NATIONAL QUALITY FORUM

Agenda

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

February 20, 2015
12:00 pm – 2:00 pm ET

Committtee Instructions:

Follow the instructions below 10 minutes prior to the scheduled start time.

1. Direct your web browser to the following URL: http://nqf.commpartners.com/se/Rd/Mt.aspx?313992
2. In the "Display Name" field, type in your first and last name and click on "Enter Meeting."
3. To participate in discussion over the phone, dial **1-855-269-9643**. You may also submit comments and questions during the webinar using the chat feature.
4. If you need technical assistance during the meeting, you may press *0 to alert an operator or send an email to: nqf@commpartners.com.
5. If you have any questions or comments in follow-up to the web meeting, please send them to NQF staff at HCBS@qualityforum.org.

Webinar Objectives:

- Build a shared understanding of the project objectives, activities, and the committee's role
- Introduce foundational information about quality measurement
- Begin to gather committee input in the development of an operational HCBS definition and conceptual measurement framework
- Request relevant sources for ongoing evidence synthesis and environmental scan of measures

12:00 pm **Welcome, Introductions, Disclosure of Interest, and Review of Meeting Objectives,**

Wendy Prins, Vice President, NQF

Jamie Kendall, Director, Office of Policy Analysis and Development, Administation for Community Living

Joe Caldwell, Ph.D., Director of Long-Term Services and Supports Policy, National Council on Aging; Committee Co-Chair

Stephen Kaye, Ph.D., Community Living Policy Center, University of California San Francisco; Committee Co-Chair

- NQF staff
- HHS partners
- Committee members

12:25 pm **Project Overview**

Andrew Anderson, Project Manager, NQF

- Project goals, scope, and intended outcomes
- Sequence of meetings and reports
- Committee's role
- Committee questions and discussion

12:45 pm **"Crash Course" in Quality Measurement**

Juliet Feldman, Project Manager, NQF

- NQF's role in the quality measurement enterprise
- Introduce important concepts
- Committee questions and discussion

1:05 pm **Opportunity for Public Comment**

1:15 pm **Crafting a Definition and Conceptual Framework for HCBS Measurement**

Sarah Lash, Senior Director, NQF

Committee Co-Chairs

- Purpose of definition and framework
- Approach for developing a project-specific definition of HCBS
- Committee suggestions and discussion:
  - What should quality measurement accomplish in the HCBS system?
  - How does this project need to account for the broader LTSS system?
  - What entities or relationships does the conceptual framework need to represent?
  - What other definition or framework sources should this project review?

1:45 pm **Opportunity for Public Comment**

1:55 pm **Looking Ahead to April In-Person Meeting and Next Steps**

Committee Co-Chairs

2:00 pm **Adjourn**

NATIONAL QUALITY FORUM

Final Committee Roster

Home and Community-Based Services Quality

COMMITTEE MEMBERS

Joe Caldwell, PhD (Co-chair)
Director of Long-Term Services and Supports Policy, National Council on Aging
Washington, DC

H. Stephen Kaye, PhD (Co-chair)
Professor, University of California San Francisco
San Francisco, California

Robert Applebaum, MSW, PhD
Professor, Scripps Gerontology Center, Miami University
Oxford, Ohio

Kimberly Austin-Oser, MS
National LTSS Policy Director, SEIU Healthcare
Washington, DC

Suzanne Crisp
Director of Program Design and Implementation, National Resource Center for Participant Directed Services
Chestnut Hill, Massachusetts

Jonathan Delman, PhD, JD, MPH
Assistant Research Professor, University of Massachusetts Medical School
Stoneham, Massachusetts

Camille Dobson, MPA, CPHQ
Deputy Executive Director, National Association of States United for Aging and Disabilities
Washington, DC

Sara Galantowicz, MPH
Senior Associate, Abt Associates Inc.
Cambridge, Massachusetts

Ari Houser, MA
Senior Methods Advisor, AARP Public Policy Institute
Washington, DC

Patti Killingsworth
Assistant Commissioner, Chief of Long-Term Services and Supports, Bureau of TennCare
Nashville, Tennessee

K. Charlie Lakin, PhD
Retired, Former Director of National Institute on Disability and Rehabilitation Research
Minneapolis, Minnesota

Clare Luz, PhD
Assistant Professor and Lead Evaluator, Michigan State University
East Lansing, Michigan

Sandra Markwood, MA
Chief Executive Officer, National Association of Area Agencies on Aging
Washington, DC

Barbara McCann, MA
Chief Industry Officer, Interim Health Care
Alexandria, Virginia

Sarita Mohanty, MD, MPH, MBA
Executive Director, Community-Clinical Care Integration, Kaiser Permanente Northern California
Oakland, California

Gerry Morrissey, MEd, MPA
Chief Quality Officer, The MENTOR Network
Boston, Massachusetts

Ari Ne'eman
President, Autistic Self Advocacy Network
Silver Spring, Maryland

Andrey Ostrovsky, MD
CEO, Care at Hand
Brookline, Massachusetts

Mike Oxford
Executive Director for Policy, Topeka Independent Living Resource Center
Topeka, Kansas

Lorraine Phillips, PhD, RN
Associate Professor, University of Missouri
Columbia, Missouri

Mary Smith, PhD
Associate Director, Decision Support, Research, and Evaluation, Illinois Division of Mental Health
Chicago, Illinois

Anita Yuskauskas, PhD
Coordinator, Health Care Policy & Administration, Pennsylvania State University
Center Valley, Pennsylvania

Robert Applebaum, MSW, PhD

Robert Applebaum is Professor of Gerontology and Director of the Ohio Long-Term Care Project at the Scripps Gerontology Center, Miami University. He has been involved in the development and evaluation of long-term care programs across the United States for more than thirty years. He has worked with a number of states on innovations in long-term care service delivery, and completed a series of state and national studies on long-term care quality. Dr. Applebaum has been a frequent speaker at national and state conferences on long-term care. He has authored more than 85 articles and monographs, and four books on long-term care.

Kimberly Austin-Oser, MS

Kimberly Austin-Oser serves as the Long-Term Care Policy Director with SEIU Healthcare. One of her primary responsibilities is leading the organization's innovative workforce development program and policy initiatives built upon the premise that front-line workforce practices and job quality are key drivers for both individual and service system quality improvements. Kimberly has spent the majority of her 25-year human services career dedicated to all aspects of the development and administration of HCBS for older adults and individuals living with developmental and other disabilities. Prior to joining SEIU Healthcare, she served as the Elderly and Disability Services Division Director and the Developmental Disabilities Deputy Division Director for the state of New Mexico. She also served as the Medicaid Disability Policy Coordinator and Consultant for Special Populations for the state of Ohio.

Joe Caldwell, PhD

Joe Caldwell is Director of LTSS Policy at the National Council on Aging. He has over 20 years of experience in the field of HCBS as a researcher, policy expert, provider and parent of a son with disabilities. He leads Disability and Aging Collaborative, a coalition of 37 national aging and disability organizations working together to advance HCBS policy. Joe is also an Adjunct Research Professor at the University of Illinois at Chicago, where he earned his doctorate in Disability Studies. He has a strong research background in outcomes of family support and HCBS programs for consumers and family caregivers.

Suzanne Crisp

Suzanne Crisp is Director of Program Design and Implementation for the National Resource Center for Participant Directed Services. She is a national expert on participant direction and in-home services on both the state and federal levels. She is the Center's expert in managed care. She was the Arkansas Assistant Director of Aging Services and Director of Integrated Services at the Centers for Medicare & Medicaid Services. She has over 25 years of experience developing, managing, and evaluating state and national programs. She implemented the first Cash & Counseling Demonstration and Evaluation program in the nation and participated in all aspects of its empirical evaluation. In her position with CMS, she assessed and approved all state Medicaid waiver and demonstration programs that offered participant-direction and later provided national technical assistance to develop quality management strategies and in-home services for CMS. Suzanne was an active member of the National Quality Enterprise which was a CMS sponsored group developed to provide states with guidance on quality assurance and improvement strategies. Area of concentration was performance indicators directly tied to participant direction.

Jonathan Delman, PhD, JD, MPH

Jonathan Delman is currently an Assistant Research Professor, University of Massachusetts Medical School, Department of Psychiatry and is the director of the Program for Recovery Research. From January 1999 to June 2011, Dr. Delman served as the founding executive director,

Consumer Quality Initiatives, Inc. where he developed a nationally recognized model for consumer-driven results-oriented evaluation and developed a nationally recognized model for conducting community-based participatory action mental health research. He received his PhD from the Boston University School of Public Health and holds a JD from the University of Pennsylvania School of Law.

Camille Dobson, MPA, CPHQ

Camille Dobson is a certified professional in healthcare quality. She holds an MPA from GWU and has spent the past 18 years working in Medicaid policy and development, with a particular emphasis on Medicaid managed care. She directed the team which crafted CMS' principles for state MLTSS programs (released in May, 2013) and was the Medicaid project lead for an intra-agency group working to address HCBS measure gaps at CMS. She has a deep understanding of program development and management at both the state and Federal level, and clearly understands the nexus between quality measurement and program improvement.

Sara Galantowicz, MPH

Sara Galantowicz has two decades of health policy and disability research and evaluation experience, with an emphasis on publicly-funded long-term services and supports. Her areas of expertise include quality metrics and quality improvement, home and community-based services, Medicare post-acute care, and Medicaid claims analysis. In addition, she has more than ten years' practice in experience-of-care survey development and testing, including cognitive and field testing, with a focus on self-reports from people with disabilities. Ms. Galantowicz has significant project and client management experience, and has given multiple conference presentations and trainings. She is currently a Senior Associate with Abt Associates; previously she was a Research Manager for Truven Health Analytics and a Senior Evaluator at the U.S. Government Accountability Office. Ms. Galantowicz holds an economics degree from Princeton University and a Masters in Public Health from the University of Michigan.

Ari Houser, MA

Ari Houser is a Senior Methods Advisor in the AARP Public Policy Institute, where his work includes demographics, disability, quality and patterns of use of long term services and supports, family caregiving, and methodological advising on many topics. Prior to joining the AARP Public Policy Institute, Mr. Houser worked at the RAND Corporation on a variety of topics including occupational health and safety management. He has a bachelor's degree from Swarthmore College and is a Ph.D. candidate (ABD) in measurement, statistics, and evaluation at the University of Maryland.

H. Stephen Kaye, PhD

H. Stephen Kaye is a professor at the Institute for Health & Aging and the Department of Social and Behavioral Sciences at the University of California San Francisco. He serves as director and principal investigator of the Community Living Policy Center, a Rehabilitation Research and Training Center funded by the National Institute on Disability and Rehabilitation Research and the Administration for Community Living, U.S. Department of Health and Human Services. He received a Ph.D. from Stanford University in 1983. His primary research interests focus on community-based long-term services and supports needed by people with disabilities of all ages, employment issues among people with disabilities, use of information and assistive technology, and disability measurement and data collection.

Patti Killingsworth

Patti Killingsworth is an Assistant Commissioner and Chief of Long Term Services & Supports for the Bureau of TennCare. She has led the implementation of an integrated MLTSS system for

seniors and adults with physical disabilities, expanding access to HCBS and rapidly moving toward a rebalanced long term care system in Tennessee. Her commitment is to changing systems to better meet the needs of consumers and families, promoting the development and expansion of HCBS, and ensuring that that the voice and perspective of consumers, family members, and other key stakeholders is brought to bear in policy and program decision-making processes.

K. Charlie Lakin, PhD

K. Charlie Lakin has more than 40 years' experience in disability services. Between 2011 and 2014 he served as Director of the National Institute on Disability and Rehabilitation Research. Prior to coming to NIDRR, Mr. Lakin spent 35 years at the University of Minnesota, including 23 years as director of the Research and Training Center on Community Living. At Minnesota Mr. Lakin directed dozens of research projects and (co-)authored more than 300 publications based on that work. He frequently consulted with state, federal and international agencies on policy, research and evaluation. Among recognitions deriving from Mr. Lakin's work are presidential appointments by Presidents Clinton and Obama as well as service, research, leadership and humanitarian awards from the American Association on Intellectual and Developmental Disabilities, the American Network of Community Options and Resources, The Arc of the US, the Association of University Centers on Disability, the National Association of County Behavioral Health and Developmental Disabilities Directors, and the National Association of State Directors of Developmental Disabilities Services. He is also a recipient of the University of Minnesota's Outstanding Community Service Award.

Clare Luz, PhD

Clare Luz is the Assistant Professor in Family Medicine at Michigan State University. She has over 30 years of HCBS experience, as a provider in long-term care settings then as a gerontologist/ health services researcher. Her research focuses on functional health of older adults and programs and policies that improve quality of care, health outcomes, and life. Most recently, Dr. Luz served as Michigan's principal investigator for a national demonstration/community-based project to develop and test a training program for personal care aides who provide home care to older adults. She teaches research methods and serves on the Governor's Long Term Care Supports and serves on the Governor's Long Term Care Supports and Services Commission.

Sandra Markwood, MA

Sandra Markwood is the CEO of the National Association of Area Agencies on Aging (n4a), which represents the nation's Area Agencies on Aging that provide critical home and community-based services throughout the United States. Prior to joining n4a, Markwood worked for the National Association of Counties, National League of Cities and as Assistant to the County Executive in Albemarle County, VA.

Barbara McCann, MA

Barbara McCann is a 25 year national leader and facilitator of consensus around standards of care, quality measurement and actionable improvement in the delivery of home and community based care with experience as: a social work professional delivering care in the home; national staff support to current Medicaid/Medicare providers in 36 states and dual demonstrations in 6 states; staff of a national payer (Blue Cross and Blue Shield) and a national accreditation body, JCAHO: and a Board member of the Community Health Accreditation Program. Over the past two years she have also added the experience of working with Interim Health's sister companies in Ireland, the UK, and Australia in operationalizing new regulation, including the use of standardized assessments to develop packages of community services delivered to the disabled and elderly, and directed by those individuals at their choice. She brings a breadth of national and international experience, as well as daily involvement with those delivering this care in a variety

of urban and rural communities.

Sarita Mohanty, MD, MPH, MBA

Sarita Mohanty is the Executive Director, Community-Clinical Care Integration for Kaiser Permanente, Northern California, with a focus on operations, strategy, and delivery of the social care services. Dr. Mohanty has over 15 years of experience in health care delivery, quality improvement, and health services research. From 2011-2014, Dr. Mohanty was the Senior Medical Director for LA Care Health Plan, where she was instrumental in the implementation of Long Term Services and Supports. Dr. Mohanty earned her BA from UC Berkeley, her MD from Boston University, and her MPH from Harvard University. In 2012, she obtained her MBA from UCLA's Anderson School.

Gerry Morrissey, M.Ed, MPA

Gerry Morrissey is Chief Quality Officer for The MENTOR Network, he has designed a quality improvement program that established a clear set of standards and expectations, increased capacity to monitor and report on key quality indicators, and directs quality improvement initiatives across all Network operations. As the Commissioner of the Massachusetts Department of Developmental Services, he led the design and implementation of a new client information system to enhance the capacity to use data for driving decisions and improving outcomes. As past president of the NASDDDS, he was engaged in the development of the National Core Indicators for IDD services.

