



# **Cancer and the Workplace:**

## The Employer Perspective

By: Jeremy Nobel, MD, MPH; Emily Sasser, MPH;  
Jennifer Weiss, MA; & Laurel Pickering, MPH  
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# Introduction

Northeast Business Group on Health (NEBGH) has initiated a project on Cancer and the Workplace, designed to identify key issues employers face with respect to employees and family members with cancer, shed light on some of the complex and confusing aspects of this disease for employees and employers alike, and uncover potential opportunities for improvement in outcomes and support for those with a cancer diagnosis.

As part of an early phase of this initiative, NEBGH’s Solutions Center conducted a survey and initiated a discussion with senior benefit professionals from self-insured employer members to gauge the relative importance of cancer-related issues in their workplaces and begin to identify specific areas of concern. A multi-stakeholder workshop was then held that included employers, health plans, experts in specialty pharmaceuticals and molecular diagnostics, and benefits consultants to discuss some of the newer cancer-related initiatives currently delivered by plans, understand the role of specialty pharmaceuticals in the cancer equation, and touch on advances in genomic testing.

Most importantly, this multi-stakeholder group was charged with identifying and prioritizing significant issues related to cancer treatment and patient support to guide further NEBGH efforts.

**What follows is a summary of NEBGH’s Solutions Center findings thus far. The “Opportunities” cited in various sections are comprised of suggestions by employers themselves, as well as observations by NEBGH highlighting what might be worth undertaking to address gaps identified in the report.**

## **Mind The Gap**

The blue “Mind the Gap” section throughout the report indicates gaps between what employers say they need in order to optimize quality and cost of cancer care, and the current knowledge and resources that exist.

 **Employers report a level of complexity in managing employees' cancer-related needs beyond that associated with any other type of disease or condition.**

# Cancer: A Disease Unlike Any Other

Employers report a level of complexity in managing employees' cancer-related needs beyond that associated with any other type of disease or condition. This complexity relates to the costs and definition of quality cancer care, the extensive number and array of services needed to support employees and their families when faced with a cancer diagnosis, and the multi-faceted role a benefit professional must play in assisting employees. Perhaps above all, the most important factor driving complexity in workplace cancer management may be the range and depth of intense emotions, most notably fear, that often accompanies the diagnosis. Dealing with an employee's understandable fear is usually the first issue benefit professionals mention when asked about what comes to mind when dealing with cancer in the workplace and, as several put it, "fear drives cost."

## **Employers and the Cost Equation**

Costs for cancer care are growing at twice the rate of costs for other healthcare expenses. And while the medical costs of cancer care are high—cancer treatment accounts for 12% of total medical costs for employers in the US, though only 1% of claims—direct costs are actually outweighed by the indirect costs resulting from lost productivity. Total cancer-related costs for employers were \$264 billion in 2010, with \$125 billion spent in direct medical costs and \$139 billion accrued in indirect costs. This figure is not surprising, given that cancer is one of the primary causes of short-term and long-term disability, both leading to losses in productivity. Cancer also contributes significantly to early retirement and premature death.

In terms of direct costs, spend continues to rise, often in parallel with access to more effective treatments. The area of specialty pharmaceuticals stands out as significant in treating employees with cancer and has a complex and often confusing payment structure, partially paid for as a medical benefit and partially as a pharmacy benefit. Advanced diagnostic testing, extensive inpatient hospital stays (both planned and on an emergency basis), and the need for ongoing and expensive complicated treatments all contribute to high direct costs.

Employers feel fairly comfortable with cancer prevention and early detection strategies already in place, but expressed a substantial interest in better understanding how to improve the quality and reduce the cost of treatments once a diagnosis is made.

### **Mind The Gap**

Recently escalating co-payments and deductibles, if not thoughtfully applied in the oncology arena, may place unintended roadblocks for employees seeking access to care. While high deductible health plans – increasingly popular among employers – may help employers control costs, they need to be further assessed in terms of their potential to cause avoidance or delay in employees seeking needed treatments and prescriptions – a potentially serious downside, especially in cancer care.

