

Research and Applications

Rethinking the outpatient medication list: increasing patient activation and education while architecting for centralization and improved medication reconciliation

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ABSTRACT

Objective: Identify barriers impacting the time consuming and error fraught process of medication reconciliation. Design and implement an electronic medication management system where patient and trusted healthcare proxies can participate in establishing and maintaining an inclusive and up-to-date list of medications.

Methods: A patient-facing electronic medication management system was deployed within an existing research project focused on elder care management funded by the AHRQ, InfoSAGE, allowing patients and patients' proxies the ability to build and maintain an accurate and up-to-date medication list. Free and open-source tools available from the U.S. government were used to embed the tenets of centralization, interoperability, data federation, and patient activation into the design.

Results: Using patient-centered design and free, open-source tools, we implemented a web and mobile enabled patient-facing medication manager for complex medication management.

Conclusions: Patient and caregiver participation are essential to improve medication safety. Our medication manager is an early step towards a patient-facing medication manager that has been designed with data federation and interoperability in mind.

Key words: medication reconciliation, health record, personal, RxNorm, Information Dissemination, patient participation

Patient is an unreliable historian. I called the patient's husband (who manages her medications) about the typewritten list in her chart. He confirmed that it is an up to date medication list for his wife. I asked about diltiazem and Keppra, which were not on the list and he stated "she doesn't take those anymore." When I asked when his wife stopped, he stated "on the last PCP visit, her doctor said she could stop taking those medications." I don't know if I was confusing him or if he had some confusion about her medications but he stated that the Synthroid was to help her sleep at night. He also stated that he had the Synthroid filled at CVS in Kingston but no fill history there for that medication. I did find out from PCP that it is filled through mail order. Dr H's office faxed a recent active med list from the patient's last visit. Diltiazem is still active as well as Keppra. Keppra is

prescribed through University Hospital and not through the patient's PCP office. I removed these two medications from the active outpatient medication list because of the husband's statements and list. Diltiazem is still active per PCP, but I cannot confirm if Keppra is.

- pharmacist note describing the process of obtaining the "best possible medication list"

INTRODUCTION

Medication management outside the hospital involves a complex network of multiple prescribers, various pharmacies, and several over-the-counter medications. Transitions of care, ensuring proper dosage and administration, and tracking medications with potential

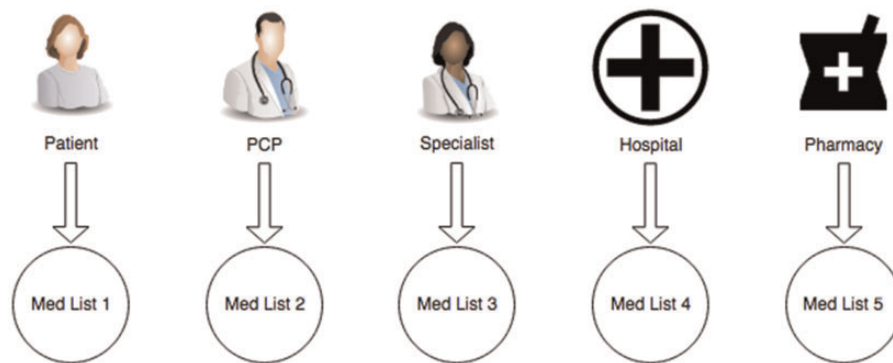


Figure 1. Siloed medication lists. These are all separate and typically no two are the same.

side effects all serve to increase the difficulty.^{1,2} Discrepancies and inaccuracies among medication lists can cause duplicate or contraindicated prescriptions with confusion and improper medication administration by the patient, resulting in adverse drug events (ADEs) along with increased morbidity, mortality, hospital readmission, and increased health-care-related costs.^{3–7} Most patients are easily confused regarding complex medications, the interchange of generic and trade names, and unclear indications and dosing information. The medication list can be difficult for patients to maintain, and from their perspective, offers little benefit other than showing other providers the often outdated and incomplete list, thus leading to low patient engagement and perceived benefit and a disincentive to keep an accurate and up-to-date list.

