PERSONALIZING HOSPITAL-BASED STROKE EDUCATION: DESIGNING A NOVEL RECOVERY APP TO PREPARE STROKE PATIENTS FOR THE TRANSITION HOME

by
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A thesis submitted to Johns Hopkins University
in conformity with the requirements
for the degree of Master of Arts

Baltimore, Maryland
March, 2020

ABSTRACT

Stroke is a leading cause of adult disability in the United States. It is a complex disease for which timely intervention and treatment has the highest yield. Individualized patient education is crucial for optimizing recovery, preventing recurrence, and improving patient outcomes. Current hospital-based education is largely paper-based and suboptimal for meeting the varied, yet precise educational needs of the stroke patients and their care partners (carers). To augment the current education program, the multidisciplinary stroke team at the Johns Hopkins Comprehensive Stroke Center is building a mobile app that will provide individualized, interactive, and accessible education to prepare hospitalized stroke patients and their carers for the transition from hospital to home. This thesis project lays groundwork for the development of the app by designing its overall structure and navigation, and by prototyping specific paths demonstrating key features and functions of the app.

User-centered methodology was implemented to focus each stage of app design on the fulfillment of unmet learning needs of stroke patients and carers in acute hospital care and after hospital discharge. Key identified needs were synthesized into four enabling objectives and the underlying information architecture that informed the scope and structure of the app. Digital prototypes of seven key tasks that translated the abstract groundwork into concrete visuals were developed in an iterative and collaborative process with stakeholders.

The core features designed were (i) personalization of daily educational content, (ii) actionable recovery goal-setting, (iii) progress tracking, and (iv) improved two-way communication between patient and care team. Corresponding information architecture, interactive digital prototypes, and a model for progressive personalization were constructed. Together, these contributions provide the foundation for development of the first iteration of the app, and serve as valuable communication tools for continued collaboration and planning

between stakeholders. The user-centered methodology imparted structure and strategy to the design process, while iteration enabled adaptability to new insights. Frequent usability testing, inquiry, and collaboration with stakeholders were essential to design refinement. The continued use of these methods during app development will maximize usability and efficacy of this novel personalized educational resource for early stroke recovery.

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ACKNOWLEDGEMENTS

This project has been a remarkable journey of learning and insight. It would not have been possible without the support and expertise of many individuals, to whom I am extend my deepest gratitude:

Cory Sandone, my advisor and Professor in the Department of Art as Applied to Medicine. Thank you for providing your unwavering support and thoughtful guidance through every stage of this project. I look up to you as a role model for exceptional leadership and collaboration.

Mona Bahouth, my preceptor and Assistant Professor of Neurology. Thank you for sharing your work, your ideas, your time, and your extensive knowledge with me. It was a privilege to collaborate with you and to observe firsthand the dedicated hard work of the multidisciplinary team to serve stroke patients and their families.

Rachel Fabian-Mace, my content advisor and Research Speech Language Pathologist. Thank you for sharing your time, your positivity, and your expertise about swallowing therapy with me. Your generous provision of key insights was invaluable for designing realistic modules.

The multidisciplinary stroke care team at the Johns Hopkins Hospital. Thank you to the various doctors, nurses, and therapists who took time to share their work with me and answer my questions. You helped me to begin to understand the complexity of post-stroke care.

Marlene Riley, Clinical Associate Professor in the Department of Occupational Therapy and Occupational Science at Towson University. Thank you for actively reaching out to me to share your expertise, provide me with shadowing opportunities, and connect me with other experts in your field. You provided me with greater perspective about the continued recovery journey that lies ahead for discharged stroke patients.

The Faculty and Staff of the Department of Art as Applied to Medicine: **David Rini, Tim Phelps, Jennifer Fairman, Lydia Gregg, Juan Garcia, Jeff Day, Gary Lees, Ian Suk, Donald Bliss, Anne Altemus, Norman Barker, Fabian De Kok-Mercado, Graham Johnson, Sandra Gabelli, Sarah Poynton, Mike Linkinhoker, Veronica Falconieri, Carol Pfeffer,** and **Dacia Balch.** Thank you for being incredibly supportive and for sharing your rich skillsets that have helped me develop into a well-rounded visual communicator.

My talented classmates in the Class of 2020: **Noelle Burgess, William Guzman, Jamie Peterson, Kellyn Sanders, Morgan Summerlin,** and **Jenny Wang.** Thank you for your inspiration, collaboration, and countless hours of laughter.

My family and friends: **Lisa Zang, Yuan Tang, Patricia Cowan,** and **Cam Cowan**. Thank you for always being there for me whenever I needed it. Your constant love, support, and practical guidance have fueled me through all the ups and downs to reach the finish line.

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INTRODUCTION

Background

Stroke, a cerebrovascular disease characterized by sudden disruption in blood flow to the brain, is currently the fifth leading cause of death and the most common cause of long-term disability in the United States (CDC 2020). Each year, approximately 795,000 Americans have a stroke, with about 140,000 dying from stroke-related causes (Benjamin et al. 2019, 282-85). Those who survive must adapt to a new neurological baseline and often experience disabilities that may span physical, cognitive, emotional, and social dimensions. Proper treatment and management of this chronic and multifaceted disease is often complex, requiring stroke survivors and carers[1] to navigate multiple healthcare settings (Duncan, et al. 2005, 113).

Post-stroke care begins in the hospital, ideally in a dedicated acute stroke unit, where early treatment and rehabilitation is coordinated and delivered by a multidisciplinary team of healthcare providers, including neurologists, emergency medicine physicians, physiatrists, rehabilitation therapists, nurses, and social workers (Adeoye, et al. 2019, 192-3; Duncan, et al. 2005, 100-3). During their hospital stay, patients receive emergency care to stabilize critical conditions, treatments to attempt to reverse stroke symptoms and prevent another stroke, and rehabilitation therapy to minimize physical and cognitive disabilities due to stroke (CDC 2019). These services are determined on an individual basis, depending on the timing, type, and severity of a patient's stroke. The coordinated efforts of a multidisciplinary care team are needed to cover the multiple aspects of acute stroke care, including prevention of recurrent stroke and complications, management of general health functions, regaining mobility and independence in self-care, and provision of emotional support to the patient and family (Duncan, et al. 2005, 104).

1. "Carers" of stroke survivors are family members or friends who provide long-term physical, emotional, and/or practical support during the recovery process.

Although significant improvements in the standardization and quality of care delivered in acute care hospitals have contributed to a decline in stroke mortality rates from the third to fifth cause of death in the US over the last decade (Broderick et al. 2015), a major challenge lies in coordinating continuity of care for stroke survivors making the transition from hospital to home, nursing facility, or rehabilitation center. After a brief hospital stay of 5 days on average (Jackson, et al. 2019), discharged stroke survivors and their carers must learn how to manage on their own the continued medical treatment, rehabilitation, and care assistance that is needed for recovery. Common post-stroke disabilities that require ongoing therapy include weakness, paralysis, cognitive impairment, and speech and swallowing problems (NIH 2014). Complications patients face include both short-term complications, such as seizures, urinary infection, and aspiration pneumonia, as well as long-term complications including pain syndromes, pseudobulbar affect, and depression and anxiety (Benjamin et al. 2019, 296).

Patients and their carers are often left to cope with these drastic and demanding changes for weeks without follow-up, with only 24% of patients having a scheduled neurology appointment within 30 days of discharge (Leppert, et al. 2020). Moreover, the patient's primary care physician who is usually responsible for coordinating long-term care often does not receive all the patient's discharge information needed to properly execute their specific plan (Broderick and Abir, 2015). This gap in care continuity and knowledge transfer contributes to patient dissatisfaction and confusion (Forster et al. 2012; Hafsteinsdóttir et al. 2011), poor treatment adherence (Cheiloudaki et al. 2019), and high rates of preventable hospital readmission (Nahab et al. 2012). In order to better prepare patients for the transition home, it is essential that hospitals directly equip stroke survivors and carers with the necessary information regarding their specific disease and care plan.

Need for Improved Stroke Education and Information Provision in Hospitals

Effective patient education by healthcare professionals reduces stroke patient and carer distress and is crucial for optimized stroke recovery and secondary prevention. However, current provision of stroke education by hospitals frequently fall short of patient needs, from the perspectives of both stroke patients and their healthcare providers (Hafsteinsdóttir et al. 2011; Ting et al. 2019; Hoffman et al. 2007).

Hospitals in the United States predominantly rely on written handouts and verbal instructions to educate patients and their carers about stroke (The Joint Commission, 2007). These handouts contain a high volume of comprehensive information, yet fail to highlight patient-specific needs. Many patients and their carers do not use the handouts, citing difficulty comprehending medical terminology, cognitive impairment, fatigue, lack of interest, or forgetfulness and misplacement of papers (Ing et al. 2015). As a result, even basic stroke knowledge may not be achieved, with a high percentage of stroke survivors unable to identify stroke signs and symptoms, common risk factors, and secondary prevention methods (Ing et al. 2015). Given that 90% of stroke risk is attributable to modifiable factors and 25% of strokes are recurrent (Benjamin et al. 2019, 282, 286), ensuring that patients have basic stroke education is critical.

In addition to general knowledge, stroke survivors require specific information regarding management of medications, risk factors, common complications, and ongoing appointments; home and lifestyle changes; and reintegration into the community. Individualized education and instruction is in large part delivered verbally, during the difficult period immediately after stroke, when memory and learning are frequently impaired. Written discharge instructions are individualized, but may be brief and undetailed; and providers may struggle to maintain the fifth grade reading level when attempting to summarize complex medical conditions. Patients and caregivers may also feel too intimidated to ask their providers targeted questions about their care

(Ing et al. 2015). As a result, key information is missed, and patients and their carers are seldom fully equipped with the specific knowledge they need to take strides toward recovery.

Modernizing Stroke Education with a Personalized Recovery App

The Johns Hopkins Hospital's Comprehensive Stroke Center is a quaternary, urban stroke center with 600 admissions per year. In an effort to improve hospital-based stroke education, Dr. Mona Bahouth, Medical Director of the Brain Rescue Unit, and the multidisciplinary stroke team have prioritized the development of a mobile application that provides individualized, interactive, and accessible information to stroke patients. Designed for use in the first few days to weeks after stroke, this innovation will improve real-time communication between patient and hospital care team for education and scripted recovery activities in the post-stroke period.

In a digital health age increasingly focused on patient empowerment and personalized medicine, numerous mobile applications have been developed to improve the lives of stroke survivors. These apps target specific areas of care, such as public awareness and education, secondary prevention, rehabilitation, and social support (Blek et al. 2018). None, however, were specifically designed to prepare patients for the difficult transition between hospital-based acute care and their return home.

By harnessing the dynamic capabilities of digital health technology, hospitals can overcome many of the current limitations faced in stroke education. Instead of choosing between brevity at the cost of leaving out information; and comprehensiveness at the risk of inundating the patient, a mobile app makes it possible to prioritize highly relevant information for patients. Information can be conveyed in a variety of audio, visual, and written formats that maximizes user accessibility and increases learner success. The ability to store real-time communication between patient and healthcare team takes the burden of immediate information retention off of the patient and carer. The incorporation of interactive, patient-directed components, such as

recovery exercises, patient journaling, and goal-setting empowers patients to take an active role in their recovery process.

Project Objective and Scope

The purpose of my project is to design a personalized recovery app that improves upon current hospital-based stroke education. The overall objective of the app is to increase patient and carer knowledge about their unique condition in order to improve self-management and measurable recovery outcomes after hospital discharge. This will be accomplished by incorporating the following features: (i) individualized education, (ii) goal-setting, (iii) progress tracking, and (iv) patient-provider communication. The primary users will be stroke patients and their carers, and the secondary users will be members of the stroke care team and other healthcare providers.

The development of this mobile app will be a long-term, iterative process that may evolve in response to changes in resources, input from additional stakeholders, and future beta-testing results. The goal of my contribution is to lay groundwork upon which the first iteration of the app can be developed. I have defined the scope of my contribution as follows:

(i) Design and convey the overall structure and organization of a fully functional app.

(ii) Prototype specific paths that demonstrate key features and functionalities of the app, using dysphagia[2] as an example focus area for recovery.

2. Dysphagia (disordered swallowing) is a common post-stroke impairment affecting up three-quarters of stroke patients (Martino et. al 2005). Patients with dysphagia require specialized treatment and education to prevent complications such as aspiration pneumonia, dehydration, and malnutrition. (Duncan, et al. 2005).

MATERIALS AND METHODS

This section provides an overview of the guiding principle that underpinned chosen methodology, the workflow within which methods were implemented, and a detailed description of each method involved.

Guiding Principle: User-centered Design

The fundamental challenge with current hospital-based stroke education is that it is not able to respond to the highly variable, specific needs that stroke patients and their carers experience. As a result, desired learning goals are often not achieved. To address this problem at its root, user-centered design was made the core pillar underlying methodology. User-centered design places the user's goals, expectations, and needs at the forefront during every stage of design. Implemented correctly, the resulting product is highly usable and provides an exemplary user experience (UX) that guides users efficiently, even "delightfully," to their goals.

In his book *Elements of User Experience* (2010), Jesse James Garrett defines the core principles of UX, which are widely referenced by web and UX designers around the world. He breaks down the process of user-centered design into five stacked component planes of intentional decision-making: **strategy**, **scope**, **structure**, **skeleton**, and **surface**. A product's UX results from the sum of decisions made on each plane, layered from the bottom (abstract) to the top (concrete).

Although Garrett's user-centered model was originally intended for web design, it is highly applicable to mobile app design as well. Key methods used for this project followed his bottom-to-top approach and can be mapped to his model (Figure 1).

The **strategy** of the app is shaped by the goals and expectations of its creators and intended users, expressed in an *overall objective,* and explored through *needs assessment and market research*. The **scope** outlines *enabling objectives*, with associated features and functions,

that will deliver on the strategy. The **structure** organizes these features and functions into a unified, navigable product, represented in the *information architecture*. The **skeleton** consists of *prototypes,* an aggregate concrete expression of the structure that defines the placement of user interface elements, such as text, images, and buttons. The **surface**, which overlies the skeleton, is the resulting *finalized app* screen made up of fine-tuned user interface elements that are viewed, tapped, and swiped by the end user. User-centered design is built upwards from strategy to surface, with each plane dependent on the plane below it. In Garrett's words, "the important consideration here is to not build the roof of the house before you know the shape of its foundation" (27).

