

Health information management practices in informal caregiving:**An artifacts analysis and implications for IT design**

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Highlights

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- Informal caregivers perform personal health information management (PHIM)
- Caregivers' PHIM practices support daily care management and decision-making
- Caregivers acquire, integrate, maintain, update, use, and communicate information
- PHIM challenges include information workload and integrating PHIM into daily life
- Tools such as CARE Kit assisted informal caregivers in managing health information

ABSTRACT

Introduction: Unpaid informal caregivers of adult care recipients, including persons with dementia, experience multiple unmet information needs and information management challenges.

Objectives: To understand the current personal health information management (PHIM) practices in informal caregiving for adults with and without dementia.

Methods: Semi-structured interviews were performed with ten informal caregivers—half of whom were caring for persons with dementia—and four formal caregivers at an adult day service. Interviews centered on a paper-based tool distributed by the day service, the CARE Kit, permitting an artifacts analysis of the tools used by participants for PHIM. Qualitative thematic analysis was applied to interview data.

Results: Caregivers' PHIM practices aimed to support daily care management and decision-making on behalf of care recipients, through: 1) information *acquisition and integration* across multiple sources and records; 2) information *maintenance, updating, and use* over time; and 3) information *sharing and communication* with healthcare professionals and other family caregivers. Participants reported advantages and challenges of their PHIM practices and tools, including fitting PHIM into their daily lives, managing PHIM-related cognitive workload, the functionality of PHIM tools, and the dynamic, longitudinal nature of PHIM.

Conclusion: The study produced a number of implications for caregiver health information management information technology (CHIM IT), based on findings about the nature of caregivers' practices for managing information for adult care recipients. We present CHIM IT requirements related to privacy and security, customization and flexibility, ease of use, credibility and sensitivity, situation awareness, information integration, delegation and shared use, updating and maintenance, archiving and versioning, communication, agency and information access, and validation.

Keywords: Personal health information management (PHIM); unpaid care; Alzheimer's disease and related dementias (ADRD); aging; consumer health information technology (CHIT); qualitative research; user-centered design (UCD)

1. INTRODUCTION

Approximately 43.5 million Americans provide unpaid care to another person; 79% of whom are caregivers for an older adult [1]. Unpaid or *informal caregiving* for a care recipient often involves helping with activities of daily living (ADLs) such as eating, bathing, dressing, toileting, and ambulating; aiding instrumental activities of daily living (IADLs) such as managing finances, transportation, medications, shopping, meal preparation, and home maintenance; monitoring the care recipient's health and performing medical or nursing tasks; communicating with healthcare professionals; and advocating for the person to providers, services, and agencies [1,2].

Nearly half of all informal caregivers who assist an older adult provide care to a person with Alzheimer's disease and related dementias [3]. Caring for a person with dementia often involves additional physical and emotional effort and has been reported to lead to higher levels of psychological, financial, and role stress compared to other caregivers [4,5]. Caregivers of persons with dementia are at a higher risk for employment complications, caregiver strain, mental and physical health problems, reduced time for leisure and other family members, and family conflict [6–9].

Eighty-four percent of all caregivers report having unmet information needs [1]. These needs span topics including diagnostic information, how to assist with everyday caregiving tasks, end-of-life, and self-care [10–15]. Table 1 lists the many specific knowledge and information needs of dementia caregivers reported in the literature. However, while the literature documents the information needed by caregivers, little is known about the *management* of this information by caregivers of adults, including persons with dementia. Before reporting on our investigation of informal caregivers' health information management, we briefly introduce the concept of personal health information management (PHIM) [16] as a framework for this study.

1.1. Personal health information management (PHIM)

PHIM refers to people's use of personal health information for monitoring and assessing health, making health-related decisions and planning, performing preventive care and delivering treatment [17,18]. PHIM has been extensively studied in the context of preventive care and management of chronic illnesses such as cancer and diabetes [17–21]. PHIM processes include acquisition, integration, organization, maintenance, retrieval, and sharing of information related to personal risk factors, medications, test results, and appointment and contact information for various clinicians and support groups. These activities are accomplished using various cognitive processes (remembering, checking, comparing) and may be aided by digital or paper tools (spreadsheets, lists, business cards, contacts, email, calendar, printouts), images (paper and electronic), and devices (computer, cell phone, PDA, glucose monitor, pill box) [18,23]. In addition, illness management is intertwined with individuals' personal and professional lives, meaning PHIM could be conceptualized as "life information management" [18,24]. In addition to integrating personal, professional, and health-related information, challenges of PHIM include using information from multiple sources to make health-related decisions and sharing information with individuals from social, professional, and health care networks while maintaining personal privacy [22,24–27]. PHIM for caregivers of persons with dementia or other cognitive impairment may pose additional challenges, for example, having to make substituted decisions for the care recipient based on potentially imperfect information [24,28,29].

1.2. Study of health information management in informal caregiving

The 2009 Agency for Healthcare Research and Quality (AHRQ) report on PHIM and health information technology (IT) [30] identified six critical gaps in the PHIM literature, one of which

was research on “PHIM practices of subpopulations that have not been studied to date.” To our knowledge, PHIM practices have not been studied among caregivers of adults with or without dementia, thus motivating the present study of that important subpopulation. Examining the PHIM of caregivers is important because of potentially unique information coordination challenges related to potentially multiple caregivers managing information for someone else and for themselves. This situation also raises sensitive questions of autonomy, agency, and confidentiality. PHIM for dementia caregivers may be even more nuanced due to the care recipient’s memory and affective impairments, which may affect, for example, access to historical information.

The objective of this study was **to understand the current health information management practices involved in informal caregiving for adults with and without dementia**. We approached this objective by performing qualitative semi-structured interviews with unpaid informal caregivers and formal caregivers affiliated with an adult day service. We chose this sample because the informal caregivers had all been provided with a paper-based PHIM system called CARE Kit, a physical binder with divisions for storing important documents, including templates and worksheets for documenting information deemed important for caregiving for impaired individuals. The formal caregivers we studied had been involved in developing and distributing the CARE Kit. When performing the interviews, we were thus able to ask about how CARE Kit as a specific tool used for PHIM as well as to conduct an artifact analysis of CARE Kit itself. Artifact analyses not only describe tools used but also reveal individuals’ underlying cognitive activities and needs [31]. The study addressed the following specific research questions: What are informal caregivers’ current PHIM practices? How do tools such as CARE Kit fit into these practices? What are the challenges associated with PHIM and current PHIM tools?

