

## Working to Fill the Information Gaps in Cancer Care

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Upon hearing the words “you have cancer” many questions are apt to run through a patient’s mind. Key among them is: *Where do I go to get the best care?* Today, meaningful information to help patients answer this question is lacking. The California HealthCare Foundation (CHCF), an independent philanthropy based in Oakland, is funding projects to try to fill this gap.

### BACKGROUND

At first blush, there seems to be an abundance of material about cancer on the Internet and elsewhere. Yet scratch the surface and it is apparent that, while you may be able to find out which providers are famous, there is scant information about who is actually good at delivering clinical care. And when it comes to cancer care, knowing who is good is critical. Choosing the well-known provider (who may not actually be that good at clinical care) could mean frequent long-distance travel, requiring a network of support (child care or transportation) and/or major expenses (going “out of network”). These elements add additional burden to an already-burdensome disease, so being able to weigh these types of trade-offs with reliable, relevant information matters.

A patient’s first stop is usually his or her medical group or health plan’s website. These entities mostly offer basic information, such as hospital and medical group name and location. A variety of websites, including Medicare.gov, Consumer Reports, HealthGrades, and Yelp offer ratings of providers (hospitals, medical groups, individual doctors). Notably lacking is valid, reliable information about outcomes of cancer care (the survival “bottom-line”), other patients’ experiences with given providers, and cost.

The lack of meaningful data about quality in particular is not just problematic for patients. Referring physicians typically may only know whether past patients liked a particular oncologist or surgeon, but such anecdotal assessments do not necessarily correlate with clinical excellence.

### WHY INFORMATION GAPS EXIST

Logical reasons exist why there is not better information about the quality of cancer care. Cancer is not one disease, but many; the heterogeneity of the illness is only increasing as we learn more about genetics. This makes it hard for the measurement science to keep up.

Another major challenge is that there is no perfect data source to which the measures can be applied. Information needed to assess quality is found in disparate sources, such as claims or billing data, electronic health records, and state cancer registries, which are proprietary or difficult to access. Regarding the latter, cancer is a disease for which registries are

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mandated by all 50 states. While this puts cancer ahead of many other diseases, these registries were designed for public health surveillance, not quality assessment and reporting. This means that there are obstacles to using state registry data for quality measurement and public reporting by provider.

On the cost front, dollar figures are often proprietary and vary by a patient’s specific terms of insurance coverage, making it difficult to report treatment costs that are accurate for a given individual.

### CHCF’S EFFORTS TO FILL THE GAPS

Four years ago, CHCF launched an effort to promote cancer care transparency—specifically reporting of information about cancer care quality and costs—as part of a larger effort to improve the transparency and accountability of California’s health care system. In recent years, we have focused on conditions and procedures that are more “shoppable”—that is, where the patient actually has choices and the time to make those choices—like hip and knee replacements and maternity

care. Through our cancer effort we are supporting projects that will lead to public reporting at the levels of the health care system that are meaningful to patients, providers, and other key stakeholders to encourage quality improvement and better decisionmaking—such as at the level of the cancer center or medical group. This work tries to take advantage of the improved transparency of health care information set in motion by the Affordable Care Act.

We began our current work by conducting in-depth interviews with a variety of cancer care stakeholders (e.g., researchers, clinicians, consumer advocates, state and federal agencies) in California and nationally over many months. We probed them for ideas and asked for their thoughts about cancer care quality measurement, spending, gaps, and challenges. In addition, with assistance from an external consultant, we reviewed the published literature and lay press on these topics. This background research was critical in understanding the landscape and stakeholder concerns, and in pinpointing where CHCF could add value.

In the end, we chose to fund projects in four areas: big picture/landscape, which we felt was especially important for educating critical audiences about the problem, and three areas important to patients, providers, and payers: clinical care, patient experience of care, and costs of care.

To help improve understanding of the landscape, we cofunded the Institute of Medicine to produce a [report](#) about the status of cancer care quality in the United States and a vision for moving forward. Additionally, CHCF produced a [report](#) describing who gets cancer in California, who pays for treatment, what treatment costs, and what is known about the quality of care. We plan to update this state-level report in 2015.

On the clinical front, we commissioned the design of an [interactive map and reports](#) about geographic variation in breast and prostate cancer treatment—part of a larger project on medical variation in California encompassing a range of elective procedures. We also have projects in play to publicly report on our consumer website, [www.calqualitycare.org](http://www.calqualitycare.org), the number of cancer procedures performed by hospital for cancer procedures where there is an established volume-outcomes link, and to explore the reporting of cancer care quality metrics by medical group. Importantly, we are also funding a workgroup to examine the barriers and opportunities for leveraging the California Cancer Registry in measuring, publicly reporting on, and improving the quality of cancer care.

With regard to patient experience, we are supporting development of a patient experience of cancer care survey instrument (known the Cancer Consumer Assessment of Healthcare Providers and Systems or “Cancer CAHPS”), in conjunction with the National Cancer Institute and the Agency for Healthcare Research and Quality. Our funds are supporting a survey field test in community oncology settings in California where 75 percent of cancer is delivered (vs. academic medical centers).

Finally, we are funding a report on cancer care spending in

California, a topic about which surprisingly little is known at the state level.

## PARTING THOUGHTS

In the United States, approximately 14 million people have had cancer and more than 1.6 million men and women are diagnosed with cancer each year (SEER 2014). In California (CHCF’s focus) the numbers are also staggering: about 140,000 Californians are diagnosed with cancer each year—that is 16 new cases every hour (CDPH 2014). At some point, if we are not at that point already, it will be very difficult to find someone whose life has not been affected by cancer. It is fair then to ask: should not the information housed in various databases, populated at their core by patients, be shared with the cancer patient community to help inform their care decisions? And should we not, as a society, know more than we do about the quality and costs of services provided by the cancer segment of the health care industry on which we spend upwards of \$125 billion per year in the United States?

CHCF believes it is time to improve the information that we have to make informed decisions about where to get the best cancer care and its costs. While we have made some progress, we are keenly aware that this work is complicated and has only just begun. We encourage other foundations to consider investing in this space.

For more information, visit <http://www.chcf.org/cancer>.

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*This summary is based on a Health Affairs GrantWatch blog post that appeared in 2012, which has been adapted and updated here for the Grantmakers In Health audience.*

## SOURCES

California Department of Public Health (CDPH). “Cancer in California.” Accessed July 2014. <http://www.cdph.ca.gov/HEALTHINFO/DISCOND/Pages/Cancer.aspx>.

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