An Integrated and Adaptable mHealth System to Support Individuals with Chronic Conditions and Disabilities: Development, Evaluation, and Exploration for Future Works

by

I Made Agus Setiawan

Bachelor of Science, Sepuluh Nopember Institute of Technology, 2004

Master of Computer Science, Universitas Indonesia, 2011

Master of Science in Engineering, Norwegian University of Science and Technology, 2012

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SCHOOL OF HEALTH AND REHABILITATION SCIENCES

This dissertation was presented

by

I Made Agus Setiawan

It was defended on

March 14, 2024

and approved by

Daqing He, PhD, Professor, Department of Informatics and Networked Systems

Brad E. Dicianno, MD, Professor, Department of Physical Medicine and Rehabilitation

Leming Zhou, PhD, Associate Professor, Department of Health Information Management

Dissertation Advisor: Bambang Parmanto, PhD, Professor, Department of Health Information Management

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I Made Agus Setiawan, PhD

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Mobile health (mHealth) is a promising solution for delivering effective self-management support to individuals dealing with chronic conditions, particularly those with spina bifida, spinal cord injury, and cerebral palsy. This work develops and evaluates an integrated and adaptable mobile health system to support self-management for individuals with chronic conditions and disabilities, and to implement and evaluate its use in a real-world setting. The system consists of a cross-platform client and caregiver app, a web-based clinician portal, and a backend server equipped with a secure communication protocol that allows for two-way communication. The developed system facilitates collaborative care coordination and is designed to possess the adaptability necessary to address the complex needs of individuals whose care requirements are multifaced and evolve over time.

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Preface

Om Swastyastu,

--- *may you always find safety and protection under God's care.*

I would like to express my gratitude for the innumerable blessings and supports that have guided me throughout my PhD journey. When I look back on the past decade of my journey, I am reminded that it has not always been an easy path. The challenges posed by immigration issues and the COVID-19 pandemic only served to make the journey more arduous. Despite these obstacles, I have been fortunate to receive continuous encouragement and support from a multitude of wonderful people around me.

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Om Dewa suksma parama acintyàya namah swàha, Sarwa karya prasidhàntam.
Om Sàntih, Sàntih, Sàntih, Om.

--- *O God, in the form of Parama Acintya, the most supernatural and the masterpiece,*
It is only by your grace that this work is successful.
May there be peace, peace in heart, peace in the world, peace forever.

I Made Agus Setiawan

1.0 Introduction

1.1 Background

Chronic medical conditions have become a significant challenge for the United States health care system, with 60% of adults in the country dealing with at least one chronic condition, and 42% experiencing several chronic conditions simultaneously (Buttorff et al., 2017). Around 25% of individuals suffering from chronic diseases also have some form of disabilities, which can limit daily activities and impede social engagement, significantly affecting their overall quality of life (Andersson, 2010; Buttorff et al., 2017).

The term “persons with chronic conditions and disabilities” (PwCCDs) describes a population of people with chronic diseases and disabilities, including those with Spina Bifida, Cerebral Palsy, and Spinal Cord Injury. Spina Bifida (SB) is the prevailing congenital anomaly leading to permanent disability in the United States, characterized by inadequate closure of the neural tube, leading to sensory loss and significant muscle weakness in the lower extremities (Mitchell et al., 2004; Parker et al., 2010). Cerebral palsy (CP) is characterized by the deterioration of motor function caused by brain damage, typically affecting the cerebral motor cortex. People diagnosed with CP encounter diverse degrees of activity restriction, gastrointestinal and urinary complications, abnormal neurological regulation, atypical sensory perception, psychological well-being, epileptic episodes, and cognitive impairment (Aisen et al., 2011; Gulati & Sondhi, 2018; Krigger, 2006; Rosenbaum et al., 2007). Spinal cord injury (SCI) is a severe medical condition resulting from trauma, disease, or degenerative disorders affecting the spinal cord, causing temporary to permanent changes in sensation, movement, strength, and body functions (Ara et al., 2023; Choi et al., 2023; Craig et al., 2022; unitedspinal.org, n.d.). Some of these problems can lead to secondary conditions like urinary tract infections and pressure injuries (Kinne et al., 2004; Mahmood et al., 2011; Verhoef et al., 2004). The potential consequences of these secondary complications can significantly affect various dimensions of an individual's life.

Self-management is a comprehensive approach to managing chronic conditions that involves active participation by individuals in their own care, in collaboration with healthcare providers (Grady & Gough, 2014). It is beneficial not only for preventing secondary and tertiary health problems but also for avoiding primary health issues by encouraging individuals to make healthy choices and engage in healthy behaviors. Self-management empowers PwCCD to actively participate in the ongoing management of their own condition, health, and well-being by providing them with a wide range of knowledge, attitudes, activities, and skills. It is an important component in health care and is applicable across multiple age groups, including children, adolescents, young adults and older adults (Catarino et al., 2021; Long et al., 1984; Lorig et al., 1993, 1999, 2001).

Supporting the self-management of PwCCD empowers those individuals to effectively manage their condition in their daily lives (Dwarswaard et al., 2016; Lozano & Houtrow, 2018; Hardman et al., 2020; Salemonsen et al., 2020). This support can take many forms including education, coaching, counseling, and peer support, and it should be designed to enhance PwCCD’s knowledge, self-efficacy, and skills to improve their quality of life (Salemonsen et al., 2020). Additionally, self-management support has been reported to help PwCCD avoid secondary problems (Bellin et al., 2013; Dicianno et al., 2016; Hardman et al., 2020; Parmanto et al., 2013; Sattoe et al., 2015).

Mobile health (mHealth) is a promising solution for delivering effective self-management support to individuals dealing with chronic conditions, particularly PwCCD. mHealth can encourage proactive self-management skills and improve well-being, reducing secondary complications and healthcare costs (Fiordelli et al., 2013; Klasnja & Pratt, 2012; Marcolino et al., 2018). Studies have shown that mHealth can improve adherence to intervention regimens, such as medication adherence and self-tracking capability, and promote health-related activities (Parmanto et al., 2013).

However, providing self-management support to PwCCD is a challenging task due to their diverse needs, evolving life situations, and varying emotional states (Glassgow et al., 2019; Lorig & Holman, 2003). In fact, very few mHealth apps are available that are designed specifically for these individuals, and they often struggle to use these apps. Moreover, most mHealth apps available in the market only partially support the self-management needs of PwCCD. To effectively manage chronic and complex conditions, it is essential to adopt a patient-centered, team-based care approach, which involves collaboration among healthcare professionals, patients, caregivers, and family members to provide comprehensive and integrated care. Furthermore, an integrated and adaptable approach that considers the PwCCD's needs, how their conditions change over time, and the multilevel social environment is crucial for supporting their long-term well-being.

This work developed an integrated and adaptable mHealth system to support self-management of PwCCD. The system is expected to be able to support individuals in their daily life by helping them build the skills they need, such as medication management, helping them build their confidence by providing educational content that is relevant to their conditions, and offering a communication channel to connect with their healthcare providers and daily caregivers. The system should be able to provide tailored support to individual needs and allow treatment adaptation. The system should also accommodate care coordination services to foster collaborative relationships and cater to different needs over time.

To ensure a clear understanding of the context, several terms are defined below. An *integrated* system refers to the seamless integration of a variety of features within the mHealth system, with the aim of providing comprehensive support for self-management. This includes, but is not limited to medication management, bowel and bladder programs, wound management, nutrition and physical activity tracking, mood tracking, education, and other relevant supports that can be delivered through a mobile application. The integration concept also encompasses the facilitation of care-collaboration and social support, in which the system connects the PwCCD with their family caregiver and providers.

The term *adaptable* system refers to the ability of users to adjust the mHealth system to enable the delivery of a combination of a range of features to PwCCDs to address the multifaceted needs of PwCCD over time. In this particular case, the provider has the ability to activate relevant features to be delivered to PwCCDs through the mHealth app to support their self-management tasks. Finally, the term *personalization* is occasionally used in this work, and it refers to the ability of the users to customize the appearance of the app. In this case, the PwCCDs have the ability to adjust the user interface of the mHealth app according to their preferences. Further details surrounding these terms and the features to which they refer are elaborated in section 2.6.

1.2 Previous Studies

Several years ago, a novel mobile health system called Interactive Mobile Health and Rehabilitation, version 1.0 (iMHere 1.0) was introduced to provide self-management support for individuals with chronic condition and disabilities (PwCCD), particularly those with spinal cord injury (SCI) and spina bifida (SB) (Parmanto et al., 2013). The iMHere 1.0 system was comprised of two parts: a mobile health app for PwCCD, and a web-based portal for healthcare providers, which allowed healthcare providers to monitor the progress of the treatment. The app and web-based portal were linked through a secure communication protocol that allowed for easy exchange of information between PwCCD and healthcare providers, such as when PwCCD were seeking medical advice on minor issues or receiving treatment plans.

The app was initially developed only for an Android platform and had five modules to aid in self-management, including medication management (MyMeds), bowel movement and bladder management (BMQ and TeleCath), mood assessment (Mood), and minor skin problem reporting (Skincare). To address minor issues identified in multiple studies on the system's usability and accessibility, iMHere 1.0 was refined and used in two clinical trials (Dicianno et al., 2016; A. Fairman et al., 2016; A. D. Fairman et al., 2013, 2016; Parmanto et al., 2015; D. Yu et al., 2013, 2019; D. X. Yu et al., 2017; D. X. Yu, Parmanto, Dicianno, & Pramana, 2014; D. X. Yu, Parmanto, Dicianno, Watzlaf, et al., 2014).

Feedback from users on iMHere 1.0 included additional modifications that could not be addressed through refining the existing system. Implementing these suggestions and expanding the scope of the iMHere system to include different diagnoses, such as Cerebral Palsy (CP), and demographics, including children as young as 12 years old, would require a significant architectural change to the system. As part of addressing these needs, in this project the system was enhanced with additional modules designed to offer greater support and compatibility with multiple platforms, primarily Android and iOS devices. This enhancement enables participants to use their personal devices through a Bring Your Own Device approach, and also supports collaborative care among individuals, physicians, and caregivers.

1.3 Specific Aims

The main objective of this work is to develop, evaluate, and investigate the usefulness of an integrated and adaptable mHealth system, with the aim of supporting self-management for individuals with chronic conditions and disabilities (PwCCDs). The specific aims are all focused on achieving this main goal, which is to help PwCCDs to manage their conditions effectively. Each specific aim provides unique insights that are essential to achieving the overall goal, including the design and development, usability evaluation, adaptability assessment, and practical implementation of the mHealth system. The overall objective of these specific aims is to advance the understanding and implementation of technology-based solutions that are tailored to meet the unique needs of PwCCDs, thereby enhancing their quality of life.

Specific Aim 1: *To develop an integrated and adaptable mHealth system to support self-management for PwCCD.*

An integrated mHealth system will be developed that supports PwCCD self-management and that can be adapted to accommodate changing treatment plans according to PwCCD's evolving needs over time. This aim is to answer the following question:

RQ1: How can an mHealth system be developed to integrate support for self-management and adapt to the evolving needs of People with Chronic Conditions and Disabilities (PwCCDs)?

The developed system is anticipated to facilitate collaborative care coordination and is designed to possess the adaptability necessary to address the complexity of PwCCD.

Specific Aim 2: *To evaluate the usability of the built mHealth system.*

The usability of the developed system will be investigated iteratively to obtain feedback for system refinement. Usability studies will be performed to evaluate the system, and structured interviews will be conducted to acquire feedback from the participants. This aim is to answer the following question:

RQ2: What specific usability issues are identified through iterative usability studies, and how do those impact the overall user experience for individuals with chronic conditions?

The developed system is intended to be useful for PwCCDs in supporting their self-management routines.

Specific Aim 3: *To evaluate the adaptability of the mHealth system to diverse needs and evolving life situations over time*.

Chronic conditions can present new challenges as they evolve over time. An adaptable mHealth system enables those challenges to be identified and addressed as they arise. The adaptable capability of the built system will be investigated using a *vignette-based simulated interaction* evaluation.

RQ3: To what extent can the mHealth system effectively provide support in addressing diverse needs and evolving life situations among PwCCDs over time?

The developed system is expected to be adaptable to individuals' evolving needs over time.

Specific Aim 4: *To conduct an exploratory evaluation of the mHealth system in delivering comprehensive support for self-management in clinical settings.*

The workflow integration strategies and user engagement will be investigated through small scale pilot implementation in a real-world setting. Feedback from users will be collected, challenges identified, and system refined based on lessons learned.

RQ4: How well does the mHealth system adapt to the workflows and processes in clinical settings?

RQ5: What challenges and barriers arise during the pilot implementation of the mHealth system in clinical settings?

The developed system is expected to accommodate effective adaptation to workflows and processes in clinical settings. Additionally, we anticipate identifying challenges and barriers during the pilot implementation of the developed system in clinical settings.

1.4 Significance of the Study

Self-management support is crucial for individuals with chronic and complex conditions. Self-management support empowers individuals to effectively manage their conditions on a daily basis by enhancing their knowledge, confidence, and skills (Lozano & Houtrow, 2018). However, given the long-term nature of these conditions, the diverse needs of the individuals experiencing them, the changes in their needs over time, and taking into account their functional limitations due to disabilities, it is essential to develop an appropriate strategy to address these challenges.

To the best of my knowledge, there is currently no mHealth platform that provides self-management support for individuals with various types of chronic conditions and disabilities. While one study developed an mHealth system called "Intellicare," a suite of 13 mobile apps for depression and anxiety care (Mohr et al., 2017), this system is designed for mental health and does not offer any means of collaborative support from caregivers and clinicians.

The proposed system, iMHere 2.0, is an integrated and adaptable mHealth system that aims to address the existing challenges by utilizing multiple care delivery models and introducing a care-coordination approach within the system workflow.

1.5 Innovation

In order to address the complex, diverse, and evolving self-management support requirements of PwCCDs, we have created an adaptable mHealth system that consists of a cross-platform client and caregiver app, a web-based clinician portal, and a back-end server equipped with a secure communication protocol that allows for two-way communication. This system delivers treatment support tailored to the specific needs and progress of each individual (Collins et al., 2004). The treatment strategies can be modified over time in response to the individual's performance and evolving needs.

The system architecture is highly scalable and adaptable, allowing for independent addition of new self-management services as needed. A total of 12 diverse and commonly used app modules were developed for both the client and caregiver apps to demonstrate the system's flexibility and scalability.

The web-based clinician portal is designed to prescribe personalized treatment strategies for individuals with chronic conditions, which can be followed by those individuals in the client app for self-management. Throughout the treatment process, clinicians can modify the strategies based on the individual's performance. Any updates to the treatment strategies made by the clinician on the portal are synchronized with the client and caregiver apps. The portal also facilitates the clinician’s monitoring of the individual's adherence to the prescribed strategies and secure communication with the individual through instant messaging.

Social support is a critical factor for long-term engagement in self-management (Barlow et al., 2002; Bellin et al., 2013). In the iMHere 2.0 system, the caregiver app allows caregivers to monitor the performance of PwCCDs and provide social support. Previous research has shown that leveraging social influence is an effective strategy to motivate PwCCDs to adhere to treatment regimens (Clark, 2003). Family members, including partners, parents, children, and siblings, can significantly influence long-term engagement in health care (Clark, 2003). Therefore, motivational messages from caregivers may help PwCCDs to endure lengthy treatment procedures. Additionally, instant secure messages exchanged between PwCCDs, and clinicians can provide further social support for long-term engagement with the treatment plan.

The versatility of multiple caregiver modes enables caregivers to offer appropriate support to individuals with chronic conditions. While family members may lack formal medical training, their close relationships and extensive knowledge about the individual's situation enable them to provide intimate, loving, and encouraging motivational messages. Paid caregivers, on the other hand, typically possess some patient care training, and thus, their motivational messages take the form of professional suggestions and reminders of the benefits of consistent self-management. In terms of access to personal health information, it is essential to have varying levels of access for different types of caregivers, such as family members and professional caregivers. This feature is currently under development and will be implemented in the near future.

The client and caregiver apps for the iMHere 2.0 system are designed to be cross-platform, allowing users to access the system on a range of mobile devices, including Android, iOS, and Windows Phone. This feature ensures that PwCCDs can utilize the system on their current mobile devices, as the majority of mobile operating systems used worldwide are Android and iOS (Statista.com, 2018). Moreover, the cross-platform functionality enables PwCCDs and caregivers to use the system on multiple devices with different operating systems without losing the ability to manage their conditions effectively.

The iMHere 2.0 system is designed with accessibility in mind to ensure that PwCCDs can use the system comfortably. In a study of iMHere 1.0, participants with fine motor impairments requested the ability to change text size, button size, and color (D. X. Yu, Parmanto, Dicianno, & Pramana, 2014). Consequently, iMHere 2.0 includes these accessibility features, allowing users to adjust the font size, font style, button size, spacing between lines and buttons, and hand preference. These accessibility features are crucial for long-term usage, as they enable users to customize the system according to their changing needs. For instance, as people age, their vision may decline, making it difficult to read materials on the system. With the accessibility features, users can adjust the font size to ensure continued use of the system.

1.6 Dissertation Outline

The remainder of this dissertation consists of:

- Chapter 2 provides background and literature review of work referenced in this dissertation.
- Chapter 3 describes the design and development process of the iMHere 2.0.
- Chapter 4 describes the development of vignettes toward vignette-based simulated interaction evaluation.
- Chapter 5 describes the evaluation of iMHere 2.0 system including usability, feasibility, and vignette-based evaluation.
- Chapter 6 describes the pilot implementation of iMHere 2.0 in a clinical setting.
- Chapter 7 provides summary and discussion of the works conducted in this dissertation, reviewing each specific aim.

2.0 Literature Review

2.1 Population with Chronic Conditions and Disabilities

2.1.1 Prevalence overview

Chronic medical conditions have emerged as one of the most significant challenges for the healthcare system in the United States (Buttorff et al., 2017). They are defined as persistent conditions that progress gradually and require ongoing monitoring or treatment (Bernell & Howard, 2016; Buttorff et al., 2017). According to a survey conducted in 2017, nearly 60% of adults in the United States had at least one chronic condition, while 42% had multiple chronic conditions. Notably, 12% of individuals had five or more chronic conditions (Buttorff et al., 2017). Healthcare expenditures are disproportionately high for individuals with chronic conditions, accounting for approximately 90% of overall expenditures (Andersson, 2010; Buttorff et al., 2017). The spending on healthcare services increases with the number of chronic conditions an individual has, with the subset of Americans comprising 12% of the population and suffering from five or more chronic illnesses responsible for approximately 41% of the overall healthcare expenditure. Furthermore, it is important to note that 25% of individuals with chronic diseases also have some form of disability, which can limit daily activities and social engagement, ultimately affecting their quality of life. These disabilities may also increase the risk of developing additional complications (Andersson, 2010; Buttorff et al., 2017).

2.1.2 Diverse Conditions: Beyond General Prevalence

To gain a comprehensive understanding of the numerous long-term conditions and disabilities that affect individuals, it is important to explore the anatomy and physiology of the spinal cord and how it is affected by specific medical issues, including spina bifida, cerebral palsy, and spinal cord injury. The result of this investigative approach highlights the complex and diverse nature of the experiences of those affected by these conditions, emphasizing the need for tailored and compassionate care.

2.1.2.1 Understanding Spinal Cord

The spinal cord is a vital organ that facilitates communication between the brain and the rest of the body. It originates at the base of the brain and extends through the center of the spinal column, where it is enclosed and protected by the vertebrae. It is comprised of bundles of neurons that transmit signals that control a variety of physiological functions. These signals include sensory information such as touch, pressure, and heat, which the brain processes. Additionally, the spinal cord regulates autonomic processes, including blood pressure, body temperature, breathing, bladder, bowel, and sexual function. Injuries to the spinal cord can have a significant impact on an individual's quality of life (spinal-research.org, n.d.).

Medical convention organizes the vertebrae into distinct segments, each of which controls a different part of the body. Figure 1 illustrates the areas that each segment of the spine controls.

Figure 1 Diagram of Spinal Vertebrae and Dermatomes Map (sbcan.ca, n.d.)

The left-hand side of Figure 1 illustrates the vertebral segments of the spinal cord, each of which is marked with the corresponding region and vertebrae number. Each segment is responsible for regulating the movement of specific body parts. The ability of the nerves to instruct the body to move is referred to as motor control. Each nerve is responsible for regulating a distinct set of muscles, and different muscles of varying strengths are involved in the process of movement (sbcan.ca, n.d.). The right-hand side of the figure depicts a side view of dermatomes. A dermatome is a specific area of skin whose nerves are associated with a particular segment of the spine, allowing for the perception of sensations such as touch, temperature, and pain. If the nerves in a dermatome are impacted, the individual may experience a diminished or complete lack of sensation related to touch, temperature, and pain (sbcan.ca, n.d.).

The severity and location of a spinal injury significantly impacts the extent of functions affected. For instance, an injury that occurs higher up on the spinal cord is more likely to impair multiple functions (spinal-research.org, n.d.). Nevertheless, it is important to recognize that each case of injury is unique, and individuals with the same level of injury may experience varying degrees of impact on their functions. Understanding the location of the spinal cord that has been affected helps determine the loss of sensation and movement an individual may experience. Table 1 represents spinal injury levels and their typical effects on individuals:

Table 1 Spinal cord injury levels and general effects on individual (spinalinjury101.org, n.d.)

Spinal Segment	General Effects
CERVICAL C1 - C4	• Paralysis in arms, hands, trunk, and legs (*tetraplegia* or *quadriplegia*). • Patients may not be able to breathe on his or her own, cough, or control bowel or bladder movements. • The ability to speak is sometimes impaired or reduced. • Requires complete assistance with activities of daily living, such as eating, dressing, bathing, and getting in or out of bed. • May be able to use powered wheelchairs with special controls to move around on their own
C5 – C6	• Likely to have paralysis in wrists, hands, trunk, and legs (*tetraplegia* or *quadriplegia*). • Patients can raise their arms and bend their elbows. • Little or no voluntary control of bowel or bladder. • Can speak and use diaphragm, but breathing will be weakened. • Will need assistance with most activities of daily living, but once in a power wheelchair, can move around independently.
C7 - C8	• Likely to have paralysis in hands, trunk, and legs (*tetraplegia* or *quadriplegia*). • They have elbow extensions and some hand movement. • May be able to grasp and release objects. • Most can straighten their arms and have normal movement of their shoulders. • Little or no voluntary control of bowel or bladder. • Independent with most activities of daily living but may need assistance with more difficult tasks.
THORACIC T1 – T5	• Typically, they have paralysis in their trunk and legs (*paraplegia*). • Injuries usually affect the chest, abdominal, mid-back muscles, and the legs. • Have normal arm, hand, and upper-body movement. • Independent with most activities of daily living. • Typically use a manual wheelchair.

Table 1 (Continued)

Spinal Segment	General Effects
T6 – T12	• Typically, they have paralysis in their trunk and legs (*paraplegia*). • Injuries usually affect the abdominal, lower back muscles, and the legs. • Have normal arm, hand, and upper-body movement. • Little or no voluntary control of bowel or bladder. • Independent with most activities of daily living. • Typically use a manual wheelchair.
LUMBAR L1 – L5	• Injuries generally result in some loss of function in the hips and legs. • Little or no voluntary control of bowel or bladder. • Depending on the strength of their legs, the injured person may need a wheelchair and may also walk with braces.
SACRAL S1 – S5	• Injuries generally result in some loss of function in the hips and legs. • Little or no voluntary control of bowel or bladder. • People with a sacral spinal cord injury will most likely be able to walk.

2.1.2.2 Spina Bifida

Spina bifida is a congenital anomaly that affects the spine and spinal cord (CDC, 2023b). It is the most common congenital defect of the central nervous system and can result in lifelong disability (Hassan et al., 2022). Spina bifida occurs when the spine and spinal cord do not form properly during development, leading to defects in the spinal cord and bones of the spine (R & Ramesh, 2022). Spina bifida is a type of neural tube defect (NTD) that might cause physical and intellectual disabilities that range from mild to severe, depending on the type of defect, size, location, and complications (Benmassaoud et al., 2023; CDC, 2023b). Spina bifida affects approximately 1,427 babies in the United States each year, or 1 in every 2,758 births (CDC, 2023c) and it is estimated that the lifetime cost of caring for an individual with spina bifida is substantial (Ouyang et al., 2007).

Spina bifida can manifest in two forms: open spina bifida (*spina bifida aperta*), where the lesion (the defect) is visible on the body surface, and closed spina bifida (*spina bifida occulta*), where the lesion is not visible (Opšenák et al., 2021). Genetic, nutritional, and environmental factors may contribute to the development of spina bifida (Opšenák et al., 2021). Individuals with spina bifida may experience a range of neurological effects depending on the severity and location (Figure 2). These can include muscle weakness in the lower extremities, difficulties controlling urination, and limitations in daily activities (CDC, 2023a). Individuals with spina bifida located in the upper regions of the spine, closer to the head, may experience paralysis in their legs and need wheelchairs for mobility (CDC, 2023a). Individuals with spina bifida occurring at a lower location on the spinal column, closer to the hips, may exhibit greater mobility in their legs (CDC, 2023a). They may rely on crutches, braces, or walkers for assistance, or they may possess the ability to walk unaided (CDC, 2023a). The most frequent sites for spina bifida (the lesion) are typically found in the lumbar and/or sacral regions (sbcan.ca, n.d.).

Figure 2 Type of spinal dysraphism (Opšenák et al., 2021)

The three most common types of spina bifida are (CDC, 2023b):

- Spina Bifida Occulta

  Spina bifida occulta is considered the least severe form of the condition, often called "hidden" spina bifida. It is typically identified in late childhood or adulthood and characterized by a small gap in the spine that is not accompanied by an opening or sac on the back. Unlike other types of spina bifida, it does not typically cause significant disabilities.

- Meningocele
  Meningocele is characterized by the presence of a sac containing cerebrospinal fluid protruding through an opening in the spinal column, without the accompanying spinal cord. This condition typically results in minor impairments and limited nerve damage and may affect bladder and bowel function.
- Myelomeningocele
  Myelomeningocele is considered the most severe form of spina bifida, often resulting in significant impairments, including difficulty with bladder and bowel function, reduced sensation in the lower extremities, and limited mobility, caused by the presence of a sac of cerebrospinal fluid within the spine.

Spina bifida can have an impact on the brain as well, especially in infants who have an open NTD such as myelomeningocele. When the neural tube is open in the spine, the result is a pull on the developing brain that obstructs the normal flow of cerebral spinal fluid (CSF), a fluid that surrounds the brain. Two common effects of this are hydrocephalus and Arnold-chiari 2 malformation. Hydrocephalus affects the ventricles of the brain, while Arnold-chiari 2 malformation affects the cerebellum (sbcan.ca, n.d.).

The management of spina bifida is highly individualized and contingent upon the severity of the condition. In severe cases, multiple treatments may be required, including early surgical intervention, which, despite its common use, may not always completely remediate the issue (CDC, 2023b). According to Mitchell (2004), individuals diagnosed with SB face significant risks of experiencing paralysis, urinary dysfunction, gastrointestinal issues, and orthopedic deformities.

2.1.2.3 Cerebral Palsy

Cerebral palsy (CP) is a neurodevelopmental condition that results in abnormalities in muscle tone, movement, and motor skills, and is caused by brain damage during a prenatal or early postnatal stage (ucp.org, n.d.). The damage, which often affects the cerebral motor cortex, is non-progressive and leads to impairments in motor function, cognition, vision, speech and language function, psychological issues, and swallowing, as well as to epilepsy, bowel/bladder dysfunction, and orthopedic deformities (Aisen et al., 2011; Gulati & Sondhi, 2018; Krigger, 2006; Rosenbaum et al., 2007).

CP is the most common chronic childhood motor disability, with approximately 3.3 of every 1,000 children in the United States affected. The prevalence is higher in boys than in girls (ucp.org, n.d.). It is estimated that there are 764,000 children and adults with cerebral palsy symptoms in the U.S., with around 10,000 babies and 1,200-1,500 preschool-age children diagnosed each year (ucp.org, n.d.). CP can result from a range of factors, such as periventricular white matter injury, asphyxia, and injury to the developing brain.

There are three types of Cerebral Palsy (ucp.org, n.d.):

- *Spastic Cerebral Palsy*: characterized by muscle stiffness and permanent contractions.
- *Athetoid or Dyskinetic Cerebral Palsy*: characterized by uncontrolled, slow, writhing movements.
- *Ataxic Cerebral Palsy*: characterized by poor coordination and balance.

An individual who has CP may display several different symptoms, including muscle tightness or spasticity, disturbances in gait or mobility, involuntary movements, difficulty swallowing, and problems with speech (ucp.org, n.d.). They may also have trouble with feeding, impairment of sight, hearing, or speech, abnormal sensation and perception, seizures, difficulties with bladder and bowel control, intellectual disability, learning disabilities, problems with breathing due to postural difficulties, and skin disorders due to pressure sores (ucp.org, n.d.).

To effectively manage CP, a comprehensive approach that integrates the diagnosis and treatment of co-morbidities and employs a multidisciplinary team comprising rehabilitation, orthopedic, psychological, and social care providers is essential (Gulati & Sondhi, 2018). While there is currently no known cure for CP, targeted training and therapy can enhance muscle function and coordination. Research indicates that early intervention services, such as physical and occupational therapy, can significantly improve the quality of life in children by promoting more typical developmental trajectories (ucp.org, n.d.).

2.1.2.4 Spinal Cord Injury

Spinal cord injury (SCI) is a serious medical condition that arises from trauma, disease, or degenerative disorders affecting the spinal cord (Ara et al., 2023; unitedspinal.org, n.d.). SCI can be caused by direct harm to the spinal cord or damage to surrounding tissue and bones (ninds.nih.gov, n.d.). SCI is classified into two categories: traumatic (tSCI) and non-traumatic (ntSCI). tSCI is caused by external forces such as accidents or falls, while ntSCI is caused by factors other than trauma, such as degenerative diseases or infections, Cancer Osteoporosis, Multiple sclerosis, Arthritis, and inflammation of the spinal cord (Choi et al., 2023; spinalinjury101.org, n.d.). The consequences of SCI can range from temporary to permanent changes in sensation, movement, strength, and body functions (unitedspinal.org, n.d.).

In the United States, tSCI is the most common type of SCI. There are currently an estimated 1,462,220 individuals currently living with the condition, which is more than five times the number reported in 2007 (Armour et al., 2016; Reeve Foundation, n.d.). The annual incidence of tSCI is approximately 54 cases per one million people, resulting in around 18,000 new tSCI cases each year (unitedspinal.org, n.d.).

SCI can cause a range of symptoms, depending on the severity and location of the injury. Paralysis, characterized by an inability to move muscles or the experience of muscle weakness below the site of the injury, is among the most common symptoms associated with SCI. High-level injuries can result in paralysis throughout most of the body and affect all limbs, which is known as *tetraplegia* or *quadriplegia* (ninds.nih.gov, n.d.). In contrast, lower-level injuries may only impact the lower body and legs, leading to *paraplegia* (ninds.nih.gov, n.d.). It is important to note that paralysis can occur either immediately after the injury or develop over time due to bleeding, swelling, and cell death in the spinal cord. If the injury causes minimal or no cell death, a full recovery may be possible (ninds.nih.gov, n.d.). Furthermore, there may be a loss of sensation or alterations in sensation, changes in reflexes, and changes in autonomic functions such as sweating and blood pressure regulation. Other common symptoms include headache, neck pain, back pain, loss of bowel and bladder control, and difficulty breathing (unitedspinal.org, n.d.).

Individuals with SCI often face a range of psychosocial challenges when adapting to their new circumstances. These challenges can include changes in sexuality, weight gain, disrupted sleep patterns, cognitive impairment, and chronic pain, as well as relationship stress, breakdowns, social discrimination, and limited employment opportunities. Consequently, individuals with an SCI are at an increased risk of developing mental health issues, such as substance abuse, depression, and anxiety disorders (Craig et al., 2022).

SCI can be classified as either complete or incomplete (ninds.nih.gov, n.d.). Incomplete injury permits limited communication between the spinal cord and the brain, preserving certain functional abilities. In contrast, complete injury results in a complete disruption of nerve communication, leading to the loss of all functional capacities below the injury site.

Comprehensive rehabilitation programs are essential for improving outcomes and addressing the challenges associated with SCI (Ara et al., 2023). These programs should be provided in specialized centers and delivered by interdisciplinary teams. Effective therapies and recovery strategies can only be developed by understanding the mechanisms of SCI (Ara et al., 2023).

2.1.3 Challenges Over Time

Understanding the ever-changing nature of chronic diseases and the different life situations that come with them is crucial. These factors typically develop and evolve in specific stages and patterns over time (Audulv, 2013). The course of many chronic illnesses is often characterized by variations in health status, which might include periods of decline if left untreated, but which can also demonstrate improvement with proper treatment. The consistent change highlights the necessity for a healthcare approach that is adaptable and can effectively meet the changing needs of patients as their disease progresses.

Moreover, chronic diseases have a significant effect on emotional well-being, sometimes causing individuals to experience feelings of frustration and depression (Lorig & Holman, 2003). It is crucial to understand that these emotional changes are not static but are likely to fluctuate as the physical condition changes. For instance, a decline in physical well-being might result in increased emotional distress, whereas effective treatments could lead to a positive change in emotional wellbeing. Understanding and dealing with these emotional conditions is crucial for a comprehensive treatment strategy, which demands not only medical intervention but also specialized psychological and emotional support in order to meet the changing needs of the individual.

When an individual experiences a change in either physical or emotional states, it is essential to make appropriate adjustments to the treatment plan. For example, an individual who is feeling frustrated or depressed may need supplementary mental health support incorporated into their treatment plan. Likewise, the presence of pressure sores, commonly associated with a deterioration in health, requires a change in the approach to care - transitioning from preventative measures to targeted treatment protocols once a sore becomes evident.

Personalization is key in handling the management of chronic conditions. For instance, different individuals experience pressure sores distinctly, depending on the location and depth of the sores. Ideally, personalized care extends beyond the treatment of wounds to include a wider range of options for self-management, including preventative measures. As individuals progress through different stages of their conditions, the support needed for self-management evolves. Therefore, the strategies utilized to support self-management are not fixed but adaptable, customized to the individual's specific needs and conditions, and evolving throughout their lifespan. Understanding this underscores the significance of adaptability and tailored treatment in enhancing the overall well-being of individuals who have chronic conditions.

2.2 Self-Management

Having a comprehensive understanding of what self-management entails is the first step to create an approach that effectively helps people manage their chronic health conditions and disabilities. The successful approach will involve empowering persons with chronic condition and disabilities (PwCCD) to actively take control of their everyday well-being. This section explores the conceptualization, development of skills, and study of models that are necessary for effectively managing oneself in the context of long-lasting conditions.

2.2.1 The concept of self-management in healthcare

Self-management is a term that commonly refers to an individual's healthful behaviors and promotion of their own health, particularly with respect to the management of chronic conditions and disabilities[1]. Self-management is individual-centered care, in which the individual living with a chronic condition or disabilities is primarily responsible for their own day-to-day care and so takes an active role in their own treatments (Lorig & Holman, 2003). They undertake the day-to-day tasks needed to control or reduce the impact of the condition or disease on their physical and mental health over the course of their illness. Because of the long-term and debilitating nature of the conditions, self-management becomes a lifetime task for most of these people.

Self-management, self-care, self-monitoring, symptom management, and self-efficacy are a group of concepts referring to what is needed for an individual to achieve optimal health and well-being. Although the terms are often used interchangeably, they have slightly different meanings. Barlow (2002) defined *self-management* as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition". Richard and Shea (2011) defined self-management as "the ability of the individual, in conjunction with family, community, and healthcare professionals to manage

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[1] Chronic Condition, according to U.S. National Center for Health Statistics, is the health condition of a person that last more than 3 months and can last as long as their lifetime.

symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions". From the point of view of the individuals performing the daily tasks, Richard and Shea found that there are more commonalities than differences between self-management, self-care, and self-monitoring. As can be seen from the conceptual model below, there are overlapping between the concepts (Richard, 2011).

Self-care is defined as "the ability to care for oneself and the performance of activities necessary to achieve, maintain, or promote optimal health (including activities specific to acute and chronic health conditions)" (Lorig & Holman, 2003). Self-care is the broadest concept and incorporates self-management, self-monitoring, and symptom-management when performed by an individual for that individual's self. *Self-monitoring* is defined as "awareness and measurement of specific physiologic parameters or symptoms of a health condition that are indicators of the need to take action or consult with a healthcare provider" (Lorig & Holman, 2003). With this definition, self-monitoring refers to specific activities that represent one aspect of self-management. *Symptom management,* when performed by the person experiencing the symptoms, is the element of self-management and self-monitoring, that is defined as "the awareness of and response to subjective physiologic, cognitive, or functional changes or sensations" (Lorig & Holman, 2003). Meanwhile, *self-efficacy* is the level of confidence in one's ability to perform self-care activities. Self-efficacy is the moderator/mediator of self-care, self-management, self-monitoring, and symptom management (Lorig & Holman, 2003).

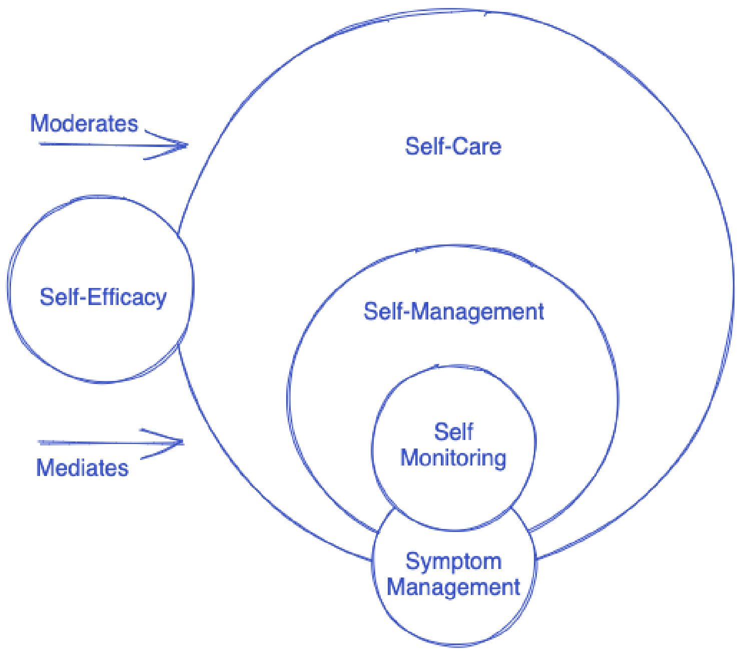

Figure 3 Conceptual Model of relationships between self-care, self-management, self-monitoring, symptom management, and self-efficacy (Lorig & Holman, 2003).

The nature of chronic conditions and disabilities means that self-management is a lifetime task for the people experiencing them. According to Lorig and Holman, there are three self-management core tasks that PwCCD need to address when managing their chronic conditions and disabilities: 1) medical/behavioral management, 2) role management, and 3) emotional management (Lorig & Holman, 2003).

- *Medical/behavioral management* of a condition involves tasks such as making health-related appointments, following treatment plans, tracking symptoms, taking medication as directed and adhering to a special diet. Individuals with spina bifida, cerebral palsy, and spinal cord injury face commonalities in their medical/behavioral management. These conditions require consistent healthcare check-ups, specialist consultations, and therapy sessions. Adherence to treatment plans is crucial, as it optimizes health outcomes and manages the long-term impact.

Monitoring symptoms is vital for early intervention and adjustment of treatment plans. Medication regimens are essential for managing pain, preventing complications, and addressing secondary conditions. Adhering to special diets is also common, as some conditions may require specific nutritional considerations. The commonality lies in the proactive engagement individuals must undertake to manage their health effectively.

- *Role management* is a process that involves coordinating and organizing the various daily roles and responsibilities related to work, family, community, and self-care. This process also includes adapting these roles and activities to align with the individual's health conditions. By doing this, individuals can continue to participate in meaningful life activities, which contributes to their overall well-being and sense of identity. For instance, a person with spina bifida may encounter challenges in engaging in traditional modes of mobility, such as recreational activities. In such cases, they may choose to explore adaptive sports like wheelchair basketball or adaptive swimming, which enables them to maintain an active lifestyle while accommodating the physical constraints associated with their condition.
- E*motional management* is a universal aspect of living with chronic conditions. It is related to self-control over one’s emotional state, such as anger, fear, and frustration after having a chronic condition. It is important to mention that people who have chronic conditions, such as spina bifida, cerebral palsy, and spinal cord injury, often share similarities in how they handle their emotions. These shared characteristics include seeking social support, developing adaptive coping strategies, building psychological resilience, embracing self-identity and empowerment, and seeking professional mental health support. For instance, connecting with others who share similar experiences can be highly beneficial for these individuals, as it allows them to learn coping mechanisms and foster a positive mindset despite the adversity they face.

Moreover, empowerment through self-expression and the pursuit of passions can significantly enhance the overall quality of life for those with these conditions.

Self-management is a comprehensive approach to managing chronic conditions that involves active participation by individuals in their own care, in collaboration with healthcare providers (Grady & Gough, 2014). It is not only beneficial for preventing secondary and tertiary health problems but also for avoiding primary health issues by encouraging individuals to make healthy choices and engage in healthy behaviors. Research has shown that self-management programs can enhance health outcomes and instill a sense of responsibility in individuals for managing their chronic illnesses. Nurses play an indispensable role in advancing the science of self-management and implementing innovative practices in clinical settings. The ultimate aim is to develop more sophisticated self-management models tailored to different health conditions and situations (Grady & Gough, 2014).

According to Lorig and Holman (2003), self-management is problem focused. As such, support for self-management must be tailored to address individual's specific concerns. Consider individuals with spina bifida who frequently encounter sensory impairments, which can contribute to an increased vulnerability to pressure sores. Instead of a one-size-fits-all education program aimed at preventing disability, effective support should prioritize developing skills related to sensory awareness and maintaining skin integrity. To effectively support self-management, as outlined by Lorig and Holman (2003), promoting skills such as problem-solving, decision-making, and action planning become imperative. This approach empowers individuals to actively engage in their own health management, addressing a specific concern associated with their conditions and enhancing their overall well-being.

2.2.2 Self-management skills

Developing self-management skills is essential for PwCCD to effectively care for themselves. As outlined by Lorig and Holman (2003), five core self-management skills must be acquired to support self-management. These skills are as follows:

- *Problem Solving*: Instead of being taught the solution to their problem, individuals are taught the basic problem-solving skills. These include: 1) problem definition, 2) generation of possible solutions, either from a friend's suggestion or from health care professionals, 3) solution implementation, and 4) evaluation of results.
- *Decision Making*: Individual with chronic condition will need to make day-to-day decision in response to changes in their conditions. In order to do this, PwCCD need to have enough and appropriate knowledge and information to support their decisions. Some examples of self-evaluation questions that require decision-making include: 1) How do I know when I have exercise enough or too much? 2) How do I know whether a symptom is medically serious? 3) Should I continue taking my medications when I have a fever?
- *Resource utilization*: This skill is basic but often overlooked in traditional health promotion and patient education programs. Resources that can be useful to patients include the phone book, the internet, the library, and the community resource guides. Many programs tell participants about resources but do not teach participants how to use them.
- *Forming a partnership between the patient and healthcare provider*: In previous style of care, the role of the patient was to seek healthcare to treat an acute illness, and the role of the provider was to diagnose and treat that illness. Recent styles of care have changed these roles so that the health care providers take role of a teacher, a partner and a professional supervisor.

Meanwhile, the patient has the added responsibilities of accurately reporting the trend and tempo of their condition or disease, making informed choice about treatment and discussing it those choices with the provider.

- *Action Planning*: The final skill of self-management is the ability to plan the action needed. It could be a short-term action plan that is specific, short in duration and that the patient is confident they will be able to carry out.

2.2.3 Review of self-management model and theory

Behavioral interventions rely heavily on behavior change models and theories, which serve as a crucial conceptual framework for explaining the structural and psychological determinants of behavior (Painter et al., 2008). By identifying theoretical constructs to target (e.g., beliefs, attitudes, self-efficacy), pinpointing the mechanisms underlying specific behavior change techniques (e.g., knowledge, skill, motivation), and selecting the most appropriate participants (e.g., individuals with negative attitudes), these models and theories guide the development and refinement of interventions (Webb et al., 2010).

Theory refers to an idea or set of ideas formulated to explain and predict facts or phenomena (Hayden, 2019). In the context of behavior change, theories are utilized to explain behavior and inform strategies to achieve it. A *model*, on the other hand, is a combination of ideas derived from multiple theories and applied together (Hayden, 2019). Models can be beneficial in helping to comprehend a specific problem in a particular setting, where a single theory may not be sufficient (Hayden, 2019). In both theory and model, the *concept* serves as the primary component, while the construct represents the specific way the concept is utilized (Hayden, 2014).

Three theoretical perspectives from psychology have dominated chronic disease self-management intervention: self-efficacy theory, self-regulation theory and social cognitive theory. Self-efficacy theory and self-regulation theory are not only independent constructs, but both also serve as components in other theories and models.

1. Self-Efficacy Theory

The Self-Efficacy Theory was first introduced by Bandura in 1977. According to this theory, self-efficacy is an individual's belief in their ability to successfully carry out a task in order to achieve a desired outcome (Bandura, 1977). People are more likely to attempt tasks that they believe they can accomplish and will avoid tasks that they believe they will fail at. The Self-Efficacy Theory posits that an individual's perception of their efficacy is influenced by four factors: mastery experience, vicarious experience, verbal persuasion, and physiological states (Bandura, 2010). *Mastery experience* refers to learning from past accomplishments where an individual mastered difficult or feared tasks. *Vicarious experience* refers to learning through observing others. *Verbal persuasion* refers to encouragement from others, typically from clinicians who motivate patients to continue their efforts to change their behavior. Finally, *physiological states* such as stress, anxiety, fear, fatigue, and mood states can provide information about an individual's efficacy expectation. Stressful situations or feared tasks can create emotional arousal, which in turn influences an individual's perception of their ability to cope with the situation or complete the task. Self-efficacy is not only a theory but also a construct in other theories, such as the Social Cognitive Theory (Bandura, 1986) and the Health Belief Model (Rosenstock et al., 1988).

2. Self-Regulation Theory

Self-regulation theory refers to an individual's ability to manage and control themselves through the acquisition of concrete skills (Clark et al., 2014; Glanz et al., 2008). By believing in their ability to perform a task using the skills they possess and anticipating the likely outcome, individuals are more likely to take action to accomplish the task. The more salient the goal, the more likely the person is to engage in self-regulation behavior. This theory views individual self-regulation of health-related behavior as central to achieving desired treatment outcomes, with its first application in asthma control by Clark & Starr-Schneidkraut (1994). Bandura identified six strategies to promote self-regulation: self-monitoring, goal-setting, feedback, self-reward, self-instruction, and enlisting social support (Glanz et al., 2008).

3. Social Cognitive Theory

Social Cognitive Theory (SCT), originally known as *social learning theory*, was introduced by Bandura in 1977 and later renamed to incorporate concepts from cognitive psychology (Bandura, 1986). The fundamental concept of SCT is *reciprocal determinism*, which refers to the dynamic interplay between personal factors, the environment, and behavior (Glanz, 2008). This theory posits that an individual's interpretation of their personal factors and environment influences their behavior, which in turn affects their personal factors and environment. Self-efficacy, expectations, expectancies, reinforcement, and self-regulation are among the key constructs of SCT that contribute to the reciprocal determinism process (Hayden, 2014). *Self-efficacy* is a central concept in SCT and is considered the single most important determinant of behavior (Hayden, 2014). When individuals possess the necessary skills and knowledge to perform a task, their belief in their ability to do so drives them to actually complete the task (Hayden, 2014). *Expectations* are the anticipated outcomes of specific behaviors, and people tend to engage in certain actions because of the expected results. *Expectancies* refer to the value placed on the expected outcome, which influences behavior. For instance, if an individual expects a negative outcome from a blood test (e.g., an HIV diagnosis), they may be less likely to undergo the test. *Reinforcement* involves a system of rewards and punishments that encourages or discourages certain behaviors. People engage in behaviors to obtain rewards or avoid punishments. *Self-regulation* suggests that individuals are motivated to self-regulate by a desired goal or behavioral endpoint, which is associated with a value for the individual (Clark et al., 2014; Glanz et al., 2008).

4. Health Belief Model

The Health Belief Model (HBM) is considered to be one of the most widely used and oldest models in health promotion (Glanz, 2008). The fundamental principle of the HBM is that an individual's beliefs or perceptions regarding a health condition influence their behavior (Hayden, 2014). These beliefs encompass perceived susceptibility, perceived severity, perceived benefits, and perceived barriers.

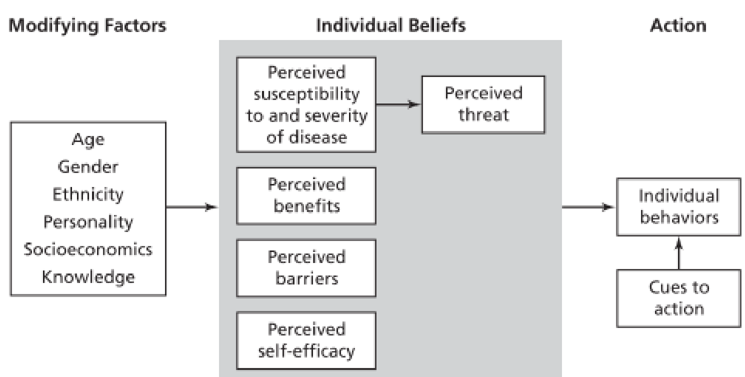

Figure 4 Health Belief Model (Glanz, 2008)

Perceived susceptibility refers to an individual's beliefs about the likelihood of contracting a condition. *Perceived severity* relates to an individual's beliefs about the severity of the condition. *Perceived benefits* are the beliefs that the new behavior will provide value or benefits in reducing the risk of the condition. *Perceived barriers* are the beliefs that obstacles or challenges that may hinder the adoption of the new behavior. According to the HBM, an individual is likely to adopt a new behavior if they feel threatened by their current behavior and believe that the new behavior will provide benefits at an acceptable cost.

5. Pediatric Self-Management Model

As discussed above, self-management is a multifaceted behavior that varies among individuals and their specific conditions. Although individual involvement is central to self-management, a range of factors, such as family support, clinical expertise, work/school environment, community resources, and policy considerations also play a role (Clark, 2003). Modi et al. (2012) proposed a conceptual model of self-management that provides insight into the behavior and its relationships with these various influences.

The Pediatric Self-Management Model is a conceptual framework for understanding self-management in pediatric care, which lists the individual-, family-, community-, and health system-level influences that affect adherence to treatments and, ultimately, outcomes (Modi et al., 2012). According to Modi et al. (2012), self-management consists of the health behaviors and related processes that patients and families engage in to manage chronic conditions. This definition presents self-management as a neutral concept. That is, efforts to manage one’s condition can either positively or negatively affect health outcomes, and these consequences are not always anticipated. Adherence, on the other hand, is defined as the extent to which a person's behavior aligns with medical or health advice.

As shown in Figure 5, self-management consists of three interconnected components: 1) self-management behaviors, which are situated at the center, 2) contextual variables that span across different domains, such as individual, family, community, and health system influences, and 3) self-management processes that connect these influences on self-management behaviors. The impact of domain-specific influences on self-management is mediated by cognitive, emotional, and social processes. Reviewing the extent to which self-management behaviors influence adherence and lead to positive outcomes can result in modifications of these behaviors (Modi et al., 2012).

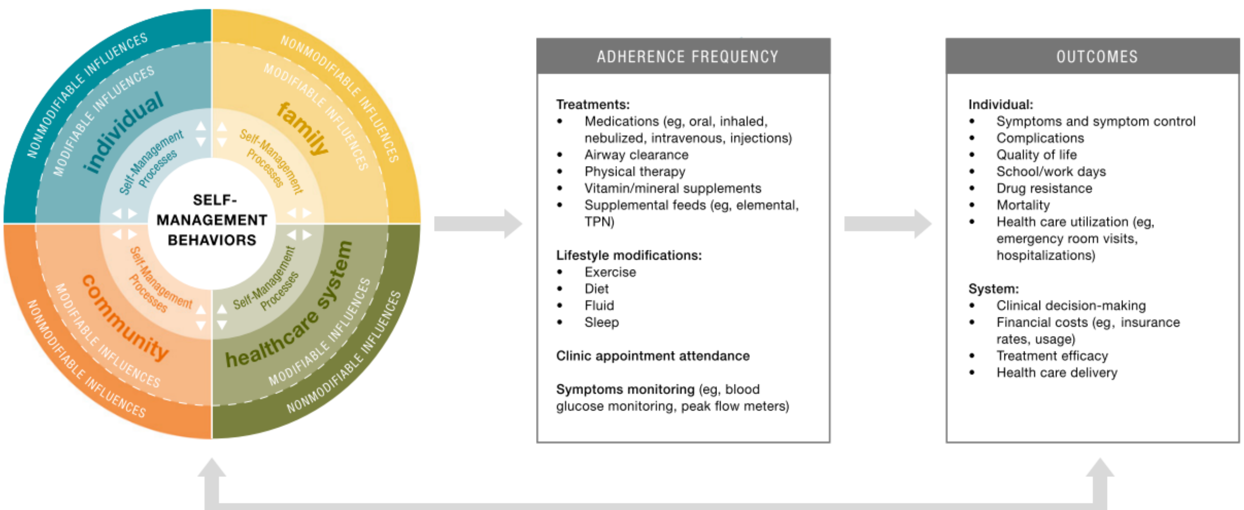

Figure 5 Pediatric Self-Management Model (Modi et al., 2012)

Self-management has been shown to improve health outcomes by increasing adherence to treatment plans and by fostering the individual's ability to overcome obstacles and find solutions (Lozano & Houtrow, 2018). Modi's Pediatric Self-Management Model was originally developed for pediatric self-management, but it was based on adult self-management as a generic approach. As a result, this model will be used as a reference for the system design and development process.

2.3 Self-Management Support

Support for self-management is crucial for individuals with chronic and complex conditions. Self-management supports (SMS) encompass services provided by health systems and community agencies to aid individuals with chronic conditions and their families in managing their health issues (Lozano & Houtrow, 2018). SMS involves collaboratively assisting individuals with chronic conditions and their family/relatives in acquiring the necessary skills, knowledge, and confidence to effectively manage their health problems, including regular assessments of progress and challenges, goal setting, and problem-solving support (Bodenheimer et al., 2002; Pearson et al., 2007).

2.3.1 Role of healthcare providers in facilitating self-management

Dwarswaard et al., (2016) investigated the type of support patients' needs to manage their chronic conditions, specifically from the patient's point of view. They distinguished three types of self-management support: 1) instrumental support, 2) psychosocial support, and 3) relational support. Additionally, Dwarswaard et al., (2016) discuss the "dynamic" of SMS, namely individuals' support needs are unique and changeable over time, based on the factors related to their diseases and to individual factors. Below is a description of the three types of self-management and the two factors that make SMS needs dynamic, according to Dwarswaard et al., (2016).

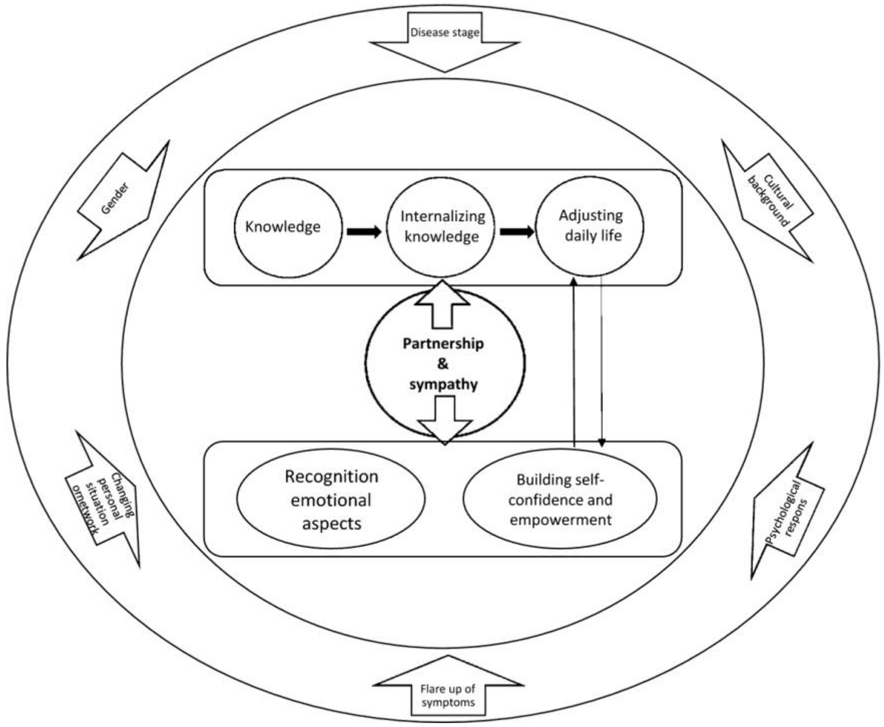

Figure 6 Interrelations between the identified patient needs (Dwarswaard et al., 2016)

1. Instrumental Support

   This type of support is related to the disease and focuses on its medical management. This support evolves in three stages:

   - Knowledge – gained from information and instruction the patient receives.
   - Internalizing that knowledge
   - The patient adjusting their daily life to incorporate the knowledge

2. Psychosocial Support

   This type of support is related to strengthening the emotional and psychological resources needed to manage the illness. There are two kinds of supports that emerge from the study:

   - Recognition of emotional aspects of the chronic condition
   - Building self-confidence and empowerment

3. Relational Support

   This type of support refers to helpful interaction with others, specifically partnership and sympathy.

4. Disease-related Factors of Dynamic in SMS

   The most important disease-related factor is disease progress. Every disease has different stages, and self-management behavior is related to these stages. Hence, a patient's need for support and information will vary depending on the disease itself and the stage of the disease.

5. Individual-related Factor of Dynamic in SMS

   This factor is related to the individual self, such as age, cultural background, and gender. The need for support and information should be age appropriate. Cultural background influences the need for support and preferred type of support. Talking about a specific disease could be taboo in a particular ethnic group, which will affect those individuals' willingness to join self-help groups or their confidence to ask for advice.

2.3.2 Barriers to effective self-management support

Providing effective self-management support to individuals with chronic conditions and disabilities is a challenging task that is hindered by various factors, including both patient-related and organizational-related barriers. The complex social, emotional, and medical needs of patients, limited health literacy, and the impact of multiple long-term conditions as well as symptoms of anxiety and depression are some of the barriers related to the individuals (Christensen et al., 2023; Kelly et al., 2022; Woodward et al., 2023). On the other hand, high staff turnover, insufficient time and resources for healthcare professionals, inadequate supervision, lack of support for staff, as well as inadequate social supports are some of the organizational-related barriers (Kelly et al., 2022). Other individual barriers could be fear of revealing one's condition, coupled with the uncertainty of disease patterns and the occurrence of flare-ups, and these barriers may hinder self-management, resulting in a feeling of powerlessness over one’s life, which could impact confidence (Dwyer et al., 2022). Additional barriers that can hinder self-management include unclear roles and responsibilities, legislative constraints, the cost of set-up, the cost of billing and coding education, and the sustainability of services based on current reimbursement models (Kelly et al., 2022). These financial barriers can contribute to poor mental health and well-being, making self-management especially challenging for PwCCD experiencing socioeconomic deprivation (Woodward et al., 2023). The impact these barriers can have emphasizes the necessity for healthcare providers to recognize the challenges faced by individuals with chronic conditions and to offer personalized, adaptable, and responsive support that involves patient participation in the development and execution of self-management interventions(Schoemaker et al., 2022).

2.4 Chronic Care Model (CCM)

The Chronic Care Model refers to framework for organizing and providing care to people with chronic disease (Edward H. Wagner et al., 2001). The model is widely used as an excellent tool for improving care at the individual and population level. There is significant evidence that the model is effective in chronic care management[2] and practice improvement (Woltmann, 2012).

[2] Chronic care management refers to care coordination provided outside of the regular office visit, for patients with multiple chronic conditions

This model was developed with the assumption that an improvement in the quality of chronic illness care would not be possible when only focusing on the efficaciousness of tests and treatments but would also require "system changes that produce better care and quality of improvement methods to implement such changes" (Woltmann, 2012). A collaboration that incorporates the patient, the healthcare provider, and the system is required for improvement of care.

