Town Hall Meeting Agenda

• 6:30 pm – Welcome and Introductions – Bernard M. Rosof, MD, MACP
• 6:40 pm – Dinner Service
• 7:00 pm – Moderated Discussion
• 9:00 pm – Adjournment
Town Hall Discussants

• Christopher M. Dezii, RN, MBA, CPHQ, Bristol-Myers Squibb Company
• Patricia M. Doykos, PhD, Bristol-Myers Squibb Foundation
• Ryan McCabe, PhD, American College of Surgeons
• Gary A. Puckrein, PhD, Founder and CEO, National Minority Quality Forum
• Jeanne M. Regnante, Chair, Merck & Co, Inc
• Fatima Scipione, Takeda Pharmaceuticals
• Ellen Miller Sonet, JD, MBA, CancerCare
• Dana Wollins, American Society of Clinical Oncology
Cancer Diverse Communities Working Group: Town Hall Meeting
The Immortal Life of Henrietta Lacks

Doctors took her cells without asking. Those cells never died. They launched a medical revolution and a multimillion-dollar industry. More than twenty years later, her children found out. Their lives would never be the same.

Rebecca Skloot
<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization</th>
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<tr>
<td>Jeanne M. Regnante</td>
<td>Chair</td>
<td>Merck &amp; Co, Inc</td>
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<td>Luther T. Clark</td>
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<td>Deanna Darlington</td>
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<td>Christopher M. Dezii</td>
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<td>Elizabeth Hanpeter</td>
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<td>Gail Larkins</td>
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<td>Coleman K. Obasaju</td>
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<td>Eli Lilly and Company</td>
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<td>Ellen Miller Sonet</td>
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<td>CancerCare</td>
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<td>David P. Winchester</td>
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<td>American College of Surgeons</td>
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<td>Karen Marie Winkfield</td>
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<td>Wake Forest Baptist Medical Center</td>
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<td>Dana Wollins</td>
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<td>American Society of Clinical Oncology</td>
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<td>Andrew Womack</td>
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<td>Genentech, Inc</td>
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Call to Action

• Spotlight existing inequities in order to identify and deliver solutions and innovations in cancer screening, referral, access to treatment, care, support and inclusive research for all.
Project Goals

➢ Better understand the distribution and impact of cancer among underserved and diverse populations around the country

➢ Help clinicians increase cancer screening, prevention counseling, and specialist referral in minority and poor communities

➢ Promote patient and community understanding of the importance and opportunities for improving cancer outcomes among diverse populations

➢ Better understand and increase diversity in cancer clinical research
• Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer.

• Comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance.

• All CancerCare services provided by oncology social workers and world-leading cancer experts.

• All services are available free of charge to anyone affected by cancer; including people with cancer, caregivers, loved ones and the bereaved.

• CancerCare serves clients in every state and 86 percent of all U.S. counties.

• Headquarters are located in New York City, with additional offices in CT, NJ and LI, NY.

• 100+ full-time employees, including 35+ masters’ prepared oncology social workers.

• In 2016,
  • programs and services helped 180,000 people affected by cancer
  • hosted 2.3 million visits to websites
  • provided emotional and practical support to more than 90,000 people through counseling & support groups
  • experts in oncology led 65 Connect Education Workshops, drawing more than 41,000 participants
  • provided more than $14.2 million in financial assistance to more than 22,000 people for treatment-related costs such as transportation, home care, child care and co-payment assistance
  • distributed more than 540,000 publications to health care providers, patient, caregivers
Background and Objectives

Background

• Need to more fully understand the broad range of experiences and needs of people with cancer

Goal

• Field a significant national study the findings of which will visibly and effectively represent the voice of cancer patients, advocate for their access to the best and most advanced care, and define and promote patient engagement to enhance their quality of life and optimize their outcomes.

Objectives

• Define engagement specifically as it relates to cancer patients
• Identify barriers to cancer patient engagement with care providers
• Characterize the financial, emotional, social and quality of life costs of cancer to patients and families
• Recommend strategies and programs to promote cancer patient access and engagement
Methodology

Six Surveys
1. Understanding the diagnosis
2. Participation in treatment decisions and planning
3. Communications with the care team
4. Financial and Insurance Issues
5. Symptoms, Side effects and quality of life
6. Survivorship

Questionnaire Development
• Guided by CancerCare Social Workers; Advisory Board vetted; Piloted with CancerCare clients

Sample
• Recruited through on-line panel vendors; not through advocacy orgs or CancerCare clients
• 50/50 mix of top 4 and all other,
• Designed to be nationally representative within each survey; Adults 25+, ~ 30% non-white
  • 25% from Northeast, Midwest, Southeast, Southwest/West
  • Recruitment quotas on age, education, income, cancer type; prioritized diversity

Format
• Online, average 41 questions, 20 minutes to complete
S1: 17. Please think back to when you first learned you definitely had cancer. How much of the information you needed on the following topics did you have?

