## PEER REVIEW HISTORY



## ARTICLE DETAILS

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| **TITLE (PROVISIONAL)** | HOW PATIENTS WANT TO ENGAGE WITH THEIR PERSONAL HEALTH RECORD: A QUALITATIVE STUDY |
| **AUTHORS** | Kerns, John; Krist, Alexander; Longo, Daniel; Kuzel, Anton; Woolf, Steven |

## VERSION 1 - REVIEW

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| **REVIEWER** | Thomas Bodenheimer<br>UCSF, USA<br><br>No competing interests. |
| **REVIEW RETURNED** | 18-Apr-2013 |

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| **RESULTS & CONCLUSIONS** | The authors' limitations discussion explains the problem of inadequate representativeness.<br><br>I didn't see any supplementary documents. |
| **GENERAL COMMENTS** | This is a nice study of what elements are needed for patients to engage on-line with their care team.<br><br>P 4 line 26: Not clear what is meant by "solely for use by patients"<br><br>Last paragraph on page 4 is not clear. What is the point the authors are trying to make. Seems to be a random selection of sentences. Paper much clearly starting page 5.<br><br>Nowhere is it clear what the IPHR does. Perhaps that is clear in a previous publication, but it needs to be clear here. Does it provide lab results? Does it allow patients to make appointments? Does it allow patients to email their clinician with nonurgent questions? Does it allow patients to request prescription refills? Please clearly list what the IPHR does.<br><br>The discussion seems unnecessarily long, and is repetitive with the results.<br><br>The quotes are good. But Table 4 some quotes don't seem to relate to the PHR, e.g. the nurse called me. In general, the Table 4 quotes seem to relate more to the visit interaction rather than the electronic interaction. The Efficiency portion works well. Overall, it sounds more like patients are reacting to a website, except that the website is from their medical office. Is that that the IPHR is? That's why it is necessary to describe what it is and what it offers patients. |

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| **REVIEWER** | James Ralston, MD MPH<br>Associate Investigator<br>Group Health Research Institute |

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| | Seattle, WA USA |
| **REVIEW RETURNED** | 11-May-2013 |

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| **THE STUDY** | The investigators have undertaken a potentially valuable qualitative study of an online health profile integrated with an electronic health record. Prior studies have described the adoption and value of other PHR services such as using secure messaging to communicate with healthcare providers, obtaining medication refills and viewing visit summaries and other portions of the electronic health record. We have less understanding of the value of providing patients with an interactive health profile generated by a combination of EHR and patient reported data. This study focuses on the perceived value of one such system among users and non-users.<br><br>The study's approach and analysis in its current form, however, make it difficult to cohesively understand the findings. The paper would benefit from some revision.<br>1. More clearly distinguish the functionality offered by the iPHR system from the more commonly offered online services integrated with the EHR(e.g. the standard 8 functions of Epic's MyChart, MyHealtheVet et cetera) including current and forthcoming meaningful use requirements. A table may help.<br>2. Clarify the methodological framework. Based on the introduction, a goal of the paper appeared to be to inform a technology acceptance model tailored to adoption of patient online services or PHRs. Yet, in the methods, there is no information on the framework used to develop the question guide.<br>3. Explain why the descriptive analytic approach is appropriate or choose a different qualitative analytic method. Since the paper appeared to be focused on understanding a model of adoption, the reason behind the choice of the descriptive analytic approach is not clear. The descriptive analytic approach usually provides a general approach to qualitative inquiry rather than the model building focus of grounded theory or other similar approaches. |
| **RESULTS & CONCLUSIONS** | 4. There are some good nuggets of themes in the details of the analysis but the analysis and themes need to hang together better within a methodological framework. Two of the three major themes- "relevance" and "functionality"- are nonspecific and are more abstract groupings or domains than themes. Consider either sticking to a description of themes grounded in patient language or identify themes in an analysis more clearly focused on building out a model of PHR adoption.<br>5. The analysis should also clarify where the findings apply across the different functionality of the iPHR and where the findings suggest functionality the iPHR may be lacking. Direct linking of the themes to the individual functions of the PHR wherever appropriate would make the study hang together better and provider more easily actionable results for PHR development and implementation.<br><br>6. Clarify in introduction and discussion what is meant by low adoption of PHRs and how the iPHR may address this. Does low adoption mean less or slower adoption in certain patient populations or certain healthcare environments? As reported in the literature, a few large healthcare organizations have over half of their enrolled populations online interacting with online services through PHRs integrated with EHRs. Other studies have also described adoption patterns in different patient populations as well as the contributions of primary care providers in patient adoption. Describe how the current study's findings expand on these other adoption and use |

