



# Effective Health Care Program

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Future Research Needs Paper  
Number 44

## **Long-Term Care for Older Adults: Future Research Needs**



Agency for Healthcare Research and Quality  
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# *Future Research Needs Paper*

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Number 44

## **Long-Term Care for Older Adults: Future Research Needs**

**Identification of Future Research Needs From Comparative Effectiveness Review No. 81**

**Prepared for:**

Agency for Healthcare Research and Quality  
U.S. Department of Health and Human Services  
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Rockville, MD 20850  
[www.ahrq.gov](http://www.ahrq.gov)

**Contract No. 290-2007-10064-I**

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**AHRQ Publication No. 13-EHC120-EF  
July 2013**

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None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.
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**Suggested citation:** Wysocki A, Butler M, Kane RL, Shippee T. Future Research Needs: Long-Term Care for Older Adults. Future Research Needs Paper No. 44. (Prepared by the University of Minnesota Evidence-based Practice Center under Contract No. 290-2007-10064-I). AHRQ Publication No.13-EHC120-EF. Rockville, MD: Agency for Healthcare Research and Quality; July 2013. [www.effectivehealthcare.ahrq.gov/reports/final.cfm](http://www.effectivehealthcare.ahrq.gov/reports/final.cfm).

## Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

An important part of evidence reports is to not only synthesize the evidence, but also to identify the gaps in evidence that limited the ability to answer the systematic review questions. AHRQ supports EPCs to work with various stakeholders to identify and prioritize the future research that is needed by decisionmakers. This information is provided for researchers and funders of research in these Future Research Needs papers. These papers are made available for public comment and use and may be revised.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality. The evidence reports undergo public comment prior to their release as a final report.

We welcome comments on this Future Research Needs document. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to [epc@ahrq.hhs.gov](mailto:epc@ahrq.hhs.gov).

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# Long-Term Care for Older Adults: Future Research Needs

## Structured Abstract

**Objectives.** To identify gaps in the current research on long-term care (LTC) for older adults that limited the conclusions of the comparative effectiveness review (CER) “Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care” in order to inform those who conduct and fund research about the research needs on this topic.

**Methods.** We used a deliberative process to identify specific research needs and research design considerations. We refined a list of evidence gaps from the CER and recruited a diverse stakeholder panel to supplement this list of gaps. Based on stakeholder feedback about the current policy environment and consumer preference for home and community-based services (HCBS), we developed two sets of research questions and separated each set into methodological questions and topical questions. The first set addressed the topic of the CER, which was the comparison of LTC for older adults delivered through HCBS and in nursing homes (NHs). The second set addressed broader LTC issues that stakeholders raised as salient for the current policy environment; this set framed questions about these settings and services separately rather than as a comparison. We sent both sets of research questions to stakeholders to rank by priority, and we calculated unweighted and weighted scores based on their rankings. We identified breakpoints in the weighted rankings that separated high- and moderate-/low-priority research questions. Highly prioritized research questions were considered research needs. We discussed research design considerations for research needs.

**Results.** Of 13 stakeholders invited to participate, 10 completed the ranking exercise. Among the methodological questions for the comparison of LTC delivered through HCBS and in NHs, the identification of standardized outcome measures for HCBS and NH recipients was the highest priority. For the broader set of methodological questions about LTC through HCBS and in NHs, the highest rankings were given to four questions related to outcome measures and descriptions of the interventions. For the topical questions for the comparison of LTC delivered through HCBS and in NHs, the highest rankings were given to questions related to the pattern of transitions for LTC uses, and the factors leading to transitions. We also identified four high-priority topical questions primarily related to the populations that benefit most from interventions and the types of interventions that lead to improved outcomes. Future studies on LTC for older adults should aim to reduce bias as much as possible through research design and statistical techniques. Larger sample sizes will allow more research on subpopulations, and longer followup times will allow a better understanding of how interventions may modify outcomes over time.

**Conclusions.** The clinical and policy context of LTC is changing. Comparative effectiveness may be less salient than understanding what makes such care effective in the first place for various client groups. Therefore, we reported research needs related to the comparison of HCBS and NH care that was the focus of the CER, and we also reported research needs from the broader set of questions that stakeholders deemed important within the current policy

environment. Future research in this area will create a broader and stronger evidence base for making care and policy decisions.



# Contents

<b>Executive Summary</b> .....	ES-1
<b>Background</b> .....	1
Context.....	1
Long-Term Care for Older Adults .....	1
Findings of the CER.....	6
Evidence Gaps .....	6
Methodological Research Gaps .....	6
Topical Research Gaps .....	7
<b>Methods</b> .....	8
Engagement of Stakeholders.....	8
Handling Conflicts of Interest.....	8
Refinement of Research Gaps.....	8
Prioritization .....	8
Research Design Considerations.....	10
<b>Results</b> .....	11
Research Needs.....	11
Prioritization Results.....	11
Methodological Research Needs.....	13
Topical Research Needs.....	14
Considerations for Potential Research Designs .....	16
<b>Discussion</b> .....	18
<b>Conclusions</b> .....	19
<b>References</b> .....	20
<b>Abbreviations</b> .....	21
 <b>Tables</b>	
Table 1. Stakeholder prioritization of research gap questions about the benefits and costs of care delivered through HCBS versus NHs.....	11
Table 2. Stakeholder prioritization of research gap questions about LTC through HCBS and in NHs.....	12
Table 3. Design considerations: What is the pattern of transitions of LTC users? What factors lead to transitions? .....	16
Table 4. Design considerations: What works for whom? How does HCBS affect different subpopulations/subgroups? .....	16
Table 5. Design considerations: How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare? .....	16
Table 6. Design considerations: What services within HCBS result in better outcomes for individuals? .....	17
Table 7. Design considerations: How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS? .....	17

**Figures**

Figure 1. Analytic framework corresponding to the Key Questions .....5  
Figure 2. Project flow .....10

**Appendixes**

Appendix A. Selection Criteria for New Research: Long-Term Care for Older Adults Research Needs  
Appendix B. Minnesota Evidence-based Practice Center (MN EPC) Long-Term Care for Older Adults Research Needs Project: Stakeholder Conference Call Information  
Appendix C. Minnesota EPC Long-Term Care for Older Adults Research Needs Stakeholder Meeting Agenda

# Executive Summary

## Background

This future research needs (FRN) report is a followup to the 2012 comparative effectiveness review (CER) “Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care.” The review was intended to support policy and research decisionmaking. FRN projects identify gaps in the current research that limit the conclusions in CERs and inform researchers and research funders about these gaps. They aim to encourage research likely to fill the gaps and make the body of evidence more useful to decisionmakers.

The CER addressed the following two Key Questions targeting direct comparisons of long-term care (LTC) provided through home and community-based services (HCBS) and in nursing homes (NHs) to older adults aged 60 and older:

**Key Question 1: What are the benefits and harms of LTC provided through HCBS compared with institutions such as NHs for older adults, aged 60 and older, who need LTC?**

- a. To what extent do HCBS and NHs serve similar populations?
- b. How do the outcomes of the services differ when tested on similar populations?
- c. What are the harms to older adults as a result of HCBS and NHs? (Reported harms include accidents, injuries, inadequate preventive care, unnecessary hospitalizations, and concerns about abuse or neglect.)

**Key Question 2: What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource use and family burden.**

- Direct costs of care refer to public program and individual spending on LTC services for HCBS recipients and NH residents.
- Resource use includes program and individual spending on acute care services such as physician and hospital care as well as spending by other subsidy or transfer programs.
- Family burden includes the opportunity costs of care.

LTC refers to a broad range of services designed to provide assistance over prolonged periods to compensate for loss of function due to chronic illness or physical or mental disability.<sup>1</sup> LTC includes hands-on, direct care as well as general supervisory assistance. HCBS refers to services provided in an array of noninstitutional settings. These include recipients’ homes; community-based group-living arrangements such as congregate housing, adult foster care, and residential care and assisted living (AL) facilities (the last two terms are sometimes used interchangeably, but we refer to AL exclusively); and community settings such as adult day care and adult day health. NHs are state-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care.

Results from relevant observational studies were qualitatively synthesized; no relevant randomized controlled trials (RCTs) were identified. The authors found that on average, NH residents had more limitations in physical and cognitive function than both HCBS recipients and AL residents, but mental health and clinical status were mixed. The studies that compared the

outcome trajectories of HCBS recipients or AL residents with NH residents over time had high risk of bias, resulting in low or insufficient evidence for all outcomes examined. In comparing AL with NH, low-strength evidence suggested no differences in outcomes for physical function, cognition, mental health, and mortality. In comparing HCBS with NHs, low-strength evidence suggested that HCBS recipients experienced higher rates of some harms while NH residents experienced higher rates of other harms. Evidence was insufficient for other outcome domains and comparisons. Evidence was also insufficient for cost comparisons.

Overall, the CER concluded that it is difficult to determine whether and how the delivery of LTC through HCBS versus NHs affects outcome trajectories of older adults due to scant evidence and the methodological limitations of studies reviewed. The authors concluded that more and better research is needed to draw robust conclusions about how care settings influence outcomes and costs of LTC for older adults.

