

APRIL 2015 -  
MARCH 2016

# ANNUAL REPORT

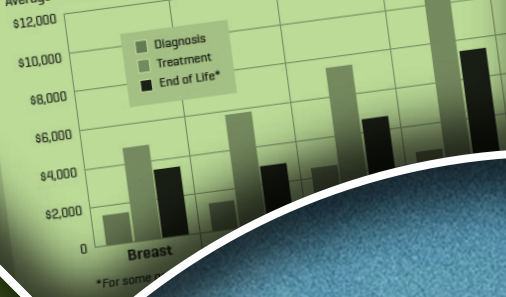


## ESTIMATED OUT-OF-POCKET COSTS

### ESTIMATED OUT-OF-POCKET COSTS:

### ESTIMATED OUT-OF-POCKET COSTS - BY PHASE OF CARE

Average cost, by cancer site



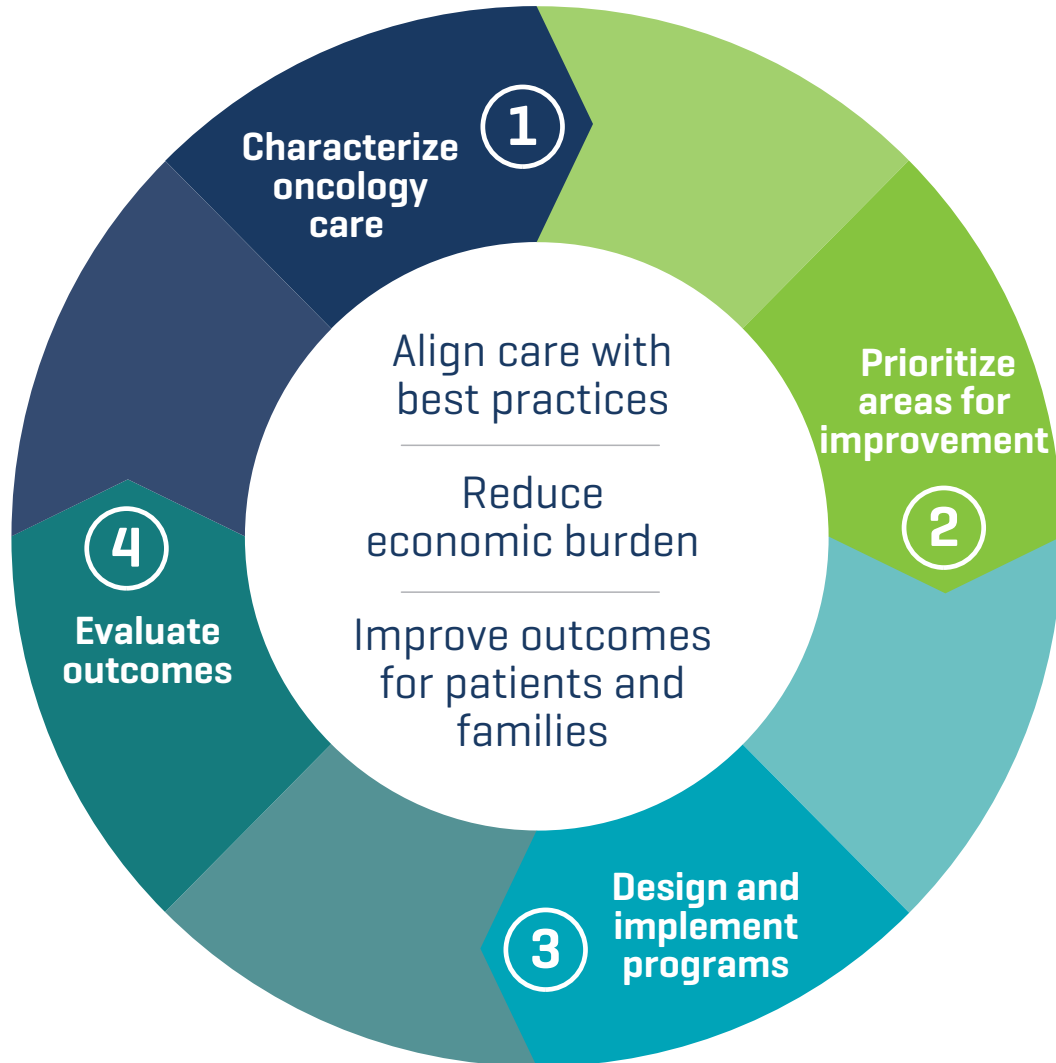
FRED HUTCH



HUTCHINSON INSTITUTE FOR  
CANCER OUTCOMES RESEARCH



# HOW WE WORK



**1**

**2015 Summit Reports**

- ASCO Choosing Wisely 2012 "5 Things Physicians and Patients Should Question"