Individual clinical institutions, by order of the Joint Commission, attempt to obtain the “best possible medication list,” a time-consuming, inconsistent and error-fraught process.^{8–12} While a centralized, inclusive list is often pointed to as the “gold standard,” little has been accomplished in envisioning what such a list would look like and how it would fit into the current infrastructure of healthcare. We propose that by employing the least well-utilized resource in healthcare, the patients and their families,^{13,14} we can increase the accuracy and usefulness of the patient’s medication list. We present here a patient-facing electronic medication list management solution by utilizing techniques to encourage patient activation and education. Of great significance is the use of free and open source tools provided by the U.S government as the backbone of the information for the application.

“Medication Harmony” is a vision in which the complete and accurate medication list is available at all times to all the appropriate people and involves patient-centered medication list management with the ability for synchronization across providers. Considering the current environment and barriers to easy medication reconciliation, we feel the following tenets to be fundamental to the design and development of the medication manager to help bring us a step closer to medication harmony:

- Centralization
- Interoperability
- Data federation
- Patient activation

Centralizing the Medication List to Establish a “Single Source of Truth”

A dedicated system to act as a medication manager must be implemented. As multiple studies have demonstrated, there is a large

amount of time, effort, and cost associated with efforts to obtain an accurate medication list.^{8–12,15–18} Despite this, each institution repeats this process at every patient encounter to maintain their own list. (Figure 1) Furthermore, even if one list is deemed accurate at a single point in time, the other lists become out of synch. Attempting to improve upon the current workflow of institution-specific list maintenance remains neither scalable nor sustainable. Laws and regulations allowing the exchange of information are still unfulfilled, but it is our view that the curve bends towards the appropriately managed, free exchange of information. Our goal is to design for this future.

Interoperability

Medication information must be available to all authorized parties in a just-in-time manner and must fit within the current workflow of providers. A standardized medication ontology that electronic health records (EHRs) and their respective drug formularies rely on must be utilized. Aside from making an Application Programming Interface (API), such as Fast Healthcare Interoperability Resources (FHIR)¹⁹ available, changes to the existing architecture should not be needed to import and export data. Additionally, the SMART on FHIR²⁰ project aims to make a multi-platform application easily importable into existing EHR applications.

Data Federation and Reconciliation

Collecting information from disparate sources (Figure 2) provides a starting point of information that can be verified and adjusted, thereby eliminating the burden of building the medication list from scratch. As noted, various sources attempt to keep an accurate list of current medications including pharmacies, doctors’ offices, hospitals, and patients. We should not expect that the process of reconciliation be a completely automatic process. Rather, the collection of information from various sources and the simple visualizations that allows recognition of overlap and source in order to provide a streamlined view for final human verification should be our goal.

Patient and Caregiver Activation

The patient or patient caregiver is the person ultimately responsible and knowledgeable about what medications the patient is taking. Patient and family participation in medication management, however, is all-too-often overlooked. Without the cooperation of this “end user,” it will be impossible to obtain an accurate account of medication administration. We know that older adults find it difficult to manage and share their medication regimes during transitions of care²¹ and caregivers are willing and able to use technological

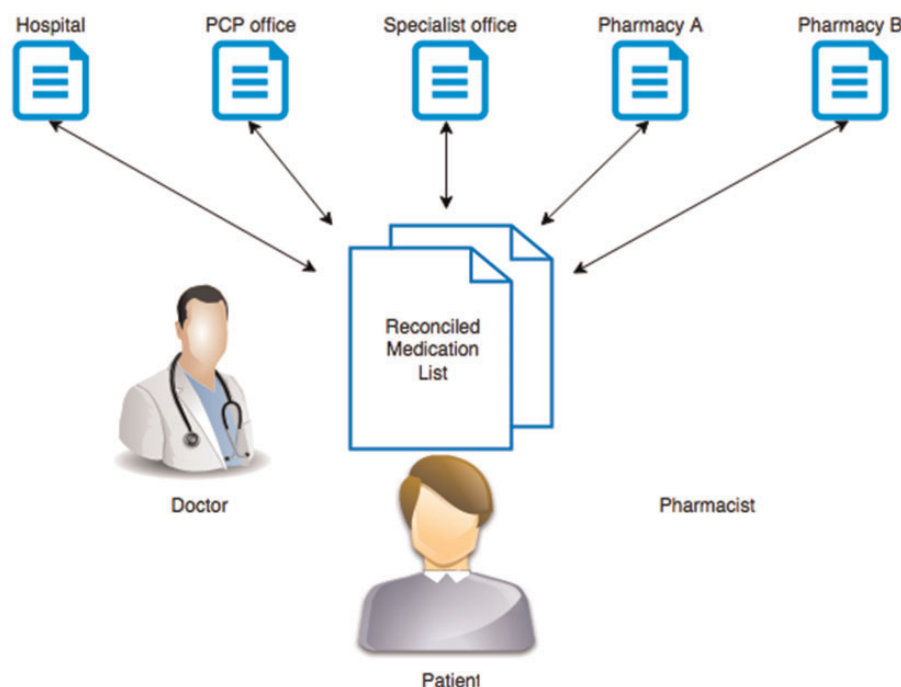


Figure 2. Data federation.

