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

Initial Components of the Conceptual Framework

INTERIM REPORT

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NATIONAL QUALITY FORUM

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EXECUTIVE SUMMARY

Demand is rising for community-based, long-term supports and services that enable people to live well outside of institutional settings. Multiple factors contribute to this demand, including the demographic shift brought on by the aging American population and an increasing number of children and adults who live with disabilities of various types. Consumer preferences and the policy environment also continue to favor community living over more restrictive environments. An array of home and community-based services (HCBS) now exist to maximize the ability of people to live independently in the community, but the quality of those services is not yet measured systematically.

In 2013, the Commission on Long Term Care noted that current annual costs for long-term supports and services were $130 billion, with approximately two-thirds provided by federal and state funding.[1] Similarly, researchers at the AARP Public Policy Institute estimated the economic value of family caregiving in the United States to exceed $450 billion in 2009.[2] Taken together, these massive investments and the fundamental importance of HCBS to people who have long-term care needs point to the need to better understand the quality and value of HCBS.

In response, the National Quality Forum, under a contract with the Department of Health and Human Services, is convening a multistakeholder Committee to develop recommendations for the prioritization of measurement opportunities that would address gaps in HCBS quality measurement. This work will identify high-leverage areas for performance measurement and recommend the development or refinement of measures. In doing so, it will contemplate the range of populations that use or need HCBS, varied community settings, payers, delivery systems, and accountable entities. This two-year project will involve:

- The creation of a conceptual framework, including an operational definition for HCBS;
- A synthesis of evidence and environmental scan for measures and measure concepts;
- The identification of gaps in quality measurement; and
- Recommendations for prioritization in measurement.

This interim report details the Committee's work to develop a conceptual framework for quality measurement. To support this goal, the Committee crafted an operational definition for HCBS to reach a common understanding of what it does and does not include. The resulting draft definition of HCBS is:

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

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 is 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.

With the goal of providing a unified picture of HCBS quality measurement, the project will be guided by related efforts and build on previously completed work. It will provide a framework through which stakeholders can align broader measure development efforts by ensuring that financial and human resources are purposefully targeted. The Committee's deliberations will be informed by an ongoing environmental scan and synthesis of evidence. This first of three interim reports will communicate significant Committee findings to the public and invite their comments. The project will conclude with a final report outlining recommendations for addressing gaps in HCBS quality measurement. NQF Members and the public are encouraged to participate and provide feedback throughout the project as it continues through September 2016.

THE NEED FOR A MEASUREMENT FRAMEWORK FOR HOME AND COMMUNITY-BASED SERVICES

Performance Measurement Landscape in HCBS

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 measures 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 Department of Health and Human Services' (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.[3] One important gap is in measures that address home and community-based services (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 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 report, the first of four to be produced over the life of the project, presents the initial findings and guidance of the Home and Community-Based Services Quality Measurement Committee. The Committee roster is provided in **Appendix A**.

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. 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) projects that the number of people 65 years 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.[4] 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).[5] In addition, approximately 60 million Americans experience a mental illness annually, and 13.6 million people are currently living with chronic mental illness.[6] Finally, projections show that 21 million individuals are expected to be living with multiple chronic conditions by 2040, many of whom will require LTSS.[7] An increasing share of LTSS is comprised of HCBS, promoting independence and wellness outside of institutional settings.

This project utilizes a comprehensive approach to considering all types of people who could, and do, use HCBS. It is inclusive of both government and private sector funding sources for HCBS. In 2011, 3.2 million people received Medicaid-funded HCBS.[8] People who purchase or otherwise receive HCBS can generally access the same type of supports as people with Medicaid or other public benefits; however, their costs are borne out-of-pocket. The project considers all types of consumers; older adults, people with multiple chronic conditions, and people with disabilities comprise the core target groups. The project will also incorporate the specialized HCBS needs of people with mental disorders, traumatic/acquired brain injury, HIV/AIDS, and other distinct subpopulations as part of the larger group of people with disabilities. It will also consider the population of children and adults who experience developmental delay, recognizing that delays place them at increased risk for disability.

