

From Santa Barbara To Washington: A Person's And A Nation's Journey Toward Portable Health Information

The Santa Barbara data exchange project was a learning zone for the entire nation.

by **David J. Brailer**

ABSTRACT: The Santa Barbara County Care Data Exchange recently decided to disband. Because I founded the Santa Barbara Project and went on to lead U.S. health information technology (IT) efforts, it has been suggested that federal health IT policy relied too heavily on the approach used in Santa Barbara. Concerns have been expressed that the U.S. health IT effort rests upon a weak foundation and may be unsustainable. Conversely, the lessons of Santa Barbara were evident to investigators, including myself, long before its termination. These lessons, not the original assumptions and methods used in Santa Barbara, were applied to federal policy. [*Health Affairs* 26, no. 5 (2007): w581-w588 (published online 1 August 2007; 10.1377/hlthaff.26.5.w581)]

OUR VAST HEALTH CARE INDUSTRY SPAWNS many experiments and innovations. We usually only learn about those that suggest that change is warranted in how medicine is practiced. The so-called negative studies, which themselves hold important lessons for the health care industry, are rarely probed.

The Santa Barbara County Care Data Exchange, commonly referred to as the Santa Barbara Project, recently decided to disband. This was an attempt at innovation that failed, making it in many ways a negative study. However, it is one that holds many lessons for the nation's health information technology (IT) aspirations.

I designed and advised the Santa Barbara Project from 1997 to 2002 before leading the nation's health IT effort from 2004 to 2006. Some therefore might be concerned that the project was prematurely replicated across the nation or that its goals were wrongly embedded into federal policies and strategies. Others may worry that our national health IT infrastructure rests upon a shaky foundation

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because of an undue reliance on the precepts of the Santa Barbara Project.

The project's recent demise certainly illustrates how hard it is to make health information truly portable and to get inertial health care stakeholders to look to the future. Naysayers will use its closing to validate their belief in health care's status quo ante. However, it gave us something much more meaningful and positive, as the best research always does: It provided us with new ideas to test and lessons to apply in our daily work. I applied these lessons when I led the nation's health IT initiative. In fact, many of the decisions I made as the national coordinator for health IT were based on the Santa Barbara Project's lessons.

The endgame of the Santa Barbara Project was evident in 2002. The experiment had run its course, and it was time to move forward and apply what was learned. The lessons were clear to me long before I went to the federal government. I and others wrote a white paper in 2003 documenting what was known to date and how it affected what was by then a burgeoning national movement.¹ Robert Miller and Bradley Miller have brought this up to date with their *Health Affairs* paper that accompanies this one.²

In this paper I go further and describe why the Santa Barbara Project ended and, more importantly, summarize the lessons I learned from it and applied to federal policy. I hope that the dialogue it inspires will ensure that our national health IT efforts remain on the proper path.

The Beginning And End Of The Santa Barbara Project

■ **Origins of the project.** When I proposed the Santa Barbara Project in 1997, I did not seek to inspire a national movement. I studied and taught about Community Health Information Networks (CHINs)—expensive and ultimately unsuccessful efforts in the 1980s to share health information—and supply-chain management at the Wharton School. I observed that these ideas might be feasible in post-Internet, post-integration health care. The Santa Barbara Project grew out of my interest in developing a way to apply a modernized CHIN approach to the collection of populationwide, longitudinal health information for quality and public health improvement. Real-time data access in clinical decision making, although it had the potential to add enormous value to care delivery, was well beyond our goal.

We set out to test population health data collection in a large-scale field experiment on an order that is rarely seen in health services research. To minimize bias and confounders in the study, we selected a community that had a stable, isolated, and provider-dominated health care market and that welcomed participation in research. This was longitudinal research, not a prototype or a beta test, so having an environment that was stable over time and protected from other currents was essential. We did not select Santa Barbara for sustainability, business case, governance, provider investment, prior history of health care innovation, or any other factor that is deemed minimally necessary by today's regional health information organizations (RHIOs). If anything, we selected it because the health care leaders

there were willing to be the subject of this experiment.

■ **The 2002 turning point.** Our 2003 white paper and Miller and Miller's *Health Affairs* paper discuss the project and its progress between 1998 and 2002, so I do not address that further here. However, by 2002, it was clear that the project faced diminishing returns and that further progress would be unlikely. Like all good experiments, it was time to stop and write about what happened and what we learned.

