure concerns rules. On the subject of rules, English businessman, adventurer, and philanthropist Sir Richard Branson once tweeted (2013): “If everybody followed the rules, nothing would ever change. Without change there would be no progress.” The project data are in line with this message, especially as they relate to the data system development process. Within the Department of Public Health, certain rules dictate how such processes can be undertaken, and the CSR/CCP has followed those rules. However, following those rules has meant having the Eureka Team of the cancer registry serving as the contractor for the data system, and, as has been described above, that team has made no real progress in terms of delivering a functional data system. In short, the rules here dictated how the process has had to go...and that process has not had a good result.

The key informant¹³⁹ most immersed in that process, had this to say about the situation:

“...if we are able to [pause] [sigh] utilize external contractors for developing [pause] an IT project more flexibly and more freely and that would be, that would make a project much more efficient, but I don’t think we can do that, so [pause] and that’s why we were stuck with internal sort of state government internal [pause] work with the cancer registry.”

Another informant¹⁴⁰ shared these concerns about how the rules have impacted the program’s ability to have a functional data system, saying: “I think our contractual, our limit...limitations in contracting, are a huge [pause] issue.” She continued on this subject of how certain rules have constrained the CSR/CCP’s ability to achieve its goals, particularly related to the development of the data system:

“I think we stuck with a contract that wasn’t working for a long time because we didn’t really feel we had another alternative to go elsewhere, and I think that speaks directly to [pause] constraints within, you know, our, our...partly state government and the department, specifically.”

¹³⁹ Phase II, Key Informant #3.

¹⁴⁰ Phase II, Key Informant #6.

As these data suggest, certain rules obligated the registry to take certain action (i.e., to contract with the CCR's Eureka Team for the data system development), and this action has not had a great result. Specifically, as has been described above, a functional data system has not been developed and delivered. The lack of a functional data system has been problematic for the CSR/CCP Team, as major data-driven programmatic activities (like recruitment and quality improvement) have been hampered and key partners (e.g., LEMSA partners) have been less engaged. As a result, the current operational state is out of alignment (and "less than") that which has been hoped for, as per the program's original vision.

c. **Cultural Factors**

Continuing with context, the third line of inquiry concerns the impact of cultural factors on the registry's operations. Within this line of inquiry are two topic areas of interest: how the organizational culture defines and carries out planning; and how it handles innovation. These particular practices can, to some degree, dictate how the organization operates. If regular planning occurs, then, holding all else equal, the likelihood of goal achievement is considerably greater (than it would be in the absence of such planning) (Bryson, 1995). Moreover, if the organizational culture promotes and allows for innovation, then the organization likely will be able to achieve and sustain success (Davila, Epstein, and Shelton, 2012). Within the present project, in analyzing 41 source documents in NVivo, Version 10, some themes related to planning and innovation emerged; each is discussed in succession.

The planning processes devolved

According to the data, over the years, the planning processes of the CSR/CCP devolved from forward-thinking and strategic; to incremental and tactical; and, eventually, to just plain reactionary. Early on, as described in Chapter 1, the registry itself actually came out of the

strategic planning process carried out by the California Heart Disease and Stroke Prevention and Treatment Task Force (2007)¹⁴¹. Then, as the registry staff members worked to secure federal funding for the so-called “homegrown registry,” they built on this practice of long-range planning, even inviting Task Force Members to be part of a new Advisory Committee. This early planning process was further supported by the release of California’s State Stroke Care Plan, (named and) discussed in the Year 1 Annual Report:

“The Task Force recognized the many technical and policy issues inherent in the development of Stroke Systems of Care and recommended the establishment of a Stroke Work Group to further develop a state stroke plan. In 2007, the Work Group was convened by CDPH. The deliberations and recommendations of the Work Group were published in *Recommendations for the Establishment of an Optimal System of Acute Stroke Care for Adults*. This document (often referred to as the “Recommendations” document) has been approved by the California Health and Human Services Agency (CHHS) and serves as the State Stroke Care Plan...”

Thus, using the momentum, proven practices, and the work products of the Task Force and one of its Work Groups, the CSR/CCP staff members were able to utilize long-range planning efforts of their own in pursuit of their goals. One key informant¹⁴² spoke about those early days and the long-range thinking:

“...it really helped focus the development of the stroke registry from a grassroots level, and we had [pause] leadership that had a long-term vision for what this registry could be and what we could provide to hospitals and to the EMS world here...here in California.”

Another key informant¹⁴³ (from the AHA/ASA) spoke about these efforts, too, noting how successful they were. She remarked: “...even though there wasn’t funding yet, but the idea was to plan ahead and that, and, of course, it showed the success of the registry where you ended up getting Coverdell funding in the end.” As these data suggest, the registry’s early planning processes were met with success.

¹⁴¹ This process culminated in the development of California’s Master Plan, as noted in Chapter 1.

¹⁴² Phase II, Key Informant #1.

¹⁴³ Phase II, Key Informant #5.

As things changed within and around the registry (as has been discussed above), the CSR/CCP's planning processes began to devolve. One particular change of note occurred within the Branch in which the registry resides: Senior leadership within the Branch chose to direct its efforts away from the disease-specific plans already in place (like the one used to help guide the registry), in favor of something more consolidated. This paradigm shift led to the development of a new plan called the "Wellness Plan." One informant¹⁴⁴ describes this situation and what it has meant for the registry:

"There's something they've called the "Wellness Plan," and, apparently we've, we're included in it somehow, but we were unaware. I'm not even sure how [pause] we're included, but it's definitely not a document that we look to. As a program, we do not look to that for any kind of guidance."

She also had this to say:

"And, so, because we don't fit into any of these things in a, in a strong way [pause] I don't feel that management ever looks to us to help fulfill any of those goals that they've set forth. And if they do come to us, it's [pause] it's more out of convenience that we can help them, not because we're actually, in my opinion, seen as an important piece of a long-term plan or goal for them."

With this shift, the prior plans were rendered obsolete; furthermore, all momentum from the earlier strategic planning processes was lost. Plus, no accommodations were made for the registry, which was essentially "rudderless." As a result, there was a cultural change related to planning within the registry. This same informant concluded her remarks with this sentiment: "...we used to be more long-term and now we're probably more incremental just given those same barriers and changes here..."

What came next was the use of an incremental approach, whereby registry staff made plans by building on what was already in place. This practice of incrementalism was discussed (as a possible cause of the registry's alleged sub-par state) in Chapter 2 (along with [a] the

¹⁴⁴ Phase II, Key Informant #1.

application of a “Philosophy of Improvement” within a single subsystem and [b] bounded rationality). One informant¹⁴⁵ summed up the registry’s practice of incrementalism this way:

“I think if [pause] again, as we’ve spoke before, the culture of the [pause] department or the Branch doesn’t get in the way, I think that [pause] those incremental goals can be met to reach the long-range goal.”

This philosophy was what guided the registry’s efforts going forward for a time, just because the longer-term strategic planning wasn’t really supported – or possible, really, given the cultural shifts within the Branch. One programmatic activity that was impacted considerably by this new paradigm was the development of the registry’s data system. The informant most involved in that effort¹⁴⁶ had this to say about the development process: “...it seems that this project [pause] was developed without [pause] a comprehensive design of how we’re gonna create [pause] the California Stroke Registry...” He continued: “...from a comprehensive point of view, it was not successful because there’s no vision about the entire picture of the project.” Certainly, this incremental approach affected the ongoing operations of the registry. It also changed the collective mindset, in a way, as staff members began to look only at the present. This statement by another key informant¹⁴⁷ sums it up well:

“I feel like our current state is more incremental, like, “Let’s just deal with what we have on the plate now and try and get through it, and even if in the end, we aren’t reaching our end goal, but this is just what we need to do now.”

As this collective mindset shortened its focus to the present, the registry’s planning processes really just dropped off completely. In fact, as stated in another interview¹⁴⁸, the culture around planning devolved further such that it was now strictly reactive. She stated this:

“...because of the challenges and constraints and limitations on resources, I think our decision- [pause] making process has been largely reactive. It has been kind of [pause]

¹⁴⁵ Phase II, Key Informant #2.

¹⁴⁶ Phase II, Key Informant #3.

¹⁴⁷ Phase II, Key Informant #1.

¹⁴⁸ Phase II, Key Informant #6.

“What’s on fire today?” or, “What’s the most important thing... What’s due to CDC today? What’s due to the Branch today? What’s due tomorrow? What do we have to do to stay alive another day?” and that’s, I think has made it very... And we have stayed alive, and we have lived to see another day.”

And she continued:

“I think that much of our [pause] process has just been very reactive to what’s in front of us, and not looking down the road to next month, to three months from now, to six months from now, and I think that’s been very impactful, you know, on our work and, you know, again, if, if...there’s just a sense, I would describe it as kind of treading water. We’ve stayed afloat, but we haven’t really... We haven’t sunk, but we haven’t really been able to make proc...progress in the way we would have liked.”

To summarize, the organizational culture, particularly within the Branch in which the registry resides, underwent some significant philosophical changes, such that the registry’s planning process devolved and its ongoing operations waned.

Innovation...without implementation

The second emergent theme related to culture (the third contextual construct) concerns innovation. As stated in one of the key informant interviews¹⁴⁹, innovation was part of the culture in the early days of the registry:

“...in the registry’s history, there have been multiple examples of being innovative. First, you know, developing a homegrown registry without the support of a federal grant, and, secondly, trying to develop this data system that would help [pause] help us move forward in our efforts in terms of the pre-hospital and in-hospital setting.”

In that same interview, while commenting on the spirit of innovation that was a part of the registry’s culture earlier on, this was stated:

“...that was the thought, ‘Why not start something, be innovative in it, figure out a way to make it work, and, also, then, be able to show it?’ and that alone co...resulted in multiple good things afterward, at least for the, you know, couple of years...”

As mentioned above, this spirit of innovation within the CSR/CCP led to the earlier-discussed partnership with the cancer registry’s Eureka Team, for the purpose of developing the

¹⁴⁹ Phase II, Key Informant #5.

data system. At first, this venture seemed to be the epitome of innovation within state government. One key informant¹⁵⁰ had this to say:

“I think the idea itself was [pause] a very good one, to combine the resources that had already been developed within the cancer registry, in collecting data. They’re very comfortable in [pause] working with hospitals and collecting information from hospitals. They’re very comfortable with integrating dative...data from a wide variety or sour-...resources. So I think that was a very innovative idea.”

As has been described above, this innovative data system development process has failed to deliver what was promised. This failure means that the registry lacks a data system, certainly, but it means more than that. This failure also means that there is now somewhat of a reluctance to be innovative, at least with something of this magnitude. In short, the current state of the CSR/CCP is one with a diminished spirit of innovation, given the past innovation...without implementation. This statement from one of the key informant interviews¹⁵¹ sums it up well: “I think that’s just the, the nature of our culture and [pause] you know, we would want to be innovative, but we can only be innovative to a certain extent.”

d. **Programmatic Reach**

Wrapping up the contextual factors construct, this fourth and final line of inquiry considers how programmatic reach impacts the registry’s operations. For the CSR/CCP, in following guidance from Mirambeau and Losby (2011), reach typically has referred to the extent to which the program has been able to attract its intended audience. Moreover, the CSR/CCP staff members have learned that whether the program’s reach is extensive...or narrow...or somewhere in-between can affect its operations, perhaps mediated by resources and/or morale and/or some other factors. Project data related to reach reveal some key themes, which are discussed below.

¹⁵⁰ Phase II, Key Informant #6.

¹⁵¹ Phase II, Key Informant #3.

*“Geographically, this state is so large, we, our program couldn’t... ”*¹⁵²

The first key theme related to reach concerns size: The CSR/CCP has as its intended audience the California population, which is quite numerous, notably diverse, and widely dispersed within a vast geographic area – and that intention becomes important, in terms of how the program operates. As one informant¹⁵³ stated: “however you wanna define ‘reach,’ if that reach is limited [pause] then our subsequent actions are also going to be limited.” In other words, the sheer size of the population, residing within the great expanse of California, can pose some challenges, particularly in terms of directing resources. Another informant¹⁵⁴ said this:

“California is a huge state and we’ve always known that the funding that we will receive from this grant would never really be enough for us to reach every part of the state that we would like to, and that deserves to be [pause] you know, reached out to...”

She continued:

“We try to focus on certain regions in the state to make sure that we have some representation in, at least, the major population zones in the state. We’ve [pause] had some limitations on that, as I’ve mentioned before, just given lack of resources and funding, staffing...”

Similar sentiments related to reach were shared by an informant¹⁵⁵ from a partner organization.

He shared this:

“I think the resources and the, and the manpower, so to speak, is a significant portion, because if you really can’t kind of take that message out or take that information out, with adequate coverage, with, with adequate resources to really try to connect...”

He stated further: “...the potential reach is so great and you know you can’t get there.” He followed up with these words on how these challenges dictate ongoing operations:

“...so then you begin to [pause] kind of prioritize or, you know, just make decisions on [pause] where you’re gonna spend your time and your energy and sometimes it’s the, you know, the path of least resistance.”

¹⁵² From the interview with Phase II, Key Informant #2.

¹⁵³ Phase II, Key Informant #3.

¹⁵⁴ Phase II, Key Informant #1.

¹⁵⁵ Phase II, Key Informant #4.

A summary statement for this first theme on how reach has impacted operations was recorded in an interview with an informant¹⁵⁶ who works with pre-hospital providers: “...we have more work than our program staff can accomplish, in part because of the, just the size and diversity of California, and the sheer number of stroke patients [pause] annually.”

The program’s reach has been differential across the clinical settings

As has been discussed above (particularly related to the recruitment efforts and the data system development process), the CSR/CCP has tended to focus its efforts almost exclusively within the in-hospital setting, to the near exclusion of the pre-hospital setting. This has been the case for reach, as well. This difference was highlighted by one informant¹⁵⁷ who shared this:

“...we also were charged with targeting our work towards the EMS agencies. I don’t feel that we really met the goals we set forth, though, in working with them and, given certain challenges and changes here with our program and in the larger structure of the department, we tended to focus more on what existed already with our relationships at the hospitals [pause] and we did have some progression, though, with the local EMS agencies in a really positive way, but it wasn’t as extensive as we had hoped it would be, given the lack of development in certain areas.”

As these statements indicate, the program’s reach, particularly within the pre-hospital setting, was less than anticipated. There were some reasons for that, as this informant suggested later:

“...we’ve been able to [pause] in some ways, focus more on the hospitals just because we had already had previous relationships with those hospitals even before this grant funded, um, grant was funded and we had a lot of support, previously, as well, from the American Heart, American Stroke program from that standpoint.”

Another informant¹⁵⁸ suggested that the reach was differential across the two clinical settings, in part, because of the registry’s partnership with AHA/ASA, given that AHA/ASA has a financial interest in reaching out to hospitals – as hospitals are able to purchase AHA/ASA’s Get With The Guidelines®-Stroke for improving stroke care. She said this: “...the American

¹⁵⁶ Phase II, Key Informant #6.

¹⁵⁷ Phase II, Key Informant #1.

¹⁵⁸ Phase II, Key Informant #2.

Heart, American Stroke Association was a key resource that enabled us to get into the hospitals [pause] which we didn't have exactly the same way when we were reaching out to the LEMSAs.” This idea was reinforced by another key informant¹⁵⁹ who described how the AHA/ASA's financial interests have tended to drive the program's outreach efforts to the hospitals (and not the EMS agencies). He had this to say:

“I think, it is challenging sometimes, certainly, when you're working with some of the partners because, you know, there's sometimes, there...I don't know about competition, but... You know, like, for example, with American Heart Association [pause] you know, sometimes... I mean they're, they have a, a role and it seems like it's mainly focused on [pause] you know, getting hospitals to join the Get With The Guidelines...”

In short, having the financially interested AHA/ASA as a registry partner may have resulted in hospital-focused (i.e., not EMS-focused) outreach. Accordingly, the program's reach has been differential across the clinical settings. It follows, too, that the differential reach has, in part, dictated the day-to-day workload, and, therefore, the registry's current operational state.

To sum up, there are contextual factors (to include historical events, structural factors, organizational culture, and programmatic reach) that have had an impact on the CSR/CCP's current operational state, as discussed earlier. Of course, these factors represent just one type of influence on the registry, as suggested above. What follows next are findings related to Operational Challenges, before discussing Held Beliefs.

2. **Operational Challenges**

Why These Challenges Matters

Second, in determining what has given rise to the registry's current operational state, it is informative to look at the kinds of challenges that have been dealt with by the registry. While a number of the contextual factors discussed above have tended to be operating externally with

¹⁵⁹ Phase III, Key Informant #1.

respect to the registry, some of the challenges discussed below are operating from within it (now). These challenges have been part of the registry's experience and development over the years, and some of them, somehow, have come to persist within the registry – perhaps because of the registry's configuration, its composition, and/or its capacities. Within this project, the operational challenges of interest relate to these two areas: programmatic constraints and sharpness of focus. Below, the findings for each of these two areas are presented, before finishing up with the third main area of inquiry (within Phase II), held beliefs.

The Challenges

a. Programmatic Constraints

In carrying out its scope of work over the years, the CSR/CCP Team has had to deal with various programmatic constraints¹⁶⁰. Some of these constraints have been foisted upon the program by external sources; however, they have not really been turned aside. Instead, they have become part of the day-to-day experiences of the program. They have come to be almost internal to the CSR/CCP's current operational state. In analyzing the information provided by the 41 data sources utilized in this project, two themes regarding programmatic constraints became apparent. Each is discussed in succession.

The registry has been financially constrained

In reporting the study results thus far, some mentions have been made of having limited financial resources, while discussing other emergent themes. Even so, the topic of finances merits further mention, however, since it was so prominently featured in the source documents. In fact, during twelve of the fourteen key informant interviews, a number of statements (80) were

¹⁶⁰ This experience of having constraints is consistent with the notion of bounded rationality (Simon, 1991); this was introduced and discussed in Chapter 2 as being a cause of suboptimization, as were (a) the practice of incrementalism and (b) the application of a "Philosophy of Improvement" within a single subsystem.

made about the program's fiscal constraints. Furthermore, in two of these key informant interviews¹⁶¹, statements related to finances comprised more than one-tenth of the total interview content (respectively, 11.3% and 17.7% of each one's total content), which suggests that it is a topic of considerable interest. It is noteworthy as well that these 80 statements from the interviews represent only half of the total number of references (169) related to finances as sixteen of the Phase I documents also addressed finances.

The data sources revealed that financial constraints were apparent already during the first year of Coverdell funding (i.e., 2012-13). First, in the Reapplication for Year 2, it was noted how the fiscal situation was having an impact on the first year's programmatic activities:

“The current level of funding is directly impacting implementation decisions. Hospitals with the largest number of annual stroke cases are being actively recruited for participation in the stroke registry. This strategy makes the best use of limited staff resources and favorably impacts the greatest number of Californians; however, from a QI perspective, the needs of the smaller hospitals are not being addressed.”

As this reference indicates, the CSR/CCP Team has been cognizant of the fiscal limitations and has sought to carry out the scope of work with them in mind. Finances also have driven how human resources have been directed and utilized. From this same source document comes this statement: “...our Y2 program is comprised of 1.95 FTEs and a subcontract; however, the program leverages resources from within the leadership team in order to carry out all of the activities.” In short, the program's funding level was inadequate to support all of the human resources necessary to complete the program's scope of work. Next, in the Year 2 Site Visit materials (i.e., in a November 18, 2013 Memorandum written by AV from the CDC), the registry's fiscal situation was further documented, as a representative from the funding agency described what was witnessed during the visit: “They have concerns about their budget and staff roles.” Another statement from this data source reinforced this concern: “...they are struggling

¹⁶¹ Phase II, Key Informant #1 and Phase II, Key Informant #7.

with maintaining resources and staff.” Indeed, as early as during the first year of the federal grant, financial constraints were evident.

The registry continued to experience these constraints as the grant cycle continued. As was noted above (when discussing those historical external decisions that impacted the CSR/CCP’s operations), two individuals who worked with the registry (i.e., TH, a senior scientific consultant, and LC, the original principal investigator) were laid off by the Branch Management, purportedly for budgetary reasons. These layoffs occurred midway through the second year of the grant cycle (TH) and early into the third year (LC). Below are the reports about the layoffs of TH and LC, respectively, as stated in the January 2014 and September 2014 State Updates (names has been replaced with initials):

“As of early December, 2013, TH, who has been an integral part of our state’s stroke registry efforts (particularly those related to our data collection and reporting system) since our early, pre-Coverdell work, was laid off, with the stated reason that there was insufficient funding to support his part-time contract position...”

And:

“On August 8, 2014, LC, the original PI of the State stroke registry – who most recently served as a medical consultant to the registry – was transitioned out of the Department/Center/Division/Branch in which the registry resides, as a result of funding-related decisions made by the Branch Chief. This is a tremendous loss not only to the registry but also to the public health of California.”

Other facets of the program have been impacted by the fiscal constraints as well. In fact, certain programmatic activities have had to be designed in a way that takes advantage of economies of scale. One example of this is the conduct of quality improvement initiatives. Given the resource constraints, it has been prudent to use a one-to-many approach...wherein one intervention can be of benefit to many clinical partners. This statement from the Year 2 Annual Report makes this point:

“...the Program reinforced its understanding that the ‘scope’ needs to be a consideration when implementing a quality improvement initiative – especially given the Program’s limited resources. An intervention that can be used in several hospitals (rather than in one hospital) has the potential to have a larger impact, relative to that which would result from an effort taking place in just one setting.”

In other words, the program has had to be very strategic in carrying out its activities, in order to practice good stewardship of its limited funds. This has proven to be challenging, given the amount of funding that has been dedicated to the development of the data system (often called the IDP, or Integrated Data Platform). As one key informant¹⁶² noted, the CSR/CCP “...funneled quite a bit of money in the direction of that contractor.” She described this fiscal issue further, and, in so doing, also spoke to decision-making within the Branch (discussed above) and the program’s locus of control (discussed below):

“...another decision was made that some of the, the funding we received, which was a little less than what we had initially applied for, that almost half of our budget would go towards the development of the IDP – and I know I’ve talked about that earlier – and because of that, we have significantly less money to put towards any quality improvement activities that we did want to, to have in place. And there was also less money for staffing, and so even if we thought maybe we could hire another staff person to help with fiscal or administrative duties, that was no longer an option.”

As she continued, she commented on the CSR/CCP’s ability to move past some of these constraints, saying: “...I feel like our hands have really been tied now for especially the last year.” To be sure, being fiscally constrained has been difficult for the registry. Finally, on the subject of finances, this key informant noted this:

“But we would either need additional funds, I think, directed towards us from, possibly, the block grant¹⁶³ or some other funding source. So if we had support from upper management to give us that money, that would be great because it could help fund an additional staff person. And [pause] I think that would just, that would make a big difference for all of us.”

¹⁶² Phase II, Key Informant #1.

¹⁶³ This is the federal Preventive Health and Health Services Block Grant.

As this informant describes above, the CSR/CCP has been impacted financially, to some degree, as the senior management within the Branch within which the program resides (1) has dictated how the program's budget is to be spent; and (2) has chosen to use its various funding streams in support of other areas (i.e., not the stroke registry) – a finding that correlates, perhaps, with the above notion that the registry's secondary prevention focus (in contrast to the prevailing primary prevention focus) has resulted in the registry being deprioritized. Another informant¹⁶⁴ shared this sentiment, saying this (about the registry): "...it hasn't had the support it's needed to [pause] jump off and be, reach its full potential. I think that [pause] if it [pause] it had the dedicated resources, it would [pause] it would flourish."

Finally, the following comment from one of the key informant interviews¹⁶⁵ sums up this notion that the registry has had to deal with fiscal constraints in striving to carry out its scope of work:

"Well, I think there have been, obviously, a number of challenges and restraints – financial, fiscal has been a, a huge one. The only source of funding for this program has been the funding that was obtained from CDC and as we learned over the past three-year cycle, that was not enough to do the activities that were being required to be done."

*Constrained because of "...more control that's been put in place"*¹⁶⁶

The second theme to emerge (with respect to constraints) is that the CSR/CCP has had to contend with diminishing autonomy over its ongoing operations, as a result of various controls that have been put in place, organizationally (i.e., external to the program). These imposed controls have altered the program's locus of control over the years, as the programmatic actions as of late are, for the most part, no longer performed independently (Harris and Hartman, 2002). Earlier in this chapter, when presenting the results related to decision-making processes and

¹⁶⁴ Phase II, Key Informant #2.

¹⁶⁵ Phase II, Key Informant #6.

¹⁶⁶ From the interview with Phase II, Key Informant #1.

budgeting, this idea of control has been discussed. However, since it (i.e., the locus of control) has become an increasingly more prominent constraint over time (as the registry staff members have been progressively more bound in their activities), it merits further mention here, in terms of the capacity to work with clinical partners; the involvement in how resources are directed; and the process to develop the registry's data system.

Clinical Partnerships

One area in which the program's inability to exert its control is evident is its work with its local clinical partners, particularly LEMSAs. In the reporting on the registry's interactions with these established partners during the first year of Coverdell funding (i.e., 2012-13), this situation is documented as follows (in the Reapplication for Year 2, page 8 of the Narrative):

“...the Program staff came to recognize that, according to the LEMSA's own schedules and strategic plans, the LEMSAs could – at any time – ask the CSR/CCP to assist their designated hospitals with some facet of participation in the local system of care and/or the registry, in order to enable the system to be launched and operational in a timely manner...and the CSR/CCP had to be responsive.”

Moreover, each time an attempt was made to engage another LEMSA, this control issue emerged, thereby challenging the registry's ongoing operations. As one CDC staff member (AV) stated in the Year 2 Site Visit materials: “The timing of when a LEMSA wants to partner with the CSR depends on when the LEMSA is establishing its stroke system of care.” In the Reapplication for Year 3 (page 8 of the Narrative), this same message is communicated: “...in some of our attempts to coordinate our efforts with certain LEMSAs, we have had to adjust our workloads to match their timetables, which usually correlate to the rolling out of their local systems of care.” Thus, the ongoing workload of the registry, in terms of what happens and when it happens, is, at times, determined by other entities. This suggests an external locus of

control for the program's efforts in this area, something which has impacted the program's operational state.

Programmatic Resources

The second way in which the locus of control has become a noteworthy constraint is the manner in which the programmatic resources are directed. As has been discussed at length above, the decision-making processes related to budgets and staffing no longer occur within the registry as they did during the program's early days; instead, they now occur external to the registry, within the scope of the Branch management. In the Reapplication for Year 3 (page 25 of the Narrative), the following report about this was made to the CDC:

“...the concept of control is one that impacts the programmatic efforts – as certain actions and situations are beyond the control of the Program staff. For example, progress during Y2-to-date has been hampered by a number of things that are external to Coverdell, including human resources redirections and reductions occurring within the Branch; personnel changes made by program partners; and information asymmetries occurring at various times and for various activities.”

One key informant¹⁶⁷ had this to say about the Branch-level decisions and how they have impacted the program:

“...there were decisions made in our Branch that, oh, they should restructure [pause] the staffing here in our Branch, as well as, obviously, the way the programs are structured, and we lost key staff in our Branch, and our program is no longer ...as it stood before.”

Later she commented on this subject again, saying: “...it just seems that the Branch tries to have a lot more control in terms of [pause] how the, everything is handled.” And she concluded her interview with these statements:

“I feel like we have sort of a negative culture around here and it's [pause] our morale is impacted, for sure, staff morale. We've had a lot of [pause] I guess controls, like I mentioned before, put in place, which can be really frustrating for us.”

¹⁶⁷ Phase II, Key Informant #1.

Indeed, the CSR/CCP has experienced a change in its locus of control, as the Branch in which it resides has taken over those decisions which concern budgets and staffing. This change in its locus of control has constrained the registry and played a part in determining its current operational state.

Data System Development

Lastly, the locus of control has become a significant constraint within the process to develop the registry's data system (often called the IDP, or Integrated Data Platform), which also has been discussed earlier in this chapter¹⁶⁸. The problems began early on in this process, as reported in the Year 1 Annual Report (page 21 of the Narrative): "The IDP process was stalled, in part, due to shifts in the staffing – out of the Program's immediate control." Without any input from the CSR/CCP staff, these shifts occurred within the Eureka Team of the cancer registry, which has been under contract to develop the system. With new Eureka developers on board, there were delays (for the developers, first, and the Program, second) due, in part, to "...a lack of clarity...with respect to the Program needs for the IDP" (Year 2 Annual Report, page 25 of the Narrative). As noted in that same annual report about the development process (page 31): "These changes have introduced considerable inefficiencies, as 'learning curves' and adjustments have become important AND time-consuming." To make matters worse, as previously reported, TH from the CSR/CCP Team – the individual working most closely with the Eureka Team on the data system development – was laid off by Branch management making a unilateral decision. Again, this is a constraint that was imposed externally – out of the control

¹⁶⁸ Note these statements (from the Year 2 Annual Report), which describe the decision to contract with the Eureka Team: "...the Program realized early on that having flexibility in receiving and using data from all kinds of in-hospital collection and reporting systems would allow the Program to partner with any hospital in California. Moreover, the Program reasoned that the design plan for this (envisioned) data system should include a mechanism for the collection, linkage, and use of the pre-hospital data (i.e., with the in-hospital data), as well. Hence, to develop this system, the Program opted to tap into the resources and expertise of the State's Cancer Registry's Eureka Team."

of the registry – but now has become part of the ongoing operations, especially with respect to the data system development process.

To be sure, without a functional data system, there has been spillover in other areas, as has been suggested above; again, this means that the registry staff members have had to face even more constraints over which they have no control. One key informant¹⁶⁹ described these concerns:

“...unfortunately, because we don’t have this completed IDP, we aren’t able to accept data from hospitals not using Get With The Guidelines, so that limits our scope in terms of working with other hospitals throughout California and also not being able to link data from local EMS agencies.”

She continued:

“...in trying to build our partnerships with more EMS agencies throughout the state, not having a functioning IDP limits us in terms of what we can, we can offer them and [pause] you know, we, it doesn’t look as attractive to...EMS agencies, either, to work with us, when we aren’t able to accept data from all of their hospitals in their catchment areas, and then link their data to their hospital data.”