Ari Ne'eman

Ari Ne'eman is the President and co-founder of the Autistic Self Advocacy Network. In 2009, President Obama nominated Ari to the National Council on Disability, a federal agency charged with advising the executive branch. He currently chairs the Council's Entitlements Committee. From 2010 to 2012, he served as a public member to the Interagency Autism Coordinating Committee, a Federal advisory committee that coordinates all efforts within HHS concerning autism. Ari also served as an adviser to the DSM-5 Neurodevelopmental Disorders Workgroup convened by the American Psychiatric Association.

Andrey Ostrovsky, MD

Andrey Ostrovsky is a practicing physician and social entrepreneur who leads Care at Hand's executive management and strategic vision. Dr. Ostrovsky has led teams at the World Health Organization, United States Senate, and San Francisco Health Department toward health system strengthening through technology. He has contributed to legislation at the city and national level to advance care delivery for vulnerable populations. He is a published researcher in public health informatics, quality improvement, healthcare innovation, social entrepreneurship, and care coordination.

Mike Oxford

Mike Oxford has been Executive Director of Topeka Independent Living Resource Center over 20 years. His experience with long term services & supports (LTS&S) ranges from direct support worker, to developing and providing innovative services, to using services. Programs Mike operates are known for innovation and quality and he has been very involved with policy and research over the past two decades. Recipient of a HCFA Director's Citation of Merit in for innovation and quality in LTS&S in 1997, Mike has presented on LTS&S and has served on many public and private research panels, forums and academic research projects.

Lorraine Phillips, PhD, RN

Lorraine Phillips' studies focus on the health and functioning of elders in long-term care settings, in particular, the role of late-life physical activity on disability progression. As a gerontological nursing educator, researcher, and clinician, she has expertise in care delivery in both home-based and institutional settings. Her work on the Aging-in Place (AIP) research team at the University of Missouri has involved longitudinal measurement of functional outcomes of TigerPlace senior housing residents as well as comparison of AIP costs to nursing home costs (1, 2, 3). She is also the principal investigator on a NIH-funded longitudinal study, Physical Activity and Disability in Residential Care/Assisted Living (RC/AL) Residents. Dr. Phillips prior research includes analysis of the Minimum Data Set to identify predictors of new depression and psychometric analysis of depression measures specific to persons with dementia. As a registered nurse from 1978 to 1993, she has worked in acute and tertiary care settings, including hospitals, offices, home care, and long-term care that includes assisted living. She practiced as a Family Nurse Practitioner from 1996 to 2010 within family, internal medicine, women's health, cardiology, and long-term care practices. Dr. Phillips has expertise in evidence synthesis, quantitative methods, and geriatric functional assessment.

Mary Smith, PhD

Mary Smith is the Associate Director of Decision Support, Illinois DHS Division of Mental Health with responsibility for developing/implementing policy regarding MIS design, performance measurement, and coordination of research/evaluation activities including MIS design/data analysis for the Williams vs. Quinn Olmstead Consent Decree. She is the principal investigator for a series of SAMHSA data infrastructure contracts, and a past chair of the MHSIP Policy Group, co-authoring the Mental Health Quality Report. She has provided consultation in the use of data for planning, performance measurement, and MIS implementation. Dr. Smith holds a Ph.D. in organizational/social psychology.

Anita Yuskauskas, PhD

Anita Yuskauskas has been appointed program coordinator and full-time instructor in Health Policy Administration and Rehabilitation and Human Services. She received her doctoral degree in rehabilitation from Syracuse University. She previously taught at the University of Delaware in Newark, and also served as Technical Director for Quality in Medicaid Home and Community Based Services with the Centers for Medicare and Medicaid Services. She also served as a liaison with American Indian-Alaska native tribes regarding HCBS issues. She was previously an Analyst at CMS involved with HCBS self-direction. Preceding her federal tenure, Anita served as a Division Chief in Hawaii's Department of Health, overseeing the developmental disabilities, Hansen's disease, and brain injury programs. She also served as Chief Policy Analyst for the Center for Outcome Analysis in Rosemont, Pennsylvania. She conducted numerous program evaluation and research projects specializing in organizational change, and taught undergraduate and graduate courses in human services and special education. Anita previously volunteered her time as an advisor for Speaking for Ourselves, a statewide self-advocacy organization in Pennsylvania, and is a trained mediator.

Home and Community-Based Services Quality

HHS ADVISOR BIOGRAPHIES

Ellen Blackwell, MSW

Ms. Ellen Blackwell is a geriatric social worker with a background in disability services. At CMS, she works on programs that impact quality, efficiency, accessibility, and beneficiary satisfaction that support better care, smart spending, and healthier people. She joined the Federal service in 2001 as a Presidential Management Fellow. Prior to joining CMS, Ms. Blackwell worked at The Horizon Foundation, a philanthropic organization that promotes local health and wellness. She interned as a graduate student at The Hilltop Institute, a health research center at the University of Maryland, Baltimore County, and at the Howard County Maryland Office on Aging. Ms. Blackwell founded the Howard County chapter of the Autism Society in 1992. She also self-directs the home and community-based services of an adult family member. Ms. Blackwell graduated from the University of Maryland - Baltimore, and the University of Wisconsin.

Jennifer Burnett, BA

Jennifer Burnett is the Director of the Division of Community Systems Transformation in the Disabled and Elderly Health Programs Group at the Centers for Medicare & Medicaid Services. Prior to her appointment at CMS in 2011, she served as the Deputy Secretary for Long-Term Living in Pennsylvania's Departments of Aging and Public Welfare, where she was responsible for overseeing long-term living programs for seniors and persons with disabilities. Earlier, she served as Chief of Staff in the Office of Long-Term Living and for 4 years in the Governor's Office of Health Care Reform, as the Strategic Operations Administrator for the Long-term Living project. Jen has been involved in systems change at the state and federal levels for more than three decades. Before her work in government, she built a successful consulting business, specializing in grant management, public relations and disability rights. Her clients included the Commonwealth of Pennsylvania, Statewide Independent Living Councils in Maryland and Pennsylvania, Speaking for Ourselves, the National Council on Independent Living, and the American Association of People with Disabilities. As Project Director of PA Transition to Home, a nursing home transition demonstration funded by Center for Medicare & Medicaid Services, she built and administered a program for Pennsylvania. The project has been rolled out statewide to become a program serving thousands of people. In 2012, Ms. Burnett (with others) was awarded the CMS Administrators Special Citation Award for her work on defining a set of principles for home and community-based services, and in 2013, she received the Key Executive Leadership in Government Certificate from American University.

Corette Byrd, MS

Ms. Corette Byrd is a nursing professional with over a decade of experience in leading and directing projects and programs, quality management, ensuring regulatory compliance, and developing national and local policies and procedures. In 2012, Ms. Byrd joined CMS to lead the "National Consensus Development and Strategic Planning for Healthcare Quality Measurement" portfolio of work. This work involves endorsing standardized health care performance measures, making recommendations on an integrated national quality strategy and priorities for healthcare

performance measurement, and convening multi-stakeholder groups for input on national priorities and the Secretary's selection of quality and efficiency measures. Prior to joining CMS, Ms. Byrd was a Senior Associate with the American College of Physicians (ACP) where she led various programs, developed policies related to the Patient-Centered Medical Home model of care, and represented senior leadership in a variety of forums. Prior to ACP, Ms. Byrd oversaw the quality, risk management, and corporate compliance areas at a large federally-qualified health center, Unity Health Care. Ms. Byrd has nursing experience in critical care, public health, and urgent care; and she continues practicing today. Additionally, Ms. Byrd holds national certifications in Healthcare Compliance and Healthcare Quality. Ms. Byrd holds degrees from The University of Alabama – Birmingham, Georgetown University, and George Mason University.

Venesa Johnson Day, MPA

Ms. Venesa Johnson Day is currently Technical Director with the CMS Office of Federally Coordinated Health Care (the Medicare-Medicaid Coordination Office or MMCO, leading the Office's quality efforts around improving care for Medicare-Medicaid Enrollees. In addition, she leads the Office's Managed Fee-For-Service Financial Alignment Demonstrations team. The Managed Fee-For-Service team is responsible for developing the policy and quality frameworks for demonstrations designed to provide better, more coordinated, more cost effective care for Medicare-Medicaid fee-for service beneficiaries. She has worked at CMS for 15 years in various areas including Medicaid financial management. In her previous role, Venesa served as the payment lead for Medicaid provider-preventable conditions policy working across Agency components on payment driven quality initiatives. Prior to coming to CMS Venesa worked for the Department of Labor, Bureau of Labor Statistics as a budget analyst. Venesa earned a BA in Political Science (International Relations and Policy) from Morgan State University, and an MPA from The American University.

Jamie Kendall, MPP

Jamie Kendall is currently the Acting Director, Independent Living at the Administration for Community Living, U.S Department of Health and Human Services. She also serves as the Director of the Office of Policy Analysis and Development, at the Center for Policy and Evaluation at the Administration for Community Living (ACL). Jamie began her federal career working at the Administration for Children and Families at HHS and has also worked at the Social Security Administration, developing policies for low income families and individuals with disabilities. She holds a Masters in Public Policy (MPP) from Georgetown University. She previously served as the Deputy Commissioner at the Administration on Intellectual and Developmental Disabilities (AIDD) between December 2010 – March 2013 where she provided leadership to the programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the Help America Vote Act.

Lisa Patton, PhD

Dr. Lisa Patton is a clinical psychologist and Chief of the Quality, Evaluation, and Performance Branch within the Center for Behavioral Health Statistics and Quality, SAMHSA. Dr. Patton serves as the quality and evaluation lead for the Center. Prior to joining SAMHSA, she worked in the Division of Aging, Long-term Care, and Policy within the office of the Assistant Secretary for Planning and Evaluation. Dr. Patton conducted mental health services research in the private sector for over a decade. She also worked in community mental health, working primarily with adult survivors of trauma and persons with serious mental illness. Throughout her career, her work has focused on ensuring that vulnerable populations receive services.

D.E.B. Potter, MS

Ms. D.E.B. Potter has worked for the U.S. Department of Health and Human Services (HHS) for

over 25 years. Her work focuses on improving the measurement of vulnerable populations including the disabled, frail elders, persons needing long-term services and supports (LTSS), and behavioral health (BH) care. Efforts include quality measures development; data collection and instrument design; measuring health care use and quality; and estimation issues involving persons that use institutional and home and community-based services (HCBS). For over 20 years with the Agency for Healthcare Research and Quality (AHRQ), she is now a Program Analysts with the HHS's Office of the Secretary, Assistant Secretary for Planning and Evaluation (ASPE). She currently leads an ASPE, AHRQ and Centers for Medicare & Medicaid Services (CMS) joint project to develop risk adjustment methods for quality measures for HCBS populations. Other responsibilities include managing the development of BH quality measures and advancing quality measurement for the population with dementia. While at AHRQ she oversaw AHRQ's work in response to the Deficit Reduction Act to develop quality measures for the HCBS population and AHRQ's Assisted Living Initiative. Ms. Potter currently serves on numerous Technical Expert Panels (TEP) and across Agency workgroups including the HHS Liaison Group that oversees the current National Quality Forum HCBS measures project, the Measure Applications Partnership (MAP) Duals Eligible Workgroup, the HHS Committee for the Consensus-Based Entity, CMS's HCBS Experience with Care Survey, and on the National Advisory Panels for AARP's State Scorecard for LTSS, and the National Long Term Quality Alliance (LTQA). In 2002, she (with others) received HHS Secretary's Award "for developing and implementing a strategy to provide information the Department needs to improve long-term care."

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

Committee Web Meeting

February 20, 2015

NATIONAL QUALITY FORUM

Welcome

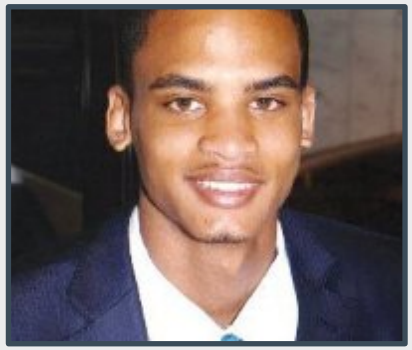
NQF Project Staff

Wendy Prins, MPH, MPT

Vice President

Sarah Lash, MS

Senior Director



Andrew Anderson, MHA

Project Manager

Nadine Allen, MEd

Project Analyst

Juliet Feldman

Project Manager

HHS Project Team

- Jamie Kendall, ACL
- Coretté Byrd, CMS
- Ellen Blackwell, CMS
- Jennifer Burnett, CMS
- Venesa Day, CMS
- D.E.B. Potter, ASPE
- Lisa Patton, SAMHSA

Biosketches of the HHS Team and Committee members are in your meeting materials.

Introductions and Disclosure of Interests

HCBS Quality Committee

Please introduce yourself by describing why this work is important to you.

- Joe Caldwell (Co-Chair)
- Stephen Kaye (Co-Chair)
- Robert Applebaum
- Kimberly Austin-Oser
- Suzanne Crisp
- Jonathan Delman
- Camille Dobson
- Sara Galantowicz
- Ari Houser
- Patti Killingsworth
- Charlie Lakin
- Clare Luz
- Sandra Markwood
- Barbara McCann
- Sarita Mohanty
- Gerry Morrissey
- Ari Ne'eman
- Andrey Ostrovsky
- Mike Oxford
- Lorraine Phillips
- Mary Smith
- Anita Yuskauskas

Webinar Objectives

- Build a shared understanding of the project objectives, activities, and the committee's role
- Introduce foundational information about quality measurement
- Begin to gather committee input in the development of an operational HCBS definition and conceptual measurement framework
- Request relevant sources for ongoing evidence synthesis and environmental scan of measures

Project Overview

Why Measure Quality of HCBS?