Our secondary objective was to develop design implications and requirements for IT to support caregiver health information management (see section 4.2), to address the need for “articulation of functional requirements of tools and design philosophies,” a second critical gap identified by the AHRQ report on PHIM [30].

2. METHODS

The research design was a cross-sectional semi-structured interview study about PHIM practices, including an analysis of CARE Kit and other tools used by participants to accomplish PHIM. The study originated from joint interest between researchers and a community partner in improving informal caregivers’ PHIM and creating a digital PHIM system for adult day service clients. The Indiana University Institutional Review Board (IRB) approved this study.

2.1. Setting and participants

This study was conducted with informal caregivers and paid staff associated with Joy’s House, a not-for-profit adult day service provider in Indianapolis, Indiana, USA. This setting was appropriate because Joy’s House created and freely disseminated to their clients a paper-based PHIM system, the CARE Kit. All participants had adequate experiences with informal or formal caregiving and the formal caregivers also described one of their roles as helping informal caregivers acquire information and access caregiving resources.

We used purposive convenience sampling to recruit ten informal caregivers and four formal caregivers (staff) through Joy’s House newsletters and personal solicitations. By design, half of the caregivers were included if they were primary or secondary caregivers for a person with Alzheimer’s disease and related dementias, while the other half who cared for adults with other

life-altering health conditions were included to better understand variation in PHIM and CARE Kit use. Caregivers self-defined their role as primary based on providing the vast majority of the care recipient's informal care and secondary if they played a supporting role to another caregiver. Caregivers were excluded if they did not speak English or could not complete consent due to cognitive or communication difficulty. Caregivers who did not use the CARE Kit were not excluded; instead, we expanded our semi-structured interview protocol to learn how else they accomplished PHIM and why they did not use the CARE Kit. All participants provided consent and informal caregivers received a \$20 gift card.

2.2. Procedure

Each interview session was performed in a private room at Joy's House, lasted 60-75 minutes, and was audio-recorded. Interviews followed a semi-structured interview guide (see Appendix A). The interview first asked respondents about their caregiving experiences then prompted them to produce a narrative or story about their PHIM and CARE Kit use. The interviewer followed up with unscripted probes to ensure coverage of major PHIM categories: collecting and assembling information; retrieving and using information; maintaining and updating information; and sharing and communicating information [32]. Additional questions probed participants' use and adaptation of the CARE Kit over time, perceived advantages and challenges, and perceived areas of improvement. The interview was designed to elicit a narrative of the journey [33] of caregiving and PHIM, of which CARE Kit use was a central component. Centering interviews on a specific artifact prompted individuals to remember concrete events over time and provided a common language for caregivers to report divergent experiences. Interviews were conducted by a single researcher who made incremental changes to the order and phrasing of interview probes based on interim reviews of the data [34], with consultation with the research team.

At the end of the interview, nine out of ten informal caregivers performed a closed card-sorting task [35]. They received eight cards depicting the sections of the CARE Kit (e.g., emergency, household, and medical information about the care recipient etc.) and were instructed to sort them into “low,” “medium,” and “high” categories based on: 1) frequency of updating; 2) relevance to everyday caregiving; and 3) any other dimension relevant to them.

2.3. Analysis

During analysis, interviews were transcribed and subjected to a six-phase essentialist/realist thematic analysis [36]. One author (YK) performed the first two analysis stages: familiarizing with data and generating initial codes. Then, two analysts (YK, TP) worked as one unit to develop, name, and define themes and to iteratively assign passages to these themes. This was done using the affinity diagramming method, in which segments of data are grouped by similarity until logical categories can be defined by the group of analysts [37]. Conflicts were discussed and resolved in real time during this process and each analyst also performed digital reviews – the ‘walk the wall’ technique – to continually identify gaps in the coding scheme as well as to generate design ideas [38]. Furthermore, the senior researcher (RJH) performed a secondary corrective review of themes and associated transcribed passages under each; he reported 93% agreement with the two analysts’ assignment of passages to themes and noted instances of disagreement, which were subsequently resolved by discussion.

To analyze card sort data, we used a descriptive method demonstrated in another study where card sort data were intended to probe the participants further and supplement interview and observation data [39]. We calculated the percent of participants sorting each of the eight information cards into “low,” “medium,” and “high” categories. We noted any cards categorized “low,” “medium,” or

“high” by $\geq 33\%$ of participants. Other methods for analyzing card sort data [35] were considered but dismissed due to sample size (cluster analysis) and data distribution (pile sort).

The ultimate goal of this project was to develop requirements, and subsequently design specifications, for an IT or other system to support caregivers’ PHIM. To this end, analysts walked the digital “wall” of analyzed data to generate a user environment design [40]. Using this method, we first wrote down design implications based on reviewing the themes and salient individual scenarios from the data. We then wrote concise non-functional and functional requirements from these implications. Requirements are statements about what a system should be like (non-functional) and what it should do (functional) to support PHIM practices and overcome PHIM performance barriers. The requirements were written so they could be met by any number of designs, both digital and paper-based.

3. RESULTS

Fourteen participants (10 informal and 4 formal caregivers), completed interviews. Participant characteristics are described in Table 2. All participants were females ranging in caregiving experience from one month to 28 years. Among caregivers, CARE Kit use ranged from using most of its sections to no use at all. In the results below, all quotes are from informal caregivers unless noted otherwise.

3.1. CARE Kit overview

The CARE Kit is a physical binder with templates for emergency, medical, legal, financial, household, daily needs, and end-of-life information about the patient. In addition to the templates, users could add customized templates and additional records. Formal caregivers described the primary purpose of the CARE Kit as enabling the effective and efficient assembling, sharing,

updating, and management of patient information. The day service facility provided the CARE Kit as a tool for the primary informal caregiver to use proactively and throughout the progression of the care recipient's disease.

3.2. Informal caregivers' PHIM practices and the role of the CARE Kit

Informal caregiver PHIM practices aimed to support: 1) daily care management (ADLS, IADLs) and 2) informal caregiver decision-making. PHIM processes towards these goals included acquiring and integrating information; maintaining, updating, and using information; and sharing and communicating information with healthcare professionals and other family caregivers.

