

Solving the Connecticut Data Deficit through Collaboration

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Without data that could be monitored over time, how could those interested in improving the health of Connecticut residents track progress or measure success? This was the question the Aetna Foundation and the Connecticut Health Foundation (CT Health) asked on a Monday afternoon in the summer of 2010. Both foundations, along with several other health funders in the state, were making progress on various health issues, but lacked consistent data to measure progress in reducing health disparities and the impact of philanthropy's efforts to advance health equity.

Aggregate health data in Connecticut paint a positive picture of the health of its residents. Yet, when you stratify racial and ethnic data, a huge gap emerges between the majority population (whites) and racial and ethnic populations. Moreover, existing public data were fragmented, difficult to access, lacked a patient's perspective, and were not specific enough to Connecticut to be useful.

In recent years, several national foundations, such as The Henry J. Kaiser Family Foundation and The Commonwealth Fund, have conducted large-scale surveys of patient health that made it possible to illustrate the health status of specific demographic groups within the larger population and demonstrate philanthropy's impact on improving health and health care. Equally as important, survey results became important sources of information for many other organizations, stakeholders, and advocates looking to change institutional systems and develop public policies to improve health outcomes.

Several foundations were eager to commission a similar patient health survey focused specifically on Connecticut. But we understood that implementing a study modeled on these national surveys would be very expensive and beyond the resources of any one foundation. Instead, multiple funders would need to come together to pool financial and human resources to make it happen.

COLLABORATION

Collaboration comes with abundant opportunities for organizations to increase their impact. And yet, an irony in the field of philanthropy is that we often ask our grantees to collaborate, but we often do not "walk the talk" ourselves. Collaboration is hard work. It takes time and demands difficult conversations around delicate issues, such as roles and responsibilities.

Yet, the ability to measure the health of Connecticut residents would make collaboration worth the effort. To find partners for the work, the Aetna Foundation and CT Health brought the idea of a patient health survey to the Funding Health Affinity Group (FHAG), a consortium of the Connecticut Council for Philanthropy (CCP), a statewide association of grantmakers.

Many foundations were excited about the opportunity but coming together around a common theme took some time. Although the members of FHAG have "health" in common, each funder approaches health from its own unique mission. Ultimately, not everyone signed on. We learned that it was not realistic to expect all 20 members of the group to fund a statewide survey.

Ultimately, five foundations—the Aetna Foundation, CT Health, the Donaghue Foundation, the Foundation for Community Health, and the Universal Health Care Foundation of Connecticut (Universal)—agreed to collaborate and move forward with a statewide patient health survey in the fall of 2010.

As the scope of the survey changed, another funder came back into the fold. Initially, the survey was not going to include children due to cost issues, and the Children's Fund of Connecticut, which works solely on issues related to children, opted not to join at that time. In the process of the survey design, however, this changed, and the Children's Fund was asked to come back to the table to be a part of the collaboration.

We each had our own way we wanted to employ the survey findings. CT Health and the Aetna Foundation focused on racial and ethnic health disparities, while Universal was interested in health reform more broadly. The Foundation for Community Health prioritized the health of rural populations, while Donaghue wanted to target patient experience data. The Children's Fund was interested in access to community-based health and mental health care for children.

Despite the diverse priorities in the collaborative, the fact that we still came together demonstrates our commitment to the value of collaboration and the importance of health data in shaping future foundation initiatives.

IMPLEMENTATION

With the collaborative formed, the time came to hash out the delicate details. First and foremost was the issue of finances. Who would contribute what? The endowments of our foundations varied widely—would putting in the most amount of money entitle that foundation to dictate the direction of the project? Or would everyone equally share decisions around survey development?

To determine the financial piece, we first laid out the scope and scale of the project and developed a budget estimate. With that number firmly in place, we were able to engage in frank conversations about what each of us could contribute.

Collective ownership can become obscure ownership if roles are not well defined. We decided on the creation of a memorandum of understanding that specified equal votes for all, named a project director, and named CCP as a fiscal agent for the project.

Survey design and data usage were other discussion points. We recognized that many surveys used provider-reported data to generate conclusions about health. Not all of us were satisfied that this was the most accurate measure of residents' health. Instead, we decided to use resident or patient self-reporting to measure the health of the state. And, as we were interested in disparities data, we were deliberate about ensuring appropriate oversampling of underserved communities, including minority populations, people with low incomes, and the uninsured.

We also wanted to ensure that data were used in a way that created change. Ultimately, we decided that a series of policy briefs outlining survey results would be the most efficient and effective method of disseminating survey data.

Working out these details took approximately eight months. The result of our hard work was a stronger, more clearly defined collaboration with a solid groundwork from which to launch the project.

MOVING FORWARD

With these parameters firmly defined, we created a call for letters of intent to conduct the survey, and then asked for a

full proposal. Ultimately, we selected the University of Massachusetts Medical School Office of Survey Research to receive the grant.

The hand-off was a huge transition for everyone involved in the project. We began to think about maintaining our momentum and clarity, and keeping people engaged and on message. Simultaneously, the CEOs of the collaborating foundations were transitioning the day-to-day management over to project managers and senior program officers. We were also intentional about making the grantee's experience of partnering with multiple funders as frictionless as possible.

We experienced a microcosm of the "who does what?" conundrum even with communicating to the media about the project. As communications staff across the organizations came together to determine who would do what, there was a desire to both not step on toes, but to make sure each organization could highlight its involvement. The results were positive: we whetted our media contacts' appetite for the results to come, shared contacts, and maintained a consistent strategy and messaging in our press releases. Seven media pieces were also picked up by national and local media in radio, print, and on-line publications. We hope the de-identified data set will be broadly available to researchers, stakeholders, advocates, and others by early 2013.

One outstanding question remains— who owns the data and future follow-up surveys? We are interested in transitioning this information to the Connecticut Department of Public Health. We know, however, that state resources for this type of data collection can be difficult to guarantee in the future. The collaborative will need to evaluate this and other ideas down the road.

RECIPE FOR SUCCESS

We learned in real time that several ingredients are important for a successful collaboration. Big-picture, persuasive visionaries are needed to guide and create commitment among interested parties. Laying the groundwork of executive logistics early on in the collaboration leads to fewer issues down the road. What makes these ingredients stick together are a sense of trust, open and candid conversation, and a sense of excitement about the work and its outcomes. And, it does not hurt to have a grantee (or fiscal agent) who has the patience and good will necessary to work with a group of funders.

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