Strategy Session #1 – Approaches to Identifying Individuals with Serious Illness

On July 17 2018, the National Quality Forum (NQF) hosted the first of four Serious Illness Strategy Sessions. The purpose of this meeting series is to develop and disseminate a set of recommendations for overcoming specific challenges and barriers that impede the advancement of quality measurement for serious illness. For the purposes of these Sessions, serious illness is defined as, "a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers."[i] During the first Strategy Session, an expert panel addressed the variability in approaches used to identify individuals with serious illness. This topic represents a challenge to quality measurement for two reasons. First, an *existing* quality measure's specifications describe which patients can be included in the calculation of the quality measure. Variability in identification approaches makes it difficult to assess whether a given approach to identifying serious illness aligns with an existing quality measure's specifications. Second, the development and testing of *new* quality measures requires clearly defined measure specifications. These specifications should align with identification approaches to facilitate comparisons in quality measure performance. A better understanding of current identification approaches and recommendations for bringing more clarity to and consistency across approaches will help with assessing where existing measures can be appropriately applied and inform the development of new quality measures that capture important aspects of care not covered by existing quality measures.

The specific goal of this first Strategy Session was to develop a set of guiding principles for the identification of serious illness. These guiding principles aim to bring greater clarity and consistency to the approaches used to identify individuals with serious illness and provide guidance to providers on the issues to consider when developing and implementing identification approaches. The specific objectives of the Session were to: (1) share current approaches to identifying individuals with serious illness and identify lessons learned from each approach; (2) apply lessons learned to two healthcare use cases; and (3) develop a set of guiding principles. NQF convened an expert panel of 12 individuals with backgrounds in serious illness, palliative care, and quality measurement (see Appendix A) to discuss current approaches and develop the initial set of guiding principles.

Approaches to Identifying Individuals with Serious Illness

To identify existing identification approaches and inform the expert panel's discussion, NQF staff conducted an environmental scan of published reviews and materials from the National Academies of Science, Engineering, and Medicine's roundtable meetings on serious illness.[ii,iii,iv,v,vi] Results indicated several programs target the seriously ill population, but limited information is available about the specific approaches used. In general terms, these programs use specific disease diagnoses, utilization patterns, indicators of functional decline, social determinants (e.g., lack of social support or access to nutritious food), and provider referral to identify program participants. The most common data sources include data from medical claims and medical records, primarily electronic medical records. To supplement the findings from the environmental scan, invited panelists presented information on the approaches used in their own programs or projects (see Appendix B).

Lessons Learned

Figure 1 shows a list of lessons learned from the presented approaches. These lessons belonged to one of two categories – lessons related to the use of program-centric approaches and lesson related to data challenges. The purpose and resources of a specific program drive program-centric approaches. These approaches contribute to significant variation across programs in terms of participating patients' characteristics. This variation, in turn, makes it difficult to compare programs, particularly on quality measure performance. Lessons related to data challenges included issues with data availability and completeness. Many approaches rely heavily on claims data. This data can provide information about an individual's diagnoses and utilization patterns, but is does not capture key information about an individual's unmet needs (e.g., functional status, caregiver needs). Functional status and caregiver assessment tools can provide this information, but there is limited guidance on which tools to use or how to store this data within a patient's health record.

Figure 1. Lessons Learned

Program-Centric Approaches

- Most approaches use a specific program's inclusion criteria as way to identify individuals with serious illness, resulting in an approach driven by the program's purpose (e.g., reduce ER admissions) and resources (e.g., access to data, anlaytic capabilities).
- Program-centric approaches tend to focus on diagnoses, costs, and utilization. Such approaches likely overlook individuals who may have significant unmet needs, but who do not exhibit high utilization rates or costs.
- Many programs include clinician referral as an approach to identifying individuals with illness. This approach helps promote access, but can contribute to increased variabilty in the program's patients in terms of diagnoses, functional status, medical and social needs, etc.
- Program-centric approaches vary by program, leading to variation in patient characteristics across programs. Such variation may make program comparisions difficult, particularly on quality measures.

Data Challenges

- Data availability and completeness can vary significantly by data element, setting of care, and program.
- Claims data is useful for identifying some markers of serious illness (e.g., diagnoses), but provide limited or no information related to important markers of unmet need (e.g., functional status, caregiver strain).
- Some programs collect data on functional status and caregiver strain, but identifying and collecting this information from the electronic medical record is difficult and there is variation across programs with respect to the tools used for these assessments.
- When possible, data captured on functional status and caregiver strain should be used to identify individuals with serious illness **and** inform the development and implementaiton of individual's plan of care.