Figure 7 The Chronic Care Model

The Chronic Care Model identifies the essential components of the healthcare system that encourage high-quality chronic disease care. ICIC divided the model into six components of healthcare delivery (see Figure 7), which are:

1. *Health System / Organizational Support*: related to organizational culture that promotes safe and high-quality care.
2. *Community Resources*: related to the mobilization of community resources to meet a patient's needs

3. *Self-Management Support*: empowers patients to self-manage their health and health care
4. *Delivery System Design*: assures the delivery of effective, efficient clinical care and self-management support.
5. *Decision Support*: promotes clinical care that is consistent with scientific evidence and a patient's preferences, such as clinical practice guidelines
6. *Clinical Information System*: organize a patient's and population's data to facilitate efficient and effective care.

2.5 Mobile Health Technologies

Mobile health (mHealth) refers to the use of mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices to support medical and public health practices (World Health Organization, 2011). It is a subset of a broader term, eHealth, which refers to health services and information enhanced through the Internet and related technologies, aiming to improve local, regional, and worldwide health care through networked, global thinking (Eysenbach, 2001). mHealth uses mobile devices and communication to deliver health care, aiming to increase access, engage patients in treatment, improve post-treatment care, and monitor treatment progress. Mobile devices offer a ubiquitous, accessible platform for mHealth, recording a wide range of data including audio, video, location, time, and device kinematics, making mobile devices widely adopted.

Mobile health technology has evolved over time with the introduction and dominance of smartphones. Initially, mHealth was seen as a transformative area for healthcare, but it became focused on smartphone applications and services, leading to a divide between the commercialization of mHealth and the scientific aspects of health management (Istepanian, 2022).

The evolution of mHealth research has been closely tied to changes in mobile technologies, with personal digital assistants (PDAs) dominating before 2007, basic and feature phones being used from 2007 to 2012, and smart devices (smartphones, tablet PCs, and iPod touches) being widely used after 2012(Ali et al., 2016; Istepanian, 2022).

mHealth technology has revolutionized the treatment of chronic conditions by providing person-centered, accessible, and scalable tools (Executive Board, 2017). Utilizing mobile and wireless information and communications technologies, mHealth integrates sensors, movement, light, proximity sensors, and Bluetooth technology into mobile devices, apps, and wearable technologies (eHealth, 2011). This evolution has improved healthcare accessibility and availability, enabling individuals to monitor their health, receive personalized interventions, and access resources remotely. The integration of various sensors and technologies in mHealth has made it a more convenient and accessible approach to managing chronic conditions. The use of mobile technology has made it convenient to monitor health in real-time, leading to the generation of big data in the healthcare industry (Saxena & Saxena, 2020). Clinicians have become more willing to accept mHealth technologies and use patient-generated data over time, but there are still barriers to using mHealth in clinical practice (Bradway et al., 2018).

The use of mobile health devices, such as smartphones, has been validated in supporting self-management and monitoring adherence, particularly in populations with chronic conditions, such as spina bifida (Parmanto et al., 2013). Review of mHealth for general chronic conditions management showed a beneficial impact of mHealth in chronic disease management, such as improving symptoms, reducing hospitalizations, and reducing weight in overweight and obese patients (Allegrante et al., 2019). Hamine et.al. (2015) reviewed the use of mHealth to facilitate adherence to chronic disease management of diabetes mellitus, cardiovascular disease, and chronic lung diseases from 1980 to 2014, and they found that the short message service was the most commonly used tool, with usability, feasibility, and acceptability being generally high. Half of the studies reviewed showed significant improvement in adherence behaviors when mHealth was employed.

Despite the potential mHealth has to support self-management for person with chronic conditions and disabilities (PwCCD), such as providing practical support, monitoring, and easy access to advice or support, the evidence supporting mHealth's current effectiveness is mixed, and further research should focus on understanding and improving how mHealth tools can overcome barriers of adoption, such as acceptance of technology, complexity of the user interface, lack of technology skills, lack of digitization of medical data, access to individual data security, and age-related physical and cognitive decline (Hamine et al., 2015; Lukkahatai & Junxin, 2022; Stefanicka-Wojtas & Kurpas, 2022). A review conducted by Bernard et.al (2023) focusing on mHealth technologies to support individuals with SCI found that almost half of the identified tools were highlighting accessibility, design, and information quality concerns. They also reported that mHealth tools do not address all self-management tasks, such as medical/behavioral management, role management, and emotional management. Research has demonstrated that mHealth interventions can be effective for the cerebral palsy (CP) population. However, the low methodological quality of scientific articles makes it challenging to generalize the use of mHealth interventions in the healthcare sector (Rodríguez Mariblanca & Cano de la Cuerda, 2021). According to available studies, mHealth applications designed for PwCCD typically feature elements like physical activity monitoring, personalization, and customization. However, there has been a lack of attention given to other important aspects of comprehensive self-care management, such as social support and patient-physician partnership (Glassgow et al., 2019; Kheirinejad et al., 2023).

The focus of mHealth research has primarily been on chronic medical conditions, but there is potential for it to expand to other areas of healthcare delivery (Fiordelli et al., 2013). The advancements in mobile technology have also led to the collection of big data in healthcare, which can contribute to real-time monitoring and personalized medicine (Saxena & Saxena, 2020).

2.6 Integrated and Adaptable Support Systems

Chronic disease management is a systematic approach to managing chronic illnesses that focuses on patient-centered care, team-based care, action plans, regular monitoring, education, and self-management support (Glassgow et al., 2019). It involves collaboration among healthcare professionals, patients, and caregivers to provide comprehensive care. Action plans outline specific goals, interventions, and self-management strategies for PwCCD. Regular monitoring helps track progress, adjust treatment plans, and address emerging issues. Education and self-management support empower patients to participate in their care and make informed decisions. Preventive measures, such as lifestyle modifications, are prioritized to improve overall health outcomes.

2.6.1 The concept of adaptability

The ability to adapt is the ability to adjust or modify oneself, a system, or a behavior in response to changes in the environment or circumstances (Oppermann, 2005; Tzafestas, 2018;

Ulanowicz, 2002). In healthcare research, adaptability refers to the customization of interventions or treatments to meet the specific needs and characteristics of individuals or populations. Additionally, it can involve the modification of existing interventions or strategies to improve their effectiveness or relevance in different settings or populations. In the context of mHealth technology, the importance of adaptation lies in the development of personalized and customizable healthcare solutions that can be tailored to individual needs and preferences.

In the field of software development, it is common practice to adjust system characteristics during either the development or operational phase to accommodate the dynamic nature of changing environments (Oppermann, 2005). The use of adaptation techniques in systems is a common practice among developers in order to quickly respond to changing conditions. However, it is important to differentiate between two types of adaptation techniques: manually and automatically performed processes. The term "adaptation" can be further broken down into two terms: "adaptivity" and "adaptability" (Oppermann, 2005).

Adaptivity refers to a system's ability to automatically adjust to the needs of users in response to evolving circumstances. This type of system is known as an *adaptive system*. The term *adaptiveness* can also be used in a similar manner. An adaptive mHealth system typically employs adaptive intervention, and the adaptation process is triggered automatically by the system. This type of automatic adaptive intervention is called just-in-time adaptive interventions (JITAI). With JITAI, the adaptation of the intervention is triggered automatically by the system when it is needed, at the right time and with the right type of support based on the data collected dynamically by the system (Hardeman et al., 2019; Nahum-Shani et al., 2014; Naughton, 2017). Adaptive intervention refers to an intervention that provides varying levels of prevention or treatment components to individuals over time based on their unique needs (Collins, 2018; Collins et al., 2004). mHealth technology, utilizing portable devices, enhances intervention delivery by providing real-time feedback, enabling the design of interventions aimed at delivering behavior change support as soon as it is needed. Other terms have been used in similar manner as JITAI, such as context-aware interventions, ecological momentary interventions (EMIs), and real-time interventions (Hardeman et al., 2019).

On the other hand, *adaptability* refers to the ability of users to modify the system through personalized configuration. This type of system is known as an *adaptable system*. This dissertation will focus on this type of adaptation, particularly in the context of chronic illness management. This is a complex area, as individuals with chronic illnesses often have multiple conditions simultaneously (*comorbid)*, and the nature of these conditions can change over time. In addition, the social environment plays a role in their health. By adapting the treatment to these changing circumstances, an "adaptable mHealth system" can ensure that the treatment remains effective and relevant.

It is important to note that this distinction does not mean that adaptive and adaptable systems are mutually exclusive. Rather, both methods are complementary to one another, and their combined use increases the likelihood that the system will be able to meet the needs of its users and remain flexible throughout its usage (Oppermann, 2005).

2.6.2 Adapting to the changing needs of individuals

Chronic conditions are characterized by their ever-changing nature and the varying life situations they present. Both with and without proper treatment, chronic conditions can lead to changes in the health of the person experiencing them. Emotional well-being is also a significant factor, and dealing with chronic conditions can often result in PwCCD experiencing feelings of frustration and depression. As the chronic conditions change, the PwCCD’s emotions can fluctuate, necessitating a comprehensive treatment strategy that includes specialized psychological and emotional support. Adjustments to treatment plans are necessary when emotional states change due to physical changes, such as when a patient is dealing with pressure sores. Personalization is crucial in managing chronic conditions, as self-management strategies need to evolve with the individual's progress. This emphasizes the importance of adaptability and tailored treatment in enhancing the overall well-being of those with chronic conditions.

2.6.3 Integrated solutions for comprehensive care

Managing long-term health conditions and disabilities is a complex and demanding process, especially when there are multiple conditions present and care requirements are multifaced and evolve over time. It can be a significant time commitment for individuals, healthcare professionals, and caregivers, and incorporating self-management strategies into daily routines can be difficult. Therefore, it is essential to foster collaboration among all stakeholders involved to facilitate informed decision making and promote positive health outcomes. The need for patient-centered and integrated approaches to care can be met with an integrated mobile health (mHealth) system that can provide a range of supports and facilitates care collaboration by providing real-time monitoring and reporting, as well as point-of-care interaction. This integration enables the provision of self-management support within a single app, facilitating collaborative care coordination among all parties involved. Real-time monitoring and reporting allow for prompt responses to client concerns. To effectively manage chronic conditions and disabilities, it is crucial to have integrated and adaptable systems.

2.7 mHealth Evaluation

To create an mHealth app that is inclusive, accessible, and effective for individuals with chronic conditions and disabilities, several key factors must be considered during development and usability evaluation. These factors include employing a user-centered design approach, incorporating personalization and adaptability, ensuring accessibility, prioritizing privacy and security, integrating with wearable devices, conducting usability testing, and implementing regular updates and feedback loops (Krug & Matcho, 2010; mHIMSS App Usability Work Group, 2012; Nietzio et al., 2012; World Health Organization, 2011). By considering these elements in the development and usability evaluation of the app, it can be tailored to meet the unique needs of its diverse user base and can be easily used over time without expending unwarranted effort (Bernard et al., 2023).

Usability testing is a widely used method in user-centered interaction design that aims to assess the usability of a product by employing a group of representative users (Sauro & Lewis, 2016). Usability, as defined by ISO 9241(ISO, 2018), refers to the extent to which a product can be utilized by designated users in achieving specific goals with effectiveness, efficiency, and satisfaction in a particular context. The usability of a product is associated with these five factors (Sauro & Lewis, 2016):

1. *Learnability*: The system should be easy to learn so that the user can rapidly start getting some work done with the system.
2. *Efficiency*: The system should be efficient to use, so that once the user has learned the system, a high level of productivity is possible.
3. *Effectiveness*: The system should be able to support the user in a high degree of accuracy while performing the associated task.

4. *Errors*: The system should have a low error rate, so that users make few errors during the use of the system, and so that if they do make errors, they can easily recover from them. Further, catastrophic errors must not occur.
5. *Satisfaction*: The system should be pleasant to use, so that users are subjectively satisfied when using it; they like it.

There are no specific guidelines on how to measure these five factors. However, a large survey of usability test reported by (Sauro & Lewis, 2009) shows that most tests contain a combination of completion rates, errors, task time, task-level satisfaction, test-level satisfaction, and lists of usability problems that address levels of problem frequency and severity.

1. *Completion Rates*, also known as success rates, are typically collected as a binary measure of task success (coded as 1) or failure (coded as 0). Completion rates on a task are calculated by dividing the number of users who successfully complete the task by total number of users who attempted it.
2. *Time to Complete*, or task time, is how long a user spends on a task. Most often, this is the amount of time it takes for a user to complete a task.
3. *Errors* are any unintended action, slip, mistake, or omission a user makes while attempting a task. Typically, the number of errors is collected in conjunction with the type of the error. Errors provide excellent diagnostic information on why a user is unable to complete the task (Sauro & Lewis, 2016).
4. *Satisfaction rating* is an overall measure of users' satisfaction with the system, reflecting their subjective feelings and opinions about their interaction. This can be completed either

immediately after a task (post-task questionnaire) or at the end of the usability session (post-test questionnaire).

Usability can be measured using various instruments, such as the System Usability Scale (SUS)(Brooke, 1996), Post-Study System Usability Questionnaire (PSSUQ) (Lewis, 1992), Telerehabilitation Usability Questionnaire (TUQ) (Parmanto et al., 2016), and the mHealth App Usability Questionnaire (MAUQ)(Zhou et al., 2019), which is the most recent measurement instrument. These instruments provide quick and reliable assessments of a system's perceived usability, user experience, information quality, interface quality, ease of use, usefulness, satisfaction, and usability of specific features. In light of the research objective, target population, and the simplicity of the instrument, this study will utilize two questionnaires: SUS and TUQ. The SUS was selected due to its brevity, consisting of only a few questions. Conversely, TUQ was chosen as the most appropriate measure for an mHealth system, because mHealth is one form of telerehabilitation. At the time of development and evaluation, MAUQ was unavailable.

The SUS, which was first published in 1996, is a post-test assessment instrument that delivers a comprehensive evaluation of subjective user assessments of usability. It evaluates the user's perception of usability and user experience, as well as the ease of use, learnability, and user-friendliness of the software. Additionally, it offers insights into the effectiveness, efficiency, and satisfaction of software interaction. The scale comprises 10 Likert-rated items that users rate on a scale from strongly agree to strongly disagree and provides quantitative data on user satisfaction. Since its inception, it has emerged as the most widely utilized post-task and post-test scale for measuring user satisfaction in usability testing. The TUQ is an effective and comprehensive measure of the quality of computer-based user interfaces and telehealth interactions and services.

Comprised of twenty-one questions, the TUQ evaluates various usability factors, including usefulness, ease of use, effectiveness, reliability, and satisfaction.

2.8 Vignette as Methodology in mHealth Research.

Vignettes are short narratives that depict fictional scenarios or characters and have been utilized in healthcare education and research since the 1950s. These narratives are derived from personal clinical experiences, are realistic, clear, and relevant to the subject matter, and are concise with language appropriate for the intended audience (St. Marie et al., 2021). Although vignette-based methodology is not commonly utilized in qualitative studies involving healthcare professionals, it is recognized as an effective approach for reflecting on and allowing participants to discuss sensitive topics such as adversity, team functioning, and ethical dilemmas in a safe and controlled environment (Tremblay et al., 2022). Vignettes are also valuable in intervention research, as they facilitate collaboration between experts in the field and researchers to identify problems and develop solutions (Tremblay et al., 2022).

Vignette methods are considered the most efficient and effective methods of identifying and describing healthcare clinician decisions (Payton & Gould, 2022). They have been shown to accurately measure the actual practice variation and quality of care delivered by clinicians. Vignette methods are cost-effective relative to other methods of measuring quality of care.

2.8.1 Vignette development framework.

The use of vignettes as a tool for describing hypothetical characters in specific situations is considered effective, although there is no universally accepted definition or application in mHealth research (McInroy & Beer, 2022; St. Marie et al., 2021). This lack of consensus has led to a variety of uses, including both fictional scenarios and real-life events. Despite the lack of clarity in the literature regarding the utilization of vignettes, there is a need to overcome identified risks to quality by reporting an explicit definition of vignette-based methodology, details about vignette development steps (internal validity), and a rich description of vignette utilization (external validity). Matza et al. (2021) attempt to offer a development framework in building vignettes, particularly in the healthcare domain.

Before undertaking a vignette-based study, it is essential to evaluate the justification for this method, as per Matza et al. (2021). The vignette approach offers several advantages, one of which is its ability to approximate events in individuals with medical conditions and treatment attributes that may be difficult or impossible to obtain in real life. Matza et al. (2021) identify several instances in which vignette methods may be beneficial:

1. For patients who are challenging to access, such as those with rare diseases, young children, or patients with debilitating impairments or highly intensive treatments, a vignette study may be the only feasible way to estimate.
2. In cases of acute and temporary health states, vignette-based methods can be used to estimate the effects of medical conditions that involve flares or exacerbations, where it may be challenging to administer measures during these temporary events.

3. For health states that change over time, a "path state" vignette can represent a patient's progression through a sequence of temporary experiences in the typical course of a medical condition and its treatment.

Matza and colleagues (2021) propose a method for creating vignettes that involves the following steps:

1. Determine the number of vignettes that will be developed, along with the expected level of detail. These decisions should be based on anticipated modeling needs, while considering feasibility of the eventual valuation task. 2. Obtain evidence to inform vignette content. Vignettes must be supported by the best available evidence. Possible sources of support include: • Publicly available citations including published scientific literature, information from established medical organizations, medication labels, and/or medical device instructions for use • Qualitative interviews (or group discussions) with individuals who have insight into the relevant medical condition or treatment (e.g., patients, clinicians, caregivers) • Quantitative data (e.g., patient-reported outcome measures in clinical trials) • Qualitative analysis of social media data such as online patient discussion forums 3. Draft the health state descriptions. General principles include: • Vignettes should be designed to maximize comprehension (e.g., brief descriptions, simple language, avoid medical jargon) • Vignettes should represent the typical patient experience. • Vignettes should be designed to facilitate comparison between health states with parallel structure when appropriate. • Supplemental materials such as images, videos, and medical devices may be used to provide respondents with a more accurate understanding of the health states. • Avoid uncertainty in health states as much as possible. • Consider advantages and disadvantages of naming the disease in the health state (i.e., the disease label).

- Format vignettes to maximize comprehension and reduce error in the valuations (e.g., bullet points, large clear font, generous spacing, headings, colors, bolding, shading)

4. Refine the vignettes: The initial draft should be edited and refined based on two sources of information.
   - Clinicians and/or patients should review the draft health states to confirm that they clearly and accurately represent the typical patient experience.
   - The vignettes and utility valuation methods should be tested in a pilot study to assess clarity and comprehension of the health states, as well as the number of vignettes each participant can value.

Although the insights generated by the vignette approach can provide valuable information, it is essential to acknowledge the limitations and potential biases associated with this method (Matza et al., 2021).

2.8.2 Application of Vignettes

Researchers employ vignettes in a variety of studies for diverse purposes. Vignettes are often used as a research tool to evaluate health communication programs by gathering responses on hypothetical individuals' attitudes, beliefs, and behaviors (Riley et al., 2021). They are also used in qualitative social work research to efficiently elicit values, attitudes, and decision-making processes (Bain, 2024). In both quantitative and qualitative research, vignettes are used to collect comprehensive data, particularly in cross-cultural research (Erfanian et al., 2020). In educational research, vignettes are used to explore value-laden constructs such as teacher beliefs and understandings (Skilling & Stylianides, 2020). In health communication research, vignettes are utilized to elicit responses on hypothetical scenarios, attitudes, beliefs, and actions, providing insights into individual-level attitudes, behaviors, and knowledge (Su & Steiner, 2020).

Vignettes have been widely used for simulation and system evaluation in various fields such as education, healthcare, and information systems. They provide a visual representation of plausible situations and help measure processes in different practice settings (Butler & Wallentine, 1991). To create vignettes systematically, one can determine the content elements, choose a realistic scenario, draft a script, and assess the concepts illustrated (Stacey et al., 2014). For instance, vignettes can be used to simulate patient profiles and symptoms to evaluate diagnostic algorithms and differential diagnostic systems (Satyal et al., 2020). In addition, vignettes can be utilized in information systems courses to promote better teamwork by presenting potential team problems and setting expectations for team member performance (Cappel, James J., 2008). Moreover, filmed vignette monologues have been used as a cost-effective method to evaluate and compare how different users record the same clinical scenario in electronic healthcare records (Glew et al., 2018).

3.0 An Integrated and Adaptable mHealth System to Support Individual with Chronic Conditions and Disabilities: Design and Development of iMHere 2.0

3.1 Introduction

The iMHere system was created through years of collaborative work by an interdisciplinary research team on self-management support for PwCCD. In 2005, the team developed a face-to-face wellness program for individuals with SB and received funding support from the Highmark Foundation (Brad E. Dicianno, M.D.; Pamela Peele et al., 2012). Based on the information gathered from the wellness program, the team developed a tele-rehabilitation system called iMHere 1.0 to deliver the same services (Parmanto et al., 2013). The iMHere 1.0 system consisted of an mHealth app for PwCCD and a web-based portal for clinicians, connected by a two-way secure communication protocol. Several studies were conducted to evaluate this system, and a substantial amount of feedback was collected (A. D. Fairman et al., 2013, 2016; Parmanto et al., 2013, 2015; D. X. Yu et al., 2017; D. X. Yu, Parmanto, Dicianno, & Pramana, 2014). To prepare for a clinical trial on Spina Bifida (SB) and Spinal Cord Injury (SCI) populations, various adjustments were made to the iMHere 1.0 system (Dicianno et al., 2016; A. Fairman et al., 2016). Over time, feedback was collected from 265 participants, including from PwCCD, caregivers, and clinicians.

Based on the feedback provided by users of iMHere 1.0, it was determined that further improvements were necessary that could not be achieved through simple refinements to the existing system. To address these suggestions and expand the iMHere system to include various diagnoses, such as Cerebral Palsy (CP), and different demographics, including children as young as 12 years old, a significant architectural change to the system was required. This change provided an opportunity to add additional features designed to offer greater support and compatibility with multiple platforms, primarily Android and iOS devices. The compatibility enhancement enabled participants to use their personal devices through a Bring Your Own Device approach, and it also supported collaborative care among PwCCD, physicians, and caregivers.

This chapter focuses on the design and development process of the iMHere 2.0 system, which represents the next generation of the iMHere platform. The chapter highlights the evolution of the iMHere system, tracing its development from its initial inception to its current state. This process utilized user feedback, technological advancements, and healthcare trends to refine the system. The iMHere 2.0 system employs mobile technology and cloud computing to deliver adaptable and personalized self-management support to PwCCD. This system is designed to meet the unique needs and conditions of these individuals, allowing them to effectively manage their health and potentially prevent secondary conditions, thereby improving their quality of life.

3.2 Methods

3.2.1 Feedback from past studies

To start this project, the information and experience gained from previous studies were gathered and analyzed to gain insight and direction for developing the next generation of iMHere. Table 2 provides a concise summary of the studies on self-management support for PwCCD, along with funding support details. From these studies, approximately one hundred crucial feedback items were collected. Several themes emerged that were extremely helpful in shaping the design of the new system. In addition to new feature requests, the themes that emerged included improvements in the accessibility of the app, scheduling flexibility, cross-platform support, reward mechanism support, privacy-related concerns, and support for another language. More details on these feedback summaries can be found in Appendix A.1.

Table 2 Timeline of studies on self-management support for PwCCD

Detail Timeline	Description	N	Reference(s)
2005 -- Original Wellness Program was developed for persons with Spina Bifida 2006 -- Funding obtained from the Highmark Foundation initiated	In-Person Pilot Program for young adults with SB	31	(Brad E. Dicianno, M.D.; Pamela Peele, 2012)
2009 R3 study developed for submission to RERC-TR renewal	Survey Respondents Including persons with SB, family members and clinicians	107	(A. D. Fairman, 2013)
March 2010 Software development of iMHere 1.0 started	Not applicable		(Parmanto, 2013)
April 2011 - February 2012 Usability and accessibility testing of iMHere 1.0 Modules in R3 study	Adults with SB, N=14. Adults with SB, specifically persons with dexterity impairments, N=6, N=9. Phase I, adults with SB age 18-40 years, N=7.	35	(Parmanto, 2013; D X Yu, 2014; Daihua X Yu, 2017) (A. D. Fairman, 2016)–Phase I
Dec. 2011 – October 2013 R3 Randomized Controlled Trial (RCT)	Adults with SB age 18-40 years Intervention Group, N = 13	23	(Brad E. Dicianno, 2016)
July 2013 Grant submitted to Neilsen Foundation, RCT	Adults with SCI age 18+ years Intervention Group, N=19	31	(A. Fairman, 2016) One in Process
SBIR CDC Grant	Phase II, rehabilitation professionals, N=25. Phase III, PwCCD age 18+ years, N=13.	38	(A. D. Fairman, 2016)-Phase II & III

3.2.2 Initial development

The iMHere 2.0 system was developed through an iterative process, involving users at every stage of its design, development, and evaluation. The general workflow of the system is illustrated in Figure 8. The needs and preferences of individuals with diverse diagnoses and demographics were taken into account, as they provided valuable input and feedback throughout the process. The iMHere 2.0 system was carefully designed and refined to ensure its effectiveness and usability for a wide range of users.

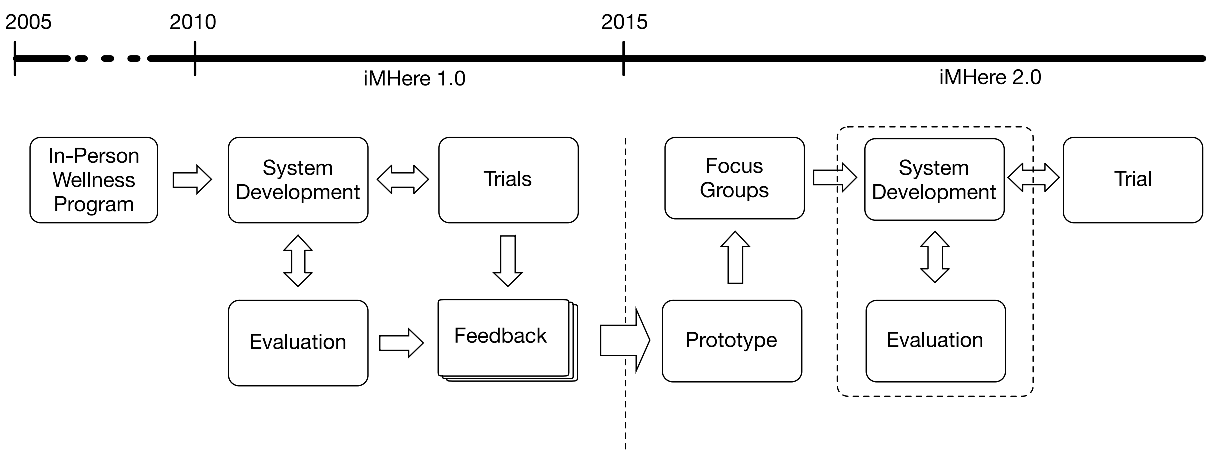

Figure 8 Timeline and workflow of the iMHere 2.0 system development

Employing a user-centered approach (UCD) was essential for the development of the upgraded system, as our aim was to extend its use to various diagnoses and demographics. To gather insights into the additional requirements, focus groups and surveys were utilized as data-collection methods. These methods were employed to gain a better understanding of the user needs, particularly for long-term self-management among the expanded target population, which included adolescents as young as 12 years old and their caregivers. The initial prototype of the application was created by leveraging feedback from the iMHere 1.0 system, and it was tested during the focus groups. The results from the six focus groups, involving 16 youth and young adults with brain and spinal anomalies and 11 caregivers, identified five main themes, as detailed in Bendixen (2017). These themes were: 1) make it easy, 2) engage, 3) educate and prepare, 4) motivate and support, and 5) personalize.

3.2.3 System Requirements

The findings from the previous studies and the themes elicited from the focus groups are highly consistent, and they reveal that a significant architecture change was necessary to improve the iMHere platform. Following are several major changes incorporated in the iMHere 2.0 system in response.

- Redesign of the overall architecture of the system to make it scalable and convenient to add more components and new mobile app modules into the system
- Implementation of adaptable intervention approaches to allow the system to address different characteristics and needs in different individuals and within individuals over time
- Incorporation of social support from caregivers via a mobile app in order to maintain PwCCD's long-term engagement in the mHealth system (Bendixen et al., 2017)
- Ability of the mHealth apps to run on different platforms, including Android and iOS, which makes the iMHere 2.0 system available to almost any PwCCD
- Enhancement of the five existing mobile app modules of iMHere 1.0, and addition of seven new modules to meet the need for diverse types of self-management support
- Addition of accessibility features to increase the ease of use of the mobile app, especially for individuals with fine motor and visual impairments (D. X. Yu et al., 2017)

3.3 System Design

3.3.1 Stakeholders

Managing chronic conditions and disabilities is a daunting task that requires PwCCDs to alter their behavior. It is a time-consuming process that involves the individual, healthcare providers, and family members or caregivers. It is not an easy process to incorporate self-management support into one's daily routine and practice. However, a collaborative relationship among all parties involved has been found to be useful in supporting individuals in making good choices and maintaining healthy behaviors (Woltmann et al., 2012).

Several stakeholders play a role in providing services and support to PwCCD (Bendixen et al., 2017). These stakeholders include, but are not limited to, family members or relatives (such as parents and siblings), professional caregivers, healthcare professionals (such as clinicians and nurses), community health workers (such as attendants, service workers), friends or partners, care coordinators (such as case managers), service coordinators (such as service managers), and agencies or service providers.

The level of support required by individuals with chronic conditions varies depending on the severity of their conditions and disabilities, as well as the availability of support from stakeholders and funding. As shown in Figure 9, the spectrum of support needed ranges from complete independence, where the individual is able to perform daily activities without assistance, to full dependence, where strong support from caregivers and other services is necessary.

3.3.2 System Implementation model

A study of the relationships between stakeholders and PwCCDs leads to three possible design models for implementing the system, which are illustrated in Figure 9: the consumer model, the medical model, and the community-based model. Each implementation model presents a different approach to actualizing the system design. These models play a crucial role in steering the development process towards attaining the specified goals.

Figure 9. Relationship matrix between stakeholders and condition of person with disabilities (Possible combinations of interactions exist beyond what is represented on this chart)

1. The Consumer Model enables users to use the system independently, without the involvement of a clinician or wellness coordinator.
2. The Medical Model allows clinicians or wellness coordinators to become involved in the treatment process, provide suggestions, and monitor progress. Their involvement is integrated into the system.
3. The Community-based Model enables community service organizations to maintain close contact with their clients and provide care/service coordination through the system.
4.

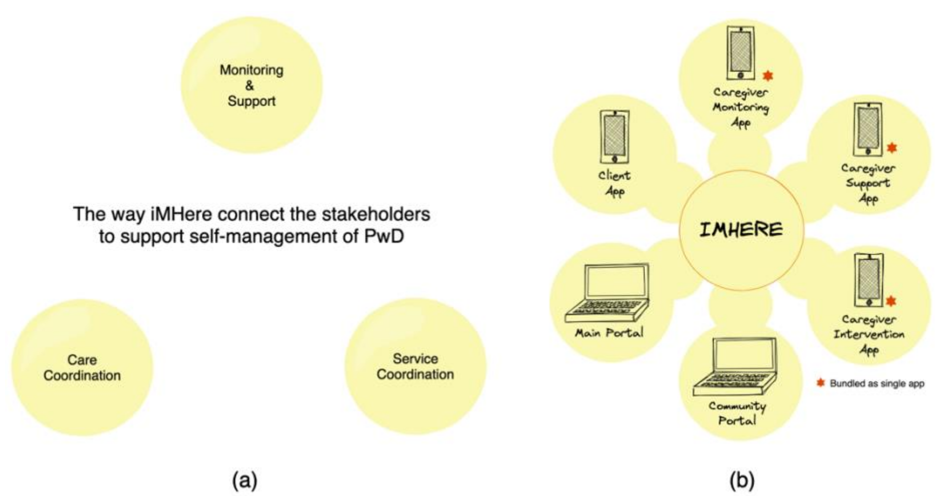

Figure 10. a) Roles of the system, b) components of the system to enable collaborative relationship between stakeholders

The iMHere 2.0 system aims to achieve three primary and necessary objectives in the context of self-management: monitoring and support, care coordination, and service coordination. To operationalize these roles, the system includes several key components: a customized Client app for PwCCD, a dedicated Caregiver app for the caregiver, and a comprehensive Web Portal designed for coordinators to streamline the care and service coordination processes Figure 10.

These components work together to equip users with the necessary tools and resources to manage their health effectively, while also enabling seamless communication and collaboration among all stakeholders involved in the care process.

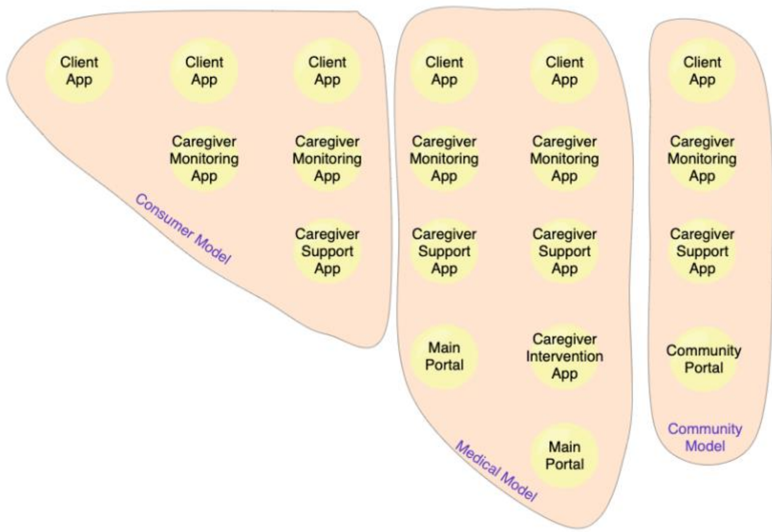

Figure 11. Utilization of the system components

Figure 11 illustrates the various combinations of system components based on the implementation approach. In the consumer model, the primary component is the client app, which may be accompanied by the optional caregiver apps. In contrast, the medical model integrates the client app, caregiver app, and a web portal dedicated to care coordination. The Community model encompasses the client app, caregiver app, and a community portal specifically designed for service coordination. These variations in the configurations of components permit customized system implementations that address a wide array of individual user requirements and organizational settings.

3.3.3 A Scalable System Architecture

The iMHere 2.0 system comprises five components, including a client app, a caregiver app, a web-based clinician portal, a backend server, and a secure communication protocol. The client app, caregiver app, and web-based portal are front-end components that face the user.

The client app is designed for the PwCCD to manage their care using a set of modules tailored to their needs. The app can synchronize care data across multiple personal mobile devices, the caregiver's app, and the web-based portal. The caregiver app enables family members, friends, and professional caregivers to monitor and provide social support to the PwCCD. Both the client and caregiver apps are compatible with Android and iOS phone systems. The web-based portal displays data from the client app, allowing clinicians to evaluate the PwCCD's progress and adjust intervention regimens as needed. Clinicians can update their intervention strategies for an individual PwCCD in real-time via the web-based portal and synchronize it with the client and caregiver apps. The secure communication protocol enables real-time communication between all three front-end components.

All three components are interconnected and supported by a highly scalable backend server that employs micro-services to amplify its capabilities, as depicted in Figure 12. Micro-services involve breaking down applications into smaller, independent services that can be developed and deployed individually (Wolff, 2018). This approach enables us to extend the iMHere 2.0 system without disrupting the other existing components. For instance, we can add a new app module to the iMHere 2.0 system for PwCCD to address unmet needs in the current version; we can also connect the iMHere 2.0 system with an external EHR system to exchange patient information.

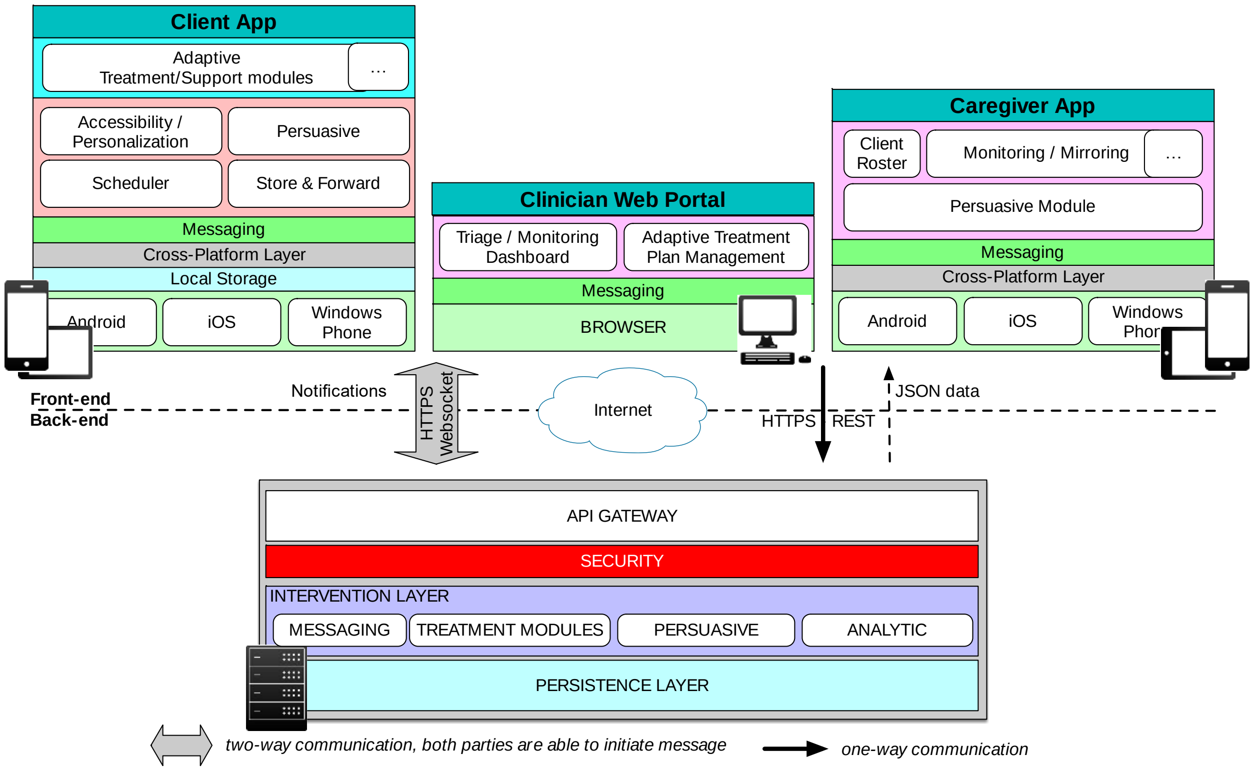

Figure 12. The architecture of the iMHere 2.0 system.

The scalable system architecture provides a foundation for creating various types of self-management app modules to accommodate the diverse needs of PwCCD. The following section outlines 12 app modules developed on this scalable architecture to demonstrate this capability.

3.3.4 A Web-Based Clinician Portal for Personalized and Adaptable Interventions

The web-based portal's primary function is to enable clinicians to develop tailored treatment plans for PwCCD, monitor their conditions and adherence to intervention regimens, adjust the regimens as needed based on PwCCD's progress, and communicate with PwCCD via instant messaging, as illustrated in Figure 13. The portal provides clinicians with all the necessary information regarding PwCCD's adherence to intervention regimens and data from the client app to evaluate PwCCD's progress. If clinicians need to discuss any issues with PwCCD, they can use the messaging feature to communicate with them. Once clinicians make any adjustments to PwCCD's treatment plan on the web-based portal, the changes are immediately synced with the client and caregiver apps.

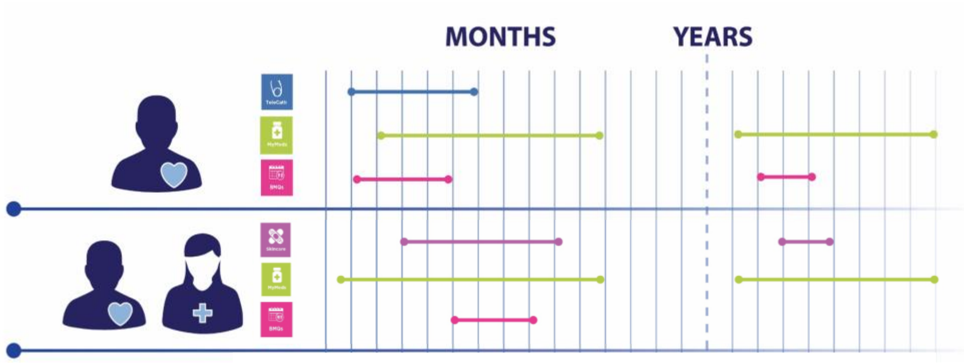

Figure 13 Different support between clients and for one client across time. The icon and color of the line correspond to a specific app module and the length of the line shows the duration of using each app module.

3.3.5 Client App Modules for Diverse Self-Management Needs

The iMHere system initially consisted of five core modules: MyMeds, BMQ, TeleCath, Mood, and Skincare. Following feedback collection, these modules were revised, and additional modules were introduced to enhance the system's capabilities. The update focused on providing more flexible scheduling options and improving accessibility. The updated modules enable users to create detailed schedules for reminders, including the ability to create separate schedules for weekdays and weekends, as well as hourly-based schedules. To aid in skin assessment, a customized camera feature was added to the Skincare module, which guides users in taking consistent wound pictures. Furthermore, a physical button was included to trigger the camera, in addition to the soft button on the screen (D. X. Yu, Parmanto, Dicianno, & Pramana, 2014; D. X.

Yu, Parmanto, Dicianno, Watzlaf, et al., 2014). These five updated modules are designed to provide support for medication management, bowel management, bladder self-catheterization, mood assessment, and skin problem reporting and tracking, respectively. For instance, the latest version of the MyMeds module includes a mechanism for tracking PRN medication intake, such as medication for pain.

Given that the client application is intended for long-term use, conducting complete screening tests for depression and anxiety using the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder (GAD-7) on a weekly basis may impose a significant burden on users. Consequently, the updated Mood module utilizes shortened versions of these two instruments, namely PHQ-2 and GAD-2 (Kroenke et al., 2003, 2007). If the screening results are positive, a subsequent evaluation needs to be performed using the comprehensive PHQ and GAD versions.

In all five modules, a feedback mechanism was added to inform the user of their adherence status. This feature was designed to provide users with real-time information on their progress towards achieving the desired level of compliance and to help them stay on track and make any necessary adjustments to meet the requirements. The implementation of this feature was intended to improve overall user experience and increase the likelihood of successful adherence.

The other seven app modules were entirely new and have been incorporated into the iMHere 2.0 system to offer a broader range of self-management support options to PwCCD. These app modules are described below:

1. *Exercise:* This module enables PwCCD to monitor and record their daily physical activity, including the duration of each activity. A comprehensive list of 49 activities, such as stretching, hand-cycling, gardening, shopping, strolling, and horseback riding, is provided in the activity

library to facilitate selecting each activity and recording its duration. Additionally, PwCCD have the option to add new activities that are not included in the library.

2. *Nutrition*: This module incorporates a version of the MyPlate program, which has been slightly modified to align with PwCCD's needs (Department of Agriculture, n.d.). The module empowers PwCCD to track their daily food and drink consumption by indicating the serving amounts for each category. It covers a wide range of food and drink categories, including water, fruit, vegetables, grains, protein, dairy, cheese, fast food, snacks, and caffeine.
3. *Education*: This module is comprised of 12 major sections that cover topics essential to facilitating self-management routines, such as information about Spina Bifida, Cerebral Palsy, Spinal Cord Injury, skin integrity, bowel and bladder management, exercise, nutrition, time management, relationships, stress management, and anxiety. This module can deliver health-related information to PwCCD that is tailored to their specific conditions. Various types of information delivery approaches are included in the Education module, including text, pictures, audio, and video. Self-assessment in the form of quizzes is provided to PwCCD to evaluate their own knowledge.
4. *Goals*: This module allows PwCCD to register their goals. They can subsequently monitor their progress towards these goals and periodically assess their advancement using a 10-point scale.
5. *Personal Health Record* (PHR): This module empowers PwCCD to effectively manage their own health information, including medical history, surgical history, past and current medications, allergies, immunization history, family history, and social history. The PHR was developed to encourage individuals to take a more proactive role in managing their health data and to ensure that important health records are easily accessible when needed.

6. *Supplies*: With this module, PwCCD maintains an inventory of their necessary care-management items and sets reminders to reorder each supply at a specified time.
7. *Wheelchair*: This module serves as a guidebook for PwCCD who use wheelchairs. It includes comprehensive information about both manual and power wheelchairs, such as details about wheelchair components and instructions on how to properly set up the chair, as well as video tutorials that teach essential wheelchair use skills.

The iMHere 2.0 system offers a variety of self-management services through its app modules, which are outlined here. The system's scalable design enables us to expand its capabilities by adding app modules as needed to address the requirements of other PwCCD populations in the future.

3.3.6 Caregiver App for Monitoring and Social Support

The iMHere 2.0 caregiver app functions as a companion app for PwCCD caregivers. Designed to mirror the app modules in the client app, this app enables caregivers to monitor the status of a PwCCD in each module and deliver positive reinforcement in the form of thumbs up symbols and motivational messages. Caregivers can choose from prebuilt templates or create custom messages to inspire the people for whom they care.

As outlined in section 3.3.1, the quantity and type of caregivers a PwCCD needs varies depending on their conditions. A PwCCD may have no caregiver, one caregiver, or multiple caregivers. Caregiving can be provided by relatives, friends, or professional (paid) caregivers. In some cases, the paid caregivers are PwCCD's family members or friends. The iMHere 2.0 system was designed to accommodate all of these caregiver situations. Each type of caregiver is represented as a distinct role in a role-based access control approach. When a caregiver becomes a member of a PwCCD's care team and selects a specific caregiver role, the relevant settings are applied to the caregiver app, allowing the caregiver to monitor the PwCCD's situation and provide appropriate encouragement via the caregiver app.

3.3.7 Accessibility

An accessible version of iMHere 1.0 was developed and studied separately to accommodate users with dexterity impairments (D. Yu et al., 2013; D. X. Yu, Parmanto, Dicianno, Watzlaf, et al., 2014). The ability to change text size and color, to change button size, to choose thematic colors for modules, and to activate only relevant modules in the app significantly helps the user (D. X. Yu, Parmanto, Dicianno, Watzlaf, et al., 2014). This promising result motivates the integration of the same features into the new iMHere 2.0 client app. A set of accessibility features was planned in the new app including font size and style, button-size, line and button space, hand preference, modules with thematic color, and a soft-button for vertical scrolling. The idea of a cloud-based accessibility profile was considered to support seamless synchronization over multiple devices (Friberg, 2015). For instance, a wheelchair user with a mounted tablet and smartphone could install the app on both devices, and any adjustment on the accessibility profile on one device will be applied to the other immediately.

3.4 System Development

3.4.1 Technology Requirement

To assess the technical requirements of the iMHere 2.0 system and determine its feasibility and suitability for its various components, a technology analysis was conducted, including the client app, caregiver app, web-based portal, and backend server. The purpose of this analysis was to ensure that the system met the necessary technical specifications.

At the time of the development, there were multiple technologies available to support the system. To ensure compatibility with both Android and iOS, the decision was made to use a technology that supported cross-platform development. From the options available, a mobile development framework called Cordova was chosen. Apache Cordova[3] is an open-source mobile development framework that enables the use of standard web technologies, such as HTML5, CSS3, and JavaScript, for cross-platform development. To enhance its capabilities, several plugins, most of which were adapted from PhoneGap, were employed, such as plugins for the camera, filesystem, dialog, local storage, keyboard, device, local notification, push notification, and any other plugin that supported the required features.

Table 3 Technology Components for Client app and Caregiver app

Technology	Version
Cordova	9.0.0
Angular	1.5
NodeJS	6.9.1
Npm	3.10.8

[3] https://cordova.apache.org/

To facilitate the development of the web portal and decrease the learning curve for new technology, the decision to use the same technology as the app was made. Since the app was built using web technology, the portal was developed using the same framework. This ensures that the development process is streamlined and that the learning process for new technology is minimized. The use of web technology in both the app and the portal ensures that the development process is efficient and that users can easily navigate the portal.

Table 4 Technology Components for Web Portal

Technology	Version
Angular	1.5
NodeJS	6.9.1
Npm	3.10.8

The backend server was built using a microservices approach, which theoretically allows for any backend technology to be used for each service. In the current development stage, Java-based technology was chosen to align with the existing technology used in the previous iMHere system version. The MySQL DBMS is currently being employed as the database server.

Table 5 Technology Components for Backend

Technology	Version
MySQL	5.7
Java	1.8
SpringBoot	1.5

3.4.2 Dynamic Interactions in the iMHere 2.0 System

The iMHere 2.0 platform is comprised of five key components, which include a cross-platform client app, a cross-platform caregiver app, a web-based clinician portal, a secure two-way communication protocol, and backend servers. The interactions among these three front-end components are illustrated in Figure 14, and the communication protocol and backend server work seamlessly to support all activities in these components.

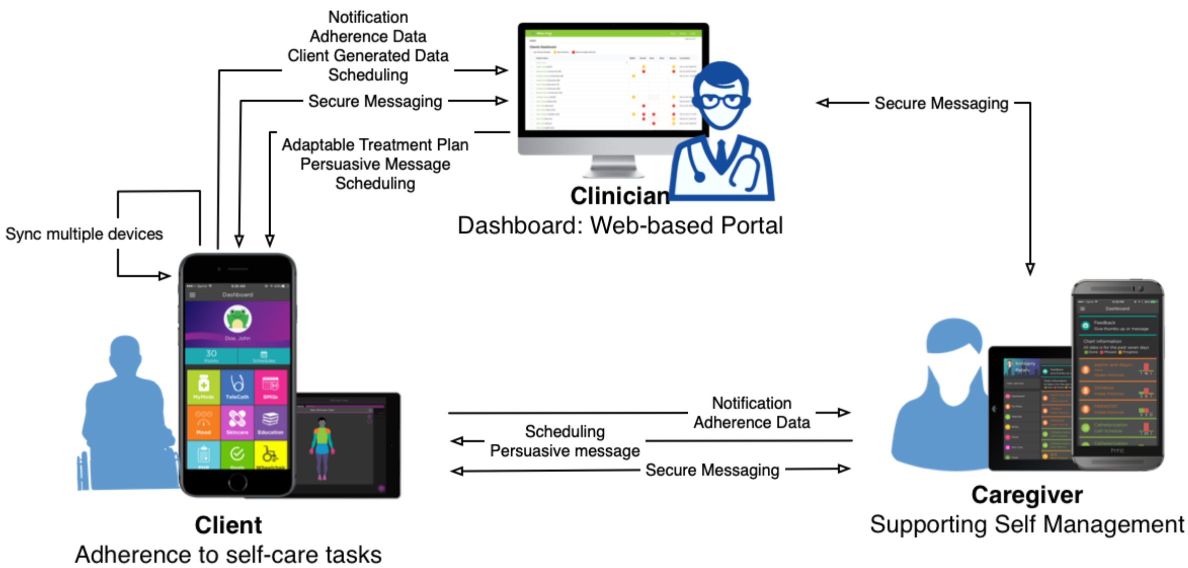

Figure 14 The interactions among the three front-end components in the iMHere 2.0 system.

3.4.3 Client App

The iMHere 2.0 client app consists of 6 core modules and 12 adaptable modules, as shown in Table 6. The user interfaces were designed with accessibility consideration in almost all the pages. Interaction using swapping or scrolling gesture was reduced, such as long vertical page, and tap-based interaction was preferred.

Table 6 List of Features

Modules	**Description**
Profile	Manage patient's demographic information, list of providers, insurances, and legal information
Scheduler	Create reminders based on specified schedule. This feature is used across modules that need cues / reminders
Secure instance messaging	Provide a way to communicate securely between patient and clinicians/caregivers in real-time
Contacts	Manage contacts data. This feature is integrated across modules that have any contact information
Store and Forward	Store data locally whenever internet connection is unavailable and continue transferring data to the backend when internet connection is back online.
Accessibility & Personalization	Personalize interface. Patients activate accessibility mode to specify font-size and style, button-size, line and button space, hand preference, and soft-button for vertical scrolling. Patients can select different modules' thematic color, avatar, and dashboard background.
Adaptable modules	
MyMeds	Manage medication track all the medications the patient is currently taking. Adherence is tracked.
Telecath	Manage bladder self-catheterization by providing scheduled cues for bladder program. Adherence is tracked.
BMQ	Manage bowel function by providing scheduled cues for bowel program. Adherence is tracked.
Mood	Track mood related symptoms. This module utilizes the short version of Patient Health Questionnaire (PHQ-2) to screen for depression and Generalized Anxiety Disorder (GAD-2) to screen for anxiety. Further evaluation should be performed if the screening results are positive. Adherence is tracked.

Table 6 (Continued)

Modules	**Description**
Skincare	Track skin care and skin problems. Adherence is tracked.
Education	Deliver tailored education content. This module consists of 12 major sections covering relevant topics for the target population, including information about spina bifida, cerebral palsy, spinal cord injury, skin integrity, bowel & bladder, exercise, nutrition, stress & anxiety etc. Quizzes are provided on some sections to allow patients to evaluate their knowledge
Personal Health Record (PHR)	Manage patient's health-related information. This secure module allows patients to manage their own health-related information. It consists of 8 sections including medical history, surgical history, medications, allergy, immunization history, family medical history, accommodation, and social-related information
Exercise	Track patient's daily activities. Patients record the duration of each activity in minutes. There are 49 predefined activities with individual icon patients can select from the library, including walking, gardening, yoga, etc.
Nutrition	Track patient's daily food and drink consumption. A slightly modified *MyPlate* program was used to guide the daily food and drink consumption of each patient, including water, fruits, vegetables, grains, protein, dairy, cheese, fast food, snacks, and caffeine.
Goal	Manage patient's own goals and rate progress toward each periodically using the 10-scales patient specific functional scale (PSFS). Reward points could be given for each goal by clinician/caregiver.
Supplies	Track supplies needed for self-care tasks.
Wheelchair	A wheelchair guidebook for patient with wheelchair.

The home screen of the iMHere 2.0 app consists of two primary sections. The first section is the default dashboard, which includes the user's name, schedule for the day, and a list of available modules (as shown in Figure 15a). The second section is a side menu, which can be accessed by clicking on the sandwich button located in the top left corner (as shown in Figure 15b). This side menu contains links to various functions of the iMHere 2.0 app, such as sending or reading messages (as shown in Figure 15b), adding contact information, viewing the user's profile, and customizing the app settings. From the portal, the clinician can customize the modules that appear on the dashboard page.

(a) (b) (c)

Figure 15 (a) Main layout, (b) dashboard with side menu, and (c) instant messaging

Every button on the dashboard leads to a specific module of the patient's journey. The design of the modules is consistent, with a list of schedules and a floating action button (fab) at the bottom corner (Figure 16a). Modules with adherence tracking allow patients to create schedules and collect information when the module reminds them to. The schedules are configurable from the client app, clinician portal, and caregiver app, and the scheduling and response process is consistent across modules. As demonstrated in Figure 16b, the scheduling page is utilized across modules, with different color-coding for each module. A custom time-picker was developed to provide a similar design across both the iOS and Android platforms, with a simple tap-based interaction (see Figure 16c). All schedules created in any module are consolidated into one summary page for easier access (see Figure 16d). The patient can then report on the reminders that have gone off using a consolidated reminder page (see Figure 16e).

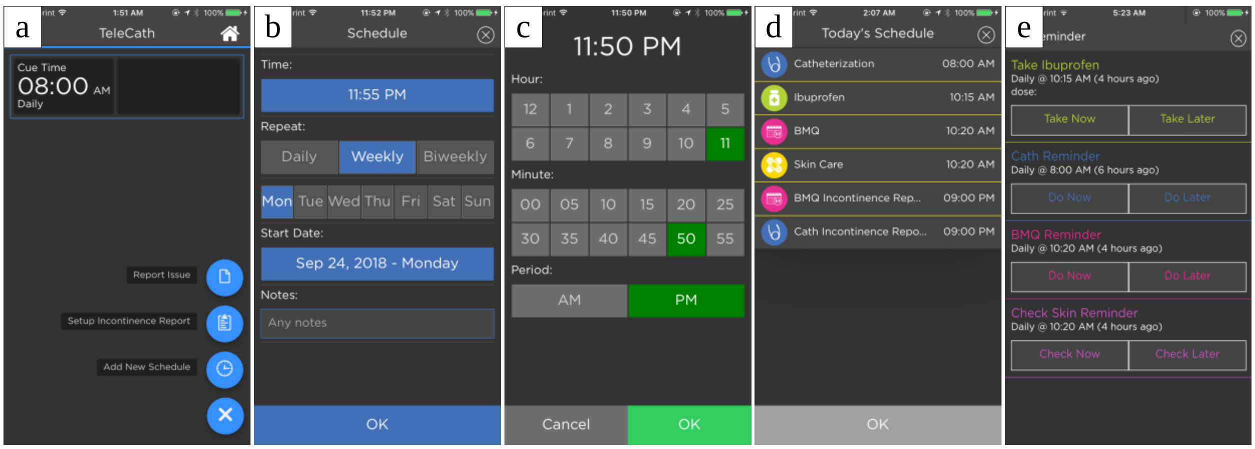

Figure 16 Consistent design for page's module (a), scheduling page (b), customized time-picker (c), summary of today's schedules (d) and reminder page (e)

The medication module features a layout that is slightly different from the others. The main page displays a list of medications, along with their respective schedules and accompanying medication photos (as shown in Figure 17a). To ensure accuracy in medication names and strengths, the standard drug database from the National Drug Code (NDC) of the Food and Drug Administration (FDA)[4] is utilized when managing medications. Patients are able to search for their intended medications within the database, selecting the appropriate brand name, strength, and pharmaceutical company (as illustrated in Figure 17, b and c).

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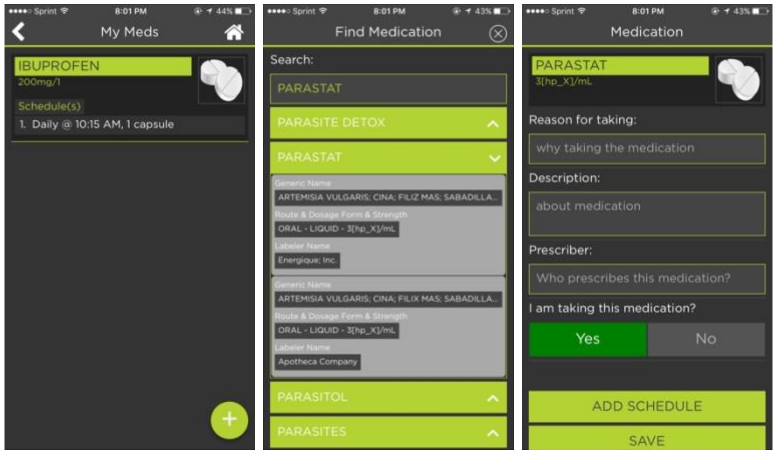
[4] https://www.fda.gov/drugs/drug-approvals-and-databases/national-drug-code-directory



(a) (b) (c)

Figure 17 Medication module

The Skincare module utilizes a color-coded, tappable body map to enable patients to accurately identify the precise location of their skin concerns (as illustrated in Figure 18, a and b). Furthermore, the extensive skin-care report form was divided into multiple pages, each equipped with navigation buttons situated at the bottom (as depicted in Figure 18, c, d, and e). This approach attempted to enhance user experience by simplifying navigation and facilitating ease of use throughout the process.