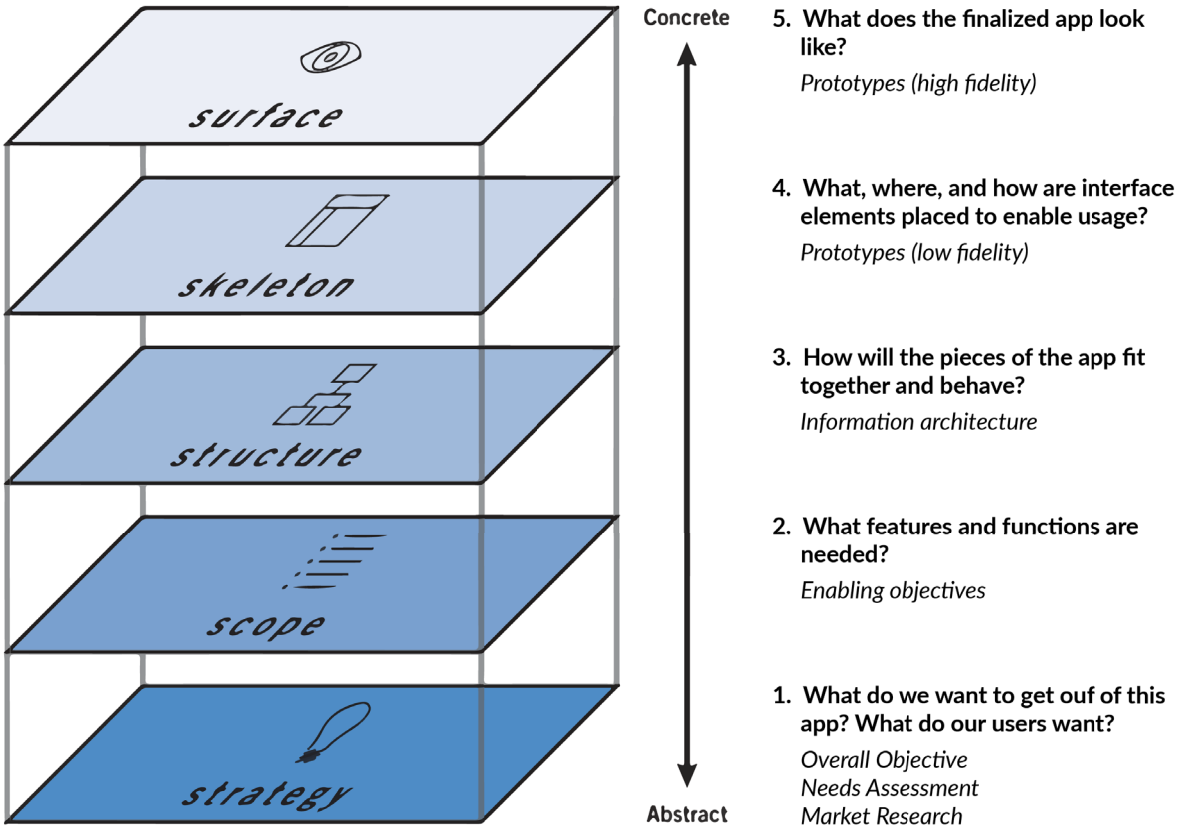


Figure 1. **Key methods mapped onto Five Planes in User Experience Design.** Figure from *Elements of User Experience* (Garrett 2010, 22).

Workflow of Applied Design Methods

The methods can be contextualized within a larger workflow (Figure 2) that begins with an identified challenge and ends with a generated solution. Adapted from the Double Diamond framework (UK Design Council 2019), this workflow can be segmented into four progressive phases: **Discover**, **Define**, **Design**, and **Develop**. The double diamond shape represents two sets of divergent, then convergent phases. The first set, **Discover** and **Define**, focuses on finding the right solution. The second set, **Design** and **Develop,** focuses on creating the solution in the right way. Divergent phases require opening up to freely explore many ideas and potential avenues in a comprehensive way. Convergent phases require condensing findings and narrowing ideas to determine the optimal direction to pursue.

Put into practice, the workflow is iterative and fluid rather than linear, with methods in different phases sometimes applied concurrently and often revisited. This maximizes adaptability to changes in scope and influx of new knowledge, which occur frequently in ambitious projects involving multiple stakeholders and collaborators. The scope of this thesis project fell within the **Discover**, **Define**, and **Design** phases. A contracted app developer then assumed responsibility for implementing the **Develop** phase. The initial challenge was to improve upon current hospital-based stroke education. The opportunity to meet that challenge, proposed by the multidisciplinary stroke care team, was to design a personalized stroke recovery app.

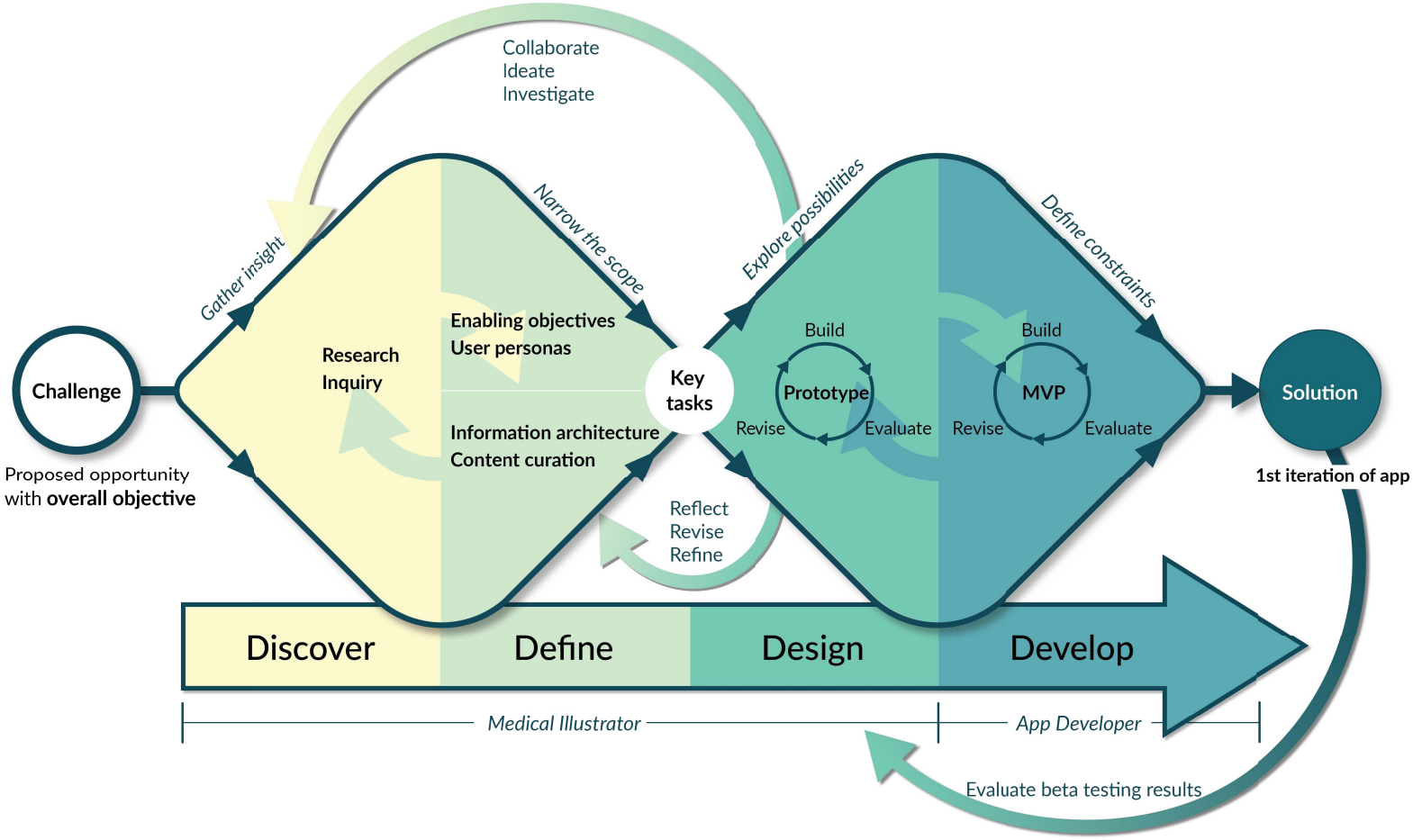


Figure 2. "Double Diamond" workflow for app design and development. Adapted from UK Design Council 2019.

In the **Discovery** phase, *research* and *inquiry* were conducted to contextualize the challenge within the existing stroke care infrastructure, and to better understand the needs and goals of the target users (patients, carers, and providers) within the full timeline for stroke recovery. From analysis of discovered findings, *enabling objectives* and *user personas* were created to **define** the scope of the app, by listing its potential functions and features and evaluating their utility for different user types. *Information architecture* in the form of flowcharts was drafted to **define** the structure of the app, by organizing functions and features into navigable components and populating the components with corresponding *curated content.*

In order to demonstrate the app's core objectives and functions within project time limits, *key tasks* were identified and prioritized to concentrate efforts in the **Design** phase. During this phase, core app components from the information architecture and the identified key tasks were visually and interactively demonstrated through *prototypes*. Prototypes were built, evaluated, and revised in an iterative and collaborative process that frequently involved conducting further *research* of available resources and *inquiry* with the clinical team to *curate content* with increasing specificity. As a result, prototypes ranged from "skeleton plane" low-fidelity to "surface plane" high-fidelity representations of the app. The *information architectur*e was revised and refined to tie together the individual prototypes, communicating how these visually demonstrated components would fit together and synergistically function as a unified, personalized recovery app.

Together, the prototypes and corresponding information architecture communicated different possibilities to the team going forward into the **Develop** phase. Using these assets as a basis for discussion, a *minimal viable product (MVP)* was defined that will be coded, iterated, and delivered as the first version of the app. This iteration will be the first, beta-tested version of the solution to address the complex challenge of educating hospitalized stroke patients, preparing the patient for discharge to home and providing a mechanism to track early recovery.

Detailed Methods

Overall Objective and Usage

It was important to establish and define a shared vision with Dr. Bahouth before the project proceeded. The incentive for this novel recovery app was to improve hospital-based stroke education to better prepare patients for the transition from hospital to home.

An **overall objective** for the app was defined as follows:

> The app will increase patient knowledge about their unique condition in order to improve self-management, motivation, and measurable recovery outcomes.

The context of usage was established as follows:

> The app's **primary users** will be stroke patients and their carers. Ideally, the patient will be the primary user, who gives shared access to their carers. However, for patients with a prohibitive level of impairment, primary usage will fall to the carer until the patient is able to engage with the app. The **secondary users** will be members of the interdisciplinary stroke team and other healthcare providers. The **targeted usage period** will be between the first days (in the hospital) and weeks (at home) following stroke.

Research

In order to better inform the strategy forward for accomplishing the overall objective, preliminary research was conducted to *contextualize the problem* within established stroke care systems and *assess user needs*. Research activities were as follows:

Searching the literature

- Web search for key terms: stroke prevalence, hospital care, rehabilitation, stroke information needs, dysphagia, etc.
- Existing stroke survivor resources: rehabilitation devices, apps, podcasts, websites, videos, pamphlets

- Relevant existing mobile apps: self-care, cognitive games, games requiring finger dexterity
- Information needs from the stroke patient/ carer and healthcare provider perspectives

Reviewing stroke education materials used at Johns Hopkins Hospital

- Stroke education paper handouts
- Sample discharge paperwork

Clinical shadowing and observation

- Neurology stroke care team conducting rounds at Johns Hopkins Hospital and Johns Hopkins Bayview Hospital
- Physical, occupational, and speech-language therapists during sessions in Johns Hopkins Hospital acute care rehabilitation
- Nursing in the Johns Hopkins Stroke Center
- Occupational and speech-language therapists during outpatient group speech, language and occupational therapy sessions at Towson University's Institute for Well-Being

Conducting informal interviews with stakeholders: patients; neurologist; physical therapists (PT), occupational therapists (OT), and speech-language pathologists (SLP)

- Example questions for patients:
    - *Do you think you got enough information for you to take care of yourself?*
    - *Did you use the stroke packet you received?*
    - *If an app tailored for you were available in the hospital, would you use it?*
    - *What information would you like it to have?*
- Example question for neurologist:
    - *How is stroke education delivered to the patients?*
    - *How could enhanced education improve patient outcomes?*
    - *What percentage of patients experience dysphagia?*
    - *Is low adherence to treatment and rehabilitation recommendations due to lack of know-how or patients' perceived lack of importance?*

- Example questions to therapists:
    - *Are patients given exercises to practice on their own?*
    - *I see you are documenting patient goals into the Electronic Health Record (EHR). To what extent do you actively involve patients in goal-setting?*

Reviewing previously conducted studies pertaining to JHH stroke education and care

- Key themes emerging from three focus groups of stroke survivors and carers, invited to provide feedback and areas for improvement based on their experience in the hospital.
- "Recovery Journey binder" pilot study for 20 patients. The sample binder and results (n=12) were obtained and reviewed. See Appendix E.

Enabling Objectives

Enabling objectives break down the overall objective into smaller manageable objectives that directly inform the functionalities and features of the app. Enabling objectives with corresponding features of the app were defined by grouping together key information needs and themes that emerged from research findings (detailed in Results). They were organized into a Word document, found in Appendix A, and summarized in Table 1 below.

Enabling Objectives	**Feature of the App**
Contextualize patient's stroke experience in a securely stored, modifiable location.	Individualized education
Involve patient in setting and working toward realistic, achievable goals for recovery.	Goal-setting Exercises (Actionable goals)
Enable patients to track and reference incremental progress.	Progress tracking
Document 2-way communication between patient/carer and stroke care team.	Effective communication with stroke care team.

Table 1. Summary of enabling objectives with corresponding app features.

Particular attention was paid to eHealth services suggested by Davoody et al. 2016 in his study of post-discharge stroke patient's informational needs, because of its comprehensive investigation of patient information needs in specific relation to potential eHealth services.