This key informant concluded her remarks on the problematic external process to develop the registry’s data system with these statements:

“...from a fiscal standpoint, I feel like our hands have really been tied now for especially the last year, and [pause] we’ve really been trying to get this IDP off the ground, and it was really elevated to the highest priority in order, you know, with the hopes that [pause] once this IDP is off the ground, we’ll be able to move forward in those other areas.”

In other words (as stated later about the registry during that same interview): “...we were fiscally constrained and it was a decision [pause] that was out of our control that, that led to that constraint.”

In sum, the data system development process was out of the CSR/CCP’s immediate control, from early on, by design; as shown above, this arrangement has constrained the registry’s ability to carry out its work. This situation was exacerbated when the Branch in which

¹⁶⁹ Phase II, Key Informant #1.

the registry resides took over the decision-making processes related to budgets and staffing (as described earlier) and, in so doing, instituted changes that have impeded the data system development process. As this process has been impeded, so have the ongoing operations of the registry overall, as has been suggested above.

b. **Sharpness of Focus**

Second, beyond the multi-faceted challenge of bounded rationality discussed above, the CSR/CCP Team has been challenged in terms of the sharpness of its focus. This sharpness of focus refers to the program's emphasis on a particular aspect of its workload – perhaps resulting in a lack of attention elsewhere. Put differently, a focus that is especially sharp in just one program area can create an imbalance in effort and achievement across all program areas. In Chapter 2, this idea was first introduced; it was referred to then as the application of a “Philosophy of Improvement” within a single subsystem, as per Trivedi (2002). Within the CSR/CCP, the interest is in whether the programmatic efforts have been more focused on one care setting (i.e., in one subsystem) than in the other, as that practice would mean that there is a resultant imbalance – and having an imbalance is an important finding in terms of the registry's current operational state. Analyses of the 41 data sources in this project revealed that this differential focus has, indeed, been happening, related to both the outreach efforts and the data-related activities. Within these programmatic areas, the focus (of the work) has been more on the in-hospital setting than on the pre-hospital setting. One key informant¹⁷⁰ put it like this:

“...there's the landscape out there, across the two clinical settings and that landscape means that our work with [pause] within each of the two settings would be different, just because of the different, the different situations and maybe that [pause] that [pause] difference that exists for us has caused us to focus more on the hospitals, because it's more clearly defined.”

¹⁷⁰ Phase II, Key Informant #1.

In elaborating on this idea of having an imbalance across the two clinical settings of interest (i.e., pre-hospital and in-hospital), the registry's work related to outreach and to data are discussed below, in succession.

Skewed Outreach to Potential Clinical Partners

As has been shared earlier (when covering the contextual construct of reach), the CSR/CCP has had more of a presence in the in-hospital setting than it has had in the pre-hospital setting. Likely, this situation has come about because of both what the program has had in its sights (in terms of seeing the number of potential recruits – which speaks to reach, discussed above) and what the program has been able to muster (in terms of marshalling targeted programmatic resources – which speaks to focus, discussed below). In analyzing the data from the nineteen data sources which address outreach to the potential clinical partners (i.e., the 83 captured references), the mentions of hospitals outnumber the mentions of LEMSAs, nearly two to one (i.e., 2638 versus 1492). In the State Update for September 2012, the following was noted, relative to the in-hospital setting:

“First, we contacted each of the hospitals with which we have been partnering over the years (prior to becoming a Coverdell state) to formally announce our new funding and to extend an invitation to become a Coverdell hospital. We have just now begun to receive responses and are very encouraged by them. Second, after strategically inventorying the more than 300 general acute care hospitals in California not participating in the registry (by geographic location, annual volume of stroke discharges, and use of GWTG-S), we developed several possible recruitment strategies. During the CDC Coverdell Team Site Visit (held 8/21/12), we shared these strategies and sought advice from the CDC on them. Moving forward, we are planning to invite hospitals that have 400 or more annual stroke discharges to participate in the registry.”

The source documents originating during the months which followed included multiple reports of outreach efforts carried out in collaboration with the AHA/ASA, including sending emails and letters as well as making phone calls. Following these various correspondences, the first of three such recruitment events was held: “...on December 12, 2012, a webinar was co-

hosted by the CHDSPP and the AHA/ASA to provide invited hospitals even more information about joining the program; representatives from a total of 27 hospitals participated in that webinar (State Update from January 2013).” Two more such events followed during the first quarter of 2013, one in February and a second in March. After these targeted outreach activities took place, the CSR/CCP staff members followed up with all of the interested hospitals and assisted them in completing the registry enrollment process. A summary statement from the Year 2 Annual Report (page 2 of the Project Narrative) describes this collaborative outreach effort overall: “We, in partnership with AHA/ASA, are in active communication with many other hospitals throughout the state on becoming involved with the registry.”

Of note is that there was not one mention of conducting outreach within the pre-hospital setting during this all of this reporting. The first mention of outreach to the LEMSAs¹⁷¹ appears on page 10 of the Project Narrative for the Reapplication for Year 2: “...we will need to be as efficient as possible with our resources to meet the needs of each LEMSA as we establish more partnerships.” It is noteworthy that this short reference, which was reported well into the first year of the 2012-15 funding cycle, uses the future verb tense. In other words, while much was being reported about the outreach to hospitals, what little was written about outreach to LEMSAs spoke of the registry’s plans for the future. More about this was written in the State Update from July 2013: “Plans are being developed to reach out to other LEMSAs in hopes of establishing new partnerships.”

During the subsequent years of the grant, these outreach efforts still tended to favor the in-hospital setting over the pre-hospital setting as it did during the first year; however, even these efforts were curtailed somewhat given some of the challenges discussed earlier (e.g., losing staff,

¹⁷¹ This refers to outreach targeting the LEMSAs not already in partnership with the registry (i.e., in partnership from before the federal grant was awarded).

both within the registry and the AHA/ASA; experiencing delays in the data system development process). One key informant¹⁷² suggested that perhaps this skewed focus (on hospital outreach) just came about somewhat naturally, since the hospitals were used to collecting and reporting standardized data, more so than were the LEMSAs. He said this: “...the natural bent probably to get started would be a place where, you know, information’s currently being gathered at a pretty extensive rate, so I think that [pause]...that it’s probably been more focused on the in-hospital side.” Another informant¹⁷³ agreed, suggesting that the emphasis on the in-hospital side might also have been motivated by the registry’s partner (AHA/ASA) and its funder (CDC). About this, she said:

“And I think, also, at that time, when, even from CDC, the direction was really a push to, as you know, AHA and CDC have a relationship nationally, as well, and so trying to kind of hone in on the hospital side is true.”

Then, when commenting on trying to work in the pre-hospital setting, she had this to say about the LEMSAs:

“...everybody was at a different place to start or not to start and so it’s probably taken longer, first of all, and, and, second, need a lot more lead time to try and get their buy-in in terms of the deliverables and what the registry could do [pause] more than probably from in-hospital, ‘cause they were already used to collecting data.”

This notion (about the LEMSAs) was reinforced by a key informant¹⁷⁴ who works within the pre-hospital setting:

“...in California, EMS is different in Riverside County than it is in Sacramento County, and they’re both different from LA and Yolo County, and there are thirty-three different local ESM agencies in California, and no two of them practice EMS exactly the same way.”

Given this, it may be the case that the CSR/CCP’s skewed outreach focus is simply a function of the program staff members taking the path of least resistance¹⁷⁵. Regardless of how it came to

¹⁷² Phase II, Key Informant #4.

¹⁷³ Phase II, Key Informant #5.

¹⁷⁴ Phase III, Key Informant #6.

be, the data suggest that the registry's outreach efforts have been focused within the in-hospital setting, much more than within the pre-hospital setting. The result is an imbalance, in terms of the registry's presence within these two clinical settings.

*"Should we have included EMS data? Of course."*¹⁷⁶

This statement – which speaks to how the registry's efforts related to data collection have tended to favor the in-hospital setting over the pre-hospital setting – conveys the second emergent theme concerning focus. As presented earlier, the plans for the data system include the receipt, standardization, storage, and linkage of in-hospital data and pre-hospital data – such that the resultant linked dataset can be used to drive programmatic activities and facilitate quality improvement initiatives. One key informant¹⁷⁷ described the planned data system like this:

"...one of our long-term goals has always been to develop a data system, platform. We've called it the 'Integrated Data Platform,' or 'IDP,' and that would allow us to bring data in from multiple sources, standardize those data to create one, one uniform dataset...that's a really instrumental piece in working with [pause] all the hospitals in California that use different data systems to collect their stroke data, as well as the local EMS agencies, because we can take their data and then link it to the hospital data is, is the ultimate goal, and so we'll have a nice view of what has happened with a patient from calling EMS to being discharged from a hospital."

In sharing the vision for this system, this informant enumerated the three development phases that comprise the contractor's scope of work (in this order): processing the in-hospital data; processing the pre-hospital data; and linking the two datasets. However, as has been discussed above (related to infrastructure), the data system development process has stalled for a variety of reasons; to-date, it (i.e., the process) has yet to complete even this first phase (i.e., handling the in-hospital data), though a small amount of exploratory work has been done in the

¹⁷⁵ Of note is that this idea of taking the path of least resistance was brought up in the earlier discussion on reach.

¹⁷⁶ From the interview with Phase II, Key Informant #3.

¹⁷⁷ Phase II, Key Informant #1.

second phase (i.e., handling the pre-hospital data). Accordingly, the focus has been almost entirely on the in-hospital data.

In this same interview, the following statements were made, reinforcing the notion that the differential focus on the in-hospital data has had an impact on the operational state of the registry:

“...in neither of the in-hospital or pre-hospital setting are we close to what we originally envisioned. Secondly, our efforts have been focused more on the in-hospital setting [pause] primarily because of the, the data issue. And, thirdly, because we [pause] are...falling short of our original vision, then our kind of day-to-day operations aren’t what they ought to be...”

Certainly, the focus on the in-hospital data has meant several things for the registry, in terms of its operations. First, this differential focus has impacted recruitment, as has been discussed above. Without the capacity to receive and link data from both of the clinical settings, the overall appeal of membership in the registry is less (for potential partners). This issue was reported in the Year 2 Annual Report (Page 24 of the Project Narrative): “...and our ‘enticement’ (i.e., the IDP), for appealing to the LEMSAs, has remained under development, as described above (so it has not been much of an ‘enticement’).” With a functional data system (as planned and expected), the likelihood of bringing on more LEMSAs partners is probably higher.

Next, the CSR/CCP’s capacity to measure performance across the care continuum has been impeded. While there are established, widely-used in-hospital performance measures (as presented in the first two chapters), the same cannot be said for the pre-hospital care setting. It is stated this way in the Year 2 Annual Report (page 10 of the Narrative): “Given that the Program collected no primary pre-hospital data during Year 2, no EMS performance measures were implemented.” In other words, with its focus squarely on the in-hospital data, the program has been able to monitor performance only within that one clinical setting.

Finally, the CSR/CCP's ability to work on pre-hospital quality improvement initiatives has been impacted, given the skewed data focus. As discussed above, the program's only work in this area has been the provision of hospital-specific summary data tables¹⁷⁸ to interested LEMSAs, upon request. In the Reapplication for Year 3 (page 6 of the Project Narrative), this activity is described:

“...during Y2, as in Y1, we provided a number of summary data tables to our current LEMSA and hospital partners, as per their requests. These summary data tables, which were produced according to the expressed needs of the LEMSAs, included hospital-specific data on patient demographics and outcomes.”

As noted in the Year 2 Annual Report (page 29 of the Project Narrative), this activity isn't really what the CSR/CCP has been intending to do in the area of pre-hospital quality improvement:

“The summary data tables continue to be a stopgap method to provide data to the LEMSAs; the IDP will later meet this need.” In other words, from the early days of the registry, there have been plans to provide, via the CSR/CCP's (planned) data system, patient-level treatment data across the stroke care continuum. The differential focus on the data (in conjunction with the delayed development of the data system) has affected these plans – as well as the overall operational state of the registry.

3. **Held Beliefs**

Why These Beliefs Matters

Third, in assessing what has been instrumental in determining the current operational state of the CSR/CCP, it is helpful to look at beliefs (regarding change), held by the program staff and key stakeholders. As discussed earlier (i.e., in the fourth section of the literature review presented in Chapter 2), these kinds of change-related beliefs address not only a need to change,

¹⁷⁸ These tables, though prepared for the LEMSAs, contain in-hospital data.

but also an ability to change. Additionally, these beliefs can be cross-cutting with respect to the program, its resources, and the environment in which it operates. In sum, these change-related beliefs matter for every facet of the program. If the program staff and the key stakeholders feel that the program does not need to change – or if they feel that it just cannot change (even when it should) – then the status quo will continue. Indeed, a continuing status quo makes for a very predictable operational state. Within this project, the held beliefs of interest are if the program should change and if the program can change. Below are the findings for each of these two areas.

The Beliefs

a. Need to Change

*“...it needs to change...”*¹⁷⁹

In assessing a need to change, key data came from eleven of the fourteen key informants, all of whom agreed that some degree of change must occur within the CSR/CCP¹⁸⁰. Their statements on change ranged from being rather general (e.g., “We always had a sense of, ‘We need to make a change’”¹⁸¹) to being quite specific (e.g., “...it should change in a way that we achieve more of our quality improvement goals and working with our partners in a, in a more effective way”¹⁸²). Further, during these interviews, a number of statements were made to suggest that the registry’s clinical partners would appreciate it if the registry were to enter into a change process. One key informant¹⁸³ (while speaking from the partners’ perspective) shared this:

¹⁷⁹ From the interview with Phase II, Key Informant #1.

¹⁸⁰ While they did not comment specifically on the registry’s need to change, the other three informants did provide recommendations with respect to the registry’s future activities; these recommendations are discussed later.

¹⁸¹ Phase II, Key Informant #3.

¹⁸² Phase II, Key Informant #1.

¹⁸³ Phase II, Key Informant #1.

“You know, no one has ever really said, ‘You need to do more for us,’ but I have gotten the impression a couple of times in conversations that people don’t understand, or they wonder like, ‘Well, what else should I be getting?’ [laugh] you know? And from the local EMS agencies, I think that they would like to see more, too.”

She continued:

“...both of these groups would love to see even more because [pause] I think we’re capable of giving them more and, and so anything we can give ‘em, they’re always appreciative of that and I think they would like to see that.”

Another informant¹⁸⁴ spoke about change from the perspective of the registry’s clinical partners, saying:

“I think our partners would wanna see more leadership and coordination from us, more communication, more convening of the different partners... I think that that was something that we wanted to change as staff members, and I believe it’s something that the external partners would wanna see.”

To be sure, it is important for the registry to be aware of – and attentive to – the interests of the clinical partners. As this same informant suggests (along these lines), the registry needs to be well aware of what is happening all around it, particularly when contemplating change: “...one thing that I think we were a little slow to recognize is [pause] changes that were happening externally.” Thus, there is a need to change...particularly in ways that are of benefit not only to the CSR/CCP per se but also to all of the clinical partners who are invested in this effort as well.

b. Ability to Change:

“*Let’s pave the way and make it happen.*”¹⁸⁵

As discussed in the second chapter, simply acknowledging the need to change does not mean that change will happen; there must also be the ability to make it happen. During the interviews, nine of fourteen key informants spoke about the registry’s ability to change. The message was that the registry does, in fact, have the ability to change, though it won’t be easy.

¹⁸⁴ Phase II, Key Informant #6.

¹⁸⁵ From the interview with Phase II, Key Informant #5.

As one informant¹⁸⁶ stated: “...in a public entity, it is [pause] tremendously difficult to [pause] make any change to a project.” Other informants recognized this and made suggestions on how a change process might be facilitated. “I think if we [pause] are able to have [pause] receive some more support...” (i.e., financial support) was one idea.¹⁸⁷ Another informant¹⁸⁸ concurred:

“...nothing will happen without resources, so we can all have a belief in change, but if we don’t have resources to support our jobs and to support our program, then the change will be that the program will end.”

A second idea concerned partnerships:

“...another key element that I think would be a significant piece [pause] is to say, ‘What requires additional staffing, you know, for us to kind of walk out what we’re trying to accomplish, and what requires a deeper level of partnership?’”¹⁸⁹

Still another idea had to do with the registry being given more autonomy: “I think if [pause] again, as we’ve spoke before, the culture of the [pause] department or the Branch doesn’t get in the way, I think that [pause] those incremental goals can be met...”¹⁹⁰ Finally, change is possible for the CSR/CCP, according to another informant¹⁹¹, so long as the program staff members are “...being visionary as opposed to being complacent and trying to just hope that things change.” However, even with all of these affirmations of the program’s ability to change particularly if these resources were available, one informant¹⁹² cautioned:

“...it’s not gonna be a quick change... You know how some things, they’re like, ‘Oh, my gosh, yes, we have to do that, and let’s make it happen.’ I don’t know that this is gonna be one of those things...”

With this third main area of inquiry related to the second research question now presented, this summary statement is offered: The current operational state of the registry is what

¹⁸⁶ Phase II, Key Informant #3.

¹⁸⁷ From the interview with Phase II, Key Informant #1.

¹⁸⁸ Phase II, Key Informant #6.

¹⁸⁹ From the interview with Phase II, Key Informant #4.

¹⁹⁰ From the interview with Phase II, Key Informant #2.

¹⁹¹ Phase II, Key Informant #4.

¹⁹² Phase II, Key Informant #5.

it is, in large part, because of the influences of the contextual factors, the operational challenges, and the held beliefs – all present within and around the registry; furthermore, the potential future operational state of the registry is also partially predicated upon these influences. It is also predicated upon whatever changes might be implemented. The third and final research question explores suggestions for change.

C. Research Question 3: Findings

How might change occur within the program, such that the program's secondary prevention efforts can be broadened?

This third research question is raised to explore changes the CSR/CCP might make in order to usher in a better future state – that is, one which exists more broadly along the secondary prevention spectrum. In seeking an answer to this question, the primary method of data collection used was the conduct of the Phase III key informant interviews; however, as with the prior two research questions, the final data set analyzed using NVivo, Version 10, is comprised of the data from all 41 sources (i.e., program documents and key informant interviews).

During the Phase III interviews, key informants were asked to share their ideas and suggestions regarding utilizing existing assets (e.g., technology, human resources, and partnerships) in new ways, as well as employing new practices and/or resources (e.g., using knowledge management and cross-functional teams). Additionally, the key informants were invited and encouraged to speak about the process of going through organizational change, as well as factors that might help or hinder such a process. As noted in the previous chapter, the data generated in this third phase of the study were shared with an ad hoc advisory group, and, from working with that group, a series of foundational and operational recommendations for the

CSR/CCP emerged. As described earlier, these recommendations feed into the Action Research Spiral, with the expectation that they will enable the program to move (eventually) towards a better future state.

In discussing the Phase III results, as with the Phase II results above, a narrative approach is used. The narrative includes four sections: First are the findings related to using assets in new ways. Second are the results related to the adoption of new practices. Each of these first two sections starts with commentary on why these results matter before turning to the emergent themes. Third is a discussion of the information collected, related to undergoing change a change process, and fourth are the foundational and operational recommendations.

1. **Using Existing Assets in New Ways**

Why This Matters

As discussed earlier, one of the challenges faced by the CSR/CCP is dealing with fiscal constraints. This challenge has dictated how some of the ongoing operations of the program have been handled. For example, the hospital and LEMSA recruitment efforts have been designed and carried out in ways that are meant to produce the biggest yields of new registry members, perhaps without always giving due consideration to the needs of the potential registry members. Additionally, financial considerations have also impacted the registry's ability to utilize human resources. As has been suggested above, certain (purportedly) financially-based decisions have necessitated that the registry staff members have, at times, had to take on and complete tasks that are outside of their usual scopes – and, perhaps, outside of their skill sets. Finally, fiscal concerns have also driven the decisions related to the conduct of quality-improvement-related work. Indeed, when possible, this work has been carried out using

economies of scale, which has been mostly advantageous; however, this practice has also meant that there has been some loss of local interest or control. Given this fiscal concern, it was deemed important to first pursue options for using existing assets in new ways – that is, to use them, as one informant¹⁹³ put it: “....very strategically and efficiently...”

The Emergent Themes

From the analyses of the 41 data sources, three themes emerged related to using existing resources in new ways. These three themes relate to using technology, using human resources, and using partnerships in new ways in order to improve the operations of the registry going forward. These three themes are discussed in succession:

“They just need, they need the tools; they need easy tools to follow through...”¹⁹⁴

During several of the interviews, the key informants talked about using technology and data that already exist, in order to support the ongoing work of the registry and its partners. The informants spoke specifically to enhancing communication, reporting data, and collaborating with partners. First, eight of the fourteen informants addressed **communication**, and their remarks ranged from being very general (e.g., “...there’s gotta be effective ways for information to flow from, essentially these siloed entities...”¹⁹⁵) to being rather specific (“...California having their health information exchange and the stroke reg... Is there a way to embed the stroke registry to be part of that as an automatic...”^{196, 197}). In short, the informants suggested that there must be some means to enhance communication, given existing structures and assets.

¹⁹³ Phase III, Key Informant #4.

¹⁹⁴ From the interview with Phase III, Key Informant #3.

¹⁹⁵ From the interview with Phase II, Key Informant #4.

¹⁹⁶ From the interview with Phase II, Key Informant #5.

¹⁹⁷ The informant is questioning whether the communication needs of the registry can be addressed by having the registry be situated under (or within) a larger information-related infrastructure that exists “higher” within the organizational structure. This would allow the registry to utilize that system’s functionality and communications channels.

Another informant¹⁹⁸ suggested using infrastructure that is in place elsewhere (i.e., external to the stroke registry) for other similar efforts already underway within the larger organization. In fact, his suggestion for the CSR/CCP was to consider the approach that is now underway within the state registry in which he works. He described the approach this way:

“The other sort of related piece to that would be, ‘cause we’ve been looking at, we, we’ve, we’ve been looking at all different time-critical diagnoses, such as STEMI¹⁹⁹ or cardiac-arrest or trauma and so [pause] I try to align what we do in those [pause] systems, in those areas, because the audiences that we’re [pause] looking at are the same in a pre-hospital field and [pause] what we wanna do with them, whether that be training, whether that be [pause] making, creating or coordinating between hospitals in EMS, developing protocols, these are all topics that we have a common audience with [pause] in those other, those other topic areas...”

Again, the idea is to utilize existing technology and data in order to enhance communication. In this example, the coordination between stroke and STEMI and/or cardiac arrest and/or trauma enables the messaging (even for one specific time-critical diagnosis) to be amplified, because of the synergy that is created with this collective approach. The message is to look for opportunities for synergy.

Second, nine of the fourteen informants spoke about using existing technological resources for **improving the reporting of data** and “...*using those data to tell that story...*”²⁰⁰ Put differently, according to the informants, the existing infrastructure should be used to share more information more broadly. One informant²⁰¹ gave this advice:

“...take a look at the data system and see how to optimize data sharing [pause] in that data system with, maybe, particular attention on the pre-hospital clinical providers because, unlike the hospitals [pause] the pre-hospital clinical providers seem to be a little more siloed, maybe a little more fragmented...”

¹⁹⁸ Phase II, Key Informant #5.

¹⁹⁹ STEMI is ST segment Elevation Myocardial Infarction.

²⁰⁰ From the interview with Phase III, Key Informant #2.

²⁰¹ Phase II, Key Informant #4.

While the suggestion here is to improve data sharing overall, there is an interest in focusing on the data within the pre-hospital setting. Having more attention being paid to the pre-hospital setting is a recurring theme. Another informant²⁰² made comments related to data sharing in the pre-hospital setting. In speaking about his program's experiences trying to get existing pre-hospital data (from another data system) and using them (in conjunction with in-hospital data), in order to inform programmatic efforts, he said this:

“...we're trying to utilize that system and the data that they collect, which includes the data that we want, which we think includes the data that we want specifically about stroke care, so that they don't have to collect data again...you know, and then utilizing that data system, trying to connect it and link it to our [pause] our hospital registry data so that we can get a, a full picture...”

His recommendation (which was also explicitly voiced by two other informants²⁰³) was that the CSR/CCP ought to work on that kind of an endeavor, too. He shared another data-related effort (by his program) which he felt the CSR/CCP ought to pursue as well. This effort was undertaken in order to provide the registry with greater scientific capacity – during those occasions when such capacity was required:

“Taking a [pause] swipe at our data that we have available and being able to [pause] draw from those data to either answer questions that we knew might be asked or to, and, and to tell, tell the story for what we needed to present to legislators, to, to other experts, to our internal leadership, using those data to tell that story to present, so when the time came, to talk to people and to be in front of a senate committee or a house committee, we were prepared with, with evidence, with the answers.”

He further suggested the use of other, non-registry data to support this kind of work:

“...if you have hospitalization [pause] administrative data that have information about just general demographic distribution, sheer numbers. Th...that kind of data can be presented [pause] as well, by, by itself, without having sort of a direct connection to the Get With The Guidelines data.”

²⁰² Phase III, Key Informant #2.

²⁰³ Phase III, Key Informants #3 and #4.

In short, this informant provided the CSR/CCP with several models of how to use existing systems to report and use data. Such data use should help the program in keeping its stakeholders engaged and in meeting its programmatic objectives. A summary statement (on this topic) was provided by another informant²⁰⁴, who said this: “...you just need to use what you have and do the best with it and, and make full use of it and share it as widely as possible through all different channels and mechanisms.”

Third, ten of the fourteen informants shared information about using existing technology to **enhance the registry’s work with its partners**. One informant²⁰⁵ spoke about some fundamental technology-based methods for working with partners, including virtual meetings, teleconferences, listservs, and online surveys. He suggested utilizing these methods in this way: “...about every few months, information-sharing, where, basically, the folks in the registry can kind of share what’s working, what’s not, with each other.” Another informant²⁰⁶ concurred, saying this about using technology to communicate with program partners:

“...so, we do it through, through a, a listserv, a group email like that, and share best practices, but then we also have, every other month, we have a conference call and we get together, we decide on goals, statewide...”

This idea of using some simple technology-based methods was also discussed by other key informants as well. One informant²⁰⁷ described how it is essential to stay organized and how there are tools that can assist with this. She described her own experience like this:

“...working with stroke coordinators, we built lists of [pause] EMS coordinators, ED managers, directors of nursing, et cetera. So, at a certain point, you know, you can’t just be doing distribution lists and ConstantContact²⁰⁸ became an effective tool to keep people up to date on, you know, program updates.”

²⁰⁴ Phase II, Key Informant #5.

²⁰⁵ Phase III, Key Informant #1.

²⁰⁶ Phase III, Key Informant #6.

²⁰⁷ Phase III, Key Informant #3.

²⁰⁸ ConstantContact, while not currently used by the CSR/CCP, is an existing resource within the larger organization; therefore, it could be utilized by the CSR/CCP Team.

Another informant²⁰⁹ spoke about her program's regular use of webinars to ensure that program partners are able to stay informed and engaged:

"...we also would have periodic webinars [pause] to invite both hospitals and EMS to the webinars to discuss the data in the aggregate and share what areas we thought were do...you know, were going really well, and what areas we needed to improve on, so that both sides of the coin could be working collaboratively in the same areas of focus."

She continued:

"...we did copy the concept that CDC was doing with the evaluation coffee breaks and we had [pause] just our stroke care QI coffee breaks where they would be about twenty minutes and we would [pause] take a topic of interest, and sometimes it would be data and how to better analyze and use the data to [pause] drive stroke care quality improvement."

To conclude, the advice she gave as the interview was coming to an end serves as an apt summary of using data in working with partners. She said:

"...everyone got a summary of the information periodically, so that you could still put your two cents worth in and maybe you knew someone else who needed to be at the table. You had a resource that you had met, you know, in, in whatever avenue you were working in. So we really did try to [pause] keep each other informed."

*"...what people can do and what they have been doing or what they might do..."*²¹⁰

Secondly, in addition to using technology in new ways, the data suggest that human resources might also be used in new ways. Several key informants described how programmatic changes necessitated adjustments in how human resources have been deployed (within their programs). One informant²¹¹ had this to say:

"We knew we were gonna have to reconfigure some resources, both human and financial resources, to meet our needs, but we needed to be very clear on what those were, first...so, we [pause] we did some changing around of hats, we really looked at [pause] where people's strengths were, and [pause] and really tried to play upon those, as well as the strengths of our program..."

²⁰⁹ Phase III, Key Informant #4.

²¹⁰ From the interview with Phase III, Key Informant #2.

²¹¹ Phase III, Key Informant #4.

Another informant²¹² described how his program recognized that their “data guru” (his words) was very skilled at forming and nurturing relationships – right when the program was having a problem collaborating with certain partners. Therefore, the decision was made to have this “data guru” also serve as a mediator between the program and these partners. The informant described this situation like this: “...we really utilized her strength, her relationships that she had, and got her on board...and she became our, kind of our go-to person, our mediator.” He continued: “So by kind of using her as a mediator, we were able to [pause] move things around quickly and, and really get some information back quickly, and get some support...” A similar experience was shared by another informant²¹³ whose program had an unmet need related to the conduct of trainings. As this informant described (about an employee hired to conduct medical chart abstractions):

“...even though she was originally hired mainly to focus on chart abstraction, direct abstraction or to do the re-abstractions...we actually expanded the scope of that resource to not only do the abstractions, but also to do trainings...so that’s the way we’ve used resources – the chart abstractor and expanding that work to also do trainings...”

For the CSR/CCP, this idea of optimally (re)directing human resources is rather apropos, given current staffing patterns, as has been discussed above and in light of the testimony of one particular key informant²¹⁴. She describes the current situation (which was brought about, in large part, because of unilateral decisions made by senior management within the Branch²¹⁵) as follows:

“...there’s been a lot of frustration, because we haven’t been able to accomplish the things we thought we would be accomplishing and the things we want to actually be doing, because we’re spending a lot of time doing things that we [pause] didn’t think we

²¹² Phase III, Key Informant #5.

²¹³ Phase III, Key Informant #1.

²¹⁴ Phase II, Key Informant #1.

²¹⁵ This is the Chronic Disease Control Branch, which is the organizational unit in which the registry resides. That senior management within this Branch has unilaterally made staffing decisions which have negatively impacted the registry is a finding which has been presented above.

would be charged with doing, and that we also aren't interested in doing, 'cause they technically aren't our jobs and what we're trained to do."

