



Connecting the Dots: California Cancer Care Quality Roundtable

Twenty-seven cancer care stakeholders came together on October 24, 2012, in Oakland to begin a dialog about how to improve measurement and reporting of cancer care quality in California. The participants included key representatives from state government, academia, consumer advocacy organizations, and the provider and payer communities. (See “Participants” on page 8.) The California Cancer Care Quality Roundtable was hosted by the Institute for Population Health Improvement at the University of California, Davis, and the California HealthCare Foundation.

This invitational roundtable began with short talks that provided context and described the current cancer care quality landscape; participants then engaged in focused discussion about improving both clinical and patient-centered measurement, as well as ways to connect the data and fill the information gaps. An important focus was to consider how best to leverage various existing resources, including especially the California Cancer Registry.

CANCER CARE IS VITALLY IMPORTANT IN California, both clinically and economically, said CHCF chief executive Mark Smith, MD, kicking off the meeting. “And the economic and social burden on society is increasing.” A great deal is known about the incidence of cancer in the state through the California Cancer Registry (CCR), which captures data related to tumor diagnosis and staging, as well as death and survival statistics, he said. However, little information exists about how the many types of treatment affect outcomes from both clinical and patient perspectives.

“Cancer care is an appropriate and timely target for quality measurement and transparency efforts,” Smith said, because both patients and providers are interested in knowing more about what works best, and because there is “a growing appetite for data for public reporting.” California is fortunate to be rich in cancer care-related resources, noted Smith, including 10 of the National Cancer Institute’s 66 designated cancer centers, and the CCR, which is widely recognized as one of the world’s leading population-based cancer registries

and a cornerstone of oncology research in the state. Compared to other diseases and conditions, Smith said, “cancer starts on third base. Our job is now to find ways to fill in the missing pieces of data to obtain a full picture of care. What we are endeavoring to do, collectively, is to connect the dots.

“Cancer care quality is a ‘target rich environment’ for improvement.”

“We recognize that the science of measuring care quality is still young and presents a number of technical challenges,” he continued. “During this roundtable, we will discuss these challenges, examine how others have dealt with them, and consider new ways to move ahead in providing reliable and valid information about the quality of cancer care in California.”

SUMMARY

Creating a Common Understanding: Key Messages from the Presenters

Variation Is a Worthy Target

Kenneth W. Kizer, MD, MPH, distinguished professor in the UC Davis School of Medicine and Betty Irene Moore School of Nursing and director of the IPHI, provided context for the roundtable discussion. He noted that IPHI was recently awarded a five-year contract to operate the CCR. Kizer had been instrumental in securing the legislation to authorize statewide reporting of cancer in 1985 and oversaw establishment of the CCR in 1988, when he was director of the former California Department of Health Services. He described how the understanding of cancer care quality has evolved over time, quoting the IOM definition “...providing appropriate services in a technically competent manner, with good communication, shared decisionmaking, and cultural sensitivity.”¹

Although the overall quality of cancer care is reasonably good in the US, Kizer said, “it varies widely.” Variation in cancer care is especially important to understand, he said, because care is both expensive and potentially harmful; the quality of treatment affects resource use, quality of life, long term survival, and risk of recurrence. He noted that measuring the quality of oncology care is more complex than for other diseases because our understanding of the biology of cancer and its complexity is quickly expanding and because patients frequently undergo multiple forms of treatment (e.g., surgery, chemotherapy, and radiation) that are provided by separate medical specialties — and sometimes in different settings of care. Compared with many other diseases and conditions, assessing and measuring the quality of cancer care is especially difficult because it involves so many moving parts.

Because there are few validated performance measures and many gaps in the evidence base, he continued, cancer care quality is a “target rich environment” for improvement.

Although several initiatives have been launched to measure and monitor cancer care quality, he said, “they have not been integrated or harmonized.”