User Personas

User personas are fictional characters designed to reflect key user types. Five patient personas were created to capture the heterogeneity of stroke survivor identity, build empathy by inhabiting the patient perspective, facilitate discussion and gain consensus with stakeholders, and make user-centered design decisions directly responding to the needs and goals of patients. Each persona consists of a name and photo, key demographics, a quote, a background story, motivators and barriers to recovery, medical history, stroke effects, key traits, and core needs (Figure 3). The fictional name and photo (free stock downloaded from www.pexels.com) help make the user a real and relatable person. Demographics were ascribed to the set of personas in a way that reflects stroke prevalence and risk in the US (United Health Foundation 2020). The background story, medical history, and stroke effects reflect a wide range of resultant stroke needs, reinforcing the need for personalization of recovery goals. Patient personalities, attitudes, and behaviors were derived from in-person observation in the hospital, interactions with hospitalized stroke patients, and stories shared by stroke survivors in the podcasts *StrokeCast, Stroke Stories,* and *Stroke Recovery* and on the website *healthtalk.org* (2019). These qualities were translated into recovery motivators, barriers, and key traits for the user personas. Core needs were written last, upon reflection of each persona as a whole, taking into consideration how an app might best meet that individual's needs. Five user personas can be viewed in Appendix B.

Figure 3. Example user persona of a stroke survivor.

Information Architecture

The information architecture organizes proposed app components and features into a flowchart that helps conceptualize its structure and navigation. After brainstorming on paper and analyzing information architecture of existing apps with similar goals (Appendix C), the first iteration of information architecture was created using Adobe Illustrator (Figure 4).

A path for the first-time user is outlined: introduction to the app using trailer widgets, input of basic information, and user registration. Five key components of the app are proposed: *Home*, *Rehabilitation*, *Learn*, *Calendar*, and *Profile. Home* represents the daily hub that provides users with bite-sized, individualized education, and the ability to log information. *Rehabilitation* provides a progression plan for recovery and actionable steps to recovery, designed to be entered with the assistance of the patient's therapists. *Calendar* provides a means for record-keeping and tracking. *Learn* houses a library of general stroke knowledge typically included in current stroke

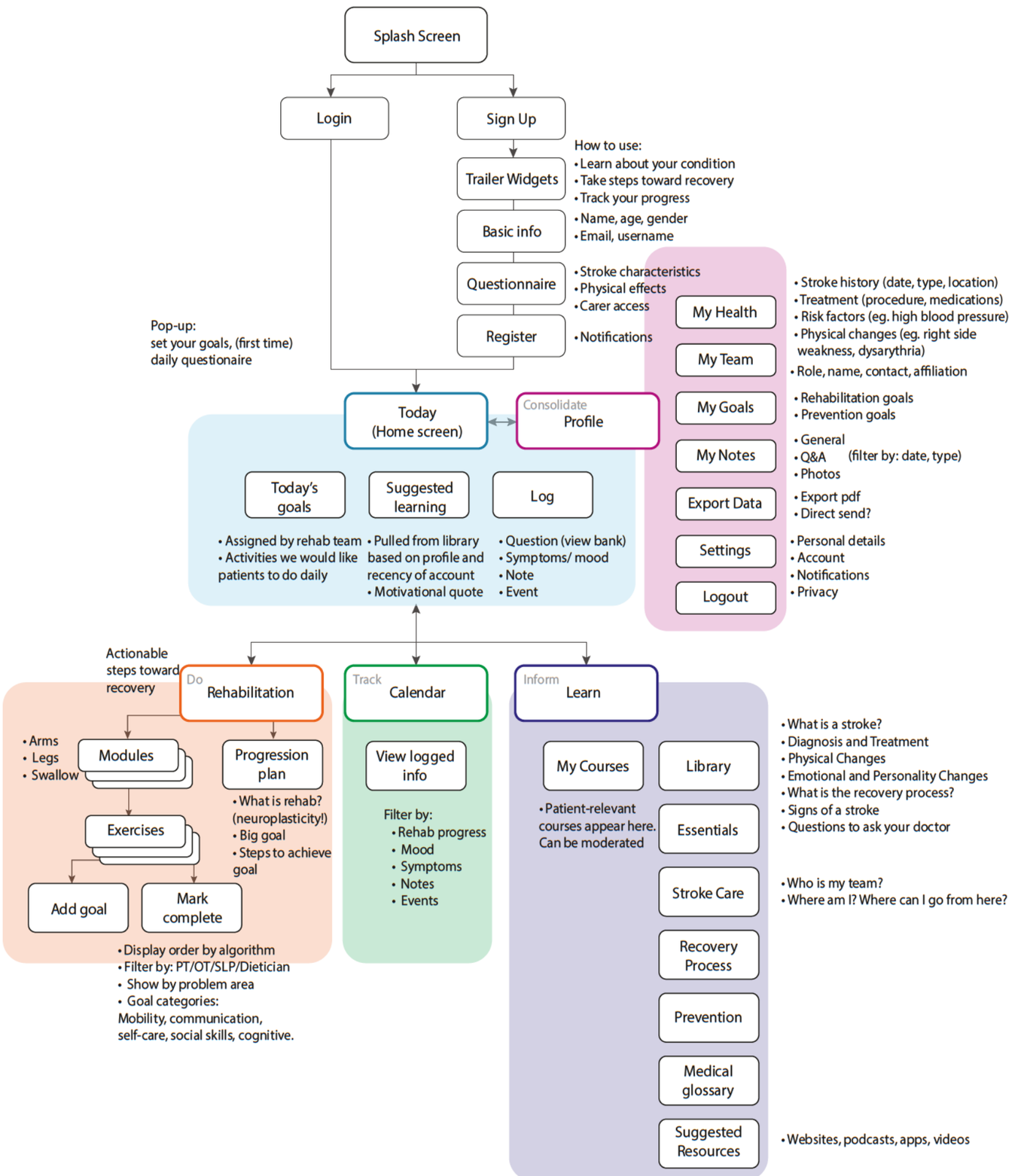


Figure 4. First iteration of information architecture.

packets, within which specific modules displayed can be personalized. *Profile* consolidates patient-specific information, including stroke team contacts, notes, and notification settings. Important information categories discovered from user needs assessment were consolidated next to corresponding components using annotated bullet points.

The initial information architecture was used to facilitate discussion with Dr. Bahouth and rehabilitation therapists regarding prioritization of functions and information types. It also served to introduce additional information about current education practices. For example, clinical information regarding risk factors, treatment, and medical history are already available on patient's *MyChart,* and was subsequently deprioritized in the app design. As part of an iterative workflow, the information architecture is not a static, rigid structure, but rather a user-centered guideline that was adjusted to reflect growth and change as design progresses. The second iteration of the information architecture was made using Lucidchart and is included as Figure 60 in Results.

Content Curation

Content curation is the process of gathering specific information to populate the components, individual prototypes, and ultimately finalized screens of the app. Content curation and design refinement were ongoing, interdependent processes that moved in a direction of increasing specificity.

Learn

Content to inhabit the *Learn* component was procured during the initial phase of research. General stroke knowledge written for a patient audience, such as type of stroke, treatment, risk factors, and prevention were found from multiple stroke pamphlets (American Stroke Association 2019, Canadian Heart & Stroke 2018, Dartmouth-Hitchcock Medical Center 2012) and websites

(American Stroke Association 2020, CDC 2020). Topics of interest were commonly organized under three major learning priorities:

1. **Treatment:** Recognize stroke symptoms and when to call 911; medications; physiology of stroke
2. **Prevention:** Common stroke risk factors; risk reduction for stroke recurrence
3. **Rehabilitation:** How to manage and adapt to problems or disability after a stroke

Strategies for personalizing this type of information were brainstormed, including interactive quizzes for learning about stroke type and risk factors (Appendix H, pages 2-3).

Logging

The general information categories *Daily Check-in, Question, Notes, Tests, Appointment, Rehabilitation,* and *Goal* were selected as options for the logging function. These categories were selected based on (i) the types of information commonly documented by patients in the pilot "My Recovery Journey" binder (Appendix E), which included tests and procedures, definitions, new symptoms, appointments, questions, and self-reminders, (ii) categories provided for documentation in American Stroke Association's *Life After Stroke* packet (specific diagnostic tests and treatment names; physical, emotional, and communication effects; rehabilitation goals; general notes), and (iii) patient information needs from literature search.

Daily Check-in

Subjective changes the patient could document on a regular basis were organized under two general categories: Body and Emotion. The specific selectable tags (e.g. weakness, fatigue, pain, dysphagia, spasticity; calm, tired, lonely, social, forgetful) were primarily derived from *Life After Stroke* (American Stroke Association 2019). Selection of specific body regions for reporting numbness, weakness, and pain was based on check-box options provided in *Life After Stroke* (12), as well as from patient self-reporting on web support forums, such as the StrokeNet Message Board ("Symptoms" 2019).

Rehabilitation

Complex functions such as goal-setting and performing proper rehabilitation exercises rely on the active involvement of rehabilitation therapists to communicate the treatment plan and rationale to patients and carers in an understandable, documentable way. Specific, sometimes overlapping focus areas for stroke rehabilitation are targeted during physical, occupational, and speech-language therapy. Dysphagia (disordered swallowing), one of the common post-stroke complications for which assessment and treatment is the speech language therapist's (SLP) responsibility, was chosen as an example focus area. Curating detailed content for these screens required additional research and inquiry. Screenshots of sample EHR documentation by an SLP were obtained to understand realistic swallowing goals and activities (Appendix F). SLPs were regularly consulted for information and feedback. Enabling objectives, information architecture, and iterative prototypes were used as communication tools to gain specific, nuanced content from members of the multidisciplinary team. Because content for the app was frequently discussed in clinician's jargon, reorganization and rewording were needed to repurpose the information for a patient audience.

Identification of Key Tasks

The originally drafted enabling objectives were reviewed and slightly reorganized to better reflect the latest goals and priorities (Table 2). Key tasks directly contributing to these enabling objectives were identified to focus the prototyping efforts. This action was taken to ensure that the important functionalities reflecting the enabling objectives were concretely demonstrated, within the scope of the project.

Enabling objective	Key tasks
Learn and retain information pertinent to their stroke	• Document stroke diagnosis (eg. imaging, electrical impulse, or blood flow tests) • Document early treatment (eg. Clot-busting med, clot removal, bleed-stopping procedures) • Learn about physical, communication, cognitive, and emotional changes
Make the most of care team's expertise while in the hospital	• Communicate with rehabilitation therapists to set appropriate goals for recovery (establish baseline and time-based targets). • Document verbal instructions for rehabilitation specialists • Ask the right questions and record answers
Take charge of their recovery	• Create time-based goals that can be acted upon on a daily basis • Know options going forward (rehabilitation, prevention) • Set motivators (big picture goals) • Have access to appropriate stroke recovery resources (apps, websites, videos, podcasts, programs)

Table 2. Enabling objectives with corresponding key tasks.

Prototypes

A prototype is a preliminary visualization of the final functioning product. Prototypes transform the abstract ideas proposed in the information architecture and enabling objectives into tangible screens that can be seen, interacted with, and most importantly, tested. Prototyping contributed tremendously to design progress by enabling clear communication of envisioned ideas, revealing design flaws and false assumptions, and generating new and improved solutions.

Prototypes ranged in appearance from low-fidelity paper wireframes to high-fidelity digital mock-ups (Figure 5). The term "fidelity" reflects how closely the prototype looks and

behaves like the final product. The more user interface (UI) design principles applied to a prototype, the higher its fidelity.

Key tasks were prototyped in repeated cycles of *building* screens, *evaluating* performance through usability testing and inquiry, and *iterating* based on feedback and findings. With each cycle, the prototype generally evolved in appearance from low toward high fidelity. Prototypes were designed for iPhone 7 dimensions, as this model is currently the most commonly used iOS device in the US (Device Atlas 2019).

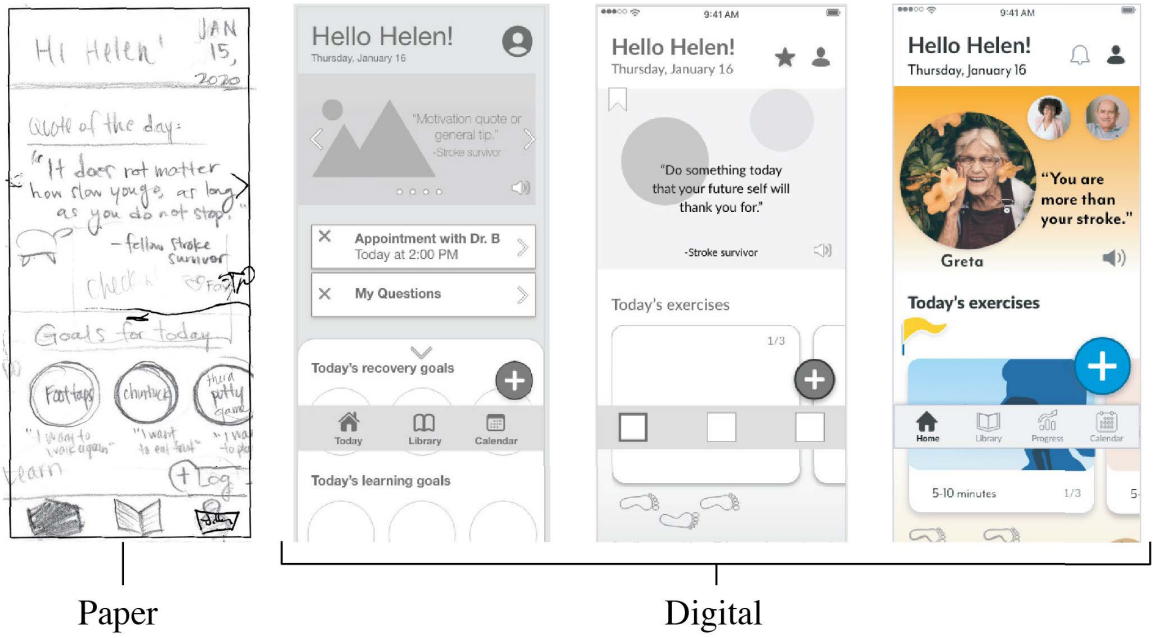


Figure 5. Range of prototype fidelity from low (left) to high (right). Text not intended to be read.