## Methods

We used a deliberative process to identify specific research needs and research design considerations. First, we refined and developed a list of evidence gaps from the comparative effectiveness review (CER). Second, we recruited a diverse panel of stakeholders who represented a variety of perspectives relevant to the topic. We sought research representatives who were national experts familiar with evidence-based research and aware of the obstacles faced in conducting well-designed research in health services. We invited representatives from organizations supporting or conducting relevant research and/or programs including the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, the Visiting Nurse Service of New York, LeadingAge, and others, as well as policy and payer representation from the U.S. Centers for Medicare & Medicaid Services (CMS). We engaged consumer and provider groups, including AARP and the National Center for Assisted Living, because the decisional dilemmas faced by these groups are critical to identifying and prioritizing research questions. Many stakeholders were also involved in the CER process as Key Informants, technical expert panel members, or peer reviewers. A total of 13 stakeholders across these groups responded to our invitation and expressed an interest in participating in this project.

We then held conference calls with stakeholders to refine the research gaps identified in the CER. We revised the preliminary research gaps based on our stakeholder discussions and phrased the identified gaps as research questions.

Many stakeholders raised the important question of whether research should continue to compare the relative effectiveness of HCBS and NH care given the changes in social thinking that have occurred and the preference in most cases for HCBS. Based on the stakeholder feedback, we grouped research questions into two major sets that we further divided into methodological questions and topical questions. The first set addressed the narrow issue that was the topic of the CER—the comparison of LTC delivered through HCBS and in NHs. The second set addressed broader LTC issues that stakeholders (and reviewers from the CER) raised as salient for the current policy environment. The second set did not frame research questions as a comparison of HCBS and NHs, but rather, treated these settings and services separately.

We sent the two sets of research questions to stakeholders and asked them to rank the questions by priority. For the first set of research questions addressing the comparison of HCBS with NHs, stakeholders numerically ranked their top three of seven methodological research questions, and their top one of three topical research questions. For the second set of broader research questions on LTC for older adults, stakeholders numerically ranked their top 4 of 11

methodological research questions, and their top 5 of 12 topical research questions. We calculated unweighted and weighted scores based on their rankings. We identified breakpoints in the weighted rankings that separated high- and moderate-/low-priority research questions. Highly prioritized research questions were considered research needs. We discussed research design considerations for research needs.

## Results

Of 13 invited stakeholders, 10 completed the ranking exercise.

### Methodological Research Needs

Among the methodological questions for the comparison of LTC delivered through HCBS and in NHs, the number one priority was the identification of standardized outcome measures for HCBS and NH recipients. Eight of 10 stakeholders ranked this as a priority. For the broader set of methodological questions about LTC through HCBS and in NHs, the most highly ranked were four questions related to outcome measures and descriptions of the interventions.

- What standardized outcome measures should be used for HCBS and NH recipients that fully measure benefits and harms and are capable of showing meaningful change?
- What should be included in a taxonomy of HCBS, and how do we measure a “service” to enable research across different types of HCBS?
- What is the minimum set of potential outcomes for HCBS and NH recipients? For example, outcomes may include abuse, loneliness (as an intermediate outcome that could predict institutionalization), and transitions (likelihood of being discharged from a NH after an individual enters a NH, likelihood of going back to a NH after discharge from the NH, and likelihood of being rehospitalized after experiencing a hospitalization).
- What quality-of-life measures and disease-specific measures should be used to capture an individual’s experience in LTC?
- What should be included in a taxonomy for assisted living to assess the effectiveness of services and to compare to other HCBS?

Addressing methodological research needs will enhance the utility of future research on LTC for older adults. The methodological research needs identified by stakeholders as the highest priorities pertain to the outcome measures that are appropriate within these care settings and important to care recipients and to the definition of services that individuals receive.

The CER highlighted that comparing results was difficult because studies used different outcome measures and methods of data collection. The differences in care environments, including which measurements are used and who collects the data, may impact results. These differences can make it challenging to determine whether different effects across different studies are due to outcome measurement issues or other issues. Stakeholders also indicated that finding standardized outcome measures is an important priority. Additionally, the CER and stakeholders stressed the importance of examining outcomes that measure an individual’s experience across multiple domains, including outcomes that are most important to individuals when they choose between care settings. There was insufficient evidence for most outcomes examined in the CER, including outcomes related to quality of life and experience of care. Consensus on outcome measures would improve future research and the ability to understand how different types of LTC affect outcomes of older adults.

The CER emphasized that most studies did not sufficiently describe the settings and services received, and few studies specified the type, frequency, or intensity of services. The nature of HCBS and AL services can vary widely, so a description of services is necessary to judge applicability. Our discussions with stakeholders, and the results of the ranking process, indicate that creating and using a standardized taxonomy for HCBS and AL is important to understanding research on these types of care. CMS has been working with contractors to produce a taxonomy of services ([www.nasuad.org/documentation/hcbs2011/Presentations/W10RegencyA.pdf](http://www.nasuad.org/documentation/hcbs2011/Presentations/W10RegencyA.pdf)). Using this taxonomy in future research will increase the usefulness and comparability of research efforts.

## Topical Research Needs

The highest priority ranked among the topical gaps for the comparison of LTC delivered through HCBS and in NHs related to the pattern of transitions and the factors leading to transitions for LTC users. We also identified four high-priority topical questions to address for LTC delivered through HCBS and in NHs. All topical research needs primarily addressed populations and interventions.

- What is the pattern of transitions of LTC users? What factors lead to transitions?
- What works for whom? How does HCBS affect different subpopulations/subgroups?
- How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare?
- What services within HCBS result in better outcomes for individuals?
- How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS?

LTC users commonly transition through different settings as needs and preferences change, but evidence from the CER suggests that these transitions are rarely characterized or modeled in studies. Studies infrequently follow individuals as they move in and out of different settings, and they are often not explicit about individuals' transitions over time or factors that led to transitions. Stakeholders indicated that understanding LTC users' transitions would help us develop interventions to avoid or improve transitions.

No studies evaluated in the CER addressed outcomes for subgroups. Stakeholders rated the understanding of the efficacy of different interventions for different subgroups as an important priority. Subgroups might be defined by characteristics such as race/ethnicity, socioeconomic status, and diagnoses. In our discussions, many stakeholders indicated the need to better understand managed LTC programs, including how outcomes and costs compare for managed LTC users compared to fee-for-service users. From a policy and payer perspective, this resonated as a particularly salient research question.

Stakeholders were particularly interested in understanding how different services within the package of HCBS improve outcome trajectories for individuals. They were also interested in how the policy and payment environment affects HCBS and NH use. These topics were rated as high priorities to address in future research.

## Considerations for Potential Research Design

Randomization can increase the likelihood that HCBS and NH populations are comparable on measured as well as unmeasured factors. However, randomization to HCBS versus NH or to AL versus NH is generally precluded for practical and ethical reasons. Those with a strong preference for community care would be unlikely to accept a NH placement, and many individuals who believe they need NH care have already decided to enter a NH.

While RCTs are not likely to be used for the HCBS versus NH comparison, stakeholders suggested that RCTs could be used to compare the effects of variations of HCBS. Randomization would allow for more robust research about the efficacy of different type of services within HCBS and about the efficacy of HCBS for different subgroups.

RCTs are expensive and difficult to implement, and therefore unlikely to be widely used in this topic area. Moreover, there is likely to be a strong sampling bias in who agrees to be randomized, raising questions about applicability. Cohort studies are less resource intensive and produce applicable results. Longitudinal cohort studies follow individuals over a period of time and would be practical to examine the outcome trajectories of LTC users. Large sample sizes will be necessary to allow for subgroup and interaction analyses, but this is easier to attain in cohort studies than in RCTs.

Prospective cohort studies enroll and follow patients over time to assess outcomes. Because individuals within an LTC setting are at different points on an outcome trajectory, it can be difficult to understand how interventions may modify the trajectory. Using an LTC admission cohort with a prospective cohort design would allow researchers to follow individuals along their entire trajectory for a defined period of time. This type of design would indicate how the intervention does or does not modify outcomes over time. The ability of this design to assess differences can be improved by using consistent measures and observation schedules and by ensuring data is collected by independent observers.

Like RCTs, cohort studies can be costly and there can be issues with attrition as individuals are lost over time. The lack of randomization may also create potential selection bias. Therefore, studies need to use statistical techniques to adjust for selection to ensure that the comparisons between groups are unbiased. These techniques include multivariate analysis, propensity scores, instrumental variables, and frontier analysis.<sup>2</sup> Frontier analysis identifies groups with specific clusters of key patient characteristics that pertain to a specific health issue. Factors considered for adjustment should include LTC attitudes held by both clinicians and consumers and availability of informal support. Studies should adjust for case mix and account for changes in the composition of the populations that result from deaths or transfers to different settings.

In discussions with stakeholders, other research design considerations that were mentioned included the need for studies with more generalizable samples and populations of private pay LTC users.

