



Technical Brief Disposition of Comments Report

Title: Strategies for Patient, Family, and Caregiver Engagement

Draft report available for public comment from February 04, 2020 to March 06, 2020.

Citation: Bennett WL, Pitts S, Aboumatar H, Sharma R, Smith BM, Das A, Day J, Holzhauser K, Bass EB. Strategies for Patient, Family and Caregiver Engagement. Technical Brief No. 36. (Prepared by the Johns Hopkins University Evidence-based Practice Center under Contract No. 290-2015-00006-I.) AHRQ Publication No. 20-EHC017. Rockville, MD: Agency for Healthcare Research and Quality; August 2020. DOI: <https://doi.org/10.23970/AHRQEPCTB36>. Posted final reports are located on the Effective Health Care Program [search page](#).

Comments to Draft Report

The Effective Health Care (EHC) Program encourages the public to participate in the development of its research projects. Each draft report is posted to the EHC Program Web site or AHRQ Web site for public comment for a 3-4-week period. Comments can be submitted via the Web site, mail or E-mail. At the conclusion of the public comment period, authors use the commentators' comments to revise the draft report.

Comments on draft reports and the authors' responses to the comments are posted for public viewing on the Web site approximately 3 months after the final report is published. Comments are not edited for spelling, grammar, or other content errors. Each comment is listed with the name and affiliation of the commentator, if this information is provided. Commentators are not required to provide their names or affiliations in order to submit suggestions or comments.

This document includes the responses by the authors of the report to comments that were submitted for this draft report. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

Summary of Peer Reviewer Comments and Author Response

We appreciated the comments from the Key Informants, Peer and Public Reviewers. We addressed the comments and note below the common themes:

1. Overall the reviewers believed that the report was well written and clear and appreciated the Figures, especially the Evidence Map.
2. We aimed to address questions and concerns about Figure 1, the Conceptual Model. In particular, we described the rationale for adapting the original model (by Carman and colleagues) and the steps we took to adapting it. We also revised the “examples” of engagement strategies in the Figure.
3. We clarified definitions for levels of patient and family engagement in terms of direct patient care, health system and organization level, and community/policy level. We also provided more examples, and presented these definitions earlier in the Executive Summary.

Peer Reviewer, Technical Expert/Key Informants, and Public Comments and Author Response

	Commentator & Affiliation	Section	Comment	Response
1.	KI Peer Reviewer #1	Evidence Summary	<p>Executive Summary, Key Points, 1st point. Re. "The majority of systematic reviews on patient and family engagement for chronic conditions..." We are not interested in engaging patients and families "for chronic conditions". I think the authors mean "...to help improve care for chronic conditions."</p> <p>Then they can go on to explain that we were interested in engagement strategies for engaging them at the personal level (to engage them in improving their own care), at the health system level (to engage them in improving care in their clinic or health system, and at the community level (to engage them in improving care in their community). This needs to be made clear throughout the manuscript and consistent language should be used.</p>	<ul style="list-style-type: none"> - We edited the text as suggested. - We worked to clarify and make the wording more consistent throughout the report, and also noted the overlap between the levels. We added these definitions to the Evidence Summary as well.
2.	Public Reviewer #1: Debbi Carmody	Evidence Summary	<p>More research is needed to address a large gap in evidence on patient and family engagement at the health system and community/policy levels. That's it in a capsule, and personally, I believe this statement supports the need for reports like these to be conducted and continued for more patient/caregiver engagement in general</p>	Thank you.
3.	Public Reviewer #2: Pam Carroll-Solomon, Retired; Patient Advocate	Evidence Summary	<p>Based on my other comments related to studies, I believe some aspects of the discussion are missing so it is hard to provide substantive comments on the evidence.</p>	We addressed the other specific comments as indicated for each comment.

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4.	Public Reviewer #3: American Psychological Association	Evidence Summary	<p>While this may be outside of the scoping review for the technical brief, it would be important to highlight the need for more research in strategies to engage patients and families in community mental health systems alone or in tandem with primary care services.</p> <p>One of the ways to identify effective strategies for engaging patients and families in addiction and mental healthcare systems is by having the patient and family involved in assessing the patient experience (for example, Currie et al., 2020).</p>	<p>We did identify mental health conditions that were addressed in studies included in the report, and these are highlighted in the results.</p> <p>We appreciated the citation you provided (Currie SR and colleagues). The article describes the development of a novel, comprehensive patient experience measure that can be used to assess patient and family engagement, so we referred to the article in the Discussion.</p>
5.	KI Peer Reviewer #2	Introduction	<p>The conceptual framework used by the authors (Carman et al.) is focused on the delivery of health care, as evidenced by their definition of patient and family engagement: "patients, families, their representatives, and health professionals in various levels across the health care system" (p. 2, line 20).</p> <p>The brief is also weighted towards chronic disease management, which the authors acknowledge.</p> <p>Even so, "the heterogeneity of tested interventions, different measures, and low quality of the original studies" (p. 3, line 36) make it difficult to create a clear map of patient and family engagement strategies.</p> <p>This is a challenge not only for research, but also for efforts to translate research into practice and justify the return on investment.</p>	<p>We agree with the reviewer's comments about the focus of the report, as that was our intended focus. As indicated in responses to other comments, we made changes to enhance the clarity of the map of engagement strategies.</p>
6.	KI Peer Reviewer #3	Introduction	<p>Clear and comprehensive, given the current state of the field and the evidence</p>	<p>Thank you.</p>

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7.	Peer Reviewer #4	Introduction	<ul style="list-style-type: none"> - I prefer the Carman definition of PFE - please define patient activation. Those familiar with the topic will get it, but those newer will not follow the differences between ctivation/engagement/empowerment etc. - -good use of chronic care model - perhaps can also add some rationale as to the growing prevalence of chronic diseases, the shift from inpatient-based care to complex outpatient based care which puts more burden/responsibility on PFE for chronic disease management - another example i use for "community and policy" would be for example a disease-specific group of patients lobbying for more funding to study a rare disease, or a community group who is engaged in a sugar-sweetened beverage or tobacco-related local policy - really like your Figure 1. well-organized and a nice reference to guide those setting up evaluations. well-done! - small point, but i think the existence of a portal isn't engagement in and of itself - but rather if the setting actually supports patients to access it and learn from the information available in it. My \$0.02. 	<ul style="list-style-type: none"> - We changed the first Introduction sentence to focus on the definition for engagement that Carman used to be consistent with the Methods. - We added a definition of patient activation to the Introduction. - We added additional rationale about the prevalence of chronic disease and need for outpatient-focused management systems. - We added these examples for community engagement. - We addressed the comment by editing the reference to portals in the Figure.

