Dialogue Proceedings / Advancing Oncology Care Quality in the Era of Immuno-oncology and Other Evolving Treatments

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TABLE OF CONTENTS

EXECUTIVE SUMMARY ....................................................... 1
INTRODUCTION ................................................................. 2
DEFINING WHAT QUALITY MEANS ....................................... 3
ONCOLOGY QUALITY MEASURE LANDSCAPE AND EXISTING GAPS .......... 4
PRIORITIZING MEASURE GAP AREAS .................................... 5
BRAINSTORMING MEASURE CONCEPTS ................................ 7
PRIORITIZING MEASURE CONCEPTS .................................... 7
DISCUSSION ON TOP PRIORITY MEASURE CONCEPTS .................... 9
TOP PRIORITY MEASURE CONCEPTS: BARRIERS/CHALLENGES AND NEXT STEPS .......... 13
CONCLUSION ................................................................. 15
APPENDIX A: MEETING PARTICIPANTS, MEETING FACILITATORS, AND OBSERVERS .......... 17

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EXECUTIVE SUMMARY

Cancer is a high-priority disease with substantial burden impacting millions of people in the United States. While cancer mortality has been in decline in past decades, there is room for improvement in the quality of cancer care. Avalere, in collaboration with the American Society of Clinical Oncology (ASCO), Cancer Support Community, Community Oncology Alliance, and Patient Advocate Foundation, and with support from Bristol-Myers Squibb, brought together leaders from the patient, payer, health information technology, provider, and research communities to discuss challenges and opportunities to advance the quality of cancer care. “Advancing Oncology Care Quality in the Era of Immuno-oncology and Other Evolving Treatments,” the “Dialogue,” was held on June 15, 2016. The objectives of the Dialogue were to: 1) gain consensus on gaps in current cancer care and the need for advancing quality of cancer care in the era of immuno-oncology and other emerging treatments, 2) discuss potential quality measure topics and what may be prioritized, and 3) determine a set of consensus-based recommendations to advance quality of cancer care.

Takeaways from the Dialogue

• The participants reaffirmed that the same measurement gaps have been identified over the past eight years, yet little movement has been made to close them. These include patient-reported outcomes, cost, survival, appropriateness of care, care coordination, quality of life, and health and well-being, among others.
• In the era of immunotherapy and precision/personalized medicine, the need to define quality is increasingly important. While there is an abundance of oncology quality measures, they are not the right measures to comprehensively address oncology care from the patient perspective.
• The group agreed on person- and family-centered care, care coordination, efficiency, cost, clinical and patient outcomes, and disparities as high-priority measure gaps.
• The participants identified survival and shared decision-making as the measure topics of highest priority.
• Other high-priority concepts included social, emotional, and spiritual health of the patient, genomic sequencing in diagnosis and treatment decisions, accuracy of diagnosis and comprehensive treatment, and screening/management for depression.
• Advancing high-priority measure concepts will require collection of more granular oncology data, including survival and impact of shared decision-making on patient outcomes; a refined quality measure development methodology; and research to establish best practices in shared decision-making.
INTRODUCTION

Cancer is a high-priority disease with substantial burden impacting millions of people in the U.S. It is estimated that 1.7 million new cancer diagnoses will occur and approximately 600,000 people will die from cancer in the U.S. this year. While overall cancer mortality rate has significantly decreased in past decades, various stakeholders including patients deemed the quality of cancer care suboptimal. As the U.S. healthcare system shifts to an emphasis on value rather than volume, and cancer care advances with new treatments such as immunotherapy, the need to measure the quality of care delivery from the patient perspective has become critical. To that end, Avalere, in collaboration with the American Society of Clinical Oncology (ASCO), Cancer Support Community, Community Oncology Alliance, and Patient Advocate Foundation, brought together leaders from the patient, payer, health information technology, provider, and research communities to discuss challenges and opportunities to advance the quality of cancer care.

The Dialogue, “Advancing Oncology Care Quality in the Era of Immuno-oncology and Other Evolving Treatments,” sponsored by Bristol-Myers Squibb, was held on June 15, 2016. The objectives of the Dialogue were to:

1. Gain consensus on gaps in current cancer care and the need for advancing quality of cancer care in the era of immuno-oncology and other emerging treatments,

2. Discuss potential quality measure topics and what may be prioritized, and

3. Determine a set of consensus-based recommendations to advance quality of cancer care.

A total of 18 attendees representing varying perspectives in cancer care actively participated in the discussion and activities (see Appendix A for the list of participants, facilitators, and observers). Kristi Mitchell, senior vice president at Avalere Health, facilitated discussion throughout the day. In order to encourage open and honest discussion, the facilitators used the Chatham House Rule, in which participants are free to use the information received, but neither the identity nor the affiliation of the speakers, nor that of any other participant, may be revealed.