## Discussion

This FRN project refined and prioritized research needs relevant to the Key Questions addressed in the CER “Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care.” We refined and developed a list of evidence gaps from the CER, including methodological gaps that limited the utility of the current research and topical gaps that limited conclusions about efficacy and comparative effectiveness of LTC for older adults delivered through HCBS and in NHs. We used a deliberative process to refine and

expand our set of research gaps through conversations with stakeholders who represented diverse perspectives of expertise on the topic. Our stakeholder group included researchers, research and funding organizations, payers, providers, and consumer groups. Some stakeholders offered two or more perspectives. We revised the preliminary research gaps based upon these discussions and phrased the identified gaps as research questions.

Our stakeholder group raised an important question early: given the changes in social thinking about the relative roles of institutional care and HCBS, should further research continue to address relative effectiveness or should it assume that HCBS is preferable in most situations? Based on the stakeholder feedback, we grouped research questions into two major sets, each of which was further subdivided into methodological questions and topical questions. The first set addressed the narrow issue that was the topic of the CER—the comparison of LTC delivered through HCBS and in NHs. The second set addressed broader LTC issues that stakeholders raised as salient for the current policy environment. Stakeholders then ranked research questions, and the most highly ranked questions were deemed research needs.

Addressing methodological research needs will enhance the utility of future research on LTC for older adults. A standardized set of patient-centered outcomes, with guidance on interpreting changes in outcomes, will provide researchers with an approach to determine the effectiveness of various types of LTC. The quality of the evidence will also be enhanced if researchers use a standardized definition of LTC services. Following consensus on these issues, more comparable studies on LTC for older adults should become available.

Topical research priorities reflected the need to better understand which interventions are effective for which populations. Identifying how subpopulations are affected by different interventions and which services are most effective will help consumers and policymakers choose better modes of care. Characterizing LTC users' transitions will improve research about the most effective type and timing of interventions.

Future studies on LTC for older adults should aim to reduce bias as much as possible, using research design and statistical techniques. Larger sample sizes will allow more research on subpopulations, and longer followup times will allow a better understanding of how interventions may modify outcomes over time.

It should be noted that the prioritized research needs reflect the opinions of these stakeholders and may not be generalizable to the population of stakeholders on this topic.

## Conclusions

We identified specific research needs that should be useful in future efforts to address the effectiveness of LTC for older adults delivered through HCBS and in NHs. The clinical and policy context of LTC is changing. Comparative effectiveness may be less salient than understanding what makes such care effective in the first place for various client groups. Therefore, we reported research needs related to the comparison of HCBS and NH care that was the focus of the CER, and we also reported research needs from the broader set of questions that stakeholders felt were more important priorities in the current policy environment. Future research in this area will create a broader and stronger evidence base for making care and policy decisions:

- What standardized outcome measures should be used for HCBS and NH recipients that fully measure benefits and harms and are capable of showing meaningful change?
- What should be included in a taxonomy of HCBS and how do we measure a “service” to enable research across different types of HCBS?



- What is the minimum set of potential outcomes for HCBS and NH recipients? For example, outcomes may include abuse, loneliness as an intermediate outcome that could predict institutionalization, transitions (likelihood of being discharged from a NH after an individual enters an NH, likelihood of going back to an NH after discharge from the NH, and likelihood of being rehospitalized after experiencing a hospitalization).
- What quality-of-life measures and disease specific measures should be used to capture an individual's experience in LTC?
- What should be included in a taxonomy for assisted living to assess the effectiveness of services and to compare to other HCBS?
- What is the pattern of transitions of LTC users? What factors lead to transitions?
- What works for whom? How does HCBS affect different subpopulations/subgroups?
- How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare?
- What services within HCBS result in better outcomes for individuals?
- How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS?

## Glossary

AL	Assisted living
CER	Comparative Effectiveness Review
CMS	Centers for Medicare & Medicaid Services
FRN	Future research needs
HCBS	Home and community-based services
LTC	Long-term care
NH	Nursing home
RCT	Randomized controlled trial

## References

1. Feder J, Komisar HL, Niefeld M. Long-term care in the United States: an overview. *Health Affairs*. 2000;19(3):40-56. PMID: 10812780.
2. Johnson PE, Veazie PJ, Kochevar L, et al. Understanding variation in chronic disease outcomes. *Health Care Manag Sci*. 2002 Aug;5(3):175-89. PMID: 12363045.

# Background

## Context

This future research needs (FRN) report is a followup to the 2012 comparative effectiveness review (CER) “Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care.” The CER was conducted by the Minnesota Evidence-based Practice Center (EPC) to compare long-term care (LTC) for older adults delivered through home and community-based services (HCBS) with care provided in nursing homes (NHs) by evaluating (1) the characteristics of older adults served through HCBS and in NHs, (2) the impact of HCBS and NH care on outcome trajectories of older adults, and (3) the per-person costs of HCBS and NH care as well as costs for other services such as acute care and family burden. The review was intended to support policy and research decisionmaking. FRN projects identify gaps in the current research that limit the conclusions in CERs and inform researchers and research funders about these gaps. They aim to encourage research likely to fill the gaps and make the body of evidence more useful to decisionmakers.

## Long-Term Care for Older Adults

LTC refers to a broad range of services designed to provide assistance over prolonged periods to compensate for loss of function due to chronic illness or physical or mental disability.<sup>1</sup> LTC includes hands-on, direct care as well as general supervisory assistance. The type, frequency, and intensity of services vary; some people need assistance for a few hours each week, whereas others need full-time support. LTC differs from acute or episodic medical interventions because it is integrated into an individual’s daily life over an extended time.<sup>2</sup>

HCBS refers to services provided in an array of noninstitutional settings. These include recipients’ homes; community-based group-living arrangements such as congregate housing, adult foster care, and residential care and assisted living (AL) facilities (the last two terms are sometimes used interchangeably, but we refer to AL exclusively); and community settings such as adult day care and adult day health. Services provided via HCBS include care coordination or 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 services, telephone reassurance services, emergency help lines, equipment rental and exchange, and transportation. Care through HCBS also includes educational and supportive group services for consumers or their families. Some aspects of HCBS are construed as respite care meant to relieve family caregivers. For the review, AL was examined as a separate subset of HCBS because it encompasses aspects of both community-based and institutional care.

NHs are state-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care. NH services may include personal care, support for activities of daily living, medical management, nursing management, medication management, restorative nursing, palliative care, physical rehabilitation (either as a short-term service associated with postacute care or as maintenance rehabilitation), social activities, and transportation.

The CER addressed the following two Key Questions targeting direct comparisons of LTC provided through HCBS and in NHs to older adults aged 60 and older:

**Key Question 1: What are the benefits and harms of LTC provided through HCBS compared with institutions such as NHs for older adults, aged 60 and older, who need LTC?**

- a. To what extent do HCBS and NHs serve similar populations?
- b. How do the outcomes of the services differ when tested on similar populations?
- c. What are the harms to older adults as a result of HCBS and NHs? (Reported harms include accidents, injuries, inadequate preventive care, unnecessary hospitalizations, and concerns about abuse or neglect.)

**Key Question 2: What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource use and family burden.**

- Direct costs of care refer to public program and individual spending on LTC services for HCBS recipients and NH residents.
- Resource use includes program and individual spending on acute care services such as physician and hospital care as well as spending by other subsidy or transfer programs.
- Family burden includes the opportunity costs of care.

The population included in the CER were older adults (age  $\geq 60$ ) receiving LTC either through HCBS or in NHs. The age ceiling was adjusted for the Program of All-Inclusive Care for the Elderly (PACE), which begins eligibility at age 55. Figure 1 displays the analytic framework for the CER.

Patient characteristics that could modify outcomes included age, race/ethnicity, sex, socioeconomic status, functional status, clinical status, cognition, rural/urban, morbidities, mental illness, payer, prior service use, and disability history. Studies focusing on postacute care, such as Medicare home health services, were not included. Postacute care is care provided to individuals discharged from a hospital; it aids in their recuperation and rehabilitation and typically lasts less than 30 days.

