Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living:

Synthesis of Evidence and Environmental Scan

INTERIM REPORT

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NATIONAL QUALITY FORUM

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EXECUTIVE SUMMARY

The Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living Project aims to develop a shared understanding and approach to assessing the quality of home and community-based services (HCBS) and to identify gaps in current HCBS quality measurement as well as high-leverage opportunities for measure development. Understanding the quality of HCBS becomes increasingly important as government funding shifts from institutional to community-based settings, and demand for HCBS rises. A growing number of programs offer services and support to help individuals live independently in integrated community settings. However, despite this growth, there is a lack of systematic measurement of the quality of HCBS across payers and delivery systems.

To address this issue, the National Quality Forum (NQF), under a contract with the Department of Health and Human Service (HHS), convened a **multistakeholder Committee** to develop recommendations for the prioritization of measurement opportunities to address gaps in HCBS quality measurement. The two-year project involves:

1. the creation of a conceptual framework for measurement, including an operational definition of HCBS;
2. a synthesis of evidence and environmental scan for measures and measure concepts;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. recommendations for prioritization in measurement.

The first interim report, **Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework**, presented the Committee's foundational work of creating an operational definition, characteristics of high quality HCBS, domains of measurement as well as an illustration of the function of performance measurement in HCBS. This report, building on the first report and related efforts, focuses on the findings of the synthesis of evidence and environmental scan for measures.

The purpose of the synthesis of evidence and environmental scan is to assess the current HCBS quality measurement landscape. The findings will be used to inform the Committee's efforts to prioritize measure gaps and identify opportunities for measure development. NQF conducted a multi-step approach to the synthesis of evidence and environmental scan which included the collection and review of information sources as well as a review of example state-level (Minnesota, Oregon, and Washington) and international (England, Canada, and Australia) quality measurement initiatives.

Under the guidance of the Steering Committee, the Department of Health and Human Services Advisory Group, NQF members, and the public, over 270 information sources were identified. An annotated bibliography contains these sources, which were obtained from research publications, grey literature, measure repositories, and previous environmental scans. NQF extracted measures,

measure concepts, and instruments from these sources that assess the quality of HCBS and closely match the domains of measurement identified by the Committee. For the purposes of this work, NQF defined measures, measure concepts, and instruments as follows:

- A measure is a metric that has a specific numerator and denominator and has undergone scientific testing.
- A measure concept is a metric that has a specific numerator and denominator, but has *not* undergone testing.
- An instrument is a psychometrically tested and validated survey, scale, or other measurement tool.

NQF identified 261 measures, 394 measure concepts, and 75 instruments, which are displayed in the **compendium of measures**. The majority of measures, measure concepts, and instruments were found in the domains of Service Delivery, System Performance, Effectiveness/Quality of Services, Choice and Control, and Health and Well-Being. No or fewer measures, measure concepts, or instruments were found in the domains of Consumer Voice, Equity, Community Inclusion, and Caregiver Support.

NQF also reviewed state-level and international quality measurement activities in three states and three countries. These example initiatives were reviewed to illustrate the types of efforts happening within the U.S. and abroad. For instance, Washington State is currently developing two measures sets to assess a variety of consumer outcomes like improved health status and improved satisfaction with quality of life. Oregon and Minnesota are currently piloting and utilizing new instruments to better evaluate HCBS consumer experience. Similarly, governing bodies within England, Canada, and Australia have begun developing and implementing standard measure sets and frameworks to assess the quality of their HCBS systems.

During the next steps of the project, the Committee will discuss the findings of the synthesis of evidence and environmental scan. They will also consider the feasibility of measurement, barriers to implementation, and mitigation strategies for identified barriers. As this is an iterative process, there will be several opportunities for the Committee, NQF members, and the public to provide feedback throughout the project as it will continue through September 2016.

BACKGROUND AND CONTEXT

Environmental Context

The United States is experiencing a major shift in the nation's demographics with a rapid increase in the number of people who require long-term services and supports (LTSS). LTSS are generally considered to include assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) for older adults and/or people with disabilities who cannot perform these activities on their own due to a physical, cognitive, or health condition. The category of LTSS is broad and includes care and service coordination for people who live in their own home, a residential setting, a nursing facility, or other institutional setting. Home and Community-Based Services (HCBS) is a subset of LTSS that functions outside of institutional care to maximize independence in the community. Both LTSS and HCBS also include supports provided to family members and other unpaid caregivers of individuals with LTSS needs.

Demand for these services is increasing and will continue to do so. The Administration for Community Living (ACL) reports that the number of people 65 years of age and older will exceed 70 million by 2030, accounting for 19 percent of the population and doubling the total number of older Americans since 2000.[1] In 2013, 37 million people in the U.S. were classified as having a disability, with more than 50 percent of that total in their working years (18-64).[2] In addition, approximately 60 million Americans experience a mental illness annually, and 13.6 million people are currently living with chronic mental illness.[3] Finally, projections show that 21 million individuals are expected to be living with multiple chronic conditions by 2040, many of whom will require LTSS.[4] An increasing share of LTSS is comprised of HCBS, promoting independence and wellness outside of institutional settings.

HCBS accounted for a majority of Medicaid long-term services and supports (LTSS) expenditures for the first time in federal fiscal year (FY) 2013. Total federal and state LTSS spending was $146 billion, including $75 billion for HCBS and $71 billion for institutional LTSS. These expenditures are expected to grow dramatically in concert with demand.[5] Given the anticipated growth in Medicaid coverage and the breadth of services covered through HCBS, this is a critical time to better understand performance of these services and their contribution to the HHS goals of building a health system that delivers better care, spends healthcare dollars more wisely, and makes communities healthier. Through the federal-state partnership of Medicaid, the Centers for Medicare & Medicaid Services (CMS) and states are the dominant funders of HCBS. As a result, CMS and states also drive much of the current quality monitoring and quality measurement activity in the marketplace.

However, HCBS extends well beyond services purchased by Medicaid. First, a host of other federal, state, and local programs provide HCBS. These include ACL, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Administration for Children and Families (ACF), the Health Resources and Services Administration (HRSA), and others. In addition, there is a large and growing private-pay market for HCBS. Finally, HCBS consumers receive assistance from family members, friends, and volunteers in the form of informal care, in addition to paid or formal services. As a quality measurement framework for HCBS continues to emerge, a number of issues must be considered. These include the relationships between various funding streams, regulators, the extensive and diverse network of HCBS providers, service delivery models including self-direction, and the potential implications for how measurement systems will align across the evolving health and LTSS systems.

PROJECT OVERVIEW

Over the past decade, the National Quality Forum (NQF) has endorsed hundreds of performance measures to address important areas for improving health and healthcare. At the same time, many measure gaps have been identified, but the lack of an organizing framework through which to analyze and prioritize them has presented a challenge in determining where scarce resources should be allocated for future development. With the development of the HHS National Quality Strategy for Improvement in Health Care (National Quality Strategy or NQS), a clear blueprint is now in place to better assess critical gaps in quality and efficiency measures.[6] One important gap is the lack of measures that address HCBS that support community living. NQF's completed and current measure gap prioritization projects lay a foundation for setting goals and coordinating action in measure development in high-impact areas. The significance of quality measurement in HCBS is heightened as more care is being delivered in community settings.

The purpose of this project is to further advance the aims and priorities of the Affordable Care Act (ACA), the NQS, and the previous work of HHS' Community Living Council by identifying priorities for performance measurement, scanning for potential measure concepts to address these priorities, and developing multistakeholder recommendations for future measure development and advancement. This project utilizes a comprehensive approach to considering all types of people who could, and do, use HCBS. It includes both government and private sector funding sources for HCBS. This report, the second of four to be produced over the life of the project, builds on the first interim report that presented the conceptual framework and operational definition drafted by the Home and Community-Based Services Quality Measurement Committee. The Committee roster is provided in **Appendix A**.