None of the info:
- Understanding the kind of cancer I had: 28%
- Understanding the stage of cancer I had: 38%
- Insurance coverage for the diagnosis process: 32%
- Finding emotional and practical support: 32%
- Patient support organizations: 32%

n=500
Activities within 2 months of diagnosis

- Contacted a patient support organization
- Talked with a religious or spiritual advisor
- Exercised more than before I was diagnosed
- Made an appointment with a doctor to treat my cancer
- Looked for info on complementary & non-traditional therapies
- Talked with other cancer patients
- Searched on the computer for info about my cancer
- Talked with a professional for emotional support
- Saw another doctor for a second opinion
- Joined a patient support group

Whites 25-54
African Americans 25-55
### Patient Complaints about Medical Care

<table>
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<tr>
<th>Complaint</th>
<th>Often or Always Agree</th>
<th>White (n=360)</th>
<th>African American /Hispanic (n=121)</th>
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<tbody>
<tr>
<td>I am uncomfortable talking with my care team about how my cultural, religious, and personal values affect my treatment</td>
<td>7%</td>
<td></td>
<td>20%</td>
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<tr>
<td>I can’t speak with my care team members in my preferred language</td>
<td>6%</td>
<td></td>
<td>17%</td>
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<tr>
<td>My doctor shows a lack of respect for my cultural, religious, and personal values</td>
<td>5%</td>
<td></td>
<td>17%</td>
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<tr>
<td>I feel that 'I'm not being heard'</td>
<td>4%</td>
<td></td>
<td>16%</td>
</tr>
<tr>
<td>It’s hard to understand what the doctor is saying about my treatment</td>
<td>4%</td>
<td></td>
<td>19%</td>
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<tr>
<td>The services to translate communication into my preferred language aren't good</td>
<td>3%</td>
<td></td>
<td>22%</td>
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*Indicates statistically greater at 90% confidence level*

S. 3 Q.32. The following are complaints that some patients have about medical care. Please indicate how often you have or had these complaints during your cancer treatment.
11. How distressed (anxious, extremely upset, or in emotional pain, for example) have you been due to the impact cancer has had on the following aspects of your life?
To Keep in Mind

- Patients need more information
- Cancer causes significant stress on many levels
- Some patients have great difficulty understanding and communicating with their physicians
Ryan McCabe, PhD
American College of Surgeons
Commission on Cancer’s National Cancer Database NCDB

The NCDB, jointly sponsored by the American College of Surgeons and the American Cancer Society, is the preeminent multidisciplinary national clinical cancer registry system dedicated to continuous quality improvement for the evaluation, management and surveillance of cancer patients in the U.S. This mission is accomplished through our unique interface with providers at the point of cancer care at the local community level.
NCDB by the Numbers

- Started in 1989
- 1400 Commission on Cancer Hospitals
- 70% newly diagnosed cancers across U.S.
  - 1.3 million new submissions annually
  - 34 million cases reported since 1985
  - 75 disease sites
- 250 clinical datapoints per patient (limited dataset)
  - AJCC Staging, Diagnosis
  - Tumor Characteristics
  - Treatment Modalities and Dates
  - Long Term, All Cause Survival
Initiatives of the NCDB

- Clinical Quality Measures
  - Multi-disciplinary, hospital-based
  - Reports 20 quality measures for eight primary sites
  - 5 measures endorsed by the National Quality Forum
- Rapid Quality Reporting System (RQRS)
  - Real Clinical Time QMs and Patient Alerts
- Survival and Query tools
- Participant User File (PUF)
  - De-identified case level data
  - Site specific

More information: https://www.facs.org/quality-programs/cancer/ncdb
Dana S. Wollins, MGC
Senior Director, Health Policy
Policy & Advocacy Department
American Society of Clinical Oncology
ASCO’s Efforts to Address Health Disparities & Improve Quality in Medically Underserved Communities

❖ ASCO’s Mission: Conquering cancer though research, education, and promotion of the highest quality patient care
❖ Addressing Health Disparities & Improving Health Equity through:
  ✓ Policy Change to Improve Access to Care and Promote Research
  ✓ Education & Awareness to Improve Cultural Competency
  ✓ Mentorship to Improve Workforce Diversity
  ✓ Targeted Action to Improve Quality of Care in Medically Underserved Communities
ASCO Pilot Program: Improving Quality of Care in Medically Underserved Communities

Practice QI Goals

“Increase oral chemo adherence from 30% to 50% by December 2016”

“Improve QOPI Pain Assessment from 59% to 85% by Spring 2017”

“Reduce No-Show Rate from 39% to 20% within 6 months”

“Document using NCCN Distress Screening tool from 0% to 80% by December 31, 2016.”

Initial Findings

Practices are meeting their performance goals and are meeting or exceeding QI performance of peers

However, common challenges:
- Abstraction bandwidth, QI infrastructure
- Patient-related issues
  - Finances
  - Communication (no phone or changing numbers; no computer)
- Transportation/access
- Cultural/trust factor
- High distress levels
- Professional development/mentorship

Next Steps: Codify lessons learned, identify targets and expand offerings (including continued support to ensure sustainability)
Christopher M. Dezii, RN, MBA, CPHQ, Bristol-Myers Squibb Company
Previous Gaps Identified in Cancer Care

EXISTING MEASURE GAPS

PATIENT OUTCOMES
- Cancer-and-stage-specific survival
- Patient-reported outcome measures

SAFETY
- Febrile neutropenia
- Surgical site infections

DISPARITIES
- Risk-stratified process/outcome
- Access measures

COST AND EFFICIENCY OF CARE
- Total cost
- Underuse, and overuse

PERSON-AND-FAMILY CENTERED CARE
- Shared decision making
- Patient experience

PEDIATRICS
- Hematologic cancers
- Transitions to adult care

APPROPRIATENESS OF CARE
- Expected clinical benefit vs expected clinical risk

CARE COORDINATION
- Transition communication between providers
- Medication reconciliation

TREATMENT BY CANCER TYPE
- Prevalent cancers
- Less prevalent cancers

HEALTH AND WELL-BEING
- Quality of Life
- Social and Emotional Health

PREVENTION
- Public Outreach and Education

EVOLVING TREATMENTS
- Clinical trials
- Immuno-oncology
- Precision medicine

Source: Modified from Performance Measure Coordination Strategy for PPS Exempt Cancer Hospitals 2012
To learn more or become a part of the Cancer Working Group: contact Dr. Laura Lee Hall at: lhall@shcllc.info