REPORT

Measuring complexity

Moving toward standardized quality measures for the field of complex care

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About the Institute for Healthcare Improvement

For more than 25 years, the Institute for Healthcare Improvement (IHI) has used improvement science to advance and sustain better outcomes in health and health systems across the world. We bring awareness of safety and quality to millions, accelerate learning and the systematic improvement of care, develop solutions to previously intractable challenges, and mobilize health systems, communities, regions, and nations to reduce harm and deaths. We work in collaboration with the growing IHI community to spark bold, inventive ways to improve the health of individuals and populations. We generate optimism, harvest fresh ideas, and support anyone, anywhere who wants to profoundly change health and health care for the better. Learn more at **ihi.org**.

Acknowledgements

The publication of this report would not have been possible without the collaboration of a number of organizations and individuals. We would like to thank the interviewees who shared their insights, experience, and wisdom with us, and who are listed in Appendix A.

This report was chartered and overseen by the Complex Care Field Coordinating Committee (FCC) as a first step in developing a set of standard measures that can be used by programs across the country. The FCC was launched in 2019 to oversee complex care field-building activities taking place across the country and to be accountable to fulfilling the 11 recommendations outlined in the *Blueprint for Complex Care*. The five organizations of the FCC were chosen based on their investment in developing the field, strong networks, and system-level perspectives. They are:

- Alliance for Strong Families and Communities
- Camden Coalition’s National Center for Complex Health and Social Needs (project lead)
- Center for Health Care Strategies
- Community Catalyst’s Center for Consumer Engagement in Health Innovation
- Institute for Healthcare Improvement

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Executive summary

Introduction

In 2018, the *Blueprint for Complex Care* released by the National Center, the Center for Health Care Strategies (CHCS), and the Institute for Healthcare Improvement (IHI) outlined the emerging field of complex care.

The *Blueprint* identified measurement as a primary area in need of attention and standardization. In response, this report sought to identify what work currently exists or is needed to establish a set of potential quality measures for the field. Measurement is critical to allow groups to track how well they improve patient outcomes and make sure that we are able to determine the effectiveness of complex care programs across the United States.

To that end, IHI completed a search of the literature, interviews with subject matter experts, and a scan of existing quality measurement efforts to identify quality measures currently in use, work still needed to develop or clarify measures, and potential partners in this work. Our research led to findings across four areas: 1) defining the population, 2) data availability and potential sources, 3) measure domains, and 4) measures and measure concepts. For each area, the report outlines a set of recommendations for future work.

Assessment of the current state of quality measures in the complex care field

If the goal is to understand which programs provide high-quality care to individuals with complex needs and to allow the field of complex care to track how well each program meets that goal, it is important to understand who should be considered part of the complex care population and what data are available to capture this information. Allowing groups to define individuals with complex needs differently based on who they serve must be balanced with creating a population definition that can be implemented across programs to allow us to compare how well each delivers care and improves outcomes in a way that is fair and consistent.

Current complex care programs use several criteria to identify people who would be considered to have complex health and social needs, including their age, chronic conditions such as diabetes or heart disease, behavioral health, what insurance they have, and how many times they use the emergency department or are admitted to the hospital. These programs also have access to different types of data such as insurance claims and medical records but not everyone uses the same sources and may not collect the same information. Because of this variation between programs, we need to identify a standard way to define these individuals and how to collect that data.

The same challenge exists in identifying what areas are most important to measure since complex care programs may prioritize different measures. Most track whether they are able to decrease use of the healthcare system and/or costs along with other measures on specific areas of interest to that program. Based on our literature searches and conversations with experts, we propose important areas or domains of measures that expand the current focus beyond just cost and identified what measures or measure concepts might be considered for use within each area. We also identified areas where other solutions such as reporting stratified data or creating standards might be better solutions.

Recommendations

While the four areas could be viewed as barriers to moving forward, they can also be viewed as opportunities due to the number of groups working within this space and the interest of many to advance this field. Based on our findings, we developed the following recommendations:

1. **Determine a process for measure development/alignment based on the intended use(s) of the measures.** If the goal is to compare how well programs provide care and improve patient outcomes, then there will need to be agreement on who should be considered "complex" and what data will be used.

2. **Determine a pathway toward a standard denominator.**

3. **Consider alternative approaches to standardization.** For example, could we allow groups to use their own screening tools as long as we are able to map the results back to standardized data definitions?

4. **Target measurement, standards, and data stratification within five domains:** Effectiveness/quality of services, equity, health and well-being, service delivery, and cost/utilization.

5. **Promote the development and selection of measures based on patient-driven priorities.**

6. **Develop and/or select a core set of measures for longitudinal evaluations of program effectiveness paired with additional sets based on the populations of interest and prioritized domains of care.**

7. **Collaborate with key partners working in this space.**

8. **Build capacity and processes to capture best practices and innovative approaches used in the field for broader dissemination.**

Next steps

Based on this work, we believe that the next step is to form a quality measures expert working group to address these recommendations. This working group would create a set of measures, standards, and data stratification within the five domains identified in Recommendation 4 and begin to advance the field of complex care.

Introduction

Recent efforts led by the Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs (National Center) sought to establish a new field of complex care. These efforts culminated in the *Blueprint for Complex Care (Blueprint),* developed and launched by the National Center, the Center for Health Care Strategies (CHCS), and the Institute for Healthcare Improvement (IHI) in December 2018.[1] Since that time more than 75 organizations have endorsed the *Blueprint*.

The *Blueprint* described the need for a series of workstreams that would contribute to the development and strengthening of such a field of complex care including activities around quality measurement. The IHI is exploring what work currently exists or is needed to establish a set of potential quality measures for the field. The results of this project will inform any future work around quality measurement.

This report describes the findings from IHI's analysis and research, which aimed to:

- Document the current state of quality measurement in this space;
- Identify key challenges associated with measurement in this field; and
- Understand where there is active research and measure development in the field.

The findings are intended to inform future work to establish a standard set of measures to track both improvement of patient outcomes and the effectiveness of complex care programs across the United States.

During a three-month period, we sought to analyze current and past programs, available research, and interviews with subject matter experts (Appendix A) to understand how the complex care population is defined, how data are collected/available, and the key domains of measurement identified within literature and programs. In addition, a scan of measures and concepts that are currently in development or use was completed and information on groups or activities relevant to the area of measurement for the complex care population was summarized. This report provides an analysis of our findings across four areas: 1) defining the population, 2) data availability and potential sources, 3) measure domains, and 4) measures and measure concepts as well as recommendations for future work.

Based on our findings, it is clear that there is the potential for future efforts around the measurement of individuals with complex care needs and to evaluate the effectiveness of the programs that provide these services. Much of the work could build on existing measures and collaborations with key partners may assist in accelerating measurement in this field. Within each of the four areas, we outline a potential strategy and recommendations that could be adopted in total or as phases of work.

Section 1: Defining the population

We first begin with examining how other groups defined the population of "complex care." Performance measurement calls for the identification of the population of interest, or denominator, as one of the initial steps during measure development and/or selection.

Understanding which individuals may be considered for inclusion in a measure will assist in determining the degree to which data collection and aggregation can be standardized, if desired, and what similarities or variations (such as the populations of interest or available data sources) exist across programs that will promote or limit widespread implementation. Our review of the literature, research, and interviews attempted to identify whether there were similar approaches and definitions that could be used to define and standardize a denominator of complex care for future use.

As interest in this new area accelerates, multiple national reports presented their definitions of what is captured by the term, "complex care." Two reports served as the basis for much of our environmental scan and research: the National Academy of Medicine (NAM) report on *Effective Care for High-Need Patients* and the *Blueprint*.[2,3]

The NAM report outlines a taxonomy by which "complex care" individuals can be classified.[4] The starter set of patient groups included:

- Children with complex needs;
- Non-elderly disabled (with end-stage renal disease or disability);
- Multiple chronic (with one complex diagnosis along with more than one condition considered noncomplex);
- Major complex chronic (at least two complex diagnoses or six or more noncomplex conditions);
- Frail elderly; and
- Advancing illness.

The report also acknowledges that there are variables that will also impact an individual's health and needs across these groups and specifically identified factors for social risk (i.e., low socioeconomic status, social isolation, community deprivation, housing insecurity) and behavioral health (i.e., substance use disorders, serious mental illness, cognitive decline, chronic toxic stress).

"Complex care" individuals would be classified into a clinical and functional group followed by whether they had additional behavioral health and social services needs. This classification would enable determinations of what services were required.