**2015 Palliative Care Summit Reports**

- End of Life Measures

**2016 Summit Reports**

- Updated ASCO Choosing Wisely and End of Life Measures
- Cost of Care Measures

**2**

**2014 Summit**

- Top six broad priority areas identified

**2015 Summit**

- Top three priority areas identified and refined
  - Breast Cancer Surveillance
  - Hospitalizations During Treatment
  - Cancer Care at End of Life

**3**

**2013 Regional Pilot Launched**

- Improving Appropriate Use of Breast Cancer Surveillance and Colony Stimulating Factors

**2015 National Study Funded in Partnership with SWOG**

- Improving Adherence to Evidence-Based Guidelines for Colony Stimulating Factors

**4**

**Evaluate Outcomes**

- Evaluate expected change in practice patterns, patients' outcomes, costs and value

# FROM THE DIRECTORS



**Scott Ramsey  
MD, PhD**

*Director*

Scott Ramsey is a practicing internist, an internationally recognized health economist and a leader in comparative and cost-effectiveness research.



**Gary Lyman  
MD, MPH**

*Co-Director*

Gary Lyman is a practicing medical oncologist, an internationally recognized clinical oncology researcher and a leader in clinical practice guidelines and cancer policy.

The HICOR team is committed to finding solutions to reduce the economic burden of cancer for patients, families and society. We view this critical issue through the lens of value — asking ourselves how our work can contribute to ensuring that patients receive the highest quality care and the best possible results without the financial devastation that too often accompanies a cancer diagnosis.

We started with the simple yet vital concept of measurement. Could we gather and analyze the data necessary to create a picture of how cancer care is delivered in our community? The short answer, built on the hard work and expertise of our data and clinical analytics team, is yes. Thanks to their efforts, HICOR partners have access to routinely updated performance metrics through our web-based user portal known as HICOR IQ.

HICOR has shown that we can measure what matters in oncology. But how can we use this information to improve patient experience and outcomes, lower costs and increase the quality of care? This year, we established community-based working groups to tackle those questions. Payers, providers, patients and health system leaders actively worked together to develop intervention proposals in three clinical areas and presented their work at the 2016 Value in Cancer Care Summit. Patient voices were essential to shaping these proposals, and as we look ahead to implementation, we are honored that a number of thoughtful patient partners continue to dedicate their time and expertise to this work.

On the national stage, this year marked the launch of our Patient-Centered Outcomes Research Institute (PCORI)-sponsored pragmatic trial to improve adherence to evidence-based guidelines for prescription of colony stimulating factors (CSF). Conducted within the cancer clinical trials group SWOG, the trial will test a systems-based intervention to improve guideline-adherent CSF prescribing. The launch of this trial is both a marker of our progress and a guide for our future. It is a culmination of our early efforts to measure adherence to ASCO Choosing Wisely guidelines, identify areas for improvement, and test interventions to change practice. We also envision it as the first in an ongoing portfolio of pragmatic clinical trials focused on the factors influencing the delivery and outcomes of cancer care.

Our scientific team continues to grow. This year we welcomed new Staff Scientist Laura Panattoni, PhD, who brings expertise in health economics and the costs of practice transformation, an essential ingredient to our efforts to launch health care delivery experiments in real world clinical settings. We look forward to continued growth of our faculty team and the collaboration it inspires.

**Scott Ramsey**

A handwritten signature in black ink, appearing to read "Scott Ramsey".

**Gary Lyman**

A handwritten signature in black ink, appearing to read "Gary Lyman".

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# CANCER, BANKRUPTCY AND DEATH: STUDY FINDS A LINK

BY DIANE MAPES

Fred Hutch News Service Story Excerpt

A January 2016 study conducted by HICOR researchers has found that the financial toxicity resulting from the high cost of cancer care can be deadly for cancer patients.

"It varies from cancer to cancer, but for cancer patients who face bankruptcy — and about 2.5 percent of cancer patients go bankrupt — the risk of dying goes up dramatically," said lead author Dr. Scott Ramsey.

Ramsey and colleagues linked patient data from the Western Washington Cancer Surveillance System (part of the national SEER cancer registry) with federal bankruptcy records to see how bankruptcy affected patients' survival.

Bankruptcies are a proxy of sorts for cancer's heavy financial toll; since filings are tracked and measurable, researchers can use them to determine how skyrocketing cancer costs impact society. In a watershed study published in 2013, Ramsey found that cancer patients, on average, were about 2.7 times more likely to declare bankruptcy as those without cancer.