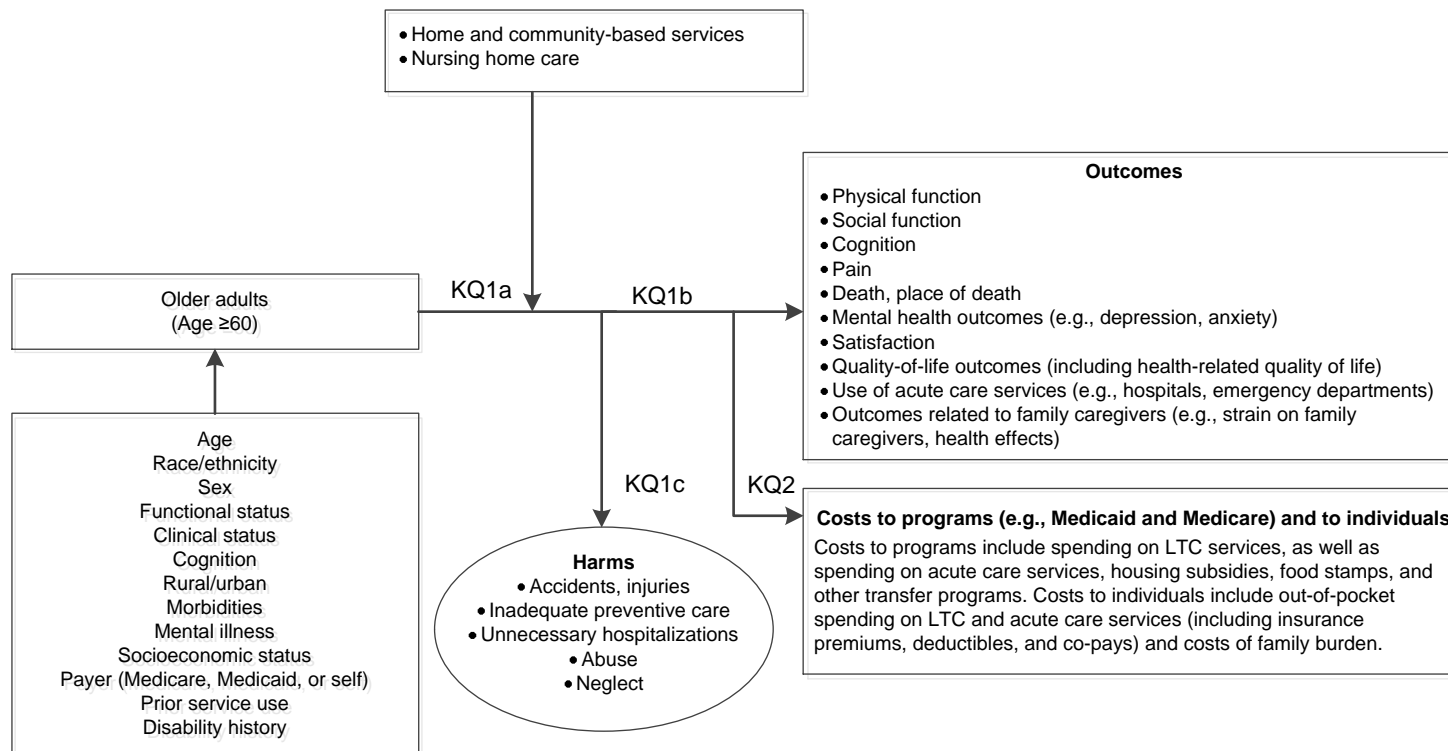
Resident outcomes and costs were examined separately. Data from cross-sectional studies were used to compare the characteristics of HCBS recipients and NH residents, and data from longitudinal studies were used to assess change in outcomes over time between HCBS recipients and NH residents. Cross-sectional studies compare outcomes across settings at a specific point in time; whereas longitudinal studies compare changes in outcomes over a defined time period from 6 months to 5 years.

Outcomes of interest included physical function, mental health outcomes (e.g., depression and anxiety), quality of life, social function, satisfaction, outcomes related to family caregivers, death, place of death, use of acute care services (e.g., hospitals, emergency departments), and harms such as accidents, injuries, pain, abuse, and neglect.

For the examination of costs, all relevant costs to programs such as Medicaid and other public programs and costs to individuals and their families were considered. These costs included spending on LTC services, acute care services, and transfer programs, and opportunity costs to family caregivers.

The review included studies published in English from 1995 to March 2012. Published and grey literature from the United States and published literature from economically developed countries with well-established health and LTC systems were examined.

**Figure 1. Analytic framework corresponding to the Key Questions**



KQ = Key Question; LTC = long-term care

## **Findings of the CER**

Results from relevant observational studies were qualitatively synthesized; no relevant randomized controlled trials (RCTs) were identified. The authors found that on average, NH residents had more limitations in physical and cognitive function than both HCBS recipients and AL residents, but mental health and clinical status were mixed. The studies that compared the outcome trajectories of HCBS recipients or AL residents with NH residents over time had high risk of bias, resulting in low or insufficient evidence for all outcomes examined. In comparing AL with NH, low-strength evidence suggested no differences in outcomes for physical function, cognition, mental health, and mortality. In comparing HCBS with NHs, low-strength evidence suggested that HCBS recipients experienced higher rates of some harms while NH residents experienced higher rates of other harms. Evidence was insufficient for other outcome domains and comparisons. Evidence was also insufficient for cost comparisons.

Overall, it was concluded that determining whether and how the delivery of LTC through HCBS versus NHs affects outcome trajectories of older adults is difficult due to scant evidence and the methodological limitations of studies reviewed. The authors concluded that more and better research is needed to draw robust conclusions about how the setting of care delivery influences outcomes and costs of LTC for older adults.

## **Evidence Gaps**

Because evidence was low-strength or insufficient for all outcomes examined, the CER included recommendations to improve future research on LTC for older adults. We refined and developed a list of evidence gaps from the CER. This preliminary set of research gaps (below) are separated into two categories: (1) methodological research gaps that need to be addressed to enhance the usefulness of current research, and (2) topical research gaps that have not been sufficiently addressed within the current literature.

### **Methodological Research Gaps**

#### **Reporting Issues**

##### **Recommendations from CER**

- Need detailed descriptions of the settings and services, including the nature and extent of services, for the intervention and comparison groups.
- Need to characterize the composition of persons served through HCBS and in NHs using standardized measures and systematic data collection.

#### **Measurement Issues**

##### **Recommendations from CER**

- Need to use standardized outcome measures for both HCBS and NH recipients that are capable of showing meaningful change.
  - Measure outcomes at appropriate and comparable intervals of time.
  - Utilize measurements that fully measure benefits and harms, including psychological and social benefits and harms.

- Use standardized measures of quality-of-life and social function that are applicable to both HCBS and NH settings.
- Need to make cost comparisons that account for LTC costs and all other relevant costs, including the cost of room and board, costs of public subsidies (rent, transportation, and food stamps), cost of informal care provided by family members, and costs for other public programs such as Medicare.

## **Design Issues**

### **Recommendations from CER**

- Need to take floor and ceiling effects into consideration when examining declines in function and cognition.
- Need to make efforts to adjust for selection bias.
  - Methods include propensity score analysis, instrumental variables analysis, “frontier analysis,” multivariate analysis.
  - Include measures of social support and attitudes.
- Need to deal with attrition, particularly attrition due to death.
  - Modeling death as worst functional case or using two-stage models.
- Need to account for persons moving from one type of care to another.

## **Topical Research Gaps**

### **Recommendations from CER**

- Need longitudinal studies that examine change in status over time.
  - Use admission cohorts and follow recipients through various stages of LTC service use.
- Need more generalizable samples.
- Need to focus on differences within subgroups, defined by diagnosis, functional capacity, socioeconomic indicators, and access to care.
- Need to define and weight outcomes.
  - Determining what type of care is best requires weighting the multiple possible outcomes, in which the outcomes are multidimensional.
- Need more studies that focus on non-Medicaid populations, specifically private pay clients.

## Methods

This FRN report identifies and prioritizes specific gaps in the current literature on LTC for older adults to encourage researchers and funders to fill these gaps in order to make the body of evidence more useful to decisionmakers. We used a deliberative process to identify specific research needs and research design considerations. Figure 2 illustrates the eight steps used to accomplish the objectives of this project.

### Engagement of Stakeholders

We recruited a diverse panel of stakeholders panel who represented a variety of perspectives relevant to the topic. We followed guidance on stakeholder engagement for recruitment and communication.<sup>3</sup> We sought to recruit stakeholders who were actively involved in research on LTC for older adults or providing LTC for older adults and who wished to help shape future research priorities. We identified potential stakeholders via several means. We sought recommendations from the CER project team, including select Key Informants and Technical Expert Panel members. We sought research representatives who were national experts familiar with evidence-based research and aware of the obstacles faced in conducting well-designed research in health services. We invited representatives from organizations supporting or conducting relevant research and/or programs including the Office of the Assistant Secretary for Planning and Evaluation, the Visiting Nurse Service of New York, LeadingAge and others, as well as policy and payer representation from the Centers for Medicare & Medicaid Services (CMS). We engaged consumer and provider groups, including AARP and the National Center for Assisted Living, because the decisional dilemmas faced by these groups are critical to identifying and prioritizing research questions. Many stakeholders were also involved in the CER process as Key Informants, Technical Expert Panel members, or peer reviewers. A total of 13 stakeholders across these groups responded to our invitation and expressed an interest in participating in this project.

### Handling Conflicts of Interest

We collected disclosures of conflicts of interests from all stakeholders. Disclosed interests did not bar any stakeholders from participation, but allowed the EPC to evaluate contributions based upon possible conflicts. Stakeholders used a Web-based survey to rank specific topical research questions during the prioritization exercise, thus researchers and funders were blind to the others' stated opinions.