3.2.1. Information acquisition and integration

Informal caregivers needed to acquire multiple types and pieces of information before assembling them in the CARE Kit or other PHIM system. Acquiring and integrating information was demanding and usually performed incrementally over time:

“...it was finding time and setting short periods of time, saying, next time I meet dad, I am going to ask him these questions. It wasn't a (one-time) project, it was a little bit here and there, most critical things first, and (then) the less critical. The difficulty was to compile the information.”

Informal caregivers initially compiled and stored information in paper records, such as lists, phone books, and binders. These records had the potential to be inaccurate, outdated, or difficult to find:

“Dad had the information. I just took the information and put it together in this format. He tends to write, but he is a horrible writer. He should be a doctor. I can read it but nobody else could. So that was one of the difficulties. There were questions about the medications

because he wasn't updating it.... A lot of it changed. I initially took everything he gave me and put it in the CARE Kit."

Much more rarely, caregivers drew on electronic records. For example, two caregivers accessed care recipients' financial information through online banking accounts. However, surprising to the researchers, none of the caregivers used online personal health records (PHR) systems. Reasons offered for not using PHR systems included being unaware of them, not having access, being unable to synchronize between multiple health systems' PHRs, and being more familiar with paper records.

Another common source of information was the care recipient him or herself, to the extent they were capable of providing it verbally or by sharing paper records before their abilities declined. All informal caregivers stated the superior reliability of information originating with the care recipient. Accessing information from the care recipient was more or less difficult depending on the health condition; among those caring for patients with dementia, memory loss could effectively "wipe out" information kept by care recipients, emphasizing the need to gather information before it was too late:

"They [parents] were very vibrant up until recently when my mom went down. So, it would have helped me to be more proactive before she went down. And had them fill it out when capable."

In contrast, a caregiver of a person without dementia described her ability to gather data after her father's catastrophic health event: *"I was lucky that my dad could give me some information."*

Despite the realization that gathering data proactively could be useful, caregivers were concerned that gathering data too early could violate care recipients' privacy:

“I felt like, I was just being nosy, just peeking into papers that she had. But then off course, I realized that I had to do it to take care of her.”

End-of-life information was especially challenging to gather because of the emotional nature of this process. Additionally, gathering end-of-life information was more difficult if done after the care recipient’s abilities had declined.

For those who used it, the CARE Kit was a useful place for compiling disparate pieces of information. The CARE Kit also served as a checklist for what to include. Another system commonly used for compiling information was a desk or wall calendar. Caregivers remarked on the visibility, accessibility, ease of use, tangibility, and familiarity of calendars as an organizing tool. However, those using calendars for PHIM still had to separately gather and file copies of laboratory reports, discharge sheets, prescriptions, bills, receipts, and prescription medication lists. Interestingly, while CARE Kit supported consolidation, caregivers noted that it did not always integrate information across sections or from other information systems. For example, care recipients’ appointments were listed separate from the caregiver’s personal events calendar, despite the interdependence of these two types of information:

“I look at the appointment calendar daily and it is hard to divide medical appointments from others because you have to schedule all of those around each other.”

3.2.2. Information maintenance, updating, and use

Maintaining and updating their information systems was an important task for informal caregivers, who perceived the use of outdated information to be a safety risk when making decisions or communicating with healthcare professionals.

Certain types of information required frequent updating, particularly medical information such as medication, diagnosis, appointments, and clinic visit summaries. Informal caregivers of persons with dementia in particular reported frequently updating the sections of the CARE Kit on diagnosis, abilities, and behavioral and psychological symptoms:

“In terms of taking care of him, I would write some notes. Then I decided it is ridiculous to write it every time. Now, I put it on the computer, so I could tweak it and change it.”

Other information (e.g., legal, financial), was more rarely updated, except in specific circumstances such as transferring the power of attorney between caregivers. Table 3 presents the results of the card sort performed by informal caregivers reporting the frequency with which various categories of information were updated. Interestingly, formal caregivers believed household and diagnosis related information was updated more frequently than informal caregivers actually reported.

According to both informal and formal caregivers, a PHIM system was especially useful and used for making financial, end-of-life, and treatment decisions:

“It was just coming up then like where are you getting buried? With elder (care) attorney, it was clear that they had a clear idea. They talked to each other, but I didn’t know half of it and I was the point contact. So, I think this care kit did a wonderful job.”

Informal caregivers described decision-making as a process with many steps: integrating information, interpreting changes, understanding available options, applying knowledge about the disease, and synthesizing information. However, some noted difficulties with this decision-making process due to information overload and changing information:

“I have so many places that make demands that I keep track of this – CICOA [Area Agency on Aging], Joy’s House, Medicare, Medicaid, her neurologist, I have so many places I need to keep track of I would need a secretary to take care of all these records. I just slam records into a drawer and I hope I die before I need it.”

Consequently, informal caregivers sought information integration and simplification strategies. For example, all participants used a calendar to update upcoming appointments and tasks. This not only provided a centralized and easier way to make updates, but also offered reminders:

“For medical information, I keep a calendar on my desktop which has all the appointments. I got off my computer and just decided to put it on a nice foldout--monthly foldout where I can see it everything If I have to make a phone call, this is real handy.”

A special case of decision-making was care decisions during emergencies. Because these were not planned events, informal caregivers described the value of proactive PHIM strategies as input into future decisions, as opposed to reactively gathering or updating information during the emergency:

“At 2:00 in the morning it’s hard to accumulate everything to get to the emergency room.”

Contrary to researcher expectations, while caregiver respondents expressed great difficulty assembling information, they found it relatively easier to maintain, update, and use the information once it was gathered. Participants’ comments suggested that managing information at some point became routine and therefore less challenging, even if it was difficult at first.

3.2.3. Information sharing and communication

Informal caregivers discussed sharing information stored in CARE Kit and other systems with two groups: 1) family and friends and 2) healthcare professionals. Interestingly, formal and informal caregivers had contrasting views of how information was or should be shared. Formal caregivers

believed a tool such as CARE Kit could facilitate information sharing, particularly handing-off care between primary and secondary caregivers, as explained by one staff participant:

“If you are caring for husband and you are going away for the weekend and sister is coming in ... Everything that she needs to take care, it’s all in one place. You can truly take a break and have the peace of mind that he is going to be cared for and that if something comes up there is a way to get that information without making a phone call to you.”

In contrast, while some informal caregivers shared copies of records with other family caregivers, most preferred verbal exchanges of information. Several were especially loath to duplicate paper information because copied information could become outdated:

“It is there for when we need it but we never made copies of it. But as soon as we do, it is going to be outdated, medications may be wrong, we may be telling the doctor wrong information, we didn't want to risk it.”

