

# Transitions of Care: A Patient-Centered Perspective of Health Information Systems That Support Post-Acute Care

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**Abstract** In this article we discuss the implications of a few critical drawbacks associated with the present state of Long-term and Post-Acute Care processes. This is discussed in some detail using a hypothetical example. Using this example the authors identify some of the key design challenges in developing these systems. This is followed by a discussion on future research directions and necessary developments in the design and implementation of Long-term and Post-Acute Care systems.

**Keywords:** Technology for post-acute care, electronic health records, remote care technologies, health information systems, and interoperability

## 1. Introduction

Long-term and Post-Acute Care (LTPAC) refers to a range of medical care services and technologies that support patient recovery from illness to the continued management of a chronic condition or disability. While LTPAC patients are often elderly, LTPAC services are also provided to younger patients with disabilities (HealthIT.gov, 2013b). LTPAC encompasses a wide range of services from skilled nursing services provided by specialty hospitals and nursing homes to home health and community-based services. Nearly forty percent of all Medicare beneficiaries discharged from hospitals go on to receive post-acute care (Anderson & Wiener, 2015). These transitions across acute, post-acute, and long-term care settings are common and can be economically detrimental to the healthcare consumer (Bates, 2015). According to the Medicare Payment Advisory Commission (MedPAC), Medicare's payments to LTPAC providers was \$59 billion in 2013, which was more than double of the expenditure in 2001 (Bowles *et al.*, 2015). In spite of this, nearly 16% of LTPAC beneficiaries are readmitted to the hospital within 30 days (Bates, 2015). This is partially due to a lack of care coordination in patients' transition between different LTPAC providers. For instance, one study found 60% of medication errors occur during times of transition (Bates, 2015).

Given this increase in LTPAC expenditures and concerns about continuity of care, the United States House of Representatives passed the Improving Medicare Post-Acute Care Transformation Act of 2014 (IMPACT Act) requiring long-term care hospitals, skilled nursing facilities home health agencies, and

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inpatient rehabilitation facilities to standardize the reporting of patient assessment data and to ensure interoperability so that the data can be shared seamlessly between LTPAC providers (CMS.gov, 2015). Interoperable health information systems can help to improve not only the continuity of care for patients, but also improve patient outcomes (Dykes *et al.*, 2014). However, in practice, research on the design, implementation, and integration of health information systems tends to focus more on supporting health services associated with episodic, inpatient, acute, or ambulatory care (Gurupur & Tanik, 2012). In contrast, very little emphasis has been placed on health information systems that support patients after they have been discharged from a medical facility and transitioned into LTPAC. Our position is that the LTPAC sector poses unique design challenges regarding the statutory regulations, usability issues, integration, and interoperability considerations for health information systems that support LTPAC patients and providers.

In this paper, we adapt a case study approach to illustrate some of these unique challenges by narrating an in-depth patient journey (HealthIT.gov, 2015) through the various transitions of LTPAC care. Using the Case Study Method by R. Lin, we have taken into consideration the chose a case study that best illuminates the complexities of the LTPAC industry (Lin, 2004). Therefore, we use an amalgamation of actual patient experiences, as observed in the acute and post-acute industry, to highlight the complex myriad of services and systems that patients and/or providers may leverage to support LTPAC care, reduce readmission rates, and improve long-term patient health outcomes. We also provide key insights into the complexities of the LTPAC industry by highlighting some of the nuances associated with LTPAC services, transitions between services, and the systems that support them.

By focusing on a patient-centered perspective of LTPAC, this paper emphasizes the broader spectrum of total patient care and is able to pinpoint some of the key challenges for designing and implementing health information systems that support LTPAC patients and providers through these transitions of care.

## **2. Background: Health Information Systems for LTPAC**

For LTPAC, effective health information systems include, not only interoperable Electronic Health Record (EHR) systems, but also health information technology (health IT) enabled care coordination, such as remote monitoring or tele-monitoring devices that support patient care in the home (Anderson & Wiener, 2015). These health information systems improve patient care and help to create a person-centered healthcare infrastructure to empower patients, families, and caregivers to communicate and engage in informed decision making (HealthIT.gov, 2013a). Using health information systems to improve patient care, especially of older adults, is a growing need and has been spurred on by recent federal policies such as the Health Information Technology for Economic and Clinical Health (HITECH) Act (HealthIT.gov, 2013b). The use of health information systems among patients and providers in the LTPAC settings is crucial not only for the achieving interoperability, but also to improve care delivery and reduce the cost of care (LTPAC HIT, 2012).

While the diffusion of electronic health record technology has increased rapidly for acute-care hospitals and ambulatory care, adoption among LTPAC providers has remained slow (MedPAC, 2015). This is partially due to the fact that federal incentive programs, such as the Medicare and Medicaid EHR Incentive program, did not include LTPAC providers (HealthIT.gov, 2013a). Further, research specifically in the area of health information systems for LTPAC is lacking. For instance, there are a number of studies focused on assistive technologies that can be used in a residential setting (Cortelyou-Ward *et al.*, 2012; Pardue *et al.*, 2014), but these studies are generally not embedded in the context of LTPAC creating a disconnect between design and actual use. For example, studies have shown that LTPAC patients experience lack of information at discharge and feel excluded from management decisions made by providers about their care (Parks, 2015). In addition, there is a need for improved health information exchange efficiency between the LTPAC providers and pharmacies, attending physicians, and during transitions of care (Sanger *et al.*, 2014).

A potential solution to this problem would be the adoption of Longitudinal Care Plans (LCPs) that reflect patients' preferences and disease treatment goals, which would be comprised of structured data to

allow for seamless integration into all electronic systems associated with a patient's LTPAC plan to support the coordination of care (LTPAC HIT, 2012). The use of patient centered applications and LCPs can help improve communication, coordination, and the patient experience. Yet, LTPAC have a long way to go before this type of solution is a viable reality. To encourage progress toward this direction, IMPACT Act, calls for patient assessment data be standardized to enable providers to facilitate coordinated care in hopes for better patient outcomes (CMS.gov, 2015). Therefore, the goal of this paper is to fill the gap in the current research by contextualizing health information systems within the LTPAC industry by way of an in-depth case study to showcase some of the key design and implementation challenges that should be addressed in future research.

