

Comparative Effectiveness Research Review Disposition of Comments Report

Research Review Title: Closing the Quality Gap: Revisiting the State of the Science: Improving Healthcare and Palliative Care for Advanced and Serious Illness

Draft review available for public comment from December 27, 2011 to January 24, 2012.

Research Review Citation: Dy SM, Aslakson R, Wilson RF, Fawole OA, Lau BD, Martinez KA, Vollenweider D, Apostol C, Bass EB. Improving Health Care and Palliative Care for Advanced and Serious Illness. Closing the Quality Gap: Revisiting the State of the Science. Evidence Report/Technology Assessment. No. 208. (Prepared by Johns Hopkins University under Contract No. 290-2007-10061-I.) AHRQ Publication No. 12(13)-E014-EF. Rockville, MD: Agency for Healthcare Research and Quality. October 2012.
www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Comments to Research Review

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

Comments on draft reviews and the authors' responses to the comments are posted for public viewing on the EHC Program Web site approximately 3 months after the final research review 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.

The tables below include the responses by the authors of the review to each comment that was submitted for this draft review. 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.

Comment#	Commentator & Affiliation	Section	Comment	Response
1	1	Clarity and usability	Yes it is well structured and organized. I don't think the conclusions can inform policy or practice. It is limited to review of measures.	Thank you for your comment
2	2	Clarity and usability	<p>My general comments provide suggestion for restructuring the report.</p> <p>Further work is needed to describe effect size and less reliance on statistical significance.</p> <p>For me the key finding is the lack of research - with a priority being looking at QI interventions in the hospice setting.</p>	<p>We tried to do this but most studies did not report effect size. This information is captured in the evidence tables where present.</p> <p>In the methods section, under data abstraction, we note: "We abstracted effect size whenever possible, and both numerical and statistical results"; and under data synthesis, we note: "Since many studies did not report effect size but only a p value, we calculated the percentage of studies with a statistically significant improvement in outcomes with the intervention compared to control. "</p> <p>Also, the discussion, under strengths and limitations states "Studies often did not report effect size or complete results, which did not allow for estimation of the magnitude of effect."</p> <p>This is emphasized in future research</p>
3	3	Clarity and usability	Thoroughly enjoyed this report--but it required very careful reading and some interpretation on my part. While not stated explicitly, the implications for policy and practice are enormous.	Thank you for your comment

Comment#	Commentator & Affiliation	Section	Comment	Response
4	4	Clarity and Usability	I have no doubt that this report contains important information gleaned from the 93 studies selected for review. However, as currently written and organized, it is difficult to reach conclusions to inform policy or practice. Because I have confidence in the content itself, I anticipate that re-writing for clarity will yield conclusions that do have the desired impact.	<p>Changes have been made throughout the report and include an expanded results section, discussion section, and strengths and limitations section. For example, we have:</p> <ul style="list-style-type: none"> - Addressed noncancer literature - added to Strengths and limitations: "Few studies focused on specific non-cancer populations, such as patients with heart failure." - Clarified/added on quality improvement in the last section on multiple targets which includes most of the quality improvement-oriented studies, and in the discussion as well - Expanded the discussion, as per reviewers' specific comments

Comment#	Commentator & Affiliation	Section	Comment	Response
5	5	Clarity and Usability	Developing a report like this is difficult as there are so many different parts that need to be put together and because it is a review without meta-analysis due to the breadth and heterogeneity of the studies -- I am sure writing it is difficult. The figures help.	<p>Changes have been made throughout the report and include an expanded results section, discussion section, and strengths and limitations section. For example, we have:</p> <ul style="list-style-type: none"> - Addressed noncancer literature - added to Strengths and limitations: "Few studies focused on specific non-cancer populations, such as patients with heart failure." - Clarified/added on quality improvement in the last section on multiple targets which includes most of the quality improvement-oriented studies, and in the discussion as well - Expanded the discussion, as per reviewers' specific comments, e.g., comment 11 and 15 <p>Changes have been made throughout the report, as detailed in responses to other comments that should improve the clarity of the report.</p>
6	6	Clarity and Usability	Organization clear and conclusions well formulated.	Thank you for the comment.
7	7	Clarity and Usability	<p>Well organized. Concise. Main points presented.</p> <p>It raises the point that most palliative care literature done in end stage cancer and not in end stage non-cancer conditions. May need to state stronger that more research is needed and more funding directed towards palliative care.</p>	<p>Thank you for the comment.</p> <p>The following statement was added to the Strengths and Limitations section that addresses the non cancer literature: "Few studies focused on specific non-cancer populations, such as patients with heart failure."</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
8	8	Clarity and Usability	<p>I find the paper well written, structured, and organized. The main points are clearly presented.</p> <p>While the conclusions can be used to inform policy, it likely needs some fleshing out of concepts like the quality improvement taxonomy with some modification.</p> <p>More discussion on what is needed to maximize the value of the studies would be helpful. I am not sure if the sophistication of this paper would be used by most hospice or nursing home clinicians to make practice decisions.</p> <p>I think for that, the paper needs to be written in a more colloquial way. I think the larger providers would use the paper and appreciate it, but if the goal is to penetrate the diverse provider community geographically, then a version of the paper that is easier to read would be appropriate.</p>	<p>Thank you for the comment.</p> <p>Point reflected by other reviewers as well; we have clarified/added language on quality improvement in the last section on multiple targets which includes most of the quality improvement-oriented studies, and in the discussion as well.</p> <p>We expanded the discussion section to further specify gaps in the evidence and opportunities for future research. For example, we emphasize the importance of caregiver burden in the future research section: "In addition, few studies evaluated caregiver burden as an outcome; this is a critical area for seriously ill patients that requires further research."</p> <p>We have expanded the term "health disparities" to "diverse populations and disparities in care" in several places (including future research conclusions).</p> <p>In addition, in the future research section in the conclusions, we also note: "Finally, studies evaluating the impact of policy changes on patient outcomes are needed."</p>
9	9	Clarity and Usability	<p>The report is well-written. The methods are thorough and clearly explicated and the results are very readable.</p> <p>(Totally minor detail: page 32 of the file and 21 of the report. A sentence is repeated L17-19 and again L22-24.)</p>	<p>Thank you for the comment.</p> <p>The repeated sentence has been deleted</p>
10	12	Clarity and Usability	<p>This is a highly valuable report that is well written, well organized and the main points are very clearly presented. It is likely to have an important impact in informing policy as well as practice decisions. Congratulations on a superb report!</p>	<p>Thank you for your comment</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
11	1	Discussion/ Conclusion	More detail could be provided as to specifically what the research priorities should be.	The future research needs section has been expanded to address this comment. For example it now specifically notes the need for future research on caregiver burden in the future research section: "In addition, few studies evaluated caregiver burden as an outcome; this is a critical area for seriously ill patients that requires further research," and on policy evaluations: "Finally, studies evaluating the impact of policy changes on patient outcomes are needed."
12	2	Discussion/ Conclusion	Limitations are adequate. No literature omitted (except new studies on pain management in hospice by Herr and colleagues) Future research needs further elaboration and guidance.	We have screened these articles – they do not meet inclusion criteria Have added to this as per other reviewers' specific comments
13	3	Discussion/ Conclusion	I would recommend consideration of stating a bit more strongly the number of studies that created the percentiles discussed. The reader will not remember that of 18540 retrieved studies, only 93 studies met the criterion for this review, and of these 93, the percentiles are extremely small when thinking about strength of evidence in regards to outcome and linkages to practice. I also believe that there is a clear message that studies are extremely heterogeneous, that methods are often missing in design and control, and that various populations or disease/conditions lack any substantive evidence (e.g., pediatrics, health disparities). These are very powerful findings and they might be brought forward a bit more.	We have added in the number of studies, not just the percentage, in places where this was missing. The following was also added to limitations: "...particularly those that did not focus on patients with very advanced or serious disease (only 93 studies were included in this review from a much larger literature)." Regarding the issue of heterogeneity, the following language was added to limitations: "Despite this focus, studies were still very heterogeneous, and even descriptive synthesis across such different studies has limitations." Added to strengths and limitations: "Studies often did not clearly report study design or details on the intervention." Added pediatrics to executive summary implications – pediatrics and disparities are mentioned in multiple places in discussion