Another deficiency of paper-based systems related to sharing was the inability to quickly produce a summary or to filter the most important information. While paper systems could be complete and comprehensive, this made them suboptimal for concise, precise communication. For example, one informal caregiver noted the information overload of browsing sequentially through all the categories of information to retrieve the required information:

“... my mom likes to see stuff, so she wanted to have that file for her so that she can look into it for the information because she would be confused and frustrated by looking into the book (CARE Kit) like this and she wouldn't be able to find what she need it. Because like I said, my mom has dementia and sometimes she just doesn't remember. She is not going to take the time to look at the tabs and find out exactly where is the information.”

Informal caregivers also mentioned that sharing the entire CARE Kit when less information was needed could compromise privacy and security as a result of oversharing:

“Depends on the person. This woman who stays with him, I don't want her to know everything. There are only a couple of people who I would give it to. I lock the file cabinets. I shut down the computer. If my brother or sister look into any of my files, I wouldn't care.”

Instead of sharing all the information, the primary informal caregiver often mentally synthesized and verbally communicated key information to others. Consequently, informal caregivers described that an all-encompassing PHIM system such as CARE Kit would pass on to other family members or caregivers only if they assumed primary caregiving responsibility as well:

“The only thing I think I should do is give my brother a key to the fire file. In case something happened to me, everything he needs to know is in there.”

When communicating with paid caregivers or other healthcare professionals, informal caregivers used both verbal communication and paper records, particularly those that provided a summary of the care recipient, such as a medication or activity schedule. When communicating with healthcare professionals who lacked access to medical information, informal caregivers used medication lists and personal notes with their observations of daily living, i.e., summaries of everyday behavior, actions, and changes in abilities [41]. Even when informal caregivers had written observations of daily living documents, they used verbal communication to summarize, annotate, and interpret this and other paper records to others:

“I would say it got much better, more communicative, in the last 12-18 months because of the progression of the disease. We like to talk... we just tend to talk.”

In contrast to informal caregivers' preferences for efficient information summaries, formal staff caregivers believed CARE Kit could serve as a comprehensive living record of clinical encounters and other relevant notes, akin to a diary, that could be frequently consulted and shared when interacting with healthcare professionals. For example, one staff participant described her vision:

“The upcoming doctor’s visit, with questions to discuss, outcome diagnosis and next steps to where they can really take notes leading up to the doctor’s visit and then continue to take notes when the doctor is with them. Medical progress notes, vaccinations, important tasks, I think all of that is really good.”

3.3. Advantages and challenges of PHIM practices and the CARE Kit

3.3.1. Advantages and challenges of PHIM in general

Caregivers highlighted familiarity and compatibility with their needs as big advantages of current PHIM practices: *“The advantage of my system is that it is all I have. I have to go by what I know, how my brain works. I understand it and I know it and it works for me.”*

Informal caregivers praised PHIM practices that fit into their lives and evolved as life changed. This included, for example, systems that were intuitive (e.g., lists to represent multiple objects such as medications) and that could be used at their discretion as time permitted. Informal caregivers also described the value of PHIM system simplicity: *“...because when I sat down last night I have the list on the back of an envelope. So, I only must think once every two weeks.”*

On the other hand, informal caregivers described how the PHIM process could be repetitive and tedious or lacked dynamic just-in-time support:

“It takes time to mark out and redo the things. As I said, the calendar should be updated and changed and if I forget to pick up a card and put it by the phone I may not have the right number at the right time.”

3.3.2. Advantages of CARE Kit for PHIM

CARE Kit users reported how CARE Kit served as an educational roadmap – a means of becoming aware of and planning for future caregiving duties. For example, one informal caregiver realized she would require the care recipient’s birth certificate for end-of-life planning. She proactively contacted other family members to acquire it and plan a funeral. Informal caregivers described qualities that made CARE Kit and other PHIM tools helpful for managing cognitive demands and reducing reliance on memory: customizability, including being able to personalize and add content; tangibility; duplicability; and portability for everyday use:

“Customizing is huge for me. Being able to put the list of contacts and I could then take this out and print it for family and friends, family physicians and oncologists, and anybody who was able to do anything for the kids was huge... Being able to add other pages of things that had nothing to do with the CARE Kit. Being able to add a section for my kids was invaluable. To be able to keep all the records for my husband was important.”

All caregivers who used the CARE Kit noted its usefulness for emergency management, because it consolidated in a central location many types of information that might otherwise be difficult to remember or locate in an unplanned moment of need:

“It is a one-stop shop. In a moment of crisis, you don't think of all the ten thousand answers you have to provide to all the doctors and nurses or anybody who wanders into the room, to the kids and grandkids. I know a person who was hit by a car, her husband was killed,

she was in coma for 6 weeks, how do we pay the bills? Do you find the checkbook and make sure we keep the lights on in the house? That is all the things we have to think about. It is difficult to do it in the moment.”

According to informal caregivers, the CARE Kit offered unique advantages for emotional support. For example, sections of the CARE Kit encouraged informal caregivers to engage in emotionally difficult topics, including end-of-life planning. For some, the CARE Kit helped focus on the pragmatic rather than emotional aspects of these topics:

“That personal property memorandum, that is good. And like “what is your legacy”? Someday I will be writing their obituary, I want to write what they are. I want a good representation of that. Probably very hard to write when you are grieving. I felt like that is like a nice preparation.”

Furthermore, having a PHIM system reassured informal caregivers that they were fulfilling their caregiving responsibilities by becoming more aware of caregiving basics and planning for the future.

Formal caregivers reported the following advantages of the CARE Kit:

- An easy to access and complete information repository (a “*loved one’s bible*”);
- A conversation starter for starting “*dramatic, intense, uncomfortable, and awkward*” conversations, such as those about end-of-life;
- A “*guidebook, an educational tool*” to inform current caregiving and anticipate future needs; and
- A communication tool (“*...so they can mention that to the doctor, maybe the medication is wrong but they know that they can track that in the Kit*”).

3.3.3. *Challenges of CARE Kit*

While some caregivers reported how CARE Kit facilitated PHIM and was easy to use, CARE Kit was universally usable for all caregivers or all tasks. One PHIM challenge, especially common among those caring for a person with dementia, was adopting PHIM strategies proactively, before the care recipient's decline or a medical emergency. For example, informal caregivers described being unprepared for record keeping tasks and that care recipients' own records were also imperfect in the time leading up to their diagnosis, when they had already begun to experience cognitive impairments.