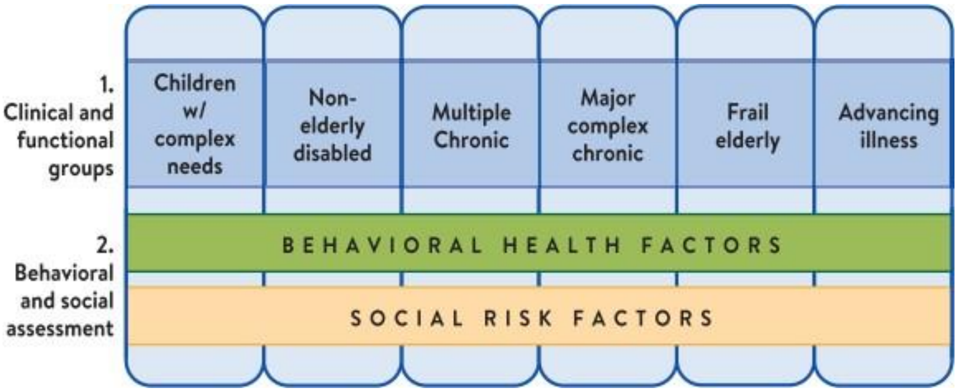

Figure 1. Visual of the NAM Taxonomy of Complex Care Patients[3]

The *Blueprint's* definition of the population is "…a relatively small, heterogeneous group of individuals who repeatedly cycle through multiple healthcare, social service, and other systems but do not derive lasting benefit from those interactions." This definition is less precise but gives a general sense of to whom the term "complex care" is intended to refer based on combinations of physical, behavioral, and social needs that collectively lead to high utilization and poor outcomes.

Our literature search was intentionally broad to ensure that we captured the numerous definitions and categories by which groups identified individuals with complex care needs. A SCAN Foundation report, *What Matters Most*,[5] outlining the essential attributes of a high-quality system of care for individuals with complex care needs, identified several definitions from organizations interested in this area. Most definitions described characteristics of such "complex care" individuals to include multiple chronic conditions, frequent users of healthcare (and potentially then contributing to a larger proportion of costs), functional limitations, unmet social needs, or behavioral health needs. Their working group developed the following definition: "Individuals having two or more mental and/or physical chronic conditions, and additional functional limitations that collectively have an effect on health status and quality of life."

Studies also sought to identify those patients with complex needs, which may provide additional input on how the field has defined complex care. Researchers conducted qualitative interviews with physicians who worked in primary care in academic and community settings to determine how they defined complexity.[6] Complexity was viewed as not just chronic medical diagnoses but also if an individual had at least one additional factor that further increased their need for intervention such as behavioral health needs or unmet social needs. Participants reported a lack of control in addressing the needs of these individuals, particularly when related to social factors. Jeffs and colleagues used a modified Delphi process to identify which measures might be used to measure outcomes for individuals with complex needs transitioning across settings of care.[7] This work identified individuals who had multiple chronic conditions, behavioral health concerns, dementia, limited social support, and/or take multiple medications.

Information on how those organizations within the field also identified those who are in need of targeted services due to their medical and/or social complexity can inform the populations for which a set of performance measures might be developed and/or selected. For example, the California Health Care Foundation interviewed 20 programs that serve these individuals and found that all used one or more of the following data sources and tools for patient selection: claims alone, claims supplemented with risk scores, utilization, internally developed risk assessments, identification by team members, and self-referral.[8] Table 1 provides an overview of the characteristics and criteria by which a large number of programs identify individuals with complex needs. These programs were gathered from two publications[9,10] as well as recommendations and input from those interviewed.

Table 1: Criteria for individuals with complex needs by program

Program	**Criteria used**
Support and Services at Home	Target population is older adults and people with disabilities who are Medicare beneficiaries
Camden Coalition of Healthcare Providers	Two or more chronic conditions and two or more barriers that may include, but are not limited to: ▪ Polypharmacy (defined as 5 or more medications) ▪ Lack of social support at home or in the community ▪ Housing instability ▪ Active drug use ▪ Physical disabilities (e.g., hearing or vision impairment) ▪ Difficulty accessing services (e.g., language barrier, limited mobility) ▪ Significant mental health conditions (e.g., schizophrenia, bipolar disorder)
CMS PACE Program[11]	Participants must be: • Age 55 or older • Meet a nursing facility level of care • Live in the PACE organization service area
Medicaid Innovation Accelerator Program (BCNs)	Beneficiaries with complex needs and high costs (BCNs) are defined by the individual programs but target: • Medicaid beneficiaries identified as "super-utilizers" with a variety of medical, behavioral, and psychosocial needs (**source**) • Agencies may use risk stratification through methods such as tiering or predictive modeling[12]
CMMI Accountable Health Communities[13]	High-risk individuals are: • Community-dwelling with a health-related social need and self-report two or more emergency department visits in the 12 months before initial social screening
Denver Health[14]	Risk stratification: • Assign patients to a risk tier • Apply additional risk factors such as recent acute care use or high-risk diagnoses
Medicaid Managed Care in North Carolina (**source**)	Criteria includes: • Age • Income • Long-term services and support needs status • Disability status

Program	**Criteria used**
Aetna's Medicare Advantage Provider Collaboration Program	• Risk score ○ Internal Aetna Algorithm (**source**) • Frequent admission/ED visits • Predictive algorithm for readmission • High-risk diagnoses • Advanced illness predictive algorithm (risk of death in 12 months)
AtlantiCare Special Care Center	Health risk assessment based on diagnoses, medication counts, acute care utilization, and psychosocial issues
Care Management Plus	• Risk score ○ Risk stratification, disease condition, and algorithms • Frequent admissions • Specific high-risk medication changes • Confirmation by primary care team review • Patients with multiple chronic diseases who are often older or have behavioral health and social needs, and who are at high risk for poor health outcomes
CareOregon Health Resilience Program (working on behalf of Health Share of Oregon)	• Referral • Utilization threshold: ○ >1 non-obstetrics hospitalization admissions with or without ED visits within 12 months OR admission or 6+ ED visits with or without hospitalization within 12 months • Secondary population considerations formally identified after patient is engaged: ○ High prevalence of trauma in their lives (past and/or present) and, as a result, may have difficulty problem solving and planning proactively ○ Distrust of traditional authority figures ○ Inability to connect with previous primary care services and/or relate to previous clinical providers ○ Inadequate access to psychiatric assessment and mental health services (which can be a driver of the utilization referenced as a primary driver/patient identifier) ○ Higher than average incidence of addiction ○ Culture of poverty, and/or frailty ○ Cognitive and health literacy challenges ○ Social isolation and depression (**source**)

Program	**Criteria used**
Community Care of North Carolina (Community Care of the Sandhills)	• Frequent admissions (greater than anticipated for disease "burden") • Multiple chronic conditions (3M Clinical Risk Groups) • Referral from primary care
The Everett Clinic	• High cost • High utilizers
Fletcher Allen Health Care—Vermont Blueprint Community Health Team (CHT)–Burlington	• Frequent inappropriate utilization • Poorly controlled chronic conditions • Referral
Geisinger ProvenHealth Navigator	• Risk score ○ Predictive models and risk stratification software based on claims data along with clinical/team input (**source**) • Referral
Genesys HealthWorks Health Navigator	• Poorly controlled chronic conditions • Acute medical or social care need • Intermediate (not the highest) cost
Geriatric Resources for Assessment and Care of Elders (GRACE)	• Risk score ○ High risk of hospitalization based on probability of repeated admissions (PRA)—score >0.4/hour
Guided Care	• Risk score ○ ACG risk score from Johns Hopkins (**study, ACG**) • Physician referral (current)
Health Quality Partners	• Medicare: One or more high-risk chronic conditions (CHF, CAD, diabetes, or COPD) combined with one or more hospitalizations in prior year • Aetna Medicare Advantage Risk score plus one or more high-risk chronic conditions • Sutter Health Questionnaire
King County Care Partners	• Risk Score ○ "Risk bands" based on proprietary modeling software categorize patients by risk of future utilization (**source**)
Massachusetts General Hospital Care Management Program	• Risk score combined with annual cost of care ○ Combination of historical cost data and Hierarchical Condition Category (HCC) scores (**source**)

Program	**Criteria used**
New York City Health and Hospitals Chronic Illness Demonstration Project: Hospital to Home	• Medicaid • Risk score • Had a risk score ≥0.5 (a 50-percent or higher chance of hospitalization) (**source**)
Oklahoma SoonerCare Health Management Program	• Risk score ○ Medical Artificial Intelligence (MEDai) Acute Risk Score and Chronic Risk Score (**source**) • One or more chronic conditions

Sutter Care Coordination Program	• Referral
	• Any one of the following:
	  ○ Unplanned readmission within 30 days
	  ○ Two or more admissions in past year
	  ○ Two or more ED visits in past year
	  ○ Seven or more medications
	  ○ Diagnosis of congestive heart failure, chronic obstructive pulmonary disease, or pneumonia
	  ○ Three or more chronic conditions

