



## Evidence-based Practice Center Technical Brief Protocol

**Project Title: *Evidence Map on Home and Community Based Services***

### **I. Background and Objectives**

One in four adults in the United States live with some form of disability that impacts their cognitive function, physical function, and independence.<sup>1</sup> As a result, over 2.5 million of these individuals with disabilities receive Home and Community Based Services (HCBS) to support their individual needs.<sup>2</sup> HCBS are an array of person-centered services delivered in the home and community and are considered as a means to improve the lives of people with functional limitations to keep them living independently and safely in the community. A variety of services and interventions are available to prioritize individual needs, preferences, goals, aiming to enhance well-being, quality of life, and independence.

The aging population has diverse and unique complexities that pose a challenge to evaluating HCBS care plans. These complexities arise from numerous factors including variations in medical needs, functional limitations, and social and environmental influences. Furthermore, the health conditions and care needs of older adults can change over time: most experience progressive conditions or multiple comorbidities that require dynamic and flexible care approaches. Identifying critical elements of HCBS is a challenging task when there is no one-size-fits-all model for each situation, which is due to the heterogeneity of patient needs, variability in intervention approaches, lack of consensus in outcome measures, and the sustainability of resource allocation for these high-risk populations requiring longitudinal support. While person-centered home-based interventions, a type of integrated intervention that are driven by individual's needs and desires and support shared decisionmaking between individuals and providers, are critical to improving the lives of people with functional disabilities, it is unclear which services are the most impactful for individual considerations.

The diversity of interventions creates a matrix of complexity when it comes to identifying effective interventions. Services provided in long-term dementia care is different than one that is provided for acute rehabilitation following joint surgery.<sup>3,4</sup> Therefore, there is no specific standardization of care, and it is largely crafted by a primary care or subspecialty team. Although many quality and outcome measures that have been studied, there is a general lack of consensus on which ones are the most impactful and meaningful. Potential outcome measures include quality of life, functional independence, general satisfaction of care, mortality risk, time to nursing home placement, hospitalization, general clinical outcomes (falls, disease related), caregiver burden, and cost effectiveness/resource utilization.

### **Purpose of the Review**

This Technical Brief will provide an evidence map that summarizes service categories of HCBS, effectiveness of these interventions for specific conditions, and quality measures relevant to HCBS. This Technical Brief will also identify gaps in the evidence base. This work will help

inform policy development by the Administration for Community Living and the Centers for Medicare & Medicaid Services.

## II. Guiding Questions

1. Describe the available research on the effectiveness of person-centered HCBS interventions, for adults aged 60 or older with a functional limitation in home and community-based settings.
  - a. What HCBS interventions have been studied in relation to person-centered approaches?
    1. For which person-centered HCBS interventions are systematic reviews available?
    2. For which person-centered HCBS interventions are sufficient primary research studies available to justify a new systematic review?
  - b. What populations have been studied with person-centered HCBS interventions?
  - c. What primary outcomes of person-centered HCBS interventions have been studied?
  - d. What mediating factors have been identified in the literature that could affect outcomes such as the presence of unpaid family caregivers as part of the overall care team?
  - e. What study designs have been used to evaluate the effectiveness of person-centered approaches to HCBS interventions?
2. What quality measures related to person-centered HCBS interventions exist or are under development (See [NCQA measures of person-centered outcomes](#) under development, including the [University of Minnesota's efforts](#))?
3. Describe the gaps that exist in the current research.
  - a. Which person-centered HCBS interventions identified by experts as currently relevant have no or inadequate evidence?
  - b. Which patient populations and outcome measures have no or inadequate evidence?
  - c. Are there gaps in evidence related to taking person-centered planning approaches to these interventions?

## III. Methods

We will search peer-reviewed published literature and gray literature. Findings will be synthesized with additional information from Key Informant (KI) interviews. We will create an evidence map that shows the distribution of evidence related to the Guiding Questions.

### 1. Data Collection:

#### A. Discussions with Key Informants

We plan to recruit six to nine KIs with different expertise, backgrounds, and professional affiliations from the following perspectives: Area Agencies on Aging, Federal agencies, HCBS providers, HCBS researchers, and patient advocates. We will initially schedule one or two group conferences, each separated by two sections: one for patient advocates, and one for HCBS providers, researchers, and policymaker. The section for patient advocates will focus on their HCBS experiences, quality measures and outcomes that are important and relevant to patients, and factors involved in the decision to choose HCBS. The section with HCBS providers,

researchers, and policymakers will seek input on their experience, opinions, and challenges related to HCBS.