Kizer also noted the central role that health information exchange (HIE) could play in the provision of evidence-based, patient-focused cancer care. He leads the newly established California Health eQuality (CHeQ) program, a federally funded collaboration with the California Health and Human Services Agency (CHHS), to develop and implement HIE programs in California. CHeQ’s purpose, in brief, is to facilitate the rapid and secure flow of health and health care-related information among physician offices, hospitals, and other providers through use of health information exchange technology.

Advances in science and technology are making cancer care far more complicated, while at the same time providing the potential to improve outcomes, Kizer said. “If there’s any disease for which HIE could help improve the quality of care, it is cancer. HIE could play a pivotal role.”

Changing Evidence Base

Douglas Blayney, MD, Ann and John Doerr Medical Director of the Stanford Cancer Institute, started with examples of basic and clinical research upon which measurement of cancer care quality should be based. Death rates from cancer are declining for both sexes, as least partly due to application of evidence-based treatment as well as to improved and more widespread application of cancer screening. Characterizing research as “an attempt to predict the future,” Blayney gave examples from the growing clinical research evidence base applied to patient care. He cited findings about survival improvement for breast cancer patients treated with tamoxifen following surgery. Translating the clinical trial results into patient care, he noted, requires a multidisciplinary team. “We know that all of this [teamwork] together reduces mortality in breast cancer.” Though it is known that teamwork and evidence-based

treatment should lead to good outcomes, Blayney continued, measuring process adherence is the current state of quality measurement. Outcome measurement in cancer medicine is still an immature science, he acknowledged.

Blayney stressed the importance of preparing registry and other data systems for the individualization of cancer care — particularly to account for the development of genomically driven medicine. With some irony, he cited the example of Steve Jobs, portrayed by his biographer Walter Isaacson as one of the first people to have the genes of his cancer DNA sequenced. His doctors hoped to individualize his therapy to directly target the molecular pathways driving Jobs' tumor growth. Though the multiple and shifting molecular basis for Jobs' cancer was known, these data could not be applied for long-term treatment success. This example, Blayney noted, suggests that as cancer-specific data become available, physician and public demand for its use to individualize treatment will increase.

Such individualization, he said, will be enabled by increasing amounts of data, which will strain the current registry, analysis, and reporting systems. Eventually, Blayney said, genomic medicine will have important practical applications in cancer care as well as care quality assessment. “We need to factor in genomics because each genomic alteration may define its own disease and treatment target.”

Incorporating Patient-Reported Outcomes

Patient quality of life is increasingly recognized as an important factor in assessing cancer care, said Patricia A. Ganz, MD, director of cancer prevention and control research at UCLA's Jonsson Comprehensive Cancer Center. She offered a historical perspective of the inclusion of quality-of-life measures in clinical trials. “By the 1990s we were lobbying hard to get these measures included,” she said. After that an evidence base accumulated that clearly demonstrated how valuable

the patient perspective is in cancer care. She cited some examples of the improved situation today:

- All National Cancer Institute-funded clinical concepts and protocols must indicate whether patient-reported outcomes (PROs) were considered for inclusion.
- Common toxicity ratings will soon be reported by patients and not by observers.
- PRO symptom reporting, such as pain, is being captured in hospitals and some other clinical settings.

The most important patient-reported measures, she said, are functional status, disease symptoms, psychological functioning, and social functioning. “These should be used in medical product development to support labeling claims.”

Ganz described several efforts underway that aim to collect patient-reported outcomes, including:

- The Georgia Cancer Project's development of a consolidated cancer data resource for the state, including patient-reported data.
- Use of the American College of Surgeons accredited hospitals for the Rapid Quality Reporting Program through the National Cancer Data Base (NCDB).
- Collaboration between the American Cancer Society and NCDB to obtain patient-reported systems shortly after diagnosis.
- Development of a Consumer Assessment of HealthCare Providers and Systems (CAHPS) survey for cancer care with funding from AHRQ, NCI, and CHCF. This survey solicits information from patients about their experience of care delivery such as doctor-patient communication and care coordination.