AccessHealth Spartanburg	• One or more diagnosed chronic conditions • Hospital utilization in the last 12 months AND • Uninsured

Boston Health Care for Homeless Program	• Experiencing or have recently experienced homelessness; AND
	• Top 10% highest-cost Medicaid patients:
	  ○ Six or more ED visits in the past six months OR
	  ○ Two or more inpatient admissions within the last six months

Center for Health Care Services' Restoration Center Crisis Unit	• At risk to themselves or others • Brought in by law enforcement due to mental illness or addiction • Severely mentally ill • Substance use disorder AND/OR • Experiencing homelessness (as defined by the U.S. Department of Housing and Urban Development, and the Substance Abuse and Mental Health Services Administration – housing insecure, open air, or car)
Los Angeles County's Care Connections Program	• Diabetes with HbA1c >9 and co-occurring mental illness or substance use disorder • One acute care utilization equivalent in the past year PLUS a history of any "high-risk" conditions OR • Two acute care utilization equivalents in the past year

Program	**Criteria used**
Maimonides Medical Center	• Super-Utilizer (SU) project o Four or more inpatient visits in one year OR o Four or more ED visits in one year • Critical Time Intervention (CTI) project o Behavioral health issues AND/OR o Substance use disorder AND o Three or more inpatient admissions in one year OR o Three or fewer episodes of psychosis
Mountain-Pacific Quality Health	• Two or more inpatient hospital admissions in six months AND/OR • Two or more ED visits AND • Chronic disease AND/OR • Need for additional primary care
Redwood Community Health Coalition's Partnership Health Plan Intensive Outpatient Case Management Program	• Medi-Cal coverage through Partnership Health Plan AND o One or more chronic medical conditions OR o Diagnosis of severe mental illness (major depression, bipolar disorder, or psychotic disorder) AND ▪ One inpatient stay in the last 12 months OR ▪ Three or more ED visits in the last 12 months OR ▪ Chronic homelessness AND ▪ At least two separate insurance claims for the eligible condition
San Francisco Health Plan's Community Based Care Management Program	• Two or more inpatient admissions in last 12 months • One inpatient and five or more ED visits in last 12 months OR • Six or more ED visits in last 12 months
University of New Mexico ECHO Institute's Complex Care Program	• Age 18 or older OR Insured through Medicaid • Two or more chronic conditions (which may or may not include mental health or substance use disorder) AND • One hospitalization in past six months AND • One hospitalization in past 12 months OR • Three ED visits in past six months

Program	Criteria used
New York State Health Homes—Comprehensive Care Management (**source**)	• Must be enrolled in Medicaid and must have ○ Two or more chronic conditions (e.g., substance use disorder, asthma, diabetes) OR ○ One single qualifying chronic condition: ▪ HIV/AIDS or ▪ Serious Mental Illness (SMI) (Adults) or ▪ Serious Emotional Disturbance (SED) or Complex Trauma (Children)
Washington State Health Home Program (**source**)	• Apple Health clients of all ages, including Medicaid/Medicare dual eligible clients, may be eligible for the Health Home program if they ○ Have at least one chronic condition and are at risk for another ○ Have a PRISM predictive risk score of 1.5 (**per WAC 182-557-0225**) ○ Meet Apple Health (Medicaid) eligibility criteria

Several themes emerged during interviews with subject matter experts with most supporting the general approaches and criteria used by programs outlined in the table above. There was unanimity that it remains critical to continue to examine each of the characteristics and features of the various subpopulations as unique traits, which limits our ability to group everyone into one denominator for complex care.

Interviewees also stated that the use of strict criteria to define individuals with complex care needs must be balanced with nuances such as local/geographic context since one set of criteria will not apply perfectly to each community. In addition, an approach primarily focused on high cost/utilization will not capture those individuals at risk who do not have ready access to services. As a result, many experts believed that identification should not be solely reliant on cost and utilization or clinical factors and must look beyond information that can only be accessed through administrative claims.

Synthesis of findings

Based on the NAM report, other published articles, and examinations of existing programs, it is clear that a multi-step approach is preferable and potentially more effective at identifying those individuals with complex health and social needs rather than creating one standardized denominator definition.

Many programs use an objective set of criteria to select participants; yet, several individuals we interviewed highlighted limitations to this approach. Specifically, they noted the limited viewpoint that occurs when the selection criteria begins with cost/utilization of healthcare. This approach can be very healthcare-focused and does not address the broader concept of health since it does not necessarily capture those individuals at risk who have not yet interacted with the healthcare system.

We also sought to analyze common criteria by which individuals are identified as having complex needs using information from the 37 programs in Table 1. Criteria were included in Table 2 if five or more programs used it. Many of the programs use criteria consistent with the published definitions such as the one from the NAM report and the three most frequently used are chronic conditions, cost/utilization, and risk scores. While there are some criteria on which many of the programs base their identification of these individuals, it should be noted that this table does not adequately demonstrate the variability in the specific information collected within each criterion. For example, while many use risk scores, very few programs use the same tool.

Table 2: Common criteria for identifying individuals with complex needs: frequency across programs

Criterion	Number of programs using this criterion
Age	5
Behavioral health	6
Chronic conditions	13
Cost/utilization	21
Insurance status	9
Referral	6
Risk score	13
Social needs	8

The lack of consistent use of the same criteria to define individuals with complex needs could present challenges to this work moving forward, but the need for standardization is largely dependent on the intended uses of the measures and resulting data. Standardizing and precisely specifying a denominator becomes increasingly important as the intended use of measurement moves from quality improvement to accountability. If the goal or intended use of any measure is to evaluate the effectiveness of these programs, which could be considered as a form of accountability, some degree of standardization of measures and specifications will be needed to enable reliable and valid comparisons.

The National Quality Forum (NQF) outlined the following definition for using measurement for accountability:

> "Use of performance results about identifiable, accountable entities to make judgments and decisions as a consequence of performance, such as reward, recognition, punishment, payment, or selection (e.g., public reporting, accreditation, licensure, professional certification, health information technology incentives, performance-based payment, network inclusion/exclusion)."[15]

Because NQF endorses measures that are intended primarily for accountability purposes, their criteria on which measures are evaluated also provides guidance on the level of rigor that is needed if any type of accountability application is considered. Specifically, all measures are evaluated to determine whether each is evidence-based, scientifically acceptable, feasible and useable for the intended purpose.[16] While the intended goal of establishing more standardized measures for complex care may not be to seek or achieve NQF endorsement, their criteria indicate the minimum expectations for measures that may be used for comparisons, public reporting, or similar uses.

Specifically, specifications including definitions and code sets must be well-defined to enable consistent implementation across organizations and sites (reliability) and ensure that we measure what we intend to measure (validity).[17] They must also use data elements and coding that are readily available to those organizations to which the measure will apply (feasibility). Moving forward, it will be critical to determine:

- The intended use(s) of the measures;
- The feasibility to collect and aggregate the required data by those entities to which the measure will apply (e.g., availability, data collection burden); and
- The degree of precision with which the denominator (population of interest) and numerator can be defined.

While there are additional factors that will need to also be considered during the development and/or selection of measures such as the underlying evidence, the ability of the measure to represent performance in a reliable and valid manner, and its effectiveness in driving and measuring meaningful improvement over time, targeting these three areas would advance the field and serve to focus measurement efforts.

Implementation of a broad measurement strategy must be balanced with the focus and current capabilities and capacity of the various complex care programs. Early in the process of conducting our landscape analysis, we outlined a set of potential subpopulations in an effort to begin to standardize the denominator based on the NAM report, other published literature, current programs, and interviews. The findings from IHI's research and analysis were presented to the Complex Care Field Coordinating Committee (FCC) and subject matter experts. We quickly encountered the same issues discussed above around the uniqueness within communities and heterogeneity of the individuals, leading to additional recommendations.

To date, the following characteristics have been identified as potentially signifying individuals who could have complex clinical and/or social needs:

- Functional status;
- Cost/utilization;
- Social needs (e.g., homelessness, exposure to violence, poverty);
- Children with complex needs;
- Non-elderly disabled;
- Multiple and/or major complex chronic conditions;
- Behavioral health needs;
- Frail elderly;
- Advancing illness;
- Maternal and neonatal care; and
- Lesbian, gay, bisexual, transgender, and questioning (or queer).

This is not a complete list of all potential groups with complex needs, but outlines the potential subgroups or characteristics to which complexity could be associated.

Our review of the current state found no clear solutions or methods by which a standardized denominator could be easily or quickly achieved and some degree of flexibility and imprecision will likely be required. It is in part due to the absence of consistent strategies to identify individuals with complex needs as well as their heterogeneity within and across communities.