In 2013, the Commission on Long Term Care issued a Report to the Congress noting current annual costs for LTSS were $130 billion—approximately two-thirds provided by federal and state funding. These expenditures are expected to grow dramatically in concert with demand.[9] Outlays for HCBS now constitute nearly half of Medicaid's long-term care expenditures, and have risen significantly in recent years.[10] 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. Recognizing its importance, this project will deliberately consider the role of Medicaid and the program's diversity across states.

The Committee's approach also recognizes that 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, it must contemplate the relationships between various funding streams, regulators, accountable entities, the extensive and diverse network of HCBS providers, modern service delivery models including self-direction, and potential implications for how aligned measurement systems would be put into place across the evolving health and LTSS systems.

Setting Priorities for Home and Community-Based Services Quality Measurement

HHS has contracted with NQF to convene a multistakeholder Committee of experts to prioritize performance measurement opportunities in HCBS. 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 encompasses:

1. creating a conceptual framework for measurement, including a definition for HCBS;
2. performing a synthesis of evidence and environmental scan for measures and measure concepts;
3. identifying gaps in HCBS measures based on the framework and scan; and

4. making recommendations for short- and long-term efforts to develop reliable and valid HCBS measures.

This project is intended to build upon any 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 systems-level framework, described later in the report, reflects the values and philosophy of HCBS, demonstrating person-centeredness and inclusiveness. 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.

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.[11] While the scan is now several years old, it was very thorough and included more than 200 measure sources. NQF is updating and building upon this work and other previously completed efforts to identify measures and potential measure concepts 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.[12] 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, important activities are emerging around electronic service plans for long-term supports and services (eLTSS). CMS's Demonstration Grant for Testing Experience and Functional Tools (TEFT) initiative is currently working on a HCBS consumer experience of care survey, Continuity Assessment Record and Evaluation (CARE) tool functional item set, and development of standards for electronic and personal health records.[13] These efforts are laying the groundwork to develop an eLTSS health record and interoperability standards to exchange records across providers. They are also demonstrating the use of personal health record systems with beneficiaries who use HCBS. Progress is currently being fostered through Medicaid, but there is potential to expand and share the results.

These are just a few 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 serious deficit in the quality measurement enterprise. 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.

OPERATIONAL DEFINITION AND CONCEPTUAL FRAMEWORK

This section presents an operational definition for HCBS and a draft conceptual framework for quality improvement through measurement developed by the multistakeholder Committee. The operational definition is the first component of the measurement framework. The project's operational definition of HCBS is meant to provide the Committee, as well as public and private stakeholders, with a common understanding of HCBS to allow for a more systematic identification and categorization of HCBS. It is not meant to replace any existing regulations or guidance previously crafted for a specific purpose. Rather, the definition and measurement framework will be used to organize the deliberations of the Committee by clarifying the role of quality measurement in the broader HCBS system and within the larger healthcare system. In that vein, the definition and framework will also guide future quality measurement efforts in HCBS.

Definition of Home and Community-Based Services

Given the heterogeneity of people who use HCBS, the myriad ways in which services are funded, and the variety in the services themselves, one of the Committee's major goals in developing an operational definition is to maintain a broad and inclusive orientation as to what might be considered part of HCBS. At the same time, the definition needs to be specific enough to be meaningful and consistent. Committee members understand that the boundaries of the universe of HCBS are porous, even potentially subjective. There are differences of opinion regarding whether certain services should be considered part of HCBS and/or a clinical health service, human service, or any other categorization. Additionally, the Committee is attempting to establish an operational definition that is positive in tone, devoid of value statements, plain-language, and concise. The resulting draft definition of HCBS is:

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

To create a concise and usable definition, the Committee avoided relying upon specific examples that would have made it longer and more elaborate. For example, the definition purposefully excludes lists of services (e.g., personal care services, caregiver respite), specific groups of consumers that use HCBS (e.g., people with dementia, people with Autism Spectrum Disorder), and types of settings in which HCBS is delivered (e.g., private home, workplace). This consensus-based definition of HCBS will be used throughout the NQF project and can also inform researchers and other stakeholders in the field as we move toward a shared understanding.