8.	Peer Reviewer #5	Introduction	<p>The background section notes that they have “adapted a widely used conceptual framework on patient and family interventions by Carman and colleagues...”</p> <p>The authors have adapted the initial framework, and while they briefly summarize the model as they show it, they do not articulate how and why the initial framework was adapted.</p> <p>Adapting the framework is certainly appropriate as frameworks are meant to evolve. It would have been very helpful for the authors to have articulated the reason for the changes, and how they have either improved on the framework or the reasons for the updated version -- example, the authors eliminated the continuum of input to partnership That would place this framework in an evolving research context. There are two areas in the framework I wish to highlight.</p> <p>1. One decision to adapt the framework introduces potential conceptual confusion that should be addressed. The “levels” of patient and family caregiver engagement are described as: direct patient care, health care organization and system, and community policy level. The definition of “health system level strategy” as a strategy that has an impact beyond the individual’s health care (e.g., informing changes to the services of the clinic and the health care system), mixes two concepts. The first concept, which was intended to distinguish “direct care” versus “health care organizations” was how interventions to support individual’s engagement in their own care is quite different that interventions that offer genuine opportunities for patients (and caregivers) to engage in the decisions in the organizations that delivery care (e.g., PCMH’s, hospitals, ACO’s, etc.) in hiring, patient safety committees, participating in improvement design, advisory groups, and board membership etc.</p> <p>In the current adaptation, the authors add a second concept, any elicitation of “input” from patients and caregivers about their experiences of care, as well as what the organizations do in response to the feedback or input, as organizational level patient engagement.</p> <p>This second use of the term “organization and system engagement” is quite distinct, and how an organization chooses to act, ignore, etc. input from patients and caregivers at the direct care level is not an act of supporting engagement at the</p>	<p>Thank you for these helpful comments.</p> <p>In the Introduction and Methods, we described the rationale for and changes we made to adapt the framework, including how we addressed the continuum of engagement. We have added text (in the Introduction and Discussion) to describe how we addressed the continuum of engagement in this report [see first and second paragraphs under Conceptual Framework on page 2].</p> <p>We added a statement in the limitations section on the impact of the heterogeneity of interventions along the continuum of care.</p> <p>We did not intend to modify the definition of a health system level strategy. We agree that input from patients and caregivers broadly, such as through patient experience surveys, does not generally constitute patient engagement at the organizational level. We added language to describe that there could be overlap between direct care and health system interventions, or that one intervention could have several components and expected outcomes.</p> <p>We have clarified the definition of a health system level strategy. [Please see the second paragraph under Conceptual Framework on page 2].</p> <p>In addition, we have modified the figure, removing the third and fourth bullets from the figure to eliminate this confusion. In place of these bullets, we have added a third bullet to broadly represent strategies not included in bullets 1 & 2.</p> <p>2. It was our goal to capture all potential outcomes and categorize them in these</p>
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			<p>organization level. It could be considered supporting patient engagement at the direct patient care level, as it asks them to talk about how they experience care, or quality improvement, but it is not, conceptually, a mechanism where the organization invites patients and caregivers to participate in the organization and design of care.</p> <p>I think this decision might have consequences for the ultimate findings of this project, and this combining of concepts might muddy the findings, especially the questions that support the elements about implementation, findings of what works, etc.</p> <p>2. The potential outcomes and measures seem quite narrow and it is not clear if the outcomes as stated should track to the levels of engagement.</p>	<p>groups The figure is intended to accommodate the possibility that each type of outcome could be relevant to any of the levels of engagement.</p>
9.	KI Peer Reviewer #6	Introduction	<p>I agree with the model, in that it is clear and already established. I appreciate the definitions here as well.</p> <p>However, I am confused by "direct patient care" definition, page 2.</p> <p>Do you mean that a person ("patient" who may be well and may or may not be connected with a health care provider) must be with a provider to get "direct patient care"? With my lens as a payer providing direct patient engagement, in that we regularly call patients in the hospital in need of transition management, patients with chronic conditions, patients who are vulnerable based on social determinants or a mixture of conditions (such as including mental health), are these calls direct patient care? Please clarify.</p> <p>Maybe the model puts all actions relating to insurers in the health system bucket? I think the provider incentives for engagement are system-based. I think the employer's wellness or nurse programs are also "direct patient care" and systems.</p>	<p>Thank you . In the Introduction, we clarified that "direct patient care" includes payer providing services <i>directly</i> to a patient, such as transition management. We agree that interventions focused on patients and families as individuals are "direct" and not systems, although the definitions can sometimes be confusing.</p>
10.	KI Peer Reviewer #7	Introduction	<p>Background: Good</p>	<p>Thank you.</p>

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11.	KI Peer Reviewer #1	Introduction	- Background: page 2, lines 18-24. Definitions here need clarification. Especially sentence: "We applied the definition of patient and family engagement from this framework as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system — direct care, organizational design and governance, and policymaking — to improve health and health care." Consider changing this to "...working in active partnership at various levels across the health system and the community..." If you do not add "in the community" here you cannot say you are looking at all 3 parts of the framework.	We made revisions using your suggested language.
12.	Public Reviewer #1: Debbi Carmody	Introduction	The final questions asking about covering gaps that exist in the current research are good and seem vital to discovering answers to the challenges that exist for patients, their family and caregivers in being proactively involved in their care.	We agree.
13.	Public Reviewer #2: Pam Carroll-Solomon, Retired Patient Advocate	Introduction	There needs to be clear definition and distinction related to patient satisfaction and patient experience: these are two different concepts and should not be used interchangeably.	For the purposes of this report, we did not use these terms interchangeably, but stated "patient experience or satisfaction" throughout.
14.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Introduction	Instead of opening up with the purpose, this draft started with a list of key points. Without setting the context, these key points meant nothing. Also, some definition setting would have been useful. I found that in the ending, on page 38. If this statement was the first paragraph in the beginning, my reading would have gone a lot smoother because all the time, I was wondering what parts were included where. Such as: did the health system level include the use of EHR's? Does the community level include school nurses and councilors who are a vital part in a child's development and the first round of help when a child is in need?	We worked to make the definitions and Key Points clearer and also adhere to the format required by AHRQ.

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15.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Introduction	Going back to making the first paragraph, I would take the quote I copied up above and rewrite it to be a bit more friendly to the stranger like this: "In this Technical Brief, we built on a conceptual framework on patient and family engagement. To categorize the engagement strategies, we used from Carman and colleagues' framework to create three categories. 1. Direct patient care = Strategies that directly impacted individual patients' treatment or decision making), 2. Health system level = strategies with a health system impact beyond the individual patient's care) 3. Community/policy level = strategies that engage consumers and communities in health care policies) (Figure 1).39" I found after reading the final chapter, the beginning (evidence summary, introduction) made much more sense.	We revised the section describing the conceptual framework, but the team decided not to add the numbering of the categories.
16.	Public Reviewer #3: American Psychological Association	Introduction	Could you explain a little more about how "cognitive behavioral therapy" was utilized in engaging patients, families, and caregivers in a medical setting as this was not specified beyond listing this strategy in the introduction section.	Because of our reliance on the use of systematic reviews, we were unable to include more information about intervention details like use of cognitive behavioral therapy. We noted this in the Limitations.
17.	KI Peer Reviewer #8	Methods	We did not assess the risk of bias in the original studies. Why not?	In a Technical Brief, assessment of the quality of original studies and the risk of bias was beyond the scope of this project. We noted this in the Limitations.
18.	KI Peer Reviewer #2	Methods	The brief does an effective job of mining key findings from the discussions with key informants, though only limited information is provided about these conversations. The criteria for the lit reviews was similarly effective, though, as mentioned before, hamstrung by the lack of a consistent theoretical framework or metrics to compare results.	Thank you.
19.	Ki Peer Reviewer #3	Methods	Good	Thank you.
20.	Peer Reviewer #4	Methods	Excellent PICOTS. One question is if you had any more definitive criteria on what defines a chronic condition. -One rather major limitation is that PUBMED and CINAHL dont have great MESH terms to link to PFE, especially for the system level. Gray literature search is a plus. -another limitation is that its very, very hard to find system level PFT strategies that have a compelling comparison group -did you use any software to assist in this technical brief?	Chronic conditions were broadly defined. We used MESH and other search terms for chronic conditions (see Appendix). We agree that there are not great MESH terms for PFE; we developed and tested each search string to capture these articles.