- Home and community-based services (HCBS) are critical to promoting independence, wellness, and self-determination for people with long-term care needs
  - Most people prefer to live in community-based settings
  - Examples of HCBS services include personal care, supported employment, and family caregiver supports
- States continue to shift resources from institutional care to HCBS
- Outlays for HCBS constitute nearly half of Medicaid's long-term care expenditures
  - Beyond Medicaid, HCBS are also provided for by other federal agencies, a significant "private pay" market, and informal supports of family members and friends

HCBS Quality

- A high-quality HCBS system is needed to support older adults, people with multiple chronic conditions, and people with disabilities of all ages
- Established frameworks and quality domains for evaluating long-term supports and services (LTSS) and HCBS exist
- Availability and uptake of performance measures remains limited and lacks uniformity across states and other accountable entities (e.g., providers, managed care organizations)

Measuring HCBS Quality Project

Provide multistakeholder guidance on the highest priorities for measurement of home and community-based services that support high-quality community living

- Offers an opportunity to address the gaps in HCBS measurement and provide direction for future performance measurement
- Supports the aims of the Affordable Care Act, the National Quality Strategy, and HHS' Community Living Council
- Will maintain a broad and inclusive orientation to community living and maximize opportunities for public input

Project Components

Under contract with the Department of Health and Human Services (HHS), this two-year project will entail:

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 framework and scan
4. Making recommendations for HCBS measure development

Project Components

This project will NOT:

- Emphasize a clinical point of view
  - The medical system is measuring itself. Healthcare can be an important part of good person-centered care and outcomes, but our emphasis is on how to measure the other supports and services that enable community living
- Review specific measures for NQF-endorsement
  - While the committee may identify measures or quality improvement strategies it would like to promote, endorsement review is conducted through a separate formal process

Committee Role

- Contribute content knowledge and expertise over the course of the project
- Ensure input is obtained from relevant stakeholders
- Assist with the identification of existing research, measures, and resources to identify performance measure needs
- Work together as a group to craft consensus on complex issues
- Ultimately, make recommendations for the future state of HCBS quality measurement, including measure development

Project Meetings

Activities	Dates
Committee web meeting	February 20, 2015, 12-2pm ET
In-Person Committee meeting (2-day)	April 29-30, 2015
Committee web meeting	September 2015
In-Person Committee meeting (2-day)	March 2016
Public webinar	July 2016

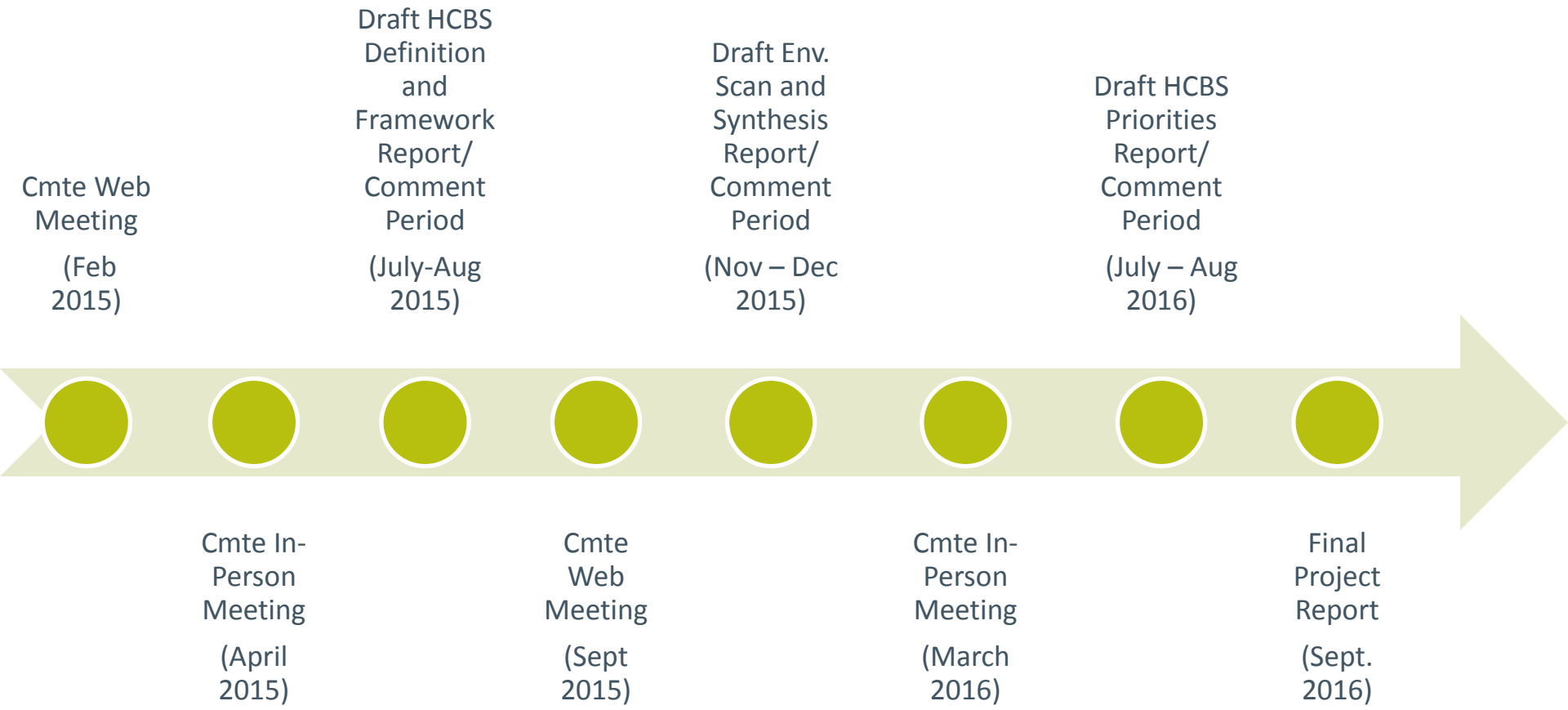
All meetings are open to the public and NQF members
Meetings are webcast and recordings are posted on the project page.

Project Reports and Public Comment Periods

Reports	Due Dates
Draft Report: Operational Definition and Draft Conceptual Framework for HCBS Performance Measurement	July 15, 2015
Draft Report: Environmental Scan of Measures and Synthesis of Evidence for HCBS	November 15, 2015
Draft Report: Recommendations on HCBS Measure Concepts for Translation and Advancing Measurement	July 15, 2016
Final Report: Recommendations on Addressing Performance Measure Gaps in HCBS to Support Community Living Quality	September 4, 2016

Public comment periods (30-day) to follow each draft report

Project Timeline 2015-2016



Q&A Session

“Crash Course” in Quality Measurement

The Measurement Imperative

Not everything that counts can be counted, and not everything that can be counted counts

But….

You can't improve what you don't measure

National Quality Strategy

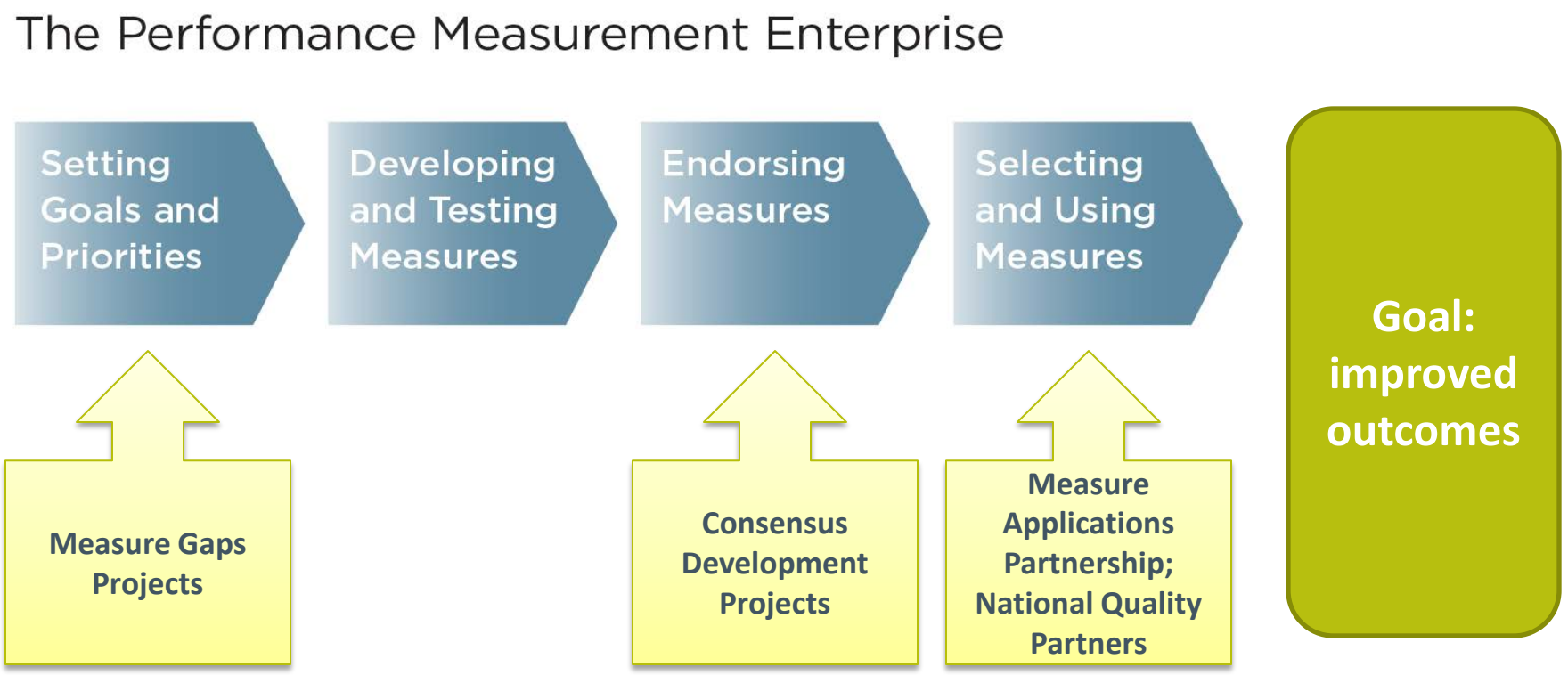
National Quality Forum (NQF)

NQF work catalyzes healthcare improvement & innovation

- **Gold Standard for Quality**—selects & endorses best healthcare quality measures
- **An Essential Forum**—420 organizational members and more than 800 volunteer leaders that span healthcare
- **Quality Leadership**—convenes private and public sector leaders to reach consensus on complex issues

This project on HCBS is NQF's most significant foray into non-medical services to date

NQF and Measurement



Why Measure?

For many reasons, including:

- Measures drive improvement.
- Measures inform consumers and other stakeholders.
- Measures influence payment.

It's important to keep performance measurement in context – measurement is not an end in itself.

What is a measure?

Meas•ure

n. A standard: a basis for comparison; a reference point against which other things can be evaluated; “they set the measure for all subsequent work.”

v. To bring into comparison against a standard.

A performance measure is a way to calculate whether and how often the system does what it should.

Components of a Measure

- The result of a measure is usually shown as a ratio or a percentage.
- Performance measures ***allow for comparison*** to other entities and benchmarking

Numerator - # of consumers with a person-centered plan of care
Denominator - # of consumers enrolled in a program

- Not every number is a measure. Performance measures are NOT:
  - Raw counts or totals (e.g., Agency ABC provided 15,000 hours of personal care services)
  - Point-in-time assessment results (e.g., Ms. Smith needs assistance with three ADLs)

Types of Quality Measures

- **Structure**

  Features of a organization or provider relevant to capacity or capabilities. This may include, but is not limited to, measures that address health IT infrastructure, provider capacity, systems, and other infrastructure supports.

- **Process**

  Measures whether an action was completed on behalf of a consumer – such as writing a prescription or providing a particular type of counseling.

- **Outcome**

  Takes stock not of the processes, but of the actual results of the care or services received - such as experience of care or quality of life.

- **Composite**

  - Combine the result of multiple performance measures to provide a more comprehensive picture of quality.

Person-reported (also known as patient-reported) Outcomes and Measurement

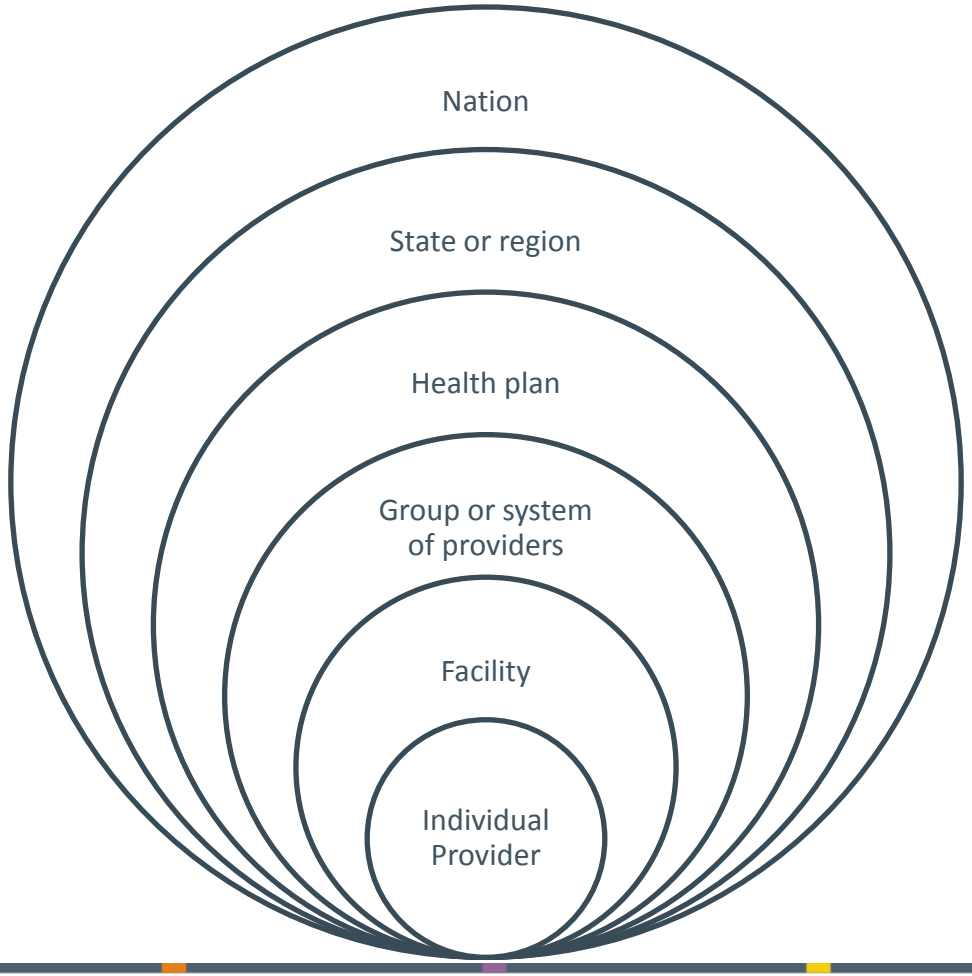
Consumers are often the best source of information on outcomes. This data can be used as the basis for measures.

- **Person-reported outcome (PRO)**: information about the consumer, as communicated by that person
- **PRO measure (PROM)**: an instrument, scale, or single-item measure that gathers the information directly from the consumer
- **PRO-based performance measure (PRO-PM):** a way to aggregate the information that has been shared by the consumer and collected into a reliable, valid measure of system performance.

PRO, PROM, PRO-PM

Concept	Patients with Clinical Depression	Persons with Intellectual or Developmental Disabilities
PRO (person-reported outcome)	Symptom: depression	Functional Role: employment
PROM (instrument, tool, single-item measure)	PHQ-9©, a standardized *tool* to assess depression	Single-item measure on National Core Indicators Consumer Survey: *Do you have a job in the community?*
PRO-PM (PRO-based performance measure)	Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711)	The proportion of people with intellectual or developmental disabilities receiving HCBS who have a job in the community

Who Can Be Measured?
Levels of Analysis



How Measures Drive Change: Accountability Programs

Accountability programs tie rewards to performance on quality measures.

- When incentives such as payment , reputation, and market competition are on the line, measurement programs have more impact and also come under more scrutiny.
- **Private reporting**: sharing results with internal stakeholders only, such as within a state Medicaid agency
- **Public reporting**: sharing results with the general public, such as through a website or printed report.
- **Performance-based payment**: payment for services that is contingent on performance measurement results.

