



Genomics and Public Health Practice: Lessons from State Pilot Projects

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Over the last several years, genetics has begun to play a greater role in state public health departments (Wang and Watts, 2006). The traditional agency placement for genetics has been within maternal and child health with programs for newborn screening, surveillance of congenital disability, and maternal nutrition. As research has expanded into the genomics of adult-onset chronic conditions, a handful of public health departments have begun to incorporate genomics into their work in these areas as well.

This is an interesting time to examine these public health genomics programs. The programs have been in place for several years now, but genomic science continues to be in flux with new findings emerging each day. Some question the utility and applicability of genomics research because translation from bench to bedside remains somewhat elusive. Yet, others point to the ways that genomics is transforming health and medicine.

The purpose of our study was to compare state genomics programs in order to understand their evolution over time, to document their successful activities, to assess the facilitators and barriers that program administrators encountered, and to evaluate how programs integrated into public health more broadly. Ultimately, our findings are intended to support other states that choose to develop genomic programs and provide them with strategies for doing so.

We used a case study approach to examine seven states: Connecticut, Oregon, Michigan, Minnesota, New York, Utah, and Washington. These states were chosen because they have been active in the areas of genetics and genomics. Four states had cooperative agreements with the Centers for Disease Control (CDC) National Office of Public Health Genomics (OR, MI, MN, UT), but three states did not (CT, NY, WA). We examined states' documents and states' websites that communicated information about genetics and genomics. We also conducted semi-structured telephone interviews in spring 2008 with up to three individuals per state resulting in interviews with eighteen individuals.

State Characteristics

While we selected our sample states because of their shared interest in genetics and genomics activities, the seven states had many unique characteristics. Interviewees noted demographic, geographic and political factors that helped shape their programs and approaches. Educational levels, population age, religious beliefs and cultural values of the respective state populations often affected the interest in and acceptance of genomics programs. Interviewees

noted that more highly educated populations were more likely to understand genetics and genomics, and this understanding contributed to greater interest in public health genomics. Several interviewees also reported that young people “really get it.” Religious beliefs were also important. For example, a large percentage of the population in one state is affiliated with the Church of Jesus Christ of Latter Day Saints whose long tradition of interest in family history resulted in an early and broad acceptance of genetic services and technologies. Cultural values also play a role in public acceptance of genetics and genomics. Several interviewees noted that the diversity of cultural values in their states presented challenges to finding a broadly acceptable approach to program activities.

Geographic characteristics of states affected genetics programs in much the same fashion as they affect other public health programs. Interviewees reported that service delivery was more challenging and more expensive in large states, states with geographic barriers (e.g. mountain ranges), and states with large rural territories.

Political characteristics of states also affected the nature of genetic and genomic programs across states. Our interviewees related program success to access to key stakeholders in the political process and the stability of the political landscape in their states because of the centrality of state funding to program budgets. While states with CDC funding were less reliant on state support during the five years of the cooperative agreements, program managers in all states underscored the importance of state funding over the long term. Changes in important stakeholders – from governors to health department agency heads – created the need for program staff to spend additional time and resources to educate new personnel about program activities and challenges. A number of interviewees also mentioned the importance of their states’ political culture. In some states, a political culture of cooperation enhanced the ability of programs to work together for mutual benefit. In other states, a culture of competition among programs created challenges for joint activities.

Finally, program activities are influenced by the lens through which states approach genetic and genomic services. Where genetic services are seen as a necessary response to existing problems, program activities tend to be narrower and more traditional (e.g., newborn screening). Where genomic services are seen as essential to a vision of maximizing the benefits from emerging technologies, program activities are more likely to be broader with a larger focus

on adult and chronic disease and prevention strategies. On the other hand, however, the stability of financial support from state funds, especially during lean budget years, is related to the centrality of program activities to immediate and measurable population needs.

Public Health Genomics Activities

Public health genomics programs were engaging in similar activities across the seven states. Programs continued in their traditional work in the maternal child health area, but interviewees discussed incorporating a broader lifespan approach in order to expand into adult health and wellness. Many programs were working on implementing and updating state plans that included both genetics plans as well as plans from other health programs like cancer. Staff members were building relationships with and collaborating with chronic disease partners. Programs prioritized educating the workforce and peers in public health. Finally, states were exploring family health history by incorporating family health history questions into population-based surveillance systems.

Factors Contributing to Program Success

Without a doubt, the most often cited factor contributing to success was the creativity, perseverance, and commitment of program staff. Program staff in each of the seven states could quickly name the often singular person who had provided the initial vision for the program, made the key strategic decisions about program placement or function, or worked tirelessly on behalf of the program mission with modest resources – often all three. While the specific expertise of the person varied by state, her energy, creativity, and passion were constants across jurisdictions.