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21.	Peer Reviewer #5	Methods	The methods as outlined are appropriate.	Thank you.
22.	Ki Peer Reviewer #6	Methods	I wasn't clear if the search included reviews of engagement that came from employers? I'm thinking of employer-based incentives for wellness? Mobile and web-based apps for counseling and education and how to make appointments? Please state if this is in scope and if not, perhaps why not and that it is a limitation.	Employer-delivered programs would have been included in the scope of this review. Incentives for wellness would have been excluded because we focused on chronic disease management. The chronic disease focus is described as a limitation of the scope of the review in the Discussion.
23.	KI Peer Reviewer #7	Methods	Methods: Fine-	Thank you.
24.	KI Peer Reviewer #1	Methods	sentence 1 and 2 are unclear. Consider changing to: "We employed an established framework that categorizes patient and family engagement strategies according to whether they are deployed at the direct patient care, health system, or community/policy level. This framework was adapted using key informant input."	This is addressed in the revised description of the Conceptual Framework in the Introduction. We do not think it needs repeating in the Methods.
25.	KI Peer Reviewer #1	Methods	Page 5, lines 13-14. In retrospect, the limited sample of types of key informants may have biased the search strategy. To m did not include patient and family key informants involved in RHICs. All kinds of RHICs -include AHA, ACS, Etc? Page 6. Table 2. Under Interventions row and "Community-level interventions, including:" you need to add "health policy initiatives", "community-wide public reporting of health care quality information", community chronic condition screening and self-management initiatives". Or, less pleasing to me, you could explicitly exclude these but then you need to note the major limitation to the framework.	We did not include representative of professional organizations like ACS and AHA but included these organizations' websites in our grey literature. We had a very broad search strategy and did not limit the search based on KI input. We included these interventions in this section of the PICOTS Table.
26.	Public Reviewer #1: Debbi Carmody	Methods	Interviewing patients and families is one of the most important ways to collecting data that will identify opportunities as stated in the method section. These interviews allowed us to characterize different engagement strategies that may not appear in either the grey or published literature	We agree.
27.	Public Reviewer #2: Pam Carroll-Solomon, Retired Patient Advocate	Methods	There was no mention of patient activation measures (PAMs).	Patient activation measures (if assessed) were captured under patient-reported outcomes. We added this to the table to be clearer.

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28.	Public Reviewer #5: Jennifer Coldren, Children's Hospital Association	Methods	Would encourage expanding the grey literature search to include, The Beryl Institute, The Lucile Packard Foundation and the Children & Hospital Association for additional literature around pediatric healthcare and best practices for patient and family engagement.	We added the relevant information from these publicly available sites
29.	Public Reviewer #6: Lowrie Ward, Children's Hospital Association	Methods	This might be explained more in picots framework, but curious why you excluded some of the less intense patient feedback interventions? To me, these could be useful subgroup analysis or useful to see effort vs results continuum.	Our engagement definition included interventions that had 2-way interaction and we excluded low-intensity interventions such as handing out pamphlets that did not involve 2-way (patient-provider) interaction.
30.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Methods	Looks good. The only thing I wonder is if the people interviewed knew that appointment reminders and calling a patient to see if they will confirm are examples of engagement strategies.	Our Key Informants were selected because of their range of knowledge about patient engagement methods.
31.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Methods	In the brief, it stated that the articles reviewed were at the latest from 2015. Yet, going to the AHRQ website for this page, I saw other direct pages describing patient engagement strategies that were from 2015 and would have provided a large amount of data and detail into this report. Here are some of the links and references that I found on the AHRQ website, but were not included here: (Multiple references are attached in pdf)	We had full access to these reports as well and had reviewed them as part of the topic refinement process for this report.
32.	KI Peer Reviewer #2	Results	Page 38, line 23 aptly conveys the difficulty of surveying the literature on engagement: "What it means to do patient and family engagement vastly differs by setting, scale, and intended outcomes." Still, the review found value or potential value for most patient engagement interventions that it looked at, and it found no interventions that caused harm. This is significant.	Thank you.
33.	KI Peer Reviewer #3	Results	Clear; figures were helpful	Thank you.
34.	Peer Reviewer #4	Results	In results, I don't see a rigorous assessment of evidence quality. I do find the summation of positive/negative evidence figures extremely helpful, but an evidence quality level to ground these figures is needed. Overall, with the caveat of the quality/rigor assessment of evidence, I found this technical brief easy to follow with excellent visual depictions. I look forward to citing this and sharing with my research group.A9	We noted the limitation of not assessing quality of the evidence, given the limited scope of a Technical Brief. Thank you for your compliments.

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35.	Peer Reviewer #4	Results	<p>I would not combine adolescent with adult. I find from practical and research experience that these have distinct needs as populations.</p> <p>-I don't know if Figure 6 added much useful information -what were examples of "other" chronic conditions category?</p>	<p>We agree, but several reviews included both adults and adolescents, and we opted to include these reviews but report them in a separate section.</p> <p>We added a footnote to describe the other chronic conditions.</p>
36.	KI Peer Reviewer #6	Results	<p>I wouldn't say insurance "provider" (p.9, line 38). How about insurance "carrier"? Or an insurer? Just to make sure we don't confuse "provider".</p> <p>I was confused by the use of the word "modality," in Figure 5 (p. 14) and in the Evidence Table 3 in the appendix. The list seemed like it was a mix of the communications channel (mobile, telehealth), the content of the communications (counseling, peer support), and the person or thing providing the communications (nurse/case manager, team, community health worker).</p> <p>Please explain why these categories were chosen and the rationale. If the idea is the "who"--who is providing the content, then we need more information on the "who." To me, a RN case manager based in the hospital may be different from a certified case manager specialist in behavioral health based at a health plan, just to illustrate. Training, employer, credential, I would think is important. The employer is particularly important if we are thinking broadly about incentives (ACO? value-based contracts?--this idea is mentioned on p.31, line 28 because the payment model is a barrier). For example, if a patient is a member of Kaiser health plan and seeing Kaiser doctors, the incentive to manage costs is different, and the case manager is working for a health plan and a provider. I did see a sentence about case managers (p.13, line 37) and another sentence on the variety of persons in the telehealth modality (p. 17, line 25) but this kind of idea is more important than two sentences. To further illustrate, maybe advance care planning is useful in a complex hospital-provider system based on out of primary care, and maybe that same message is not well received from their insurance company. Maybe these aren't described or this detail is out of scope. Then this is a limitation.</p>	<p>We agree with using the 'insurer' term and have edited the report accordingly.</p> <p>We clarified in the methods that the term modality was used to describe the interventions in regard to how they are being delivered and by whom. The categories were chosen based on expert input on features of commonly tested interventions, and then included in abstraction forms so that we could systematically collect information on those from all included reviews. Given the broad scope of this project and the need to rely on systematic reviews, it was not possible to abstract information about each of the tested interventions at a more granular level, thereby limiting our ability to report on difference between individual studies. The reviews typically included large numbers of heterogenous studies without detailed information on the interventions in each of the studies. We agree that this is a limitation of this report and we have added this to our discussion/limitations section.</p>

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37.	KI Peer Reviewer #7	Results	Findings: Good	Thank you.
38.	KI Peer Reviewer #1	Results	<p>Findings: Excellent presentation and summary of studies reviewed. The review is comprehensive and thorough for the 2 areas of the framework assessed.</p> <p>Page 33, lines 18-51 -Community/Policy Engagement Strategies and Results from the Grey Literature very minimal and incomplete as a result of methodological approach.</p> <p>Pages 34-35 -A number of changes might result here depending on how framework and methodology issues addressed.</p>	<p>Thank you.</p> <p>We expanded on this concern in the Limitations and agree that the inclusion strategy, though broad, may have missed some community-based strategies.</p>
39.	Public Reviewer #1: Debbi Carmody	Results	<p>In the Grey Literature section of results- In addition, we identified several tools for health care providers and systems to use to engage patients and families in conversations with their providers (e.g., Supporting the Supporters: What Family Caregivers Need to Care for a Loved One with Cancer from the Institute for Healthcare Improvement); I can relate to support needs- learning how to administer food through a feeding tube, antibiotics through a port, draining an aspire drain, administering heparin shots in the belly....etc. are challenging if you have no nursing experience.</p>	<p>We appreciate the reviewer's comment, which reinforces the value of referring to the tool on supporting family caregivers.</p>