### **Specialty Pharmacy in Cancer Treatment: Costs Going Up, Meaningful Data Hard to Obtain**

The number of specialty pharmaceuticals available to treat cancer continues to expand, with an increase of both injectable and oral medications. While new therapies can result in remarkable outcomes for certain patients, payers and health plans struggle with continuously increasing costs. Patients undergoing chemotherapy often receive drugs directly from oncologists who purchase the drugs themselves from a formulary under the “buy and bill” model. The cost of those drugs is typically much higher in the hospital setting than in the community setting.

Most cancer patients have a choice of where they can receive chemotherapy treatments—a decision often influenced by benefit design. Therefore, employers can attempt to control cancer drug spend by implementing tiered benefit designs to direct employees to a specific site of care. However, reliable and detailed information to evaluate and determine the optimal site of care based on cost and outcomes is often hard to obtain. Employers have little insight into total cost of care, or even care components like medication, due to variation in claims processes based on billing source (e.g., pharmacy, physician office, home health, outpatient hospital, etc.).

### **Mind The Gap**

Employers do not have data to analyze actual cost of drugs related to variances based on site of care. For employers, in addition to the cost of the drugs themselves, the cost of chemotherapy is also dependent on claims from the provider—an outpatient hospital, physician office, or home health clinic. Non-standardized performance measures limit the usefulness of even the existing data.



## **Employer Concerns**

"I can't get answers about outcomes. My plans always respond with information about activities instead of outcomes."

"Plans are all over the map when it comes to cancer. We need help to develop a more unified approach."

"I've seen stats that indicate oncology drugs are nearly 70% of the oncology revenue stream. That causes me to say, 'wow, the patient doesn't matter.'"

"I feel like we're left on our own when it comes to value-based purchasing for cancer. We need a coalition that can provide influence in creating more standard approaches."

# What Comprises Quality When It Comes To Cancer Care?

Employers voiced an interest in better understanding the underpinnings and standards related to assessing cancer care quality in order to manage cancer care benefits in the same way other, more familiar benefits are managed, like chronic conditions such as diabetes. This includes addressing standards used to define and measure quality, and to what extent achievement of quality-related outcomes may or may not be decipherable from the data they receive from health plans. Since the global definition of cancer quality is elusive, employers are unsure how to assess whether employees have access to the best treatments and provider institutions, or how to measure the outcomes of care from an ongoing and value-oriented perspective. Some also indicated the challenge of determining whether the Centers of Excellence (COE) strategies they have been pursuing to guide employees to particular medical centers, actually improve outcomes.

## Mind The Gap

Determining the definition of quality cancer care is confusing for employers. Because cancer is not one disease but hundreds, the array of terms, principles and guidelines that apply, and the variety of organizations involved in setting standards, create a particularly confusing landscape for employers. Data about the relative efficacy of cancer treatments is rarely available, and measures relating to their own employee populations are often buried in difficult-to-decipher troves of claims data.

Employers say that plans tend to make information readily available on care-related resources utilized and services billed for, but when it comes to actual outcomes, obtaining useful intelligence is often a challenge. Even among cancer practitioners, the definition of quality cancer care appears to differ, based on a myriad of varying expert opinions for different types of cancers.

Despite uncertainty about the definition of quality for most types of cancer care, there is a set of common decisions relating to quality care that must be made by employers. These include the design of employee benefits for cancer treatment that require evaluating oncology networks, choosing sites of care for treatment, directing (or not) employees to COEs, and providing coverage for various diagnostic and therapeutic options. Institutions such as the American Society for Clinical Oncology (ASCO), the National Comprehensive Cancer Network (NCCN) and programs such as the American Board of Internal Medicine's "Choosing Wisely," establish guidelines and make other recommendations for cancer care, but conflicting opinions on indices for quality and insufficient reporting on quality measure adherence complicate matters for employers.