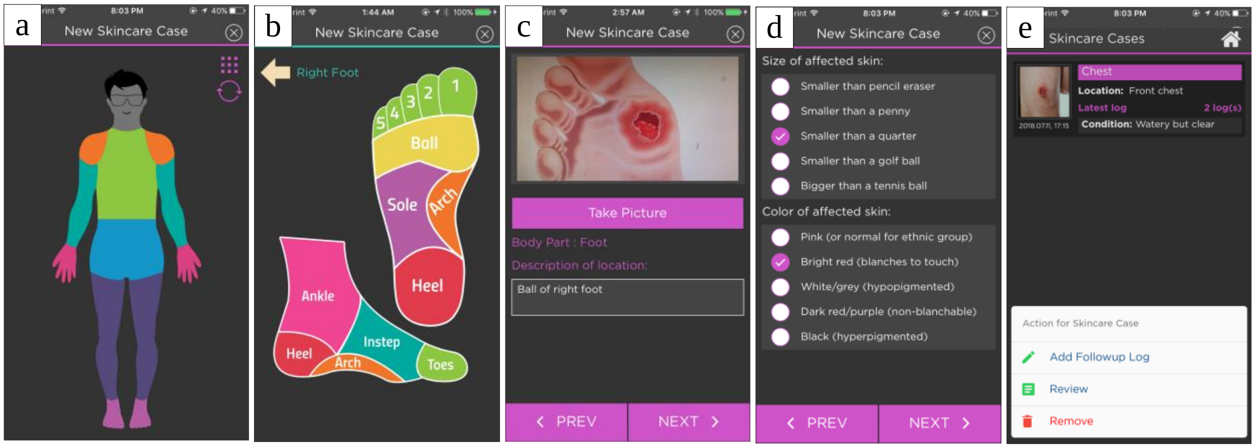
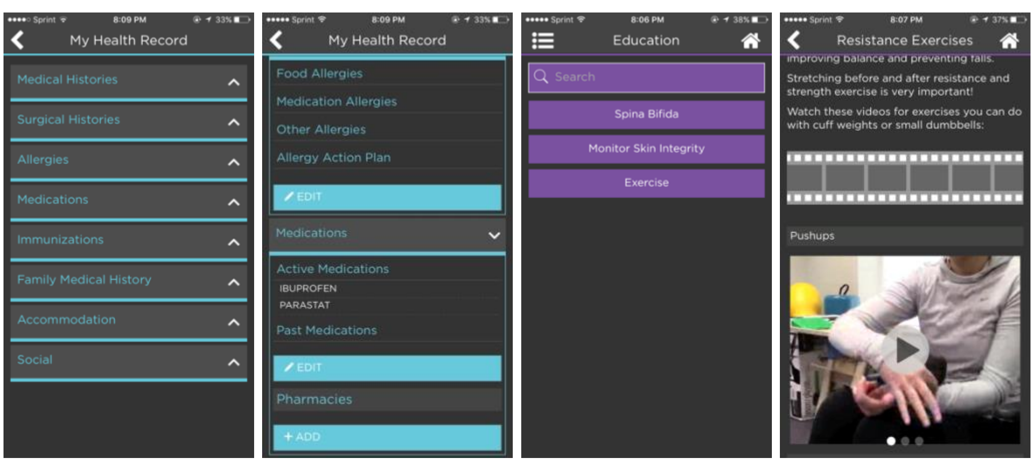


Figure 18 Skincare module: body map with rotated front and back facing (a), foot-detail map (b) wound image record (c), detail about wound condition (d), Skincare cases (e)

The Personal Health Record (PHR) module is divided into expandable sections, as illustrated in Figure 19a. Patients have the ability to add new records to the PHR or edit existing ones. A distinctive feature of this module is its automatic integration with medication data. Any medication listed in the medication module will be automatically populated in the PHR, as shown in Figure 19b. The same mechanism applies to any medication that is no longer active. This PHR module enables patients to conveniently access their health records and provide accurate information to their clinicians when necessary.



(a) (b) (c) (d)

Figure 19 Personal Health Record – PHR (a), expanded section on PHR (b), Education main page (c), example of education content (d)

The educational module is comprised of a total of 12 key sections, with the exceptional capability for clinicians to personalize the content delivered through the portal. By breaking the information down into sections, the module is able to present the content in smaller, more manageable packages, than it would if all the information was presented together. As a result, the module became more accessible and user-friendly (as depicted in Figure 19, c and d).

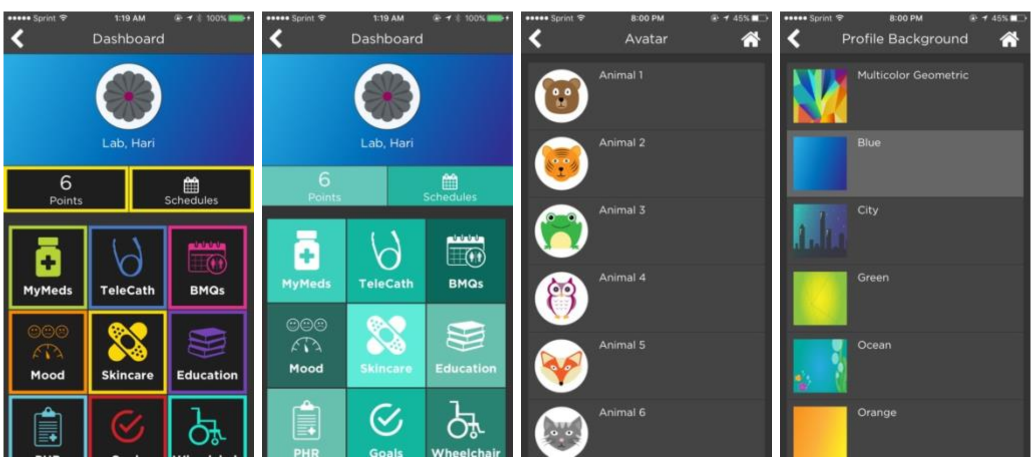
The primary objective of the exercise and nutrition modules is to monitor daily activities and food and drink consumption, without placing an unnecessary burden on them. With this goal in mind, the user interfaces were designed to be as simple as possible. As illustrated in Figure 20, patients merely need to specify the duration of their exercise activity and the number of food and drink items consumed using checkboxes, via a tap-based interaction.

(a) (b) (c) (d)

Figure 20 Exercise predefined activities (a), Exercise main page (b), Nutrition main page (c), goal main page (d)

The goal module in the iMHere 2.0 app enables patients to monitor their progress toward their goals with the assistance of caregivers or clinicians. The caregivers or clinicians work with the patients to identify the goals and add them to the system. The caregivers or clinicians also determine the number of points associated with each achieved goal, while the patients report their progress using a 10-star scale.

The iMHere 2.0 app has been designed to be flexible, user-friendly, and convenient by introducing personalization features. For instance, the system offers a range of different colors and icons for various modules, which patients can select according to their preferences (Figure 21 a and b). Patients can also choose their desired avatar and profile background (Figure 21 c and d) to personalize their experience. Once the options have been selected, the chosen theme, profile background, and avatar will be applied to the main page. Each app module is also assigned a different color to facilitate the client's identification of the appropriate module while using the app (D. X. Yu et al., 2017). These customizable features provide the patients with a personalized experience to enhance their engagement with the platform.



(a) (b) (c) (d)

Figure 21 Personalization, different themes (a, b), avatar (c), home background (d)

Implementing a synchronization mechanism was necessary to ensure that the state of the data could be maintained across multiple devices, as the client application needed to support offline functionality. The purpose of the mechanism was to ensure that the data remained consistent regardless of the device being used, which the mechanism achieved by effectively managing and updating the data in real-time.

3.4.4 Caregiver App

The iMHere 2.0 Caregiver app is designed to serve as a companion for the families and caregivers of patients. Its layout mirrors that of the client app, featuring a main dashboard page with an expandable side menu. As shown in Figure 22, the side menu provides access to secure instant messaging on the left-hand side. The main dashboard comprises the patient's information, their active modules, and two horizontal buttons for positive reinforcement and monitoring. The patient roster, located at the top-left corner, displays the names of all patients under the caregiver's responsibility, along with their respective avatars. This feature was added to facilitate quick access to the patients' data. By selecting a roster item, the app displays all the data related to the selected patient. The module list shows only the modules currently used by that patient, presented in a grid-based format. Each module button on the dashboard directs the caregiver to a specific module’s page. On each module's page, the focus is on monitoring the patient's progress, as evidenced by the progress chart displayed. Furthermore, the caregiver can assist the patient in creating a schedule, if needed, and can view the same educational content as the patient.

(a) (b) (c) (d)

Figure 22 Caregiver app layout, (a) side menu, (b) main dashboard, (c) reinforcement page, (d) consolidated patients' adherence

The application provides a means for caregivers to deliver positive reinforcement to patients through the use of thumbs and motivational messages. These motivational messages could be selected from a pre-defined template or entered manually through a provided textbox. Additionally, the goal module incorporates a reward mechanism, allowing caregivers to set the value of points for each goal and immediately update the client app. A comprehensive progress chart is displayed on a single page (Figure 22d) to enable monitoring of patient progress. As the primary objective of the app is to facilitate monitoring, it has been designed to function even when an internet connection is not available.

3.4.5 Clinician Web Portal

The primary elements of the web-based platform comprise a triage dashboard (shown in Figure 23a), a patient-context panel (depicted in Figure 23b), and a care team management page (illustrated in Figure 23c). The triage dashboard features a roster of PwCCD, each accompanied by indicators that correspond to the respective modules selected by clinicians in accordance with PwCCD's requirements and circumstances. These indicators represent the severity level and urgency of the PwCCD's condition, allowing the clinician to prioritize treatment accordingly. In case of an urgent or severe situation occurring while the clinician is not logged into the Web portal, the iMHere 2.0 system sends notifications to the clinician via text messaging or email, facilitating a prompt response from the clinician.

The name of each PwCCD listed on the triage dashboard serves as a link to direct clinicians to the patient-context panel. This panel showcases all relevant aspects of the PwCCD's treatment, including module management, care-team management, and instant messaging.

As part of the adaptable treatment plan, clinicians can choose the app modules the PwCCD will be able to utilize at any time in the settings page. With these selected modules, clinicians can provide tailored interventions to the PwCCD based on their specific needs. For instance:

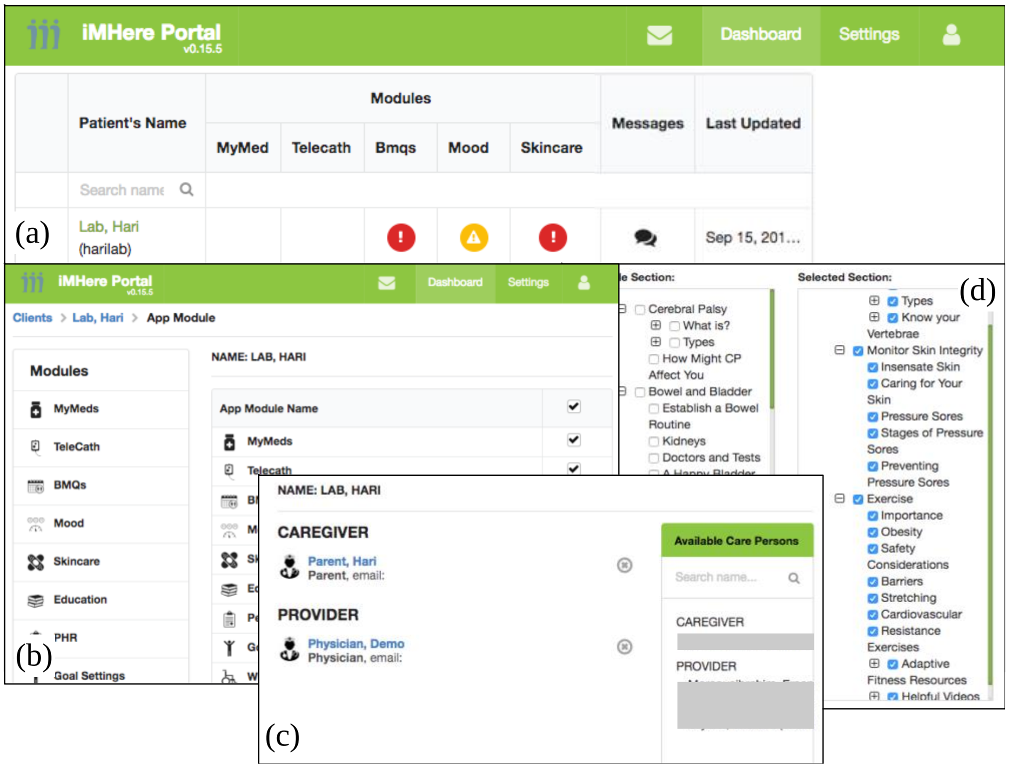


Figure 23 Portal page, triage dashboard (a), adaptability through module selection (b) care-team management (c) and personalized education content (d)

- Clinicians can select appropriate modules based on the PwCCD's baseline evaluation or their preferences. PwCCDs can also request particular modules verbally during face-to-face sessions or via the instant messaging service available within the app.
- When a client reports an issue related to a condition, such as a wound, via instant messaging or the Skincare module, the clinicians can modify the existing intervention based on the information the clients provide, such as adjusting the skin check reminder frequency.
- If the MyMeds module is selected, clinicians can modify prescriptions, including medication, dosage, and schedule, on the web portal.
- If the Skincare module is selected, the clinicians can view pictures of wound sites taken by PwCCD and provide treatment.

- If the Education module is selected, clinicians can choose relevant patient education materials from several major sections and subsections on the web portal and deploy them as "care-bundles" (Figure 23, at the bottom-right).

The adjustments made on web portal are immediately synced with both the client and caregiver apps after they are saved and applied on the portal.

3.4.6 Education Module

The development of an education module for iMHere 2.0 involves two critical components: content and presentation, particularly the presentation available through a mobile app. Both components are intended to enhance usability, with a focus on accessibility and readability. Additionally, the design should facilitate personalized and adaptable content delivery processes (Setiawan et al., 2019).

3.4.6.1 Content

The education content is divided into different sections, where each section focuses on a single topic that is further broken down into various sub-topics. This organization follows a similar structure to that of a typical book, which facilitates the development of the content and allows for future expansion. Additionally, this approach provides an effective way to deliver tailored content. As illustrated in Figure 24, main topics such as Cerebral Palsy and Spina Bifida have several sub-topics and sub-sub-topics. Customization will depend on the selection of relevant sections and sub-sections. To simplify the content, the level of detail for each topic should be limited to 2-4 sub-levels.

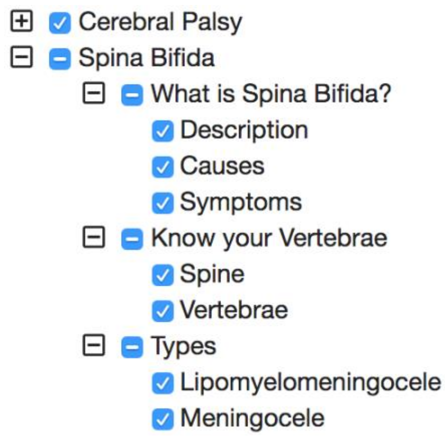


Figure 24 Organization of education content

Currently, the education module contains 12 main sections of content that are aimed at supporting self-management and cover relevant topics for the target population. These include information about spina bifida, cerebral palsy, spinal cord injury, skin integrity, bowel and bladder health, physical activity, nutrition, managing stress and anxiety, related medical issues, social health, transitions, and wheelchairs. To assess their understanding of the subject, clients can take self-evaluation quizzes, which are provided for each of the sections. The complete layout of the content is depicted in Figure 25, which displays a multi-level pie chart (sunburst) illustrating the distribution of the topics.

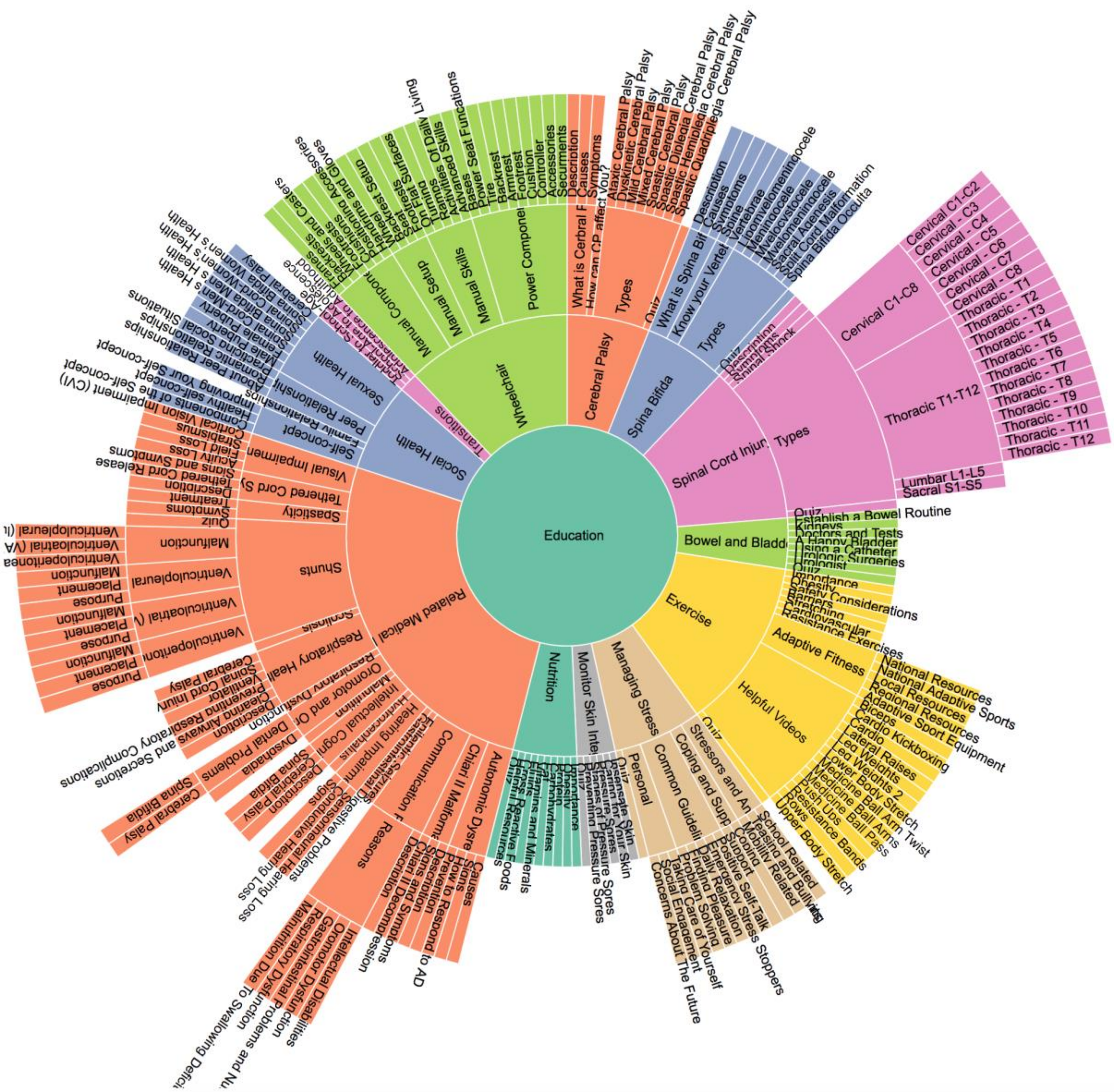
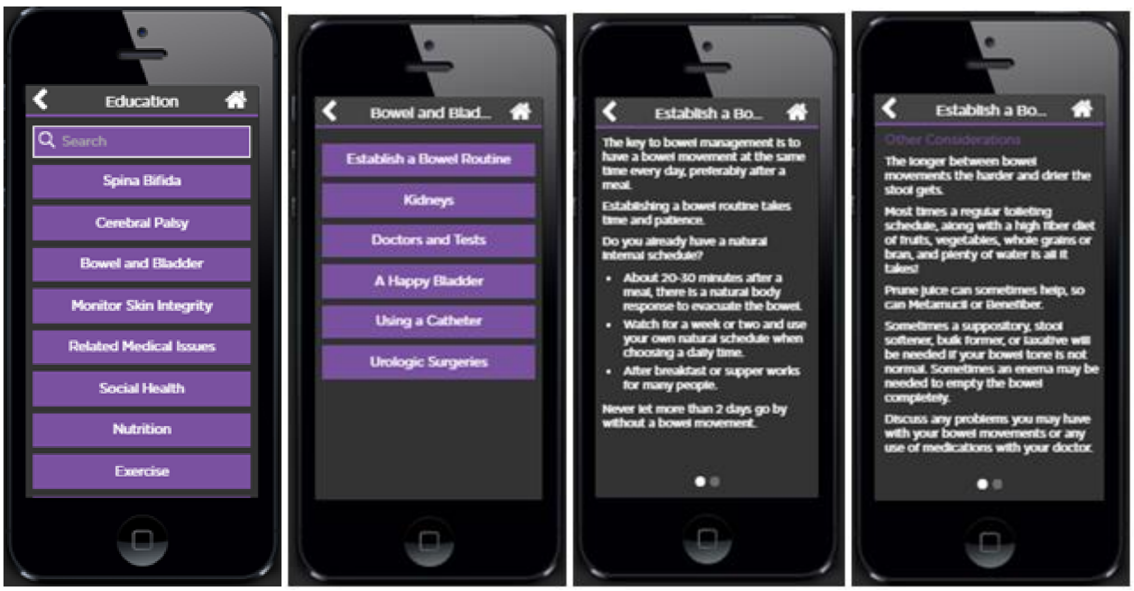


Figure 25 Education content layout with 12 sections

3.4.6.2 Mobile App Presentation

Presenting educational content on mobile devices poses numerous challenges. These devices vary in terms of screen size, computing power, resolution, and operating system platforms, among other specifications. The small screen size can limit the amount of content that can be displayed without increasing user interaction through scrolling. Additionally, lower computing power can restrict the types of content that can be displayed without encountering any issues. Furthermore, different operating systems have varying ways of supporting certain types of content, which can lead to compatibility issues within and across platforms. Given these challenges, designing educational content requires careful consideration. The presentation of educational content in the initial version of the app is depicted in Figure 26.

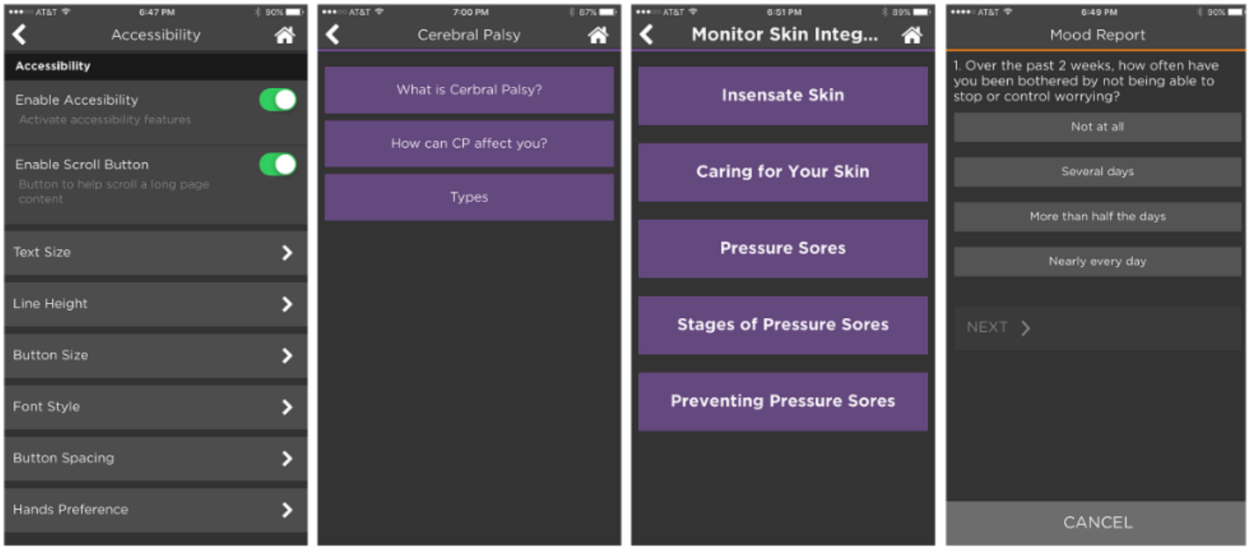


(a) (b) (c) (d)

Figure 26 An example of the iMHere bowel and bladder educational modules

3.4.7 Accessibility Features

The iMHere 2.0 client app is equipped with several accessibility features, including adjustable font sizes, font styles, line spacing, button sizes, button spacing, a scroll button, color and contrast preferences, and hand preferences, as can be seen in Figure 27. The accessibility



(a) (b) (c) (d)

Figure 27 Accessibility features settings in client app. (a) list of configurable accessibility features, (b) a page in education module with accessibility features off (c) a page in the education module with accessibility features on (d) self-assessment within mood module with large button spacing

feature settings page is shown in Figure 27a, with specific options listed in Table 7. The page difference in the education module before and after changes is shown in Figure 27 b, c, and d.

Table 7 Options for several accessibility features available in the iMHere 2.0 client app

Accessibility Features	**Options**
Font-size	Small, Medium[a], Large, Extra Large
Font-style	Normal[a], Bold
Line-height	Narrow, Medium[a], Wide, Extra Wide
Button-size	Small, Medium[a], Large, Extra Large
Button-spacing	Small, Medium[a], Large
Hand-preference	Left, Right[a]
Scroll-button	False[a], True
Color themes	Set of themes, e.g. Colorful[a], Frame, Bright, etc
[a]Default options	

Edge-to-edge buttons and soft keyboard options are also available. By default, all customizable accessibility features are disabled. Users can choose specific accessibility features according to their needs and apply them to the entire iMHere 2.0 client app.

3.4.8 Backend Services

In order to integrate all of the iMHere 2.0 system's features and functionalities, a number of services were developed to handle the various capabilities of the mobile app and portal. These services were designed to communicate using the REST API, with the frontend and backend working together seamlessly. The following services were created:

- Account Service: This service manages all client account-related data, including devices, configurations, and authentication services.
- Module Service: This service handles data for the majority of the app's available modules.
- Messaging Service: This service facilitates communication between iMHere system components, such as in-app chat messaging, internal workflow communication, and push notification delivery.
- Dashboard Service: This service provides the necessary information to be displayed on the web portal's triage page.
- Log Service: This service provides audit and tracking functionality, ensuring that all actions taken within the system are accurately recorded and tracked.

All of these services were thoughtfully designed to be deployed using a containerization approach. This decision guarantees streamlined deployment, management, and scalability, thereby enhancing efficiency and resource utilization across the entire system.

3.5 Discussion

This chapter presents the design and development process of iMHere 2.0, a mHealth system specifically designed to support self-management for individuals with chronic conditions and disabilities (PwCCD). iMHere 2.0 features a cross-platform client and caregiver app, a web-based clinician portal, and a backend server with a secure 2-way communication protocol. The system delivers adaptable treatment regimens tailored to the individual's specific needs and ongoing performance during treatment, with the ability to adjust treatment strategies over time based on the individual's performance and needs.

The system's architecture is scalable, allowing for the addition of new self-management services independently as needed. Using the system's scalability and flexibility, twelve highly diverse and commonly used app modules were created for the client and caregiver apps.

The web-based clinician portal allows providers to create tailored treatment plans for individuals with chronic conditions. These personalized plans can be accessed and followed by the patient through the client app, while the clinician can make adjustments as needed based on the patient's progress. Once the clinician modifies the treatment plan on the web-based portal, it is immediately synced with the client and caregiver apps. The portal also enables the clinician to keep track of the patient's adherence to the treatment plan and communicate with them via secure messaging.

Social support is a crucial factor for persistent self-management. With iMHere 2.0, caregivers can easily monitor PwCCD's performance and provide social support through the caregiver app. Previous research has shown that leveraging social influence is an effective strategy for motivating PwCCD to follow treatment regimens (Clark, 2003). For example, family members (partners, parents, children, and siblings) have a considerable influence on long-term engagement in healthcare. Thus, motivational messages from caregivers can help PwCCD endure lengthy treatment procedures. Additionally, the instant secure messages exchanged between PwCCD, and clinicians can also provide the necessary social support for long-term engagement with the mHealth system.

The ability to offer multiple caregiver modes allows caregivers to provide appropriate support for people with chronic conditions. Family members, for instance, may not have formal medical training, but they may have a close relationship with the person with the chronic condition and extensive knowledge about their situation. As a result, motivational messages from family members typically convey intimacy, love, and encouragement. Paid caregivers, on the other hand, usually have some patient-care training and therefore provide more professional suggestions and reminders of the potential benefits of consistent self-management.

The client and caregiver apps are compatible with Android and iOS, providing flexibility for users to access the apps on their preferred devices. With the majority of the global mobile OS market share belonging to Android and iOS (Statista.com, 2018), PwCCD can generally use the iMHere 2.0 system on their existing mobile devices. This cross-platform feature also allows PwCCD and caregivers to continue using the system on different mobile devices with varying operating systems or switch between operating systems without losing access to the iMHere 2.0 system for self-management.

The real-time synchronization of data entered by PwCCD, caregivers, and clinicians is only possible when a network connection is available. However, if a connection is unavailable at any given moment, PwCCD can still use most of the app modules since the data is temporarily stored locally on the mobile device and securely transmitted to a remote secure server using the Secure Sockets Layer protocol once the connection is restored. The only exception is the PHR module, which requires a network connection to protect the security of patient data, as personal medical records are not stored on the local device, even temporarily. Since all data is stored securely on a remote server, PwCCD or caregivers can still access their complete data even if they switch to new mobile devices.

The iMHere 2.0 system is designed specifically for PwCCD, and as such, its accessibility is of paramount importance. In the previous version of the app, iMHere 1.0, certain accessibility features were introduced and their effectiveness in assisting individuals with fine motor impairment was studied. The findings indicated that participants desired the ability to modify text size, button size, and color (D. X. Yu, Parmanto, Dicianno, Watzlaf, et al., 2014). Consequently, in iMHere 2.0, these accessibility features have been incorporated to enable PwCCD to adjust the font size, font style, button size, space between lines and buttons, and hand preference. These features are invaluable for the long-term use of the iMHere 2.0 system, as they allow users to customize the app according to their specific needs. For example, PwCCD age, their vision may decline, making it difficult to read the materials within the system. Without the accessibility features, they may be forced to switch to a different mHealth app. However, with the accessibility features available in iMHere 2.0, users can easily adjust the settings to suit their requirements, such as selecting a larger font size, and continue to use the app without any issues.

Overall, the iMHere 2.0 system has been rebuilt as an enhanced version of the original. Although the original version passed many evaluations in the past, the introduction of new technology and the ability to use it on multiple platforms necessitated further assessment of the updated version. The iMHere 2.0, like any other new system, needs to be evaluated to identify any potential issues that may hinder its use in optimal fashion. In Chapter 5, a thorough evaluation of the system will be discussed, including its usability. By doing so, any potential problems can be gathered, assessed, and addressed through refining the system in an iterative manner.

4.0 Vignette Development Toward Vignette-based Evaluation Through Simulated Interaction: Case Study iMHere 2.0

4.1 Background

Evaluating the capability of mHealth systems, such as iMHere 2.0, can be challenging because they deal with complex chronic conditions and disabilities. These conditions are characterized by their long-lasting and potentially life-long nature, making it difficult to assess the system's adaptability to provide support based on individual needs that evolve over time. Vignettes offer a promising solution to this problem by allowing us to simulate realistic scenarios and test the system's capabilities under various conditions over time. Vignettes are "short, detailed stories or scenarios that are believable enough to mimic real events" (St. Marie et al., 2021). While vignettes offer a promising solution for evaluating the capabilities of mHealth systems like iMHere 2.0, their accuracy relies on the relevance and realism of the scenarios used to simulate real-life situations within the case (St. Marie et al., 2021). Therefore, it is crucial to use relevant vignettes that properly reflect real-life situations when evaluating the system's adaptability over time.

4.2 Objectives

The primary objective of this portion of the study is to develop and validate vignettes to be used for assessing the adaptable capability of iMHere 2.0. The focus will be on evaluating the relevance and realism of the content of the vignettes that represent the case of PwCCD in real life.

4.3 Methods

Brief narratives, known as vignettes, are created to emulate real-life events. To accurately represent the real-life situation of individuals with brain and spinal cord anomalies, the focus is on ensuring these stories are relevant, realistic, and comprehensive. The vignettes have the following structure:

- Persona: A semi-fictional individual representing distinct characteristics, health history, goals, challenges, and a contextualized situation, serving as the central figure in the constructed scenario.
- Scenario: The story of health-related events that happened to the person within a certain period.
- Key Events: Important events that significantly influence the outcome of the persona.
- Simulated Interaction: Projected engagement with mHealth system tailored for the persona.

4.3.1 Development

Developing a vignette begins with collecting preliminary data from participants in past iMHere studies. This information serves as the basis for creating the vignette. The data collected includes the participant's age, gender, health-related condition, any health-related issues, their context and circumstances, and any potential health-related events. To maintain privacy, no personally identifiable information is used; instead, a random name is selected for labeling purposes. The initial data used for creating the vignette can be found in Table 8.

Table 8 Initial Seed Data for Vignettes Development

ID	Seed Information
1	50-year-old female, born with spina bifida. She has a history of neonatal hypoxia and seizures. Her vision and hearing are impaired.
2	32-year-old male, Ethan, born with spina bifida and has shunted hydrocephalus. He uses a power wheelchair. He relies on his mother for prompting much of his medical care because he lacks ability to follow through.
3	52-year-old male with spina bifida, diabetes and visual problems.
4	Susan, 55-year-old female with spastic quadriplegia and cerebral palsy, scoliosis, mild intellectual disability, and depression. She lives in a group home and uses a wheelchair.
5	John, 23-year-old Caucasian male with spinal cord injury. He is a high school graduate and currently not working due to his medical condition. He relies on his mother for self-care.
6	Rachel, 35-year-old female with spina bifida. She is proactive toward healthcare.
7	Bob, 33-year-old male with spinal cord injury in childhood. He uses a power wheelchair.
8	14-year-old Caucasian female with spina bifida: Myelomeningocele. She has additional diagnoses of Neurogenic bladder, hydrocephalus, Non-Verbal Learning (NVL) disability. She is a high school student. She is able to do activity daily living by herself but needs some assistance with medication management and relies on her parents for bowel management.
9	Nancy, 17-year-old female with spina bifida. She has NVL disability and memory issues. She relies on her parents to support her self-care. She is currently a high school student.
10	67-year-old Caucasian female with spina bifida myelomeningocele. She has kidney failure. She is mostly independent on self-care, but she required some assistance from her sister-in-law when she had an ulcer on her buttocks 2 years ago. She is a retired project manager in IT with a bachelor’s degree.

With the recent growth of generative AI (Artificial Intelligence), we utilize large language model (LLM) to produce vignettes based on seed information, which supports the designation of the persona as "semi-fictional". Modifications are made to the generated vignettes to maintain the narrative's consistency.

One aspect of the persona highlights the individual's proactive and forward-thinking approach to managing their health. Proactiveness entails actively engaging in healthcare decision-making, treatment strategies, and self-assessment, typically to prevent health issues and foster long-term well-being. There are four distinct approaches or strategies:

1. Active: Proactively seeks health information, adheres with prescribed treatments, practices preventive measures, and may utilize technology for self-monitoring and communication with healthcare practitioners.
2. Passive: Mainly depends on healthcare professionals for advice, adheres to treatment regimens without actively seeking more information, and tends to have a more reactive response to health issues.
3. Semi-Active: Demonstrates involvement in certain health-promoting activities, may seek information on specific health topics, and actively participates in aspects of treatment.
4. Semi-Passive: Demonstrates partial engagement in health-related activities, occasionally seeks information, participates in healthcare as necessary, and may not regularly adopt a proactive approach.

4.3.2 Validation

To assess the correctness and validity of the vignettes, an expert evaluation is conducted. This process involves reviewing the relevant and realistic nature of the vignettes and is a crucial step in the development and validation of the vignettes. The aim of this evaluation is to ensure that the vignettes accurately reflect the characteristics of individuals with chronic conditions and disabilities, in this case SB, CP, and SCI.

Content Validity Index (CVI) is a widely employed method for assessing the content validity of instrument development, specifically in the case of the vignettes (Rodrigues et al., 2017). There are two methods for calculating CVI, one of which is calculating using item-CVI (I-

CVI). I-CVI is determined by dividing the number of experts providing the highest rating for each item by the total number of experts. The I-CVI value ranges from 0 to 1, with items considered relevant if the I-CVI is greater than 0.79, in need of revisions if the I-CVI is between 0.70 and 0.79, and eliminated if the I-CVI is less than 0.70 (Rodrigues et al., 2017).

For this project, experts evaluated two aspects of each vignette: relevance and realism (see Table 9). Both dimensions were measured using a 4-point Likert scale, and the possible responses were: *1 = not relevant/realistic, 2 = somewhat relevant/realistic, 3 = quite relevant/realistic, and 4 = very relevant/realistic*. Ratings of 1 and 2 were considered content invalid, while ratings of 3 and 4 were considered content valid (Rodrigues et al., 2017). The minimum goal for this project was to achieve an acceptable scenario that is close to the case in real life, so for the I-CVI calculation, a more relaxed rule was applied. Instead of only considering the highest rating, the current calculation considers ratings of 3 and 4 for both dimensions. The item's CVI is then calculated by averaging the CVIs across the two dimensions.

Table 9 Validation Measurement Dimensions

Dimension	Description
Relevance	The extent to which the content of the vignettes is relevant to the experiences, challenges, and events of individuals with chronic conditions and disabilities.
Realism	The degree to which the vignettes portray realistic and plausible situations, reflecting the authentic experiences of individuals with chronic conditions and disabilities.

4.4 Results

4.4.1 Principal Results

Ten vignettes were successfully constructed to represent the diverse population of individuals with chronic conditions and disabilities. These vignettes aim to provide a comprehensive representation of the diverse range of individuals who may utilize iMHere 2.0 system by considering various scenarios and contexts. Table 10 shows descriptive statistic of the vignettes.

Table 10 Descriptive statistic of the developed vignettes (N=10)

Variables	Description
Age	Range: 14 – 67 years Avg: 39
Gender	Male: 4 Female: 6
Education	high school: 4, vocational: 2 bachelor's degree: 3, some college: 1
Diagnosis	Spina Bifida: 7 Spinal Cord Injury: 2 Cerebral Palsy: 1
Caregiver	Family: 3, Friends: 4, Mother: 2, Parent: 2, Sister-in-law: 1, Prof. Caregiver: 1

Figure 28 displays one of the vignettes developed. This vignette presents personal information, health condition, and characteristics of an individual with spina bifida. The key events highlight the detailed timeline of events that occur in the individual's life. Further information can be found in Appendix B.2.

Persona

Personal Detail:

Name: Nancy
Age: 17
Gender: Female
Race: Caucasian

Occupation: High School Student
Education: Currently in High School
Housing: Lives with parents
Lives in: Erie, Pennsylvania

Health Condition:
Spina Bifida

Proactiveness to healthcare:
Passive

Biography:
Nancy is a 17-year-old high school student living in Erie, Pennsylvania, with her parents. She has Spina Bifida, which has necessitated a close-knit relationship with her caregivers for her daily needs. Nancy's community is supportive, with local health resources and a school that accommodates her learning disability, Nonverbal Learning Disorder (NVLD), and memory issues. However, Nancy's passive attitude towards her healthcare, largely due to her dependence on her parents, has been a barrier to developing self-care skills critical for her impending adulthood. Her parents are actively seeking ways to foster her independence, including involving her more in her healthcare decisions and self-management.

Health History:
- Nancy has experienced multiple occurrences of Urinary Tract Infections.
- She takes 8 medications daily.
- She uses anticholinergic medications to manage her overactive bladder.

Health Goals:
Short-Term:
- Nancy aims to learn to recognize the early signs of a Urinary Tract Infection.
- She wants to participate in selecting her own healthcare providers.
- She seeks to understand her medication regimen fully.

Long-Term:
- Nancy's goal is to manage her self-care independently.
- She is working towards preventing recurrent Urinary Tract Infections.
- She plans to develop a personal healthcare plan for her adulthood.

Caregiver: Parent

Challenges:
- Learning disability (NVLD)
- Memory issues
- Passive approach to healthcare

Positive Traits:
- Resilient
- Supportive community and family
- Access to local health resources

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	Moderate	Frequently

Scenario

As Nancy approaches adulthood, she is determined to take charge of her healthcare journey. With the support of her parents and wellness coordinator, she has made significant strides in advocating for herself. She has started tracking her physical activity to improve her overall health and has set a goal to learn more about nutrition to manage her weight and well-being. During a routine check-up, her physician emphasized the importance of skincare to prevent wounds, prompting Nancy to prioritize her skincare routine. With the guidance of her wellness coordinator, Nancy and her parents have worked together to decrease parental involvement in her medication management, giving her a sense of independence and responsibility. As she continues to navigate her healthcare journey, Nancy is focused on developing a comprehensive healthcare plan for her future, ensuring that she is actively involved in selecting her healthcare providers and managing her overall well-being.

Key Events

Date	Event
06/01/2021	Nancy experiences the early signs of a Urinary Tract Infection, including discomfort and increased frequency of urination.
09/15/2021	Nancy's parents notice her struggling to remember her healthcare appointments.
12/10/2021	Nancy expresses a desire to be more involved in selecting her healthcare providers.
03/22/2022	Nancy's parents encourage her to start tracking her physical activity to improve her overall health.
07/05/2022	Nancy has a routine check-up where her physician emphasizes the importance of skincare to prevent wounds.

Figure 28 Example of Vignette

4.4.2 Validation Results

Four experts were contacted via email to evaluate the drafted vignettes. The purpose and basis for the evaluation were outlined in the document, along with the scoring system and ten vignette samples. These specialists included a physician specializing in spina bifida, an occupational therapist, and two fellows focusing on spina bifida and spinal cord injuries. Of the four experts, two provided the requested responses, one provided feedback through a recorded discussion, and the remaining did not provide any results despite indicating initial willingness to do so.

Table 11 CVI scoring calculation

VignetteID	Components	E1	E2	#Reviewer w/ Content Valid	I-CVI	Overall CVI
1	Relevance	3	4	2	1	1
	Realism	3	3	2	1	
2	Relevance	3	4	2	1	1
	Realism	3	4	2	1	
3	Relevance	3	4	2	1	1
	Realism	3	3	2	1	
4	Relevance	3	4	2	1	0.75[b]
	Realism	1	3	1	0.5	
5	Relevance	3	4	2	1	0.75[b]
	Realism	2	4	1	0.5	
6	Relevance	2	3	1	0.5	0.5[a]
	Realism	1	3	1	0.5	
7	Relevance	3	4	2	1	1
	Realism	3	4	2	1	
8	Relevance	2	4	1	0.5	0.5[a]
	Realism	1	4	1	0.5	
9	Relevance	3	4	2	1	1
	Realism	3	4	2	1	
10	Relevance	2	4	1	0.5	0.5[a]
	Realism	2	4	1	0.5	

[a] eliminated
[b] needs revision

According to Table 11, five of the vignettes were considered valid (Overall CVI=1) and both experts concurred on their relevance and realism. However, two of the vignettes required improvement to increase their relevance and realism. Additionally, three of the vignettes were found to be in the range of eliminated scores, indicating that the content was considered unrealistic and irrelevant to the evaluation's purpose.

4.4.2.1 Feedback Themes

The feedback and recommendations provided by the experts were analyzed. Several themes emerged for improving the quality of the vignettes. These themes are terminology clarity and consistency, medical accuracy, realistic timeframe, realistic employment, realistic treatment, and realistic activity.

4.4.2.1.1 Terminology clarity and consistency

Consistency in medical terminology is crucial for clear communication, understanding patient conditions, and preventing misunderstandings and inadequate care planning. As E1 recommended in vignette #10:

> *“Throughout these scenarios would use these terms more consistently. MMC is a type of SB. Most people with MMC also have hydrocephalus that is shunted.”*

E1 also emphasized clarity when using terms related to familial relationships, and job descriptions.

> *"Health related what? Health related conditions? Also, what is relative?... Describe as mother or father rather than parent”*

4.4.2.1.2 Medical accuracy

Accurately conveying information about medical conditions, their treatments, and the relationships between them is crucial for effectively communicating the content's intent. It is also important to clarify the patient's emotional state and its cause and to recognize the value of in-person evaluations for managing spasticity in upper-motor-neuron-disease patients. In vignette #1, E1 provided feedback on the health history of the persona, pointing out that the diagnosis seemed inaccurate. The persona listed spina bifida as the individual's condition, but E1 pointed out that the health history showed the patient had experienced neonatal hypoxia. E1 stated:

> *"This would cause Cerebral Palsy not spina bifida.*
>
> *……*
>
> *Hearing and vision impairments are not necessarily related to spina bifida.*

E1 highlighted that people with spina bifida could potentially experience sensory impairments, which may prevent them from feeling pain or discomfort when skin breakdown occurs, as stated:

> *"(redness and discomfort) … May not feel pain if she does not have sensation."*

E1 emphasized the illogical causality of the patient's emotional state in the scenario vignette #10 by stating that:

> *"Why was the mood issue a result of the check-up?"*

In vignette number four, E2 articulated the following regarding the nature of the situation:

> *"A patient with upper motor neuron disease (CP) who is reporting worsening spasticity would likely require an in-person visit to evaluate any management change needs. This need is made even more clear if there is wound development."*

4.4.2.1.3 Realistic Timeframe

E1 expressed concern about the unrealistic timeframe shown in the timeline, specifically regarding the individual hospitalized after a correction intervention for shunt malfunctions. According to E1, the hospitalization period of almost two months in vignette #1 is not realistic:

> *"This would be a very long hospitalization (over two months). Not realistic Should be 1 week or so."*

4.4.2.1.4 Realistic Employment

When determining the employment status of individuals with disabilities, it is important to consider their abilities and limitations. When an individual resides in a group home, it typically signifies that they have a significant cognitive impairment, and it is unlikely that they would hold a job. Volunteer work would likely be their most realistic occupation. E1 stated this:

> *"Living in a group home implies the person has significant cognitive impairment ……… Volunteer would be more realistic - if she lives in a group home she would not likely have a job."*

In general, E1 stated that:

> *"A lot of people (in this population) are unemployed in real life."*

4.4.2.1.5 Realistic Treatment

In terms of treatment, the experts raised concerns about the unrealistic treatments depicted in the vignettes, such as the use of PRN antidepressants, medication usage frequency, and physical therapy that are not provided in a timely manner. Both experts, E1 and E2, commented on vignette #5 regarding the anti-depressant medication. E1 stated that:

> *"Antidepressant medications are not taken 'occasionally'."*

Meanwhile E2 stated:

> *"In my experience, I have not commonly come across the use of PRN anti-depressants."*

E1 also stated:

> *If the wound is infected, the physician might prescribe an antibiotic, but typically would not prescribe one to PREVENT infection. Other wound care treatments would be more realistic. I don’t think infection prevention would be a reason for any medications prescribed.*

The unrealistic treatment was highlighted as well in vignette #5, as E1 pointed out:

> *"He would not be getting PT now for a SCI if it happened a long time ago."*

4.4.2.1.6 Realistic Activity and Participation

As E1 highlighted in vignette #4, it is crucial to consider an individual's abilities and limitations when discussing their participation in events or describing their level of independence. Each event or key point must make sense within the context of their capabilities. Specifically, in vignette #4, it is not realistic to portray a hardworking individual who can participate in vocational training and work part-time as someone with serious health challenges. This scenario involves an individual living in a group home, which would not align with the description of their level of activity and independence. E1 stated that the persona in vignette #4:

> *"….is described as being much too proactive and independent. This is not realistic for someone who lives full time in a group home"*

Similarly, E1 highlighted the same issue in vignette #6, where the individual's limitations did not correspond with the activities in which they were engaging. In vignette #6, the expert wrote:

> *"Maybe she could be participating in a walk and roll. If she uses a PWC she could not walk 5K"*

4.4.2.2 General Feedback

Experts are able to offer comprehensive guidance when constructing scenarios involving individuals with chronic conditions and disabilities, including spina bifida, cerebral palsy, and spinal cord injuries. The aim is to ensure that every aspect of the story is coherent and avoids vague or contradictory details.

1. Psychological Well-being

   Mental health plays a critical role in healthcare management, especially for individuals with chronic conditions like spina bifida. Depression can significantly impact a person's motivation to manage their health and can lead to disengagement from self-care activities. Providing adequate mental health support is essential to address underlying issues and promote overall well-being, enabling individuals to actively participate in their healthcare. As E3 stated:

   > *"……that behavior where a person stops trying is probably one of the greatest predictors of what their outcome is going to be and that's not just spina bifida but that's all in general person stops trying and doesn't want to get better."*

   The opposite can also be true, as E3 pointed out:

   > *"….I've seen that happen with people over the years where someone else could have a very, very severe injury and problem and be very motivated to do better and recover"*

   E3 highlighted the concept of *proactiveness to healthcare* depicted in the vignette. E3 acknowledged that emotions are not constant, but rather fluctuating in nature. Consequently, individuals may exhibit motivation and proactivity in self-care at one moment but display the opposite behavior at another time. Therefore, it is crucial to exercise caution when utilizing this characteristic.

2. Understanding Impact of Condition

   The effects of a chronic condition or disease on a patient's ability to engage in self-care can be profound. For example, sensory impairment from spina bifida impacts the patient's experience of and tendency to develop skin problems. That same sensory impairment means that the patient is not likely feeling pain from the wound. This correlation between sensory impairment and the wound is a point that E3 emphasized.

> *" …. I would caution the ones where you're, …., describing that the person is experiencing pain because of their pressure ulcers. So, persons with spina bifida, part of the reason why they get the pressure ulcers is because they don't feel it……... so they don't feel that pain or they don't feel that achiness. There's no pain associated with it"*

It is vital to consider similar associated conditions when addressing any chronic condition and its effects. Providing specific details about a person's health condition allows providers to adequately assess their needs. For instance, if indicating that the person has spina bifida myelomeningocele, it is important to specify the level of their lesion, as it directly correlates to the severity of functional impairment. When the lesion is located higher on the spine, it results in more significant impairments affecting motor function, sensation, and bowel/bladder control, which consequently impacts the type and level of support needed for daily activities and healthcare management. Similarly, for individuals with spinal cord injuries, it is necessary to indicate the level of the injury they have sustained. Providing this information can significantly impact the level of support that the person requires.

Another example E3 noted is about the impact of hydrocephalus on cognitive disabilities. E3's explanation follows:

> *"… pressure on the brain is causing not just issues with dizziness and headaches and all that, It also is essentially causing brain damage and that's*

where you see the cognitive disabilities like the issues with memory, the issues with executive function, … you have the nonverbal learning disability common in this population"

3. Consideration of Variations

   Expert E1 suggested incorporating various vignettes that demonstrate the diverse experiences and capabilities of individuals with the same medical condition. These vignettes should illustrate the different scenarios that can arise in such cases.

4. Role of Caregiver

   Expert E1 emphasized the importance of considering the pivotal role played by caregivers in various scenarios, particularly when addressing the needs of individuals with significant disabilities. This recommendation highlights the critical impact that caregivers have on the well-being and support of individuals with disabilities. By acknowledging and addressing the role of caregivers, interventions can be tailored to better meet the complex and diverse needs of individuals with disabilities, ultimately promoting enhanced quality of care and support.

4.5 Discussion

This chapter presents the development and validation of vignettes to be used as an instrument to assess the adaptable capability of iMHere 2.0 system. A total of ten initial vignettes were successfully developed and underwent thorough evaluation to ensure their relevance and realism. The process involved assessment of the content validity to ascertain that the vignettes accurately represented real-life scenarios and effectively captured the diverse experiences of individual with chronic condition and disabilities, in this case SB, CP, and SCI.

Three of the ten vignettes were deemed unacceptable or in need of significant revision based on their overall Content Validity Index (CVI) scores. These vignettes were #6, #8, and #10, each of which depicted an individual with spina bifida. Two of the vignettes required revision to make them more realistic: vignette #4 and #5. The remaining vignettes were deemed acceptable in terms of relevance and realism.

The experts provided feedback that helped identify the critical factors needed to improve the vignettes. These factors were categorized into several themes, including terminology clarity and consistency, medical accuracy, realistic timeframe, realistic employment, realistic treatment, and realistic activity. It was essential to have a thorough understanding of the conditions and their consequences on individuals and their lives when constructing a realistic scenario. Mental health plays a crucial role in healthcare management, and it can significantly impact an individual's motivation to manage their health. Lack of mental health can potentially lead to disengagement from self-care activities.

To evaluate the adaptability of an mHealth system, it is important to consider incorporating a wider range of vignettes that depict diverse medical experiences and emphasize the crucial role that caregivers play in addressing the complex needs of individuals with disabilities.

This study has acknowledged its limitations, such as the insufficient number of experts for content validation. However, the feedback collected has proven to be invaluable for the subsequent stages of the process. Consequently, instead of rigidly adhering to the rules of elimination, the next step will be more lenient in nature, allowing all collected feedback to be utilized for revising the vignette, which will then be employed to evaluate the mHealth system.

4.6 Conclusion

This chapter highlights the importance of developing realistic vignettes that can be utilized as an instrument to assess the adaptable capability of mHealth systems such as iMHere 2.0. A set of vignettes was successfully developed and validated. By refining vignettes based on expert feedback, the study lays the groundwork for extensive evaluations and enhancements of mHealth technologies. In chapter 5, the refined version of the vignettes was used to evaluate the adaptable capability of the iMHere 2.0 system to support self-management for people with chronic conditions and disabilities.

5.0 An Integrated and Adaptable mHealth System to Support Individual with Chronic Conditions and Disabilities: Evaluation of iMHere 2.0

5.1 Introduction

Chapter 3.0 focuses on the design and development of the iMHere 2.0 system. As with any new system, it is crucial to evaluate iMHere 2.0 to identify potential issues that may hinder its optimal performance. By conducting evaluations, any existing problems can be identified and addressed, allowing for refinement in an iterative manner. Two studies were carried out to assess the iMHere 2.0 system, one of which was a usability study, and the other was a feasibility study.

In addition to these studies, an evaluation was performed to assess the adaptability of the iMHere 2.0 system. The vignettes developed in Chapter 4.0 were utilized to evaluate the mHealth system using simulated interaction approaches. The evaluation involved several vignettes of PwCCD and potential health-related events they might experience over time. The capability of the mHealth system was then assessed to determine whether it could address the needs of the individual.

The fundamental premise of iterative development is to engage in ongoing refinement, with enhancements made continuously based on the outcomes of evaluations and feedback received. This approach aims to produce a system that is both effective and efficient, and which achieves its intended objectives. In this instance, all feedback and evaluation results will be taken into account when making improvements to the iMHere 2.0 mHealth system, with the goal of creating a usable tool that supports individuals with chronic conditions in managing their health and well-being effectively.

5.2 Usability Evaluation

5.2.1 Methods

The objective of the usability study was to identify usability problems in the client app and refine the design of the iMHere 2.0 system. The study protocol was approved by the IRB office at the University of Pittsburgh. Participants were recruited in the Greater Pittsburgh area via clinician referrals. The selection criteria were individuals with SB, SCI, or CP. This study was conducted in the natural environment (participants used their own mobile devices), the assessment was administered at the participant's preferred location.

Seven app modules (MyMeds, BMQ, Mood, Skincare, Education, PHR, and Instance Messaging) were used in this usability study. The participants were first guided to install the client app onto their own mobile device. A brief demonstration of the 7 modules was provided to the participants. These participants were then asked to use the client app for a few weeks prior to a face-to-face usability study session.

During the face-to-face study session, all study participants were asked to perform 14 tasks in the 7 selected app modules. Table 12 shows these 14 tasks and the specific operations study participants were requested to perform in those tasks (see Appendix C for more detail on the tasks). A modified version of the SUS questionnaire and the Telehealth Usability Questionnaire (TUQ) were used at the end of the session to measure participants' impression of the app (Parmanto et al., 2016; Sauro & Lewis, 2011) (see Appendix G for the questionnaire forms).

Table 12 The tasks assigned to participants during the face-to-face usability study session

Modules	Tasks	Needed Operations in the Module
MyMeds	Schedule a reminder for an indicated medication	Search for and locate the correct medication, and set up the specific time of the reminder for taking the medication daily with a specific dosage
	Respond to the medication taking reminder	Indicate whether or not he/she takes the medication
Mood	Set up a reminder for regular mood assessment	Choose the frequency and time of a day for conducting mood assessment
	Respond to the mood assessment reminder	Complete the mood assessment questionnaire
BMQ	Set up a reminder for regular bowel movement	Indicate the frequency and time for daily bowel movements
	Respond to the bowel movement reminder	Report any indication of bowel movement problems
	Review existing schedules	Open one existing schedule and determine whether it needs to be updated or removed
Education	Search for one education topic	Search for “Tethered Cord Release Surgery Recovery” and read the content
Skincare	Report a minor skin problem	Select a body part from the body map, take a picture of the wound site, and answer four questions about the wound condition
	Set up a reminder for regular skin condition check	Choose the frequency and time for regular wound check
	Respond to the skin check reminder	Select a body part from the body map, take a picture and answer 4 questions to report the condition of the wound
	Perform a follow-up for an existing skin problem	Report the progress of an existing wound, take a picture, and update the wound condition
Messaging	Communicate with a caregiver through an instant message	Write a new message to a caregiver
PHR	Update the information in the personal health record	Add a new record in the Medical History section of PHR

5.2.2 Usability Study Results

Nine participants were recruited for the usability study. Six participants had SB (five had SB Myelomeningocele, one had Hydrocephalus, and one had SB Occulta), one participant had CP, and two participants had SCI. The ages of the participants ranged from 23 to 51 years old (Mean=37.33, SD=7.937); five were males (56%) and four were females (44%); seven were Caucasian, (78%) and two were Hispanic (22%). Three (33%) participants were iOS system users, and six (67%) participants were Android system users.

All nine participants were able to finish all the tasks. The most common problems encountered during the study were related to "affordance." According to Everett (2010), affordance is part of intuitive component in which "visually, the user interface has clues that indicate what it is going to do." The study revealed that 72% (n=64) of the problems were related to affordance (Table 13), meaning that the user interfaces (UI) on those tasks did not provide enough indication about how the tasks should be done. These problems caused patients to get confused, to tap the wrong element of the UI, and prompted us to provide cues to help them continue the task after idling for a certain amount of time.

Table 13 Problems classification

Type of Problems	Severity			Total
	Low (%)	Medium (%)	High (%)	
Affordance	3 (5%)	40 (63%)	3 (5%)	46 (72%)
Bug			2 (3%)	2 (3%)
Responsiveness			2 (3%)	2 (3%)
Unavailable UI function	1 (2%)	1 (2%)		2 (3%)
Unexpected UI action		3 (5%)	2 (3%)	5 (8%)
User preference	2 (3%)	1 (2%)		3 (5%)
Workflow issue	1 (2%)	3 (5%)		4 (6%)
Grand Total	**7 (11%)**	**48 (75%)**	**9 (14%)**	**64 (100%)**

Additional analysis of the problems caused by the affordance issue revealed several important findings that need to be addressed:

1. *Floating action button (fab) issue*: There were two types of actions on a fab menu button: 1) A one-step action in which the icon typically using “+” sign (Figure 17a) and tapping the fab button immediately trigger an action.; 2) A two-step action in which the first step exposes a sub-menu, and the second step triggers an action (Figure 16a). Six of the participants experienced similar issues related to the fab button. These participants failed to figure out what the action button for the required task was, mostly on two-steps actions. Four participants were not able to find the skincare report page menu, which is in a sub-menu. Of these four participants, three tapped the wrong sub-menu button; instead of the menu button for skincare case, they tapped the new schedule button. Similar errors occurred with the mood fab button.
2. *Unclear direction on PHR sections and form*: PHR sections were designed as a vertical list with expandable sections. The icon “V” was used as an indicator that the section was expandable (Figure 19a). Five participants were not able to figure out how to view the PHR data, and even more participants were unable to find how to add new data, since the section needed to be expanded to view the edit/add button.
3. *Action-sheet menu model*: The action-sheet is a hidden menu option that is typically triggered when an item from a list is selected/tapped (Outsystem SILK UI, n.d.)(Figure 18e). This is a common pattern in mobile apps and is usually used for contextual actions. However, the test revealed that five participants failed to figure out the way to do a follow up log for skincare. The participants did not know that they needed to tap the list item to expose the follow-up log menu under the action sheet.

4. *Selection of medication*: To add a new medication to their care plan, patients need to search for and find the correct medication name from the list. After the patients input the first 3 characters of the medication name, a list of several medications, each with an expandable section, is exposed (Figure 17b). To select the correct medication, the patient needs to expand the appropriate section and find the name, strength, and the label of the prescription. The medication list can be long because of the various strengths and labels associated with each medication. Four participants failed to locate the required medication. They were not aware that the list was scrollable, could not find the medication, or could not find the correct strength or label.
5. *Unclear shutter button on skincare camera*: The skincare camera was a custom camera plugin that required patients to take wound pictures in landscape mode (Figure 29). The camera supported a soft-shutter button and a hard-shutter option, which allowed participants to take pictures using their phone's volume button. However, instead of tapping the soft-shutter, or volume button, two participants mistakenly tapped the screen.