The recommendations generated through this project will be instrumental in identifying high-impact areas for future HCBS measurement and influential on the process of developing a nationally endorsed and accepted quality measure set for HCBS. The two-year NQF project involves:

1. the creation of a conceptual framework for measurement, including an operational definition of HCBS;
2. a synthesis of evidence and environmental scan for measures and measure concepts;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. recommendations for prioritization in measurement.

This project is intended to build upon previous and/or ongoing work related to HCBS quality in order to provide a unified picture of HCBS quality measurement and to identify opportunities for measure development. Its intent is to provide a framework through which stakeholders can align broader measure development efforts by ensuring that financial and human resources are purposefully targeted. The work will quicken the pace of development and use of national measures of HCBS that matter to consumers, families, and stakeholders at all levels of the system who have a role in improving HCBS quality.

Initial Components of the Conceptual Framework

In the first interim report, the Committee crafted an operational definition for HCBS to reach a common understanding of what it does and does not include. Following the creation of the definition, the Committee identified characteristics of high-quality HCBS that outline how services should be delivered. The Committee's list of characteristics is extensive but important for framing the vision for quality. These characteristics express the importance of ensuring the adequacy

of the HCBS workforce, integrating healthcare and social services, supporting the caregivers of individuals who use HCBS, and fostering a system that is ethical, accountable, and centered on the achievement of an individual's desired outcomes.

The Committee delineated a universe of domains and subdomains for quality measurement as the first step towards later prioritization. The Committee identified a total of 11 quality measurement domains which point to important areas for measurement and/or measure development. Numerous potential subdomains for measurement exist under each of the domains, and the Committee has begun the process of defining them. Finally, these components of the conceptual framework and other aspects of the Committee's discussion are represented in an illustration of the function of quality measurement. The most recent iteration of the operational definition, characteristics of high-quality HCBS, and domains appear in **Appendix D**. The Committee will continue to refine these components throughout the project.

Related Efforts in HCBS and Measurement

There have been several ongoing and related efforts, at the federal policy level and in the realm of quality measurement, to support improvement in HCBS. For example, the Deficit Reduction Act (DRA) of 2005 (PL 109-171, Section 6086(b)) directed the Agency for Healthcare Research and Quality (AHRQ) to develop HCBS quality measures for the Medicaid program. To lay the groundwork for meeting these requirements, AHRQ contracted with Thomson Reuters (now Truven Health Analytics) to conduct an environmental scan of existing and potential measures.[7] While the scan is now several years old, it was thorough and included more than 200 measure sources. NQF is updating and building upon this work and other previously completed efforts to identify measures, potential measure concepts, and instruments for HCBS.

CMS has sponsored the development of an HCBS taxonomy further explaining the types and uses of HCBS. Under Medicaid, a wide array of services and supports has been approved as HCBS including personal care, homemaker, habilitation, transportation, case management, supported employment, environmental modifications, respite care, and support broker and financial management services that may be required in self-directed service delivery models.[8] This taxonomy is to be implemented into the new version of the Medicaid Statistical Information System (MSIS), which gathers national eligibility, enrollment, program utilization, and expenditure data.

In addition, CMS awarded Testing Experience and Functional Tools (TEFT) planning grants to nine states to test quality measurement tools and demonstrate e-health in Medicaid community-based long-term services and supports (CB-LTSS).[9] The TEFT initiative is currently working on a HCBS consumer experience of care survey, functional assessment of standardized items (FASI), and development of standards for an electronic long-term services and supports (eLTSS) health record and a personal health record.[9] Progress is currently being fostered through Medicaid, and there is potential to expand and share the results.

These are examples of the dozens of important inputs to the Committee's work. Despite the existence of several established frameworks and/or lists of quality measurement domains for LTSS and HCBS, the availability and uptake of performance measures remain limited and lack uniformity across states and across other levels of analysis (e.g., provider, managed care organization). In light of the increasing use of HCBS nationally and the associated costs, this is a deficit in quality measurement. Stakeholders have called for more systematic measurement for many years, but the current environment reflects the fragmented nature of the decentralized HCBS system as well as a historical lack of consensus about the best path forward for implementation of measurement. NQF will continue to research previous and current efforts to advance this project.

PURPOSE AND OBJECTIVES

This report details the synthesis of evidence and environmental scan for measures, measure concepts, and instruments that assess the quality of HCBS. The purpose of the synthesis of evidence and environmental scan is to inform the Committee's task to identify measure gaps and promising opportunities for measurement by providing an overview of the current HCBS quality measurement landscape. The approach to the synthesis and scan was carefully developed by NQF staff, with input from the Steering Committee and Department of Health and Human Services Advisory Group (**Appendix A**) crafted to capture the wide range of HCBS populations, services, and settings that align to the domains and subdomains developed by the Committee. The objectives of the synthesis of evidence and the environmental scan are to:

- identify existing measures, measure concepts, and instruments that are being used or proposed conceptualized for use to assess HCBS quality, with an emphasis on those that map to the draft conceptual framework's domains and subdomains;
- identify examples of HCBS measures to guide the Committee's discussion of implementation barriers and mitigation strategies, that is, a selection of measures that lend themselves to examination as "test cases"; and
- facilitate the Committee's deliberations on the identification of key measurement gaps and prioritization of measure concepts and instruments that should be developed into future HCBS performance measures.

The measures that were found are not exhaustive but provide a detailed overview of the current state of measurement. The Committee will review and interpret the findings of the environmental scan during the next phase of the project. Throughout this project, NQF will continue to be guided by related efforts (e.g., the CMS planning grants (i.e., TEFT) and build on previously completed work such as the Prioritizing Measure Gaps projects on Alzheimer's Disease and Related Dementias, Care Coordination, and Person-Centered Care and Outcomes. As this is an iterative process, there will be several opportunities for the Committee, NQF members, and the public to further refine and make additions to the findings of the environmental scan as this work continues.

METHODOLOGY

Approach

NQF conducted a three-step approach to the synthesis of evidence and environmental scan which included: (1) a collection of information sources; (2) the review of information sources (i.e., extraction of measure, measure concepts, and instruments); (3) and a review of state-level (Minnesota, Oregon, and Washington) and international (England, Canada, and Australia) HCBS systems to highlight burgeoning quality measurement initiatives. For the purpose of this project, NQF defined measures, measure concepts, and instruments:

- A measure is a metric that has a specific numerator and denominator and has undergone scientific testing for reliability and validity.
- A measure concept is a metric that has a specific numerator and denominator, but has not undergone scientific testing.
- An instrument is a psychometrically tested and validated survey, scale, or other measurement tool.

Although the term "measure" is often used to refer to multi-item instruments used to obtain data from individuals about a particular domain of health status, quality of life, or experience with care (e.g., Patient Health Questionnaire-9 [PHQ-9]), such instruments alone do not constitute a performance measure. However, if considered a reflection of performance, aggregated data from such instruments can be used as the basis of a performance measure, with additional scientific testing. Psychometrically tested and validated instruments directly relevant to HCBS were collected in the scan, but NQF staff did not extract individual items from the instruments found. However, in some cases, measures or measure concepts items already in use from an instrument (e.g., Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey measures) were identified and included.

Collection of Information Sources

NQF conducted a search for information sources relevant to HCBS that met the inclusion and exclusion criteria outlined in Appendix B. During this search, NQF examined the grey literature (e.g., technical reports, preliminary progress reports, and white papers), peer-reviewed research publications, measure repositories, and relevant environmental scans. Previous NQF reports and environmental scans were included in the grey literature search. Databases for the literature review included Academic Search Premier, PubMed/Medline, Google Scholar, PsychINFO, PAIS International, Ageline, Cochrane Collaboration, and Campbell Collaboration. NQF conducted a targeted search within these databases using various combinations of keywords that were derived from the domains and subdomains of the Committee's conceptual framework. The keywords used in this search can be found in Appendix C. The Steering Committee, the HHS Advisory Group (AG), and several HCBS stakeholder groups assisted in identifying additional information sources. Over 270 information sources were identified and reviewed. Many of these sources were used to inform the development of the components of the conceptual framework detailed in the first interim report. These sources were also used to identify measures, measure concepts, and instruments for the environmental scan. These sources can be found in the Annotated Bibliography.