# Opportunities

## Tools to Understanding Quality

**There is a clear need for “bringing employers up to speed” when it comes to cancer care quality. The tools that would benefit employers include:**

A primer that would familiarize benefit professionals with basic cancer quality terms, organizations and guidelines.

A framework of basic principles to include structural, procedural, and outcomes-based aspects of quality that also takes into account the patient-centered financial, emotional and social considerations of cancer care.

Based on that framework, a user-friendly scorecard that features measures and benchmarks for cancer treatment.

A data reporting system for providers and plans that quantifies quality cancer care based on agreed-upon benchmarks and metrics, available to all employers and purchasers in a transparent and timely fashion.

## Value Enhancing Opportunities

**Once the foundations of cancer care quality are better developed, accepted and utilized, employers will be better able to derive more value from their cancer-related expenditures. Value-enhancing opportunities in cancer care could include:**

Employers working collaboratively with health plans to promote value-based purchasing, a strategy that aligns purchaser contracts with high value care, is an effort already underway with various employers and plans. Fundamental to this strategy is developing metrics that can be used to define and reward improved performance contractually for providers and health systems. Potential payment strategies health plans can implement include episode pricing, gain sharing and shared savings, capitation, and monthly management fees, but all need to be calibrated against a required threshold for quality outcome metrics.

Other approaches to enhancing quality are emerging. For instance, where geographically achievable, employers can request that plans explore the use of community-based high performance oncology medical homes. All of these approaches must incorporate outcome-driven and evidence-informed access to specialty pharmacy and palliative care — critical services for people with cancer.

With a clearer understanding of quality, employers can request that health plans ensure access to high performing networks and COEs where appropriate, and use value-based benefit design to steer employees towards these institutions.

 **"Precision medicine" is the most transforming thing that's happened.**

**– Dr. Harold Varmus,  
Former Director of the National Cancer Institute**

### **Genomics and Cancer: Personalized Medicine**

Given the promise of genomics in oncology, purchasers, plans and providers should identify opportunities ripe for meaningful and broad scale application, and promote them. Genetic testing, for example, may be able to predict risk for specific cancers more precisely by focusing on a single known gene or the presence or absence of existing individual genes, or on the expression and interaction of groups or components of genes. This is important because genomically-guided approaches to cancer diagnosis and treatment may reduce potentially harmful side effects of chemotherapy and radiation. Overtreatment not only hurts patients but also increases cost. Approaching genomics with a mentality of “the right treatment in the right setting” has the potential to relieve patient burden, increase value to employers and decrease specialty pharmacy costs for chemotherapy.

#### **Mind The Gap**

Overall, the potential for personalized medicine is exciting. However, all stakeholders must consider application of current technologies individually, and assess their value in specific clinical scenarios.

# The Multi-Faceted Cancer Journey

Supporting an employee with a new cancer diagnosis or who is receiving treatment differs from other illnesses. Assisting the cancer patient and the family from time of diagnosis, or pre-diagnosis, through the course of the illness is typically more clinically intensive and emotion-laden than with other chronic conditions.

## **Employees Or Family Members With A Cancer Diagnosis Face Challenges In Three Main Arenas:**

- 1) Deciding which treatment regimen is most medically appropriate for them and then where and with whom to get that care;
- 2) Understanding and managing their healthcare, disability and other employee benefits and the impact of disease on finances, lifestyles and logistics; and
- 3) Enduring significant emotional and social issues in the workplace, at home and in their communities.

Even before treatment begins, employees diagnosed with cancer would benefit from access to resources and counseling to guide decision making regarding treatment options and other care considerations including treatment timing and location. During treatment, employees may require guidance and support to maintain adherence with their treatment plan or to manage their work schedules around chemotherapy, radiation therapy and other care-related appointments. If the employee is a caregiver for someone with cancer, they may need similar guidance and support. In certain circumstances, employees with cancer may also need help in knowing if, when and how to integrate palliative care services, or how to talk with providers about end-of-life care or in making end-of-life decisions.