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40.	Public Reviewer #2: Pam Carroll-Solomon, Retired Patient Advocate	Results	<p>While I applaud the effort, it also disheartens me as the studies mentioned in the report appear to focus on how providers want to engage patients and families not necessarily how patients and families want to be engaged.</p> <p>As an industry, we need to look further and do more research on this aspect as it drives not only patient outcomes but the patients safety whether in their home or other setting and as related to medication, mobility, nutrition, etc.</p> <p>The number of key informants does not seem to be representative: why only 2 health system perspectives, 1 payer, etc. Why no representation from major players like Press Ganey or NRC for patient surveying/research perspective?</p> <p>Related to the studies and lack of harm reported. Have to wonder if this is a limitation as it is unclear how harm is being defined and if this is based on self reporting. Did any of the studies look at rates of patient grievances/complaints? This could further inform, especially when it comes to harm reported.</p>	<p>Thank you.</p> <p>Office of Management and Budget (OMB) Policy (https://www.usability.gov/how-to-and-tools/guidance/pa-overview.html) limit the number of people can be included. Many of the experts on our project team have experience working with health systems, payers, and other stakeholders such as Press Ganey.</p> <p>We agree this is a limitation of the report, as we were not able to extract that level of detail from the systematic reviews we included.</p>
41.	Public Reviewer #5: Jennifer Coldren, Children's Hospital Association	Results	Appreciated that the results were separated by adults and children.	Thank you
42.	Public Reviewer #6: Lowrie Ward, Children's Hospital Association	Results	<p>The separation of groups is confusing. Adults vs adults/children vs children only.</p> <p>Is there a way to have it just be adults or children? I expect that the literature review conclusions wouldnt be as applicable in this way, but it would read simpler.</p> <p>I also am curious why so many of the articles with children focused on lower complexity children when there is quite a bit of literature bout high complexity children.</p>	<p>This was a limitation of the previously published reviews. Some included both children and adults. We wanted to include these reviews and elected to describe them in a separate section.</p> <p>We highlighted the health conditions we identified. Overall, there was a paucity of evidence in high complexity children and we added this in the Discussion.</p>

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43.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Results	From page 18 to page 22, most of that was just text repeating what the graphs already said. As a UX Designer, that text should have been a data table attached to the figures because the problem you'll find is that figures start to get disjointed. Page 18 mentions "Fig 9" while showing "Fig 8" and page 21 calls out "Fig 8" when "Fig 9" is the figure directly before the paragraph. For some of the data paragraphs that did not have figures but listed off numbers and categories, I would have suggested using a donut graph. A brief is supposed to be concise, and having more visuals would decrease the reader's cognitive load.	We appreciate these suggestions, particularly the use of a donut chart. Our team, including our medical illustrator/designer, discussed these suggestions and we elected to retain the current presentations. We will consider the use of a donut graph in our future work.
44.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Results	For some of the data paragraphs that did not have figures but listed off numbers and categories, I would have suggested using a donut graph. A brief is supposed to be concise, and having more visuals would decrease the reader's cognitive load. I've taken certain sections of text that could be cut out and replaced with better graphs/tables. (See pdf)	Thank you for your suggestions. We appreciate these suggestions, particularly the use of a donut chart. Our team, including our medical illustrator/designer, discussed these suggestions and we elected to retain the current presentations. We will consider the use of a donut graph in our future work.
45.	Public Reviewer #4: Roxana Hasanat, UX/UI Designer	Results	In the brief, it stated that the articles reviewed were at the latest from 2015. Yet, going to the AHRQ website for this page, I saw other direct pages describing patient engagement strategies that were from 2015 and would have provided a large amount of data and detail into this report. Here are some of the links and references that I found on the AHRQ website, but were not included here:	We only included articles that met the eligibility criteria defined in our protocol, as explained in the Methods section. .
46.	Peer Reviewer #4	Results (Figures)	Figure 9: very helpful, really appreciate this organization - for section "Implementation of Health System and Organization Strategies – In Patients with Chronic Conditions (Guiding Question 1.d-1.f)" --> http://www.annfam.org/content/16/2/175.full kiran et al provide an excellent example of data-based recruitment strategy to achieve diverse/representative input. -RE community input: Please look into the "Boot camp translation" studies conducted regarding asthma and hypertension out of the University of Colorado (Norman et al.) these might not meet inclusion criteria but in case you did not assess them.	Thank you very much for these suggestions. We reviewed them but these articles did not meet criteria for inclusion. We have added a limitation acknowledging that we may have missed innovative methods that have not yet been evaluated for their impact on outcomes. We cited these articles in the Discussion.
47.	Peer Reviewer #4	Results (Figures)	Figure 16: do the colors have any significance?	The colors were selected for consistency across figures and do not have significance.

	Commentator & Affiliation	Section	Comment	Response
48.	Peer Reviewer #4	Results (Figures)	-Figure 17 is an excellent depiction.	Thank you.
49.	KI Peer Reviewer #1	Results (Figures)	<p>Page 3, Figure 1, 3rd Purple Column. Please add several examples here of community and policy level patient and family engagement.</p> <p>Specifically, I would suggest adding the following examples:</p> <ul style="list-style-type: none"> -Regional health improvement collaboratives [In text you can detail examples like: https://www.nrhi.org/ and https://www.commonablehealth.org/] -Health professional advocacy organizations (e.g. American Cancer Society, American Heart Association, and American Lung Association) -Consumer health advocacy organizations (e.g. AARP, Families USA, Community Catalyst [https://www.communitycatalyst.org/initiatives-and-issues/initiatives/center-for-consumer-engagement-in-health-innovation/full-description]) -Philanthropic Foundations (i.e. RWJF [AF4Q Initiative], KFF) https://www.communitycatalyst.org/ and <p>Missing much information here because even though patients, families, and caregivers in this sector are involved in these initiatives, in these initiatives they are not identified as patients or patient surrogates; they are identified as community members and their status as a patient is secondary (but still critical).</p>	We updated our grey literature review with these excellent suggestions.
50.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	Results (Figures)	Figure 1 is not a good representation of the conceptual framework. I've created a rough copy on what would be more useful: (Please pdf of public comments for her suggested figures).	We decided to retain Figure 1 with edits to address reviewers' comments.
51.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	Results (Figures)	I'm not sure Figure 5 is the correct figure for this evidence. ((Please pdf of public comments for details)	We reviewed and it is the correct figure.