Crafting the Consensus-Based Operational Definition

The process of creating a consensus-based operational definition for HCBS was iterative and incorporated both formal research and Committee members' expert opinions. When beginning the process, the Committee understood that HCBS have been defined in a multitude of ways in the literature and in practice. To support the Committee's development of its own operational definition of HCBS, the project reviewed more than 200 information sources and identified 27 existing definitions of HCBS and LTSS.[14] Though

the definitions varied widely as a result of the purposes for which they had originally been constructed, participants observed several commonalities in the definitions' components and themes. Definitions frequently described the purpose of HCBS or the goals the services are intended to accomplish, the types of services provided, characteristics of consumers who use HCBS, and the location where the services are delivered (see Exhibit 1).

Despite their commonalities, existing definitions developed for purposes such as research or program regulation could not be easily translated to an operational definition for this project.

Therefore, using the existing definitions as a starting place, the Committee conducted a multistage process to develop its own operational definition. First, each Committee member reviewed the results of the literature search and provided his or her own definition of HCBS. NQF also requested suggestions for definitions from the public audience and HHS partners during a Committee web meeting. Staff compiled a draft definition based on all submissions for the Committee's review and refinement at a subsequent in-person meeting. The Committee made significant changes to arrive at the consensus definition previously presented.

EXHIBIT 1. EXAMPLES OF HCBS DEFINITIONS IDENTIFIED IN THE LITERATURE

Source	HCBS Definition
AARP Public Policy Institute "Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers[15]	Home and community-based services (HCBS) refer to assistance with daily activities that generally helps older adults and people with disabilities remain in their homes. Many people with LTSS needs require individualized services or supports to live in a variety of settings: their own homes or apartments, assisted living facilities, adult foster homes, congregate care facilities, or other supportive housing.
CMS State Plan Section 1915(i) Final Rule[16]	HCBS is defined as having the following qualities: • The setting is integrated in the greater community, including opportunities to seek employment in competitive integrated settings and engage in the community • The setting is selected by the individual • The setting ensures individual rights of privacy, dignity, and respect and freedom from coercion and restraint • The setting optimizes individual initiative, autonomy, and independence in life choices • The setting facilitates individual choice regarding services and supports, including who provides them
Medicaid.gov[17]	Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted population groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.

Characteristics of High-Quality Home and Community-Based Services

Stemming from the process of creating the definition of HCBS, the Committee went on to identify specific characteristics of a high-quality HCBS system. This was necessary because the operational definition is more functional than aspirational, and it does not communicate the Committee's vision for what HCBS *should* be. Through extensive discussion, the Committee established that high-quality HCBS should be delivered in a manner that:

- Provides for a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals (e.g., employment, enjoying life);
- Promotes social connectedness by including people who use HCBS in the community to the same degree as people who do not use HCBS;
- Includes a flexible range of services that are accessible, appropriate, effective, sufficient, dependable, and timely to respond to individuals' strengths, needs, and preferences;
- Integrates healthcare and social services to promote well-being;
- Protects the individual's human and legal rights, including privacy; dignity; freedom from abuse, neglect, and exploitation; respect; and independence;
- Ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires;
- Utilizes and supports a workforce that is trained, adequate, and culturally competent;
- Supports family caregivers;
- Engages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance;
- Reduces disparities by offering equitable access to and delivery of services;
- Coordinates and integrates resources to maximize affordability and long-term sustainability;
- Supplies valid, meaningful, integrated, aligned, and accessible data; and
- Fosters accountability through measurement and reporting of quality and outcomes.

One discussion focused on the degree to which traditional health services (e.g., doctors' visits and hospital stays) should be integrated with non-health services that are a part of HCBS. There was recognition that coordination and integration of HCBS with medical care is important, but "over-medicalizing" HCBS must be avoided. Participants expressed concern that a greater emphasis within HCBS on health services and health outcomes would diminish opportunities for individuals to shape and direct their own services. This would be contrary to the consumer-driven philosophy that the Committee has encouraged. However, creating strict boundaries between health-related and other services is neither practical nor productive from the perspective of fostering holistic wellness and acknowledging the role that both clinical services and HCBS have in the healthcare system.