Informal caregivers who used CARE Kit partially or not at all attributed their usage levels to being a long-term caregiver and having a PHIM in use before being introduced to CARE Kit or having adopted the care recipient's information management system when they suddenly became a caregiver. Infrequent users also reported challenges with unclear instructions and feeling intimidated by the amount of information to be compiled. Those who used CARE Kit fully, on the other hand, had difficulties finding specific information to incorporate into the CARE Kit, for example, related to legal and end-of-life sections. They also experienced problems with legibility of handwritten notes and portability of the CARE Kit binder as its size increased. Another limitation had to do with accommodating change over time, for example, the lack of forms customized to different points of disease progression or a way to document changing self-care abilities and associated care plans. Related to this, informal caregivers described that paper documents posed challenges to accurate updating of CARE Kit contents and assessing accuracy when multiple caregivers were involved:

“What would help me as a secondary caregiver is that if I was confident in the information I had. I would not be confident about the information from a paper CARE Kit on the big stuff - medication and dosage.”

All participants mentioned that a physical PHIM system-imposed challenges including privacy, security, and access, for example, having updated versions in both the care recipient’s and informal caregiver’s homes. One informal caregiver summed this up: *“If you forget it anywhere, you have a problem on your hands.”*

Another informal caregiver more generally discussed the disadvantage of using a paper system compared to digital technologies:

“You have to make sure that it is easy - take a picture and upload or upload a link or you cut and paste or something along on those lines. The CARE Kit is for the generation of my parents which is paper, which is handwritten. But I’m from the generation who will be caregiving very quickly... I’m sitting in a doctor’s office, he gives a new medication, I could hit a new button, update it, take a picture of the prescription and send it, change things on my phone on an app. It needs to be easier for me to do in the moment.”

In addition to difficulties with PHIM systems in general and CARE Kit specifically, several participants described that when they first began their caregiver role, they were surprised by the information they were missing. Although the caregivers we interviewed had developed routines and described robust strategies for PHIM, many recalled earlier times when they had struggled with the gathering, management, and sharing of information. This struggle was particularly salient among those managing highly stressful caregiving situations, such as caring for a person with dementia.

4. DISCUSSION

Our study examined informal caregivers' PHIM practices and their use and perceptions of PHIM systems, including the paper-based CARE Kit distributed by an adult day service provider, *Joy's House*. Findings included the structuring of PHIM practices around information input (acquiring, integrating); processing (maintenance and updating) and use (for care and decision making); and output (sharing and communicating with others). We note that this input-process-output cycle was repeated many times, especially as conditions changed or healthcare professionals modified the plan of care. Also noteworthy is the finding that PHIM practice involved healthcare professionals, who provided input into the PHIM system and received information from the PHIM system during planned and unplanned healthcare encounters.

4.1. Caregiver health information management (CHIM) implications

We identified a process that to our knowledge has not been formally described in the PHIM literature: caregiver health information management (CHIM). CHIM is a special case of PHIM in which the primary actor is the informal caregiver or network of informal caregivers who manage a care recipient's health information. CHIM involves: 1) information *acquisition and integration* across multiple sources and records; 2) information *maintenance, updating, and use* over time; and 3) information *sharing and communication* with healthcare professionals and other family caregivers. All of this is done in support of everyday care for the care recipient and health-related decision-making. Four broad implications can be drawn from the findings to inform future research and practice on CHIM.

First, CHIM involves supplementing health information with other information management required by individuals in daily life, conceptualized by others as life information management [24,42]. Indeed, we found that the distinction between so-called medical and personal information

was in some cases artificial, for example, when planning one's calendar. CHIM requires information integration as informal caregivers are responsible for life information management of themselves as well as of care recipients. At times there are multiple caregivers, care recipients (e.g., an adult child caring for two parents), and health systems producing information. Long-term primary caregivers appear able to both synthesize information and manage separation between personal and care-recipient records. Informal caregivers exhibited an affinity to continue using and if possible, incorporating new information, into their existing information management systems. This desire to add rather than subtract was somewhat paradoxical given several mentions of being overwhelmed by information. It is possible that the most desirable solution is one that integrates disparate systems rather than simply adds information to the multiple personal and health-related systems one already uses (e.g., calendar, PHR system, educational materials, banking system). The goal may be to reduce information chaos, rather than simply adding or eliminating information. Information chaos has been defined in the context of healthcare delivery as information overload, information underload, information scatter, information conflict, and erroneous information [43].

Second, when possible, informal caregivers retrieved, synthesized, and shared the least amount of information required to accomplish situational tasks such as communication and decision-making. A major challenge of PHIM reported by all participants was synthesizing information from multiple sources and summarizing it to another individual as appropriate to the circumstances. Merely storing and presenting stored information is inadequate to support CHIM [44]. More is needed in terms of summary visualization, sorted or filtered information retrieval, and situation-appropriate, just-in-time decision support. An additional support need is for ascertaining information accuracy, validating accurate data, and suppressing inaccurate or outdated data. This should have implications for the design of future PHR systems, especially given the surprising

finding that none of the caregivers in our study were using available PHR systems to address their PHIM needs.

Third, CHIM needs to be addressed during education and other interventions as a key part of informal caregivers' knowledge needs. Most work on informal caregiver knowledge needs focuses on symptom management, knowledge about disease, observations of daily living, and communication [14,45,46]. However, participants in this study found it challenging to locate, update and otherwise manage required information. CHIM as a process may therefore require education, training, and supporting artifacts such as templates to guide informal caregivers in planning their caregiving journey and making contingency decisions. For dementia caregivers, education and assistance planning for future decision making and negotiation of agency with care recipients can contribute to "assisted autonomy" [47] for persons with dementia. As suggested by the participants, by becoming aware of and beginning CHIM early in the caregiving journey, caregivers can proactively reduce inconsistencies in information.

Fourth, the overhead of accessing, organizing, updating, and retrieving information is often "invisible" or "opaque" and requires efficient management of information [48, 49]. CHIM may be neglected or underappreciated, as is the case with other examples of invisible work, or effortful work that is taken for granted by those who do not perform it [25,50]. We also note the added emotional burden of making decisions on behalf of care recipients. Overall, there is a need to make both informal caregivers and other stakeholders aware of the tremendous value and cost of CHIM, as well as the need to make it more efficient and effective. Toward this end, we next present study implications for the design of IT to support CHIM.