Review of Information Sources

Sources were ranked according to their relevance and were assigned impact ratings based on three evaluation criteria (i.e., impact, improvability, and inclusiveness) from the Institute of Medicine's *Priority Areas for National Action: Transforming*

Health Care Quality report. These ratings are outlined in Appendix B. Measures, measure concepts, and instruments were extracted from the information sources that were rated highly and were evaluated based on criteria developed from the 2010 AHRQ Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services. These criteria can be found in Appendix B. Each measure was rated according to the information that was available within the source from which it was extracted.[a]

Many measures and instruments contained in the literature have been captured in web-based measure repositories. NQF searched measure repositories and extracted measures by applying the inclusion and exclusion criteria outlined in Appendix B. Some of these repositories include the HHS Measures Inventory, the AHRQ National Quality Measures Clearinghouse, CMIT Inventory, Health Indicators Warehouse, HCBS Clearinghouse, and the National Inventory of Mental Health Quality Measures. NQF also reviewed its internal measure repository which includes all measures that have ever been submitted to NQF for endorsement (i.e., endorsed and not endorsed). The complete list of measures, measure concepts, and instruments are displayed in the Compendium of Measures.

Review of Federal Programs Materials

NQF reviewed materials pertaining to federal agency programs involved with the delivery of, or payment for, HCBS. This process began by identifying and compiling a list of these programs through a review of the information sources from the annotated bibliography as well as team discussions. These included programs funded by CMS (e.g., section 1915(c)Medicaid HCBS waivers and State Plan Amendments; the Program for All-Inclusive Care of the Elderly Program), the Administration for Community Living (e.g., Older Americans Act programs), the Substance Abuse and Mental Health Services Administration (e.g., suicide prevention programs, mental health block grants), the Department of Housing and Urban Development (e.g., Housing for Persons with Disabilities), the U.S. Department of Agriculture (e.g., Senior Farmers' Market Nutrition Program), and the Veterans Health Administration (e.g., the Home Base Primary Care program). For each non-Medicaid program, NQF staff reviewed information sources related to the program, reviewed program websites, and contacted program staff in the three selected states to inquire about the use of measures or instruments.

Given the large role Medicaid plays in the delivery of HCBS, a more detailed description of the review strategy for Medicaid programs is provided below. Review of Medicaid programs began with the section 1915(c) HCBS Waivers. The program was examined by reviewing a repository of state section 1915(c) performance measures at a point in time provided to NQF by the HHS AG. The AG also furnished a list of services CMS has approved as HCBS. This repository contained the performance measures (n=10,709) included in the 1915(c) applications from 46 states and the District of Columbia. The review of this document included:

1. removal of 2,461 performance measures that did not specify a numerator or denominator
    a. This step was completed by searching the performance measure descriptions for the words "numerator," "number," or "percentage" or the symbols "#" or "%".
2. removal of 1,634 performance measures from waivers with waiver expiration dates prior to 2015[b]
3. categorization and review of the remaining 6,614 performance measures across assurance categories[c]

a If testing information was not available in the source from which the measure was extracted, the measure would be attributed to evidence level B or level I, and classified as a measure concept.

b Performance measures for 1915(c) waiver programs on temporary extensions may not be represented in this sample set.

c Assurances are those areas for which each state must propose performance measures for the purposes of monitoring and assuring the quality of services offered within the waiver program. The assurance categories are Administrative Authority, Level of Care, Qualified Providers, Service Plan, and Financial Authority.

Upon review of these categories, it was determined that many states utilized similar measures across assurance categories. Performance measures from Minnesota, Oregon, and Washington waiver programs were chosen to serve a sample set of section 1915(c) waiver performance measures. These states were considered ideal for in-depth analysis as their HCBS spending as a percentage of LTSS spending is among the highest in the country. To ensure that all section 1915(c) waiver performance measures from these three states were included in the sample set, NQF staff crossed-checked the waivers included in the measure repository provided by the HHS AG with the section 1915(c) waiver applications available for each selected state on the CMS Medicaid Demonstrations and Waivers website. Through this cross-check, additional 1915(c) waiver applications were identified and reviewed for performance measures. Any identified performance measures, measure concepts, or instruments were extracted and added to the compendium. For the section 1915(b) waivers, section 1915(i), State Plan Amendments, section 1915(j), and 1115 Medicaid demonstration waiver programs, documentation (i.e., applications, submitted State Plan Amendments) for Minnesota, Oregon, and Washington were retrieved from the CMS Medicaid Demonstrations and Waivers website and reviewed. NQF reviewed available documentation for the section 1915(k) Community First Option State Plan Amendments, for all participating states, specifically Oregon, Washington, California, Montana, and Texas. For the Balancing Incentive Program, documentation available from The Technical Assistance Center for the Balancing Incentive Program was reviewed. This Center provides a summary of services, quality, and outcomes data collected by the 20 participating states.. Measures or instruments listed in this summary were retrieved, if possible, and reviewed. For CMS's "rebalancing" demonstration program, Money Follows the Person, the evaluation and report documents available on the Money Follows the Person Medicaid websites were reviewed. Any measures, measure concepts, or instruments identified in the review of these programs were extracted and added to the **compendium of measures**. The National Balancing Indicators Project provided information to refine eighteen common core indicators and short-term developmental indicators. This work, which supported state system rebalancing efforts, was also reviewed.

Review of Selected State and International Quality Measurement Activities

NQF interviewed state officials from Washington, Oregon, and Minnesota and reached out to individuals who work in the HCBS systems of England, Canada, and Australia to identify current and emerging HCBS quality measurement initiatives. The states and countries were selected to illustrate performance measurement in high-performing systems. Representatives provided information on seminal works, relevant legislation, and quality measurement frameworks as well as the overall structure of how HCBS is delivered (i.e., funding, key organizations, and governance). NQF also conducted a high-level literature review to identify information sources (e.g., peer-reviewed literature, white papers, and government reports) that provided additional context and insight into the three international HCBS systems. Examples of frameworks, measures, and instruments used in these systems are provided in the Results section.

RESULTS

NQF staff identified a total of 261 measures, 394 measure concepts, and 75 instruments as being directly relevant to HCBS quality; these are displayed in the Compendium of Measures. NQF staff assigned measures, measure concepts, and instruments to the domains and subdomains of HCBS quality measurement defined by the Committee (see Appendix D).

Measures, Measure Concepts, and Instruments Across Domains

The majority of measures, measure concepts, and instruments identified fell within the domains of Service Delivery (n=256), System Performance (n=211), Effectiveness/Quality of Services (n=149), Choice and Control (n=132), and Health and Well-Being (n=82). No or few measures, measure concepts, or instruments were found related to Consumer Voice (n=0), Equity (n= 8), Community Inclusion (n=16), and Caregiver Support (n= 18). Although there are a number of measures, measure concepts, and instruments assigned to the domain of Choice and Control—the level to which individuals who use HCBS are able to choose their services and control how those services are delivered—no measures, measure concepts, or instruments were found within the domain of Consumer Voice—the level of involvement individuals who use HCBS have in the design, implementation, and evaluation of the HCBS system at all levels.

Table 1 displays the number of measures, measure concepts, and instruments mapped to each domain of measurement. As the domains are not mutually exclusive, some measures, measure concepts, and instruments were assigned to more than one domain or subdomain. In most cases, NQF, with input from the Committee Co-Chairs, assigned the measure, measure concept, or instrument to the domain to which it most closely aligned. In a few cases, the measure, measure concept, or instrument was assigned to up to three domains that closely aligned with the subject or purpose of the measure, measure concept, or instrument. Examples of measures and measure concepts were extracted from the compendium of measures and are shown in Table 2; examples of instruments are shown in Table 3.