Successful programs found an appropriate balance between directly leading the charge for genomics activities and supporting the development of those activities among other parties. Creating these secondary opportunities was crucial both to make the best use of limited resources but more importantly to assure the continuation of genomics activities. In states with CDC cooperative agreements, interviewees who were most optimistic that their genomics activities would continue beyond the end of the cooperative agreement period were those who felt they had come to do at least as much supporting as leading. “Capacity was increased,” stated one interviewee, “even if I haven’t been the one to place it there.”

One strategy used to extend genomics activities beyond program boundaries was to identify other early adopters of genomics technology and forge collaborations with them.

Program staff in several states spent time understanding the activities of early adopters and found ways to weave genomics into their work. One interviewee reported going through the grants that supported related programs so she could point out specific places where genomics might fit with the existing grant objectives. Another interviewee reported that her approach was to “make genomics a solution to other peoples’ problems.” Collaborative activities often included developing genomics content for education and communication materials for other programs’ projects. In one state, this took the form of an online continuing medical education training module for diabetes educators; in another, inclusion of an explanation of the importance of family history in an educational brochure disseminated by the chronic disease program. Integrating genomics content into graduate education, particularly in the online curriculum, in state schools of public health grew out of program collaborations with one or more universities in the state.

Another successful collaboration was working with other programs and agencies to expand existing data collection efforts to include family health history questions, most often through the Behavioral Risk Factor Surveillance System (BRFSS). This activity was mentioned in three of our seven states. In one state, program staff worked with the cancer division to use geographic information systems (GIS) to analyze the distance that persons with early onset cancer traveled to access services. In another state, genomics program staff obtained access to an existing database that already included family health history questions that had never been analyzed in the 20 years of its collection. As a result, they were able to provide the cancer program with a quantitative analysis of the family health history of women who received mammograms.

Some states, but not all, had people who championed genetics and genomics activities. These individuals believed in the importance of genomics and voiced support for program activities, provided key connections for staff, and were generally helpful at every opportunity. While most champions came from within the states’ Departments of Health as directors of chronic disease programs, cardiac, diabetes, cancer, obesity, or asthma programs, individuals with other affiliations were also mentioned. In several states, there were champions within universities, generally within schools of public health or family medicine. In one state, the academic champions were within the environmental health division in the school of public health

and an associate dean of public health practice. Other champions included the legal counsel for the department of health, the state surgeon general, faculty in genetic counseling programs, and the head of radiology at the state school of public health. Often these champions served on the program's official or unofficial advisory body.

Explicit partnerships were another important contributor to program success. With limited budgets and limited personnel, genomics programs relied on the assistance of other agencies and organizations to extend their work. Productive partnerships were formed with other state programs and agencies, formal and informal advisory committees, universities, genomics programs in other states (an activity often facilitated by the CDC), and other interested parties including families, providers, and local public health personnel. These partnerships generally focused on the same kinds of activities as the collaborations: joint development of educational content, technical assistance, joint grant preparation, and data collection.

There were organizational factors that related to program success as well. Some states already had state genetics and genomics plans. Thus, these states had road maps in place, and the CDC cooperative agreements provided a mechanism to move down the road with a clear vision and destination.

A number of interviewees noted the importance of maximizing the windows of political opportunities as they arose. Programs increased their visibility and value by undertaking activities related to state interests as they arose. For example, a focus on biobanking in one state was a response to state concerns about economic development. Another program became involved in providing staff support for privacy and anti-discrimination legislation. A legislative interest in newborn screening provided an opportunity for an expansion of genetic services, while another program took advantage of its state's weariness with bioterrorism to offer genomics as an exciting and productive new direction. An interviewee described how her program used an aggressive marketing campaign by Myriad to create interest in genetic testing education.

Barriers to Program Success

Programs also encountered barriers to carrying out their missions. Limited funding was, of course, a frequently cited barrier to program success. According to our interviewees, this lack of funding was often the result of a limited understanding of the importance of genetic and

genomic services among those making budget decisions. Genomics, in particular, was given a low priority in many states due to the pressing demands of tight state budgets.

Those programs without a well-placed and enthusiastic champion faced more difficulties receiving recognition and financial support of their agencies. Insufficient resources in addition to limited funding (e.g. staff and time) were also noted as barriers. Finally, interviewees reported that a constantly changing funding base also created challenges for successful and stable program operations. In programs with only one or two full time employees, staff time spent identifying and soliciting new sources of funding was time taken away from program activities.

Another barrier that was cited by many interviewees was the dependence on a funding base with a changing focus. Program staff were frustrated that at a point when they felt they were finally getting traction for genomics activities in their states, the CDC cooperative agreements were ending and being replaced by a program with very different objectives.