assistance with older adults.²² The difficulty has been providing our patients and caregivers easy to use tools that provide incentive for participation.

An Interactive Medication Manager

With the tenets of “Medication Harmony” in mind, we designed an electronic medication manager – an internet-connected list that is easy to use and update and can enable the sharing of information when needed, as well as providing educational opportunities for patients and their families. The manager was designed to enable use of a widely available structured ontology with around-the-clock availability, portability, and the ability to send and receive information. The manager offers providers, patients and family members with read/write access to the same centralized medication list in order to decrease the time and effort needed for each office to capture, update, and enter information at the point of care, thereby ensuring that patients and providers all have the same information.

METHODS

The medication management application is an extension of the InfoSAGE project,²³ an AHRQ-funded grant project that provides a free private social network for elder care coordination and management. Use of InfoSAGE is not limited to any particular patient population. Participation in the InfoSAGE study, however, requires an elderly person, over the age of 75, (designated a “keystone”) and a caregiver partner to be enrolled as a “dyad.” Keystones do not have to be users of the system, but are invited to be active participants. We survey participants at baseline and every six months thereafter for the duration of the study. Surveys ask about health information needs, functional status, caregiver burnout, and usability. We partnered with two local retirement/continuing care communities’ areas to recruit potential participants as well as provided early feedback.²⁴

Specific to building the medication manager, several data sources were used to build the medication management web and mobile application including:

- RxNorm (which includes interactions)²⁵
- The Dietary Supplement Label Database (DSL)²⁶
- RxIMAGE²⁷
- The National Drug File - Reference Terminology (NDF-RT)²⁸
- The Consumer Health Vocabulary (CHV)²⁹
- MedlinePlus³⁰

Of notable significance, these databases are associated with the U.S. government, maintained by governmental resources and available for free. RxNorm and the DSL are medication ontologies maintained by the National Library of Medicine (NLM) and provide the underlying data structure for medication and supplement information. Any medication either over the counter or prescribed with a listed active ingredient available in the United States is available within the RxNorm database. The DSL contains the label information from dietary supplement products that are currently on the U.S. market. The RxIMAGE database is the nation’s only portfolio of curated, freely available, increasingly comprehensive, high-quality digital images of prescription pills. The NDF-RT is produced by the U.S. Department of Veterans Affairs and allows the ability to query approved indications to a specified medication. The CHV, provided by the Unified Medical Language System (UMLS) Metathesaurus, allows more “consumer-friendly” indications by mapping terms such as “hyperlipidemia” to “high cholesterol.” MedlinePlus, a product offered by the National Institutes of Health (NIH) provides extensive information on prescription and nonprescription drugs, among a number of other services. These services are accessed via Representational State Transfer (REST) APIs, providing several administrative and software developmental advantages.