DEFINING WHAT QUALITY MEANS

At the outset of the discussion, participants were asked what they wanted to gain from the Dialogue. This open-ended question brought forth a variety of responses from participants. Participants shared goals to advance quality measures in oncology, but also voiced some frustration with the challenges associated with measure development, data disparities, and the lack of progress over the last decade. The importance of considering the impact of quality measurement on providers was also shared by the group.

Each participant ultimately was aligned with the goal of advancing oncology care quality through better measurement as their motive for attending the Dialogue, aspiring to truly move the needle forward. Participants were also asked to write down and submit what quality meant to them, a sample of which is depicted in Figure 1. Common themes from the quality “definitions” included taking into consideration patient goals and preferences, comprehensive care, and improving patient outcomes through evidence-based care.

Figure 1: Quality Is…

- “Evidence-based care focused on patient goals that uses resources wisely for the betterment of population health.”
- “Ensuring evidence-based practices are used to provide necessary treatment to the patient.”
- “Patient-engaged care.”
- “Right thing at the right time for the right person.”
- “Thriving –not just serving.”
- “Quality care is informed care.”
- “Comprehensive care consistent with patient goals and success in achieving those goals over time”
- “Care that recognizes how challenging cancer is for the individual and his or her family.”
ONCOLOGY QUALITY MEASURE LANDSCAPE AND EXISTING GAPS

The first exercise was followed by two presentations related to cancer care advances and gaps in quality measurement. Minnie Song, senior manager at Avalere Health, presented the recent advances in cancer care, including immunotherapy and precision medicine, which provided the context of the discussion throughout the day in addition to considering patient perspectives. She also presented the current landscape of cancer measures. Although there exist more than 300 oncology quality measures, she pointed out that the majority of the existing measures are process measures and only 16 percent of the existing measures are endorsed by the National Quality Forum (NQF).

“The measures that exist, exist for a good reason, and they actually have been created through a credible process. It’s just [that] they are probably necessary…but insufficient.”

Melissa Mariñelarena, senior director at NQF, gave an insightful presentation on the current portfolio of NQF-endorsed cancer measures and the gaps identified by NQF committee members to date. Dialogue participants reaffirmed the need for developing quality measures that can fill the gaps and matter to patients, as Melissa highlighted that similar gaps have been called out by NQF committee members since 2008 (Figure 2).

Figure 2: Previous Gaps Identified in Cancer Care

<table>
<thead>
<tr>
<th>Patient Outcomes</th>
<th>Safety</th>
<th>Disparities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer- and stage-specific survival</td>
<td>Febrile neutropenia</td>
<td>Risk-stratified process/outcome</td>
</tr>
<tr>
<td>Patient-reported outcome measures</td>
<td>Surgical site infections</td>
<td>Access measures</td>
</tr>
<tr>
<td>Cost and Efficiency of Care</td>
<td>Person- and Family-Centered Care</td>
<td>Pediatrics</td>
</tr>
<tr>
<td>Total cost</td>
<td>Shared decision-making</td>
<td>Hematologic cancers</td>
</tr>
<tr>
<td>Under- and overuse</td>
<td>Patient experience</td>
<td>Transitions to adult care</td>
</tr>
<tr>
<td>Appropriateness of Care</td>
<td>Care Coordination</td>
<td>Treatment by Cancer Type</td>
</tr>
<tr>
<td>Expected clinical benefit vs. expected clinical risk</td>
<td>Communication among providers</td>
<td>Prevalent cancers</td>
</tr>
<tr>
<td></td>
<td>Medication reconciliation</td>
<td>Less prevalent cancers</td>
</tr>
<tr>
<td>Health and Well-Being</td>
<td>Prevention</td>
<td>Evolving Treatments</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Public outreach and education</td>
<td>Clinical trials</td>
</tr>
<tr>
<td>Social and emotional health</td>
<td></td>
<td>Immuno-oncology</td>
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PRIORITIZING MEASURE GAP AREAS

Following a detailed review of known gaps in the oncology care continuum, the attendees broke out into two smaller groups. Each group was tasked with prioritizing the top three gaps for measure development.