TABLE 1. DOMAINS OF HCBS QUALITY MEASUREMENT AND ASSIGNED MEASURES, MEASURE CONCEPTS, AND INSTRUMENTS[a,b]

Domains for Measurement	Measures n=261	Measure Concepts n=394	Instruments n=75
Service Delivery	75	173	8
System Performance	42	166	3
Effectiveness/ Quality of Services	111	13	25
Choice and Control	17	61	34
Health and Well-Being	60	6	16
Workforce	10	65	6
Human and Legal Rights	4	28	1
Community Inclusion	4	15	7
Caregiver Support	4	3	11
Equity	4	4	0
Consumer Voice	0	0	0

[a] NQF staff deleted duplicate measures and measure concepts from the measure scan to the extent possible; however, due to retrieval and extraction from numerous sources, identifying and deleting duplicates from the scan was not straightforward, and some duplicate measures and measure concepts may exist.

[b] In some cases, information sources contained measures that were constructed from instrument items. These measures were extracted and included as measures, and the instrument as a whole is included under instruments.

TABLE 2. EXAMPLES OF MEASURES AND MEASURE CONCEPTS WITHIN DOMAINS AND SUBDOMAINS

Domain and Subdomain(s)	Title	Description	Numerator	Denominator
Service Delivery: Accessibility	Access to Plan Coordinators	Percentage of individuals who express that they are able to contact appropriate Person-Centered Plan Coordinators (PCPC) when needed	Number of service recipients who express they are able to contact the appropriate PCPC when needed	All service recipients who respond to the satisfaction survey
System Performance: Availability of services	Percent of children with special healthcare needs (CSHCN) receiving care in a well-functioning system	Percent of children with CSHCN receiving care in a well-functioning system (family partnership, medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition)	Number of CSHCN ages 0 through 17 that received all components of a well-functioning system	Number of CSHCN ages 0 through 17
Effectiveness: Preferences met	Satisfaction with Performance of Service Providers	The percentage of waiver participants and family members responding to the National Core Indicators (NCI) survey who indicated satisfaction with the performance of their service providers	Waiver participants responding to the NCI survey with provider performance satisfaction	Waiver participants responding to the NCI survey[a]
Choice and Control: Self-direction	Long-Term Services and Supports (LTSS) Managed Care Organization (MCO) Process Measure	Percent increase in enrollees that receive participant-directed personal care.	Current number of enrollees receiving participant-directed personal care – previously reported # of enrollees receiving participant-directed care	Previously reported number of enrollees receiving participant-directed care
Health and Well-Being: Health status and wellness	Discharged to Community	Percentage of home health episodes after which patients remained at home	# of home health episodes where the assessment completed at the discharge indicates that the patient remained in the community after discharge	# of home health episodes of care ending with a discharge or transfer to inpatient facility during the reporting period

Domain and Subdomain(s)	Title	Description	Numerator	Denominator
Workforce: Skilled; demonstrated competencies when appropriate	Staff access to dementia-care training	Health and social care managers should ensure that all staff working with older people in the health, social care, and voluntary sectors have access to dementia-care training that is consistent with their roles and responsibilities	# of staff at care service or facility that receive specific dementia-care training on a regular basis, at least once a year	# of staff at care service/facility
Human and Legal Rights: Freedom from abuse and neglect	Community First Choice (CFC) Plan Recipient Abuse	The percentage of participants who are victims of substantiated abuse, neglect, or exploitation.	Participants who are victims of substantiated abuse, neglect, or exploitation	All CFC services recipients
Community Inclusion: Social connectedness and relationships; social participation	Proportion of adults with disabilities participating in social, spiritual, recreational, community, and civic activities to the degree that they wish	Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish	# of people with disabilities who participate in social, recreational, community, and civic activities to the degree that they wish	# of people with disabilities
Caregiver Support: Training and skill building; caregiver well-being; caregiver and/or family assessment and planning	Care Plans for Caregivers	Caregiver care plans include interventions tailored to caregivers' needs and preferences (e.g., psycho-education and training courses, services and benefits, and dementia-care problem solving	# of caregivers of people with dementia offered psychosocial interventions, tailored to their needs and preferences	Total # of caregivers of people with dementia
Equity: Safe, accessible, and affordable housing	Housing status for individuals with an HIV diagnosis	Percentage of patients who were homeless or unstably housed in the12-month measurement period	# of persons with an HIV diagnosis who were homeless or unstably housed in the 12-month measurement period	# of persons with an HIV diagnosis receiving HIV services in the last 12 months

[a] The NCI is survey is broadly administered within states to people with intellectual and/or developmental disabilities (IDD) receiving state-funded IDD services. This measure concept was extracted from a state Medicaid HCBS waiver program and targets only waiver enrollees.

TABLE 3. EXAMPLES OF INSTRUMENTS

Domains	Title	Description
Choice and Control; Effectiveness/ Quality of Services; System Performance; Health and Well-Being	National Core Indicators – Aging and Disability (NCI-AD)	Developed to measure approximately 50 "indicators" of good outcomes of LTSS for older adults and adults with physical and other disabilities, excluding adults with intellectual and/or developmental disabilities
Effectiveness/Quality of Services; Choice and Control	Home Health Care Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey	Designed to measure the experiences of people receiving services from Medicare-certified home health agencies that are provided by nurses and therapists, including physical, occupational, and speech-language therapists. The survey was designed to: (1) produce meaningful data on the patient's perspective to allow comparisons between agencies; (2) incentivize agencies to improve quality of care through public reporting; and (3) enhance accountability.
Choice and Control; Human and Legal Rights; Effectiveness/Quality of Services; Health and Well-Being	Money Follows the Person Quality of Life Survey	Designed to measure quality of life in seven domains: living situation, choice and control, access to personal care, respect/dignity, community integration/ inclusion, overall life satisfaction, and health status of people who have moved from institutional to community settings.
Choice and Control	Personal Experience Outcomes - Integrated Interview and Evaluation System (PEONIES)	Evaluates a broad set of individual experiences using person-centered language
Choice and Control	Personal Life Quality Protocol and Component Scales	This is a battery of instruments used to assess quality of life in individuals with intellectual or developmental disabilities. Outcomes Scales include California Development Evaluation Report (CDER) Behavior Scale - Adaptive Behavior; CDER Behavior Scale – Challenging Behavior; Individual Goal Progress; Decision Control Inventory; Integrative Activities; Productivity; Satisfaction; and Environmental Qualities.
Choice and Control; Effectiveness/ Quality of Services	Personal Outcome Measures® (POM)	Focuses on the choices people have and make in their lives. The Council and Quality and Leadership (CQL) developed a list of 21 personal outcomes to assess whether individuals are supported in a way that achieves the outcomes that are most important to them.

Examples of HCBS Quality Measurement Activities

Washington, Oregon, and Minnesota are the three states previously discussed in the section, Review of Federal Program Materials, in which measures from these programs were identified and added to the compendium of measures.

Washington, Oregon, and Minnesota are also each engaged in the innovative use of measures or instruments within their HCBS systems. Washington is the early stages of implementing two measure sets within the state—one for use in contracts with agencies providing HCBS services and the other for public and private health providers. Oregon and Minnesota are currently utilizing new instruments within their HCBS systems to evaluate consumer experience. Within England, Canada, and Australia, the implementation of quality frameworks and new initiatives surrounding the delivery of HCBS are currently underway. Details for each of these initiatives are included below.

