Effective Health Care

Change Management Interventions for Patients and Family Engagement

Results of Topic Selection Process & Next Steps

The nominators, a health informatics and quality specialist at Alabama Regional Center and a group of health systems invited to participate in an AHRQ-LHS meeting, are interested in a new evidence review on Change Management Interventions for Patients and Family Engagement to inform decisions about which interventions to implement and how to adapt them to account for local context and available resources. An evidence report on more effective PFE practices will help LHSs understand how to incorporate them into their efforts to improve the quality of care as well as patient experience of care. It would also help to inform LHs how best to invest their resources. The Alabama Regional Medical Center is especially interested in underserved populations.

Question 1 from this topic will go forward as a new technical brief. To sign up for notification when this and other Effective Health Care (EHC) Program topics are posted for public comment, please go to https://effectivehealthcare.ahrq.gov/email-updates.

For Question 2, the topic will be reconsidered in the next few years as the literature is rapidly growing on this question.

Topic Brief

Topic Number and Name: Change Management Interventions for Patients and Family Engagement

Nomination Date: 08/22/2018 and 02/04/2019

Topic Brief Date: 3/26/2019

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Conflict of Interest: None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

Background

Carman et al defined patient and family engagement as a process in which “patients, families, [and] their representatives [are] working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.”[1] The Centers for Medicare and Medicaid Services (CMS) Quality Strategy includes a specific goal to “strengthen person and family engagement as partners in their care.”[2] The CMS Patient and Family Engagement (PFE) Strategic Plan is aligned with the CMS Quality Strategy, specifically:[3]

1. Ensure all care delivery incorporates person and caregiver preferences
2. Improve experience of care for persons, caregivers and families
3. Promote person self-management

With the increasing emphasis on the role of PFE as a quality improvement strategy – and emerging evidence from AHRQ and CMS about the benefits of PFE on quality and safety outcomes, health systems are seeking evidence on how to help their patients be more engaged in their health and health care.

There is also an increasing emphasis and mandates to report patient-reported outcome measures (PROMs) and financial incentives tied to patient outcomes (e.g., hospital readmissions) and potentially influenced by level of patient engagement and social determinants of health. For example, the CMS Meaningful Measures initiative seeks to align quality measures with patient experience of care, including measures such as patient reported functional outcomes and community engagement.[4]
Evidence on the most effective interventions and strategies to engage patients in their health, health care, and health outcomes will help healthcare providers partner with patients and their family members to improve quality and safety outcomes as well as the patient experience. If appropriate contextual information is provided, it is possible that learning health systems (LHSs) could learn to be more targeted in their interventions and help to reduce healthcare costs for all stakeholders in healthcare. In sum, this evidence would potentially help achieve better care, better health outcomes, and more affordable care, in accordance with the National Quality Strategy.

Nominator and Stakeholder Engagement

The topic was nominated by two separate nominators. The first was a health informatics and quality specialist at Alabama Regional Center. The second was a panel of Learning Health Systems (LHS) invited to participate in an AHRQ-LHS meeting.

The nominators are interested in using a systematic review process to inform decisions about which interventions to implement and how to adapt them to account for local context and available resources. An evidence report on more effective PFE practices will help LHSs understand how to incorporate them into their efforts to improve the quality of care as well as patient experience of care. It would also help to inform LHs how best to invest their resources. The Alabama Regional Medical Center is especially interested in underserved populations.

Many of the organizations represented on the LHS Panel are members of the High Value Healthcare Collaborative (HVHC) and could potentially distribute this report to other HVHC members. The HVHC is a provider learning network committed to improving healthcare value through data and collaboration. To accomplish this, the HVHC measures, innovates, tests, and continuously improves value-based care. Rapidly disseminate and facilitate adoption of proven high value care models across HVHC members and beyond. This evidence report will be most relevant to leaders at all levels of the organization, including the members of the executive teams and Boards of Directors, as they decide how to prioritize resources and how to implement change management interventions in the most cost-effective manner.

Additionally, several of the LHS panel members are members of the Health Care Systems Research Network (HCSRN), an innovative consortium of research centers based on community-based health delivery systems. Thus, the LHS panel members could potentially disseminate this report to other HCSRN members.