Unfortunately, although some cancer clinical trials do incorporate PROs, Ganz said, few clinical settings measure PROs such as pain measurement and psychological distress or depression. Currently, there

is no prospective, wide-scale collection of PROs for quality reporting, and few clinical and policy decisions incorporate quality-of-life considerations. She noted that it is important to drill down into PRO findings because global assessments can mask variation in social functioning versus psychological functioning, and vice versa.

Ganz's vision for the future includes the routine collection of PROs from the patient in the waiting room; these data could be reviewed by the physician; then patient and physician would share in decisionmaking with attention to symptoms. Additionally, aggregated information could be shared with consumers and providers to improve understanding of options and decisionmaking about care.

Measuring Quality

Jennifer Malin, MD, PhD, medical director for oncology care management at WellPoint and a recognized expert in cancer quality measurement, reiterated the Donabedian framework for assessing quality of care, which focuses on three components: structure, process, and outcomes. She noted that while there are several efforts underway to assess the structural components of cancer care quality, fewer initiatives are directed toward processes or outcomes. Among several examples she shared with the group were the ASCO Quality Oncology Practice Initiative (QOPI), and the Commission on Cancer Rapid Quality Reporting System (RQRS).

Malin pointed to a number of data sources that could be used to measure cancer care quality, including: cancer registry data (e.g., CCR and the NCDB), Medicare and private payer claims data, encounter data, pharmacy data, hospital discharge data, EMR structured data, paper medical record data, patient self-reported information, linked datasets such as SEER-Medicare, and California's Office of Statewide Health Planning and Development (OSHPD).

However, she stressed, each data source has relative strengths and weaknesses, and no single source provides all of the necessary data elements. For example, she said, the CCR contains accurate and complete information about cancer diagnosis (tumor staging), which is critical for quality measurement, but does not include detailed information about the initial treatment and has even less information about recurrence and subsequent treatment. In contrast, claims data contain extensive information about treatment and costs, but not tumor staging. To get a full picture, therefore, requires data to be linked, she said.

Malin also provided an overview of existing cancer quality measures, noting that important gaps exist. For example, she said, the lack of variability of many National Quality Forum-endorsed process measures limits their usefulness for public reporting or pay-for-performance.² Measures may not be specific enough to address misuse as opposed to underuse. Further, she said, low scores on some measures often represent data problems as opposed to quality problems. Other gaps include the lack of measures of overuse and few validated outcomes measures.

Despite the growing need for information about what works, she said, measuring quality in cancer care is still hobbled by a number of factors such as failure to document or collect valuable information, and inaccessibility of documents. However, she said, much information is available that could be leveraged right now.

Finally, Malin emphasized that data collection needs to be value-based and should take the patient perspective into consideration. For example, echoing earlier comments by Ganz, Malin said, "We have almost 14 million cancer survivors now. Quality of life has always been an 'implied outcome' and now that we have so many survivors, it is even more important. We must ask the patients what their goals are."

Roundtable Discussion: Looking for “Specific and Actionable” Ideas

The afternoon discussion centered on improving clinical and patient-centered measurement, as well as exchanging ideas for connecting data and filling in the gaps. The roundtable participants brought diverse perspectives about the sticking points that hinder quality measurement and make it hard to use data to improve patient outcomes. At the same time, participants saw a broad array of opportunities to move ahead. Most of the challenges and ideas fell into four general categories: (1) data measures, collection, and use; (2) patient-centered care; (3) public reporting; and (4) making the economics work better.

As a parameter for the discussion, the group was asked to focus on ideas that were specific and actionable.

Data Measures, Collection, and Use

Link measures to decision support. As quality measures are created, they should be linked not only to outcomes, but also to decision-support tools. It is important to give providers information that will proactively help them do a good job, rather than simply measuring after the fact whether they did a good job. This should be driven at the system level and built into the health information technology architecture.

Collect sufficiently granular data. To increase usefulness, data entry needs to be more fine-tuned. For example, radiation therapy should be recorded in detail, including dosage. Surgical data should include margin clearance and other markers.

