Author’s response to reviews

Title: A qualitative analysis of information sharing for children with medical complexity within and across health care organizations

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Author’s response to reviews: see over
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Dear Ms. Flory Mae Calumpita,

We thank you kindly for your editorial comments and review of manuscript: 1269718009994695, “A qualitative analysis of information sharing for children with medical complexity within and across healthcare organizations. We have revised the manuscript based on the helpful comments provided by the reviewer. We believe that these revisions (highlighted below) strengthen the manuscript. We look forward to your response.

Sincerely,

Laura Quigley

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Editors Comments

1. Line numbering: Please revise your manuscript to include line and page numbers.

   Line numbers have been added to the manuscript.

Reviewer #1

1. The revised version of the manuscript is an improvement over the previous version. Two main weaknesses with this work remain: (1) the fact that, in the main, data which had been collected previously to address other questions, were used to address the present research questions. I think this contributes to the next point; (2) it seems difficult to discern internally coherent and relevant themes and subthemes. I still find it difficult to see how some of the subthemes really fit under some of the main themes identified.

   One suggestion is that the authors somehow acknowledge that their secondary analysis of previously collected data is actually quite a big limitation (presently it is only mentioned as a limitation in passing), and one which has likely had an impact on their ability to identify clean and coherent themes related to the present research question.

   Thank you for your comments. We agree that the secondary analysis of previously collected data is an important limitation to our study. We have added a line in the Discussion section to increase transparency of this limitation. Furthermore, we re-reviewed all the themes and subthemes, and made slight adaptions to the theme titles, which have hopefully helped clarify the organization of the themes/sub-themes presented in the manuscript. We renamed Theme 1 to “Issues Related to the Availability and Use of a Common
Platform.” Each of the subthemes under Theme 1 identify barriers related to the use of a common platform for electronic information sharing. We edited the subtheme titles (see below) to more clearly show how the themes and subthemes are related. We renamed Theme 2 to “Fragmentation of the Health Care System” and moved the subtheme “Lack of a common language across organizations and health care providers” from under Theme 1 to under Theme 2 because we feel it is a better representation of the fragmentation within the health care system.

New line focused on the limitation (Discussion, page 23, line 485-490): “Given that this study consists largely of a secondary analysis of previously collected data, the identification of themes related to information sharing may have been less than if the interview guides focused solely on information sharing. However, given the ample amount of data available from secondary data sources and triangulation through interviews with privacy officers, the study may be useful in helping to create an initial model of the barriers and facilitators to information exchange.”

New edits related to themes/subthemes:


Edited line (Results, page 11, line 246-247, new text is underlined): Families, HCPs, steering committee members (SCs), and privacy officers all identified various barriers related to the availability and use of a common platform for storing and sharing health related information.

Edited subtheme title (Results, page 12, line 251-252, new text is underlined): Difficulty amalgamating multiple information systems and lack of a common platform in use across organizations

Edited subtheme title (Results, page 12, line 279, new text is underlined): Concerns with the Security of the Platform.

Edited subtheme title (Results, page 13, line 290, new text is underlined): Concerns about how the platform is utilized to help share information within the circle of care.

New theme title (Results, page 14, line 303): (Deleted: Focus on episodic care). Fragmentation of the Health Care System

Text moved from Theme 1 to Theme 2 (Results, page 14, line 309-316): Lack of Common Language across Organizations and Health Care Providers: A barrier to communication between organizations is that each organization uses a different
language. For example, one organization may call a child a patient while another organization may call a child a client.

“...we didn’t start even with a shared nomenclature or a shared vocabulary or a shared language about even how to cases review. Depending on which key worker started the conversation, you know, it was a very different approach.” (ICCM Study, Steering Committee Member)

2. One further point is the emergence of 'Barriers' and Facilitators'. Did these arise as discovered themes? Or was there a priori interest in grouping under these banner headings? This should be explained.

**Barriers and facilitators were an a priori goal. Thank you for helping us clarify.**

**New line (Methods, page 5, line 133-134):** The study focused on identifying themes and subthemes from the data which were relevant to information exchange and considered either a barrier or facilitator.