### Refinement of Research Gaps

We provided members of our stakeholder panel with a preliminary set of research gaps prior to conference calls. During conference calls, we sought stakeholder input to further refine the research gaps (i.e., organization and wording of the gaps, identification of additional research gaps, and elimination of research gaps with limited value). To facilitate this input, we provided stakeholders in advance with background material including the draft CER executive summary and the Effective Health Care Program Selection Criteria (Appendix A, Appendix B, and Appendix C). We conducted two conference calls with available stakeholders in April 2012. Of the 13 stakeholders who

responded to our invitation, 11 were able to participate in the calls. All participants provided input on the calls. We circulated summaries of group calls to all participants, including the two additional stakeholders who were unable to participate in the conference calls. We invited stakeholders to clarify or supplement the call summaries or to suggest additional research questions in response to the call summaries, and one did so via email. We revised the preliminary research gaps based upon these discussions and email communications and phrased the identified gaps as research questions.

Many stakeholders raised the important question of whether research should continue to compare the relative effectiveness of HCBS and NH care given the changes in social thinking that have occurred and the preference in most cases for HCBS. Based on the stakeholder feedback, we grouped research questions into two major sets, each of which was further divided into methodological questions and topical questions. The first set addressed the narrow issue that was the topic of the CER—the comparison of LTC delivered through HCBS and in NHs. The second set addressed broader LTC issues that stakeholders (and reviewers from the CER) raised as salient for the current policy environment. The second set did not frame research questions as a comparison of HCBS and NHs, but rather, treated these settings and services separately.

## **Prioritization**

We and our stakeholders evaluated the revised set of research questions according to specified criteria. The Effective Health Care Program Selection Criteria provided a starting point (Appendix A), including Current Importance, Potential Impact, Incremental Value, and Feasibility. The Current Importance (Appropriateness) criteria are de facto met because LTC for older adults was accepted as an AHRQ topic.

We addressed redundancy by updating the bibliographic search for the CER through March 2012 and by checking suggested studies from reviewers of the CER.

We then asked stakeholders to rank the research questions focusing on the Potential Impact criteria (i.e., the likelihood that addressing the research gap question would inform clinical practice and policy). We developed a Web-based survey using SurveyMonkey™ to collect stakeholder prioritization of the research gap questions.<sup>4</sup> The 13 stakeholders who responded to the stakeholder invitation (9 were non-Federal employees) were invited to rank research questions identified via the stakeholder conference calls. For the first set of research questions addressing the comparison of HCBS with NHs, these stakeholders numerically ranked their top three of seven methodological research questions, and their top one of three topical research questions. For the second set of broader research questions on LTC for older adults, these stakeholders numerically ranked their top 4 of 11 methodological research questions, and their top 5 of 12 topical research questions.

Unweighted scores were calculated based on a count of the number of stakeholders voting for a research question, regardless of the number ranking that they assigned to the research question. Weighted scores were also calculated. Stakeholder rankings were weighted according to their assigned numerical ranking. If a stakeholder assigned a question the number one priority, that question received the highest number of points for that specific set (e.g., for the set where stakeholders ranked their top three priorities, the number one priority received three points and for the set where stakeholders ranked their top four priorities, the number one priority received five points). Each subsequent number



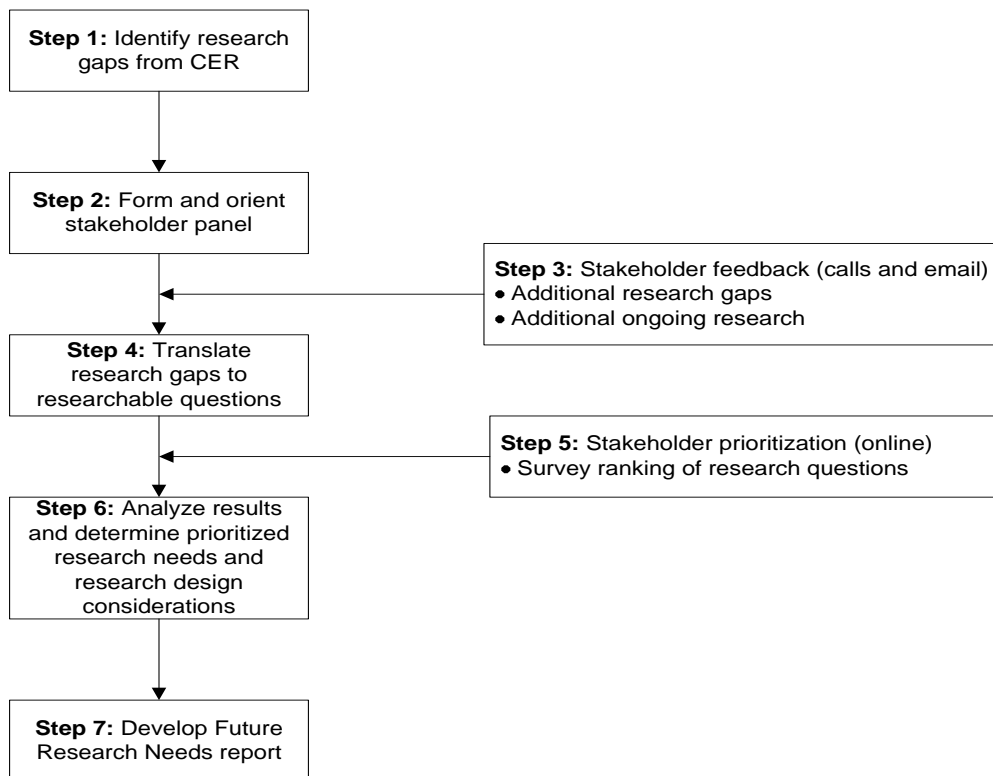
ranking was assigned a point value decreasing by one point for each rank. We identified breakpoints in the weighted rankings that separated high and moderate/low priority research questions. Highly prioritized research questions were considered research needs.

We then evaluated the Feasibility criteria for research needs. We framed Feasibility in terms of anticipated research designs. For example, factors that affect the feasibility of conducting randomized controlled trials include the sample size needed for the outcome, the size of the available pool of potential subjects, followup duration, willingness to randomize, and applicability issues. In contrast to randomization and applicability, observational studies face feasibility issues related to measuring study variables using different data sources and unobserved variables that create risk of bias.

## Research Design Considerations

We generated research design considerations for identified research needs. We provided context and described resources and research design considerations potentially useful to researchers, facilitators, and funders of this type of research. For topical research needs, we also highlighted the relevant PICOTS (population, intervention, comparison, outcome, timing, setting) element(s). We did not separately consult with stakeholders for input on research design considerations. However, we incorporated stakeholder feedback from conference calls and email communications that related to research design considerations.

**Figure 2. Project flow**



CER = comparative effectiveness review

# Results

## Research Needs

### Prioritization Results

Many stakeholders raised the important question of whether research should continue to compare the relative effectiveness of HCBS and NH care given the changes in social thinking that have occurred and the preference in most cases for HCBS. Stakeholders discussed a number of research questions about HCBS and NH care that they felt are relevant but do not compare the relative effectiveness of HCBS and NH care. In order to address the issues that stakeholders felt are most important for future research on LTC for older adults, we grouped research questions into two major sets, each of which was further divided into methodological questions and topical questions. The first set addressed the comparison of LTC delivered through HCBS and in NHs. The second set addressed broader LTC issues by treating HCBS and NHs separately, rather than as a comparison. Stakeholders separately ranked methodological and topical research questions for the two sets of identified research questions. We discuss results for each set of ranked questions. A total of 10 stakeholders, out of the 13 who were invited to participate, completed the ranking exercise. Participating stakeholders included representatives from all groups that we engaged in the process. We analyzed weighted stakeholder rankings for each research question to identify breakpoints (Tables 1 and 2). High-priority methodological research questions and high-priority topical research questions were deemed research needs.

**Table 1. Stakeholder prioritization of research gap questions about the benefits and costs of care delivered through HCBS versus NHs**

Research Gap Questions	Ranking Total (Points)*
<b>Methodological Questions (n=10)</b>	
<b>Tier 1: High Priority</b>	
What standardized outcome measures should be used for HCBS and NH recipients that fully measure benefits and harms and are capable of showing meaningful change?	8 (19)
<b>Tier 2: Moderate/Low Priority</b>	
How should we characterize the settings and services and the composition of persons served for the intervention?	4 (11)
What sources of payment for HCBS should be included to assure a fair comparison of costs?	4 (8)
How should floor and ceiling effects be taken into account when examining decline in certain outcomes like function or cognition?	5 (7)
How should attrition be dealt with, particularly attrition due to death?	4 (6)
How should we adjust for selection bias (methods such as propensity scores, instrumental variables, and "ideal types")?	3 (6)
How should we account for persons moving from one type of care to another?	2 (3)

<b>Topical Questions (n=10)</b>	<b>Total (Points)*</b>	<b>PICOTS Element</b>
<b>Tier 1: High Priority</b>		
What is the pattern of transitions of LTC users? What factors lead to transitions?	6 (6)	P, O
<b>Tier 2: Moderate/Low Priority</b>		
How does HCBS versus NH care differ for subgroups?	2 (2)	
What are the benefits and costs of HCBS versus NH care for non-Medicaid recipients?	2 (2)	

HCBS = home and community-based services; LTC = long-term care; NA = not applicable; NH = nursing home

\*The first number reflects the total number of individuals who ranked the item. The second number (in parentheses) reports the weighted total point score. For the methodological topics, stakeholders ranked their top 3 priorities so the total point score was created by assigning questions ranked #1 by stakeholders with 3 points, #2 by stakeholders with 2 points, and #3 by stakeholders with 1 point. . For the topical questions, stakeholders ranked their top 1 priority so the total point score was created by assigning the question ranked #1 by stakeholders with 1 point.