The Committee also had extensive discussion about the concept of safety and how to incorporate it in a balanced manner that empowers the consumer. For example, a strong emphasis on safety as a desirable outcome could convey that it is more important than other goals, such as mobility and socialization, when this is not the case. Attitudes toward safety and how it should be balanced with other goals vary greatly among consumers. The Committee agreed that supports chosen to promote safety should be selected in a person-directed or person-centered way that takes into account other priorities. Of course, no person's safety can be guaranteed, and it is impossible to eliminate risk. All individuals take

risks in their daily lives, some infinitesimally small, others significant, and it should be a principle of high-quality HCBS that the system maximizes individual autonomy and self-determination. This "dignity of risk" is fundamental in a person-centered system.

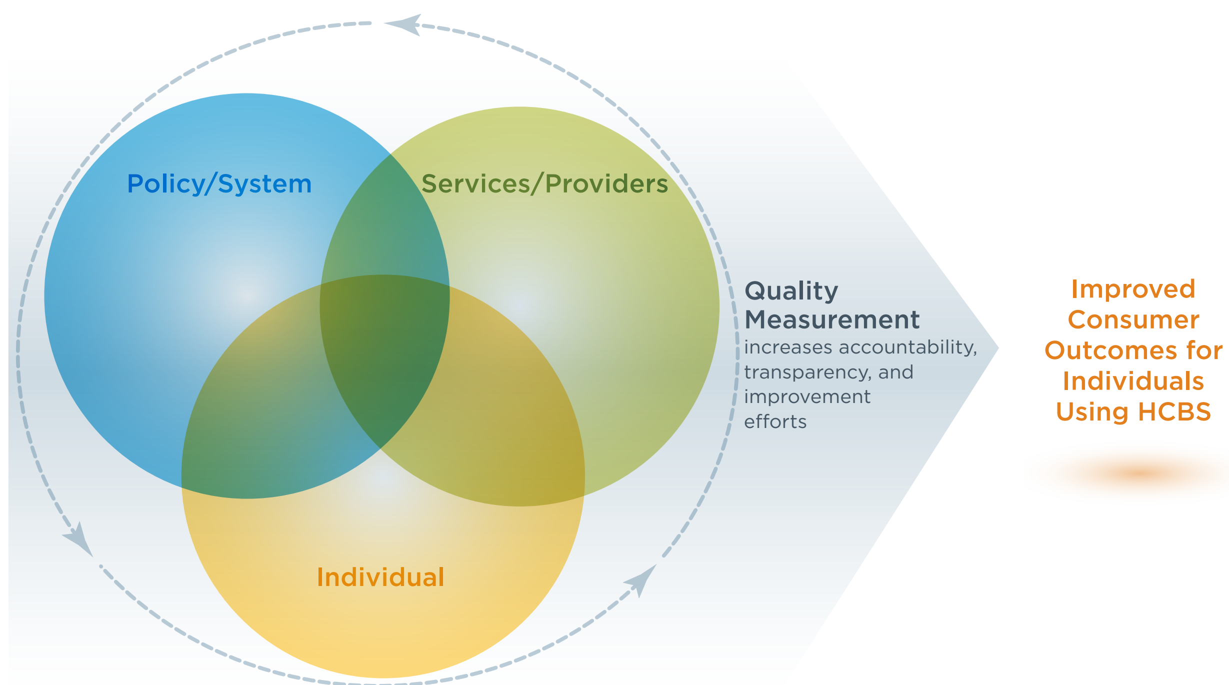
Other concepts for which additional consensus-building will be necessary include how best to support paid and unpaid caregivers and what is meant by culturally competent services. The Committee invites public comment on whether the characteristics of high-quality HCBS are balanced, understandable, and communicate an achievable vision for high-quality HCBS.