Tradeoffs must be examined since purely objective assessments using criteria such as cost/utilization or insurance coverage could yield selection of individuals who, on paper, might be considered to require additional services, but due to their current living situation, support system, or other characteristics may not need additional assistance. The alternative is also possible, where individuals may be missed because they do not interact with the healthcare system in traditional ways through the use of the emergency department, for example. Each of these scenarios will impact the ability to define and standardize the population of interest for measurement purposes.

Recommendations for future work

Recommendation 1: Determine a process for measure development/alignment based on the intended use(s) of the measures.

Measures that are intended for quality improvement can have a degree of imprecision in what data sources are used, how patients are included or excluded, and what surveys could be considered acceptable, for example. Measures that are intended to be used for some accountability purpose such as accreditation or certification, value-based purchasing, or in this instance, potentially evaluating the effectiveness of these programs, require additional rigor to the specifications and data source. Often when measures are used for accountability applications, those entities that are measured expect that the performance scores produced are reliable and valid. This standardization also provides further credibility to the assessment of how the field of complex care is advancing.

It may be useful to consider multiple intended uses of measures across the full spectrum, from quality improvement to accountability, in light of the various needs of the different stakeholders. Defining the desired goal(s) at the beginning will enable the development of a measurement roadmap and an efficient timeline that uses resources and time wisely. The recommendations within this report seek to enable that broader strategy while still advancing the field of complex care forward as quickly as possible. For example, an approach could be implemented that would create the glide path to desired end goals of accountability and reliable and valid comparisons across programs. The key steps along the way would include:

- Define the purpose of a set or sets of measures (e.g., program level measurement for public reporting) focusing on those measures that are most meaningful to patients and demonstrate the effectiveness of these programs;
- Identify what measures may be available to fit within these sets that could be implemented as specified or would require some refinement;
- Determine to what extent will geographic variations and heterogeneity of programs impact which measures could be implemented and for what purpose;
- Determine what data are available that could be collected and aggregated for those measures or determine the feasibility of new data sources that may be needed;
- Implement one or more pilot projects to assess the usefulness and feasibility of the measure set(s); and
- Begin to assess whether the measure set(s) and resulting data will assist in achieving the long-term goal.

Recommendation 2: Determine a pathway toward a standard denominator.

Due to the potential need to define individuals with complex needs for purposes broader than just for performance measurement, it may be worthwhile to address the question of a common definition through standards development work rather than through performance measurement. Regardless of the approach, there is a clear need to begin to further define the population and we outline potential approaches to create this common definition that could be used regardless of which area or group oversees the work.

Initially, it may be worthwhile to allow groups to identify individuals with complex needs in their own way but collect how each defines their population in a systematic manner. This would enable measurement efforts to begin quickly rather than wait until all of the questions around how to standardize the denominator are resolved. If data are publicly reported, cautions or caveats can be provided to ensure that individuals who review and potentially use this information understand the potential limitations in the results (e.g., each program may target different populations).

Creating a systematic way to catalog the denominator information will assist in the identification of commonalities and enable the development of standard definitions and code sets. At some point in the process, agreement could be reached on one or two risk scores and definitions with code sets for specific populations that could be used to increase alignment across programs. Even though the collection of standard definitions and code sets may still result in multiple subpopulations of interest, this approach would further increase the reliability and validity of the underlying data used for comparisons.

Assuming that there will always be heterogeneity across these individuals, one or more methodologies that standardize the logic by which individuals are identified as complex could be developed. For example, could a process where individuals are first identified through utilization or interaction with the healthcare system paired with data on clinical or social needs or input from the healthcare team flagging the individual as having complex needs be one potential pathway by which individuals are identified? Could an alternative pathway in which individuals that may not interact with the healthcare system but are identified in a standardized way within the community also be leveraged?

It would be useful to define the extent to which some lack of standardization will be acceptable regardless of the intended use of the measure. Explicitly outlining what those parameters might be will enable the field to identify the "knowns and unknowns," while continuing to advance measurement and improving the overall health of these individuals.

Section 2: Data availability and potential sources

The degree of specificity with which measures must be specified and standardized is very dependent on the intended use of the measures and must consider what data are available and to whom the data can be reliably and validly applied. Because the purpose of this scan is to be intentionally broad, we sought to identify to the extent possible what data is currently collected and/or available in those programs and initiatives that provide services to these individuals. We did not limit our search to specific uses or applications (i.e., payment or accountability vs. learning or quality improvement). We explored any new or emerging technologies or solutions (e.g., predictive modeling, geospatial hot spotting) that could inform this work. These new data sources have the potential to enable programs to identify the social components and complexities that can contribute to the needs and required services for these individuals.

Much of this information may not be readily available at the individual level or at the level for which measurement is desired. As a result, it will be increasingly important to begin to collect and aggregate this information in a standardized and meaningful way – first to ensure that the appropriate services and interventions are provided and second to leverage this information for measurement purposes. This section is not intended to provide a comprehensive view of what data may already be available or what could be used moving forward; rather, our goal is give a sense of what data types might be accessible now and in the future.

The NAM[18] report, a report by RAND,[19] and interviews identified the traditional data sources by which most complex care populations are defined and measures are aggregated including:

- Administrative claims data – It should be noted that the use of just claims data will not be sufficient to move toward the measures that are of most interest such as outcomes on clinical and social needs or patient-reported outcomes.
- Electronic health record systems (EHRs) – Several individuals noted that use of EHRs data that are not just in structured fields but can be collected using natural language processing (NLP) holds promise to enable the capture of clinically rich data with minimal impact to clinical workflow. NLP is still relatively new, immature, and not widely used but could serve as a key source for data in the future.
- Patient-reported surveys/instruments – Some groups may use nationally available screening tools but many are developing their own questionnaire or tool. While this customization is appealing to enable tailoring of questions based on the population of interest, leveraging the resulting data may be challenging and limited due to the lack of standardized questions and data sets.

There are other tools and resources that could be used to further develop the needed data both to define the populations of complex care and to collect information on the processes and outcomes of interest. Various screening tools such as the Social Needs Screening Toolkit from Health Leads, the Vermont Self-Sufficiency Outcomes Matrix, the Support and Services at Home (SASH) assessment or Medicaid Behavioral Health Risk Factor Surveillance System Survey (BRFSS) are used at the community and state levels.[20,21,22] Each uses a different approach based on the needs of the individuals within the community or state, services available to them, data that can be accessed and at what level of specificity, and other unique characteristics. Groups such as CarrotHealth[23] use predictive modeling more frequently to begin to identify those at risk for higher utilization of services.

There are also efforts to integrate social determinants of health such as the University of Chicago and the Alliance Chicago’s work on diabetes and lead poisoning where data from other sources such as census data, building assessments, and home inspections are used to further predict an individual’s risk. Other programs such as those participating in the Medicaid Innovation Accelerator program leverage various risk stratification tools such as Chronic Illness Disability Payment System, CRG Classification System, or Adjusted Clinical Groups (ACG®) Case-Mix.[24]

Geospatial hot spotting enables health plans, communities, and others to identify where there are disproportionate shares of patients with complex health and social needs. In addition, a few individuals mentioned the Area Deprivation Index as a potential source to capture social needs data at the community level. Recent analyses to determine the degree to which these aggregated data at the ZIP code level would be representative of the individual served by a complex care program determined that the results of these indices were not correlated to individual-level data.[25] The authors also identified the alternative to have limitations when patient-level data are aggregated to represent the current state of the community since it may not be representative of all individuals living within that area. Both approaches will impact the validity of the data and additional work is needed to determine what uses and at what level these data might be most meaningful.

All of these data sources could serve to build the denominators for measurement and provide information needed around data that are currently sparse and disparate such as social needs data, but much work is still required to enable wider use. Specifically, some standardization of the various tools and/or how data are structured must occur before it could be used for widespread national measurement efforts.

To that end, Social Interventions Research & Evaluation Network (SIREN)[26] continues to research and catalog efforts around medical and social care integration and PRAPARE[27] is one example of a national effort to assist health centers and others to collect social determinants of health data in a way that is actionable at the point of care. Based on our searches and conversations with subject matter experts, it is clear that there is significant variability in the tools and risk scores used to screen and track progress on individual characteristics, particularly related to social needs.

Synthesis of findings

Determining the intended use(s) of a measure or set of measures involves understanding what data may currently be available and what emerging sources might be leveraged in the future. As noted previously, administrative claims, EHR data, and information through patient-reported surveys are used to some extent across the various programs.

What remains challenging is the degree of variability within those data sources. For example, most programs have some access to administrative claims data but depending on how broadly applicable the measures are desired to be, not all organizations who deliver services to these individuals may have access to these data. EHRs present their own challenges since vendor systems differ in their capabilities and data capture and often the most relevant information to measure critical processes and outcomes is not captured in structured fields.