### 3. Case Study Overview

The following case study was developed as a way to illustrate a patient's journey as she transitions from an emergency hospital admission to post-acute care. While Mabel, the patient discussed in this case study, is a fictitious character, her story represents an accurate portrayal of multiple patients' actual experiences in LTPAC, as witnessed by the first author of this paper. Some details may have been altered or contrived in order to protect patient identities, improve the flow of the narrative, or to emphasize the focus on different LTPAC services and systems.

#### 3.1. Introducing Mabel

Mabel Jones is an 80 year old female living in a small ranch-style home in Central Florida. She has no children and her husband died two years earlier. She has no family but receives some degree of support from her neighbors and members of her church. Mabel's financial resources are limited. The minimal monthly income from her Social Security and pension leaves little for savings. Mabel has Medicare and should qualify for Medicaid but she does not know how to apply.

Mabel is mentally sharp but physically small and frail with a history of falls. She also suffers from diabetes, Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), and does not maintain a healthy diet. Mabel has a Primary Care Physician (PCP) but has not had a check-up in two years.

#### 3.2. Mabel's acute hospitalization

A neighbor finds Mabel on the floor of her home and calls 911. Mabel is sent to a nearby hospital, which will be addressed as "Riverside," (for this manuscript) where she is diagnosed with a hip fracture. Surgery is carried out to repair the hip but Mabel is going to require extensive rehabilitation. Despite this, Mabel refuses to go to a skilled nursing facility for rehabilitation. Mabel is recovering well from surgery, but she has a long way to go before she can enjoy the independence she once enjoyed.

Prior to hospital discharge, Mabel is assigned a hospital case manager, Bridget. Bridget is very concerned about Mabel's adamancy about going home right away. Post operatively, Mabel's mobility is now limited and her risk of future falls is even higher. Mabel's home is not conducive to her projected recovery needs as a slippery fall out of the bathtub after a shower was the reason Mabel ended up at the hospital in the first place. Additionally, Bridget is concerned about how Mabel will manage her chronic conditions during her convalescence without professional help. These concerns, combined with Mabel's history of falls, make her a very poor candidate for continuing living in a private residence without being accompanied by a caregiver. Bridget contacts Jessica who will be Mabel's Care Navigator to help coordinate a sensible discharge plan.

*LTPAC Insight: Care navigators are either masters-prepared social workers (MSW) or registered nurses (RN). They are well-versed on services available not only through the health system but also those provided by various agencies and organizations in the community. Mabel's health system has partnered with a large university in town to create a social work field unit staffed*

by graduate students who help to coordinate the discharge plan and monitor patients for up to 90 days post discharge. This program has been documented to help reduce readmissions, is a strong patient satisfier for those who elect the service, provides a valuable educational experience for students, and can also set the stage for future employment with the hospital. This program is considered state-of-the-art as most hospital systems do not provide a single point-of-contact to manage a patients' LTPAC plan.

Together, Bridget and Jessica focus on creating a discharge plan that meets Mabel's needs for a safe recovery and that also meets Mabel's goals concerning her desired quality of life.

### 3.3. Mabel's discharge plan

One of the first challenges with Mabel's discharge plan is that she refuses to go to a rehabilitation facility.

***LTPAC Insight:** This particular health system owns a 60 bed skilled nursing facility (SNF) located on their campus. A SNF is designed to care for both short and long term patients. These facilities have comprehensive rehabilitation programs primarily designed for short term patients (20-25 day average length of stay). Reimbursement is typically covered by Medicare, Insurance, Medicaid and in some cases Veterans Administration (VA) benefits. This particular SNF specializes in the care of orthopedic patients, has a gym, and features a world class rehabilitation program. The facility also has large private rooms complete with private showers, large flat screen TV's, and a sofa couch that can accommodate visitors during the day and those that might want to sleep overnight. Most facilities only offer semi-private rooms. This facility can also provide outpatient services for patients requiring additional therapy post discharge.*

***LTPAC Insight:** LTPAC facilities, and thus their health information systems, often have to address unique challenges associated with meeting patients' quality of life concerns that may otherwise be irrelevant to their medical conditions.*

Jessica arranges a virtual tour of the facility, including the room planned for Mabel. With her laptop in Mabel's hospital room, Jessica makes a live video connection with Hakim at the SNF facility. Utilizing an I-Pad, Hakim tours Mabel around the facility ending at the room reserved for her. After the virtual tour, Mabel agrees to go to the rehabilitation facility upon discharge.

***LTPAC Insight:** Since LTPAC facilities are often chosen by a patient and their families based on personal preferences, such as distance from the patient's home or proximity to family, LTPAC providers like SNF's benefit from having technology in place to enable virtual tours to familiarize patients with the amenities provided by that particular location. In this case, it would have been a hardship for Mabel to travel to the facility herself because of her limited mobility and lack of family support.*

Jessica also works with Bridget from hospital to get the discharge orders from Mabel's attending doctor. Bridget sends the doctor's orders for the skilled nursing services electronically to the SNF from Riverside's EHR system to the SNF's EHR system. The orders include specific information for Mabel's physical rehabilitation, her current list of medications, and her diet due to her chronic health conditions (e.g., Diabetes and CHF). Bridget also prints Mabel's extended medical history and gives it to Mabel to bring with her to the SNF. Before Mabel leaves the hospital, Jessica gets Mabel to agree to complete an application for Medicaid and that information is sent via email to Hakim.