Focus on measures that assess the value of care. Measure what is costly, what is most important to patients, and what is treatable. Seek ways to leverage registry data with other data in order to move forward quickly without further burdening the CCR.

Find measures that discriminate low from high performers. Develop measures that move beyond the

low-hanging fruit, ones that actually discriminate the quality of care rendered by providers.

Assess care leading to diagnosis. Despite excellent care after diagnosis, the diagnosis itself often comes too late. Direct some measurement earlier in the process and make staging information available rapidly.

Integrate data from disparate sources. Currently, important data about cancer care are housed in a variety of places. Medical oncology data are maintained in the pharmacy and physician records; much of the surgical information is in the hospital record; and radiation therapy information could be in several places depending on where that care is delivered. Some integrated systems make all types of data available at both the provider and system level, but currently this is not the norm. These systems can serve as models for others.

Encourage EMR improvements. Unstructured EMR data are very difficult to extract. Improvements to EMRs have stalled in recent years, and existing data need to be leveraged better to improve care and measure quality. For example, many EMRs do not have fields to record basic tumor staging information. Use of structured data reporting in EMRs should be explored, and incentives may be needed to make strides in the design on EMRs to better suit oncology.

Learn from integrated systems. Because of their data technology and large patient population, integrated systems may be in a position to move ahead rapidly. In one example, Kaiser Permanente established a new center for leveraging data, including many projects related to cancer. They also make use of the ABIM Choosing Wisely program, which helps physicians and patients consider the appropriateness of particular tests and procedures. To the extent possible, we need to learn from these systems and try to incorporate what is successful into non-integrated models.

Keep measures current. Because cancer care is dynamic, it is important to know when the measures themselves become outdated due to standardization of treatment or updated guidelines.

Patient-Centered Care

Get and use feedback from patients. There is an urgent need to collect patient-reported outcomes data for use in real-time care management as well as for aggregated learning about best treatment pathways. But it is important to devise collection methods that are not onerous for providers. In addition, strategies must be devised to uniformly capture data about psychosocial function so that it can be weighed as effectively as pain, insomnia, nausea, and other specific symptoms common to cancer care.

Integrate quality-of-life measures into appropriate trials. Cancer trials should include QOL measures where scientifically relevant and/or the information would be important for patient decisionmaking, so that a strong data record on various treatment protocols will accumulate.

Make end-of-life care more patient-centered. Because much of the cost and suffering has to do with metastatic cancer, focus on patient-centered measures in end-of-life care. For example, look at instances of chemotherapy in the last two weeks of life or the mortality associated with aggressive treatment or ICU care. When hospitals have to report on these kinds of quality measures, they have an incentive to develop and use palliative care programs. Because randomized trials have shown that early palliative care not only improves quality of life but also extends life, concurrent palliative care should be the standard of care.

Public Reporting

Educate patients about quality of care data. Advertisements for the “latest and greatest” cancer treatments and technologies motivate patients to seek care that is often unproven and costly. Additionally, because

advertising sometimes purports to compare quality outcomes for particular institutions and plans, consumers may believe there is more reliable information about the quality of cancer care than actually exists.

Monitor and curb overuse. Pharmaceutical product manufacturers appear to be incentivized to resist comparisons, arguing that each treatment must be individualized, thereby making comparative data meaningless. This line of thinking may be resulting in overuse of some pharmaceutical agents. Such overuse will be hard to curb until CMS, which is the biggest payer of cancer care, begins to monitor overuse as carefully as private plans do. Continuing advances in care will require advances in measurement to ensure that personalized care is high-quality and effective.

Incorporate appropriate non-use into measure targets. Regardless of clinical potential, not all treatments are the best choice for everyone. It is important to get both the numerator and the denominator right. For example, although radiation therapy is the recommended treatment for breast cancer patients after surgery, the goal is not 100% of patients. For some individuals, such as medically fragile elderly, the burden of a daily treatment for many weeks may not be worth the small benefit of decreasing the risk of local recurrence, especially given that such recurrences are easily treated.