	Commentator & Affiliation	Section	Comment	Response
52.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	Results (Figures)	Original Fig: Figure 12: When using simple bar graphs as a percentage, at first glance, the graphic is a bit misleading. Using a donut graph would be clearer. Or, if you are dead set on using the graph, a simple revision would be to eliminate the “Self-management” and “Shared Decision making” labels that are being repeated for each bar because you have a key at the bottom. (See pdf for more details)	We decided not to remove the bars.
53.	KI Peer Reviewer #2	Discussion and Conclusions	<p>Guiding Questions: The guiding questions are well formulated within the constraints of the brief. The brief supports the widely held notion that patient and family engagement contributes positively to health outcomes, though the specificity and weight of the evidence for this belief may not be convincing to everyone.</p> <p>What is needed, as the authors point out, is the "explicit development of a theoretical framework for understanding the key elements of a system-level patient and family engagement strategy" (p. 40, line 47). Several opportunities for future research are noted in the brief, including improved tools and more interventions aimed at specific populations. The authors emphasize the lack of research on health system and community strategies. Many systems are implementing engagement strategies but may not be rigorously studying and reporting them. There may be opportunities to collect and study what is going on in these systems.</p> <p>As for community approaches, I wonder if there may be additional studies that were overlooked, since public health initiatives have been aimed at engaging targeted populations for years and population health initiatives have rapidly increased in recent years. The big question, though, remains the same: How do we bring structure and consistency to the concept of patient and family engagement so that we can talk about it more rigorously? What slightly compromised readability for me--and this may be unavoidable in a review of reviews like this--were the long lists of details, often repeated, as the results of the various studies were summarized.</p>	<p>Thank you for this thoughtful summary. We are glad that you're able to reflect on the take-home messages from this report.</p> <p>We agree and additionally highlighted some studies that were excluded because of our inclusion criteria requiring comparison groups and relevant outcomes.</p>
54.	KI Peer Reviewer #3	Discussion and Conclusions	Guiding Questions: Appropriate, esp. the emphasis on the gaps in current research Clear outline of needs for future research in Guiding Question 2 and related evidence maps (Fig. 16 & 17)	Thank you

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55.	Peer Reviewer #4	Discussion and Conclusions	<p>Guiding Question 2: What gaps exist in the current research? –</p> <p>I'd love to know your groups' thoughts on how to implement comparison groups when conducting patient and family engagement. I almost never see this -- at best sometimes a pre-post- assessment. Suggestions for front-line implmentors on how to do comparisons and analysis for system-level PFE has been a longstanding challenge in my work.</p>	<p>While we understand the merits of this, such an analysis is beyond the scope of this report. Because of the large scope of the project, including direct patient care and health system interventions, we were looking for reviews of studies that had a comparison group, except for studies that only assessed implementation of an intervention [inclusion/exclusion criteria].</p> <p>Comparison groups are possible for health system interventions that use time series analyses or simple pre- and post-analyses where the pre-intervention phase is the comparison group. We identified few studies that used innovative health services research methodologies and described this gap in the Discussion.</p>
56.	Peer Reviewer #5	Discussion and Conclusions	<p>Guiding Questions: The authors did not include a question that assessed whether the type of involvement in projects -- whether patients and caregivers had a more substantial role in collaborating or making decisions in the approach to the interventions had an impact.</p>	<p>The organization that nominated the topic established the guiding questions. In addition, it was beyond the scope of this project to extract the details on the individual articles included in the reviews.</p> <p>A future, more focused review on health system or community strategies would benefit from extraction and assessment of the role of patients and families in the interventions and further assessment on impact.</p>

57.	Peer Reviewer #5	Discussion and Conclusions	<p>Guiding Question 1: The various figures and discussion do a thorough job of explaining the various reviews, what is included in the studies, and which interventions show benefits (or not). The format is especially helpful.</p> <p>The paucity of systematic reviews in the areas of organization and policy levels, it leaves these sections pretty minimal. Even though implementation was lacking, for what information was provided, a clearer summary across levels would be helpful</p> <p>Guiding Question 2: The identification of the gaps, which are the first few paragraphs, seem appropriate to the review. The description of what research studies need to be conducted has a few problems. The first recommendation suggests that valid and reliable measures of patient engagement beyond patient satisfaction with care need to be developed. This is not appropriate, as measures of satisfaction are in no way measures of engagement, nor are they developed with that intent. So this shows a clear lack of understanding of the measurement area.</p> <p>The fourth recommendation, about testing patient portals with lower literacy individuals seems completely at odds with the findings. The findings of the value of patient portals does not seem strong enough or targeted enough to warrant this. What would be helpful is to understand what kinds of portals and functions in portals actually support engagement -- like bi-directional communication with clinicians, access to reading and writing records, etc.</p> <p>The fifth recommendation comes out of the blue, suggesting the cost effectiveness of self management strategies. What is this based on, and cost effectiveness for whom? There has been no discussion of cost in review. So this seems completely unsupported.</p> <p>It would also be helpful to call for measures that might reflect whether systems are supporting the engagement of patients and caregivers.</p> <p>There are many areas of engagement that might impact individuals care at the direct, organizational and system level. It would be helpful to call for more work beyond self management.</p>	<p>Thank you.</p> <p>We worked to make the discussion clearer and highlighted the gaps.</p> <p>Thank you, we agree. We wanted to be inclusive of all types of studies and many did report patient satisfaction measures, which we described. We edited "patient satisfaction" to be broader, i.e., patient experience.</p> <p>We agree that the evidence for EHRs in terms of patient and family engagement is very low. However, we were unable to assess the types of communication the EHRs have at this level of detail (see Discussion). This is an important area of investigation for future work.</p> <p>We did include cost in our revised model and it was an outcome we included, when it was available. Unfortunately, very few studies measured and reported on cost (see Appendices). We retained this description because it fit with our model and is important to health system and insurer stakeholders, as well as patients.</p> <p>This is helpful, and we added it to the Discussion.</p> <p>Thank you, we agree that this is the take home point from our review. Because of this Technical Brief, we believe the next</p>
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				step will be to do a focused review on health system and community approaches to expand beyond direct approaches.
58.	Peer Reviewer #5	Discussion and Conclusions	<p>The broad nature of engagement and lack of clear agreement on how to achieve it mean that the approaches and literature are heterogenous. that is to be expected, as theoretical and conceptual underpinnings for why to engage differ. The conclusion and implications could do a better job of explaining how this affects the review and understanding of the interventions and literature.</p> <p>When the goal is to engage patients to do what you think they should do, this likely needs to specific set of solutions and interventions.</p> <p>When the expectation is that patients co-lead their care and decisions, this leads to a very different set of solutions and interventions.</p> <p>So, a better understanding of why certain underlying conceptualizations of engagement might lead to such disparate findings would be helpful.</p> <p>Of course, the authors chose to exclude this domain from the framework, and it makes sense in the review as authors to not place themselves on this continuum. but recognizing that such a continuum exists might better aid putting the findings and next steps into context.</p>	Thank you for the comment. We worked to highlight these points in the Discussion and also described the model changes (i.e. without the continuum) in the Methods and Discussion.
59.	KI Peer Reviewer #6	Discussion and Conclusions	<p>Guiding Questions: These are relevant and clear. I struggled a bit with how 1a-c and 1d-f were combined. Maybe some comment to explain how the document is organized or why these are combined? I would have like to hear a conclusion for each of the sub-questions for 1, particularly d-f.</p>	Thank you. We provided a description of the organization in the Methods.
60.	KI Peer Reviewer #6	Discussion and Conclusions	<p>I would like to see a synthesis statement on the role of payers and employers in engagement. Everyone cares about cost, or they should. Please do not mention that only providers whose payment is affected cares about costs (p.34, line 46).</p> <p>I love the comments (p.40, line 47) about diverse voices and about (p.41, line 11) about how synthesis statements are challenging due to the variation.</p>	We agree this is important, but these were not data that we extracted during our review.
61.	KI Peer Reviewer #7	Discussion and Conclusions	<p>Guiding Questions: Good. I'm not sure it's built for wider audience of patient partners but helpful to clinicians and researchers</p>	Thank you