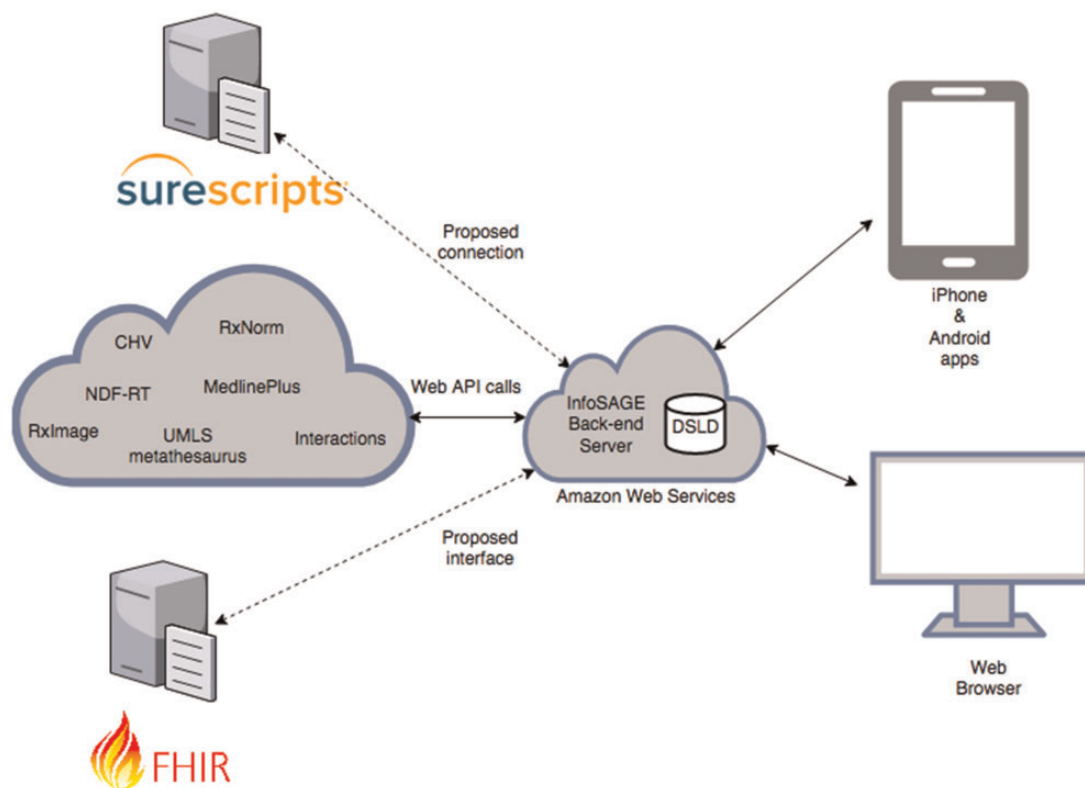


Figure 3. Data model for information coordination.

RESULTS

By stitching together information from each of these individual databases, we combined these disparate sources into a single, elegant, medication manager solution. (Figure 3) InfoSAGE, including the medication manager is free, open to the public and can be accessed at <http://infosagehealth.org>. iOS and Android mobile versions are available on the respective app stores.

Ultimately, the medication manager allows the user to search for their medication, checking for common misspellings, and suggesting alternatives. Translations between trade and generic names are displayed along with specific formulations and routes of administration. Based on medication name (whether generic or trade-name) and formulation, a curated list of images is generated allowing the user to choose which one matches the one they take. A customized list of indications is provided in easy to understand language, allowing the patient to choose why they take the medication. Users can further specify frequency and dose, and have a space to make customized free-text notes. Drug-drug interactions are checked among active medications, and the user is notified if an added medication interacts adversely with an existing one. Both an active and inactive medication list is maintained. Finally, for each medication, the appropriate MedlinePlus page is linked and available for the user to obtain trusted, authoritative, layperson-friendly information. We recently introduced functionality within our mobile platform to take a picture of the label of a prescription or non-prescription drug, and to use Optical Character Recognition (OCR) to match the medication based on this photo. We also allow patients to take a photo of their own medication in case an image for their specific medication is not available within the database.

Permissions for viewing and editing medications follow a structure that was previously designed by InfoSAGE service. Each elder

(keystone) can designate an associated network of people with various levels of permissions. In this model, the “keystone” (primary elder), can view, edit, and email the list. In addition, the keystone can choose to make a medication private to limit the number of viewers. This can be utilized for sensitive medications the elder may not want others to have knowledge about. The keystone can designate a “proxy” who has all the abilities of the keystone. The “caregiver” can view the medications (other than ones made private by the keystone or proxy). A final tier of users, “participants,” have no access to medication information but do have access to other parts of InfoSAGE, such as “tasks” and “communications.”

The enhanced medication manager was introduced to our community as a proof of concept and to help further refine our design. We aggregated feedback from product demonstration and observational studies. We witnessed increased user enrollment and increased addition of medications within the InfoSAGE platform demonstrating interest and some adoption of the product.

Nine InfoSAGE participants responded to a survey regarding their comfort with technology, personal habits on medication lists, safety and sources of knowledge. Most had a smartphone or tablet device and reported feeling “comfortable” or “very comfortable” with using the Internet. All of them used a computer or smart device on a daily basis. Elders had a range of 2 to 6 prescribers with an average of 3.3 and median of 3. They used on average of 1.7 pharmacies, with a median of 2. All respondents believed that their PCP had an accurate updated list of their medications including over-the-counter medications and most expected that if they showed up to an emergency department, the ER would have a list of their medications. Respondents did qualify this with noting that the ED they would frequent would be in the same “system” as their PCP office.