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| | evaluations? |
| **REPORTING & ETHICS** | Qualitative study. Consort not relevant. |
| **GENERAL COMMENTS** | The investigators have undertaken a potentially valuable qualitative study of an online health profile integrated with an electronic health record. Prior studies have described the adoption and value of other PHR services such as using secure messaging to communicate with healthcare providers, obtaining medication refills and viewing visit summaries and other portions of the electronic health record. We have less understanding of the value of providing patients with an interactive health profile generated by a combination of EHR and patient reported data. This study focuses on the perceived value of one such system among users and non-users.<br><br>The study's approach and analysis in its current form, however, make it difficult to cohesively understand the findings. The paper would benefit from some revision.<br><br>1. More clearly distinguish the functionality offered by the iPHR system from the more commonly offered online services integrated with the EHR(e.g. the standard 8 functions of Epic's MyChart, MyHealtheVet et cetera) including current and forthcoming meaningful use requirements. A table may help.<br>2. Clarify the methodological framework. Based on the introduction, a goal of the paper appeared to be to inform a technology acceptance model tailored to adoption of patient online services or PHRs. Yet, in the methods, there is no information on the framework used to develop the question guide.<br>3. Explain why the descriptive analytic approach is appropriate or choose a different qualitative analytic method. Since the paper appeared to be focused on understanding a model of adoption, the reason behind the choice of the descriptive analytic approach is not clear. The descriptive analytic approach usually provides a general approach to qualitative inquiry rather than the model building focus of grounded theory or other similar approaches.<br>4. There are some good nuggets of themes in the details of the analysis but the analysis and themes need to hang together better within a methodological framework. Two of the three major themes- "relevance" and "functionality"- are nonspecific and are more abstract groupings or domains than themes. Consider either sticking to a description of themes grounded in patient language or identify themes in an analysis more clearly focused on building out a model of PHR adoption.<br>5. The analysis should also clarify where the findings apply across the different functionality of the iPHR and where the findings suggest functionality the iPHR may be lacking. Direct linking of the themes to the individual functions of the PHR wherever appropriate would make the study hang together better and provider more easily actionable results for PHR development and implementation.<br>6. Clarify in introduction and discussion what is meant by low adoption of PHRs and how the iPHR may address this. Does low adoption mean less or slower adoption in certain |

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| | patient populations or certain healthcare environments? As reported in the literature, a few large healthcare organizations have over half of their enrolled populations online interacting with online services through PHRs integrated with EHRs. Other studies have also described adoption patterns in different patient populations as well as the contributions of primary care providers in patient adoption. Describe how the current study's findings expand on these other adoption and use evaluations? |

**VERSION 1 – AUTHOR RESPONSE**

RESPONSES TO REVIEWER #1

'P 4 line 26: Not clear what is meant by "solely for use by patients"'

We appreciate this comment and have clarified that we were referring to PHRs integrated into clinicians' EMRs and care. (lines 20-23)

'Last paragraph on page 4 is not clear. What is the point the authors are trying to make. Seems to be a random selection of sentences. Paper much clearly starting page 5.'

We agree with the reviewer that these two paragraphs were previously confusing and addressed too many concepts We have focused the paragraph on the current state of creating and testing patient-centered information systems – a central concept for our manuscript. (lines 26-35)

'Nowhere is it clear what the IPHR does. Perhaps that is clear in a previous publication, but it needs to be clear here. Does it provide lab results? Does it allow patients to make appointments? Does it allow patients to email their clinician with nonurgent questions? Does it allow patients to request prescription refills? Please clearly list what the IPHR does'.

We appreciate this reviewer and the second reviewer's recommendation to more clearly describe the IPHR. The nature of the IPHR is central to our focus group discussions and findings. We have more clearly described the IPHR and clarified how it is similar and different from existing PHRs (lines 41-52).

'The discussion seems unnecessarily long, and is repetitive with the results.'

We agree, and have substantially shortened the discussion so that it is more focused and less repetitive.