This latest study, published in the *Journal of Clinical Oncology*, showed that cancer patients who go bankrupt have an 80 percent higher mortality risk than patients with the same cancer who don't. Some cancers had even higher mortality rates. Prostate cancer patients who filed for bankruptcy were almost twice as likely to die; bankrupt colorectal cancer patients were 2.5 times more likely to die as those not done in by debt.

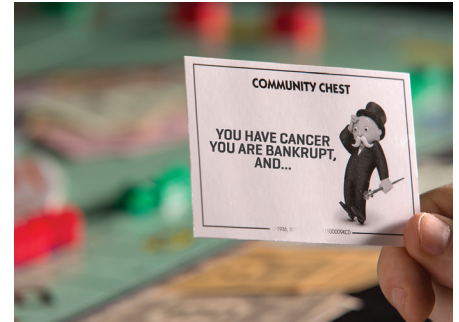


Photo illustration by Robert Hood / Fred Hutch

"That blows away the survival benefits of many, if not most, treatments," said Ramsey. "To me, it's one thing if you go bankrupt. Financially, you're really in bad shape but you come out of it with your cancer treated. But what if it actually is a double hit, where your very survival is affected? That is profound."

The study, which looked at two groups of around 3,800 cancer patients (one group bankrupt, the other not) diagnosed between 1995 and 2009, found that the mortality rate was not related to whether patients were diagnosed with metastatic disease. It also hinted that cancer patients who had "financial difficulty short of bankruptcy" might also be at risk.

The study raises two questions: how this happens, and what can be done to reduce the risk. Answering these questions are now priority areas for HICOR researchers. To address the first, HICOR is proposing a study to look deeply into the care of patients who experience severe financial distress, asking questions about whether patients skipped or cut back on treatments, or delayed their care while they took care of their financial crisis. To address the second, HICOR investigator Veena Shankaran is conducting a pilot study to identify cancer patients who are at risk for financial catastrophe and to intervene early with financial counseling to reduce that risk.

"To me, it's one thing if you go bankrupt. Financially, you're really in bad shape but you come out of it with your cancer treated. But what if it actually is a double hit, where your very survival is affected? That is profound."

— Scott Ramsey



# ENHANCING THE IMPACT OF CLINICAL TRIALS

In its report “A National Cancer Clinical Trials System for the 21st Century,” the National Cancer Institute called for improving selection, prioritization and completion of clinical trials, and for bolstering participation of both patients and physicians. The development of methodological tools to predict trial accrual, quantify the value of proposed trials to aid trial selection, and increase trial participation is a cornerstone of the HICOR research agenda.

## DESIGNING HIGH-IMPACT CLINICAL TRIALS

Despite the importance of clinical trials in advancing cancer care, only 3-5 percent of cancer patients enroll in them, according to a 2010 report from the Institute of Medicine.

In addition, nearly one in five studies supported by the National Clinical Trials Network close due to poor accrual. Trials with low accrual are often unable to answer the clinical question being studied and result in wasted financial and human resources. With limited funds available for cancer research, the design and prioritization for funding of high-impact, feasible studies that can meet their enrollment targets are crucial.

HICOR Affiliate Dr. Carrie Bennette and colleagues identified twelve key predictors of low trial accrual and developed a preliminary prediction model published in the Journal of the National Cancer Institute in December 2015. This foundational work is envisioned to support development of tools to help researchers design more successful studies

and aid sponsors in trial selection and portfolio management.

## BREAKING DOWN BARRIERS TO TRIAL PARTICIPATION

In October 2015, HICOR collaborator and SWOG investigator Dr. Joe Unger released a study showing that patients with lower household income are 32 percent less likely to participate in clinical trials. “We know that financial burden impacts patients’ experience and outcomes; this is another aspect of that equation,” said Dr. Unger. “It is critically important that clinical trials are accessible to patients at all income levels.”

### Clinical Trials by the Numbers

#### KEY PREDICTORS OF LOW TRIAL ACCRUAL



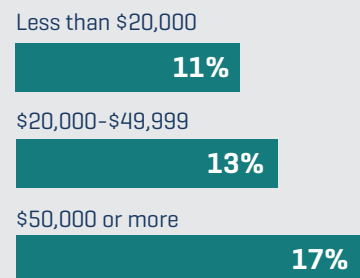
#### TRIALS CLOSING

1 in 5 clinical trials close due to low accrual



#### HOUSEHOLD INCOME AFFECTS PARTICIPATION

The new study found that the lower a patient’s income, the lower the chance that he or she will take part in a clinical trial. Just 11 percent of those surveyed making less than \$20,000 a year took part in clinical trials, compared with 13 percent of those making between \$20,000 and \$49,999 and 17 percent of those making more than \$50,000.