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
14	4	Discussion/ conclusion	<p>The Discussion section is generally easy to read, but is limited in impact due to many of the issues detailed above.</p> <p>On p. 90 the authors make a global statement of about the quality of evidence that is misleading, simply because of the challenges of reviewing this heterogeneous body of evidence. First, they note there are few high quality studies in the group of 93 reviewed; in the next sentence they speculate that RCTs (which traditionally define high quality evidence) may not be the most meaningful study design for organizational change interventions. In this paragraph, they capture (but do not solve) the conundrum of their own review.</p> <p>Perhaps the authors would be willing to consider these "key questions" –</p> <p>1) What do we know from the highest quality studies in this review? (presumably many of these will be RCTs)</p> <p>2) What do we know from the highest quality QI interventions in this review -- studies which cannot meet traditional definitions for research evidence, but which meet SQUIRE standards?</p>	<p>Good point – throughout the report, we have rephrased “high-quality” to “high- and medium-quality” to be inclusive of the non-RCTs. Also have rephrased this 2nd sentence as “RCTs are important in this field, and many of the highest-quality studies were RCTs, but since RCTs are often challenging or may not be the most appropriate study design for QI interventions requiring institutional change, including the non-RCT literature was also important for this review.”</p> <p>We’ve added information on this in several places: Methods, data synthesis: “Because the results of higher-quality studies might differ from those of lower-quality studies (more likely to have methodological issues and lower sample size), we evaluated for potential differences in results in two ways. In the grading process, we compared the strength of the evidence for both RCTs and non-RCTs. Also, because quality improvement on the organizational level often cannot be conducted as an RCT and these studies would therefore not be graded as high-quality, as a sensitivity analysis, for the target of continuity, we determined whether results of the evidence synthesis were different when including only the high- and medium-quality studies” Under Risk of Bias, have emphasized that we tried to find a way to differentiate the QI studies – but this was a challenge: “Although we considered assessing risk of bias separately for non-randomized quality improvement studies, we were unable to identify any validated tools that worked well in this literature and could be compared to risk of bias tools designed for</p>

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>

Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
				<p>randomized trials”.</p> <p>At the end of the KQ1 results for the continuity section: “For all outcomes, when including only the results of the high- and medium-quality studies (excluding the low-quality studies), the overall findings were consistent.”</p> <p>In the grading sections: “Study results did not generally differ between the RCTs and non-RCTs.”</p> <p>In Limitations of the review: “Due to the heterogeneity in the types of studies and the need to use one method for assessment of study quality across all studies, we used a risk of bias assessment tool for randomized trials, which did not capture many issues of methodologic quality within non-randomized quality improvement studies.”</p>
15	5	Discussion/ Conclusion	<p>The future research areas related to lack of sufficient research on effectiveness, especially related to quality of life indicates that there is an important gap in our knowledge. These same issues are being identified by the NQF MAP efforts. Highlighting issues of caregiver burden as central to our understanding is also important.</p> <p>Highlighting the significant gap in research on diverse populations and the need to address and reduce health disparities is also essential.</p> <p>Especially as the ACA is implemented - implantation studies and studies that connect policy and patient outcomes will be essential.</p>	<p>We emphasized caregiver burden in future research section by noting the following “In addition, few studies evaluated caregiver burden as an outcome; this is a critical area for seriously ill patients that requires further research.”</p> <p>In order to better highlight that future research is needed both in diverse populations and in the area of health disparities, we have expanded the term “health disparities” to “diverse populations and disparities in care” in several places (including future research conclusions).</p> <p>We have added this – in future research conclusions, “Finally, studies evaluating the impact of policy changes on patient outcomes are needed.”</p>
16	6	Discussion/ Conclusion	Clear results and recommendations.	Thank you for your comment

Comment#	Commentator & Affiliation	Section	Comment	Response
17	8	Discussion/ Conclusion	<p>The major findings are clearly stated as are the limitations of the review/studies. You may consider, if appropriate, explaining the impact of these limitations and what would have reduced these limitations so that readers can consider implementing the concepts in future research.</p> <p>The Future Research section could benefit from focusing the research on which areas of research should be done, how it would progress the industry, what sorts of priorities should be considered.</p>	<p>We added the following language to the limitations section (as per specific suggestions of other reviewers): "Due to the heterogeneity in the types of studies and the need to use one method for assessment of study quality across all studies, we used a risk of bias assessment tool for randomized trials, which did not capture many issues of methodologic quality within non-randomized quality improvement studies."</p> <p>Future research section has been expanded as per specific suggestions of other reviewers. For example, we noted that "...few studies evaluated caregiver burden as an outcome; this is a critical area for seriously ill patients that requires further research."</p>
18	9	Discussion/ Conclusion	The discussion is a succinct recap of the results. A bit more reflection on the progress reflected by the results, or a comparison of the findings with those in other patient populations would have been illuminating.	Changes were made to the discussion section, that now includes additional detail on the strengths and limitation of the literature, applicability and additional specificity on areas for future research .
19	12	Discussion/ Conclusion	Implications are clearly stated and future research section is well developed and clear.	Thank you for your comment
20	7	Discussion/ Conclusion:	Implications clear. Future research section clear. I wonder about stating costs of care and the role of palliative care in health care reform.	We added to limitations that we did not address costs: "Due to our focus on clinical outcomes, we also did not address the issue of costs"
21	PC: Joyce Reitzner (ACCP)	Executive Summary	Approve, with out comments. The Quality Improvement Committee of the American College of Chest Physicians (ACCP) appreciates the opportunity to comment on the "Closing the Quality Gap Series: End-of-life and Hospice Care". After review the ACCP approves this report, in it's entirety, without comments.	Thank you for your comment
22	PC: Susie Sherman (AGS)	Executive Summary	Overall, The American Geriatrics Society (AGS) believes that AHRQ has developed a comprehensive draft report. There are several areas of the report that we feel could be strengthened and clarified, which we have outlined below.	

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
			<p>While the focus on quality improvement interventions is logical, the rationale for this is not adequately described and should be discussed more fully in order to interpret these results in context.</p> <p>There is an important body of literature that is part of the evidence base that would lead to deciding to do a QI intervention, which is also relevant to an organization that decided it wanted to do QI for palliative care. Specific comments that would address this general point more fully include:</p> <p>When looking at Figure 2 and the table: “Quality improvement definitions relevant to hospice and palliative care” (pg. 25), it appears that a large number of potentially eligible studies relevant to palliative care are not included. It would be useful to address how many studies were trials of palliative care interventions, as these could potentially function as an evidence base in guiding an organization to decide to implement a QI intervention.</p> <p>More granularity in the exclusion tree would be helpful.</p>	<p>The report did indeed look at a broad array of interventions, including healthcare and palliative care interventions. In order to clarify this we have made a number of changes, including clarifying in the title, abstract, executive summary, introduction and methods that palliative care interventions are included in this report as well as healthcare studies. For example, the title now includes the term “healthcare and palliative care”. We have rephrased in the introduction and methods that we included a broader array of interventions. In the 2nd paragraph of background, have rephrased this section: “These interventions can include changes in the way care is provided within a system, such as palliative care consultation services, and interventions to change how patients/families interact with the healthcare system, such as a patient self-management program for pain that is integrated with patients’ healthcare. They can also include quality improvement interventions,”</p> <p>The figure details all of the specific reasons reviewers were able to provide for exclusion at the abstract screening and article screening levels. It was unclear</p>