Group A focused on the health outcomes heavily, which they felt consisted of two different elements: patient-reported outcomes and clinical outcomes. The group also felt that treatment by cancer type and appropriateness of care were critical to address. In conjunction with treatment by cancer type, the group felt that evolving treatments must be addressed. So many patients, said one participant, feel that clinical trials are their last resort. In reality, they could be their first, and best, line of treatment. The group also felt cost and efficiency are important, especially in the context of care coordination. Efficiency is especially relevant in the person- and family-centered care concept.

Group B recognized the role, albeit insufficient, that existing measures have played in improving the quality of care. The group also discussed that there are opportunities to develop measures that actually reflect system capabilities and the abilities to manage a patient over time, across a variety of care settings. It is important to define the elements of a comprehensive care delivery system and how, for each patient, the services and goals connect. It is acceptable, participants said, to be somewhat aspirational in envisioning the ideal care delivery and quality measurement for cancer patients. Ultimately, the group prioritized areas that need immediate attention, that are cross-cutting, system-oriented, and that incent people to think differently.

"The most important thing to me is to have all the possible testing available to me…I think it's not only important to believe that you're getting the best treatment, but that the best treatment is available, and you are on the best treatment for your cancer. And that I can afford to have access to it."

It is important to note that the prioritization efforts of the two groups yielded similar results, as outlined in Table 1, below. Both groups prioritized person- and family-centered care, care coordination, efficiency, cost, and patient outcomes. Overall, the groups noted it is challenging to narrowly define measurement gaps of priority when they are all so interwoven.
Table 1: Breakout Group Prioritized Measure Gaps

<table>
<thead>
<tr>
<th>Group A</th>
<th>Group B</th>
</tr>
</thead>
</table>
| 1. Patient-Reported Outcomes/Clinical Outcomes  
   a. Treatment by type  
   b. Appropriateness of care  
   c. Evolving treatments | 1. Person- and Family-Centered Care  
   a. Patient outcomes  
   b. Disparity  
   c. Cost and efficiencies |
| 2. Care Coordination  
   a. Cost and efficiencies  
   b. Person- and family-centered care | 2. Care Coordination  
   a. Patient outcomes  
   b. Disparity  
   c. Cost and efficiencies |
| 3. Health and Well-Being  
   a. Patient outcomes  
   b. Disparity  
   c. Cost and efficiencies | |

“It’s crucial you understand what the patient wants and how you get data to build the measure. If you don’t really get to what the patient truly wants, and you don’t have the data to actually [fulfill] the measure, it just becomes another measure.”

In the ensuing dialogue, participants encouraged focus on “measures that matter,” measures that are “meaningful to the patient,” and measures that align with “what the patient wants.” Measures must respect and reflect the uniqueness of patients. It is important, participants said, for outcomes to not only matter to patients, but be actionable from a clinical standpoint. Current patient-reported outcomes measures (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS®]) do not, said some participants, measure patient experience in ways that are important to patients.

Repeated concerns surrounding the continued inability to effectively capture data for use in advancing care surfaced. In particular, with respect to the electronic health record (EHR) system, clinicians struggle to understand their own performance. If they don’t have the actionable data, they can’t parse it and change their behavior in pursuit of quality improvement. Participants also shared ideas around capturing true feedback directly from the patient through social media, as often patients are afraid to be honest with providers, ask questions, and provide negative feedback. Participants expressed the importance of trusting providers and noted the difficulty in measuring a patient’s level of trust or confidence in a provider’s care, as well as the need for data to help provide optimal care. Further, a participant emphasized “the totality of the experience” where how the care has
been provided is as important as what care patients received. Participants voiced concern around increasing provider reporting burden, which ultimately decreases time with patients. Providers are overwhelmed, according to participants, by proliferating numbers of quality measures on top of their clinical workload and administrative responsibilities, which can jeopardize the actual delivery of high-quality care to patients. In that regard, it was re-emphasized that the solution should be “better measures” rather than “more measures.”