# ECONOMIC PERSPECTIVES ON PRECISION ONCOLOGY

Precision medicine — which promises to tailor therapies to specific molecular profiles of disease — has emerged as a national priority through the President’s Precision Medicine Initiative and the National Cancer Moonshot Initiative. Realizing the promise of precision medicine requires the development of diagnostics, including biomarkers and imaging technologies, to accurately identify patients for whom a targeted therapy is likely to work.

## A NATIONAL ROADMAP FOR DIAGNOSTICS

HICOR Co-Director Gary Lyman served on the Institute of Medicine [IOM] panel assessing the potential of precision medicine to impact patient care. IOM’s 2016 report



Dr. Gary Lyman, HICOR Co-Director

“Biomarker Tests for Molecularly Targeted Therapies” issued 10 key recommendations designed to move precision medicine forward in a way that will ensure patients have timely access to

appropriate and accurate tests and also prevent the potential harm from poorly validated or inappropriately used tests. “You need good science to establish that the test is reliable, that the test is associated with the disease and an outcome of interest and finally that the treatment actually improves patient outcomes compared to standard treatment or usual care,” said Dr. Lyman. First among the committee’s recommendations is the development of common evidence standards to demonstrate that diagnostics improve patient outcomes in real world clinical practice.

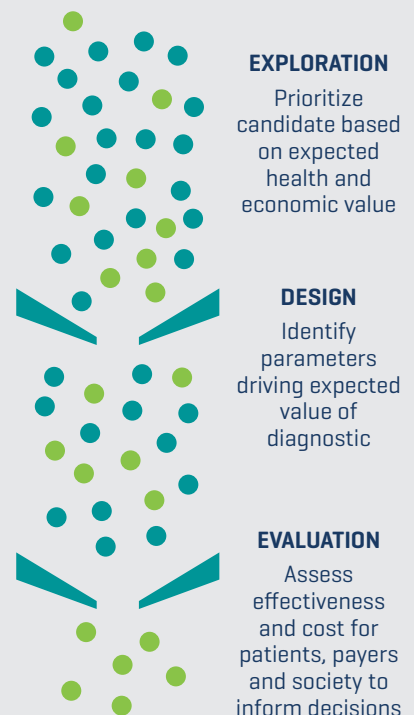


Dr. Lotte Steuten, HICOR Associate Member

## ACCELERATING DIAGNOSTIC DEVELOPMENT

The journey from discovery to clinical realization of new personalized medicine approaches is typically long, costly and uncertain. Along this process the challenge is to select, from a multitude of options, those diagnostics that are most likely to add value. HICOR investigator Dr. Lotte Steuten has developed methods to evaluate diagnostics at each phase of the development pipeline. In the exploratory phase we determine which candidate markers should be prioritized based on expected health and economic value. In the design phase we determine which specific parameters drive the expected value, e.g., prevalence of the marker, treatment effectiveness or financial aspects. As these require the most precise data, this informs the design and optimal sample size of further studies. Finally, we assess the effectiveness and cost to individual patients, payers and society. This is crucial information to inform fair reimbursement and pricing decisions.

### Stages of diagnostic evaluation



# 2016 VALUE IN CANCER CARE

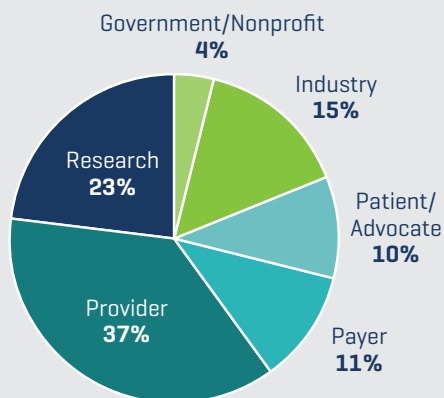
## PATIENT VOICES HELP DRIVE CHANGE

The 2016 Summit focused on developing interventions to improve cancer care, understanding the ethical implications of introducing value in the patient/provider relationship, and measuring the costs of care. A broad range of attendees — from patient partners, to payers, to clinicians, researchers and others — shared perspectives and debated key issues in this highly interactive forum.