***LTPAC Insight:** While some LTPAC organizations leverage EHR systems, the systems are often very specific to the line of service that is being provided (e.g., rehabilitation services). Additionally, hospitals, SNFs, home health services, and assisted living health information systems all have very limited interfaces that integrate between the respective systems, essentially making each system its own silo. Therefore, continuity of care also suffers as the process of transferring*

*pertinent patient information is often done manually through phone calls, faxes, email, and even through paper documents.*

The following day Mabel is admitted into the SNF and greeted by Gary, the SNF admissions coordinator. Mabel hands Gary the print outs from the hospital and takes Mabel to the central office. Mabel then completes her SNF admissions paperwork prior to being shown to her room.

***LTPAC Insight:*** *The Minimum Data Set (MDS) is a federal assessment form required for all patients admitted to a SNF. It is a living, breathing document that remains with the patient throughout their stay at the SNF. This tool evaluates patient outcome and drives SNF reimbursement. Most SNF EHRs have integrated billing components that take data from the MDS and incorporate that information on the appropriate billing forms. Although all patients must have an MDS, only Medicare reimbursement is impacted by this data. Insurance, Medicaid, VA and Private Pay reimbursement are not derived from MDS.*

Following the doctor's discharge orders, Mabel receives intensive physical therapy each day and eats a low sugar, low sodium diet at the SNF. After a couple of weeks, she is able to walk unassisted with a walker, though her pace is slower than what it once was. With her new diet, she says that she "feels wonderful" and "has more energy than I have had in years." Mabel has also made quite a few friends at the SNF, fellow patients and staff, who have all become quite fond of Mabel.

### **3.4. Mabel's preparation to return home**

The average rehabilitation stay for patients with Mabel's clinical history is between 20 to 25 days. After fifteen days of rehabilitation, Mabel is approaching her discharge date. She has adapted well to the facility but both are eager to get back home. Hakim and Ricardo, the SNF's Social Worker, agree that Mabel will almost assuredly need Skilled Home Health Services to continue her rehabilitation at home. Ricardo speaks with Mabel, and she agrees to the services and asks Ricardo to pick an agency for her.

***LTPAC Insight:*** *Riverside also owns a large skilled and non-skilled home health agency ("Transitions") with capacity to care for patients who are returning home. The skilled services are provided under the order of a physician. This agency provides a free assessment of the patient's home by a physical therapist (PT) or occupational therapist (OT) to facilitate a more effective transition. Medicare and/or Insurance are the primary payers.*

Ricardo contacts the hospital's medical equipment company OxyCare to see if they would be willing to provide an in-home assessment from one of the PT or OT's provided by Transitions, a home health agency, and they agree. Mabel consents to this after she learns there is no cost to her for the assessment. Mabel and Ricardo coordinate the appointment with Mabel's neighbor, as the assessment will need to be completed prior to Mabel returning home.

***LTPAC Insight:*** *As part of their vertical integration strategy, the health system also owns a durable medical equipment (DME) company called OxyCare featuring a variety of assistive devices which could be deployed to assist Mabel with her recovery. In addition to standard equipment such as walkers, wheelchairs, and 3-1 commodes, the company offers multiple technologically advanced devices to assist patients in their in-home care transition. These include, but are not limited to, medication reminders, notification equipment in case of fall or other incapacitation, and monitors and sensors to track a patient's movements throughout the day. This information is valuable, of course, when documenting a patient's Activities of Daily Living (ADL's) as part of an ongoing effort to evaluate needs and modify the discharge plan when necessary.*

After OxyCare and Transitions complete the assessment of Mabel's home, they report back to Ricardo. Mabel's home is the same house she spent the last 25 years with her husband and is not suited to her current needs as an 80 year old woman who is recovering from a hip fracture. For instance, there are no grab bars to assist Mabel getting in and out of the shower or off of the toilet, which is why she slipped on

the wet tile bathroom floor. Therefore, OxyCare recommends that these be installed before Mabel returns home. They also suggest the use of an emergency call pendant, so that Mabel can get assistance immediately should she fall again. Mabel is on several new medications and does not follow her nutritional plan without prompting. Therefore, OxyCare also suggests that Mabel take advantage of their medication reminder system and behavioral tracking sensor system to ensure Mabel continues with her new diet. While the equipment is not overly expensive, OxyCare estimates that the total cost would be about \$500 to install the grab bars and purchase the monitoring equipment. The ongoing monthly monitoring would run about \$30.00.

**LTPAC Insight:** *There is a large market of assistive, in-home technologies available to LTPAC patients. However, Medicare and Medicaid rarely provide full coverage for such technologies. Thus, skilled home health services must work with patients individually to determine the most appropriate combination of technologies to support positive patient outcomes given the cost.*

Ricardo communicates these recommendations to Mabel. Mabel is not opposed to OxyCare installing the grab bars in her bathroom, as she does not want to have another fall. Yet, she is hesitant about using the more advanced monitoring technologies such as the medication reminder system and behavioral tracking sensor system. At 80 years old, Mabel does not own a cell phone and is not interested in learning how “new-fangled” technology gadgets work. Additionally, she does not have the money to pay for any of the equipment.

**LTPAC Insight:** *The HHA “Transitions” has specialized tele-medicine equipment that monitors a patient’s key vital signs on a daily basis that includes Blood Pressure, Oxygen Saturation, Weight and a variety of other key data points to assure the patient’s health is stable. The tele-medicine unit is a self-contained system that can monitor the patient at night, wake them up, and even prompt the patient with simple directions on how to use the unit properly. The data collected by the unit is transferred to the HHA’s HER system on a daily basis.*

Ricardo contacts Jessica, Mabel’s Care Navigator, to update her on the new discharge plan and discuss some of Mabel’s concerns. Jessica submits OxyCare’s proposal to the hospital’s Discharge Support program, including the ongoing monitoring fee for a period of six months. This expenditure makes good business sense to the hospital as it potentially prevents a serious post-operative complication and/or an unnecessary readmission. Therefore, they approve the proposal at no cost to Mabel. Since Mabel likes the idea of “getting something for nothing” and is ready to go home, she agrees to the new discharge plan.