Conceptual Framework for Measuring Home and Community-Based Services

After specifying the operational definition and characteristics of high-quality HCBS, the Committee began developing an illustration of the conceptual framework for how the mechanism of performance measurement operates in HCBS. NQF staff presented several conceptual frameworks from related projects to assist the Committee with the abstract thinking involved in conceptual framework development.[18] These examples also served as a starting point for the discussion. The Committee noted features of the example frameworks that they thought would be useful to adapt to the HCBS measurement framework. The Committee intends to create a nationally relevant framework that is simple in style and reflective of the primary importance of improved outcomes for individuals using HCBS.

Each of the circles in the framework, arranged in a Venn diagram to indicate their overlapping nature, represents a level at which measurement can be applied: to the broadest level of policy or systems, to an intermediate level of accountability including providers and services, and to the most targeted level of individuals who use or are involved in HCBS. Measurement at each of these levels of analysis serves different purposes and responds

EXHIBIT 2. ILLUSTRATION OF CONCEPTUAL FRAMEWORK FOR MEASURING HCBS



to different information needs. The circling arrows surrounding the three circles indicate the transmission of information necessary to operate a dynamic, learning system. Measurement topics, arranged by domains, could apply to all of the levels of analysis, or to a subset. The measurement domains are described in a later section. The large arrow in the background of the figure represents the "action" of measurement and that it is intended to increase accountability, transparency, and quality improvement efforts system-wide. The primary purpose of the measurement, and also for the existence of the HCBS system itself, is to improve outcomes for individuals who use HCBS to live independently.

Most immediately, the measurement framework will organize the Committee's deliberations and help to guide the environmental scan of HCBS measures taking place in the next phase of this work. The measurement framework will also guide future quality measurement and measure development efforts by signaling where measurement should occur.

Committee Recommendations: Priority Measure Domains and Subdomains

The next components of the conceptual framework are measurement domains and subdomains. The Committee developed the high-level domains and more detailed subdomains to highlight the topics for quality measurement in HCBS and begin the process of prioritizing them. The domains will also direct NQF staff to look for measures and evidence related to specific topics during the ongoing environmental scan. Because this project is meant to build on previously completed work, the Committee reviewed the domains for measurement most commonly cited in the literature (See **Appendix B**).

HCBS Domains of Measurement

The Committee carefully considered various opportunities for measurement and the best terminology to describe each of the domains of measurement. After thoughtful deliberation, they reached consensus on a list, provided in Exhibit 3, below. The selected domains relate to the previously outlined characteristics of high-quality HCBS, though they do not have a 1:1 relationship. However, additional deliberations will be required to accurately explain the terms chosen to describe each domain, the subdomains contained within, and the domains' parameters.

EXHIBIT 3. DOMAINS OF HCBS QUALITY MEASURMENT

Domains for Measurement	Description of Domain
Workforce/Providers	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
Full 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

HCBS Subdomains of Measurement

The Committee began to establish subdomains to assist with defining each domain's scope and articulating ideas for measurement. The list of subdomains below is not exhaustive and will be refined, expanded, and/or consolidated as the project evolves (Exhibit 4). As currently written, the domains and subdomains overlap in important topic areas such as care coordination and self-direction. This illustrates the interrelated nature of many concepts the Committee finds important.

The Committee acknowledged that measures related to some of the sub-domains would operate at multiple levels of analysis. Specifically, they might be applied at the system level (e.g., a state or states' HCBS waivers or other HCBS programs), the intermediate accountable entity level (e.g., managed care plan, local agency) and/or individual level (e.g., caregivers or individuals who use HCBS). Each domain and sub-domain can include multiple measures as well as measures of different types. As this is an iterative process, there will be several opportunities for the Committee, NQF members, and the public to further shape and refine the domains and sub-domains as this work continues.

EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT

Domains for Measurement	Subdomains Corresponding to Each Domain
Workforce/Providers	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
Full 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

Mapping of the Domains to the Conceptual Framework

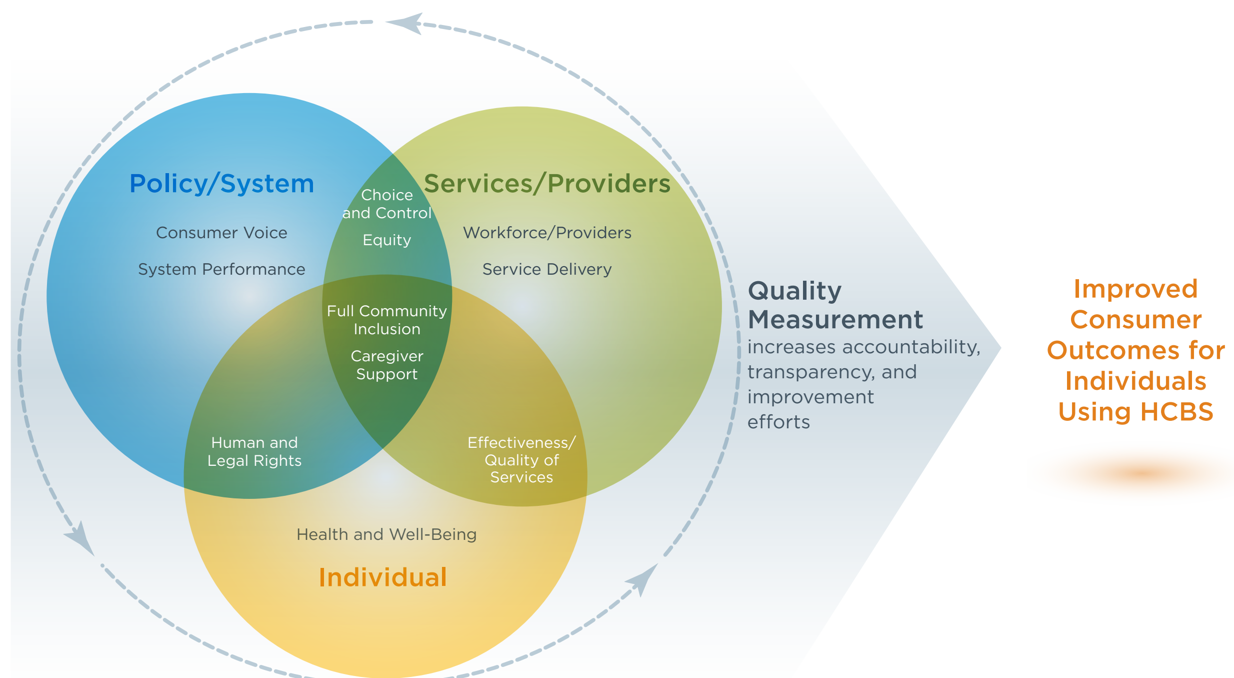
Exhibit 5, below, is a first attempt to organize the domains of measurement within the conceptual framework illustration. Recognizing that measures within each domain may operate within all three measurement areas, the domains were assigned their preliminary locations based on where the majority of measures within each domain might be applied. It would have been possible to map all of the domains within the center of the Venn diagram, but this would not be meaningful. During the environmental scan of measures, each measure found will be categorized by its level of analysis, thus identifying how well existing measures fit the Committee's framework. Additionally, the environmental scan will inform refinement of the domains and their placement within the conceptual framework.

Prioritization of Measurement Domains

In the next phase of the project, the Committee will review any currently available measures within each domain and elaborate on potential new measurement concepts for development. They will begin the process of identifying and organizing gaps in measurement and prioritizing opportunities for measurement. The priorities will be selected based on the areas of greatest need for quality improvement, the availability of measures, and other factors. Prioritization may also involve discussion of measures applicable to the subdomains. However, this project does not include NQF's formal endorsement process to review measures. The Committee will seek to understand the landscape of available measures to inform its recommendations about the path forward and use the knowledge to better identify priority gaps.