Key Questions and PICOs

The key questions for this nomination were developed with the LHS panel:

1- What is the effectiveness of change management (or implementation) strategies to help patients, families and caregivers manage their chronic conditions and improve patient health outcomes?
   a. What are the characteristics of patients/conditions? What is the specific role for families and caregivers?
   b. What are the characteristics of these change management (implementation) strategies?
   c. Which elements must be implemented to have fidelity? Which elements can be adapted to reflect the local context without losing fidelity?
   d. What is the cost-effectiveness of the change management (implementation) strategies?
   e. What resources are required to implement these interventions and what are the associated costs?
   f. What change management (or implementation) strategies support sustainment of the changes after implementation?

2- In studies of the clinical use of patient reported outcomes to help to engage patients in necessary health behavior changes, what is the evidence of improved patient health outcomes?
   a. What specific patient reported outcomes and domains have been studied
   b. What are the characteristics of the patients/conditions that have been studied?
   c. How were the patient reported outcomes implemented?
      i. How were the patient reported outcomes collected? In what setting?
      ii. How was the information used by the clinician?
      iii. How was the information shared back to the patient?
      iv. What was the follow-up after the initial collection/clinic visit?
   d. What resources are required to collect patient reported outcome information and present to the patient and clinician in actionable form and what are the associated costs?

Terminology: Implementation strategies are “methods or techniques used to enhance the adoption, implementation, and sustainability of a clinical program or practice.” [5]
To define the inclusion criteria for the key questions, we specify the population, interventions, comparators, outcomes, timing, and setting (PICOTS) of interest (Table 1).

Table 1. Key Questions and PICOTS

Key Questions	**1- What is the effectiveness of change management (or implementation) strategies to help patients, families and caregivers manage their chronic conditions and improve patient health outcomes?**	**2- In studies of the clinical use of patient reported outcomes to help to engage patients in necessary health behavior changes, what is the evidence of improved patient health outcomes?**

Population	• Patients with chronic medical conditions eg: DM, HTN, ESRD, and their families and caregivers
	• Subpopulations
	  • Ethnic racial minority
	  • Homeless
	  • Limited language skills
	  • Low literacy
		• Patients with chronic medical conditions eg: DM, HTN, ESRD
		• Subpopulations
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Interventions	• Patient level interventions:
	  o Educational resources (paper and online)
	  o Health IT approaches including cell phone/mobile apps
	• Community level interventions:
	  o Caregiver support
	  o Peer support
	  o Social support (rides to physician office, food banks)
	• Practice, Health System (HS) and Reimbursement interventions:
	  o Medical home/team based care
	  o Models under alternative payment mechanisms
		• Collection of patient reported outcome information

Comparators	Any Comparator	No collection of patient reported outcomes or comparison of different methods, instruments, etc.

Key Questions	**1- What is the effectiveness of change management (or implementation) strategies to help patients, families and caregivers manage their chronic conditions and improve patient health outcomes?**	**2- In studies of the clinical use of patient reported outcomes to help to engage patients in necessary health behavior changes, what is the evidence of improved patient health outcomes?**
Outcomes	• Intermediate Outcomes o Clinician behavior change o Clinical Staff behavior change o Cost/Value o Provider Satisfaction o System Level Changes • Patient Outcomes o Morbidity o Mortality o Quality of Life	• Intermediate Outcomes o Patient knowledge o Patient behavior/attitude change o Patient Satisfaction o Patient engagement with PCP and HC o Trust • Patient Outcomes o Fatigue o Quality of Life o Morbidity o Mortality • Implementation outcomes o Fidelity o Sustainability o Costs
Timing	• Right after implementation strategy (within 3 months) • Longer follow up (3 months to 12 months) • More than 12 months	
Setting	All settings (acute/subacute/chronic/primary care)	

Abbreviations: DM=diabetes mellitus; ESRD= end stage renal disease; HTN= hypertension; IT= information technology; PCP= primary care physician

Methods

We assessed nomination Change Management Interventions for Patients and Family Engagement for priority for a systematic review or other AHRQ EHC report with a hierarchical process using established selection criteria. Assessment of each criteria determined the need to evaluate the next one. See Appendix A for detailed description of the criteria.

1. Determine the *appropriateness* of the nominated topic for inclusion in the EHC program.
2. Establish the overall *importance* of a potential topic as representing a health or healthcare issue in the United States.
3. Determine the *desirability of new evidence review* by examining whether a new systematic review or other AHRQ product would be duplicative.
4. Assess the *potential impact* a new systematic review or other AHRQ product.
5. Assess whether the *current state of the evidence* allows for a systematic review or other AHRQ product (feasibility).
6. Determine the *potential value* of a new systematic review or other AHRQ product.

Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

Desirability of New Review/Duplication

We searched for high-quality, completed or in-process evidence reviews published in the last three years on the key questions of the nomination. See Appendix B for sources searched.

Impact of a New Evidence Review

The impact of a new evidence review was qualitatively assessed by analyzing the current standard of care, the existence of potential knowledge gaps, and practice variation. We considered whether it was possible for this review to influence the current state of practice through various dissemination pathways (practice recommendation, clinical guidelines, etc.).

Feasibility of New Evidence Review

We conducted a literature search in PubMed from March 2014 to March 2019. See Appendix C for the PubMed search strategy and links to the ClinicalTrials.gov search.

We screening the first 20 abstracts for each key question.

No studies were found for question 2, so a supplementary search was also run (see appendix C). 66 studies were found, and the first 20 were screened.

A supplementary search was also run on clinicaltrials.gov for question 2. 515 studies were found. The first 100 were screened.

Value

We assessed the nomination for value. We considered whether or not the clinical, consumer, or policymaking context had the potential to respond with evidence-based change; and if a partner organization would use this evidence review to influence practice.

Results

See Appendix A for detailed assessments of all EPC selection criteria.

Appropriateness and Importance

This is an appropriate and important topic. This topic addresses prevalent conditions including chronic conditions such as hypertension, diabetes and COPD. This topic addresses health disparities: one nominator is particularly interested in patient engagement tools that could be used with underserved populations. This topic represents important uncertainty: a lot of "advice" has been published about how to improve patient engagement, but not a lot based on evidence. This topic has potential health care cost implications: implementing patient engagement strategies might be high cost which is why health systems want to know which are the most evidence based strategies.

Desirability of New Review/Duplication

Question 1: A new evidence review would not be duplicative of an existing product. Although 21 reviews were found, the reviews in general focus on either specific strategies or specific clinical conditions or both, and there is not an overall framework and synthesis that could support health system decision making. See Table 2 for relevant systematic reviews.

Question 2: A new evidence review would not be duplicative of an existing product. Although 5 reviews were found, the reviews in general focus on specific clinical conditions and there is not an overall framework and synthesis that could support health system decision making. Further the existing reviews do not address areas of interest to the health systems, including implementation issues (how was the information collected and used) and relationship to quality measures.

Reviews by policy or other organizations (that are not typically found in PubMed) may be more relevant to the questions from the nominators. For example, Avalere Health published a report in December of 2018 on “Adopting Patient-Reported Outcomes in Clinical Care: Challenges and Opportunities”[6] (https://avalere.com/wp-content/uploads/2018/12/20181204-Avalere-Adopting-Patient-Reported-Outcomes.pdf), See Table 2.
See Table 2, Duplication column.

Impact of a New Evidence Review

A new systematic review may have high impact due to substantial uncertainty about best practices and potential improvement in patient outcomes.

Feasibility of a New Evidence Review

Question 1: A new evidence review will be very feasible, with an estimate of >150 studies published in the last five years. After screening the first 20 titles/abstracts, 15 were found to be relevant. Because such a large percentage were found to be relevant, and a quick title review indicated that the pattern would persist, we have high confidence that there is a substantial amount of literature. The initial literature search found a variety of interventions and patient populations. The RCTs focused on discrete evaluation of specific self-management programs. The observational, qualitative studies and mixed methods studies compared interventions and outcomes across settings, looked at components of interventions, and barriers and facilitators. See reference section for list of primary studies. See Table 2.

Question 2: There are 30 estimated studies found in the feasibility review. After screening the first 20 titles/abstracts, 9 were found to be relevant to question 2. Because such a large percentage were found to be relevant, and a quick title review indicated that the pattern would persist, we have high confidence that there is a moderate amount of literature.
The number of studies and clinical conditions covered are similar to what was found in the Avalere review[6]. The Avalere report found that current PRO tools are limited in their applicability to clinical practice, there are barriers to implementation, and the clinical conditions where PROs have been tested in clinical practice are narrow. The studies found in this search seem to confirm the conclusions of the Avalere study, and suggest that at this time, the value of a new review would be low. However, all of these studies are very recent (no studies were found from more than five years ago) and this is an extremely active area in clinicaltrials.gov, with a projected estimate of 93 studies recruiting. Further there is a lot of work in progress on implementation issues, for example, the Step Up App Challenge at AHRQ.7 Therefore, we recommend that this topic be reconsidered in a year or two when it is likely that much more relevant information will be available. See Table 2, Feasibility column.