Another informant²¹⁶, rather familiar with the administrative aspects of the CSR/CCP, described this specific staffing situation like this: "...professional classifications now tasked to doing administrative work..." Indeed, these reports about the CSR/CCP's staffing situation suggest that existing human resources may need to be reevaluated and, possibly, reconfigured. For this to happen, counsels this key informant, the decision-making authority (as discussed earlier) would need to be returned to the program. She put it this way:

"I would think [pause] for the actual program, Coverdell, to be able to make executive decisions and decisions that are based on their experience with the program, and [pause] without Branch management kind of controlling how it goes. I think, just in a nutshell, that's kind of what I see being beneficial..."

In sum, the data suggest that in order to improve its current state of operations, the CSR/CCP might need to find new ways of utilizing its current staff resources.

*"I think if you have the right partners pushing, it might ha...come a little bit faster..."*²¹⁷

Thirdly, as with technology and human resources discussed above, the data suggest that existing partnerships can be utilized in new ways, in order to improve the program's status quo. Several different ideas along these lines emerged. First, one informant²¹⁸ suggested that partners might not only share in the workload but also provide accountability:

"And, and I think that's also where the partnerships come in, right, because then when you have relationships, then expectations are created, you know, vision is kind of tied in or intertwined. There's accountability in terms of, 'Okay, is everybody kind of moving forward to do their part for us to get to this bigger goal?'"

Next, in addition to providing accountability, certain partners are also able to provide other benefits to the registry, such as lobbying. For example, an informant who has directed the

²¹⁶ Phase II, Key Informant #7.

²¹⁷ From the interview with Phase II, Key Informant #5, on the subject of change.

²¹⁸ Phase II, Key Informant #4.

State's stroke registry in another state²¹⁹ described how one key strategic partner provided lobbying services for the registry. He said this:

“...probably five or six years ago, maybe not that long ago, but American Heart Association worked with our stroke task force to lobby the legislature to secure some funding for the registry...because of that funding, we've been able to do a lot of things...”

As this informant reports, the partner's lobbying efforts resulted in additional financial resources for the program.

Other objectives have been achieved (elsewhere) from the lobbying efforts carried out by a local affiliate of this same partner. In this case, the local affiliate lobbied the state legislature to change state statutes and authorize the State's Department of Health to designate certain hospital as stroke facilities. The director of the stroke registry within this state²²⁰ described how this came to be:

“...that was [pause] basically a, a long process, maybe over the course of four or so years – I would say about four years in the making. And it was really spearheaded with, in a partnership with the American Heart Association. The one key component to this is that we had a government relations director at the Heart Association who had a vision for this and that vision was developed in partnership, in concert with our goals at the health department in terms of the stroke system development.”

He continued:

“I can't emphasize that enough, it was really necessary to have a champion who [pause] who could help articulate the message and figure out what the potential barriers were, understand the political context and have the, the wherewithal, the knowledge and experience and tactics to [pause] to put forward legislation...”

In sum, existing partnerships are potentially able to provide additional services (i.e., beyond those which are currently provided) in order to advance the work of the registry. As has been suggested, the CSR/CCP may need to explore these kinds of opportunities.

²¹⁹ Phase III, Key Informant #1.

²²⁰ Phase III, Key Informant #2.

Finally, not all of those services provided by partners have to be of the magnitude described above. In fact, another informant²²¹ spoke about how an existing partner has stepped up (in her state) to help with the stroke registry's day-to-day operations, specifically related to the pre-hospital clinical setting. She described how this partner "...helped...a lot, both in meetings and electronically and on their website and, and that kind of thing with, you know, working more with pre-hospital..." About this notion of providing assistance, this informant had this to say:

"...there's a fifty-fifty chance that if you ask one of your partners to let you do something or to help you do something, there's a fifty-fifty chance that the answer will be 'yes,' and, so, you know, just not hesitating to ask, you know, if you think there is a potential channel, is to just [pause] figure out a way..."

At the same time, she provided this caution: "...bring them in when you critically need them, and keep them informed and engaged, but don't necessarily keep them at the table for everything." To conclude, existing partners can be utilized in new ways –including providing accountability, lobbying for funding or for changes in statute, or assisting with the daily ongoing work of the program.

2. **Employing new practices and/or resources**

Why This Matters

In this second section of the Phase III findings, ideas related to new practices and/or new resources are discussed. This idea is an important one, as the CSR/CCP has been looking to expand its reach and impact within California. To be sure, as the reach and impact are expanded, it may be necessary to employ new practices and/or resources. This notion was supported by the information provided by eleven of the fourteen key informants, including all seven of the

²²¹ Phase III, Key Informant #4.

informants who completed the Phase III interviews. During their interviews, the eleven key informants spoke about employing the new practices of knowledge management and cross-functional teamwork; each of these practices is discussed below.

The Emergent Themes

With respect to each of these new methods of interest – i.e., practicing knowledge management and utilizing cross-functional teams – a number of examples were shared during the interviews. These examples can potentially serve as models for the CSR/CCP when it seeks to operationalize the recommendations presented later. What follows are two narratives; the first concerns knowledge management and the second discusses cross-functional teams.

“Data is just, it just is the new currency...”²²²

As this statement suggests, having, sharing, and using key information is essential; this idea was expressed many times during the conduct of the Phase III interviews. One informant²²³ stated it rather simply. He said that it is critical to be continuously “...looking for those key pieces of information and trying to figure out how to best summarize that information for immediate use...” Indeed, effectively using information was discussed in every one of these eleven (contributing) interviews; some informants even suggested specific methods for doing so. One informant²²⁴ touted mapping as an effective way to share data (visually). He said this:

“...utilizing mapping expertise or mapping resources that you may or may not have right now, but being able to plot even simplistic information such as what hos...like the capacities of hospitals, whether they’re primary stroke centers or not, being able to plot that and overlay population densities and drive-times to and around those facilities, that’s, that was a huge thing.”

²²² From the interview with Phase III, Key Informant #6.

²²³ Phase III, Key Informant #1.

²²⁴ Phase III, Key Informant #2.

This idea was supported by another informant²²⁵ who had this to say: “...if the state could provide things like do GIS²²⁶ mapping, that would be really helpful, catchment areas for hospitals...”

To be sure, this approach (i.e., mapping) provides information on the clinical service areas; however, informants also expressed the need for information on the quality of those clinical services. As one informant²²⁷ stated, it is important to know (about the clinical providers) “...what areas they’re doing well in...” This, he suggested, then enables his program to share with the providers (in his words) “...about what areas we recommend improving in, and then specific next steps about [pause] our suggestions for making those improvements...” Data-driven improvement was addressed by another informant²²⁸ who said this (about looking at quality of care across multiple providers): “...it also helps some of our coordinators to see if there’s one particular site that’s high-performing in a certain and we can, you know, collaborate with each other and talk about best practices within our organizations...” Finally, concurrence was provided during an interview with another informant²²⁹; during that interview, this was stated:

“...you have figured out a very successful way to manage your data, to share your data, and then improve the quality of your data, so that once you use those data, you can better inform processes and programmatic actions.”

In sum, the value in capturing, sharing, and using information is evident. Whether these data describe the populations being served or the care being provided or something else...and whether these data are being presented in tables or on maps or in some other formats, the key

²²⁵ Phase III, Key Informant #6.

²²⁶ GIS is Geographic Information Systems.

²²⁷ Phase III, Key Informant #1.

²²⁸ Phase III, Key Informant #7.

²²⁹ Phase III, Key Informant #5.

here is that these data can, in fact, be made available. For the CSR/CCP, this is a real concern, given the problems related to the data system, as discussed above.

In this regard, key informants were asked to provide their thoughts regarding what actions the CSR/CCP might take with respect to its incomplete data system – that is, whether to enhance it or to replace it – so that it could more effectively manage organizational knowledge. The responses varied somewhat. As one informant²³⁰ advised: “...take a look at the data system and see how to optimize data sharing [pause] in that data system with, maybe, particular attention on the pre-hospital clinical providers...” His statement seems to suggest that data sharing can be optimized within the system, perhaps with some enhancements. A few others suggested working further on the current system, including augmenting it with some sort of patient navigation functionality²³¹. In contrast, another informant²³² suggested proceeding with a whole new project. His comments were as follows:

“...in the beginning of a, a, or of any project, it is very important to [pause] to [pause] gather [pause] as many stakeholders as possible and to form a consensus – not [pause] uu... unanimous consensus, but, you know, to the extent possible to make consensus [pause] or agreement, I should say, agreement on how to proceed a project. What is the domain of the data [pause] collection? [pause] Who would be developing this, and commitment of that organization? [pause] Those things need to be [pause] established in the beginning...”

He continued, saying: “...change the developer from one organization to another – that’s a huge change, you know, system would change, the personnel would change, and so forth.” Likewise, from another interview²³³ came the statement that perhaps “...there’s a way to [pause] utilize different technology [pause] or different, maybe a, a different system, different tools, in order to

²³⁰ Phase II, Key Informant #4.

²³¹ This idea was suggested by Phase II, Key Informant #5 and Phase III, Key Informant #3.

²³² Phase II, Key Informant #3.

²³³ Phase III, Key Informant #3.

get a more [pause] kind of a more broad look at the data across the continuum.”²³⁴ To be sure, even with the likely formidable challenges that would be faced, this suggestion of creating something new would certainly be within the realm of possibilities, considering another informant²³⁵ stated that her state registry did, in fact, develop a new data system (while the program was already underway):

“...we had created a re...an [pause] original database, but we [pause] when we went into [pause] the last phase of Coverdell, when we started working more intentionally with EMS, we actually contracted with our [pause] EMS performance improvement center in North Carolina to create a new database that would allow us to [pause] dovetail our data with NEMSIS data, so be able to directly link [pause] EMS data, pre-hospital data, with hospital data...we built a, a linkage to that data system, so that we could capture pre-hospital data and match that up with acute care hospital data.”

Perhaps the experience in North Carolina might serve as a model for the CSR/CCP with respect to constructing a new system that allows for effective data sharing – even as the program continues to carry out its scope of work. In support of this thought, an informant from within the CSR/CCP made this statement (also shown in Table XVII above): “I think if the opportunity arises that we could find someone else who could help us develop a system that we need, I think if we can afford to work with that per...that person or group, that we should do that.”

“This whole group has taken on a life of its own...”²³⁶

The second theme related to employing new practices and/or resources concerns the use of cross-functional teams, which one informant²³⁷ characterized as follows:

“...bringing these different components together [pause] is, is [pause] it’s a different perspective. I think it’s a unique perspective that we at the health department are, should be compelled to take, and nobody else really, necessarily, needs to take but we’re trying to get each of these parts involved [pause] into our, into our, kind of our, our perspective.”

²³⁴ Two informants (Phase III, Key Informant #6 and Phase III, Key Informant #7) were particularly vocal about the collection and use of data from pre-hospital side of the care continuum.

²³⁵ Phase III, Key Informant #4.

²³⁶ From the interview with Phase III, Key Informant #6.

²³⁷ Phase III, Key Informant #2.

Another informant²³⁸ described working in cross-functional teams as: “...finding the common interests and [pause] getting everybody to, to [pause] see the vision and, and work together...”

Given the CSR/CCP’s staffing patterns historically, as well as its relatively small number of key strategic partners (as discussed above), there has not been a bona fide cross-functional approach to carrying out the scope of work.

In contrast, all of the key informants from Phase III described their own experiences using these teams. One informant²³⁹ stressed the importance of establishing these teams early on to facilitate strategic planning efforts. He said that it was essential “...to bring together experts and, and opinion and thought leaders and the stakeholders to [pause] to really get a firm grasp of what we wanted to do...” He continued, describing how the convener has benefitted from “...utilizing their expertise, their connections, their infrastructures...” Finally, he stated this opinion about using cross-functional teams, particularly early in the program’s development: “And that’s a much more efficient strategy than us trying to do it on our own.”

Other informants described the importance of keeping these cross-functional teams connected, if not intact. One informant²⁴⁰ described his experience with a “...group that meets monthly to talk about the issues we’re facing, and it’s really good to get their feedback and the direct input into the team...” Similarly, this statement was made by another informant²⁴¹, stressing the value in being able to talk as a team about the issues before them:

“...we not only include all the coordinators and the EMS [pause] leadership, but we also have the facilities’ ED physicians, the neurology champions or medical directors, and all the facilities’ organizational leadership to also talk about other issues that impact stroke care across the whole continuum...”

²³⁸ Phase III, Key Informant #3.

²³⁹ Phase III, Key Informant #2.

²⁴⁰ Phase III, Key Informant #5.

²⁴¹ Phase III, Key Informant #7.

Another informant²⁴² talked about how these cross-functional teams could also be used to vet certain ideas that were in the developmental stage:

“We could bring in whoever we thought, you know, we should bring in, like, for the hospital support and QI, we would, you know, oftentimes bring in ad hoc members that were from our [pause] participating hospitals, for example, and say, you know, ‘What do you think in the real world?’ you know, ‘This is what we think, but you’re in the trenches. Is this gonna work? Is this not gonna work?’”

Additionally, she described how these cross-functional teams could be used for a one-time project:

“We brought some small core groups together just to pilot certain things and to give feedback, but, you know, we told them up front, you know, ‘We need you to help us pretty intensively for maybe a month, and then we’re gonna [pause] set you free...’”

To be sure, the key informants described a number of benefits from using cross-functional teams. As one informant put it: “...So utilizing, utilizing groups such as that is, is incredibly beneficial and really helps to... That group does the work for you...”

While beneficial, the practice of utilizing cross-functional teams does bring with it some additional responsibilities. According to the informants, one of these additional responsibilities is facilitation. “I really see our [pause] [laugh] our role, or my role, at the state as being a bridge-builder, a facilitator,” said one key informant²⁴³. She continued, further describing her task of “...finding the common interests and [pause] getting everybody to, to [pause] see the vision and, and work together.” Similarly, another key informant²⁴⁴ described her role as a facilitator:

“...so I was kind of that person that [pause] would listen and figure out where the work of the various groups intersected and [pause] you know, where we needed to collaborate more or where we needed to bring more people in, and we also would share updates...”

²⁴² Phase III, Key Informant #4.

²⁴³ Phase III, Key Informant #3.

²⁴⁴ Phase III, Key Informant #4.

Finally, an informant²⁴⁵ from within the CSR/CCP had this to say about facilitating the efforts of cross-functional teams: “I think there is an opportunity for the state to help, to play a role in coordinating and [pause] you know, bringing some of those innovators together.”

Another responsibility that comes with using cross-functional teams is managing communications within and between teams. One informant described the importance of communication:

“...we just got out of silos, we don’t wanna crawl back into them, so we had to be really intentional about... You know, we had to make ourselves communicate with each other. And I think that’s a big piece of when you are working cross-functionally, it works really well if you’re communicating well...”

Another informant²⁴⁶ spoke about communicating within the context of using these teams:

“...get everybody on, back on the same page and/or [pause] making sure people understand the vision and how to, to communicate and educate and get people thinking along those lines.”

Finally, this statement, made by another informant, underscores the need to manage communication, so that the expectations within the team are appropriate: “...we were quite open about our limitations of staff and, and timing and [pause] there were some things where, you know, I directed [pause] directly and really cared for. A lot of things were really delegated.”

Lastly, using cross-functional teams adds the responsibility of identifying champions (for different program efforts) and being able to defer to them and support them. One informant²⁴⁷ made this comment about champions: “...at those, those meetings, we would present this information and ask them to [pause] be champions within their own organizations...” Another informant²⁴⁸ had a more strategic approach to finding champions. He described it this way:

²⁴⁵ Phase II, Key Informant #6.

²⁴⁶ Phase II, Key Informant #2.

²⁴⁷ Phase III, Key Informant #2.

²⁴⁸ Phase III, Key Informant #5.

“...so, really, by looking at the key personnel that you already had in place, their desires and their strong suits, we were able to identify champions, uh, from each facility and each, uh, really, each area of focus and, and let them run with it. One thing, we recognized that if, if you choose the right people and they have a passion for it, things get done.”

He continued:

“...trying to find those key champions, putting them in place, keeping that high energy up, keep invigorating and reminding them the, the focus that we had, which is what really, what, why my role was, reminding them what the end goal was, the, the possibilities...”

In sum, according to the key informants, a potentially beneficial new approach for the CSR/CCP is the use of cross-functional teams. Certainly, this strategy requires some additional effort, including facilitating group work, managing communications, and empowering champions. Even so, as was stated during one of the key informant interviews²⁴⁹: “...there’s a richness for each one of those things, you know, using your, your information wisely, and also utilizing resources, you know [pause] cross-functionally and across organizations...”

3. **Undergoing a Change Process**

Why This Matters

In this third section of the Phase III findings, ideas related to undergoing a change process are shared. These ideas provide insight into what the CSR/CCP staff members and stakeholders might encounter as they strive to (eventually) put the foundational and operational recommendations (discussed below) into action. In the second chapter, this notion of taking action is depicted in the conceptual framework (Figure 1), and it merits mention here – particularly in terms of what that effort entails. The framework shows that, in addition to the set of proffered recommendations, the Action Research Spiral contains other

²⁴⁹ Phase III, Key Informant #4.

inputs – to include influences related to the registry’s current state. During the interviews, key informants spoke about two types of these influences, the ongoing operations of the registry and the held beliefs of its stakeholders. Each of these types of influences on the change process is discussed below as the emergent themes are presented.

The Emergent Themes

Before discussing the organizational capacity to change or the held beliefs regarding change, it is notable that one informant²⁵⁰ made this statement: “I mean it’s because, first of all, you wanna, you know, you wanna see things get better, you wanna see things improve and, and get better, but you also have to trust...that it’s the right thing to do.” Her remark suggests that in order to embark upon a change process, there needs to a level of trust in what is to come. With that in place, there are other considerations, as follows.

“...do that at the same time as fulfilling your current...responsibilities...”²⁵¹

The first theme concerns being able to take on a change process, given the current programmatic state – to include its assets and liabilities as well as its ongoing responsibilities, since a future process will be impacted by the present reality. After all, commented one informant²⁵², part of going through a change process is having “...to negotiate who was gonna do what and how the best way to keep informed, and who’s gonna manage, you know [pause] resources...” In fact, this informant, describing a recent experience her program had with undergoing change, said this:

“...in the midst of a, a, a lot of change, there became some turmoil and then, you know, and then losing staff and... You know, so those are certainly a lot of [pause] barriers...um, you know, because there was a lot of change going on.”

²⁵⁰ Phase III, Key Informant #4.

²⁵¹ From the interview with Phase III, Key Informant #2.

²⁵² Phase III, Key Informant #4.

This informant's story is one of success, as she described it, even amidst all of the turmoil, because she and her colleagues came together early on during the change process and had this kind of a conversation:

“‘What do we do about this?’ you know, because if we wanna move forward, we have two choices. We can kick up and mess up and explode here and we’re not gonna go anywhere, or we can kind of suck up and [laugh] you know, figure out what we can do, even if it’s co...even if it’s messy...”

Certainly, successfully completing the change process was contingent upon the program's capacity to figure out who would be taking which steps...and how to keep taking those steps, even when the path ahead became difficult to navigate.

While the above described experience was positive, others have been negative. Another informant²⁵³ spoke of how programmatic capacity can work against a change process. Here he described some difficulties that can arise when an organization enters into a change process:

“...how to [pause] make the time, or have the time, to [pause] push that, articulate that, that vision and articulate the specific goals and objectives for where we wanna go. A lot, lot of times...we have kind of a general idea, but we have no idea of what those intermediate steps need to be or the process that need...needs to be taken. And so making the time to plot that out, I guess, is a barrier. Having the ability to do that, first of all, I guess, is, is a barrier sometimes. Some people just can't do that.”

He continued:

“...being able to articulate and figure out what that is, having the time to do that [pause] and to get other people involved to do that, and then related to that is trying to do that at the same time as fulfilling your current [pause] responsibilities and the things that you are accountable today. That's like how do you do all that at the same time?”

In short, this informant's comments underscore how people's present skills and resources (including time) can determine their future situations.

On this subject of capacity, another informant²⁵⁴ had this to say:

²⁵³ Phase III, Key Informant #2.

²⁵⁴ Phase III, Key Informant #3.

“...we’re making baby-steps in the process towards change that began with, you know, building relationships, identifying where there were gaps and needs, putting in place some [pause] some steps, like outreach events or these quality improvement challenges, um, that, that are working toward positive change.”

In this case, there was recognition that the process needed to utilize “baby-steps,” as this informant described, in order to identify and fill gaps, so that progress could be made towards a better future state. Even so, as this informant elaborated on the process her program completed, she indicated, “There have also been some technical issues that have been challenging.” Again, this reinforces the idea that the program’s capacity not only to meet its current responsibilities but also to take on a new challenging change process has bearing on its future operational state.

“...that, that was a start and I, I think [pause] we have the belief...”²⁵⁵

Beyond the current programmatic capacity, the change-related beliefs of the program’s staff members and stakeholders can impact a change process, according to the key informants.

One informant²⁵⁶ described how knowledge and beliefs vary across stakeholders. He said this:

“There are some people who are very big thinkers and understand what I’m talking about here, wha...where, where we’re going. Most people, though, it’s sort of like we always have to kind of start from the, ‘Here’s the... Here’s where we started. Here’s where we’re going. This is what we’re doing,’ and it’s, it’s, it kind of, it, it may take two, three times or more to get people from a place that they can look outside their own little world of their clinical practice, their hospital practice or, or whatever they’re doing, just within their own sort of scope, and being able to expand their world and understand how, where, what we’re trying to do collectively.”

Further, he added that attempting to unify their understanding can be challenging: “Try to, to expand our scope and change to, to, to that wide, comprehensive view while getting all these individual players together – that’s, that’s a huge challenge.” Other informants spoke about this

²⁵⁵ From the interview with Phase III, Key Informant #3.

²⁵⁶ Phase III, Key Informant #2.

challenge, as well. One²⁵⁷ described her attempts to create a shared understanding among stakeholders:

“I have very much been a champion – no, maybe champion’s the wrong word, but more of a cheerleader, I guess [pause] saying, you know, to facilitate, ‘What is, what is this group’s vision?’ Because it’s not the state’s vision. I think the advisory board, these different stakeholders, they’re the ones in the field. It’s really up to them.”

In this vein, she continued, commenting on getting to that shared understanding:

“...it, it’s no longer my vision or our team’s vision, but we have partners who really believe this is possible, and we’ve talked through sustainability, and [pause] they have a framework for really seeing what they need to do. So then it’s no longer like the state, trying to, you know, like Sisyphus, roll the stone up the hill, which it often feels like working at the state.”

She concluded her remarks by noting that “...change is slow, as you know. System level change, changes in process, are slow [pause] even when they are agreed upon and [pause] and desired by the people involved.” These comments were echoed by another informant²⁵⁸ speaking on change-related beliefs. He said this:

“And, so, really, being very transparent of what you wanna do, where you wanna do it, who’s working with you, so that there’s that high level of trust. And, and that’s, that’s one of the things, if you don’t have the trust of, of all the stakeholders, uh, if you don’t have their confidence, then things are very, very slow and apprehensive.”

Finally, in terms of held beliefs, one informant²⁵⁹ suggested the following:

“...if you believe that it can change, you [pause] look at, you know, how can you make that...what is the change that needs to happen and how can you, you know, what do you need to make that work. So, you start looking at what you’re doing, what’s not working, and [pause] what...you know, what would need to happen to make it work.”

And she continued: “...we can all have a belief in change, but if we don’t have resources to support our jobs and to support our program, then...the program will end.” Indeed, as this informant suggests, in addition to organizational capacity and held beliefs, a program’s

²⁵⁷ Phase III, Key Informant #3.

²⁵⁸ Phase III, Key Informant #5.

²⁵⁹ Phase II, Key Informant #6.

likelihood of successfully completing a change process is improved when additional resources are brought to bear.

4. **The Set of Recommendations for Change**

In this fourth section of the Phase III findings, the set of data-driven recommendations for change is presented. This set, which includes both foundational and operational recommendations (defined below), was developed in conjunction with the ad hoc advisory group that was used to vet the data – as was described in the third chapter. Enumerated below and elaborated upon in the next chapter, the foundational recommendations tend to be more overarching, while the operational recommendations are more applicable to the program’s daily operations.

The Foundational Recommendations

1. Within and across all of the CSR/CCP stakeholders, view change not as correction but as an improvement process, the very construct which undergirds the program.
2. Raise the visibility of the CSR/CCP, such that it is better poised for support as it endeavors to achieve a better future state.
3. Both internally and externally, improve the communication practices of the CSR/CCP.
4. Improve the coordination capacity and practices of the CSR/CCP²⁶⁰.
5. Broaden the coalition of strategic partners and stakeholders, looking to include others whose interests broadly match those of the CSR/CCP.

²⁶⁰ This fourth foundational recommendation included the suggestion of creating and filling a new staff position for handling this coordination-related workload.

6. In conjunction with the AHA/ASA, explore the possibility of having a legislative mandate for the CSR/CCP, in support of its efforts to achieve a better future state.

The Operational Recommendations

1. (Without or until there is a legislative mandate:) Reconsider the CSR/CCP's current approach to the recruitment and retention of clinical partners²⁶¹.
2. Revisit the program's ability to collect and report data – and enhance or replace the current data system, via a new development team; in short, do not maintain the status quo in this regard²⁶².
3. With respect to the data system, ensure that the collection and reporting of the core pre-hospital and in-hospital data elements, at a minimum, are standardized.
4. As appropriate and feasible, utilize and share data liberally.
5. Reconsider staffing patterns within the CSR/CCP, as well as how strategic partners are utilized, with an eye towards developing and using cross-functional teams.
6. In facilitating quality improvement initiatives, utilize proven, scalable programs²⁶³.

D. Chapter Summary

In this fourth chapter, the results from all three phases of the project were presented. These results, when taken together, suggest the following: First, the current operational state of the CSR/CCP has fallen short of its original vision. This deficiency is evident in several areas:

²⁶¹ This first operational recommendation included the suggestion of starting recruitment with the LEMSAs (not the hospitals) and then bringing on a given LEMSAs and all of its designated stroke hospitals at once, in batch.

²⁶² This second operational recommendation included the suggestion of partnering with the State Emergency Medical Services Authority for the development of the data system, given that agency's work-to-date with state-level trauma data.

²⁶³ One (provided) example of a proven, scalable program is the Advanced Stroke Life Support ® course.

the program's attempts to recruit local clinical partners into the registry; its capacity to build its infrastructure – particularly in regard to the data system and human resources; its ability to foster and maintain relationships with key strategic partners; and its ability to engage in quality improvement activities, in both the pre-hospital and in-hospital clinical settings. Second, in getting to this programmatic state, a number of factors have been very influential. Some of these factors are contextual in nature (e.g., those elements related to organizational structure and culture), while others are operational challenges that have been faced by the program (e.g., those trials related to budgets and staffing). As well, change-related beliefs have been impactful in shaping the CSR/CCP's current operational state. The third main theme also relates to change, and it is this: There are certain changes the CSR/CCP ought to consider making, in order to move to a better future state – one more aligned with the program's original guiding vision. To this end, out of this project comes the set of twelve recommendations enumerated above. With the eventual implementation of these recommendations, the program's resultant future state should be a model for how clinical medicine and public health can come together in partnership to improve health at the community level. In the next chapter, these results are discussed, and some key findings are highlighted within the contexts of the program and the field.

Introduction

The purpose of this fifth and final chapter is threefold. First, this final chapter provides a discussion of the key findings by research question. This discussion highlights each finding's importance to, and impact on, (a) the California Stroke Registry/California Coverdell Program (CSR/CCP) and (b) the field, as well as how each finding is addressed via at least one recommendation for action²⁶⁴ – and this action requires leadership²⁶⁵ (which is also taken up here). Second, this final chapter shares ideas with respect to how the original conceptual framework²⁶⁶ might be revised, given the findings presented in the prior chapter. Third, this final chapter presents the limitations of the present project, leading into the final project conclusion.

A. Key Findings

In the prior chapter, the results of the analyses of the data from all 41 data sources (i.e., the 27 documents reviewed during Phase I and the 14 key informant interviews conducted during Phases II and III) are presented. This presentation, which is organized by research question, is comprehensive, as it addresses all of the constructs included in the conceptual framework presented in Chapter 2. In discussing the findings in this chapter, the scope is intentionally narrow, as there is a sharp focus on the project's key findings. These key findings are those which have been found to do the following: (a) connect and unite multiple other project findings;

²⁶⁴ The recommendations were enumerated in Chapter 4.

²⁶⁵ This crosswalk from the findings to the implications is summarized in Appendix VI.

²⁶⁶ The original conceptual framework is presented in Chapter 2.

(b) include both local (program) and global (field) implications; and (c) lend themselves to at least one of the recommendations for change proffered during this project.

The presentation of the key findings follows this format: First, the given finding is summarized. In each summary are statements which relate the finding of interest to one or more of the project's other findings. Next, the importance of the given finding is stated and described. Further, the impact(s) this finding has on the program – and on the field – is (are) discussed. Finally, the relevant recommendation(s) is (are) noted, as is (are) the implication(s) for leadership. Three key findings – one from each phase of the project – are covered in this final chapter; they are presented in succession.

1. **Key Finding #1 (related to Research Question 1/Phase I)**

The first research question sought to find out about the current operational state of the CSR/CCP. Four constructs were examined in this pursuit: (1) the recruitment of clinical partners; (2) the state of the program infrastructure – to include the data system, the performance measures, and the staffing patterns; (3) the quality of the relationships with the registry's key strategic partners; and (4) the registry's efforts related to improving quality of care. Via this examination, the current operational state of the registry was found to be lacking in all of these areas, though the shortfall within one area was particularly salient: the data system. Hence, the first key finding: **Even with an expected completion date of early 2013, the registry's data system has not yet been completed by the contractor, the Eureka Team of the California Cancer Registry.** This finding, per se, seems rather matter-of-fact; however, not having a functional data system has been a significant and far-reaching liability for the registry.

The extent to which this data-system-related problem has become a liability becomes known, upon recognizing the importance (i.e., to the CSR/CCP) of having a functional data

system and what that would mean in terms of programmatic capacity. As described earlier, the registry's data system has been designed to perform these three tasks: (1) onboard all clinical partners (i.e., both pre- and in-hospital partners), regardless of how a given clinical partner's local data are collected; (2) standardize and link all of the data from the two clinical settings, at the patient-level, in order to enable a comprehensive look at treatment across the continuum of care; and (3) provide the registry's end users with summary data that can be used to (a) inform the local quality improvement initiatives and (b) evaluate the local stroke systems of care.