Overall, the goal of prioritizing the HCBS measurement domains is to stimulate research, to guide quality improvement efforts, and to signal to measure developers areas of importance for future measurement. Given the complexity of issues and variation in various aspects of HCBS, the Committee will continue to be deliberate in its approach to maintaining an inclusive orientation towards the prioritization of domains. Several controversial topics have already been revealed (e.g. safety, workforce training, and prioritizing types of consumer outcomes) and the public and NQF members are encouraged to participate in the consensus process by submitting comments to assist the Committee in its work.

EXHIBIT 5. MEASUREMENT DOMAINS WITHIN THE CONCEPTUAL FRAMEWORK ILLUSTRATION



NEXT PHASE OF PROJECT WORK

NQF is conducting a two-pronged research effort to inform Committee deliberations. It includes a synthesis of evidence supporting community living and high-quality HCBS, as well as an environmental scan for relevant HCBS performance measures and concepts. These activities will support the goal of winnowing a broad set of potential measurement opportunities into a prioritized subset of measures that inform and address the conceptual framework set forth by the multistakeholder Committee.

Continuing Environmental Scan

The first portion of the environmental scan focused on the collection of available resources to inform the development of the operational definition and conceptual framework, particularly any existing scans. More than 200 sources were identified and reviewed for information relevant to constructing the definition and framework. As the project progresses, the specific objectives for the environmental scan of measures and measure concepts are to:

1. Identify existing measures applicable to HCBS, with an emphasis on those that map to the conceptual framework's domains and subdomains
2. Identify examples of HCBS quality measures to guide Committee discussion of implementation barriers and mitigation strategies, that is, a selection of measures that lend themselves to examination as "test cases"
3. Identify measure concepts and ideas that should be further developed into future performance measures that will best support community living quality

Although the term "measure" is sometimes used to refer to multi-item instruments or scales used to obtain data from individuals about a particular domain of health status, quality of life, or experience with care (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS]; Patient Health Questionnaire-9 [PHQ-9]), such instruments or scales alone do not constitute a performance measure. However, if considered a reflection of performance, aggregated data from such instruments or scales can be used as the basis of a performance measure. For purposes of this environmental scan, psychometrically tested and validated surveys, scales, or other instruments directly relevant to HCBS, especially those that assess quality of life and experience with HCBS, will be captured. During the scan, NQF may perform an initial prioritization of the measures and measure concepts with the greatest potential for later review by the Committee.

Continuing Synthesis of Evidence

A synthesis of other evidence related to HCBS quality and measurement is also taking place throughout the project. In the first phase of the synthesis of evidence, 38 of the most critical and high-impact sources were reviewed in depth to inform the definition and conceptual framework development. The specific objectives of the synthesis of evidence are to:

1. Directly inform the development of the operational definition of HCBS and the conceptual framework for quality measurement
2. Support the environmental scan to identify existing measures applicable to HCBS as well as promising concepts and ideas that should be measured or further developed into future performance measures
3. Inform the prioritization of measurement gaps based on their impact, improvability, and inclusiveness.[19] Generally, what is meant by these criteria from the Institute of Medicine is:

- *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
- *Inclusivenes*s: 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

In support of these objectives, the Committee will continue to focus on literature and other materials associated with best practices and challenges related to measuring the delivery and outcomes of HCBS.

Future Milestones

This report is the first of three interim reports containing draft content. The next report, to be issued later in 2015, will focus on the environmental scan of measures and synthesis of evidence. The third report 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 undergo Committee review, influence work going forward, and be made publicly available, but 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.

