

Addressing Residents' Goals, Preferences and Priorities

Nursing home residents should be empowered to direct their care to meet their goals, preferences and priorities (GPPs). Despite federal regulation and community consensus, some nursing homes may lack an effective system to achieve that goal. To advance best practice and support improved federal regulations, the Coalition will develop or adapt a data-supported, tech-enabled process for collecting GPPs, documenting them in a person-centered care plan, and measuring the degree to which the care provided reflects residents' needs and wishes.

Guiding Recommendation from NASEM's The National Imperative to Improve Nursing Home Quality

"As a critical foundation to operationalizing person-centered care that reflects resident goals and preferences, the committee recommends compliance with regulations for person-centered care." (Recommendation 1A, p. 503)

"The U.S. Department of Health and Human Services should fund the development and adoption of new nursing home measures to Care Compare related to [...] implementation of the resident's care plan [...] and] receipt of care that aligns with resident's goals and the attainment of those goals."
(Recommendation 6C, p. 532-533)

*The Coalition thanks the
Person-Centered Care, Quality Measurement & Improvement
and Health Information Technology Committees
for writing this Action Plan.*

Purpose

Person-centered care and well-being are recognized as essential aspects of quality of life and care in long-term care communities. Provisions such as the Code of Federal Regulations (42 483), the Center for Medicare & Medicaid Services' Reform of Requirements for Long-Term Care Facilities Final Rule, and pivotally the Omnibus Budget Reconciliation Act of 1987 (OBRA 87) support optimal person-centered care that bolster a resident's locus of control, empowerment, autonomy, dignity and optimism.

Following federal and state regulations, many nursing homes are working to improve the way they gather residents' goals, preferences and priorities (GPPs), develop a unique care plan, implement the care plan, and ensure that care is aligned with each resident's needs and wishes. These efforts are essential to nursing home residents receiving the services, care, and support they need. Aligning care with residents' GPPs represents an opportunity to improve outcomes and reduce disparities associated with race, ethnicity, gender orientation, and other characteristics.

However, in some nursing homes, information about residents' GPPs is not consistently and reliably collected; in others, residents' responses are not included in their care plans; and even when documented, GPPs are not always addressed during actual care delivery. Across the board, public reporting does not include whether care is consistent with the resident's goals.

One underlying challenge is that approaches to GPPs and person-centered care are not standardized across activities – collection, care planning, implementation, and measurement – or across existing tools and regulations. The Coalition seeks to assemble a process, collection tool, and measure that can ultimately be used in a standardized manner and exchanged across care settings, without increasing provider burden. In addition to preparing this approach for testing, the Coalition will also seek to engage the Centers for Medicare and Medicaid Services (CMS) about how this work could be integrated into national data collection through the Minimum Data Set (MDS), shared publicly through Care Compare, and used to improve other regulations and policies.

Goal: Develop or adapt a comprehensive, tech-enabled GPP collection tool, care planning process and care concordance measure ready for pilot testing in nursing homes. The Coalition will work with policymakers and stakeholders to make sure the process, tool and measure are realistic, accessible and have the potential for integration into care delivery, regulation, payment, and quality reporting and oversight systems.

Phases of Work

Progress To Date

The Coalition with the partnership of the Columbia University School of Nursing have begun an analysis of a large data set of over 10,000 individuals' care preferences to identify a core set of GPP categories for the development of a nursing-home specific documentation tool. The Coalition has also begun to identify a comprehensive list of existing tools used in assessment and care planning to identify GPPs.