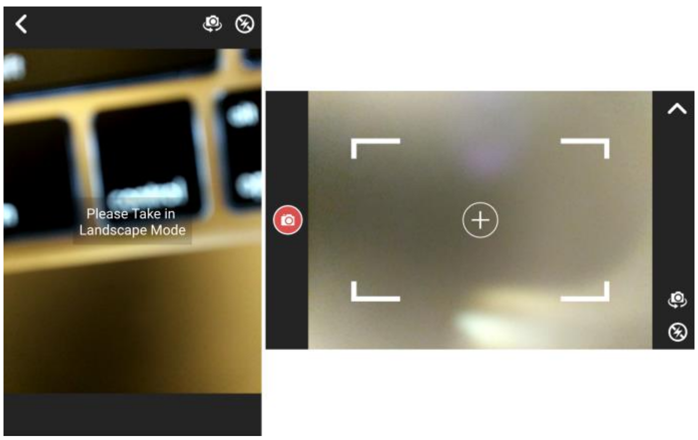


Figure 29 Skincare Camera

At the end of the testing session, all nine participants completed the poststudy questionnaires, both SUS and TUQ. The sample size is considered appropriate according to the Problem Discovery Rate Model, which is widely used to estimate sample size in formative usability study (Turner et al., 2006). According to the model, 85% of usability problems were revealed using five participants, and at least 15 participants are required to discover all the usability problems in a design. In fact, this study successfully discovered 96% of the usability problems that occurred at least once, with p=0.31. The participants rated the app as highly usable with a mean SUS score of 83.06 (SD=20.34). The average TUQ score for all participants was 5.79 (out of 7 possible points, SD=1.55). As shown in Table 14, participants were satisfied with the iMHere 2.0 client app, and would consider using it in the future (average score: 6.17). In assessing room for improvement, the section for "ease of use & learnability," "interface quality," "interaction quality," and "reliability" receives scores lower than 6.

Table 14 Satisfaction rating

Variable	***Score (SD)***
SUS	**83.06 (20.34)**
TUQ	**5.79 (1.55)**
Usefulness	5.59 (1.47)
Ease of Use & Learnability	5.89 (1.48)
Interface Quality	5.78 (1.51)
Interaction Quality	5.83 (1.56)
Reliability	5.17 (2.12)
Satisfaction & Future Use	6.17 (1.34)

One participant (#203) experienced difficulty in updating the app after revisions were made during the study. The old android version of the participant's device (android 4) and the poor internet connection did not allow the participant to update to the newer version of the app.

Participants expressed that the iMHere 2.0 client app was helpful to them. Participant #203 mentioned: "*The schedules are extremely helpful to me, because I tend to be forgetful about Cathing and Bowel schedules. This application helps me with the scheduling of my day-to-day life.*" The Education module received positive responses, as participant #208 stated: "*The education content is the most helpful for me in this application. The search bar is helpful in the education application if I know what I want to be looking for*."

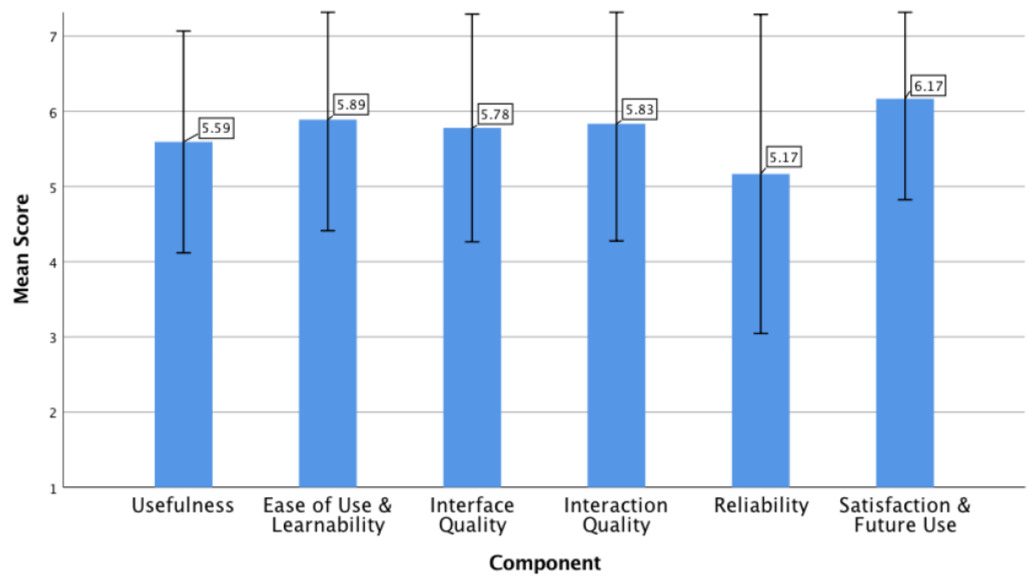


Figure 30 TUQ Usability Scores

Participants also provided valuable feedback in terms of further improvement. Participant #202 desired more concise education materials: *"Education is too wordy for someone with cognitive difficulty."* Participants #201 and #203 expected more options in scheduling. Participant #201 stated: *"There should be an every-four-hours option,"* while participant #203 mentioned that: *"There should be every other day option in MyMeds."* These desired features will be incorporated into an updated version of the client app.

During the study, the iMHere 2.0 system was able to tailor the modules and the content of the Education module. Participant #205 chose to use only the module to manage the medication (MyMeds). Participant #208 chose to use MyMeds and Education, and participant #209 chose to use almost all the modules. Different education sections were successfully delivered to the participants' education module. A specific education section about the participant's diagnosis was delivered according to the participants' condition—a CP section for participant #202, an SCI section for participant #207 and #208, and an SB section for the rest of the participants. Education sections about common experiences of PwCCD, such as social-health, stress-and-anxiety, exercise, and nutrition, were delivered to all of the participants. In general, participants liked the ability to show only the modules and content that were relevant to them, and their preferences were diverse.

5.3 Feasibility Study

5.3.1 Methods

The feasibility evaluation was performed to gauge the extent to which self-management support can be successfully delivered to the intended participants (PwCCD) via the iMHere app and to identify issues that affect the implementation process. The feasibility study was conducted in the natural environment of the participants using their personal mobile devices. The participants were first guided on how to install the app on their own devices and how to use the app for self-management. All 12 modules were made available to them. They were encouraged to use the app for about 3 months regularly. Their app usage data was collected and summarized.

5.3.2 **Results**

For this feasibility study, six participants were recruited. They had all been diagnosed with spina bifida and their ages were between 23 and 50 years old. Two participants were iPhone users, and 4 participants were Android phone users. Data for 90 days of app usage for each participant was extracted from the system and analyzed.

The most accessed module during the study was Education (315 times), followed by messaging (116 times). The rest of the modules were accessed 1-50 times. The most frequently visited Education sections were “bowel and bladder” (55 times), “monitor skin integrity” (40 times), and “spina bifida” (35 times).

Among these six participants, P06 was the most active participant, who interacted with the app actively on 73 days (out of 90, 81%) during the study period (Figure 31). P06 was also the participant who was the most compliant with reminders generated by the app, with 764 responses to 861 scheduled reminders (89%) during the study period. The frequently visited modules by P01 were Education, messaging, TeleCath, and MyMeds. P04 and P05 lived together and were the least active participants, barely using the app. Unfortunately, it was extremely difficult to reach them using any communication approach (phone, email, text message, or letter) to investigate the reasons behind their underutilization of the app.

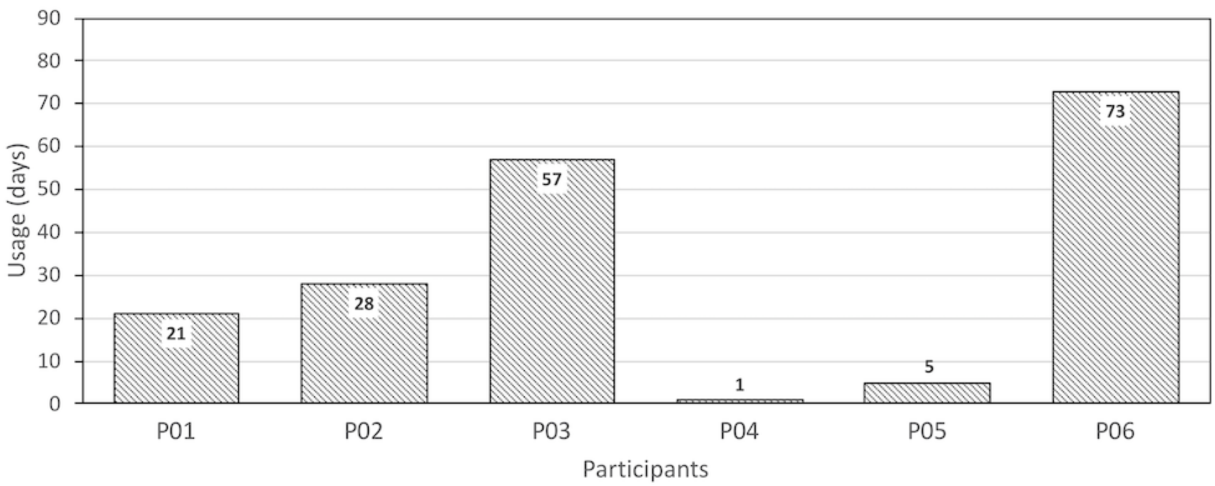


Figure 31 Days the participants actively used the app during the study

P01 and P03 had problems with the reminders. Both of them had a part-time job and their work schedule was not predictable. This made it difficult for them to set up a regular schedule or respond to the reminders generated according to the schedule. P01 was active in this study for 21 days (out of 90, 23%) and responded to 5 out of 13 scheduled reminders (38%). P03 was active in this study for 57 days (out of 90, 63%) and responded to 349 out of 441 scheduled reminders (79%). Both participants frequently visited Education, messaging, and Skincare modules. The different levels of interaction in spite of being in the same situation can be explained by the level of support needed by the two participants. P01 explicitly mentioned that "*...I would not need reminders for certain tasks since I am able to complete the task independently by my own*."

P02 had to stop using the app due to technical problems. P02 had an old Android device (Samsung S3), which could run an older version of the app, but not the newer version, and the newer version was the one used in a major part of the study. P02 was active for the first 28 days (out of 90, 31%) and responded to 112 out of 177 scheduled reminders (63%). The most frequently visited modules for P02 were Education, messaging, MyMeds, and TeleCath.

During the study period, participants with Android devices had a number of technical issues, such as incompatible Android versions, interaction problems (screen protector issues, stylus issues, small keyboard), and the app freezing while in use.

Regarding the app, P01 believed that there were too many confirmation steps required when sending a report. More flexible scheduling was preferred by P01, P02, P03, such as an hourly basis or “every other day” options in MyMeds, or an “every two weeks” option in Mood. The app has been modified accordingly by reducing confirmation steps in reporting and adding more flexible scheduling options.

5.4 Vignette-based Evaluation

5.4.1 Methods

The primary objective of this study was to showcase that the iMHere 2.0 system is adaptable to address the unique needs of individuals with chronic conditions and disabilities throughout the duration of their condition. A series of vignettes, which were developed and validated in a previous research study (discussed in Chapter 4.0), were utilized to simulate the interactions between the user and the system as per the scenarios described in the vignettes. The premise is that if the iMHere 2.0 system can effectively accommodate the self-management needs of an individual during the key events of their life, as represented in the vignettes, then it can be deemed an adaptable system. Thus, the utilization of these vignettes for the evaluation of the iMHere 2.0 system serves as a proxy for real-life interactions, allowing for meaningful conclusions to be drawn.

Eight refined vignettes were employed to simulate the evolution of user needs and potential interactions with the iMHere 2.0 system, which can be found in Appendix B.2.2.

5.4.2 Results

Each of the prepared vignettes was used to simulate an interaction that connects the key event in an individual's life to the potential solution that the system can offer to support them in managing their health. As an example, Figure 32 showcases a simulated interaction involving the persona from vignette #5. The interactions between the individual, their healthcare provider, and the app are illustrated below using a user journey map approach.

- Initial Setup: During the individual's clinic visit, their physician recommends the use of the iMHere 2.0 app to assist them in managing their self-care routine. Upon agreement, the physician sets up the app with initial modules, such as medication management, mood tracking, and an educational content module.
- Stable Use: The individual consistently uses the app over an extended period, with no significant changes in their needs.
- Changing Needs: The individual experiences a compromise in their skin integrity, leading to the development of a pressure injury, which is a common complication for individuals with limited mobility, such as those with spinal cord injuries (SCI). The individual reports their symptoms to their physician.
- Adaptation: As the iMHere 2.0 system includes a module to support skin integrity tracking, the physician adapts the app to include a new activated module to help the individual track their skin condition over time.
- Continued Use: The individual continues to use the app effectively due to its adaptability.

Interaction	John's physician activates the medication management, mood tracking, and tailored educational content modules on the iMHere 2.0 app. John begins to use the app to set reminders for his medications and to record his daily mood fluctuations.	John uses the app to regularly update the status of his wound and receives automated reminders to check and care for his skin to prevent further deterioration.	John sets small, achievable goals within the app to help boost his mood and track his progress over time. He also uses the messaging function to communicate his emotional state with his wellness coordinator.
Solution	John's physician recommends the iMHere 2.0 app to help him manage his medications and track his mood, as well as to provide him with educational content about self-care and spinal cord injuries. The physician activates the medication management, mood tracking, and tailored educational content modules on the iMHere 2.0 app. John begins to use the app to set reminders for his medications and to record his daily mood fluctuations.	The skincare/wound tracking module is activated to help John monitor the healing process and to ensure he follows up with proper wound care.	The mood tracking module already in use is now supplemented with goal setting to help John work towards improving his emotional well-being.
Key Event	John experiences severe pain and limited mobility due to his spinal cord injury, making it difficult for him to manage his self-care activities.	John's skin integrity is compromised, leading to the development of a pressure injury, a common complication for individuals with limited mobility.	John feels isolated and experiences a decline in his emotional well-being, leading to increased reliance on his anti-depressant to cope with the psychological toll.
Stages	Initial Setup	Changing Needs	Changing Needs
Timeline	**3/1/18**	**6/15/18**	**9/10/18**

Figure 32 Simulated Interaction from vignette #5

The study assessed every simulated interaction in each vignette, and the system was capable of addressing changing needs and adapting the user's app by activating the appropriate module, as long as the required support was available within the system. This ability to adapt was demonstrated consistently across all interactions.

5.5 Discussion

5.5.1 Principal Results

This chapter presents the evaluation studies conducted to assess the iMHere 2.0 system. These studies encompass the usability evaluation of the client app, the feasibility of the system, and the adaptability of the iMHere 2.0 system.

The usability evaluation aimed to reveal usability problems in the client app and refine the design of the iMHere 2.0 system. This study was carried out with nine participants—six with SB, one with CP, and two with SCI. The study successfully discovered 96% of the usability problems that occurred at least once, with p=0.31. Among the various issues that surfaced, 75% were found to be related to affordance. Specifically, the user interfaces were inadequate in providing clear indication of how tasks ought to be performed, leading to confusion and errors on the part of patients. The participants rated the app as highly usable, with a mean SUS score of 83.06 (SD=20.34). The average TUQ score for all participants was 5.79 (out of 7 points, SD=1.55). Participants were satisfied with the iMHere 2.0 client app and would consider using it in the future (average subscale score: 6.17).

The feasibility study included six individuals with Spina Bifida, aged from 23 to 50, who used the app for 90 days. The Education and messaging modules were the most frequently accessed. The most frequently visited Education sections were "bowel and bladder" (55 times), "monitor skin integrity" (40 times), and "spina bifida" (35 times). The highest level of engagement reached during the study period was 90.81%, and the highest number of reminders generated by the app, resulted in 89% of self-reports being submitted in response to the reminders (764/861). One interesting issue discovered was related to the participants' real-life situations, which influenced the use of the reminder feature. Specifically, an unpredictable work schedule made it difficult for them to establish a regular schedule or respond to the reminders generated according to the schedule. This finding suggests that such considerations are often overlooked or not given sufficient thought during the design and development stages.

The vignette-based evaluation approach was utilized to assess the adaptability of the iMHere 2.0 system through simulated interactions. The results showed that the system could address the evolving needs of individuals. The physician was required to activate the appropriate module to provide adaptable support to the patient.

5.5.2 Limitations

The evaluation of the adaptability nature of the iMHere 2.0 system was subject to one limitation worth mentioning. The vignettes utilized in the evaluation were developed by the author, which may have introduced bias, as the selected key events within the simulated interaction were aligned with the features offered by the system. However, these vignettes were validated by experts. The validation adds credibility to their alignment with the system features, suggesting that any potential bias introduced by the author's development may have been mitigated to some extent. Furthermore, the frustration level and mental state of the individual over the course of using the app were not taken into consideration throughout the evaluation. These factors are crucial in determining whether the user is able to maintain their level of engagement with the system or not, as it is a significant determinant in deciding whether the user has sufficient motivation or experiences an unrecoverable breakdown that leads to withdrawal. Nevertheless, the primary focus of the evaluation was on the extent to which the system is capable of adapting its support to meet the evolving needs of the individual, rather than on engagement.

5.5.3 Conclusion

The evaluation studies conducted to assess the iMHere 2.0 system have provided valuable insights into its usability, feasibility, and adaptability. The usability evaluation revealed significant usability problems in the client app, primarily related to affordance issues, which were successfully identified and addressed, leading to high usability ratings from participants. The feasibility study demonstrated promising engagement levels among individuals with spina bifida, particularly in accessing education and messaging modules, despite challenges related to real-life scheduling conflicts. This highlights the importance of considering users' practical constraints during system design and implementation. Furthermore, the vignette-based evaluation approach underscored the system's adaptability in addressing evolving user needs, emphasizing the role of physicians in activating appropriate modules to provide tailored support. Overall, these findings contribute to the ongoing refinement and optimization of the iMHere 2.0 system, enhancing its utility and effectiveness in supporting individuals with complex health conditions.

6.0 Improving Interoperability in Healthcare: A Novel Approach to Integrate mHealth System into Clinical Practice

6.1 Introduction

Interoperability in healthcare is becoming increasingly important in today's systems. It refers to the ability of different systems or devices to exchange information and work together effectively (Blumenthal, 2018). It has many benefits that have a big effect on patient care by reducing costs, boosting efficiency, and making it easier to control the health of whole populations (Li et al., 2022; Seneviratne, 2023; Weber & Heitmann, 2021). Data interoperability enables a connected and interoperable healthcare ecosystem and facilitates the exchange of information between different healthcare systems, despite underlying heterogeneity, through standardized terminologies, coding systems, and data models (Pournik et al., 2023). Interoperability improves the quality of care provided to patients and reduces resource waste by integrating various health information systems to ensure the seamless exchange of data (Torab-Miandoab et al., 2023). Additionally, interoperability accelerates advances in the practice of medicine by making data understandable and meaningful, and for making informed decisions using that data, which is vital for safe and secure data exchange (Fernando, 2022). It is not surprising that interoperability has become highly desired feature given the numerous advantages it offers. Medical professionals frequently inquire about interoperability between digital health solutions, especially when introducing mHealth systems into clinical settings and integrating them with existing electronic health records (EHRs).

Interoperability is crucial for creating a connected healthcare ecosystem. Technically, integrating various technologies is feasible, but there are numerous obstacles to their full implementation as an integrated whole (Walker et al., 2023). Data can become fragmented across several platforms and formats (Seneviratne, 2023). Technological challenges, such as implementation issues, and variations in interoperability capabilities across stakeholders contribute to the difficulty of achieving interoperability (Shear et al., 2023; Walker et al., 2023). Organizational barriers, including privacy and security concerns, cultural and strategic alignment issues, also pose challenges to data interoperability (Walker et al., 2023). Addressing these challenges is essential for a more interconnected healthcare ecosystem.

One potential solution to such challenges is to utilize intermediary services when integrating an mHealth system with EHRs, which helps to mitigate the associated security risks to the EHRs. By reducing direct interactions between EHRs and various partners, the likelihood of security breaches can be minimized. Additionally, intermediary service providers can offer value-added services and features beyond those provided by the current EHR system. One example of an intermediary service is Xealth[5], which enables medical professionals to prescribe digital content or interventions directly from their EHR system.

This chapter aims to explore the use of Xealth in enhancing interoperability between the iMHere 2.0 system and EHR systems in an attempt to implement an mHealth system into clinical settings. It begins with a general overview of the development and assessment of a system that

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[5] Xealth is revolutionizing digital health programs, connecting clinicians and patients with unified platforms for care delivery, reducing healthcare disparities, and raising $53.6 million in funding (https://www.xealth.com/company/about/).

utilizes Xealth's intermediary service, and it goes on to highlight the challenges associated with integrating various healthcare technologies to offer recommendations for future research and practical applications in healthcare interoperability.

6.2 Literature Review

Digital health is a field that utilizes digital technologies to address health-related issues, rooted in eHealth and mobile health. It encompasses eHealth, mobile wireless technologies, and emerging areas like big data, genomics, and artificial intelligence (*WHO Guideline Recommendations on Digital Interventions for Health System Strengthening*, 2019). Digital health systems have the potential to improve national healthcare and patient outcomes, but few attempts have been made to scale-up implementation due to lack of interoperable electronic health records (EHRs) (Shull, 2019). Interoperability is crucial in digitalization, as it enables a connected and interoperable healthcare ecosystem by allowing systems to work together seamlessly to facilitate the exchange of information between different healthcare systems (Pournik et al., 2023).

Interoperability is a concept with numerous definitions, each highlighting its importance and potential benefits (Albouq et al., 2022). Interoperability often refers to the ability of different systems or devices to exchange information and work together effectively (Blumenthal, 2018). This concept is particularly relevant in healthcare, where interoperability allows different health information systems, devices, and applications to share data efficiently and cooperatively across organizational, regional, and national boundaries, as stated by Healthcare Information and Management Systems Society (HIMSS), a well-known and influential organization (himss.org, 2020). The goal of interoperability in healthcare is to facilitate the timely and uninterrupted flow of information to enhance the health and well-being of individuals and populations globally.

Defining an interoperable healthcare system is not straightforward, given the intricate nature of interoperability. To facilitate a better understanding of this concept, HIMSS has categorized interoperability into four distinct levels: Foundational, Structural, Semantic, and Organizational (himss.org, 2020):

- Foundational (Level 1): Establishes the necessary interconnectivity for secure data communication between different systems or applications, enabling exchange data between systems.
- Structural (Level 2): Specifies the data exchange format, syntax, and organization, including field-level data interpretation. This level enables different systems to share data even if they are not identical.
- Semantic (Level 3): Provides a common data model and coding framework, using standard terminology and coding systems from publicly available value sets, to ensure shared understanding and meaning for users. The use of various medical terminologies and non-standard methods of recording critical clinical details in disparate, disconnected healthcare systems has resulted in significant obstacles in achieving interoperability at this level. It is not only the different terms for the same concepts that pose a challenge, but also the identical terms with contrasting meanings.
- Organizational (Level 4): Includes governance, policy, social, legal, and organizational factors that facilitate secure, seamless, and prompt data communication and use between and within organizations, entities, and individuals. These components enable shared consent, trust, and integrated user processes and workflows.

The National Academy of Medicine (2018) employed slightly different terminology to define the levels of interoperability, but the underlying concept remains the same as the one defined by HIMSS. As illustrated in Figure 33, technical interoperability is positioned at the bottom, serving as the fundamental standard to facilitate all the aforementioned initiatives, while organizational interoperability is situated at the top, representing the highest level. The higher the level, the more seamless and automated the process becomes.

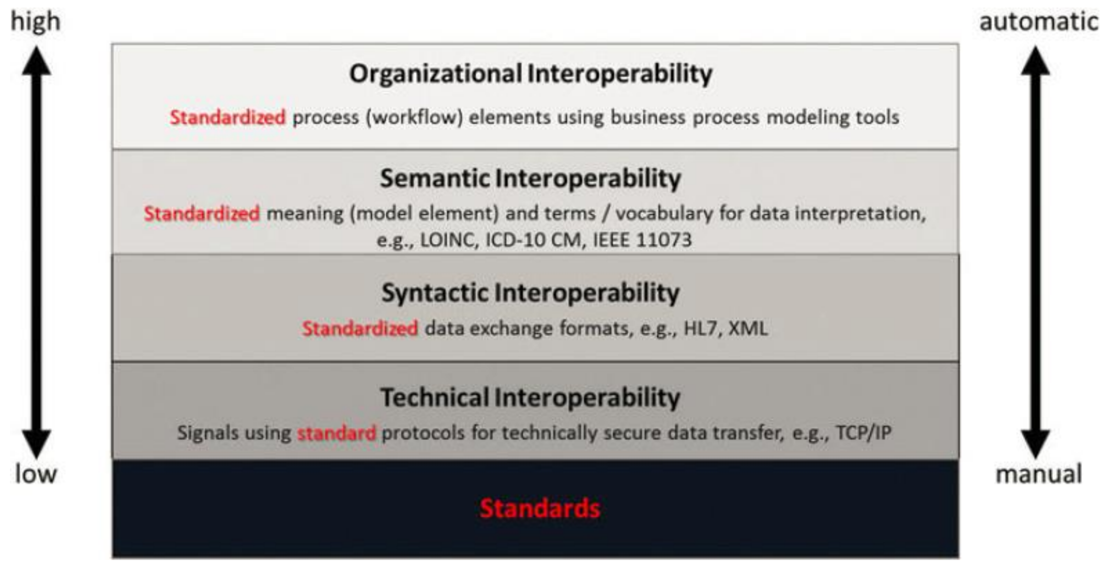

Figure 33 Level of Health IT Interoperability (National Academy of Medicine et al., 2018)

As the figure illustrates, standardization is crucial for fostering shared understanding, exchanging information, and collaborating effectively. Standards enable interoperability between systems and devices, improving healthcare coordination and delivery by allowing clinicians, labs, hospitals, pharmacies, and patients to share data regardless of applications. There are numerous standards in place to facilitate interoperability, including those for vocabulary/terminology, content, transport, privacy and security, and identifier standards (himss.org, 2020).

Some of the standards that facilitate shared understanding and meaning between users through standard terminology include ICD-10, LOINC, and SNOMED-CT. ICD-10 is a medical classification list developed by WHO that contains codes for diseases, sign and symptoms, and other relevant information related to diagnosis. LOINC stands for Logical Observation Identifiers Names and Codes, and it is a universal coding system for identifying laboratory and clinical observations and related content that helps health data more understandable between different systems (loinc.org, n.d.). SNOMAD-CT[6] or Systematized Nomenclature of Medicine-Clinical Terms, is a comprehensive clinical health terminology product from SNOMAD International that facilitates the consistent and processable representation of clinical content in electronic health records (EHRs).

Health Level Seven (HL7)[7] is widely recognized as a leading content standard for structuring and organizing data content in electronic health information exchange. It provides a comprehensive framework for the exchange, integration, sharing, and retrieval of health information. Fast Healthcare Interoperability Resources[8] is an HL7-based transport standard for electronic healthcare information exchange, focusing on health data formats and elements. The goal of FHIR is to establish a common set of resources that can be used across various applications, by defining a core structure and set of information, along with a mechanism for adding additional content as needed. FHIR provides advantages such as seamless data exchange, reduced operational

[6] https://www.snomed.org/about-us

[7] https://www.hl7.org/

[8] https://www.hl7.org/fhir/overview.html

costs, a simpler learning process, patient-driven data management, and an enthusiastic community of users.

The growing interest in ensuring seamless interoperability among various applications has prompted numerous initiatives to address this issue. Studies have proposed different strategies to promote interoperability, such as incorporating it into device design, fostering collaboration through APIs, employing middleware, and developing dictionaries for common concepts (Albouq et al., 2022). Another possible way to achieve this is by utilizing an intermediary service, such as the one provided by Xealth.

An intermediary service can be defined as a type of service that operates as a bridge between parties or systems, enabling communication, transactions, and interactions, and facilitating the exchange of data and information. Unlike other methods that aim to establish communication between systems that were previously incompatible or lacked interoperability capabilities, Xealth's intermediary service also focuses on connecting systems that are capable of interoperability, such as the well-known EHR system EPIC. However, despite these systems having the necessary capabilities, interoperability may still be hindered by external factors such as organizational restrictions, EHR policies, and security concerns.

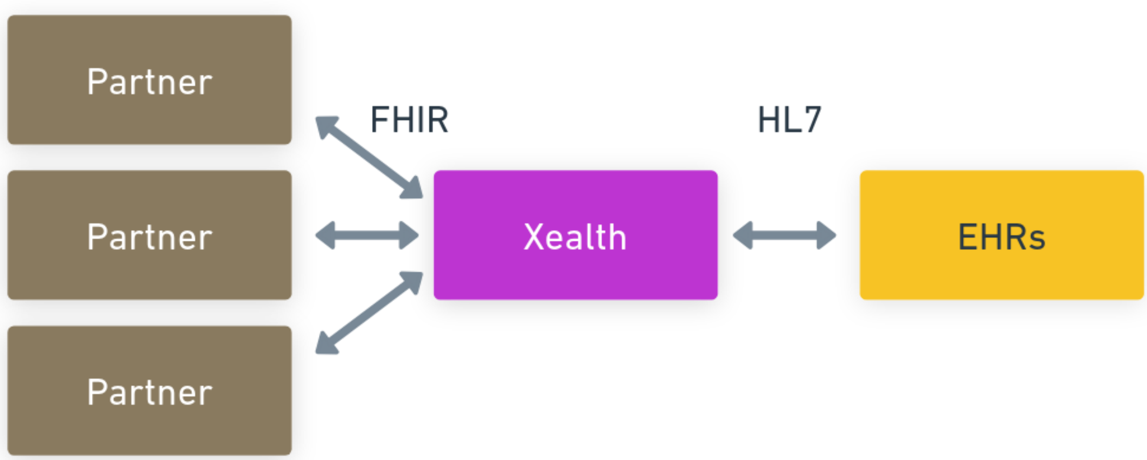

Figure 34 General overview of Xealth’s interoperability

As can be seen from Figure 34, the Xealth service generally offers an effective means for digital health providers (partners) to communicate with EHRs without directly contacting the system. Instead, Xealth ensures seamless interaction by wrapping it with the HL7 standard. Additionally, Xealth provides FHIR-based application programming interfaces for partners to interact with. This approach is noteworthy, as it reduces the potential for security breaches by limiting direct interactions between EHRs and multiple partners. Furthermore, intermediary service providers like Xealth can offer value-added services and features beyond what is currently offered by the EHR system. One such capability that Xealth provides is a streamlined clinical workflow for care teams, which allows medical professionals to prescribe digital content (such as interoperable system) or interventions directly from their EHR system.

6.3 Methodology

Integrating digital health systems into real-world clinical settings can be a challenging task that extends beyond the scope of research studies. Medical professionals often call for the integration of mHealth systems into their existing electronic health records (EHRs) when trying to incorporate such systems into their clinical workflows. As part of the efforts to address this challenge, a pilot implementation for the iMHere 2.0 system is currently being conducted at a Spina Bifida clinic in Pittsburgh, with Xealth acting as the intermediary service within the Epic Care EHR system.

iMHere 2.0 is a cutting-edge mobile health system designed to support self-management for individuals with chronic conditions and disabilities (Setiawan et al., 2019). It offers a range of features, including reminders for self-management tasks, health-related information tracking, and communication between clients, caregivers, and clinicians via the web-based portal. The system can be used independently as a reminder and tracking tool, or in conjunction with the iMHere Caregiver app for enhanced oversight of reminder compliance and health-related issues. The app's modules are customizable, and users can select which ones they wish to use. However, the app offers more functionality when it is connected to the portal. Then it allows for care-plan delivery, tracking, and response to medical issues, and clinician-client communication through its internal messaging system. The system comprises a total of 18 modules, 12 of which are designed to support self-management, while the remaining modules are focused on activity daily living management.

Xealth, a company established by the creators of Swype and Boost Mobile, is actively promoting digital health initiatives within major US healthcare facilities. By connecting healthcare providers and patients to digital tools and services, Xealth simplifies the process of ordering and accessing content, as well as obtaining prescriptions. Xealth's capabilities[9] include a digital health formulary strategy, a care team clinical workflow, digital front door activation, a clinical AI engine, monitoring, notification, and data management as well as integration management.

The integration strategy to be used involves incorporating iMHere 2.0 into the clinical workflow of the clinic. The clinic is presently utilizing the Epic Care EHR system provided by UPMC[10]. This system has been leveraging Xealth's service for a while, particularly its care team clinical workflow capability to consolidate various digital tools into a unified user interface within

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[9] https://www.xealth.com/capabilities/

[10] https://www.upmc.com/about

Epic Care. Xealth's Unified User Interface functions similarly to a plugin within an EHR system, seamlessly integrating the Xealth service into the EHR and enabling the digital health solutions to be prescribed directly from within the system. Having this capability and the integration management provided by Xealth opens up the possibility for the iMHere 2.0 system to be incorporated into the clinic's workflow.

To effectively integrate iMHere 2.0 into the clinic's daily operations, a set of essential functional requirements must be met, including:

1. Providers should be able to prescribe the iMHere 2.0 app for patients through EHR.

   This requires establishing a mechanism for registering new patients in the iMHere 2.0 system. Providers may include doctors, nurses, or any other member of the patient's care team.

2. Providers should be able to select the necessary modules to include within the app from the EHR.

   The iMHere 2.0 app is equipped with self-management support modules that can be personalized to meet the individual needs of patients at any given moment. In light of this, it is crucial to provide the option of selecting the appropriate module during the initial order.

3. Patients should be able to provide consent before utilizing the iMHere 2.0 app.

   Patient consent is a crucial principle in medical ethics and legal practice, promoting autonomy, informed decision-making, protection from harm, legal obligations, privacy, and enhanced patient satisfaction. It ensures patients are informed about the nature of the intervention, its benefits and risks, and safeguards against unnecessary interventions. Failure to obtain consent can lead to legal liability or disciplinary action for the care provider.

4. Providers should be able to monitor the patient’s use of the iMHere 2.0 app from EHR. In order to integrate the self-management support modules into the clinical workflow, it is essential that the providers have the ability to view the patient's progress in using the app directly from the EHR. By doing so, the providers can minimize the disruption to their existing workflow and avoid the need to access a separate system. Xealth's Care Team Clinical Workflow functionality has supplied the structure; all that remains is to include the details of each patient's progress information.

Although the iMHere 2.0 system contains a total of 12 modules, for the purpose of this pilot program, eight of these modules were selected in order to simplify the initial integration process. These eight modules are: medication management, mood, exercise, nutrition, bowel program, tele-catheterization, personal health record, and education. Patients participating in this pilot program utilizes the iMHere 2.0 application independently, without communication support or assistance from caregivers and physicians within the app. Instead, the clinic monitors the patient’s progress from the EHR, and any interactions with the care team are conducted either during clinic visit or through alternative methods.

To evaluate the pilot implementation of the integrated system that uses Xealth to enable interoperability between the iMHere 2.0 system and EHR systems in clinical settings, a mixed-methods approach will be employed. This evaluation involves analysis of usage data and qualitative feedback from stakeholders, including healthcare providers and patients. The data from both the iMHere 2.0 system and Xealth analytics will be utilized to gather usage information. The analysis of usage data will assess various aspects such as enrollment process, installation rates, and any challenges encountered during setup, including technical issues or workflow disruptions.

The evaluation process will measure the level of engagement among patients. To aid this evaluation, an engagement metric known as FITT, which stands for frequency, intensity, time, and type (Short et al., 2018), will be employed. This metric will be useful in analyzing engagement data by examining the frequency and duration of system usage and interactions with specific modules.

Apart from usage data analysis, it is important to gather early feedback from providers and patients involved in the pilot implementation. To obtain feedback from patients, a structured survey will be presented to them, using a validated mHealth questionnaire called MAUQ, with modifications made to ensure relevance (Zhou et al., 2019). These questions aim to assess the perceived usability, usefulness, and satisfaction of the system, with the goal of identifying areas for improvement. It is important to note that the data from patients will be collected voluntarily within the app, similar to the way data is collected in regular app usage in real-life scenarios. Conversely, feedback from providers will be collected during the implementation at any time during the study.

For this pilot implementation, patients who visit the clinic and are willing to participate will be prescribed the iMHere 2.0 app. This population will consist of individuals with spina bifida, which the clinic specializes in. From the provider's side, physicians and nurses within the clinic will be involved in this pilot program.

By prioritizing usage data analysis and voluntary surveys, the evaluation will provide valuable insights into the enrollment process, setup challenges, engagement levels, and user feedback. This information will enable a comprehensive assessment of the pilot implementation's success and will be influential in informing future iterations of the integrated system.

6.4 Results

6.4.1 Integration Design

The design of the integration workflow depicted in Figure 35 was created to kickstart this initiative. The primary objective is to enhance the clinical workflow by incorporating the capability for providers to digitally prescribe iMHere 2.0 app. The outline below describes the step-by-step workflow of the integration:

1. Ordering / iMHere 2.0 app Prescribing: The providers typically initiate the interaction while the patient is visiting the clinic. They make an order to prescribe the app to the patient through the EpicCare system's Xealth unified interface. During this process, the provider selects any necessary modules for the patient and sends the order.
2. iMHere Patient Registration: When the iMHere system receives the app order, it takes care of the entire registration process internally and communicates with the Xealth service.
3. Notification: After Xealth service successfully detects the registration completion signal for a patient, an email notification is generated and sent to the patient's email address. This notification is also accessible through the myUPMC patient portal.
4. Disclaimer and Consent: The email notification includes a disclaimer about the app and a consent button, allowing patients to initiate the consent process. Upon agreeing and

providing consent, patients will be directed to the iMHere 2.0 app download page, where they will be presented with either an iOS or Android app link.

5. Application Setup: After the patient has downloaded the app, they should proceed to set it up by registering the device for approval.
6. Application Utilization: After the device has been approved, the app can be utilized with the chosen modules.
7. Usage Data Collection: As the app is being utilized, data on its usage is collected in conjunction with self-reported information.
8. Monitor Progress: The progress of self-management support is regularly monitored by providers using a unified user interface provided by Xealth and integrated into the EHR system.
9. iMHere Dashboard: The iMHere dashboard is displayed and accessible for monitoring within the Xealth platform in the EHR. This dashboard allows providers to assess medication adherence, exercise levels, daily nutrition intake, bowel and bladder program, and mood.

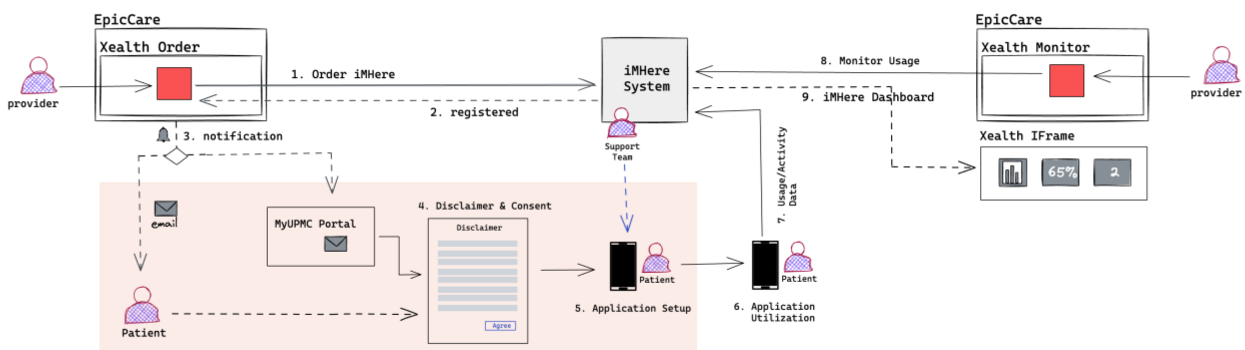

Figure 35 General workflow of iMHere 2.0 – Xealth digital health integration

The schematic on the left side of Figure 36 on the left depicts a simplified version of the workflow, which includes two actors: the physician and the patient, as well as an integrated system between Xealth and iMHere. On the right side of Figure 36, the workflow for setting up the application is shown. After patients download and install the app on their own devices, they must register their device by providing any description, such as the initials of their name, to indicate their identity. However, simply registering does not grant the patient immediate access to the app. Instead, their registration must be approved by the system admin and associated with the correct account, which was established during the prescribing process. Once approved, the iMHere app is ready for daily use.

The implementation of all steps in the integration process requires the utilization of Application Programming Interfaces (APIs) from the iMHere 2.0 platform and the Xealth service. Xealth provides a set of APIs to aid in the integration of the workflow as part of its integration management responsibilities. In addition to modify existing services, we have created a new service called imhere-xealth integration service and a monitoring dashboard to complement the iMHere 2.0 system and expand its capabilities for this integration according to the specified requirements. Fortunately, the iMHere 2.0 system was originally designed with modular approaches and microservices, making it simple to add additional services. NodeJS version 16 was used to build the service with ExpressJS[11] as the main web application framework. Meanwhile, the dashboard component for monitoring was built using Dash[12] from Plotly, a low-code framework for rapidly building data apps in Python.

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[11] https://expressjs.com/

[12] https://dash.plotly.com/

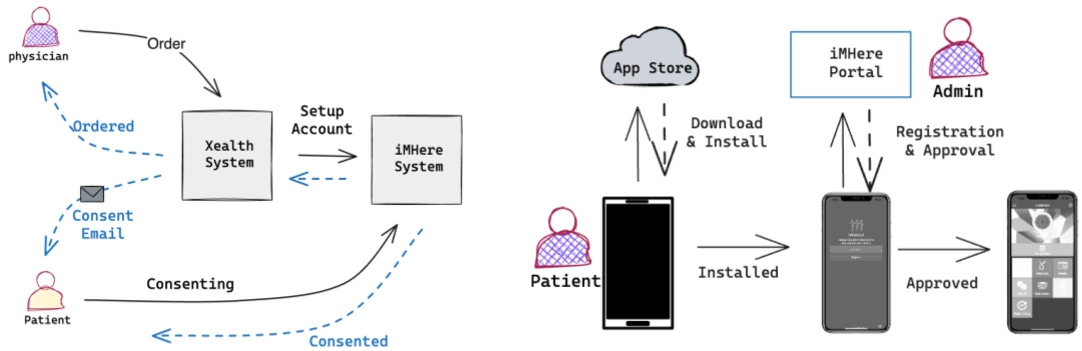


Figure 36 (Left) Workflow of iMHere 2.0 App Prescribing Process, (Right) Enrollment Process

6.4.2 User Interfaces

There are two main sections of Xealth's unified user interface, as illustrated in Figure 37: Order, and Monitor. The order section is used by providers to prescribe the iMHere 2.0 app, and the monitor section lists all prescribed digital tools for a particular patient, including the iMHere 2.0 app.

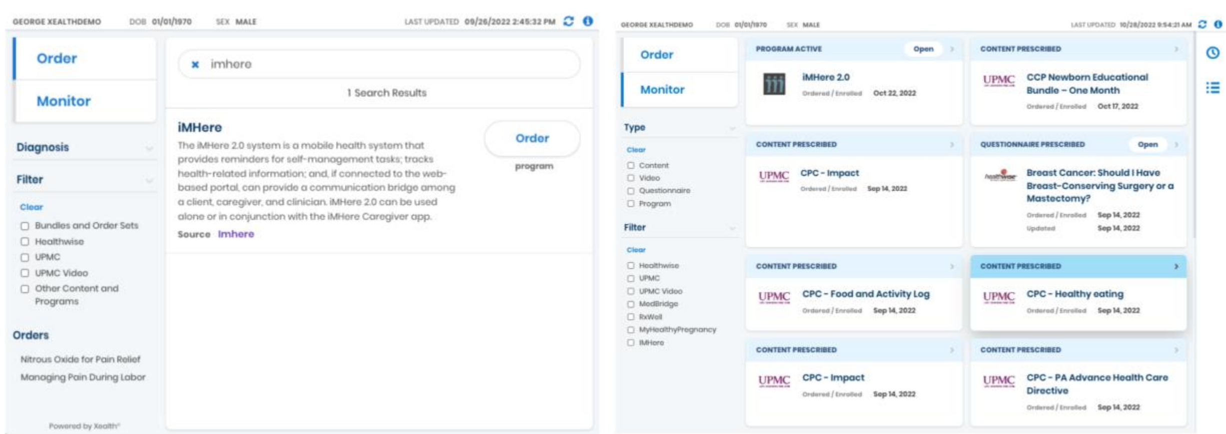


Figure 37 Xealth's Unified User Interface

In order to have the iMHere 2.0 app listed and prescribable within the current structure, several API endpoints must be implemented within the service, as depicted in Figure 38. These include the `pre_order`, `get_programs`, and `get_program_urls` endpoints, which will be heavily utilized during the monitoring process by the clinic. Figure 39 illustrates the internal integration workflow for the monitoring process. This figure shows how the iMHere 2.0 dashboard is presented within the Epic Care system using an `Iframe`. The inline frame (Iframe)[13] element is an HTML element that allows for a nested browsing context and the embedding of another HTML page within the current page. This approach enables the presentation of an external webpage from the partner's service to the provider within the EHR system. In this case, the external webpage is the iMHere dashboard.

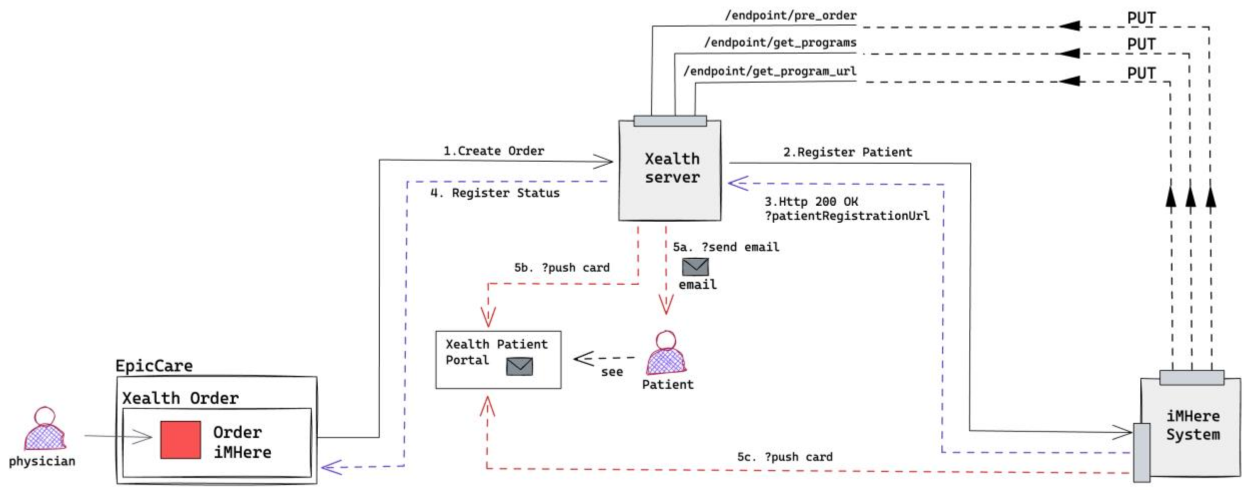


Figure 38 Internal integration workflow for Order process

The system will generate an order form that looks like the illustration in Figure 40 once the requisite API endpoints have been established. Upon clicking the order button, the provider will

[13] https://developer.mozilla.org/en-US/docs/Web/HTML/Element/iframe

be directed to a patient information verification page, where they will have the opportunity to select any modules they want to activate initially for the patient.

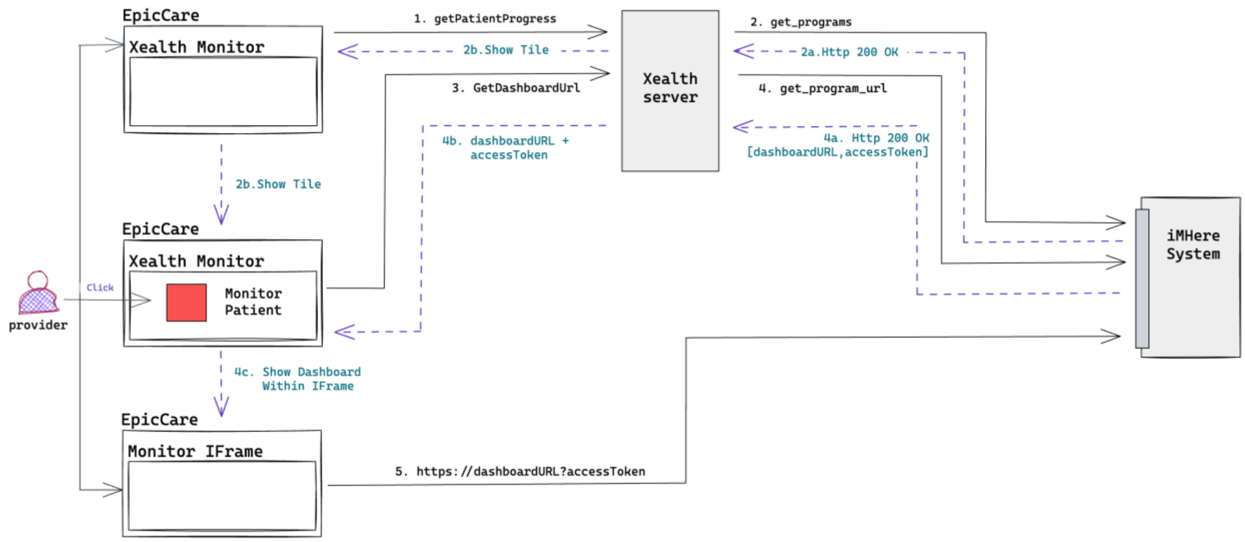


Figure 39 Internal integration workflow for Monitor process

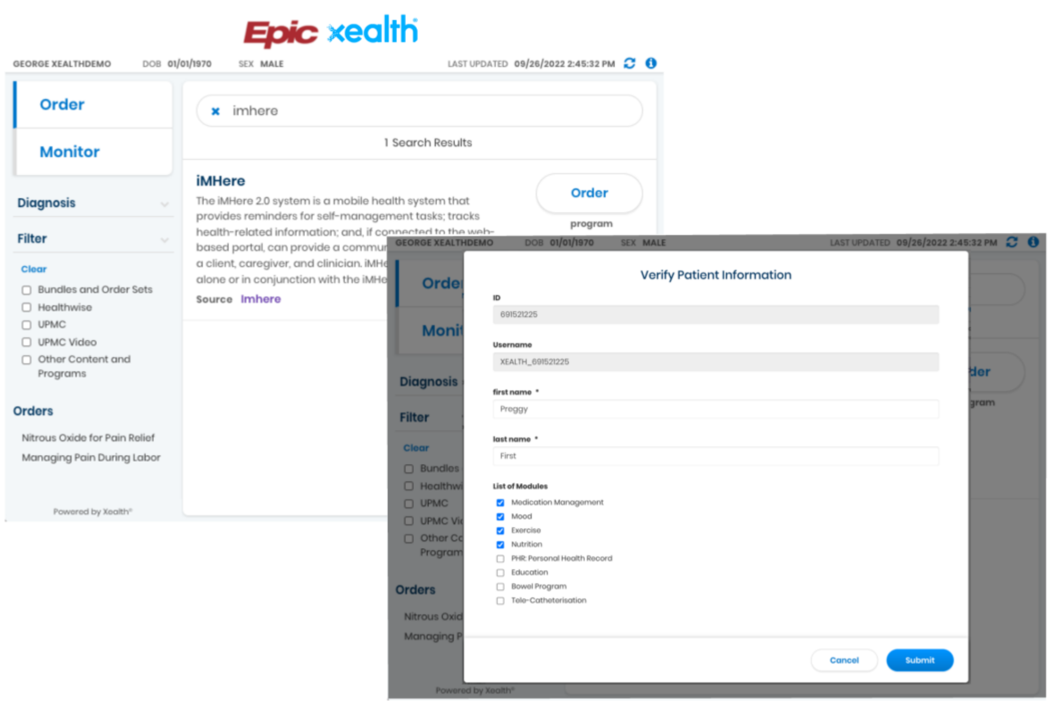


Figure 40 Ordering/Prescribing form for iMHere 2.0 App

Following the completion of the prescribing process, an email notification with a disclaimer and consent form is sent to the patient's email address. As shown in Figure 41, once the patient accepts the program, the patient will be directed to the app's download page where they can choose their device's platform (iOS or Android) and download the app to their device.

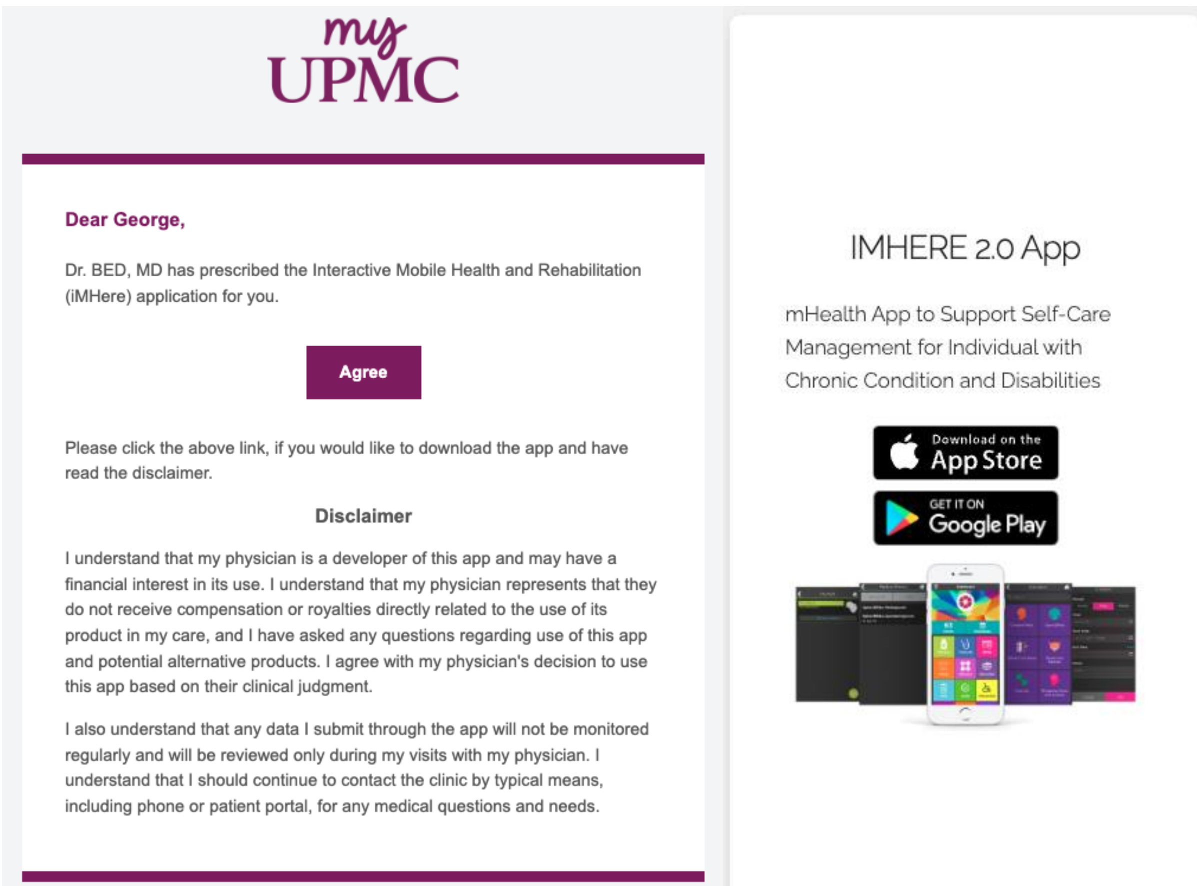


Figure 41 Disclaimer and Consent form (left) in email notification content, and App download page (right)

Figure 42 displays the iMHere 2.0 dashboard, which allows providers to monitor patient's progress. The charts visible on the dashboard will correspond to the active modules that were set during the prescribing process.

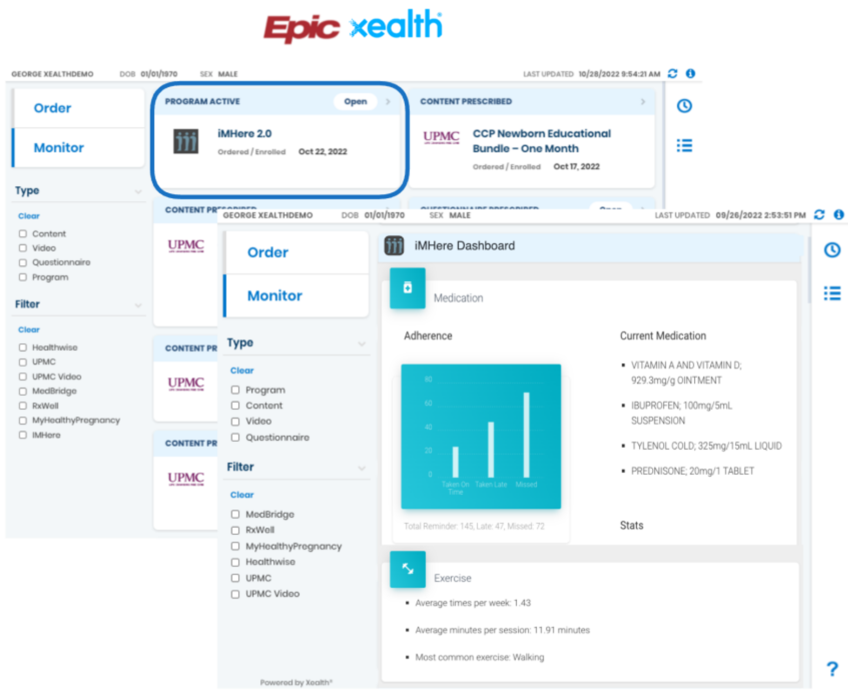


Figure 42 iMHere 2.0 Dashboard within Xealth Unified User Interface

6.4.3 Data Collection and Analysis

The pilot implementation is currently in progress. As part of the initial data analysis, enrollment and app usage data were being collected from May 1st, 2023, to January 31st, 2024.

6.4.3.1 Enrollment

During the nine months of the pilot, 62 patients were prescribed from Xealth Unified Interface. Altogether, 78 email notifications were sent to these patients, and 55 of them (88.7%) opened the email. Among these patients, 53 (85.48%) clicked the consent button to indicate their consent to the prescription of the iMHere 2.0 app. A significant number of patients, 80.65% (50/62), installed and completed the registration process, including one patient who did not give their consent for the prescription. Additionally, 79.03% (49/62) of the registration applications were approved, indicating that the patients had officially enrolled in the program. Most of the patients, 47 out of 53 (88.67%), consented to the prescription within 2 days of its being ordered. Furthermore, 82% (41/50) of the patients who installed and completed the registration process did so within 2 days of its being ordered, and all patients completed the process within 16 days. Notably, 73.47% (36/49) of the registered apps were approved within 2 days, and only 2 were approved beyond the one-month point. Of the 36 patients who were enrolled within 2 days, 17 (47.2%) had their registration approved within 3 hours of its being ordered. An average of 6.89 new patients received prescriptions for the iMHere 2.0 app every month (SD=3.65; range=2-13). Figure 43 illustrates the enrollment patterns on a monthly basis for the pilot period. Furthermore, the distribution of users based on the duration of their enrollment's key stages, such as the time to consent, time to register, and time to enroll, can be found in Appendix F.1.

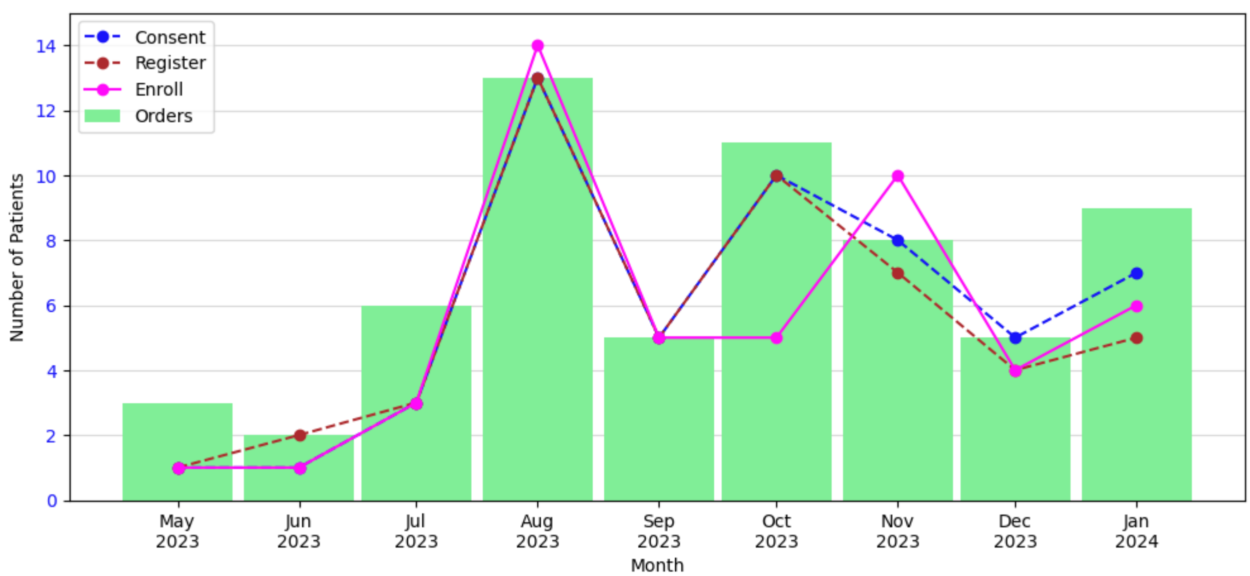


Figure 43 Monthly enrollments statistics

Each month, on average, about 7 patients were prescribed the iMHere 2.0 app through EpicCare. Of those, an average of 6 patients per month responded to the email notification, provided their consent, installed and registered the app, and received approval. These details are further elaborated in Table 15.