BRAINSTORMING MEASURE CONCEPTS

To begin this part of the Dialogue, participants discussed how they would innovate in the quality measurement space given the existing measures, as well as areas of focus for future quality measure development activities. The group was asked to brainstorm as many measure concepts as possible that would help fill those gap areas discussed in earlier parts of the Dialogue using a worksheet. The Avalere team provided examples of quality measure concepts, including shared decision-making, quality of life, symptom management, survival rate, and psychosocial needs. Once the brainstorming was complete, participants split again into their breakout groups to compile and refine their measure concepts. The Avalere team facilitated discussion to help each group make a list of concepts to bring forward.

PRIORITIZING MEASURE CONCEPTS

Prior to beginning this activity, the Avalere team compiled the lists of measure concepts from both breakout groups, ensuring that all measure concepts provided by participants were represented in the list. Several topics appeared on both groups’ lists of measure concepts, so these topics were consolidated and only appeared once in the final list. The participants discussed a measure concept prioritization framework (Table 2), which helped to encourage thinking around the feasibility and impact of their created concepts.

Table 2: Measure Concept Prioritization Framework

<table>
<thead>
<tr>
<th>Impact</th>
<th>Feasibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>Ability to be captured electronically</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Available evidence and data sources</td>
</tr>
<tr>
<td>Providers</td>
<td>Opportunity for improvement</td>
</tr>
<tr>
<td>Payers</td>
<td>Level of specificity to patient and patient treatment plan</td>
</tr>
<tr>
<td>Health System</td>
<td>Time required for development</td>
</tr>
<tr>
<td>Society</td>
<td></td>
</tr>
</tbody>
</table>
The participants generally believed that feasibility was slightly more important than impact, in that if the measure cannot be developed and used in the real world, it has no chance to have any impact at all. The participants also commented on how “actionable” a measure is, noting that this is perhaps a third consideration when prioritizing concepts. The participants also felt that what is most impactful can always become feasible with drive and the right stakeholders at the table. Once the participants had discussed these prioritization criteria, they were asked to vote on the measure concepts by writing the number of the concept(s) for which they wanted to prioritize on green and yellow dots provided to them. On the green dot, participants wrote the number of their top priority measure concept. On the yellow dots, participants wrote the numbers of their lower priority measure concepts. Participants could use all of their votes on one measure concept or spread them across up to three concepts. The final list of measure concepts for voting is below:

1. Efficiency and effectiveness of shared decision-making
2. Availability of care plan present and provided to patient at time of treatment
3. Shared decision-making with family members and incorporation of family into patient’s care plan
4. Patient access to services that address their needs (e.g., community resources, psychological resources)
5. Social, emotional, and spiritual health of the patient
6. Patient functional status (e.g., ability to perform activities of daily living)
7. Patient re-integration into society and education around life after treatment (survivorship)
   Chronic toxicity outcomes and related patient education
8. Patient delight
9. Caregiver well-being
10. Transitions of care and accountability of care team members (shared communication)
11. Patient care coordinator across care team
12. Appropriateness and efficiency of care
13. Survival (risk adjusted)
14. Patient access to clinical trials and evolving treatments
15. Genomic sequencing in diagnosis and treatment decisions
16. Accuracy of diagnosis and comprehensive treatment
17. Personalized/targeted, evidence-based treatment
18. Screening/management for depression prior to treatment
19. Treatment benefit weighed against risk and affordability

“What is most impactful can become feasible when you push for it hard enough.”
DISCUSSION ON TOP PRIORITY MEASURE CONCEPTS

Following the voting process, the Avalere team compiled the votes for each measure concept to determine the prioritized concepts. The two concepts prioritized by the group were: (1) efficiency and effectiveness of shared-decision making; and (2) survival.

Table 3: High-Priority Measure Concept Votes

<table>
<thead>
<tr>
<th>Concept</th>
<th>Votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Efficiency and effectiveness of shared decision-making</td>
<td>6</td>
</tr>
<tr>
<td>Survival</td>
<td>6</td>
</tr>
<tr>
<td>Social, emotional, and spiritual health of the patient</td>
<td>2</td>
</tr>
<tr>
<td>Genomic sequencing in diagnosis and treatment decisions</td>
<td>1</td>
</tr>
<tr>
<td>Accuracy of diagnosis and comprehensive treatment</td>
<td>1</td>
</tr>
<tr>
<td>Screening/management for depression</td>
<td>1</td>
</tr>
</tbody>
</table>