Lastly, as expressed by many of the subject matter experts, patient-reported data are essential when assessing the effectiveness and impact of these programs; yet, the amount of time and effort to integrate data collection into existing workflows presents one of the biggest barriers. Use of risk scores to identify critical components such as social determinants of health may also require additional testing to ensure that the results at the individual patient level produces reliable and valid results for accountability uses.[28]

Recommendation for future work

Recommendation 3: Consider alternative approaches to standardization.

While it is often the goal of measurement to use standard definitions and tools to enable comparisons, it could be useful to consider an alternative approach that allows for customization of the screening tools as long as they are mapped to standardized data definitions. The Gravity Project led by the Health Level 7 International (HL7) is one such example.[29] This effort, which began in May 2019, will define data elements and code sets to represent these data within EHRs for screening, diagnosis, planning, and interventions. The first phase targets data set development on food insecurity, housing instability, quality, and transportation access.

This effort could enable the tailoring and selection of specific screening tools by individual implementers based on their population's needs, while producing a standard set of data that could be used for other purposes such as aggregation for measurement. The need to ensure that comparable data are collected to enable reliable comparisons across entities will become increasingly important and intentional decisions on what degree of precision and standardizations will need to be made.

Section 3: Measurement domains

As with the various definitions and subpopulations used to identify individuals with complex care needs, it is also critical to determine what potential domains and subdomains of measurement would be prioritized by patients with complex care needs, define high-quality care for these individuals, and assess effectiveness of these programs. Several resources were examined including the NAM and *Blueprint* reports, articles outlining what a successful care model should be, as well as the measures used by existing programs and organizations that deliver services to these individuals. In addition, understanding the processes of care or key characteristics of these programs that demonstrate clear links to improved outcomes, while also reducing unnecessary cost, may also provide guidance on what domains should be targeted.

NAM[30] determined that successful complex care models would produce positive outcomes within three domains: health and well-being, care utilization, and costs. As such, common delivery features of successful complex care models, which would primarily be assessed through process measures, are:

- Teamwork;
- Coordination;
- Responsiveness;
- Timely clinician feedback and data from remote patient monitoring;
- Medication management including reconciliation;
- Outreach;
- Integration with social services; and
- Follow up, particularly after hospitalizations.

The authors also emphasized that in order for measurement to be effective in driving improvements we must move toward metrics that are broad in applicability in populations and settings and focus on areas that better reflect the concerns and needs of these individuals rather than have measurement driven by clinical conditions alone. The *Blueprint*[31] further emphasized that a balance is needed whereby cost and utilization measures should not be the primary focus and health and wellbeing must also be addressed.

Our searches also identified other reports and frameworks, which may serve as examples and guide the development of a preliminary set of domains and subdomains for any future measure development and selection work. A report by The Commonwealth Fund[32] sought to determine the strength of evidence regarding which care models were most successful in improving outcomes and minimizing costs and resulted in characteristics focused primarily on structures and processes of care. Those initiatives in which care was delivered by a multi-disciplinary team; supplemented primary care through the use of interventions such as case management, preventive services, and education around disease self-management and to the caregiver; and targeted transitions and interventions to expedite discharge from hospital to home demonstrated the ability to improve a patient's quality of life and in some instances the quality of care. While some of these interventions were also able to reduce costs and length of inpatient stays, they were not universal findings. This report also identified common attributes of successful care models (Table 3).

Table 3: Common attributes of successful care models

Content/features	**Execution/models**
• Targeting individuals most likely to benefit from intervention • Comprehensive assessment of patients' health-related risks and needs • Evidence-based care planning and routine patient monitoring • Promotion of patients' and family caregivers' engagement in patient self-care • Coordination of care and communication among the patient and care team • Facilitation of transitions from hospital to post-acute care and referral to community resources • Provision of appropriate care in accordance with patients' goals and priorities	• Effective interdisciplinary teamwork (e.g., defined roles and scope of work, trusting relationships, use of team meetings) • Specially trained care manager builds rapport through face-to-face contact with patients and collaborative relationship with physicians • Use of coaching and behavior-change techniques to teach self-care skills • Use of standardized processes for medication management, advanced care planning • Effective use of health IT to provide timely and reliable information on hospital use, enable care management, remote monitoring, analytics • Outcomes measurement to evaluate and improve performance

This synthesis also identified several barriers to sustaining and spreading these types of care models including the need to provide incentives for care coordination and supportive services based on the current payment structures, the capacity of organizations and providers to implement change, the required shift in culture and needed training to facilitate that change, the needed infrastructure to facilitate this work through information technology and interoperability, and the limitations in the current evidence to support wide-scale implementation of these models to broader settings and populations than what was analyzed.

The SCAN Foundation released a report earlier this year outlining the essential attributes of a high-quality system of care for adults with complex care needs.[33] This work where experts were convened to review existing frameworks and definitions and determine what characteristics or processes that inherently impact a system's ability to be successful, defined four essential attributes:

> "Attribute 1: Each individual's range of needs and goals, both medical and non- medical, as well as for family/caregivers, are identified and re-evaluated on an ongoing basis to drive care plans.
> Attribute 2: Each individual's needs are addressed in a compassionate, meaningful, and person-focused way and incorporated into a care plan that is tailored, safe, and timely.
> Attribute 3: Individuals have a cohesive, easily navigable delivery system so that they can get the services and information they want by themselves or with support when needed, and avoid the services they do not need or want.
> Attribute 4: Individuals and their family/caregivers continually inform the way the delivery system is structured to ensure that it is addressing their needs and providing resources tailored to them."

These services would be delivered through multiple avenues including behavioral healthcare, community and social supports, family caregivers, long-term services and supports, and primary and acute care. These attributes are intended to reflect a system that is targeted toward the specific needs and goals of each individual while also providing a holistic approach in the delivery of services.

The Well Being in the Nation[34] collaboration of more than 100 organizations across the United States and supported by the National Committee on Vital and Health Statistics selected a set of measures to represent well-being, enable identification of inequities, and create solutions collectively. This work includes a set of core metrics that address the well-being of people and places and equity as well as leading indicators and additional measures that could be considered for use. The topics covered are community vitality, economy, education, environment and infrastructure, equity, food and agriculture, health, housing, public safety, transportation, well-being of people, and demographics. Most of the metrics and underlying data would be collected from census, labor statistics, and surveys such as BRFSS or the National Survey of Children's Health.

Another initiative that targets interventions on the broader picture of health is the Full Frame Initiative.[35] This framework targets:

- Social connectedness to people and communities;
- Stability;
- Safety;
- Mastery; and
- Meaningful access to relevant resources.

The National Quality Forum[36] (NQF) developed a framework for measurement in home- and community-based services with 11 domains and 40 subdomains around which measurement could be developed. These domains and subdomains, which are mostly focused on structures and processes rather than the outcomes of care, are:

Table 4: NQF domains and subdomains for home and community-based services

Domain	**Subdomain**
Service delivery and effectiveness	• Delivery • Person's needs met and goals realized
Person-centered planning and coordination	• Assessment • Person-centered planning • Coordination
Choice and control	• Personal choices and goals • Choice of services and supports • Personal freedoms and dignity of risk • Self-direction
Community inclusion	• Social connectedness and relationships • Meaningful activity • Resources and settings to facilitate inclusion
Caregiver support	• Family caregiver/natural support well-being • Training and skill-building • Family caregiver/natural support involvement • Access to resources
Workforce	• Person-centered approach to services • Demonstrated competencies, when appropriate • Safety of and respect for the worker • Sufficient workforce numbers, dispersion, and availability • Adequately compensated, with benefits • Culturally competent • Workforce engagement and participation

Domain	Subdomain
Human and legal rights	- Freedom from abuse and neglect - Optimizing the preservation of legal and human rights - Informed decision-making - Privacy - Supporting individuals in exercising their human and legal rights
Equity	- Equitable access and resource allocation - Transparency and consistency - Availability - Reduction in health disparities and service disparities
Holistic health and functioning	- Individual health and functioning - Health promotion and prevention
System performance and accountability	- Financing and service delivery structures - Evidence-based practice - Data management and use
Consumer leadership in system development	- System supports meaningful consumer involvement - Evidence of meaningful consumer involvement - Evidence of meaningful caregiver involvement

The Moore Foundation[37] convened experts in the field of serious illness to assist in defining this population and what would be required to move toward an accountability program, including core competencies and quality measurement. While this work focused on one of the subpopulations contained within the field of complex care, it could provide useful information on which this work could build. The experts selected the domains and potential measures to promote patient-centered care and care coordination, minimize burden, and avoid unintended consequences and believed that measures should align with the core competencies and involve patients and families. The core competencies and proposed measure domains are:

Table 5: Core competencies and quality measurement domains for serious illness

Core competencies	Quality measurement domains
- Identification of the target population - Team-based care - Caregiver training - Attention to social determinants of health - Communication training and supports - Goal-based care plans - Symptom management - Medication management - Accessibility (including 24/7 coverage) - Transitional care - Measurement of value for accountability and improvement	- Well-being of patients and caregivers - Experience of care - Clinical care - Safety - Cost and utilization - Access

Using a modified Delphi process and with input from patients, Jeffs and colleagues developed indicators that would be useful for accountability purposes as well as ones that had the potential for broader quality improvement efforts for patients with complex care needs during transitions of care.[38] The final set of measures for accountability were:

- Readmission rates within 30 days;
- Primary care visit within seven days post discharge for high-risk patients;
- Medication reconciliation completed at admission and prior to discharge;
- Readmission rates within 72 hours; and
- Time from discharge to home care nursing visit for high-risk patients.