Further, the promise of a data system that is able to do these things has been a key incentive for getting local clinical partners to join the registry, given the lack of a legislative mandate for the registry. Without a functional data system, these tasks cannot be accomplished and registry participation cannot be incentivized. Thus, the program's capacity has been limited.

This lack of a functional data system serves as an indicator that the CSR/CCP has not been operating as it had anticipated to have been (by this time); moreover, this lack of a functional data system has created problems that can be observed across other constructs studied in this project. For example, the registry's recruitment efforts were less effective than they otherwise would have been (in part, because the appeal to participate in the registry has been diminished, as suggested above). As well, the quality improvement initiatives were fewer in number than they otherwise would have been (as there was a dearth of data to drive such initiatives). Finally, in connection to the organizational culture construct (studied in Phase II), having a failed data system development process (which was an innovative idea) may suppress the spirit of innovation – one aspect of organizational culture (Sarros, 2008) – from this point forward.

There are higher-level impacts, too, of not having a functional data system in place. At the State-level, the CSR/CCP has been hampered in its ability to facilitate efforts to ensure that stroke patients receive high quality coordinated comprehensive patient care, since there are limited data to drive such efforts, especially in the pre-hospital setting (i.e., across the 33 LEMSAs). As well, inefficiencies have been created: At the State-level, the CSR/CCP Team has had to utilize limited staff resources to carry out tasks that would have been handled by the data system (e.g., the provision of summary data tables to the local clinical partners), and this allocation of resources has meant that other programmatic areas have had fewer dedicated resources (than would have been the case otherwise). As one informant²⁶⁷ stated, concerning the use of staff resources:

“...if you’re looking at our re...staff resources as a, kind of zero sum game, that means taking away from our time and effort toward the acute treatment or post-treatment, or even public awareness, attention towards those, those topic areas.”

Finally, after many years of unfulfilled promises (made by the contractor), the lack of a functional data system may have undermined the credibility of the CSR/CCP staff members, who repeated those promises (regarding the data system) to the CSR/CCP’s local clinical partners. As one informant²⁶⁸ stated: “I think...some of the external partners kind of gave up on us – they got tired of waiting for things...” In sum, the lack of a functional data system meant that both the local clinical partners and the State-level staff were impeded in their respective and collaborative efforts to optimize stroke care in California.

This situation also has an impact on the larger field, as this project finding is an exemplar of a public health program facing an impediment (i.e., the limited ability to have and use data is the impediment) to fully integrating its efforts with those of clinical medicine – an action which

²⁶⁷ Phase III, Key Informant #2.

²⁶⁸ Phase II, Key Informant #6.

is essential to improving health at the population level. This integration, which (of course) is the basic premise of the CSR/CCP, is an evolving process – one with facilitators (and barriers), as well as various ancillary components. First, in terms of facilitators, an earlier statement, made in Chapter 1, bears repeating: According to the Institute of Medicine’s report on integration (2012a), ongoing efforts to integrate have been (and will continue to be) facilitated by the sharing of health information, along with the passage of the Patient Protection and Affordable Care Act. Together, these facilitators motivate healthcare providers to engage with the public health system in health planning at the community level. In short, even with new legislation, a lack of data means a lack of engagement.

Next, with respect to the ancillary components, Honoré (2014) suggests that the efforts to integrate providers’ efforts ought to include the provision of workforce professional competence, an idea which is (also) deeply-rooted in the quality improvement philosophy of the CSR/CCP. Honoré cites two national reports, “Priority Areas for Improvement of Quality in the Public Health System” and the “National Public Health Workforce Strategic Map” which call for the assurance of such competence – in part, through inter-professional education. To be sure, this kind of effort can only occur with ongoing engagement. Again, even with a strategic map, a lack of data means a lack of engagement, as suggested above; if engagement wanes, the provision of workforce professional competence could be in jeopardy.

Montero, Moffatt, and Jarris (2015) discussed the integration of clinical medicine and public health, as well, and cited five key levers for improvement, which are reproduced in the Institute of Medicine’s recent report on collaboration (2016): (1) a commitment from leadership; (2) linkages of community and clinical resources; (3) the use of data to inform action; (4) the establishment of standardized protocols; and (5) the leveraging of multiple funding streams. In

using these five key levers appropriately, contend the authors, it will be possible for “...public health, clinical, and community leaders to sustain and spread models of successful population health improvement...” It follows, then, that if any of these five key levers is in some way compromised, then the sustainability and spread of such models could be limited. As has been suggested, this is what has been happening in the present project: The use of data to inform action (i.e., the third lever) has been compromised (because of the lack of a functional data system); therefore, the attempts to improve population health are stifled. In sum, this finding represents a missed opportunity for effective, data-driven efforts in this regard.

To address this situation (within the registry) – and enable the registry to be an exemplar of success rather than one of failure, a key operational recommendation was made by the ad hoc group of advisors who reviewed the project findings: Revisit the program’s ability to collect and report data – and enhance or replace the current system, via a new development team²⁶⁹. This recommendation is consistent with testimony from several of the key informants. In fact, one informant²⁷⁰ suggested very explicitly that the CSR/CCP should be “...looking at new partners, a new way of doing the data management...” She continued: “It’s, you know, the, the new partners, it’s...the new data system.” Ultimately, the goal for data collection, as stated by another informant²⁷¹, is as follows:

“...once they’ve arrived at the hospital, you know, there’s then a, a record of their care from when [pause] when the first responders arrived through the hospital discharge and, and you need to be able to know from the data how that all went, and if there are problems, then you need to have the data that will help you to figure out how to address those problems.”

Closely related to this data-system-related recommendation are two other operational recommendations that merit mention here. First, the CSR/CCP Team – along with its

²⁶⁹ This is the second operational recommendation presented in Chapter 4.

²⁷⁰ Phase II, Key Informant #6.

²⁷¹ Phase III, Key Informant #6.

development team – must work to ensure that the collection and reporting of the core pre-hospital and in-hospital data elements, at a minimum, are standardized. Second, as appropriate and feasible, the CSR/CCP Team must utilize and share data liberally – with registry partners and stakeholders.

With these three operational recommendations proposed, there is a clear implication for leadership. Simply put, per the Practical Playbook (Duke University Medical Center, 2016): Leaders must find ways to enable the sharing of data in ways that promote the collaborative efforts of clinical medicine and public health to improve population health. For the future success of the CSR/CCP, this means that registry leadership must enable the development of a functional data system; this is a top priority, one which likely requires a new development team.

2. Key Finding #2 (related to Research Question 2/Phase II)

The second research question investigates those factors which have been impactful in bringing about the current operational state of the CSR/CCP. To this end, three main constructs were examined: operational context, operational challenges, and held beliefs. Through this inquiry, it was found that all three constructs were influential in shaping the registry; however, one aspect of the operational context construct was particularly important, namely, the contrasting prevailing notions of prevention within the program and within the Branch in which the program resides. Specifically, this is the second key finding: **The CSR/CCP’s scope deals primarily with secondary prevention – as it seeks to reduce the impact of an event (i.e., a stroke) that has already occurred through immediate appropriate treatment; in contrast, the focus of nearly every other public health program within the larger organization is on primary prevention – to prevent disease before it ever occurs.** Given this contrast, there

remains somewhat of a “lack-of-fit” within the organization for the CSR/CCP, and this situation has been impactful on its operational state.

Because of this “lack-of-fit,” the CSR/CCP has been, to some extent, deprioritized within the larger organization. As cited above, one informant²⁷² felt that the registry has not been “...elevated to a level of importance within the [pause] structure...or in the view of all of upper management...” She also felt that the upper management is not focused on the registry and that “...they don’t truly understand everything that we [meaning the registry] do and what we’re trying to do.” Consequently, the amount of support and recognition given to the CSR/CCP by upper management is comparatively less than that received by other programs with a better “fit.” With limited resources and a “low standing,” the CSR/CCP has been challenged in its ability to carry out its scope of work.

Some of these notable challenges include the following: First, as discussed above, the CSR/CCP has received almost no financial support from the Branch over the years, which means that the registry’s entire scope of work has been carried out almost exclusively via the use of the dedicated CDC funds. Second, via unilateral Branch-level decisions (as discussed above), staff members have been removed from the CSR/CCP and assigned to work on other programs within the Branch in which the CSR/CCP resides – thereby requiring existing CSR/CCP staff to take on additional duties. This decision has meant that existing CSR/CCP staff were overburdened, and inefficiencies in program operations were created. As cited above, one key informant commented on this saying this about the registry: “...it’s been so different from other traditional public health programs, I think it hasn’t gotten recognition from leadership. It certainly hasn’t gotten any additional financial support or resources.” Finally, given its unique notion of prevention and resultant lack of fit – along with the two above-mentioned challenges, the

²⁷² Phase II, Key Informant #1.

CSR/CCP has, over the years, strayed somewhat from its original work plan. For example, as stipulated in that work plan, the CSR/CCP had intended to work with Branch leadership, as well as its key strategic partners, to develop a model for sustainability, one which did not require federal funding; however, such a model was never developed. One informant²⁷³ commented on this saying: "...not understanding what it was, how it functioned, why it was important, wh...how it fit in – with all the changes that happened, I think it got kind of lost a little."

Much like what was discussed for the first key finding, there are greater impacts for the CSR/CCP, related to its "different" notion of prevention (relative to that of the larger organization). First, because the CSR/CCP has been relegated to a level of relative unimportance, as per the views of upper management within the larger organization, its visibility is low. Low visibility, in turn, has complicated the registry's efforts to coordinate broad-based inter-agency efforts to improve the quality of care for stroke across the state – and this means that there is less value created, as per Moore (1995). Dyer, Kale, and Singh (2001) describe this creation of value, stressing the importance of external visibility, along with knowledge management, internal coordination, and accountability. These authors suggest that "...external visibility can enhance the reputation of the company [or the organization] in the marketplace [or the field] and support the perception that alliances are adding value." Indeed, low visibility impacts the program's ability to create public value.

A second significant impact for the CSR/CCP, related to its "different" notion of prevention, is that the CSR/CCP has become a subculture within the larger organization, which, in and of itself, is not necessarily a bad thing. Gerdhe (2012) defines a subculture as an organizational unit that has "...a value system that may not conform to the predominant value system that defines an organization's corporate culture." Further, according to Gerdhe, different

²⁷³ Phase II, Key Informant #5.

types of relationships can exist between a subculture and the dominant culture within the organization. These relationships may be characterized as enriching, disagreeing, opposing, and supporting. Within the present study, as has been described above, the relationship between the registry and the larger organization would be considered disagreeing. This situation is critical, states Gerdhe, and it must be addressed in order to strengthen the culture:

“If the companies have the ability to assess and improve the visioning process, to modify the communication of values to various subcultures and lastly, if the artifacts and behaviors support the vision and values, the companies can create a strong culture (the subcultures’ alignment).”

Thus, even though there are contrasting prevailing notions of prevention within the CSR/CCP (i.e., the subculture) and the Branch in which the CSR/CCP resides (i.e., the dominant culture), they (i.e., the notions) don’t have to be characterized as disagreeing. Rather, with some work (as suggested above), the subculture/dominant culture relationship could be characterized as enriching. Certainly, this would be of benefit to the CSR/CCP.

This current state (of disagreeing, with respect to prevention) and the consequent deprioritization of the registry have impacted the field, as any heretofore efforts (by the registry) to integrate clinical medicine and public health have been, to some extent, muted. This muting represents a failure by the larger organization to appreciate and build on a model (i.e., the registry) that is designed to promote collaboration between these two professional fields. Moreover, such a failure allows gaps in coordination to persist, thereby reinforcing the silos that are inconsistent with the spirit of healthcare reform (Institute of Medicine, 2012a, 2012b). Finally, such a failure strengthens those countervailing forces which promote fragmentation and stagnation and undermine prudent efforts to improve population health (Leischow et al., 2008).

What should happen instead – i.e., what the registry has been attempting to do – is described by Leischow et al. (2008):

“There is a critical need for governmental agencies to take a leadership role in fostering increased transdisciplinary and translational collaboration and to employ an approach that recognizes that public health is the culmination of a complex, adaptive federation of systems that no one organization can or should control.”

These authors continue:

“While comprehensive, centralized, hierarchical control is not the desired system goal here, there is an essential facilitative role that needs to be played by hierarchical centralized organizational entities like the federal government [or the state government, in this case], which can provide the leadership essential to developing a framework for action, and encourage and support the process of fostering collaboration among a diverse group of stakeholders.”

Within the context of this project, this would mean that the CSR/CCP’s efforts to work collaboratively with local clinical providers should be encouraged and supported by the senior leadership within the organization within which it resides.

In line with this vision are some key recommendations from the ad hoc group of advisors who reviewed the project findings. First, there is a foundational recommendation to raise the visibility of the CSR/CCP, such that it is better poised for support as it endeavors to achieve a better future state – and as it serves as a model for transdisciplinary and translational collaboration. Additionally, in order to impel these happenings, there are two foundational recommendations for improvement, as follows: to improve the communication practices of the CSR/CCP both internally and externally; and to strengthen the coordination capacity and practices of the CSR/CCP. These very ideas were also voiced by a key informant²⁷⁴ who said this:

“I think our partners would wanna see more leadership and coordination from us, more communication, more convening of the different partners. I think that that was something that we wanted to change as staff members, and I believe it’s something that the external partners would wanna see.”

²⁷⁴ Phase II, Key Informant #6.

In sum, it is recommended that the CSR/CCP strives for greater visibility, better communication, and greater coordination, all of which are assets for improving the operations of the CSR/CCP, as well as for fostering integration and collaboration across the clinical medicine and public health communities.

Acting on these three foundational recommendations requires leadership. Indeed, leaders must find ways to promote collaborative efforts of clinical medicine and public health via the reconciliation of differing notions of prevention and the promotion of shared leadership; to these ends, leaders must employ essential skills. Fernandez, Noble, Jensen, and Steffen (2014) identify twenty such skills – ten core leadership skills and ten organizational and institutional skills, as listed below in Table XVIII:

Table XVIII: Twenty Leadership Skills

Core Leadership Skills	Organizational and Institutional Skills
1. Self-awareness	1. Creating Organizational Culture
2. Communication	2. Systems Thinking
3. Negotiation	3. Bench Building/Succession Planning
4. Conflict Management	4. Leading Change/Change Management
5. Visioning	5. Cultural Competence
6. Innovation	6. Stakeholder Analysis
7. Emotional Intelligence	7. Futuring
8. Transformational Leadership	8. Collaboration/Creative Partnerships
9. Reflective Leadership	9. Innovation/Performance Management
10. Career Management	10. Advocacy

To conclude the discussion on this second key finding: Even though the subculture of the CSR/CCP is somewhat at odds with that of the dominant culture of the organization²⁷⁵, this situation can be remedied. Moreover, following the foundational recommendations mentioned above – while utilizing these twenty skills – should enable the CSR/CCP Leadership to foster

²⁷⁵ This is a situation which has contributed to the deprioritization of the CSR/CCP.

(and model) increased transdisciplinary and translational collaboration, consistent not only with its mandate but also with the spirit of healthcare reform.

3. **Key Finding #3 (related to Research Question 3/Phase III)**

The third research question was raised to explore changes the CSR/CCP might make in order to usher in a better future state. Potential areas for change included using existing resources (e.g., technology, staffing, and partnerships) in new ways and acquiring new resources and/or practices (e.g., knowledge management and cross-functional teams). As was reported in the previous chapter, the data suggest a number of ideas along these lines – including enabling technology to improve communication and data sharing practices; assigning and balancing workloads according to team members’ skills and abilities; engaging key strategic partners more fully – thereby enabling a more broad-based approach to achieving shared objectives; practicing knowledge management (i.e., making the best use of information); and forming and deploying cross-functional teams.

One of these ideas was stressed above the others – namely, the use of cross-functional teams. The use of these teams is a new concept for the CSR/CCP, even though this way of doing business is a “best practice” – as described in the literature (Kochan and Useem, 1992; Proehl, 1996; McDermott, 1999; Wegner and Snyder, 2000) and as reported by all seven of the Phase III key informants. Even so, **for the CSR/CCP, given its past staffing patterns, as well as its relatively small group of strategic partners (i.e., the AHA/ASA, the California Cancer Registry’s Eureka Team, the CDC, and the group of “other” partners, as discussed in the previous chapter), there has not been a bona fide cross-functional approach to carrying out**

the scope of work. This third key finding,²⁷⁶ though most relevant to the infrastructure construct's section on staffing, cross-cuts other areas, including the partnerships-related constructs and the locus of control constraint under the operational challenges construct.

The importance of this third key finding is underscored upon knowing that (1) the CSR/CCP has thus far failed to achieve a number of its goals, including those related to recruitment, the data system, and quality improvement²⁷⁷; and (2) a primary reason for the CSR/CCP's inability to achieve these goals is that the CSR/CCP has not been able to optimize the use of human resources, both those within the program and those within the key strategic partners – for example, via the use of cross-functional teams. Consequently, the CSR/CCP did not reap the kinds of benefits one key informant²⁷⁸ described: "...we were able to build on some of the strengths that they had, their knowledge base and, and really to, to, really get the good ideas of, of what the issues were..." He further noted this:

"...having 'em actually all together in one spot and working on it, getting a good plan in place was really effective and, and really just showing the benefits of, that we would derive from each of our, uh, agencies was a plus..."

The CSR/CCP's experience has not been like what is being promoted here. It stands to reason that the CSR/CCP's achievements differ, as well. Therefore, in working to realize a better future state, the CSR/CCP will need to utilize a different approach to employing human resources, and using cross-functional teams is one such (proven) approach. Without adopting a new approach, the CSR/CCP likely will maintain its status quo, which means that future efforts to recruit clinical partners will not have improved yields; the process to develop the data system will

²⁷⁶ While this particular finding was not explicitly revealed, per se, in this research project, it was, however, highlighted (for the CSR/CCP) by drawing a contrast with what was discussed by all seven of the Phase III key informants, each one of whom described her or his very positive experiences with the use of cross-functional teams.

²⁷⁷ These findings were presented in Chapter 4.

²⁷⁸ Phase III, Key Informant #5.

continue to languish; and the facilitation of local quality improvement initiatives will be not better than it has been.

In terms of program impact, the use of cross-functional teams by the CSR/CCP should mean the following: First, key personnel from multiple agencies (including from the CSR/CCP and its key strategic partners) come together for a specific time, in order to accomplish a specific goal or task. To that end, ideas, knowledge, expertise, and innovation are brought to bear (Santa, Ferrer, Bretherton, and Hyland, 2009), thereby increasing the likelihood of achieving success²⁷⁹. With such success, the CSR/CCP moves closer to achieving its goals – and is more aligned with its original vision. Next, using this model should enable the CSR/CCP to be more of a learning organization²⁸⁰, as per Senge (1994), who offered this: “One of the worst kept secrets in management is that most of the real work gets done by teams, not by lone individuals in the splendid isolation of corner offices” (Senge, 1991). Finally, using cross-functional teams should also mean improvements in the facilitation of collaborative efforts; the management of interagency communications; and the identification and cultivation of key leaders (Proehl, 1996).

This third key finding also has implications for the larger field. First, the failure of the CSR/CCP to use an established best practice means that it is, at present, an inappropriate model for other similarly-charged public health programs to follow – and this is a bit of a departure, as this “copycatting” behavior exists, both locally and on a much larger scale. For instance, William Lowry, in his book on pollution control policies, describes how “...California initiatives still provide examples for other states and the federal government to emulate...” (p. 90). Other

²⁷⁹ This is consistent with the Human Resource frame of Bolman and Deal (2008).

²⁸⁰ The current state of the CSR/CCP – i.e., a state which does not utilize a cross-functional approach – suggests that it (i.e., the CSR/CCP) is not now a learning organization, as per Senge (1994); this is because (a) personal mastery has been stifled due to heavy individual workloads; (b) mental models are incomplete since only one perspective is represented; (c) team learning cannot occur without a team; (d) systems thinking is precluded since the “system” being viewed is incomplete; and (e) there is no sharing of a vision, since no one else is present.

“copycat” examples abound, as well, perhaps in part due to California’s status as a large, wealthy, early innovator (Volden, 2006; Centers for Disease Control and Prevention, 2014b; Shipan and Volden, 2014; Zielinski, 2015). In short, though California is usually a model, in this case – with respect to the use of this particular best practice within the CSR/CCP, it is not.

The second implication for the larger field is that the CSR/CCP’s failure to use an established best practice may put the credibility of the program – as well as the larger organization – into question. This by itself is disconcerting; what is more is that this could negatively impact future funding possibilities, as well. According to the Community Tool Box (CTB), from the Work Group for Community Health and Development at the University of Kansas (2015), credibility is damaged when there is a failure to adopt best practices, given that the organization is neither using tested processes nor ensuring that it is doing the best job possible. Additionally, as per the CTB, an organization which has not adopted established successful methods is likely to be viewed less favorably by potential funding agents than are those organizations which have adopted such methods.

Certainly, were this problematic situation to be remedied, the benefits could be realized both locally and globally: First, for the CSR/CCP, adopting this “best practice” team approach could foster collective learning (within the team) and enable a level of performance that exceeds the sum of the individual contributions. As well, it could enable the CSR/CCP to make progress towards realizing a better future state. Second, benefits could be realized globally, as the CSR/CCP could serve as a model...in this case, for turning things around. Specifically, the behaviors of interest would be these: (a) conducting the research related to using a particular best practice (here, the use of cross-functional teams) and (b) assessing how that particular practice might be adopted. Perhaps at the organizational level, achieving and demonstrating success in

this kind of “about-face” scenario might be akin to a leader regrouping in order to model the way (Kouzes and Posner, 2007).

With respect to this third key finding, the following key operational recommendation was offered by the ad hoc group of advisors who reviewed the project findings: Reconsider staffing patterns within the CSR/CCP, as well as how strategic partners are utilized, with an eye towards developing and using cross-functional teams. This cross-functional approach should enable the CSR/CCP to experience “wins” that bring the program closer to achieving its goals (as per Kotter, 1995; Biech, 2007).

Even so, it is noteworthy that the tone of this operational recommendation is somewhat cautious. Surely, the CSR/CCP is advised be careful in possibly moving to this new paradigm, which is appropriate given the added responsibilities associated with such teams, as discussed in the previous chapter: facilitating team members’ efforts, managing various communications, and identifying/cultivating champions. Given these considerations, perhaps the CSR/CCP’s experience with this (or any) potential paradigm shift might be enhanced by the presence of interested others – which touches on a second operational recommendation: Broaden the coalition of strategic partners and stakeholders, looking to include others whose interests broadly match those of the CSR/CCP. This idea is consistent with guidance found in the Practical Playbook, written to help bridge gap between public health and primary care (Duke University Medical Center, 2016).

Acting on the above-listed recommendations requires leadership, in order to effect change for both the program and the field. In terms of the program, leaders need, first, to craft the vision as to what program’s new human resources paradigm might be and, second, to share that vision with the program’s stakeholders. With respect to the field, leaders, in general, must

seek out opportunities to adopt evidence-based best practices; in so doing, leaders will both challenge the current process (Kouzes and Posner, 2007) and enable others to act in ways that improve the status quo (Kanter 1983; Tichy and Devanna, 1986).

B. Revising the Original Conceptual Framework

In the second chapter, the original conceptual framework was presented (Figure 1). This framework proposed that the current operational state of the CSR/CCP has come about because of various influences, including contextual factors, operational challenges, and held beliefs. Additionally, this framework suggested that perhaps the CSR/CCP might move to a better future state, via the use of key recommendations for change, adopted and operationalized within a deliberate action-oriented process. The findings presented in the fourth chapter and discussed above substantiate this conceptual framework, for the most part. However, to make this framework better reflect the “current” reality – as described by the analysis and interpretation of the project data, several changes must be made. These changes to the conceptual framework are discussed below, and a revised conceptual framework is shown in Figure 10²⁸¹.

In evaluating – and striving to improve – the utility of original conceptual framework (i.e., to capture what is really happening), it is important to assess the following: (1) which “boxes”²⁸² are “most telling” and which are “least telling;” (2) whether the language used within the boxes and/or the positioning of the boxes within the framework accurately reflect(s) what is now known; and (3) what, if anything, is missing from the original conceptual framework. First, in terms of which boxes (in the original framework) are most telling, the data suggest that the

²⁸¹ Because this project concerns change, it follows that any proffered conceptual framework for this project would be subject to change. Accordingly, though Figure 10 shows a revised conceptual framework, it should be understood that this framework may continue evolve as the CSR/CCP seeks to achieve a better future state.

²⁸² The “boxes” are the components of the conceptual framework.

operational context and the operational challenges constructs provide considerable insight into how the CSR/CCP arrived at its current state, while the stakeholder beliefs construct provides less understanding in this regard. To elaborate, the operational context construct is particularly informative because it highlights key historical decisions (made related to the program), as well as staffing choices (made) for the program, while the operational challenges construct is important because it describes the impacts of both limitations faced – and subsequent choices made – by the program. In contrast, the held beliefs construct²⁸³ was less informative, perhaps because the CSR/CCP Team has already begun to move away from the long-time status quo. This movement towards a better future state essentially renders the notions of “the program should change” and “the program can change” moot.

Next, in assessing whether the language used within the boxes and/or the positioning of the boxes within the original framework accurately reflect(s) what was learned, the following judgements were made: First, within the Operational Context construct, the terms Program History, Program Structure, and Program Culture²⁸⁴ were found to be too general, once the data were collected and analyzed. Instead, these terms have emerged: Past Decisions, Staffing Choices, and Planning Processes. These three terms better represent some of the contextual events that have shaped the CSR/CCP, as discussed above, and they need to be used in the revised framework. Second, out of the Program History component of the Operational Context construct, the key finding related to the registry’s unique notion of prevention emerged, as discussed above; however, in the original framework, this idea is not obvious. Therefore, the revised framework needs to accommodate this unique notion. Third, the positioning of the boxes within the original framework seems to suggest that the Operational Context, the Operational

²⁸³ This refers to the change-related beliefs of the CSR/CCP staff members and stakeholders.

²⁸⁴ These terms came out of the literature, as described in Chapter 2.

Challenges, and the Stakeholder Beliefs are conceptually similar; however, the research suggests something different. In fact, the research suggests that there should be some differentiation between ideas that are actions and ideas that are assets²⁸⁵. Accordingly, the revised framework should more accurately represent the Operational Context, the Operational Challenges, and the Stakeholder Beliefs by including this distinction.

Finally, an assessment is made as to whether there are any missing components in the original framework. Given the findings discussed earlier, the framework has been found to be lacking, particularly in the area of “assets,” as introduced immediately above. Specifically, the revised framework ought to include some mention of these three assets²⁸⁶: Visibility, Ability to Coordinate, and Ability to Communicate. To be sure, these three assets were discussed during multiple key informant interviews and are included in the list of foundational recommendations. As well, given the addition of these three assets, along with the above-mentioned intentional emphasis on the CSR/CCP’s unique notion of prevention (and the resultant impact on “organizational fit”), the revised conceptual framework needs to convey that certain influences are tangible actions, while other influences are intangible assets.

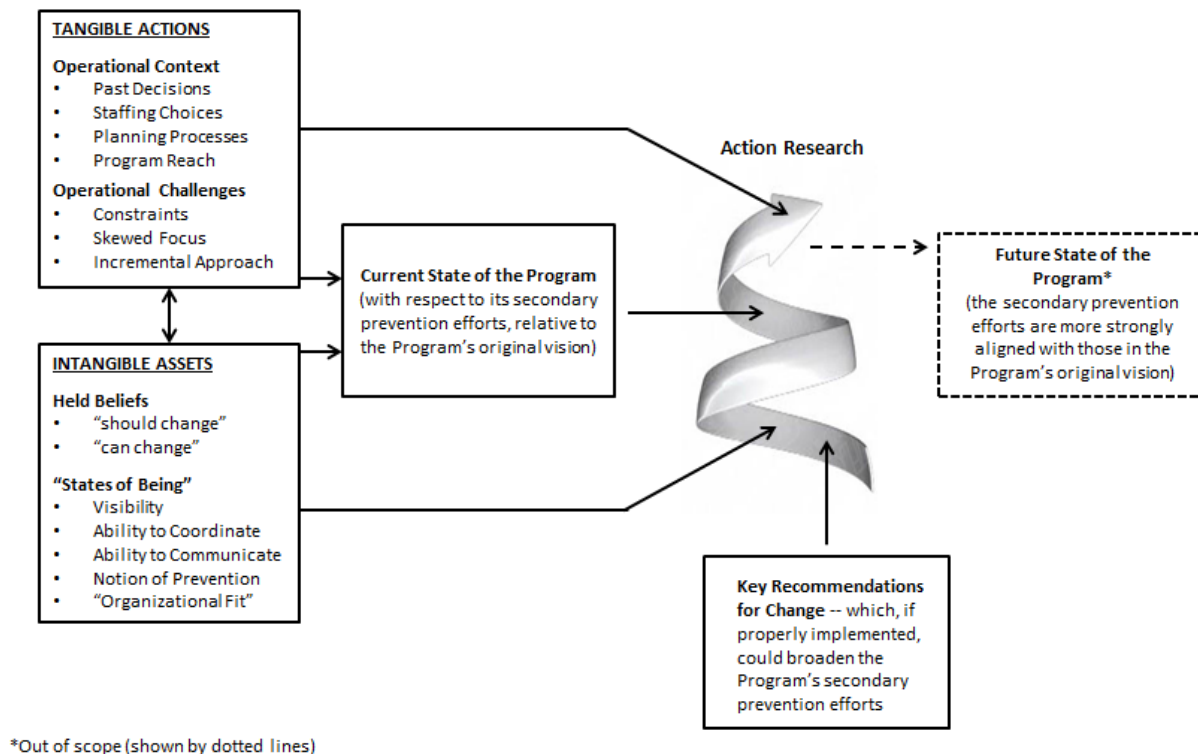
Thus, because of these considerations, a revised conceptual framework has been created. This revised framework, shown below in Figure 10, incorporates new terminology; emphasizes the key findings; differentiates influences as either actions or assets; and includes three new ideas, namely visibility, coordination, and communication – all of which were included in the foundational recommendations discussed earlier. Even with these changes, it must be stated that

²⁸⁵ This distinction is akin to having both foundational and operational recommendations; the former are assets, while the latter are actions.