Table 15 Enrollment metrics

Metric	Rate
Total Order	62
Consent Rate	85.48% (53/62)
Installation Rate	80.65% (50/62)
Enrollment Rate	79.03% (49/62)
Stages/Metric	**Monthly Rate**
Orders	6.89 (SD=3.66)
Consent	5.89 (SD=4.04)
Install/Register	5.56 (SD=3.88)
Enroll	5.44 (SD=4.22)

6.4.3.2 User Engagement

This section examines user interaction and activity within the iMHere 2.0 app, with the aim of thoroughly analyzing and comprehending the level of engagement among app users. The analysis is divided into two parts:

1) The level of user interaction as a whole from the perspective of system implementation, from the first deployment in May 2023 through January 31, 2024. To put it simply, this analysis will be conducted in the calendar days mode, which is typically used in engagement analysis. This is referred to as system engagement in this writing.
2) The level of user interaction from the perspective of the patient, from the first day of enrollment through January 31, 2024. This is a more in-depth analysis because the system is capable of tracking each patient's activity when they were using the iMHere 2.0 app. The patients' data were aligned based on the number of days since their enrollment date. In this writing, this is referred to as user engagement.

6.4.3.2.1 Perspective of System Implementation Timeline

Over the course of the 9-month pilot implementation period, 38 patients actively engaged with the app. To be considered active, a user must have accessed or opened the app at least once during the period, regardless of the number of interactions they made. The adoption rate was 61.29% (38/62), meaning that 61.29% of the patients who were prescribed the app actively engaged with the app. This shows a high level of acceptance and interest among the target patients. This is about 77.55% of the enrolled patients. Among the active patients, the length of time since enrollment varied from 2 days to 8 months and 15 days (M=117.10; SD=63.75).

These active patients engaged in a total of 952 app sessions, with an average of 8.66 interactions per session (SD=19.48; median=4; range 1-337). Each active user initiated approximately 216.92 interactions (SD=732.70; median=39.5; range 4-4535) and spent about 1 hour and 25 seconds total (SD=9082.78s; range 4s-54019s) using the app during the implementation period.

The data was examined on a monthly basis, and it was found that there were roughly 8 unique users who actively utilized the app each month (M=7.56; SD=4.75; Median=9; Range 1 - 15). The average number of sessions per month was 105.78 (SD=67.59; Median=95; Range 8 - 210), and the total time spent by all users was approximately 4 hours and 15 minutes (M=15307.44; SD=14347s; M= 10456; Range 77s – 40785s).

Analyzing it more deeply, each user completed around 14 sessions per month (SD=29.15; median=3.00; Range 1-154), spending an average of 33 minutes and 46 seconds per user per month (M=2025.99s; SD=3822.16s; Median=586.50s; Range 4s-17312s), which is approximately 2 minutes and 25 seconds per session (M=144.71s; SD=498.67s; median=25.00s; range 1s-6673s).

To gain a better understanding of the level of user engagement and the frequency of interactions relative to the total user base, a metric known as *stickiness* was calculated. Stickiness is the ratio of daily unique active users (DAU) to monthly unique active users (MAU). During the pilot implementation period, the average DAU was 1.22, and as previously mentioned, the average MAU was 7.56. This resulted in a stickiness ratio of 0.16 (or 16.11%). This suggests that, on average, 16.11% of monthly active users interact with the platform on a daily basis.

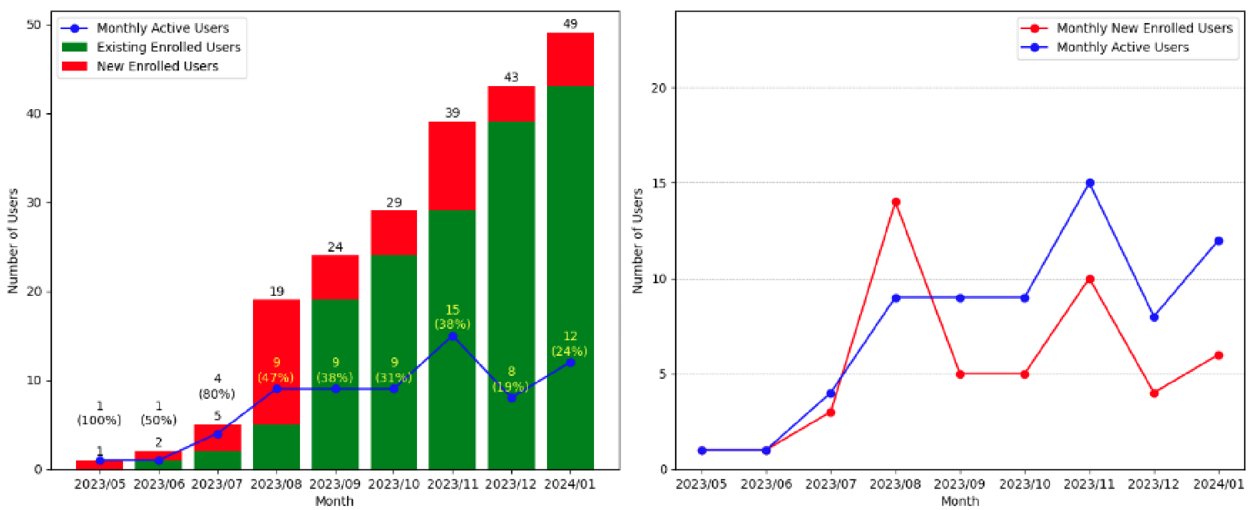


Figure 44 Monthly Active Users and New Enrolled Users Growth

When examining the mean and median values for each metric, it's evident that the mean surpasses the median in most cases. This observation suggests a positive skew in the data distribution for these metrics. Such skewness indicates the presence of relatively few instances of exceptionally high values, possibly indicating that a small number of patients engaged with the app extensively during the implementation period. The only exception pertains to the monthly active users, as their mean value falls below their median. This indicates a negative skew, which is further supported by the distribution chart presented in Figure 44.

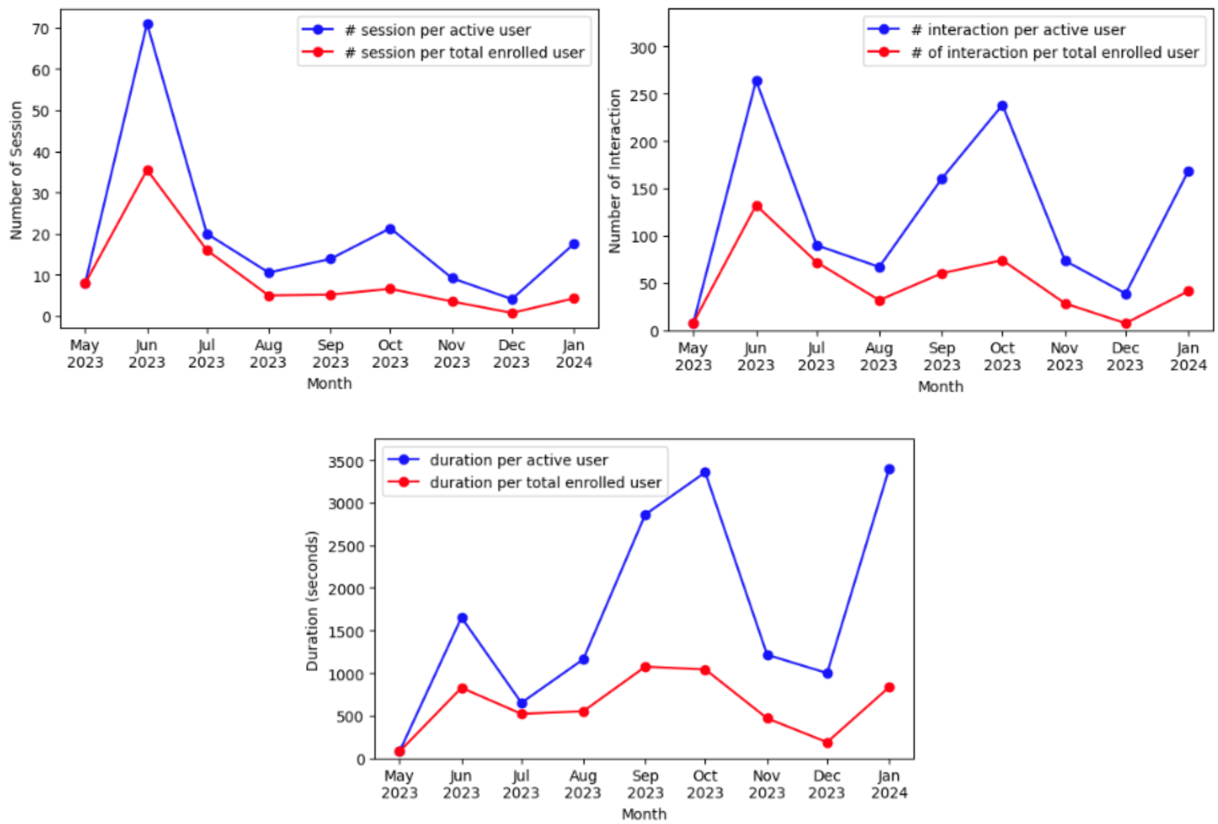


Figure 45 Monthly Utilization Rate per Active and Enrolled Users.

(TopLeft) Number of Session, (TopRight) Number of Interaction, (Bottom) Time Spent

The monthly trend for each utilization rate can be observed in Figure 45, which shows that during the initial pilot implementation, users generally engaged in a high number of sessions and interactions, but they spent a relatively short amount of time using the app. In contrast, during the middle and end of the implementation, users activated fewer sessions but stayed engaged with the app for longer periods of time with high levels of interaction.

The app's capacity for retaining users and maintaining their interest over time was assessed by calculating a *retention rate* on a monthly basis. This rate reflects the percentage of users who continue to utilize the app every month. A high retention rate indicates that the app provides enduring value and effectively meets users' needs. As depicted in Figure 46, during the initial implementation phase, when the number of users was relatively low, the app achieved a 100% retention rate, suggesting that all active users in June 2023 persisted in using the app in July 2023. However, as the number of enrolled users increased, the number of active users remained static or grew, with the result that the retention rate began to decline. This suggests that the drop-in retention rate might be due to the fact that the active users from the previous month were new users who did not continue to use the app in the following month.

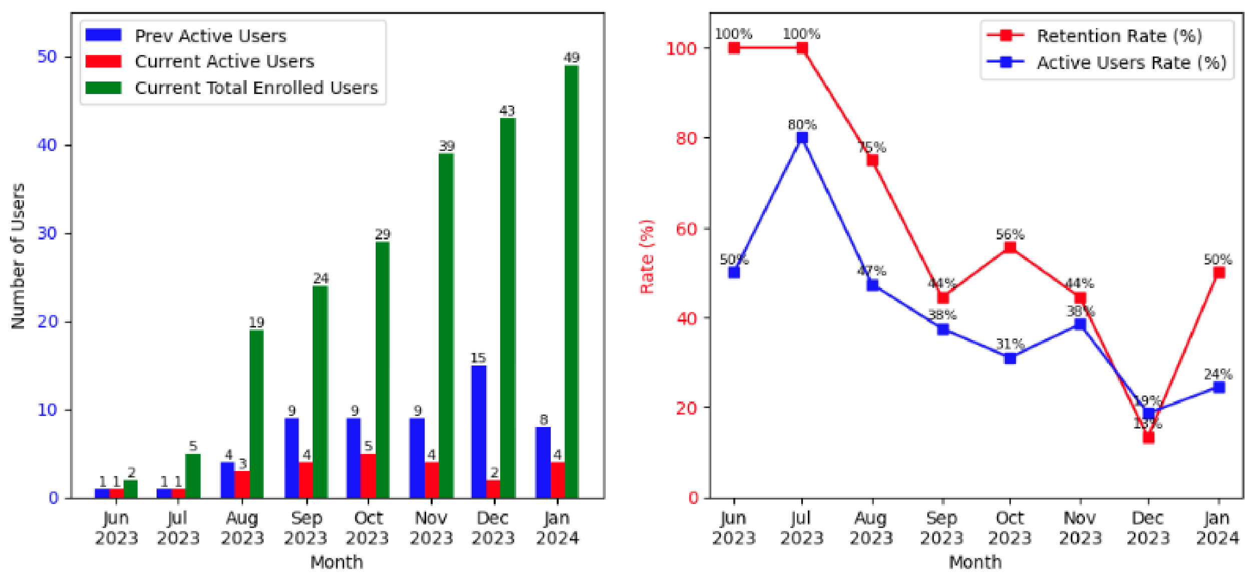


Figure 46 Monthly Active Users Rate and Retention Rate

6.4.3.2.2 Perspective of Patient Interaction Timeline

A total of 49 patients were enrolled in the iMHere 2.0 app from the implementation start date until January 31st, 2024, as illustrated in Figure 47. The distribution of these patients based on their enrollment duration is depicted in the figure. The average enrollment days per patient was 117.1 (SD=63.75; Median=120; Range 2-255). Approximately 87.76% (43/49) of the patients were enrolled for more than 30 days, 65.31% (32/49) for more than 90 days (3 months), and 16.33% (8/49) for more than 180 days (6 months).

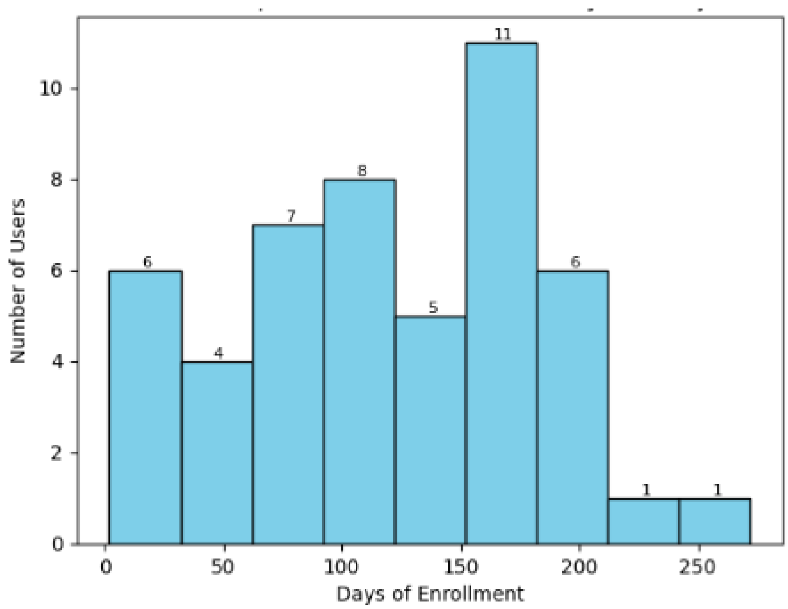


Figure 47 Distribution of enrolled patients over days of enrollment (with 30 days bin size)

To gain a better understanding of patients' app usage activity levels throughout their enrollment period, the daily number of active users was calculated. As depicted in Figure 48, out of the 49 total enrolled patients, 31 accessed the app on their first day of enrollment, accounting for approximately 63.27% of the total. Each user initiated approximately 2.7 sessions on the initial day (SD=3.437; Median=2), spending an average of 17 minutes and 3 seconds (M=1023.61; SD=1881.87; Median=409), which equates to roughly 6 minutes and 17 seconds per session.

The lower number of active users on the first day of enrollment can be attributed to the fact that patients are only considered enrolled after their registration is manually approved by the system administrator, which may take some time. Moreover, patients may not have utilized their phones until the day after they received approval. This is evidenced by the second-day data, which indicates that only 15 active users were retained from the first day, while the total number of active users for the second day was 17. Consequently, two users engaged for the first time on the second day.

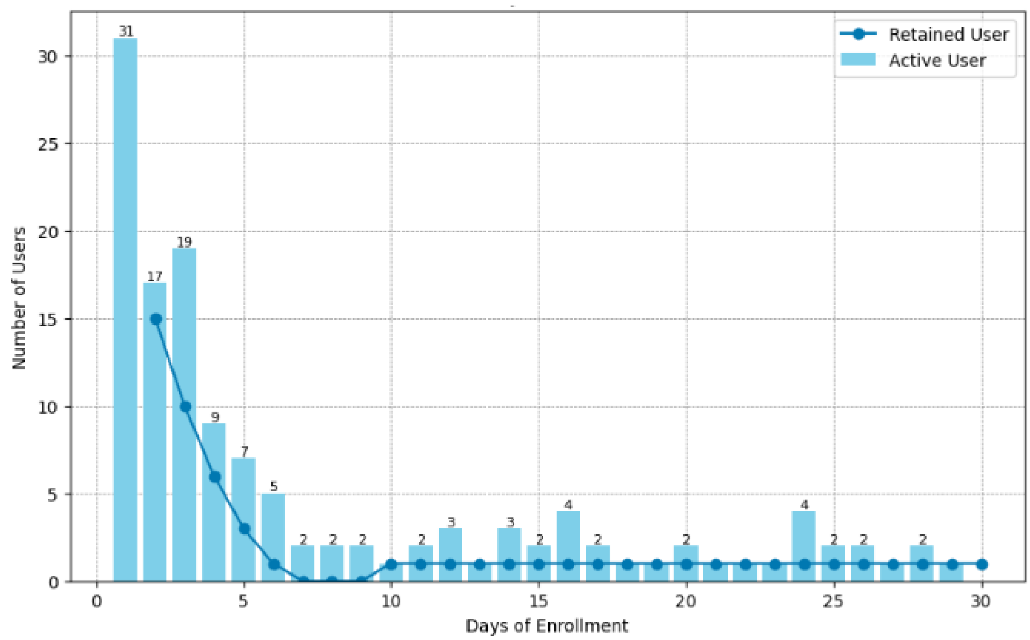


Figure 48 Number of Active Users by Days of Enrollment for the first 30 days (inclusive)

The trend of active users consistently declining after they use the app for a few days is evident. From the first day to the second day, the number of active users decreases by approximately 45.16% (17/31). That same day, however, the number of sessions per user increased approximately 43.3%. The average was 3.88 sessions per user (SD=3.179; Median=3), with each session lasting approximately 5 minutes and 24 seconds. Although there was a slight bounce on the third day, the number of active users dropped even more, a decline of roughly 52.63% (9/19) from the second day. By the end of the first week, only two active users remained. When tracking user activity more deeply, the retention rate on the second day was about 48.39% (15/31), indicating that 15 patients from the first day continuously engaged with the app on the second day. Of the 17 users from the second day, 10 (58.82%) continuously accessed the app on the third day.

As the figure shows, the retained users kept declining until the end of the first week of enrollment. None of the daily active users consistently used the app for several days in a row, likely because they only occasionally checked the app or had the app reminder set for a frequency that was not daily. Only one user consistently used the app through the first 30 days of enrollment, as shown by the retained user trend in the figure.

It's important to mention that the first 30 days of user data are inclusive, meaning that it covers all enrolled users, even those who have only been enrolled for a short period of time. As a result, this may lead to a slightly biased representation of daily active users. Figure 49 presents the exclusive version of the trend, which only includes users who have been enrolled for at least 30 days. This figure demonstrates that the number of daily active users has been corrected for the first few days, however the trend itself remains similar.

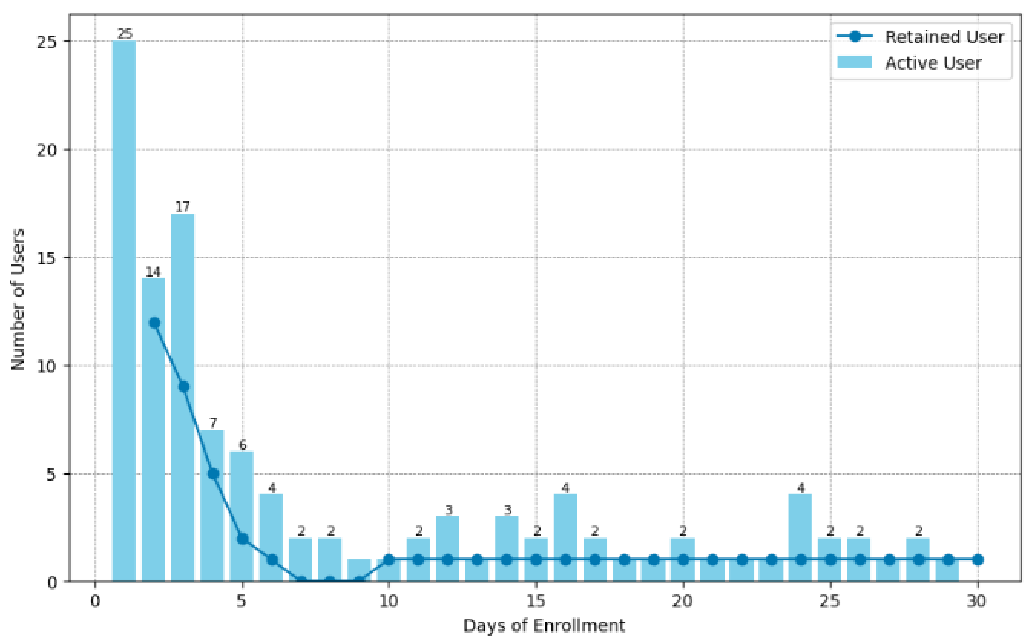


Figure 49 Number of Active Users by Days of Enrollment, exclusive enrolled for 30 days

The trend shown in Figure 50 reveals that in the first week after enrollment, a substantial portion of enrolled patients, approximately 73.47%, actively engaged with the app. Each user participated in roughly 6.8 sessions on average (SD=10.53; Median=4). The duration spent on the app was about 30 minutes and 52 seconds (M=1851.97; SD=3241.76; Median=538). This translates to around 4 minutes and 32 seconds per session. However, the following week saw a significant decline of 77.78% in the number of active users, with only 8 out of 36 users remaining from the previous week, representing a retention rate of 19.44%. During the second week, active users engaged in an average of 4.125 sessions, a decrease of 39.38% from the previous week, with

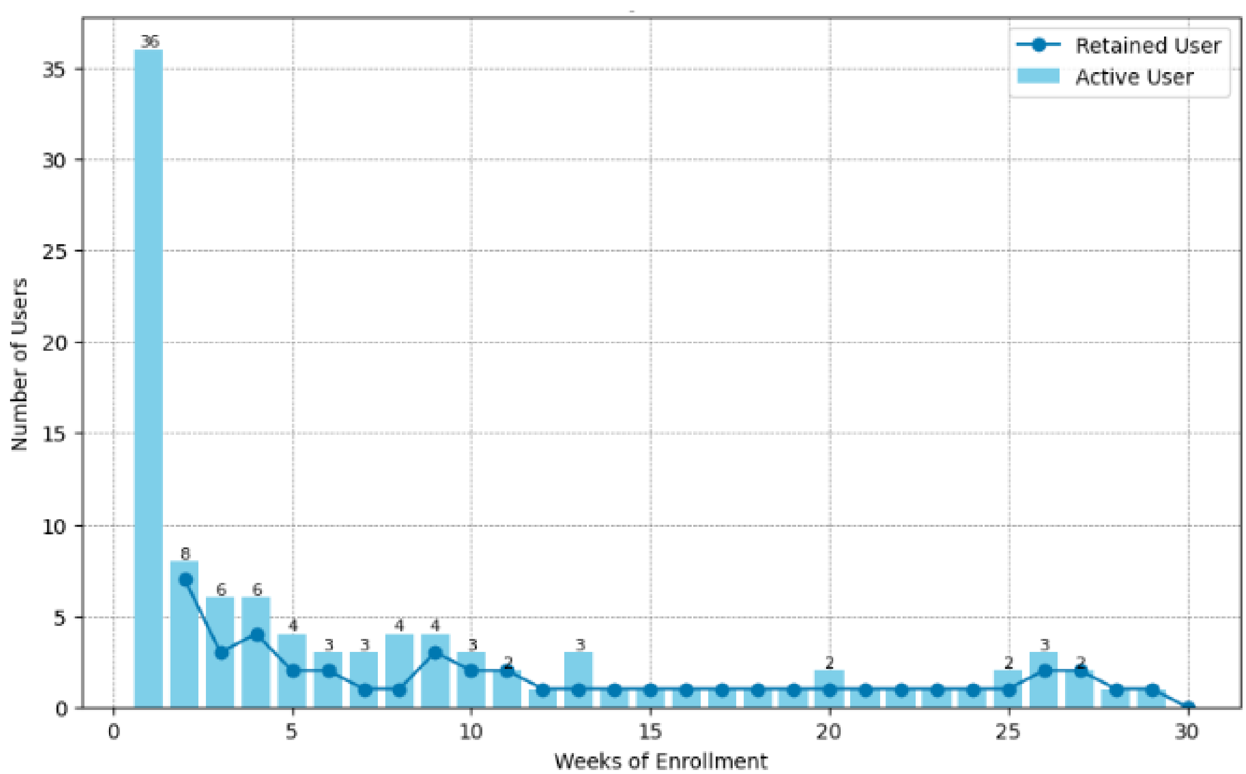


Figure 50 Number of Active Users by The Week of Enrollment (inclusive)

each session lasting approximately 2 minutes and 8 seconds. From the third week onwards, the number of users remained consistent, ranging from 3 to 6 users per week, with some retaining their engagement. Notably, one user continuously used the app from the 12th week for the next 12 weeks (3 months).

The monthly pattern also exhibits a similar trend, as depicted in Figure 51. Among the 49 enrolled users, 75.5% (37) were actively using the app within the first month of their enrollment, with an average of 8.97 sessions per user (SD=14.38; Median=4) totaling approximately 32 minutes and 40 seconds per month (M=1960.73; SD=3336.85; Median=554). This translates to an average of 3 minutes and 38 seconds per session. In the subsequent month, the number of active users decreased by 75.68% to 9 users, of whom 8 were continuous users from the previous month, resulting in a retention rate of 21.62% (8/37). During the first three months of using the app, the number of active users was relatively high, but after that, the number of active users decreased significantly. Specifically, only 3% to 6% of the enrolled users continued to engage with the app, with the number of retained users ranging from 1 to 2.

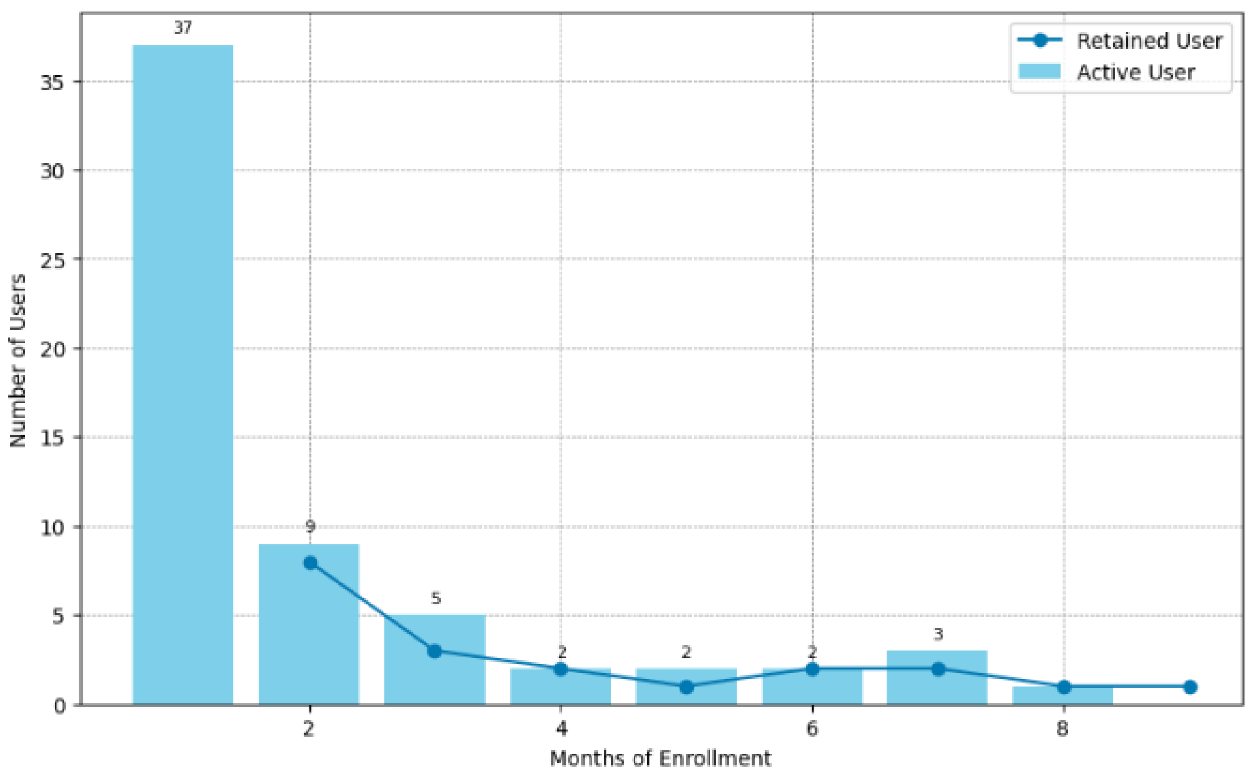


Figure 51 Number of Active Users by the Month of Enrollment

Figure 52 presents the monthly trend of user engagement with the app in terms of the number of sessions, interactions, and time spent. For the initial three months of usage, the trend remained consistent for all three metrics. After that, there was a significant increase in the number of sessions, interactions, and time spent on the app for a few months, followed by a drop in the subsequent month, only to rebound again. It appears that the stagnant low number of active users, starting from the fourth month, influenced this pattern. However, in terms of the duration per session per user, the median displayed a distinct pattern. This pattern indicated that the data distribution had a positive skew, where the data was clustered more towards shorter time spent on the app, and a few extreme instances of time spent per session per user drove the average. As evident from the figure, the median for time spent on the app fell between 10 to 31 seconds.

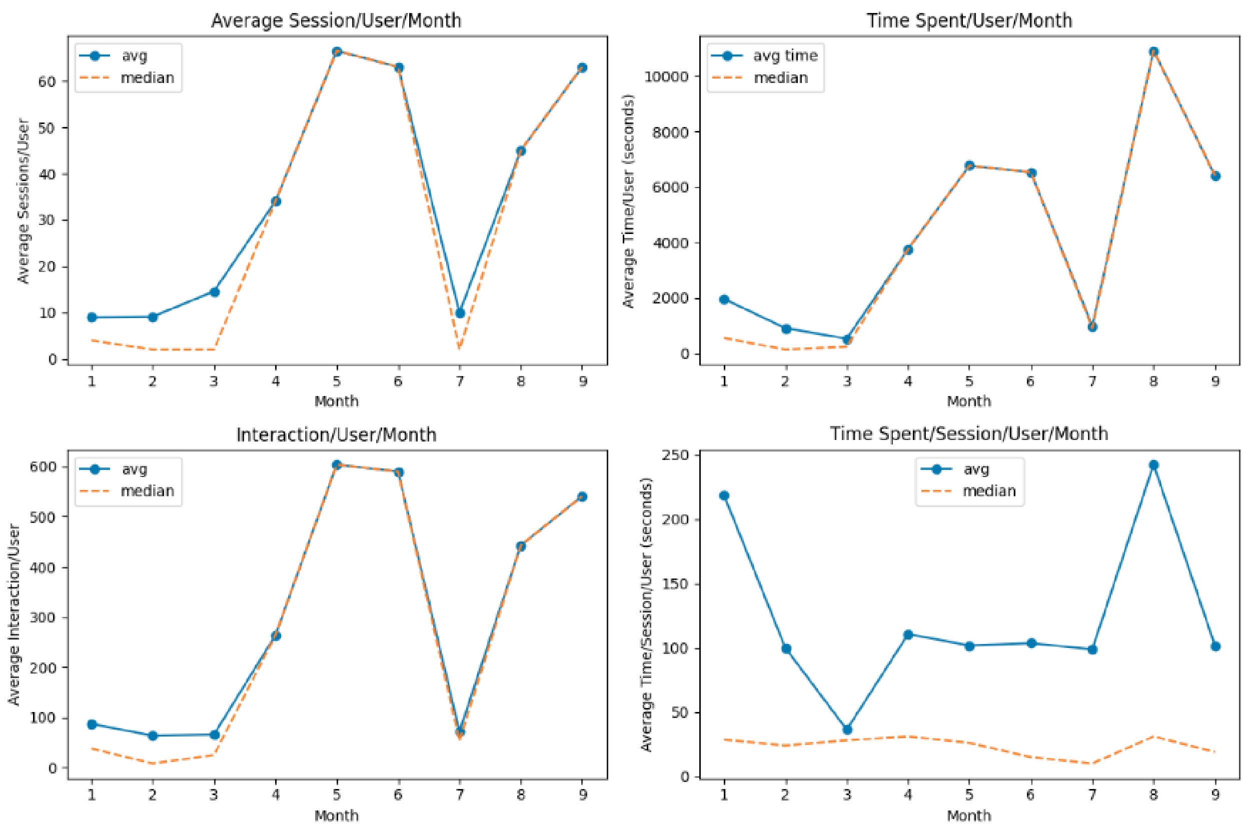


Figure 52 Monthly trend of user engagement for session, interaction, and time spent on the app

Active user engagement rates were calculated to compare the frequency of user engagement with the app over the days since their enrollment. Figure 53 depicts the distribution of these rates. A majority of the active users, 79% (30/38), had a user engagement rate below 10% (M=10.59; Median=3.06; SD=17.54; Range 0.55 – 81.18). This indicates that these users spent only about 10% of their days since enrollment using the app. As shown in the scatter plot on the right of the figure, the rate trend declines with longer the user's enrollment days is. Furthermore, most of the user engagement rates fall below the trend line. This suggests that there was a change in user behavior when using the app around the second month. Some new users had relatively moderate usage within their first 30 days of enrollment. One user, who was found to be the only one to continue using the app for a longer period in previous analysis, appears on the top right and has a high engagement rate of approximately 81% for around 255 days in the program, which translates to 207 days of consistent app usage.

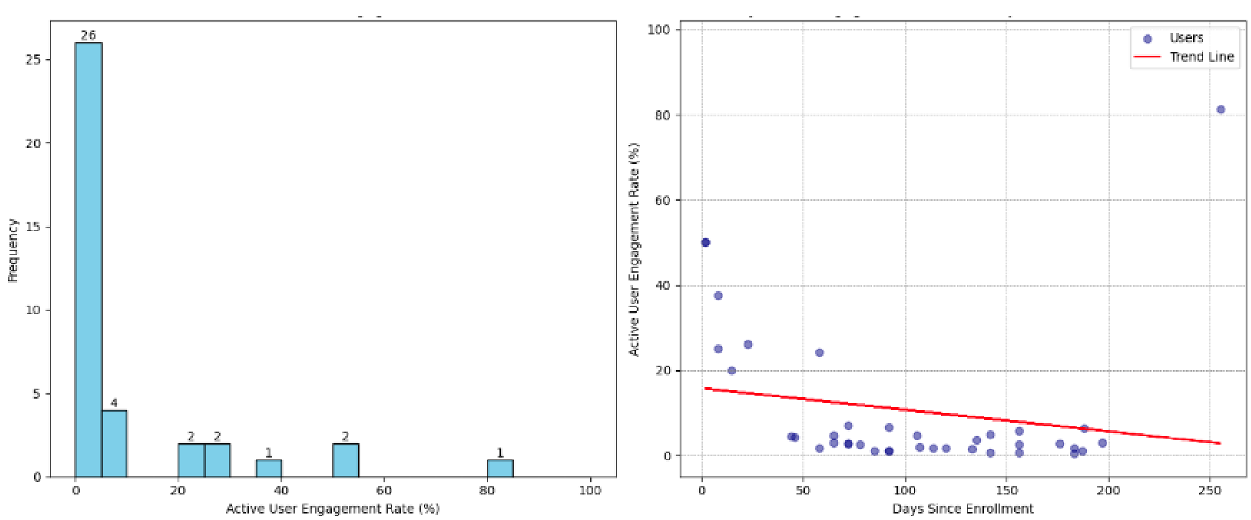


Figure 53 Distribution of user engagement rate

Analyses were performed to assess user engagement at the module level in this pilot implementation. There are eight modules that providers can select when prescribing the app: Medication Management (MyMeds), Mood, Bowel Management (BMQs), Telecath, Exercise, Nutrition, Phr, and Education. These modules are evaluated based on user intensity, which is shown in Table 16. This table displays the results of a 30-day evaluation for users who have been enrolled for more than 30 days, which represents approximately 83.76% (43/49) of all enrolled users. The evaluation considers two types of events: active and passive. Active events are initiated by the user to send self-reporting information, such as medication intake, reminder response, nutrition intake, and exercise report. Passive events, on the other hand, are made by the user within the app without submitting any information. For example, users may simply browse the progress page of each module or read educational content.

The time spent by users on the Education module was the highest, amounting to approximately 3 minutes and 5 seconds. Time spent on the MyMeds module was comparable at 3 minutes and 2 seconds. The education module was designed as passive activities in this implementation. A total of 251 events were generated by users, amounting to an average of 9.3 events per user. In contrast, the MyMeds module had the largest number of active events, with a total of 193 events within 30 days, or an average of 4.6 events per user per day, despite having the second lowest number of users, which was only 33% of the total number prescribed (16 out of 48). The Phr module was the third most time-consuming, with users spending approximately 2 minutes and 4 seconds on the module and generating a total of 5.77 passive events per user per day. The least amount of time spent on any module was for the BMQs module, with users spending an average of 27 seconds per day on the module. Despite being designed to support self-reporting, no active events were generated by users, suggesting that the feature was not utilized.

Table 16 Intensity interaction per module per user per day

Module Name	Prescribed users	avg time spent per user (s)	number of unique users (%)	total active event (avg/user)	total passive event (avg/user)
BMQs	46	00:00:27	17 (37)	0 (0)	37 (1.48)
Education	48	00:03:05	21 (44)	0 (0)	251 (9.3)
Exercise	49	00:00:59	15 (31)	2 (0.12)	26 (1.53)
Mood	43	00:00:39	22 (51)	17 (0.46)	36 (0.97)
MyMeds	48	00:03:02	16 (33)	193 (4.6)	59 (1.4)
Nutrition	49	00:00:38	19 (39)	30 (0.6)	45 (0.9)
Phr	49	00:02:04	22 (45)	13 (0.42)	179 (5.77)
Telecath	47	00:00:48	16 (34)	12 (0.6)	24 (1.2)

The majority of the app's users accessed the modules frequently during the first five days of usage. After this initial period, the number of users stabilized at around 1-2 per day. Further information on this distribution can be found in Appendix F.3.1.

6.4.3.3 User Engagement Xealth Analytic Dashboard

To assist partners in maintaining and monitoring the performance of the integration, Xealth offers an analytic dashboard known as the Xealth Digital Command Center to provide user engagement data from both provider and patient. This dashboard provides several key performance metrics, some of which are also available within the iMHere 2.0 system, such as the number of orders created and the number of unique patients. However, iMHere cannot capture certain metrics provided by Xealth, such as the total number of notifications, patient open and click rates, patient card interaction rates, patient interaction rates, and the number of monitor view requests.

During this implementation, providers at the clinics reportedly created 66 orders for 65 unique patients using only the iMHere 2.0 app. However, three test orders were initially created and not removed from the data, which may account for the discrepancy in the reported numbers. Figure 54 illustrates how the dashboard reports the metrics.

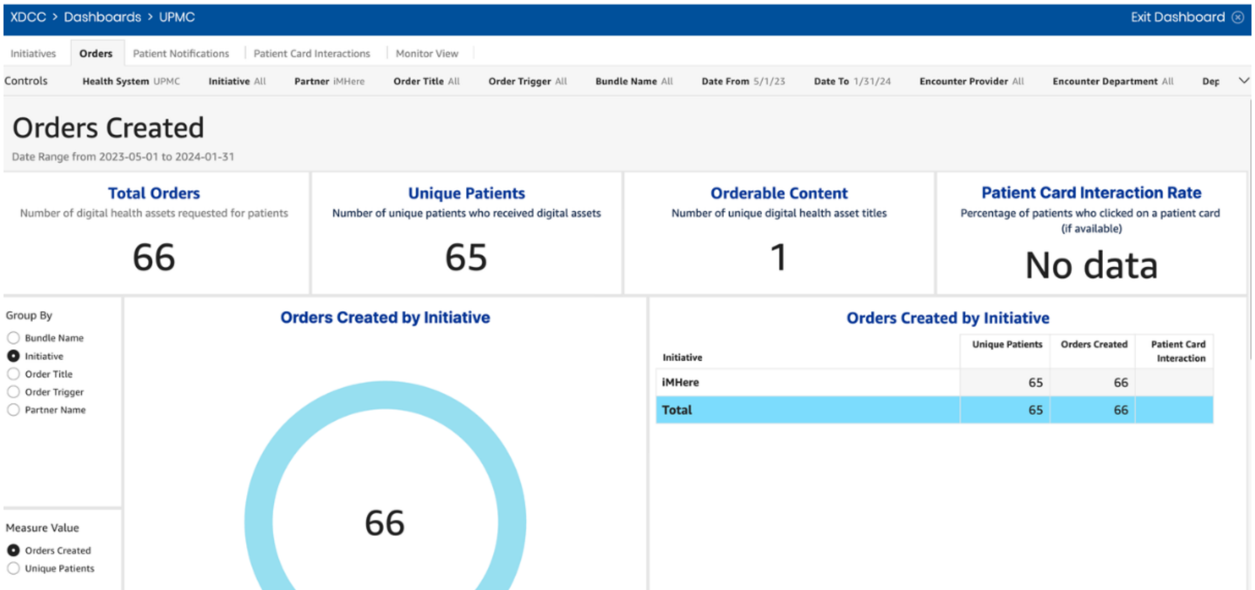


Figure 54 Orders Section of analytic dashboard

In the Patient Notifications section, the dashboard reported the creation of 78 email notifications to inform 63 patients. Of these, 55 patients opened the notifications, accounting for 87.3% of patients, and 84.1% clicked the consent button presented in the email. Providers sent a total of 33 monitor view requests to see the patient's dashboard generated by the iMHere 2.0 system. This averages out to 3.57 requests per month (SD=1.618). Considering that the monthly average for active patients is 7.56, the check rate for the monitored patients was 47.2%, indicating that not all patients were monitored by the providers. When inspecting the distribution, as shown in Figure 55, the initial few months showed increasing engagement, which was higher than the engagement after the fourth month. This pattern seems to match the new enrolled patients in August. From Figure 43 and Figure 44, it can be seen that the number of new orders and new enrolled users were the highest in August, hence the activity of providers checking the monitor section was also high in August. However, the number of monitor view requests were still less than the number of created orders or new enrolled users.

At this point in the implementation, there is no need for the Patient Card feature within the workflow; therefore, it was not utilized, and no engagement information is available.

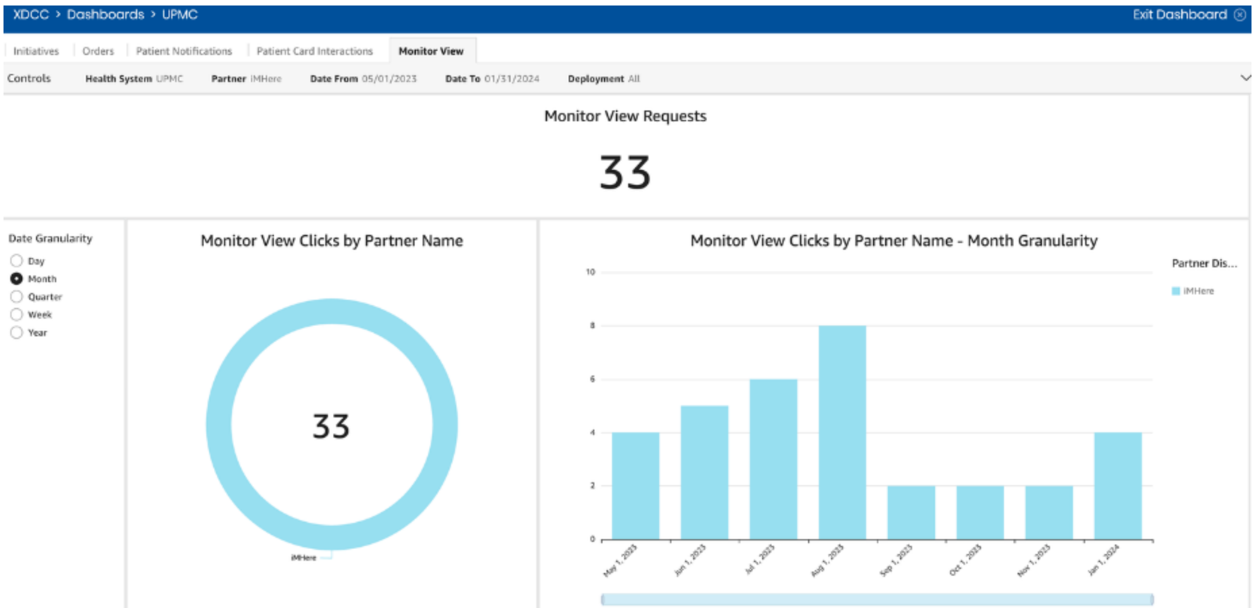


Figure 55 Monitor View Click by Partner

6.4.3.4 Flyer and Activation Code Implementation

During the initial weeks of the pilot implementation, several patients experienced difficulties with the enrollment process. Notably, patients encountered problems with registering after consenting to the app via email notification. Physician observations and reports suggest that patients struggled to comprehend the process, despite verbal instructions provided by the physician and nurses in the clinic.

To address the issue, various options were discussed, taking into account the timeline for implementation. A physician suggested that the quickest solution that could be implemented immediately was to create flyers explaining the enrollment process. The second option was a semi-automated enrollment process that utilizes an activation code. The process is referred to as "semi-automated" because it still requires a manual step to enter the activation code during registration. Once the registration is complete, the app is automatically approved, and system administrator intervention is not required, allowing patients to use the app immediately. However, this solution takes more time to implement than the first option. The last option considered was an automatic enrollment process using a QR code, which requires the longest implementation time since it involves multiple modifications to the front-end and back-end of the system. This solution would feature a QR reader during registration.

At the time of this analysis, the first two solutions had been carried out. Flyers were created and distributed to patients who joined the program after August 10, 2023. To implement the second solution, an activation code was sent to patients after they provided their consent. This solution was introduced to the workflow on November 9, 2023. The amended workflow is depicted in Figure 56, which may be compared to the previous version of the workflow shown in Figure 41.

To evaluate the effectiveness of these solutions, the time it took for patients to finish the enrollment process after consenting for the iMHere app was calculated as the *approval time*. Approval time is used as a proxy to indicate whether the solutions are able to help the enrollment process. The collected data was then organized into three groups: the pre-distribution of flyers group, denoted as Group 0; the post-flyer distribution group, referred to as Group 1; and the post-implementation of the activation code group, known as Group 2.

The average duration of the enrollment process was approximately 4 days, with half of the approvals being completed within approximately 5.5 hours (N=49; M=347455.2s; Median=19615s; SD=1263131.6s). The longest approval time was approximately 85.54 days, while the quickest enrollment process took around 66 seconds. The variability in approval times was substantial, as evidenced by the large standard deviation of approximately 14.625 days.

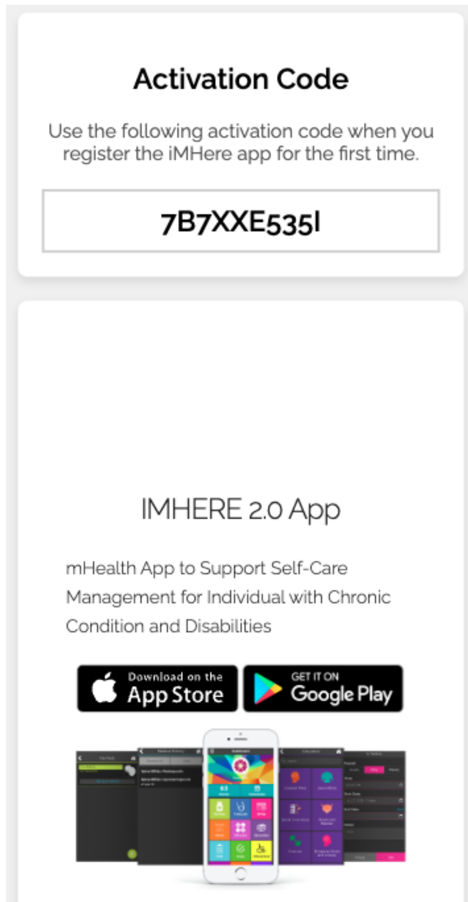


Figure 56 Download Page Enhanced with Activation Code Integration

The duration of the enrollment process varies across different groups. For the first group, composed of patients who enrolled prior to the distribution of flyers, the average approval time was approximately 7.7 days, with a median of approximately 1.3 days (N=12; M=664,916.8s; Median=112,649.5s; SD=1,418,246.1s). This group displayed a considerable range of approval times, ranging from roughly one hour to 58.82 days, indicating substantial variability. The standard deviation of approximately 16.42 days further emphasizes this variability.

In contrast, for the second group after the flyer was distributed, the enrollment process took a shorter average approval time of about 4.5 days, with a median of 6.85 hours (N=22; M=385403s; Median=24678s; SD=1565904.6s). The range of approval times in this group is from 27.5 minutes to 85.54 days, with a standard deviation of roughly 18.125 days.

Once the activation code feature had been implemented, the enrollment process exhibited the shortest mean approval time of approximately 10.5 hours, with a median of 2 minutes and 18 seconds (N=15; M=37829.1s; Median=138s; SD=142961.4s). The range of approval times in this group spans from 66 seconds to approximately 6.42 days, with a standard deviation of around 1.7 days.

These findings suggest that the introduction of these two solutions helped to shorten the time for the enrollment process, with initial approval times of about 7.7 days on average, to approximately 4.5 days after the distribution of flyers, and approximately 10.5 hours, after activation code had been introduced.

To investigate the effectiveness of these two solutions on the enrollment process, further statistical analysis was performed. Based on Shapiro-Wilk test for normality, the data among the groups is not normally distributed, with p-value < 0.001 for all groups. Hence a non-parametric test was performed instead of the t-test. Since there are three groups of data, the Kruskal-Wallis test was performed instead of Mann-Whitney U test. The Kruskal-Wallis[14] test is used to compare medians among three or more independent groups and to identify whether the medians are statistically significant different among groups. Further pairwise comparisons between groups

[14] https://www.statology.org/kruskal-wallis-test/

were performed to determine which specific groups differed from each other, using Bonferroni correction post-hoc tests.

The results of the Independent-Samples Kruskal-Wallis test indicate a statistically significant difference among the three groups ($p < .001$). The result of pairwise comparisons are as follows:

1. Group 2 compared to Group 1: The test statistic is 17.921 with a standard error of 4.784, resulting in a standardized test statistic of 3.746 ($p < .001$). This indicates a statistically significant difference between Group 2 and Group 1.
2. Group 2 compared to Group 0: The test statistic is 26.217 with a standard error of 5.534, resulting in a standardized test statistic of 4.737 ($p < .001$). This indicates a statistically significant difference between Group 2 and Group 0.
3. Group 1 compared to Group 0: The test statistic is 8.295 with a standard error of 5.128, resulting in a standardized test statistic of 1.618 ($p = .106$). This comparison does not reach statistical significance ($p > .05$), suggesting that there is no significant difference between Group 1 and Group 0.

These results indicate that there are significant differences among the three groups. The implementation of the activation code has proven to be effective; the improved performance of the enrollment process is evidenced by the significant reduction in approval times compared to the previous implementation. Specifically, Group 2 showed an approximately 816-fold and 179-fold reduction in median approval time from Groups 0 and 1, respectively. Furthermore, there was an 18-fold and 10-fold reduction in average approval time from these same groups. However, the comparison between Groups 0 and 1 suggests the opposite. Although there was a reduction of about 5-fold and 2-fold in median and average approval time, respectively, the distribution of flyers did not significantly improve the performance of the enrollment process, as no statistically significant differences were found.

6.4.3.5 User Feedback

Feedback collection is a crucial aspect of any pilot implementation. To ensure that we receive as much information as possible, we implemented three channels for collecting feedback. The first of these channels is a manual process, where patients communicate directly with providers to report any issues encountered while using the app. Providers then register these issues onto a shared spreadsheet. Additionally, providers provide feedback on their experience with the Unified User Interface, which is also recorded in the shared spreadsheet. To make the feedback

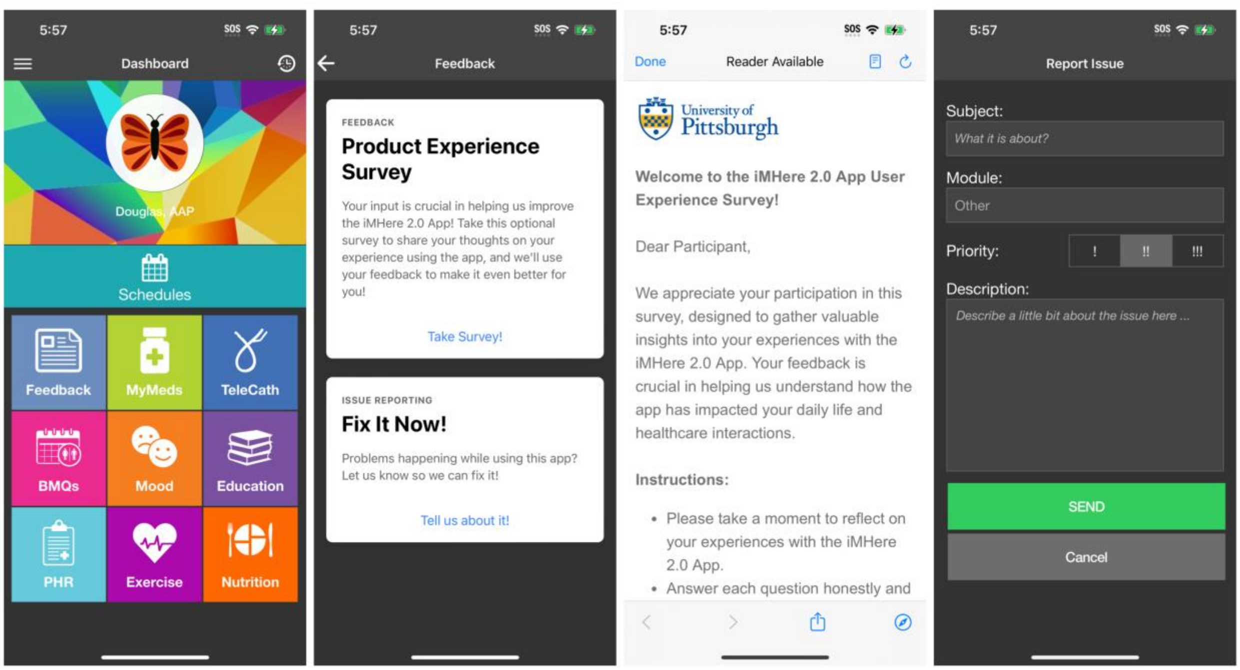


Figure 57 Feedback module includes experience survey and issue reporting

process even easier, we introduced feedback features within the iMHere 2.0 app after the implementation started. These features include a product experience survey and an issue reporting system, as shown in Figure 57. All feedback, whether it is collected manually or through the app, is carefully reviewed and considered to improve the overall experience of using the app.

The feedback collected during the pilot implementation of the project was analyzed, and three main themes emerged: dashboard, app, and enrollment. These themes were identified from the 20 items of feedback received, as shown in Table 17. The Dashboard theme refers to any feedback related to the monitoring dashboard presented in the Unified User Interface within Epic Care from Xealth. App refers to any feedback related to the iMHere 2.0 app. Enrollment refers to any feedback or issues related to the enrollment process. Of the 20 items of feedback received, 70% (14 out of 20) have already been addressed, and the remaining 6 are currently being addressed.

Table 17 Feedback data

Themes	Feedback	Total
Dashboard	Missed medications showing as "n/a", Nutrition data missing, Confusion about "Avg time of Exercise Per Week", Zero exercise sessions displayed	4
App	Nutrition, BMQ, Mood modules disappearing, Unresponsive buttons in education module, Missing content, Failed medication module response, Disappeared medication history, Authentication failure, Medications disappearance	10
Enrollment	Request to transfer app to another device, Change "description" to "Initials or Activation Code", Missing registration code, Server switching issue, Email deletion request, Inadequate flyer instructions	6

The feedback module within the app was deployed around November 2023. Since its inception, only two survey responses have been retrieved from the participants through it. The usability score for the iMHere 2.0 app yielded an average of 5.208 (SD=1.444). This score suggests that the patient's experience is generally favorable, and there is a noticeable inclination towards agreement that the app is usable to some extent, but not completely. Users may have encountered some difficulties, or they may see some room for improvement and, therefore, not fully endorse the app.

The results from evaluating the subscales reveal that patients have mixed opinions about the usability of the iMHere 2.0 app. While they generally agree that the app is easy to use (M=5.167; SD=1.462) and are satisfied with it (M=5.5; SD=1.604), they are somewhat divided on the usefulness of the app for their health (M=5.125; SD=1.553). There are some concerns regarding certain questions that yielded a usability score of around 4, particularly question 3, which received an average score of 4.5 (SD=0.707). Although this score is not low, it suggests that patients may have faced some difficulties in recovering from mistakes made while using the app. The patients' average usability score of 4 (SD=0) for question 8, which assesses the app's usefulness for their health and well-being, indicates that they have a neutral opinion on the matter. The lack of variation in responses (SD=0) indicates that patients have a unanimous view on the app's usefulness. Nevertheless, to some extent, patients do agree that the app could be helpful in managing their health effectively.

Patients provided an average score of 4.5 (with a standard deviation of 0.707) when evaluating the iMHere 2.0 app's ability to deliver healthcare services effectively, including accessing educational materials, tracking personal activities, and conducting self-assessments (as seen in question 12). This score suggests that patients generally hold a positive view of the app's suitability as a platform for receiving healthcare services. Additionally, the relatively low standard deviation of 0.707 indicates a consensus among participants regarding the app's acceptability in facilitating healthcare-related activities, which highlights the app's potential as a tool for users to manage their health effectively and engage in self-care practices. The complete usability score can be found in Table 18.

Table 18 Qualitative Usability Score (based on adapted MAUQ, see Appendix G.3)

Questions	P1	P2	Score	Subscales	
Q1	7	4	5.5 (SD=2.121)	Ease of Use	
Q2	7	4	5.5 (SD=2.121)	Mean	SD
Q3	5	4	4.5 (SD=0.707)	5.167	1.472
Q4	7	4	5.5 (SD=2.121)	Satisfaction	
Q5	7	4	5.5 (SD=2.121)	Mean	SD
Q6	7	4	5.5 (SD=2.121)	5.5	1.604
Q7	7	4	5.5 (SD=2.121)		
Q8	4	4	4 (SD=0)	Usefulness	
Q9	7	4	5.5 (SD=2.121)	Mean	SD
Q10	7	4	5.5 (SD=2.121)	5.125	1.553
Q11	7	4	5.5 (SD=2.121)		
Q12	5	4	4.5 (SD=0.707)		
Overall			**5.208 (SD=1.444)**		

6.5 Discussion

6.5.1 Principal Results

This study investigates Xealth's usefulness in facilitating the interoperability between iMHere 2.0 and EHR systems to support the implementation of the iMHere 2.0 application in clinical settings. This initial rollout constitutes the preliminary attempt to incorporate the iMHere 2.0 system into clinical settings, following the identification of Xealth as an intermediary service that enables the iMHere 2.0 system to be prescribed directly from the EHR.