**"I know my employees won't even pick up the phone if they see their health plan on their Caller ID."**

Employers are concerned that programs and services to assist employees through the cancer patient journey appear to be limited and/or uncoordinated. Studies indicate that patients who access support programs and take a more active role in managing their condition adhere better to treatment plans and may also incur fewer costs. Employers are searching for the best way to engage employees beyond traditional health plan programs. While anecdotal reports are often positive, services are typically underutilized. Employees often think the health plan is calling them about payment and not to support them in their treatment.

# What Health Plans Are Doing

Recognizing the burden of skyrocketing healthcare costs and the ever-increasing oncology spend for both employers and families, health plans are introducing various payment reform models to promote the use of performance contracting and bundled or episodic payments to rein in costs. At the most recent NEBGH roundtable, health plans shared pilot projects and their vision for oncology care in the future. These included oncology medical homes, pathways to reduce non-evidence based treatment, credentialing COEs and shared-savings contracts. While well intended, health plan programs are often constrained by limited employee confidence and trust.

**The table on the following page lists current cancer programs, ongoing pilots and programs under development by health plans. This is not intended to be an exhaustive list, but highlights current and planned activities by several major national carriers.**

## Mind The Gap

While many employers offer various versions of cancer nurse helplines, there is typically only anecdotal evidence that these helplines are useful, suggesting a need for outcomes-oriented and measurement-driven programs. Also, too often, support programs do not engage the patient until treatment decisions have been made, limiting efficacy. Concurrent management and workplace programs are not integrated well and plans are not a trusted source for medical treatment information.

In addition, programs are needed that help overcome stigma and address the emotional impact of the cancer journey, particularly programs that integrate new, creative approaches. One employer noted, “If you can, get patients to tell their stories, it’s very powerful.”

## Current Health and Cancer Programs

### Preventative Services

Prevention and detection screening programs

### Member Support

Online educational resources for patient support

Traditional claims-based RN telephonic patient navigation

Online patient support communities

### Networks

Centers of Excellence (COEs)

## Health Plan Pilots and Future Programs

### Member Support

Workplace transition programs

Interactive web portals and apps for patients and survivors

Earlier initiation of care management reward programs

Value-Based Benefit Design: Waving co-pays and deductibles for care management enrollees

### Provider Support

Web-based decision support for guidelines and pathways

EMR-integrated decision support for guidelines and pathways

### Payment Transformation

Oncology medical homes

Episode-based/bundled payments

ACO and Integrated Delivery Networks

Benchmark-driven pay for performance

Gainsharing and shared savings models

### Innovation in Quality Metrics and Reporting

Tracking ASCO/NCCN Guideline and Compendium adherence

Tracking chemotherapy-related emergency department (ED) visits and hospital admissions

Collecting patient experience reports following chemotherapy visits

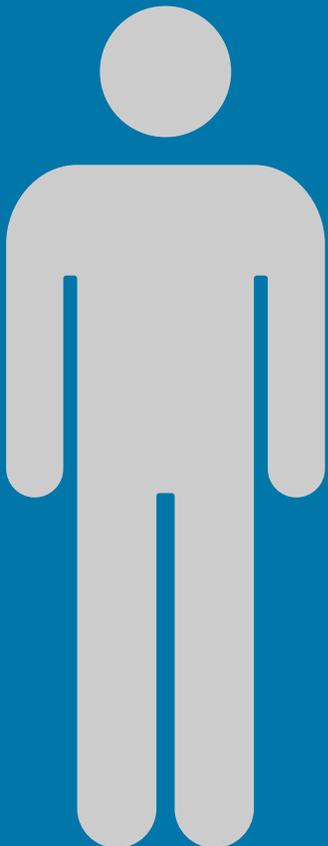
# Opportunities

**Opportunities for improved patient and caregiver support will need collaborative efforts among employers, health plans and other organizations. Here are some to consider:**