Priorities and measurement areas targeted by organizations that are currently providing care to these individuals along with any demonstrated improvements in outcomes also serve as guides toward which domains, subdomains, and measures may be relevant. While not widely available, we were able to gather this information from published literature[39] and interviews with subject matter experts on the following programs in Table 6.

Table 6: Prioritized domains by program

Program	**Domains**
Support and Services at Home[40]	• Health and well-being • Clinical areas such as controlled hypertension, preventive care (e.g., vaccinations), advance directives • Safety such as patient falls • Cost and utilization
Camden Coalition of Healthcare Providers[41]	Health and well-being Engagement: • Initial home visit • Weekly visits • **7-Day Pledge** • **COACH model**: "I do, We do, You do" • Last outreach attempts • Medication adherence
CMS PACE Program[42]	• Utilization of services (e.g., decreased inpatient hospitalizations and emergency room visits) • Participant and caregiver satisfaction • Outcome measures • Effectiveness and safety of staff-provided and contracted services • Non-clinical areas such as grievances and appeals Programs are required to report on the following areas: • Routine immunizations • Grievances and appeals • Enrollments/disenrollments/prospective enrollees • Readmissions • Emergency (unscheduled) care • Unusual incidents • Deaths • Falls • Infectious disease outbreaks • Pressure ulcer • Traumatic injuries

Program	**Domains**
Medicaid Innovation Accelerator Program (BCNs)[43]	Utilizes Medicaid Adult, Child and Home Health Core Sets Domains include: • Primary care access and preventive care • Maternal and perinatal health • Care of acute and chronic conditions • Behavioral healthcare • Experience of care • Dental and oral health services (child only)
CMMI Accountable Health Communities[44]	• Healthcare utilization ○ Emergency department visits ○ Inpatient admissions ○ Readmissions ○ Utilization of outpatient services • Total cost of care • Provider and beneficiary experience
Denver Health[45, 46]	Utilizes measures from the Medicaid Adult and Child Core Sets Domains include: • Medication management • Education on health conditions • Cost/utilization (e.g., emergency department visits, admissions, access to primary care) • Experience of care
Medicaid Managed Care in North Carolina (**source**)	• Prenatal and Postpartum Care • Avoidable or preventable utilization (e.g., readmissions, emergency department visits, inpatient hospitalizations) • Screening for social determinants of health • Screening for pregnancy risk • Satisfaction of both clinician and patient (e.g., CAHPS surveys) • Population health (e.g., BRFSS) • Additional measures from the Medicaid Adult and Child Core Sets

Program	**Domains**
Care Management Plus	• Emergency department visits • Annual mortality rates • Stratified according to disease
CareOregon Health Resilience Program (working on behalf of Health Share of Oregon)[47]	• Admissions • Emergency department/Inpatient visits • Experience of care • Expenditures
New York Health Home (**source**)	• Preventive care • Care for chronic conditions • Mental health • Substance use disorders • Utilization • Avoidable utilization
Washington Health Home	• Access to care • Quality • Utilization • Cost ○ All based on Medicare claims data (**source**)

Understanding the extent to which current programs and efforts striving to improve the quality of life and care for these individuals will also assist in identifying and targeting those areas in which true improvements in outcomes may be possible. Table 7 outlines some of the outcomes that are publicly available on programs that provide services to individuals with complex care needs and/or one of the subpopulations of interest.

Table 7: Outcomes demonstrated by programs

Program	**Demonstrated outcomes**
Support and Services at Home[48]	• Reduced Medicare expenditures, the number of falls, improved controlling hypertension, and increasing immunizations • Saved an estimated $1,227 per person per year in Medicaid expenditures, but did not translate to groups created after 2011 (**source**)
CMS PACE Program[49]	• Better functional outcomes were associated with having a medical director, more effective teams, staff comprised of more aides than professionals, staff with more ethnic similarities between aides and enrollees, and enrolled in programs with lower hospitalization rates • Better self-assessed health was associated with higher staffing levels (long term), diverse staff that provides diverse services, and program maturity (short and long term) • Survival/mortality was associated with having more professionals and higher concentration of services
Aetna's Medicare Advantage Provider Collaboration Program	• Decreased admissions by 38% (year 1), 35% (year 2), 30% (year 3) vs. controls • 30-day all-cause hospital readmission rates were 5% (year 1), 11% (year2), and 9% (year 3)
AtlantiCare Special Care Center	• Demonstrated 23% fewer outpatient procedures, 41% fewer inpatient hospital admissions, and 48% fewer emergency department visits during a one year period when compared to members of a control group (**source**)
Care Management Plus (CM+)	• The controlled clinical trial at Intermountain in the early 2000s found that patients enrolled in CM+ had: ○ Slightly more emergency department visits but lower annual mortality rates than those in the control group. ○ Patients with diabetes especially benefited. In addition to lower mortality, they had significantly fewer hospitalizations than patients with diabetes in the control group. ○ The potential savings to Medicare from decreased hospitalizations were estimated at $70,349 per clinic per year for patients with diabetes enrolled in the program. (**source**)
CareOregon Health Resilience Program (working on behalf of Health Share of Oregon)	• Decreased non-obstetric hospital admissions by 34% • Decreased ED visits by 33% • Clinic staff reported deep connection with patients, decreased burden, and increased satisfaction
Washington Health Home	• Report Medicare savings of over 18% in the first two periods of the Washington demonstration (**source**)

Many individuals with whom we spoke expressed a desire to move beyond the more traditional priority areas such as care coordination and management of clinical conditions. These interviews generated additional priority areas or topics for which measurement might be considered. These topics may be better suited to identify the populations and inform a more precise denominator but given the potential to develop or select measures that first facilitate standardized data collection, they are outlined here:

- Social integration/isolation;
- Social determinants of health – screening through integration of data into care delivery to outcomes;
- Effectiveness of community services;
- Patient activation, empowerment, resilience, and meeting self-identified goals;
- Nurse-family partnership; and
- Patient-reported outcome performance measures.

Synthesis of findings

As demonstrated in our review of available frameworks and existing priorities, there is significant variability in what priority areas are selected both nationally and within specific complex care programs. Beginning with the NAM report and other frameworks available, we developed a preliminary list of domains for consideration. Throughout the last two months, we vetted this list with the FCC and subject matter experts. Many individuals with whom we spoke expressed a desire for measures that evaluate:

- The impact of the services and interventions on an individual's health and well-being;
- Access to needed resources both within the healthcare system and in the community; and
- Retention in a program.

Our review of the current available evidence to determine what domains might be most effective in driving improvements in the health of individuals with complex needs found that targeted interventions might reduce costs and utilization, can improve clinical processes and tools, and impact the relationship and collaboration between the program team and individual. Perhaps not surprisingly due to the heterogeneity of the population(s), the results showed that improvements can be made across a diverse set of topics (e.g., immunizations, falls, clinical conditions, mortality, utilization) and it is not clear to what extent a "one-measure-fits-all" approach is useful and feasible.

Recommendation for future work

Recommendation 4: Target measurement, standards, and data stratification within five domains.

We intentionally defined a set of domains and subdomains to broadly represent health and not just healthcare that could serve as the starting point for measure development and/or selection. These domains are based on the desire to capture outcomes, processes, and structures beyond just cost and utilization and enable measurement focused on patient-driven priorities and assessments of program effectiveness to meet them. It should also be noted that not all of these domains would be best suited for measurement; rather, some may be better addressed through standards or stratification of the data.

Domain 1: Effectiveness/quality of services

Includes subdomains of admissions/readmissions, community tenure, experience with care, follow-up, function, medication management, retention, and social needs.