A system expansion was successfully developed to enhance the capabilities of the iMHere 2.0 system by incorporating the required functionality for integrating the iMHere 2.0 system with the EHR system through Xealth intermediary service. All of the functional requirements were addressed, enabling providers to prescribe digital content, such as the iMHere 2.0 app, directly from EpicCare. During the 9-month pilot implementation, 62 orders were created. In the ordering process, providers could customize which modules the patients would see on the app based on the patients' needs at that specific point in time. This flexibility highlights the adaptable capability of iMHere 2.0 system. Each patient could have a different set of activated modules, as illustrated in Table 16.

As a standard procedure in the healthcare field, obtaining consent is crucial to ensure that patients fully comprehend and agree to the proposed treatment, thereby upholding ethical standards and respecting patient autonomy. In this study, 78 email notifications were sent to patients to obtain their consent for using the iMHere 2.0 app. Out of the 62 patients, 55 (88.7%) opened the notification, and 53 (85.48%) of them provided their consent.

Providers were able to monitor their patients' progress in utilizing the iMHere 2.0 app through the EHR system. Providers used the iMHere 2.0 system to generate 33 monitor view requests to see a patient's dashboard. This averages out to 3.57 requests per month. An average of 7.56 patients were active on the app each month, but the check rate for the monitored patients was 47.2%, indicating that not all patients were monitored by the providers.

During the pilot implementation period and the data collection end phase, the installation rate was 80.65%, with 50 out of 62 patients installing the app. The enrollment rate was 79.03%, with 49 out of 62 patients enrolled. The adoption rate of the implementation was 61.29%, meaning 38 patients actively used the app out of the total 62 ordered, which constituted 77.55% of the 49 enrolled patients. On average, each active patient spent approximately 33 minutes and 46 seconds per month on the app, or about 2 minutes and 25 seconds per session. However, it is important to note that this monthly average time spent was positively skewed due to one patient actively using the app for 207 days out of 255 days (81%) since enrollment, which generated extreme interaction compared to the other patients. The median value of 9 minutes 36 seconds spent per user per month indicates that half of the active patients spent the median amount of time or less.

After analyzing the retention rate of patients based on their usage pattern, it was discovered that the iMHere 2.0 app was only able to retain most of the patients for the first 7 days after their enrollment. However, one patient consistently used the app, as previously mentioned. The number of active patients was relatively high during the first month of usage, but it significantly decreased afterwards. The retention rate for the second month was 21.62%, with only 8 out of 37 patients remaining active. By the fourth month, only 3% to 6% of the enrolled users continued to engage with the app, with the number of retained users ranging from 1 to 2. Unfortunately, the majority of patients, 79% (30 out of 38) of active patients, had a user engagement rate below 10%, indicating that they only spent 10% of their days using the app following their enrollment.

A few significant issues were encountered during the pilot implementation, one of which was the enrollment process. Patients faced difficulty registering for the app, and manual approval was required before they could use it. Despite distributing flyers with instructions on how to register, the enrollment process did not improve significantly. However, automatic approval with an activation code proved to be highly effective in streamlining the process.

Several patients reported technical issues with the iMHere 2.0 app, including bugs, missing modules, data loss, and inconsistencies. These issues could potentially impact patients' perceptions of the app. However, patients generally found the app easy to use and were satisfied with it. While they were somewhat divided on its overall usefulness for their health, they did agree that it could be helpful in managing their health effectively to some extent.

6.5.2 Limitations and Recommendations

There is significant potential for improvement in streamlining the integration and enhancing patient engagement with the app, particularly with regard to long-term usage.

- The low retention rate may suggest that patients are not fully comprehending how to use the app. Unlike previous controlled studies, this implementation lacks any special sessions for training on app usage. Therefore, incorporating an onboarding process or self-training mechanism within the app could facilitate a better understanding of its usage among patients. Additionally, providing an online manual detailing how to use specific features could be helpful. Although the iMHere 2.0 system has an online user manual, presenting it within the app in a different manner may prove beneficial to users.

- Providing technical support is a challenging task due to the lack of direct communication between the support person and the patient. Currently, when a patient contacts the clinic with an issue, the information is then passed on to technical support. Although the app was eventually equipped with a mechanism for reporting issues, it has not yet been fully utilized. It would be even more beneficial if the app included a chat session, allowing patients to interact with support personnel directly and on-the-go, potentially enhancing their overall perception of the app.
- As this is a pilot implementation, the focus is on delivering the app for patient use. Therefore, patient data has not yet been transmitted back to the EHR. The capabilities of Xealth have not yet been fully utilized. In the future, if necessary, the iMHere 2.0 system may transmit important data back to the EHR and store it as part of the EHR data.
- A user engagement report that is systematically generated holds great importance, as it functions as an essential resource for promptly addressing any issues that arise and devising effective measures to improve them. This proactive strategy guarantees that challenges are promptly recognized and resolved, allowing for the seamless delivery of solutions in a timely manner. This is especially important when scaling-up the implementation to accommodate a larger patient population.

6.5.3 Conclusion

Xealth, as an intermediary service, plays a critical role in healthcare by enabling digital health solutions, such as the iMHere 2.0 app, to be delivered directly to patients from EHR.

Medical professionals frequently raise this direct delivery issue regarding the interoperability of digital health solutions, especially when integrating mHealth systems into clinical settings.

The initial expansion of the iMHere 2.0 system was aimed at increasing its capacity to support integration with EHR through the Xealth Service. The pilot implementation of the integrated solution successfully streamlined the app delivery to patients, with a relatively high conversion rate. However, some critical issues were immediately addressed to improve delivery, and others will need to be addressed in the future.

In conclusion, intermediary services, such as Xealth, can bridge the gap and overcome the challenges of implementing digital health solutions, such as the iMHere 2.0 app, in clinical settings. With some improvements to the workflow, it has the potential to help deliver the app to a larger population.

7.0 Summary and Conclusion

7.1 Result Summary

This section provides a thorough summary of the study's results and its implications.

7.1.1 Specific Aim 1: To develop an integrated and adaptable mHealth system to support self-management for PwCCD.

The development of the iMHere 2.0 system, which is comprised of a client app, a caregiver app, a web-based portal, and backend services, was initiated. The iMHere 2.0 system is an upgrade of the original iMHere system. The changes were based on feedback from past studies and aimed to expand the target population to include individuals with Cerebral Palsy and children as young as 12 years old. The design phase took into consideration the implementation models, which determine how the system integrates support from family and caregivers as well as healthcare providers. Additionally, the objective of collaborative care coordination and the adaptable capacity of the system to address the diverse needs of individuals with complex care needs over time were taken into account.

The web-based clinician portal allows the creation of tailored treatment plans for individuals with chronic conditions. These personalized plans can be created and followed by the patient through the client app, while the clinician can make modifications as needed based on the individual's progress. Once the clinician updates the treatment plan on the web portal, it is immediately synced with the client and caregiver apps, which then can support the collaborative coordination among stakeholders. The portal also enables the clinician to monitor the patient's adherence to the treatment plan and communicate with them securely through messaging.

To enhance the system's functionality, social support was integrated by providing a caregiver app for the individual’s family or caregivers. They can easily monitor the individual’s progress and offer social support through the app. Encouraging messages from caregivers can help the patient endure lengthy treatment procedures. Additionally, the instant secure messages exchanged between the patient, caregiver, and clinician can also provide the necessary social support for long-term engagement with the mHealth system.

The client and caregiver apps are compatible with both Android and iOS, granting users the flexibility to access the apps on their preferred devices. This cross-platform feature allows PwCCD and caregivers to maintain access to the iMHere 2.0 system for self-management across various mobile devices with different operating systems or switch between operating systems without losing access to the system.

Ultimately, the iMHere 2.0 system has been redesigned as an enhanced version of the original iMHere 1.0 to support the self-management of PwCCD with adaptable capabilities and facilitate collaborative care coordination among stakeholders throughout an individual's self-management journey.

7.1.2 Specific Aim 2: To evaluate the usability of the built mHealth system.

The evaluation phase of the study yielded a substantial amount of constructive feedback and unearthed issues the app was having. This study successfully discovered 96% of the usability problems that occurred at least once, with p=0.31. Among the various issues that arose, 72% were found to be related to affordance. Specifically, the user interfaces proved insufficient in providing clear indication of how tasks ought to be performed, leading to confusion and errors on the part of patients. Consequently, we provided cues to help them resume their activities after a period of inactivity.

The participants rate the app as highly usable with a mean SUS score of 83.06 (SD=20.34). The average TUQ score for all participants was 5.79 (out of 7 points, SD=1.55). Participants were satisfied with the iMHere 2.0 client app and would consider using it in the future (average score: 6.17).

7.1.3 Specific Aim 3: To evaluate the adaptability of the mHealth system to diverse needs and evolving life situations over time.

The vignette-based evaluation approach was utilized to assess the adaptability of the iMHere 2.0 system through simulated interactions. The results showed that the system was capable of addressing the evolving needs of individuals. The physician was required to activate the appropriate modules to provide adaptable support.

7.1.4 Specific Aim 4: To conduct an exploratory evaluation of the mHealth system in delivering comprehensive support for self-management in clinical settings.

The iMHere 2.0 system demonstrates a high degree of adaptability to the established clinical workflows and processes in clinical settings. By utilizing an intermediary service, such as Xealth, the mHealth system was able to seamlessly integrate with the clinic's EHR system and successfully streamline the app delivery to patients, with a relatively high conversion rate. The scalable design of the iMHere 2.0 system enables it to extend its functionality in alignment with the clinical workflow's requirements. At the time of writing, the installation rate was 80.65%, with 50 out of 62 patients installing the app. The enrollment rate was 79.03%, with 49 out of 62 patients enrolling. The adoption rate of the implementation was 61.29%, indicating that 38 patients actively used the app out of the total 62 ordered, which accounted for 77.55% of the enrolled patients (49). On average, each active patient spent approximately 33 minutes and 46 seconds per month, or about 2 minutes and 25 seconds per session. The median value of 9 minutes 36 seconds spent per user per month suggests that half of the active patients spent a similar amount of time or less.

The implementation of the iMHere 2.0 system in clinical settings encountered several challenges and barriers:

- The enrollment process experienced hurdles due to its manual steps and unclear instructions, which made it difficult for participants to complete.
- Low retention rate may suggest that patients are not fully comprehending how to use the app. In a real-world setting, the availability of human resources for training is not always guaranteed, so incorporating an onboarding process or self-training mechanism within the app could improve patients' understanding and use of the app.
- Technical issues, such as glitches and connectivity problems, may hinder the proper functioning of the iMHere 2.0 app.
- Providing technical support is a challenging task due to the lack of direct communication between the support person and the patient.

The first challenge was promptly addressed, as this issue serves as the initial gateway to successful implementation. To streamline the process, automatic approval accompanied by an activation code proved to be highly effective.

7.2 Limitations

When examining the scope of this research, it is essential to acknowledge the limitations encountered throughout the study, highlighting areas that require further investigation and consideration.

- The iMHere 2.0 platform includes a client app, a caregiver app, and a web-based portal, all of which are designed as user interface for the users. Thus far, the majority of evaluations have been centered on the client app and the system's ability to integrate with electronic health records. However, there has been an insufficient amount of assessment conducted on the caregiver app and the web portal for the benefit of clinicians and providers. Currently, the caregiver app is undergoing an extensive development to include assessments and interventions aimed at promoting the well-being of caregivers, in addition to its initial purpose of providing social support to care-recipients and monitoring their progress. Future studies that focus on dyadic interventions have the potential to effectively measure the system's effectiveness in providing support to both care-recipients and caregivers.
- The evaluation of the vignettes content validation through expert review was conducted on a limited scale, with only one iteration and a small number of evaluators. While constructive feedback was gathered, it would be beneficial to run additional iterations of the evaluation to further refine the vignettes and improve their quality. Considering the high cost of evaluating the long-term capabilities of an mHealth system, using a vignette-based simulation approach offers a cost-effective solution, provided that the set of vignettes used is of high quality, relevant, realistic, and clear.

- During the assessment and implementation of the iMHere 2.0 system, it became clear that no real-time or periodic user engagement reports were being generated. These reports are of great significance, as they act as a vital resource for identifying emerging issues on a global scale, enabling prompt resolution and the development of effective measures to improve them. By adopting a proactive approach, challenges can be promptly identified and addressed, ensuring the timely delivery of solutions.

7.3 Conclusion

The iMHere 2.0 system, an integrated and adaptable mHealth solution designed to support self-management for individuals with chronic conditions and disabilities, was successfully developed as an enhanced version of the original system. This system possesses adaptable capabilities and promotes collaborative care coordination among stakeholders throughout an individual's self-management journey. The participants found the iMHere 2.0 app highly usable, and they were satisfied with the iMHere 2.0 client app, expressing a willingness to use it in the future. A substantial amount of high-priority feedback was addressed. The pilot implementation of the system in clinical practice was successfully carried out with the help of Xealth as the intermediary service to the EHR system. This implementation provided valuable insights that will be useful for larger-scale implementation preparations.

Further development of the system can be done in multiple directions. As it is designed to be scalable and extensible, incorporating additional features to support self-management should not pose a significant challenge. The caregiver app, for instance, is undergoing extensive development to incorporate assessments and interventions aimed at enhancing the well-being of caregivers, in addition to its initial purpose of providing social support to care-recipients and monitoring their progress. Another potential direction is the integration of generative artificial intelligence (GAI). The iMHere 2.0 system currently supports care coordination and provides in-app messaging for users to communicate directly with their care team about their condition, consultation, or any other health-related matters. However, this functionality is ideally suited for research settings. In clinical practice, human resources may be limited and not available every day. With a generative AI approach, an agent-based care assistant can be developed to expand the system's capabilities, enabling it to respond to user queries immediately, 24/7. This agent-based approach appears promising and feasible, given the rapid progress of GAI technology in recent years.

Appendix A Feedback

Appendix A.1 Summary of initial feedback from past studies

The following is a summary of feedback collected from past studies. Please note that this may not be a comprehensive list of every item reported and collected.

Theme	Source	Study	Issues
Accessibility	P-App	R3 – Phase I (Yu et al., 2017)	- Contrast of text - Target sizes - Notes for clarity - Personalized backgrounds - Thematic colors - Alternative camera button - Personalized modules - Simplified layout
	P-App	SBIR	- Overall accessibility improvements - Options for visual impairment - Navigation enhancements
	SkinCare	SBIR	- Navigation improvements
	Apps	SBIR	- Integration into daily life - Visual improvements
	TeleCath	R3 - Phase III	- Privacy concerns
	Messaging	R3 - Phase III	- Message organization
	All Apps	R3 - Phase III	- Data security - Consistent button labeling - Text alignment - Navigation improvements
	Dashboard	SBIR	- Customizable dashboard alerts
	MyMeds	SBIR	- Customizable drop-down menus - Consistent button labeling - Text alignment - Navigation
	SkinCare	R3 - Phase I	- Camera flash feature
	Apps	R3 - Phase I	- Color scheme optimization - Icon clarity
	Blog	SBIR	- Internal social networking
	Apps	SBIR	- Visual display enhancements
	Messaging	SBIR	- Message categorization improvements
	MyMeds	SBIR	- Medication duration options - Information on side effects and interactions
Scheduling	P-App	R3 - Phase III	- Flexible scheduling
	Apps	SBIR	- Task scheduling improvements
	Overall	SBIR	- Adaptability to schedule changes - Cross-platform compatibility
Rewards	P-App	R3 - Phase III	- Personalized rewards

	Overall	R3 - Phase III	- Actual rewards vs. social recognition
Language Support	P-App	R3 -Phase I	- Availability in Spanish or other languages
Flexibility	TeleCath	R3 -Phase I	- Scheduling flexibility
	P-App	R3 -Phase I	- Customizable alarms
	BMQs	R3 -Phase I	- Bowel program scheduling flexibility
Privacy	TeleCath	SBIR	- Preventing sensitive cues in public
	All Apps	R3 -Phase III	- Data security measures
	Messaging	SBIR	- Privacy concerns
New Features	Overall	R3 -Phase III	- Social media integration - Alert for low medication supply - Selfie stick for photos
	Apps	SBIR	- Custom availability disclaimer
	MyMeds	SBIR	- Linking to side effects and interactions
	TeleCath/BMQ	SBIR	- Track other self-care needs
	Mood	SBIR	- Additional questions for detail - Customizable emergency contacts - Enhanced data security
	Apps	SBIR	- Improved snooze function - Visual icons for modules - Streamlined empty folder icon
	Alerts	SBIR	- Tracking clinician data access
	Portal	SBIR	- Daily summary for clinicians - Patient schedule overview - Customizable dashboard

Appendix B Vignette Expert Review

Appendix B.1 Introduction

The purpose of expert review is to validate the developed vignettes. It is crucial to use relevant vignettes that properly reflect real-life situations when evaluating the system's adaptability over time. Hence the focus will be on evaluating the relevance and realism of the vignette content representing the characteristics of individuals with complex and chronic conditions and disabilities.

The evaluation of the vignette should consider the relevant and realistic representation of the persona and realistic events that potentially happen which is narrated in the scenario and the key events sections. The simulated interaction serves as further information in this context, demonstrating the potential projected engagement with the mHealth system.

Since the objective is to have relevant and realistic vignettes, rating of the relevance and realism of each vignette are expected, along with any feedback and suggestions for improvement. The rating for relevance and realism uses Four Point Likert Scale: 1 – Not, 2 – Somewhat, 3 – Quite, 4 – Very (Relevant/Realistic). Here is descriptive statistic of the vignettes (N=10).

Variables	Description
Age	Range: 14 – 67 years Avg: 39
Gender	Male: 4 Female: 6
Education	high school: 4, vocational: 2 bachelor’s degree: 3, some college: 1
Diagnosis	Spina Bifida: 7 Spinal Cord Injury: 2 Cerebral Palsy: 1
Caregiver	Family: 3, Friends: 4, Mother: 2, Parent: 2, Relative: 1, Prof. Caregiver: 1

Appendix B.2 List of vignettes

Appendix B.2.1 1st Iteration

Vignette #1
Persona

Personal Detail:

Name: Margaret
Age: 50
Gender: Female
Race: Caucasian

Occupation: Volunteer
Education: High School Diploma
Housing: Apartment
Lives in: Pittsburgh

Health Condition:
Spina Bifida

Proactiveness to healthcare:
Active

Biography:
Margaret lives in a small apartment in Pittsburgh. She is an active member of her community and regularly volunteers at a local charity organization. She has a supportive group of friends and family who help her with daily tasks due to her impaired vision and hearing. Margaret is determined to maintain her independence and manages her health conditions with a proactive approach. She is diligent about attending her medical appointments and staying on top of her medication regimen.

Health History:
- She experienced neonatal hypoxia at birth.
- She has a history of seizures.
- Her vision is impaired.
- She has hearing impairments.
- She has a history of earwax buildup.
- She takes 10 medications daily.

Health Goals:
Short-Term:
- Manage medication dosage for seizures.
- Monitor and manage impaired hearing.

Long-Term:
- Maintain overall well-being.
- Prevent complications from spina bifida.
- Improve mobility.

Caregiver: Family & Friends

Challenges:
- Impaired vision and hearing
- Managing multiple health conditions

Positive Traits:
- Proactive
- Responsible
- Determined

Technology Access:

☑ Computer	tablet	☑ smartphone

Technology	**Experience**	**Use**
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	High	Frequently

Scenario

Margaret had been dealing with consistent back pain for quite some time, suspecting that it was related to her spina bifida condition. She also noticed signs of a potential skin breakdown, with redness and discomfort in an area that was subjected to prolonged pressure. During a routine check-up, her clinician confirmed the early stage of a pressure ulcer and prescribed a topical antibiotic to be applied twice a day. Fortunately, by the time the holidays rolled around, Margaret was pleased to report that her pressure ulcer was healing well. However, she then experienced headaches and nausea, raising concerns about a possible shunt malfunction. Following a successful intervention to correct her shunt malfunction, Margaret returned home to recover. With the help of physical activity tracking and tailored exercises provided by the app, her back pain subsided significantly. Feeling empowered by her improved health management, Margaret volunteered at a local charity event. At her follow-up appointment, her clinician praised her for the effective management of her health conditions.

Key Events

Date	Event
06/15/2021	Margaret began experiencing consistent back pain, suspecting it might be related to her spina bifida condition.
08/03/2021	Margaret noticed signs of a potential skin breakdown, with redness and discomfort in an area subjected to prolonged pressure.
10/12/2021	During a routine check-up, Margaret's clinician confirmed the early stage of a pressure ulcer and prescribed a topical antibiotic.
12/25/2021	Margaret celebrated the holidays with her family and was pleased to report that her pressure ulcer was healing well.
03/07/2022	Margaret experienced headaches and nausea, raising concerns about a possible shunt malfunction.
05/14/2022	Following a successful intervention to correct her shunt malfunction, Margaret returned home to recover.
07/22/2022	Margaret's back pain subsided significantly, and she attributed this improvement to the physical activity tracking and exercises.
09/30/2022	Margaret volunteered at a local charity event, feeling empowered by her improved health management.
12/10/2022	Margaret attended a follow-up appointment, where her clinician praised her for the effective management of her health conditions.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
06/15/2021	Margaret began experiencing consistent back pain, suspecting it might be related to her spina bifida condition.	Margaret's physician recommended the iMHere 2.0 app to help manage her condition. After a discussion, they activated the medication management, physical activity tracking, personal health record, and tailored educational content modules to address her needs.	Margaret started using the app to track her back pain and set reminders for her anti-seizure medication, which she takes three times a day.
08/03/2021	Margaret noticed signs of a potential skin breakdown, with redness and discomfort in an area	Using the iMHere 2.0 app, Margaret documented the skin issue in the skincare/wound tracking module and set a reminder for daily wound checks.	Margaret communicated the skin issue to her wellness coordinator via the messaging function in the app, who

	subjected to prolonged pressure.		advised her to schedule an in-person visit.
10/12/2021	During a routine check-up, Margaret's clinician confirmed the early stage of a pressure ulcer and prescribed a topical antibiotic.	Margaret used the medication management module to set reminders for the topical antibiotic application.	She regularly updated the wound's progress in the app, allowing her caregiver to monitor the healing process remotely.
12/25/2021	Margaret celebrated the holidays with her family and was pleased to report that her pressure ulcer was healing well.	The iMHere 2.0 app's goal setting module helped Margaret stay motivated and on track with her skincare regimen.	She shared her progress with her family through the personal health record feature, which they could access with her permission.
03/07/2022	Margaret experienced headaches and nausea, raising concerns about a possible shunt malfunction.	Margaret reported her symptoms using the iMHere 2.0 app, which alerted her physician at the spina bifida clinic.	The physician used the web portal to review Margaret's symptoms and recommended an immediate evaluation at the hospital.
05/14/2022	Following a successful intervention to correct her shunt malfunction, Margaret returned home to recover.	The app's medication management module was updated to include new medications prescribed post-surgery, which she needed to take twice a day.	Margaret's caregiver used the caregiver app to help manage her post-operative care and ensure medication adherence.
07/22/2022	Margaret's back pain subsided significantly, and she attributed this improvement to the physical activity tracking and tailored exercises provided by the app.	The app's physical activity tracking module helped her stay consistent with her exercises, which were crucial for her recovery.	Margaret shared her exercise milestones with her wellness coordinator through the app, receiving positive feedback and encouragement.
09/30/2022	Margaret volunteered at a local charity event, feeling empowered by her improved health management.	The iMHere 2.0 app's personal health record allowed her to share her volunteer activities and their impact on her well-being with her healthcare team.	Margaret used the goal setting module to set new objectives for her volunteer work, integrating her health management with her passion for community service.
12/10/2022	Margaret attended a follow-up appointment, where her clinician praised her for the effective management of her health conditions.	The app's appointment and transport management modules ensured she never missed a medical appointment and always had a ride arranged in advance.	Margaret's clinician reviewed her app data during the appointment, making informed decisions about her ongoing care plan.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #2

Persona

Personal Detail:

Name: Ethan
Age: 32
Gender: Male
Race: Caucasian

Occupation: Freelance Graphic Designer
Education: Vocational Training
Housing: Apartment
Lives in: Philadelphia

Health Condition:
Spina Bifida and Shunted Hydrocephalus

Proactiveness to healthcare:
Semi-Passive

Biography:
Ethan lives in an urban area and relies on his power wheelchair for mobility due to his spina bifida and shunted hydrocephalus. He has a close relationship with his mother, who provides support and prompts him for medical care. Despite his vocational training, Ethan's health condition has posed ongoing challenges in maintaining consistent follow-up and documentation. His living environment is supportive, but his reactive approach to healthcare has led to difficulties in managing his medical needs.

Health History:
- He has history of recurrent pressure ulcers and wound infections.
- She takes 10 medications daily.

Health Goals:
Short-Term:
- Healing of current wounds
- Regular follow-up with healthcare providers
- Improved adherence to medical care

Long-Term:
- Prevention of future pressure ulcers
- Increased independence in self-care
- Better management of overall health

Caregiver: Mother

Challenges:
- Dependence on caregiver for medical care
- Reactive approach to healthcare
- Difficulty in following through with medical recommendations.

Positive Traits:
- Creative
- Resilient
- Determined

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	High	Frequently
Tablet	-	-
Smartphone	Moderate	Sometimes

Scenario

Ethan has been diligently working on a graphic design project, but he begins to experience discomfort and notices a new pressure sore developing on his sacral area. During a follow-up visit, his clinician prescribes an antibiotic to prevent infection. However, Ethan's mother becomes concerned when he starts experiencing headaches and nausea, suspecting a potential shunt malfunction. After undergoing shunt revision surgery, Ethan requires strict medication management for pain and infection prevention. Despite these challenges, he successfully completes a major graphic design project, boosting his confidence in managing work alongside his health conditions. However, he later develops back pain, prompting him to schedule an appointment with his physician to assess the cause. After months of diligent self-care, his pressure sore has healed significantly, reducing his risk of infection. Unfortunately, he experiences symptoms of a urinary tract infection, indicating the ongoing challenges he faces in managing his health conditions.

Key Events

Date	Event
04/01/2021	Ethan experiences increasing discomfort and identifies a new pressure sore developing on his sacral area, likely due to prolonged sitting while working on a graphic design project.
06/15/2021	During a follow-up visit, Ethan's clinician is concerned about the slow healing of the pressure sore and prescribes an antibiotic, Cephalexin, to be taken three times a day to prevent infection.
09/30/2021	Ethan's mother notices he has been experiencing headaches and nausea, raising concerns about a potential shunt malfunction.
12/01/2021	Ethan successfully undergoes a shunt revision surgery to address the malfunction. Post-surgery, he requires strict medication management for pain and to prevent infection.
03/22/2022	Ethan completes a major graphic design project, which is a significant personal achievement and boosts his confidence in managing work alongside his health conditions.
07/14/2022	Ethan develops back pain, which he suspects might be due to his spina bifida condition. He schedules an appointment with his physician to assess the cause.
10/05/2022	After several months of diligent self-care and system engagement, Ethan's pressure sore has healed significantly, reducing his risk of infection.
01/20/2023	Ethan experiences symptoms of a urinary tract infection, including discomfort and fever. He quickly recognizes the signs due to the education he received through the app.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
04/01/2021	Ethan experiences increasing discomfort and identifies a new pressure sore developing on his sacral area, likely due to prolonged sitting while working on a graphic design project.	Ethan is onboarded to the iMHere 2.0 app by his physician, who activates the Skincare/Wound Tracking module and the Education module to help Ethan manage his wound and learn more about pressure sore prevention.	Ethan begins using the Skincare/Wound Tracking module to document his wound's progress and receives educational content on proper seating and repositioning techniques to prevent further skin breakdown.
06/15/2021	During a follow-up visit, Ethan's clinician is concerned about the slow healing of the pressure sore and prescribes an antibiotic, Cephalexin, to be taken three	The Medication Management module is activated to help Ethan track his antibiotic intake and ensure adherence to the treatment plan.	Ethan receives reminder notifications from the Medication Management module to take his Cephalexin at the prescribed times.

	times a day to prevent infection.		
09/30/2021	Ethan's mother notices he has been experiencing headaches and nausea, raising concerns about a potential shunt malfunction.	Ethan's physician is notified through the iMHere 2.0 messaging function, and the Personal Health Record module is updated with his symptoms.	Ethan uses the messaging function to report his symptoms to his wellness coordinator, who arranges for an urgent neurology consultation.
12/01/2021	Ethan successfully undergoes a shunt revision surgery to address the malfunction. Post-surgery, he requires strict medication management for pain and to prevent infection.	The Medication Management module is updated with Ethan's new medications, including pain reliever Acetaminophen, to be taken every six hours, and antibiotic Amoxicillin, twice a day.	Ethan relies on the app's reminders to take his post-operative medications on time and to track his recovery process.
03/22/2022	Ethan completes a major graphic design project, which is a significant personal achievement and boosts his confidence in managing work alongside his health conditions.	The Goal Setting module helps Ethan to set new personal and health-related goals, including taking on more projects and improving his physical activity levels.	Ethan uses the Goal Setting and Physical Activity Tracking modules to monitor his work-life balance and to stay motivated in achieving his new goals.
07/14/2022	Ethan develops back pain, which he suspects might be due to his spina bifida condition. He schedules an appointment with his physician to assess the cause.	The Appointment and Transport Management module assists Ethan in organizing his medical visits and arranging transportation.	Ethan uses the system to keep track of his upcoming appointments and to receive reminders for when it's time to leave for the clinic.
10/05/2022	After several months of diligent self-care and system engagement, Ethan's pressure sore has healed significantly, reducing his risk of infection.	The Skincare/Wound Tracking module allows Ethan to document the healing progress, and the system's educational content continues to support his understanding of pressure sore prevention.	Ethan regularly updates his wound status in the app, which allows his caregiver and healthcare providers to monitor his progress remotely.
01/20/2023	Ethan experiences symptoms of a urinary tract infection, including discomfort and fever. He quickly recognizes the signs due to the education he received through the app.	The system's messaging function enables Ethan to communicate his symptoms to his primary care physician, who prescribes an antibiotic, Nitrofurantoin, to be taken twice daily.	Ethan uses the Medication Management module to track his Nitrofurantoin intake and sets up reminders to ensure he completes the full course of antibiotics.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #3

Persona

Personal Detail:

Name: Michael
Age: 52
Gender: Male
Race: Caucasian

Occupation: Rehabilitation Specialist
Education: Bachelor's Degree
Housing: Apartment
Lives in: "Philadelphia

Health Condition:
Spina Bifida and Diabetes

Proactiveness to healthcare:
Active

Biography:
Michael lives in a bustling city neighborhood in Philadelphia. He is an active member of his community, participating in local events and volunteering at the neighborhood center for people with disabilities. He has a supportive group of friends and colleagues who understand his health conditions and provide encouragement. Michael is dedicated to his job as a rehabilitation specialist, using his expertise to help others with disabilities lead fulfilling lives. He is also an advocate for accessibility and inclusion in his community.

Health History:
- He has visual problems.
- He takes 8 medications daily, including insulin for diabetes and medication for spina bifida.

Health Goals:
Short-Term:
- Stabilize blood sugar levels.
- Improve mobility through physical therapy.
- Manage visual impairment with vision rehabilitation.

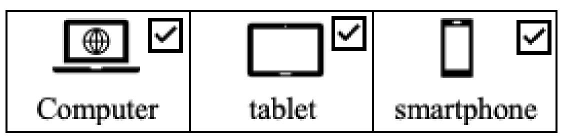
Long-Term:
- Maintain overall well-being through regular exercise and balanced diet.
- Continue thriving in professional and personal life.
- Stay proactive in managing health conditions.

Caregiver: Family & Friends

Challenges:
- Fluctuations in blood sugar levels
- Physical limitations due to spina bifida

Positive Traits:
- Proactive
- Dedicated
- Positive attitude

Technology Access:



Technology	Experience	Use
Computer	High	Frequently
Tablet	Moderate	Sometimes
Smartphone	High	Frequently

Scenario

After experiencing frequent headaches and nausea, Michael suspects a potential shunt malfunction and attends a follow-up appointment with his physician. The physician confirms the shunt malfunction and schedules surgery for Michael. Post-surgery, Michael experiences back pain, likely due to his spina bifida condition. Despite these challenges, Michael receives recognition at work for his dedication to helping others with disabilities. During a routine check-up, Michael is advised to adjust his insulin regimen due to fluctuating blood sugar levels. He then develops a pressure sore, prompting him to seek medical advice. In response, Michael decides to focus on his nutritional health to aid in wound healing and diabetes management. As a result, his pressure sore shows significant improvement, and he continues his commitment to a healthy lifestyle. Approaching the end of the 18-month timeline, Michael remains proactive in managing his health conditions and maintains a positive outlook on life.

Key Events

Date	Event
06/01/2020	Michael begins to experience frequent headaches and nausea, suspecting a potential shunt malfunction.
07/15/2020	Michael attends a follow-up appointment where his physician confirms a shunt malfunction and schedules surgery.
08/05/2020	Post-surgery, Michael experiences back pain, likely due to his spina bifida condition.
10/22/2020	Michael receives recognition at work for his dedication to helping others with disabilities.
12/10/2020	During a routine check-up, Michael is advised to adjust his insulin regimen due to fluctuating blood sugar levels.
03/15/2021	Michael develops a pressure sore, prompting him to seek medical advice.
05/20/2021	Michael decides to focus on his nutritional health to aid in wound healing and diabetes management.
07/30/2021	Michael's pressure sore shows significant improvement, and he continues his commitment to a healthy lifestyle.
12/01/2021	Approaching the end of the 18-month timeline, Michael remains proactive in managing his health conditions and maintains a positive outlook on life.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
06/01/2020	Michael begins to experience frequent headaches and nausea, suspecting a potential shunt malfunction.	Michael's physician prescribes the iMHere 2.0 app to help manage his symptoms and track his health condition. The Medication Management and Personal Health Record modules are activated to monitor his symptoms and medication adherence.	Michael inputs his daily medication data, including acetazolamide taken twice a day, and logs his symptoms in the app.
07/15/2020	Michael attends a follow-up appointment where his physician confirms a shunt malfunction and schedules surgery.	The Appointment and Transport Management module is utilized to organize pre-surgery consultations and transportation.	Michael schedules his appointments and arranges for transport through the app, ensuring he has a smooth process leading up to the surgery.
08/05/2020	Post-surgery, Michael experiences back pain,	The Physical Activity Tracking and Skincare/Wound Tracking modules are	Michael logs his physical therapy exercises and checks

	likely due to his spina bifida condition.	activated to help Michael manage his recovery and monitor for any signs of skin breakdown.	his skin for pressure sores daily using the app.
10/22/2020	Michael receives recognition at work for his dedication to helping others with disabilities.	The Mood Tracking module helps Michael monitor his emotional well-being during this high point in his career.	Feeling proud and motivated, Michael records his mood and shares his achievement with his wellness coordinator through the messaging function.
12/10/2020	During a routine check-up, Michael is advised to adjust his insulin regimen due to fluctuating blood sugar levels.	The Medication Management module is updated to reflect the new insulin dosage and frequency.	Michael adjusts his medication reminders and logs his blood sugar readings in the app to track the effectiveness of the new regimen.
03/15/2021	Michael develops a pressure sore, prompting him to seek medical advice.	The Skincare/Wound Tracking module enables Michael to document the wound and share updates with his healthcare provider for remote monitoring.	Michael takes photos of the wound and logs his skincare routine, while his provider reviews the progress and provides guidance through the app's messaging function.
05/20/2021	Michael decides to focus on his nutritional health to aid in wound healing and diabetes management.	The Nutrition Tracking module is activated, allowing Michael to record his meals and receive tailored educational content on balanced diets.	Michael diligently logs his food intake, tracks his nutritional goals, and receives feedback from his wellness coordinator through the app.
07/30/2021	Michael's pressure sore shows significant improvement, and he continues his commitment to a healthy lifestyle.	The Goal Setting module helps Michael set new health goals to maintain his progress and prevent future skin breakdown.	Michael sets goals for daily skin checks and physical activity, using the app to remind him and track his adherence.
12/01/2021	Approaching the end of the 18-month timeline, Michael remains proactive in managing his health conditions and maintains a positive outlook on life.	The iMHere 2.0 app continues to support Michael's self-care activities, with all previously activated modules being regularly used to manage his complex health needs.	Michael communicates with his caregivers and healthcare team through the app, ensuring a collaborative approach to his ongoing health management.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #4

Persona

Personal Detail:

Name: Susan
Age: 55
Gender: Female
Race: Caucasian

Occupation: Part-time worker
Education: Vocational training
Housing: Group home
Lives in: Pittsburgh

Health Condition:
Cerebral Palsy, Spastic quadriplegia, scoliosis, mild intellectual disability, depression

Proactiveness to healthcare:
Semi-Active

Biography:
Susan has been living in a group home in Pittsburgh for the past several years. She is a determined and hardworking individual who has been able to participate in vocational training and work part-time despite her health challenges. The staff at the group home provide her with the necessary support to manage her various health conditions. Susan is a friendly and sociable person who enjoys spending time with her caregivers and fellow residents. She is committed to maintaining her overall well-being and actively engages with her healthcare team.

Health History:
- She experienced episodes of depression.
- She takes 10 medications daily, including anti-depressants and medications for spasticity and scoliosis.

Health Goals:
Short-Term:
- Manage depression symptoms.
- Prevent pressure ulcers.

Long-Term:
- Improve mobility.
- Enhance mental well-being.

Caregiver: Professional Caregiver

Challenges:
- Mobility limitations
- Managing multiple health conditions

Positive Traits:
- Determined
- Hardworking
- Sociable

Technology Access:

Computer	tablet ☑	smartphone ☑

Technology	Experience	Use
Computer	-	Never
Tablet	Moderate	Sometimes
Smartphone	High	Frequently

Scenario

Susan's increased spasticity and discomfort due to her cerebral palsy have been affecting her daily life at the group home. She struggles to work and participate in activities, which has been a source of frustration for her. As a result, she notices signs of a developing pressure ulcer and becomes concerned about wound management. This, coupled with her worsening depression symptoms, has made it difficult for Susan to maintain a positive mood. Additionally, she is having difficulty managing her bowel and bladder routines, leading to occasional accidents. To make matters worse, Susan is running low on medical supplies, which could disrupt her self-care routine. With an upcoming appointment at her spina bifida clinic, Susan is also worried about transportation. Despite these challenges, Susan is determined to improve her nutritional habits to support her overall health and well-being.

Key Events

Date	Event
03/15/2021	Susan experiences increased spasticity and discomfort due to her cerebral palsy, affecting her ability to work and participate in activities at the group home.
04/22/2021	Susan notices signs of a developing pressure ulcer and is concerned about wound management.
07/08/2021	Susan feels her depression symptoms worsening and struggles to maintain a positive mood.
09/30/2021	Susan is having difficulty managing her bowel and bladder routines, leading to occasional accidents.
11/12/2021	Susan is running low on medical supplies, which could disrupt her self-care routine.
01/20/2022	Susan has an upcoming appointment with her spina bifida clinic but is concerned about transportation.
02/28/2022	Susan wishes to improve her nutritional habits to support her overall health and well-being.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/15/2021	Susan experiences increased spasticity and discomfort due to her cerebral palsy, affecting her ability to work and participate in activities at the group home.	Susan's physician recommends the iMHere 2.0 app to help manage her medication schedule and track her physical activity. The physician activates the medication management and physical activity tracking modules.	Susan begins using the app to receive medication reminders and logs her daily physical activities, which helps her to maintain consistency in her self-care routine.
04/22/2021	Susan notices signs of a developing pressure ulcer and is concerned about wound management.	The skincare/wound tracking module is activated on Susan's iMHere 2.0 app, allowing her to monitor the condition of her skin and track wound healing progress.	Susan regularly inputs information about her skin condition into the app, and the caregiver app allows her caregivers to monitor these updates and assist as needed.
07/08/2021	Susan feels her depression symptoms worsening and struggles to maintain a positive mood.	The mood tracking module is enabled to help Susan track her mood patterns and identify triggers for her depression.	Susan starts to log her mood daily, which provides valuable data for her wellness coordinator and clinicians to review and adjust her treatment plan accordingly.
09/30/2021	Susan is having difficulty managing her bowel and	The Telecath and BMQs modules are added to her iMHere 2.0 app profile	Susan receives reminders for regular catheterization and

	bladder routines, leading to occasional accidents.	to assist Susan in maintaining a regular schedule and preventing incidents.	bowel programs, reducing the frequency of accidents and increasing her confidence in self-management.
11/12/2021	Susan is running low on medical supplies, which could disrupt her self-care routine.	The supplies management module is activated to help Susan track inventory levels and reorder supplies before they run out.	Susan uses the app to monitor her supply levels, and the app sends her notifications when it's time to reorder, ensuring she always has the necessary items on hand.
01/20/2022	Susan has an upcoming appointment with her spina bifida clinic but is concerned about transportation.	The appointment and transport management module are utilized to organize her upcoming visits and arrange transportation.	Susan schedules her appointments through the app and confirms transportation arrangements, which alleviates her concerns about getting to the clinic on time.
02/28/2022	Susan wishes to improve her nutritional habits to support her overall health and well-being.	The nutrition tracking module is enabled to help Susan monitor her dietary intake and make healthier food choices.	Susan logs her meals and snacks in the app, which provides insights into her eating habits and helps her make informed decisions about her nutrition.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #5

Persona

Personal Detail:

Name: John
Age: 23
Gender: Male
Race: Caucasian

Occupation: Unemployed
Education: High School Graduate
Housing: Lives with his mother in a suburban house
Lives in: Pittsburgh

Health Condition:
Spinal Cord Injury

Proactiveness to healthcare:
Passive

Biography:
John lives in a close-knit suburban community in Pittsburgh, Pennsylvania. He has always been an active and outgoing individual, enjoying outdoor activities and sports before his spinal cord injury. His mother has been his primary caregiver, providing him with emotional support and assistance with daily activities. John's passive attitude towards healthcare stems from his frustration and feelings of dependency, but his mother remains dedicated to helping him navigate his medical journey and improve his overall well-being.

Health History:
- He takes 8 medications daily.
- Occasional anti-depressant.
-

Health Goals:
Short-Term:
- Regain independence in self-care routine.
- Improve emotional well-being.

Long-Term:
- Regain mobility.
- Achieve emotional stability.

Caregiver: Mother

Challenges:
- Feelings of frustration and helplessness
- Dependency on mother

Positive Traits:
- Resilient
- Determined to improve.

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	High	Frequently

Scenario

Despite the progress in his physical therapy, John continues to struggle with the limitations caused by his spinal cord injury. His compromised skin integrity has led to the development of a pressure ulcer, adding to his physical discomfort. As a result, John's emotional well-being has taken a hit, causing him to rely more on his anti-depressant medication. The stress of managing numerous medical appointments has also taken a toll on him, making it difficult for him to stay on top of his recovery process. Despite slight improvements in mobility, John still requires assistance with daily activities, leaving him feeling helpless and isolated.

Key Events

Date	Event
03/01/2018	John experiences severe pain and limited mobility due to his spinal cord injury, making it difficult for him to manage his self-care activities.
06/15/2018	John's skin integrity is compromised, leading to the development of a pressure ulcer, a common complication for individuals with limited mobility.
09/10/2018	John feels isolated and experiences a decline in his emotional well-being, leading to increased reliance on his occasional anti-depressant.
12/01/2018	John struggles to keep track of his numerous medical appointments, which adds to his stress and hampers his recovery process.
02/20/2019	John's physical therapy results in slight improvements in mobility, but he still requires assistance with daily activities, leading to feelings of helplessness.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/01/2018	John experiences severe pain and limited mobility due to his spinal cord injury, making it difficult for him to manage his self-care activities.	John's physician recommends the iMHere 2.0 app to help him manage his medications and track his mood, as well as to provide him with educational content about self-care and spinal cord injuries. The physician activates the medication management, mood tracking, and tailored educational content modules on the iMHere 2.0 app. John begins to use the app to set reminders for his medications and to record his daily mood fluctuations.	John's physician activates the medication management, mood tracking, and tailored educational content modules on the iMHere 2.0 app. John begins to use the app to set reminders for his medications and to record his daily mood fluctuations.
06/15/2018	John's skin integrity is compromised, leading to the development of a pressure ulcer, a common complication for individuals with limited mobility.	The skincare/wound tracking module is activated to help John monitor the healing process and to ensure he follows up with proper wound care.	John uses the app to regularly update the status of his wound and receives automated reminders to check and care for his skin to prevent further deterioration.
09/10/2018	John feels isolated and experiences a decline in his emotional well-being, leading to increased reliance on his occasional anti-depressant.	The mood tracking module already in use is now supplemented with goal setting to help John work towards improving his emotional well-being.	John sets small, achievable goals within the app to help boost his mood and track his progress over time. He also uses the messaging function to communicate his emotional

			state with his wellness coordinator.
12/01/2018	John struggles to keep track of his numerous medical appointments, which adds to his stress and hampers his recovery process.	The appointment and transport management module are activated to assist John in organizing his healthcare schedule and arranging transportation.	John inputs his medical appointments into the app, which then provides him with reminders and helps coordinate transportation to and from his appointments.
02/20/2019	John's physical therapy results in slight improvements in mobility, but he still requires assistance with daily activities, leading to feelings of helplessness.	The personal health record module is utilized to track John's physical therapy progress and to share this information with his specialists.	John records his physical therapy achievements in the app's personal health record, allowing his specialists to monitor his progress and adjust his treatment plan accordingly.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #6

Persona

Personal Detail:

Name: Rachel
Age: 35
Gender: Female
Race: Caucasian

Occupation: Social Media Manager
Education: Bachelor's Degree
Housing: Apartment
Lives in: Pittsburgh

Health Condition:
Spina Bifida

Proactiveness to healthcare:
Active

Biography:
Rachel is a proactive and independent individual who lives in a bustling city. She is passionate about advocating for people with disabilities and is actively involved in her community. Rachel faces challenges with transportation due to her spina bifida, but she is determined to overcome these obstacles. She has a supportive network of friends and family who assist her with daily activities and provide emotional support. Rachel is well-informed about her health condition and is actively involved in managing her healthcare. She is tech-savvy and uses various digital tools to track her health and communicate with her healthcare providers.

Health History:
- She takes 8 medications daily, including medications for managing spina bifida symptoms and
- Occasional anti-depressants for mood changes.

Health Goals:
Short-Term:
- Improve bladder symptoms.
- Heal leg sore.
- Manage skin issues on lip.

Long-Term:
- Increase mobility with power chair.
- Reduce frequency of UTIs.
- Improve overall quality of life.

Caregiver: Family & Friends

Challenges:
- Transportation issues
- Insurance denials
- Mood changes

Positive Traits:
- Proactive
- Determined
- Tech-savvy

Technology Access:

Computer ☑	tablet ☑	smartphone ☑

Technology	Experience	Use
Computer	High	Frequently
Tablet	Moderate	Sometimes
Smartphone	High	Frequently

Scenario

Rachel's journey with her health has been a challenging one. After noticing increased difficulty with bladder control and a persistent sore on her leg, she experienced a fall that resulted in a minor arm injury, leading to concerns about her mobility. As her leg sore continued to not heal and she experienced skin issues on her lip, she also struggled with mood changes and sought ways to manage her mental health better. Dealing with a UTI and transportation issues that made it difficult for her to attend her healthcare appointments, Rachel also faced swelling in her legs and concerns about her circulation. Finally, her power chair was approved, but she needed to learn how to use it effectively. As she prepared for a 5K walk and wanted to improve her physical fitness, she encountered insurance denials for an orthotic insole, causing discomfort and mobility issues. Despite these challenges, Rachel remained determined to prioritize her health and well-being.

Key Events

Date	Event
01/15/2018	Rachel notices increased difficulty with bladder control and a persistent sore on her leg.
03/10/2018	Rachel experiences a fall, resulting in a minor arm injury, and she is concerned about her mobility.
05/22/2018	Rachel's leg sore has not healed, and she is experiencing skin issues on her lip.
08/01/2018	Rachel is struggling with mood changes and seeks ways to manage her mental health better.
10/12/2018	Rachel has a UTI and is reminded of the importance of consistent self-care.
12/30/2018	Rachel faces transportation issues that make it difficult for her to attend her healthcare appointments.
02/25/2019	Rachel is experiencing swelling in her legs and is concerned about her circulation.
04/18/2019	Rachel's power chair is finally approved, and she needs to learn how to use it effectively.
06/30/2019	Rachel is preparing for a 5K walk and wants to improve her physical fitness.
07/20/2019	Rachel encounters insurance denials for an orthotic insole, causing discomfort and mobility issues.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
01/15/2018	Rachel notices increased difficulty with bladder control and a persistent sore on her leg.	Rachel decides to use the iMHere 2.0 app after her clinician suggests it could help her manage her symptoms more effectively. She activates the medication management, bowel and bladder management, and skincare/wound tracking modules.	Rachel inputs her medication schedule into the app and sets up reminders for wound care and catheterization. She begins tracking her bladder symptoms and leg sore condition.
03/10/2018	Rachel experiences a fall, resulting in a minor arm injury, and she is concerned about her mobility.	The iMHere 2.0 app's physical activity tracking module is activated to help Rachel monitor her activity levels and adapt her exercises to prevent future falls.	Rachel logs her daily physical activities and sets goals for increasing her strength and balance to improve her mobility.
05/22/2018	Rachel's leg sore has not healed, and she is experiencing skin issues on her lip.	The app's tailored educational content provides Rachel with information on wound care and skin health. The goal-setting module helps her establish a plan for skincare.	Rachel reviews the educational content on skincare, sets a goal for daily wound care, and tracks her progress in healing her leg sore and lip issues.

08/01/2018	Rachel is struggling with mood changes and seeks ways to manage her mental health better.	The mood tracking module is utilized to help Rachel record her mood fluctuations and identify patterns or triggers.	Rachel regularly logs her mood in the app, which helps her and her healthcare provider to adjust her treatment plan for mood changes.
10/12/2018	Rachel has a UTI and is reminded of the importance of consistent self-care.	The app provides reminders for Rachel to adhere to her medication schedule and prompts her to schedule regular check-ups to prevent UTIs.	Rachel confirms receipt of medication reminders and uses the appointment management feature to schedule a follow-up with her doctor.
12/30/2018	Rachel faces transportation issues that make it difficult for her to attend her healthcare appointments.	The app's transport management module helps Rachel plan her trips to healthcare providers and track transportation arrangements.	Rachel schedules her transport to upcoming appointments using the app and receives reminders to ensure she doesn't miss them.
02/25/2019	Rachel is experiencing swelling in her legs and is concerned about her circulation.	The app's nutrition tracking module is recommended by her clinician to help Rachel monitor her diet, which can impact swelling and circulation.	Rachel begins logging her food intake and receives nutritional advice through the app to help reduce swelling.
04/18/2019	Rachel's power chair is finally approved, and she needs to learn how to use it effectively.	The wheelchair educational content module is activated to provide Rachel with resources on how to best utilize her new power chair.	Rachel accesses instructional videos and tips through the app to become more proficient with her power chair.
06/30/2019	Rachel is preparing for a 5K walk and wants to improve her physical fitness.	The app's goal-setting and physical activity tracking modules support Rachel in setting fitness goals and tracking her progress.	Rachel sets a goal for the 5K walk, logs her training activities, and monitors her improvements in endurance and strength.
07/20/2019	Rachel encounters insurance denials for an orthotic insole, causing discomfort and mobility issues.	The supplies management module helps Rachel keep track of her orthotic needs and manage her inventory.	Rachel uses the app to monitor her supply levels, set reminders to reorder insoles, and document any insurance correspondence.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #7

Persona

Personal Detail:

Name: Bob
Age: 33
Gender: Male
Race: Caucasian

Occupation: Part-time Librarian
Education: Some College
Housing: Adapted single-story home
Lives in: Erie, Pennsylvania

Health Condition:
Spinal Cord Injury

Proactiveness to healthcare:
Semi-Passive

Biography:
Bob, a resilient 33-year-old, navigates life in Erie, Pennsylvania, from the seat of his power wheelchair, a constant companion since a childhood spinal cord injury. His home, modified for accessibility, allows him the independence he cherishes, although the absence of nearby family means he often relies on friends and community services. Bob's days are enriched by his part-time work at the local library, where he's known for his keen intellect and willingness to help patrons. Despite his challenges with wound care and health management, Bob often reacting to issues as they arise. His social interactions, though limited, are meaningful and provide a network of support that bolsters his spirits.

Health History:
- Skin breakdown (pressure ulcer)
- Bob takes 9 medications daily to manage his health.
- He occasionally uses antidepressants and anticholinergic medication for an overactive bladder.

Health Goals:
Short-Term:
- Bob aims to improve the healing process of his wounds.
- He is working on reducing the risk of infections.
- He seeks to optimize his wheelchair use to enhance comfort and mobility.

Long-Term:
- Bob's goal is to achieve and maintain stable skin integrity.
- He wants to ensure the health of his urinary system.
- Increasing community involvement and social engagement is important to him.

Caregiver: Friends

Challenges:
- Financial difficulties
- Limited family support
- Issues with accessing and managing healthcare.

Positive Traits:
- Resilient
- Intellectually curious
- Helpful

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	High	Frequently
Tablet	-	-
Smartphone	Moderate	Sometimes

Scenario

Bob's history of health setbacks and challenges with medication adherence had taken a toll on his overall well-being. His struggle with pressure ulcers and infections had led to increased discomfort and a decline in his mood. As a result, Bob felt isolated and recognized the need to increase his social engagement and community involvement as part of his long-term goals. However, managing the supplies needed for his self-care had become increasingly difficult, putting him at risk of running out of essential items. It was clear that Bob needed support in maintaining his regimen and ensuring he had access to the necessary supplies to prevent recurrence of pressure ulcers and infections.

Key Events

Date	Event
03/01/2019	Bob noticed a new pressure ulcer on his left heel and experienced increased discomfort while using his wheelchair.
06/15/2019	Bob was struggling with medication adherence, leading to minor health setbacks.
09/30/2019	Bob felt isolated and noticed a decline in his mood, which he suspected was affecting his overall health.
12/01/2019	Bob's pressure ulcer showed signs of infection, prompting an urgent need for medical advice.
03/15/2020	Bob experienced a urinary tract infection, which he recognized from previous symptoms.
07/01/2020	Bob's pressure ulcer began to heal, but he needed to maintain his regimen to prevent recurrence.
10/20/2020	Bob wanted to increase his social engagement and community involvement as part of his long-term goals.
12/30/2020	Bob was having difficulty managing the supplies needed for his self-care, risking running out of essential items.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/01/2019	Bob noticed a new pressure ulcer on his left heel and experienced increased discomfort while using his wheelchair.	Bob's physician recommended the iMHere 2.0 app to help manage his wound care and wheelchair use. The Skincare/Wound Tracking and Wheelchair Educational Content modules were activated to address his immediate needs.	Bob began documenting the status of his pressure ulcer in the Skincare/Wound Tracking module and reviewing educational material on proper wheelchair use.
06/15/2019	Bob was struggling with medication adherence, leading to minor health setbacks.	The Medication Management module was activated to assist Bob in keeping a consistent medication schedule.	Bob started receiving reminder notifications for his medication times and was able to track his adherence through the app.
09/30/2019	Bob felt isolated and noticed a decline in his mood, which he suspected was affecting his overall health.	The Mood Tracking module was suggested by his caregiver to help Bob monitor his emotional well-being.	Bob began recording his daily mood and emotional triggers, which allowed his caregiver to monitor his mental health more closely.
12/01/2019	Bob's pressure ulcer showed signs of infection, prompting an	The Messaging function allowed Bob to communicate the issue to his wellness coordinator and receive timely advice.	Bob sent a message through the app detailing his symptoms, and his wellness coordinator

	urgent need for medical advice.		arranged for immediate medical intervention.
03/15/2020	Bob experienced a urinary tract infection, which he recognized from previous symptoms.	The Personal Health Record module enabled Bob to share his symptoms with his specialist.	Bob documented his symptoms in the app's Personal Health Record, which was then reviewed by his specialist for appropriate treatment.
07/01/2020	Bob's pressure ulcer began to heal, but he needed to maintain his regimen to prevent recurrence.	The app's Goal Setting module helped Bob establish and track progress towards his short-term health goals.	Bob set specific, measurable goals for his wound care routine and tracked his daily activities to ensure he was following his care plan.
10/20/2020	Bob wanted to increase his social engagement and community involvement as part of his long-term goals.	The app's tailored Educational Content provided Bob with resources on community programs and social activities suitable for his condition.	Bob explored the app's educational resources to find local events and support groups, which he could attend to enhance his social life.
12/30/2020	Bob was having difficulty managing the supplies needed for his self-care, risking running out of essential items.	The Supplies Management module was activated to help Bob track and manage his inventory of medical and self-care supplies.	Bob started using the module to monitor his supply levels, set reminders for when to reorder, and maintain an adequate stock of necessary items.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #8

Persona

Personal Detail:

Name: Emily
Age: 14
Gender: Female
Race: Caucasian

Occupation: Student
Education: High School
Housing: Single-family home
Lives in: Erie, Pennsylvania

Health Condition:
Spina Bifida: Myelomeningocele, Neurogenic bladder, Hydrocephalus, NVL disability

Proactiveness to healthcare:
Semi-Active

Biography:
Emily is a 14-year-old high school student living in Erie, Pennsylvania, with her parents and younger brother. Despite her challenges with Spina Bifida: Myelomeningocele, she maintains a positive outlook. Her family is supportive, and her parents are actively involved in her healthcare management. Emily's home is adapted to her needs, and her community is inclusive, offering resources for individuals with disabilities. However, she sometimes feels isolated due to her condition and relies heavily on her parents for certain aspects of her care, such as bowel management. She is part of a local support group for teens with chronic conditions, which helps her feel connected and understood.

Health History:
- Emily takes 8 medications daily to manage her health condition.
- She occasionally uses antidepressants.

Health Goals:
Short-Term:
- Emily aims to learn how to manage her medications independently.
- She wants to increase her knowledge about her condition.
- She is working to prevent urinary tract infections.

Long-Term:
- Emily's goal is to achieve greater independence in her daily living activities.
- She aspires to pursue higher education.
- She is determined to advocate for individuals with similar conditions.

Caregiver: Parent

Challenges:
- Limited mobility
- Dependence on parents for certain care aspects
- Risk of social isolation

Positive Traits:
- Resilient
- Optimistic
- Eager to learn.

Technology Access:

☑ Computer	tablet	☑ smartphone

Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	High	Frequently

Scenario

After experiencing a challenging day at school, Emily's fatigue and difficulty managing her medication schedule became more apparent. Feeling isolated from her peers, she expressed a desire to gain more independence in her self-care. Her parents noticed that she was running low on supplies for her bowel management more frequently than expected, prompting them to reassess her needs. During a routine check-up, Emily's physician discussed the importance of skincare and wound prevention due to her limited mobility, leading to a greater focus on her overall health management. As a result, Emily expressed an interest in learning how to manage her neurogenic bladder more independently and set a goal to participate in a school science fair. With the encouragement of her physician, she started setting long-term health goals and made significant progress in her overall health management.

Key Events

Date	Event
03/01/2019	Emily experienced a challenging day at school due to increased fatigue and difficulty managing her medication schedule.
06/15/2019	Emily felt isolated from her peers due to her condition and expressed a desire to gain more independence in her self-care.
09/30/2019	Emily's parents noticed she was running low on supplies for her bowel management more frequently than expected.
01/20/2020	During a routine check-up, Emily's physician discussed the importance of skincare and wound prevention due to her limited mobility.
05/10/2020	Emily expressed an interest in learning how to manage her neurogenic bladder more independently.
08/25/2020	Emily had a goal to participate in a school science fair but was concerned about managing her health during the preparation period.
12/01/2020	Emily's physician noted that she was making significant progress and encouraged her to start setting long-term health goals.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/01/2019	Emily experienced a challenging day at school due to increased fatigue and difficulty managing her medication schedule.	Emily's physician recommended the iMHere 2.0 app to assist her in medication management. The Medication Management and Education modules were activated to provide support.	Emily began using the app to set reminders for her medication times and to learn more about Spina Bifida through the educational content provided.
06/15/2019	Emily felt isolated from her peers due to her condition and expressed a desire to gain more independence in her self-care.	The Mood Tracking and Goal Setting modules were activated to support Emily's emotional well-being and independence.	Emily started tracking her mood regularly and set personal goals for increasing her self-care activities.
09/30/2019	Emily's parents noticed she was running low on supplies for her bowel management more frequently than expected.	The Supplies Management module was added to Emily's iMHere 2.0 app to assist with tracking and managing her supply inventory.	Emily used the app to monitor her supply levels and receive notifications when it was time to reorder, reducing the risk of running out.