**LTPAC Insight:** *While Medicare will cover many LTPAC services, some tools, such as the specialty DME and assistive hardware are not covered. In some cases, hospitals invest in these technologies on the patient’s behalf to avoid hospital readmissions or other negative patient outcomes, such as falls or untimely deaths. Through the generous support of the community, this particular health system has been able to establish a dedicated Discharge Support Fund which can in certain cases offer additional assistance to patients like Mabel.*

At this point, Ricardo and Jessica review the tentative discharge plan for Mabel. Jessica agrees with the plan and will coordinate Mabel’s discharge from the SNF to skilled home health services when that time comes. During the next week, OxyCare prepares Mabel’s apartment for her homecoming. Forty-eight hours prior to Mabel’s SNF discharge, Ricardo contacts Jessica and briefs her on Mabel’s upcoming discharge and goes over the plan and associated resources for her care at home.

While Jessica will be overseeing the overall discharge planning for Mabel’s return home, she assigns one of the university MSW Interns, Saundra, to make periodic site visits to check on Mabel to provide feedback on Mabel’s progress. Saundra will act as the home health services liaison between Mabel and Transitions while Jessica’s oversight strictly will be from the main office. Saundra will also follow Mabel’s Medicaid application and complete a more detailed financial analysis to see if there are any additional programs which may provide additional assistance for Mabel. Saundra schedules a visit to Mabel’s home within twenty-four hours of her discharge. Saundra will be accompanied on this visit with

a Registered Nurse (RN) who will perform the initial admissions paperwork for Mabel's Home Health recovery.

**LTPAC Insight:** *The Outcome and Assessment Information Set (OASIS) is a federal assessment form required for all patients admitted to a Skilled Home Health Agency (HHA). This tool evaluates patient outcomes and drives the HHA reimbursement rate. Most EHRs for HHAs have an integrated billing component that takes the data from the OASIS and populates the appropriate billing claim forms.*

As Jessica is finalizing Mabel's discharge plan, she realizes that once Mabel gets home, she will not initially be able to drive to follow-up doctor's appointments or to pick up her prescriptions. Because of Mabel's other chronic illnesses, Jessica feels that it is important to monitor Mabel's weight and vital signs on a daily basis once she returns home. Fortunately, Jessica is aware of the health system's tele-medicine "House Call" program and offers the program to Mabel as a medical bridge until home health services are no longer needed. Mabel readily agrees to the plan since she has not been in to see her PCP in over two years.

**LTPAC Insight:** *As part of Riverside's transition services division, there is a House Calls program, staffed with MD's and ARNP's, who can see patients in the comfort of their own home. Coupled with this program is a HIPAA-compliant video technology popularly known as "Tele-Housecalls" to facilitate remote communications with patients and caregivers in the field.*

Mabel is pleased when she is told that Morgan, one of the nurse practitioners who has worked with her in the SNF, will also be her House Call clinician. Mabel feels much better knowing that someone she already knows and trusts will be coordinating her home health services with Transitions. Prior to discharge, Morgan orders the services of a home health physical therapist three days per week along with a home health aide once per week to assist Mabel with bathing. He also prepares the orders for Mabel's medication and modified nutrition plan while Mabel is at home. Because the SNF's EHR system does not talk to the skilled home health services' EHR, Morgan prints out these orders and gives them to Mabel. Morgan reminds Mabel to give these orders directly to Saundra, her home health liaison, so that Saundra can ensure that Mabel continues to follow the discharge plan once Mabel is back in the comfort of her own home. Morgan also demonstrates the tele-medicine technology and explains how an aide will come to Mabel's home and set up a remote video connection with him and any other clinicians involved with Mabel's care.

**LTPAC Insight:** *Transitions, Riverside's HHA, has been an early adopter of tele-medicine technologies that allow clinicians to meet virtually with patients from the comfort of their own homes. Many LTPAC facilities have demonstrated great patient outcomes utilizing this equipment, as well as cost reductions to the providers by having lower cost resources travel to the patient's homes to proactively monitor patients' weight and vital signs (non-emergent). This timely monitoring significantly reduces the risk of an avoidable hospital readmission while at the same time providing effective education for patients on how to best manage their specific chronic conditions. Although the remote visits are currently not billable to patients, they may be in the future. The onsite visits are billable to Medicare with co-payments for the patients.*

At first, Mabel is surprised and upset by the idea of meeting with Morgan using a computer screen. Then, Morgan explains that he will also be conducting occasional visits to Mabel's house, but this technology allows him to meet with Mabel more frequently at no additional cost to Mabel. Jessica also uses the hospital's partnership with GCS Pharmacy to ensure that Mabel has all of her medications prior to discharge. A pharmacist from GCS will consult with Mabel over telephone prior to discharge and her medications will be delivered directly to the SNF facility so that she will have them to take home with her.

**LTPAC Insight:** *The health system has also partnered with a large retail pharmacy (GCS) in a "Medication at Bedside" program. Upon discharge from either the hospital or SNF, a patient's*

*medications can be delivered directly to the bedside in tamper proof containers. As part of the protocol for this program, a Pharmacist interviews the patient prior to discharge to ensure the patient understands the medication plan. They also follow up with the patient 72 hours post discharge to check on the patient's status and answer any questions.*

### **3.5. Mabel's homecoming**

With the help of a wheel-chair transport service (at Mabel's expense), Mabel and Muffin arrive home safely. After being away from home for about a month, the small apartment is dusty, the refrigerator needs to be cleaned out and restocked, and Muffin needs new litter and kibble. Mabel feels like she cannot handle all of these chores on her own and is concerned because she does not have the money to pay for a housekeeper. Fortunately, Sandra visits Mabel's home that evening. Mabel gives Sandra the papers she had gotten from Morgan and the two discuss potential solutions to Mabel's concern. Sandra contacts Jessica who discusses these concerns with Bridget at the hospital. Because the hospital is committed to avoiding patient readmissions, Bridget is able to arrange a non-skilled home health service to come to Mabel's home for the next two weeks. With each visit, the service will spend four hours helping Mabel get her home back into livable condition and assist Mabel with meals and bathing.