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
			<p>The definition of quality improvement is only noted on page 25, and is not conveyed in any detail in the remainder of the report.</p> <p>As noted above, there are effective trials of palliative care that are predecessors of QI interventions, and it would be helpful to further contextualize this within the abstract, executive summary, and intro.</p> <p>When framing the discussion around results, we believe it will be important to do so within the context of quality improvement interventions and point out when there are high quality non-QI trials that should guide practice as well, even when they have not been implemented widely. Without this context, it is possible that one could come away with the message that we know less about palliative care than we really do.</p>	<p>what additional detail was being requested by the reviewer. Important point, and we have included this in other places –including the introduction, as above, and discussion.</p> <p>We have clarified throughout that our definition of QI includes palliative care, and rephrased in some places that these are “interventions to improve quality” to make it clear that these are broader interventions.</p> <p>We used a relatively broad definition of quality improvement based on the original Closing the Quality Gap report, including studies conducted within or linked with the healthcare system and that have at least some element of system change. Palliative care consultation interventions, and interventions focusing on patient education and self-management, were included as part of this definition. Although these may not always be considered as quality improvement studies, they were included here because they are important methods for improving quality of care in patients with advanced and serious illness, particularly for pain management. We have clarified this throughout the report.</p>
23	1	General Comments	I think the title of this report seriously overstates the content. The title of "Closing the Quality Gap" and "State of the Science End-of-Life and Hospice Care" implies a broad evaluation of care delivery. This report is much smaller in scope and really is limited to analysis of a small set of measures. The title is very misleading.	We have revised the title with AHRQ approval, as per suggestions of other reviewers, to be clear that this report only addresses healthcare and palliative care interventions and is not a state of the science of the entire field of end-of-life care. The revised title is: “Interventions to Improve Healthcare and Palliative Care for Advanced and Serious Illness”
24	2	General Comments	(See subsections below)	

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
24a			<p>The goal of this review is to review the effectiveness of quality improvement intervention in end of life care. This is an important goal and the task given to the team is comprehensive set of questions with several important methodological challenges that make this task difficult. An inherent difficulty of this task is the definition of quality improvement intervention and the limited literature that can assess the impact of QI interventions for those in the last years of life and/or the seriously ill with a life defining illness.</p> <p>There are much strength to this work including comprehensiveness of the literature review to the point including all possible articles that could be considered a QI intervention. My main suggestion for the team to consider is applying a more stringent definition of QI, but continuing to report all possible intervention research regarding the paucity of research. Inherent to the definition of the Quality Improvement intervention is notion of team approach of applying scientific methods to gain knowledge and intervene over variation in processes of care (See Tindall and Stewart, 1993). The CDC in its definition of QI notes that it is deliberate and defined process that us PDCA or PDSA process to guided activities to improve the population health and provide care that is responsive to the community need. The CMS in its definition of QI project for a Peer Review Organizations is a process of audit, formation of intervention that impact process of care, and collecting data to assess the impact of this intervention. My concern is that many of the studies would not meet this notion of CQI, but more focused on single interventions to changing provider behavior.</p>	<p>There are multiple definitions for what constitutes a QI intervention. We have included a broader set of interventions for this report and have clarified this issue in multiple places, as per other reviewers' comments in the report to rephrase that we included healthcare and palliative care interventions, and that quality improvement was only part of this. For example, in the background, we note: "These interventions can include changes in the way care is provided within a system, such as palliative care consultation services, and interventions to change how patients/families interact with the healthcare system, such as a patient self-management program for pain that is integrated with patients' healthcare. They can also include quality improvement interventions..."</p>
24b			<p>For example, I am not sure that I would include a study where that sole intervention is education. Evidence Table 3 is an important, but I would be clear on what you mean by organizational intervention.</p>	<p>Organizational intervention is defined in Table 2: Organizational changes (PDSA, collaboratives, multidisciplinary teams, shifting from paper-based to computer-based recordkeeping, long-distance case discussion between professional peers).</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
24c			<p>Many of these studies are RCTs of a fixed intervention which some would argue does not fully integrate the spirit of dynamic inquirer and changing interventions in typical CQI intervention. A CQI study could be an RCT, but it would need to be cluster-randomized design. Another important distinction is CQI embraces the notion of stage, multifaceted interventions that are needed to change provider and/or patient behavior. If you accept this premise, I suggest that you consider describing the QI interventions studies first and their impact rather than focus on separate outcome states. The reason for this recommendation is your state goal evaluating the evidence of the effectiveness of QI interventions in end of life care. You could apply a more stringent definition first and then given the paucity of studies state conclusion about studies that have elements of the intervention aimed at changing a provider and/or family behavior. There is British Journal of Surgery article</p>	<p>We have reframed the report as “healthcare and palliative care interventions” and stated that quality improvement interventions are a subset of this</p>
24d			<p>There are some important conclusions that you need to emphasize.</p> <p>First, the small number of studies that embrace the CQI framework.</p> <p>Second, virtually small number of studies that actually has hospice as the site of care.</p> <p>Third, outcomes where there is paucity of research.</p>	<p>We have addressed in the discussion that many quality improvement types were infrequently addressed, and few studies were comprehensive quality improvement interventions</p> <p>We have noted that only 2 studies were in hospice</p> <p>We have emphasized in the discussion that some outcomes (e.g., caregiver burden) had little research</p>
24e			<p>Minor points</p> <p>1. The most important reason for your 2000 cut off is the existing systematic literature review rather than stating that palliative care began as subspecialty in 2000. Those in hospice are going to argue the benefit dates back to early 80s.</p>	<p>We have described our rationale for using the 2000 cutoff in the introduction and methods sections based on the previous systematic reviews</p>
24f			<p>2. The title really does not fit with the state goal of the study.</p>	<p>The title has been revised and now addresses “healthcare and palliative care interventions”</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
24g			3. I would report some measure of effect size rather than statistically significant results.	Unfortunately, effect size was not reported in many of the studies; therefore, the only way to include all studies (which reported results in many different ways) was to report statistically significant results
24h			4. For some outcomes, there are just too few studies. That is important conclusion. Systematic review of the application of quality improvement methodologies from the manufacturing industry to surgical healthcare. Nicolay CR, Purkayastha S, Greenhalgh A, Benn J, Chaturvedi S, Phillips N, Darzi A. Source: Division of Surgery, Imperial College London, St Mary's Hospital Campus, London, UK. c.nicolay@imperial.ac.uk.	We have noted that here were too few studies for some outcomes (e.g., caregiver burden) in the discussion
25	3	General Comments	This report focuses on an essential area of end-of-life care and has particular relevancy in regards to the efficacy of interventions and practice. The findings carry enormous implications as to the state of practice, future research needs, and the impact on future policy. I applaud AHRQ for this important review. I appreciated the careful attention to defining the overlap--as well as the nexus points--within the body of language jargon used throughout end-of-life, hospice, and palliative care areas. The report's operational definitions will be important as the public reviews the document. The lexicon for the field is, in many ways, still being developed. The key questions are reiterated throughout the piece--this is helpful as one wades through an enormous amount of information. The questions are stated clearly.	Thank you for your comment

Comment#	Commentator & Affiliation	Section	Comment	Response
26	4	General Comments	<p>This report covers important topics, but several features of the report limit its meaningfulness to clinical practice and quality improvement. The 93 studies selected for review -- the content of the report -- are likely to be of value to the field. The report's organization and writing style currently limit its impact due to</p> <ul style="list-style-type: none"> a) use of terms "quality improvement" and "end of life", b) confusing Results organization, lack of reference from text to data tables, and failure to provide citations so that statements are linked to specific groupings of studies, and c) failure to define high quality studies and the evidence they provide as distinct from the overall body of evidence. 	<p>We have made the following changes to address reviewers' comments:</p> <ul style="list-style-type: none"> a) clarified quality improvement section by rephrasing this as "healthcare and palliative care interventions" that can include quality improvement, and replacing the term "end of life" with "advanced and serious illness" b) improving section describing organization of the report c) have reorganized the strength of evidence tables by separating out RCTs from non-RCTs which should better emphasize the higher quality studies. Also risk of bias was assessed for all studies as a way to additionally assess study quality. It should be noted that evidence was pretty much always consistent between the 2 types of studies.