A number of interviewees expressed the view that rapid changes in technology and expansion of new scientific knowledge were often overwhelming, making it difficult for program staff to feel confident that their knowledge base was current. Most agreed that the CDC newsletter provided a valuable source of updated scientific information, and all relied on external partners as well as internal expertise for this purpose.

Double-Edged Swords

Program staff viewed the use of the media as a double edged sword. On the one hand, media attention helped to increase the public's general awareness of genomics. However, interviewees noted their concerns that visibility in the media created expectations that their programs were unable to fulfill. In general, interviewees reported that they took a more reactive than a proactive approach to media coverage, responding when asked, but largely without a specific strategic approach.

In many cases, the timing of the CDC cooperative agreements was fortuitous for states wishing to implement existing plans for genetic and genomic services. In other cases, CDC funds were the catalyst for expanding services beyond traditional newborn screening and maternal and child health programs. In a few cases, CDC funds restricted activities that were deemed to be too research focused for the objectives of the cooperative agreements. In terms of the amount of funding, a number of interviewees reported that the funds were adequate until the

programs were successful, at which point more demands were made on programs than their CDC funds alone could support.

Disciplinary Backgrounds

Staff members of public health genomics departments tended to identify with one of the two disciplinary backgrounds: public health or genetics, but rarely both. These disciplines and training brought different strengths to programs. Having a background in public health helped programs because staff members were comfortable with the public health culture of health departments and could mold genomics to fit within the goals of other more traditional public health programs. These public health practitioners were trained to incorporate a population-based perspective that drew on a breadth of fields. As a result, they could comfortably discuss social determinants of health as well as biological risk factors and the interaction between them. Further, they were able to communicate genomics messages to a range of audiences. One interviewee expressed the success of this approach succinctly: “It’s not about genomics, it’s about public health.”

In contrast, persons whose first disciplines were genetics offered credibility to the programs and to their messages about new research. With an expertise in the science, they did not need to go outside of the department to find genomics consultants. These staff members who were often trained as genetic counselors also felt comfortable in their communication and education duties.

Structural Approach

Programs took two different approaches to structuring themselves within public health departments. One strategy was to develop and to maintain a distinct genomics unit, separate from diabetes units, cancer units, maternal and child health units, etc. The benefits of this tactic were that the genomics programs retained control in setting and furthering their agendas. They could promote leadership within departments of health in the area of genomics, thereby creating more visibility for themselves. In addition, distinct structures were able to communicate consistent and cohesive messages to stakeholders.

In contrast, some genomics programs opted to integrate themselves within other existing health units. Examples of integration included participating in the stroke prevention unit’s workgroups or incorporating information about genomics and family health history into state

cancer plans. This approach kept genomics programs as well as genomics as a topic flexible and versatile and occurred through enhancing partnerships with other units. As partners increasingly recognized the cross cutting nature of genomics, they also perceived genomics as being less threatening and became more interested in learning how genomics could enhance their existing projects. This made the efforts of genomics programs more sustainable in the long run as genomics became an underlying concept within multiple units' work.

Sustainability

Sustainability was a very large concern of all the CDC-funded programs. Most of our key informants questioned the wisdom of changing the direction of the CDC cooperative agreements just at the point when successful programs had been built, but could not yet be sustained with state-only funds. Most interviewees expressed the view that their programs would revert to the narrower genetics (as opposed to genomics) focus of the pre-grant era. There appeared to be little prospect for additional state funds for the broader program activities, but staff in all CDC-states were exploring new grants and collaborations to maintain their work. Those programs that had maintained a strong connection to maternal and child health staff, including the states without CDC cooperative agreements, felt less vulnerable. Those programs that had focused on integrating genomics into the activities of other departments and agencies were optimistic that their work would be sustained at some level even if their program was not.

Lessons Learned

Our review of the genomics activities in seven states provides lessons that can be useful to other states as they create new programs or broaden the focus of existing programs. Perhaps the most important observation flows from the nature of genomics as a perspective with cross-cutting applications. As a result, programs do not always have to lead in order to succeed. Supporting early adopters, partnering, and pursuing windows of opportunities (particularly in the areas of data collection and education) as they arose were all successful strategies employed by program staff in our sample states. Program structure mattered less than the passion and collaborative abilities of program staff, the existence of champions, and the fit between program activities and the demographic, cultural, and political context in which the program operated.

As the current round of CDC cooperative agreements end, the sustainability of state genomics programs remains to be seen. States are unlikely to replace the CDC funds with funds

from their own coffers. However, to the extent that program staff members have been able to instill a genomics perspective in the minds of the broader public health community, genomics activities will continue to grow.