'The quotes are good. But Table 4 some quotes don't seem to relate to the PHR, e.g. the nurse called me. In general, the Table 4 quotes seem to relate more to the visit interaction rather than the electronic interaction. The Efficiency portion works well. Overall, it sounds more like patients are reacting to a website, except that the website is from their medical office. Is that that the IPHR is? That's why it is necessary to describe what it is and what it offers patients.'

We apologize for the understandable confusion. The patients are reacting to using the PHR/IPHR and how that use impacted care both via the IPHR and in person. We have added text to the tables to better explain the relation of the IPHR to the actions in the quotes. We have also added clarification to the text (lines 84-85). (See also lines 41-52 for IPHR explanation.)

RESPONSES TO REVIEWER #2

‘1. More clearly distinguish the functionality offered by the iPHR system from the more commonly offered online services integrated with the EHR(e.g. the standard 8 functions of Epic’s MyChart, MyHealtheVet et cetera) including current and forthcoming meaningful use requirements. A table may help.’

See response to Reviewer #1 above (lines 41-52). We deferred adding a table about how the IPHR is different from existing PHRs as we thought this additional text afforded the needed information. However, if the editors prefer we can add a table as well.

‘2. Clarify the methodological framework. Based on the introduction, a goal of the paper appeared to be to inform a technology acceptance model tailored to adoption of patient online services or PHRs. Yet, in the methods, there is no information on the framework used to develop the question guide.’

We agree. Lines 69-70 were added about question guide development. Since our work on models emerged from working with the data (see below), question guide development did not involve a specific technology acceptance or success model.

‘3. Explain why the descriptive analytic approach is appropriate or choose a different qualitative analytic method. Since the paper appeared to be focused on understanding a model of adoption, the reason behind the choice of the descriptive analytic approach is not clear. The descriptive analytic approach usually provides a general approach to qualitative inquiry rather than the model building focus of grounded theory or other similar approaches.’

Again, we agree. Although our initial analytic lens was a descriptive interpretive view, the data itself appeared to suggest the possibility of process modeling. We then employed additional analytic methods (abstract, lines 65-67 and 106-110) to develop the model.

‘4. There are some good nuggets of themes in the details of the analysis but the analysis and themes need to hang together better within a methodological framework. Two of the three major themes- “relevance” and “functionality”- are nonspecific and are more abstract groupings or domains than themes. Consider either sticking to a description of themes grounded in patient language or identify themes in an analysis more clearly focused on building out a model of PHR adoption.’

We apologize for our lack of clarity in fleshing out our approach. As noted above, starting from a descriptive analytic approach, we found our work also implied a model of PHR use. Further iterative analysis in this vein was done in a grounded theory manner. Although not shown in our quotation tables, both Relevance and Functionality were words used by participants, and the relational importance of Relevance as a theme surfaced during grounded theory rather than descriptive work.

‘5. The analysis should also clarify where the findings apply across the different functionality of the iPHR and where the findings suggest functionality the iPHR may be lacking. Direct linking of the themes to the individual functions of the PHR wherever appropriate would make the study hang together better and provider more easily actionable results for PHR development and implementation.’

Areas depicting inconsistencies between what participants want and what is offered by the IPHR have been added (lines 41-52,195) and exist in current text (e.g. in Relevance lines 138-144). Beyond what is offered by the IPHR versus what participants wanted, our hope is that Figure 1 links the themes to actionable areas for PHR development and implementation.

‘6. Clarify in introduction and discussion what is meant by low adoption of PHRs and how the iPHR may address this. Does low adoption mean less or slower adoption in certain patient populations or certain healthcare environments? As reported in the literature, a few large healthcare organizations have over half of their enrolled populations online interacting with online services through PHRs integrated with EHRs. Other studies have also described adoption patterns in different patient populations as well as the contributions of primary care providers in patient adoption. Describe how the current study’s findings expand on these other adoption and use evaluations?’

Additional text has been added regarding adoption rates in large healthcare organizations as opposed to the majority of the US population (lines 18-19) as well as clarifications of how this study adds to other use and adoption evaluations (e.g. lines 231-243). Our findings have shown that the patient-centered IPHR by itself doesn’t address low adoption, but rather that integration into care in a patient-centered fashion and in the context of the patient-clinician relationship, does.