Q&A Session

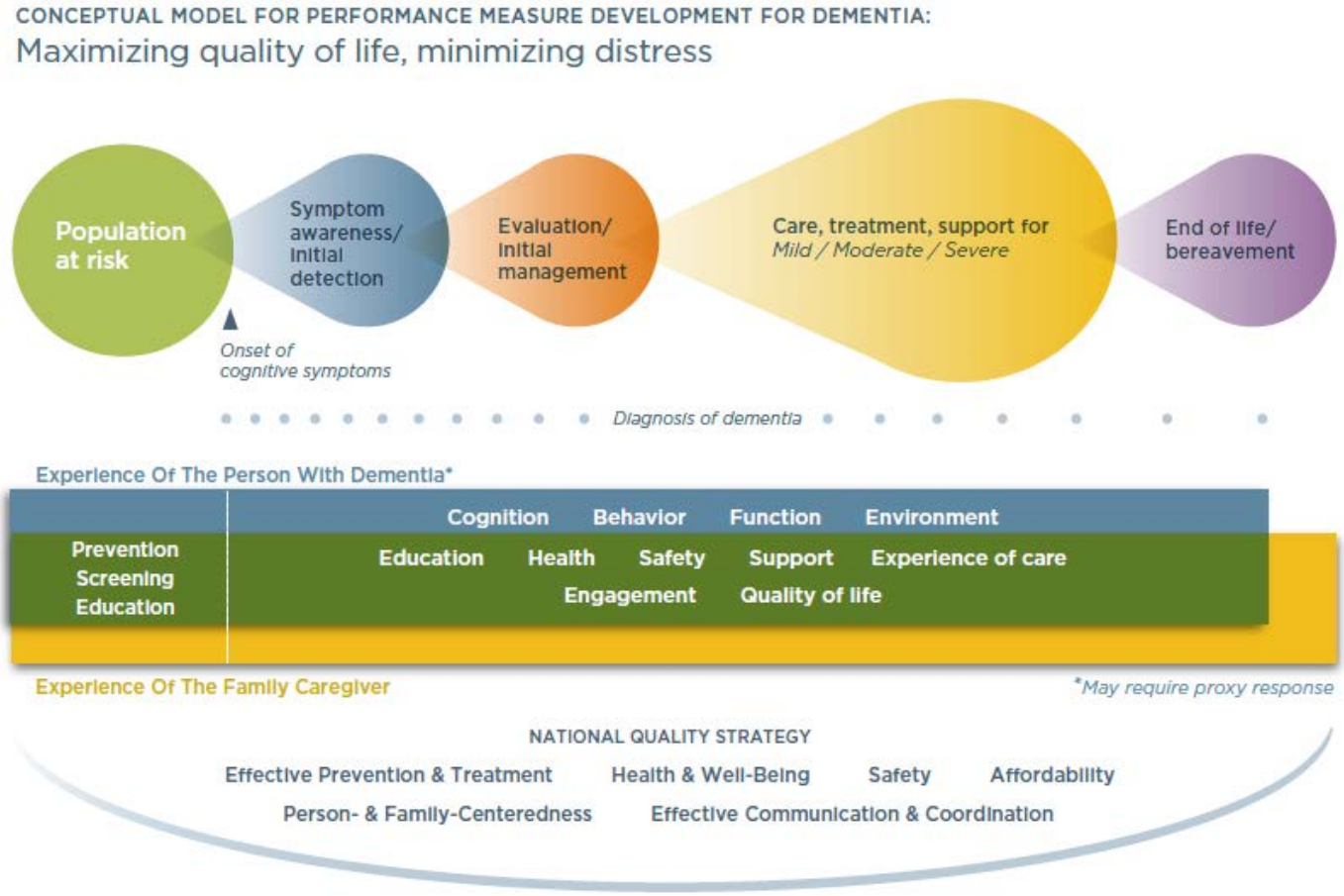
Opportunity for Public Comment

Crafting a Definition and Conceptual Framework for HCBS Measurement

Definition and Conceptual Framework

- Committee to develop and use a conceptual measurement framework to prioritize measurement needs
- To assist in the framework development, Committee will create a broadly applicable definition of HCBS for purposes of this project
  - Definition and framework can be adapted from an existing source or created *de novo*
- Development will be iterative with multiple opportunities for Committee and public input
  - Draft Operational Definition and Conceptual Framework Report due July 15, 2015 (30-day public comment period to follow)

Example Conceptual Framework



Evidence Review To-Date

- The definition is the first component of the broader framework.
- The project's definition is not meant to replace any existing regulations or guidance
- To support creation of the project-specific definition, NQF staff reviewed approximately 200 sources for definitions and frameworks related to HCBS.
- 27 definitions related to HCBS or LTSS were identified
  - List of definitions included in meeting materials

Definition Approach: What Should it Include?
Common Threads in Existing Definitions

Goals of HCBS	HCBS Population	Types of Services
• Allows recipients to remain in a non-institutional setting • Fosters independence, autonomy, self-determination and participation in community life • Enhances well-being and quality of life	• People who experience functional limitations or other challenges participating in community life • Older adults and people with disabilities	• Personal assistance or personal care • Assistance with ADLs and/or IADLs • Respite care for caregivers • Case management

Existing definitions have been developed for specific purposes – like research or program regulation. None translate directly to this work but components can provide a starting place.

Additional Context:
HCBS Definition from CMS Final 1915(i), (c), and (k) Regulations

- For purposes of the Medicaid program, an HCBS setting is defined as having the following qualities (abbreviated):
  - 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 service and supports, including who provides them

http://www.ecfr.gov/cgi-bin/retrieveECFR?gp=1&SID=dd23c612cc3ff5391169388fb5749c0b&ty=HTML&h=L&n=pt42.4.441&r=PART#sp42.4.441.g

Definition Approach: How Should the Definition Work?

- Allow the committee to reach a common understanding of what is meant by the term "HCBS"
- A brief but broadly inclusive statement that emphasizes the goals of HCBS
- Positive in tone, plain-language
- A definition that can be used across public and private payers and accountable entities
- Contribute to an understanding of *high quality* HCBS as part of the conceptual framework
  - Person-centered, enhances quality of life, shared responsibility, accessible, flexible, coordinated, integrated, enables self-determination
- Project-specific: not meant to replace existing guidance or regulations
- To maximize applicability, avoid a laundry list of services, specific consumer populations or settings

Committee Discussion

- Do you agree with this approach to developing a definition of HCBS? Why or why not?
- Are any important components or considerations missing?

- Please send us *your* draft definition by next Friday, February 27
  - Aim for fewer than 100 words
  - hcbs@qualityforum.org
- NQF team will combine your ideas and this discussion to craft a working draft for the April meeting.

Other Context:
Features of a High-Quality LTSS System

- Promotes community living
- Equitable
- Economically sustainable yet able to meet demand
- Fosters independence and self-determination
- Consumers have choice and control over their services
- Support for paid and family caregivers
- Measures outcomes related to services and consumers' quality of life
- Others?

Committee Discussion

- Questions for exploration during the project:
  - What should quality measurement accomplish in the HCBS system?
  - How does this project need to take into consideration the broader LTSS system?
  - What entities and/or relationships does the conceptual framework need to represent?
- What other definition or framework sources should this project review?

Opportunity for Public Comment

Looking Ahead to April In-Person Meeting and Next Steps

Preliminary Objectives for April 29-30 In-Person Meeting

- Discuss and finalize operational definition and framework domains and subdomains
- Continue discussions of priorities for the framework
- Receive guidance on scoping the environmental scan and potential measure concepts
- Identify potential challenges and barriers to be addressed (e.g., related to existing evidence base, measure development, data collection) for further exploration and discussion

Next Steps

- Submit your draft definition by the end of next week
- Send the team additional resources related to:
  - Operational definition and conceptual framework
  - Evidence synthesis and environmental scan of measures
- Prepare for April in-person meeting
  - Follow-up related to definition and framework
  - Travel logistics memo to be sent in March

Adjourn

Thank you for participating!

National Quality Forum: Measuring HCBS Quality

Existing Definitions of HCBS and LTSS

Source #	Source Title and Organization	Definition	Applicability Ranking
104	AARP Public Policy Institute/The Hilltop Institute's discussion paper. Characteristics of a high-performing long-term care system.	The ultimate goal of a long-term care (LTC) system is to enhance the well-being and quality of life of individuals who experience functional limitations because of chronic conditions, illness, injury, or other causes of disability.	HIGH
107	AARP, The Commonwealth Fund, and The SCAN Foundation's "Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers" – 2014	Long-term services and supports (LTSS) may involve, but are distinct from, medical care for older people and adults with disabilities. Definitions of the term vary, but in this report we define LTSS as: > Assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) provided to older people and other adults with disabilities who cannot perform these activities on their own due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically 90 days or more. > LTSS include human assistance, supervision, cueing and standby assistance, assistive technologies and devices and environmental modifications, health maintenance tasks (e.g., medication management), information, and care and service coordination for people who live in their own home, a residential setting, or a nursing facility. LTSS also include supports provided to family members and other unpaid caregivers. > Individuals with LTSS needs may also have chronic conditions that require health or medical services. In a high-performing system, LTSS are coordinated with housing, transportation, and health/medical services, especially during periods of transition among acute, post-acute, and other settings. > For the purpose of this project, people whose need for LTSS arises from intellectual disabilities (ID) or chronic mental illness (CMI) are not included in our assessment of state performance. The LTSS needs for these populations are substantively different than the LTSS needs of older people and adults with physical disabilities. Including services specific to the ID and CMI populations would have required substantial additional data collection, which was beyond the scope of this project. 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	HIGH

*HCBS definitions highlighted in yellow.

National Quality Forum: Measuring HCBS Quality

Existing Definitions of HCBS and LTSS

Source #	Source Title and Organization	Definition	Applicability Ranking
196	CMS Final 1915(i) regulation	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	HIGH
119	Center for Personal Assistance Services at the University of California San Francisco selected quality of life measures for measuring consumers' personal experiences	The proper goal of LTSS programs is not merely to ensure survival, or to reduce institutionalization (for community-based programs) or hospitalization, but also to foster as much independence, self-determination, and participation in community life as possible. To ensure that these goals are not forgotten as the transition to managed LTSS proceeds, oversight must include not only monitoring outcomes specifically related to services received, but also more general measures of consumers' personal experiences, or what might be termed their quality of life (QOL). "	HIGH
148	Kaye, H. S. (2014) Toward a Model Long Term Services and Supports System: State Policy Elements. Gerontologist.	A model system of long-term services and supports (LTSS) could be characterized as one that promotes community living over institutionalization, integration over segregation, and full social participation over isolation (Commission on Long-Term Care, 2013; Harkin, 2013). Such a system should be equitable across age groups, disability categories, and other individual characteristics, economically sustainable yet generous enough to reasonably meet demand, and targeted broadly to include all people at risk of institutionalization, isolation, or functional decline in the absence of services (AARP, 2013). It should promote independence and autonomy, offering people the desired level of control over their services, and support in handling that responsibility (AARP, 2013; NCD, 2005). Family caregivers should be supported, and workers providing paid services should be given decent jobs and offered training to provide stable, reliable, respectful, and high-quality services (Commission on Long-Term Care, 2013; NCD, 2005). Finally, the entire LTSS system should be accountable through measurement and reporting of quality and outcomes, including indicators of expenditures, utilization, health status, and consumer quality of life, participation,	HIGH

*HCBS definitions highlighted in yellow.

Source #	Source Title and Organization	Definition	Applicability Ranking
		and satisfaction (AARP, 2013; DREDF & NSCLC, 2013).	
149	Kaye, H.S., Harrington, C. (2015) Long-term services and supports in the community: Towards a research agenda. Disability and Health Journal.	Long-term services and supports (LTSS) comprise the personal assistance, technology, and health care-related services needed by people who are unable to perform routine daily activities without assistance. National surveys indicate that as many as 12 million Americans get help from others in either activities of daily living (ADLs, such as bathing, dressing, and eating) or instrumental activities of daily living (IADLs, such as preparing meals, shopping, and managing money). LTSS can be provided in nursing homes and other institutional settings or in community settings, such as private homes, group homes, and assisted living facilities. The vast majority of those needing LTSS live in the community (about 10 million people), and roughly half are under age 65.LTSS received in the person's home, a day health or activity center, or some other non-institutional setting are often known as home- and community-based services (HCBS), especially when those services are provided through government programs	HIGH
198	Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much? H. Stephen Kaye, Charlene Harrington, Mitchell P. LaPlante. Health Affairs. January 2010	"Long-term care provided outside of institutions, known as personal assistance services, personal care services, or home and community-based services, also enables many people with disabilities to maintain their independence; avoid institutionalization; and participate in family, community, and economic activities." Article presents three tiers of population estimates based on the level of identified need. > The broadly defined long-term care population needs help with one or more ADLs or IADLs. > The intermediate long-term care population is composed of people needing ADL help > The narrowly defined long-term care population includes people needing help with two or more ADLs (for example, bathing and dressing together, but not bathing alone)	HIGH
195	Medicaid– Home & Community Based Services	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.	HIGH
11A	Long-Term Care: Status of Quality Assurance and Measurement in Home and	"Health, personal care and social services provided over a sustained period to persons who live outside of congregate residential settings and who have lost some	HIGH

*HCBS definitions highlighted in yellow.

Source #	Source Title and Organization	Definition	Applicability Ranking
	Community-Based Services. (1994) United States Government Accountability Office.	capacity for self-care because of a chronic condition or illness. These services include a broad range of supports, from skilled nursing services to assistance with basic activities of daily living (ADIS) (such as bathing, toileting, and dressing) and help with instrumental activities (such as shopping, meal preparation, housekeeping, and laundry). The services may be provided singly, by one or more providers, or in combination, as when a home health aide provides incidental assistance with ADLS."	
11E	Long-Term Care: Implications of Supreme Court's Olmstead Decision Are Still Unfolding. United States Government Accountability Office. Allen, K (2001)	"HCBS provided under what is called the 1915(c) waiver program includes a broad range of services such as case management, homemaker, home health aide, personal care, adult day health, respite care, and, for individuals with chronic mental illness, outpatient clinic services."	HIGH
12	The Home and Community-Based Service (HCBS) Experience Survey Part A. CMS (2012)	"Home and community-based services (HCBS), enable chronically ill and disabled Medicaid beneficiaries to receive care at home instead of being institutionalized." Continuation: "HCBS programs serve beneficiaries with a broad range of severe physical, mental, and developmental conditions, through a wide array of providers. These long-term care services complement acute-care services, to maintain individual health and quality of life and enable this population to live in the community rather than an institution."	HIGH
21	Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care. Minnesota Evidence-based Practice Center, Wysocki, A (2012)	"LTC spans three realms: (1) assistance with essential, routine activities such as eating, bathing, dressing, and tasks required to maintain independence, such as preparing meals, managing medications, shopping for groceries, and using transportation; (2) housing; and (3) medical care. Often, LTC is associated with institutional settings such as nursing homes (NHs). However, LTC is also provided in a variety of non-institutional settings collectively referred to as Home and Community-Based Services (HCBS)." Continued: "Care through HCBS may be provided in a variety of settings, including recipients' homes; group living arrangements such as congregate housing, adult foster care, residential care (RC) and assisted living (AL) facilities (the last two terms are often used interchangeably although they are not always synonymous—we use the term AL throughout this report); and community settings such as adult daycare and adult day health. Services provided via HCBS may include care coordination or	HIGH

*HCBS definitions highlighted in yellow.