Building prototypes

Paper prototypes (Low fidelity). Low-fidelity paper prototypes were created primarily to quickly generate multiple ideas, communicate them to stakeholders, and identify focal points to direct further prototyping efforts. Blank paper and then paper printed with rectangles of iPhone7 dimensions were drawn on to create these prototypes (Appendix H, pages 1-2). Although cheap (virtually free) and fast, this method had significant limitations. The size and proportion of

interface elements drawn at a quick speed deviated far from the real product. Furthermore, it was difficult to indicate smartphone interactivity beyond tapping for buttons (eg. scrolling and swiping). Therefore, once tasks and scenarios were prioritized in discussion, prototyping efforts were continued in digital format.

Digital prototypes (Low to high fidelity). Digital prototypes, ranging from low to high fidelity, were created as artboards using Adobe® XD® software. Compared to paper prototypes, digital prototypes improved accuracy and clarity in conveying envisioned ideas, with limited sacrifice of speed. Rough concept sketches and outlines were still made on paper before creating prototypes digitally. For low fidelity digital prototypes, no color was used, text was typed with the default font Lato, graphic content was replaced with a stand-in "image" symbol, basic user interface elements (buttons, checkboxes) were created with system tools, and icons were inserted from Apple SF® Symbols® library. Low fidelity digital prototypes were used in early rounds of usability testing. They also facilitated inquiry sessions with content experts, by quickly conveying the current vision, exposing knowledge gaps, and drawing out necessary information for the next iteration.

High fidelity digital prototypes evolved from iterations with increasing specificity of content and application of UI design principles, discussed later in this section. The graphic content for these prototypes included photographs downloaded from www.pexels.com and illustrations created in Adobe® Illustrator®. User interface elements were created in Adobe® XD® and Adobe® Illustrator®. High fidelity prototypes looked more familiar to users, delivered a clear vision of what the actual product might look like to stakeholders, and directly contributed to development by providing transferable assets.

Interactive prototypes. Interactive digital prototypes are individual prototypes linked together by interactions. Their primary function is to demonstrate navigation and evaluate performance through usability testing. Using the *Prototype* feature in Adobe® XD®, artboards

were linked together by assigning user triggers (eg. “tap” button) and subsequent actions (eg. “transition” to new screen) to simulate a real, functional app. Prototypes across different key scenarios were linked to reflect and refine the user-driven navigation outlined in the initial information architecture (Figure 6).

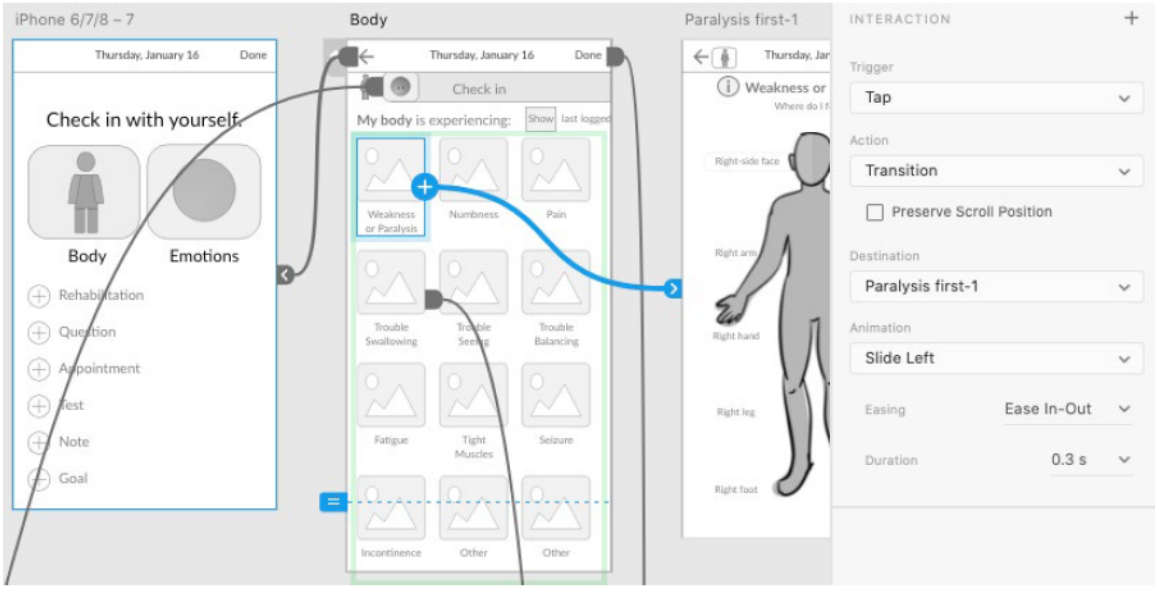


Figure 6. Using *Prototype* feature in Adobe® XD®. Assigning triggers and actions link artboards together to simulate interactivity. Text not intended to be read.

Evaluating prototypes

Usability testing. Interactive prototypes were informally shared with representative users, including therapists, physicians, nurses, and laypersons of different ages, to identify usability problems and to get feedback regarding user satisfaction. *Share links* in Adobe® XD® were generated and opened on a computer screen or a mobile phone (within the Adobe® XD® app.) Users were verbally given an identity and scenario and asked to complete certain tasks, starting from the initial screen prototype shown to them. Subsequent interactions were observed, and users were encouraged to verbalize ongoing thought processes.

Example:

To test the first iteration of the Daily Check-in feature, the following statement was made to usability test volunteers:

> "You are a new user. You are currently feeling mild weakness on the right side of your face, and you just had an assessment with your speech and language therapist, who told you that you have trouble swallowing. Walk and talk through what you might do."

Low fidelity screens were tested in this sequence (Figure 7).

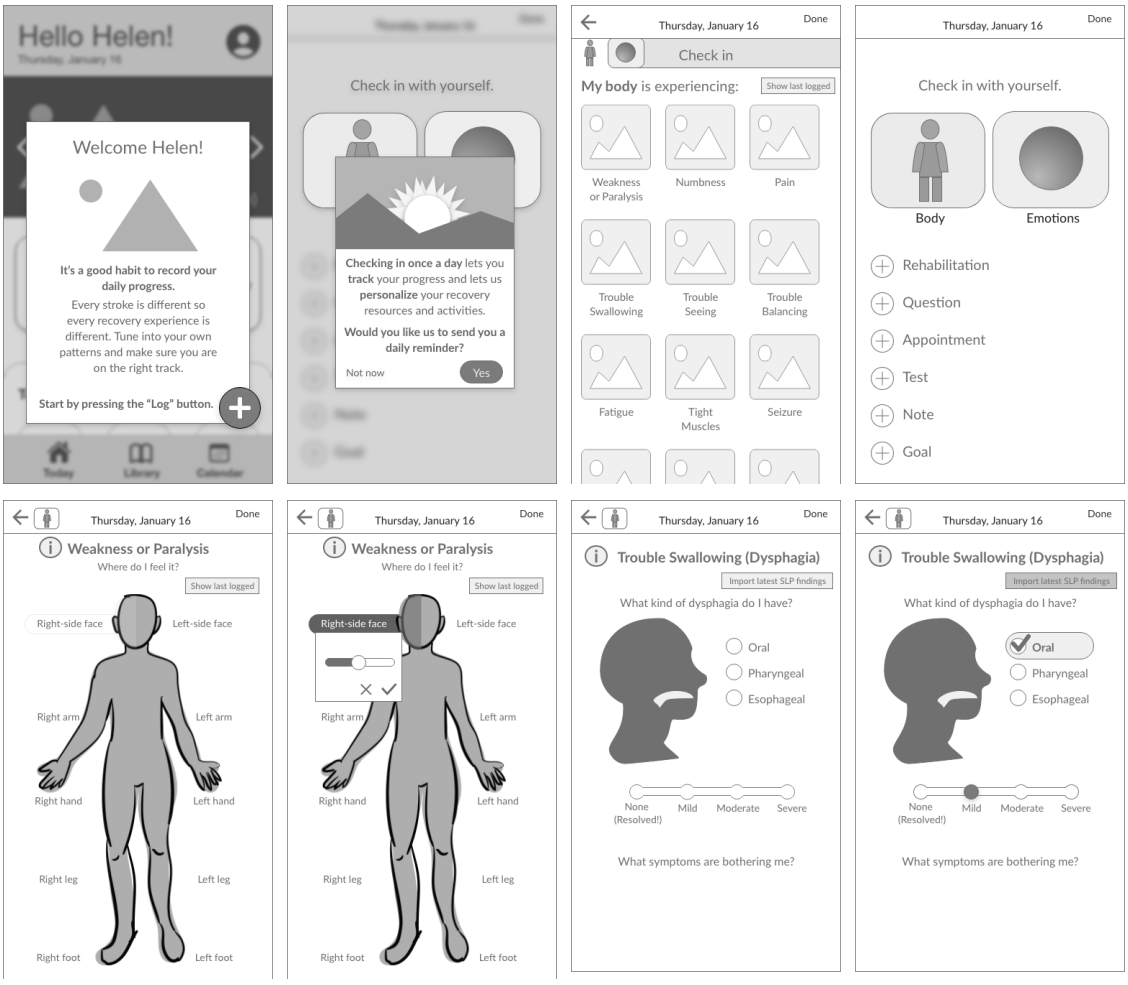


Figure 7. Example of prototypes in Daily Check-in usability testing sequence. Top left screen was presented to users as a starting point for interaction. Text not intended to be read.

Usability inquiry. Usability testing was often followed up with inquiry sessions, in which users were asked a combination of open-ended and specific questions. Some prototype sequences that were not ready for usability testing because they lacked key content and/or interactivity were subjected only to usability inquiry, with content experts and stakeholders. From these inquiry sessions, the missing content and valuable feedback were obtained that shaped subsequent iterations in a time-saving manner.

Example questions:

"Do you think users would take the time to identify and log all of their symptoms? Would it be better to simplify choices at the cost of losing details?" (Figure 8).

Figure 8. Screen used for feedback on design. Text not intended to be read.

Iterating prototypes

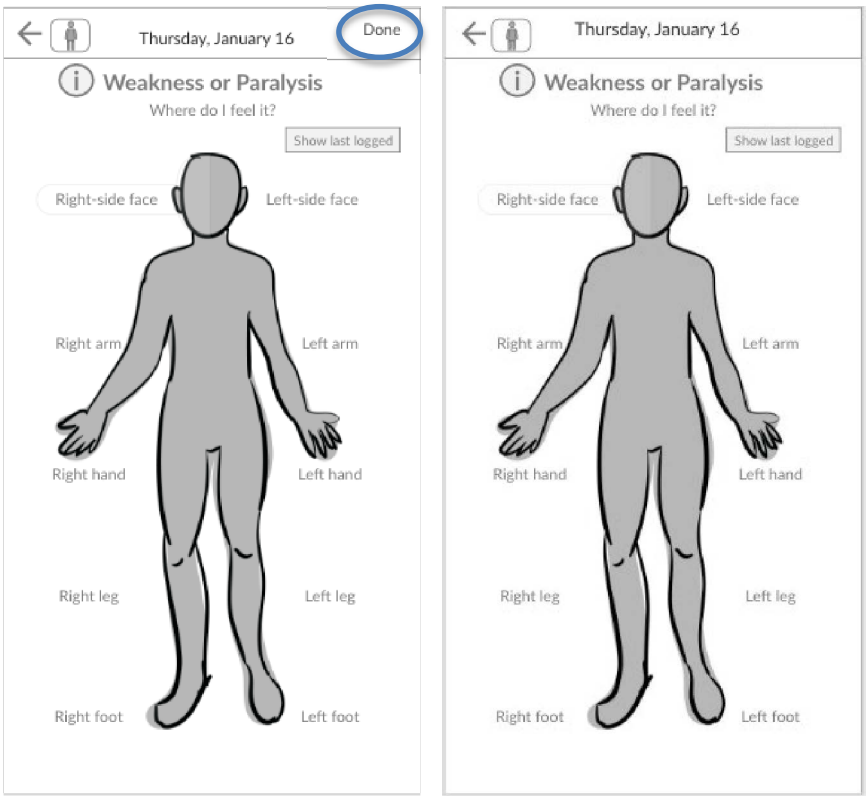
Insights and content gained from usability testing and inquiry were applied to subsequent prototype builds.

Example 1 (Figure 9):

Script from usability test: "You are a new user. You are currently feeling mild weakness on the right side of your face, and you just had an assessment with your speech and language therapist, who told you that you have trouble swallowing. Walk and talk through what you might do."

Observation: User successfully logs right-sided facial weakness, but presses "Done" rather than "Back" to log swallowing.

Revision: Remove "Done" button and keep only "Back" arrow (in upper left corner) on screens for specific symptoms. This directs users back to the main Log Physical screen to encourage logging of all experienced symptoms before pressing "Done."



A **B**

Figure 9. Iteration to improve completion of logging. Note that the "Done" button seen in screen A (circled in blue) is removed in screen B**.** The "Back" arrow (upper left corner) is left as the only navigation option. Text not intended to be read.

Example 2 (Figure 10):

Script from usability test: "You finished your suggested swallowing exercise on the home page and want to do more exercises for swallowing. What would you do?"

Observation: User taps the word "Exercise" rather than scrolling down.

Revision: Add a card labeled with the instruction, "swipe up." Add drop shadows behind the card and tab bar to create depth. Make tapping an alternative action to swiping that also results in successful navigation to exercises.

A **B**

Figure 10. Iteration to improve navigation. UI elements were altered; screen on the right depicts card with "Swipe up" instruction and drop shadows to create depth.