Table 2. Key Questions and Results for Duplication and Feasibility

Key Question	Duplication (3/1/2019-3/1/2016)	Feasibility (3/1/2019-3/12014)
KQ 1: Effectiveness of patient engagement strategies	Total number of identified systematic reviews:21 • EPC[8] • Cochrane: 3[9-11] • Other group: 17[12-28]	Size/scope of review Relevant Studies Identified: 15 • RCT: 5[29-33] • Observational:5[34-38] • Qualitative: 5[39-43] Projected estimate: RCT: >50 Observational Study: >50 Qualitative: >50 Clinicaltrials.gov • Recruiting: 10 • Active: 15 • Complete: 33
KQ 2: effectiveness of collection of PRO data in clinical settings.	Total number of identified systematic reviews: 5 Other group: 5[44-48]	Size/scope of review Relevant Studies Identified: 9[49-58] Projected Estimate: 30 Protocols: 2[59, 60] Clinicaltrials.gov (recruiting): 18/100 Projected estimate: 93

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; KQ=Key Question

Value

The potential for value is high. A lot of effort is placed in trying to improve patient engagement to improve outcomes, and a new review will help inform future policies. Further this topic has partners who are interested in implementing the findings of the report.

Summary of Findings

- Appropriateness and importance: The topic is both appropriate and important.
- Duplication:
  - Question 1: A new review would not be duplicative of an existing product. Although 21 reviews were found, the reviews in general focus on either specific strategies or specific clinical conditions or both, and there is not an overall framework and synthesis that could support health system decision making.
  - Question 2: A new evidence review would not be duplicative of an existing product. Although 5 reviews were found, the reviews in general focus on specific clinical conditions and there is not an overall framework and synthesis that could support health system decision making. Further the existing reviews do not address areas of interest to the health systems, including implementation issues (how was the information collected and used) and relationship to quality measures. Reviews by policy or other organizations (but not found in PubMed) may be more relevant to the questions from the nominators. For example, Avalere Health published a report in December of 2018 on “Adopting Patient-Reported Outcomes in Clinical Care: Challenges and Opportunities”

- Impact: A new systematic review has high potential.

- Feasibility:
    - Question 1: A new evidence review will be very feasible, with an estimate of >150 studies published in the last five years.
    - Question 2: There are 30 estimated studies found in the feasibility review. The number of studies and clinical conditions covered are similar to what was found in the Avalere review. The Avalere report found that current PRO tools are limited in their applicability to clinical practice, there are barriers to implementation, and the clinical conditions where PROs have been tested in clinical practice are narrow. However, all of the existing studies are very recent (no studies were found from more than five years ago) and this is an extremely active area in clinicaltrials.gov, with a projected estimate of 93 studies recruiting. Further there is a lot of work in progress on implementation, for example, the Step Up App Challenge at AHRQ.
- Value: The potential for value is high.

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Appendix A. Selection Criteria Assessment

Selection Criteria	**Assessment**
1. Appropriateness	
1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the U.S.?	Yes
1b. Is the nomination a request for a systematic review?	Yes
1c. Is the focus on effectiveness or comparative effectiveness?	Yes
1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic?	Yes
2. Importance	
2a. Represents a significant disease burden; large proportion of the population	Chronic conditions such as hypertension, diabetes and COPD, are very prevalent
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the US population or for a vulnerable population	Yes, one nominator is particularly interested in patient engagement tools that could be used with underserved populations.
2c. Represents important uncertainty for decision makers	Yes, a lot of "advice" has been published about how to improve patient engagement, but not a lot based on evidence.
2d. Incorporates issues around both clinical benefits and potential clinical harms	Yes
2e. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers	Yes, implementing patient engagement strategies might be high cost which is why health systems want to know which are the most evidence based strategies.
3. Desirability of a New Evidence Review/Duplication	
3. Would not be redundant (i.e., the proposed topic is not already covered by available or soon-to-be available high-quality systematic review by AHRQ or others)	No
4. Impact of a New Evidence Review	
4a. Is the standard of care unclear (guidelines not available or guidelines inconsistent, indicating an information gap that may be addressed by a new evidence review)?	Yes (see importance above)
4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)?	Yes (see importance above)
5. Primary Research	
5. Effectively utilizes existing research and knowledge by considering: - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies)	*Yes for Question 1* *For question 2, a lot of new information is likely to be available in the next year or two and it may be better to reconsider this topic then.*
6. Value	
6a. The proposed topic exists within a clinical, consumer, or policy-making context that is amenable to evidence-based change	Maybe. But a lot of effort is placed in trying to improve patient engagement to improve outcomes, and a new review will help inform future policies.