*LTPAC Insight: While skilled home health services often include a weekly aide to assist in health-related activities, such as patient bathing and meal preparation, they otherwise provide very limited services for home care. These services do not require a physician order and care giver is typically a non-licensed professional usually a Certified Nursing Assistant or Home Health Aide. These agencies provide services such as light housekeeping, meal preparation, and assistance with activities of daily living, often at the patient's expense. However, to avoid the additional cost of re-hospitalization, some hospitals may invest in these services at their own expense. In this case, the housekeeping services would cost the hospital approximately \$200.*

Sandra calls Mabel the next day to tell her the solution that she was able to work out with Bridget and Jessica. Mabel is appreciative that Sandra was able to take care of this for her, and she also wanted to tell Sandra that she found two additional pieces of paper that Morgan had given her that she was supposed to provide Sandra. However, before she got the chance to mention it, Mabel receives a call-waiting. Mabel switches over to answer it. It is the GCS pharmacist calling seventy-two hours after Mabel returned home to see how Mabel is doing and to make sure she is taking her medications as prescribed. Mabel quickly tells the pharmacist that everything seems to be fine and explains she is on another call. Mabel switches back over to Sandra, but all she hears is a dial tone. "Oh dear," Mabel thought. She has never quite gotten the hang of call-waiting! "Oh well," Mabel thought, "I'll just let her know next time I talk to her."

### **3.6. Mabel's recovery at home**

After a few weeks at home, some of the LTPAC adjustments are working for Mabel while others are not. The grab bars in the bathroom have prevented her from having any new falls. On one occasion, Mabel used the emergency alert pendant when she had a dizzy spell and became faint. The emergency responders arrived quickly and determined that Mabel's blood sugar level had dipped into the mid-40's. They put her on a Dextrose drip to stabilize her blood sugar and reminded her to use her Glucometer to make sure to keep her Diabetes in check.

Mabel admitted that she had forgotten to eat breakfast that day and that she does not use the behavioral tracking technology OxyCare installed earlier that month. OxyCare installed a sensor on Mabel's refrigerator to detect when the door is opened and closed. The sensor is connected wirelessly to a handheld console. The first time Mabel opened her refrigerator after returning home, the console beeped displaying the message, "Hi, Mabel. You just went into your refrigerator. What did you find to eat/drink?" Mabel went over to the console and momentarily picked it up. It seemed like it was prompting her to enter something, but she did not see a keyboard anywhere so that she could type that she had simply gotten a glass of orange juice. She was puzzled that it knew when she was opening and closing her refrigerator!



That was “none of their business,” Mabel thought. She immediately unplugged it and went on with her day.

***LTPAC Insight:** Home monitoring technologies, such as sensors and cameras, can be installed in LTPAC patient’s homes to track their physical movements. This may include opening the refrigerator door, sitting down on the toilet, or other behaviors indicative of daily living. While there are a variety of innovative technologies available to patients at home, they can sometimes be cost prohibitive and often patients are leery of these technologies, especially due to privacy concerns. From the first author’s experience, tele-medicine technology that monitors the patient’s vital signs on a daily basis is generally accepted by patients. However, more invasive monitoring utilizing sensors and cameras can make patients nervous and they often will resist these technologies.*

The tele-medicine unit was the beneficial for Mabel’s long-term recovery. In fact, they saved her life. It turns out that the pieces of paper Mabel had forgotten to give Sandra included her prescription for her Diuretic (needed for her heart condition) and her modified nutrition plan. As a result, once Mabel ran out of the Diuretic pills, she did not bother following-up to get a refill. Without her pill and not following a low sodium diet, fluids began to build up throughout Mabel’s body, causing excessive weight gain. Mabel realized that she was not feeling as well as she had a few weeks before, but she attributed it to “cheating” on her diet. However, when Morgan checked Mabel’s vital signs that were uploaded to the HHA’s EHR from Mabel’s in-home tele-medicine unit, he realized that her blood pressure was elevated and the weight gain was also concerning. Therefore, Morgan promptly sent an aide to Mabel’s home. In addition to giving Mabel a full check-up the aide also double-checked her medications. She uncovered that Mabel had stopped taking her Diuretic and immediately called GCS to get a refill. Mabel asked one of her neighbors to pick it up for her that afternoon. Once Mabel was back on her medication, Morgan said she should see reduced fluid retention. If Mabel does not see this in the next three days, she may have to be readmitted to the hospital.

Morgan also asked Mabel if someone from skilled home health had come to provide her instructions on proper nutrition for keeping her Diabetes and Congestive Heart Failure in check. Mabel was perplexed and informed that Sandra never mentioned that this would happen. Morgan was frustrated and told Mabel that he had written explicit instructions on this. He could not understand why Mabel was so far off from her discharge plan regarding her medications and modified diet. Then, Mabel remembered the two sheets of paper that she had tucked away in her roll-top desk. She brought them to Morgan, and sure enough, there were her Diuretic prescription refill and orders for nutritional consultation. Morgan rewrote these orders and had them faxed directly to Transitions once he got back to the office to ensure that they were uploaded to the skilled home health service’s EHR system.

***LTPAC Insight:** One of the primary services HHA’s are to provide is education and teaching related to the patient’s clinical condition. The purpose of this is to modify behavior so that patients can avoid exacerbating their health status. If this explicitly ordered by the doctor, then the HHA would be considered out of compliance and consequences may occur if an audit is performed or negative patient outcomes are identified.*

Once Mabel was back on her Diuretic, she immediately saw reduced leg swelling and started feeling a little better. After Mabel received the proper training on why it was important for her to maintain a low sugar, low sodium diet, she began to change some of her eating habits. Still, Mabel refused to use the behavioral tracking system, “whatever the heck that was,” so that Transitions could remotely monitor her daily meals and water in-take. She tried to input one of her meals into the system, but she simply could not figure it out. Overall, she felt that it was more of a hassle than what it was worth. Besides, Mabel decided to cancel her Internet services because she rarely used her home computer. Sandra explained that the system needed an Internet connection to be able to upload the data. However, Mabel’s husband had bought the computer and set up the Internet service prior to his death. He was fond of technological

gadgets, whereas Mabel never saw the appeal. Before Mabel injured her hip, she could afford the Internet service. However, now that Mabel has to pay out-of-pocket (the hospital was only willing to pay for two weeks of service) for a weekly housekeeping service because house chores were getting to be too much for her, she just could not justify the additional cost. Otherwise, things were starting to go back to normal.