**Table 2. Stakeholder prioritization of research gap questions about LTC through HCBS and in NHs**

<b>Research Gap Questions Ranking</b>	<b>Ranking Total (Points)*</b>
<b>Methodological Questions (n=10)</b>	
<b>Tier 1: High Priority</b>	
What should be included in a taxonomy of HCBS and how do we measure a 'service' to enable research across different types of HCBS?	6 (17)
What is the minimum set of potential outcomes for HCBS and NH recipients? For example, outcomes may include abuse, loneliness as an intermediate outcome that could predict institutionalization, transitions (likelihood of being discharged from a NH after an individual enters a NH, likelihood of going back to a NH after discharge from the NH, and likelihood of being rehospitalized after experiencing a hospitalization).	4 (16)
What quality-of-life measures and disease specific measures should be used to capture an individual's experience in LTC?	6 (14)
What should be included in a taxonomy for assisted living to assess the effectiveness of services and to compare to other HCBS?	4 (12)
<b>Tier 2: Moderate/Low Priority</b>	
How should ADLs and IADLs be measured to accurately assess service needs and outcomes within different environments?	3 (9)
Which set of marginal benefits and marginal costs of the care should be assessed in HCBS research?	4 (8)
What can be added to current administrative data or surveys to facilitate research on LTC?	5 (7)
What information do we need to develop better risk adjusters in order to make comparisons across different HCBS programs?	3 (7)
How do we collect and combine information across all transitions in LTC?	3 (6)
What could be used as a standardized tool to collect case-mix and outcomes data on HCBS recipients? For example, can the Medicare CARE Tool be used for HCBS programs?	1 (3)
What sources of payment for HCBS should be included to assure a fair comparison of costs?	1 (1)

<b>Topical Questions (n=10)</b>	<b>Total (Points)*</b>	<b>PICOTS Element</b>
<b>Tier 1: High Priority</b>		
What works for whom? How does HCBS affect different subpopulations/subgroups?	7 (27)	P, I
How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare?	9 (26)	P, I, O
What services within HCBS result in better outcomes for individuals?	6 (21)	I
How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS?	5 (19)	P, S
<b>Tier 2: Moderate/Low Priority</b>		
How does increasing burden on families affect individuals staying in home and community settings?	5 (14)	
What is the pattern of hospital admissions and readmissions for LTC users in various settings?	5 (13)	
What is the pattern of transitions of LTC users? What factors lead to transitions?	4 (13)	
How does staff turnover in different settings impact quality of care for LTC recipients?	3 (7)	
Can case management improve HCBS outcomes?	3 (4)	
How is training of the workforce related to quality of care in HCBS? (There is variation across settings in what services are being delivered and how the services are implemented by care providers.)	1 (3)	
How does NH environment and design affect quality of care and health outcomes of residents?	1 (2)	
What is the use and role of technology (for information and assistance) in LTC? How does it impact outcomes?	1 (1)	

LTC = long-term care; HCBS = home and community-based services; NA = not applicable; NH = nursing home

\*The first number reflects the total number of individuals who ranked the item. The second number (in parentheses) reports the weighted total point score. For the methodological topics, stakeholders ranked their top 4 priorities so the total point score was created by assigning questions ranked #1 by stakeholders with 4 points, #2 by stakeholders with 3 points, #3 by stakeholders with 2 points, and #4 by stakeholders with 1 point. For the topical questions, stakeholders ranked their top 5 priorities so the total point score was created by assigning the question ranked #1 by stakeholders with 5 points, #2 by stakeholders with 4 points, #3 by stakeholders with 3 points, #4 by stakeholders with 2 points, and #5 by stakeholders with 1 point.

## Methodological Research Needs

Among the methodological questions for the comparison of LTC delivered through HCBS and in NHs, the identification of standardized outcome measures for HCBS and NH recipients was the number one priority. Eight out of 10 stakeholders ranked this as a priority. The rankings of six other methodological questions for the comparison of LTC delivered through HCBS and in NHs ranked much lower than the top tier. For the broader set of methodological questions about LTC through HCBS and in NHs, four questions related to outcome measures and descriptions of the interventions ranked highly compared with the other seven questions.

- What standardized outcome measures should be used for HCBS and NH recipients that fully measure benefits and harms and are capable of showing meaningful change?
- What should be included in a taxonomy of HCBS and how do we measure a “service” to enable research across different types of HCBS?
- What is the minimum set of potential outcomes for HCBS and NH recipients? For example, outcomes may include abuse, loneliness (as an intermediate outcome that could predict institutionalization), and transitions (likelihood of being discharged from a NH after an individual enters a NH, likelihood of going back to a NH after discharge from the NH, and likelihood of being rehospitalized after experiencing a hospitalization).

- What quality-of-life measures and disease specific measures should be used to capture an individual's experience in LTC?
- What should be included in a taxonomy for assisted living to assess the effectiveness of services and to compare to other HCBS?

Addressing methodological research needs will enhance the utility of future research on LTC for older adults. The methodological research needs identified by stakeholders as the highest priorities pertain to the outcome measures that are appropriate within these care settings and important to care recipients and to the definition of services that individuals receive.

The CER highlighted that the variation in outcome measures and data collection used across studies made it difficult to compare results. The differences in care environments, including which measurements are used and who collects the data, may affect results. These differences can make it challenging to determine whether different effects across different studies are due to outcome measurement issues or other issues. Stakeholders emphasized the importance of finding standardized outcome measures. Additionally, the CER and stakeholders stressed the importance of examining outcomes that measure an individual's experience across multiple domains, including outcomes that are most important to individuals when they choose between care settings. There was insufficient evidence for most outcomes examined in the CER, including outcomes related to quality-of-life and experience of care. Consensus on outcome measures would improve future research and the ability to understand how different types of LTC affect outcomes of older adults.

The CER emphasized that most studies did not sufficiently describe the settings and services received, and few studies specified the type, frequency, or intensity of services. The nature of HCBS and AL services can vary widely, so a description of services is necessary to judge applicability. Our discussions with stakeholders, and the results of the ranking process, indicate that creating and using a standardized taxonomy for HCBS and AL is important to understanding research on these types of care. CMS has been working with contractors to produce a taxonomy of services ([www.nasuad.org/documentation/hcbs2011/Presentations/W10RegencyA.pdf](http://www.nasuad.org/documentation/hcbs2011/Presentations/W10RegencyA.pdf)). Using this taxonomy in future research will increase the usefulness and comparability of research efforts.

## Topical Research Needs

The highest priority ranked among the topical gaps for the comparison of LTC delivered through HCBS and in NHs related to the pattern of transitions and the factors leading to transitions for LTC users. We also identified four high priority topical questions to address for LTC delivered through HCBS and in NHs. All topical research needs primarily addressed populations and interventions.

- What is the pattern of transitions of LTC users? What factors lead to transitions?
- What works for whom? How does HCBS affect different subpopulations/subgroups?
- How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare?
- What services within HCBS result in better outcomes for individuals?
- How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS?

LTC users commonly transition through different settings as needs and preferences change, but evidence from the CER suggests that these transitions are rarely characterized or modeled in studies. Studies infrequently follow individuals as they move in and out of different settings, and they are often not explicit about individuals' transitions over time or factors that led to transitions. Stakeholders indicated that understanding LTC users' transitions would help us develop interventions to avoid or improve transitions.

No studies evaluated in the CER addressed outcomes for subgroups. Stakeholders rated the understanding of the efficacy of different interventions for different subgroups as an important priority. Subgroups might be defined by characteristics such as race/ethnicity, socioeconomic status, and diagnoses. In our discussions, many stakeholders indicated the need to better understand managed LTC programs, including how outcomes and costs compare for managed LTC users compared to fee-for-service users. From a policy and payer perspective, this resonated as a particularly salient research question.

Stakeholders were particularly interested in understanding how different services within the package of HCBS improve outcome trajectories for individuals. They were also interested in how the policy and payment environment affects HCBS and NH use. These topics were rated as high priorities to address in future research.