If either the elder or the caregiver had general questions regarding a medication, they most often turn to the Internet for the answer and less often turn to a doctor, family member or brochure. More than half believed they knew the side effects of each medication as well as whether any of their medications could be potentially interacting with one another. Respondents were split evenly on worrying about interactions of prescribed medications and one patient stated, “I figure my PCP would notice.” Although all respondents acknowledged that they believed over the counter medications could interact with prescribed medications, not all were concerned about this. Those with questions about interactions were more likely to ask a pharmacist or doctor rather than the Internet. All respondents believed they knew why they take each medication, and all agreed that it was their responsibility to keep track of their own medications. They most commonly kept track of medications via a hand-written list, or a combination of a hand-written and typed list, while one person kept a list on her phone. One respondent had a list printed by the PCP office and stated that she liked that the “doctor keeps it up-to-date and mails it to me with my next appointment date;” another noted “OTCs don’t make it onto the CVS list.” Patients and caregivers reported that the lists include OTC, PRN, and herbal medications. Most reported that strength and frequency were present on the list and 5 of 9 respondents reported that indication was present on the list. Of the patient’s reporting answers, most found the utility of the list either useful or very useful. But only half report updating it every time a medication change took place. One patient who reported that keeping a list was very useful also stated, that what he finds most difficult about keeping the list is “paying attention to it and bothering to make changes.”

When maintaining a medication list, users generally reported, “My way works.” Concerns arise with misplacing the list, not being “sure who ordered what” because of multiple prescribers, lists not addressing “any chance of a negative reaction to the combo of pills,” remembering to update the list, and that it is “short and informal.” Only one person reported using an electronic list. None of the respondents answered “yes” to the question, “If you were offered an electronic medication list that both you and your doctors were able to see and share, would you have concerns?” and only one patient reported being “somewhat concerned” regarding privacy and security with such a list while the others expressed “no concern.” Patients expressed frustration with the inability to find a match secondary to a possible misspelling of the medication, and irritation choosing from dropdown menus when using electronic medication lists.

DISCUSSION

Medication safety depends on the accuracy of one’s medication list as well as knowledge surrounding the medication itself. Currently, maintaining an up-to-date medication list requires time and vigilance by patients and providers. Finding information online depends on comfort with search engines and the ability to discriminate trustworthy sources. Paper lists, notations on medication bottles and one’s memory will never be able to provide comprehensive information, common indications, and a drug-drug interaction checker. Further, these methods are subject to memory lapse, incomplete information, and misplacement. To easily share, update, and capture complete data, migrating from paper to electronic records is essential. Since patient participation is crucial in maintaining the medication list, we must provide incentives that increase both

engagement and education in addition to easing the transition to an electronic list.

Elderly patients and patients with multiple chronic illnesses stand to benefit the most given their overall medical complexity and the number of medications they typically take. Many patients do not realize the consequences of an erroneous list. Often, it is only after a hospitalization or medical event where list inconsistencies prove to be dangerous and time-consuming problems to solve. Our respondents verify the assumption that most patients expect their providers to know every medication they are taking, while studies have shown otherwise. Multiple lists provided by multiple parties, such as providers and pharmacies (which lack inclusion of over-the-counter medications) exacerbate complexity. Merging these lists often involves taking one list as “mostly correct” and then changing that list based on the merger and input of other lists. This can result in potential overlaps or deletions causing adverse drug events.

Our approach and solution is novel for several reasons. It recognizes that patients are essential to the process of maintaining an electronic medication list. It acknowledges that a list of medications in and of itself means little to most people, and patients often keep a list simply because their doctor asks. It enables not only the patient to maintain the list, but, if desired, also formally involves a trusted proxy. It is designed using open source standard terminology that has the ability to integrate information from commercial drug compendia that a hospital or pharmacy may use. During this pilot program, we have demonstrated the ability to design and implement a web and mobile medication manager for use by elderly patients and their healthcare network using free and open-source tools provided by the U.S. government. We observed a desire by patients and their families to have access to an advanced medication manager.