01/20/2020	During a routine check-up, Emily's physician discussed the importance of skincare and wound prevention due to her limited mobility.	The Skincare/Wound Tracking module was activated in Emily's iMHere 2.0 app to help her monitor her skin condition and prevent wounds.	Emily began using the app to perform daily skin checks and log any concerns, which she could then share with her physician.
05/10/2020	Emily expressed an interest in learning how to manage her neurogenic bladder more independently.	The Bowel and Bladder Management module was activated to provide her with the necessary tools and education.	Emily used the app to track her bladder routines and received reminders for catheterization, helping to prevent urinary tract infections.
08/25/2020	Emily had a goal to participate in a school science fair but was concerned about managing her health during the preparation period.	The Personal Health Record and Appointment Management modules were activated to help her stay organized with her health appointments and records.	Emily was able to schedule her health-related appointments around her school activities and access her health records to communicate effectively with her school nurse.
12/01/2020	Emily's physician noted that she was making significant progress and encouraged her to start setting long-term health goals.	The Goal Setting module in the iMHere 2.0 app was updated to include long-term goal planning features.	Emily refined her goals within the app, focusing on achieving greater independence and pursuing higher education while managing her health condition.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #9

Persona

Personal Detail:

Name: Nancy
Age: 17
Gender: Female
Race: Caucasian

Occupation: High School Student
Education: Currently in High School
Housing: Lives with parents
Lives in: Erie, Pennsylvania

Health Condition:
Spina Bifida

Proactiveness to healthcare:
Passive

Biography:
Nancy is a 17-year-old high school student living in Erie, Pennsylvania, with her parents. She has Spina Bifida, which has necessitated a close-knit relationship with her caregivers for her daily needs. Nancy's community is supportive, with local health resources and a school that accommodates her learning disability, Nonverbal Learning Disorder (NVLD), and memory issues. However, Nancy's passive attitude towards her healthcare, largely due to her dependence on her parents, has been a barrier to developing self-care skills critical for her impending adulthood. Her parents are actively seeking ways to foster her independence, including involving her more in her healthcare decisions and self-management.

Health History:
- Nancy has experienced multiple occurrences of Urinary Tract Infections.
- She takes 8 medications daily.
- She uses anticholinergic medications to manage her overactive bladder.

Health Goals:
Short-Term:
- Nancy aims to learn to recognize the early signs of a Urinary Tract Infection.
- She wants to participate in selecting her own healthcare providers.
- She seeks to understand her medication regimen fully.

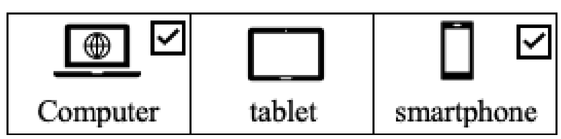
Long-Term:
- Nancy's goal is to manage her self-care independently.
- She is working towards preventing recurrent Urinary Tract Infections.
- She plans to develop a personal healthcare plan for her adulthood.

Caregiver: Parent

Challenges:
- Learning disability (NVLD)
- Memory issues
- Passive approach to healthcare

Positive Traits:
- Resilient
- Supportive community and family
- Access to local health resources

Technology Access:



Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	Moderate	Frequently

Scenario

As Nancy approaches adulthood, she is determined to take charge of her healthcare journey. With the support of her parents and wellness coordinator, she has made significant strides in advocating for herself. She has started tracking her physical activity to improve her overall health and has set a goal to learn more about nutrition to manage her weight and well-being. During a routine check-up, her physician emphasized the importance of skincare to prevent wounds, prompting Nancy to prioritize her skincare routine. With the guidance of her wellness coordinator, Nancy and her parents have worked together to decrease parental involvement in her medication management, giving her a sense of independence and responsibility. As she continues to navigate her healthcare journey, Nancy is focused on developing a comprehensive healthcare plan for her future, ensuring that she is actively involved in selecting her healthcare providers and managing her overall well-being.

Key Events

Date	Event
06/01/2021	Nancy experiences the early signs of a Urinary Tract Infection, including discomfort and increased frequency of urination.
09/15/2021	Nancy's parents notice her struggling to remember her healthcare appointments.
12/10/2021	Nancy expresses a desire to be more involved in selecting her healthcare providers.
03/22/2022	Nancy's parents encourage her to start tracking her physical activity to improve her overall health.
07/05/2022	Nancy has a routine check-up where her physician emphasizes the importance of skincare to prevent wounds.
10/18/2022	Nancy's parents and her wellness coordinator work together to decrease parental involvement in her medication management.
01/30/2023	Nancy sets a goal to learn more about nutrition to help manage her weight and overall health.
05/15/2023	As Nancy approaches adulthood, she aims to develop a comprehensive healthcare plan for her future.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
06/01/2021	Nancy experiences the early signs of a Urinary Tract Infection, including discomfort and increased frequency of urination.	After discussing with her physician, Nancy is prescribed the iMHere 2.0 app. The physician activates the medication management and bladder management modules to help Nancy track her symptoms and medication adherence.	Nancy begins using the app to log her symptoms and set reminders for her medication schedule.
09/15/2021	Nancy's parents notice her struggling to remember her healthcare appointments.	The appointment and transport management module are activated on Nancy's iMHere 2.0 app to help her keep track of upcoming appointments and arrange transportation if needed.	Nancy starts to input her healthcare appointments into the app and receives reminders for each one.
12/10/2021	Nancy expresses a desire to be more involved in selecting her healthcare providers.	The personal health record module is utilized to store information about potential providers and Nancy's healthcare preferences.	Nancy, with the help of her parents, begins to review and manage her personal health record within the app.
03/22/2022	Nancy's parents encourage her to start tracking her	The physical activity tracking module is activated to help Nancy set and monitor her fitness goals.	Nancy uses the app to log her daily physical activities

	physical activity to improve her overall health.		and track her progress toward her fitness goals.
07/05/2022	Nancy has a routine check-up where her physician emphasizes the importance of skincare to prevent wounds.	The skincare/wound tracking module is activated to help Nancy monitor her skin condition and identify any potential issues early.	Nancy starts to perform regular skin checks and logs any concerns in the app, which she can then discuss with her healthcare provider.
10/18/2022	Nancy's parents and her wellness coordinator work together to decrease parental involvement in her medication management.	The caregiver app is used by Nancy's parents to monitor her medication adherence from a distance, allowing Nancy more independence while ensuring her safety.	Nancy continues to use the client app for medication management, while her parents receive updates through the caregiver app.
01/30/2023	Nancy sets a goal to learn more about nutrition to help manage her weight and overall health.	The nutrition tracking module is activated to assist Nancy in understanding her dietary habits and making healthier food choices.	Nancy begins logging her meals and receives tailored educational content on nutrition through the app.
05/15/2023	As Nancy approaches adulthood, she aims to develop a comprehensive healthcare plan for her future.	The goal setting module is used to outline Nancy's long-term health goals and the steps needed to achieve them.	Nancy reviews her progress on her health goals and adjusts her plan as needed with the guidance of her healthcare team through the app.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Vignette #10

Persona

Personal Detail:

Name: Margaret Johnson
Age: 67
Gender: Female
Race: Caucasian

Occupation: Retired IT Project Manager
Education: Bachelor's Degree
Housing: Single-story home adapted for accessibility
Lives in: Erie, Pennsylvania

Health Condition:
Spina Bifida: Myelomeningocele

Proactiveness to healthcare:
Passive

Biography:
Margaret lives alone in a quiet suburb of Erie, where she enjoys the peace of her garden and the occasional visit from her sister-in-law, who lives nearby. Her home is equipped with various assistive devices to accommodate her mobility challenges due to spina bifida myelomeningocele. Margaret has a strong sense of independence but has become increasingly passive in managing her health since retirement, often deferring to her doctors' recommendations without much question. Her sister-in-law was instrumental in providing care when Margaret developed a pressure ulcer, highlighting the importance of family in her support system. She is part of a community that respects her privacy but is always ready to lend a hand when needed.

Health History:
- She has kidney failure.
- She recently experienced a complication with a Pressure Ulcer.
- She takes 8 different medications daily.

Health Goals:
Short-Term:
- Margaret aims to prevent urinary tract infections.
- She is working to maintain healthy skin integrity.

Long-Term:
- One of her goals is to manage her kidney health effectively.
- She seeks to avoid hospital readmissions.
- - Preserving her current level of independence is important to her.

Caregiver: Relative

Challenges:
- Margaret tends to take a passive approach to healthcare.
- She faces mobility limitations.
- There is a risk of skin breakdown that she needs to be mindful of.

Positive Traits:
- Independent
- Organized
- Resilient

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	High	Frequently
Tablet	-	-
Smartphone	Moderate	Sometimes

Scenario

After experiencing increased fatigue and a decrease in her appetite, Margaret became concerned about her kidney condition. She then noticed a minor pressure ulcer on her lower back, prompting her to prioritize regular skin checks. During a routine check-up, her doctor expressed concern about her lack of physical activity, emphasizing its importance for her overall health and mobility. As a result, Margaret felt isolated and noticed mood fluctuations, possibly due to her limited social interactions. Her struggles were noticed by her sister-in-law, who observed her difficulty in keeping track of her upcoming medical appointments. Margaret also had concerns about her nutrition and how it might be affecting her kidney health. Additionally, she ran out of catheter supplies, causing her anxiety and potentially leading to a urinary tract infection.

Key Events

Date	Event
01/15/2019	Margaret noticed increased fatigue and a decrease in her appetite, which she recognized as potential signs of her kidney condition worsening.
03/05/2019	Margaret experienced a minor pressure ulcer on her lower back, reminding her of the importance of regular skin checks.
06/10/2019	During a routine check-up, Margaret's doctor expressed concern about her lack of physical activity, which is crucial for her overall health and mobility.
09/20/2019	Margaret felt isolated and noticed mood fluctuations, possibly due to her limited social interactions.
12/01/2019	Margaret's sister-in-law noticed that Margaret was struggling to keep track of her upcoming medical appointments.
04/18/2020	Margaret had concerns about her nutrition and how it might be affecting her kidney health.
08/12/2020	Margaret ran out of catheter supplies, which caused her anxiety and could have led to a urinary tract infection.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
01/15/2019	Margaret noticed increased fatigue and a decrease in her appetite, which she recognized as potential signs of her kidney condition worsening.	After discussing her symptoms with her physician, she was prescribed the iMHere 2.0 app to help manage her health more proactively. The physician activated the medication management, personal health record, and tailored educational content modules to address her immediate needs.	Margaret began using the medication management module to keep track of her complex medication schedule and used the personal health record to log her symptoms and dietary intake.
03/05/2019	Margaret experienced a minor pressure ulcer on her lower back, reminding her of the importance of regular skin checks.	The skincare/wound tracking module was activated on her iMHere 2.0 app, allowing her to monitor the healing process and prevent further complications.	Margaret set up daily reminders for skin checks and wound care, and she documented the progress of her ulcer healing in the app.
06/10/2019	During a routine check-up, Margaret's doctor expressed concern about her lack of physical	The physical activity tracking module was added to her iMHere 2.0 app to encourage regular exercise within her capabilities.	Margaret began logging her daily physical activities in the app and set goals to gradually increase her movement.

	activity, which is crucial for her overall health and mobility.		
09/20/2019	Margaret felt isolated and noticed mood fluctuations, possibly due to her limited social interactions.	The mood tracking module was recommended by her wellness coordinator and activated in her iMHere 2.0 app to help her identify patterns and triggers.	She started to track her mood swings and shared this information with her caregiver and wellness coordinator through the app's messaging function.
12/01/2019	Margaret's sister-in-law noticed that Margaret was struggling to keep track of her upcoming medical appointments.	The appointment and transport management module are activated to assist Margaret in organizing her healthcare schedule more efficiently.	Margaret used the app to schedule her appointments, set reminders, and arrange transportation when necessary.
04/18/2020	Margaret had concerns about her nutrition and how it might be affecting her kidney health.	Although the iMHere 2.0 app did not have a specific kidney tracking module, the nutrition tracking module was activated to help her monitor her diet.	Margaret began to log her food and fluid intake to ensure she was following a kidney-friendly diet, using the app's personal health record to note any symptoms or concerns.
08/12/2020	Margaret ran out of catheter supplies, which caused her anxiety and could have led to a urinary tract infection.	The supplies management module was activated to help her keep track of her inventory and avoid running low on essential items.	She set up notifications in the app to alert her when supplies were running low, allowing her to reorder in a timely manner.

Review

Component	1 – Not	2 – Somewhat	3 – Quite	4 – Very
Relevance				
Realism				

Feedback	Type here or add comment on text…

Appendix B.2.2 Revised version

Two vignettes, #6 and #8 were canceled due to too much confliction and unrealistic

Vignette #1

Persona

Personal Detail:

Name: Margaret
Age: 50
Gender: Female
Race: Caucasian

Occupation: Volunteer
Education: High School Diploma
Housing: Apartment
Lives in: Pittsburgh

Health Condition:
Spina Bifida Myelomeningocele and shunted Hydrocephalus

Proactiveness to healthcare:
Active

Biography:
Margaret lives in a small apartment in Pittsburgh. She is an active member of her community and regularly volunteers at a local charity organization. She has a supportive group of friends and family who help her with daily tasks due to her impaired vision and hearing. Margaret is determined to maintain her independence and manages her health conditions with a proactive approach. She is diligent about attending her medical appointments and staying on top of her medication regimen.

Health History:
- Undergone multiple surgeries
- She has a history of seizures.
- Her vision is impaired.
- She has hearing impairments.
- She takes 3 medications daily.

Health Goals:
Short-Term:
- Manage medication dosage for seizures.
- Monitor and manage impaired hearing.

Long-Term:
- Maintain overall well-being.
- Prevent complications from spina bifida.
- Maintain mobility.

Caregiver: Family & Friends

Challenges:
- Impaired vision and hearing
- Managing multiple health conditions

Positive Traits:
- Proactive
- Responsible
- Determined

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	High	Frequently

Scenario

Margaret had been dealing with consistent back pain for quite some time, suspecting that it was related to her spina bifida condition. She also noticed signs of potential skin breakdown, with redness in an area that was subjected to prolonged pressure. During a routine check-up, her clinician confirmed the early stage of a pressure injury and prescribed a wound care gel to be applied twice a day. Fortunately, by the time the holidays rolled around, Margaret was pleased to report that her pressure injury was healing well. However, she then experienced headaches and nausea, raising concerns about a possible shunt malfunction. She went to the emergency room and was admitted to the hospital. Following a successful surgery to correct her shunt malfunction, Margaret returned home to recover. With the help of physical therapy, along with physical activity tracking and tailored exercises provided by the app, her back pain subsided significantly. Feeling empowered by her improved health management, Margaret volunteered at a local charity event. At her follow-up appointment, her clinician praised her for the effective management of her health conditions.

Key Events

Date	Event
06/15/2021	Margaret began experiencing consistent back pain, suspecting it might be related to her spina bifida condition.
08/03/2021	Margaret noticed signs of potential skin breakdown, with redness in an area subjected to prolonged pressure.
10/12/2021	During a routine check-up, Margaret's clinician confirmed the early stage of a pressure injury and prescribed a topical antibiotic.
12/25/2021	Margaret celebrated the holidays with her family and was pleased to report that her pressure injury was healing well.
03/07/2022	Margaret experienced headaches and nausea, raising concerns about a possible shunt malfunction.
05/14/2022	Following a successful surgery to correct her shunt malfunction, Margaret returned home to recover.
07/22/2022	Margaret's back pain subsided significantly, and she attributed this improvement to the physical therapy along with activity tracking and tailored exercises.
09/30/2022	Margaret volunteered at a local charity event, feeling empowered by her improved health management.
12/10/2022	Margaret attended a follow-up appointment, where her clinician praised her for the effective management of her health conditions.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
06/15/2021	Margaret began experiencing consistent back pain, suspecting it might be related to her spina bifida condition.	Margaret's physician recommended the iMHere 2.0 app to help manage her condition. After a discussion, they activated the medication management, physical activity tracking, personal health record, and tailored educational content modules to address her needs.	Margaret started using the app to track her back pain and set reminders for her anti-seizure medication, which she takes three times a day.
08/03/2021	Margaret noticed signs of potential skin breakdown, with	Using the iMHere 2.0 app, Margaret documented the skin issue in the	Margaret communicated the skin issue to her wellness

	redness and in an area subjected to prolonged pressure.	skincare/wound tracking module and set a reminder for daily wound checks.	coordinator via the messaging function in the app, who advised her to schedule an in-person visit.
10/12/2021	During a routine check-up, Margaret's clinician confirmed the early stage of a pressure injury and prescribed a wound gel.	Margaret used the medication management module to set reminders for the wound gel application.	She regularly updated the wound's progress in the app, allowing her caregiver to monitor the healing process remotely.
12/25/2021	Margaret celebrated the holidays with her family and was pleased to report that her pressure injury was healing well.	The iMHere 2.0 app's goal setting module helped Margaret stay motivated and on track with her skincare regimen.	She shared her progress with her family through the personal health record feature, which they could access with her permission.
03/07/2022	Margaret experienced headaches and nausea, raising concerns about a possible shunt malfunction.	Margaret reported her symptoms using the iMHere 2.0 app, which alerted her physician at the spina bifida clinic.	The physician used the web portal to review Margaret's symptoms and recommended an immediate evaluation at the emergency room
03/14/2022	Following a successful intervention to correct her shunt malfunction, Margaret returned home to recover.	The app's medication management module was updated to include new medications prescribed post-surgery, which she needed to take twice a day.	Margaret's caregiver used the caregiver app to help manage her post-operative care and ensure medication adherence.
07/22/2022	Margaret's back pain subsided significantly, and she attributed this improvement to the physical therapy she was receiving as well as physical activity tracking and tailored exercises provided by the app.	The app's physical activity tracking module helped her stay consistent with her exercises, which were crucial for her recovery.	Margaret shared her exercise milestones with her wellness coordinator through the app, receiving positive feedback and encouragement.
09/30/2022	Margaret volunteered at a local charity event, feeling empowered by her improved health management.	The iMHere 2.0 app's personal health record allowed her to share her volunteer activities and their impact on her well-being with her healthcare team.	Margaret used the goal setting module to set new objectives for her volunteer work, integrating her health management with her passion for community service.
12/10/2022	Margaret attended a follow-up appointment, where her clinician praised her for the effective management of her health conditions.	The app's appointment and transport management modules ensured she never missed a medical appointment and always had a ride arranged in advance.	Margaret's clinician reviewed her app data during the appointment, making informed decisions about her ongoing care plan.

Vignette #2

Persona

Personal Detail:

Name: Ethan
Age: 32
Gender: Male
Race: Caucasian

Occupation: computer lab assistant
Education: Associates degree
Housing: Apartment
Lives in: Philadelphia

Health Condition:
Spina Bifida and Shunted Hydrocephalus

Proactiveness to healthcare:
Semi-Passive

Biography:
Ethan lives in an urban area and relies on his power wheelchair for mobility due to his spina bifida and shunted hydrocephalus. He has a close relationship with his mother, who provides support and prompts him for medical care. Ethan's health condition has posed ongoing challenges in maintaining consistent follow-up and documentation. His living environment is supportive, but his reactive approach to healthcare has led to difficulties in managing his medical needs.

Health History:
- He has history of recurrent pressure injuries and wound infections.

Health Goals:
Short-Term:
- Healing of current wounds
- Regular follow-up with healthcare providers
- Improved adherence to medical care

Long-Term:
- Prevention of future pressure injuries
- Increased independence in self-care
- Better management of overall health

Caregiver: Mother

Challenges:
- Dependence on caregiver for medical care
- Reactive approach to healthcare
- Difficulty in following through with medical recommendations.

Positive Traits:
- Creative
- Resilient
- Determined

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	High	Frequently
Tablet	-	-
Smartphone	Moderate	Sometimes

Scenario

Ethan, a college computer lab assistant, diligently attends to his tasks when he observes a new pressure injury developing on his sacral area. During a follow-up visit, his clinician prescribes medication to address potential infection concerns and provide symptomatic relief. However, Ethan's mother becomes concerned when he starts experiencing headaches and nausea, prompting suspicion of a potential shunt malfunction. After undergoing shunt revision surgery, Ethan requires strict medication management for symptom control. Despite these challenges, he successfully completes his tasks, boosting his confidence in managing work alongside his health conditions. However, he later experiences a change in his physical sensations, prompting him to schedule an appointment with his physician to assess the cause. After months of diligent self-care, his pressure injury heals significantly, reducing his risk of complications. Unfortunately, he experiences symptoms of a urinary tract infection, indicating the ongoing challenges he faces in managing his health conditions.

Key Events

Date	Event
04/01/2021	Ethan notices a new pressure injury developing on his sacral area, likely due to prolonged sitting while working.
06/15/2021	During a follow-up visit, Ethan's clinician prescribes the antibiotic Cephalexin three times a day to treat any potential infection.
09/30/2021	Ethan's mother notices he has been experiencing headaches and nausea, raising concerns about a potential shunt malfunction.
10/07/2021	Ethan successfully undergoes a shunt revision surgery to address the malfunction. Post-surgery, he requires medication management for pain
03/22/2022	Ethan successfully manages his tasks as a college computer lab assistant, demonstrating his ability to balance work and health conditions effectively.
07/14/2022	Ethan develops back pain, which he suspects might be due to his spina bifida condition. He schedules an appointment with his physician to assess the cause.
10/05/2022	After several months of diligent self-care and system engagement, Ethan's pressure injury has healed significantly, reducing his risk of infection.
01/20/2023	Ethan experiences symptoms of a urinary tract infection, including discomfort and fever. He quickly recognizes the signs due to the education he received through the app.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
04/01/2021	Ethan notices a new pressure injury developing on his sacral area, likely due to prolonged sitting while working.	Ethan is onboarded to the iMHere 2.0 app by his physician, who activates the Skincare/Wound Tracking module and the Education module to help Ethan manage his wound and learn more about pressure injury prevention.	Ethan begins using the Skincare/Wound Tracking module to document his wound's progress and receives educational content on proper seating and repositioning techniques to prevent further skin breakdown.
06/15/2021	During a follow-up visit, Ethan's clinician prescribes the antibiotic Cephalexin three times a day to treat any potential infection.	The Medication Management module is activated to help Ethan track his antibiotic intake and ensure adherence to the treatment plan.	Ethan receives reminder notifications from the Medication Management module to take his Cephalexin at the prescribed times.
09/30/2021	Ethan's mother notices he has been experiencing headaches and nausea, raising concerns about a potential shunt malfunction.	Ethan's physician is notified through the iMHere 2.0 messaging function, and the Personal Health Record module is updated with his symptoms.	Ethan uses the messaging function to report his symptoms to his wellness coordinator, who arranges for an urgent neurosurgery consultation.
10/07/2021	Ethan successfully undergoes a shunt revision surgery to address the malfunction. Post-surgery, he requires medication management for pain	The Medication Management module is updated with Ethan's new medications, including pain reliever Acetaminophen, to be taken every six hours	Ethan relies on the app's reminders to take his post-operative medications on time and to track his recovery process.
03/22/2022	Ethan successfully manages his tasks as a college computer lab assistant, demonstrating his ability to balance work and health conditions effectively.	The Goal Setting module helps Ethan to set new personal and health-related goals, including taking on more projects and improving his physical activity levels.	Ethan uses the Goal Setting and Physical Activity Tracking modules to monitor his work-life balance and to stay motivated in achieving his new goals.
07/14/2022	Ethan develops back pain, which he suspects might be due to his spina bifida condition. He schedules an appointment with his physician to assess the cause.	The Appointment and Transport Management module assists Ethan in organizing his medical visits and arranging transportation.	Ethan uses the system to keep track of his upcoming appointments and to receive reminders for when it's time to leave for the clinic.
10/05/2022	After several months of diligent self-care and system engagement, Ethan's pressure injury has healed significantly, reducing his risk of infection.	The Skincare/Wound Tracking module allows Ethan to document the healing progress, and the system's educational content continues to support his understanding of pressure injury prevention.	Ethan regularly updates his wound status in the app, which allows his caregiver and healthcare providers to monitor his progress remotely.
01/20/2023	Ethan experiences symptoms of a urinary tract infection, including discomfort and fever. He quickly recognizes the signs due to the education he received through the app.	The system's messaging function enables Ethan to communicate his symptoms to his primary care physician, who prescribes an antibiotic, Nitrofurantoin, to be taken twice daily.	Ethan uses the Medication Management module to track his Nitrofurantoin intake and sets up reminders to ensure he completes the full course of antibiotics.

Vignette #3

Persona

Personal Detail:

Name: Michael
Age: 52
Gender: Male
Race: Caucasian

Occupation: Rehabilitation Specialist
Education: Bachelor's Degree
Housing: Apartment
Lives in: Philadelphia

Health Condition:
Spina Bifida: Myelomeningocele and Diabetes

Proactiveness to healthcare:
Active

Biography:
Michael lives in a bustling city neighborhood in Philadelphia. He is an active member of his community, participating in local events and volunteering at the neighborhood center for people with disabilities. He has a supportive group of friends and colleagues who understand his health conditions and provide encouragement. Michael is dedicated to his job as a rehabilitation specialist, using his expertise to help others with disabilities lead fulfilling lives. He is also an advocate for accessibility and inclusion in his community.

Health History:
- He has visual problems.
- He takes 8 medications daily, including insulin for diabetes

Health Goals:
Short-Term:
- Stabilize blood sugar levels.
- Improve mobility through physical therapy.
- Manage visual impairment with vision rehabilitation.

Long-Term:
- Maintain overall well-being through regular exercise and balanced diet.
- Continue thriving in professional and personal life.
- Stay proactive in managing health conditions.

Caregiver: Family & Friends

Challenges:
- Fluctuations in blood sugar levels
- Physical limitations due to spina bifida

Positive Traits:
- Proactive
- Dedicated
- Positive attitude

Technology Access:

☑ Computer	☑ tablet	☑ smartphone

Technology	Experience	Use
Computer	High	Frequently
Tablet	Moderate	Sometimes
Smartphone	High	Frequently

Scenario

After experiencing frequent headaches and nausea, Michael suspects a potential shunt malfunction and attends a follow-up appointment with his physician. The physician confirms the shunt malfunction and schedules surgery for Michael. Post-surgery, Michael experiences back pain, Despite these challenges, Michael receives recognition at work for his dedication to helping others with disabilities. During a routine check-up, Michael is advised to adjust his insulin regimen due to fluctuating blood sugar levels. He then develops a pressure injury, prompting him to seek medical advice. In response, Michael decides to focus on his nutritional health to aid in wound healing and diabetes management. As a result, his pressure injury shows significant improvement, and he continues his commitment to a healthy lifestyle. Approaching the end of the 18-month timeline, Michael remains proactive in managing his health conditions and maintains a positive outlook on life.

Key Events

Date	Event
06/01/2020	Michael begins to experience frequent headaches and nausea, suspecting a potential shunt malfunction.
07/15/2020	Michael attends a follow-up appointment where his physician confirms a shunt malfunction and schedules surgery.
08/05/2020	Post-surgery, Michael experiences back pain. In light of this, he seeks consultation with his physician to discuss potential pain management strategies that are appropriate for his postoperative condition.
10/22/2020	Michael receives recognition at work for his dedication to helping others with disabilities.
12/10/2020	During a routine check-up, Michael is advised to adjust his insulin regimen due to fluctuating blood sugar levels.
03/15/2021	Michael develops a pressure injury, prompting him to seek medical advice.
05/20/2021	Michael decides to focus on his nutritional health to aid in wound healing and diabetes management.
07/30/2021	Michael's pressure injury shows significant improvement, and he continues his commitment to a healthy lifestyle.
12/01/2021	Approaching the end of the 18-month timeline, Michael remains proactive in managing his health conditions and maintains a positive outlook on life.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
06/01/2020	Michael begins to experience frequent headaches and nausea, suspecting a potential shunt malfunction.	Michael's physician prescribes the iMHere 2.0 app to help manage his symptoms and track his health condition. The Medication Management and Personal Health Record modules are activated to monitor his symptoms and medication adherence.	Michael inputs his daily medication data, including acetazolamide taken twice a day, and logs his symptoms in the app.
07/15/2020	Michael attends a follow-up appointment where his physician confirms a shunt malfunction and schedules surgery.	The Appointment and Transport Management module is utilized to organize pre-surgery consultations and transportation.	Michael schedules his appointments and arranges for transport through the app, ensuring he has a

			smooth process leading up to the surgery.
08/05/2020	Post-surgery, Michael experiences back pain. In light of this, he seeks consultation with his physician to discuss potential pain management strategies that are appropriate for his postoperative condition.	The Physical Activity Tracking and Skincare/Wound Tracking modules are activated to help Michael manage his recovery and monitor for any signs of skin breakdown.	Michael logs his physical therapy exercises and checks his skin for pressure injuries daily using the app.
10/22/2020	Michael receives recognition at work for his dedication to helping others with disabilities.	The Mood Tracking module helps Michael monitor his emotional well-being during this high point in his career.	Feeling proud and motivated, Michael records his mood and shares his achievement with his wellness coordinator through the messaging function.
12/10/2020	During a routine check-up, Michael is advised to adjust his insulin regimen due to fluctuating blood sugar levels.	The Medication Management module is updated to reflect the new insulin dosage and frequency.	Michael adjusts his medication reminders and logs his blood sugar readings in the app to track the effectiveness of the new regimen.
03/15/2021	Michael develops a pressure injury, prompting him to seek medical advice.	The Skincare/Wound Tracking module enables Michael to document the wound and share updates with his healthcare provider for remote monitoring.	Michael takes photos of the wound and logs his skincare routine, while his provider reviews the progress and provides guidance through the app's messaging function.
05/20/2021	Michael decides to focus on his nutritional health to aid in wound healing and diabetes management.	The Nutrition Tracking module is activated, allowing Michael to record his meals and receive tailored educational content on balanced diets.	Michael diligently logs his food intake, tracks his nutritional goals, and receives feedback from his wellness coordinator through the app.
07/30/2021	Michael's pressure injury shows significant improvement, and he continues his commitment to a healthy lifestyle.	The Goal Setting module helps Michael set new health goals to maintain his progress and prevent future skin breakdown.	Michael sets goals for daily skin checks and physical activity, using the app to remind him and track his adherence.
12/01/2021	Approaching the end of the 18-month timeline, Michael remains proactive in managing his health conditions and maintains a positive outlook on life.	The iMHere 2.0 app continues to support Michael's self-care activities, with all previously activated modules being regularly used to manage his complex health needs.	Michael communicates with his caregivers and healthcare team through the app, ensuring a collaborative approach to his ongoing health management.

Vignette #4

Persona

Personal Detail:

Name: Susan
Age: 55
Gender: Female
Race: Caucasian

Occupation: Unemployed
Education: High school Diploma
Housing: Group home
Lives in: Pittsburgh

Health Condition:
Cerebral Palsy, Spastic quadriplegia, scoliosis, severe intellectual disability, depression

Proactiveness to healthcare:
Semi- Active

Biography:
Susan resides in a group home in Pittsburgh, where she receives essential support from caregivers due to her health challenges. Diagnosed with cerebral palsy, spastic quadriplegia, scoliosis, severe intellectual disability, and depression, Susan's daily life is significantly impacted. She engages actively with her healthcare team but relies heavily on assistance for daily tasks. Despite her challenges, Susan remains determined to maintain her well-being and enjoys spending time with caregivers and fellow residents

Health History:
- She experienced episodes of depression.
- She takes 10 medications daily, including anti-depressants and medications for spasticity and pain.

Health Goals:
Short-Term:
- Manage depression symptoms.
- Prevent pressure injuries.

Long-Term:
- Maintain mobility.
- Enhance mental well-being.

Caregiver: Professional Caregiver

Challenges:
- Mobility limitations
- Managing multiple health conditions

Positive Traits:
- Determined
- Hardworking
- Sociable

Technology Access:

Computer	tablet ☑	smartphone ☑

Technology	Experience	Use
Computer	-	Never
Tablet	Moderate	Sometimes
Smartphone	High	Frequently

Scenario

Susan's increased spasticity from cerebral palsy has significantly impacted her daily life in the group home. Participating in activities has become difficult, leading to frustration. She notices signs of a developing pressure injury and becomes concerned about wound management. Susan's worsening depression further complicates matters, making it hard for her to maintain a positive mood. Managing her bowel and bladder routines has become challenging, resulting in occasional accidents. To exacerbate the situation, Susan is running low on medical supplies, which could disrupt her self-care routine. With an upcoming appointment, transportation worries add to her stress. Despite these challenges, Susan remains determined to improve her nutritional habits to support her overall health and well-being.

Key Events

Date	Event
03/15/2021	Susan experiences increased spasticity due to her cerebral palsy, affecting her ability to participate in activities at the group home.
04/22/2021	Susan notices signs of a developing pressure injury and is concerned about wound management.
07/08/2021	Susan feels her depression symptoms worsening and struggles to maintain a positive mood.
09/30/2021	Susan is having difficulty managing her bowel and bladder routines, leading to occasional accidents.
11/12/2021	Susan is running low on medical supplies, which could disrupt her self-care routine.
01/20/2022	Susan has an upcoming appointment with her spina bifida clinic but is concerned about transportation.
02/28/2022	Susan wishes to improve her nutritional habits to support her overall health and well-being.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/15/2021	Susan experiences increased spasticity due to her cerebral palsy, affecting her ability to work and participate in activities at the group home.	Susan's physician recommends the iMHere 2.0 app to help manage her medication schedule and track her physical activity. The physician activates the medication management and physical activity tracking modules.	Susan begins using the app to receive medication reminders and logs her daily physical activities, which helps her to maintain consistency in her self-care routine.
04/22/2021	Susan notices signs of a developing pressure injury and is concerned about wound management.	The skincare/wound tracking module is activated on Susan's iMHere 2.0 app, allowing her to monitor the condition of her skin and track wound healing progress.	Susan regularly inputs information about her skin condition into the app, and the caregiver app allows her caregivers to monitor these updates and assist as needed.
07/08/2021	Susan feels her depression symptoms worsening and struggles to maintain a positive mood.	The mood tracking module is enabled to help Susan track her mood patterns and identify triggers for her depression.	Susan starts to log her mood daily, which provides valuable data for her wellness coordinator and clinicians to review and adjust her treatment plan accordingly.
09/30/2021	Susan is having difficulty managing her bowel and bladder routines, leading to occasional accidents.	The Telecath and BMQs modules are added to her iMHere 2.0 app profile to regular schedule and preventing incidents.	Susan receives reminders for regular catheterization and bowel programs, reducing the frequency of accidents and increasing her confidence in self-management.
11/12/2021	Susan is running low on medical supplies, which could disrupt her self-care routine.	The supplies management module is activated to help Susan track inventory levels and reorder supplies before they run out.	Susan uses the app to monitor her supply levels, and the app sends her notifications when it's time to reorder, ensuring she always has the necessary items on hand.
01/20/2022	Susan has an upcoming appointment with her spina bifida clinic but is concerned about transportation.	The appointment and transport management module are utilized to organize her upcoming visits and arrange transportation.	Susan schedules her appointments through the app and confirms transportation arrangements, which alleviates her concerns about getting to the clinic on time.
02/28/2022	Susan wishes to improve her nutritional habits to support her overall health and well-being.	The nutrition tracking module is enabled to help Susan monitor her dietary intake and make healthier food choices.	Susan logs her meals and snacks in the app, which provides insights into her eating habits and helps her make informed decisions about her nutrition.

Vignette #5

Persona

Personal Detail:

Name: John
Age: 23
Gender: Male
Race: Caucasian

Occupation: Unemployed
Education: High School Graduate
Housing: Lives with his mother in a suburban house
Lives in: Pittsburgh

Health Condition:
Spinal Cord Injury

Proactiveness to healthcare:
Passive

Biography:
John lives in a close-knit suburban community in Pittsburgh, Pennsylvania. He has always been an active and outgoing individual, enjoying outdoor activities and sports before his spinal cord injury a year after his high school graduation. His mother has been his primary caregiver, providing him with emotional support and assistance with daily activities. John's passive attitude towards healthcare stems from his frustration and feelings of dependency, but his mother remains dedicated to helping him navigate his medical journey and improve his overall well-being.

Health History:
- He takes 8 medications daily. anti-depressant.

Health Goals:
Short-Term:
- Regain independence in self-care routine.
- Improve emotional well-being.

Long-Term:
- Regain mobility.
- Achieve emotional stability.

Caregiver: Mother

Challenges:
- Feelings of frustration and helplessness
- Dependency on mother

Positive Traits:
- Resilient
- Determined to improve.

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	High	Frequently

Scenario

Despite diligently adhering to his physical therapy regimen, John continues to confront persistent challenges. Recently, he developed a pressure injury due to compromised skin integrity, which poses unique challenges for him. Given the nature of his injury, John may not perceive physical sensations in the same way others do. Nonetheless, the pressure injury adds another layer of complexity to his condition. Emotionally, John finds himself increasingly reliant on his antidepressant medication to cope with the psychological toll of his circumstances. The strain of managing multiple medical appointments has heightened his stress levels, hindering his ability to fully engage in his recovery process. While there have been slight improvements in his mobility, John still requires assistance with daily activities, intensifying feelings of helplessness and isolation.

Key Events

Date	Event
03/01/2018	John experiences severe pain and limited mobility due to his spinal cord injury, making it difficult for him to manage his self-care activities.
06/15/2018	John's skin integrity is compromised, leading to the development of a pressure injury, a common complication for individuals with limited mobility.
09/10/2018	John feels isolated and experiences a decline in his emotional well-being, leading to increased reliance on his anti-depressant to cope with the psychological toll.
12/01/2018	John struggles to keep track of his numerous medical appointments, which adds to his stress and hampers his recovery process.
02/20/2019	John's physical therapy results in slight improvements in mobility, but he still requires assistance with daily activities, leading to feelings of helplessness.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/01/2018	John experiences severe pain and limited mobility due to his spinal cord injury, making it difficult for him to manage his self-care activities.	John's physician recommends the iMHere 2.0 app to help him manage his medications and track his mood, as well as to provide him with educational content about self-care and spinal cord injuries. The physician activates the medication management, mood tracking, and tailored educational content modules on the iMHere 2.0 app. John begins to use the app to set reminders for his medications and to record his daily mood fluctuations.	John's physician activates the medication management, mood tracking, and tailored educational content modules on the iMHere 2.0 app. John begins to use the app to set reminders for his medications and to record his daily mood fluctuations.
06/15/2018	John's skin integrity is compromised, leading to the development of a pressure injury, a common complication for individuals with limited mobility.	The skincare/wound tracking module is activated to help John monitor the healing process and to ensure he follows up with proper wound care.	John uses the app to regularly update the status of his wound and receives automated reminders to check and care for his skin to prevent further deterioration.
09/10/2018	John feels isolated and experiences a decline in his emotional well-being, leading to increased reliance on his anti-depressant to cope with the psychological toll.	The mood tracking module already in use is now supplemented with goal setting to help John work towards improving his emotional well-being.	John sets small, achievable goals within the app to help boost his mood and track his progress over time. He also uses the messaging function to communicate his emotional state with his wellness coordinator.
12/01/2018	John struggles to keep track of his numerous medical appointments, which adds to his stress and hampers his recovery process.	The appointment and transport management module are activated to assist John in organizing his healthcare schedule and arranging transportation.	John inputs his medical appointments into the app, which then provides him with reminders and helps coordinate transportation to and from his appointments.
02/20/2019	John's physical therapy results in slight improvements in mobility, but he still requires assistance with daily activities, leading to feelings of helplessness.	The personal health record module is utilized to track John's physical therapy progress and to share this information with his specialists.	John records his physical therapy achievements in the app's personal health record, allowing his specialists to monitor his progress and adjust his treatment plan accordingly.

Vignette #7

Persona

Personal Detail:

Name: Bob
Age: 33
Gender: Male
Race: Caucasian

Occupation: Part-time Librarian
Education: Some College
Housing: Adapted single-story home
Lives in: Erie, Pennsylvania

Health Condition:
Spinal Cord Injury

Proactiveness to healthcare:
Semi-Passive

Biography:
Bob, a resilient 33-year-old, navigates life in Erie, Pennsylvania, from the seat of his power wheelchair, a constant companion since a childhood spinal cord injury. His home, modified for accessibility, allows him the independence he cherishes, although the absence of nearby family means he often relies on friends and community services. Bob's days are enriched by his part-time work at the local library, where he's known for his keen intellect and willingness to help patrons. Despite his challenges with wound care and health management, Bob often reacts to issues as they arise. His social interactions, though limited, are meaningful and provide a network of support that bolsters his spirits.

Health History:
- Skin breakdown (pressure injury)
- Bob takes 9 medications daily to manage his health.
- anticholinergic medication for an overactive bladder.

Health Goals:

Short-Term:
- Bob aims to improve the healing process of his wounds.
- He is working on reducing the risk of infections.
- He seeks to optimize his wheelchair use to enhance comfort and mobility.

Long-Term:
- Bob's goal is to achieve and maintain stable skin integrity.
- He wants to ensure the health of his urinary system.
- Increasing community involvement and social engagement is important to him.

Caregiver: Friends

Challenges:
- Financial difficulties
- Limited family support
- Issues with accessing and managing healthcare.

Positive Traits:
- Resilient
- Intellectually curious
- Helpful

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	**Experience**	**Use**
Computer	High	Frequently
Tablet	-	-
Smartphone	Moderate	Sometimes

Scenario

Bob's history of health setbacks and challenges with medication adherence had taken a toll on his overall well-being. His struggle with pressure injuries and infections had led to increased challenges and a decline in his mood. As a result, Bob felt isolated and recognized the need to increase his social engagement and community involvement as part of his long-term goals. However, managing the supplies needed for his self-care had become increasingly difficult, putting him at risk of running out of essential items. It was clear that Bob needed support in maintaining his regimen and ensuring he had access to the necessary supplies to prevent recurrence of pressure injuries and infections.

Key Events

Date	Event
03/01/2019	Bob noticed a new pressure injury on his left heel and experienced increased challenges while using his wheelchair.
06/15/2019	Bob was struggling with medication adherence, leading to minor health setbacks.
09/30/2019	Bob felt isolated and noticed a decline in his mood, which he suspected was affecting his overall health.
12/01/2019	Bob's pressure injury showed signs of infection, prompting an urgent need for medical advice.
03/15/2020	Bob experienced a urinary tract infection, which he recognized from previous symptoms.
07/01/2020	Bob's pressure injury began to heal, but he needed to maintain his regimen to prevent recurrence.
10/20/2020	Bob wanted to increase his social engagement and community involvement as part of his long-term goals.
12/30/2020	Bob was having difficulty managing the supplies needed for his self-care, risking running out of essential items.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
03/01/2019	Bob noticed a new pressure injury on his left heel and experienced increased challenges while using his wheelchair.	Bob's physician recommended the iMHere 2.0 app to help manage his wound care and wheelchair use. The Skincare/Wound Tracking and Wheelchair Educational Content modules were activated to address his immediate needs.	Bob began documenting the status of his pressure injury in the Skincare/Wound Tracking module and reviewing educational material on proper wheelchair use.
06/15/2019	Bob was struggling with medication adherence, leading to minor health setbacks.	The Medication Management module was activated to assist Bob in keeping a consistent medication schedule.	Bob started receiving reminder notifications for his medication times and was able to track his adherence through the app.
09/30/2019	Bob felt isolated and noticed a decline in his mood, which he suspected was affecting his overall health.	The Mood Tracking module was suggested by his caregiver to help Bob monitor his emotional well-being.	Bob began recording his daily mood and emotional triggers, which allowed his caregiver to monitor his mental health more closely.
12/01/2019	Bob's pressure injury showed signs of infection, prompting an	The Messaging function allowed Bob to communicate the issue to his wellness coordinator and receive timely advice.	Bob sent a message through the app detailing his symptoms, and his wellness coordinator

	urgent need for medical advice.		arranged for immediate medical intervention.
03/15/2020	Bob experienced a urinary tract infection, which he recognized from previous symptoms.	The Personal Health Record module enabled Bob to share his symptoms with his specialist.	Bob documented his symptoms in the app's Personal Health Record, which was then reviewed by his specialist for appropriate treatment.
07/01/2020	Bob's pressure injury began to heal, but he needed to maintain his regimen to prevent recurrence.	The app's Goal Setting module helped Bob establish and track progress towards his short-term health goals.	Bob set specific, measurable goals for his wound care routine and tracked his daily activities to ensure he was following his care plan.
10/20/2020	Bob wanted to increase his social engagement and community involvement as part of his long-term goals.	The app's tailored Educational Content provided Bob with resources on community programs and social activities suitable for his condition.	Bob explored the app's educational resources to find local events and support groups, which he could attend to enhance his social life.
12/30/2020	Bob was having difficulty managing the supplies needed for his self-care, risking running out of essential items.	The Supplies Management module was activated to help Bob track and manage his inventory of medical and self-care supplies.	Bob started using the module to monitor his supply levels, set reminders for when to reorder, and maintain an adequate stock of necessary items.

Vignette #9

Persona

Personal Detail:

Name: Nancy
Age: 17
Gender: Female
Race: Caucasian

Occupation: High School Student
Education: Currently in High School
Housing: Lives with parents
Lives in: Erie, Pennsylvania

Health Condition:
Spina Bifida Myelomeningocele

Proactiveness to healthcare:
Passive

Biography:
Nancy is a 17-year-old high school student living in Erie, Pennsylvania, with her parents. She has Spina Bifida, which has necessitated a close-knit relationship with her parents for her daily needs. Nancy's community is supportive, with local health resources and a school that accommodates her learning disability, Nonverbal Learning Disorder (NVLD), and memory issues. However, Nancy's passive attitude towards her healthcare, largely due to her dependence on her parents, has been a barrier to developing self-care skills critical for her impending adulthood. Her parents are actively seeking ways to foster her independence, including involving her more in her healthcare decisions and self-management.

Health History:
- Nancy has experienced multiple occurrences of Urinary Tract Infections.
- She takes 8 medications daily.
- She uses anticholinergic medications to manage her overactive bladder.

Health Goals:
Short-Term:
- Nancy aims to learn to recognize the early signs of a Urinary Tract Infection.
- She wants to participate in selecting her own healthcare providers.
- She seeks to understand her medication regimen fully.

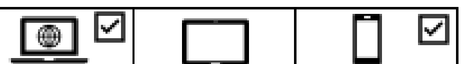
Long-Term:
- Nancy's goal is to manage her self-care independently.
- She is working towards preventing recurrent Urinary Tract Infections.
- She plans to develop a personal healthcare plan for her adulthood.

Caregiver: Parent

Challenges:
- Learning disability (NVLD)
- Memory issues
- Passive approach to healthcare

Positive Traits:
- Resilient
- Supportive community and family
- Access to local health resources

Technology Access:



Computer	tablet	smartphone

Technology	Experience	Use
Computer	Moderate	Sometimes
Tablet	-	-
Smartphone	Moderate	Frequently

Scenario

As Nancy approaches adulthood, she is determined to take charge of her healthcare journey. With the support of her parents and wellness coordinator, she has made significant strides in advocating for herself. She has started tracking her physical activity to improve her overall health and has set a goal to learn more about nutrition to manage her weight and well-being. During a routine check-up, her physician emphasized the importance of skincare to prevent wounds, prompting Nancy to prioritize her skincare routine. With the guidance of her wellness coordinator, Nancy and her parents have worked together to decrease parental involvement in her medication management, giving her a sense of independence and responsibility. As she continues to navigate her healthcare journey, Nancy is focused on developing a comprehensive healthcare plan for her future, ensuring that she is actively involved in selecting her healthcare providers and managing her overall well-being.

Key Events

Date	Event
06/01/2021	Nancy experiences the early signs of a Urinary Tract Infection, including discomfort and increased frequency of urination.
09/15/2021	Nancy's parents notice her struggling to remember her healthcare appointments.
12/10/2021	Nancy expresses a desire to be more involved in selecting her healthcare providers.
03/22/2022	Nancy's parents encourage her to start tracking her physical activity to improve her overall health.
07/05/2022	Nancy has a routine check-up where her physician emphasizes the importance of skincare to prevent wounds.
10/18/2022	Nancy's parents and her wellness coordinator work together to decrease parental involvement in her medication management.
01/30/2023	Nancy sets a goal to learn more about nutrition to help manage her weight and overall health.
05/15/2023	As Nancy approaches adulthood, she aims to develop a comprehensive healthcare plan for her future.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
06/01/2021	Nancy experiences the early signs of a Urinary Tract Infection, including discomfort and increased frequency of urination.	After discussing with her physician, Nancy is prescribed the iMHere 2.0 app. The physician activates the medication management and bladder management modules to help Nancy track her symptoms and medication adherence.	Nancy begins using the app to log her symptoms and set reminders for her medication schedule.
09/15/2021	Nancy's parents notice her struggling to remember her healthcare appointments.	The appointment and transport management module are activated on Nancy's iMHere 2.0 app to help her keep track of upcoming appointments and arrange transportation if needed.	Nancy starts to input her healthcare appointments into the app and receives reminders for each one.
12/10/2021	Nancy expresses a desire to be more involved in selecting her healthcare providers.	The personal health record module is utilized to store information about potential providers and Nancy's healthcare preferences.	Nancy, with the help of her parents, begins to review and manage her personal health record within the app.
03/22/2022	Nancy's parents encourage her to start tracking her	The physical activity tracking module is activated to help Nancy set and monitor her fitness goals.	Nancy uses the app to log her daily physical activities

	physical activity to improve her overall health.		and track her progress toward her fitness goals.
07/05/2022	Nancy has a routine check-up where her physician emphasizes the importance of skincare to prevent wounds.	The skincare/wound tracking module is activated to help Nancy monitor her skin condition and identify any potential issues early.	Nancy starts to perform regular skin checks and logs any concerns in the app, which she can then discuss with her healthcare provider.
10/18/2022	Nancy's parents and her wellness coordinator work together to decrease parental involvement in her medication management.	The caregiver app is used by Nancy's parents to monitor her medication adherence from a distance, allowing Nancy more independence while ensuring her safety.	Nancy continues to use the client app for medication management, while her parents receive updates through the caregiver app.
01/30/2023	Nancy sets a goal to learn more about nutrition to help manage her weight and overall health.	The nutrition tracking module is activated to assist Nancy in understanding her dietary habits and making healthier food choices.	Nancy begins logging her meals and receives tailored educational content on nutrition through the app.
05/15/2023	As Nancy approaches adulthood, she aims to develop a comprehensive healthcare plan for her future.	The goal setting module is used to outline Nancy's long-term health goals and the steps needed to achieve them.	Nancy reviews her progress on her health goals and adjusts her plan as needed with the guidance of her healthcare team through the app.

Vignette #10

Persona

Personal Detail:

Name: Margaret Johnson
Age: 67
Gender: Female
Race: Caucasian

Occupation: Retired IT Project Manager
Education: Bachelor's Degree
Housing: Single-story home adapted for accessibility
Lives in: Erie, Pennsylvania

Health Condition:
Spina Bifida: Myelomeningocele

Proactiveness to healthcare:
Passive

Biography:
Margaret lives alone in a quiet suburb of Erie, where she enjoys the peace of her garden and the occasional visit from her sister-in-law, who lives nearby. Her home is equipped with various assistive devices to accommodate her mobility challenges due to spina bifida. Margaret has a strong sense of independence but has become increasingly passive in managing her health since retirement, often deferring to her doctors' recommendations without much question. Her sister-in-law was instrumental in providing care when Margaret developed a pressure injury, highlighting the importance of family as social support. She is part of a community that respects her privacy but is always ready to lend a hand when needed.

Health History:
- She has kidney failure.
- She recently experienced a complication with a Pressure Injury.
- She takes 8 different medications daily.

Health Goals:
Short-Term:
- Margaret aims to prevent urinary tract infections.
- She is working to maintain healthy skin integrity.

Long-Term:
- One of her goals is to manage her kidney health effectively.
- She seeks to avoid hospital readmissions.
- Preserving her current level of independence is important to her.

Caregiver: Relative

Challenges:
- Margaret tends to take a passive approach to healthcare.
- She faces mobility limitations.
- There is a risk of skin breakdown that she needs to be mindful of.

Positive Traits:
- Independent
- Organized
- Resilient

Technology Access:

Computer ☑	tablet	smartphone ☑

Technology	Experience	Use
Computer	High	Frequently
Tablet	-	-
Smartphone	Moderate	Sometimes

Scenario

After experiencing increased fatigue and a decrease in her appetite, Margaret became concerned about her kidney condition. She then noticed a minor pressure injury on her lower back, prompting her to prioritize regular skin checks. During a routine check-up, her doctor expressed concern about her lack of physical activity, emphasizing its importance for her overall health and mobility. She felt isolated and noticed mood fluctuations, possibly due to her limited social interactions. Her struggles were noticed by her sister-in-law, who observed her difficulty in keeping track of her upcoming medical appointments. Margaret also had concerns about her nutrition and how it might be affecting her kidney health. Additionally, she ran out of catheter supplies, causing her anxiety and potentially leading to a urinary tract infection.

Key Events

Date	Event
01/15/2019	Margaret noticed increased fatigue and a decrease in her appetite, which she recognized as potential signs of her kidney condition worsening.
03/05/2019	Margaret experienced a minor pressure injury on her lower back, reminding her of the importance of regular skin checks.
06/10/2019	During a routine check-up, Margaret's doctor expressed concern about her lack of physical activity, which is crucial for her overall health and mobility.
09/20/2019	Margaret felt isolated and noticed mood fluctuations, possibly due to her limited social interactions.
12/01/2019	Margaret's sister-in-law noticed that Margaret was struggling to keep track of her upcoming medical appointments.
04/18/2020	Margaret had concerns about her nutrition and how it might be affecting her kidney health.
08/12/2020	Margaret ran out of catheter supplies, which caused her anxiety and could have led to a urinary tract infection.

Simulated Interaction

Date	Key Event	System Solution	System Interaction
01/15/2019	Margaret noticed increased fatigue and a decrease in her appetite, which she recognized as potential signs of her kidney condition worsening.	After discussing her symptoms with her physician, she was prescribed the iMHere 2.0 app to help manage her health more proactively. The physician activated the medication management, personal health record, and tailored educational content modules to address her immediate needs.	Margaret began using the medication management module to keep track of her complex medication schedule and used the personal health record to log her symptoms and dietary intake.
03/05/2019	Margaret experienced a minor pressure injury on her lower back, reminding her of the importance of regular skin checks.	The skincare/wound tracking module was activated on her iMHere 2.0 app, allowing her to monitor the healing process and prevent further complications.	Margaret set up daily reminders for skin checks and wound care, and she documented the progress of her injury healing in the app.
06/10/2019	During a routine check-up, Margaret's doctor expressed concern about her lack of physical activity, which is crucial	The physical activity tracking module was added to her iMHere 2.0 app to encourage regular exercise within her capabilities.	Margaret began logging her daily physical activities in the app and set goals to gradually increase her movement.

	for her overall health and mobility.		
09/20/2019	Margaret felt isolated and noticed mood fluctuations, possibly due to her limited social interactions.	The mood tracking module was recommended by her wellness coordinator and activated in her iMHere 2.0 app to help her identify patterns and triggers.	She started to track her mood swings and shared this information with her caregiver and wellness coordinator through the app's messaging function.
12/01/2019	Margaret's sister-in-law noticed that Margaret was struggling to keep track of her upcoming medical appointments.	The appointment and transport management module are activated to assist Margaret in organizing her healthcare schedule more efficiently.	Margaret used the app to schedule her appointments, set reminders, and arrange transportation when necessary.
04/18/2020	Margaret had concerns about her nutrition and how it might be affecting her kidney health.	Although the iMHere 2.0 app did not have a specific kidney tracking module, the nutrition tracking module was activated to help her monitor her diet.	Margaret began to log her food and fluid intake to ensure she was following a kidney-friendly diet, using the app's personal health record to note any symptoms or concerns.
08/12/2020	Margaret ran out of catheter supplies, which caused her anxiety and could have led to a urinary tract infection.	The supplies management module was activated to help her keep track of her inventory and avoid running low on essential items.	She set up notifications in the app to alert her when supplies were running low, allowing her to reorder in a timely manner.

Appendix C Usability Tasks

Appendix C.1 Usability Tasks

Subject ID ________________________ Date ___ / ___ / 20___

Session ID ________________________ Usability & Accessibility Study

Section 9a: Usability Tasks

Section 6a: Remember to complete The Patient Specific Functional Scale

Completed: Yes No

Session 1 Tasks	Sets	Steps	Module	Type	Level
A. Add Ibuprofen to your schedules. It should be 1 oral tablet daily. The tablet should be 800 mg/1 and from the Walgreens corporation.	4	14	MyMeds	Schedule	Complex
B. Respond to medication reminder for 'Ibuprofen (Walgreens Corporation)'	4	3	MyMeds	Reminder	Simple
C. Add mood reminder daily 5 min from now.	3	7	Mood	Schedule	Simple
D. Respond to complex reminder: Respond to mood alarm, responding 'several days' to all answers.	3	12	Mood	Reminder	Complex
E. Add BMQ reminder daily 5 min from now.	2	7	BMQ	Schedule	Simple
F. Respond to BMQ alarm, responding with 'color' as problem and list 'stool is black and tarry,' in notes. (10 steps)	2	8	BMQ	Reminder	Complex

G. Search for Info from Educational Module: Under the related medical issues education, find the section called 'Tethered Cord Release Surgery Recovery.'	3	7	Education	Search	Simple
H. Add skin check reminder daily 5 min from now.	1	7	Skincare	Schedule	Simple
I. Respond to skin check alarm, responding that 'I have a problem with my skin' and list problem as 'right elbow that is pink' in notes.	1	8	Skincare	Reminder	Complex
J. Send new message to provider with the subject 'Hello' and the body with today's season.	2	9	Message		Simple
K. Review schedule of alarms for BMQ.	1	2	BMQ	Review Schedule	Simple
L. Edit the personal health records, to include the condition 'Hydrocephalus.'	4	8	PHR	Edit	Simple
M. Initiate skin check to indicate problem on chest. Take picture of table, and respond that the skin is 'smaller than a golf ball and 'bright red,' 'watery but clear,' and 'greater than .5 cm.' (18 steps)	3	18	Skincare	Self-Initiated	Complex
N. Complete follow up skin check for chest. Take picture of table, and change 'watery but clear' to 'dry and clear.' (16 steps)	3	15	Skincare	Self-Initiated	Medium

Appendix D Statistical Analysis Result

Appendix D.1 Flyer and Activation Code Implementation

Frequencies

Statistics

		approval_delta_consent
N	Valid	49
	Missing	0
Mean		347455.204
Median		19615.000
Std. Deviation		1263131.56
Range		7391498.0
Minimum		66.0
Maximum		7391564.0

Appendix D.1.1 As 3 groups

Flyer was introduced on August 10th, 2023, and Activation Code workflow was introduced on November 9th, 2023. Hence the data is split into are three groups

act_group0

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	12	24.5	24.5	24.5
	1	22	44.9	44.9	69.4
	2	15	30.6	30.6	100.0
	Total	49	100.0	100.0	

Descriptive Statistics

act_group0		N	Minimum	Maximum	Mean	Std. Deviation
0	approval_delta_consent	12	3590.0	5014166.0	664916.833	1418246.13
	Valid N (listwise)	12				
1	approval_delta_consent	22	1650.0	7391564.0	385403.000	1565904.61
	Valid N (listwise)	22				
2	approval_delta_consent	15	66.0	554545.0	37829.133	142961.4173
	Valid N (listwise)	15				

Descriptives

	act_group0			Statistic	Std. Error
approval_delta_consent	0	Mean		664916.833	409412.3917
		95% Confidence Interval for Mean	Lower Bound	-236193.765	
			Upper Bound	1566027.432	
		5% Trimmed Mean		460032.259	
		Median		112649.500	
		Variance		2011422077330.697	
		Std. Deviation		1418246.1272	
		Minimum		3590.0	
		Maximum		5014166.0	
		Range		5010576.0	
		Interquartile Range		660386.5	
		Skewness		3.087	.637
		Kurtosis		9.944	1.232
	1	Mean		385403.000	333851.9844
		95% Confidence Interval for Mean	Lower Bound	-308880.209	
			Upper Bound	1079686.209	
		5% Trimmed Mean		53791.172	
		Median		24678.000	
		Variance		2452057244973.524	
		Std. Deviation		1565904.6092	
		Minimum		1650.0	
		Maximum		7391564.0	
		Range		7389914.0	
		Interquartile Range		79911.3	
		Skewness		4.680	.491
		Kurtosis		21.932	.953

2	Mean		37829.133	36912.4792
	95% Confidence Interval for Mean	Lower Bound	-41340.261	
		Upper Bound	116998.527	
	5% Trimmed Mean		11220.648	
	Median		138.000	
	Variance		20437966828.267	
	Std. Deviation		142961.4173	
	Minimum		66.0	
	Maximum		554545.0	
	Range		554479.0	
	Interquartile Range		1113.0	
	Skewness		3.871	.580
	Kurtosis		14.992	1.121

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	act_group0	Statistic	df	Sig.	Statistic	df	Sig.
approval_delta_consent	0	.368	12	<.001	.508	12	<.001
	1	.501	22	<.001	.248	22	<.001
	2	.514	15	<.001	.292	15	<.001

a. Lilliefors Significance Correction

NPar Tests

Kruskal-Wallis Test

Ranks

	act_group0	N	Mean Rank
approval_delta_consent	0	12	36.75
	1	22	28.45
	2	15	10.53
	Total	49	

Test Statistics[a,b]

	approval_delta_consent
Kruskal-Wallis H	24.777
df	2
Asymp. Sig.	<.001

a. Kruskal Wallis Test

b. Grouping Variable: act_group0

Nonparametric Tests

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The distribution of approval_delta_consent is the same across categories of act_group0.	Independent-Samples Kruskal-Wallis Test	<.001	Reject the null hypothesis.

a. The significance level is .050.

b. Asymptotic significance is displayed.