Comment#	Commentator & Affiliation	Section	Comment	Response
27	4	General Comments	<p>First, the report does not explicitly define included quality improvement interventions -- in terms of research methods or intervention methods. This omission leaves readers uncertain of the type of intervention being reviewed. This issue may be semantic; the authors may be using the term "quality improvement" quite loosely and inclusively. If true, it may be more clear to describe their review as inclusive of a range of clinical interventions.</p> <p>Second, many included studies are graded as low in quality; however, results are descriptively pooled without attention to research quality resulting in equal attention to poor quality and good quality data.</p> <p>Third, the included interventions are remarkably heterogeneous as are the descriptively pooled outcome measures. Even qualitative summation is deceptive, as it clouds the meaning of diverse interventions with varied effects on diverse outcome measures.</p>	<p>We have rephrased the report as addressing "healthcare and palliative care interventions". There is an extensive section in methods discussing definitions of quality improvement as well.</p> <p>We have reorganized the strength of evidence tables by separating out RCTs from non-RCTs, which should better emphasize the higher quality studies. Also, risk of bias was assessed for all studies as a way to additionally assess study quality. It should be noted that evidence was pretty much always consistent between the 2 types of studies.</p> <p>We added language to include concerns about study heterogeneity in the discussion section. We also included additional details describing the the interventions. We also revised the continuity section so that table 1 now includes descriptions of the interventions.</p>
28	5	General Comments	I believe this report is clearly written and pulls together a broad amount of information that is tied to well-articulated key questions.	Thank you for your comment
29	6	General Comments	Yes, I found the report clinically meaningful.	Thank you for your comment
30	7	General Comments	I think is meaningful as it addresses both hospice and palliative care. It also looks at literature in a variety of diseases.	Thank you for your comment

Comment#	Commentator & Affiliation	Section	Comment	Response
31	8	General Comments	<p>Well written. The target population and audience are explicitly stated (more so in the paper than in the Executive Summary). I found the Key Questions to be well stated and get to the critical issue of tying the research to usefulness in the clinical setting. I am not sure I find the report clinically meaningful in the sense that most of the key data for the QI settings resulted in a grade of "low". This did not provide a path to follow but rather the need for more research. It is informative but not actionable in a clinical setting. Since the report results in mostly grades of "low" it would help to explain the grading system (specifically include it on Table 1) and if possible provide any insight into differentiating between all of the grades of "low".</p> <p>Note that the Table of Contents numbering does not match the paper.</p> <p>Note that on P3 the Outcome measures for each Key Question section has a bullet for Health care utilization that includes hospital admissions but does not mention ER use. The frequency of ER use whether or not it results in a hospital admission would be useful if supported by the research.</p> <p>Note on P9 BPI is used but not defined.</p> <p>Note P11 Key Question 2a states that the Evidence about Types of Quality Improvement was not applicable to this target on Communications and Decision Making. Why not? How can that be???</p>	<p>We have added a short footnote to Table 1 to help briefly explain the grading: **Strength of evidence is based mainly on the strength of the study designs (with randomized trials considered as the strongest design, and on consistency based on both the direction and range of effect size, including the percentage of studies with a statistically significant effect on the outcome.</p> <p>Unfortunately, we cannot really differentiate between the grades of "low" given AHRQ methodology</p> <p>Thank you, the table of contents has been corrected</p> <p>These are important issues, but were not addressed in any of the research</p> <p>We have spelled this out – Brief Pain Inventory</p> <p>We have changed the wording on these to "not analyzed" and have added the explanation in the Executive Summary: "We evaluated each target for whether Key Question 2a or 2b was most applicable, and only one of these questions was analyzed for each target (they were mutually exclusive)."</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
32	9	General Comments	<p>This report will contribute substantially to the availability of thoughtful syntheses of the evidence forming the foundation for care of the seriously ill at the end of life. The authors very clearly define their target population, though it is somewhat less clear how representative this definition is of those who die or how easily that definition could be operationalized during the literature review. For example, roughly 25% of decedents end life in a nursing home. Yet that group is much more diverse than the group defined as the target population for this study (seriously ill persons such as those with advanced cancer or at high risk of death in an intensive care unit). What role does the target definition play in explaining the low number of nursing home studies eligible for inclusion? Indeed, an unknown proportion of decedents in general are likely to fall outside this target definition as they die, or if they do pass through a period where they would be recognized as high risk of death, that phase is so short that study recruitment is not feasible. The authors make reference to including samples with a 1-year mortality greater than 50%, though it is unclear how frequently sample data are available to permit use of this inclusion criteria. In short, the authors are to be commended for explicitly defining the end-of-life population targeted for this report. However, it is a difficult population to define, and a sentence or two about the shortcomings of the stated definition would be quite appropriate to remind the reader about the reports limitations.</p>	<p>We have made sure that the issues of heterogeneity of the literature, and limitations of the definition, are clearer throughout the documentation and in the limitations of the report.</p> <p>We have added these sentences to the limitations: “The definition that we developed, studies with a majority of patients with advanced or serious illness, was sometimes challenging to apply to studies because illness characteristics were not reported in detail, and also may have excluded some studies including some relevant populations.”</p> <p>And</p> <p>“In addition, although 25% of patients end their life in a nursing home, general nursing home populations would not have met the definition for “a majority of patients with advanced or serious illness” and studies in these populations were excluded.”</p> <p>Note that we have changed the title to “advanced and serious illness” rather than “end-of-life” as well, as per other reviewer comments</p>
33	11	General Comments	<p>Thank you for the opportunity to review this document. It is a topic that I know well, and a literature with which I am very familiar.</p> <p>I applaud the authors for doing an enormous amount of work. This is tough. However, I am not sure that the report or the conclusions are informative. This isn't due to the content of the review, but rather how it is conceptualized. My comments have two broad themes.</p>	Thank you for your comment.
34	11	General Comments	<p>The overarching message is about “end of life” (EOL) and quality improvement (QI).</p> <p>1. End of life care?: The authors provide a definition of care of the person with life-threatening illness on page 26</p>	We have addressed these concerns by changing the title and definition of the