Begin with retrospective reporting. Insurance plans and CMS could help find answers to questions such as whether a hospital that is excellent for colon cancer is also excellent for breast cancer. Retrospective reporting would be less politically sensitive.

Making the Economics Work Better

Line up the provider incentives. Payers need to do a better job of lining up the incentives for providers. For example, high payments for chemotherapy may discourage more appropriate, less intense treatments for some patients in terms of outcome or quality of life.

Ask CMS to lead the way. Rather than continuing to rely primarily on “reasonable and necessary” guidelines determined by physicians and patients, CMS should structure payment levels on a solid evidence base that includes patient-reported outcomes. Such a change would require the addition of measures that would be well-supported by providers. In addition, CMS should monitor and address poor coordination of care, waste, overuse, and underuse.

Consider bundling payments. CMS could use a bundled payment method for Medicare, where the bulk of cancer patients will have their coverage, especially as the population ages. Medi-Cal, likewise, could link payment with results. Currently, the Center for Medicare and Medicaid Innovation (at CMS) is funding an Oncology Medical Home model to inform CMS what a bundled care model might look like. Commercial payers are also exploring bundled/episode payment. The results of these pilot efforts will inform the cancer provider and payer communities whether bundling promises better quality at lower costs.

Start with limited experiments. To limit risk, pilot testing could be used. For example, a medical group could apply as many measures as possible to see what is feasible. CalPERS members or another discrete group might be considered as a test population.

A Note of Urgency

While the California Cancer Quality Roundtable was not intended to create an action plan, it did serve as a platform for the exchange of ideas and suggestions for moving forward. A few closing remarks from participants:

- “Focusing on quality of life for the patient and family should now be considered the standard of care to reach for.”
- “We can make better use of what we already have in hand — data on 4 million cases. We need to link this to other databases, and speed up the pipeline.”

- “I’m an advocate for letting the light shine on what we know and what we don’t know.”

Kizer wrapped up the session on a note of urgency. The “financial imperative window of opportunity is closing,” he said. The cost of cancer care is rising disproportionately fast relative to health care overall — which itself is rising faster than other areas of the economy. “The opportunity exists to pursue advanced telecommunications to make databases more useful,” he emphasized, “not simply to automate ineffectual processes. Now is the time to rethink how and why we do things, and look for action steps that will make a difference in both clinical and patient-centered outcomes.”

Fortunately, noted Smith, “doctors and patients will help us achieve our goals.” Cancer care providers want to get the best possible outcomes for their patients and they want information that’s going to help them do that, he said. Patients will help by considering their options and participating in decisionmaking, he continued. “You generally don’t have to persuade patients to do or not do something when you simply tell them the truth. They need to hear the downside of various treatments, including cost, so they can choose. And when you talk with them about symptoms, you have to be very specific.”

Policymakers have a role to play, he continued. In order to use the cancer registry data for quality measurement and especially public reporting by provider, statutory change will be needed. For example, regulators can mandate electronic reporting of data to the registry. “It is therefore important for cancer care stakeholders to give voice to patients’ and providers’ need for information.”

Finally, Smith noted the strong interest that has been expressed in the topic of cancer care quality measurement. “I’m struck by everybody’s interest in collaboration despite separate data and separate areas of expertise,” he said. “The roundtable provided a jump-start for an ongoing

discussion that we hope will lead to collaboration among a broad and diverse range of stakeholders — those who attended this initial meeting and many, many others.”

ENDNOTES

1. IOM, “Ensuring Quality Cancer Care,” 1999.
2. The National Quality Forum is the national entity that reviews and endorses health care quality measures.

MORE INFORMATION

For more information about the California HealthCare Foundation’s cancer transparency work, please see: www.chcf.org. Additional CHCF cancer-related work can be found at: www.chcf.org.

For more information about the Institute for Population Health Improvement at the University of California, Davis, go to: www.ucdmc.ucdavis.edu.

ABOUT THE FOUNDATION

The California HealthCare Foundation works as a catalyst to fulfill the promise of better health care for all Californians. We support ideas and innovations that improve quality, increase efficiency, and lower the costs of care. For more information, visit us online at www.chcf.org.