²⁸⁶ Note that the inclusion of these three assets (i.e., Visibility, Ability to Coordinate, Ability to Communicate) does not necessarily mean that they are positive aspects of the program; rather, their inclusion simply suggests some direct (i.e., not inverse) association between the assets and the program’s operational state. For example, these could be negative aspects of the program: An inability to communicate and/or coordinate might mean a (current) state of disarray. Moreover, a lack of visibility might mean that the state of disarray persists, as it goes unnoticed.

this revised conceptual framework is neither perfect nor definitive. Likely, it still has inaccuracies and omissions; accordingly, it will continue evolve as the CSR/CCP seeks to achieve a better future state²⁸⁷.

Figure 10: The Revised Conceptual Framework



C. Project Limitations

When contemplating the findings from this project, a number of limitations must be considered. These limitations, which provide a cautionary lens through which the results should be viewed, are discussed within four areas: Data Sources, Data Collection, Data Analysis, and Data Interpretation.

Data Sources

²⁸⁷ This is out-of-scope for the present project.

With respect to the data sources used within this project, there are two potential concerns of note. First, with respect to the 27 source documents used within Phase I, timing might have been a factor – specifically the timing as to when these documents were produced. From the writing of the first document analyzed to the writing of the last document analyzed, more than three years elapsed. It is possible that over that timeframe, some of the earlier ideas may have been repeated (e.g., in multiple annual reports), and this repetition may have impacted the coding, as multiple references to one idea may give additional, undue credence to that one idea. In other words, the timing of the source documents may have allowed for multiple mentions of one idea, therein potentially “inflating” the importance of that idea. As Dahlin, Weingart, and Hinds (2005) suggest, “...depth could be artificially inflated by verbosity.”

Second, in terms of the data sources, from the start of this project, not only was there a relatively small pool of key informants to interview (as shown in Chapter 3, Figures 3 and 4), there was also a number of these key informants who ultimately were not interviewed. In Phase II, one informant refused, another informant consented then backed out later, and a third informant was lost to follow-up; additionally, in Phase III (before saturation occurred and certain informants were intentionally excluded), one informant was lost to follow-up. Given this, the concern is whether the would-be contributions of those who were not interviewed are consistent with the contributions of those who were interviewed. This is a type of a non-response bias (Barriball and White, 1994).

Data Collection

In terms of data collection, the following limitations merit mention. First, the data collection process may have included some bias. Specifically, three types of bias may have introduced into the process: (a) bias and preconceptions on the part of the researcher, while

developing the document review guide and the interview guides, all of which drove the data collection process (Miles and Huberman, 1994); (b) a recall bias on the part of the key informants (particularly in Phase II), given that some questions (e.g., those concerning historical aspects of the program) required relatively long recalls (Durand and Chantler, 2014); and (c) a type of acquiescence bias on the part of the key informants (in both Phases II and III), who may have unconsciously provided “more agreeable” results (than otherwise)²⁸⁸ – knowing that the researcher has a vested interest in having the CSR/CCP undergo a change process (Gomm, 2009). To be sure, these potential biases are of the unconscious or uncontrollable type...that is, they are “mental contamination,” as per Wilson and Brekke (1994).

Second, there may be a limitation related to data collection (during Phases II and III) as a result of transcription choices and/or errors (e.g., handling inaudible speech, making omissions, and/or committing grammatical errors), which would render the data in NVivo, Version 10, somewhat “different than” what was captured on the audio recording. While this is unlikely (since the interviews were conducted using appropriate audio equipment; the transcription services were performed by a professional transcriber; and the researcher conducted member checking²⁸⁹), a significant choice or error, were it to occur, could alter the data – and, therefore, the results of the analyses.

Data Analysis

Regarding the data analysis component of the present project, two potential limitations exist. First, one potential limitation is the bias of the researcher during the coding of the raw data

²⁸⁸ This possible bias on the part of some of the informants could have been balanced by a possible bias on the part of some of the other informants – specifically, those who were once with the program but no longer are, especially when the departures were not by choice. In this kind of a scenario (in which there may be some lingering hard feelings), these responses, on the whole, may have been biased to a comparable degree but in the opposite direction.

²⁸⁹ All of these actions are described in Chapter 3 and all are consistent with recommendations made by Poland (1995) for improving rigor in qualitative research.

in NVivo, Version 10. It is possible that certain captured codes may have been associated with particular constructs because of the researcher's subjectivity and values; again, this is "mental contamination," as per Wilson and Brekke (1994). Even so, were this to have occurred, the results of the analyses of the data could have been impacted to some degree. However, in the present project, the researcher employed two proven safeguards against this particular limitation: (a) reflexivity – which is "...examining the way one's own subjectivity influences one's research..." (Auerbach and Silverstein, 2003); and (b) double-coding – as mentioned in Chapter 3 and described in Appendix IV. The former practice should minimize the subjective choices being made, while the latter practice can confirm that the former practice was successful.

Second, also related to coding and analyzing the data, there is this potential limitation: As per Gale, Heath, Cameron, Rashid, and Redwood (2013), the computer-assisted approach (used in this project) to code and analyze data has been found to introduce a temptation to only quantify (or even to over-quantify) the qualitative data and not interpret (or perhaps to under-interpret) the content. This practice can be problematic as it tends to yield summary statements that have essentially no value to the research (e.g., "X of Y data sources stated that..."), given that the data sources are particular to a specific project and not representative of some larger collection. In the present project, particularly in Phase I when attempting to compare the CSR/CCP's current state with its "hoped for" state, this temptation was genuine. Even so, in the present study, the researcher was very deliberate about avoiding this pitfall in the analysis phase by performing both content and thematic analyses of the data sources.

Data Interpretation

Finally, there were other opportunities for "mental contamination" (as per Wilson and Brekke, 1994), resulting in the misinterpretation of the data – which, if it did happen, would be a

major limitation of this project. First, there could have been confirmation bias (Rabin and Schrag, 1999) which occurs when a researcher unconsciously (and perhaps aggressively) uses the data to confirm her or his original ideas. In the present project, this would mean that the researcher essentially forced the data to fit the original conceptual framework; however, as was discussed above, it has become known (because of the data) that the original conceptual framework does not fully explain the past events or the present situations or relationships under investigation. Hence, any confirmation bias is likely minimal.

Second, in the interpretation of the data, there could have been some type of a halo effect (Nisbett and Wilson, 1977) which occurs when a researcher unknowingly interprets more-or-less neutral data as being positive because she or he has positive feelings about the data source. In this study, this would have occurred if the researcher, in some way, over-emphasized certain testimony of a particular informant – perhaps because the two of them have had a positive working relationship – just to corroborate his own thinking. Again, because the findings in the present study extended the researcher’s thinking (i.e., the findings introduced new ideas in response to the three study questions of interest), any real impact of the halo effect is likely negligible.

In sum, while this project has certain limitations related to Data Sources, Data Collection, Data Analysis, and Data Interpretation, it is believed that the potential impacts (of these limitations) are likely relatively benign. Even so, because these limitations do exist, the study results should be viewed with caution.

D. Final Conclusions

This study was conducted to do three things: assess the current state of the California Stroke Registry / California Coverdell Program (CSR/CCP); understand the factors that have

given rise to this current state; and consider the possible future state of the program. Imbedded in this three-fold purpose is the supposition that the CSR/CCP's current state ought to be improved; accordingly, the project was designed to elicit recommendations that might catalyze actions that could usher in a better future state – one that enables the program to work more broadly along the prevention spectrum and to align more closely with its original guiding vision. In short, this is about motivating and managing change.

On the subject of change, one informant²⁹⁰ had the following to say, and it serves to set the tone for the CSR/CCP Team as the Team members, together with their partners and stakeholders, seek to achieve this better future state (which is beyond the scope of this project):

“You know, um [pause] I realize that change [pause] it, is sometimes a, a bad word to people. You know, it, people get automatically apprehensive and fearful when you say, “We wanna change things.” Um, and, and that’s... Once they get that feeling, it’s hard to overcome, so we’ve always tried to kind of push not, not so much change, but, you know, a gradual process of improvement...”

One of foundational recommendations presented in Chapter 4 was motivated by this particular sentiment: Within and across all of the CSR/CCP stakeholders, view change not as correction but as an improvement process, the very construct which undergirds the program. Bearing this in mind – along with the other proffered recommendations and the three key findings discussed above, the CSR/CCP Team (in truth, the CSR/CCP Community) ought to do the following, thoughtfully and methodically: (1) fix the non-functional data system situation; (2) address concerns related to the differing notions of prevention; and (3) utilize well-established transferrable and scalable best practices²⁹¹.

Taking these three actions should have implications for both the program and the field. In terms of the former, several advances are likely to be made. First, the CSR/CCP Community

²⁹⁰ Phase III, Key Informant #5.

²⁹¹ This ties in with the sixth operational recommendation presented in Chapter 4.

should become more broad-based and more fully supported. Second, a better future operational state should be achieved – in terms of registry membership, infrastructure, partnerships, and quality improvement. Third, the CSR/CCP should become a learning organization, as it more fully embraces Senge’s five disciplines²⁹² (1994).

Next, with regard to the latter (i.e., the implications for the field), two key points must be made: First, with an (eventual) much improved stroke registry in California, the burden of stroke should be reduced, in terms of morbidity, mortality, and costs. Certainly, this is the ultimate goal of those working in the field. Second, an (eventual) much improved stroke registry in California could also serve as a model, one which represents not only transformation – as it works to achieve this better future state, but also integration – as it brings clinical medicine and public health together to improve health at the community level.

Finally, now that the research questions have been answered and a plan is in place, the battle cry is needed. Fortunately, one was recorded during the interview with Phase II, Key Informant #4, and it reproduced here to serve as this project’s final thought:

“I would say it’s, it’s exciting, it’s an exciting time to be in California, it’s an exciting time to be involved, you know, in anything related to stroke [pause] you know, really from a history standpoint we’re in an exciting place, altogether, in regards to stroke care, so how the registry can kind of expand that and us as a, you know, stroke association can expand in working with you guys... Yeah, I, I just think it’s... I’m, I’m excited about the direction things are going...”

²⁹² This includes heeding the recommendation related to using teams.

VI.

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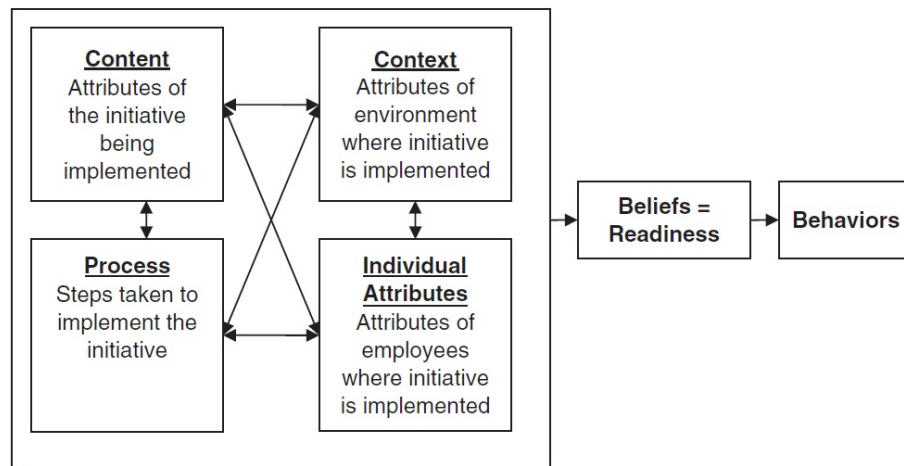
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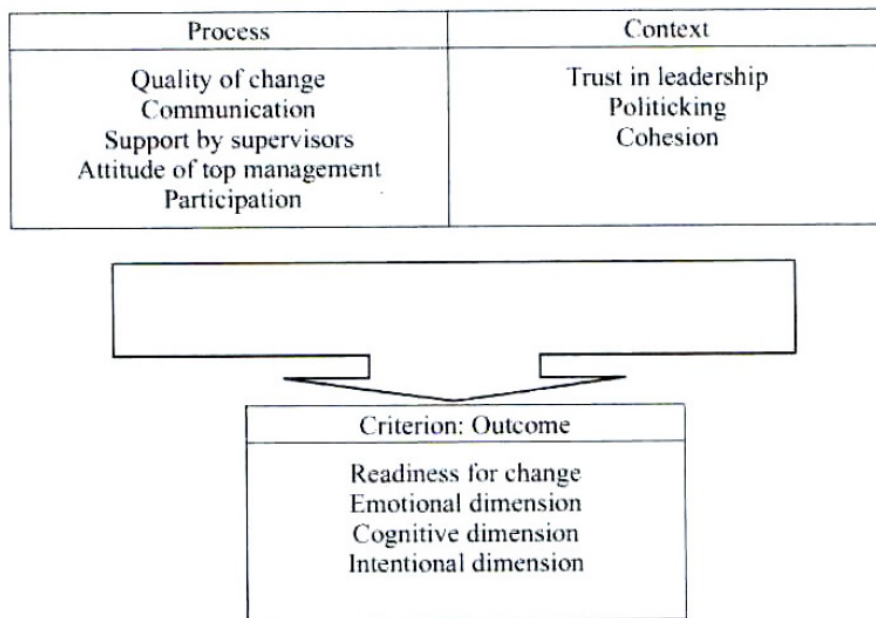
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Appendix I: Beliefs-related Conceptual Models from the Literature

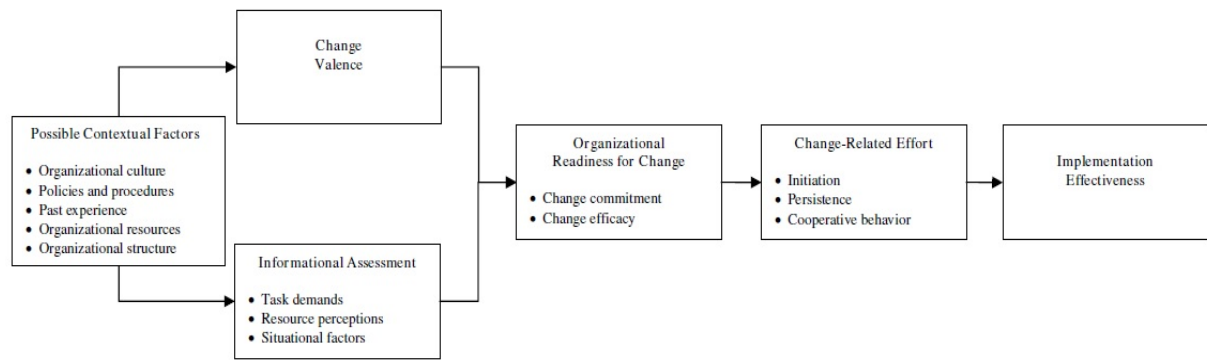
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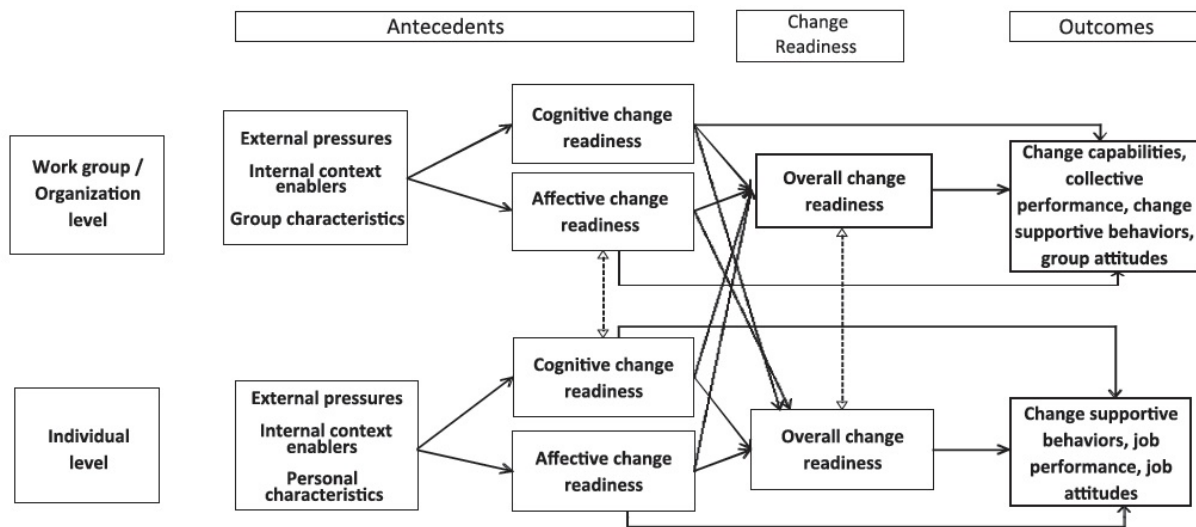
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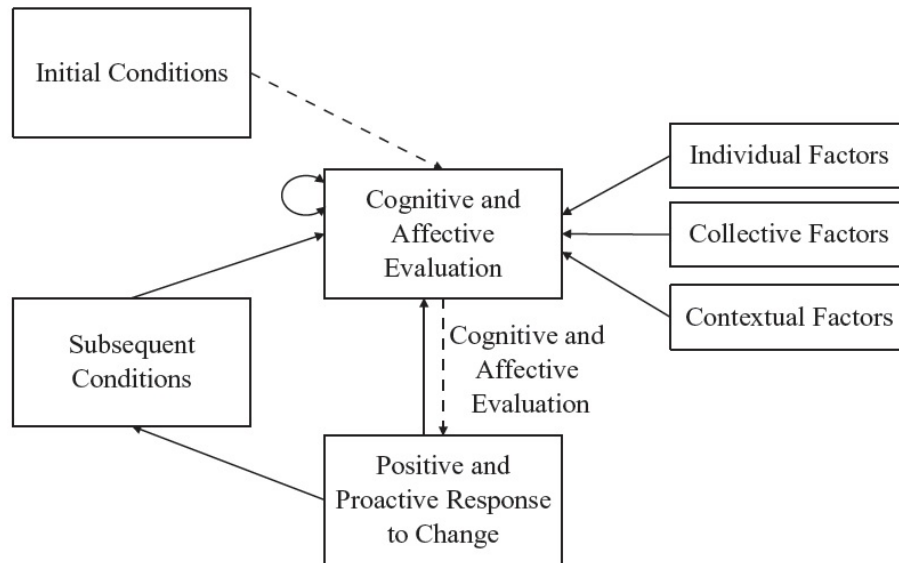
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Appendix II: A. Document Review Guide

B. Key Informant Interviews: Set-Up and Questions

A. Document Review Guide:

For FOA process documents, Periodic Reporting documents, and Site Visit documents, use this 2-page guide (i.e., use one copy of the guide for each document reviewed):

Type of Document: _____ Title of Document: _____ Date of Document: _____ Document Author: _____		
For what audience/purpose was the document written/prepared? _____ Does this document relate to “ <i>anticipated</i> ” or “ <i>actual</i> ” efforts? (state here) _____ (Note: The Response to the FOA document would include “ <i>anticipated</i> ,” not “ <i>actual</i> ,” efforts.)		
Content Review: Below and by setting, list instances (i.e., words, phrases, or statements from the document) that are explicit or implicit mentions of the constructs of interest within the pre-hospital (PH) or in-hospital (IN) clinical setting. (This section pertains to Phase I.)		
Construct	PH	IN
Recruitment – this refers to the action of recruiting providers	List statements as to: ▪ the recruitment of local EMS agencies	List statements as to: ▪ the recruitment of partner hospitals
Infrastructure – this refers to the use of the data system, the establishment of performance measures; and the use of human resources	List statements as to: ▪ the data system’s capacity to collect EMS data ▪ actual data (collected/expected) ▪ the number and use of EMS performance measures ▪ staff focused on EMS work	List statements as to: ▪ the data system’s capacity to collect hospital data ▪ actual data (collected/expected) ▪ the number and use of hospital performance measures ▪ staff focused on in-hospital work
Partnerships – this refers to the ways in which the program has formed and used partnerships	List statements as to: ▪ the number of program partners working in the EMS setting ▪ the ways in which the partners are working	List statements as to: ▪ the number of program partners working in the in-hospital setting ▪ the ways in which the partners are working
QI Initiatives – this refers to Quality Improvement work, jointly undertaken by the program and the clinical providers	List statements as to: ▪ the established need for conducting QI initiatives in the EMS setting ▪ the number of QI initiatives jointly conducted in this setting	List statements as to: ▪ the established need for conducting QI initiatives in the in-hospital setting ▪ the number of QI initiatives jointly conducted in this setting

Content Review continued:

Below, list instances (i.e., words, phrases, or statements from the document) that are explicit or implicit mentions of the constructs of interest. (This section pertains to Phase II – though not all of the Phase II constructs are included* – as data from the document reviews can provide support to that which is collected via the key informant interviews, the primary means for collecting Phase II data.)

Construct	Instances
Operational Context <u>History</u> - this refers to those events/actions in the program's past which, in part, have brought about the current operational state	List statements as to: <ul style="list-style-type: none"> the staffing changes/rate of change, especially as imposed on the program the position of the program within the larger organization the differential view of prevention by the larger organization
Operational Context <u>Structure</u> - this refers to the program make-up/its "environs" and how it functions (as a result of these traits)	List statements as to: <ul style="list-style-type: none"> the hierarchically-motivated stalls (in operations) the inefficient decision-making practices the prohibitive rules
Operational Context <u>Culture</u> - this refers to values and behaviors which describe the working environment	List statements as to: <ul style="list-style-type: none"> the approaches used in planning the processes by which decisions are made the extent to which innovation is encouraged
Operational Context <u>Reach</u> - this refers to the extent to which the program is in operation with its clinical partners across the state (i.e., how far reaching it is...)	List statements as to: <ul style="list-style-type: none"> the proportion of hospitals and LEMSAs "on board" the observed gaps in geographical reach the proportion of the population served
Operational Challenges <u>Constraints</u> - this refers to those things within the program that hamper its ability to achieve its mission	List statements as to: <ul style="list-style-type: none"> the impact of the budget (e.g., magnitude, cuts) the loss of staff members the imposition of restrictions on program operations
Operational Challenges <u>Focus</u> - this refers to the program's emphasis on a particular aspect of its workload (in this case, having a differential focus, relative to the two clinical settings)	List statements as to: <ul style="list-style-type: none"> the narrowness of the recruitment efforts (i.e., for the clinical partners) the setting-specific focus on data collection and reporting the setting-specific focus on performance measures
Operational Challenges <u>Approach</u> - this refers to the processes that are utilized in order to bring about change or move forward in some aspect of the program (e.g., incrementalism)	List statements as to: <ul style="list-style-type: none"> the presence (absence) of a strategic plan for guiding programmatic activities the decision-making processes that occur (given the absence of a strategic plan)

B. Key Informant Interviews: Set-Up and Questions

1. E-mail Invitation

With the subject line of “Research Project aimed at broadening the secondary prevention efforts of the California Stroke Registry/California Coverdell Program (CSR/CCP),” the following text will be included in the e-mails that are sent to selected, prospective key informants:

Hello, [Recipient’s Name]. I hope this email finds you doing well. I am writing to you today, not as the Co-Principal Investigator of the CSR/CCP, but as a doctoral student at the University of Illinois at Chicago School of Public Health (UIC SPH). The purpose of this e-mail is to ask you to participate in my dissertation research project.

This project seeks to describe the current secondary prevention efforts of the CSR/CCP and understand the factors that have been impactful on these efforts. Furthermore, this project aims to uncover ways to broaden the program’s secondary prevention efforts, such that the program is able to be more fully engaged across the continuum of care for stroke – and by that, I mean that the program is more engaged in the pre-hospital, or EMS, setting.

Several methods are planned to accomplish these study aims, including document reviews, two cycles of key informant interviews, and an iterative process to consider and vet the information generated during the conduct of the project. Because of your background and expertise, you have been selected to be a key informant.

What this will require is your willingness to be interviewed by me for perhaps one hour. I anticipate conducting the interview via telephone and recording our conversation so it can be transcribed – in order to facilitate the data analysis. The interview will be semi-structured, which means that I will introduce several general questions, one after the next, and then ask you to share your personal thoughts and ideas about each one.

Your participation in this research project is voluntary. Whatever you share will be kept confidential and you will not be named in the research findings. No one will. Once the project has been completed, I will gladly share my findings with you, if that would be of interest to you.

Thank you so much for your consideration of this request. In about five business days, I will be calling you to discuss your interest in participating in this project, as well as answer any questions you might have. If you would like to have a discussion before then, please do not hesitate to contact me by phone, at 916-606-7768, or via e-mail, at dreyne2@uic.edu.

Thanks again, and I’ll look forward to our next correspondence.

Sincerely,

*David J. Reynen, MA, MPPA, MPH, CPH
DrPH Candidate, UIC SPH*

2. Phone Script as a Follow-up to the E-mail

As a follow-up, I will call each selected key informant to whom I had earlier sent an e-mail that included the text above, and I will use the following as a script for the call:

Hello. This is David Reynen, calling to follow up on an e-mail I sent to you last week, asking if you would be interested in participating in my dissertation research project. How are you doing? (Wait for reply and respond appropriately.)

(Then continue:) As I mentioned in the e-mail, my project has three aims: First, to describe the present secondary prevention efforts of the California Stroke Registry/California Coverdell Program; second, to understand the factors that have been impactful on these efforts; and, third, to uncover ways to broaden the program's secondary prevention efforts...that is, into the pre-hospital, or EMS, setting.

As I indicated, I would like you to assist me in this project by serving as a key informant. This means that I would be asking you some questions related to the project aims. Our conversation would be recorded and the recording would be transcribed. However, your responses will be confidential, and no names, including yours, will be shared in the findings of the project. If you would be interested, I will share my results with you at the conclusion of the project.

Would you be interested in participating in this project? (Wait for a response.)

(If the response is "Yes," then respond:) Thank you very much. To make it convenient for you, I will re-send the earlier e-mail, and include some additional information related to consent. Then you can read over it again and reply to that e-mail, acknowledging your interest in participating and giving your consent. I will be in touch soon to set up the interview. If you have any questions about this, please do not hesitate to contact me by phone, at 916-606-7768, or via e-mail, using this address: dreyne2@uic.edu. Thank you in advance for your time and effort, and I look forward to talking with you soon.

(If the response is "No," then respond:) Thank you for your consideration. Have a nice day and good-bye.

3. Consent Language

For those who have verbally agreed to participate as key informants, the previous e-mail that was sent (which includes the text presented above) will be re-sent, and the following text will be included in the body of the second e-mail (i.e., the one which “introduces” the re-sent e-mail):

Hello. Thank you so much for agreeing to participate in my doctoral research project. In the forwarded e-mail below, you can again read about the project’s purpose and the request I am making of you.

What I would like you to do is to read over the following statements related to consent. After reading them, I need you to respond to this email, indicating that you have read and understand all of these statements and that you are willing to participate in this project:

- *I am aware that this project is being completed by a student at the University of Illinois at Chicago School of Public Health (UIC SPH).*
- *My participation in this project entails completing a semi-structured interview, which will be recorded and transcribed.*
- *All of my responses are confidential, as is my identity.*
- *I understand that there are no foreseeable risks to me from participating in this project, unless my reflection during the interview in some way imposes a risk.*
- *I understand that the benefits of this project include at least the following: academic progress for the student; critical insights for the California Stroke Registry/California Coverdell Program; and greater secondary prevention efforts for all who could be impacted by stroke.*
- *If I have any questions or concerns about this project or my participation in it, I am free to contact Dave Reynen by phone, at 916-606-7768, or via e-mail, using this address: dreyne2@uic.edu.*
- *If I have any questions about research participants’ rights and/or research-related injuries or adverse effects, I can contact the UIC SPH Office for the Protection of Research Subjects by phone, at 1-866-789-6215, or via e-mail, using this address: uicirb@uic.edu.*

*If you agree to participate in this study as a key informant, please respond to this e-mail and include this statement in your response: **“I have read and understand what participation in your dissertation research project entails, and I agree to participate.”***

Thanks again, and I’ll look forward to hearing back from you.

Sincerely,

*David J. Reynen, MA, MPPA, MPH, CPH
DrPH Candidate, UIC SPH*

4. Interview Guide/Questions for Phase II and III

Phase II

For the interviews conducted in Phase II of this study, the following serves as a guide, provided informed consent has been secured:

Introduction

Thank you for agreeing to participate in this project focused on broadening the secondary prevention efforts of the California Stroke Registry/California Coverdell Program (which will be called “the registry” from here on out). The project is currently in Phase II, which is focused on learning about different influences on the current work of the registry.

Your knowledge regarding the program’s operational state (that is, how it currently functions on a daily basis) and the factors that have given rise to it will be invaluable, as I seek to learn about working more broadly along the secondary prevention spectrum – that is to say, with a greater emphasis on working in the pre-hospital, or EMS, setting.

Specifically, I will be asking what you know about contextual factors and programmatic challenges, as well as the idea of change – all related to how the registry currently functions.

Our interview will be recorded and the information you provide will be used in my doctoral research project. What you tell me will be kept confidential and no names will be used in any of the reporting I do. I anticipate that we will be finished with the interview in less than an hour.

So – let’s begin...

Setting the Stage

First, I wanted to share with you that preliminary findings from earlier work in this project suggest that the registry has focused its efforts almost exclusively in the in-hospital setting...to the near exclusion of the pre-hospital, or EMS, setting. Based upon your knowledge of the registry, I am wondering about your thoughts on that.

Does this suggestion of being focused more on the hospitals than on the EMS agencies seem reasonable to you? Do you feel like the registry has, indeed, focused more on the hospitals?

(If “Yes”☺ Can you provide an example of any programmatic decisions or activities which would support this idea...that is, that the focus has been on the hospitals, much more than on the EMS agencies?

(If “No”☺ Why doesn’t this suggestion seem reasonable to you? Do you believe that the focus is balanced? ...or skewed in the other direction (i.e., towards EMS)? What makes you think that?

The Constructs

Now I would like to ask you about the factors that have been influential in bringing about the registry's current operational state – that is to say, how it now exists and functions as it does. I am particularly interested in certain types of factors – so I'll be asking specific questions about those.

[Part A: Contextual Factors]

First, I'm interested in hearing from you about the contextual factors – that is, those things that are “part of the landscape” for the registry and likely have shaped its experiences, both past and present. Often, but not always, these contextual factors tend to be more extrinsic to the registry.