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
			<p>as a spectrum where “palliative care” is the most broadly and then a definition of EOL on page 11 that is more limited to the group of people (presumably requiring palliative care) that are likely not to recover from their illness. Why is this important? Well, the studies selected in this report represent patient populations from across the illness trajectory. These are not all EOL studies. Palliative care studies have been chosen and then put in the EOL box. That isn’t appropriate, especially as you try and summarize the evidence needs for EOL care. In fact, the methodological rigor – or not – is completely predicated on where in the illness trajectory the study was done. This creates problems in the report in many ways:</p> <p>a. In some places in the report interventions targeted early in the illness trajectory are combined with interventions for late in the trajectory (e.g. in the pain section – you have combined DuPen and Syrjala with Keefe). They all may be RCTs, but outside of that, I do not know what combining these studies tells you. Look at DuPen and Keefe more closely. In DuPen – patients obtained the outcomes because the intervention was targeted early in the trajectory; in Keefe, outcomes were seen in caregivers but in general patients were just too sick to demonstrate a benefit in the pain PRO.</p> <p>b. There is an assumption then that patient reported outcomes (PROs) are appropriate and/or obtainable in all of the studies gathered and combined (e.g. QOL, symptoms and satisfaction). Without knowing the study population and place in the illness trajectory, making summary claims about PROs doesn’t make sense. I have similar issues with other outcome classes.</p> <p>c. At times the language of EOL and hospice predominates (e.g. Figure 1), which would normally highlight certain kinds of outcomes (e.g. healthcare utilization, family satisfaction) that are secondarily addressed in this report.</p>	<p>population included as serious and advanced illness and not EOL</p> <p>We have addressed this heterogeneity as per others’ comments in the limitations: “Despite this focus, studies were still very heterogenous, and even descriptive synthesis across such different studies has limitations.” We have also added this as a further description of the heterogeneity in the pain section: “Moreover, studies were heterogeneous in the respect that interventions were delivered at different points in patients’ illness trajectories, and study participants varied in health status at the time of the interventions.”</p> <p>We have clarified that we focused on patient-centered outcomes, not just PROs; and therefore included outcomes such as quality and utilization</p> <p>We have addressed this through de-emphasizing the EOL/hospice focus and reterming as “advanced and serious illness”</p>

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
35	11	General Comments	<p>2. Quality improvement? Equally difficult for me was whether this was a report of quality improvement interventions. I don't think so. The authors clearly were struggling with this themselves, as they spent a lot of time grappling with the definitions. In fact, this is a systematic review of interventions intended to ultimately improve the quality of palliative care. However, they were research studies of health service delivery models for the most part. Also called implementation studies. Calling them quality improvement studies implies that all of the interventions were well developed and tested in efficacy models and now ready for full dissemination and implementation. This is not the case. Again, look at Keefe – this was a pilot study. The Temel study in the NEJM was done at a single site essentially as a randomized Phase II trial. This report is a systematic review of health services models, where the targets vary from pain to place of care. Getting this nomenclature correct has many important implications:</p> <p>a. Palliative care is struggling with optimizing what is the best model. We don't know. Research is needed. QI follows.</p> <p>b. IRBs and local process improvement teams will get mixed up based upon this language. Groups that need to be able to do true local QI that falls outside of the purview of research and the Common Rule need to be able to understand how their work is distinct.</p> <p>c. It isn't appropriate to routinely implement something that isn't well demonstrated unless there is clear face value and little risk of harm. As described, many of the pilot studies included in this report are health services interventions in testing, not QI.</p>	<p>We used a relatively broad definition of quality improvement based on the original Closing the Quality Gap report, including studies conducted within or linked with the healthcare system and that have at least some element of system change. Palliative care consultation interventions, and interventions focusing on patient education and self-management, were included as part of this definition. Although these may not always be considered as quality improvement studies, they were included here because they are important methods for improving quality of care in patients with advanced and serious illness, particularly for pain management.</p> <p>We have clarified throughout that our definition of QI includes palliative care, and rephrased in some places that these are “interventions to improve quality” to make it clear that these are broader interventions.</p> <p>We have clarified that we included healthcare and palliative care interventions.</p>
36	11	General Comments	<p>Finally, I recommend that the authors work with a well-recognized nomenclature for describing palliative care study populations, especially when the studies are about health services interventions. See: Currow DC, Wheeler JL, Glare PA, Kaasa S, Abernethy AP. A framework for generalizability in palliative care. J Pain Symptom Manage. Mar 2009;37(3):373-386. 10.1016/j.jpainsymman.2008.03.020</p>	<p>We have clarified that this report is part of a larger series of reports, and therefore we needed to use a consistent taxonomy to classify interventions and could not use a framework that is specific to palliative care as cited in the Currow article.</p>
37	11	General Comments	<p>Introduction, Methods, Results, Discussion/ Conclusion, Clarity and Usability: See above</p>	<p>NA</p>

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
38	12	General Comments	This is a well written thorough report which elucidates the current state of the science for end-of-life and hospice care. Every attempt was made to include all populations including children and the elderly and those with diverse backgrounds. The report describes the strengths of the current state of the science and importantly areas in need of great improvement. The key questions were right on target and explicitly stated.	Thank you for your comment
39	1	Introduction	The title should be restated and introduction should clearly limit the scope of the work.	Have rewritten the title, as per others' comments
40	2	Introduction	The introduction needs to consider why a QI study and the range of proposed definition. Be clear on how it differs from a study that focuses on changing behavior or provider or patient. This section needs expanding and a more coherent approach.	We used a relatively broad definition of quality improvement based on the original Closing the Quality Gap report, including studies conducted within or linked with the healthcare system and that have at least some element of system change. Palliative care consultation interventions, and interventions focusing on patient education and self-management, were included as part of this definition. Although these may not always be considered as quality improvement studies, they were included here because they are important methods for improving quality of care in patients with advanced and serious illness, particularly for pain management. We have clarified throughout that our definition of QI includes palliative care, and rephrased in some places that these are "interventions to improve quality" to make it clear that these are broader interventions.

Comment#	Commentator & Affiliation	Section	Comment	Response
41	3	Introduction	The Introduction is critical for defining to the reader what is meant by Quality Improvement, the distinctions of interrelated areas of palliative care, end-of-life care, and hospice care. It is also a kudos to the authors to have taken the time and space to clearly discuss the specific targets selected to improve end-of-life care and how they were parsed out when multiple targets or interventions were cited. The section on Settings of Care was clear in regards to the need to address a systematic review on QI in hospice settings--as well as nursing homes. I have made a few general comments in an up-loaded attachment file that pertains to small points in the Introduction.	We have added this to the introduction, as per others' comments. We have clarified in the title, abstract, executive summary, introduction and methods that palliative care interventions are included in this report as well as healthcare studies. Title now includes the term "healthcare and palliative care". We have rephrased in the introduction and methods that interventions were included more broadly and did not need to neatly fit into the definitions of quality improvement In the 2 nd paragraph of background, we have rephrased this section: "These interventions can include changes in the way care is provided within a system, such as palliative care consultation services, and interventions to change how patients/families interact with the healthcare system, such as a patient self-management program for pain that is integrated with patients' healthcare. They can also include quality improvement interventions."
42	4	Introduction	Title and throughout text: 1. The term "end-of-life" implies a population known only in retrospect (after death), and to many readers suggests attention only to the final days or weeks of life. Recommend replacing with "palliative care" or "serious life-limiting illness care" which is far better representations of the patient populations prospectively included in the quality improvement studies discussed in this report. On p. 12 the authors themselves define the population of interest as "seriously ill patients and those with advanced disease who are unlikely to be cured, recover or stabilize." The key questions use the term "palliative care;" the title and text throughout should use this term for clarity.	We have addressed the title and this issue in the text, with others' comments – see comment 23: We have revised the title with AHRQ approval, as per suggestions of other reviewers, to be clear that this report only addresses healthcare and palliative care interventions and is not a state of the science of the entire field of end-of-life care. The revised title is: "Interventions to Improve Healthcare and Palliative Care for Advanced and Serious Illness"