### VCC by the numbers

**48** ORGANIZATIONS  
IN ATTENDANCE

**147** ATTENDEES



**225** MINUTES, or nearly half of summit agenda, dedicated to discussion and stakeholder feedback

**42** WORKING GROUP MEMBERS

**13** PATIENT PARTICIPANTS

**9** COST METRICS PRESENTED

**3** PHASES OF CARE

**456** DATA POINTS SHARED

**85** TWEETS

**4.5** TWEETS PER TWITTER PARTICIPANT



#ValueSummit2016

#HICOR



President and Founder of Cierra Sisters  
Bridgette Hempstead



Panelists from left to right: Dr. Wylie Burke and Janet Freeman-Daily



University of Washington bioethicist Dr. Wylie Burke and patient activist Janet Freeman-Daily

PHOTOS BY ROBERT HOOD



# ER CARE SUMMIT

## CHANGE IN CANCER CARE



Jennie Crews, Dr. Patricia Dawson, Diane Mapes, and Courtney Preusse

*“Often providers will start a conversation with, ‘How do you want to be remembered?’ Instead they should ask, ‘What matters to you?’ We need to help patients think about what is important to them. What are their values and goals of care?”*

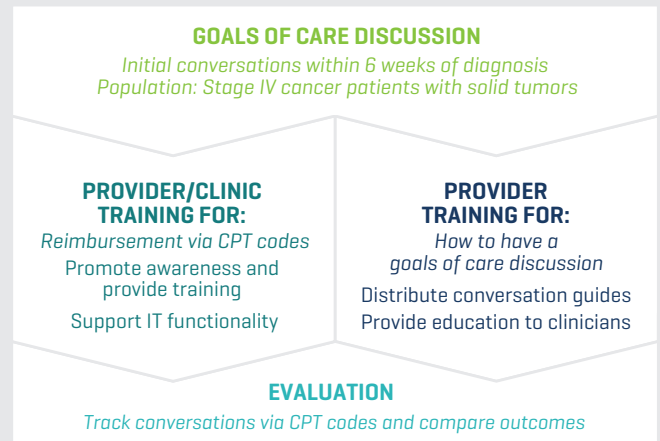
— Janet Freeman-Daily



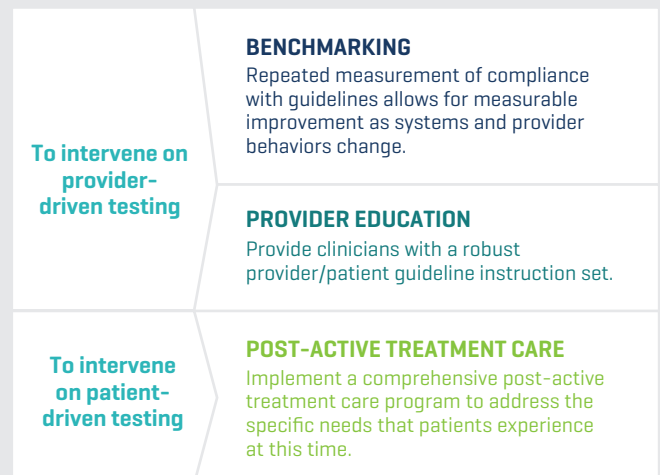
Keynote speaker Dr. Craig Earle of Cancer Care Ontario and the Ontario Institute for Cancer Research

Community-based **Intervention Working Groups** collaborated to propose improvements to cancer care in three priority areas.