We will use a semi-structured interview guide to guide the group conferences. The conferences will be led by two clinical and research experts, who will document responses using real-time transcription and audio recording. The conferences will be conducted according to KIs' preferred method (i.e., over the phone or via video conference). The duration of the conference, after formal agreement to participate has been documented, will last approximately 60 minutes. We will identify key points and produce a meeting summary. This meeting summary will be sent to KIs for verification and clarification. Potential questions for KIs are listed below:

### **Questions for providers, researchers, and policymakers**

1. We plan to describe person-centered HCBS interventions. What do patients want to accomplish with HCBS (i.e., goal of treatment)? How do patients, providers, and policymakers define success?
2. What concerns do patients have when they receive person-centered HCBS interventions?
3. What concerns do providers and policymakers have regarding person-centered HCBS interventions and the alternatives of HCBS (i.e., institutional care without HCBS)?
4. We expect to encounter a large number of heterogeneous interventions, what frameworks can we use to organize or categories these interventions?
5. We plan to report a wide range of HCBS interventions (full list in the Interventions section of Table 1). Should we make any changes to this list?
6. How do patients, providers, and policymakers define quality of patient-centered HCBS interventions? Do you know of any commonly used quality measures or quality measures under development?
7. We plan to include studies published after the year 2000 and studies conducted in the United States. The goal of these limitations is that studies from countries with other health systems will provide evidence that is less likely relevant to the context in the United States. Studies published over 20 years ago may also be irrelevant considering the advancements in communication, virtual care, and remote monitoring and changes in legislation and policy. Do the KIs agree with this approach?
8. What important studies would the KIs suggest that we consider?

### **Questions for patient advocates**

1. What are the goals of patients and caregivers receiving person-centered HCBS and how do they define quality of service?
2. What concerns do patients, families, and caregivers have when seeking person-centered HCBS? What prevents them from seeking HCBS?
3. What burdens or harms do patients have regarding the use of HCBS compared with alternatives (such as nursing homes, long-term care)?

### **B. Gray Literature search.**

We will search the following sources for gray literature: U.S. Food and Drug Administration, ClinicalTrials.gov, Health Canada, U.K. Medicines and Healthcare Products Regulatory Agency (MHRA), conference proceedings, web search engines (Google), and Federal and State Government websites, patient advocate groups, and medical societies. In addition, a Supplemental Evidence and Data for Systematic Reviews (SEADS) portal will be available to

collect additional study-specific information from industry stakeholders, professional societies, and researchers. A Federal Register Notice will be posted for this review.

### C. Published Literature search.

We plan to conduct a comprehensive database search, including Embase®, Epub Ahead of Print, In-Process & Other Non-Indexed Citations, MEDLINE® Daily, MEDLINE®, Cochrane Central Registrar of Controlled Trials, Ovid® Cochrane Database of Systematic Reviews, and Scopus® from the year 2000 to the present. We have developed a preliminary database search strategy (Appendix A) and found that these databases can adequately identify the relevant literature. We will use relevant systematic reviews and meta-analyses to identify additional existing and new literature. Reference mining of relevant publications will be conducted. The search strategy will be peer-reviewed by an independent information specialist. An experienced librarian will conduct the search. An update using the same search strategy will be conducted during the draft report public comments stage to identify any new studies. All citations identified through the process will be imported to a reference management system (EndNote® Version X9; Thomson Reuters, Philadelphia, PA).

For abstract screening, we plan to use a validated Natural Language Processing (NLP) algorithm developed by DistillerSR® (Evidence Partners Incorporated, Ottawa, Canada). Each abstract will be screened by one human reviewer and the NLP technique with constant surveillance of possible misclassified citations for quality control. Consensus for inclusion and conflicts will be advanced for full-text screening. For full text screening, independent reviewers, working in pairs, will screen the full-text version of eligible references. Discrepancies between the reviewers will be resolved through discussions and consensus. If consensus cannot be reached, a third reviewer will resolve the difference.

We will apply the following inclusion and exclusion criteria for the studies identified from the published literature search, KI interviews, and peer and public reviews (Table 1). We will limit the literature to studies published in English and published after the year 2000. For Guiding Question 1, we will include RCTs, comparative observational studies, and systematic reviews/meta-analyses. For Guiding Questions 2 and 3, in addition, we will include narrative reviews, surveys, qualitative studies, and mixed-method studies. We plan to focus on studies conducted in the United States.