Comment#	Commentator & Affiliation	Section	Comment	Response
43	4	Introduction	In the Abstract: 1. Provide inclusion criteria for studies, with methods and content criteria 2. Provide a statement regarding the quality of the evidence; to assist interpretation of the summative results presented	We are limited to a very small number of words in the abstract and have chosen to focus on the results in this portion of the report. These details are provided in the Executive Summary and in the main report.
44	4	Introduction	Objective (p.12): Although the conceptual grid references the National Consensus Project domains for palliative care quality, the text describing content focus lacks this grounding; "distress" is not defined, and emotional and spiritual needs appear to be omitted.	Emotional and spiritual are included in the grid and are part of distress. A short definition of distress is now included in the objective; "(defined as an unpleasant emotional experience that can be psychological, social, and/or spiritual).
45	4	Introduction	Chapter 1 provides an overview of prior systematic reviews. Many of these reviews are dismissed as failing to focus on "end-of-life," yet the authors themselves will continue to include a wide range of palliative care and serious illness populations. It may be more useful to summarize what current published reviews have concluded for each domain, in order to compare and contrast with the findings in this report.	We have rephrased this section to not seem as though we are dismissing these studies, but to better set the stage for how we focused the report

Comment#	Commentator & Affiliation	Section	Comment	Response
46	5	Introduction	<p>Valuable information including making clear that this is not about EOL and palliative care comprehensively but rather just focusing on the research related to Quality Improvement.</p> <p>It will be helpful to broaden the identification of groups for which this report might be useful to professional associations (SW, RN, MD) whose members participate in palliative care, hospice, EOL practices and administration of programs) as well as the national hospice and palliative care organization (NHPCO).</p> <p>One other comment in the intro relates to the section on Continuity, Coordination of care and transitions of care -- in the first paragraph -- in the line 16 - it should be continuity with physicians and other members of the health care team.</p> <p>on line 20 -- I find the definition of care management confusing - care management is a process intervention and that function can be carried out by someone already a member of the team - it does not need to be an additional person and in fact that becomes problematic for patients when they end up with 2, 3 or more care managers each looking at a soloed aspect of care needs.</p>	<p>We have clarified that this does include palliative care interventions</p> <p>We have added this information to the Uses of this Report section</p> <p>We have added a definition of continuity to the beginning of this section: "Continuity can be defined as the exchange of knowledge and the relationships between providers and patients/families, or between providers and/or provider groups"</p> <p>Agreed that this definition & using this terminology was confusing – we have taken "care management" out as a term in the introduction and in the continuity section, and now refer to this as "coordination"</p>
47	6	Introduction	Very well written	Thank you for your comment
48	7	Introduction	<p>Clear.</p> <p>Appreciated the model tying together the NCP domains with everything. However would call the title analytic model of palliative care since NCP domains tried to move palliative care upstream from the imminent period.</p>	We have retitled figure as "Interventions to improve care for patients with advanced and serious illness" to meet the new title of the report, and have taken "EOL" out of the headings in the figure

Comment#	Commentator & Affiliation	Section	Comment	Response
49	8	Introduction	<p>Other Suggestions:</p> <p>P16--The sentence in paragraph one: "However, many studies have found... should likely include a citation.</p> <p>P 16---Paragraph 3 the hospice definition should consider capturing a definition that hospice is wherever the patient resides so it is more clear that hospice is a service rather than a specific place.</p> <p>P18--The third paragraph under Pain section states: "These reviews all addressed pain in general hospital or patient populations. The term general hospital sounds odd, consider revising this term.</p>	<p>We have clarified this sentence – "However, studies in different areas..." – the citations for specific examples are given in following sentences</p> <p>We have rephrased – "which is provided, in the United States, wherever the patient resides."</p> <p>We have reworded as "broad populations with cancer or hospitalized patients"</p>
50	9	Introduction	The introduction is well written and clearly lays out the goals of the project.	Thank you for your comment
51	12	Introduction	Well written and frames the focus of the report very clearly	Thank you for your comment
52	1	Methods	<p>Are the inclusion and exclusion criteria justifiable? Are the search strategies explicitly stated and logical? Are the definitions or diagnostic criteria for the outcome measures appropriate? Are the statistical methods used appropriate?</p> <p>Yes</p>	Thank you for your comment
53	2	Methods	<p>As noted, I would exclude some studies that are really not a QI intervention. Search measures are very clear but I think that the abstraction needs to be clear on what is and what not a QI study is.</p> <p>Studies are too heterogeneous, no pooling. So there are no statistical methods to comment on.</p>	<p>We have addressed this in multiple places – trying to clarify, and emphasizing that the last section is more about quality improvement</p> <p>We have emphasized the heterogeneity in the discussion</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
54	3	Methods	<p>The inclusion criteria relies on the National Consensus Project definitions--and for those who support this work, there should not be a problem with justification of criterion. I believe specifying on page 24 that the heterogeneity of the study populations had to have a cut off of a 50% inclusion of populations is important. Some might contend this and how patients are considered "at high risk of dying", but it is my opinion that the report clearly states inclusion and exclusion parameters. Attention to QI criteria is important and clear. I have no problem with the Methods Section-- I found it particularly relevant to emphasize that Methods used followed the Closing the Gap series criteria; that sources such as the Cochrane Group were used; and, that attention was given to Risk of Bias and Strength of the Body of Evidence guidelines (kudos for this additional step which created very relevant findings). I appreciated the parsing out of RCTs from non-RCTS as this says much about the state of the science. Please see uploaded attachment for minor general comments.</p>	Thank you for your comment
55	4	Methods	<p>: Inclusion / exclusion criteria: The authors need to provide a basic definition of the study design for QI included in their review; what methods of QI intervention, use of controls, and types of outcome measures were accepted? How did they define a QI intervention as distinct from a complex clinical intervention study; RCTs were included but were these truly QI methods or simply RCTs of patient education or palliative care consultation?</p> <p>A compelling example of what this is important is on p. 48. Authors have only included 8 studies which assessed patient symptoms as an outcome, yet symptom control is a critical outcome in palliative care. Methods (and the Results reporting) fail to make it clear how these 8 studies differ from the hundreds of studies of pain, dyspnea, and other symptom treatment trials.</p> <p>Grading of the evidence: Limited detail is provided on the grading of evidence (p. 42-43) Were the SQUIRE standards used to review the quality of accepted studies of QI? If RCT evidence was available, why was evidence</p>	<p>We have clarified this - We have now clarified throughout the report by using the term "healthcare and palliative care interventions" and reworded in many places that we are reviewing interventions, including interventions traditionally defined as "quality improvement" as a subset. We used traditional methods of assessing study quality, rather than methods specific to quality improvement.</p> <p>We have clarified that there were 8 studies in the domain of continuity, coordination and transitions that addressed patient symptoms (not in the overall literature). We have included additional information to help clarify by expanding the report organization section as well to make clearer that studies are organized by target.</p> <p>The rephrasing that this report included</p>

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
			<p>from poorer quality study designs included? Review of quality standards for quality improvement methods would be expected to influence inclusion / exclusion criteria (very low quality studies would be excluded), and grading of accepted studies. However, this topic is not address in Methods.</p> <p>On p. 43 the authors indicate that blinding was not considered in Risk of Bias grading, given the difficulty of blinding in these types of interventions. However, lack of blinding is cited as a criticism throughout the Results section.</p>	<p>healthcare and palliative care interventions should help clarify this comment. We used risk of bias methods to review the quality of accepted studies, as detailed in the methods We included studies other than RCTs because RCTs were not available in all areas, and for quality improvement studies, RCTs may not always be possible or the best study design. Evidence from RCTs and nonRCTs are separated out in the grading tables and was consistent across targets.</p> <p>We have corrected this error in the methods: "We did not factor in the quality score for blinding of the intervention; we did this because blinding of patients and personnel was generally not feasible in these interventions, but blinding of outcomes assessors would have been possible." Because we did assess lack of blinding, this is included as a criticism of studies in the Results section.</p>
56	5	Methods	The search criteria and reasons for inclusion/exclusion seemed clear and well-articulated.	Thank you for your comment
57	6	Methods	Definitions and methods are clear and appropriate.	Thank you for your comment
58	7	Methods	The inclusion and exclusion criteria are generous since there hasn't been as much data specifically in palliative care. But it appropriately follows NCP domains.	Thank you for your comment
59	8	Methods	<p>No issues with the inclusion/exclusion criteria. It was clear. Likewise the search strategies are explicitly stated, logical, and practical. The diagnostic criteria for the outcome measures and the statistical methods are appropriate.</p> <p>Note that on the Study Selection section, P29., the paper discusses the abstract screen performed by two reviewers yet I did not see the qualifications for the reviewers or that of the third reviewer when needed. Please consider adding this information.</p>	<p>Thank you for your comment</p> <p>A brief statement was added to this section to clarify the qualifications of the reviewer</p>
60	9	Methods	The methods are clearly explicated and very systematic. The key questions are important ones and serve to nicely organized a morass of literature	Thank you for your comment