4.2. Design implications for CHIM IT

Our findings have implications for design of IT or other tools to support CHIM. Table 4 presents functional and non-functional requirements developed based on an analysis of study findings. Although most design specifications for PHIM could be readily applied to CHIM, we suggest that communication and scheduling should be the core functionalities of such a system. Caregivers should be able to regularly receive and document into the system any updates or changes in information such as care recipients' abilities and diagnosis. A CHIM tool should retrieve, synthesize, and share this information from multiple sources with caregivers and other parties to aid decision making and transitions of care. Providing such structures (e.g., templates and workflows) specific to care recipients' diagnosis might still require expert intervention (e.g., from an elder care advocate) and may not be currently achievable solely through technological interventions.

The requirements in Table 4 are written in a manner agnostic to the tools that could be designed to meet them. Indeed, the requirements could be implemented and supported by digital, paper-based, or hybrid digital-paper systems. Digital solutions have the advantage of flexibility across multiple platforms including multifunctional platforms such as a mobile device with the capability to simultaneously fulfill data collection, data management, and secure communication needs. Digital solutions also offer large storage space, automated timestamping, and version control to support archiving as well as online accounts management for concurrent access by multiple users with unique access and editing rights. In contrast, paper solutions can offer portability and flexibility for note-taking and duplication in any circumstance, including emergency situations. Paper is also a familiar artifact and its tangibility can increase ease of use, serve as a reminder, and facilitate collaborative activity in which multiple individuals can be,

literally, “on the same page.” In Figure 1, we show how the requirements from Table 4 could be implemented using features of a paper-based or digital system. Both kinds of systems can have the same features (e.g., a Summary or Information Board), even though they would be designed differently depending on the platform (paper binder, web, mobile app); other features (e.g., Discussion Board) are only possible using a digital platform. However, it should be clear from Figure 1 that there are many ways to achieve the requirements of a CHIM supporting system.

A potential hybrid concept for CHIM IT is what our team calls “medium-tech” solutions. Medium-tech products combine the affordances, personalization, and ease of familiar “low-tech” physical objects (paper, push buttons and dials, household objects or appliances) with sensors, circuitry, network connectivity, and other “high-tech” objects that can be embedded to provide digital benefits without the intimidation, disruption, or access issues of conventional software options (e.g., apps or websites). A simple example of this is the use of paper circuits and LED lights to enhance paper or cloth products [51].

4.3. Study limitations and future work

All participants were female, associated with a single adult day service, and living in the same geographic region. Few used digital tools for PHIM, although not always from lack of their availability. Race, education, income, and other factors that may affect PHIM practice and tool use were not recorded. It is also possible that the small volunteer sample of informal caregivers resulted in us interviewing individuals who were more organized, proactive, or conscientious than non-participating counterparts. We note that nevertheless the caregivers in our sample struggled with PHIM, although perhaps not to the extent that others might. Taken together, the above sample characteristics may limit generalizability to the broader population of informal caregivers. However, the goal of the study was not to produce generalizable results but rather to explore the phenomenon of informal caregivers managing health information – i.e., CHIM. The small sample size was also appropriate to this goal. Future work evaluating the transferability of our findings, estimating the population prevalence of CHIM processes, and testing group differences related to CHIM will require larger and more heterogeneous samples.

We note this study's cross-sectional design, which, coupled with the small sample size, made it difficult to draw conclusions about how information needs and practices change over time. One could hypothesize, for example, that those newer to caregiving have vastly different needs compared to established caregivers or that caregiver PHIM practices become more routinized and easier to perform over time. The generation and testing of hypotheses related to PHIM over time should be the subject of future research.

Interviews with specific probes about using the CARE Kit provided a way to understand actual PHIM practices, but this method is susceptible to bias from self-report including incorrect or impartial recall and the tendency to present oneself in a positive light. Of note, there may have been risks related to CARE Kit use, such as privacy and disclosure risks, which may not have been known to or reported by research participants. Furthermore, some informal caregivers used the CARE Kit partially or not at all, but we were able to learn about these caregivers' reasons for non-use as well as probe about alternative approaches to PHIM. Formal caregivers provided insight into the CARE Kit artifact itself and ideal PHIM practices but less so into informal caregivers' actual PHIM practices. Related to assessing CARE Kit as part of the study, we note the CARE Kit is a unique artifact because it was initially designed for Joy's House clients with attention to their specific needs and refined over time based on client feedback. Future work could examine the use of CARE Kit by caregivers not affiliated with Joy's House or the use of more broadly available tools (e.g., patient portals, <http://www.planyourlifespan.org/>) not designed for a specific local population.

A future research direction is to design and test health IT based on the requirements presented in Section 4.2. The work presented here has been used by our team to design the first set of low-fidelity prototypes for such a system. Future work will include participatory design to refine prototypes and design specifications [52] followed by usability testing, redesign, and eventually field testing.

5. CONCLUSION

We analyzed interviews with informal and formal caregivers and examined their use of largely paper-based artifacts in order to study informal caregiver PHIM practices. In addition to a better understanding of these practices and the specific tools involved, we learned about challenges and

requirements for effective PHIM in informal caregiving. This work lays the path for future IT design and development toward more empowered and effective informal caregiving [53].

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Authors' contributions

RJH directed the study and manuscript preparation and revision. The manuscript was primarily written and revised by RJH and YK. RJH, YK, LHC, and NRF participated in study planning and design. YK and RJH developed the research materials and YK performed data collection. RJH, YK, TP, and PK performed data analysis. All authors contributed to editing the manuscript and gave their final approval.

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Conflicts of interest

We report no conflict of interest

The authors declare no conflict of interest.

Contributions statement

RJH directed the study and manuscript preparation. The manuscript was primarily written by RJH and YK. RJH, YK, LHC, and NRF participated in study planning and design. YK and RJH developed the research materials and YK performed data collection. RJH, YK, TP, and PK performed data analysis. All authors contributed to editing the manuscript and gave their final approval.

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APPENDIX

A. Interview protocol for Informal Caregivers

Initial Questions

1. Please tell us about your caregiving responsibilities.
 - a. How long have you been a caregiver?
 - b. Did your loved one's abilities change over this period?
 - c. How did your responsibilities change with their abilities?
2. Does anybody else help you with caregiving?
 - d. How do you share responsibilities?