Independent-Samples Kruskal-Wallis Test

approval_delta_consent across act_group0

Independent-Samples Kruskal-Wallis Test Summary

Total N	49
Test Statistic	24.777[a]
Degree Of Freedom	2
Asymptotic Sig.(2-sided test)	<.001

a. The test statistic is adjusted for ties.

Nonparametric Tests

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The distribution of approval_delta_consent is the same across categories of act_group0.	Independent-Samples Kruskal-Wallis Test	<.001	Reject the null hypothesis.

a. The significance level is .050.

b. Asymptotic significance is displayed.

Independent-Samples Kruskal-Wallis Test

approval_delta_consent across act_group0

Independent-Samples Kruskal-Wallis Test Summary

Total N	49
Test Statistic	24.777[a]
Degree Of Freedom	2
Asymptotic Sig.(2-sided test)	<.001

a. The test statistic is adjusted for ties.

Pairwise Comparisons of act_group0

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig.[a]
2-1	17.921	4.784	3.746	<.001	.001
2-0	26.217	5.534	4.737	<.001	.000
1-0	8.295	5.128	1.618	.106	.317

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.
Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Appendix D.1.2 As 2 groups

Statistics

		act_group	approval_delta_consent	approval_delta_install
N	Valid	49	49	49
	Missing	0	0	0

Mean	.31	347455.204	291446.469
Std. Deviation	.466	1263131.5623	1165178.0708
Minimum	0	66.0	.0
Maximum	1	7391564.0	7391450.0

Group Statistics

	act_group	N	Mean	Std. Deviation	Std. Error Mean
approval_delta_consent	0	34	484054.941	1499752.3614	257205.4080
	1	15	37829.133	142961.4173	36912.4792

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p			Lower	Upper
approval_delta_consent	Equal variances assumed	3.895	.054	1.143	47	.129	.259	446225.8078	390279.7500	-338915.7769	1231367.3926
	Equal variances not assumed			1.717	34.339	.047	.095	446225.8078	259840.6301	-81641.9284	974093.5441

Descriptives

	act_group			Statistic	Std. Error
approval_delta_consent	0	Mean		484054.941	257205.4080
		95% Confidence Interval for Mean	Lower Bound	-39233.396	
			Upper Bound	1007343.278	
		5% Trimmed Mean		181482.016	
		Median		66164.000	
		Variance		2249257145589.391	

	Std. Deviation		1499752.3614	
	Minimum		1650.0	
	Maximum		7391564.0	
	Range		7389914.0	
	Interquartile Range		141566.8	
	Skewness		4.014	.403
	Kurtosis		16.100	.788
1	Mean		37829.133	36912.4792
	95% Confidence Interval for Mean	Lower Bound	-41340.261	
		Upper Bound	116998.527	
	5% Trimmed Mean		11220.648	
	Median		138.000	
	Variance		20437966828.267	
	Std. Deviation		142961.4173	
	Minimum		66.0	
	Maximum		554545.0	
	Range		554479.0	
	Interquartile Range		1113.0	
	Skewness		3.871	.580
	Kurtosis		14.992	1.121

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	act_group	Statistic	df	Sig.	Statistic	df	Sig.
approval_delta_consent	0	.447	34	<.001	.346	34	<.001
	1	.514	15	<.001	.292	15	<.001

a. Lilliefors Significance Correction

Test Statistics[a]

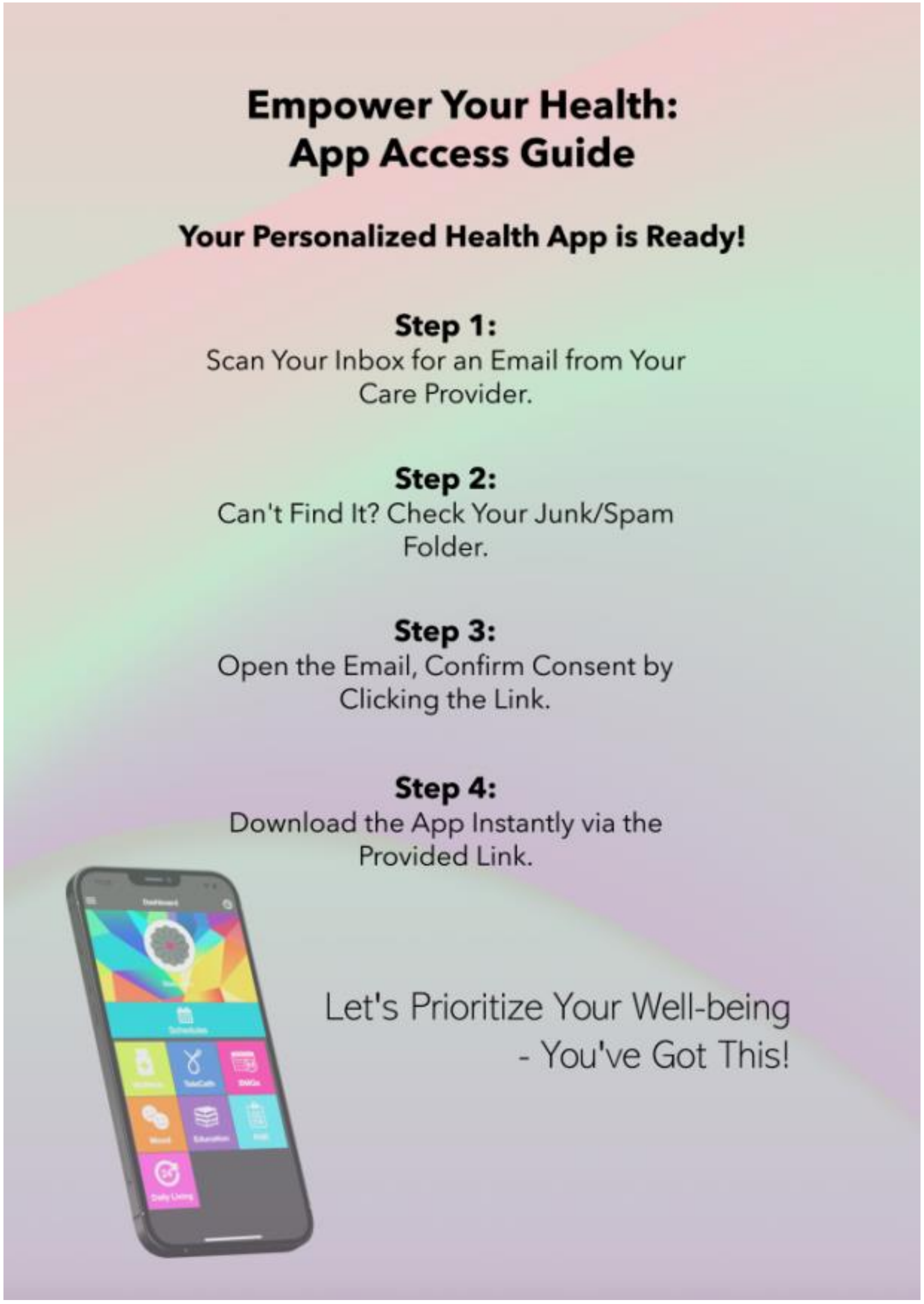
	approval_delta_consent
Mann-Whitney U	38.000
Wilcoxon W	158.000
Z	-4.707

Asymp. Sig. (2-tailed)	<.001

a. Grouping Variable: act_group

Appendix E Flyers

Appendix E.1 Activation flyer


Empower Your Health:
App Access Guide
Your Personalized Health App is Ready!
Step 1:
Scan Your Inbox for an Email from Your Care Provider.
Step 2:
Can't Find It? Check Your Junk/Spam Folder.
Step 3:
Open the Email, Confirm Consent by Clicking the Link.
Step 4:
Download the App Instantly via the Provided Link.
Let's Prioritize Your Well-being
- You've Got This!

Activation Guide

1. **Enter Activation Code or Initials**
In the "Description" box, carefully enter your unique Activation Code or your Initials, which serves as your identification for the registration process.

2. **Complete Registration**
Click on the "REGISTER" button to initiate the registration process. Ensure that all the required information is accurately provided to avoid any delays in approval.

3. **Await Admin Approval**
After submitting your registration, your application will be reviewed by the Admin for verification. This step ensures the authenticity and security of all registered users.

4. **Check Application Status**
The approval process may take some time. You can periodically check the status of your application by opening / restarting the app.

5. **Approval Confirmation**
Once your application is approved, you will receive a notification from the app. This confirmation indicates that you can proceed to the next step.

6. **Restart Your App**
Restart your application to ensure that all the changes associated with the approval are properly applied. This step guarantees that you have access to all features and functionalities.

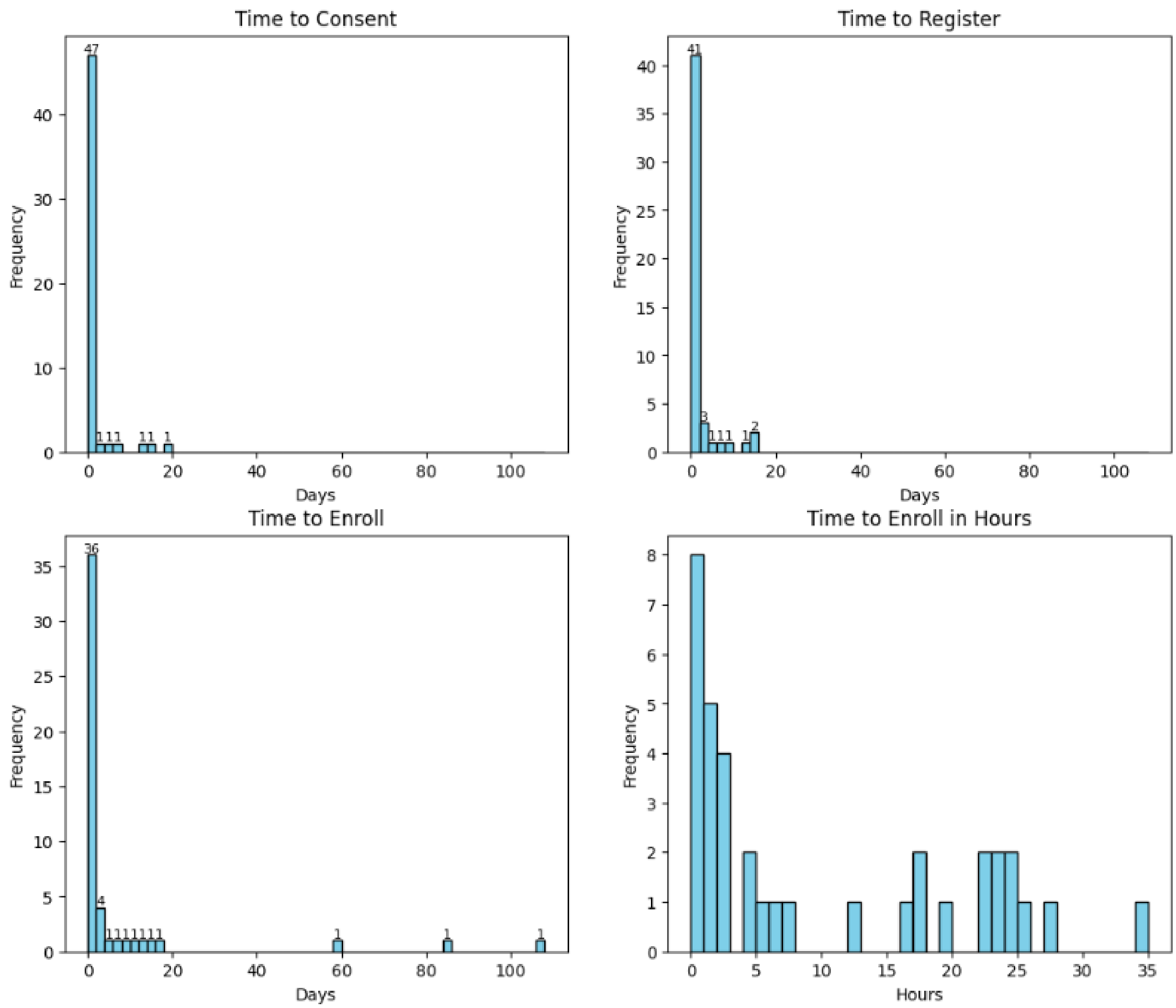
Congratulations!

You are now ready to use the iMHere app

http://bit.ly/iMHereApp

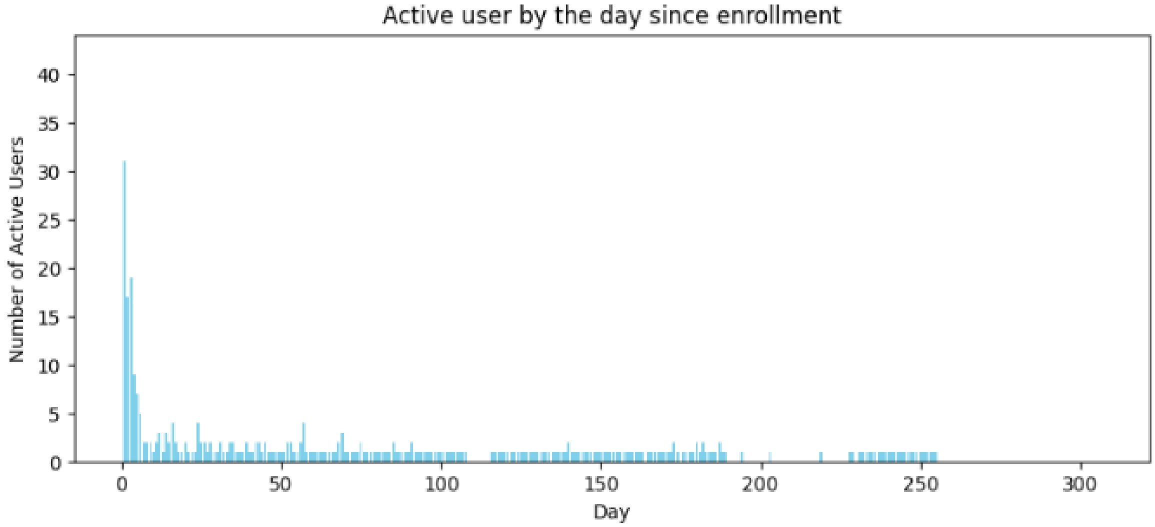
Appendix F Pilot Implementation Charts

Appendix F.1 User Distribution on Enrollment Stage

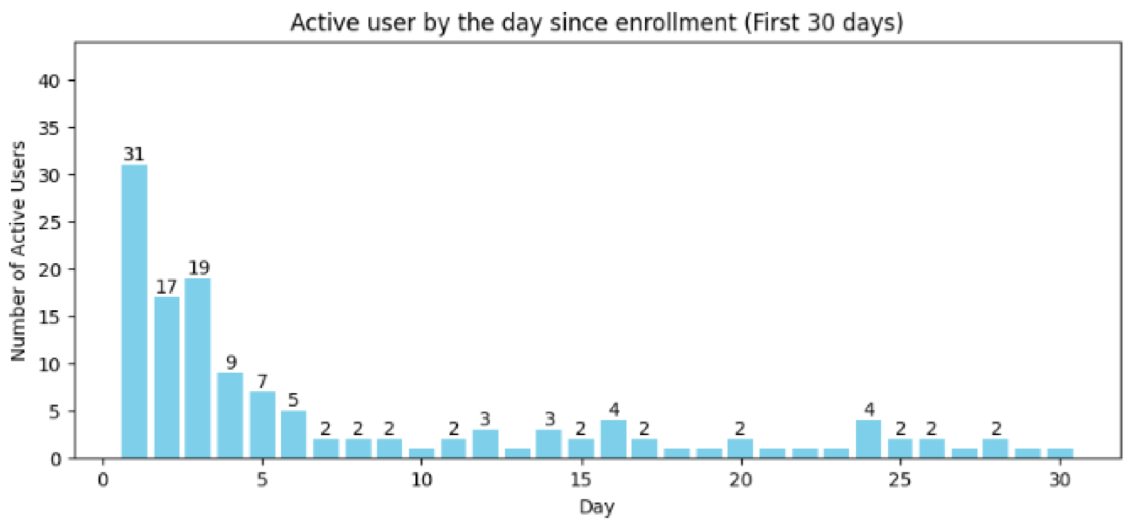


Appendix F.2 Active Users by Days of Enrollment

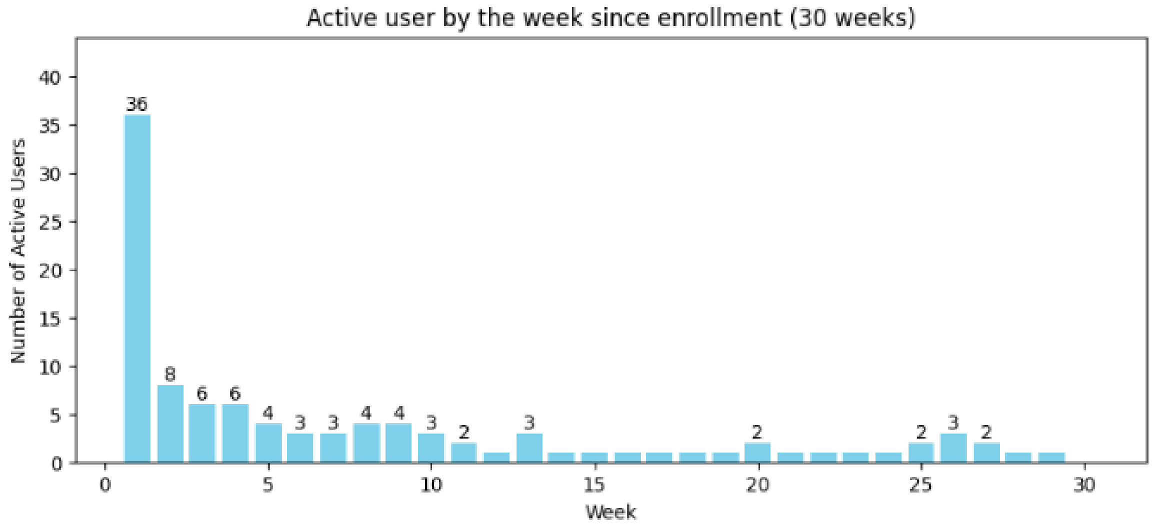
Appendix F.2.1 Inclusive data from all users



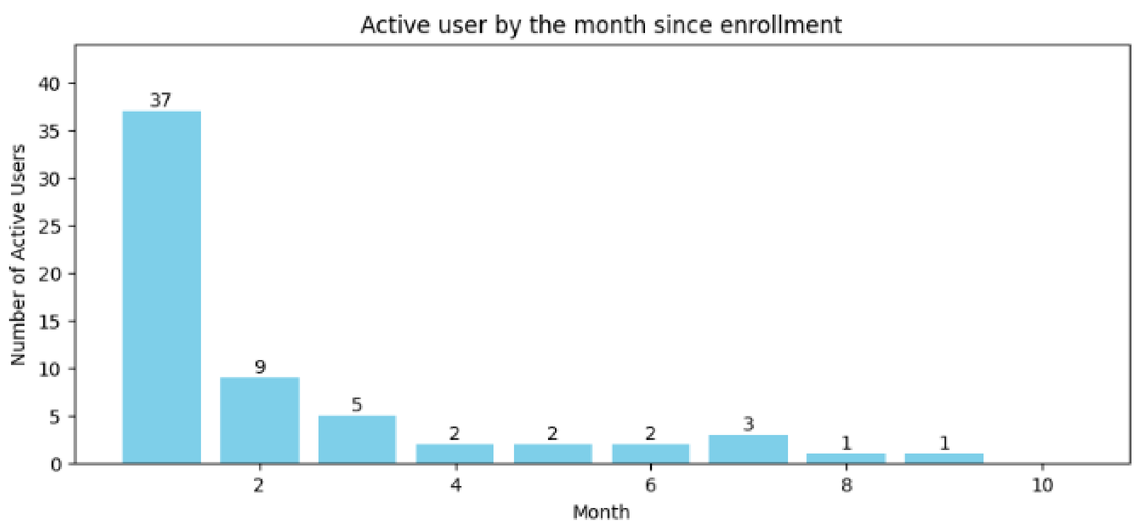
	nday	total_user	total_session	total_interaction	total_duration	avg_session	avg_duration	avg_dur_session
0	1	31	84	1103	31732.0	2.709677	1023.612903	377.761905
1	2	17	66	955	21381.0	3.882353	1257.705882	323.954545
2	3	19	40	430	8550.0	2.105263	450.000000	213.750000
3	4	9	30	166	3438.0	3.333333	382.000000	114.600000
4	5	7	17	73	552.0	2.428571	78.857143	32.470588



	nday	total_user	total_session	total_interaction	total_duration	avg_session	avg_duration	avg_dur_session
0	1	31	84	1103	31732.0	2.709677	1023.612903	377.761905
1	2	17	66	955	21381.0	3.882353	1257.705882	323.954545
2	3	19	40	430	8550.0	2.105263	450.000000	213.750000
3	4	9	30	166	3438.0	3.333333	382.000000	114.600000
4	5	7	17	73	552.0	2.428571	78.857143	32.470588



	nweek	total_user	total_session	total_interaction	total_duration	avg_session	avg_duration	avg_dur_session
0	1	36	245	2814	66671.0	6.805556	1851.972222	272.126531
1	2	8	33	191	4252.0	4.125000	531.500000	128.848485
2	3	6	24	98	714.0	4.000000	119.000000	29.750000
3	4	6	25	105	775.0	4.166667	129.166667	31.000000
4	5	4	20	80	500.0	5.000000	125.000000	25.000000



	nmonth	total_user	total_session	total_interaction	total_duration	avg_session	avg_duration	avg_dur_session
0	1	37	332	3229	72547.0	8.972973	1960.729730	218.515060
1	2	9	82	571	8185.0	9.111111	909.444444	99.817073
2	3	5	73	329	2652.0	14.600000	530.400000	36.328767
3	4	2	68	527	7519.0	34.000000	3759.500000	110.573529
4	5	2	133	1208	13534.0	66.500000	6767.000000	101.759398

Daily Statistics Days of Enrollment

Session/user/day

	nday	user	tot_session	avg_session_user	median_session_user	std_session_user
0	1	31	84	2.709677	2.0	3.436990
1	2	17	66	3.882353	3.0	3.179669
2	3	19	40	2.105263	1.0	2.282658
3	4	9	30	3.333333	2.0	3.278719
4	5	7	17	2.428571	1.0	2.935821
5	6	5	7	1.400000	1.0	0.547723
6	7	2	2	1.000000	1.0	0.000000

Time spent/user/day

	nday	user	tot_time	avg_time_user	median_time_user	std_time_user	tot_time_td	avg_time_user_td
0	1	31	31732.0	1023.612903	409.0	1881.874503	0 days 08:48:52	0 days 00:17:03.612903
1	2	17	21381.0	1257.705882	340.0	2363.796807	0 days 05:56:21	0 days 00:20:57.705882
2	3	19	8550.0	450.000000	147.0	663.477371	0 days 02:22:30	0 days 00:07:30
3	4	9	3438.0	382.000000	60.0	692.492419	0 days 00:57:18	0 days 00:06:22
4	5	7	552.0	78.857143	44.0	104.652486	0 days 00:09:12	0 days 00:01:18.857143
5	6	5	990.0	198.000000	68.0	310.500403	0 days 00:16:30	0 days 00:03:18
6	7	2	28.0	14.000000	14.0	0.000000	0 days 00:00:28	0 days 00:00:14

Time spent/session/user/day

	nday	user	tot_time	avg_time_ses_user	median_time_ses_user	std_time_ses_user	avg_time_ses_user_td
0	1	31	31732.0	377.761905	101.0	908.824259	0 days 00:06:17.761905
1	2	17	21381.0	323.954545	26.5	965.582414	0 days 00:05:23.954545
2	3	19	8550.0	213.750000	35.0	456.269531	0 days 00:03:33.750000
3	4	9	3438.0	114.600000	28.5	228.195107	0 days 00:01:54.600000
4	5	7	552.0	32.470588	27.0	34.666478	0 days 00:00:32.470588
5	6	5	990.0	141.428571	67.0	239.089842	0 days 00:02:21.428571
6	7	2	28.0	14.000000	14.0	0.000000	0 days 00:00:14

Weekly Statistics Days of Enrollment

Session/user/week

	nweek	user	tot_session	avg_session_user	median_session_user	std_session_user
0	1	36	245	6.805556	4.0	10.533808
1	2	8	33	4.125000	2.0	4.853202
2	3	6	24	4.000000	1.0	6.000000
3	4	6	25	4.166667	2.0	5.879342
4	5	4	20	5.000000	1.5	7.348469
5	6	3	15	5.000000	1.0	6.928203
6	7	3	15	5.000000	1.0	6.928203

Time spent/user/week

	nweek	user	tot_time	avg_time_user	median_time_user	std_time_user	tot_time_td	avg_time_user_td
0	1	36	66671.0	1851.972222	538.0	3241.756882	0 days 18:31:11	0 days 00:30:51.972222
1	2	8	4252.0	531.500000	294.5	610.909626	0 days 01:10:52	0 days 00:08:51.500000
2	3	6	714.0	119.000000	62.5	132.130239	0 days 00:11:54	0 days 00:01:59
3	4	6	775.0	129.166667	60.5	149.419432	0 days 00:12:55	0 days 00:02:09.166667
4	5	4	500.0	125.000000	48.0	181.714061	0 days 00:08:20	0 days 00:02:05
5	6	3	472.0	157.333333	50.0	217.828679	0 days 00:07:52	0 days 00:02:37.333333
6	7	3	2424.0	808.000000	347.0	1093.021958	0 days 00:40:24	0 days 00:13:28

Time spent/session/user/week

	nweek	user	tot_time	avg_time_ses_user	median_time_ses_user	std_time_ses_user	avg_time_ses_user_td
0	1	36	66671.0	272.126531	35.0	764.424344	0 days 00:04:32.126531
1	2	8	4252.0	128.848485	13.0	304.220841	0 days 00:02:08.848485
2	3	6	714.0	29.750000	21.5	40.011140	0 days 00:00:29.750000
3	4	6	775.0	31.000000	22.0	30.291638	0 days 00:00:31
4	5	4	500.0	25.000000	22.0	12.719649	0 days 00:00:25
5	6	3	472.0	31.466667	30.0	14.793177	0 days 00:00:31.466667
6	7	3	2424.0	161.600000	26.0	524.181784	0 days 00:02:41.600000

Monthly Statistics Days of Enrollment

Session/user/week

	nmonth	user	tot_session	avg_session_user	median_session_user	std_session_user
0	1	37	332	8.972973	4.0	14.382641
1	2	9	82	9.111111	2.0	21.733870
2	3	5	73	14.600000	2.0	27.134848
3	4	2	68	34.000000	34.0	46.669048
4	5	2	133	66.500000	66.5	91.216775
5	6	2	126	63.000000	63.0	86.267027
6	7	3	30	10.000000	2.0	14.730920

Time spent/user/week

	nmonth	user	tot_time	avg_time_user	median_time_user	std_time_user	tot_time_td	avg_time_user_td
0	1	37	72547.0	1960.729730	554.0	3336.852265	0 days 20:09:07	0 days 00:32:40.729730
1	2	9	8185.0	909.444444	134.0	1245.609300	0 days 02:16:25	0 days 00:15:09.444444
2	3	5	2652.0	530.400000	238.0	694.684677	0 days 00:44:12	0 days 00:08:50.400000
3	4	2	7519.0	3759.500000	3759.5	5110.260708	0 days 02:05:19	0 days 01:02:39.500000
4	5	2	13534.0	6767.000000	6767.0	8291.534116	0 days 03:45:34	0 days 01:52:47
5	6	2	13054.0	6527.000000	6527.0	5690.795375	0 days 03:37:34	0 days 01:48:47
6	7	3	2961.0	987.000000	910.0	643.961955	0 days 00:49:21	0 days 00:16:27

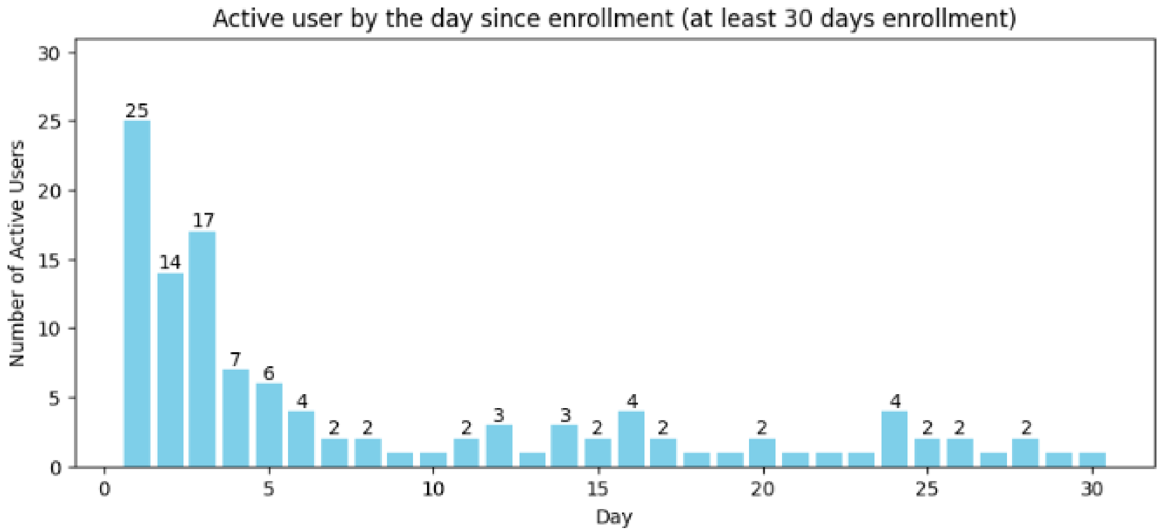
Interaction/user/week

	nmonth	user	tot_int	avg_int_user	median_int_user	std_int_user
0	1	37	3229	87.270270	38.0	123.972364
1	2	9	571	63.444444	8.0	89.994599
2	3	5	329	65.800000	25.0	113.902151
3	4	2	527	263.500000	263.5	352.846284
4	5	2	1208	604.000000	604.0	783.474314
5	6	2	1180	590.000000	590.0	630.739249
6	7	3	215	71.666667	53.0	51.597804
7	8	1	443	443.000000	443.0	NaN
8	9	1	541	541.000000	541.0	NaN

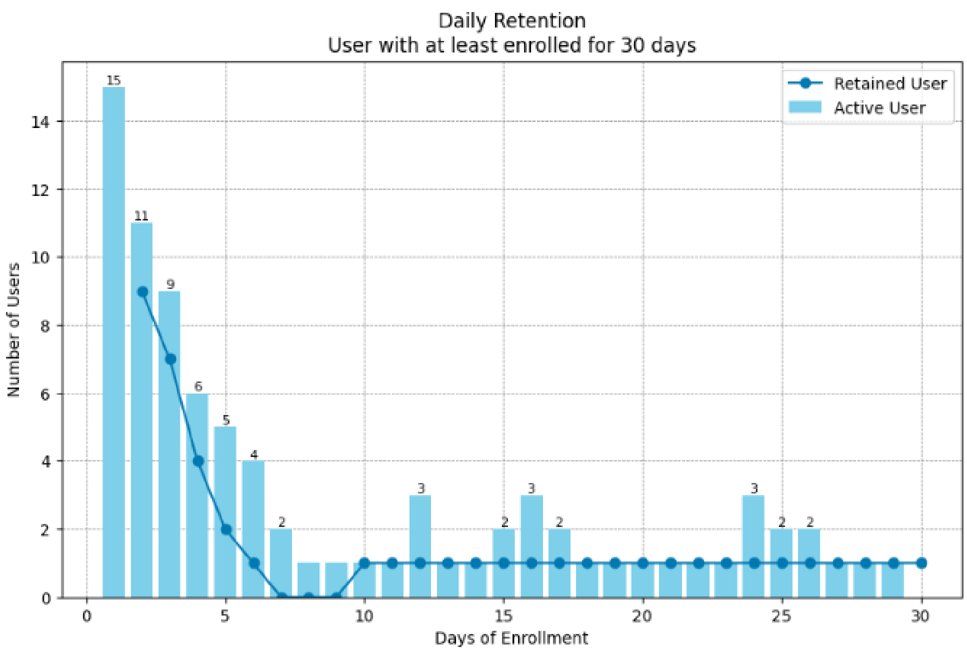
Time spent/session/user/week

	nmonth	user	tot_time	avg_time_ses_user	median_time_ses_user	std_time_ses_user	avg_time_ses_user_td
0	1	37	72547.0	218.515060	28.5	669.779841	0 days 00:03:38.515060
1	2	9	8185.0	99.817073	24.0	443.826212	0 days 00:01:39.817073
2	3	5	2652.0	36.328767	28.0	75.843599	0 days 00:00:36.328767
3	4	2	7519.0	110.573529	31.0	473.595435	0 days 00:01:50.573529
4	5	2	13534.0	101.759398	26.0	282.340144	0 days 00:01:41.759398
5	6	2	13054.0	103.603175	15.0	426.784106	0 days 00:01:43.603175
6	7	3	2961.0	98.700000	10.0	272.159835	0 days 00:01:38.700000

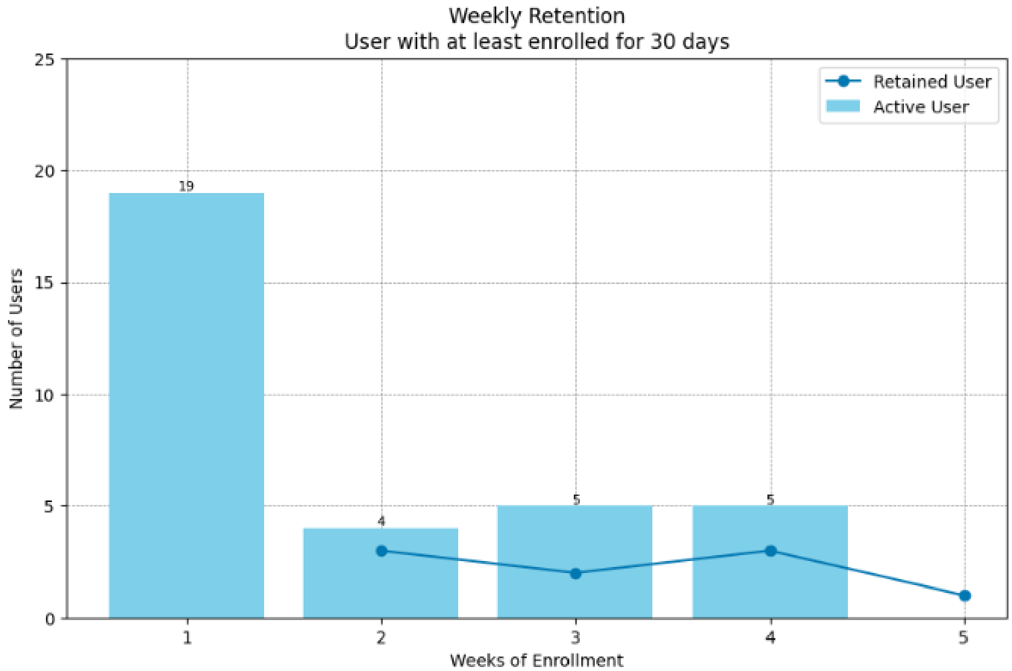
Appendix F.2.2 Exclusive data based on the length of days since enrollment.



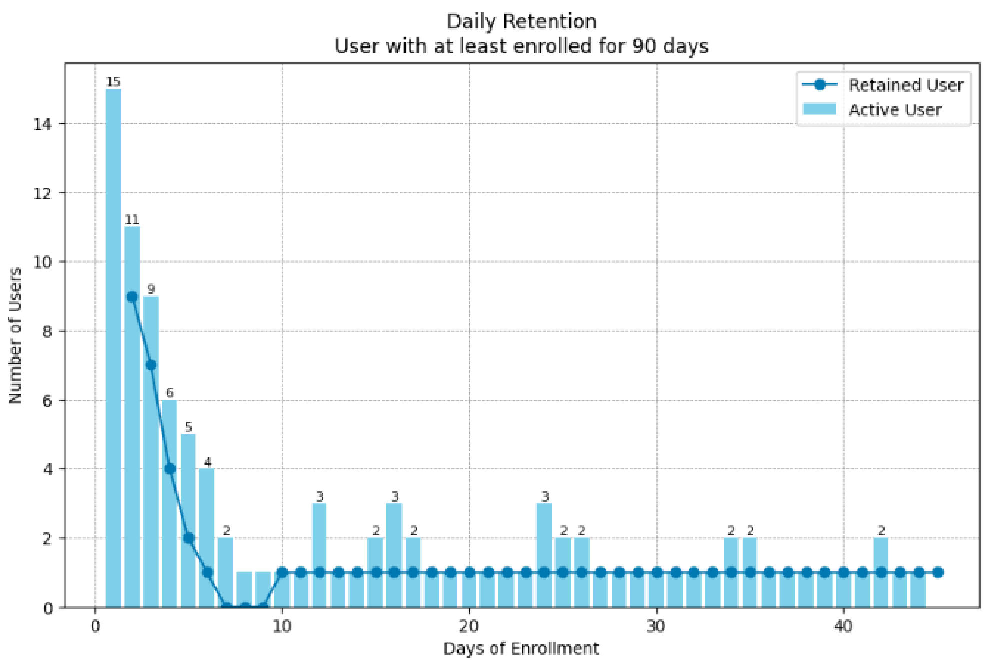
	nday	total_user	total_session	total_interaction	total_duration	avg_session	avg_duration	avg_dur_session
0	1	25	54	678	19144.0	2.160000	765.760000	354.518519
1	2	14	50	884	20765.0	3.571429	1483.214286	415.300000
2	3	17	27	392	8348.0	1.588235	491.058824	309.185185
3	4	7	18	103	1271.0	2.571429	181.571429	70.611111
4	5	6	8	31	247.0	1.333333	41.166667	30.875000



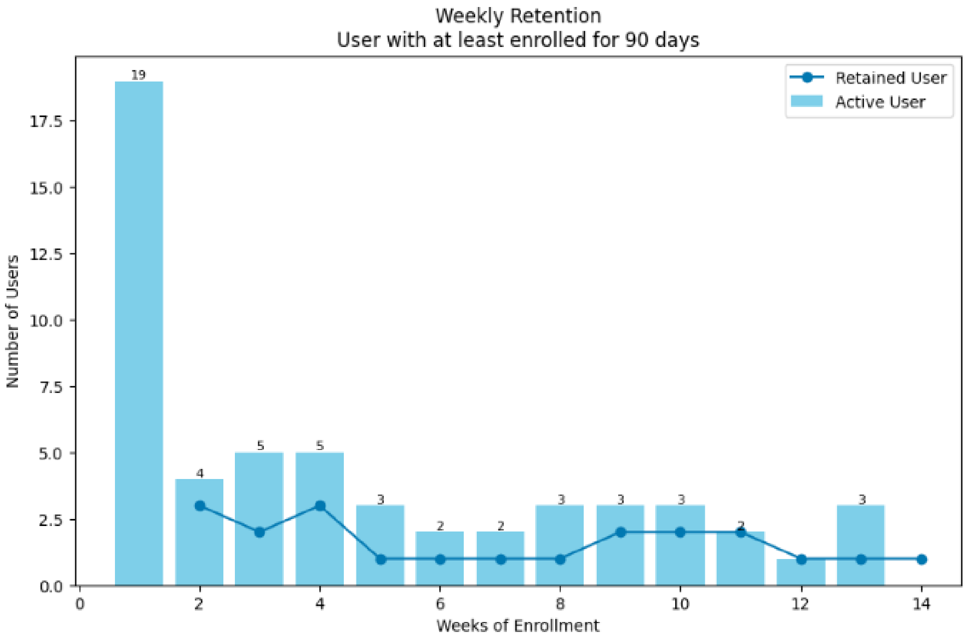
	curr_day	prev_day	retained_users	prev_active_users	active_users	retention_rate	delta_active
0	2	1	9	15	11	60.00	-26.67
1	3	2	7	11	9	63.64	-18.18
2	4	3	4	9	6	44.44	-33.33
3	5	4	2	6	5	33.33	-16.67
4	6	5	1	5	4	20.00	-20.00



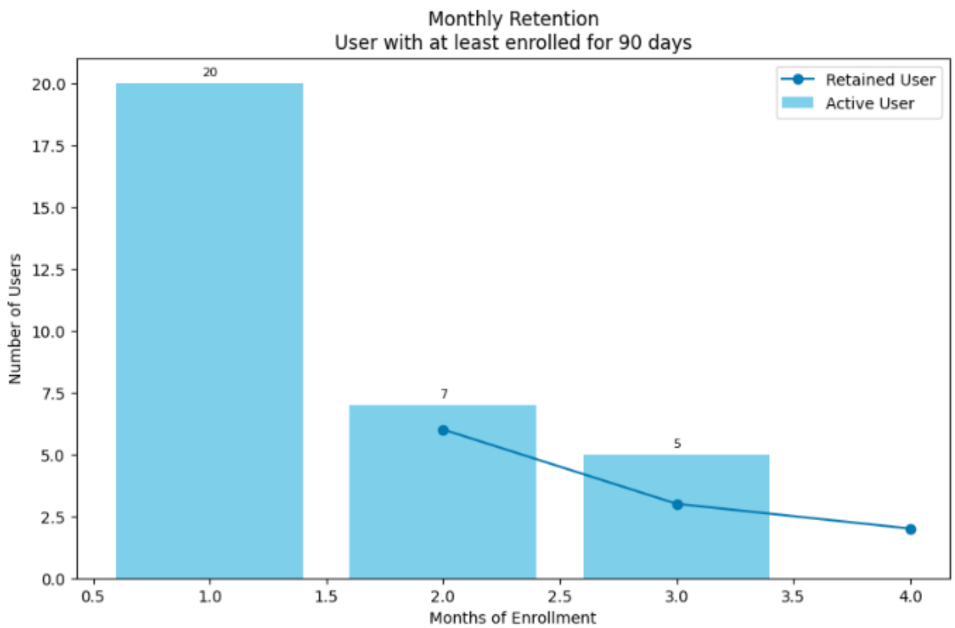
	curr_week	prev_week	retained_users	prev_active_users	active_users	retention_rate	delta_active
0	2	1	3	19	4	15.79	-78.95
1	3	2	2	4	5	50.00	25.00
2	4	3	3	5	5	60.00	0.00
3	5	4	1	5	3	20.00	-40.00
4	6	5	1	3	2	33.33	-33.33



	curr_day	prev_day	retained_users	prev_active_users	active_users	retention_rate	delta_active
0	2	1	9	15	11	60.00	-26.67
1	3	2	7	11	9	63.64	-18.18
2	4	3	4	9	6	44.44	-33.33
3	5	4	2	6	5	33.33	-16.67
4	6	5	1	5	4	20.00	-20.00



	curr_week	prev_week	retained_users	prev_active_users	active_users	retention_rate	delta_active
0	2	1	3	19	4	15.79	-78.95
1	3	2	2	4	5	50.00	25.00
2	4	3	3	5	5	60.00	0.00
3	5	4	1	5	3	20.00	-40.00
4	6	5	1	3	2	33.33	-33.33

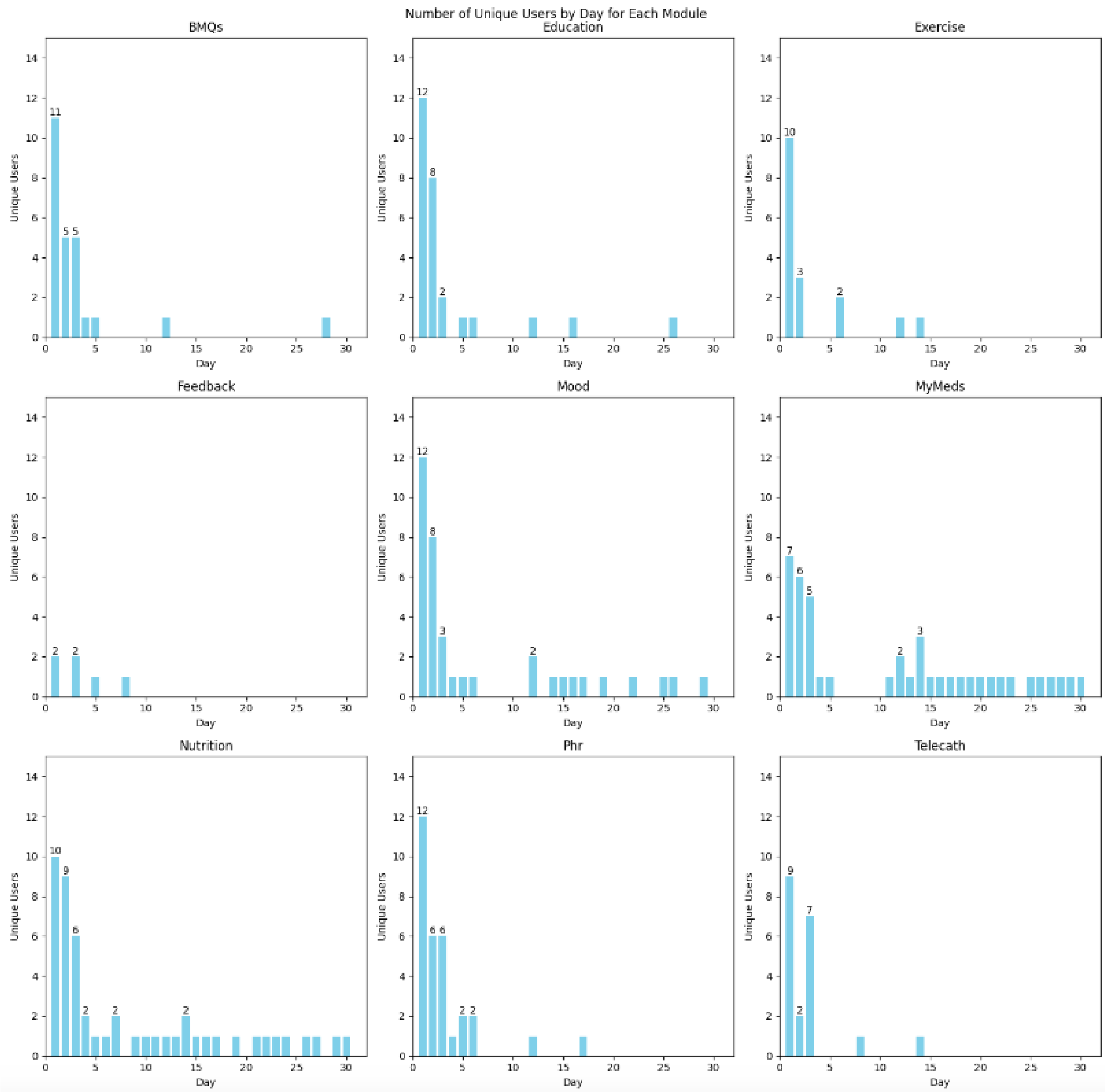


	curr_month	prev_month	retained_users	prev_active_users	active_users	retention_rate	delta_active
0	2	1	6	20	7	30.00	-65.00
1	3	2	3	7	5	42.86	-28.57
2	4	3	2	5	2	40.00	-60.00

Appendix F.3 Active Users Distribution over Modules

Appendix F.3.1 Daily data for the first 30 days

Taking into account the first 30 days of using the app after enrollment, there are 43 patients that has days of enrollment more than 30 days (87.76%).



Intensity, Type, Time per Modules Per User Per Day
30 Days evaluation, cover 43 (87.76%) enrolled user
Active user: 30 user

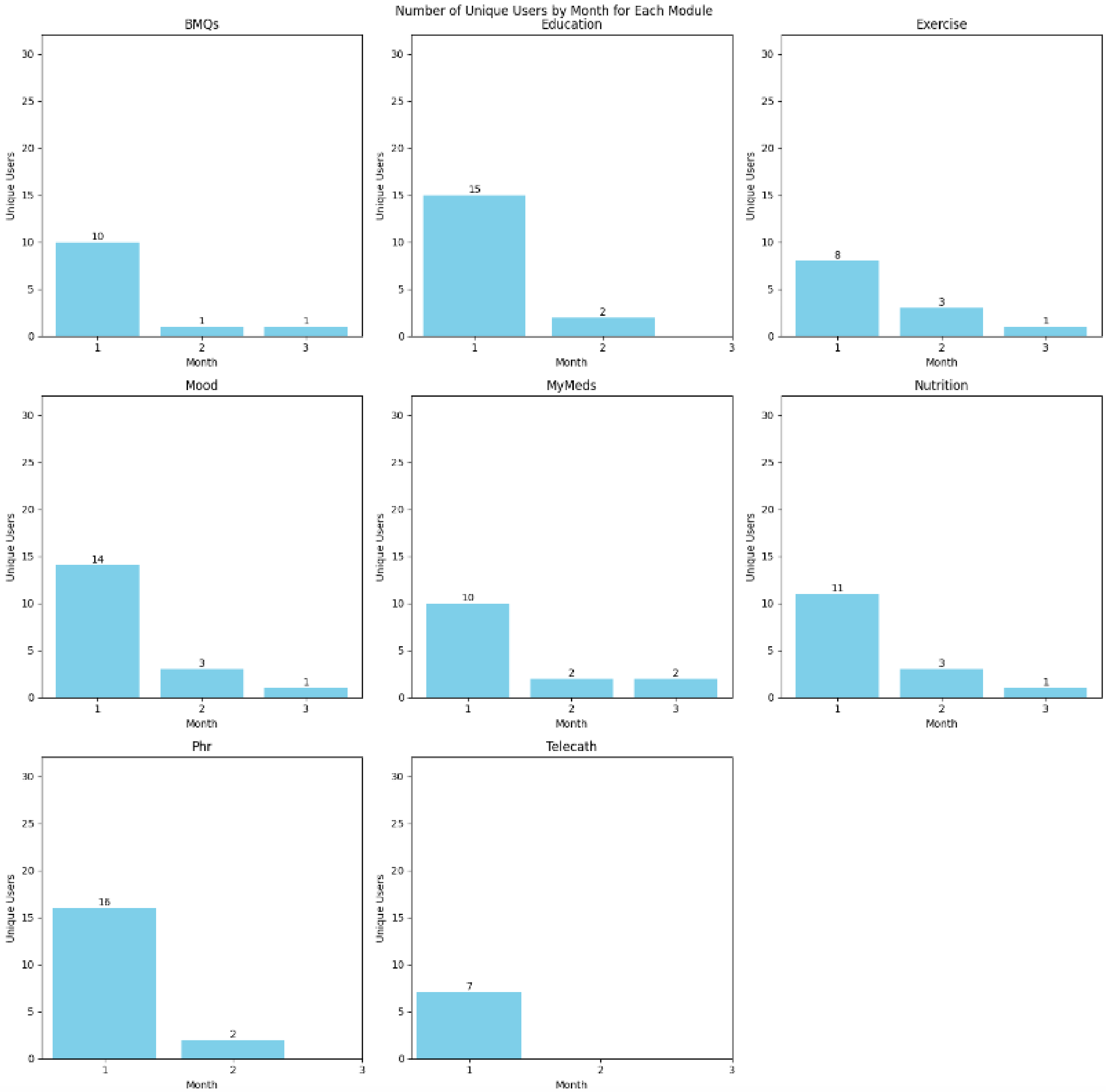
	moduleName	totusers	ndays	avg_time_spent	nusers	tot_active_event	avg_active_event	tot_passive_event	avg_passive_event
0	BMQs	46	7	27.320000	17	0.0	0.000000	37.0	1.480000
1	Education	48	8	185.925926	21	0.0	0.000000	251.0	9.296296
2	Exercise	49	5	59.823529	15	2.0	0.117647	26.0	1.529412
3	Mood	43	16	39.162162	22	17.0	0.459459	36.0	0.972973
4	MyMeds	48	24	182.214286	16	193.0	4.595238	59.0	1.404762
5	Nutrition	49	25	38.000000	19	30.0	0.600000	45.0	0.900000
6	Phr	49	8	124.064516	22	13.0	0.419355	179.0	5.774194
7	Telecath	47	5	48.600000	16	12.0	0.600000	24.0	1.200000

Appendix F.3.2 Monthly for the first 3 months

Taking into account the first 90 days of using the app after enrollment, there are 32 patients that has days of enrollment more than 90 days (65.31%).

Intensity, Type, Time per Modules Per User Per Day
90 Days evaluation, cover 32 (65.31%) enrolled user
Active user: 19 user

	moduleName	totusers	nmonths	avg_time_spent	nusers	tot_active_event	avg_active_event	tot_passive_event	avg_passive_event
0	BMQs	46	3	44.500000	11	0.0	0.000000	27.0	2.250000
1	Education	48	2	342.117647	15	0.0	0.000000	312.0	18.352941
2	Exercise	49	3	97.000000	10	10.0	0.833333	21.0	1.750000
3	Mood	43	3	63.055556	14	23.0	1.277778	32.0	1.777778
4	MyMeds	48	3	692.714286	11	676.0	48.285714	50.0	3.571429
5	Nutrition	49	3	144.733333	13	67.0	4.466667	32.0	2.133333
6	Phr	49	2	220.888889	16	14.0	0.777778	181.0	10.055556
7	Telecath	47	1	94.000000	7	12.0	1.714286	12.0	1.714286


Number of Unique Users by Month for Each Module
BMQs
Education
Exercise
Mood
MyMeds
Nutrition
Phr
Telecath
Unique Users
Month

Appendix G Questionnaires

Appendix G.1 TUQ

Subject ID ________________________ Date ___ / ___ / 20___
Session ID ________________________ Usability & Accessibility Study

Section 10: Telehealth Usability Questionnaire

TELEHEALTH USABILITY QUESTIONNAIRE (TUQ)

Subject ID: ________ Session ID: ___________Date: __________

*Telehealth in this usability study refers to mHealth (mobile health) system.

		N/A		1	2	3	4	5	6	7	
1.	Telehealth improves my access to healthcare services.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
2.	Telehealth saves me time traveling to a hospital or specialist clinic.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
3.	Telehealth provides for my healthcare need.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
4.	It was simple to use this system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
5.	It was easy to learn to use the system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
6.	I believe I could become productive quickly using this system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
7.	The way I interact with this system is pleasant.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
8.	I like using the system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
9.	The system is simple and easy to understand.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
10.	This system is able to do everything I would want it to be able to do.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
11.	I can easily update my health status with the clinician using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
12.	I can-easily manage my condition(s) using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
13.	I felt I was able to express myself effectively.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
14.	Using reminders from telehealth system, it is easy to manage my self-	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE

	care activities.		
15.	Whenever I made a mistake using the system, I could recover easily and quickly.	☐	DISAGREE ☐ ☐ ☐ ☐ ☐ ☐ ☐ AGREE
16.	The system gave error messages that clearly told me how to fix problems.	☐	DISAGREE ☐ ☐ ☐ ☐ ☐ ☐ ☐ AGREE
17.	I feel comfortable communicating with the clinician using the telehealth system.	☐	DISAGREE ☐ ☐ ☐ ☐ ☐ ☐ ☐ AGREE
18.	Telehealth is an acceptable way to receive healthcare services.	☐	DISAGREE ☐ ☐ ☐ ☐ ☐ ☐ ☐ AGREE
19.	I would use telehealth services again.	☐	DISAGREE ☐ ☐ ☐ ☐ ☐ ☐ ☐ AGREE
20.	Overall, I am satisfied with this telehealth system.	☐	DISAGREE ☐ ☐ ☐ ☐ ☐ ☐ ☐ AGREE

Please provide comments about the telehealth system and any suggestions you may have:

Appendix G.2 SUS

Subject ID ________________________ Date ___ / ___ / 20___
Session ID ________________________ Usability & Accessibility Study

Section 11: System Usability Scale

SYSTEM USABILITY SCALE (SUS)

Subject ID: ________ Session ID: __________Date: __________

		N/A		1	2	3	4	5	
1.	I think that I would like to use the app frequently.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
2.	I found the app to be simple.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
3.	I thought the app was easy to use.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
4.	I think that I could use the app without the support of a technical person.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
5.	I found the various functions in the app were well integrated.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
6.	I thought there was a lot of consistency in the app.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
7.	I would imagine that most people would learn to use the app very quickly.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
8.	I found the app very intuitive.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
9.	I felt very confident using the app.	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE
10.	I could use the app without having to learn anything new	☐	STRONGLY DISAGREE	☐	☐	☐	☐	☐	STRONGLY AGREE

Appendix G.3 App Experience Survey

This survey utilizes a modified version of the MAUQ-Patient Version. Irrelevant questions have been eliminated, and linguistic modifications have been implemented to ensure relevance. The survey's structure has been adapted from the initial version provided within the application to accommodate the available space in this document.

iMHere 2.0 App

Start of Block: Product Satisfaction

JS

Introduction **Welcome to the iMHere 2.0 App User Experience Survey!**

Dear Participant,

We appreciate your participation in this survey, designed to gather valuable insights into your experiences with the iMHere 2.0 App. Your feedback is crucial in helping us understand how the app has impacted your daily life and healthcare interactions.

Instructions:
Please take a moment to reflect on your experiences with the iMHere 2.0 App.
Answer each question honestly and to the best of your ability.
Your responses will be kept confidential.

About the iMHere 2.0 System:
The iMHere (Interactive Mobile Health and Rehabilitation) 2.0 system is an innovative self-care reminder and mobile health delivery system developed by Hari Lab at The University of Pittsburgh. iMHere 2.0 System is designed to support self-management for individual with chronic and complex conditions, such as medication management, bowel and bladder management, mood tracking, exercise and nutrition monitoring, as well as personalized educational content. The iMHere 2.0 System is now being piloted at one of our collaborator clinics. Your insights will play a key role in improving its functionality and user-friendliness.

Duration:
The survey should take approximately 2-3 minutes to complete.

Thank you for your time and valuable input.

Let's get started!

Best regards,
University of Pittsburgh
I Made Agus Setiawan

Possible response values:

- 1 = Strongly disagree
- 2 = Disagree
- 3 = Somewhat disagree
- 4 = Neither agree nor disagree
- 5 = Somewhat agree
- 6 = Agree
- 7 = Strongly agree
- 9 = Not applicable

Questions:

1. iMHere 2.0 App is easy to use?
2. It is easy for me to learn to use **iMHere 2.0 App**?
3. Whenever I made a mistake using **iMHere 2.0 App**, I could recover easily and quickly.
4. I feel comfortable using **iMHere 2.0 App** in social settings.
5. The amount of time involved in using **iMHere 2.0 App** has been fitting for me.
6. I would continue to use **iMHere 2.0 App**.
7. Overall, I am satisfied with **iMHere 2.0 App**.
8. **iMHere 2.0 App** would be useful for my health and well-being.
9. **iMHere 2.0 App** improved my access to healthcare services.
10. **iMHere 2.0 App** helped me manage my health effectively.
11. **iMHere 2.0 App** has all the functions and capabilities I expected it to have.
12. The **iMHere 2.0** App provides an acceptable way to receive healthcare services, such as accessing educational materials, tracking my own activities, and performing self-assessment.
13. What would you change or improve about **iMHere 2.0 App**?

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