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62.	KI Peer Reviewer #1	Discussion and Conclusions	Guiding Questions: Page 4, lines 6-7. Just a reminder that many of the community organizations listed above have extensively invested and studied ways to engage patients and families in community level efforts to "help patients, families, and caregivers manage their chronic conditions and improve patient health outcomes".	Thank you
63.	Public Reviewer #1: Debbi Carmody	Discussion and Conclusions	Increasingly, patients, families, and caregivers play key roles not only in managing their own health and health care, but also in contributing to the development and improvement of the health care delivery system. In retrospect, I declined contributing to the development of future health care delivery system outcomes after my husbands death. I believe this is due to the grieving process being so new, I needed time to process. I was asked too soon and believe that consideration for this process in grief is necessary for a willingness to participate in such studies. In other words, don't give up on care givers who have lost loved ones, they may be willing to participate at a later date.	We agree with this comment.
64.	Public reviewer #2: Pam Carroll-Solomon, Retired; Patient Advocate	Discussion and Conclusions	To the objective of the technical brief, I believe more research is needed. I would also strongly advocate for longitudinal surveys on patient experience. It is so difficult for patients to segment out a piece of their care especially if they had an ED visit, an inpatient visit, an office visit, home care, etc. Regardless of what survey they receive, a bad experience in one setting can color their perception of the other especially when they receive a survey months later. And, if the industry is trying to improve chronic condition outcomes, wouldn't it behoove the industry to create a cross-cutting survey instead of using a tool used more for value-based care?	We agree with this comment
65.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	Discussion and Conclusions	There were almost no discussions on trends in engagement strategies. Implications were unclear and did not build upon the impressive data introduced in the Results chapter. I've created a potential piece of graph that synthesizes the information on page 18, 25, and 29 by modifying the graphs I created for those pages. (See pdf for visuals)	We did provide 1 graph showing the trends in use of technology in the reviews we identified.

	Commentator & Affiliation	Section	Comment	Response
66.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	Discussion and Conclusions	<p>Of the entire document, the conclusions were the ones that were the most understandable.</p> <p>However, there is a line on page 40, “our review aimed to describe barriers and facilitators to implementing patient and family engagement” where I found that there was scant description on “barriers.” As a reader, I was not told why the barriers played such a large role that one could not recommend effectiveness in these engagement strategies.</p> <p>The majority of the results section text were data tables written as paragraphs. This made reading overly technical as the writing should be providing commentary and context to the results of the data.</p> <p>I’m also confused by the formatting on pages 40 and 41. “Future Research Needs” and “Conclusion” have the chapter heading font, but are placed as sections.</p> <p>Final comment: You may want to revisit the title. For me, their brief didn’t really present or go into detail on strategies. It mainly presented the results of systemic reviews.</p>	<p>Thank you for your helpful comments. We hope we were able to address them and make the report clearer.</p> <p>Unfortunately, we are not able to change the title, as it was determined as part of the Contract.</p>
67.	Public reviewer #7: Cara Coleman, Family Voices	Discussion and Conclusions	<p>Agree 100% that more research is needed to evaluate the impact of family engagement.</p> <p>Perhaps there is need to mention and research what matters most to families in terms of engagement- and that is the role that referral to a family-led organization plays in supporting a family to navigate the healthcare and multiple other systems as well as to partner in systems change for their child and all children with chronic healthcare issues.</p>	Thank you for this comment.
68.	Public Reviewer #1: Debbi Carmody	References	Complete with good resources.	Thank you.
69.	Public reviewer #6: Lowrie Ward, Children’s Hospital Association	References	There are MANY more organizations that could be included in grey lit search. Children’s Hospital Association has several white papers on this topic and sub topics.	We expanded the grey literature review.
70.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	References	<p>I’d like to add some articles and places of interest to look up for systemic reviews.</p> <p>The first one is from Patientengagementhit.com and the article is called: Patient Portal Adoption Tops 90%, But Strong Patient Use Is Needed. This part of the article kind of coincides with what I’ve already spoken about patient communication via patient portal.</p>	We included several organizations in the grey literature review.

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71.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	References	<p>The second place of interest I think would provide a current, health care system review is from Bon Secours because of their Homeless outreach program. I went to the Adventist Hospital Fall Conference in 2016 and listed to Samuel Ross, MD, MS, (Bon Secours Baltimore Health System) talk about how it is more expensive for the homeless to keep getting admitted to their hospital than it is to provide them with free housing, so they created their own housing units. They then expanded upon that to give youth activity programs and some child care. Here is a full list of their community programs: https://www.bonsecours.com/aboutus/community-commitment/community-programs/baltimore</p>	We included several organizations in the grey literature review.
72.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	References	<p>Now, if you were to contact them, they are an Epic hospital. They can create crystal reports that show metrics from their software usage (a crystal report is the nickname to a graphical report used by the EHR vendor). I listened to Patty Sengstack (in 2015, Bon Secours, Nursing Informatics) talk about new technology and from her I found out they create a lot of data dashboards. If there was some metric that you wanted to see, you can easily get it from that hospital system. As a former Epic employee, I know that the software is capable of running reports. The question is what would you like to see? I'd imagine you'd like to see how many patients use the patient portal? How many homeless people do you treat? What is their readmission rate over time? It looks like Patty Sengstack is now at Vanderbilt. That is another Epic hospital system and they are considered by the EHR vendor to be one of the best HIT builders they have. They can easily create a set of reports for AHRQ granted you know what you're testing for. And, if you need a 3rd Epic hospital, you can look up Massachusetts General or Kaiser Permanente. Both are Epic hospitals with decent development teams. They should be able to run a report.</p>	The goal of this review was not to do primary data collection from the electronic health record, but these are great suggestions for the EPIC collaboratives you described in this comment.

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73.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	Appendix	For Appendix- N/A – From my perspective, this does not provide me with anything useful.	The Appendix provides the detailed abstraction and not additional summary or synthesis.
74.	Public Reviewer #1: Debbi Carmody	Appendix	Complete and evidence of good research	Thank you
75.	KI, Peer Reviewer #8:	General	<p>Quality of the Report: Superior. That releasing of abnormal or sensitive test results to patients could cause confusion or excess worry.</p> <p>Question How did we handle? page 31 last sentence Felt end of sentence should stand along with better clarification, since so important...AS WELL AS A POSSIBLE DECREASE IN HOSPITAL ADMISSIONS. page 33 line 8 from the top What were the incentives provided to participate? page 41</p> <p>Is there anyway to move words so entire report ends on page 41? Early on learned this small “squeeze” leaves a more positive impression!</p>	<p>Thank you.</p> <p>Unfortunately, we were unable to extract this level of details about the interventions.</p> <p>We worked to reduce the text to end where you suggested.</p>
76.	KI Peer Reviewer #9	General	Quality of the Report: Superior	Thank you
77.	KI Peer Reviewer #2	General	<p>An excellent and thorough assessment of systematic reviews on patient and family engagement. The authors acknowledge and the brief affirms a core issue with the research: Though we talk often about the centrality of engaging patients and families, we don't share a precise and rigorous definition of engagement.</p> <p>Judith Hibbard's work on patient activation offers one concrete and evidence-based approach, but her definition of activation is narrower than how we use the term "engagement" broadly and is itself based on multiple levels of engagement.</p>	Thank you.
78.	KI Peer Reviewer #3	General	Quality of the Report: Good. Brief clearly and systematically lays out the limitations of the evidence about patient and family engagement	Thank you.