No one wanted to see the Santa Barbara Project come to an end, and, indeed, a few valiant people tried to turn it into a commercially viable enterprise. But any hope for this ended in late 2002, when the board of directors of CareScience—my company, the principal contractor on the project—decided to sell CareScience in what turned out to be a fateful decision. This decision reflected how the post-dot-com and post-9/11 fear psychology of Wall Street had permeated the board and senior management of CareScience. After that decision, I left the company, company budgets were cut, and staff was reduced. From that time forward, the Santa Barbara Project had little hope of realizing its commercial promise.

Lessons Of The Santa Barbara Project

Many aspects of the Santa Barbara Project offer lessons to the nation's health information exchange (HIE) movement. Its demise, though, does not seem that relevant to today's HIE projects or to the broader policy issues that surround them. HIE efforts that are trying to move from being research projects to being sustainable enterprises should examine the Santa Barbara Project closely. Projects that are financed with venture capital or through public markets should look at it for the hard realities of financial capital in the health care industry with its perverse incentives and quality-of-care externalities. However, these are beside the point for most of the U.S. health care industry. Relevant to all are the lessons that flowed from the life of the Santa Barbara Project, not its death.

I count eight major lessons that the project brought to federal policy.

■ **From top-down to bottom-up.** Orthodoxy in many IT projects teaches that there should be tight top-down control over implementation: rigorous schedules, tight project plans, and many other centralized corporate controls. This approach was applied to the Santa Barbara Project, but it became clear very quickly that this does not work in the give-and-take current and loose confederation of community efforts. The project shifted to an organic, bottom-up approach with many lateral dependencies that are not governed by a central commander.

The bottom-up approach was foundational to federal health IT efforts. The Office of the National Coordinator strove to organize and drive change, not to decide what change needed to occur. That office was just that—a coordinator, not a commander—and projects were as decentralized as possible. Some tech leaders criticized this effort for being too loose, essentially arguing that good was the enemy of perfection. Those who wanted the federal government to be the controller of every aspect of health care complained that control was being ceded to the private sec-

tor. However, looseness and grassroots energy are aspects of the national effort that have led to the most success. Many local and regional efforts now follow this approach in their efforts, to their advantage.

■ **From technology to people.** The developers of the Santa Barbara Project, including myself, were obsessed with the latest technology, devices, connectivity, and many other technical variables. There was a strong interest in applying peer-to-peer Internet methodologies (for example, Napster-like information sharing) to health care information. This resulted in an overengineered, overly complicated product that had little regard for how physicians and consumers would use it. Human factors, workflow, and how information fit into the broader goals of the community were not considered. In other words, this was a typical 1990s health IT project. The gap in the Santa Barbara Project between the technical imperative and users' needs was never closed.

The lessons from Santa Barbara's undue technology focus influenced much of the early thinking about national health IT policy. In many ways, this lesson was applied by putting authority over health IT in the hands of users and keeping the techies "who knew better" at arm's length. This is why contractors were required to build the Nationwide Health Information Network (NHIN) in collaboration with communities rather than among themselves. This is also why the Certification Commission for Health Information Technology was asked to have minimal governance representation from vendors—not to keep vendors out, but to keep the focus on the decisionmakers in health care and what they want from information tools. This turnabout was highly contested, and it took extraordinary effort to convince leaders that technology decisions were within their scope of responsibility and could not be delegated to others.

■ **From value model to business model.** I have had a long-standing interest in the strategic value of high-quality care to hospitals and physicians. CareScience pioneered the use of value analysis to support quality management strategies in the 1990s, and this was adapted for the Santa Barbara Project. The quality benefits of HIE, such as lives saved, errors reduced, emergency visits averted, and referrals eliminated, were explored in the project. In other words, hospitals and physicians were asked to adopt HIE on its merits and, by doing so, risk reducing the very activities that drive their revenue. CareScience had always worked with a self-selected group of providers that placed higher strategic value on quality, but the project demonstrated what a truly unusual collection of providers this was. It eventually shifted to a business model that showed the monetary benefits (and costs) of portable information and better care. This business model was demonstrated in the 2003 report about the Santa Barbara Project.³

The business-case lesson was applied throughout federal policy. Most providers believe that HIE harms their viability and are opposed to it, although many won't say this in public. Because of this, the Office of the National Coordinator encouraged RHIOs to identify business models for HIE that neutralize or at least

minimize these concerns. Federal contractors were encouraged to become financially self-sustaining so that business-model barriers could be considered up front and false starts would be minimized. Through these efforts, health IT has made gains in demonstrating financial viability, but progress has been limited by existing federal payment policy.