Guiding Principles for Identifying Individuals with Serious Illness

To develop the guiding principles, the expert panel applied the lessons learned to two healthcare use cases. From these use case discussions, the expert panel came to a consensus that it is not appropriate or feasible to have a single, standard approach to identifying individuals with serious illness. The population is too varied and the use of a single approach would likely result in the exclusion of individuals who would benefit from palliative care or other supportive services. With this need for flexibility in mind, the expert panel developed a set of guiding principles meant to promote more consistency in approaches, but not mandate the use of specific data or tools. After the strategy sessions, the Quality Measurement and Accountability Committees of the Serious Illness Quality Alignment Hub reviewed and refined these guiding principles. Table 2 contains the final set of guiding principles.

Table 2. Guiding Principles for the Identification of Individuals with Serious Illness

Guiding Principle	Rationale
1. The approach should attempt to include data on health conditions, functional status, and caregiver strain.	The approach should attempt to capture data on each of the major components of the serious illness definition. If data on functional status or caregiver strain is not available for identification, programs should collect this information after identification and use it to inform the delivery of care.
2. The approach should consider the specific purpose of the program in which it is being applied.	A program may target a specific sub-set of the seriously ill population and the approach may be tailored to capture the needs of that sub-set. Additional data may be required to enhance the approach's specificity and identify individuals who would be appropriate for a specific program.
3. The approach should utilize data that can be used to identify individuals with serious illness **and** inform the delivery of their care.	To minimize the burden associated with a given approach, data collected and analyzed for identification purposes should also be used to inform the delivery of care to the individual identified as seriously ill.
4. The approach should be regularly examined to determine whether newly available data could enhance the approach's effectiveness.	New sources of data are likely to emerge over time and data that is currently considered infeasible to collect (e.g., functional status) may be more easily accessed as new tools and technology are developed. Regularly examining the approach will allow for the identification and incorporation of these new data sources.
5. The approach should be monitored for unintended consequences.	Approaches may inadvertently exclude individuals who would be appropriate for services or incentivize undesirable behavior. Monitoring for these unintended consequences should be part of a regular maintenance process for the approach.
6. The approach should include the same components of the serious illness definition, regardless of the target patient population's age.	Senior, adolescent, and pediatric populations can all experience a serious illness. Regardless of the target population's age, the approaches should attempt to examine each of the major components of the serious illness definition.
7. The approach should use resources available to a wide range of settings and providers.	To promote access to care, the approach should incorporate data sources and measures that the majority of settings and providers can access.

Conclusion

This Strategy Session aimed to develop a set of guiding principles meant to bring more clarity and consistency to approaches used to identify serious illness. The guiding principles highlight the need for approaches to reflect the multi-component nature of serious illness, while also recognizing the need for flexibility across approaches. In addition, these guiding principles signal the need to assess approaches continuously to ensure the best and most appropriate data are used and the effects of the approach are assessed and addressed. This continued assessment will help address questions related to the lack of data for each component of the serious illness definition (e.g., "How can we capture data on functional status and caregiver strain on a more consistent basis?"), dosing (i.e., "How can the approach help us determine what level of services this individual needs?"), and capacity (i.e., "What resources are required to care for the individuals identified by an approach?"). The greater clarity and consistency that comes from this continued refinement will be necessary for assessing where existing measures can be appropriately applied and inform the development of new quality measures that capture important aspects of care to delivered to the seriously ill.

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[i] Kelley AS & Bollens-Lund E. Identifying the population with serious illness: The "denominator" challenge. *J Palliat Med*. 2018; 21(S2): S7-S16.

[ii] Henry M, Hudson, Scholle S & Briefer French J. Accountability for the quality of care provide to people with serious illness. *J Palliat Med*. 2018; 21(S2): S68-73.

[iii] Kerr K. *Community-Based Model Programs for the Seriously Ill*. San Francisco, CA: The Gordon and Betty Moore Foundation; 2017. https://www.moore.org/docs/default-source/patient-care-/report-model-programs-for-the-seriously-ill-may-2017-dls.pdf?sfvrsn=529b6c0c_2. Last accessed July 2018.

[iv] National Academies of Sciences, Engineering, and Medicine. 2018. Financing and payment strategies to support high quality care for people with serious illness: Proceedings of a workshop. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/25071. Last accessed July 2018.

[v] National Academies of Sciences, Engineering, and Medicine. 2018. Models and strategies to integrate palliative care principles into care for people with serious illness: Proceedings of a workshop. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/24908. Last accessed July 2018.

[vi] National Academies of Sciences, Engineering, and Medicine. 2017. Integrating the patient and caregiver voice into serious illness care: Proceedings of a workshop. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/24802. Last accessed July 2018.