Construct	Questions
<i>Contextual: HISTORY</i>	<p><i>Generally speaking, in what ways – or to what extent – do you feel a program's history can influence its present state...that is – how it exists, now...how it functions, now?</i></p> <p><i>With respect to the registry, can you tell me about how a specific event or activity from the registry's history (maybe a particular meeting or an important decision) may have been impactful on its current state...and, if so, how it was impactful?</i></p> <p><i>Are you aware of any situations or events related to the registry's staffing and/or its leadership historically –or, perhaps, any past decisions made related to its staffing and/or its leadership – that have affected its current state?</i></p> <p><i>Do you know if the registry's focus on secondary prevention has been in alignment with the larger organization's prevailing notion of prevention? Do you have any thoughts you can share on whether this “fit” (or lack thereof) has, in any way, had an impact on the registry's current state?</i></p> <p><i>Is there anything more about the registry's history that you think may have helped to shape the way it operates now?</i></p>
<i>Contextual: STRUCTURE</i>	<p><i>While still thinking about contextual factors... I'd like us to talk about the registry's structure...</i></p> <p><i>In general terms, would you please describe how a program's organizational structure...or, even, its placement within the larger organization...can influence how it operates?</i></p> <p><i>Now – getting more specific: Would you please tell me about how the larger organizational structure, in which the registry resides, may have been impactful in bringing about the registry's current state?</i></p> <p><i>Prompt: Do you have a specific example you can share – perhaps one related to the hierarchical structure of the larger organization?</i></p> <p><i>Prompt: Maybe something related to the “silos” within the larger organization?</i></p> <p><i>Are you able to provide an example of how the larger organizational structure has influenced the registry's efficiency?</i></p> <p><i>Prompt: Perhaps decision-making processes –that have impacted the registry's operations – have been inefficient...can you speak to that?</i></p>

<p>STRUCTURE <i>continued...</i></p>	<p><i>Prompt: Perhaps certain rules or regulations – or even conventions...that is, how things are done – have led to inefficiencies or other sorts of problems...can you talk about that?</i></p> <p><i>Is there anything else about the registry's structure that you think may have helped shape its current operational state?</i></p>
<p>Contextual: CULTURE</p>	<p><i>While still thinking about contextual factors... I'd like us to talk about culture...</i></p> <p><i>I'm interested in hearing your thoughts, in general, about how the particular culture which surrounds or supports a program can influence how that program functions...can you speak to that idea?</i></p> <p><i>Now, in terms of the registry: Are you aware of any aspects of the larger organizational culture – such as having or not having a long-term strategic plan...or making key decisions a certain way...or something else – that have had an impact in determining the registry's current state?</i></p> <p><i>Prompt: For example, in making its decisions, a program staff might look to the larger organization's strategic plan for guidance...are you aware if that has been happening – or not – in the registry? What can you tell me about that?</i></p> <p><i>Prompt: Can you tell me how decisions typically have been made related to the work of the registry – and whether that decision-making has been imposed on the registry (e.g., in a “top-down” fashion)...or occurring from within the registry?</i></p> <p><i>Next, can you tell me about the fostering of innovation within a program...and how that trait might affect how that program functions? Can you speak to that?</i></p> <p><i>Can you provide me with any examples of innovation within the registry – particularly an example of an innovation that has (for better or worse) impacted the registry's current operational state?</i></p> <p><i>Is there anything else about the registry's culture that you think may have helped shape its current operational state?</i></p>
<p>Contextual: REACH</p>	<p><i>Finally, while still thinking about contextual factors... I'd like us to talk about the registry's “reach” across the State, with respect to its clinical partners, in both the pre-hospital and in-hospital settings.</i></p> <p><i>Can you tell me about how the registry's “reach” may have been impactful with regard to how it functions? Perhaps there is something about the ability of the registry itself to reach out...or about the State's distribution of clinical providers...that has helped or hindered the registry in its work. What do you know about that?</i></p> <p><i>To what extent would you say that the “reach” of the registry has been in line with its original vision?</i></p> <p><i>Prompt: Do you feel that the “reach” is skewed in any way across the clinical partners – and if so, how?</i></p> <p><i>(Possible – that is, if “reach” is characterized as skewed) Prompt: How might that skewed “reach” impact the how the registry functions?</i></p>

REACH <i>continued...</i>	<i>Is there anything else about the registry's "reach" that you think may have helped shape its current operational state?</i>
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[Part B: Factors related to Challenges]

Next, I am interested in knowing about program challenges as well. Unlike the contextual factors we just discussed, these kinds of things, often-times, tend to be more intrinsic. These are things that sort of "exist" within the registry, given its configuration, its composition, and its capacities.

In asking you this next set of questions, then, I am interested in hearing from you about different kinds of challenges that have been part of the registry's experience and have impacted its development and ongoing operations.

Construct	Questions
Challenges: Constraints	<p><i>Generally speaking, what are the typical kinds of constraints that programs like the registry have to deal with, in working to meet established program goals? In your experience, how challenging – or limiting – are these kinds of constraints?</i></p> <p><i>Now, in terms of the registry: Can you provide me with an example of a constraint or limitation of the registry that has had an effect on its past and/or current operations? How has this limitation been impactful?</i></p> <p><i>Prompt: Perhaps you are aware of a fiscal or budget-related constraint (in the program or in a partner organization)... What can you tell me about that?</i></p> <p><i>Prompt: Are you aware of any limitations the registry has with respect to its decision-making processes...and if, so, can you share what you know about that?</i></p> <p><i>Prompt: Perhaps you are aware of a staffing constraint (in the program or in a partner organization)... What can you tell me about that?</i></p> <p><i>Prompt: Perhaps you can talk about the skill sets that the program staff members have (and/or the partners have)... Can you describe if or how that collection of skills has been impactful on the program's operations?</i></p> <p><i>Are there any other limitations registry has that you think may have had an impact on its current operational state?</i></p> <p><i>If so, how have these limitations affected the registry?</i></p>
Challenges: Focus	<p><i>While still thinking about registry challenges... I'd like to talk with you about focus.</i></p> <p><i>Generally speaking, how common is it for programs like the registry to lose focus – and begin to veer off course?</i></p> <p><i>How does this loss of focus typically impact a program?</i></p> <p><i>With respect to the registry's work within the pre-hospital and in-hospital clinical settings, I am hoping you can tell me how the registry has focused its efforts...</i></p>

Challenges: Focus continued...	<p><i>Has the focus been balanced across these two clinical settings...or has there been a heavier emphasis in one of the settings? Can you tell me why this is so?</i></p> <p><i>Can you provide an example which illustrates how the registry's focus has driven its workload?</i></p> <p><i>Prompt: Perhaps related to the recruitment efforts...</i> <i>Prompt: Perhaps related to the data collection and reporting...</i> <i>Prompt: Perhaps related to the performance measures...</i> <i>Prompt: Perhaps related to the quality improvement efforts...</i></p> <p><i>Is there anything else you can share about the registry's focus and how it may have had an impact on the current operational state?</i></p>
Challenges: Approach	<p><i>Finally, while still thinking about registry challenges... I'd like to talk with you about the registry's usual approach to making decisions and taking action.</i></p> <p><i>In general terms, can you share with me a few of your thoughts on the difference between conducting long-term strategic planning and carrying out an incremental approach – that is, for program planning purposes?</i></p> <p><i>Moving now to the registry: Can you describe the typical way in which strategic decisions have been made within the registry – for example...how the staff settled on a recruitment strategy or developed an evaluation plan?</i></p> <p><i>Prompt: Would you say that the registry's decision-making processes are driven by long-range planning efforts...or do they occur, instead, via an incremental approach – wherein the next decision builds upon the last one?</i></p> <p><i>Then: Can you describe an example of how a decision was reached in this way (i.e., driven by long-range planning efforts or via an incremental approach)?</i></p> <p><i>Is there anything else you can share about the registry's approach to decision-making and how this approach may have had an impact on how the work of the registry is conducted?</i></p>

[Part C: Factors related to Beliefs]

Finally, beyond the operational context and challenges we have discussed already, I am interested in learning what you know about change-related beliefs – within the context of the registry. In particular, I'm interested in hearing any information you can share about how the registry's staff members and/or the program stakeholders feel about the registry's interest in...and/or ability to change.

Construct	Questions
Beliefs: Need to Change	<p><i>In general terms, can you please share your thoughts on how change-related beliefs might influence the day-to-day operations of a program like the registry?</i></p> <p><i>Now – specific to the registry: Do you think that the registry staff members and/or stakeholders believe that the registry should change in some way? What can you tell me about their wishes for change?</i></p>

<p>Beliefs: Need to Change continued...</p>	<p><i>Prompt: What kinds of things do the staff members and/or stakeholders believe...in terms of the registry’s potential need to change?</i></p> <p><i>Then: How might that kind of a belief impact the way the registry functions?</i></p> <p><i>Is there more that you can share with me about the beliefs of the registry’s staff members and/or stakeholders, with respect to change?</i></p> <p><i>Can you think of anything else that might suggest a belief that the registry ought to change?</i></p>
<p>Beliefs: Can Change</p>	<p><i>Finally, while still thinking about beliefs... I’d like to talk about whether the registry can, indeed, change...</i></p> <p><i>Assuming that there is a held belief that the registry should change in some way (as we just discussed), do you think that there is also a belief that it can actually change?</i></p> <p><i>What can you tell me about that belief?</i></p> <p><i>Prompt: How large of a change do you think the staff members and/or stakeholders believe the registry can undertake – would you say a slight tweak? Or a modest change? Or more of a “game-changer” type of change?</i></p> <p><i>Prompt: What sorts of resources might the registry have that could enable it to change?</i></p> <p><i>In what way or ways do you think a belief in the ability to change might impact the registry’s operational state?</i></p>

Wrap Up

What other insights can you share related to those factors (either already mentioned or not) that have given rise to the registry’s current, arguably narrow operational state?

Is there anything else you would like to share?

Closing

I think that’s it for my questions. I want to thank you so much for your time. Your answers have been very informative, and I greatly appreciate your willingness to spend this time talking with me.

Again, please be assured that all you have shared with me will be kept anonymous.

Thank you!

Phase III

For the interviews conducted in Phase III of this study, the following serves as a guide, provided informed consent has been secured:

Introduction

Thank you for agreeing to participate in this project focused on broadening the secondary prevention efforts of the California Stroke Registry/California Coverdell Program (which will be called “the registry” from here on out). The project is presently in Phase III, which is focused on learning ways the registry can expand its current prevention efforts...particularly by working to a much greater extent within the pre-hospital, or EMS, setting.

Your knowledge regarding potential changes the registry should consider making – in order to broaden its ongoing secondary prevention efforts – will be very helpful in shaping the future of the program.

During this interview, then, I will be asking you what you know about potential programmatic changes, which, if properly implemented, could enable the program to work more broadly across the secondary prevention spectrum – that is, across both the pre-hospital and in-hospital clinical settings.

Our interview will be recorded and the information you provide will be used in my doctoral research project. What you tell me will be kept confidential and no names will be used in any of the reporting I do. I anticipate that we will be finished with the interview in under an hour.

So – let’s begin...

Setting the Stage

Before we address your specific ideas for change, however, I would like to hear your thoughts, in general, about the kinds of activities and/or approaches that can enable a registry to work broadly across the secondary prevention spectrum – that is, in both the in-hospital and pre-hospital settings.

Based upon your experience, can you please share some of your thoughts and ideas on what kinds of things work well, generally speaking, to enable this kind of broad-based prevention work? (Prompts here may include things like working with partners, using technology, having well-defined decision-making processes, et cetera.)

Thank you for that. Is there anything else you would like to add in this regard, before we turn to the specific questions?

Okay – thank you for your general comments. Now, I’d like us to talk about some specific ideas for change...

The Constructs

Earlier findings from this study have suggested that our registry needs to broaden its prevention efforts, so that much more effort is going into the pre-hospital setting...as compared to what has been happening thus far. Because of your knowledge and experience, I'll be asking you about specific things the registry might consider doing, in order to achieve this objective.

Additionally, as we come to the end of the interview, I will be asking you some questions about how a future change process might be impacted by current circumstances and situations.

Construct	Questions
<p>Part a</p> <p><i>First, on the subject of change, I'm hoping you can share with me your thoughts on using current resources in new ways.</i></p> <p><i>In your work, have you had occasion to change how you've used your existing resources? If so, can you share what worked well? How about something that didn't work well?</i></p> <p>Present Resources: Used in New Ways</p> <p><i>Now – in thinking about the work of a State stroke registry: Can you provide an example of an innovative way to utilize existing registry resources, in order to expand the registry's current scope?</i></p> <p>Technology</p> <p><i>Prompt: Can you please describe an innovation using technology? (Perhaps: Enabling automated reporting from a current data system...)</i></p> <p>Staff Resources</p> <p><i>Prompt: What about using current staff resources in new ways? (Perhaps: Redefining roles of current staff members to build on individual strengths...)</i></p> <p>Partnerships</p> <p><i>Prompt: With which organizations has your program partnered? What roles have these program partners served? How have these experiences been, overall?</i></p> <p><i>Then: Can you provide an example of how an existing partnership might be put to use in a new and innovative way? (Perhaps: Transferring a workload from a staff member to a partner...)</i></p> <p><i>Can you think of any other ideas related to the use of current resources in new and different ways?</i></p>	
<p>Part b</p> <p>New Practices, New Resources</p> <p><i>Next, I'd like to hear your thoughts on acquiring and using new resources and/or practices. Generally speaking, what has been your experience with this? If you've been successful in securing and using new resources and/or practices, please tell me about that... How did you accomplish this?</i></p> <p><i>Now I have some specific questions related to making changes in the registry. In asking you these questions, I am hoping to hear about ideas for change.</i></p>	

<p>Knowledge Management</p>	<p><i>First, I'd like to talk about data management and sharing. Based on your experiences in your program, can you speak to some innovative ways to manage and share data – perhaps something that is done in your program?</i></p> <p><i>In our registry, we've been wholly reliant on the Get With The Guidelines in-hospital data, though we have been trying to integrate data from other hospital systems, as well as from our EMS providers. To date, however, we haven't made much progress.</i></p> <p><i>Based on your understanding of the management and use of stroke data, can you please suggest some recommendations for change, related to how the California Stroke Registry collects and uses stroke data?</i></p> <p><i>Prompt: Can you suggest some innovative ways to more broadly use and share data – in order to carry out the work of the registry? (Perhaps: Utilizing a new data system or new ways of using and/or sharing the data...)</i></p>
<p>Cross-functional Teams</p>	<p><i>Next, I'd like to talk about registry staff and partnerships – and how to best utilize people's skills and schedules. About how many people (full-time and part-time) are employed in your program? And what about your partnerships... About how many people (again, full-time and part-time) from these partner organizations carry out some of the work of your program?</i></p> <p><i>In your program do you use cross-functional teams – that is, special, purposeful teams comprised of program staff and partners, established to meet certain program goals? If so, can you please describe any successes or challenges one of these teams has had?</i></p> <p><i>In our registry, two of us who are State Health Department employees have carried out the bulk of our scope of work, with some assistance being provided through various programmatic partnerships – including with a university and with the American Heart Association/American Stroke Association. This assistance, however, has had to be directed by the State staff, rather than delegated, which, one could argue, hasn't been the most efficient model.</i></p> <p><i>Based on your understanding of program staffing and partnerships, can you please suggest some recommendations for change, related to how the California stroke registry utilizes its available human resources? And, in your response, please give thought to the utilization of both those who work for the registry and those who work for its partner organizations.</i></p> <p><i>Prompt: What are your thoughts on having the registry develop and use cross-functional teams – particularly in collaboration with its partner organizations?</i></p> <p><i>Prompt: In what ways (if any) might the use of cross-functional teams benefit the future work of the registry?</i></p>
<p>Potential for Synergy</p>	<p><i>Can you think of ways in which these two ideas – that is, the sharing of data and the use of teams – could be implemented together?</i></p>

Part b continued...	<i>Do have any other ideas to share on the use of new resources and/or new practices?</i>
Part c <i>Impact (on a change process) of:</i> <i>Operational State</i> <i>Stakeholders' Beliefs</i>	<i>Finally, while still thinking about entering into a change process... I'd like to talk with you about facilitators and barriers to undergoing a change process.</i> <i>In your experience, what sorts of barriers might a program encounter when attempting to enact real change? Can you provide a specific example of a barrier and how it could impact such a process?</i> <i>In what ways, if any, do you think the registry's current purportedly sub-par operational state might be impactful on a change process in the future?</i> <i>Preliminary findings from earlier in this project suggest that change-related beliefs are influential in how the program has been operating.</i> <i>What can you tell me, if anything, about how these kinds of beliefs might impact the registry's ability to implement some of these recommendations you have made?</i>

Wrap Up

What other insights can you share related to the prospect of the registry undergoing a future change process?

Is there anything else you would like to share?

Closing

I think that's it for my questions. I want to thank you so much for your time. Your answers have been very informative, and I greatly appreciate your willingness to spend this time talking with me.

Again, please be assured that all you have shared with me will be kept anonymous.

Thank you!

Appendix III: The Code Book (by Phase)

Approach to Coding:

- Code the whole sentence in which a key word or phrase is found.
- A sentence can be categorized under more than one code.
- All codes and all sub-codes (i.e., from all three phases) are available to be used for coding all source documents (i.e., the documents reviewed in Phase I and the verbatim transcripts from the interviews conducted in Phases II and III).

For Phase I (Document Reviews, primarily)

CONSTRUCT	INSTRUCTIONS
Recruitment – this refers to the action of recruiting clinical providers	<p>Use this collection of codes for all mentions of recruitment-related activities (e.g., phone calls, letters, webinars, and follow-ups), whether initiated by registry staff or by others.</p> <p>While coding:</p> <ul style="list-style-type: none"> • Differentiate in the coding between the recruitment of LEMSAs and hospitals. • Note <i>actual</i> activities versus <i>anticipated</i> activities.
<p><i>While defining just two (as examples), these are the codes and sub-codes (shown in the List on the last page):</i> PI_1m_Recruit (i.e., phase 1, measure 1, Recruitment); PI_1s_Recruit_Hosp_Plan (i.e., phase 1 sub-measure 1, under recruitment: Planned Recruitment of Hospitals); PI_1s_Recruit_Hosp_Real; PI_1s_Recruit_LEMSA_Plan; PI_1s_Recruit_LEMSA_Real.</p>	
Infrastructure – this refers to the use of the data system, the establishment of performance measures; and the use of human resources	<p>Use this collection of codes for all mentions of the development and use of registry infrastructure.</p> <p>Sub-codes for specific types of infrastructure are necessary, including codes for:</p> <ul style="list-style-type: none"> • the data system • performance measures • human resources <p>While coding:</p> <ul style="list-style-type: none"> • Differentiate in the coding between the LEMSAs and hospital settings. • Note <i>actual</i> activities versus <i>anticipated</i> activities.
<p><i>While defining just one (as an example), these are the codes and sub-codes (shown in the List on the last page):</i> PI_2m_Infrast (i.e., phase 1, measure 2, Infrastructure); PI_2s_Infrast_DataSys_Hosp_Plan; PI_2s_Infrast_DataSys_Hosp_Real; PI_2s_Infrast_DataSys_LEMSA_Plan; PI_2s_Infrast_DataSys_LEMSA_Real; PI_2s_Infrast_PerfMeas_Hosp_Plan; PI_2s_Infrast_PerfMeas_Hosp_Real; PI_2s_Infrast_PerfMeas_LEMSA_Plan; PI_2s_Infrast_PerfMeas_LEMSA_Real; PI_2s_Infrast_Staffing_Hosp_Plan; PI_2s_Infrast_Staffing_Hosp_Real; PI_2s_Infrast_Staffing_LEMSA_Plan; PI_2s_Infrast_Staffing_LEMSA_Real.</p>	

Phase I continued on next page...

Phase I (Document Reviews)

Continued...

Partnerships – this refers to the ways in which the program has formed and used partnerships	<p>Use this collection of codes for all mentions of establishing and interacting with registry partners, either negative or positive. Registry partners include ASA/AHA, the California Cancer Registry (CCR), the CDC, and others, but not the LEMSAs or hospitals (as they are the clinical providers).</p> <p>While coding:</p> <ul style="list-style-type: none">Consider the negative and positive events/situations for each partnership.
<p><i>These are the codes and sub-codes (shown in the List on the last page):</i> PI_3m_Partner; PI_3s_Partner_AHAASA_Neg; PI_3s_Partner_AHAASA_Pos; PI_3s_Partner_CCR_Neg; PI_3s_Partner_CCR_Pos; PI_3s_Partner_CDC_Neg; PI_3s_Partner_CDC_Pos; PI_3s_Partner_Other_Neg; PI_3s_Partner_Other_Pos.</p>	
QI Initiatives – this refers to Quality Improvement work, jointly undertaken by the program and the providers	<p>Use this collection of codes for all mentions of quality-improvement-related activities – that is, any mention of providing baseline data, designing an intervention, or (jointly) executing an intervention (e.g., using PDSA, best practices, et cetera).</p> <p>While coding:</p> <ul style="list-style-type: none">Differentiate in the coding between the QI initiatives for LEMSAs and for hospitals.
<p><i>These are the codes and sub-codes (shown in the List on the last page):</i> PI_4m_QI; PI_4s_QI_BaselineData_Hosp; PI_4s_QI_BaselineData_LEMSA; PI_4s_QI_Design_Hosp; PI_4s_QI_Design_LEMSA; PI_4s_QI_Initiative_Hosp; PI_4s_QI_Initiative_LEMSA.</p>	

Phase II starts on next page...

For Phase II (primary: Key Informant Interviews; secondary: Document Reviews)

Operational Context

CONSTRUCT	INSTRUCTIONS
History – this refers to those events/actions in the program’s past which, in part, have brought about the current operational state	Use this collection of codes for all mentions of historical events and actions that are described as being instrumental in bringing about the registry’s current operational state. Examples include decisions, actions, and events related to staffing – perhaps resulting in vacancies, instability, and turn-over; historical approaches and trends related to prevention – perhaps suggesting misalignment for the registry; and changes in higher-level business operations – perhaps related to contracting or senior management.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_1m_Cont; PII_1s_ContA-Hx; PII_1s_ContA-Hx_Decisions; PII_1s_ContA-Hx_Staffing; PII_1s_ContA-Hx_Trends-in-Prev.	
Structure – this refers to the program make-up/its “environs” and how it functions (as a result of these traits)	Use this collection of codes for all mentions of structural components and themes, important to the shaping of the registry’s operational state. Structural examples include events such as hierarchical stalls; traits such as inefficient decision-making processes; and barriers such as prohibitive rules.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_1m_Cont; PII_1s_ContB-Struct; PII_1s_ContB-Struct_Hierarchy; PII_1s_ContB-Struct_Processes; PII_1s_ContB-Struct_Rules.	
Culture – this refers to values and behaviors which describe the working environment	Use this collection of codes for all mentions of cultural values and behaviors which are referenced in connection with (determining) the registry’s current operational state. Examples include the “culture” of planning (i.e., long-term strategic planning or short-term); the “culture” of decision-making (i.e., top-down or bottom-up); and the “culture” of innovation (i.e., able to work creatively or not)
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_1m_Cont; PII_1s_ContC-Cult; PII_1s_ContC-Cult_Planning; PII_1s_ContC-Cult_Processes; PII_1s_ContC-Cult_Promotes-Innov.	
Reach – this refers to the extent to which the program is in operation with its clinical partners across the state (i.e., how far reaching it is...)	Use this collection of codes for all mentions of how the registry’s efforts to extend its operations across the state – that is, to collaborate with LEMSAs and hospitals – has had an impact on its current operational state. Examples for reach include information on the proportion of the state’s LEMSAs participating in the registry; the proportion of the state’s hospitals participating in the registry; the proportion of the state’s population being served by the registry; and gaps in service.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_1m_Cont; PII_1s_ContD-Reach; PII_1s_ContD-Reach_Hosp; PII_1s_ContD-Reach_LEMSA; PII_1s_ContD-Reach_Service-Gaps.	

Phase II continued on next page...

Phase II continuing...
Operational Challenges

Constraints – this refers to those things within the program that hamper its ability to achieve its mission	Use this collection of codes for all mentions of constraints that have had a bearing on the registry’s current operational state. Examples include fiscal constraints (e.g., making/receiving cuts to the budget); staffing limitations (e.g., dealing with a lack of capacity/expertise); and locus of control issues (having no “say” in a particular issue/matter).
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_2m_Chall; PII_2s_ChallA-Constr; PII_2s_ChallA-Constr_Fiscal; PII_2s_ChallA-Constr_HR; PII_2s_ChallA-Constr_LOC.	
Focus – this refers to the program’s emphasis a particular aspect of its workload (in this case, having a differential focus, relative to the two clinical settings).	Use this collection of codes for all mentions of how the registry’s focus (i.e., on one or the other clinical setting) may have impacted its current operational state. Examples include the breadth of the recruitment efforts (i.e., it may be that more time was spent recruiting hospitals than LEMSAs); the sources of data (i.e., it may be that data have only been collected in the in-hospital setting); the establishment of performance measures (i.e., it may be that only in-hospital performance measures were established).
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_2m_Chall; PII_2s_ChallB-Focus; PII_2s_ChallB-Focus_Data; PII_2s_ChallB-Focus_PerfMeas; PII_2s_ChallB-Focus_Recruit.	
Approach – this refers to the processes that are utilized in order to bring about change or move forward in some aspect of the program.	Use this collection of codes for all mentions of how the registry has approached (or typically approaches) some kind of a change or change process. Examples include following a long-term strategic plan; using some other defined process (for entering into a change process), in the absence of a long-term strategic plan; and utilizing an incremental approach (i.e., via multiple, consecutive “small steps,” simply building on – while leaving mostly intact – that which already exists).
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_2m_Chall; PII_2s_ChallC-Approach; PII_2s_ChallC-Approach_LT-Strat-Plan; PII_2s_ChallC-Approach_Other-Process; PII_2s_ChallC-Approach_Utilize-IncremApp.	

Phase II continued on next page...

Phase II continuing...

Beliefs

<p>Need to Change – this refers to the beliefs of the stakeholders with regard to the program’s need to change (i.e., their thoughts as to whether change is even necessary...)</p>	<p>Use this collection of codes for all mentions of an expressed need to make a change in the status quo (i.e., as felt by the various program stakeholders). Examples of this include a stated concern or report that program goals have been or are going unmet; an expressed sense that the current program functioning/operational state is unacceptable; and an outright suggestion that change must occur.</p>
<p><i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_3m_Beliefs; PII_3s_BeliefsA-N2Change; PII_3s_BeliefsA-N2Change_Goals-Unmet; PII_3s_BeliefsA-N2Change_Poor-Operat.</p>	
<p>Ability to Change – this refers to the beliefs of the stakeholders with regard to the program’s ability to change (given a belief that change should occur)</p>	<p>Use this collection of codes for all mentions of the program’s ability to enter into (and complete) a change process (i.e., given that it should embark upon such a process). Examples include statements suggesting the presence of a feeling of dissatisfaction with the status quo/a motivation (or readiness) to make change happen; a plan for change; a collection of resources available for executing such a plan; and a support system for the change process.</p>
<p><i>These are the codes and sub-codes (shown in the List on the last page):</i> PII_3m_Beliefs; PII_3s_BeliefsB-A2Change; PII_3s_BeliefsB-A2Change_Is-Ready; PII_3s_BeliefsB-A2Change_Plan; PII_3s_BeliefsB-A2Change_Resources.</p>	

Phase III starts on next page...

For Phase III (Key Informant Interviews)
Suggestions for Change

Using Existing Resources in New Ways

CONSTRUCT	INSTRUCTIONS
Technology –using the existing technology to create efficiencies (e.g., using technology to free up already-dedicated staff resources)	Use this collection of codes for all mentions of new and innovative uses of existing technology. Examples include creating list-serves (in order to enhance communication); automating reporting of summary data (in order to facilitate QI); and hosting webinars (in order to convene and share with partners and providers).
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_1m_NewWays; PIII_1s_NewWaysA-Tech; PIII_1s_NewWaysA-Tech_Enhance-Comm; PIII_1s_NewWaysA-Tech_Report-Data; PIII_1s_NewWaysA-Tech_Share-w-Parters.	
Staff Resources – redirecting staff, e.g., to fill in existing gaps	Use this collection of codes for all mentions of suggestions for redirecting current staff members (in order to create positive changes). Examples include clarifying roles; redefining roles; and filling existing gaps (in terms of specific duties that must be performed).
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_1m_NewWays; PIII_1s_NewWaysB-Staff; PIII_1s_NewWaysB-Staff_Define-Roles; PIII_1s_NewWaysB-Staff_Fill-Gaps.	
Partnerships – utilizing the program partners to achieve program goals	Use this collection of codes for all mentions of new and innovative ways to collaborate with existing registry partners (in order to create positive changes). Examples include transferring ongoing work from current program staff to program partners; and utilizing heretofore unused (but existing) resources, available from registry partners.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_1m_NewWays; PIII_1s_NewWaysC-Partner; PIII_1s_NewWaysC-Partner_Transfer-Work; PIII_1s_NewWaysC-Partner_Utilize-Svcs.	

Phase III continued on next page...

For Phase III (Key Informant Interviews)
Suggestions for Change
Continued...

Acquiring/Utilizing New Activities/Resources

Knowledge Management – being able to capture/manage/use data to facilitate goal and objective achievement	Use this collection of codes for all mentions of change (i.e., new practices, new resources), related to knowledge management – the capture, management, and use of data. Examples include implementing data system enhancements; utilizing a new data system; and using the data from the updated or new system more broadly.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_2m_NewStuff; PIII_2s_NewStuffA-KM; PIII_2s_NewStuffA-KM_Enhance-System; PIII_2s_NewStuffA-KM_Replace-System; PIII_2s_NewStuffA-KM_Uses-of-Data.	
Cross-functional Teams – along with partners, creating/using teams focused on particular shared goals and objectives (G&O)	Use this collection of codes for all mentions of change (i.e., new practices, new resources), related to the development and use of cross-functional teams. Examples include identifying common goals and objectives (for such teams to meet); defining roles (for meeting those goals and objectives); and assigning those defined roles to members of the cross-functional teams.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_2m_NewStuff; PIII_2s_NewStuffB-CFT; PIII_2s_NewStuffB-CFT_ID-Goals; PIII_2s_NewStuffB-CFT_ID-Roles; PIII_2s_NewStuffB-CFT_Roles-Assigned.	
The Potential for Synergy – within and across teams, sharing data	Use this collection of codes for all mentions of change (i.e., new practices, new resources), related to the potential for synergy between knowledge management and the use of cross-functional teams. A general example is the sharing of data across the membership of a given cross-functional team.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_2m_NewStuff; PIII_2s_NewStuffC-Synergy; PIII_2s_NewStuffC-Synergy_Data-Sharing.	

