Assessing Commercially Available Personal Health Records Using a Standard Transition From Hospital to Skilled Home Health Care

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OLDER adults transitioning from acute care to home health face many challenges with continuity of care. The Haggerty et al. framework breaks continuity of care into three different areas: informational continuity, management continuity, and interpersonal continuity.¹ Informational continuity between home health and other health professionals is often attempted through incomplete, provider-centered verbal and written documents that leave patients and/or families out of the discussions.² Home health differs from other care environments due to the increased demand on patients and caregivers to provide self-care, and the significant patient education needed to become proficient at home care tasks.³ Previous research suggests that older adults may fail to effectively recall and share the necessary health information with their clinical providers.⁴ As shown in community dwelling environments better coordination, organization, and knowledge of their medical condition may be possible through personal health records (PHRs).⁵ The Markle Foundation describes a personal health record as “an electronic application through which individuals can access, manage, and share their health information in a private, secure, and confidential environment.”⁶ Our study aims to analyze commercially available PHRs for their suitability to accept, manage, and share data generated from a standard home health case study.

Methods: Two researchers independently reviewed the eighteen no-cost, web-based PHRs listed on MyPHR.com.⁷ Both researchers attempted to create an account for each of the systems, and enter, manage, and share information from a standard published case study detailing a 58 year old man referred to home health after an acute care episode.⁸ The data from the case study were abstracted into four categories: demographics, medical history, acute care encounter, and home health visits. After independent review, the authors met to resolve any differences from the data collection and qualitatively describe the personal health records.

Results: Of the initial eighteen PHRs reviewed, one was unable to be found through Internet searches and ten were excluded.⁹–¹⁸ The reviewers were able to enter most of the demographic information into all seven PHRs. The exception was that only three of the seven PHRs were able to accept the occupational therapy data.⁹–¹⁸ Comprehensive medical history information could be entered into six of the systems.²²–²⁴ One system only allowed users to upload PDF documents for medical history data. Four systems used structured lists to support data entry for medical conditions.²²–²⁵ This functionality caused difficulties when trying to enter exact medical condition wording. Clinical data such as provider notes, echocardiogram results, and chief complaints from an emergency department visit could not be entered directly into any of the systems. Six of the seven systems allowed the user to upload documents from clinical encounters in formats that ranged from the portable document format (PDF) to the continuity of care document standard (CCD). One system could incorporate data from a CCD into the PHR. Three PHRs offered both a graph and table format of patient reported daily weight values. One system allowed users to update a dose in an existing medication entry, while keeping a record of the previous dosage in the system. The remaining systems required the user to discontinue a medication and create a new entry to update dosage.²⁴,²⁵ Six of the systems allowed the user to view a discontinued medications list. All PHRs offered a way to export data in the medical record. Four only provided printer-friendly formats, three provided CCD/CPCDA/CCR downloads,²⁹,³¹,³³ one provided a “Blue Button” format,³³ one provided a “PHR extract” in the form of XML document,¹⁹ and one PHR allowed users to download a HTML format.²³ In addition, although not formally assessed, the reviewers found significant usability problems when navigating the systems.

Discussion: Although the seven PHRs reviewed could store critical data from the case study, the format and location of the data varied greatly between the systems. Most systems did not provide the functionality to effectively import data from other systems. Therefore the burden of incorporating data from clinical encounters would be significant for anyone with data from multiple clinical visits. In addition, the systems lacked the ability to associate data elements from a single clinical encounter, making it difficult to view and make sense of all of the changes to the record occurring from one episode. Finally, usability issues caused difficulties in tracking, updating, and managing historical medication lists. This was especially problematic when dosage, duration, or timing changes were made to existing medications.

Conclusion: More work is needed to ensure that PHRs are designed to help older adults longitudinally manage their clinical

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information. Older adults are expected to interact more with clinical providers as they age. Therefore the systems designed to store, manage, and share data generated from these visits will need to be able to accept and transmit data without a heavy burden on the user. Currently the noPcost, webBased PHR’s that we reviewed do not effectively support users with entering, managing, and sharing data from these encounters.

References