For the survival measure concept, participants discussed the challenges in developing a hypothetical measure specification given the lack of reliable data and difficulty tracking survival. Specifically, there is an absence of publicly available mortality data after 2011 because of changes in the Social Security Administration’s regulations, making it challenging for researchers to track mortality. Payers have also noted how the lack of this type of data has hindered an accurate assessment of oncology treatments. Participants stated that advocating for the reopening of the Social Security database is an option, though it could be challenging since access was cut off due to patient privacy concerns. While databases like the Surveillance, Epidemiology, and End Results (SEER) Program could be of assistance, it is important to consider the unit of measurement (e.g., state level, practice level), and other aspects of methodology, such as incorporating risk adjustment, that could affect a measure of this kind. Participants agreed that risk-adjusting the measure by cancer type as well as other factors such as stage, molecular marker, and comorbidities is a critical piece of the measure specification, otherwise the measure loses its meaning. While this would give the measure more meaning, it would also involve development of a more complex measure specification with more advanced methodology. Participants discussed the potential of the Oncology Care Model (OCM) to advance the survival measure concept, however, one participant noted that the OCM does not currently include the granular information required for proper risk adjustment. The OCM plans to establish a registry that will collect staging, molecular marker, mutation, and other genetic data that will be relevant in measuring patient outcomes and better understanding cost. Generally, participants noted that it is hard to create cancer-specific quality measures if more granular oncology data does not exist. One participant noted that it is critical to look at both structured and unstructured data in the EHR, as more relevant information can be illuminated depending on the system. Oncologists are
identifying the relevant data (ex., HER2 mutation for breast cancer patients), but it’s a matter of finding it in the record. National Comprehensive Cancer Network (NCCN) is also working to digitize outcomes data in a database through their collaboration with Flatiron Health. Several participants noted that claims data is still relevant, as it is one of the few data sources that has been vetted, validated, and used for 30 years. There is also potential to access commercial health plans, which can be used to make indirect assumptions about mortality based on whether or not a patient is submitting claims. Participants also discussed the National Testing Collaborative, a CMS activity that aims to create a test bed for measure development and testing across a network of relevant participating stakeholders, as a potential avenue for further measure development. NQF’s measure incubator has data partners that are aligned to help organizations build and test measures, so there is the potential for these two initiatives to work together. For example, NQF can help National Testing Collaborative by aligning one of its data partners to provide the assets to build and test a measure in a much more expeditious and efficient fashion than it would be otherwise.

“I think when we talk about outcome measures replacing process measures, the ultimate outcome measure in cancer is progression-free survival, overall survival.”

Ultimately, Dialogue participants felt the most critical first step would be to specify this measure through a partnership between a measure developer, consumer advocacy organizations, clinical experts, professional societies, and patients. It is also critical to note that this measure could pertain to the comparative effectiveness of systems, comparative effectiveness of clinicians, comparative effectiveness of strategies, or just disease-based survival dependent on the unit of measurement. Each of those concepts will have fundamentally different data resources and implications on quality improvement. It may be worthwhile recognizing that the actual focus of the measure needs to continue to be refined.

The group then discussed the shared decision-making concept, which included several more specific “sub-concepts” that clarify what the group felt should be encompassed in shared decision-making.

- Did the patient define his or her care/treatment goals?
- Did the patient understand the risks, benefits, and costs of his or her treatment?
- Did the patient understand the community resources available to him or her?
- Did the patient receive the correct knowledge to allow him or her to make an informed decision about his or her care that incorporates his or her preferences?
- Was palliative and end-of-life care discussed?
- Did the patient receive the care s/he chose?
- Did the system allow the shared decision-making to occur?
- Evolution of patient preferences and goals throughout the treatment process
The group also focused on the nature of the types of data and tools available for shared decision-making (e.g., the CAHPS® survey, National Business Coalition on Health tool for health plans, Dartmouth’s CollaboRATE shared decision-making measure\(^5\)), which is currently limited and may not be as detailed as necessary. One participant noted that perhaps a tool like CAHPS® could be amended to collect the more granular shared decision-making data. OCM is also including within their questionnaire a section on shared decision-making. Shared decision-making, according to one participant, has a great business case as it has been shown to significantly decrease healthcare resource utilization.\(^6,7\) Several participants felt this would make a shared decision-making measure appealing to insurers and employers. Some participants noted that payers could be drivers in this space. If payers insist these shared decision-making measures be a condition of payment, then that will help standardize shared decision-making tools and accelerate their use. The standardization of the platform used for shared decision-making is a critical piece to moving forward. In addition, in the places where bundled payment has been successful (e.g., palliative care), there is usually funding for a shared decision-making model.