Initiation

We are studying how the CARE-Kit is currently used and how it could be made easier to use and share. We'd like to know the story of your CARE-Kit. Could you please tell us how you started using the care-kit and what role the CARE-Kit plays in your caregiving?

Questioning Phase

Before any questions about the narrative, make sure the following structure is covered as part of the narrative, else, ask the participants to explain more about <missing> information.

You could use your CARE-Kit to show anything you'd like to show us. (If the participant is not comfortable to show his/her care-kit, use a blank CARE-Kit.)

Use the list below as a checklist as the interview proceeds.

1. How the caregiver collected the information required to assemble the CARE-Kit binder
 - a. who participated in assembling the CARE-Kit
 - b. retrieving information
 - c. advantages and areas of improvement
 - d. challenges and strategies to overcome challenges
2. How long did it take for you to put together the most important information so you could start using it?
 - a. Laddering: What took the most time?
3. How the CARE-Kit is used on a daily basis,
 - a. retrieving information
 - b. advantages and areas of improvement
 - c. challenges and strategies to overcome challenges
4. How the CARE-Kit is maintained,
 - a. updating information
 - b. advantages and areas of improvement
 - c. challenges and strategies to overcome challenges
5. How access to the CARE-Kit is shared,
 - a. giving access to the required information to other stakeholders when required
 - b. restricting access
 - c. collective updating
 - d. advantages and areas of improvement
 - e. challenges and strategies to overcome challenges
6. Have you changed how the CARE-Kit is arranged?

7. How the usage changed over time?
8. Missing information that is not captured by the existing CARE-Kit
 - a. challenges and strategies to overcome challenges
9. What extra information do you collect in addition to the templates here?
10. Is there anything else you'd like to share with us?

Card Sort

Have you sorted a deck of cards into categories before?

Let's go through how a card sort is done. For example, this a set of cards with names of cities on it. If you asked me to sort the cards into cities I've visited and cities I have not, this is how I'd do it (Sort the cards into two decks). Now, because the deck does not have all the cities I've visited, I'll write down extra cards if required and add them to this deck.

These cards show the various categories of information from the CARE-Kit. You may also use these blank cards to add any extra information you would like to add.

1. Please sort them into three decks of how frequently you update them - low, medium, and high.
2. Please sort them into three decks of how relevant these are in your everyday life - low, medium, and high.
3. Please sort them into decks of <criteria based on the narrative>.

After each sort, you could ask the participant to briefly talk about each deck.

B. Interview protocol for Formal Caregivers

Initial Questions

2. Please tell us about your job responsibilities.
3. Tell us about the process of introducing the CARE-Kit to a caregiver
4. Which functions of your job is the CARE-Kit useful for?

Storytelling

We are studying how the CARE-Kit is currently used and how it could be made easier to use and share. From your experience, what does the lifecycle of a CARE-Kit look like?

Before any questions about the narrative, make sure the following structure is covered as part of the narrative, else, ask the participants to explain more about <missing> information.

Use the list below as a checklist as the interview proceeds.

1. How do you help the caregivers assemble the information?
2. Which aspects of the CARE-Kit are helpful in this process?
3. What are the challenges you encounter in this process?
4. How do you participate in managing the CARE-Kit?
5. What parts of the CARE-Kit do you have access to? How is this access shared?
6. Which aspects of the CARE-Kit are helpful in this process?
7. What are the challenges you encounter in the process of getting access to this information?
8. Is there anything else you'd like to share with us?

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Figure 1. Examples of design features of paper-based or digital tools to fulfill the requirements of a caregiver health information management (CHIM) system.