Phase III continued on next page...

For Phase III (Key Informant Interviews)

Suggestions for Change

Continued...

Impact on a Potential Change Process...

Operational State Impact – feeling the impact (of the current state) on a possible change process	Use this collection of codes for all mentions of how a potential change process might be impacted by the registry's current operational state. Examples include expressed doubt (regarding the prospect of successfully undergoing positive change), given the program's current state; and shared stories of prior, unsuccessful attempts (by the program) to undergo positive change.
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_3m_Impact-on-Change; PIII_3s_Impact-on-ChangeA-Oper-State; PIII_3s_Impact-on-ChangeA-Oper-State_Doubt; PIII_3s_Impact-on-ChangeA-Oper-State_Fail.	
Stakeholders' Beliefs Impact – feeling the impact (of the beliefs of the stakeholders) on a possible change process	Use this collection of codes for all mentions of how a potential change process might be impacted by the registry stakeholders' change-related beliefs. Examples include credence being given to the stakeholders' beliefs and the resultant impact(s); and shared examples of expressed stakeholders' opinions impacting program progress (for better or worse).
<i>These are the codes and sub-codes (shown in the List on the last page):</i> PIII_3m_Impact-on-Change; PIII_3s_Impact-on-ChangeB-Beliefs; PIII_3s_Impact-on-ChangeB-Beliefs_Credence; PIII_3s_Impact-on-ChangeB-Beliefs_Examples.	

All codes are listed on the next page...

Lists of Codes (and sub-codes) by Phase:

PHASE I	PHASE II	PHASE III
PI_1m_Recruit PI_1s_Recruit_Hosp_Plan PI_1s_Recruit_Hosp_Real PI_1s_Recruit_LEMSA_Plan PI_1s_Recruit_LEMSA_Real	P1I_1m_Cont <i>P1I_1s_ContA-Hx</i> P1I_1s_ContA-Hx_Decisions P1I_1s_ContA-Hx_Staffing P1I_1s_ContA-Hx_Trends-in-Prev	P1II_1m_NewWays <i>P1II_1s_NewWaysA-Tech</i> P1II_1s_NewWaysA-Tech_Enhance-Comm P1II_1s_NewWaysA-Tech_Report-Data P1II_1s_NewWaysA-Tech_Share-w-Parters
PI_2m_Infrast PI_2s_Infrast_DataSys_Hosp_Plan PI_2s_Infrast_DataSys_Hosp_Real PI_2s_Infrast_DataSys_LEMSA_Plan PI_2s_Infrast_DataSys_LEMSA_Real PI_2s_Infrast_PerfMeas_Hosp_Plan PI_2s_Infrast_PerfMeas_Hosp_Real PI_2s_Infrast_PerfMeas_LEMSA_Plan PI_2s_Infrast_PerfMeas_LEMSA_Real PI_2s_Infrast_Staffing_Hosp_Plan PI_2s_Infrast_Staffing_Hosp_Real PI_2s_Infrast_Staffing_LEMSA_Plan PI_2s_Infrast_Staffing_LEMSA_Real	<i>P1I_1s_ContB-Struct</i> P1I_1s_ContB-Struct_Hierarch P1I_1s_ContB-Struct_Processes P1I_1s_ContB-Struct_Rules <i>P1I_1s_ContC-Cult</i> P1I_1s_ContC-Cult_Planning P1I_1s_ContC-Cult_Processes P1I_1s_ContC-Cult_Promotes-Innov <i>P1I_1s_ContD-Reach</i> P1I_1s_ContD-Reach_Hosp P1I_1s_ContD-Reach_LEMSA P1I_1s_ContD-Reach_Service-Gaps	<i>P1II_1s_NewWaysB-Staff</i> P1II_1s_NewWaysB-Staff_Define-Roles P1II_1s_NewWaysB-Staff_Fill-Gaps <i>P1II_1s_NewWaysC-Partner</i> P1II_1s_NewWaysC-Partner_Transfer-Work P1II_1s_NewWaysC-Partner_Utilize-Svcs
PI_3m_Partner PI_3s_Partner_AHAASA_Neg PI_3s_Partner_AHAASA_Pos PI_3s_Partner_CCR_Neg PI_3s_Partner_CCR_Pos PI_3s_Partner_CDC_Neg PI_3s_Partner_CDC_Pos PI_3s_Partner_Other_Neg PI_3s_Partner_Other_Pos	P1I_2m_Chall <i>P1I_2s_ChallA-Constr</i> P1I_2s_ChallA-Constr_Fiscal P1I_2s_ChallA-Constr_HR P1I_2s_ChallA-Constr_LOC <i>P1I_2s_ChallB-Focus</i> P1I_2s_ChallB-Focus_Data P1I_2s_ChallB-Focus_PerfMeas P1I_2s_ChallB-Focus_Recruit <i>P1I_2s_ChallC-Approach</i> P1I_2s_ChallC-Approach_LT-Strat-Plan P1I_2s_ChallC-Approach_Other-Process P1I_2s_ChallC-Approach_Utilize-IncremApp	<i>P1II_2s_NewStuffA-KM</i> P1II_2s_NewStuffA-KM_Enhance-System P1II_2s_NewStuffA-KM_Replace-System P1II_2s_NewStuffA-KM_Uses-of-Data <i>P1II_2s_NewStuffB-CFT</i> P1II_2s_NewStuffB-CFT_ID-Goals P1II_2s_NewStuffB-CFT_ID-Roles P1II_2s_NewStuffB-CFT_Roles-Assigned <i>P1II_2s_NewStuffC-Synergy</i> P1II_2s_NewStuffC-Synergy_Data-Sharing
PI_4m_QI PI_4s_QI_BaselineData_Hosp PI_4s_QI_BaselineData_LEMSA PI_4s_QI_Design_Hosp PI_4s_QI_Design_LEMSA PI_4s_QI_Initiative_Hosp PI_4s_QI_Initiative_LEMSA	P1I_3m_Beliefs <i>P1I_3s_BeliefsA-N2Change</i> P1I_3s_BeliefsA-N2Change_Goals-Unmet P1I_3s_BeliefsA-N2Change_Poor-Operat <i>P1I_3s_BeliefsB-A2Change</i> P1I_3s_BeliefsB-A2Change_Is-Ready P1I_3s_BeliefsB-A2Change_Plan P1I_3s_BeliefsB-A2Change_Resources	P1II_3m_Impact-on-Change <i>P1II_3s_Impact-on-ChangeA-Oper-State</i> P1II_3s_Impact-on-ChangeA-Oper-State_Doubt P1II_3s_Impact-on-ChangeA-Oper-State_Fail <i>P1II_3s_Impact-on-ChangeB-Beliefs</i> P1II_3s_Impact-on-ChangeB-Beliefs_Credence P1II_3s_Impact-on-ChangeB-Beliefs_Examples

Appendix IV: The Process of Double-Coding

In order to assure quality in the coding process (and have confidence in the data), double-coding was performed on a subset of the data (Olson, McAllister, Grinnell, Gehrke Walters, and Appunn, 2016). This activity was performed using the (paid) services of a colleague of the researcher. This colleague (MM), who now works as a health program specialist in a “sister program” to the CSR/CCP, is a former educator and curriculum specialist who conducted qualitative research during the recent completion of her master’s level degree program requirements. Moreover, MM is not only familiar with the mission and operations of the CSR/CCP, given her current professional position, but also she is well-informed with respect to this project, having earlier assisted with the pilot-testing of the interview guides.

The process to double-code the data was comprised of several steps. First, the researcher and MM had several meetings (about 120 minutes in total) to review the project in detail, going over the research questions, the conceptual framework, and the study methods. Next, the researcher shared the codebook and coding instructions (Appendix III) with MM, who, after studying them, met again with the researcher (for about 30 minutes) and asked questions – which the researcher answered. Further, with MM having a clear understanding of the codebook and the coding instructions, the actual double-coding was performed, as the researcher and MM, each, independently, coded in NVivo, Version 10, the same subset of data. Finally, using NVivo, Version 10, the two separate coding processes were compared, and Cohen’s Kappas were calculated, by node (the word for code in NVivo, Version 10), in order to describe the inter-coder reliability (Foster, Urquhart, and Turner, 2008).

Comparing the two separate coding processes (of the same subset of data) yielded node-specific Cohen’s Kappas which ranged from 0.7332 to 0.9941, as shown in Figure 11 below.

Figure 11: The Cohen's Kappas from the Double-Coding Process

Kappa Results											
Node	Source	Source Folder	Source Size	Kappa /	Agreement (%)	A and B (%)	Not A and Not B (%)	Disagreement (%)	A and Not B (%)	B and Not A (%)	
PII_1m_ContIPII_1s_ContB-Struct	PII_07_Williams	Internals	9369 chars	0	95.52	0	95.52	4.48	4.48	0	
PII_1m_ContIPII_1s_ContB-StructIPII_1s_ContB-Struct_Hierarchy	PII_07_Williams	Internals	9369 chars	0	96.89	0	96.89	3.11	0	3.11	
PII_3m_BeliefsIPII_3s_BeliefsB-A2Change	PII_07_Williams	Internals	9369 chars	0	97.75	0	97.75	2.25	2.25	0	
PII_1m_ContIPII_1s_ContB-StructIPII_1s_ContB-Struct_Processes	PII_07_Williams	Internals	9369 chars	0.7332	93.21	11.55	81.66	6.79	4.53	2.26	
PII_1m_ContIPII_1s_ContA-HxIPII_1s_ContA-Hx_Decisions	PII_07_Williams	Internals	9369 chars	0.8041	94.07	15.62	78.45	5.93	1.79	4.14	
PII_2m_ChallIPII_2s_ChallA-ConstrIPII_2s_ChallA-Constr_Fiscal	PII_07_Williams	Internals	9369 chars	0.8393	95.03	16.58	78.45	4.97	4.54	0.44	
PII_3m_BeliefsIPII_3s_BeliefsB-A2ChangeIPII_3s_BeliefsB-A2Change	PII_07_Williams	Internals	9369 chars	0.8522	99.24	2.25	96.99	0.76	0	0.76	
PII_2m_ChallIPII_2s_ChallA-ConstrIPII_2s_ChallA-Constr_HR	PII_07_Williams	Internals	9369 chars	0.875	96.67	14.12	82.55	3.33	3.29	0.04	
PII_2m_ChallIPII_2s_ChallA-ConstrIPII_2s_ChallA-Constr_LOC	PII_07_Williams	Internals	9369 chars	0.919	97.12	21.69	75.43	2.88	1.68	1.21	
PII_1m_ContIPII_1s_ContA-HxIPII_1s_ContA-Hx_Staffing	PII_07_Williams	Internals	9369 chars	0.9941	99.83	17.3	82.53	0.17	0.11	0.06	
PI_1m_Recruit	PII_07_Williams	Internals	9369 chars	1	100	0	100	0	0	0	

Notes:

1. This figure is a screenshot from NVivo, Version 10.
2. The Cohen's Kappa is equal to zero for three codes (or "buckets" as they are sometimes called), for the following reasons: In one case, the researcher coded some text into the big bucket of structure, while the second coder (MM) coded it, instead, into the little bucket (under structure) of hierarchy; therefore, that particular text was in one bucket, or in the other, but not in both. Thus, the two codes (i.e., the researcher's big bucket and MM's little bucket) have (each) text from just one coder...and, therefore, a Cohen's Kappa of zero. In a second case, the researcher coded some text into both the big bucket of beliefs and the little bucket (under beliefs) of ability to change (since, according to the researcher, that text both supported the larger theme and provided some specificity). MM coded that same text, instead, into only the latter bucket, as she focused more on the specificity (than on the larger theme); therefore, for the former bucket, since the text was coded by just one coder (i.e., by the researcher), the Cohen's Kappa is zero.
3. For any bucket that was not used by either coder, the Cohen's Kappa is, by default, one.

According to Landis and Koch (1977), the following benchmarks can be used for interpreting the Cohen's Kappa (and, therefore, the coding): 0.00 to 0.20, slight; 0.21 to 0.40, fair; 0.41 to 0.60, moderate; 0.61 to 0.80, substantial; and 0.81 to 1.00, almost perfect. Therefore, since double coding within this project yielded Cohen's Kappas ranging from 0.7332 to 0.9941 (shown above), the coding performed herein can be considered substantial or better. Indeed, achieving this level of inter-coder reliability suggests that the data used within this project are meaningful, accurate representations of the constructs being measured (McHugh, 2012). In short, the use of these data to answer the three research questions introduced in Chapter 1 is appropriate.

Appendix V: Institutional Review Board Approval Letter

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Exemption Granted

April 13, 2015

David Reynen, BS, MPH, MPPA
Public Health
10 Chicory Bend Court
Sacramento, CA 95831
Phone: (916) 422-2864

RE: Research Protocol # 2015-0379

“Towards Broadening Secondary Prevention Efforts within a State Stroke Registry”

Sponsors: None

Dear David Reynen:

Your Claim of Exemption was reviewed on April 13, 2015 and it was determined that your research protocol meets the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b))]. You may now begin your research.

Exemption Period:	April 13, 2015 – April 13, 2018
Performance Site:	UIC, California Stroke Registry/ California Coverdell Program
Subject Population:	Adult (18+ years) subjects only
Number of Subjects:	12

The specific exemption category under 45 CFR 46.101(b) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.

Phone: 312-996-1711

<http://www.uic.edu/depts/ovcr/oprs/>

Fax: 312-413-2929

2. Record Keeping You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.
3. Final Report When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).
4. Information for Human Subjects UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. When appropriate, the following information must be provided to all research subjects participating in exempt studies:
 - a. The researchers affiliation; UIC, JBVMAC or other institutions,
 - b. The purpose of the research,
 - c. The extent of the subject's involvement and an explanation of the procedures to be followed,
 - d. Whether the information being collected will be used for any purposes other than the proposed research,
 - e. A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
 - f. Description of any reasonable foreseeable risks,
 - g. Description of anticipated benefit,
 - h. A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,
 - i. A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).
 - j. A statement that the UIC IRB/OPRS or JBVMAC Patient Advocate Office is available if there are questions about subject's rights, which includes the appropriate phone numbers.

Please be sure to:

→ Use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, B.S., C.I.P.
Assistant Director
Office for the Protection of Research Subjects

cc: Paul Brandt-Rauf, Public Health, M/C 923
Christina Welter, Public Health, M/C 923

Appendix VI: Crosswalk from Findings to Implications

Research Question 1:			
What work is being done in terms of secondary prevention within the California Stroke Registry/California Coverdell Program? (<i>e.g., related to recruitment, infrastructure, partnerships, and QI</i>) How does that work compare to the program's original vision for secondary prevention?			
Key Finding	Importance	Program Impact/Recommendation	Field Impact/Implication
<p>Even with an expected completion date of early 2013, the data system has not yet been completed by the contractor, the Eureka Team of the California Cancer Registry. This lack of a functional data system is an indicator that the CSR/CCP has not been operating as it had anticipated to have been operating (by this time).</p> <p>Note: This finding relates most closely to the infrastructure construct – specifically the data system section, though it also cross-cuts another infrastructure section (i.e., recruitment), as well as quality two other constructs (i.e., recruitment and quality improvement). Finally, there is a connection to organizational culture, as an incomplete data system may suppress the spirit of innovation.</p>	<p>In brief, the data system is designed to do the following: (1) onboard all clinical partners (i.e., both pre- and in-hospital), regardless of how the local data are collected; (2) standardize and link the data from the two clinical settings, at the patient-level; and (3) provide summary data that can be used to (a) inform the quality improvement initiatives and (b) evaluate the local systems of care.</p> <p>Additionally, the promise of a data system that is able to do these things has been a key incentive for getting clinical partners to join the registry, given the lack of a legislative mandate for the registry.</p> <p>Without the functional data system, these programmatic activities cannot happen and there is less of an incentive for potential clinical partners to join the registry.</p>	<p>There are greater programmatic impacts, including the following:</p> <p>Without having a functional data system, the CSR/CCP has been hampered in its ability to facilitate statewide efforts to ensure that stroke patients receive high quality coordinated comprehensive patient care.</p> <p>As well, the CSR/CCP Team has had to utilize limited staff resources to carry out tasks that would have been handled by the data system (e.g., the provision of summary data tables); this allocation of resources has meant that other programmatic areas have had fewer dedicated resources (than would have been the case otherwise).</p> <p>Recommendation: Given this impact to the program, there is a recommendation to revisit the program's ability to collect and report data – and enhance or replace the current system, via a new development team.</p>	<p>This project finding is an exemplar of an impediment to being able to integrate the efforts of clinical medicine and public health.</p> <p>As was discussed in chapter 1, improving health at the population level must be well-integrated across clinical medicine and public health. Opportunities for such integration have come about with the passage of the Patient Protection and Affordable Care Act – which motivates healthcare providers to engage (with the public health system) in health planning at the community level.</p> <p>To enable these partners to engage in these activities, the sharing of data is essential.</p> <p>Implication: Leaders must find ways to enable the sharing of data in ways that promote the collaborative efforts of clinical medicine and public health to improve population health.</p>

Appendix VI continued...

Research Question 2:

Q2: What factors have contributed to the current state of the program's secondary prevention efforts?

- a. In what way(s) has the program's operational context – including its history, its structure, its culture, and its reach – impacted this state?
- b. What are the operational challenges which have contributed to this state? (*e.g., a set of constraints, a skewed focus, an certain approach*)
 - i. (challenges) faced by the program?
 - ii. (challenges) faced by the partners?

How have program stakeholders' beliefs, related to change, influenced the program's current secondary prevention efforts?

Key Finding	Importance	Program Impact/Recommendations	Field Impact/Implication
<p>The CSR/CCP's scope deals primarily with secondary prevention – as it seeks to reduce the impact of an event (i.e., a stroke) that has already occurred through immediate appropriate treatment; in contrast, the focus of nearly every other public health program within the larger organization is on primary prevention – to prevent disease before it ever occurs. Given this contrast, there is somewhat of a “lack-of-fit” within the organization for the CSR/CCP, and this situation has been impactful on its operational state.</p> <p>Note: This finding is germane to the operational context construct – specifically the section that concerns historical views of prevention, though it also cross-cuts other areas, including historical decision-making (e.g., in regard to human resources) and organizational culture, as well as the operational challenges construct.</p>	<p>Because of this “lack-of-fit,” the CSR/CCP has been, to some extent, deprioritized within the larger organization.</p> <p>Consequently, the amount of support and recognition given to the CSR/CCP by senior management is comparatively less than that received by other programs with a better “fit.” With limited resources and a “low standing,” the CSR/CCP has been challenged in its ability to carry out its scope of work.</p> <p>Some notable challenges include having CSR/CCP staff members being redirected away from the CSR/CCP to work on other programs within the Branch in which the CSR/CCP resides – thereby requiring existing staff to take on those additional duties. This meant that existing staff were overburdened and inefficiencies in program operations were created.</p>	<p>There are greater impacts for the CSR/CCP, related to its “different” notion of prevention (relative to that of the larger organization), including the following:</p> <p>The CSR/CCP has been relegated to a level of relative unimportance, as per the views of upper management within the larger organization. Accordingly, it has meant that the registry has been hampered in terms of support and resources, which has made it even more difficult to recruit its partners, build its infrastructure, and facilitate local level quality improvement initiatives.</p> <p>Recommendations: Given this finding and its implications, several recommendations have been made: (1) to raise the visibility of the CSR/CCP, such that it is better poised for support as it endeavors to achieve a better future state; (2) both internally and externally, improve the communication practices of the CSR/CCP; and (3) improve the coordination capacity and practices of the CSR/CCP. These actions should help improve the “standing” of the CSR/CCP.</p>	<p>This project finding is an exemplar of a missed opportunity to build connections between clinical medicine and public health in order to collectively improve population health, as per the Affordable Care Act.</p> <p>Any action which deprioritizes work within the area of secondary prevention, while promoting work within the area of primary prevention, enables gaps in coordination to persist. Persistent gaps hinder connections from being made between clinical medicine and public health. Gaps need to be closed so that these two communities can come together to improve population health.</p> <p>Implication: Leaders must promote the collaborative efforts of clinical medicine and public health to improve population health. This includes reconciling the differing prevailing notions of prevention so that all partners, across all sectors, have a shared understanding. Ultimately, leaders can (should) engage in shared leadership practices towards common ends.</p>

Appendix VI continued...

Research Question 3:

Q3: How might change occur within the program, such that its secondary prevention efforts can be broadened?

- b. How might the program utilize its present practices and/or resources in new ways (*e.g., vis-à-vis technology, staffing, and partnerships*)?
- d. How might the program acquire and utilize new practices and/or resources – and what kinds of new practices and/or resources might these be? (*Maybe knowledge management, cross-functional teams, synergy?*)
- e. How might a change process be impacted by:
 - i. the program's operational state?
 - ii. the program stakeholders' change-related beliefs?

Key Finding	Importance	Program Impact/Recommendation	Field Impact/Implication
<p>Given the CSR/CCP's staffing patterns historically, as well as its relatively small number of key strategic partners (i.e., the AHA/ASA, the Eureka Team of the California Cancer Registry, the CDC, and the group of "other" partners), there has not been a bona fide cross-functional approach to carrying out the scope of work.</p> <p>While this situation was not revealed, per se, in this research project, it was, however, highlighted by drawing a contrast with what was discussed by all seven of the Phase III key informants. Each one described her or his very positive experiences with the use of cross-functional teams.</p> <p>Note: The idea of using cross-functional teams is most relevant to the infrastructure construct's section on staffing. It also cross-cuts other areas, including the partnerships-related constructs and the locus of control constraint under the operational challenges construct.</p>	<p>The CSR/CCP has not been able to achieve a number of its goals – including those related to recruitment, the data system, and quality improvement. One reason for the inability to achieve these goals is that the CSR/CCP has not been able to optimize the use of human resources, both those within the program and those within the strategic partners. In working to realize a better future state, the CSR/CCP will need to utilize a different approach to using human resources. Using cross-functional teams is one such (proven) approach.</p> <p>Without a new approach, the CSR/CCP likely will maintain its status quo, which means that future efforts to recruit clinical partners will not have improved yields; the process to develop the data system will continue to languish; and the facilitation of local quality improvement initiatives will be not better than it has been.</p>	<p>The use of cross-functional teams by the CSR/CCP should mean the following:</p> <p>Key personnel from multiple agencies (including from the CSR/CCP and its key strategic partners) will come together for a specific time, in order to accomplish a specific goal or task. This model should enable the CSR/CCP to experience "wins" that bring the program closer to achieving its goals. As well, it should enable the CSR/CCP to be more of a learning organization.</p> <p>Using cross-functional teams will also mean improvements in the facilitation of collaborative efforts; the management of interagency communications; and the identification and cultivation of key leaders.</p> <p>Recommendation: Given this model, the recommendation is to reconsider staffing patterns within the CSR/CCP, as well as how strategic partners are utilized, with an eye towards developing and using cross-functional teams.</p>	<p>By highlighting this staffing situation with the CSR/CCP (by drawing a contrast with what is in place in many other programs), a case is made for (a) looking elsewhere to see what works and (b) assessing how that practice might work within the situation at hand. In short, this is the use of evidence-based best practices. This notion extends beyond the CSR/CCP, which (were it to achieve success via this new approach) may serve as a model for others.</p> <p>As was stated in chapter 2, this "best practice" team approach fosters collective learning and enables a level of performance that exceeds the sum of the individual contributions. As well, it is critical to understanding and possibly changing a current state, in favor of working towards a better future state.</p> <p>In sum, the CSR/CCP's adoption of best practices (and the successes that may follow), when documented, may be of benefit to the field.</p> <p>Implication: Leaders must look for opportunities to utilize evidence-based best practices.</p>

VIII:

Curriculum Vitae

David J. Reynen, MA, MPPA, MPH, CPH

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EDUCATION:

Dr.P.H. , Leadership	University of Illinois at Chicago	<i>in progress</i>
M.A. , Aging & Health	California State University Sacramento	January, 2013
G.Cert. , Gerontology	California State University Sacramento	January, 2010
M.P.P.A. , Public Policy & Admin.	California State University Sacramento	August, 1999
M.P.H. , Epidemiology	Loma Linda University	June, 1994
B.S. , Biology	Pepperdine University	April, 1992

PROFESSIONAL EXPERIENCE:

April, 2002 to present	California Department of Public Health (CDPH), Sacramento <i>(CDPH was established 7/1/2007 from non-Title XIX California Department of Health Services programs)</i> Chronic Disease Control Branch California Heart Disease and Stroke Prevention Program (CHDSPP) and Chronic Disease Epidemiology and Control Section (CDECS) Research Scientist III -- 2/07-present Research Scientist II -- 4/02-1/07
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Duties Mr. Reynen performs include the following: (a) serving as the Co-Principal Investigator for California's Coverdell Program, a quality improvement program for acute stroke care and a component of the California Stroke Registry; (b) developing State level capacity for performing chronic disease surveillance activities; (c) using this surveillance capacity to (i) document the changing disease-specific public health burdens, (ii) assess the impacts of policy-oriented and programmatic prevention efforts on reducing these burdens, and (iii) identify disparities that exist across populations of interest; (d) conducting epidemiologic research in the area of chronic disease both to help foster the identification of potential areas for intervention and/or policy-making activities and to present the research – to date, Mr. Reynen has authored or co-authored one research report, thirty-six conference presentations, and six peer-reviewed, published abstracts while with the CDECS and CHDSPP; (e) addressing the needs of federal, state, and local public and private organizations, with regard to chronic disease data, while, at the same time, strengthening the capacity of the requestor to understand and work with the data; (f) assisting in the preparation of written materials, including scientific reports, grant applications, and strategic plans.

April, 1997 to April, 2002	California Department of Health Services (CDHS), Sacramento Maternal and Child Health (MCH) Branch Epidemiology and Evaluation Section Research Scientist II -- 2/99-4/02 Research Program Specialist I -- 4/97-2/99
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Duties Mr. Reynen performed while in the MCH Branch, in accordance with Title V (of the Social Security Act) mandates, include the following: (a) conducting epidemiologic research in the area of maternal, child, and adolescent health, including authoring or co-authoring four research reports and twenty-six conference presentations; (b) serving for one year as co-lead on the data portion of the federally-funded and mandated Title V Needs Assessment/5-Year Plan process for the MCH Branch; and (c) serving for nearly two years as the lead on the data portions of two public health programs, both established at the Branch level as State/Local partnerships: (1) The Adolescent Family Life Program, for which Mr. Reynen designed and conducted a formal evaluation, and (2) The California Fetal and Infant Mortality Review Program, for which Mr. Reynen served as a consultant to the process to develop local program evaluation capacity.

PROFESSIONAL EXPERIENCE Continued...

July, 1995
to April, 1997

**California Department of Health Services (CDHS), Sacramento
Cancer Control Branch
Tobacco Control Section (TCS)**

Research Scientist I -- 6/96-4/97

Research Scientist, California Public Health Foundation contract -- 7/95-6/96
(now known as the Public Health Institute)

Duties Mr. Reynen performed while at TCS include (a) conducting an array of tobacco-related surveillance and epidemiologic research activities, including authoring three research reports and one conference presentation; (b) preparing a large collection of Harvard Graphics data presentations, for his colleagues and himself, for use in a series of strategic planning meetings; (c) consulting on and participating in the development and/or revision of a number of tobacco-related telephone surveys; (d) writing fact sheets, abstracts, and other documents for both internal and external use; (e) consulting with external contractors of the state with respect to formal research design and methodology; and (f) responding to the tobacco data-related inquiries of health educators, policy specialists, legislative officials, media staff, and the general public.

July, 1994
to June, 1995

**California Department of Health Services (CDHS), Sacramento
California Epidemiologic Investigation Service (Cal-EIS)**

Cal-EIS Resident under the tutelage of Kathleen Acree, MD, MPH, JD

Duties Mr. Reynen performed during his residency in the Chronic Disease Control Branch (CDCB) include (a) analyzing diabetes-related morbidity data and co-authoring a research report for the CDCB's Diabetes Control Program; (b) helping to write a CDC grant proposal and subsequently to develop a Skin Cancer Prevention Program; (c) helping to frame the research of the Cardiovascular disease Outreach, Resources, and Epidemiology program (later known as the California Heart Disease and Stroke Prevention Program); (d) facilitating at a conference entitled, "Partnerships to Promote Physical Activity and Healthy Eating;" (e) assisting Dr. Donald O. Lyman, (the chief of the Chronic Disease and Injury Control Division and) a medical advisor to the Governor's Council on Physical Fitness and Sports, in the preparation of a resource to monitor California's progress toward meeting the physical activity-related *Healthy People 2000* objectives; and (f) consulting, together with other CDCB staff, on study design for a case management study being considered by CDHS Medi-Cal staff.