Example 3: (Figure 11)

Iteration 1

Iteration 2

Iteration 3

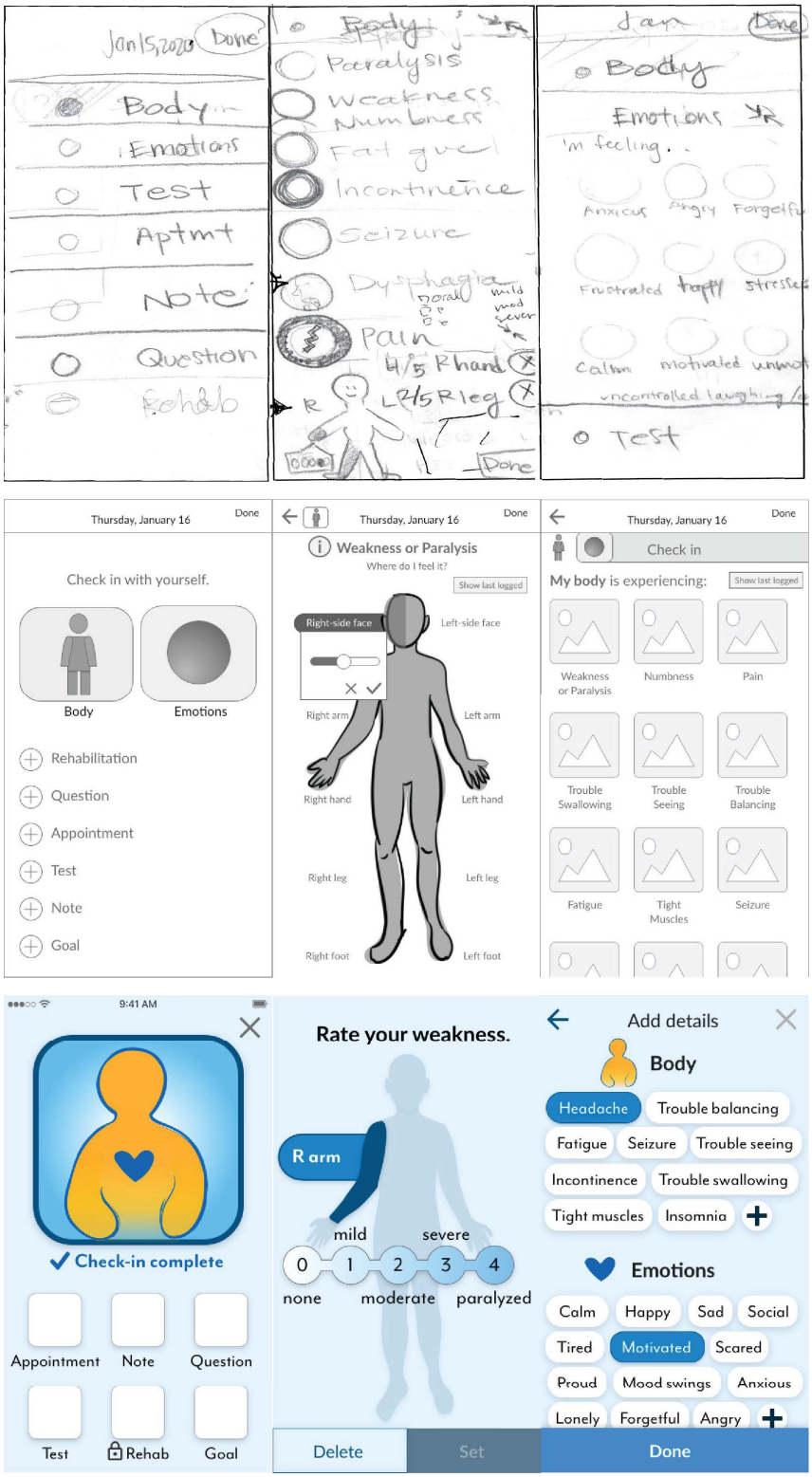


Figure 11. Three iterations of Daily Check-in screens. Paper prototype (top); low fidelity digital (middle); and high fidelity digital (bottom) shown. Text not intended to be read.

User Interface Design

UI design focuses on anticipating what actions users might take to reach a goal and ensuring the interface has elements that are easy to access, understand, and use to facilitate those actions. Increasing application of UI design resulted in higher fidelity prototypes. Principles of *visual design*, *navigation*, and *accessibility* shaped user interface design decisions. These principles were discovered and refined through experimentation, usability testing, and analysis of successful apps on the market.

Visual design principles

Visual Hierarchy: Make the most important content look the most important. Visually hierarchy was established using layout (most important parts appear at top of screen), size (most important text/graphics are larger), and contrast (eg. bold text, bright color). See Figure 12 below.

Unity: Group related items together and distinguish them from other groups. Objects belonging to the same category were presented consistently and placed in proximity to one another. This could easily be accomplished using the "Grid" tool in Adobe® XD®. Different groups were differentiated from one another by a visual cue, such as white space or an end in the background gradient.

Familiarity: Follow UI conventions that users recognize and understand how to use. To make the app as intuitive as possible, familiar interface elements were implemented, based on common trends observed in highly-rated apps and Apple's Human Interface Guidelines for iOS. Familiar elements include the navigation bar (located at the top), tab bar (located at the bottom), status bar (displaying time and connectivity), usage of a grid layout, sliders, swiping left for content hanging off the screen, and popover notifications.

Navigation principles

Minimize effort required to complete tasks. The top priority tasks - completing daily exercises, accessing learning topics, and logging - were made accessible from the home screen. One primary action was devoted to each action-oriented screen (Figure 12). If more than one action was available, the action more likely to be taken by the user (eg. "next" over "back", "set" over "delete") was made visually dominant. Multiple navigation preferences were accommodated when possible. For example, a specific module in the *Library* could be found by direct search, filtering, or simply scrolled down to.

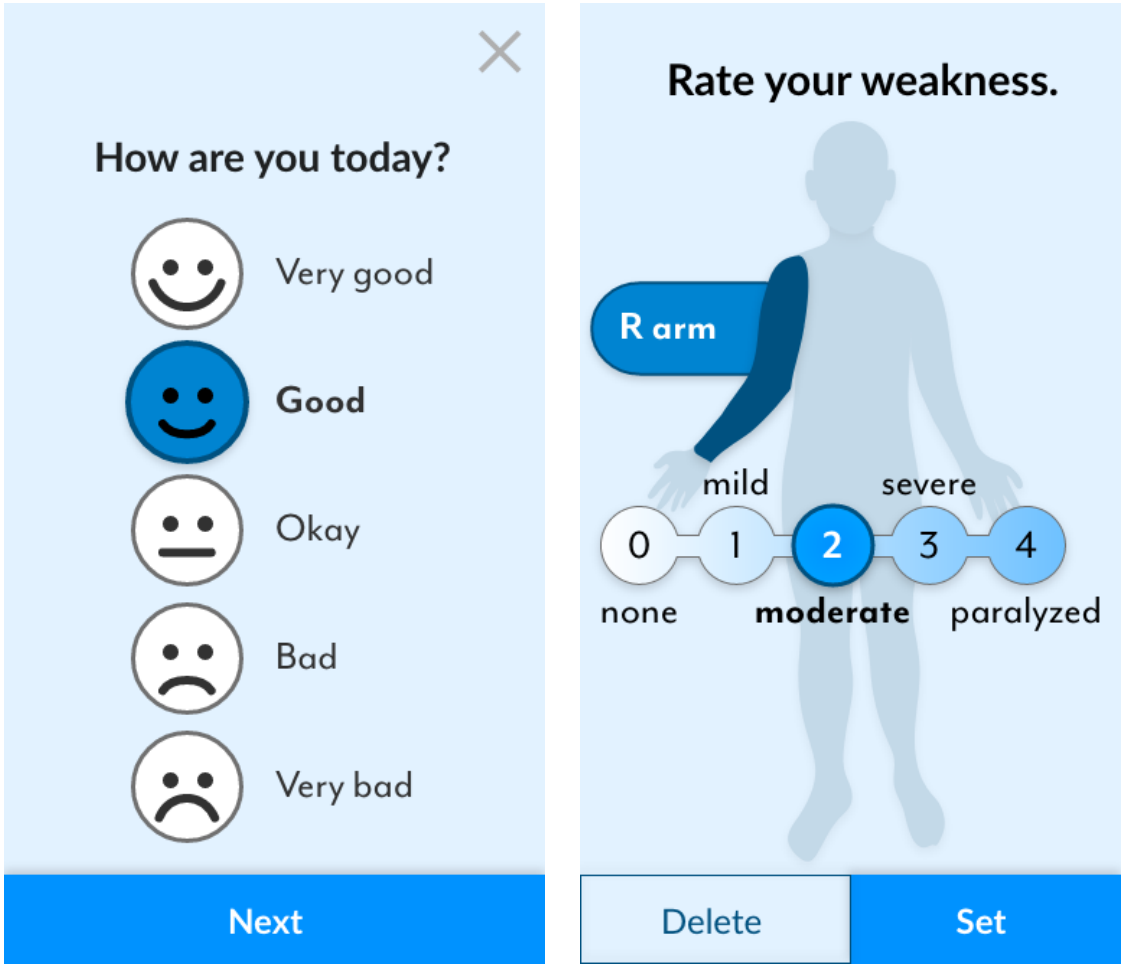


Figure 12. Prioritizing navigation using primary actions. "Next" (left) and "Set" (right) are primary actions made visually dominant using color contrast and drop shadow.

Let the user know where they are. A filled icon with bold text in the tab bar indicated whether the user was in *Home*, *Library*, *Progress*, or *Calendar* at all times. Headings in large, bold text placed at the top of screens acted as signs for the user. Sticky headers were created to keep these signs and important controls visible at the top of the screen when users scrolled (Figure 13). Functional animations (such as the overlay of a modal notification) informed users that "behind" that screen, they were still in the same location.

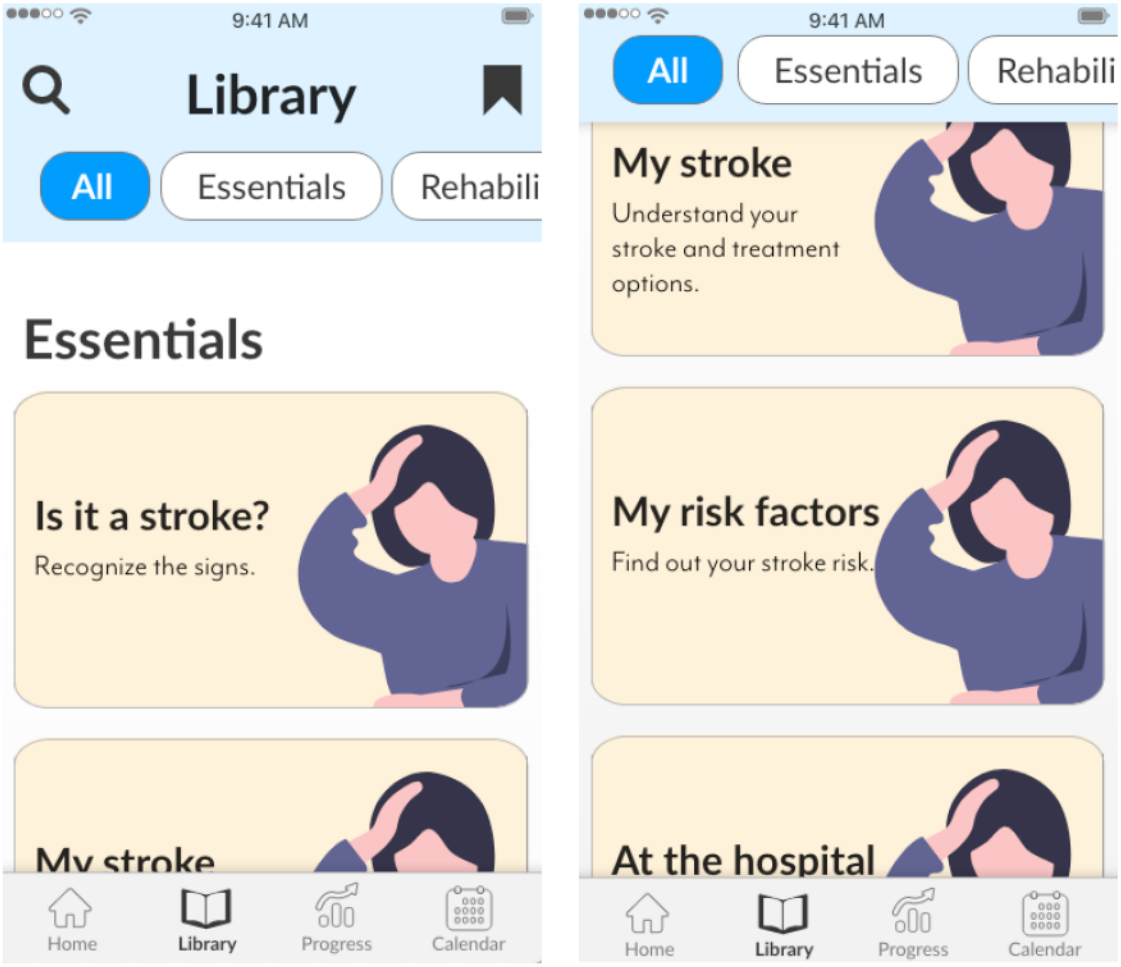


Figure 13. Example of using sticky headers to orient the user. The sticky header (screen on right) keeps orienting signs and important controls visible at the top of the screen when users scroll.

Prioritize navigation options. Prominence was given in the UI to high priority paths and destinations, that were anticipated or desired to be most frequently used. For example, personalized exercises and learning modules were prioritized by their location on the *Home* screen, even though the same modules exist in the *Library*. The activity of logging symptoms and emotions once daily was prioritized by creating a path for users to complete Daily Check-in immediately after sign-in, before directing them to *Home*. The "OK" button was made more prominent than "Not Now" when users are asked if they would like to enable notifications (Figure 14).

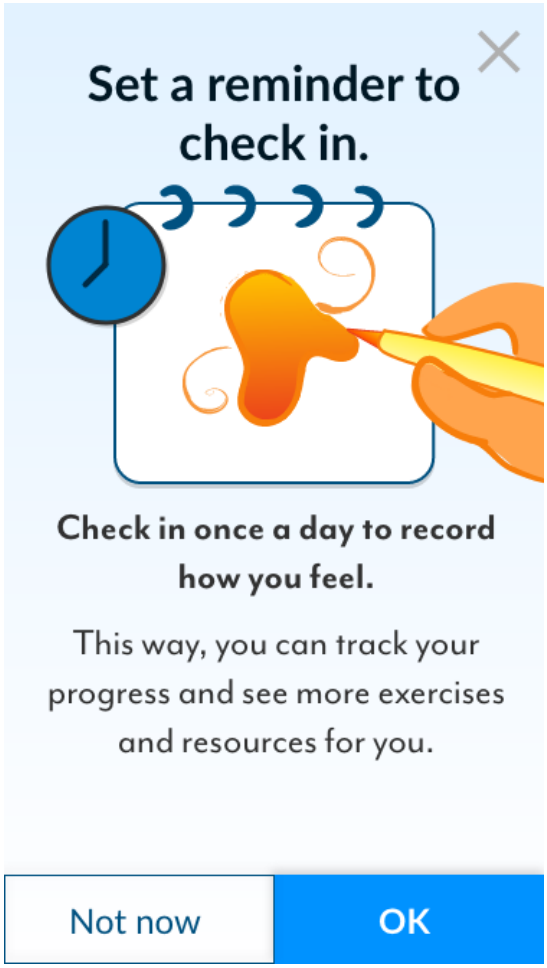


Figure 14. Prioritizing a desired navigation option. Users are encouraged to set a reminder for a daily check with the "OK" button more visually dominant than the "Not now" button.