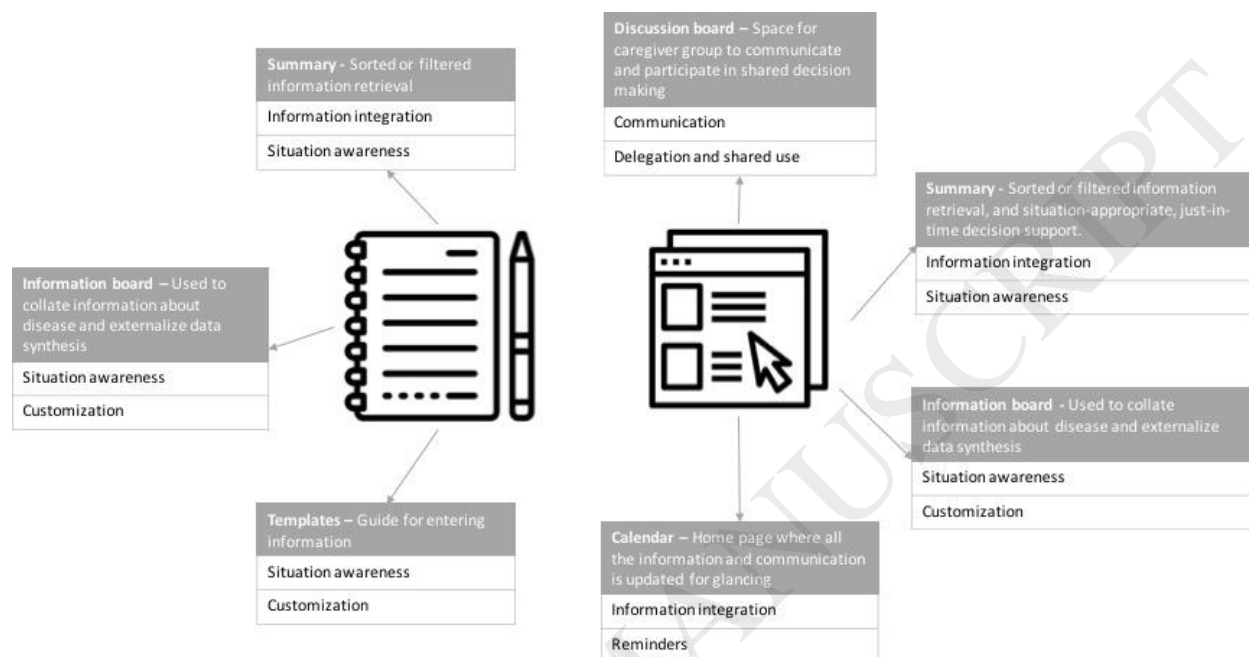


Table 1. Knowledge and information needs of caregivers of persons with dementia

| Category | Specific knowledge and information needs |
|---|--|
| General - disease and caregiving | Knowledge about the disease, caregiving, treatment options and outcomes [10,11,14,15] |
| Diagnosis, prognosis, and treatment | Information about patient's specific condition and disease progression, ongoing treatment; information for medical decision-making [10,11,14,15] |
| Everyday care | Knowledge and information about assisting with ADLs and IADLs, behavioral and psychological symptoms of dementia (BPSD), community resources, and services [10,14–16] |
| Legal and financial planning | Information about assets, insurance, power of attorney, guardianship, and will [10,11,13,15] |
| End-of-life | Information for advanced care planning and directives, funeral planning, and obituary [12,15] |
| Communication with family and service providers | Information transfer regarding medical, daily care, and disease status to professionals and family, including requests for assistance and services [10,11,13,16] |
| Decision making | Information needed to make decisions about medical care and treatment, legal matters, elder care, living arrangements and driving, and dividing care responsibilities [10] |
| Caregiver self-care | Knowledge on coping with stress and burden, physical health, mental health (depression, anxiety, etc.), and self-care assistance [11,16] |

ADLs = activities of daily living; IADLs = instrumental activities of daily living

Table 2. Participant characteristics.

| Informal Caregivers (n=10) | |
|--|-----------------|
| Gender of caregiver | |
| Female | 10 (100%) |
| Age of caregiver | |
| 35-44 years | 3 (30%) |
| 45-54 years | 5 (50%) |
| 55-64 years | 1 (10%) |
| 65-74 years | 1 (10%) |
| Care recipient condition | |
| Dementia | 5 (50%) |
| Neurological/psychological | 2 (20%) |
| Other (renal disease, cancer, post-trauma) | 3 (30%) |
| Caregiving experience | |
| Less than 1 year | 2 (20%) |
| 1-3 years | 3 (30%) |
| 3-10 years | 4 (40%) |
| More than 10 years | 1 (10%) |
| CARE Kit use | |
| No usage (used alternate PHIM system) | 3 (30%) |
| Minimal usage (used as auxiliary PHIM system) | 3 (30%) |
| Maximum usage (used as primary PHIM system) | 4 (40%) |
| Formal Caregivers (n=4) | |
| Gender | |
| Female | 4 (100%) |
| Years of experience at Joy's House adult day service, mean (standard deviation, range) | 11 (6.27, 3-18) |

PHIM = Personal health information management

Table 3. Frequency of cards sorted into “high,” “medium,” and “low” frequency of updating.

| Information type | High | Medium | Low |
|--|----------------|----------------|----------------|
| Medical information – general medical information about care-recipient, not diagnosis specific (e.g., blood type, vaccination records) | 7 (78%) | 1 (11%) | 1 (11%) |
| Emergency contact information | 4 (44%) | 3 (33%) | 2 (22%) |
| Diagnosis information – information specific to the diagnosis (e.g., latest reports, appointments, notes) | 4 (44%) | 2 (22%) | 3 (33%) |
| Legal and financial information | 4 (44%) | 4 (44%) | 1 (11%) |
| End of life care – end-of-life planning information (e.g., advance directives, physician’s orders for life sustaining treatment, funeral planning) | 3 (33%) | 4 (44%) | 2 (22%) |
| About your loved one – personal information about care recipient | 3 (33%) | 4 (44%) | 2 (22%) |
| Developing a caregiving plan – information on caregiving needs | 2 (22%) | 2 (22%) | 5 (56%) |
| Household information – about the care recipient’s household | 1 (11%) | 4 (44%) | 4 (44%) |

Bolded values are those $\geq 33\%$. Percentage is based on n=9 informal caregivers who completed the card sort task.

Table 4. Functional and non-functional requirements for caregiver health information management information technology (CHIM IT).

| Requirement | Description |
|---------------------------------------|---|
| <i>Non-functional</i> | |
| Security and privacy | Access to all information should be regulated by the primary informal caregiver. |
| Customization and flexibility | The system should facilitate creating new templates for information specific to the care recipient's diagnosis and caregiving needs. This includes the ability to select or filter situationally pertinent information. |
| Ease of use | The system should be easy to use by accommodating the range of caregivers' PHIM practices and abilities (e.g., digital literacy). |
| Credibility and emotional sensitivity | The system should convey credibility (trustworthiness) and incorporate the sensitivity required to guide a caregiver through emotionally demanding decision making. |
| <i>Functional</i> | |
| Situation awareness | New informal caregivers should be able to understand the caregiving journey in brief and have anticipatory awareness of both immediate and long-term responsibilities and needs. |
| Information integration | Informal caregivers should be able to compile information incrementally through the disease progression, so as to not become overwhelmed. Information should be in one place, to the extent possible. |
| Delegation and shared use | Informal caregivers should be able to delegate tasks such as compiling and updating information. Multiple informal caregivers should be able to concurrently work with, communicate about, and resolve conflicts regarding information in the system in order to provide shared care without redundant effort [9,27]. |
| Updating and maintenance | Informal caregivers should receive prompts to fill in new or missing information and update or otherwise maintain existing information. |
| Archiving and versioning | As information is updated, the system should automatically archive previous documents and allow users to retrieve, compare, and share different documents or versions. No longer relevant information should be easily archived and labeled as obsolete. |

| | |
|----------------------------------|--|
| Communication | Informal caregivers should be able to communicate up-to-date information during planned and unplanned transitions of care between informal caregivers or informal and formal caregivers. Communication should be efficient to initiate and allow a combination of summaries, full reports, and minimum necessary datasets as warranted by the situation. |
| Agency and access to information | Workflows should guide the caregiver through negotiation and documentation of agency with the care recipient. Information access privileges should be adjustable for transitions in caregiving or changes in preferences for agency. |
| Validation | Accuracy of information should be verifiable through source documents and versioning. Each entry or update should be linked to the source of information (notes, copy of document, etc.) and inconsistencies noted. |

C. Glossary of abbreviated terms

| | |
|-------|---|
| ADLs | Activities of daily living |
| AHRQ | Agency for Healthcare Research and Quality |
| BPSD | Behavioral and psychological symptoms of dementia |
| CHIM | Caregiver health information management |
| IADLs | Instrumental activities of daily living |
| IRB | Institutional Review Board |
| IT | Information technology |
| PHIM | Personal health information management |
| PHR | Personal health records |