Because Mabel was still homebound and unable to drive on her own, Transitions re-certified her for another sixty day plan of care and work to help her make some important behavioral changes, such as improving her diet. It is obvious that the behavioral tracking system is not the right solution for Mabel. However, thanks to the medication reminder technology and her relationship with Morgan and the pharmacist at GCS, Mabel has managed her medications well. Mabel made great progress with her home health services and is on her way to recovery. However, now that she is home and alone, Mabel feels lonely at times. During Mabel's stay at the SNF, she had grown close to the Chaplain, Father Vincent. Jessica asks Father Vincent if he could come see Mabel at her home. Father Vincent made regular visits for a couple of months to Mabel's home as part of her LTPAC plan, and Mabel found comfort in his company.

***LTPAC Services:** Understanding the need to provide more than just physical support for their patients, the health system employs non-denominational chaplains and coordinates with local clergy to offer appropriate religious and spiritual resources based on the individual needs and wishes of the patient.*

Apparently Sandra did a great job finding additional support programs for Mabel, including "Aid and Attendance." As it turns out Mabel was a nurse during the Korean War, and based on her limited income and assets, she is eligible to receive up to \$2,500 per month for home health aide services or residence at an assisted living facility. Combining the equity in Mabel's home with the monthly income from Social Security and her small pension, this could potentially qualify Mabel for placement into an assisted living facility at little additional cost should she become unable to remain at her residence. Mabel finds comfort in knowing that her medical team is available when she needs them, so that she can continue to live independently. However, she also misses the community she felt while staying at the SNF. The stress and cost of maintaining the home pushes Mabel to decide to consider the option of assisted living. Mabel calls Jessica to help her assess the available options on assisted living.

***LTPAC Insight:** The health system recently partnered with a large assisted living company (OSHN) that operates a 140 independent living units and 100 assisted living beds at a new facility adjacent to the hospital property. An assisted living facility (ALF) provides Non-Skilled services for long term patients. Care can be supplemented with Skilled Home Health services if certain criteria is met. ALF services are not covered by Medicare. Medicaid, Insurance, and VA benefits vary but most services billed as pure Private Pay.*

Coincidentally, Mabel receives a call from Charlie, a gentleman she met while at the SNF, as she is assessing her options. Charlie had also fallen in the tub and ended up with a hip fracture. Charlie and Mabel spent an hour on the phone catching up. Charlie told Mabel that he decided to go straight from the SNF to OSHN, the health systems' assisted living facility. After his wife passed away a year ago, he also struggled to maintain his family's two-story home. A fall down the stairs has left him permanently in a wheelchair. Charlie described his experience living at OSHN. He has a private room and enjoys playing cards in the evening with the other residence. Mabel is intrigued by Charlie's stories and calls Jessica to set up a tour of the facilities.

***LTPAC Insight:** While patients generally like to remain at home as long as possible, those that do make the decision to move into a Retirement Center or ALF are usually very happy with their choice. The excellent meals, activities and social interaction significantly enhance their quality of life and often extend their lifespan.*

#### 4. Mabel's Golden Years

After visiting OSHN and being reunited with Charlie, Mabel decided to sell her home and move to the assisted living facility. It was indeed cozier and offered more community than being at home alone. Mabel no longer had to worry about keeping her house tidy or paying a service to do it for her. The assisted living facility would also prepare meals for her according to her nutritional needs. To coordinate the transition between skilled home health and the assisted living facility, Jessica contacted Morgan. Morgan prepared the orders for moving Mabel into assisted living. Luckily, the assisted living facility's EHR was equipped to directly receive the orders from Transitions regarding Mabel's medical history, medications, physical therapy, and diet plan. Sandra arranged for the monitoring equipment offered by Transitions to be returned to OxyCare and for the monthly monitoring service to be discontinued. However, at Jessica's recommendation, Mabel will continue to receive the skilled home services for physical therapy and the tele-medicine services with Morgan. The assisted living facility does not have an attending doctor, so it makes sense for Mabel to maintain this continuity of care.

***LTPAC Insight:** Even though a LTPAC patient has transitioned to assisted living, skilled home health services can still be provided at these facilities. While skilled home health services cannot be used in a SNF (it's a duplication of services paid by Medicare) this does not apply in Assisted Living. If a patient qualifies for skilled home health services, these services are often utilized in the Assisted Living environment.*

Mabel moves into the assisted living facility and enjoys making new friends. Her room is modest but more than meets her current needs. However, after six months at OSHN, Mabel and Charlie have grown quite close and decide they could save money by sharing Mabel's unit.

#### 5. Discussion

The story highlights a number of unique characteristics about the LTPAC environment that current research on health information systems has not taken into account. Importantly, the case study illustrates the complex transitions of care LTPAC patients experience as they move between LTPAC facilities and their related systems. Mabel's story represents only one plausible scenario of transitioning between LTPAC services and systems but many other potential paths through LTPAC exist. Fig. 1 summarizes the LTPAC facilities discussed in the case study as well as some of the various health information systems associated with each facility.