Preserve user control. Although navigation options are prioritized to meet both anticipated user needs and the app creators' goals, the user is ultimately in control of where they want to go and what they want to accomplish. "Back" buttons allow users to course correct and "cancel" buttons give users an exit strategy. Prototypes that caused navigation difficulty, observed in misdirected tapping and swiping, were redesigned and retested with new users.

Accessibility principles

Readability. Typography choices were made to maximize readability by patients of all ages. Simple sans serif typefaces *Lato* and *Mr Eaves Mod OT* were chosen for heading and body text respectively. Large bold headers (*Lato Bold 38px)* were well distinguishable from body text, which was displayed in smaller but highly readable font (*Mr Eaves Mod OT 26px).* Adequate line spacing and color contrast were checked.

Design for touch. It is important to consider smartphone-specific interactivity when designing any mobile app. Buttons and controls must be designed for touch interaction by fingers, rather than indirect interaction through a computer mouse. Careful awareness of this fact was required when building and testing prototypes on the computer. Appropriate sizing and spacing of icons were refined by self-testing prototypes in the Adobe® XD® mobile app. It was determined that a minimum area of 50x50 pixels gave the thumb adequate real-estate to easily trigger controls on the first attempt. Buttons and labels were made large and prominent. Gestures that were incorporated using Adobe® XD® *Prototype* actions included tapping (buttons and controls), swiping (cards) and dragging (sliders).

Patient-friendly. The recent stroke survivor and their carer is likely shocked, fatigued, and overwhelmed. These patients could be of any age (10% of patients are younger than 45), gender, or race. To address the diversity of patient demographics, emphasis was placed on designing for inclusivity and supportiveness. Photos of stroke survivors that accompany

motivating quotes were chosen to represent a wide range in demographics. The main design colors chosen were blue and yellow; with the former commonly associated with trust and dependability, and the latter with happiness and optimism (Figure 15). Illustrated human figures were depicted as cartoons to reduce alienation and lift mood. Rectangular modules and buttons were given rounded corners, which are easier to look at than sharp corners (Martinez-Conde et al. 2009). Touch-responsive elements, such as buttons, modules, and controls, were intentionally made larger and more prominent than typical standards observed in other apps to maximize ease of use.

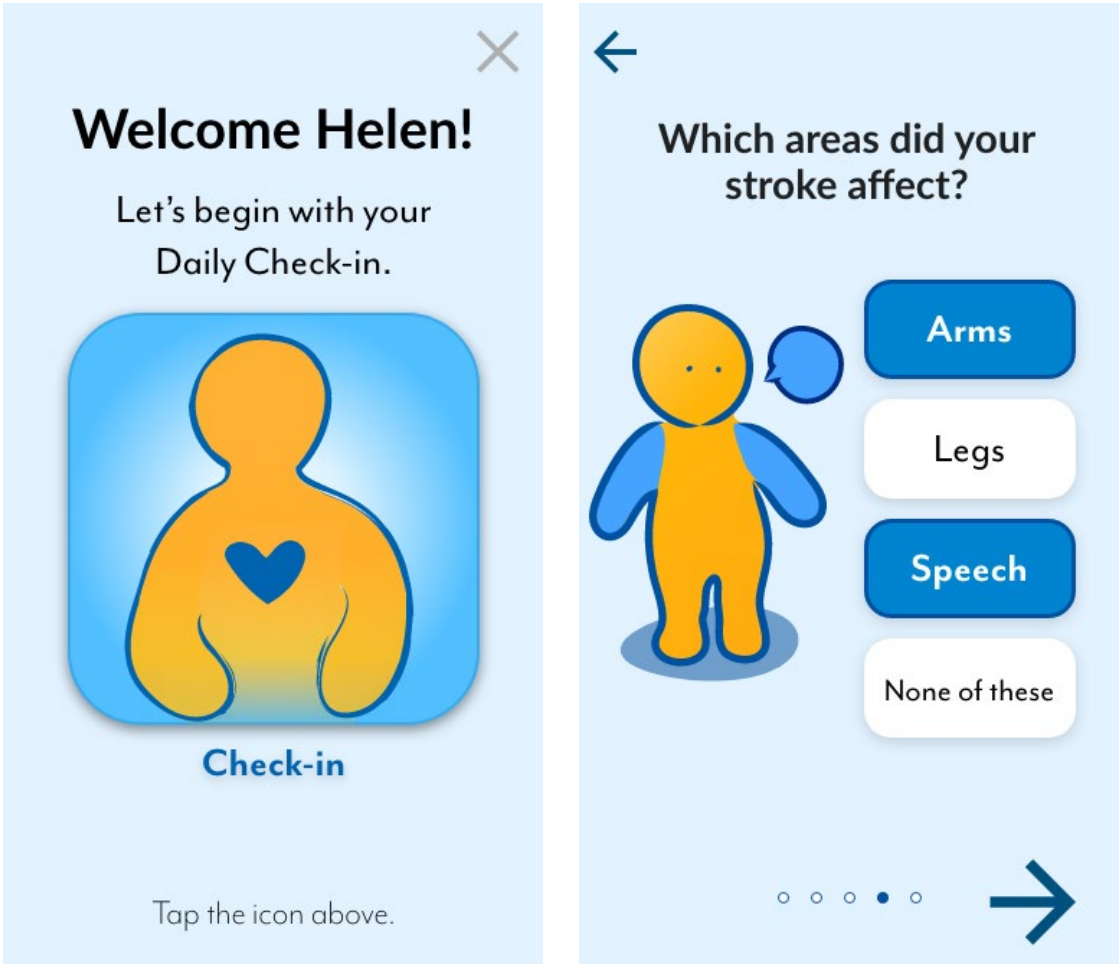


Figure 15. Patient-friendly UI design. Note the use of large text, large buttons, rounded corners, cartoon style, and blue and yellow color scheme.

RESULTS

Key Research Findings

Care for stroke patients at the Johns Hopkins Hospital (JHH)

Stroke patients are admitted via several potential locations. A majority enter the health care system through the emergency department where their condition is diagnosed, medical issues are stabilized, diagnostic tests are completed, and hyperacute treatments are administered such as clot-busting drug tissue plasminogen activator for ischemic strokes or surgical interventions to treat hemorrhagic stroke (Canadian Heart & Stroke, 24). Patients are then admitted to the stroke unit, where their treatment plan depends on the type (ischemic, hemorrhagic, TIA), location (MCA, ACA, brainstem, etc), and severity of stroke, as well as the patient's comorbid conditions. The dedicated multidisciplinary stroke team at Johns Hopkins Hospital gathers every weekday to plan the care for and to visit each patient in the stroke unit. Patients requiring therapy are seen twice daily by a physical, occupational, and speech and language therapist. In the last year, the average stay at JHH was five days, though it can range from 2-180 days, and 50% of patients are discharged to home. Patients are contacted by phone by the stroke center nursing staff after discharge. Discharged patients follow-up within one to three months depending on the severity of their condition and discharge location.

Current education given to stroke patients at JHH

Current education requirements for stroke center certification are mandated by the Joint Commission's National Quality Measure STK-8 (2016). This measure requires that stroke patients or their carers are "given educational materials during the hospital stay addressing all of the following: activation of emergency medical system, need for follow-up after discharge, medications prescribed at discharge, risk factors for stroke, and warning signs and symptoms of

stroke." Johns Hopkins Hospital's Comprehensive Stroke Center fulfills this requirement using the following:

- American Stroke Association's *Let's talk about stroke* singlet handouts (14 separate topics stapled together, spanning the categories: Prevention, Recovery, Lifestyle and Risk Reduction, without a clear hierarchy) given prior to, or upon hospital discharge
- Discharge paperwork, variable in length and readability, given upon discharge

During inpatient visits from various members of the care team, verbal instruction is the primary method used to inform and educate patients. There are several categories of education that could be enhanced with additional visual aids. For example, Speech and Language Pathologists currently use X-ray images from a patient's barium swallow test to explain the findings for dysphagia.

Currently available products and services for stroke survivors

Numerous resources designed for, or helpful to stroke survivors were discovered, including rehabilitation devices, apps, podcasts, web resources, videos, and pamphlets. A table of these resources is provided in Appendix D. Analysis of these products was useful for understanding the needs of stroke survivors and the limitations of existing resources. The large number of available resources underscored the problem of information overload, and access to specific and relevant information requires patients and carers to actively search through multiple options. There is no dearth of stroke information available; rather, the patient is at risk of information overload. Key service realms identified were education, rehabilitation, and social support.

Education. Web resources and pamphlets were easiest to procure (eg. web search for "stroke"), but many are exhaustively comprehensive, requiring time, energy, and preexisting knowledge to synthesize. A variety of free, high-quality, patient-friendly educational videos were found on YouTube, ranging from two-minute explainer videos to hour-long PowerPoint lectures.

Videos perceived as helpful to stroke survivors and carers received more likes and positive comments. The video platform's algorithm is designed to optimize visitors' viewing experience and prioritizes such videos to appear at the top of search results. Despite the optimized accessibility, however, these videos do not reach a large number of their targeted audience. Although YouTube is extremely popular and frequently used by young adults, the majority of adults age 65 and over- the age group comprising almost 75% of stroke patients- do not use YouTube (Pew Research Center 2019).

Rehabilitation. Companies specialized in personalized rehabilitation services for stroke were identified, including the digital therapy company Learning Corp and medical device companies Saebo and FlintRehab. These companies further expanded their provisions beyond rehabilitation exercises, to include advice and social support. For example, FlintRehab provides free eLearning resources, including an eBook and regular recovery blog posts in addition to their devices (eg. FitMi). The narrow focus on rehabilitation and design for use after hospital discharge are a limitation of this resource. This approach misses the opportunity to leverage the period of heightened neuroplasticity immediately following stroke; Saebo's program is based on a mantra of "No Plateau in Sight," catered towards patients who have been told that they have reached a chronic phase of stroke after the recovery plateau.

The company Accelerated Care Plus (ACP 2020) manufactures Synchrony, a therapeutic solution for dysphagia that enables patients to visualize swallowing exercises (hard swallow, tongue pullbacks, etc.) using gamified virtual reality surface electromyography (sEMG) biofeedback. This device is used frequently during JHH in-patient swallowing therapy sessions. A speech language pathologist described how sEMG greatly augments patients' ability to perform exercises properly by delivering immediate feedback about the accuracy of the movement. Staff has also observed that use of gamification is highly engaging (eg. kangaroo hopping to collect coins) and allows patients to perform the exercises for longer durations. Usage of this product

requires special training and staff supervision. The company website indicates that it was designed for SLPs to achieve better patient outcomes, not for patients to use unsupervised.

Among the most popular stroke-specific apps were those that provided a personalized approach to rehabilitation (Constant Therapy and Stroke Active). Several apps could be adapted for use by stroke patients during stroke recovery. These apps include Solitaire and Angry Birds for improving finger dexterity and hand-eye coordination; Lumosity Mind and Elevate for brain training; MediSafe for adding, tracking and sharing medication-usage; and Calm and Headspace for mental and emotional well-being. During my observation, an occupational therapist instructed a patient to play the game Solitaire on a hospital-provided iPad, encouraging him to use his stroke-affected hand. The patient appeared highly receptive to the task and continued to play after the formal session ended. A physical therapist was also observed to use Candy Crush to direct the attention of a patient with visual neglect. The music and bright colors were effective in a way that speaking and gesturing had not been.

Social support. Podcasts such as *StrokeCast* and *Recovery After Stroke* feature stroke survivors many months or years after stroke reflecting on their experiences and sharing their progress and insights. The podcast hosts are frequently stroke survivors themselves, motivated by their own struggles to cast a wide social support network and to help new survivors navigate a confusing and overwhelming time. The hosts disseminate the collective insights and experiences of long-term stroke survivors, and also host informational interviews with therapists and neuroscientists who are invited as guest speakers.

What appeared lacking is a learning resource that improves knowledge transfer between patient and providers while the patient is still in the hospital, in a way that is meaningful to the patient. The creation of a personalized directory that points patients to relevant services would also be extremely useful.

Barriers to learning

Challenging timing. Patients suffering stroke may be emotionally distressed, cognitively impaired, audiovisually impaired, and/or fatigued when information is delivered in the hospital setting, either verbally or in writing. Carers are also under emotional stress or may not be present at the time of education. Discharge instructions are handed to the patient and carer only as they are leaving the hospital.

High volume. The stroke packets contain too much information delivered all at once, which often overwhelms patients/ carers who try to read the full packet or deters them from usage all together.

Lack of personalization. By detailing every type of stroke and every aspect of care, the written stroke handouts burden the patient/ carer with the task of picking out information relevant to their specific needs. This task in itself requires pre-existing knowledge.

Poor communication with healthcare providers. Patients do not have all the information they would like from their care team because they do not know what questions to ask until much later in the stroke recovery process. Focus groups with discharged stroke patients from JHH revealed that patients often forget to ask their questions, are unsure what to ask, or feel too intimidated to ask questions. Verbal answers may be forgotten. The care team has tight timelines and must move efficiently from one patient to the next. These medical professionals are used to thinking and communicating with their peers in clinical terms, and may unknowingly adopt medical jargon or presume knowledge when communicating to patients. Patients may not communicate their lack of understanding and ask for clarification.

Low motivation. Patients often feel disinterested, depressed, and/or isolated. Fatigue after stroke is common and in itself disabling.

Information patients what to know

By mapping the viewpoints and experiences of both recent and long-time stroke survivors onto patient journey maps, Davoody et al. (2016) revealed a range of information needs that stroke survivors have over different phases of the recovery process, summarized in Table 3.

Categories	**Subcategories**
A holistic view of the care process	An overview of past events An overview of planned events
Understanding the illness	An overview of clinical information An overview of risk factors and disabilities Measurement and documentation of health-related parameters
Collaboration with care providers	An overview of care providers' contact information, their specialties and responsibilities Support for sharing of personal observations
Tracking the rehabilitation process	An overview of goals and planned activities
Practical guidance through healthcare and community services	Rights and responsibilities regarding e.g. continued rehabilitation, assistive devices and general information about health insurances An overview of patient associations and networks

Table 3. An overview of identified information categories and subcategories. (Davoody et al. 2016.)