Washington

Approximately 84 percent of Washington State Medicaid enrollees receive long-term services and supports in a home or community setting.[10] In recent years, Medicaid expansion and changes in enrollee needs (e.g., increasing proportion of enrollees with behavioral or substance abuse issues) have led to proposed restructuring of how the state delivers HCBS.[10] This proposed restructuring involves contracting with managed care and behavioral health organizations for the delivery of a variety of services. In 2013, state legislation mandated the development of a set of performance measures for inclusion in these types of contracts.[11] These measures address a variety of outcomes including improvement in client health status, improved client satisfaction with quality of life, and increased housing stability in the community. A steering committee consisting of representatives from community organizations, state agencies, and tribes identified 51 potential performance measures referred to as the Services Coordination Organizations (SCO) Accountability Measures.[11] This set includes "fully developed" measures (e.g., items from the Healthcare Effectiveness Data and Information Set) as well as those in earlier stages of conceptualization and development (e.g., suggested survey items on an individual's perceptions of respect). NQF extracted measures that met the inclusion and exclusion criteria and added them to the **Compendium of Measures**. Washington state agencies are working to select a subset of performance measures for initial adoption and inclusion in their 2016 contracts with providers.

In addition to the SCO Accountability Measure set, Washington state legislation also mandated the development of a statewide Common Set of Measures to be reported by public and private healthcare providers.[12] This measure set is not strictly focused on HCBS, as it contains more medically focused measures (e.g., the percent of the state population with influenza immunization or the percent of children with well-child visits), but it is meant to be used as a tool for helping to improve the effectiveness of healthcare purchasing and to assist in transforming the Washington state healthcare delivery system. The governor-appointed Performance Measures Coordinating Committee (PMCC) was charged with creating a measure set that is manageable in size and based on readily available healthcare insurance claims and/or clinical data. The set gives preference to nationally vetted measures, particularly those endorsed by NQF. In December of 2014, the Committee proposed a starter measure set containing 52 measures. This set included population measures (e.g., the percent of the state population with influenza immunization), clinical measures (e.g., the percent of children with well-child visits), and healthcare cost measures (e.g., the state's Medicaid per enrollee spending). This measure set is currently in its first year of implementation with 12 organizations submitting measurement data to the Washington State Health Care Authority.[13]

Oregon

In January 2014, CMS issued a Final Rule to ensure that Medicaid HCBS programs provide full access to the benefits of community living and offer services in the most integrated settings. Oregon has been working on the development and implementation of a transition plan that demonstrates how the various settings covered under its HCBS waivers and State Plan services meet the settings requirements promulgated in the Final Rule.[14,15] An important part of Oregon's transition plan is the use of consumer experience and provider self-assessment survey tools in assessing the various settings covered in their Medicaid-funded programs.

Most recently, residential settings (e.g., adult group homes) have undergone this assessment using experience tools developed by the Oregon Department of Human Services (DHS) and the Oregon Health Authority (OHA).[16] Individuals receiving services in these settings, or their representatives, were asked to complete an Individual Experience Assessment. This 49-item tool includes questions related to community access, choice of setting, personal finances, schedules, privacy, decorating options, access to food, visitation practices, and access to outside services. Providers in these residential settings were also asked to complete a Provider Self-Assessment Tool, also developed by DHS and OHA. The tool includes 73 items, asking providers to indicate how closely their setting meets the requirements of the Final Rule. Data collection on both the Individual Experience Assessment and Provider Self-Assessment Tool was completed in October of 2015.[16] In 2016, the state will share survey results with providers and use the results to determine what changes, if any, need to be made in order to bring the provider and the setting into compliance with the Final Rule.

Minnesota

Minnesota has developed a strong network of home and community-based services through a combination of federally (e.g., Medicaid Section 1915(c) Minnesota Elderly Waiver) and state-funded programs (e.g., Alternative Care Program, Consumer Support Grants Program) on which a wealth of data are collected and reported. To assess the adequacy of this network and inform policy decisionmaking, the Minnesota State Legislature has mandated that a Gaps Analysis Study on several of these programs be completed every two years.[17] Information is gathered from provider agencies, consumers, and advocates about perceived barriers, availability, and use of services. For residents receiving care through Medicaid, almost two-thirds are enrolled in a managed care program. The quality and effectiveness of these programs are monitored through the collection of Healthcare Effectiveness Data and Information Set (HEDIS)[d] and Consumer Assessment of Healthcare Providers and Systems (CAHPS®)[e] data, and programs are mandated to engage in annual performance improvement projects.[18]

In addition to these activities, Minnesota has been a leader in testing new ways of capturing consumer perspectives on HCBS through its participation in the piloting of the National Core Indicator-Aging and Disabilities (NCI-AD) survey. The National Core Indicators (NCI) are a "…standard set of measures used across states to assess the outcomes of services provided to individuals and families," and NCI surveys

d The National Committee for Quality Assurance developed HEDIS to assess various dimensions of healthcare (e.g., medication management, preventative screenings) and is often used to assess the performance of health plans.

e The Agency for Healthcare Research and Quality developed CAHPS® as a means to capture consumers' experiences with their health care providers and systems.

are the method by which data are collected for the calculation of these indicators.[19] Example indicators include the proportion of adults with developmental disabilities receiving support services who have a paid job in the community and the proportion of families who feel that services and supports have helped them to better care for their family member living at home.[19] The NCI-Adult Consumer and NCI-Family surveys were first developed in 1997, and states have the option to the use these instruments for the assessment of services delivered to individuals with intellectual and development disabilities. Currently, 39 states are administering these surveys. In 2012-2013, Minnesota was one of three states to pilot the newly developed NCI-AD survey. For this pilot study, Minnesota administered the survey to approximately 400 older adults and individuals with physical disabilities receiving publicly funded, long-term care services. Results of the pilot study supported the validity and reliability of the survey. Starting in fiscal year 2016, Minnesota will be using the NCI-AD in a number of HCBS programs including its Alternative Care Program and Older Americans Act funded services.[20]

England

In England, the Department of Health is responsible for the overall governance of the health and social care system. Within this system, home and community-based services are considered "social care."[21] Health services are available to all citizens through the National Health Service (NHS), but the NHS only funds certain kinds of HCBS (e.g., home care, home modification and equipment). However, the 2014 Care Act implemented a variety of changes that will shift how HCBS is delivered and funded, particularly in terms of providing individuals who use HCBS and their caregivers more control over their care and the services they receive under social care programs.

The National Institute for Health and Clinical Excellence (NICE) creates guidelines for quality standards and performance measurement in health and social care. Private and publicly funded HCBS are regulated by the Care Quality Commission (CQC), which ensures adherence to basic quality standards. Some of these quality standards include person-centered care, dignity and respect, and consent.[22] The Adult Social Care Outcomes Framework, first published in 2011, provides timely and relevant information about the quality of HCBS to individuals who use these services and their caregivers.[23] The framework also provides local governments with information to assist in identifying opportunities for improvement and assessing the success of local efforts in improving outcomes. At a regional level, the framework allows for benchmarking and exchange of best practices. At a national level, the framework captures the performance of the adult HCBS system (i.e., all adults who use HCBS) as a whole and informs national policy. The most recent framework focuses on measures pertaining to the four domains highlighted in Table 4.[23]

TABLE 4. ADULT SOCIAL CARE OUTCOMES FRAMEWORK DOMAINS AND EXAMPLE MEASURES – ENGLAND

Domains	Example Measures
Domain 1: Enhancing quality of life for people with care and support needs	• Proportion of people using social care who receive self-directed support, and those receiving direct payments • Carer-reported quality of life • Proportion of adults with a learning disability in paid employment
Domain 2: Delaying and reducing the need for care and support	• Permanent admissions to residential and nursing care homes, per 100,000 population • Proportion of older people (65 and over) who were still at home 91 days after discharge from a hospital into rehabilitation services • Delayed transfers of care from hospital, and those which are attributable to adult social care
Domain 3: Ensuring that people have a positive experience of care and support	• Overall satisfaction of people who use services with their care and support • The proportion of carers who report they should have been included or consulted in discussion about the person they care for • The proportion of people who use services and carers who find it easy to find information about support
Domain 4: Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm	• The proportion of people who use services who feel safe • The proportion of people who use services who say that those services have made them feel safe and secure • The proportion of completed safeguarding referrals where people report they feel safe