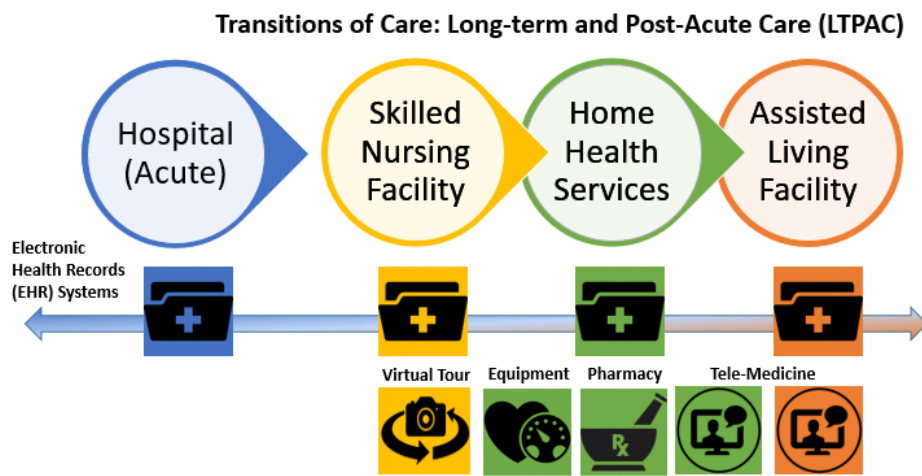


Fig. 1. Summary of the LTPAC Transitions of Care and Related Systems.

As shown in Fig. 1, Mabel's story illustrates a fairly linear path from being admitted to the hospital for an acute hip fracture, rehabilitation in a skilled nursing facility, returning home with home health services, to spending her golden years in an assisted living facility. However, the transitions between these various facilities is often not linear. For example, another fall could have meant a hospital readmission for Mabel. As another example, many patients are unable to take advantage of home health services due to severe health issues and go straight to an assisted living facility. Therefore, there are multiple patient journeys through the LTPAC, and we cannot assume that all patients will follow a path similar to Mabel's. This creates serious implications for the various systems that are leveraged within each of these facilities and how they interact with one another. For example, it is not sufficient for skilled nursing facilities to have an EHR system that integrates with hospitals and home health services; their EHR system would also need to interface with the EHR system for assisted living facilities. This makes the problem of health information systems integration for LTPAC a very complex and challenging one. Given these insights into the LTPAC environment, we will first discuss some of the clinical and policy implications associated with LTPAC services that affect the design of LTPAC health information systems. Here it is imperative to discuss some of the design implications for health information systems that support LTPAC.

### **5.1. Clinical and policy implications**

As Mabel's story illustrates, a patient's journey involves many stakeholders and transitions of care, in particular, and the compounded difficulty of effective navigation between these transitions. Accreditation bodies such as the Joint Commission and licensure agencies such as the Agency for Healthcare Administration and CMS are continuing to focus on quality of care and patient outcomes. Due to this, it is imperative that efficient and effective communication exist between caregivers, physicians, patients and families. As the case demonstrated, payments and reimbursements associated with LTPAC services are fairly complex. As hospitals move towards bundled payment systems, the need to streamline and coordinate care will be crucial for both hospitals and LTPAC providers.

In cases such as Mabel's, elderly patients on limited income are unable to defray some of the costs associated with LTPAC services and health IT systems that could potentially improve patient outcomes. While not all hospitals embrace Discharge Support programs, early adopters of these programs have found significant return on investment over the long term due to improved clinical outcomes and lower rates of re-hospitalization. Additionally, it has been found that patient satisfaction increases when hospitals have a program for discharge support.

Mabel's story also highlights some key statutory regulations and compliance issues for LTPAC providers. For example, when patients transition between LTPAC providers, communication and compliance failures increase the risk of patient injuries and death. In this particular case, Mabel experienced a disruption in the continuity of her care between the SNF and the skilled home health services provided by Transitions because she forgot to give the MSW intern the papers that the Nurse Practitioner provided upon her discharge from the SNF. As a result, Transitions did not comply with the physician's orders to train Mabel on the proper nutrition for her chronic health conditions (causing an emergency visit to Mabel's home for low blood sugar after not eating breakfast). Mabel also did not receive the refill of her Diuretic, which put her at increased risk for Congestive Heart Failure. Even though Mabel was at fault for not providing the necessary paperwork to the MSW intern, it is due to the lack of interoperability between the SNF's EHR and Transitions' EHR because the two systems did not provide a seamless interface.

Finally, measuring and improving patient outcomes is also a unique challenge clinical of the LTPAC industry. Provider reimbursement is increasingly being tied to patient outcomes. LTPAC patients, like Mabel, may be elderly patients who suffer from a number of co-morbidities, or they could be younger individuals dealing with extreme, chronic conditions that range widely. As such, LTPAC providers have to identify the range of relevant patient outcomes for each LTPAC patient, which may vary from patient-to-patient. Additionally, it is difficult to create meaningful, standardized measures for patient outcomes in LTPAC. For example, LTPAC may coincide with end-of-life care and inevitable negative patient

outcomes (e.g., degeneration of a patient's condition or death) that may be justifiable but require in-depth documentation to illustrate their cause. As such, it may be more appropriate for quality measurement to focus on LTPAC patient outcomes that are less clinical, such as activities of daily life, quality of life, and compliance with the doctor's discharge orders (e.g., medications, diet, etc.)

## 5.2. Health information systems implications for LTPAC

One of the lessons learned by studying Mabel's LTPAC care experience is that we currently have a myriad of technologies that can be extremely helpful in a LTPAC scenario. These include the more traditional EHR systems as implemented by each of the LTPAC providers, as well as cutting-edge technologies that facilitate virtual tours, tele-medicine, in-home monitoring services, and more. Mabel's story also illustrates a number of design and implementation challenges associated these health information systems and health IT that support LTPAC.