Proposed Timeline

Activity	Completion Date
Complete natural language processing analysis to identify GPP categories.	July 2023
Complete literature review and documentation of existing care planning tools and care concordance measures.	August 2023
Obtain data from CMS to support measure development work.	September 2023
Work together to finalize list of GPP categories and GPP script questions. The Coalition resident focus group, other stakeholders (direct care staff, care partners, advocates), and data science experts will provide ongoing input.	November 2023
Continue working with health information technology (HIT) vendor and/or other technology subject matter experts (SMEs) to build a GPP collection tool. The Coalition will engage standards development organizations (SDOs) to code GPPs that lack standardized codes.	February 2024
Complete a care planning process and training program focused on GPP script questions and integration that can be tested along with a robust digital GPP collection tool.	April 2024
Develop or adapt one draft concordance measure that can be tested in conjunction with GPP tools and processes.	April 2024
Prepare for initial testing of the process, tool, and measure. Engage with CMS to report on progress and discuss policy strategies for advancing goal-concordant care.	June 2024

Note on Scope: Pilot testing or demonstrations will be conducted in up to six nursing homes to test proof of concept, leading to testing in more nursing homes. Initial testing may be conducted during or after the current grant period.

Additional Details

Partners and Stakeholders

Diverse Stakeholders: Efforts to develop a realistic and effective GPP process will require the input and feedback of diverse stakeholders including:

- Nursing home providers
- Nursing home clinicians (across the interdisciplinary team)
- Advocacy organizations
- State Survey Agencies
- Ombudsman Programs
- Caregivers and care partners
- Residents
- HIT Vendors
- Federal partners such as the Office of the National Coordinator (ONC) and CMS

Subject Matter and Technical Experts: The action plan will also require the engagement of partners with technical and quality expertise. These include:

- SDOs
- HIT Vendors
- Quality Innovation Networks-Quality Improvement Organizations (QIN-QIOs)
- Measure development experts

Columbia University School of Nursing: The School of Nursing has provided in-kind support by conducting preliminary GPP data analysis.

ADVault: ADVault has granted the Columbia team access to extensive advanced care planning data.

Moving Forward Resident Focus Group: The Coalition will work closely with the Coalition's resident focus group to gain feedback and resident perspectives over the course of the year.

CMS: The Coalition will seek to develop a relationship with CMS to gain access to existing federal data and lay the groundwork for related policy efforts.

Equity

As the Coalition develops and adapts a collection tool, care planning process and measure, it will consider whether those new resources adequately meet the needs of marginalized groups in nursing homes. The Coalition will look at whether these materials successfully reflect the potentially unique GPPs and other needs of residents from marginalized racial and ethnic backgrounds, residents identifying (whether openly or not) as LGBTQ+, residents with varying cognitive conditions or developmental disabilities, and residents with diverse language backgrounds.

Initial testing of parts of action plan deliverables may be too small (1-3 homes) to reflect the true diversity of individuals cared for in the 15,000 U.S. nursing homes. Subsequent scale and spread must engage nursing homes serving a wide range of populations. In addition, evaluation at all stages will look at the impact on and inclusion of marginalized individuals in nursing homes, as well as the impact on their care partners and community members.

Sustainability and Financing

This action plan will promote optimal person-centered care, which is already part of the Code of Federal Regulations. These tools will help strengthen and advance those policies.

The Coalition recognizes that the direct-care workforce will need to be trained, empowered and supported to implement comprehensive goal-concordant care. The care planning process in development will outline clear approaches to training and support of staff in all roles – including and especially certified nursing assistants (CNAs).

Appendix

Select Definitions

Data elements/items: Discrete pieces of information in the form of questions and responses that are used by providers to assess and/or evaluate residents. Data elements/items include questions and responses about treatments, services, symptoms, and resident-reported outcomes.

Domains: Frameworks that organize a set of values or categories. Many times, these values may be data items organized by type of function.

Quality measures: A quality measure is a tool used to monitor and track outcomes. Quality measures quantify processes, outcomes, structures, or systems and are often used in healthcare. Quality measures are used to report and benchmark outcomes to improve the quality of healthcare. Many times, measures are composed of a numerator and denominator and can calculate population or resident-level outcomes.