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
61	12	Methods	Methods employed were reasonable including inclusion and exclusion criteria, search strategies, definitions, etc... One small point, on p38 line 16, in section inclusion/exclusion criteria, the authors' state, "Palliative care has existed as a specialty and service only since 2000." There is no reference provided for this specific year. Certainly there were palliative care programs in existence before 2000 and the formal starting year of the medical subspecialty was 2006, so I am wondering where this statement comes from.	Thank you for your comment We have removed this phrase
62	3	PDF General comments	Executive Summary Page 2: Spell out PICOTS Page 9: Spell out BPI line 33.	PICOTS was defined in the text and BPI was replaced in the executive summary with "Brief Pain Inventory"
63	3	PDF General comments	Draft Report Structured Abstract: Consider adding a small amount of information upstream in the abstract that defines QI per this report. The emphasis of QI, and its definition in this field, is an important point of Discussion in the final recommendations as well as in discussing the limitations of the study (e.g., from page 16 or page 24 of the full report). Health care utilization (as noted on page 37 as admissions and LOS) might also need to be carefully delineated early.	We have rephrased how QI is presented in the abstract by redefining the focus as "healthcare and palliative care interventions" and throughout the report that our definition of QI includes palliative care. We have clarified this earlier as well and in several places throughout the report
64	3	PDF General comments	Page 19: Second title "Decisionmaking" needs a space between two words? Page 22: Line 30-31: May be important to add to the NIH NCI example, two other historically lead funders in EOL research: the National Institute on Aging and the National Institute of Nursing Research.	Per AHRQ guidelines the word is spelled out as one word "decisionmaking" We have added this in
65	3	PDF General comments	Page 23: Table, Column 4. "Settings" in the text on page 29, specifies particular interest in "home" hospice settings; however, in the Table 4 column 4 it only lists "Hospice"—does "home" need to be Specified?	We have removed the word "home"
66	3	PDF General comments	Page 30, paragraph 1: Do you need a reference the use of the <i>Distillers</i> software program that was alluded to in the Methods?	A reference has been added to the Methods section

Comment#	Commentator & Affiliation	Section	Comment	Response
67	3	PDF General comments	Page 34: This Section is a bit difficult to follow when trying to match the text information in the Tables with both the cited references in the Appendices and the Reference Lists. For example, Table 3 page 41 () has 22 rows of an <i>n</i> of 25 studies listed, but and referred to in the text on page 34 paragraph refers to 22 studies, and the cited Evidence Table 3 has an <i>n</i> of 25 studies listed with references. Were the Jordhoy (2000, 2001) and the Ringdal (2001, 2002) studies combined? It is a bit confusing which ones are being referred or why combined in Table 3. Paragraph 4, therefore might need to state that the interventions in the trials for 'continuity'... have percentages based on an <i>n</i> of 25 studies?	These references all were separate publications from the same study. We have clarified that these references all are actually the same study (different reports) in a footnote in this table.
68	3	PDF General comments	Evidence Table 4 for risk-of-bias (ROB; <i>n</i> = 25) may be, instead from Evidence Table 5? Page 36, last paragraph line 52: Evidence Table 5— should that be Evidence Table 4? Table 5 is ROB information. Pages 37-40: Please check Evidence Table referencing numbering for accuracy. Pages 42 and page 44: Check order of alphabetized authors in Table 3.	The evidence table numbering has been revised
69	3	PDF General comments	Page 46: This section was a bit difficult to align the written text with the information in the presented Tables. For example, are the two Miakowski article combined and count as one for Table 7 but then studies listed separately for Table 9? At the same time, Oliver and Kalauokalani are combined in the Tables? Evidence Table 6 does not have Kovach in the list of references (but is on the table), Sometimes van Der Peet has the <i>V</i> capitalized, other times it is not capitalized (e.g., in the reference list). Check that Evidence Table 8 listed for ROB is not to be Table 9.	The evidence tables have been revised and re-scanned for references.

Comment#	Commentator & Affiliation	Section	Comment	Response
70	3	PDF General comments	<p>Page 47: Check for accuracy in Table numbering, particularly Evidence Tables). Evidence Table 9 is missing Fuch-Laselle (2008) although this was cited on Evidence Tables 6-8.</p> <p>Evidence Tables 10 and 11 may have wrong year cited on Table s for Porter, 2001 (Reference Lists, indicate year as 2010).</p> <p>Pages 48-49: Double check Evidence Table numbering for accuracy in numbering.</p> <p>Page 50: Check if Lovell, 2010 need to go on Table 6 (were on Evidence Tables 7-9).</p> <p>Page 53, 55: <i>RISK OF BIAS</i> capitalized. Check accuracy of Table Numbering pages 53-55.</p>	The evidence tables have been revised and re-scanned for references
71	3	PDF General comments	<p>Page 54: This is the first time the report specifies the name of the first author of a study. In all previous Text, studies are cited without naming, e.g., as, “One study...” Is there a specific reason for this?</p>	This inconsistency was resolved during the revision of the report
72	3	PDF General comments	<p>Page 55: Line 15 is redundant with next/following lines 19-20. Capitalized <i>RISK OF BIAS</i>.</p> <p>Page 56: Table 9 and Evidence Table 10 (p. 86) have two different dates of publication for Porter, 2011--on the Table, and 2010--in the Reference List.</p> <p>Table 9 not alphabetized.</p>	<p>Thank you, this redundancy has been corrected (P 57 of final report)</p> <p>“RISK OF BIAS” no longer occurs in the report</p> <p>Porter, 2010 has been corrected in table 9 and 10.</p> <p>All tables have been alphabetized in the report</p>
73	3	PDF General comments	<p>Page 57: The title says “<i>Communication and Decisionmaking</i>”, but the Evidence Tables do not use the term <i>Decision Making</i>. Evidence Tables have different lists of authors from Reference list (See Evidence Table 14: Burns and Daly on Table, but not on reference list. Burns, Cook, and Danz study is in the Reference List, but not on Table). Check same for Evidence Table 15 and Tables 12-13, pages 61-62.</p> <p>Pages 58-60: Check numbering of Evidence Tables.</p> <p>Capitalized <i>RISK OF BIAS</i>, page 60.</p>	<p>The evidence tables have been updated and the reference errors have been corrected.</p> <p>Table titles are consistent with the section title.</p> <p>References have been corrected in the tables on communication.</p> <p>Numbering of evidence tables has been corrected.</p> <p>“RISK OF BIAS” no longer occurs in the report.</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
74	3	PDF General comments	<p>Page 65, paragraphs 1 and 2: These individual studies are cited with authors and data/ Table 16 page 72 but the headers for the Table Column are worded differently in some cases than the areas of significant results. It takes a bit of time to cross-check this so it makes sense. As another example on page 68, lines 4 and 5 discuss two non-significant areas of patient symptoms (pain and dyspnea); however, Table 16 just lists pain as “NS.” Page 68, paragraph 3 text of significant and non-significant findings might need to add in Table 16 the NS finding of “wait times”. The Table looks as if all areas were significant “S” under Quality of Care. Page 69, paragraph 1 Hanson et al. study, Table 16 shows “S” for Quality of Care findings, but one important finding in the paragraph text notes that although there were more pain “assessments”, “pain interventions” did not significantly change. This may be important to delineate in Table 16 as assessing pain did not lead to any change in interventions as it is written.</p> <p>Page 69, line 53: <i>RISK OF BIAS</i> capitalized.</p>	<p>There was a need to use different column headings in this table—we wanted all of the information in one place in one table, and this format allowed us to do that without creating a table that spanned over multiple pagers.</p> <p>“RISK OF BIAS” no longer occurs in the report</p>
75	3	PDF General comments	<p>Page 75: This is done very nicely. I would recommend consideration that when discussing ‘percentiles’ Throughout paragraphs 1 and 2 that the total <i>n</i> of the studies are added in parentheses. The point being, that it appears that there were limited studies; thus a percentile of “67%” may have been based on only a small number of results—which tells a lot about the strength of the evidence. Remind the reader that The percentiles are based on only a small number of studies. This will strengthen the section about the Need for more research. This point comes out a bit more last paragraph, page 75.</p>	<p>We have added in the number of studies throughout the report</p>
76	3	PDF General comments	<p>Page 78, lines 31-33: This discussion regarding, “. . . pain management issues are very different in Survivors than end-stage disease” seems to need a citation source to back this up.</p>	<p>We have rephrased this part of the sentence more broadly – “since patients’ needs at different stages of illness may vary markedly”</p>