- Ensure access to a curated set of resources for employees, families and caregivers.
- Increase access to appropriate programs that connect employees and family members with trusted individuals who can assist them in navigating all components of the cancer journey.
- Work with outside organizations to create opportunities for employees to share their experiences through story-telling and creative arts programs, recognizing the growing base of evidence that indicates these approaches are popular among patients and families, and effective in terms of both impact and cost.
- Identify payment models to purchase recommended patient support programs either through the health plan, third party vendor, or the provider. This may require a payment structure that includes a monthly coordination fee for care managers or that managers are compensated for as part of a “bundled fee” to cover total cost of care.
- Promote workplace support programs that effectively address different needs at different stages of the cancer journey. Programs should include education for managers, supervisors, co-workers and the employee.

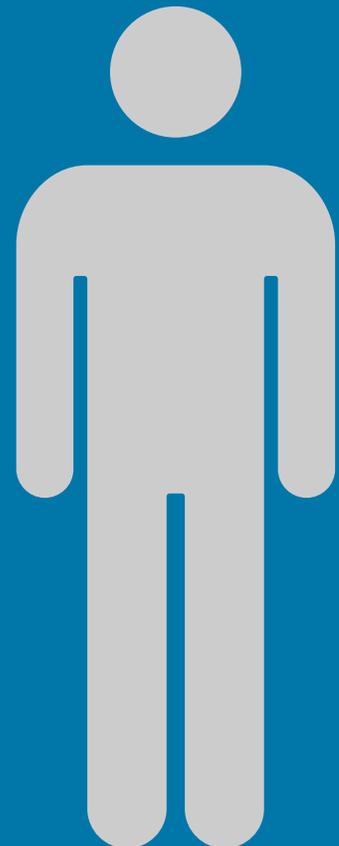
## **Benefit Professional**

Cost  
Value  
Quality  
Purchasing  
Support  
Managers  
Diagnosis  
Workforce Re-entry  
COEs  
Site of Care  
Speciality Pharma



## **Employee**

Fear  
Survival  
Family  
Chemotherapy  
Cancer  
Medical Bills  
Treatment Plans  
Multiple Opinions  
Diagnosis  
End of Life  
Job Loss  
Community  
Pain



# The Burden on Benefit Professionals: A Complex Landscape

The cancer care landscape is complex and stressful for benefit professionals, too. They reported often having to take on responsibilities to assist employees with cancer, in addition to their traditional roles. As cancer treatment effectiveness has improved, many employees are returning to work in various stages of the cancer journey.

As a result, benefit professionals must be equipped to provide re-entry and reintegration counseling, as well as accommodations for employees desiring to stay “on the job” during treatment. Benefit professionals may also need to assist employees in social and financial services relating to the cancer journey, such as communicating with family and friends about their condition and finding childcare and other services.

## **Mind The Gap**

Benefit professionals say they often feel they are “flying blind” in their current efforts to assist employees in obtaining all the services they need, and would be very interested in addressing the “info-gap” to understand what other companies and benefit professionals are doing to better serve their own employees. Employers also indicated that toolkits currently available, are sometimes too “high level” and not particularly “user-friendly.”

# Opportunities

## **Educational Resources**

One important opportunity for benefit professionals is to be connected to educational resources. Benefit professionals should have access to a clearinghouse or repository of practical and proven approaches and innovations, written clearly and with content customized to the needs of benefit professionals.

## **User-Friendly Toolkits**

In addition to lists of resources, benefit professionals need access to user-friendly toolkits to assist them in all parts of their role, addressing issues beyond benefit design, such as cancer-specific vendor management and methods for the emotional and fear-ridden aspects unique to employees with cancer.