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79.	Peer Reviewer #4	General	<p>General Comments: -well written and well-organized. I applaud the authors for using the Carman conceptual model for patient and family engagement (PFE)</p> <p>-in abstract - would appreciate a sentence detailing how you decided to focus on reviews versus individual articles, and how you conducted a quality assessment as to strength of evidence.</p> <p>I hesitate to recommend more of my own work, but you may also want to check out our paper on patient engagement in safety which had some references on self-management for medications (a component of chronic disease management) Sharma health affairs 2018 https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.0716</p> <p>IN SUMMARY: Overall well done, but I don't see a meaningful quality/rigor of evidence assessment anywhere in the results section.</p>	<p>Thank you.</p> <p>We have a brief description of how the original article search was supplementary.</p> <p>We appreciated your expertise and cited your paper in the Discussion.</p> <p>Assessment of quality for reviews and articles is generally out of scope for a Technical Brief, but should be done for larger systematic reviews, which could be the next step.</p>
80.	Peer Reviewer #5	General	<p>In general this is a well written and researched report. The descriptions, tables, etc. are easy to see and understand. The authors were also very thorough. The authors have done an admirable job of addressing one of the key challenges of this review, which was to take a broad, multi-dimensional perspective on engagement to assess the state of evidence.</p> <p>I have some questions and concerns some aspects of the conceptual framework. The execution based on the framework is strong; however, the framework as adapted seems to muddy some key issues that need clarification and might require a bit of a reconsideration of the later data tables. It might also help to address a bit of the challenge noted by the authors about the scope challenges, which require the focus on systematic reviews, and excluding individual studies</p>	<p>Thank you.</p> <p>We worked to address these concerns about the conceptual framework, which resulted in several modifications noted above in Comment #8. We worked to address the “scope issues” throughout the review, particularly in the Discussion.</p>

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81.	KI Peer Reviewer #7	General	<p>General Comments: Overall I think this is helpful- though in classic papers is repetitive-- how many times to tell the review of 134 reviews, etc. I think it's worthy of challenging how you came that these actually meet the definition of patient engagement.</p> <p>I think building on the AIR roadmap might be important place to start for this paper? Just my opinion.</p> <p>I think assuring it's clear what we mean by patient engagement critical and maybe just as important to describe what it is NOT? Is it also patient partnerships or not?</p>	<p>Thank you for these helpful comments.</p> <p>We agree that building on the AIR roadmap using this evidence review can be a good next step.</p>
82.	KI Peer Reviewer #1	General	<p>General Comments: Excellent report overall. Concise clear summary of evidence to date. My only major concern is that the methodology employed limited the review's ability to report on the substantial examples of patient and family engagement strategies that have been used at the community/policy level to help people manage chronic conditions. See suggestions on Methodology below.</p> <p>Title. Consider changing to "Strategies for Patient, Family, and Caregiver Engagement to Improve Chronic Disease Care" -there is lack of clarity in the manuscript around this. Patient and family engagement has to have a purpose. We are not interested in engaging them to play baseball for example. The purpose should inform the search strategy as described in methodology section below. And the purpose needs to be consistently described throughout the manuscript.</p>	<p>We agree about the limitations you highlighted in the other comments. We worked to address these limitations about capturing the diversity of community-level engagement strategies (see Discussion).</p> <p>We have decided not to change the title for the review, but will consider this suggestion for the other scholarly products that emerge.</p>

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83.	Public reviewer #8: David Andrews, Patient	General	<p>In the existing framework for thinking about these issues this is an excellent review of the literature and extraction of some action conclusions.</p> <p>As the first sentence implies, I think there is a difficult and different framework that needs attention and development if we are to get the greatest benefit from Patient, Family and Caregiver Engagement.</p> <p>The subtext of the existing research is “we do this” and “they do that”; and if we and they do them better things will improve.</p> <p>There is truth to that, but my opinion (after being involved in this work as a patient for something over 14 years) is that there is a cap to potential progress until we get beyond the actions of the individual actors to develop more genuine team structures and actions - where all the players work as collegial and equal status participants. Easy to say, harder to do! This is hardly an original observation.</p> <p>I think it would be useful for future research to identify (not necessarily all that easy) providers and patients who actually work together as effective teams and begin to identify the structures and qualities (and probably personal characteristics) that make that work. The closest I now see to models that actually embody that model are some of the work that is done in PCORI.</p> <p>I’d be happy to talk further about figuring out how to proceed, should it be helpful.</p>	<p>We agree with the reviewer’s point of view. We agree that PCORI has models for engagement, although most of these are focused on engagement for research studies, which we did not include in this report.</p>

84.	Public reviewer #9: Rabia Khan	General	<p>don't really see much emphasis in this brief about workforce issues and how it is a serious limitation and barrier to improved patient satisfaction. I am not a clinician/provider, but it seems odd that in a field where there is so much customer interaction that workforce satisfaction and provider culture are not identified as significant factors. There is mention of limited studies in the brief, because only 1 noted 6 organizational characteristics, including culture. The brief notes management support as an organizational factor affecting sustainability, but does not explicitly address provider burnout, shortages, and lack of consideration for provider health and experience as underlying causes or critical factors for patient experience. I would expect that within any company/industry, employee satisfaction strongly influences and impacts customer satisfaction. An underlying culture of provider health considered as secondary or health systems with little concern for provider well-being/health outcomes can affect how providers engage and care for their patients. Would someone go to a life/wellness coach knowing the person is burned out, depressed, and unable to manage their own health? I would not and if I did, I should expect a similar outcome for myself. I have encountered individuals, including family members, who work in the medical field who are forced to work 26-32 hours with little to no sleep. They then call others to help them stay awake as they operate a vehicle to just go home and sleep. Are these individuals also seeing and treating patients while deprived of sleep? Sleep deprivation can be considered torture for an individual but appears to be a rite of passage for some physicians, residents, fellows, nurses, and other staff. Could there be more emphasis in this brief about these factors and discussion about workforce issues and its correlation to patient health? We are aware of provider shortages and are expecting it to worsen with baby boomers retiring, but there is a lack of accountability and research on effective strategies that improve provider health and methods to increase the workforce. For instance, my niece is disabled (cognitive and physical) and it is extremely challenging to identify caretakers/support who are properly trained to help her grow and develop. Also, there are a lack of incentives (like benefits, organizational support/training, etc.) to maintain and grow a strong sustainable workforce. This is problematic because her needs are lifelong and this will be a long-term issue. The state program's recommendation was for someone in the family to become a caregiver, but the only family member who may be capable is my Medicare-enrolled mother with her own health issues that affect her mobility. Organizations/health</p>	<p>Thank you for your comments.</p> <p>Occupational health and employer-focused interventions that met our criteria would have been included here, but we did not identify any that met the inclusion criteria. We excluded articles focused on prevention and wellness among healthy individuals, as the focus was on improving chronic disease management.</p>
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			<p>systems creating internal workgroups to talk about workforce issues is a basic first step, but measuring and taking actions to improve life and increase workforce is needed. Quality measurement/reporting is a means to address accountability and identify health outcomes, but it is usually considered a burden. Without organizational changes to the environment/culture then it will continue to be burdensome for providers. This may not be something the industry may want to openly discuss since change is challenging, but it affects everyone who interacts with the medical field/healthcare providers.</p> <p>As a public citizen, relative of individuals with long-term needs and chronic conditions (e.g., severe obstructive sleep apnea, hypertension, etc.), and relative of those in the provider workforce, I strongly support and encourage additional research and developing the evidence base related to organizational/health system workforce and policy factors influencing patient engagement and outcomes. Beyond that, there needs to be an actionable national strategy to address these issues.</p> <p>Providers are not just the workforce, but can be patients too. Link to info on burnout: https://www.medscape.com/slideshow/2020-lifestyle-burnout-6012460</p>	
85.	Public Reviewer #1: Debbi Carmody	General	Very comprehensive and complete for a draft, good job	Thank you