Surveys/tools/assessments: Forms used to gather information. These forms may contain data elements/items and/or measures to collect evidence by means of standardized questions and responses. These tools may ask a number of questions and may contain multiple response options.

Goal Concordant Care: Care that promotes and is consistent with a resident's GPPs and for which the resident drives decision-making.

Goal Concordance Measure: A measure that assesses the degree to which care provided is consistent with (concordant) or is aligned with a resident's GPPs. A measure of this type may report outcomes that speak to whether a resident's goals were met, allowing providers to provide timely and person-centered care.

Electronic Health Record: According to ONC, an electronic health record (EHR) is a digital version of a person's paper chart. EHRs are real-time, person-centered records that make information available instantly and securely to authorized users within integrated systems.

Detailed Work Timeline

Timeline	Person-Centered Care Activities	Quality Measurement and Improvement Activities	HIT Activities
July/August 2023	<p>Develop an outline for topics and content to be included in the care planning process.</p> <p>Conduct a literature review specific to the wording of the definition of GPPs.</p>	<p>Conduct a literature review of existing care concordance measures.</p> <p>Apply for data use agreement (DUA) with CMS.</p> <p>Continue to follow work by other committees through regular calls.</p>	<p>Complete natural language processing (NLP) analysis of data to understand fewest number of categories that represent broadest group of GPPs.</p>
August 2023	<p>Complete definition of GPPs</p> <p>Identify key domains of GPP assessment from the literature. Share continuously with other committees.</p>	<p>Collaborate with other committees on GPP categorization.</p>	<p>Work with resident focus group to test initial list of categories (see above). Work to align definitions of GPPs and revise work on categories accordingly.</p>
September 2023	<p>Document complete list of GPP assessments and other care planning resources (e.g., training) and identify list of best tools based on whether they meet Coalition definition of GPPs.</p>	<p>Obtain data from CMS. Begin content review and testing. Gather initial GPP definition when available.</p>	<p>Develop questions that could be used in a HIT GPP tool. Review with other committees.</p>
October 2023			<p>Conduct cognitive testing with resident focus group and care partners to revise and update the list of questions as needed.</p>

November 2023	Develop robust resource guidebook and graphic for nursing home staff informed by the evidence and literature on how to address GPPs in care planning.	Gather final list of GPP definition when available.	Finalize list of GPP questions after collaboration with other committees. Collaborate with Committee on Quality Measurement & Improvement on measure development.
December 2023		Begin drafting or adapting concordance measure. Steps may include: combining definitions and categories into domains for a care concordance measure; mapping items with MDS items for content analysis; comparing domains to those of existing measures.	Work with a developer to begin to build a HIT GPP acquisition tool (AT)/script.
January 2024	Work to integrate digital literacy and best practices into the guidebook.		Continue HIT GPP tool development.
February 2024	Work to align the guidebook and care concordance measure. The care concordance measure will be integrated into the guidebook.		Begin work with SDO to add new codes for GPPs identified but not yet coded.
March 2024	Work to integrate GPP HIT tool under development into the guidebook.	Review portfolio of measures with key stakeholders and advisors.	Continue to work with SDO to add new codes for GPPs identified that are not coded yet.

April 2024	Finalize care planning process guidebook for testing.	Finalize portfolio of goal concordance measures ready for testing. Complete pilot test plan finalized.	HIT GPP tool – including coded GPPs – is developed and ready for testing. An SDO is engaged in coding additional GPPs that will ultimately be integrated into a developed tool.
May 2024	Work together to find funding, sites, staff, and resources for testing.		
June 2024	Work together to share progress with policymakers and make the case for how the federal government can use this combined effort to update the CMS Code of Federal Regulations or other regulatory or data collection processes.		

Acknowledgements

The Coalition thanks the Person-Centered Care, Quality Measurement & Improvement, and Health Information Technology Committees for their work on this Action Plan. Members of these Committees are listed below.

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