■ **From subsidies to market incentives.** Participation by the entire community of providers in the Santa Barbara Project was sought in the project. This was costly and required very large philanthropic grants. These subsidies were beneficial in that they allowed many organizations to participate. They did not need to have the organizational readiness, coinvestment, or know-how to get involved. It was bad for the same reason. Santa Barbara providers had nothing at risk and no hurdle of commitment in the project; they bore no cost for the philanthropic capital and faced no adverse consequences for how it was spent.

The fundamental incentives in the health care industry undoubtedly need to be aligned toward quality of care. However, Santa Barbara showed how outright subsidies and ultra-cheap capital can undermine progress. This observation caused me to be wary of explicit federal financing of health IT adoption, other than for safety-net organizations that might not be able at all to raise the capital to keep up with IT investments. This also elevated the importance of changes to the Stark and antikickback rules, which were called for in our 2003 report. These rule changes not only mobilized financial capital for health IT, but also require capital to be matched with know-how on a local basis in a way that lowers risk. A hospital won't offer an electronic health record (EHR) to one of its physicians unless it really works as promised. This is also why the overwhelming majority of federal health IT money was spent through contracts and not grants, since grants do not provide mechanisms for accountability in the way that contracts do.

■ **From providers only to all comers.** The Santa Barbara Project replicated one major, and previously unidentified, flaw in CHINs, which was that they were provider-only organizations. Physicians and hospitals dominated all aspects of these projects, and consumers, employers, health plans, labs, pharmacies, and many others were often not welcomed. After the project's provider-only approach became clearly problematic, the project tried to shift its governance toward a more inclusive and diverse model. This was disruptive and did not occur to any meaningful degree.

As a general rule, stakeholder diversity is a key to improving the outcomes of health care improvement projects. However, provider groups in Washington, D.C., are similar to providers in any market, in that they have limited experience with forming broad coalitions with other stakeholders. Because of the Santa Barbara Project, multistakeholder governance became a defining characteristic of nearly every aspect of the national health IT effort, from the formation of RHIOs to the governance requirements for federal contractors. This became most visible in the composition of the American Health Information Community, for which stakeholder diversity is a hallmark.

■ **From generalized information to specific information.** The Santa Barbara Project was a generalized HIE project. That is, it sought to exchange a broad array of clinical information. This meant that, for example, some of the information on an emergency room patient would be available, but possibly not all of the information needed to avert a hospital admission or other adverse consequence. As it became clear that HIE could drive value only if it supported clinical decisions sufficiently to influence their outcome, the project shifted to use cases that were specific in their benefits and exacting in their information requirements and operational constraints.

The tendency in Washington is to be broad and to operate at a least-common-denominator level. This would have reinforced an approach not unlike the early days of the Santa Barbara Project. However, because of the experience in Santa Barbara, the Office of the National Coordinator required tightly defined use cases and specific information for both federal and private-sector projects. This incessant focus on use cases, specificity rather than generality, and incremental evolution of HIE projects was criticized by some who wanted faster and bolder progress, but it was a key to success for much of what has occurred.

■ **From open systems to specified standards.** The Santa Barbara Project's ambition was to design a scheme by which broad sets of information were assembled and presented to clinicians. The technology was designed to be able to retrieve any information from any EHR and present it to any other EHR. To do this, the requirements for the information content had to be relaxed. The project's standards were "envelope" standards in that they focused on how to retrieve and present information. There were few standards requirements for the actual data itself (the "payload"). For example, a physician-user could retrieve a lab document for a specific patient on a certain date but could not view only those reports with abnormal results. In other words, a highly specialized and protected search engine was designed (although this term hadn't been in use at the time). It became clear that the cost and complexity of connecting to any information system was prohibitively high and that clinicians wanted the ability to assemble and integrate the data. Therefore, the project began shifting away from the search engine model to a specific and integrated data repository model, but this didn't occur until later.

The need for tightly specified information was an important lesson for national efforts. However, two challenges were encountered. First was the Health Insurance Portability and Accountability Act (HIPAA) rule that included specific information standards in the regulations themselves. These standards were, needless to say, incorrect and outmoded before they became policy ten years ago. There was no easy mechanism to keep these regulation-based standards current with new innovations. Second was a set of standards development organizations that understood the importance of standards but talked mostly among themselves and on with their own priorities on their own timetable. To apply the lessons of Santa Barbara to federal policy, vehicles for standards prioritization, development, and maintenance outside the regulatory process had to be developed. These vehicles

had to connect standards priorities and timelines to the broader agendas for health care improvement. Thus, the Health Information Technology Standards Panel and the Certification Commission for Health Information Technology were created (the latter was piloted by CareScience for the Santa Barbara Project and for community clinics in California). These efforts are still works in progress but show promise for the U.S. health IT effort.