Notably, participants desired a holistic view of the care process, including documentation of what happened in the hospital, and expressed that they "were only beginning to gradually capture and understand information when they returned home" (5). Patients were often overwhelmed by the numerous new care providers with different specialties introduced to them. They wished to have access to information about their rehabilitation including goal setting and tracking, planned activities, and follow up efforts (7). Interest in tracking subjective assessments

such as fatigue, mood history, and disabilities to better understand their illness was also expressed (6). One participant mentioned that "a compilation of disabilities could be helpful" because they "do not necessarily appear at the same time" (6). Understandable versions of their own clinical information (diagnosis, treatments, disabilities, lab results) and secondary prevention strategies were both desired, but learning about risk factors and prevention was ranked less important in the immediate aftermath of stroke (6).

Clinical observation and informal interviews revealed that the information needs of post-stroke patients vary both over time and based upon stroke severity. Some patient stakeholders currently receiving treatment in the hospital expressed satisfaction with provider communication, but wished that spoken information could be stored in some way. A stroke survivor further along in recovery felt misled in hindsight by doctors and nurses about recovery prospects, expressing that clear, honest communication about the extensive work involved in recovery would have reduced passivity and increased self-initiative at an earlier point in time.

Patients with more severe strokes appear more concerned with recovery, while patients with mild strokes appear to be more concerned with prevention and risk reduction. A pilot study, testing an interactive paper binder, titled "[My] Recovery Journey," was conducted to begin improving stroke education delivery at JHH (Appendix E). The interactive component consisted of multiple "Daily Log" pages and a page titled "My Recovery Goals." Entries were designated for the patient, PT, OT, SLP and Nursing, with the goal of facilitating patient-provider communication. The pilot recovery binder study revealed several notable findings. In the majority of patient binders, the available entries on the "Daily Log" pages were left mostly unfilled by both patients and providers (PT, OT, SLP, Nursing), suggesting hindered accessibility, inconvenience, and/or lack of interest in usage. Of the entries designated for patients, "My Notes" was most frequently filled, with patients populating this area with various kinds of information,

including tests and procedures, definitions, new symptoms, appointments, questions, and self-reminders.

Information care team providers want patients to know

From the point of view of healthcare providers, improving treatment adherence and secondary prevention are among the top priorities. This requires patients to know their personal risk factors and how to lower them (eg. blood pressure medication, improved diet), and to understand how to prevent and manage complications (eg. dysphagia, pain).

A 2019 updated policy statement from the American Stroke Association (ASA) published by Adeoye et al. issued two new recommendations for secondary/post-acute care, listed below. Bolded text indicates suggestions directly pertinent to patient information needs.

1. A stroke system should establish support systems to ensure that all patients discharged from hospitals and other facilities to their homes have appropriate follow-up with specialized stroke services when needed and primary care arranged on discharge. These efforts should include education and training for the patient and his or her family members**. Clear, comprehensive, and timely communication across the inpatient and outpatient poststroke continuum of care** is essential to ensure appropriate medical and rehabilitation care.
2. To standardize post-acute care after stroke discharge, stroke centers should comprehensively screen for post-acute complications, provide **individualized care plans** for patients during the transition of care, provide **referrals to community services**, and reinforce **secondary prevention and self-management of stroke risk factors and lifestyle changes** to decrease the **risk of recurrent stroke**. Trained stroke nurses, nurse practitioners, social workers, community health workers, and others should play a pivotal role.

Rehabilitation therapists define realistic time-based goals and activities to facilitate and measure patient recovery, which are recorded by requirement into the electronic health record (EHR). The therapists encourage patients to take an active role in the goal-setting process, in order to better manage their disabilities and achieve outcomes that are important to the patient.

Inclusion of daily log entries for Nurse, PT, OT, SLP in the recovery binder pilot (Appendix E, page 8/9), along with ASA's recommendation for trained stroke specialists to play a pivotal role in education, revealed the importance to providers of facilitating and documenting ongoing patient-care team communication. As outlined in the recovery journey binders, this communication may take the form of shared goal-setting (Big-picture goals and enabling action goals), answering questions, and patient-centered note taking.

Digital Prototypes

Digital prototypes were designed around seven specific key tasks to visually demonstrate core features and functions of the app. In this section, each of the seven key tasks is presented as a sequence of prototyped screens. Using the *Prototype* feature in Adobe® XD®, all prototypes were linked by interactions; tapping buttons and tabs takes the user to new screens (Figure 16).

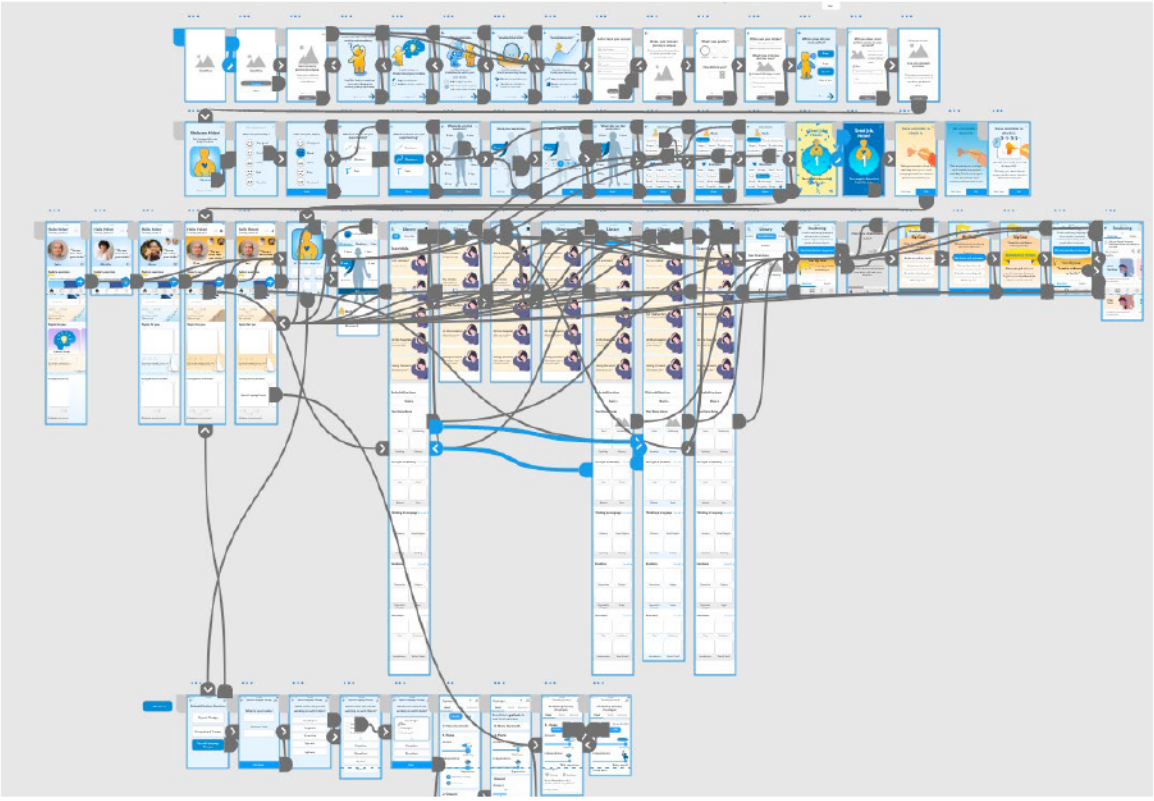


Figure 16. All prototypes are linked by interactions in Adobe® XD®.

The prototypes presented are in various stages of iteration, ranging from low to high fidelity. For demonstration purposes, the working title of the app is "StepWise," and the user's name is "Helen."

1. First-time user onboarding: Onboarding trailer

The first-time onboarding process consists of an introductory onboarding trailer, user sign-up, and a new user questionnaire. The six-screen onboarding trailer introduces the first-time user to the app. Upon opening the app, the user is presented two options: sign up as a first-time user by pressing the button "Get started," or log in as a returning user by pressing the button "Log in" (Figure 17). Upon selecting "Get started," the first-time user is taken to the onboarding trailer. These screens explain the context and purpose of the app (Figures 18-19) and introduce the user to various functions and benefits of usage (Figures 20-23). The user can choose to skip the onboarding trailer on any screen in the sequence, in order to register login details on the subsequent sign-up screen (Figure 24). The onboarding trailer serves to capture the first-time user's interest and show them what the app has to offer. Empathetic language, soothing colors, and a personable cartoon figure were used to build a positive first impression and encourage continued user engagement.

Figure 17. Start screen.

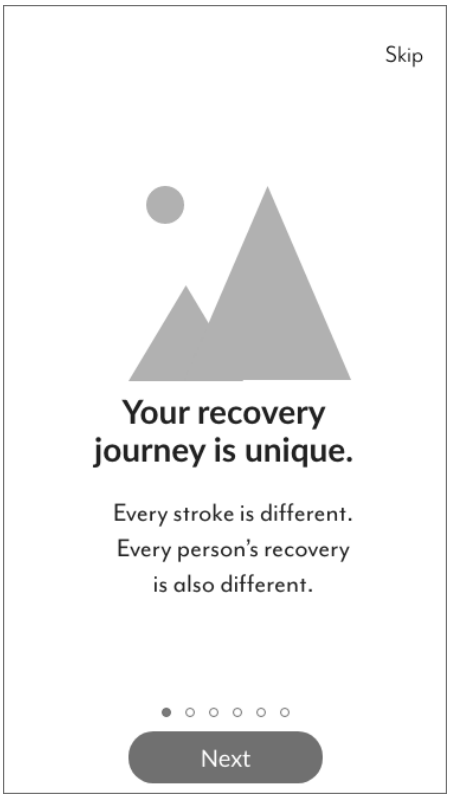


Figure 18. Onboarding trailer 1/6.

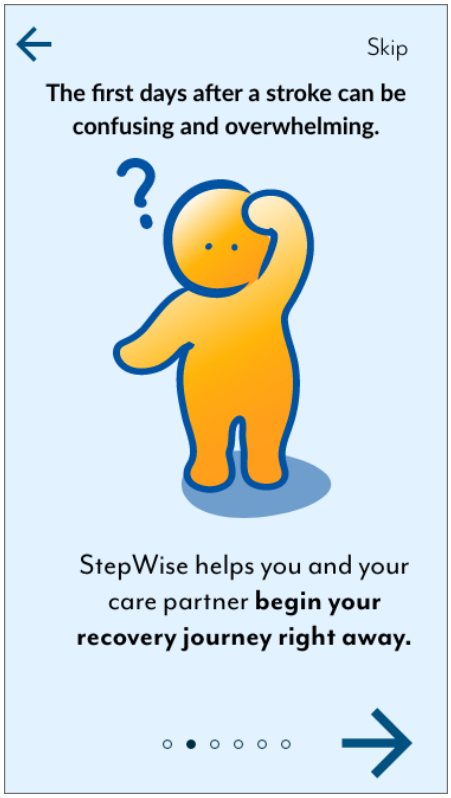


Figure 19. Onboarding trailer 2/6.

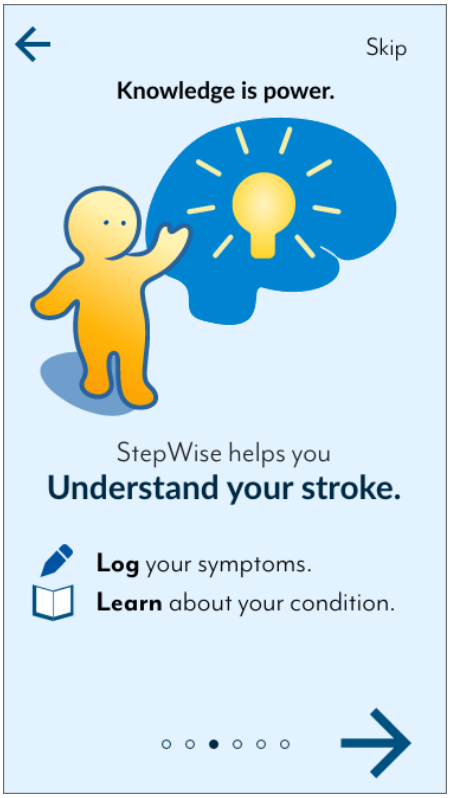


Figure 20. Onboarding trailer 3/6.

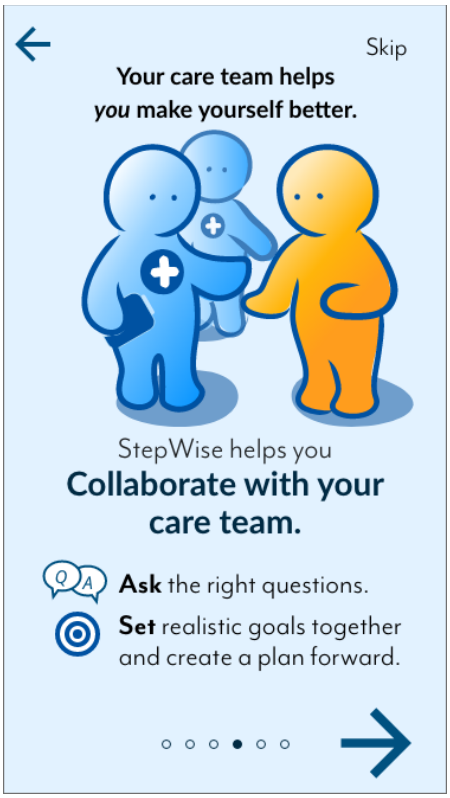


Figure 21. Onboarding trailer 4/6.

Figure 22. Onboarding trailer 5/6.

Figure 23. Onboarding trailer 6/6.