**Table 1. PICOTS (Populations, Interventions, Comparators, Outcomes, Timing, and Settings)**

PICOTS Elements	Inclusion Criteria	Exclusion Criteria
Population	<ul style="list-style-type: none"> <li>Adults aged 60 years or older with a functional limitation, requiring assistance with activities of daily living, regardless of payer source.</li> </ul>	<ul style="list-style-type: none"> <li>Animals</li> <li>Children</li> <li>Adults without disabilities</li> <li>Adults aged &lt;60 years, exclusively</li> </ul>

PICOTS Elements	Inclusion Criteria	Exclusion Criteria
<b>Interventions</b>	Person-centered HCBS, including the following person-centered approach, used alone or in combination: <ul style="list-style-type: none"> <li>• Occupational, speech, and physical therapy</li> <li>• Durable medical equipment</li> <li>• Case management (in home or via phone)</li> <li>• Caregiver and client training (training on skills to take care of a patient at home)</li> <li>• Health promotion and disease prevention (training to enabling people to increase control over, and to improve, their health like cook a healthier meal, or doing stretches to maintain flexibility again to prevent falls)</li> <li>• Hospice care</li> <li>• Senior centers and adult daycares</li> <li>• Congregate meal sites and home-delivered meal programs</li> <li>• Personal assistance such as dressing, bathing, toileting, eating, transferring to or from a bed or chair, etc.</li> <li>• Transportation and access including physical access to their homes (ramps, rails, etc.) or access to places (doctor's offices, etc.) or could also be access to healthcare setting (ride to the doctor's office).</li> <li>• Home repairs and modifications</li> <li>• Home safety assessments</li> <li>• Homemaker and chore services</li> <li>• Information and referral services (to clinical care or other community-based services)</li> <li>• Community integration services and day support</li> <li>• Behavioral health services</li> <li>• Financial services</li> <li>• Legal services, such as help preparing a will</li> <li>• Telephone reassurance</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
<b>Comparators</b>	<ul style="list-style-type: none"> <li>• Institutional care (nursing care, long-term care) without HCBS</li> <li>• No HCBS while living in the home or community</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Mortality</li> <li>• Time to nursing home placement</li> <li>• Patient satisfaction</li> <li>• Person-centered outcomes</li> <li>• Hospitalization, rehospitalization</li> <li>• Clinical outcomes (falls, disease-related outcomes)</li> <li>• Social isolation</li> <li>• Quality of life (see NQF HCBS Quality Domains Report)</li> <li>• Harms of the intervention</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
<b>Timing</b>	<ul style="list-style-type: none"> <li>• All</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
<b>Settings</b>	<ul style="list-style-type: none"> <li>• Home settings</li> <li>• Independent living</li> <li>• Assisted living</li> <li>• Studies conducted in the United States</li> </ul>	<ul style="list-style-type: none"> <li>• Nursing home</li> <li>• Healthcare setting</li> </ul>
<b>Subgroup analysis</b>	<ul style="list-style-type: none"> <li>• Geography</li> <li>• Race/ethnicity</li> <li>• Sex</li> <li>• Comorbidities</li> <li>• Social situations (community, home)</li> <li>• Clinical needs (includes activities of daily living as well as other needs to care for a person)</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>

PICOTS Elements	Inclusion Criteria	Exclusion Criteria
<b>Study design</b>	<ul style="list-style-type: none"> <li>• Guiding Question 1: <ul style="list-style-type: none"> <li>○ RCTs</li> <li>○ Comparative observational studies</li> <li>○ Systematic reviews or meta-analyses</li> </ul> </li> <li>• Guiding Questions 2-3: <ul style="list-style-type: none"> <li>○ RCTs</li> <li>○ Comparative observational studies</li> <li>○ Surveys</li> <li>○ Qualitative studies</li> <li>○ Mixed-method studies</li> <li>○ Narrative reviews</li> <li>○ Systematic review or meta-analysis</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• In vitro studies</li> <li>• Erratum</li> <li>• Editorials</li> <li>• Letters</li> <li>• Case reports/series</li> </ul>
<b>Publications</b>	<ul style="list-style-type: none"> <li>• Studies published in English as peer reviewed full-text articles</li> <li>• Studies published after Year 2000</li> <li>• Studies conducted outside of the United States</li> </ul>	<ul style="list-style-type: none"> <li>• Foreign language studies</li> <li>• Conference abstracts</li> </ul>

Abbreviations: HCBS = Home and Community Based Services; NQF = National Quality Forum; RCT = randomized clinical trials

## 2. Data Organization and Presentation:

### A. Information Management

We will develop a standardized data extraction form to extract study characteristics (author, year, study design, inclusion and exclusion criteria, patient characteristics, intervention, comparisons, outcomes, and related items for addressing the Guiding Questions). The standardized form will be tested by all study team members using randomly selected studies. We will supplement the extracted information with data derived from the KIs and gray literature. DistillerSR® will be used to create data extraction forms and facilitate data extraction.