Source #	Source Title and Organization	Definition	Applicability Ranking
		case management, personal care assistant service, personal attendant service, homemaker and personal care agency services, home hospice, home-delivered meals, home reconfiguration or renovation, medication management, skilled nursing, escort service, telephone reassurance service, emergency helplines, equipment rental and exchange, and transportation. HCBS also include educational and supportive group services for consumers or their families. Some services provided through HCBS are construed as respite care meant to relieve family caregivers."	
111	Bipartisan Policy Center – America's LTC Crisis, Challenges in Financing and Delivery (2013). (Definition taken from HCBS settings rule)	HCBS are defined as those services delivered outside of an institutional setting, which could include the beneficiary's home, a caregiver's home, or an assisted living facility.	MEDIUM
194	Home and Community-Based Long-Term Services and Supports for Older People Fact Sheet, AARP Public Policy Institute	The term "home and community-based long-term services and supports" (HCBS) refers to assistance with daily activities that generally helps older adults and people with disabilities to remain in their homes.	MEDIUM
20	Development of Quality Indicators for the Home and Community-Based Services Population: Technical Report. Center for Primary Care and Outcomes Research, Shultz, E (2012)	"HCBS programs allow states to provide long-term supports and services to Medicaid beneficiaries in a home or community setting rather than an institutional setting. For the purposes of this project, HCBS is defined broadly to include the array of long-term care services that could be provided by Medicaid as HCBS. This includes 1915 (c) waiver services and state plan services such as home health care, personal care services, and case management. Such services may be provided by a variety of state administering agencies, not just Medicaid."	MEIDUM
50	Medicaid.gov:1915(c) Home & Community-Based Waivers. CMS	"The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community."	MEDIUM

*HCBS definitions highlighted in yellow.

National Quality Forum: Measuring HCBS Quality

Existing Definitions of HCBS and LTSS

Source #	Source Title and Organization	Definition	Applicability Ranking
8	Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act ,DHHS, Sibelius, K. (2014)	"Home and community-based services (HCBS) are services and supports that assist older adults and people with disabilities (including mental health and substance use disorders) to live with dignity and independence in community settings. "	MEDIUM
11D	States' Plans to Pursue New and Revised Options for Home- and Community-Based Services. United States Government Accountability Office, 2012	"Home- and community-based services (HCBS) cover a wide range of services and supports to help individuals remain in their homes or live in a community setting, such as personal care services to provide assistance with ADLs or IADLs, assistive devices, respite care for care givers, and case management services to coordinate services and supports that may be provided from multiple sources."	LOW
19	Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services. Thomson Healthcare. Sara Galantowicz (2010)	This source does not contain a definition of HCBS. Peripherally relevant: "used a very broad definition of HCBS services and populations, including populations such as adults with severe and persistent mental illness who are not traditional recipients of Medicaid HCBS". 21 constructs were identified among 3 domains: client functioning, client satisfaction, and program performance.	LOW
22	Assessing the Health and Welfare of the HCBS Population. Agency for Healthcare Research and Quality (AHRQ) (2012).	HCBS may be offered through Medicaid State plans or through a waiver of the established Medicaid requirements. States may offer a number of different HCBS waiver plans, and HCBS waiver plans may fall under different waiver types, which are referred to by the section of the Social Security Act that is being waived: • Section 1915(c) waivers allow States to provide long-term care services in home- and community-based settings. Most HCBS-relevant waivers are Section 1915(c) waivers. • Section 1115 waivers allow States to test broad and diverse changes to Medicaid requirements, such as limiting choice of provider through mandatory enrollment in managed care. They are less likely to be directly relevant to HCBS, but some States use Section 1115 waivers to cover long-term care under a managed care model. • Section 1915(b/c) waivers allow States to enroll beneficiaries in a mandatory managed care program that includes HCBS waiver services. Only a few States have Section 1915(b/c) waivers.	LOW

*HCBS definitions highlighted in yellow.

Source #	Source Title and Organization	Definition	Applicability Ranking
		(peripherally relevant)	
23	Transitions From Medicare-Only to Medicare-Medicaid Enrollment. Mathematica Policy Research. Borck, R (2014)	This source does not contain a definition of HCBS. Peripherally relevant: defined HCBS users to include individuals enrolled in a Section 1915(c) waiver, which allow states to offer HCBS to targeted groups of Medicaid enrollees with demonstrated need for these services, or with Medicaid claims for HCBS, including services provided through a state plan and services provided under a waiver	LOW
25	An Investigation of Interstate Variation in Medicaid Long-Term Care Use and Expenditures Across 40 States in 2006. Mathematica Policy Research. Wenzlow, A (2013)	This source does not contain a definition of HCBS. Peripherally relevant: defined HCBS to include services covered under Section 1915(c) waivers and personal care, residential care, home health care, adult day care, and private duty nursing services that are mandatory or provided at state option outside of waiver programs. Institutional care includes nursing home care, ICFS/IID care, inpatient psychiatric services for people under age 21, and psychiatric hospital services for those 65 and older.	LOW
47	Medicaid.gov: Quality of Care Home and Community-Based Services (HCBS) Waivers.	This source does not contain a definition of HCBS. Peripherally relevant: Definition of 1915(c) Home & Community-Based Waivers: The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.	LOW

*HCBS definitions highlighted in yellow.

NQF Resources

- "Priority Setting for Healthcare Performance Measurement: Health Workforce, Care Coordination Between Primary Care Settings and Community, Person-Centered Care and Outcomes, and Alzheimer's Disease and Related Dementias" reports (2014)
- Behavioral health measure endorsement
- Pertinent work of the Measure Applications Partnership (MAP) Coordinating Committee including the work of its Dual Eligible Beneficiaries Workgroup (e.g.) "Measuring Healthcare Quality for the Dual Eligible Beneficiaries Population" reports (2012; 2014)
- "Patient-Reported Outcomes in Performance Measurement" report (2012)
- "Multiple Chronic Conditions Measurement Framework" report (2012)
- NQF's portfolio of endorsed measures
- Previously conducted environmental scans by NQF, particularly the scans done as part of NQF's 2013-2014 measure gaps work

HHS Resources

- Any public-facing Departmental strategy for Community Living that comes to light during the course of the scan
- 2014 Annual Report on the Quality of Health Care for Adults Enrolled in Medicaid", Nov. 19, 2014 http://www.medicaid.gov/medicaid-chip-program-information/by-topics/quality-of-care/downloads/2014-adult-sec-rept.pdf
- HHS Measure Inventory
- CMS Measure Inventory
- HHS Office of the Inspector General work on HCBS provided through the Medicaid program
- HHS Guidance on section 2402(a) of the Affordable Care Act – http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf
- HHS National Alzheimer's Plan
- HHS Multiple Chronic Conditions Strategic Framework
- Government Accountability Office reviews of HCBS provided through the Medicaid program
- HCBS experience of care survey (CAHPS-like survey in development)
- Administration for Community Living (2014). *Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act: Standards for Person-Centered Planning and Self-Direction in Home and Community Based Services Programs.* http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf
- ACL National Family Caregiver Support Program resources: http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/index.aspx
- ACL/AoA's National Survey of Older Americans Act Participants (NSOAAP)
- Aging & Disability Resource Center (ADRC) Technical Assistance Exchange (TAE) at http://www.adrc-tae.acl.gov/tiki-index.php?page=HomePage
- Agency for Healthcare Research and Quality (AHRQ). *Developing Quality of Care Measures for People with Disabilities: Summary of Expert Meeting, 2010*. Available at: http://www.ahrq.gov/research/findings/final-reports/devqmdis/index.html
- AHRQ's National Quality Measures Clearinghouse and National Guidelines Clearinghouse
- AHRQ's "Coordinating Care in the Medical Neighborhood: Critical Components and Available Mechanisms" (2011)

- AHRQ efforts in support of Deficit Reduction Act of 2005 directing AHRQ to develop measures of program performance, client functioning, and client satisfaction with HCBS under Medicaid, and to further assess the health and welfare of HCBS persons (three sets of resources):
    - Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services, 2010, by Thomson Healthcare (Truven Health Analytics):
        - Scan Methodology
        - Environmental Scan (Table of Contents to Document)
        - Tables of Tested Measures Identified Meeting Threshold Criteria: Part 1, 2, and 3
        - Details of individual measures
    - Development of Quality Indicators for the Home and Community-Based Services Population: Technical Report, 2012, by Stanford University (on the quality indicators developed for the HCBS population)
        - Appendix 1A (Review of the Literature)
        - Appendix 1B (Expert Panel Calls)
- AHRQ's "Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care" (2012)
- Assessing the Health and Welfare of the HCBS Population Findings Report, 2012 (using the quality indicators developed; Table of Contents to AHRQ report)
- ASPE Transitions from Medicare-Only to Medicare-Medicaid Enrollment paper, 2014. The ASPE Disability, Aging and LTC Policy publications are at: http://aspe.hhs.gov/office_specific/daltcp.cfm.
- ASPE Paper – Evaluating PACE: A Review of the Literature, 2014. The ASPE Disability, Aging and LTC Policy publications are at: http://aspe.hhs.gov/office_specific/daltcp.cfm.
- ASPE 40 State Medicaid Use/Expenditures Report, 2013. The ASPE Disability, Aging and LTC Policy publications are at: http://aspe.hhs.gov/office_specific/daltcp.cfm.
- ASPE paper: Informal caregiving for Older Americans: http://aspe.hhs.gov/daltcp/reports/2014/NHATS-IC.cfm
- ASPE paper: "Quality in Managed Long-Term Services and Supports Programs" http://aspe.hhs.gov/daltcp/reports/2013/LTSSqual.shtml
- ASPE paper: "Environmental Scan of MLTSS Quality Requirements in MCO Contracts" http://aspe.hhs.gov/daltcp/reports/2013/MCOcontr.shtml
- ASPE paper: "Did They or Didn't They?: A Brief Review of Service Delivery Verification in MLTSS" http://aspe.hhs.gov/daltcp/reports/2013/verifyRB.shtml
- ASPE paper: "Addressing Critical Incidents in the MLTSS Environment: Research Brief" http://aspe.hhs.gov/daltcp/reports/2013/CritIncidRB.shtml
- ASPE paper - *A Primer on Using Medicaid for People Experiencing Chronic Homelessness and Tenants in Permanent Supportive Housing* http://aspe.hhs.gov/daltcp/reports/2014/PSHprimer.pdf
- ASPE's Improving Employment Outcomes for People with Psychiatric Disorders and Other Disabilities, April 2014
- ASPE's Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends, April 2014
- ASPE's Support and Services at Home (SASH) Evaluation: First Annual Report, Sept. 2014
- "Long-Term Services and Supports: An Overview," to the National Advisory Council on Alzheimer's Research, Care, and Services, 10/27/14; contains updated stats from the 2011 National Health and Aging Trends Study, at http://aspe.hhs.gov/daltcp/napa/102714/Mtg14-Slides1.pdf

- ASPE paper - *Medicaid and Permanent Supportive Housing for Chronically Homeless Individuals: Emerging Practices From the Field* http://aspe.hhs.gov/daltcp/reports/2014/EmergPrac.pdf
- ASPE's "Performance Measures in MLTSS Programs" research brief (2013)
- ASPE paper – Seniors and Service Demonstration design
- ASPE paper – Picture of Housing and Health
- Additional ASPE materials on homelessness: Literature and Environmental Scan (2011), Issue Papers Examining Medicaid and PSH (2012): Issue Paper 1: Health, Housing, and Service Supports for Three Groups of People Experiencing Chronic Homelessness, Issue Paper 2: Medicaid Financing for Services in Supportive Housing for Chronically Homeless People: Current Practices and Opportunities, Issue Paper 3: Establishing Eligibility for SSI for Chronically Homeless People, Issue Paper 4: Public Housing Agencies and Permanent Supportive Housing for Chronically Homeless People - documents available at www.hhs.gov/homeless
- Understanding Medicaid Home and Community Services: A Primer, 2010 Edition, on the ASPE web site at http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm
- ASPE paper - *How Have Long-Term Services and Supports Providers Fared in the Transition to Medicaid Managed Care? A Study of Three States*, available at: http://aspe.hhs.gov/daltcp/reports/2013/3LTSStrans.pdf
- ASPE paper - *Participant-Directed Services in Managed Long-Term Services and Supports Programs: a Five State Comparison*, available at: http://aspe.hhs.gov/daltcp/reports/2013/5LTSS.pdf
- ASPE report - EHR Payment Incentives for Providers Ineligible for Payment Incentives and Other Funding Study, http://aspe.hhs.gov/daltcp/reports/2013/ehrpi.shtml
- ASPE report – Support and Services at Home (SASH) Evaluation, First Annual Report, September 2014.
- CDC/National Center for Health Statistics: National Study of Long-Term Care Providers and related materials: http://www.cdc.gov/nchs/nsltcp.htm
- Census Bureau disability statistics/resources: http://www.census.gov/people/disability/
- CMS - http://www.medicaid.gov/medicaid-chip-program-information/by-topics/quality-of-care/quality-of-care.html
    - The fifth Annual Secretary's Report on the Quality of Care for Children in Medicaid and CHIP
    - the first Annual Secretary's Report on the Quality of Health Care for Adults Enrolled in Medicaid
- Information on the Medicaid Home & Community Based Services waiver program, including 2014 final rule on HCBS settings and related guidance (CMS 2249-F) and Medicaid statutory authorities and policy issurances instructing states to develop and integrate a continuous quality assurance, monitoring, and improvement strategy for HCBS programs, and approved performance measures and other materials related to HCBS services
- Money Follows the Person demonstration program quality of life survey for persons transitioning from institutional to community settings
- CMS. The National Balancing Indicator Project (2010) http://dswresourcecenter.org/tiki-index.php?page=NBIP
    - Centers for Medicare & Medicaid Services. *National Balancing Indicators Project, Measure Additions and Refinement Report,* January 2013. Contract #HHSM-500-2006-00007I, Task Order HHSM-500-T0007, Division of Community Systems Transformation, Disabled & Elderly Health Programs Group Center for Medicaid & CHIP Services, Centers for Medicare & Medicaid Services. – CMS to provide