RELEVANT EXPERIENCE in a UNIVERSITY SETTING:

June, 2002
to December, 2005
(ad hoc)

California State University, Sacramento
Department of Public Policy and Administration
Research Associate

June, 1998
to February, 1999

(5-10hrs/wk)

California State University, Sacramento
The Center for California Studies' Institute for Research on Women and Families
(This institute is now the independent "California Center for Research on Women and Families")
Researcher for The California Working Families Project

March, 1993
to June, 1994
(20hrs/wk)
(20hrs/wk)
(10hrs/wk)

Loma Linda University
School of Public Health, Department of Epidemiology and Biostatistics
(9/93-6/94) Research Assistant under the tutelage of Kristian Lindsted, PhD
(6/93-9/93) Student Assistant for Kristian Lindsted, PhD
(3/93-6/93) Laboratory Instructor for John Morgan, DrPH, MPH

April, 1991
to April, 1992
(ad hoc/weekly)

Pepperdine University
Seaver College of Letters, Arts, and Sciences, Natural Science Division
Research Assistant under the tutelage of Stephen D. Davis, PhD

SCHOLARLY ACTIVITY:

1. **Reynen D.J.**, Darsie B., Kamigaki K., Bates J. *Drive-Time Proximity to Certified Stroke Centers in California, 2015*. The American Heart Association's Scientific Sessions 2016 Conference. New Orleans, LA. Upcoming 11/16.
2. **Reynen D.J.**, Darsie B., Kamigaki, A.S., Bates, J. *Geographic Analysis of Drive Time to Certified Stroke Centers in California*. The 144th Annual Meeting of the American Public Health Association (APHA), "Creating the Healthiest Nation: Ensuring the Right to Health." Denver, CO. Upcoming 10/16-11/16.
3. **Reynen D.J.**, Kamigaki K., Bates J. *Emergency Medical Services Utilization: Its Impact on Time-to-Treatment for Stroke*. The CDC Coverdell Grantee Workshop, "Spring Forward With Year 1: Coverdell Workshop." Atlanta, GA. 3/16.
4. **Reynen D.J.**, Darsie B., Kamigaki K., Bates J. *Geographic Analysis of Drive Time to Certified Stroke Centers in California*. The CDC Coverdell Grantee Workshop, "Spring Forward With Year 1: Coverdell Workshop." Atlanta, GA. 3/16.
5. **Reynen D.J.** *Moving Forward in California via Shared Leadership*. The CDC Coverdell Grantee Workshop, "Spring Forward With Year 1: Coverdell Workshop." Atlanta, GA. 3/16.
6. **Reynen D.J.**, Darsie B., Kamigaki K., Bates J. (2016). *Drive-Time Proximity to Certified Stroke Centers in California, 2015*. Stroke, Vol. 47, Issue Suppl. 1, A80.
7. **Reynen D.J.**, Darsie B., Kamigaki K., Bates J. *Drive-Time Proximity to Certified Stroke Centers in California, 2015*. International Stroke Conference 2016. Los Angeles, CA. 2/16.
8. **Reynen D.J.**, Kamigaki, A.S., Bates, J. *Emergency Medical Services Utilization and Stroke Treatment*. The 143rd Annual Meeting of the APHA, "Health In All Policies." Chicago, IL. 11/15.
9. **Reynen D.J.**, Kamigaki, A.S., Chaput, L.A. *Mode of Patient Transport and Treatment of Acute Stroke*. The CDC Coverdell Grantee Workshop, "Spring Forward With Year 2: Coverdell Workshop." Atlanta, GA. 9/13.
10. Rodgers, E.J., Hayashi, T., **Reynen D.J.**, Chaput, L.A. *Outcomes Following Transient Ischemic Attack (TIA): Do Primary Stroke Centers Make a Difference?* The CDC Coverdell Grantee Workshop, "Spring Forward With Year 2: Coverdell Workshop." Atlanta, GA. 9/13.
11. **Reynen D.J.**, Kamigaki, A.S., Chaput, L.A. *Mode of Patient Transport and Treatment of Acute Stroke*. The 140th Annual Meeting of the APHA, "Prevention and Wellness Across the Lifespan." San Francisco, CA. 10/12.
12. Dacey, D.C., Resnick, B.A. **Reynen D.J.** *Using Action Learning to Study Inadequate Access to Primary Care Medical Services for Deployed Active-duty Military Personnel*. The 140th Annual Meeting of the APHA, "Prevention and Wellness Across the Lifespan." San Francisco, CA. 10/12.
13. Rodgers, E.J., Hayashi, T., **Reynen D.J.**, Chaput, L.A. *Outcomes Following Transient Ischemic Attack (TIA): Do Primary Stroke Centers Make a Difference?* The 140th Annual Meeting of the APHA, "Prevention and Wellness Across the Lifespan." San Francisco, CA. 10/12.
14. **Reynen D.J.**, Kamigaki, A.S., Oh, S., Farrell, M., Chaput, L.A. *California's Stroke Registry: A Model of Successful Partnerships*. The 139th Annual Meeting of the APHA, "Healthy Communities Promote Healthy Minds and Bodies." Washington, DC. 10/11.
15. **Reynen D.J.**, Kamigaki, A.S., Oh, S., Gilbert, G.H., Chaput, L.A. (2011) *Data Sharing to Facilitate the Establishment of Stroke Systems of Care in California*. Stroke, Vol. 42, No. 3, p. e294.
16. **Reynen D.J.**, Kamigaki, A.S., Oh, S., Gilbert, G.H., Chaput, L.A. *Data Sharing to Facilitate the Establishment of Stroke Systems of Care in California*. International Stroke Conference 2011. Los Angeles, CA. 2/11.

SCHOLARLY ACTIVITY Continued...

17. **Reynen D.J.**, Kamigaki, A.S., Rocha, D.A., Chaput, L.A. *Racial/ethnic Treatment Patterns of Peripheral Artery Disease in California: 1998-2007*. The 138th Annual Meeting of the APHA, "Social Justice." Denver, CO. 11/10.
18. Rocha, D.A., Farrell, M., **Reynen, D.J.**, Hernandez, M., Chaput, L.A., Hayashi, T. *Improvements in Knowledge of Heart Attack and Stroke Symptoms and 911 Use Among Low-income Hispanic Women*. The 138th Annual Meeting of the APHA, "Social Justice." Denver, CO. 11/10.
19. **Reynen D.J.**, Kamigaki, A.S., Ford-Keach, P., Chaput, L.A. *Treatment of ST-Elevation Myocardial Infarction in California: Evidence of a Decade-Long Gender Bias*. The 137th Annual Meeting of the APHA, "Water and Public Health." Philadelphia, PA. 11/09.
20. **Reynen D.J.**, Kamigaki, A.S., Ford-Keach, P., Chaput, L.A. *Hypertension among California Latinos: Findings from the 2005 Behavioral Risk Factor Survey*. The 136th Annual Meeting of the APHA, "Public Health Without Borders." San Diego, CA. 10/08.
21. Kamigaki, A.S., **Reynen D.J.**, Ford-Keach, P., Chaput, L.A. *Importance of a Healthy Diet in Avoiding High Blood Cholesterol: Findings from the 2005 Behavioral Risk Factor Survey*. The 136th Annual Meeting of the APHA, "Public Health Without Borders." San Diego, CA. 10/08.
22. Pheatt, N., Kamigaki, A.S., **Reynen D.J.**, Chaput, L.A. *Developing a Master Plan for Heart Disease and Stroke Prevention and Treatment: California's Experience*. The 136th Annual Meeting of the APHA, "Public Health Without Borders." San Diego, CA. 10/08.
23. **Reynen D.J.**, Kamigaki, A.S., Pheatt, N., Chaput, L.A. *Stroke in California: A Focus on Women*. The 135th Annual Meeting of the APHA, "Politics, Policy, and Public Health." Washington, DC. 11/07.
24. **Reynen D.J.** *Non-routine Hospital Discharge of the Chronically-ill Oldest-Old in Rural California, 2004*. The 135th Annual Meeting of the APHA, "Politics, Policy, and Public Health." Washington, DC. 11/07.
25. **Reynen D.J.**, Nelson, D.F. *Californians who had no Dental Visit During the Past Year: A Focus on Latinos*. The 135th Annual Meeting of the APHA, "Politics, Policy, and Public Health." Washington, DC. 11/07.
26. **Reynen D.J.**, Kamigaki, A.S., Pheatt, N., Chaput, L.A. (2007) *The Use of Blood-Pressure Lowering Medications Among California Adults*. Hypertension, Vol. 50, No. 4, p. e131.
27. **Reynen D.J.**, Kamigaki, A.S., Pheatt, N., Chaput, L.A. *The Use of Blood-Pressure Lowering Medications Among California Adults*. The 61st Annual High Blood Pressure Research Conference 2007. Tucson, AZ. 9/07.
28. **Reynen D.J.**, Kamigaki A.S., Pheatt N., Chaput L. *The Burden of Cardiovascular Disease in California: A Report of the California Heart Disease and Stroke Prevention Program*. Sacramento, CA: California Department of Public Health. 7/07.
29. **Reynen D.J.**, Kamigaki, A.S., Pheatt, N., Chaput, L.A. *Factors Associated with Stroke Among California's Senior Population: Differences by Gender*. The 134th Annual Meeting of the APHA, "Public Health and Human Rights." Boston, MA. 11/06.
30. Kamigaki, A.S., **Reynen D.J.**, Pheatt, N., Chaput, L.A. *High Blood Pressure and the Use of Blood Pressure Lowering Medications: Findings from the 2003 California Health Interview Survey*. The 134th Annual Meeting of the APHA, "Public Health and Human Rights." Boston, MA. 11/06.
31. **Reynen D.J.**, Nelson D. (2005) *Hospitalizations for Diseases of the Oral Cavity, Salivary Glands, and Jaws, California, 1998-2002*. Journal of Public Health Dentistry, Vol. 65, Suppl. 1, p. S57-S58.

SCHOLARLY ACTIVITY Continued...

32. **Reynen D.J.**, Kotz K.J., Kurata J.H. *Factors Associated with Binge Drinking in California: Findings from the California Health Interview Survey, 2001.* The 133rd Annual Meeting of the APHA, "Evidence-Based Policy & Practice." Philadelphia, PA. 12/05.
33. **Reynen D.J.** *Alcohol Consumption Among Women of Childbearing Age: Findings from the 2003 California Health Interview Survey.* The 11th Annual Maternal and Child Health Epidemiology (MCH Epi) Conference, "Making Methods and Practice Matter for Women, Children, and Families." Miami, Florida. 12/05.
34. **Reynen D.J.**, Nelson D. *Hospitalizations for Diseases of the Oral Cavity, Salivary Glands, and Jaws, California, 1998-2002.* The 2005 National Oral Health Conference (NOHC), "Confluence of Research, Education, and Practice." Pittsburgh, PA. 5/05.
35. **Reynen D.J.** *Back-Pain-Related Morbidity in California: A Look at Disparities.* The 2005 Combined Sections Meeting of the American Physical Therapy Association, "Unmask Your Potential." New Orleans, LA. 2/05.
36. **Reynen D.J.** (2005) *Back-Pain-Related Morbidity in California: A Look at Disparities.* Journal of Orthopaedic & Sports Physical Therapy, Vol. 35, No. 1, p. A39.
37. **Reynen D.J.**, Nelson D., Kurata J.H. (2004) *Factors Associated with Having Had No Dental Visit in the Last Year: Findings from the California Health Interview Survey, 2001.* Journal of Public Health Dentistry, Vol. 64, Suppl. 1, p. S52.
38. **Reynen D.J.** *The Regular Use of Paid Childcare: Findings from the California Health Interview Survey, 2001.* The 10th Annual MCH Epi Conference, "Promoting Excellence and Expanding Horizons." Atlanta, GA. 12/04.
39. **Reynen D.J.**, Kurata J.H. *Californians aged 65 years and older who had no dental visit in the last year: Findings from the California Health Interview Survey, 2001.* The 132nd Annual Meeting of the APHA, "Public Health and the Environment." Washington, D.C. 11/04.
40. **Reynen D.J.**, Nelson D., Kurata J.H. *Factors Associated with Having Had No Dental Visit in the Last Year: Findings from the California Health Interview Survey, 2001.* The 2004 NOHC, "Lights, Camera, Call to Action: Spotlight on Oral Health." Los Angeles, CA. 5/04.
41. **Reynen D.J.**, Graham E.E. *Chronic-disease-related Hospital Discharges of the Oldest Old: Non-routine Disposition at Discharge, San Francisco, 1999.* The 131st Annual Meeting of the APHA, "Behavior, Lifestyle, and Social Determinants of Health." San Francisco, CA. 11/03.
42. Kurata J.H., **Reynen D.J.**, Kamigaki A.S., Pheatt N. *Heart Disease in California: Findings from the 2001 California Health Interview Survey.* The 131st Annual Meeting of the APHA, "Behavior, Lifestyle, and Social Determinants of Health." San Francisco, CA. 11/03.
43. Graham E.E., **Reynen D.J.** *The Impact of Language Preference on Health Insurance Status Among Non-elderly Adult California Women, 2000.* The Department of Public Policy and Administration Working Paper Series. Paper #2003-02. Sacramento, CA: California State University, Sacramento (CSUS). 9/03.
44. **Reynen D.J.**, Graham E.E. *Adolescent Suicides in California During the 1990's: A Call to Action.* The Department of Public Policy and Administration Working Paper Series. Paper #2003-01. Sacramento, CA: CSUS. 9/03.
45. **Reynen D.J.**, Troyan J., Kurata J.H. *Chronic Liver Disease/Cirrhosis-related Morbidity and Mortality in California: A Look at Disparities.* The 17th National Conference on Chronic Disease Prevention and Control (CDPC), "Gateway to Lifelong Health: The Community Connection." St. Louis, MO. 2/03.
46. **Reynen D.J.**, Motylewski-Link C.L., Kurata J.H. *Alzheimer's Disease Mortality: On the Rise in California During the 1990's.* The 17th National Conference on CDPC, "Gateway to Lifelong Health: The Community Connection." St. Louis, MO. 2/03.

SCHOLARLY ACTIVITY Continued...

47. **Reynen D.J.**, Kurata J.H. *Pregnancy-related Hospitalizations and the Presence of a Chronic Disease, California, 1999*. The 8th Annual MCH Epi Conference, "Counting the Women, Children, and Families Who Count On Us." Clearwater Beach, FL. 12/02.
48. **Reynen D.J.**, Florez C.J., Takahashi E.R., Chavez G.F. *Using Mapping to Increase the Effectiveness of State/local Teen Birth Prevention Efforts, California, 2002*. The 130th Annual Meeting of the APHA, "Putting the Public Back into Public Health." Philadelphia, PA. 11/02.
49. Weinbaum Z., **Reynen D.J.**, Perez J., Chavez G.F. *Health and Risk-Taking Behaviors Among Native American Middle and High School Students, California, 1998-1999*. The 130th Annual Meeting of the APHA, "Putting the Public Back into Public Health." Philadelphia, PA. 11/02.
50. Graham E.E., **Reynen D.**, Wells K. *Health Insurance Status of Non-Elderly Adult Women Ages 18 - 64 With Selected Socio-Demographic Characteristics, California, 2000*. Data Points, Issue 3, Number 24. Summer, 2002.
51. Graham E.E., **Reynen D.**, Wells K. *How Accurate are Women in Assessing Their Pregnancy Weight Gains? California, 2000*. Data Points, Issue 3, Number 25. Summer, 2002.
52. Florez C.J., **Reynen D.J.**, Metzinger K.J., Figueroa A.J., Heck K.E. *Teen Birth Rate Hot Spots in California, 1999-2000: A Resource Developed Using a Geographic Information Systems Approach*. Sacramento, CA: California Department of Health Services. 12/01.
53. **Reynen D.J.**, Wells K.Y., Chabot M.J., Graham E.E. *Changes in the Magnitudes of Factors Associated with Inadequate Utilization of Prenatal Care Among Young Adult Females, California, 1995 and 1999*. The 7th Annual MCH Epi Conference, "Enhancing Competencies for Informed Decision Making in Maternal and Child Health Outcomes." Clearwater Beach, FL. 12/01.
54. Graham E.E., **Reynen D.J.**, Chabot M.J., Wells K.Y. *Factors Associated with a Lack of Health Coverage Among Adult Women, 2000*. The 7th Annual MCH Epi Conference, "Enhancing Competencies for Informed Decision Making in Maternal and Child Health Outcomes." Clearwater Beach, FL. 12/01.
55. Wells K.Y., Takahashi E., Graham E.E., **Reynen D.J.** *The Impact of Intimate Partner Violence on Pregnancy and Postpartum Behaviors, California 1999*. The 7th Annual MCH Epi Conference, "Enhancing Competencies for Informed Decision Making in Maternal and Child Health Outcomes." Clearwater Beach, FL. 12/01.
56. Florez C.J., **Reynen D.J.**, Takahashi E.R. *Perinatal Outcomes for Non-teenage California Women*. The 7th Annual MCH Epi Conference, "Enhancing Competencies for Informed Decision Making in Maternal and Child Health Outcomes." Clearwater Beach, FL. 12/01.
57. **Reynen D.J.**, Weinbaum Z., Chavez G.F. *Weapon Carrying (WC) Status and Victimization Among California Middle and High School Girls, 1998-1999*. The 129th Annual Meeting of the APHA, "One World: Global Health." Atlanta, GA. 10/01.
58. **Reynen D.J.**, Adams E.J. *Fruit and Vegetable Consumption and Physical Activity Among Middle and High School Students: The California Healthy Kids Surveys, 1998-1999*. The Thirty-fourth Annual Meeting of the Society for Nutrition Education, "Full Circle: Agriculture, Nutrition, and Health." Oakland, CA. 7/01.
59. **Reynen D.J.**, Weinbaum Z., Chavez G.F. *Health-related Behaviors and Weapon Carrying (WC) Status Among California Middle and High School Students, 1998-1999*. The 2001 Maternal and Child Health (MCH) Conference, "Creating Partnerships for a Healthy Tomorrow." San Francisco, CA. 5/01.
60. Weinbaum Z., **Reynen D.J.**, Chavez G.F. *Health-related Behaviors and Teen Relationship Abuse (TRA) Among California Middle and High School Students, 1998-1999*. The 2001 MCH Conference, "Creating Partnerships for a Healthy Tomorrow." San Francisco, CA. 5/01.

SCHOLARLY ACTIVITY Continued...

61. Wells K.Y., Graham E., **Reynen D.J.**, Chabot M.J. *Proportion of High-Risk Infants Born in Appropriate Facilities By Race/ethnicity, California 1995-1999*. "Research Findings for Policy Makers" First Annual Conference. Sponsored by the Center for Health Services Research in Primary Care (CHSRPC), the Medical Center of UC Davis. Sacramento, CA. 5/01.
62. **Reynen D.J.**, Wells K.Y., Chabot M.J., Graham E. *Factors Associated with Inadequate Utilization of Prenatal Care Among California Women Aged 18 through 24 Years Who Gave Birth During 1999*. "Research Findings for Policy Makers" First Annual Conference. Sponsored by the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 5/01.
63. Graham E.E., **Reynen D.J.**, Nakagawa G. *Women Without Health Insurance in California: 2000*. "Research Findings for Policy Makers" First Annual Conference. Sponsored by the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 5/01.
64. Chabot M.J., **Reynen D.J.**, Graham E.E., Wells K.Y., Nakagawa G. *Source of Payment and Prenatal Care Utilization Among African American Women Aged 20-29 Who Experienced Late Fetal Loss, California: 1995-1999*. "Research Findings for Policy Makers" First Annual Conference. Sponsored by the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 5/01.
65. **Reynen D.J.**, Wells K.Y., Chabot M.J., Graham E. *Adequacy of Prenatal Care Utilization Among Females Under 20 Years of Age Who Gave Birth in California During 1999*. The 2nd Annual Women's Health Research Conference, "Women's Health in a Multi-Cultural Society." Sponsored by the Women's Center for Health (WCH) and the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 4/01.
66. Graham E.E., **Reynen D.J.** *Self-Assessment of Pregnancy Weight Gain: How Accurate is it?* The 2nd Annual Women's Health Research Conference, "Women's Health in a Multi-Cultural Society." Sponsored by the WCH and the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 4/01.
67. Wells K.Y., **Reynen D.J.**, Graham E. *A Lack of Exercise and Feelings of Anxiety Among Women Ages 18-44, California, 1999*. The 2nd Annual Women's Health Research Conference, "Women's Health in a Multi-Cultural Society." Sponsored by the WCH and the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 4/01.
68. Chabot M.J., Kwong S., Graham E., **Reynen D.J.**, Nakagawa G. *Trends in Folic Acid Awareness Among Reproductive Age Women in California, 1997-1999*. The 2nd Annual Women's Health Research Conference, "Women's Health in a Multi-Cultural Society." Sponsored by the WCH and the CHSRPC, the Medical Center of UC Davis. Sacramento, CA. 4/01.
69. **Reynen D.J.** *Births to California Teens: Trends, Projections, and Implications*. "Partnerships for School-Based Teen Pregnancy Prevention: Developing a Shared Vision in California" Conference. Sponsored by the Joint Work Group on School-Based Teen Pregnancy Prevention. Sacramento, CA: 4/01.
70. **Reynen D.J.**, Graham E.E. *Elementary Students' Weight-related Thoughts and Behaviors: The California Healthy Kids Surveys, 1998-1999*. The 2001 Childhood Obesity Conference, "Issues, Strategies, & Programs." San Diego, CA. 3/01.
71. Graham E.E., **Reynen D.J.** *Obesity-related Hospitalizations: Children, Adolescents, and Adults*. The 2001 Childhood Obesity Conference, "Issues, Strategies, & Programs." San Diego, CA. 3/01.
72. **Reynen D.J.**, Taylor D.J. *Descriptive Epidemiology of Adolescent Suicides and Homicides in California, During 1990 through 1998*. The 6th Annual MCH Epi Conference, "Reducing Disparities in Maternal and Child Health Outcomes." Atlanta, GA. 12/00.
73. **Reynen D.J.** *Recent Trends and Future Projections in Births to California Teens: A Focus on American Indians*. "Leadership Forum: Indian Focused Teen Pregnancy Prevention" Conference. Sponsored by the Office of Community Challenge Grants, California Department of Health Services and Indian Health, Inc. of Riverside – San Bernardino County. Morongo Band of Mission Indians Reservation. 9/00.
74. **Reynen D.J.** *Racial/ethnic Prenatal Care Utilization Trends in California*. The 2000 MCH Conference, "Realizing the Promise of Diversity in the 21st Century." San Diego, CA. 5/00-6/00.

SCHOLARLY ACTIVITY Continued...

75. **Reynen D.J.**, Chavez G.F. *Reporting of Selected Outcomes for Adolescent Family Life Program Clients*. The 5th Annual MCH Epi Conference, "Building Data Capacity in Maternal and Child Health." Atlanta, GA. 12/99.
76. Pisor C., Clemens C., Levisen L., **Reynen D.**, Weir A. *Unmasking the Fathers of Adolescents' Children*. The International Fatherhood Conference, "A Message for the New Millennium: Focusing on the Future of Fatherhood." San Francisco, CA. 5/99-6/99.
77. **Reynen D.J.**, Weinbaum Z., Russell C.M., Bal D.G. *The California Tobacco Control Program Series Article 3: Tobacco Excess...Tobacco Access*. California Morbidity. 5/99.
78. **Reynen D.J.**, Buffington T., Russell C.M., Bal D.G. *The California Tobacco Control Program Series Article 2: You Asked for It...You Got It! (Smoke-free Policies That Work)*. California Morbidity. 4/99.
79. **Reynen D.J.**, Russell C.M., Bal D.G. *The California Tobacco Control Program Series Article 1: Fewer Smokers, Fewer Smokes*. California Morbidity. 3/99.
80. **Reynen D.J.** *The Adolescent Family Life Program Reporting of Selected Outcomes for Clients Active in AFLP as of November 30, 1997*. Sacramento, CA: California Department of Health Services. 3/99.
81. Bohnstedt M., Farrar J., Lund L., **Reynen D.**, Acree K. *Diabetes Data for California Prevalence and Risk Factors*. Sacramento, CA: California Department of Health Services. 3/97.
82. **Reynen D.J.** *Does the Implementation of Smoke-free Policies Adversely Affect Business? A Study of Taxable Transactions of Eating and Drinking Places in California, 1989-1995*. Smoke-free Bars Workgroup Conference. Burlingame, CA. 11/96.
83. **Reynen D.J.**, Davis S.D. *Vulnerability to xylem embolism in Arctostaphylos glandulosa, a resprouter after fire, and Arctostaphylos glauca, a nonsprouter*. The Seventeenth Annual West Coast Undergraduate Research Conference in the Biological Sciences. San Diego, CA. 5/92. Abstract EEB9.

ASSOCIATIONS:

- Golden Key International Honour Society (University of Illinois at Chicago Chapter)
- Phi Kappa Phi, All Disciplines National Honor Society (California State University, Sacramento Chapter)
- Sigma Phi Omega, Honorary Society in Gerontology (Gamma Chi Chapter, California State University, Sacramento)
- Delta Omega, Honorary Society in Public Health (Kappa Chapter, Loma Linda University)
- American Public Health Association
- California Association of Professional Scientists

HONORS and AWARDS:

- Awarded "Love of Learning" Award (and \$500) from Phi Kappa Phi; 2012
- Inducted as a student member into Golden Key International Honour Society, for Academics, Leadership, and Service (UIC Chapter); 2012
- Inducted as an alumni member into Phi Kappa Phi, All Disciplines National Honor Society (CSUS Chapter); 2010
- Awarded five separate grants for Professional Development from the California Association of Professional Scientists; these grants (for \$300 each) were awarded in 2009, 2008, 2007, 2005, and 2004.

HONORS and AWARDS Continued...

- Inducted as a student member into Sigma Phi Omega, Honorary Society in Gerontology (Gamma Chi Chapter, CSUS); 2008
- Inducted as an alumni member into Delta Omega, Honorary Society in Public Health (Kappa Chapter, LLU); 2007
- Received, as a co-author (with EE Graham and KY Wells), the award for Second Best Abstract for *Factors Associated with a Lack of Health Coverage Among Adult Women, 2000*. The Seventh Annual Maternal and Child Health Epidemiology Conference; 2001.
- Chosen as a resident in Cal-EIS, CDHS, Chronic Disease Control Branch; 1994-5
- Awarded USDHHS, Public Health Service Public Health Traineeship Grant: administered by LLU School of Public Health, 1993-4
- Awarded Malibu/Seaver Scholarship (as an undergraduate Biology major); 1991
- Chosen to participate in Pepperdine University's Summer Undergraduate Research in Biology (SURB) program; 1991
- Honored as Co-Valedictorian, West Ottawa High School, Holland, Michigan; 1988
- Inducted into the National Honor Society, West Ottawa High School, Holland, Michigan; 1987

OTHER TRAINING and ACHIEVEMENTS:

- Completed the *Prediabetes: How Healthcare Providers Can Take Action* online course, offered by the Center for Continuing Education at the University of Albany; 2016.
- Completed the *Identifying and Assessing Mild Traumatic Brain Injury: Guidelines for EMS and Health Care Providers* online course, offered by the Center for Continuing Education at the University of Albany; 2016.
- Completed the *Crossroads: The Built Environment, Health and the New York State Prevention Agenda* online course, offered by the Center for Continuing Education at the University of Albany; 2016.
- Completed the *Confronting Health Disparities in African American Communities* online course, offered by the Center for Continuing Education at the University of Albany; 2016.
- Completed the *Bridging Gaps: The Vital Role of Cultural Competence in Healthcare* online course, offered by the Center for Continuing Education at the University of Albany; 2016.
- Completed the *Obtaining Effective Informed Consent* online course, offered by The Office of the Vice Chancellor for Research at the University of Illinois at Chicago; 2015.
- Completed the *Introduction to Quality Improvement in Public Health* online course, offered by the Office of Quality Performance and Accreditation, California Department of Public Health; 2015.
- Completed the *Logic Models and Outcome Measurement: Making Sense of What Happens As A Result of Our Efforts* online course, offered by the Northwest Center for Public Health Practice at the University of Washington; 2013.
- Completed the *Economy and Health: The Role of Public Health* online course, offered by The Centers for Public Health Education and Outreach at the University of Minnesota; 2013.
- Completed the *Leveraging Social Media and Technology for Better Health* online course, offered by the Rural South Public Health Training Center at the University of Florida; 2013.
- Completed the *Culture and Health Literacy: Beyond Access* online course, offered by The Centers for Public Health Education and Outreach at the University of Minnesota; 2013.
- Completed the *Introduction to Organizational Change* online course, offered by The State of California Department of Human Resources; 2013.
- Completed the *Public Health Budgeting and Finance* online course, offered by LIFEPAATH, The Tennessee Public Health Training Center; 2013.
- Completed the *Social/Behavioral Research Investigators and Key Personnel* online course, offered by the Collaborative Institutional Training Initiative at the University of Miami; 2012.
- Completed the *Disaster Service Worker (DSW) Training* online course, offered by the Emergency Preparedness Office, California Department of Public Health; Dec. 11, 2012.

OTHER TRAINING and ACHIEVEMENTS Continued...

- Certified in Public Health (CPH) by the National Board of Public Health Examiners; 2008 (charter class member).
- Completed the *Human Participants Protection Education for Research Teams* online course, sponsored by the National Institutes of Health (NIH); May 6, 2003.
- Trained by faculty members from the School of Public Health at Saint Louis University, St. Louis, Missouri; Mar. 11-14, 2003: *Evidence-Based Public Health*.
- Attended *Death Takes a Holiday* hosted by the California Society of Forensic Dentists, Inc., at the North Tahoe Community Conference Center, Kings Beach, California; Oct. 4, 1997.
- Trained by Computer Utilization Incorporated, Sacramento, California; Jun. 10, 1997: *Microsoft Access 7.0 Level I for Windows 95*.
- Trained by Environmental Systems Research Institute, Inc., at the State EDP Education Program Center, Sacramento, California; Jul. 24-25, 1996: *Introduction to ArcView*.
- Trained by Research Triangle Institute at The Westin St. Francis Hotel, San Francisco, California; Apr. 25-26, 1996: *SUDAAN Basics*.
- Trained by SAS Institute, Inc., at the Health and Welfare Data Center, Sacramento, California; Dec. 7-9, 1994: *Introduction to Base SAS Software*.

COMPUTER PROFICIENCY:

Software Experience: NVivo, SAS, SUDAAN, SPSS, Epi Info, Microsoft Office (including Word, Excel, Power Point, Visio, and Access), ArcView (limited); and some basic html programming

Sources of Data: original data collection during doctoral dissertation; California Stroke Registry/California Coverdell Program; California Health Interview Survey; California Healthy Kids Survey; California's Medi-Cal (Medicaid) claims and encounter data; California Women's Health Survey; Adolescent Family Life Program-Cal-Learn Program; California Vital Statistics Birth, Death, and Birth Cohort files; Fetal Infant Mortality Review Program; Current Population Survey; California Adult Tobacco Survey; California BRFSS; California Youth Tobacco Survey; California Department of Finance; California Tobacco Survey (UCSD); California Board of Equalization; U.S. Federal Trade Commission; Americans for Nonsmokers' Rights; California Office of Statewide Health Planning and Development Patient Discharge, Emergency Department, and Ambulatory Surgical Center data; California Cancer Registry; Cardiovascular disease Outreach Research and Epidemiology Program; Adventist Health Study; field data collection for undergraduate research program

REFERENCES AVAILABLE UPON REQUEST