Several commercial electronic products for medications list management are available from websites or mobile app stores. Most focus, however, on adherence or simply maintaining a medication list and few provide any information beyond the pill name and reminder of when to take it. The ability to easily add medications and provide educational opportunity directly within the application will aid in adoption and continued use of the product. Medication list prepopulation and integration of information from several sources will further drive adoption and ease of use. We must also connect information silos in an easy to understand way: if one source is not complete, clinicians, pharmacists and patients are unable to track drug-drug interactions and overlapping medications that may cause ADEs. Further development of our medication manager will focus on the ability to collect and integrate other data sources. Although the Surescripts® network has extensive information regarding an individual’s prescription medications, it is unable to capture over-the-counter purchases, herbals and may miss medications paid for out of pocket or from a pharmacy-specific discount formulary. Additionally, its customers are individual hospitals and physician practices. Therefore, information for a specific individual is not available unless it is provided to a hospital or physician directly involved in that person’s care. The Surescripts® network provides claims and prescription fill data from pharmacies participating in their service, covering about 95% of pharmacies within the United States. The company does not currently consider the people who take the medications as consumers of the data they collect. Information gathered using Surescripts® would be valuable for our project. After discussion with company representatives; however, we were informed that prior contracts and their structure for legal use of their data do not allow us to access their information. If at some point, their focus changes, we would like to incorporate their data into our product

design. As with the Surescripts® data, along with most information provided by a particular EHR portal view or specific pharmacy, the data is typically one-directional, meaning that patients are unable to augment information.

While researching access to information housed in outside institutions, ingesting C-CDA scripts has proven more difficult because this “standard” is not as standardized as would appear.³¹ Although still in the early adoption phase, the use of FHIR for trusted calls to servers and means of providing information in a standardized form appears to be the way forward. Once information is collected, it will have to be merged with the current information. TwinList,³² an open-source project from the University of Maryland, is a possible solution for this challenge. Finally, enabling the medication manager as a SMART application, with the ability to be utilized as a web-app, mobile device-app or trusted service within an EHR will help increase institutional participation.

Our pilot data reinforces the notion that the patients believe their own method used to keep track of their medications is adequate and for the most part were unwilling to invest the time needed to record another medication list. Adding medications simply by photographing a label was not yet available during the time of study, and this new feature should encourage adoption. We must educate to the benefit of an electronic list including increased safety, communication, and knowledge while continuing to focus on ease of use.

CONCLUSION

We designed and built a patient-centered medication manager on a foundation of a free and open U.S. government standardized ontology while focusing on the tenets of centralization, interoperability, data federation, and patient activation. “Medication harmony,” will decrease confusion, uncertainty, and ultimately adverse drug events surrounding the accuracy of the medication list by eliminating the need to write down every medication at each patient-provider encounter; reduce lists marred with spelling errors, cross-outs, and inaccuracies; provide a trust-worthy easily comprehensible information source regarding each medication; and enable patients and providers to have access to the same information. Updating the medication list can occur at transitions-of-care, patient-provider interactions, or at any time by the patient or caregiver.

The prospect for collaboration drove the build of our medication manager. To this end, with appropriate permissions, the ability to send and receive structured data is possible. Ultimately, a solution built with authentication for various levels of users who have appropriate permissions to view and edit information will add utility. Primary users will be healthcare providers who will rely on it to maintain an accurate list of medications that can be shared and updated by other providers; healthcare institutions, who will use it to more easily reconcile medications during points of transition; and patients, who will be able to add, delete, modify, and verify OTC and prescribed medications.

We have previously described a framework for list centralization among patients and providers.³³ Centralization naturally raises the question of who will be responsible for data storage and maintenance. Possibilities include state or federal government, hospital systems, insurance companies or an independent private company. We will continue to add features incrementally to ease the process of medication reconciliation, which is a frustrating, time-consuming and potentially dangerous task involved during care transition. The ability for such an implementation will rely more on policy, than technical ability. Involving the patient and the patient’s support

network as active participants in list accuracy is the first step towards achieving “Medication Harmony,” a vision in which the complete and accurate medication list is available to all the right people at all times.

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COMPETING INTERESTS

None.

CONTRIBUTORS

FP performed literature search, conceptualized and coded the prototype of the medication manager for integration into the InfoSAGE platform. FP drafted the manuscript. CS and AW provided project guidance. All authors provided critical revisions of the manuscript for important intellectual content.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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