Measures within this domain primarily address processes and outcomes of care. This domain could have many more subdomains but we sought to target those that would better capture the indicators of highly effective care that many programs use today. In addition, the experience with care subdomain seeks to represent the effectiveness of the relationship between the program/provider and the individual.

Domain 2: Equity

It would be worthwhile to consider the extent to which equity could be assessed through stratification of the measures and resulting data. This analysis of variations in quality and cost/utilization may require collection of additional data points (e.g., race/ethnicity, gender, insurance status, income, social needs) or data integration across systems and platforms but could inform where gaps or inequities in care exist.

Domain 3: Health and well-being

This domain does not currently have any defined subdomains but is intended to capture person-centered measurement and concepts such as goal-concordant care and goal-directed attainment. This domain may include measures that are targeted to one clinical symptom or condition as well as more general assessments of overall health.

Domain 4: Service delivery

Includes subdomains of access (e.g., integration of social services, cross-sector alignment), coordination, and workforce assessment.

Many of these subdomains are structural in nature and they could be targeted through quality improvement interventions or standards rather than traditional measurement. Individual and caregiver's evaluations (i.e., patient-reported outcome performance measures) on the extent to which the desired access, alignment, and coordination was experienced could also inform care delivery and quality improvement efforts. At the moment, most of those patient-reported outcomes that begin to measure these concepts are captured within the experience with care subdomain in Domain 1: Effectiveness/quality of services.

Domain 5: Cost/utilization

Measures within this domain will primarily be derived from administrative claims but sources such as those that provide data on social needs or circumstances (e.g., housing, transportation, insurance status) could also provide useful information to evaluate the effectiveness of these programs.

Section 4: Measures and measure concepts

Searches of the NQF Quality Positioning System, the Centers for Medicare & Medicaid Services (CMS) Measures Inventory Tool (CMIT), the CMS Merit-based Incentive Payment System Qualified Clinical Data Registry list, literature, and the Internet were completed to identify performance measures and measure concepts applicable to the complex care population. In addition, we solicited information on measures that may be in use by a program or community or in development during our interviews.

For the searches in the established databases from NQF and CMS, we used the preliminary populations of interest along with the potential domains of care as search terms. Since both databases utilize similar taxonomies, we were able to sort the measures based on key phrases or words and explore potential measures based on relevant programs (e.g., Medicaid, Dual Eligible Program). For example, searches were conducted using the term "behavioral health" and then those measures that could potentially fit within one or more of the domains were added to the excel sheet for consideration. Searches were also conducted using the domains of measurement since mapping of these terms to the measures is traditionally available in both search engines.

We also explicitly asked all individuals interviewed whether they were aware of any individuals or groups developing or using measures across these areas and completed general internet searches where there were clear gaps, primarily for equity and health/well-being. Measures that focused on single clinical conditions (unless the measure was related to behavioral health) or processes of care not relevant to the domains of interest were not included. For example, there are many measures available to examine the quality of care for patients with a diagnosis of diabetes but most are clinically oriented such as hemoglobin A1c monitoring. Those measures were not included but we included a measure if it examined a chronic condition along with another comorbidity such as serious mental illness or multiple chronic conditions.

Appendix B (Measures and concepts for complex care) includes information on the following:

- Measures tab
    - Measures that are currently available and/or in use by one or more organization or program.
    - Measures that are currently in development and for which a minimum set of information is available. This information was found primarily in the CMIT since the development is funded by CMS. Because the measures are still in development, there may be limited information available regarding items such as the numerator or denominator and what data source will be used.
- Measure concepts tab
    - Concepts are in essence ideas for measurement where some examination of the underlying evidence may have occurred but no further work to determine the feasibility of the data collection, defining the numerator and denominator with associated data sources, or testing has been completed. These concepts if developed into a performance measure could look significantly different than what is currently outlined and may ultimately be found not to be evidence-based, feasible, reliable, and/or valid.

All measures and measure concepts have been categorized using the priority domains/subdomains and populations of interest in Appendix B.

Synthesis of findings

Appendix B provides an overview of measures that are currently available or under development that could potentially be selected and refined if needed and measure concepts that could be developed. Most of the 284 measures that are currently available were not specifically developed to assess the quality of care and costs to complex care programs but some measures that are currently in development under the Measures tab target these individuals such as those intended for the Dual Eligible Beneficiary Program or the Medicare Advantage Quality Improvement Program. Most, if not all, of the measures address a key structure, process, or outcome of interest but need refinement to address the complex care population.

There is significant variation in the levels of analysis and uses for which the measures are developed and each would need to be examined to determine whether additional refinements or testing would be needed to apply a measure to a different entity. For example, measures that are developed at the individual clinician level may also be of interest to aggregate and report the data at a program level. In that instance, the specifications and data source for which the measure is specified should be evaluated and revised or testing may be needed to ensure that the measure produces reliable and valid results at the aggregated level.

Another factor that will need to be examined on a measure-by-measure basis is whether it excludes the same individuals to whom the measure would be applied in these programs. For example, the National Committee for Quality Assurance (NCQA) recently added exclusions to their HEDIS® measures to address concerns on applying these requirements to individuals with advanced illness and frailty.[50] While these exclusions may ensure that these individuals do not receive inappropriate care in order to comply with the measure, it also limits application to complex care populations.

Of the 107 concepts identified, some may currently be in use for some type of surveillance or public reporting but we were unable to identify the needed information to determine whether precise specifications, testing for reliability and validity, and other measurement details exist. As a result, we chose to categorize them as concepts rather than fully specified measures or those in development.

There is one key limitation to the measures and concepts included in Appendix B; specifically, we were only able to collect information that was publicly available. Measures that may target more structural or process components or are currently used for quality improvement efforts were difficult to identify. Several individuals interviewed stated that their organizations were in the process of implementing or had implemented measures for quality improvement purposes to meet the needs of the individuals they served but the information was not publicly available. In addition, because the databases available are focused on healthcare, it limited our ability to collect information on measures that may be used outside of the traditional healthcare arena.

Table 8: Measures and concepts by population(s) of interest

Population of interest	**Number of measures**	**Number of concepts**
All	93	77
Advancing illness	12	5
Behavioral health	48	6
Children with complex needs	40	15
Frail elderly	82	1
Multiple and/or major complex chronic conditions	2	3
Non-elderly disabled	79	0
Social needs	5	0

Note: Some measures were classified to more than one population of interest.

Based on our research, there are several populations for which there are limited sets of targeted metrics. Because the majority of measures and concepts are broadly defined and would likely address all of the populations of interest, this gap may be less of a concern but may also lead to targeted measure development to address a critical outcome or process for a subpopulation. For example, we found only a limited number of measures or concepts specifically targeting advancing illness, multiple and/or major complex chronic conditions, and social needs.

As discussed above, measures often explicitly exclude the populations of interest (e.g., those with a disability or cognitive impairment, veterans, experiencing homelessness) and work will be needed to determine the extent to which the measures as specified may require modification to be applicable to these individuals. Given the number of measures identified and because the question is dependent on the individual or group to whom the measure is intended to target, we were unable to complete a comprehensive analysis of which measures may have these issues.

Table 9: Measures and concepts by domain and subdomain

Domain	Number of measures	Number of concepts
Cost/utilization	6	0
Effectiveness/quality of services	177	32
Admissions/readmissions	23	3
Community tenure	5	0
Experience with care	48	15
Follow-up	26	3
Function	20	4
Medication management	15	0
Retention	1	0
Social needs	7	2
Equity	0	24
Health/well-being	29	22
Service delivery	72	29
Access	21	13
Coordination	43	12
Workforce assessment	8	1

There are two areas within the domains with clear gaps in measurement — equity and health and well-being. For equity, NQF identified a set of concepts that could be leveraged into performance measures, quality improvement activities, or standards but we were unable to identify any organizations currently developing measures in this area. As discussed above, existing measures could be used to begin to address inequities in care through stratification of the results based on desired characteristics. This is a strategy currently used by groups such as the Commonwealth Care Alliance. Additional data collection or use of other data sets may be needed but it would potentially provide a solution to begin to answer these questions while measures are developed.

The measurement area of health and well-being has generated much discussion, and work to address this topic continues to accelerate. Twenty-nine measures in the Measures tab in Appendix B address this domain and most are specified to address a specific issue (e.g., depression) or population (e.g., neurologic conditions, frail elderly). There are two measures that examine the broader concept of health with one under development (Healthy Days) for the Dual Eligible Beneficiaries Program and another from the National Survey of Children's Health.

During our conversations with subject matter experts, we became aware of a patient-reported tool and a set of measures in development that could be useful in upcoming work (in the Measure Concept tab of Appendix B). The first concept is one where the feasibility of data collection of the tool has been assessed but measure development would be required. The second are measures on processes and outcomes that are currently undergoing testing. All would need to be assessed as to their appropriateness for accountability uses and may be better suited to quality improvement efforts initially.