“We need to make sure that we just don’t go back down that same path that there was documentation. And again, remembering the patient perspective of decision-making and not documentation of decision-making.”

There have been some demonstrated instances of successful shared decision-making (e.g., prostate cancer), but the data does not reside in a defined repository for use in measure development. In addition, shared decision-making data tends to be used in condition-specific fashion, rather than on a broader scale. Moving forward, participants felt more generalized modules and use of shared decision-making were needed, as well as transparency around any publicly available data that could be used in this space. Participants also discussed how to encourage routine use of shared decision-making in practice. Some participants noted there are isolated areas where it is well ingrained (e.g., orthopedic procedures and imaging), but that it tends to be condition-defined and not generalized to the entire therapeutic area. Several participants felt that there is training to be done around how patients and providers have those important shared decision-making conversations. This will help ensure that everyone is on the same page for the goal of engaging in this activity.


Participants also noted from a policy perspective that the new payment system under the Merit-Based Incentive Payment System could encourage shared decision-making through its Cost or Improvement Activities categories. Shared decision-making could be an example of good resource utilization or lowering costs. Several participants noted that incorporating shared decision-making into the EHR could be a challenge. Toward the end of the session, one participant noted that one of the shared decision-making measures endorsed by NQF is a basic process measure for back pain that only ensures that the documentation of shared decision-making occurred. This participant stated that it is critical not to go down the same path of documentation and to ensure that the patient perspective of the shared decision-making is the essential piece to capture. Ultimately, participants noted the importance of ensuring that the measures developed for both shared decision-making and survival truly close the gap and address quality improvement in oncology. In some instances, according to participants, measurement may not be enough. Quality improvement programs to wrap around and outline how the measures are used are essential to enhance performance. There is measurement going on in a variety of places, but clinicians don’t understand what they’re being measured against, how they’re measuring it, or how it will impact or enhance care.

“Just measuring for measuring’s sake doesn’t move the ball forward. It becomes a conversation only about measurement when in the final analysis what we’re trying to do is advance the quality of care for patients.”

“The problem here is that there are measures, there are gaps in measures, but the biggest gap is the gap of basically how those measures are used, and how they’re used to enhance performance. Because if we’re just measuring with the idea of not ultimately improving performance then we have nothing.”

Continuing the discussion, the group reviewed an example of a foundational blueprint for advancing mental health and well-being. Blueprints are actionable documents that communicate an organizational framework for meeting a stated goal, including an outline of the activities that must be conducted to achieve that goal. The group discussed, at a high level, potential pieces of a blueprint to advance quality care in oncology by further developing the prioritized measure concepts. The discussion included elements such as policy levers, evidence generation, methodology of building robust quality measures, integrating the patient perspective, and the use of health information technology (HIT) and integration of quality measures.

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TOP PRIORITY MEASURE CONCEPTS: BARRIERS/CHALLENGES AND NEXT STEPS

The table below describes the short-term and long-term next steps and barriers/challenges associated with the prioritized measure concepts. This layout and thought process can be applied to the other measure concepts that the group discussed, especially those concepts that were considered as high priority.

Measure Focus Area #1: Survival

Survival, in simple terms, represents how many people live for a certain length of time after they are diagnosed. Cancer research has long used the outcome of 5-year overall survival or 5-year progression-free survival to determine efficacy of certain cancer treatments. Also researchers have used survival rates at the population level to compare the status of cancer care among different countries. Participants felt that a quality measure around survival was critical to develop and implement, since survival represents the ultimate outcomes for which cancer care aims. Currently, there are no cancer survival quality measures used in accountability programs. Community Oncology Alliance Oncology Medical Home collects 5-year survival rates for breast, colorectal, and lung cancer patients for quality improvement.  