Canada

In Canada, HCBS is referred to as "*home care*" and is defined as "as array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, rehabilitation, support and maintenance, social adaptation and integration, end-of-life care, and support for family caregivers."[24] HCBS is organized and delivered through federal, provincial, or territorial governments or by regional health authorities. HCBS are not considered insured services under the Canada Health Act—the law that sets pan-Canadian standards for the administration, delivery, and financing of healthcare. As a result, provinces and territories can choose to fund HCBS, but are not required by the federal government to do so.[21] Nevertheless, all provinces and territories provide some level of funding for HCBS, but coverage, eligibility criteria, and payment models are highly variable.[25] Public funding for HCBS either comes through government contracts with public or private providers or through stipends to consumers to direct their own care.[21]

Although there is no national legislated quality framework for HCBS in Canada, at a provincial level, a number of jurisdictions are involved in quality measurement initiatives. One example is Ontario's Excellent Care for All Act (2010) which requires HCBS organizations to provide the provincial quality council with an annual quality improvement plan in order to facilitate reporting and comparison of a minimum set of quality measures.[24] The measures are aligned to six attributes of quality: accessible, effective, safe, patient-centered, efficient, and population-health focus[26] and are detailed in Table 5. There is also provincial work on quality measurement targeting HCBS populations. For instance, Community Living British Columbia (CLBC)—a provincial agency funding HCBS for people with developmental disabilities and their families—is currently developing a quality framework that links dimensions of quality to CLBC values, and identifies possible performance measures within each quality dimension (e.g., percentage of individuals receiving services reporting current employment who retained employment for one year).[27]

TABLE 5. ONTARIO HOME CARE QUALITY MEASURES – CANADA

Attribute	Theme	Measures
Accessible	Waiting for nursing services	Percentage of home care patients who received their first nursing visit within five days of the date they were authorized for nursing services
	Waiting for personal support services for complex patients	Percentage of home care patients with complex needs who received their first personal support visit within five days of the date they were authorized for personal support services
Effective	Incontinence	Percentage of home care patients who have newly developed bladder incontinence or whose bladder functioning has not improved since their previous assessment
	Communication	Percentage of home care patients with a new problem communicating or existing communication problem that did not improve since their previous assessment
	Hospital readmissions	Percentage of home care patients with unplanned hospital readmissions within 30 days of referral from hospital to Community Care Access Centre after acute hospital discharge
Safe	Falls	Percentage of home care patients who fell in the last 90 days
	Pressure ulcers	Percentage of home care patients with a new pressure ulcer (stage 2 to 4)
Patient-Centered	Patient satisfaction (provincial/ CCAC)	Percentage of home care patients who were satisfied with their care from both care coordinators and service providers
	Patient satisfaction (provider)	Percentage of home care patients who were satisfied with the services provided by their service provider
Efficient	Emergency department visits	Percentage of home care patients who had unplanned emergency department visits within 30 days from referrals from hospital to Community Care Access Centre after acute hospital discharge
	Long-term care placement	Percentage of home care patients placed in long-term care who could have stayed home or somewhere else in the community
Population Health Focus	Vaccination	Percentage of home care patients who have not received influenza vaccination in the past two years.

Australia

In Australia, the Department of Health oversees the delivery of medical services (e.g., care in public hospitals, clinics) while home and community-based services, referred to as "home and community care," are overseen by the Department of Social Service (DSS).[28] The universal public health insurance program, Medicare, covers the cost of medical services offered through the public sector and subsidizes HCBS services to individuals who qualify for specific programs with program participants usually having to pay some out-of-pocket expenses. The delivery of medical and home and community care services is the responsibility of the states and territories, while issues related to funding and policy development are largely the responsibility of the federal government.[21]

Two major programs providing HCBS to Australians are the Home and Community Care Programme and the newly enacted National Disability Insurance Scheme. The Home and Community Care Programme includes Community Aged Care Packages, Extended Aged Care at Home, and Extended Aged Care at Home Dementia and the National Respite for Carers Program that primarily target older Australians who are at risk for declining independence. Services provided through these programs include nursing care, allied health care, meal delivery, personal care, respite, and transportation. Programmatic quality is guided by the Community Care Common Standards, which are maintained and monitored by DSS.[29] Three overarching standards (effective management, appropriate access and service delivery, and service user rights and responsibilities) as well as 18 expected outcomes guide the quality review process that service providers must participate in every three years. During this process, providers complete a self-assessment tool wherein they must demonstrate their compliance with the three standards as well as their achievement of the 18 expected outcomes. Providers are not mandated to report specific measures, but examples of potential measures providers can use are listed in Table 6.

TABLE 6. COMMUNITY CARE COMMON CORE STANDARDS – AUSTRALIA

Standard	Expected Outcome	Example Performance Measure
Effective Management	The service provider has effective information management systems in place.	Proportion of staff provided with training/education on the policies and procedures
Appropriate Access and Service Delivery	Each service user and/or their representative, participates in the development of a care/service plan that is based on assessed needs and is provided with the care and/or services described in their plan.	Proportion of staff provided with training/education on the principles of service delivery
Service User Rights and Responsibilities	The independence of service users is supported, fostered, and encouraged.	Proportion of staff provided training/ education on promoting and fostering independence

The National Disability Insurance Scheme (NDIS) is the result of the National Disability Insurance Scheme Act of 2013 and represents a new approach to providing services to individuals with significant and permanent disabilities who are under the age of 65.[30] In this new scheme, funding allocations for services are based on individuals' needs rather than through block grants to specific providers. This approach is meant to facilitate greater consumer choice and control and result in service delivery that is determined by the needs of the consumer, not the availability of providers or services. Services covered via the NDIS include but are not limited to accommodation support, community access, respite, supported employment, and communication support.

An NDIS Outcomes Framework is under development, and the framework domains are shown in Table 7.[31] Preliminary outcome measures associated with these domains are currently undergoing pilot testing.

TABLE 7. DOMAINS OF THE NDIS OUTCOMES FRAMEWORK – AUSTRALIA

Adults: Participant Domains	Adults: Family Domains
• Choice and control • Home • Work • Daily activities • Health and well-being • Social, community, and civic participation • Relationships • Lifelong learning	• Families have the support they need to care • Families know their rights and advocate effectively for their family member with disability • Families are able to gain access to desired services, programs, and activities in their community • Families have successful plans • Parents enjoy health and well-being

NEXT PHASE OF PROJECT WORK

The Committee will convene at a web meeting on January 29, 2016, to discuss the results of the synthesis of evidence and environmental scan, as well as the public comments received on this report. The Committee will meet again on March 30-31, 2016, for a two-day in-person meeting at NQF headquarters in Washington, DC, to continue to discuss the availability of evidence for measurement, review existing measures and measure concepts, and elaborate on potential new measurement concepts for development. They will also discuss gaps in measurement and prioritize opportunities for future measure development. The priorities will be selected based on the areas of greatest need for quality improvement, feasibility of measurement, and the availability of existing measures. The Committee will also identify promising measure concepts and instruments that demonstrate potential for being transformed into performance measures.

FUTURE MILESTONES

This is the second of three interim reports. The next report, to be issued in the summer of 2016, will include recommendations from the Committee on priorities for furthering HCBS quality measurement. Following the completion of each interim report, there will be a 30-day public comment period. Comments will be made publicly available. Committee members will review comments and use them to inform their ongoing work. However, none of the interim reports will be revised. Rather, the interim reports will build on each other and culminate in a final report that will be submitted to HHS in September 2016.