Selection Criteria	Assessment
6b. Identified partner who will use the systematic review to influence practice (such as a guideline or recommendation)	Yes, this topic was suggested by the LHS panel as well as quality specialist at Alabama Regional Center. In addition, many of the organizations represented on the LHS Panel are members of the High Value Healthcare Collaborative (HVHC) and could potentially distribute this report to other HVHC members.

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; COPD=chronic obstructive pulmonary disease; KQ=Key Question; LHS=learning health system

Appendix B. Search for Evidence Reviews (Duplication)

Listed below are the sources searched, hierarchically.

Primary Search
AHRQ: Evidence reports and technology assessments https://effectivehealthcare.ahrq.gov/; https://www.ahrq.gov/research/findings/ta/index.html; https://www.ahrq.gov/research/findings/evidence-based-reports/search.html
VA Products: PBM, and HSR&D (ESP) publications, and VA/DoD EBCPG Program https://www.hsrd.research.va.gov/publications/esp/
PubMed https://www.ncbi.nlm.nih.gov/pubmed/

Appendix C. Search Strategy & Results (Duplication and Feasibility)

Question 1:

MEDLINE(PubMed) searched on: March 8, 2019	
Concept	
Engagement and Self-Management	(((("Patient Participation"[Mesh]) OR "Self-Management"[Mesh]) OR (((self-management[Title/Abstract]) OR "patient engagement"[Title/Abstract]))))
AND	
Chronic Disease	"Chronic Disease"[Mesh]
Limits: 5 years English human adult English	published in the last 5 years; Humans; English; Adult: 19+ years
Total N=533	
SR N=20	Systematic[sb]
https://www.ncbi.nlm.nih.gov/sites/myncbi/r.relevo.1/collections/57971610/public/	
RCT N=206	((((((((groups[tiab])) OR (trial[tiab])) OR (randomly[tiab])) OR (drug therapy[sh])) OR (placebo[tiab])) OR (randomized[tiab])) OR (controlled clinical trial[pt])) OR (randomized controlled trial[pt])
https://www.ncbi.nlm.nih.gov/sites/myncbi/r.relevo.1/collections/57971638/public/	
Observational N=8	"Observational Study" [Publication Type] OR "Observational Studies as Topic"[Mesh]
https://www.ncbi.nlm.nih.gov/sites/myncbi/r.relevo.1/collections/57971672/public/	
Qualitative N=62	(((((barriers[Title/Abstract] AND facilitators[Title/Abstract])) OR obstructive beneficial[Title/Abstract]) OR restriction enablement[Title/Abstract])) OR ((("Focus Groups"[Mesh]) OR "Qualitative Research"[Mesh]) OR "Delphi Technique"[Mesh])
https://www.ncbi.nlm.nih.gov/sites/myncbi/r.relevo.1/collections/57971685/public/	
Other N=237	
https://www.ncbi.nlm.nih.gov/sites/myncbi/r.relevo.1/collections/57971699/public/	
clinicalTrials.gov 97 Studies found for: **Recruiting, Not yet recruiting, Active, not recruiting, Completed, Enrolling by invitation Studies | chronic disease | self management | Adult, Older Adult | First posted from 03/14/2014 to 03/14/2019** https://clinicaltrials.gov/ct2/results?cond=chronic+disease&term=&type=&rslt=&recrs=b&recrs=a&recrs=f&recrs=d&recrs=e&age_v=&age=1&age=2&gndr=&intr=self+management&titles=&outc=&spons=&lead=&id=&cntry=&state=&city=&dist=&locn=&strd_s=&strd_e=&prcd_s=&prcd_e=&sfpd_s=03%2F14%2F2014&sfpd_e=03%2F14%2F2019&lupd_s=&lupd_e=&sort=	

Supplementary Search (3/21/2019) on pubmed for question 2:

("patient reported outcome measures"[MeSH Terms]) AND (use in clinical care)

With “5 years” filter

Supplementary Search (3/22/2019) on clinicaltrials.gov for question 2:

patient reported outcomes clinical care

with “Recruiting Not yet recruiting Active not recruiting Enrolling by invitation” filters