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86.	Public reviewer #10: Michael Silver, Comagine Health	General	<p>A stated purpose of the brief is to inform individual health plans, providers, and purchasers as well as the healthcare system as a whole by providing important information to help improve healthcare quality. This goal would be better served if the scope of the review were expanded to include recent developments in payment policy at the federal level and among commercial payers. Providers could make better use of the evidence provided if it included review of payment modalities available to support the resources and effort required to provide highlighted elements of care. Federal policy has made major strides in this area. Relevant policy has been documented in sources such as annual updates to the Medicare Physician Fee Schedule (a source that appears not to have been included in this review). Similar information about commercial payment may require some original investigation. Further review of the current payment landscape would also inform policy making by identifying payment gaps for promising care delivery strategies.</p>	We agree completely with this comment and hope that this technical brief will stimulate future research

	Commentator & Affiliation	Section	Comment	Response
87.	Public reviewer #11: Anandi Law, Western University of Health Sciences	General	<p>Thank you for the opportunity to provide comments. As an academic researcher, I read with interest this focus on patient and caregiver engagement since it is close to my heart and the research stream I have been leading my team on - called patient accountability. I am very glad that there is attention to this area. The brief was excellent in methods, presentation and especially the areas for future research. I noticed a few areas that I had questions on:</p> <p>1. In your limitations section you mention you excluded the following:(2) exclusion of studies on patient engagement in research; (3) focus on engagement of patients with chronic health conditions, excluding reviews on chronic disease prevention;</p> <p>This surprised me since there are a few (may be 4-6) studies in this area that highlight and measure patient engagement using the PAM (Patient Activation Measure) although I am not a fan of their Guttman scaling. It is the first tool in the area and I consider some attention needed to be paid to it. Also the exclusion of chronic health conditions, since there is a special need in that area for lifelong self-care.</p> <p>2. One of the primary outcomes was medication adherence outcomes, given the volume of medications dispensed and filled but not adhered to - a health burden in terms of lost opportunity of outcomes, increased complexity of untreated conditions that are not at goal and sunk costs. Was there any consideration of focus in this area for the future (in your discussion/conclusions) there needed to be more given that med adherence was a common focus in your reviewed papers.</p> <p>3. I am working on validating our Patient Accountability Tool (PACt) based on literature, using a conceptual framework and 5 domains; an earlier version is under review for a publication now. I am VERY interested in following/collaborating on this effort with AHRQ, since we are also connecting it to medication adherence, patient outcomes, cost savings and long term motivation to be proactive in one;s own health.</p>	<p>Thank you for your comments.</p> <p>We agree that there are articles focused on prevention and also a large body of evidence around engaging patients as research partners.</p> <p>We did not exclude patients with chronic health conditions as this was the focus of the review. We checked the wording in this section to make sure it is clear and we do not believe it needs edits.</p> <p>We agree. Medication adherence was included as an outcome of interest and is included in our evidence tables.</p> <p>Thank you for sharing your interest in collaboration, as this sounds like important work.</p>
88.	Public reviewer #2: Pam Carroll-Solomon, Retired; Patient Advocate	General	This is a great first start; however, much more needed.	Thank you. We agree with this comment.

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	Commentator & Affiliation	Section	Comment	Response
89.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	General	In the EHR world, we think of patients having communities. In epic, we used the term “The Care Continuum” and at Dr First, we use “HealthiVerse.” Both mean the same thing: it’s a list of people and locations who help manage a patient’s care. For me, as a patient, I have a primary care, a dentist, and several years ago, I had a dermatologist and an eye doctor. I’m now taking therapy from a psychiatrist to treat my depression. From that list, I’ve already gotten 5 people. My medications are another list. The truth is, any one patient is a complexity of data and interactions and unless if the patient stays up on their routines, it is hard to keep your health up.	We appreciate your sharing your personal health experiences.
90.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	General	The amount of research done is impressive. I was really looking forward to learning about new trends and discoveries of different outcomes. With some revising and better formatting, the final draft will be more beneficial to my needs which is to understand and apply effective patient engagement strategies. And if something is not effective, I need to know the context and why. Despite my numerous comments, I fully intend to read the final draft of this brief in the hopes that it helps me learn more about the effectiveness of certain patient engagement strategies.	Thank you for your careful review and suggestions.
91.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	General	The evidence that was provided of specific patient engagement strategies were each described in a specific sentence, and failed to mention the barriers to each. Page 17 is perhaps the closest to what I was expecting, but it did not go into describing what are the barriers to each. I keep mentioning ‘barriers’ because that was the word used in the conclusion where it said the draft was more focused on, yet I barely see any commentary on the barriers. I’m going to take a moment to format the first paragraph on page 17 here just to show what I was more expecting to see: (See page19 in pdf)	Thank you for your careful review and suggestions.
92.	Public reviewer #4: Roxana Hasanat, UX/UI Designer	General	Q:10. Did you find this report unnecessarily difficult to read? Yes. It took me well over 10 days to read this entire document. The majority of that time was spent in the beginning section. I would revisit this with the comments I’ve made for the document. Some figures were poorly made and some used the wrong type of graph to convey the meaning of the text. Sometimes, the same type of data would be presented in the text but use different metrics. For the outcome benefit use of Adults, the text used percentages, while talking about the remaining two groups, they used number of reviews. Consistency would help.	We appreciated the suggestions and made revisions throughout the report to improve the readability.

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93.	Public reviewer #3: American Psychological Association	General	It would be interesting to see if there were differences in engagement with healthcare providers in patients, families and caregivers who employed a health interpreter (i.e., for deaf/hard-of-hearing or language diverse community members) as deaf/hard-of-hearing patients have reported significant barriers in utilizing the necessary healthcare services (Steinberg et al., 2006).	Thank you, but this point is beyond the scope of this project.
94.	Public reviewer #12: National Center for Health Research (NCHR)	General	While we commend the Technical Brief's aim to outline the currently available evidence on patient and family engagement strategies for managing chronic conditions, we have several suggestions (see attached document).	Thank you for providing detailed suggestions to improve the report.
95.	Public reviewer #12: National Center for Health Research (NCHR)	General	Does existing patient engagement research include patients who have been harmed by complications of their treatment? Such patients tend to be excluded from studies or patient engagement activities at the health system and community/policy levels if they seem angry or less likely to be cooperative, and thus their important perspective can be missed when patients are selected for engagement efforts or studies.	Yes, you are correct – studies addressing harm would be included as long as they met the other inclusion criteria.
96.	Public reviewer #12: National Center for Health Research (NCHR)	General	The Brief notes a lack of systematic measurement of potential harms, such as anxiety. For example, the Brief mentions that receiving information through patient portals may be distressing or confusing to some patients, but this potential stress was not systematically measured. Is research needed to determine how providers can be sensitive to the engagement preferences of patients, regarding patient portals and other strategies?	We included studies about patient-provider communication and portals in this review.
97.	Public reviewer #12: National Center for Health Research (NCHR)	General	We agree with the identified seven needs for future research, such as the development of technology-based tools accessible for those with little technological skill. Additionally, there were several research gaps identified in the brief that would benefit from further emphasis. These include the lack of systematic reviews addressing direct patient care for those with mental illness, and reviews on outcomes for strategies for those with multiple chronic conditions. Also, there is a need for more systematic reviews concerning children, as well as further assessment of shared decision-making and patient-provider communications on clinical outcomes.	We agree with this comment

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98.	Public reviewer #12: National Center for Health Research (NCHR)	General	In summary, this Technical Brief provides a needed analysis of the research on engagement strategies for patients, families, and caregivers. As such, it is a valuable tool to assist healthcare providers in making decisions regarding strategies for patient engagement. We recommend that the above suggestions be added to the identified needs for future research.	Thank you for your comments and recommendations.