## **Considerations for Potential Research Designs**

Randomization is an issue across all topical research needs. Randomization to HCBS versus NH or to AL versus NH is generally precluded for practical and ethical reasons. Those with a strong preference for community care would not likely accept a NH placement, and many individuals who believe they need NH care have already decided to enter a NH. However, stakeholders suggested that RCTs could be used to compare the effects of variations of HCBS. Randomization would allow for more robust research about the efficacy of different types of services within HCBS and about the efficacy of HCBS for different subgroups. The possibility of a strong sampling bias in who agrees to be randomized remains, raising questions about applicability.

Cohort studies, alternatively, are less resource-intensive and produce applicable results. Longitudinal cohort studies follow individuals over a period of time and would be practical to examine the outcome trajectories of LTC users. Large sample sizes will be necessary to allow for subgroup and interaction analyses, but this is easier to attain in cohort studies than in RCTs. An LTC admission cohort with a prospective cohort design would allow researchers to understand how interventions may modify the outcome trajectories over time. The ability of this design to assess differences can be improved by using consistent measures and observation schedules, collected by independent observers.

Studies need to use statistical techniques to adjust for selection to ensure that the comparisons between groups are unbiased. These techniques include multivariate analysis, propensity scores, instrumental variables, and frontier analysis.<sup>5</sup> Frontier analysis identifies groups with specific clusters of key patient characteristics that pertain to a specific health issue. Factors considered for adjustment should include LTC attitudes held by both clinicians and consumers and availability of informal support. Studies should adjust for case mix and account for changes in the composition of the populations that result from deaths or transfers to different settings.

In discussions with stakeholders, other research design considerations that were mentioned included the need for studies with more generalizable samples and populations of private-pay LTC users.

Tables 3-7 discuss study design elements by specific identified topical research need.

**Table 3. Design considerations: What is the pattern of transitions of LTC user? What factors lead to the transitions?**

Design Element	Proposed Approach
Research design	Observational studies will be needed; cohort design; randomization is not feasible
Ethical issues	None anticipated
Availability of data; recruitment	Can use linked files from administrative data sets such as Medicaid (MAX), Medicare, Nursing Home Minimum Data Sets (MDS). Other data such as state spending or private pay may not be available.
Population	Persons enrolled in HCBS programs (could separate waiver users from state plan users); important to include private pay individuals where possible. Given the emphasis on facilitating discharges from nursing homes, one could likewise trace those who are discharged at various lengths of stay and assess what factors are associated with remaining in the community.
Intervention	Not applicable
Comparator	Not applicable
Outcomes	Subsequent use of LTC services, especially nursing home readmissions, hospitalizations
Timing	At least one year of follow up; more is better

HCBS = home and community-based services; LTC = long-term care

**Table 4. Design considerations: What works for whom? How does HCBS affect different subpopulations/subgroups?**

Design Element	Proposed Approach
Research design	Observational studies will be needed; cohort design; randomization is not feasible
Ethical issues	None anticipated
Availability of data; recruitment	Can use linked files from administrative data sets such as Medicaid (MAX), Medicare, Nursing Home Minimum Data Sets (MDS). Other data such as state spending or private pay may not be available.
Population	Persons enrolled in HCBS programs (could separate waiver users from state plan users); important to include private pay individuals where possible Identify subgroups based on ADLs, cognition, comorbidities, informal care support, possibly ethnicity and SES
Intervention	Different HCBS arrangements (type of support, amount)
Comparator	Not applicable
Outcomes	Trajectory of ADL and cognitive status Subsequent use of LTC services; use of medical services such as ERs and hospitalizations
Timing	At least one year of followup; more is better

ADL = activities of daily living; HCBS = home and community-based services; LTC = long-term care; SES = socioeconomic status

**Table 5. Design considerations: How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare?**

Design Element	Proposed Approach
Research design	Observational studies will be needed; cohort design; randomization is not feasible
Ethical issues	None anticipated
Availability of data; recruitment	Can use linked files from Medicaid (MAX) administrative data sets for non-managed care; need cooperation of managed care organizations to make data available
Population	Persons enrolled in HCBS programs (could separate waiver users from state plan users) in managed care Separate analysis for persons who are dually eligible for Medicare and Medicaid (likely to be the majority of older people)

Intervention	Managed care
Comparator	Persons enrolled in HCBS programs (could separate waiver users from state plan users) in traditional fee-for-service arrangements
Outcomes	Trajectory of ADL and cognitive status Subsequent use of LTC services; use of medical services such as ERs and hospitalizations
Timing	At least one year of followup; more is better

ADL = activities of daily living; ER = emergency room; HCBS = home and community-based services; LTC = long-term care

**Table 6. Design considerations: What services within HCBS result in better outcomes for individuals?**

Design Element	Proposed Approach
Research design	Observational studies will be needed; cohort design; randomization may be possible in limited circumstances
Ethical issues	None anticipated
Availability of data; recruitment	Can use linked files from administrative data sets such as Medicaid (MAX), Medicare, Nursing Home Minimum Data Sets (MDS). Other data such as state spending or private pay may not be available Applicability would likely be constrained for randomized studies due to the strong possibility of sampling bias
Population	Persons enrolled in HCBS programs (could separate waiver users from state plan users); important to include private pay individuals where possible
Intervention	Classification of HCBS services
Comparator	Not applicable
Outcomes	Trajectory of ADL and cognitive status Subsequent use of LTC services; use of medical services such as ERs and hospitalizations
Timing	At least one year of followup; more is better

ADL = activities of daily living; ER = emergency room; HCBS = home and community-based services; LTC = long-term care

**Table 7. Design considerations: How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS?**

Design Element	Proposed Approach
Research design	Observational studies will be needed; cohort design; randomization is not feasible The ideal design would examine those who do and do not get HCBS, but a compromise may be to look only at those who do get HCBS and describe variation in composition of recipients by state policies, payment rates, and availability of services
Ethical issues	None anticipated
Availability of data; recruitment	The challenge in this study will be identifying prisons who would qualify for HCBS but do not receive it. Can use linked files from Medicaid (MAX) administrative data sets for persons getting HCBS but may need an independent survey to identify eligible non-recipients and compare patterns by state policies, payment rates, and availability of services Limited data on service availability in area resource files; may need to do a separate survey
Population	Persons enrolled in HCBS programs (could separate waiver users from state plan users) Persons not in HCBS
Intervention	State policies, payment rates, and availability of services
Comparator	Not applicable
Outcomes	Receipt of LTC services Characteristics of recipients
Timing	At least one year of followup; more is better

HCBS = home and community-based services; LTC = long-term care



## Discussion

This FRN project refined and prioritized research needs relevant to the Key Questions addressed in the CER “Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care.” We refined and developed a list of evidence gaps from the CER, including methodological gaps that limited the utility of the current research and topical gaps that limited conclusions about efficacy and comparative effectiveness of LTC for older adults delivered through HCBS and in NHs. We used a deliberative process to refine and expand our set of research gaps through conversations with stakeholders who represented diverse perspectives of expertise on the topic. Our stakeholder group included researchers, research and funding organizations, payers, and providers and consumer groups. Some stakeholders offered two or more perspectives. We revised the preliminary research gaps based upon these discussions and phrased the identified gaps as research questions.

Our stakeholder group raised an important question early: given the changes in social thinking about the relative roles of institutional care and HCBS, should further research continue to address relative effectiveness or should it assume that HCBS is preferable in most situations? Based on the stakeholder feedback, we grouped research questions into two major sets, each of which was further subdivided into methodological questions and topical questions. The first set addressed the narrow issue that was the topic of the CER—the comparison of LTC delivered through HCBS and in NHs. The second set addressed broader LTC issues that stakeholders raised as salient for the current policy environment. Stakeholders ranked the questions by priority, and the most highly ranked questions were deemed research needs. We included ranking results from both sets of questions.

Addressing methodological research needs will enhance the utility of future research on LTC for older adults. A standardized set of patient-centered outcomes, with guidance on interpreting changes in outcomes, will provide researchers with an approach to determine the effectiveness of various types of LTC. The quality of the evidence will also be enhanced if researchers use a standardized definition of LTC services. Following consensus on these issues, more comparable studies on LTC for older adults should become available.

Topical research priorities reflected the need to better understand which interventions are effective for which populations. Identifying how subpopulations are affected by different interventions and which services are most effective will help consumers and policymakers choose better modes of care. Characterizing LTC users’ transitions will improve research about the type and timing of interventions that may prove most effective.

Future studies on LTC for older adults should aim to reduce bias as much as possible, using research design and statistical techniques. Larger sample sizes will allow more research on subpopulations, and longer followup times will allow a better understanding of how interventions may modify outcomes over time.

This FRN project benefited from the perspectives brought by broad panel of stakeholders. However, our inability to collect a representative perspective from a larger sample of stakeholders is also a limitation. The prioritized research needs reflect the opinions of these stakeholders and may not be generalizable to the population of stakeholders on this topic. The sample size was limited by standards and guidelines for statistical surveys administered by the Office of Management and Budget requiring compliance with the Paperwork Reduction Act and Information Collections Policy (44 USC 3501-3520). The Act was designed to minimize the paperwork burden on the public, assure that high quality data are obtained, and minimize costs.

However, the approval process to allow more than nine nongovernment participants exceeded the length of time available to complete this project.