- Testing Experience and Functional Tools (TEFT) initiative: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/TEFT-Program-.html piloting the Personal Health Record, and curating e-LTSS standards with leadership and support of Office of the National Coordinator for Health IT. http://wiki.siframework.org/electronic+Long-Term+Services+and+Supports+%28eLTSS%29
- Balancing Incentive Program: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/balancing-incentive-program.html
- CMS Excel Chart – list of HCBS - CMS to provide
- CMS Excel Chart – list of PMs - CMS to provide
- CMS grant, Implementing Continuous Quality Improvement (CQI) in Medicaid HCBS programs, Sarah Galantowicz, Thomson Reuters, January 21, 2010. http://www.dpw.state.pa.us/cs/groups/webcontent/documents/document/d_007056.pdf
- CMS – performance measures used by states in section 1915(i) programs (embedded in approved State Plan amendments) (CMS to provide or NQF will create a small sample)
- CMS – review of Medicaid Health Home State Plan amendments/programs for any yield in quality measures (CMS to provide or NQF will create a small sample)
- CMS' Participant Experience Survey (PES) Tools
- CARE tool functional item set and B-Care: http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/CARE-Item-Set-and-B-CARE.html
- CMS materials on PACE programs: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-termservices-and-supports/integrating-care/program-of-all-inclusive-care-for-the-elderlypace/program-of-all-inclusive-care-for-the-elderly-pace.html
- Health Homes information can be found on Medicaid.gov: http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical- Assistance/Health-Homes-Technical-Assistance/Health-Home-Information-Resource-Center.html
- Health Homes State Medicaid Director Letter: http://www.medicaid.gov/SMDL/SMD/list.asp
- Health Home SMD on HH Core Set of Quality Measures: http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-001.pdf
- Health Home Technical Specifications for HH Core Set of Quality Measures: http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Downloads/Health-home-core-setmanual-.pdf
- CMS Medicare-Medicaid Enrollee State Profiles and Chronic Conditions Warehouse – available on-line: https://www.ccwdata.org/web/guest/home
- CMS Report to Congress: Evaluation of Community-based wellness and prevention programs under section 4202 of ACA: http://innovation.cms.gov/Files/reports/CommunityWellnessRTC.pdf
- CMS Environmental Scan on Autism: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/autism-spectrum-disorders.pdf - note scan methodology
- Centers for Medicare & Medicaid Services (CMS). *Draft Specifications for the Functional Status Quality Measures for Long-term Care Hospitals* and *Draft Specifications for the Functional Status Quality Measures for Inpatient Rehabilitation Facilities.* Available at: http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Public-Comment-Functional-Specs.zip

- Centers for Medicare & Medicaid Services (CMS). *Core measures for duals capitated programs* http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/FinalCY2014CoreReportingRequirements.pdf
- Centers for Medicare & Medicaid Services (CMS). *Core measures in FFS Duals*: https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_MFFS_Guidance_4_17_13.pdf. The State-specific measures for two models can be found at: http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/ApprovedDemonstrationsSignedMOUs.html.
- Medicaid Innovation Accelerator program: IAP updates to be posted on the IAP page on www.Medicaid.gov
- Centers for Medicare & Medicaid Services. *Independence at Home Demonstration Solicitation* [See sections on quality measures for performance monitoring and determining incentive payments], available at http://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/Medicare-Demonstrations-Items/CMS1240082.html
- Centers for Medicare and Medicaid Innovation. *Pioneer Accountable Care Organization (ACO) Model Request for Application,* 17 May 2011. http://innovation.cms.gov/Files/x/Pioneer-ACO-Model-Request-For-Applications-document.pdf (see beneficiary protection/quality measure requirements).
- Centers for Medicare & Medicaid Services (CMS). *Population groups enrolled in Managed Long-Term Care*. July 2012 http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSS-Populations.pdf
- CMS List of Section 1915(k) emergency preparedness amendments. Available on-line, includes quality measures for emergency preparedness. CMS to provide list of states with approved section 1915(k) appendices.
- CMS Home Health Quality Initiative and OASIS measures, particularly in terms of functional impairment and improvement. http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/index.html
- CMS Medicaid.gov - Home & Community Based Services webpage
- The HCBS Taxonomy: A New Language for Classifying Home- and Community-Based Services, policy brief: http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/MAX_IB19_Taxonomy.pdf
- CMS Waiver application portal: https://wms-mmdl.cdsvdc.com/WMS/faces/portal.jsp
- CMS Impact Act activities: to be updated at: www.cms.hhs.gov
- CMS Quality Strategy
- CMS MMCO Data reports: MMCO Data Reports - CMS National & State Profiles (2008), Condition Prevalence and Comorbidity among FFS Medicare-Medicaid enrollees (2009): http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Analytics.html
- CMS State of the States for People with Autism report: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf
- State Innovation Models Initiative (SIM) in the states that have received Model Testing Awards that include HCBS

- CMS/Truven Analytics "The Growth of Managed Long-Term Services and Supports (MLTSS) Programs: A 2012 Update" (2012)
- Annual information on LTSS Medicaid expenditures and HCBS/Waiver expenditures compiled by Truven. This information in now available on the CMS Medicaid site; scroll down the page http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/long-term-services-and-supports.html
- Saucier et al. 2012 analysis for CMS on managed care long-term services and supports and quality measurement
- *Commission on LTC Report to the Congress:* http://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf
- Deutsch, A., T. Kline, et al. (2012). *Analysis of Crosscutting Medicare Functional Status Quality Metrics Using the Continuity and Assessment Record and Evaluation (CARE) Item Set* (prepared for Office of Assistant Secretary for Planning and Evaluation under contract RTI HHSP23320095651 Task order number: HHSP23337021T), Final Report, Nov. 2012. Washington, DC, Office of Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services: 93 pages, available at http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/Downloads/ASPE-Report-Analysis-of-Crosscutting-Medicare-Functional-Status-Quality-Metrics-Using-the-Continuity-and-Assessment-Record-and-Evaluation-CARE-Item-Set-Final-Report.pdf [Report includes an environmental scan on measures of function (physical and cognitive)]
- Department of Housing and Urban Development: American Housing Survey/related updates, available on-line at: http://www.huduser.org/portal/datasets/ahs.html
- Department of Housing and Urban Development section 811 Supportive Housing for Persons With Disabilities portal, and the Elderly portal (separate portals)
- National Center for Health Statistics – National Health Interview Survey, National Health and Nutrition Examination Survey, NCHS links to Medicare, Medicaid, mortality: http://www.cdc.gov/nchs/
- NIDRR's "Identifying and Selecting Long-Term Services and Supports Outcome Measures" (2013)
- Office of the National Coordinator (ONC) for Health Information Technology. "HIT Trailblazer States." http://statehieresources.org/program-initiatives/hit-trailblazers-initiative/
- Office of the National Coordinator, ST eLTSS. Available at: http://www.sifframework.org/
- HHS Health IT Policy Committee. Quality Measurement Group, Recommendations to HITPC. http://www.healthit.gov/facas/sites/faca/files/HITPC_QMWG_LTPAC_BH_Rec_2014-05-06_0.pdf
- ONC/HHS – Person Centered Care slides 10/14: http://www.healthit.gov/person-centered-care
- ONC reports - Strategy and Principles to Accelerate HIE: http://www.healthit.gov/sites/default/files/acceleratinghieprinciples_strategy.pdf
- A 10 Year Vision to Achieve an Interoperable HIT Infrastructure http://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf
- Health IT in LTPAC Issue Brief http://www.healthit.gov/sites/default/files/pdf/HIT_LTPAC_IssueBrief031513.pdf.
- SAMHSA National Registry of Evidence Based Programs and Practices. http://www.nrepp.samhsa.gov/
- SAMHSA. *Recovery Management Tool.* (pending approval, Summer 2015).
- SAMHSA. *Leading Change 2.0: Advancing the Behavioral Health of the Nation 2015-2018.* 2014

- SAMHSA. Working Definition of Recovery. https://store.samhsa.gov/shin/content/PEP12-RECDEF/PEP12-RECDEF.pdf

Other Resources

- States' Plans on Aging developed under the Older Americans Act
- AARP Public Policy Institute/The Hilltop Institute's discussion paper. *Characteristics of a high-performing long-term care system.* January 2010.
- AARP Public Policy Institute. *Across the States 2012: Profiles of Long-Term Services and Supports,* Sept., 2012, [140 population based indicators, multiple years of reports to use for trends] http://www.aarp.org/home-garden/livable-communities/info-09-2012/across-the-states-2012-profiles-of-long-term-services-supports-AARP-ppi-ltc.html
- AARP Public Policy Institute. Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports, July 2012 [Examines oversight practices in eight states with experience operating managed LTSS. Appendix contains details on measures.] http://www.aarp.org/health/medicare-insurance/info-07-2012/keeping-watch-building-state-capacity-to-oversee-medicaid-managed-long-term-services-and-supports-AARP-ppi-health.html
- AARP Public Policy Institute 2011 Fact Sheet: Home and Community-Based Long-Term Services and Supports for Older People
- AARP, The Commonwealth Fund, and The SCAN Foundation's "Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers" – 2014
- Algood, CL , Hong, JS, et al. 2011 *Maltreatment of children with developmental disabilities: An ecological systems analysis*. Children and Youth Services Review. 33(7): 1142-1148.
- Area Agency on Aging 1-B (AAA 1-B) study to identify and document the extent and the impact of unmet needs among HCBS program participants
- Arizona Strategic Enterprise Technology (ASET) Office. *Arizona Health Information Exchange (HIE), Unconnected Providers Program, Arizona HIE Environmental Scan, Long-Term Care,* Dec. 2012 [Appendix includes information on efforts in 13 states]
- Kate Bazinsky and Michael Bailit. *The Significant Lack of Alignment Across State and Regional Health Measure Sets: Health Care Performance Measurement Activity: An Analysis of 48 State and Regional Measure Sets.* (Needham, MA: Bailit Health Purchasing, LLC, September 2013). http://www.bailit-health.com/articles/091113_bhp_measuresbrief.pdf
- Bipartisan Policy Center – America's LTC Crisis, Challenges in Financing and Delivery (2013)
- Bonomi, A. M., et al (2000), *Validation of the United States version of the World Health Organization Quality of Life (WHOQOL) instrument.* Journal of Clinical Epidemiology 53, 1 -12.
- Burke-Miller, JK, Swarbrick, MA 2010. *Promoting Self-Determination and Financial Security through Innovative Asset Building Approaches*. Psychiatric Rehabilitation Journal. 34(2)104 -112.
- CEAL toolkit for person-centeredness in assisted living
- Center for Health Care Strategies. Lind, A. (2013). *Quality Measurement in Integrated Care for Medicare-Medicaid Enrollees*, January 2013. Hamilton, NJ, Center for Health Care Strategies (CHCS) with support from The SCAN Foundation and The Commonwealth Fund**:** 28 pages, available at http://www.chcs.org/usr_doc/Quality_Measurement_in_Integrated_Care.pdf
- Center for Health Care Strategies. *Medicaid Accountable Care Organizations: Program Characteristics in Leading-Edge States,* Feb. 2014. http://www.chcs.org/usr_doc/ACO_Design_Matrix_022514.pdf

- Center for Health Care Strategies. *Innovations in Integration: State Approaches to Improving Care for Medicare-Medicaid Enrollees*, Feb. 2013. [Exhibit 1: is an example of "Readiness Review Criteria"] http://www.thescanfoundation.org/sites/thescanfoundation.org/files/chcs_innovations_in_integration-2-23-13.pdf
- Center for Outcome Analysis http://www.eoutcome.org/default.aspx?pg=373
    - Recent PPT - ACL to provide
    - Real Life Outcomes (2014) – ACL to provide Center for Outcome Analysis papers
    - Personal Life Quality Protocol - ACL to provide
- Center for Personal Assistance Services at the University of California San Francisco selected quality of life measures for measuring consumers' personal experiences
- Center for Self-Determination. http://www.centerforself-determination.com/
- Claes, C , Van Hove, G. 2010. *Person-Centered Planning: Analysis of Research and Effectiveness.* Intellectual and Developmental Disabilities. 48(6):432-453.
- Coalition to Protect the Rights of New York's Dually Eligible. *New York's 2012 Managed Long Term Care Report: An Incomplete Picture*, March 14, 2013. http://www.wnylc.com/health/download/401/
- Coleman Institute, University of Colorado. *State of the States in Developmental Disabilities and State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath.* http://www.stateofthestates.org/
- The Council on Quality and Leadership™ Personal Outcome Measures
- Croke, EE , Thompson, AB. 2011. *Person centered planning in a transition program for Bronx youth with disabilities.* Children and Youth Services Review. 33(6): 810-819.
- Dowler, DL , Solovieva, TI (2011). *Personal assistance services in the workplace: A literature review.* Disability and Health Journal. 4(4):201-208.
- Eiken, Sreidl, Gold et al. April 28, 2014. Medicaid expenditures for LTSS in 2012.
- Eldercare Workforce Alliance Toolkit for Advocates of Dual Eligible Beneficiaries, October 2014.
- Espiner, D , Hartnett, FM (2012). *'I felt I was in control of the meeting': facilitating planning with adults with an intellectual disability*. British Journal of Learning Disabilities. 40(1): 62-70
- Finlay, W.M.L. and Lyons, E. *Methodological issues in interviewing and using self-report questionnaires with people with mental retardation.* Psychological Assessment, 13, 319-335.
- Fyson, R, Cromby, J (2013), *Human rights and intellectual disabilities in an era of 'choice'* Journal of Intellectual Disability Research. 57(12): 1164-1172
- Garner, Mathis (July, 2009) Inclusion – Progress and Promise, Beyond the Disability Bubble. International Journal of Leadership in Public Service.
- Gervey, R, Gao, N 2009. *Person-Centered Employment Planning Teams: A Demonstration Project to Enhance Employment and Training Outcomes for Persons with Disabilities Accessing the One-Stop Career Center System*. JOURNAL OF REHABILITATION 75(2):43-49
- Giovannetti, E., E. Anderson, et al. (2013). *Environmental Scan of Assessment and Care Planning Quality Measures for Managed Long Term Services and Supports* (Prepared for NCQA's June 27th, 2013 Technical Expert Panel Meeting on Performance Measures for Medicaid Managed Long Term Services and Supports (MLTSS)), June 27, 2013. Washington, DC, NCQA**.**
- Glassel, A, Rauch, A (2012). *A case study on the application of International Classification of Functioning, Disability and Health (ICF)-based tools for vocational rehabilitation in spinal cord injury*. WORK-A JOURNAL OF PREVENTION ASSESSMENT & REHABILITATION. 41(4): 465-474.
- Gottlieb, B.H., Bergen, A. E. 2010. *Social Support Concepts and Measures*. JOURNAL OF PSYCHOMETRIC RESEARCH 69:511-520.