Comment#	Commentator & Affiliation	Section	Comment	Response
77	3	PDF General comments	Page 79, first paragraph: First sentence about “rich literature evaluating interventions in areas more related to clinical practice” perhaps should have an example as to what this means? The sentence later indicates “hospice and social work interventions” but these could be interpreted as clinical. Can you give more specific meaning to the sentence?	We have clarified this sentence: “The inclusion criteria for published, peer-reviewed evaluations also limited the inclusion of the experience evaluating interventions in areas less linked to academic medical centers and the research community, such as hospice and social work interventions, ¹⁵⁷ ...”.
78	1	Results	Is the amount of detail presented in the results section appropriate? Are the characteristics of the studies clearly described? Are the key messages explicit and applicable? Are figures, tables and appendices adequate and descriptive? Did the investigators overlook any studies that ought to have been included or conversely did they include studies that ought to have been excluded? Yes	Thank you for your comment
79	2	Results	Suggest start with overall summary More tables in the text rather than appendix. More description of the studies - including why it is counted as QI study.	The report starts with abstract and executive summary, and key points are given first for each section. We have revised the first continuity table, which did not include descriptions of the interventions, so that these are now included – and added more detail to the communications sections; all sections now include descriptions
80	3	Results	The detail given to the Results section is very much needed to support the interpretations--but sometimes I found it difficult to wade through and check back and forth between the findings stated in the text and the findings within a Table or Evidence Table and Reference List. There may be numbering problems of these Tables. Some additional text explanations are needed and careful emphasis on the number of studies used to derive a percentile score. Reiteration of the key topics always helps the reader stay on track with the purpose and goals of the review. Some tables had different author studies combined with a single result; others were on lists or Tables but not both. Please see uploaded attachment for examples.	We have clarified in a footnote that the different author studies are actually different publications on the same study

Comment#	Commentator & Affiliation	Section	Comment	Response
81	4	Results	<p>The Results section misses the trees for the forest. We gain insights into the overall quality and quantity of the published evidence, but fail to learn from the best quality science currently available.</p> <p>For example, on p. 47 the authors state there are 5 good quality studies addressing patient satisfaction as an outcome. However, no information is provided on the methods and results of these studies as separated (wheat from chaff) from the other studies in this category. I encourage the authors to add a paragraph to each Results section that describes the best quality research addressing each outcome, and what the field can learn from existing evidence.</p> <p>On p. 49 the Liverpool Pathway and Gold Standards interventions are mentioned, but with no explanation of what these interventions are composed of; most readers will not understand these terms.</p> <p>Organization of the Results section is difficult to follow. It begins with a section on continuity, jumps to a diagram of study flow, and then inserts Key Questions and a section on studies grouped by outcomes. It would be helpful to provide an introductory section to Results to explain how it is organized (the current paragraph is not effective). It may also be necessary to re-organize somewhat.</p> <p>Authors write about groups of trials without citations, so that it is difficult to follow what they reference. For example, on p. 50 "six of nine trials" use a particular approach to QI, but without citations or link to an evidence table the reader has no way to understand which 6 trials are being discussed.</p>	<p>We have added in more detailed information on these studies for these larger sections (continuity, pain, communication) by adding in an additional table describing the content of the interventions.</p> <p>We have completely rephrased this section and have reorganized in several places, which is hopefully helpful for clarity</p> <p>We have added in citations where they were missing</p>
82	5	Results	<p>I am assuming that tables and figures that are specific to content will be included in the narrative portions of the report and that just the Evidence Tables will be found at the end of report. This would enhance readability.</p> <p>I found the pulling together of very diverse material put together in a readable and understandable way.</p>	<p>Summary tables and figures are included in the report at the end of each section.</p> <p>Thank you for the comment</p>
83	6	Results	A lot of details but messages are clear.	Thank you for your comment
84	7	Results	I found it comprehensive, clear, and felt they included the important studies.	Thank you for your comment

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303>
Published Online: October 2012.

Comment#	Commentator & Affiliation	Section	Comment	Response
85	8	Results	The Results section has appropriate detail. The characteristics of the study are clear and well described. While the Key messages are explicit and applicable, they do not stand out on the page visually. The tables are adequate and descriptive with the exception of Table 16. The information is fine but the presentation is too busy/compact. Consider revising this table using shading or expanding it. The bold alone against the white makes it too hard on the eyes to spend time digesting the useful information.	Thank you for your comment We have generated the tables according to the AHRQ specifications published in the "Publishing Guidelines for Reports Developed by Evidence-based Practice Centers."
86	9	Results	The results are clearly presented. I personally would have appreciated a consistent approach of presenting the proportion by giving the numerator and the denominator, followed by the percent in parentheses. However, that approach may also contribute to some boredom for the reader, whereas my approach of calculating the percent when not provided may have kept me more alert.	We have added in the number of studies, not just the percentage, in places where this was missing
87	12	Results	Detail presented was appropriate, studies were clearly described, messages were explicit and applicable. Figures, tables and appendices were adequate and descriptive. I am not aware of any studies that were overlooked.	Thank you for your comment
88	PC: Susie Sherman (AGS)	Results	AGS recommends that those studies which focus on the dying patient across hospital, nursing home and home care settings, be far more extensively addressed. The profound experience of dying does not lend itself to enrollment or study for patients or caregivers. As a result of this, accommodation of the existential and psychosocial aspect of the profundity of dying presents enormous obstacles to standard clinical research, and we suggest that this be addressed head-on and expansively.	This is an important point: few studies addressed the needs of the patient across settings – most were specific to one setting – or addressed existential and psychosocial issues. We have added these points to the discussion section: "Importantly, some key issues of healthcare for the seriously ill and dying, such as care across settings and existential, psychosocial, and caregiving issues are challenging to address in this type of research. More coordinated initiatives, across multiple settings and providers and following patient populations over longer periods of time, will be needed to better understand how best to improve care for patients with advanced and serious illness."