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APPENDIX A:
HCBS Committee, NQF Project Staff, and HHS Advisory Group

COMMITTEE MEMBER NAME	ORGANIZATION
Joe Caldwell, PhD (Co-chair)	National Council on Aging
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Ellen Blackwell	Centers for Medicare & Medicaid Services
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Jamie Kendall	Administration for Community Living
Lisa Patton	Substance Abuse and Mental Health Services Administration
D.E.B. Potter	Office of the Assistant Secretary for Planning and Evaluation
Michael Smith	Centers for Medicare & Medicaid Services

APPENDIX B:
Inclusion/Exclusion Criteria, Impact Ratings, and Evaluation Criteria

Inclusion/Exclusion Criteria for Evidence

Included	Excluded
• Literature published after 2000 OR originally published prior to 2000 and still current (as identified by being in use or cited in recent resources) AND • Pertains to a best practice or challenge related to the delivery of or outcomes of HCBS AND • Applies to a specific HCBS population, setting, or service	• Published before 2000 and not current OR • Pertains to institutional care OR • Pertains to international efforts besides those identified by AG/ Federal Liaisons OR • Not available in English

Impact Ratings for Sources in Annotated Bibliography

Impact	The extent of the range of costs imposed (e.g., economic, impaired function, mortality), including effects on consumers, families, communities, and the nation
Improvability	The extent of the gap between current practice and evidence-based best practice and the likelihood that the gap can be closed and conditions improved through measurement and change; and the opportunity to achieve dramatic improvements in broad quality aims such as safety, person-centeredness, timeliness, efficiency, equity, and effectiveness
Inclusiveness	Equity, as defined by the relevance of an area to a broad range of people with regard to age, gender, socioeconomic status, and ethnicity/race; representativeness, as defined by the generalizability of associated quality improvement strategies to many types of populations across the spectrum of HCBS; and reach, as defined by the breadth of change effected through such strategies across a range of settings and providers

Inclusion/Exclusion Criteria for Measures, Measure Concepts, and Instruments

Included	Excluded
• Measures directly relevant to HCBS currently in use or proposed for use (have a specific numerator and denominator, and have undergone scientific testing) • Addresses a long-term physical, cognitive, and/or behavioral health need or disability • Delivered in the home or other integrated community setting • Applies to an HCBS target population • Applies to an HCBS service or support[a] • Maps onto an HCBS domain • Measure concepts (metrics that have a specific numerator and denominator, but have not undergone testing) directly relevant to HCBS • Psychometrically tested and validated surveys, scales, or other instruments directly relevant to HCBS, especially consumer and caregiver experience with HCBS and quality of life – Testing must be in the HCBS population for which the instrument is designed	• Sources published prior to 2000 • Measures or measure concepts without a specific numerator or denominator • Measures that pertain to institutional care/ setting (e.g., hospitals and nursing homes) • Measures that pertain to international efforts beyond Canada, Australia, and the UK

[a] Centers for Medicare & Medicaid Services (CMS). The HCBS taxonomy: a new language for classifying home- and community-based services website. http://www.cms.gov/mmrr/Briefs/B2014/MMRR2014_004_03_b01.html. Last accessed July 2015.

Evaluation Criteria for Measures and Measure Concepts

Evaluation Criteria	Rating Scales
1: Scientific evidence and psychometric testing	**A** – Reliability and/or validity testing documented within the information source from which the measure was extracted. **B** – Evidence of some instrument testing. This could include focus groups, or cognitive-, pilot- or pre-testing the instrument with respondents (no quantifiable statistical measure of testing results reported). **I** – No documented evidence of psychometric testing in the source from which the measure or measure concept was extracted.
2: HCBS populations of interest	**A** – Designed/tested for more than one HCBS population (e.g., people with intellectual, developmental and/or physical disabilities, mental disorders, HIV/AIDS, brain injury) **B** – Designed/tested for one HCBS population **I** – The measure was: a. Designed/tested for the general population not receiving HCBS (i.e., no relationship to LTSS) OR b. Designed/tested for persons receiving institutional care (nursing home, hospital, etc.)
3: Feasibility of data collection (data source and data collection methods)	**A** – Requires administrative/clinical data collection from single organizational source (e.g., claims, critical event reporting systems) **B** – Requires survey data collection from a single survey respondent or chart review from a single source **C** – Requires administrative/clinical data from multiple organizational sources **I** – Requires survey data collection from multiple respondents to construct the measure about a single person
4: Prevalence of use	**A** – Use or intended use by a federal government agency or national entity **B** – Use or intended use by two or more programs/entities (including state/local) **C** – Use or intended use by one program/entity (including managed care organizations) **I** – No indication of use

APPENDIX C:
Keywords for Literature Search

Databases were searched first using combinations of the primary and population keywords followed by an iterative cycle of adding Framework Domain keywords to the Primary and Population keyword combinations. A final search used the combinations of the primary and population keywords with the subdomain and HCBS concept keywords.

Tier 1. Primary Keywords

- Home & community based services
- Long term services and supports
- Evidence based practices
- Performance
- Quality
- Measure/measurement
- Process
- Measure concept
- Structure
- Outcome(s)

Tier 2. Population Keywords

- Intellectual or Developmental Disabilities
- Mental Retardation (older terminology)
- Substance Abuse
- Substance Use
- Physical disabilities
- Family caregivers
- Dually Eligible
- Older persons (65+ years of age)
- Senior/Elderly
- Alzheimer (AD)/ Dementia
- Serious Emotional Disturbance
- Serious Mental Illness
- Mental health
- Behavioral Health

Tier 3. Framework Domain Keywords

- Workforce
- Direct Support workforce
- Direct Service workforce
- System performance
- Service delivery
- Consumer Voice
- Community inclusion
- Equity
- Choice & Control
- Individual Choice and Control
- Personal Choice and Control
- Caregiver support
- Health & well-being
- Human & Legal rights
- Effectiveness/ quality of services

Tier 4. Framework Subdomain and HCBS Concepts from Statement of Work Keywords[a]

Workforce
- Capacity
- Availability
- Skilled
- Competent
- Respectful
- Compensated
- *Stability**
- *Recruitment**
- *Retention**
- *Training**

Consumer Voice
- Engagement
- Participation
- Person-centered/ driven
- Consumer-centered/ driven
- Activation
- Responsiveness
- Accountability
- *Satisfaction**
- *Experience**
- *Quality of Life**
- *Perception**
- *Stakeholder**
- *See also Choice and Control**

Choice and Control
- Freedom
- Dignity
- Goals & preferences
- Self-direction
- Accountability
- Dignity of risk
- *Financial obligations**
- *Consumer-directions**
- *Self-determination**
- *Consumer Control**
- *Self-reliance**
- *Independence**
- *See also Human and Legal Rights**

Human & Legal Rights
- Dignity
- Respect
- Informed consent
- Abuse
- Neglect
- Coercion
- Restraint
- Safety
- *(Limited/Person/ Financial) Guardianship**
- *Decision Making**
- Petitioner
- (Durable) Power of Attorney
- Supported Decision Making

System Performance
- Rebalancing
- Program design
- Data
- Outcomes
- Resource allocation
- Financing
- Evidence based practice
- *Emergency preparedness**
- *Adverse Health events**
- *Affordability**
- *Cost effectiveness**
- *Quality improvement**
- *Timely**
- *Fidelity**
- *Respect**
- *Dignity**
- *Survey**

Community Inclusion
- Enjoyment
- Employment
- Education
- Social connectedness & participation
- Accessible environment
- Transportation
- Mobility
- Housing
- Home
- Transition
- Affordable
- Person-centered
- Access to services

Caregiver Support
- Caregiver well-being
- Resources
- Caregiver assessment
- Caregiver planning
- Caregiver compensation
- Respite
- Education
- Reimbursement
- Relief
- Burden

Effectiveness/ Quality of Services
- Goal achievement
- Needs & preferences met
- Skill assessment
- Goal & preferences monitoring
- *Staff-consumer relationship**
- *Experience**
- *Timeliness**
- *Coordinated**
- *Adequate**
- *Responsive**

Service Delivery
- Program service accessibility
- Assessment
- Needs & service alignment
- Service coordination
- *Assistive technologies**
- *Technology infrastructure**
- *Medical, nursing and nutritional services**
- *Case management**

Equity
- Disparity reduction
- Access
- Waiting lists
- Housing

Health & Well-being
- Physical, emotional and cognitive functioning
- Social well-being
- Spirituality
- Behavioral health

Payers, Programs, and/ or Government Entities
- Medicare
- Medicaid
- Managed Medicaid Waiver programs
- 1915 (c),1915 (i) 1915(k), 1915(j), Community First Choice, 1115
- Balancing Incentive Program
- Health homes
- Money follows the person
- Administration on Community Living

a Italicized keywords marked with an asterisk are those added by NQF staff to ensure appropriate and relevant information sources were retrieved during the literature search.