■ **From institutional privacy to personal privacy.** Privacy concerns in Santa Barbara were major issues from the outset. More money was spent on attorneys' fees than on technology, consulting, or any other line item. This was true in part because the participants were opportunistic and therefore would not accept the risks that would accompany normal business operations. This effort was intrinsically risky because of broad disagreement about which privacy policies applied and what actions those policies required providers to take. It became clear that the substantial ambiguity in existing security and privacy policies made this problem impenetrable. Any number of lawyers would draw different conclusions from the federal and state privacy rules that were spread across many chapters of code and among many agencies. This made it difficult for fifteen provider-leaders of the Santa Barbara Project to understand or agree on what they could or should do under these rules.

I saw firsthand how the efforts to tighten privacy rules, particularly in California, had a paradoxical effect. Providers could not understand how to develop new ways to share protected health information under these incoherent rules, causing them to continue faxing and shipping medical records on paper through uncontrolled and unaccountable processes. Therefore, Santa Barbara's privacy lessons were applied to federal efforts by focusing on what the privacy schema should be for the digital era of medicine, and on how it could be enconced in a way that minimized variation and ambiguity. Among the first results of this was the formation of the Health Information Security and Privacy Consortium. This is a collaboration between the federal government and forty-three states, which is charged with developing a consensus on privacy rules for a world where health information moves alongside patients. That group is finalizing its work during the summer of 2007, and it has the potential not only to make health information more protected, but to make it more portable at the same time.

The Santa Barbara Project In Perspective

These eight lessons from Santa Barbara shaped nearly every aspect of the federal approach to health IT. Some might say that these lessons are self-evident, but that misses the point. They were not self-evident ten years ago. The Santa Barbara Project resulted from more than \$15 million and thousands of hours of field work. It was open and transparent in every aspect of its successes and setbacks and has invited scrutiny and critical examination. It helped make these obscure lessons obvious. If nothing else, it changed the state of the art in health information by its efforts and willingness to share what it learned.

Thomas Kuhn described in *The Structure of Scientific Revolutions* how the cumulative weight of research and experimentation—whether positive or negative—can hasten the collapse of an existing paradigm.⁴ We are in the earliest steps toward major upheaval in the obsolete paradigm of U.S. health care. Health IT is one of the prime forces of innovation and disruption. It will both hasten this change and soften the fall when change does occur. Projects like Santa Barbara—whether they “succeed” or “fail”—are part of a justified and relentless attack on the status quo of health care amid the unending hope for something better. Without these efforts, the old paradigm will continue, and we will have no chance for meaningful progress. Yes, Santa Barbara provided hard and sometimes bitter lessons on the ways of Wall Street, philanthropy, technology dreamers, and health care providers. But it also reinforced a much larger and more empowering lesson: to move forward toward a vision, regardless of how uncertain or difficult it seems.

I did not go to Washington to spread the Santa Barbara model to the United States. My decision to go to Washington resulted from something much deeper: my careerlong interest in developing ways to improve quality of care and to give consumers more control over their care. I went to government in part because it was clear that health care innovators could not succeed unless policies that protect the status quo of care delivery are changed.

The Santa Barbara Project was a learning zone for me. This experience utterly changed how I saw the problem and, more importantly, how the problem should be solved. I lived for years in the complexity of state-of-the-art technology, the conflicting relationships among health care stakeholders, and the paradoxical economic currents in the health care industry. I applied very different approaches to federal policy than I would have had I not done the project. It was the lessons of the Santa Barbara Project that were translated into policy, not its assumptions, hypotheses, or mistakes.

The Santa Barbara Project was also a learning zone for the nation as a whole. The issues that played out in Santa Barbara happen everywhere in the United States, and the lessons of Santa Barbara are relevant everywhere in the United States. We would not want to be three years into the federal health IT initiative without Santa Barbara’s having been tried. I hope that we take the time to fully appreciate its true lessons. Whether it succeeded or failed is not interesting. What matters is that the project happened, that it ended, and that we learned.

NOTES

1. D. Brailer, N. Augustinos, and S. Karp, *Moving toward Health Information Exchange: Interim Report on the Santa Barbara County Care Data Exchange* (Oakland: California HealthCare Foundation, July 2003).
2. R.H. Miller and B.S. Miller, “The Santa Barbara County Care Data Exchange: What Happened?” *Health Affairs* 26, no. 5 (2007): w568–w580 (published online 1 August 2007; 10.1377/hlthaff.26.5.w568).
3. Brailer et al., *Moving toward Health Information Exchange*.
4. T. Kuhn, *The Structure of Scientific Revolutions*, 3d ed. (Chicago: University of Chicago Press, 1996).