Appendix A: Expert Panel

Name	Organization
Helen Burstin (Chair)	Council of Medical Specialty Societies
Rebecca Anhang-Price	Rand Corporation
Alena Baquet-Simpson	Aetna
Hannah Cook	Duke Margolis Center for Health Policy
Torrie Fields	Blue Shield of California
Marian Grant	Coalition to Transform Advanced Care
Maureen Henry	National Committee for Quality Assurance
Amy Kelley	Icahn School of Medicine at Mount Sinai
Franziska Rokoske	RTI International
Joseph Rotella	American Academy of Hospice and Palliative Medicine
Jim Rudolph	Providence VA Medical Center
Rob Saunders	Duke Margolis Center for Health Policy

APPENDIX B: Summary of Presentations on Approaches to Identifying Individuals with Serious Illness

Program/Project	Program/Project Purpose	Criteria for Identify the Seriously Ill	Data Sources	Challenges to Implementation
Aetna Compassionate Care Program	• To provide support and assistance to members, families and caregivers across the spectrum of serious illness • To improve quality of life and member satisfaction • To assist members in better managing chronic conditions • To reduce unnecessary hospital admissions, readmissions and ER visits	• Stratifying population in terms of predicted risk of events where care management can help member achieve a better outcome o Future admission o Readmission o Avoidable ER visits o Falls o Terminal Illness • Internal referrals • External referrals (e.g., providers)	Claims data • Demographics • Diagnoses • Medical and pharmacy utilization • Gaps in care • Medication adherence Member generated data • Clinical assessment data • Text from nurse notes • Lab results External data • Census derived Social Determinants of Health data • External purchasing behavior and marketing survey data	• Lack of available data on functional status • Limited availability of clinical data (e.g., EMR data) • Limited data on individual level social determinants of health

NCQA Serious Illness Standards & Process Measures	• To evaluate the quality of care for patients living with serious illness	• Serious illness specialty practice enrollment • Clinician judgment • Patient characteristics o In-patient admission o ED visits o Diagnoses o Comorbidities o Functional status o Labs	• Electronic clinical data systems • Paper records • Claims data	• Lack of/ inaccessible documentation in EHR and paper records • Limited access to claims data
CTAC and AAHPM's Serious Illness Models	• Advanced Care Model (C-TAC) To provide an advanced APM to support **population health management** for those with **advanced illness**, focused on the **last year of life**	• Acute care utilization • Performance status (PPS) • **Functional decline (↓ ADLs)** • **Nutritional decline (wt. loss)** • **Prognosis (surprise question)**	• Claims data • Clinical & admin data* • Clinical & admin data* • Clinical & admin data* • Clinical data	• Performance status and functional and nutritional decline not captured in claims/admin data if no SNF (MDS) or home health (OASIS) stay or DME claim
	• Patient And Caregiver Support for Serious Illness (AAHPM) To provide monthly **care management** payments to support interdisciplinary teams **delivering community-based palliative care** to patients with **serious illness**	• Acute care utilization • Performance status (PPS, **ADL** or **DME**) • **Diagnosis or multiple chronic conditions (criteria different for cancer v. non-cancer)**	• Claims data • Clinical & admin data* • Claims data **(*If admin data includes OASIS, MDS, or DME)**	• Cannot identify a comparison group using only claims/admin data • Limited accuracy of clinician prognosis estimates • Diagnosis lists miss rare conditions

The Defining the Denominator Population	• 1) Project Purpose: To identify a national population of seriously ill individuals who may have palliative care needs.	• Diagnosis • Functional Status • Utilization	• Claims data (e.g., diagnosis, service, and DME codes) and survey data	• Lack of severity of illness measures in claims. • Lack of survey data generalizability to other data sources.
	• 2) Program Purpose: To identify seriously ill individuals locally for enrollment in concurrent palliative care services	• Diagnosis • Utilization	• Clinical data (e.g., medical chart/EHR data), plus Claims data for subset of population.	• Lack of available data on functional status. • Lack of timely data acquisition. • Limited "view" through only one institution.
Developing Measures of Care Experiences of Seriously Ill Individuals	• To develop survey measures that assess care experiences in serious illness programs, and serious illness care delivered by MA plans and ACOs	• All individuals receiving care from a serious illness program are considered seriously ill • Preliminary (draft) eligibility criteria for serious illness programs: o Care team must include physician, plus an RN or social worker o 24/7 access to a clinician o Minimum patient volume o Provides at least some home-based care	• Program data (may include EHRs or other patient databases)	• Wide variation across programs in: o Patient eligibility criteria o Data availability • May need method for identifying seriously ill individuals who cannot answer for themselves due to cognitive impairments