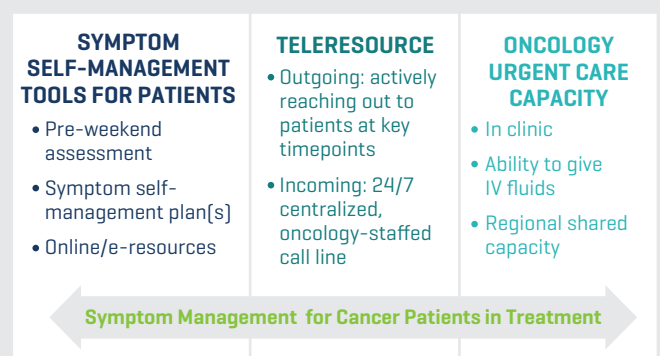
### GOALS OF CARE / END OF LIFE



### APPROPRIATE TESTING, IMAGING AND CARE AFTER BREAST CANCER TREATMENT



### REDUCE PREVENTABLE HOSPITALIZATIONS AND ER USE DURING TREATMENT

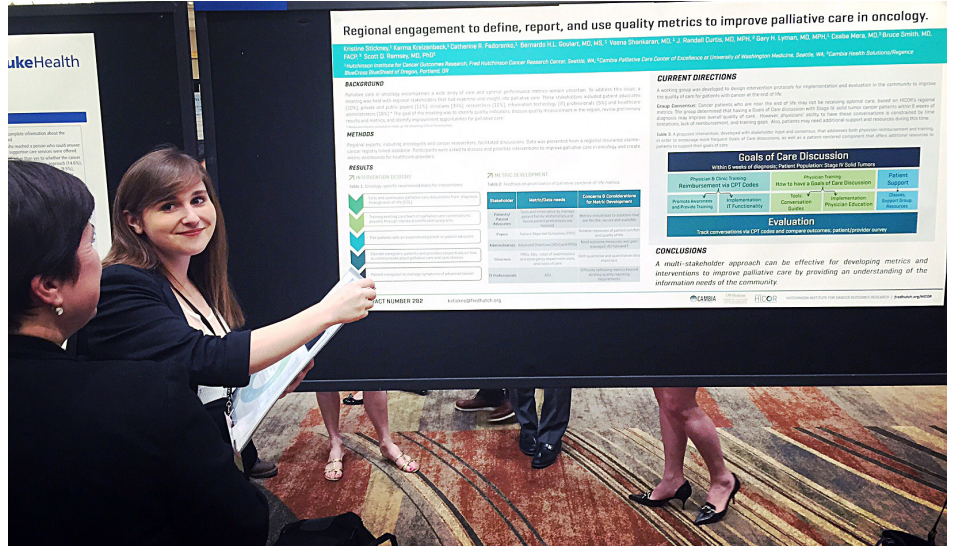


# FROM QUALITY MEASUREMENT TO CARE TRANSFORMATION

Over the past three years HICOR has established a growing presence at the American Society of Clinical Oncology Quality Care Symposium, an annual event which brings together top leaders in the field to share strategies and methods for measuring and improving the quality and safety of cancer care.

At the February 2016 symposium, the HICOR team presented a number of flagship initiatives, including our data transparency and performance reporting efforts, and methods for engaging stakeholders in intervention design. In addition, the team presented on regional collaboration efforts in palliative care and on HICOR's Choosing Wisely project to measure guideline adherence using natural language processing.

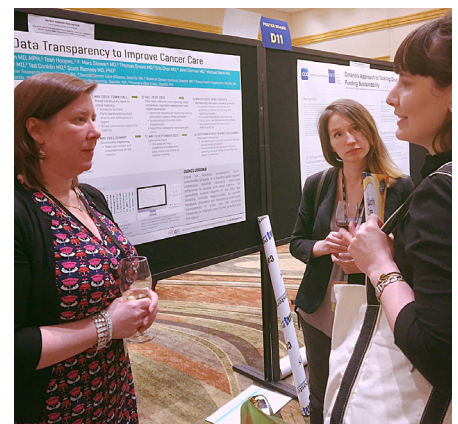
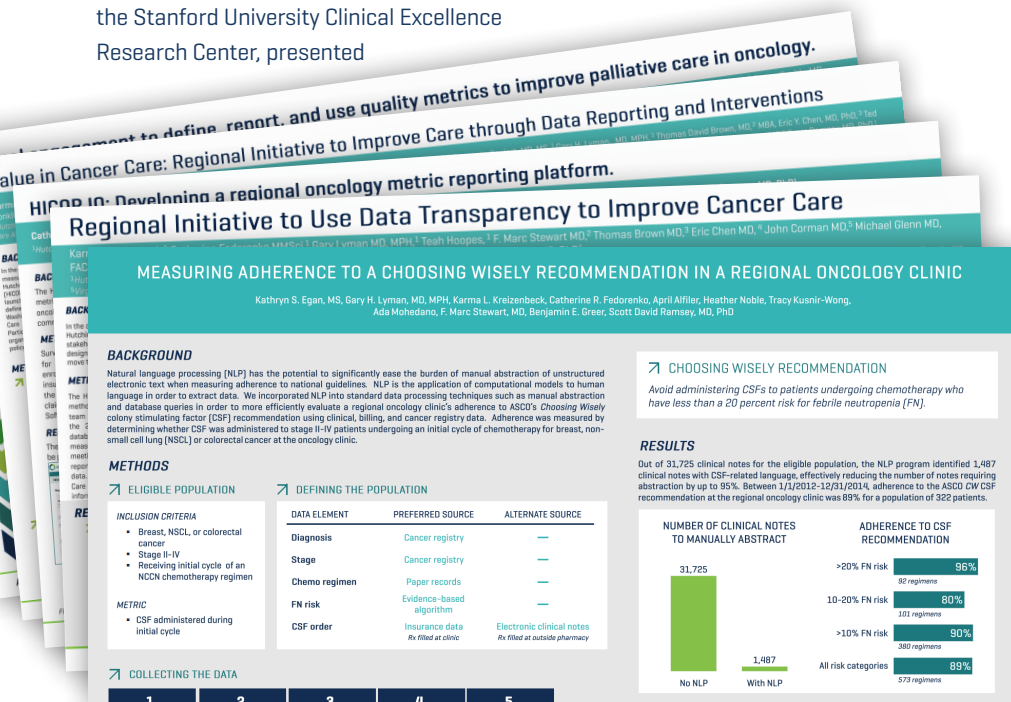
The translation of quality improvement efforts into practical, applied programs that can positively impact patients' lives is a key theme of HICOR's endeavors. Our colleague Melora Simon, a collaborator from the Stanford University Clinical Excellence Research Center, presented



HICOR team member Kristine Stickney, right, presents results.