ENDNOTES

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APPENDIX A:
Home and Community-Based Services Committee Roster

NAME	ORGANIZATION
Joe Caldwell, PhD (Co-chair)	National Council on Aging
H. Stephen Kaye, PhD (Co-chair)	University of California San Francisco
Robert Applebaum, MSW, PhD	Miami University of Ohio
Kimberly Austin-Oser, MS	SEIU Healthcare
Suzanne Crisp	National Resource Center for Participant Directed Services
Jonathan Delman, PhD, JD, MPH	University of Massachusetts Medical School
Camille Dobson, MPA, CPHQ	National Association of States United for Aging and Disabilities
Sara Galantowicz, MPH	Abt Associates, Inc.
Ari Houser, MA	AARP Public Policy Institute
Patti Killingsworth	Bureau of TennCare
K. Charlie Lakin, PhD	Retired, formerly with National Institute on Disability and Rehabilitation Research
Clare Luz, PhD	Michigan State University
Sandra Markwood, MA	National Association of Area Agencies on Aging
Barbara McCann, MA	Interim Health Care
Sarita Mohanty, MD, MPH, MBA	Kaiser Permanente Northern California
Gerry Morrissey, MEd, MPA	The MENTOR Network
Ari Ne’eman	Autistic Self Advocacy Network
Andrey Ostrovsky, MD	Care at Hand
Mike Oxford	Topeka Independent Living Resource Center
Lorraine Phillips, PhD, RN	University of Missouri
Mary Smith, PhD	Illinois Division of Mental Health
Anita Yuskauskas, PhD	Pennsylvania State University

APPENDIX B:
Crosswalk of High-Quality HCBS System Characteristics and Domains from Literature

The table below was used during the Committee's deliberations regarding measurement domains. The columns contain measurement domains described in the literature. These domains were selected from the sources found to be the most relevant to the work of this project which met specific selection criteria (e.g., breadth of scope, recency, and source type). They are presented by frequency, with those most frequently included in yellow (i.e., domains found in five or more of the selected sources), and those less often cited in purple (i.e., domains found in more than three of the selected sources). To inform the process, the domains found in related works were cross-walked with the domains developed by the Committee to ensure that the Committee had not overlooked any key concepts. An "X" denotes overlap between the domains found in the literature and domains developed by the Committee. The Committee developed the domains in the far-left column, in brackets.

Committee Domains	Domains Most Frequently Cited in the Literature							Domains Often Cited in the Literature							
	Consumer and Caregiver Experience	Access to Supports and Services	Community Integration/ Inclusion	Person Centeredness	Service/Care Coordination	Quality of Life	Safety, Security, and Order	Functional Status	Performance	Healthcare/ Service Utilization	Provider Capacity and Capabilities	Support for Caregivers	Respect/Dignity	Quality of Care	Meaningful Activity
[**WORKFORCE/PROVIDERS**] Workforce: trained, culturally competent, adequate, supported											X				
[**CONSUMER VOICE**] Participant engagement in the design, implementation, evaluation of the program															
[**CHOICE AND CONTROL**] Choice, person-driven, focused on achieving individual goals, consumer directed, control, dignity of risk				X											
[**HUMAN AND LEGAL RIGHTS**] Privacy, dignity, respect, freedom/ independence, Legal rights													X		
[**SYSTEM PERFORMANCE**] Efficient, well-aligned, well-allocated, integrated, data integrity									X						

Committee Domains	Domains Most Frequently Cited in the Literature							Domains Often Cited in the Literature							
	Consumer and Caregiver Experience	Access to Supports and Services	Community Integration/ Inclusion	Person Centeredness	Service/Care Coordination	Quality of Life	Safety, Security, and Order	Functional Status	Performance	Healthcare/ Service Utilization	Provider Capacity and Capabilities	Support for Caregivers	Respect/Dignity	Quality of Care	Meaningful Activity
[**FULL COMMUNITY INCLUSION**] Community engagement, inclusion (to the same degree as people not receiving HCBS), participation; employment and productivity, having fun; social connectedness			X												X
[**CAREGIVER SUPPORT**] Family Caregivers are supported												X			
[**EFFECTIVENESS/QUALITY OF SERVICES**] Effectiveness of services/ quality of care														X	
[**SERVICE DELIVERY**] Services are accessible, appropriate, sufficient, dependable, timely	X	X			X										
[**EQUITY**] Equitable system/fairness and distribution of services that eliminate health disparities															
[**HEALTH AND WELL-BEING**] Well-being: physical/emotional health, safety from the part of the consumer, freedom from abuse or exploitation, neglect							X	X							

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