There should be a means to support peer-to-peer sharing among benefit professionals to compare notes and best practices so they feel less isolated and more confident to manage benefit activities and address complex employee needs in the cancer arena.

# Next Steps



**Based on findings from these early exploratory efforts, NEBGH’s Solutions Center is seeking funding to better understand and meet the needs that benefit professionals have to “make sense” of what quality means with respect to cancer.**

Additionally, we think it timely to better understand and assist with the challenges employees have logistically, financially and emotionally as they deal with cancer. The goal is to empower employers with the knowledge and tools required to better support employees and families burdened by cancer, and to design benefits and support programs to deliver quality outcomes cost-effectively and with a high level of beneficiary satisfaction.

# Acknowledgements

## About NEBGH

Northeast Business Group on Health (NEBGH) is an employer-led coalition of healthcare leaders and other stakeholders that empowers its members to drive excellence in health and achieve the highest value in healthcare delivery and the consumer experience.

## About NEBGH's Solutions Center

The Solutions Center is NEBGH's unique data-gathering and discovery platform for developing initiatives that can "move the needle" when it comes to critical healthcare issues. Focused on employers as a catalyst for change, the Solutions Center's mission is to identify the most promising, innovative opportunities for improving health outcomes, and create a framework with the potential for transforming results and changing the national dialogue.

## Round Table and Work Group Participants

**Joshua Aaronson** Manager, Health & Welfare Programs, Memorial Sloan-Kettering Cancer Center; **Elena Abisidis, RN** Critical Health Solutions Manager, Goldman Sachs & Co; **Michelle Alexander, MD** Medical Director, Occupational Health, Con Edison; **Joel Beetsch, Ph.D.** Vice President, Patient Advocacy, Celgene; **Gary Behrens** Employer Account Executive, Sanofi; **Mary Bradley** Director of Healthcare Planning, Pitney Bowes; **Michael Eleff, MD** Medical Director, Regional Vice President, Anthem and Empire BCBS; **Joel Feigin, MD** Senior Medical Director, UnitedHealthcare; **Steve First** Vice President, Global Benefits, Pfizer; **Kate Fitch, RN**, Med Principle & Consulting Actuary, Milliman Inc; **Patricia Friedman** Senior Healthcare Consultant, Towers Watson; **Seth Friedman** Vice President, Client Management, Solid Benefit Guidance; **Jim Gallic** Director, Health & Productivity, Buck Consultants; **Terry Golash, MD** Senior Medical Director, Aetna; **Kathleen Harris** Vice President, Global Benefits, Time Warner Inc; **Joan Healy** National Account Executive, Anthem; **Eric Herbek** Vice President, Product Consumer Health Engagement, Cigna; **Chris Kim** Global Benefits Manager, KKR; **Ira Klein, MD** Medical Director, Aetna; **Chris Koller** President, Milbank Memorial Fund; **Michelle Martin** Vice President, HR Specialty Services, CBS Corporation; **Nathan Matthews** GHRS Pharmacy Benefits, PricewaterhouseCooper LLP; **Bob McNamara** Manager, Benefits, Time Warner, Inc; **Jill Mongeluzzo** Lead Specialist, Benefits Strategy, National Grid; **Jane Newman** National Director, Pfizer, Inc; **Stephen Nobles** National Account Manager, Strategic Markets, Genomic Health; **Erin O'Connor** President, Cammack Health LLC; **Jessica Paik** Senior Vice President, Client Development, UnitedHealthcare; **Latricia Parker** Executive Director, Global Benefits, The Estée Lauder Companies; **James Pini** Senior Account Executive, Sanofi; **William Shanahan** Vice President, HR-Total Compensation, Montefiore Medical Center; **Pam Sherman** Vice President, Client Management, Solid Benefit Guidance; **Jack Spicer** Medical Affairs Managed Care Director, Genomic Health; **Francesca Tedesco** Senior Director, US Policy, Celgene.

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