Health Leads staff used the What Matters Index, a patient reported tool that assesses an individual's confidence in managing health problems, pain, emotions, medications, and adverse side effects.[51] This tool was validated for use in patients with chronic conditions to define each individual's risk and tailor interventions.[52] Over twenty groups implemented this tool in the Health Leads project and determined that it could be collected and considered meaningful within the context of social determinants of health in adults. Because initial use of this tool in the pediatric population resulted in potentially exaggerated responses by parents and caregivers, questions from the National Survey of Children's Health were used with improved results. Data collection burden was one of the primary challenges experienced during the implementation of this index. As a result, requirements for data collection were limited and sites collected this information on a subset of individuals.

Additional work would be needed to use this measure for performance measurement purposes since it has been primarily used to report patient-level information and we could not identify any current efforts to determine how the data could be aggregated to assess performance at a site or program level. For example, questions need to be resolved such as:

- What minimum sample size of patients would be required to yield reliable and valid results;
- What period of time would data need to be collected to enable assessments of change (e.g., six months, one year);
- How should missing data be addressed (e.g., should patients who failed to complete a survey at one interaction be excluded?); and
- How should improvement be defined (e.g., increase of one point).

NCQA is currently field testing a set of measures that seek to assess whether care is being provided based on patient priorities.[53] This set includes two process measures focused on goal setting and an outcome to determine the degree to which the goal was adequately addressed from the patient's perspective. While the processes may be appropriate for accountability uses, the current thinking on the outcome measure is that it may be better suited for quality improvement due to concerns such as gaming. This work on person-centered outcomes is underway for two populations — adults with complex needs and individuals with serious illness. Populations were predetermined by the organizations currently implementing the process and collecting the data. Both projects anticipate data collection to be completed in the spring of 2020.

Recommendations for future work

Recommendation 5: Promote the development and selection of measures based on patient-driven priorities.

Throughout this scan, we consistently encountered a clear desire to ensure that any measurement effort be driven by the priorities of the individuals served. Measures must be meaningful to patients and there are multiple efforts underway by measure developers, implementers, and others to meet this goal.

For example, CMS now explicitly requires that measure developers must implement a process by which patients and caregivers can play an active and substantive role in any measure development project. The Pharmacy Quality Alliance, National Health Council, and NQF released a white paper outlining how patients should be involved throughout the measurement lifecycle through a transparent process by which patients serve as meaningfully engaged partners who represent the full spectrum of the disease or characteristics critical to the measurement effort.[54]

Expanding the collaboration and involvement of individuals with complex needs into any future work is vital. Ultimately, assessments of the effectiveness of these programs must center on what is most meaningful to patients as well as providers and involving individuals with complex needs at the beginning of this work will ensure alignment with their priorities.

Recommendation 6: Develop and/or select a core set of measures for longitudinal evaluations of program effectiveness paired with additional sets based on the populations of interest and prioritized domains of care.

Identifying a core set of measures that could be collectively tracked across all programs would begin to advance the field and enable assessments of the effectiveness of these programs in a standardized manner. It would also provide a way for the field to agree on a set of measures appropriate for future uses such alternative payment models, risk sharing, or other care delivery models. In keeping with the perspectives of the individuals with whom we spoke, this core set should not solely focus on cost and utilization but must have a broader focus. A small number (possibly no more than five) could be chosen that address critical areas of measurement such as cost/utilization, health and well-being, and cross-sector alignment.

This approach could also be supplemented by additional sets of measures focused on subpopulations, other priority domains, or processes and outcomes that are closely linked to driving improvements in the core set of measures. These sets could be specified and tested for applicability to these programs and would serve multiple purposes including comparisons across programs but primarily to facilitate quality improvement using nationally recognized and vetted measures.

Based on our research, it is clear that while some new work will be needed to develop measures in gap areas (i.e., equity, health and well-being), most could be selected and adapted from existing measures. Specification and testing may still be needed to refine the measures to reflect this population but leveraging the work of others will expedite the process and increase efficiencies. It may also enable comparisons of complex care programs to other programs using the same measures in the future.

Recommendation 7: Collaborate with key partners working in this space.

We identified several groups with whom partnerships could be established or enhanced, which would serve to address some of the gap measurement areas and/or fulfill a need around testing or implementation. Collaborating with NCQA as they further test and implement measures for goal-directed care could provide a source of measures that drive quality improvement efforts at the point of care. The recent work of Health Leads implementing the What Matters Index could provide an avenue to create and standardize a performance measure that reports a program's ability to address an individual's health confidence.

The Advancing Integrated Models (AIM) demonstration project is in the process of identifying a core set of measures by which each participating program can report and potentially evaluate progress collectively with the goal of a final set selected by the first quarter of 2020. This group could serve as a test bed for the initial core set of measures identified through this work. In addition, the project is building a library of measures that could be used by the various participants and staff are in the process of collecting what measures these groups currently use. There is an opportunity to share the findings of this work with them and for the project to provide measures from the field that could be useful for broader implementation.

Integrating patient priorities as a key driver of this work will be critical to ensure success Leveraging the National Center's National Consumer Scholars program[55] is one avenue as is a potential collaboration with the Center to Advance Consumer Partnership.

All of the organizations discussed here expressed interest in working with the National Center and IHI in the future. In addition, it would be prudent to continue to monitor the work of several groups which may inform the field such as SIREN, HL7 Gravity, and initiatives from the Center for Medicare and Medicaid Innovation.

Recommendation 8: Build capacity and processes to capture best practices and innovative approaches used in the field for broader dissemination.

Much work is underway at the local, regional, and national level to address and improve the health of individuals with complex needs. A vehicle by which individuals and programs can share learnings, best practices, and approaches with others could advance the field of complex care. For example, the AIM project is one such effort but it would be useful if there were one place where this information could be stored and publicly available. The broader that we are able to disseminate successes and failures, the greater is the potential to advance the field.

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Appendix A: Subject matter experts interviewed

Name	**Title and organization**
Adrianna Saada	Director of Quality Improvement, Health Leads
Allison Hamblin	President & CEO, Center for Health Care Strategies
Amadly Cruz	Program Manager- Care Management Initiatives Team, Camden Coalition
Amy Kelley	Associate Professor and Vice Chair of Health Policy and Faculty Development; Icahn School of Medicine at Mount Sinai
Andrew Hamilton	Chief Informatics Officer/Deputy Director- Alliance of Chicago
Angelia Bowman	Assistant Director, Research, NCQA
Ann Hwang	Director of the Center for Consumer Engagement in Health Innovation, Community Catalyst
Asaf Bitton	Executive Director, Ariadne Labs
Burton Pusch	National Consumer Scholar, Disability Advocate
Chris Koller	President, Milbank Fund
David Labby	Health Strategy Advisor, Health Share of Oregon
Dawn Wiest	Director of Action Research and Evaluation, Camden Coalition
Dayna Fondell	Senior Clinical Manager for Clinical Redesign Initiatives, Camden Coalition
Diane Meier	Director, Center to Advance Palliative Care
Jay Luxenberg	Chief Medical Officer, On Lok
Jessica Briefer French	Assistant Vice President, Research, NCQA
Joan Teno	Oregon Health & Science University
Joslyn Levy	Founder and Principal, Joslyn Levy & Associates
Larry Gottlieb	Chief Quality Officer, Commonwealth Care Alliance
Laura Gottlieb	Director, SIREN
Michelle Hinton	Impact Director, Health & Well Being Alliance for Strong Families & Communities
Nicole Filion	Associate, Joslyn Levy & Associates
Rachel Davis	Director for Complex Care, Center for Health Care Strategies
Rodney Dawkins	National Consumer Scholar, Patient Advocate

Name	**Title and organization**
Tamara Dumanovsky	Research Consultant, Joslyn Levy & Associates
Therese Wetterman	Director of Learning Network, Health Leads
Thomas Johnson	President & CEO, Family Matters of Greater Washington
Toyin Ajayi	Chief Health Officer, Cityblock Health

Appendix B: Measures and measure concepts for complex care

Download the Excel file of measures and measure concepts for complex care at:

https://www.nationalcomplex.care/wp-content/uploads/2020/05/Final-Report-Appendix-B-Measures-and-concept-complex-care.xls

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for Complex Health & Social Needs

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About the Camden Coalition

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of **complex care** by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals **in Camden** and **regionally**.

Through our **National Center for Complex Health and Social Needs** (National Center), the Camden Coalition works to build the field of complex care by inspiring people to join the complex care community, connecting complex care practitioners with each other, and supporting the field with tools and resources that move the field of complex care forward.