Measure Data Elements

The following data elements were extracted from information sources for each measure, measure concept and instrument when information was available.

Data Element	Description
Title	Name of measure or measure concept.
Description	Measure description, if available.
Numerator	Numerator statement, if available
Denominator	Denominator statement, if available
Measure Type	Measure type based on NQF taxonomy
HCBS Focus	Service type (e.g., day program, personal care, informal care, respite, self- directed services, etc.)
Target Population	Group included in measure denominator, if available (e.g., ID/DD, brain injury, older adults, mental disorder(s), etc.)
Payer	Public, Private, Any
Lifecycle Stage	Best determination of stage of measure development: Measure or Measure Concept
Measure Developer or Steward	Organization responsible for developing or maintaining the measure or concept, if available
Service Setting	Location of the delivered service/element, if available (e.g., home, school, day program, employment site)
Level of Analysis	Entity being held accountable by the measure, if available (e.g., state, individual provider, agency, consumer)
Data Source	Data source for measure information (e.g., consumer survey, administrative data, registry)
NQF #	Measures currently or previously endorsed by NQF include an NQF number
NQF Endorsement Status	Status of NQF endorsement for measures with an NQF number
HHS Inventory #	Measures and concepts include a numeric identifier imported from the HHS Inventory
Framework Domain	Measures and concepts categorized to priority gap areas based on HCBS committee framework
Framework Subdomain	Measures and concepts categorized to priority gap areas based on HCBS committee framework
Information Source	The research database or specific source of the measure or concept information (not data source)
Evaluation Criteria Rating: scientific evidence	Rating of A, B, or I
Evaluation Criteria Rating: HCBS populations	Rating of A, B, or I
Evaluation Criteria Rating: feasibility of data collection	Rating of A, B, C, or I
Evaluation Criteria Rating: prevalence of use	Rating of A, B, C, or I
Potential Duplicate	Potentially duplicate measures and concepts to be tagged and filtered out for easier viewing
NQMC #	Measures and concepts include a numeric identifier if imported from AHRQ's National Quality Measure Clearinghouse

APPENDIX D:
Definition, Characteristics, Domains, and Subdomains

Operational Definition of HCBS

The term "home and community-based services" (HCBS) refers to an array of services and supports that promote the independence, well-being, self-determination, and community inclusion of an individual of any age who has significant, long-term physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting.

Characteristics of High-Quality HBCS

1. Provides for a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals and life preferences
2. Promotes social connectedness and inclusion of people who use HCBS in accordance with individual preferences
3. Includes a flexible range of services that are sufficient, accessible, appropriate, effective, dependable, and timely to respond to individuals' strengths, needs, and preferences and are provided in a setting of the individual's choosing
4. Integrates healthcare and social services to promote well-being
5. Promotes privacy, dignity, respect, and independence; freedom from abuse, neglect, exploitation, coercion, and restraint; and other human and legal rights
6. Ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires
7. Supplies and supports an appropriately skilled workforce that is stable and adequate to meet demand
8. Supports family caregivers
9. Engages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance
10. Reduces disparities by offering equitable access to and delivery of services that are developed, planned, and provided in a culturally sensitive and linguistically appropriate manner
11. Coordinates and integrates resources to best meet the needs of the individual and maximize affordability and long-term sustainability
12. Receives adequate funding to deliver accessible, affordable, and cost-effective services to those who need them
13. Supplies valid, meaningful, integrated, aligned, accessible, outcome-oriented data to all stakeholders
14. Fosters accountability through measurement and reporting of quality and outcomes

Domains of HCBS Quality Measurement

Domains for Measurement	Description of Domain
Workforce	The adequacy and appropriateness of the provider network and HCBS workforce
Consumer Voice	The level of involvement individuals who use HCBS have in the design, implementation, and evaluation of the HCBS system at all levels
Choice and Control	The level to which individuals who use HCBS are able to choose their services and control how those services are delivered
Human and Legal Rights	The level to which the human and legal rights of individuals who use HCBS are promoted and protected
System Performance	The level of accountability within the HCBS system and the extent to which it operates efficiently, ethically, and is able to achieve desired outcomes
Community Inclusion	The level to which HCBS integrates individuals into their communities and fosters social connectedness
Caregiver Support	The level of support (e.g., financial, emotional, technical) available for the paid and unpaid caregivers of individuals who use HCBS
Effectiveness/Quality of Services	The level to which HCBS services are able to produce intended outcomes
Service Delivery	Aspects of services that enable a positive consumer experience (e.g., accessibility, respect, dependability, well-coordinated)
Equity	The level to which HCBS is equitability delivered and made available to a broad array of individuals who need long-term supports
Health and Well-Being	The level of integration between healthcare and other supportive services to promote holistic wellness

Draft Subdomains of HCBS Quality Measurement

Domains for Measurement	Subdomains Corresponding to Each Domain
Workforce	Sufficient numbers and appropriately dispersed; dependability; respect for boundaries, privacy, consumer preferences, and values; skilled; demonstrated competencies when appropriate; culturally competent, sensitive, and mindful; adequately compensated, with benefits; safety of the worker; teamwork, good communications, and value-based leadership
Consumer Voice	Meaningful mechanism for input (e.g., design, implementation, evaluation); consumer-driven system; breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; and outreach to promote accessible consumer engagement
Choice and Control	Choice of program delivery models and provider(s) including self-direction, agency, particular worker(s), and setting(s); personal freedoms and dignity of risk; achieving individual goals and preferences (i.e., individuality, person-centered planning); self-direction; shared accountability
Human and Legal Rights	Delivery system promotes dignity and respect; privacy; informed consent; freedom from abuse and neglect; optimizing the preservation of legal and human rights; sense of safety; system responsiveness
System Performance	Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate of individual outcomes; waiting lists; backlog; financing and service delivery structures; availability of services; efficiency and evidence based practices; data integrity
Community Inclusion	Enjoyment or fun; employment, education, or productivity; social connectedness and relationships; social participation; resources to facilitate inclusion; choice of setting; accessibly built environment
Caregiver Support	Training and skill-building; access to resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver and/or family assessment and planning; compensation
Effectiveness/Quality of Services	Goals and needs realized; preferences met; health outcomes achieved; technical skills assessed and monitored; technical services delivered; team performance; rebalancing
Service Delivery	Accessibility (e.g., geographic, economic, physical, and public and private awareness or linkage); appropriate (e.g., services aligned with needs and preferences, whether goals are assessed); sufficiency (e.g., scope of services, capacity to meet existing and future demands); dependable (e.g., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency); timely initiation of services; coordination (e.g., comprehensive assessment, development of a plan, information exchange between all members of the care team, implementation of the plan, and evaluation of the plan)
Equity	Reduction in health and service disparities; transparency of resource allocation; access or waiting list; safe, accessible, and affordable housing; availability; timeliness; consistency across jurisdictions
Health and Well-Being	Physical, emotional, and cognitive functioning; social well-being, spirituality; safety and risk as defined by the consumer; freedom from abuse, neglect, and exploitation; health status and wellness (e.g., prevention, management of multiple chronic conditions); behavioral health

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