Short-Term Next Steps

- Support reopening of Social Security database with increased privacy regulations
- Initiate the collection of more granular oncology data including survival through the Center for Medicare & Medicaid Innovation Oncology Care Model registry, ASCO CancerLinQ, and NCCN Outcomes Database
- Enhance the methodology for developing survival quality measures; conduct research on modifiable and non-modifiable factors impacting survival as well as how to attribute a patient over multiple providers and facilities
- Determine measure development focus area (specific cancer type and stage and population)
- Assess the feasibility to measure an analog of survival in the available data sources to avoid delaying quality improvement while barriers/challenges are addressed

Mid- to Long-Term Next Steps

- Encourage EHR interoperability work to make available information from unstructured data

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• Initiate survival measure development through a multi-stakeholder partnership facilitated by the NQF Measure Incubator and National Testing Collaborative
• Generate consensus on how to use performance data on survival quality measures at the provider, facility, and plan level (i.e., public display, differential payment, quality improvement)

Barriers/Challenges
• Variability in survival timeframe depending on different cancer types and stages
• Challenges in tracking multi-year survival
• Lack of reliable mortality data after 2011 due to change in Social Security Administration’s data disclosure policy
• Lack of granular oncology data (e.g., staging, molecular markers, genetic mutations) that might impact patient survival
• Inability to locate relevant oncology data points in unstructured EHR data
• Challenges in linking oncology data points across different datasets (i.e., interoperability)
• Complexity of incorporating stage and risk adjustment and patient attribution to the measure specification

Measure Focus Area #2: Efficiency and Effectiveness of Shared Decision-Making

Shared decision-making (hereinafter SDM) is a collaborative process that allows patients/caregivers and their providers to make healthcare decisions together. It takes into account the best clinical evidence available, as well as the patient’s values and preferences. Participants agreed that SDM represents an opportunity to support treatment adherence and enhance patient quality of life. In addition, SDM has a significant business case, as studies have shown that SDM can improve care and reduce costs. There is a wide range of existing tools available to support SDM for oncology (the majority of the tools focus on cancer screening, e.g., lung cancer screening), however, translation from SDM tools into quality measures has been minimal.* Moreover, these measures are not currently used in any public accountability programs and are process-based, involving assessing whether correct documentation has occurred.

Short-Term Next Steps


* There are two SDM quality measures in oncology—Percentage of Patients Who Have Had a Shared Decision-Making Conversation about Colorectal Cancer Screening Tests developed by Institute for Clinical Systems Improvement (ICSI) and Communication and Shared Decision-Making with Patients and Families for Interventional Oncology Procedures developed by Society of Interventional Radiology (SIR).
• Generate evidence on the impact of SDM on patient outcomes (clinical, economic, and humanistic); this will likely require the collection of prospective data through vehicles such as CancerLinQ
• Initiate research to establish best practices in SDM (e.g., NQF project to develop national standards; measurement for patient decision aids might provide some insights12)
• Collect input from providers and patients who have engaged in SDM regarding which areas of SDM to prioritize

Mid- to Long-Term Next Steps

• Initiate a local demonstration project with multiple partners (providers, payers, patient groups) to test an SDM intervention in a new payment model
• Develop draft quality measures that evaluate structure, process, and outcomes around SDM through partnerships with organizations such as the Center for Informed Choice or Society for Medical Decision Making; measure development should follow the establishment of best practices
• Support efforts to systematically collect data around SDM for quality measure development, testing, and use
• Support the development of broader provider and patient education modules based on best practices (professional societies, association of cancer hospitals and community cancer centers, patient advocacy groups)

Barriers/Challenges

• Limited data to support the development of a meaningful SDM quality measure in addition to the overall usability of the measure within a population
• Lack of data demonstrating process/outcome links between routine use of SDM and improved outcomes
• Lack of a clear definition of what constitutes effective and meaningful SDM that leads to improved patient outcomes given patient values and preferences
• Difficulty in assessing how patients’ values and preferences impact shared decision-making process and outcomes
• Variation in SDM tools (lack of content standardization)

CONCLUSION

In the era of immunotherapy and precision/personalized medicine, the need to define what quality means for oncology patients is increasingly important. This Dialogue was successful in bringing together key stakeholders to discuss their views on quality as well as tangible ways to advance quality in the oncology space. Participants confirmed that

some of the same measurement gaps identified years ago, such as patient-reported outcomes, cost, survival, appropriateness of care, care coordination, and health and well-being, still exist today. In addition, while the number of oncology quality measures has increased, these measures may not all comprehensively address care from the patient perspective. To advance high-priority measure concepts such as survival and shared decision-making, it will be critical to collect more granular oncology data, refine quality measure development methodology, and research to establish best practices in patient-centered care.
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