## Conclusions

We identified specific research needs that should be useful in future efforts to address the effectiveness of LTC for older adults delivered through HCBS and in NHs. The clinical and policy context of LTC is changing. Comparative effectiveness may be less salient than understanding what makes such care effective in the first place for various client groups. Therefore, we reported research needs related to the comparison of HCBS and NH care that was the focus of the CER, and we also reported research needs from the broader set of questions that stakeholders felt were more important priorities in the current policy environment. Future research in this area will create a broader and stronger evidence base for making care and policy decisions:

- What standardized outcome measures should be used for HCBS and NH recipients that fully measure benefits and harms and are capable of showing meaningful change?
- What should be included in a taxonomy of HCBS and how do we measure a “service” to enable research across different types of HCBS?
- What is the minimum set of potential outcomes for HCBS and NH recipients? For example, outcomes may include abuse, loneliness as an intermediate outcome that could predict institutionalization, transitions (likelihood of being discharged from a NH after an individual enters a NH, likelihood of going back to a NH after discharge from the NH, and likelihood of being rehospitalized after experiencing a hospitalization).
- What quality-of-life measures and disease specific measures should be used to capture an individual's experience in LTC?
- What should be included in a taxonomy for assisted living to assess the effectiveness of services and to compare to other HCBS?
- What is the pattern of transitions of LTC users? What factors lead to transitions?
- What works for whom? How does HCBS affect different subpopulations/subgroups?
- How do outcomes of individuals in managed care programs differ from those of individuals in fee-for-service programs? Do managed LTC programs for dual eligibles offload costs onto Medicare?
- What services within HCBS result in better outcomes for individuals?
- How do policies, payment rates, and availability of services in different areas impact who does or does not receive HCBS?

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## Abbreviations

AL	Assisted living
CER	Comparative effectiveness review
CMS	Centers for Medicare & Medicaid Services
FRN	Future research needs
HCBS	Home and community-based services
LTC	Long-term care
NH	Nursing home
PACE	Program of All-Inclusive Care for the Elderly
PICOTS	Population, intervention, comparison, outcome, timing, setting
RCT	Randomized controlled trial

# Appendix A. Selection Criteria for New Research: Long-Term Care for Older Adults Research Needs

**Current importance:** *Includes considerations such as uncertainty for decisionmakers, benefits and harms for individual LTC recipients, and high costs*

- Represents a significant disease burden; large proportion or priority population
- Is of high public interest; affects healthcare decision-making, outcomes, or costs for a large proportion of the US population or for a priority population in particular
- Represents important uncertainty for decision-makers
- Incorporates issues around both benefits and potential harms
- Represents important variation in care, or controversy in what constitutes appropriate care
- Represents high costs due to common use, to high unit costs, or to high associated costs to consumers, to patients, to healthcare systems, or to payers

**Potential impact:** *Includes the likelihood the study will inform practice and policy, whether the research addresses inequities, vulnerable and diverse populations, or ethical, legal, and social issues pertaining to the form of LTC delivery*

- Potential for significant health impact
  - To improve health outcomes
  - To reduce significant variation related to quality of care
  - To reduce unnecessary burden on those with health care problems
- Potential for significant economic impact, reducing unnecessary or excessive costs
- Potential for change
  - The proposed topic exists within a clinical, consumer, or policy-making context that is amenable to evidence-based change
- Potential risk from inaction
  - Lack of evidence for decision-making produces unintended harms
- Addresses inequities, vulnerable populations, patient subgroups with differential impact

**Incremental value:** *Includes considerations of the potential for new knowledge*

- Adds useful new information to existing portfolio of research on topic or validates existing research where a body of evidence is scant

**Feasibility:** *Includes factors related to anticipated research designs, such as generalizable samples, measurement of study variables from various data sources, and unobserved variables that may create a risk of bias*

- Interest among researchers
- Duration
- Cost
- Methodological complexity
- Implementation difficulty
- Facilitating factors
- Potential funders

(Modified for primary research from: Whitlock EP et al. AHRQ Series Paper 3: Identifying, selecting, and refining topics for comparative effectiveness systematic reviews: AHRQ and the Effective Health-Care program. Journal of Clinical Epidemiology 2010; 63: 491-501)

# Appendix B. Minnesota Evidence-based Practice Center (MN EPC) Long-Term Care for Older Adults Research Needs Project: Stakeholder Conference Call Information

This memo outlines specific areas where your expert feedback is requested for this AHRQ-funded project. The attached information forms the basis of your upcoming conference call with us, so please review it prior to our call. We are specifically interested in any additions, modifications, or deletions to the list of research knowledge gaps that you would suggest, especially if you believe that the list does not include pressing research issues that hinder the field's ability to address questions about long-term care for older adults delivered through home and community-based services versus care provided in institutional settings such as nursing homes adequately.

**Background:** The forthcoming MN EPC report, *Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care*, is currently being finalized. It focuses on two key questions related to the benefits/harms and costs of long-term care for older adults, summarizing the literature on this topic from 1995 through 2012. The key questions are listed on page 2 of this document. Broadly, the review compared the characteristics of the populations of older adults using home and community-based services and nursing homes, as well as the benefits, harms, and costs for these individuals. The outcomes examined included physical, cognitive, and mental health outcomes, mortality, adverse effects, utilization, and costs. The review found the existing literature to be sparse and of low to moderate quality, so no strong conclusions could be made regarding any outcome examined. A number of recommendations were made for further research within the report.

This project will expand and build on those recommendations to provide further specification and focus for future research endeavors. The draft report recommendations are listed in the *LTC Research Knowledge Gaps* document.

**Project objective:** The goal of this project is to use expert/stakeholder feedback to identify and prioritize the current research knowledge gaps on long-term care for older adults, and recommend the optimal research approaches to best fill those knowledge gaps to improve outcomes of older adults receiving long-term care.

**What we need from you during the conference call:** Please review the attached document, *LTC Research Knowledge Gaps*. The document summarizes the knowledge gaps identified in the forthcoming report. During the call we will discuss:

- What gaps you feel should be added or clarified.
- Which gaps should be excluded from the list due to not meeting a minimum importance threshold.
- If there are any ongoing or recently completed studies that we should be aware of.

**Timeline and Plan:** A summary of the conference call will be emailed to stakeholders within one week, where you will be given the opportunity to provide any additional comments or clarification. After comments are received, the MN EPC will draft a final list of research gaps. Stakeholders will then engage in a ranking procedure of research priorities using a web-based prioritization software through which a suggested prioritization list will be generated. A final report will be generated by the MN EPC in July, which will later be posted on AHRQ's Effective Health Care web site.

We thank you for your participation in this AHRQ-sponsored project, and look forward to working with you. If you have any questions, please feel free to contact Robert Kane at [kanex001@umn.edu](mailto:kanex001@umn.edu) or Andrea Wysocki at [wyo0014@umn.edu](mailto:wyo0014@umn.edu).

## Long-Term Care for Older Adults: A Review of Home and Community-based Services Versus Institutional Care

The following key questions (KQ) were investigated in the review for adults age 60 and older:

**Key Question 1:** What are the benefits and harms of LTC provided through HCBS compared to institutions such as NH for older adults, aged 60 and older, who need LTC?

- a. To what extent do HCBS and NHs serve similar populations?
- b. How do the outcomes of the services differ when tested on similar populations?
- c. What are the harms to older adults as a result of HCBS and NHs?  
Reported harms include safety, inadequate preventative care, unnecessary hospitalizations, and concerns about abuse or neglect.

**Key Question 2:** What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource utilization and family burden.

Direct costs of care refer to the LTC costs of HCBS recipients and NH residents. Resource use includes the costs of acute care services such as physician and hospital care as well as the costs of other subsidies or transfer programs. Family burden includes both the out-of-pocket and opportunity costs of care.



# Appendix C. Minnesota EPC Long-Term Care for Older Adults Research Needs Stakeholder Meeting Agenda

Conference Call Goal: Final list of topics to advance to the rating process

1. Ground rules for phone call:
  - a. In the interest of time, conduct roll call rather than introductions
  - b. To aid with identification, please preface all comments with your name
2. Roll Call
3. Brief overview of meeting purpose and agenda
  - a. Description of the forthcoming AHRQ report (see *LTC Review Draft Executive Summary* attachment)
  - b. Outline scope/methods for the current project
4. Presentation of identified gaps (*LTC Research Knowledge Gaps* attachment)
  - a. Cross-cutting themes identified in report.
    - i. Methodological issues
    - ii. Topical issues
  - b. Specific research questions addressed – the right questions?
5. Discussion of research gaps: what to add, what to remove
6. Discussion of the AHRQ *LTC Selection Criteria for New Research* attachment
7. Overview of web-based prioritization process
8. Outline of next steps.
  - a. Call summary emailed to stakeholders.
  - b. Comments to summary (if any) due from stakeholders within 5 working days
  - c. Minnesota EPC will circulate revised gaps list for prioritization
  - d. Stakeholders prioritization responses due within 5 working days