### B. Data Presentation

Evidence tables will be presented to summarize the main findings by the Guiding Questions. We will use graphics and tables to examine distribution of the evidence and provide an evidence map. Additional information extracted from the KIs will be synthesized and presented narratively.

## IV. References

1. Centers for Disease Control and Prevention. Disability and Health Data System (DHDS). Centers for Disease Control and Prevention; 2023. <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>. Accessed on July 27 2023.
2. Roberts MA, Abery BH. A person-centered approach to home and community-based services outcome measurement. *Front Rehabil Sci*. 2023;4:1056530. doi: 10.3389/frsc.2023.1056530. PMID: 36817716.
3. Chenoweth L, King MT, Jeon YH, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol*. 2009 Apr;8(4):317-25. doi: 10.1016/S1474-4422(09)70045-6. PMID: 19282246.
4. Olsson LE, Karlsson J, Berg U, et al. Person-centred care compared with standardized care for patients undergoing total hip arthroplasty--a quasi-experimental study. *J Orthop Surg Res*. 2014 Oct 9;9:95. doi: 10.1186/s13018-014-0095-2. PMID: 25359278.

## V. Definition of Terms

ACL	Administration for Community Living
AHRQ	Agency for Healthcare Research and Quality
EPC	Evidence-based Practice Center
HCBS	Home and Community Based Services
KI	Key Informant
MHRA	Medicines and Healthcare Products Regulatory Agency
NCQA	National Committee for Quality Assurance
NQF	National Quality Forum
NLP	Natural Language Processing
PICOTS	Populations, Interventions, Comparators, Outcomes, Timing, and Settings
RCT	Randomized Clinical Trial
SEADS	Supplemental Evidence and Data for Systematic Reviews
U.K.	United Kingdom
U.S.	United States

## VI. Summary of Protocol Amendments

In the event of protocol amendments, the date of each amendment will be accompanied by a description of the change and the rationale.

## VII. Key Informants

Within the Technical Brief process, KIs serve as a resource to offer insight into the clinical context of the technology/intervention, how it works, how it is currently used or might be used, and which features may be important from a patient or policy standpoint. They may include clinical experts, patients, manufacturers, researchers, payers, or other perspectives, depending on the technology/intervention in question. Differing viewpoints are expected, and all statements are crosschecked against available literature and statements from other KIs. Information gained from KI interviews is identified as such in the report. KIs do not do analysis of any kind nor contribute to the writing of the report and will not review the report, except as given the opportunity to do so through the public review mechanism.

KIs must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals are invited to serve as KIs and those who present with potential conflicts may be retained. The Task Order Officer and the Evidence-based Practice Center (EPC) work to balance, manage, or mitigate any potential conflicts of interest identified.

## VIII. Peer Reviewers

Peer reviewers are invited to provide written comments on the draft report based on their clinical, content, or methodologic expertise. Peer review comments on the draft report are considered by the EPC in preparation of the final report. Peer reviewers do not participate in writing or editing of the final report or other products. The synthesis of the scientific literature

presented in the final report does not necessarily represent the views of individual reviewers. The dispositions of the peer review comments are documented and may be published three months after the publication of the Evidence report.

Potential Reviewers must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Invited Peer Reviewers may not have any financial conflict of interest greater than \$5,000. Peer reviewers who disclose potential business or professional conflicts of interest may submit comments on draft reports through the public comment mechanism.

## **IX. EPC Team Disclosures**

EPC core team members must disclose any financial conflicts of interest greater than \$1,000 and any other relevant business or professional conflicts of interest. Related financial conflicts of interest that cumulatively total greater than \$1,000 will usually disqualify EPC core team investigators.

## **X. Role of the Funder**

This project was funded through an intra-agency agreement under Contract No. 75Q80120D00005/75Q80123F32004 from the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services, and the Administration for Community Living, U.S. Department of Health and Human Services. The AHRQ Task Order Officer reviewed contract deliverables for adherence to contract requirements and quality. The authors of this report are responsible for its content. Statements in the report should not be construed as endorsement by the Agency for Healthcare Research and Quality, the Administration for Community Living, or the U.S. Department of Health and Human Services.