- Groschl, S. (2013) *Presumed Incapable: Exploring the Validity of Negative Judgments about Persons with Disabilities and Their Employability in Hotel Operations* CORNELL HOSPITALITY QUARTERLY 54(2):114-123
- Harrow, M., Jobe. T. H. (2007). *Factors Involved in Outcome and Recovery in Schizophrenia Patients Not on Antipsychotic Medications: A 15-Year Multifollow-Up Study*. Journal of Nervous and Mental Disease, 195: 407-414.
- Harrow, M., Jobe. T. H. , Faull, R. N. (2014). *Does Treatment of Schizophrenia with Antipsychotic Medications Eliminate of Reduce Psychosis? A 20 Year Follow-up Study.* Psychological Medicine.
- Hagner, D, Kurtz, A et al. (2012) *Outcomes of a Family-Centered Transition Process for Students With Autism Spectrum Disorders.* FOCUS ON AUTISM AND OTHER DEVELOPMENTAL DISABILITIES. 27(1) 42-50.Higgins A, Veselovskiy G, and McKown L. "Provider Performance Measures in Private and Public Programs: Achieving Meaningful Alignment with Flexibility to Innovate." *Health Affairs* 32.8 (August 2013): 1453-1461. http://content.healthaffairs.org/content/32/8/1453.full
- Helen Sanderson and Associates, Person Centered Thinking and Planning. http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning.aspx
- Holburn, S., and Vietz, P.M. (eds) (2002). *Person Centered Planning: Research, Practice, Future Directions.* Paul H. Brookes Puplishing Co. Baltimore.
- Hughes, C, Avoke, SK 2010. *The Elephant in the Room: Poverty, Disability, and Employment.* RESEARCH AND PRACTICE FOR PERSONS WITH SEVERE DISABILITIES. 35(1-2): 5-14.
- ILRU. IL History and Philosophy: Orientation for IL Staff (4 part video series) http://www.ilru.org/il-history-and-philosophy-orientation-for-il-staff
- IOM's "The Future of Disability in America" report (2007)
- Harvard University Study 10/13 – Housing America's Older Adults – http://www.jchs.harvard.edu/research/housing_americas_older_adults
- In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012 [New] – available for download at http://ici.umn.edu/index.php?products/view/633 Authors: Sheryl Larson, Libby Hallas-Muchow, Amy Hewitt, Sandy Pettingell, Lynda Anderson, Charles R Moseley, Mary Sowers, Mary Lee Fay, Faythe Aiken, John Agosta, Yoshiko Kardell, Drew Smith
- Kaye, H. S. (2014) Toward a Model Long Term Services and Supports System: State Policy Elements. Gerontologist.
- Kaye H.S., Harrington C, LaPlante M.P. Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much? H. Stephen Kaye, Charlene Harrington, Mitchell P. LaPlante. Health Affairs. January 2010
- Krause, N., Borawski-Clarke, E. (1995) Negative Interaction and satisfaction with social-support among older adults. Journal of Gerentology: Psychological Science. 50B 59-73.
- Laudet, A. B. (2011). The Case for Considering Quality of Life in Addiction Research and Clinical Practice. Addiction Science and Clinical Practice. July.
- Leff B, Carlson C, Saliba D, Ritchie C. The Invisible Homebound: Setting Quality-Of-Care Standards For Home-Based Primary and Palliative Care. Health Affairs, 34, no.1 (2015):21-29.
- Long Term Quality Alliance (2011) Quality Measurement Workgroup Report: Measurement Opportunities and Gaps
- Massachusetts Quality Framework for Frail Elder Home and Community-Based Service, April 2007

- Measuring Systems Change and Consumer Outcomes: Recommendations for Developing Performance Metrics for State Lifespan Respite Programs, ARCH National Respite Network and Resource Center, 2014.
- Mcginnis, Crawford, Somers. Issue Brief – 2014. The Commonwealth Fund. A State policy framework for integrating health and social services. http://www.commonwealthfund.org/publications/issue-briefs/2014/jul/state-policy-framework-health-social-services
- Grading the States 2009: A Report on America's Healthcare System http://nami.org/gtsTemplate09.cfm?Section=Grading_the_States_2009
- National Core Indicators™ and NCI-AD (in development)
- Collections of measures in the NASUAD HCBS.org Clearinghouse
- *National Academy for State Health Policy. Quality Measurement to Support Value-Based Purchasing: Aligning Federal and State Efforts*, Feb. 2014. http://www.nashp.org/sites/default/files/Quality.Measurement.Support.ValueBasedPurchasing.pdf
- National Association of States United for Aging and Disabilities. *The 2012 Survey on Medicaid Funded Long Term Services and Supports*, March 2012. [Includes information on quality oversight of assessments and care plans.] http://www.hcbs.org/moreInfo.php/nb/doc/3859
- National Committee for Quality Assurance. *Integrated Care for People with Medicare and Medicaid – A Roadmap for Quality: A Whitepaper*, March 2013. http://www.thescanfoundation.org/national-committee-quality-assurance-integrated-care-people-medicare-and-medicaid-%E2%80%93-roadmap-quality
- New York State Department of Health. *2012 Managed Long-Term Care Report.* http://www.health.ny.gov/publications/3391.pdf [Includes information on specific measures.]
- NIDRR (2013). *2013 Annual Disability Statistics Compendium.* http://www.disabilitycompendium.org/docs/default-source/2013-compendium/download-the-2013-compendium.pdf?sfvrsn=0
- Palmer, M (2011). *Disability and Poverty: A Conceptual Review.* JOURNAL OF DISABILITY POLICY STUDIES. 21(4): 210-218.
- Petry, K., Maes., Vlaskamp, C. (2005). Domains of Quality of Life of People with Profound Multiple Disabilities: The Perpesctive of Parents and Direct Support Staff. 18, 35-46
- RAND's "Improving Dementia Long-Term Care: A Policy Blueprint" (2014)
- Robertson, J, Emerson, E, et al. 2007. *Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities.* JOURNAL OF INTELLECTUAL DISABILITY RESEARCH. 51:232- 243.
- Samuel, PS, Lacey, KK et al. (2013) *Benefits and Quality of Life Outcomes From Transportation Voucher Use by Adults With Disabilities.* JOURNAL OF POLICY AND PRACTICE IN INTELLECTUAL DISABILITIES 10(4):277-288
- Schalock, RL, Verdugo, MA (2012) *A Conceptual and Measurement Framework to Guide Policy Development and Systems Change*. JOURNAL OF POLICY AND PRACTICE IN INTELLECTUAL DISABILITIES. 9(1): 63-72.
- Seekins, T, Ravesloot, C et al. *Nursing home emancipation: A preliminary study of efforts by centers for independent living in urban and rural areas*. DISABILITY AND HEALTH JOURNAL. 4(4): 245-253.
- Seikkula, J., Aaltonen, J., Alakare, B., Haarakangas, K., Keränen, J., & Lehtinen, K. (2006). Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. Psychotherapy Research, 16(2), 214–228.

- Schmidt, S., Muhlan, H., Power, M. (2005). *The EUROHIS-QOL 8-item index: psychometric results or a cross-cultural field study.* European Journal of Public Health. Vol. 16, 4, 420-428.
- Smith, D, Lakin, KC et al (2011). *Changes in Residential Arrangements of Persons with Intellectual and Developmental Disabilities in the Decade Following the Olmstead Decision of 1999*. INTELLECTUAL AND DEVELOPMENTAL DISABILITIES. 49(1): 53-46.
- Stenger, M. f., Oishi, S., KAler, M. (2006). The Meaning in Life Questionnaire: Assessing the Presence of and Search for Meaning in Life. 53:1 (80-93).
- Support Development Associates. http://sdaus.com/ YouTube Series on Person Centered Thinking and Planning. https://www.youtube.com/playlist?list=PL842EFD12D441AF52
- Technical Assistance Collaborative (2013). *Priced Out is 2012: the Housing Crisis for People with Disabilities.* http://www.tacinc.org/media/33368/PricedOut2012.pdf
- The WHOQOL Group (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. Psychological Medicine, 28, pp 551-558.
- Tracy, E. M. et al (2012). *Prospective patterns and correlates of quality of life among women in substance abuse treatment*. Drug and Alcohol Dependence 124, 242-249.
- UCSF Community Living Policy Center's Conceptual Framework for Quality and Outcome Measurement in Long-Term Services and Supports (2014)
- Umberson, D, Karas Montez, J, 2010. *Social Relationships and Health: A Flashpoint for Health Policy.* JOURNAL OF HEALTH AND SOCIAL BEHAVIOR. 51(S): S54-S66.
- United Hospital Fund. Lind, A. (2011). *Measuring Quality for Complex Medicaid Beneficiaries in New York NY,* United Hospital Fund and Center for Health Care Strategies, Inc., 39 pages, http://www.uhfnyc.org/assets/962 .
- University of Colorado. State of the States in Developmental Disabilities. http://www.stateofthestates.org/index.php/what-s-new
- Venkates A, Goodrich K, Conway P. Opportunities for Quality Measurement to Improve the Value of Care for Patients With Multiple Chronic Conditions. Annals of Internal Medicine – supplement, Vol. 16, No. 10. Published on-line. November 18, 2014.
- Walsh, PN, Emerson, E et al. 2010. *Supported Accommodation for People With Intellectual Disabilities and Quality of Life: An Overview.* JOURNAL OF POLICY AND PRACTICE IN INTELLECTUAL DISABILITIES. 7(2): 137-142.
- Wheeler, PN, Sardi, I, et al. 2009. *Person-centered planning: A mixed-methods study of the experiences of people with intellectual disabilities and their careers*. 24(1): 413.
- Wisconsin Department of Health and Family Services' Personal Experience Outcomes Integrated Interview and Evaluation System (PEONIES) for consumers using HCBS
- Wonderlink, L. et al. (2013). "Recovery in Remitted First-Episode Psychosis at 7 Years of Follow-up of an Early Dose Reduction/Discontinuation or Maintenance Treatment Strategy: Long-term Follow-up of a 2-Year Randomized Clinical Trial" JAMA Psychiatry. 70(9) 913-920.
- World Health Organization (2001). International Classification of Functioning, Disability, and Health. WHO, Geneva. http://www.who.int/classifications/icf/en/
- Tennessee collaboration with CQL to become first state service delivery network to become accredited; TN also operating a value based purchasing program for HCBS providers in 2016
- Minnesota requirement for Medicaid Adult Day service providers to implement Quality Assurance performance improvement programs that will be linked to reimbursement

For Phase 1 of the environmental scan, NQF will log measures and measure concepts in the previously listed resources and will consult these additional sources:

- NQF's portfolio of endorsed measures
- AHRQ's National Quality Measures Clearinghouse and National Guidelines Clearinghouse
- HHS Inventory of measures
- CMS Measures Inventory
- The Health Indicators Warehouse
- Collections of measures in the HCBS.org Clearinghouse
- Measures under consideration by HHS for use federal programs in 2015
- Measures in use by State Medicaid HCBS waiver programs (to be provided by Federal Liaisons)
- Previously conducted environmental scans by NQF, particularly the scans done as part of NQF's 2013-2014 measure gaps work
- Presentation from Steve Kaye about LTSS quality tools

NATIONAL
QUALITY FORUM

phrase book

a plain language guide
to NQF jargon

Your Guide to this Guide

Every field develops its own terminology and jargon. Healthcare quality measurement is no exception.

Specialized words do have a purpose, but they can also disguise meaning and confuse people. All too often, those of us at the National Quality Forum (NQF) often use technical terms without providing enough context or explanation. At times it feels like a completely foreign language.

NQF brings together people and organizations working to improve healthcare quality. Our work is inclusive—strengthened by diverse perspectives. Everyone should be able to contribute, whether they are a longstanding leader in the field or new to quality measurement.

This Phrasebook is a guide to NQF's most commonly used terms. It is an attempt to translate our jargon into plain English. Just as you might use a pocket translator to order dinner abroad in Portuguese or Korean, use this booklet to understand "NQF-speak" and join us in collaborating.

Quality

Quality is how good something is. For healthcare, it is often expressed in a range. When a person receives high-quality healthcare, he or she has received the right services, at the right time, and in the right way to achieve the best possible health.

Quality Improvement

Quality improvement (QI) encompasses all of the work people are doing to improve healthcare and the health of individuals and populations. QI is both systematic and ongoing. Healthcare professionals and providers, consumers, researchers, employers, health plans, suppliers and other stakeholders all contribute to effective quality improvement.

Clinical quality improvement is a type of QI specifically designed to raise the standards for preventing, diagnosing, and treating poor health.

National Quality Strategy (NQS)

The NQS is a nationwide effort to provide direction for improving the quality of health and healthcare in the United States. It is guided by three aims: better care, healthy people and communities, and affordable care.

National Quality Forum

The *National Quality Forum* (NQF) is a nonprofit, nonpartisan, organization working toward healthcare that is safe, equitable, and of the highest value. NQF reviews, endorses, and recommends use of standardized healthcare performance measures while encouraging collaboration to accomplish quality goals. NQF is always busy with projects, large and small, and their names often get abbreviated. Some that you might encounter are:

Consensus Development Process (CDP)

NQF uses its formal CDP to evaluate and endorse different types of consensus standards. Standards are most often performance measures. They can also include best practices, frameworks, and reporting guidelines. The CDP follows carefully delineated steps to balance the opinions of all stakeholders to reach consensus. The collection of measures and other resources resulting from CDP projects are sometimes called the *NQF portfolio*.

Measure Applications Partnership (MAP)

The federal government and others who run healthcare programs are often considering new measures for their public reporting and performance-based payment programs. MAP is a large group of stakeholders that reviews those measures and makes recommendations about how they should be used. MAP also works to improve the consistency of measures being used in public- and private-sector programs.

National Priorities Partnership (NPP)

NPP is a partnership of 52 major national organizations with a shared vision to achieve better health, and a safe, equitable, and value-driven healthcare system. NPP was an early advocate for the creation of the National Quality Strategy (NQS) as a blueprint for achieving a high-value healthcare system. NPP continues to provide direction on healthcare policy and helps organizations pursuing the NQS to achieve quality improvement by making connections and helping to share information about innovative approaches.

High-Impact Condition

When a condition affects a large group of people, is expensive to treat, or has a large and long-lasting impact on a person's well-being, it is a high-impact condition. NQF has developed two lists of high-impact conditions and health risks, one for children and another for people with Medicare.

Some of the high-impact conditions in the Medicare population are depression, congestive heart failure, stroke, osteoporosis, and breast cancer.

Cross-Cutting Area

Cross-cutting areas refer to broad topics that people are interested in measuring and improving across the healthcare system. Sometimes we think about high-quality healthcare in the context of a disease, such as cancer, and making the right choices for treatment. At other times we think about factors that affect everyone receiving healthcare regardless of disease, like how well doctors and nurses communicate with patients.

Examples of cross-cutting topic areas include care coordination, healthcare disparities, patient safety, and palliative care.

Measure

A healthcare performance measure is a way to calculate whether and how often the healthcare system does what it should. Measures are based on scientific evidence about processes, outcomes, perceptions, or systems that relate to high-quality care. NQF-endorsed measures are tools that show whether the standards for prevention, screening, and managing health conditions are being met.

The result of a measure is usually shown as a ratio or a percentage. If you have a question about the health of a community or group of people or how well the health system is performing, a measure can give you the information you need.

A measure can be very narrow, such as the percentage of diabetic patients whose blood sugar reaches a certain level, or broad, such as the number of community members whose diabetes is well-managed according to specified criteria.

Please see **NQF's ABCs of Measurement**

Once a person has had a heart attack, taking aspirin daily has been shown to reduce the chance of having a second heart attack. Guidelines tell physicians to prescribe aspirin to all patients leaving the hospital after a heart attack. This practice can be measured, with higher percentages indicating better performance.

$$\frac{\text{96 HEART ATTACK PATIENTS WERE APPROPRIATELY PRESCRIBED ASPIRIN AT DISCHARGE}}{\text{100 TOTAL HEART ATTACK PATIENTS}} = 96\%$$

Types of Performance Measures

Structural measures

Structural measures assess healthcare infrastructure.