HICOR data on “Bright Spot” clinics — those with high-quality outcomes and low costs — that represent positive outliers in oncology care. These efforts led to documentation and sharing of best practices among cancer care delivery systems in the Pacific Northwest.

“While we have seen tremendous recent advances in cancer treatments, there is more work to be done to ensure health care delivery systems can provide these lifesaving measures to patients with consistent, high-quality care,” said HICOR Director Scott Ramsey. “Our goal has been to develop and test strategies to address these issues with regional partners and bring our successes to the national forum.”



HICOR team members Karma Kreizenbeck, left, and Kathryn Egan, middle, present results.

# HICOR IQ

HICOR IQ is an oncology informatics platform that integrates cancer registry and health insurance claims data to enable performance reporting in oncology.

## TRUSTED, TRANSPARENT REPORTING SOURCE



John Rieke, MD

The analytics generated by HICOR IQ are derived from a common, integrated, multisource data platform. Shared data and standardized methodologies

ensure that results are comparable across institutions, which supports collaboration and partnership across the region.

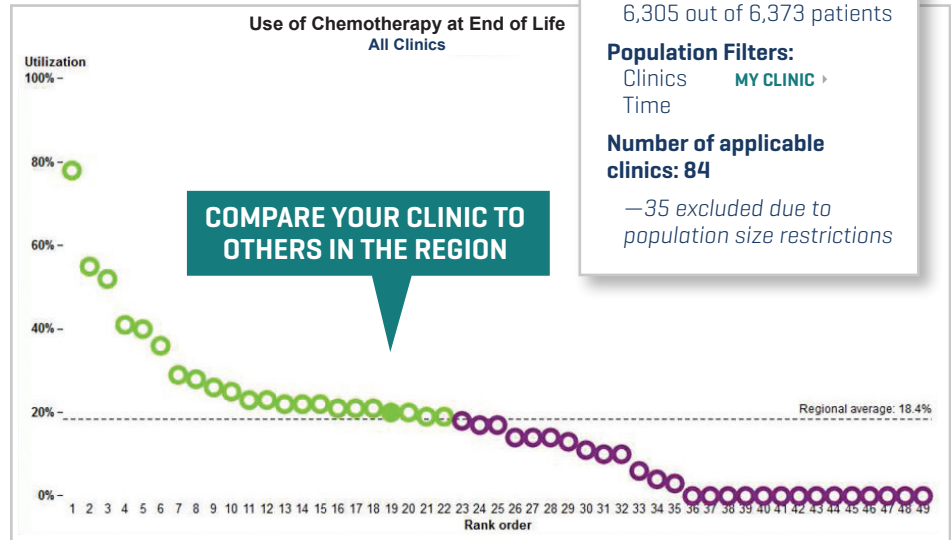
*“HICOR IQ allows us to visualize how patients are treated in our system. The reports provide new insights that are not available elsewhere, and we use that information to improve quality in our clinics.”*

— John Rieke, MD  
Medical Director, MultiCare  
Regional Cancer Center

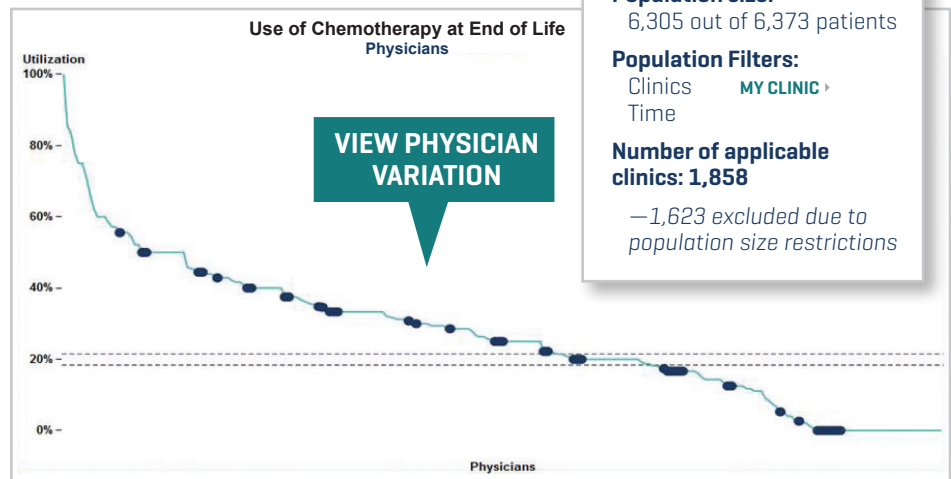
## MEASURING WHAT MATTERS

HICOR looks to our partners in the cancer care community to prioritize metrics for inclusion in HICOR IQ. Regional partners and national experts review our measurement algorithms to ensure that reports are clinically valid and meaningful.