PARTICIPANTS

Janet Bates, MD, MPH

Chief, Cancer Surveillance Section
Chronic Disease Surveillance and Research Branch
California Department of Public Health

Leslie Botnick, MD

Chief Medical Officer
Vantage Oncology

Douglas W. Blayney, MD

Ann and John Doerr Medical Director
Stanford Cancer Institute
Professor of Medicine, Stanford School of Medicine
Associate Division Chief of Medical Oncology
Past President, American Society of Clinical Oncology

Carolyn Bruzdinski, PhD

Chief Mission Delivery Officer, California Division
American Cancer Society, Inc.

Dennis Deapen, DrPH

Professor, USC School of Medicine
Director, Los Angeles Cancer Surveillance Program

Stephen B. Edge, MD, FACS

Chair, Commission on Cancer
American College of Surgeons
Alfiero Foundation Endowed Chair in Breast Oncology
Roswell Park Cancer Institute

Peter D. Eisenberg, MD

Oncologist
Marin Specialty Care

Patricia A. Ganz, MD

Professor, UCLA Schools of Medicine & Public Health
Division of Cancer Prevention & Control Research
Jonsson Comprehensive Cancer Center

Sally Glaser, PhD

CEO and Research Scientist
Cancer Prevention Institute of California

Mike Hogarth, MD

Chief Medical Information Officer
Athena Breast Health Network
Professor, Internal Medicine

Professor, Pathology and Lab Medicine
UC Davis School of Medicine

Michael J. Kelley, MD

National Program Director for Oncology/SCS/PCS
Chief, Hematology/Oncology, Durham VAMC
Associate Professor of Medicine, Duke University

Jennifer Malin, MD, PhD

Medical Director, Oncology
WellPoint

Elizabeth A. McGlynn, PhD

Director, Kaiser Permanente Center for Effectiveness &
Safety Research

Kristen McNiff, MPH

Director, Quality and Performance Measurement
American Society of Clinical Oncology

Frederick J. Meyers, MD, MACP

Executive Associate Dean
Professor of Internal Medicine
UC Davis School of Medicine

Barbara Parker, MD

Professor of Clinical Medicine, Division of Hematology-
Oncology; Medical Director, Oncology Services
UC San Diego Moores Cancer Center

Joseph Parker, PhD

Manager, Healthcare Outcomes Center
Office of Statewide Health Planning and Development

Betsy L. Thompson, MD, DrPH

Chief Medical Officer, San Francisco Regional Office
CDR, US Public Health Service Centers for Medicare
and Medicaid Services

John Santa, MD

Director, Consumer Reports Health Ratings Center
Consumers Union

Rita F. Redberg, MD, MSc, FACC, FAHA

Professor of Clinical Medicine and
Director, Women's Cardiovascular Services
UCSF School of Medicine
Editor, *Archives of Internal Medicine*

Andrew Stewart, PhD

Senior Manager, National Cancer Data Base
American College of Surgeons

Dee W. West, PhD

Executive Director
Cancer Registry of Greater California
Public Health Institute

Tom Williams, DrPH

President and CEO
Integrated Healthcare Association

Peter Yu, MD

Oncologist, Director of Cancer Research
Palo Alto Medical Foundation
Elected American Society of Clinical Oncology President,
2014 – 2015 Term

California HealthCare Foundation

Kate O'Malley, RN, MS

Senior Program Officer

Mark D. Smith, MD, MBA

President and CEO

Sandra Shewry, MPH, MSW

Director, State Health Policy

Stephanie Teleki, MPH, PhD

Senior Program Officer

Nancy Wise, MBA, MPH

Consultant to CHCF
Healthcare Technology Management Services

Institute for Population Health Improvement

Kenneth W. Kizer, MD, MPH

Distinguished Professor, UC Davis School of Medicine
and Betty Irene Moore School of Nursing
Director, Institute for Population Health Improvement
UC Davis Health System