> **EXAMPLE:** *The percentage of physicians in a state who can send prescription information to a pharmacy electronically.*

Process measures

Process measures assess steps that should be followed to provide good care.

> **EXAMPLE:** *The percentage of patients leaving the hospital who had a full, updated list of medications sent to their primary care provider within 24 hours.*

Outcome measures

Outcome measures assess the results of healthcare that are experienced by patients. They include endpoints like well-being, ability to perform daily activities, or even death. An intermediate outcome measure assesses a factor or short-term result that contributes to an ultimate outcome, such as having an appropriate cholesterol level. Over time, low cholesterol helps protect against heart disease.

> **OUTCOME EXAMPLE:** *The percentage of a health plan's members who died of cardiovascular disease in the last year.*

> **INTERMEDIATE OUTCOME EXAMPLE:** *The percentage of a health plan's members who are maintaining their blood pressure within a healthy range.*

Patient engagement and patient experience measures

Patient engagement and patient experience measures use direct feedback from patients and their caregivers about the experience of receiving care. The information is usually collected through surveys.

EXAMPLES: *The percentage of patients who said they were as involved as they wanted to be in making decisions about their treatment.*
The percentage of caregivers who felt confident about their ability to give medication to a family member properly.

Composite measures

Composite measures combine multiple measures to produce a single score. The information can be greater than the sum of its parts because it paints a more complete picture.

EXAMPLE: *How successful were care transitions after patients left the hospital after a heart attack, based on three factors: follow-up by a primary care provider, visits to the emergency department, and hospital readmissions?*

MORE AHEAD

Measure specifications

Measure specifications are the technical instructions for how to build and calculate a measure. They describe a measure's building blocks: numerator, denominator, exclusions, target population, how results might be split to show differences across groups (stratification scheme), risk adjustment methodology, how results are calculated (calculation algorithm), sampling methodology, data source, level of analysis, how data are attributed to providers and/or hospitals (attribution model), and care setting.

Taken together, measure specifications are a blueprint that tells the user how to properly implement the measure within their organization.

Disparities-sensitive measure

Performance measures identified as *disparities-sensitive* highlight inequalities in care. Measure results can be split, or *stratified,* to show whether there are differences between two or more groups. Once disparities are visible, targeted strategies can be developed to address them.

Please see **NQF's project on Healthcare Disparities and Cultural Competency**

Patient-reported outcomes and measurement

Patients are a great source of information on health outcomes. Who better to answer questions such as, “Did you understand your doctor’s instructions?” or ”Can you walk several steps without pain?” NQF is working to increase the use of patient-generated information as part of performance measurement.

PATIENT-REPORTED OUTCOME (PRO): information about the patient, as communicated by that person

PRO MEASURE (PROM): an instrument, scale, or single-item measure that gathers the information directly from the patient

PRO-BASED PERFORMANCE MEASURE (PRO-PM): a way to aggregate the information that has been shared by the patient and collected into a reliable, valid measure of health system performance.

Please see **NQF’s Fast Forward: Creating Valid and Reliable Patient-Reported Outcome Measures**

Measurement of Affordability

Affordability is emerging as a high priority in performance measurement. Many terms related to this topic have subtle differences.

Cost

An amount, usually specified in dollars, related to receiving, providing, or paying for medical care. Things that contribute to cost include visits to healthcare providers, healthcare services, equipment and supplies, and insurance premiums.

Costs can be direct, such as when a person gives a copay at a pharmacy window. They can also be indirect, such as when poor health leads to lost productivity in the workplace.

Resource Use

Resources are the goods or services that are combined to produce medical care. They are inputs that have a price assigned to them. When a procedure is done many times, resource use can be measured and predicted. For example, the people and things needed to perform cataract surgery are a set of resources.

Efficiency

This concept combines cost and quality. At a given level of quality, services can be highly efficient or inefficient. Improved efficiency comes from providing high-quality healthcare at lower cost.

Value

The value of healthcare is subjective. It weighs costs against the health outcomes achieved, including patient satisfaction and quality of life.

Quality Measurement Tools Developed by NQF

Quality Positioning System (QPS)

The Quality Positioning System (QPS) is a web-based tool developed by NQF to help people more easily select and use NQF-endorsed® measures. You can search QPS for many helpful details about endorsed measures. Give it a try!

QPS Portfolio

A portfolio is a customized collection of NQF-endorsed measures selected by a QPS user. Some users have created portfolios of measures about specific topics or programs and published them in the system for others to view and use.

Please see **NQF's Quality Positioning System**

Quality Data Model (QDM)

The QDM is part of NQF's work in health information technology. It is an "information model" that defines concepts used in quality measures and clinical care so that users can clearly and concisely locate and communicate pieces of electronic information.

The QDM can be used to help the designers of electronic health records to improve consistency between different systems. This improves automation and the ability of different systems to exchange electronic information.

Endorsement/ NQF-endorsed®

When a measure is submitted for NQF endorsement, it goes through a standard process that includes a thorough review by a multi-stakeholder group of experts, a public comment period, voting by NQF's membership, and approval by NQF's Board of Directors. Measures endorsed by NQF meet tough requirements, so national, state, and local programs often prefer to use them.

Time-limited endorsement

Under rare circumstances, a measure can receive time-limited endorsement for up to a year. In addition to meeting the NQF the Measure Evaluation Criteria, a measure with time-limited endorsement must:

- relate to a topic not addressed by an endorsed measure,
- meet a critical timeline for implementing an endorsed measure (e.g., legislative mandate),
- not be complex (e.g., requiring risk adjustment or a composite), and,
- have testing completed within the 12 month time-limited endorsement period.

Due to the urgent need for a measure that addressed dementia, a recently submitted measure on that topic was given time-limited endorsement so that data would not be lost while the required testing was completed.

Please see **NQF's Measure Evaluation Criteria**

Endorsement Maintenance

Because healthcare is always changing, measures need ongoing maintenance and updates. Endorsement maintenance is a review process completed every three years to ensure that measures continue to meet the measure evaluation criteria and that their specifications are up to date.

The endorsement maintenance process creates an opportunity to consider all available measures in a topical area, harmonize them (see page 17), and endorse the "best in class."

Measure Evaluation Criteria

NQF uses standard criteria to evaluate a measure and decide if it should be recommended for endorsement.

Importance to measure and report

This principle asks if there is evidence that measuring this topic will improve healthcare quality. The goal of this principle is to keep the focus on the most important areas for quality improvement. As the saying goes, "Not everything that can be counted counts." There must also be scientific evidence to support the topic being measured and a significant opportunity to improve achievement.

Scientific acceptability of the measurement properties

This principle asks if a measure will provide consistent and credible information about the quality of care by evaluating its reliability and validity. In case you need a reminder:

- **RELIABILITY** reflects the amount of error in a measure and how well it distinguishes differences in performance. An unreliable measure doesn't function well across users or over time.

- **VALIDITY** asks if a measure truly provides the information that it claims to. A measure that isn't valid is mistakenly evaluating something besides the topic of the measure. Such a measure will not lead to sound conclusions about the quality of care provided.

Feasibility

This principle makes sure that the information needed to calculate a measure is readily available so that the effort of measurement is worth it. The most feasible measures use electronic data that is routinely collected during the delivery of care.

Usability

This principle checks that users of a measure—employers, patients, providers, hospitals, and health plans—will be able to understand the measure's results and find them useful for quality improvement and decision-making. It asks if the measure is strong enough to be used for various types of measurement programs, including public reporting, whether it leads to actual improvement for patients, and whether the benefits of the measure outweigh any potential harms.

Please see **NQF's Measure Evaluation Criteria.**

Measure Harmonization

When measures are similar, the endorsement process will select the best one, recommend how they can be better aligned, or justify why more than one measure is needed.

Competing measures

Competing measures address the same topic **and** the same population.

> **EXAMPLE:** *Two measures that address the rate of patient falls among older adults in nursing homes.*

Related measures

Related measures address **either** the same topic or the same population.

> **EXAMPLES:** *Two measures about flu shots, one for patients in hospitals and one for patients in nursing homes (same topic). Two measures for patients with diabetes, one addressing eye exams and another addressing foot exams (same population).*

Harmonization

Having multiple similar measures can make it difficult to choose one to use**.** *Harmonization* is the process of editing the design of similar measures to ensure they are compatible. Measure developers can make changes to the way a topic or population is defined. Harmonization helps reduce the confusion of having measures that are similar but different.

> **EXAMPLE:** *Two measures may give different age ranges for the population of "children."*

Please see **NQF's "Measure Evaluation Criteria"**

Measure Developer

Measure developers are individuals or organizations that design and build measures. Many people think that NQF develops measures but we do not.

Measure Steward

An individual or organization that owns a measure is responsible for maintaining the measure. Measure stewards are often the same as measure developers, but not always. Measure stewards are also an ongoing point of contact for people interested in a given measure.

Many medical specialty societies such as the American College of Surgeons and government agencies such as the Agency for Healthcare Research and Quality (AHRQ) develop and steward measures.

Health Information Technology (HIT)

HIT is of increasing importance for healthcare. Using HIT means that computer hardware and software are doing the work of storing, retrieving, sharing, and analyzing healthcare data. HIT helps healthcare providers to communicate securely, coordinate care, and better manage services for their patients. HIT can include the use of electronic health records (EHRs) as well as personal health records (PHRs).

Electronic health record (EHR) system

An electronic health record (EHR) is just like it sounds: a systematic collection of health information about a patient or population in a digital format. At its simplest, an EHR is a computerized version of a doctor's traditional paper charts. Electronic information in EHRs can be more easily shared through connected systems and other information networks.

eMeasure

eMeasures are performance measures that have been developed for use in an EHR or other electronic system. eMeasures pull the information needed to evaluate performance directly from the electronic record. They can be far more efficient than traditional approaches of extracting data from paper charts or claims databases.

Value set

A value set is a list of specific clinical terms and the codes that correspond with them. A value set defines each of the clinical terms in the elements of a quality measure. Value sets support the calculation of eMeasures and the systematic exchange of health information.

EHR standards

Healthcare providers use different types of EHR systems that need to be able to communicate, translate, and use information from many sources. Standards are sets of rules or guidelines that allow for inter-operability (the exchange of useful data across different systems).

Code System / Code Set

Sometimes using ordinary spoken or written language is not the easiest way to communicate – like when complex and technical health information needs to be shared system-wide. A code system is a way to turn health information like a diagnosis or procedure name into numbers or code to make sharing information easier and faster. A code set is a specific version of that system's rules.

EXAMPLE: *ICD-10, Health Care Procedure Coding System (HCPCS)*

Multi-Stakeholder Input

NQF brings together different subject matter experts and organizations that want to improve healthcare quality. Because these groups include both government and private sector representatives, they are considered *public-private partnerships.*

Balancing different groups' perspectives in an open and honest dialogue is core to our work. NQF brings together many multi-stakeholder groups to build consensus. They include:

- Steering Committees and the Consensus Standards Approval Committee (CSAC) for measure endorsement,
- Health Information Technology Advisory Committee (HITAC) to provide guidance and expertise on HIT projects,
- Measure Applications Partnership (MAP) to provide input to the government on measure use, and,
- National Priorities Partnership (NPP) to provide input to the government on measurement priorities.

Measure Selection Criteria

To help guide its decisions, the Measure Applications Partnership (MAP) developed a set of Measure Selection Criteria. These criteria are guidelines for deciding the best measures to use in important programs. The criteria recommend that measures in a set:

- Are NQF-endorsed,
- Address each of the priorities of the National Quality Strategy,
- Address high-impact conditions for which measurement is needed,
- Align with measurement requirements in other programs,
- Include an appropriate mix of measure types,
- Cover a patient's entire care experience,
- Take into consideration healthcare disparities, and
- Promote efficiency in measurement.

Please see **MAP Measure Selection Criteria and the Measure Applications Partnership**

Burden

While crucial to improving healthcare quality, measurement can have a downside: *it takes a lot of hard work!* Measurement burden can be the result of a number of factors, including costs and time associated with increased, duplicative, or labor-intensive data collection, analysis, or reporting.

Parsimony

Being parsimonious with measures means using only as many measures as necessary to meet a program's goals – no more, no less. A negative view of parsimony is stinginess; a positive one is minimizing burden.

Alignment

Another way NQF is working to reduce the burden of measurement is by promoting alignment. Alignment is achieved when a set of measures works well across settings or programs to produce meaningful information without creating extra work for those responsible for the measurement.

Alignment includes using the same quality measures in multiple programs when possible. It can also come from consistently measuring important topics across settings. NQF uses several tools to promote alignment including measure harmonization and identifying families of measures and core measure sets.

Family of measures

A family of measures is a group of measures that addresses an NQS priority or high-impact condition across various settings of care, type of data analysis, populations, or reporting programs. High priority measure gaps are also included when there are few or no measures to address important elements of care for a topic. NQF's past work has defined families of measures for cardiovascular disease, diabetes, patient safety, and care coordination.

Core set of measures

A core set of measures is a group of measures identified as the best possible measures for a specific care setting. NQF's past work has developed core sets of measures for hospital care, long-term care, and ambulatory care.

Accountability programs

These programs vary in scope but all tie rewards to performance on quality measures. Accountability programs may also be referred to as incentive programs or high-stakes uses of measurement. When incentives such as payment and market competition are on the line, measurement programs have more impact and also come under more scrutiny.

- **PRIVATE REPORTING:** sharing quality measurement results with internal stakeholders only, such as within a single health system
- **PUBLIC REPORTING:** sharing quality measurement results with the general public, such as through a website or printed report.
- **PERFORMANCE-BASED PAYMENT:** payment for care that is contingent on performance measurement results.
- **MEANINGFUL USE OF HIT:** a well-known incentive program to expand the use of electronic health records. It allows eligible providers and hospitals to earn payments by meeting specific criteria regarding the use of electronic information to improve care.

Serious reportable events

Despite the doctor's vow to "first do no harm," medical errors injure or kill thousands of patients each year. NQF has defined a list of serious reportable events (SREs) that cause or could cause significant patient harm. They include preventable events such as giving medication to the wrong person, failing to follow up on critical test results, operating on the wrong side of a patient's body, or operating on the wrong patient altogether.

Please see **NQF's Serious Reportable Events In Healthcare—2011 Update: A Consensus Report**

Never events

This informal term is often used in place of *serious reportable event*. Eliminating harm completely is important but difficult to do. Because of this, NQF uses *serious reportable event* instead of *never event.*

Safe practices

Part of NQF's work in promoting patient safety includes recommending this set of actions to improve patient safety. Hand hygiene, teamwork training, and informed consent are all examples of safe practices.

Please see **NQF's Safe Practices for Better Healthcare–2010 Update: A Consensus Report**

Episode of Care

Treatment of many health conditions crosses time and place. An *episode of care* includes all care related to a patient's condition over time, including prevention of disease, screening and assessment, appropriate treatment in any setting, and ongoing management.

Please see **NQF's Episode of Care Framework**

Feedback Loops

Quality measurement is a constant work in progress. Feedback loops are a way to collect and share useful information. They can be used for healthcare quality measurement by identifying measures that need modification or areas where adequate measures are not available. Such an exchange of information promotes continuous learning and improvement across the entire healthcare system.

SEE YOU SOON!

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