## Clinic Identification and Filtering



## Physician Reporting



Explore HICOR IQ at [hicoloriq.org](http://hicoloriq.org)

## PARTNERS MAKE IT POSSIBLE

Data partners are critical to the success of this effort. HICOR IQ combines cancer outcomes data from the Cancer Surveillance System — which is part of the Surveillance,

Epidemiology, and End Results (SEER) program of the National Cancer Institute — with claims information provided by Premera Blue Cross and Regence BlueShield.

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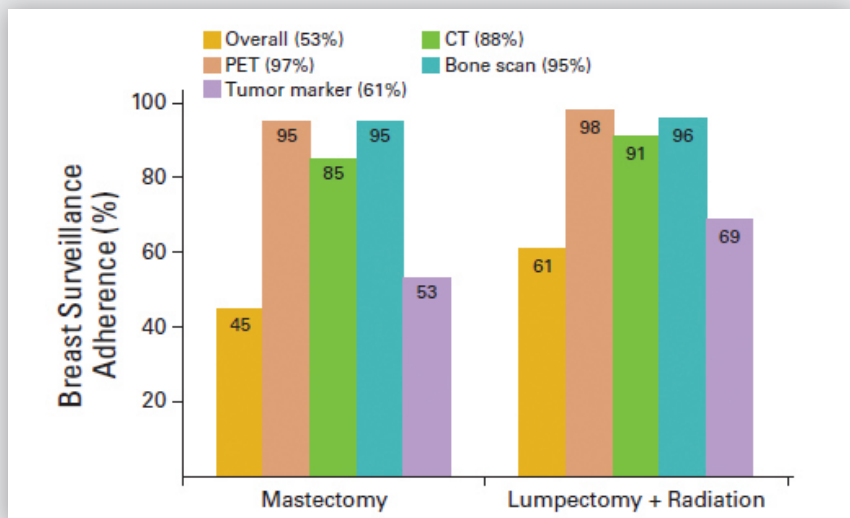
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## MEASURING ADHERENCE TO ASCO CHOOSING WISELY

Two large datasets, the Surveillance, Epidemiology and End Results [SEER] registry and enrollment and claims data from a large regional commercial insurance plan, were linked to measure adherence to the American Society of Clinical Oncology [ASCO]/ American Board of Internal Medicine [ABIM] Choosing Wisely measures. The ASCO/ ABIM Choosing Wisely recommendations prioritize appropriate use of treatment and interventions, discouraging the use of interventions that do not improve the quality of cancer care that patients receive. The large retrospective data linkage and analysis study, led by Dr. Scott Ramsey and Dr. Gary Lyman in collaboration with colleagues at HICOR and Premera Blue Cross, found that adherence rates varied widely both across measures and within each measure [i.e., by stage and cancer site]. Additionally, an increased cost of \$29 million for the nonadherent population, as compared to the adherent population, was observed in analyzing differences in total reimbursements between the two groups.

The study was among the first to characterize adherence to the ASCO/ABIM Choosing Wisely measures and garnered much interest, becoming one of the most downloaded articles on the Journal of Oncology Practice website. The study is a part of a larger effort within HICOR to analyze adherence rates in an effort to identify and develop value-based interventions that will improve the quality of cancer care patients receive.



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**From Left to Right, Back Row:** Sarah Barger, Stuart Greenlee, Annika Hanson, Julia Walker, Gary Lyman, Scott Ramsey, Karma Kreizenbeck, Lotte Steuten, Joshua Roth, Jordan Steelquist, Cara McDermott, Bernardo Goulart, Greg Warnick. **Front Row:** Catherine Fedorenko, April Alfiler, Kate Watabayashi, Teah Hoopes, Debbie Delaney, Xinyuan Dong, Kat Egan, Qin Sun, Laura Panattoni, Kristine Stickney, Veena Shankaran, Kristy Drury, Judy Nelson, Andrea Tate. **Not Pictured:** Aasthaa Bansal, Carrie Bennette, Eva Culakova, Jean McDougall and Marek Poniewierski.

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