First, Mabel's transition from the hospital, skilled nursing facility, skilled home health services, and the assisted living facility showcase a crucial problem associated with the silo-effect [14] present between many of the EHR systems of LTPAC providers. While clinically, Mabel's LTPAC plan was reasonable, it was because of the lack of interoperability between the various health information systems that Mabel's LTPAC providers made critical care errors and violated statutory regulations that ultimately resulted in negatively impacting Mabel's care. Even with one, consistent Care Coordinator (i.e., Jessica), Mabel still interacted with multiple LTPAC providers throughout her journey, and the complexity of her LTPAC transitions was too difficult for Mabel to manage on her own. This speaks to the need of health information systems that are designed for interoperability between LTPAC providers' systems as to minimize the burden of coordination of care on both LTPAC providers and patients. This leads to the idea that there is a need for a system of systems (Gurupur & Tanik, 2012) approach where every individual system, as described in the case study, is a part of a bigger, integrated system. Overall, there are two important lessons learnt from this case study:

- a) There exists a silo effect between different components and aspects of the current state of healthcare systems designed for LTPAC
- b) There is a need to develop an integrated systems that coordinates the different elements of the much needed care in terms of LTPAC

Another key insight we can garner from Mabel's case is that these LTPAC systems must encompass more than just clinical information about patients, to include broader objectives such as long-term patient goals and activities of daily living. For instance, the SNF needed to keep up-to-date records regarding Muffin's vet records as a condition of Mabel's stay. All of the LTPAC providers were charged with helping Mabel eat a specified diet ordered by the physician. Additionally, the home health services EHRs would benefit from direct integration with the tele-medicine and behavioral monitoring systems in place at Mabel's home. Even community-based services, such as Father Vincent's regular visits to Mabel's home need to be carefully coordinated as to not negatively affect the quality of living for LTPAC patients like Mabel. Unlike hospital health information systems, which tend to assume the suspension of activities of daily living, long-term, post-acute care must take these types of considerations in a more holistic view of patient health and well-being.

A final challenge for LTPAC health information systems comes from the need to design user-friendly, patient-centered technologies for home use that are trustworthy and secure. Often assistive technologies are used at home without the direct oversight of the LTPAC provider (Agree & Freedman, 2000). It was apparent in Mabel's case that the use of advanced technologies was not a viable solution once she returned home. Mabel was not tech savvy and had privacy concerns related to devices designed to track her behavior. Even when the systems were provided to Mabel free-of-charge, the complexity of the technologies coupled with Mabel's generally dislike of technology remained significant barriers to adoption and use. If investments are being made in assistive technologies, it is imperative that the technologies are designed in a way to meet users' needs and motivate continued use. Otherwise, the investment is of no value. Additionally, certain care needs to be in place that these systems are HIPAA

compliant and secure. As an example, the tele-medicine services that Mabel received would have to be certified for use. Indeed, it is possible that the video tour used by the SNF violated HIPAA compliance if a patient within the SNF came into view of the camera without their explicit consent. Even innocent interactions such as these that are enabled by technology to benefit LTPAC patients should receive a great deal of scrutiny before they are widely implemented. While privacy and security is a paramount concern in all healthcare settings, it can potentially be overlooked in the context of LTPAC, especially when the patient is back in the comfort of their own home. All of these challenges present new directions for future work.

### 5.3. Directions for future research

While considerable amount of research has been conducted in the area of developing new technologies for healthcare the biggest challenge facing healthcare engineers is that of integration and interoperability of these technologies. Development of technology for healthcare must also address the challenge of integrating it with other systems (CMS.gov, 2015) during its inception. A technology or a device that can be helpful without fulfilling the criteria of integration may not fully satiate the need of its invention. Therefore, a design framework (LTPAC HIT, 2012) that is based on the system of systems approach that can be used at during the design of the technology invention could be a critical need that may have to be fulfilled. This is very much true for patients undergoing post-acute care. Some of the key areas of research that the case study indicates can be listed as follows:

- (1). Research on design challenges associated with the interoperability of health care systems associated with post-acute care.
- (2). A study on the use of orchestration and choreography of Web services to develop integrated systems could be critical in achieving interoperability (Bowles, *et al.*, 2015).
- (3). The systems associated with LTPAC must be designed to handle a broader scope of activities.
- (4). These systems must also be designed to conform to the standards of HIPAA compliance while balancing usability and security.
- (5). There is not a great deal of research on the outcomes associated with adopting health information systems and tele-medicine in LTPAC environments, especially in the home. More research needs to be done to confirm that adoption and use of these systems actually improves patient outcomes.

## 6. Conclusion

There has been a commendable improvement in the design and development of health information systems that support remote monitoring, enhanced care planning, medication optimization, and care transitions in post-acute care settings. However, the interoperability and integration of these systems with other levels of care has not yet fully matured. If the concept of payment bundle begins to spill over the edges of the acute care system, LTPAC entities will need to be more clinically integrated with the rest of the healthcare environment. The opportunity, therefore, is to actively engage with providers in the acute care and medical practice arena to create functional networks focused on patient-centered transition services. These systems have been shown to reduce costs, unnecessary emergency room visits, and subsequent admissions to acute care. Therefore, it is important that LTPAC providers have the necessary resources to invest in these systems but also that policies view and encourage LTPAC providers to be active partners with physician groups and hospitals with a view of designing better systems associated with LTPAC for the future.

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**Pamela Wisniewski**, Ph.D., is an Assistant Professor in the Department of Computer Science at the University of Central Florida. Dr. Wisniewski graduated from the University of North Carolina at Charlotte with a Ph.D. in Computing and Information Systems. She was recently a Post Doctoral Scholar at the Pennsylvania State University. She also has over 6 years of industry experience as a systems developer/business analyst in the IT industry. Dr. Wisniewski's research interests are situated at the juxtaposition of Human-Computer Interaction, Social Computing, and Privacy. An emerging theme across her research has been regulating the boundaries between how individuals manage their relationships with technology and how they manage their social interactions with others through the use of technology. She uses an interdisciplinary approach to address these research questions by integrating literature in HCI, social psychology, and information systems in order to develop relevant theories and suggest design practices that better support how humans engage with and through technology. Her work has won best paper (top 1%) and best paper honorable mentions (top 5%) at premier conferences in her field.