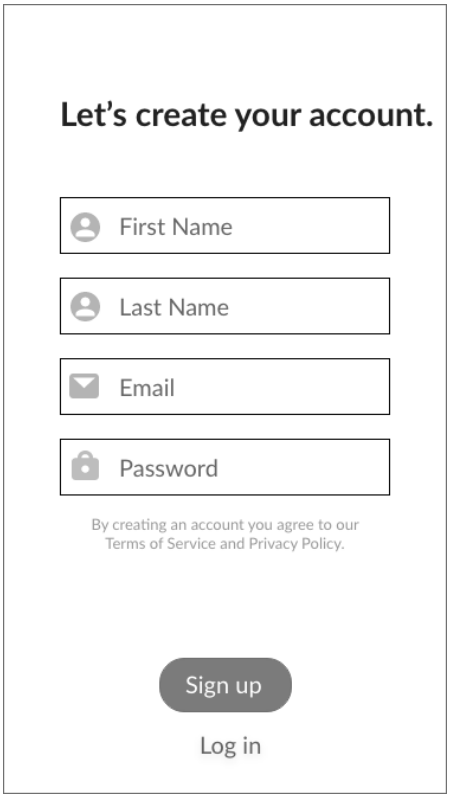


Figure 24. Sign-up screen.

2. First-time user onboarding: New user questionnaire

After sign-up, a screen prompts the first-time user to answer a short questionnaire and provides an explanation that information will be used for personalization of app content (Figure 25). In the subsequent screens (Figures 26-28), the user is asked to enter their gender, age, date of stroke, stroke type, and general areas affected by stroke. The final question, "Will you allow a care partner access to your account?" gives the patient the option to provide another person shared access (Figure 29). The user can press the "back" arrow to change answers on previous screens. These questions cannot be left unanswered, as the collected information is needed to generate a base level of content personalization. After finishing the questionnaire, the user is shown a loading screen with words of advice and affirmation while the app sets up the user account (Figure 30).

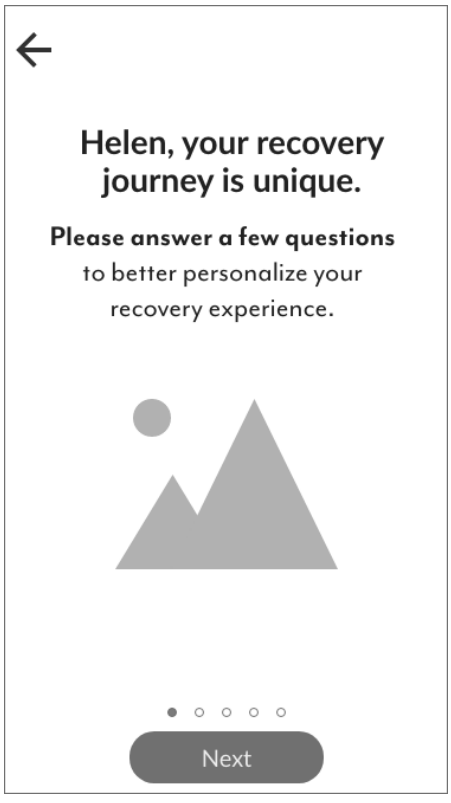


Figure 25. Questions prompt.

Figure 26. Questions screen 1/4.

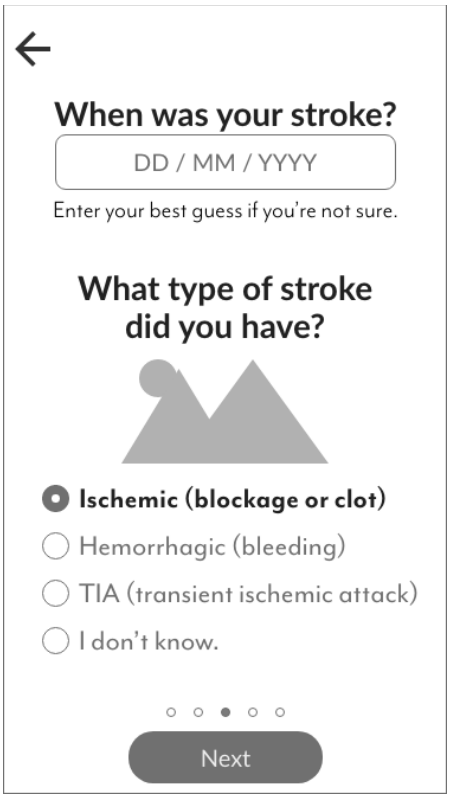


Figure 27. Questions screen 2/4.

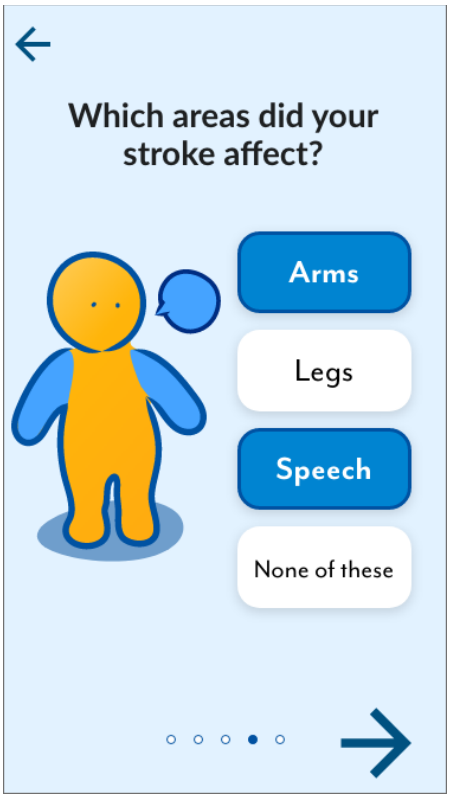


Figure 28. Questions screen 3/4.

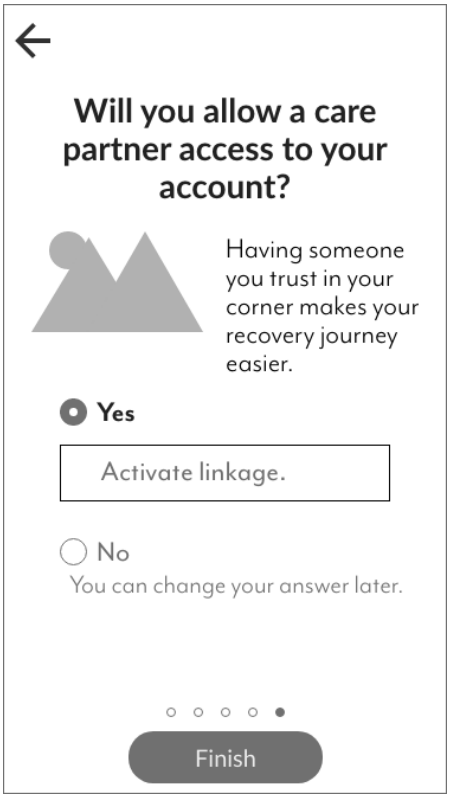


Figure 29. Questions screen 4/4.

Figure 30. Loading screen.

3. Recording physical and emotional symptoms on a regular basis: Daily Check-in

The purpose of Daily Check-in is for patients to log stroke-related physical and emotional symptoms each day. First-time users and returning users opening the app for the first time on any given day are presented with the screen to begin Daily Check-in by tapping a large icon (Figure 31). The user is asked to rate their general well-being using a 5-point Likert scale from "very bad" to "very good," with accompanying smiley faces (Figures 32-33). They are then asked to report current symptoms of numbness, weakness, or pain; more than one selection can be made (Figure 34). In the example prototyped, only weakness is reported (Figure 35). The user then marks affected body regions, by tapping either the written description or the illustrated figure; and rates the severity of weakness experienced for each region (Figures 36-39). In the prototyped examples, the patient reports moderate weakness in their right arm. If either pain or numbness were also reported, the patient would repeat the procedure to report affected regions and severity for those symptoms. The last screen for check-in provides the user the opportunity to report any additional stroke-related physical symptoms or emotions (Figure 40). Upon first-time completion of Daily Check-in, a "first Daily Check-in" badge is rewarded to motivate future engagement (Figure 41). Finally, the user is prompted to set a reminder to check-in daily, which would permit the app to send daily push notifications to the user's phone at a user-determined time (Figure 42).

While the user can cancel out of Daily Check-in at any time, it is displayed prior to the home screen once a day to strongly encourage user participation. If the user cancels, the opportunity to complete check-in will be made available on the home screen. Regular usage of this feature will allow patients and their carers to monitor changes over time and share subjective data with their providers during follow-up. The more detailed symptom information also expands upon the basic information collected from the first-user initial questionnaire to increase the level of content personalization.

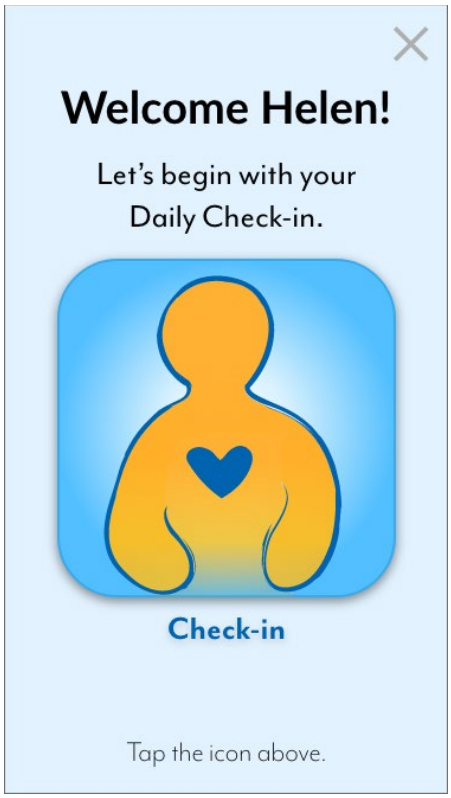


Figure 31. Daily Check-in prompt.

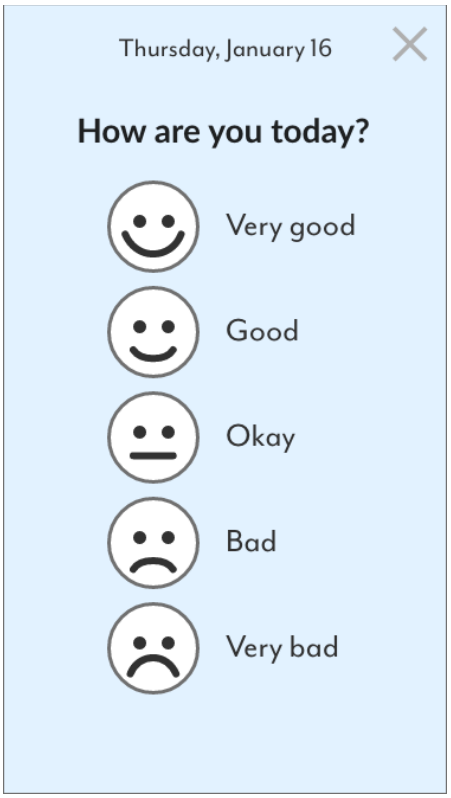


Figure 32. Well-being question.

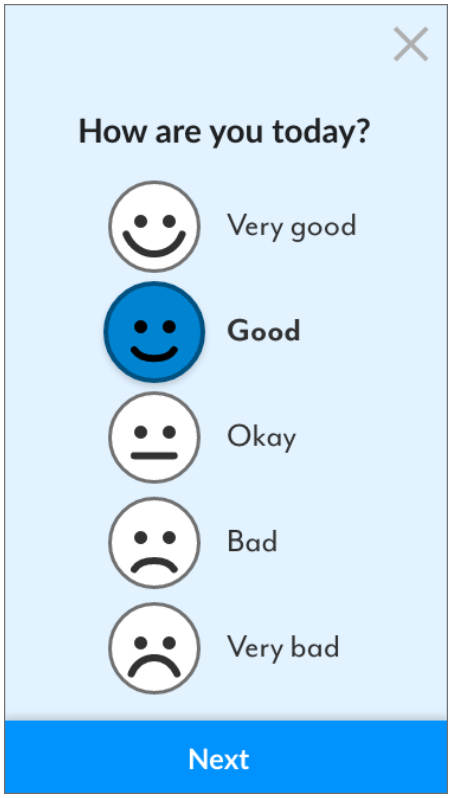


Figure 33. Well-being answer.

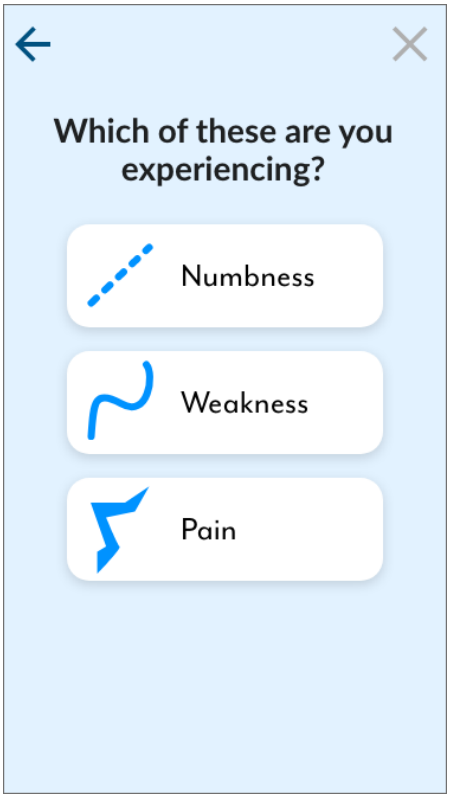


Figure 34. Symptoms question.

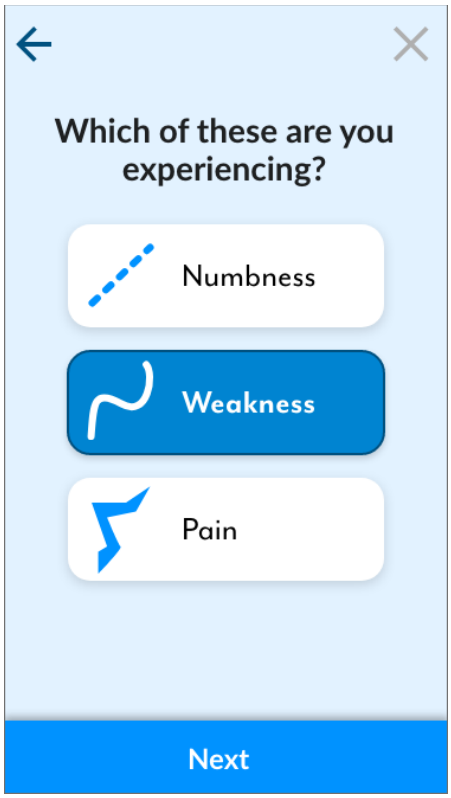


Figure 35. Weakness reported.

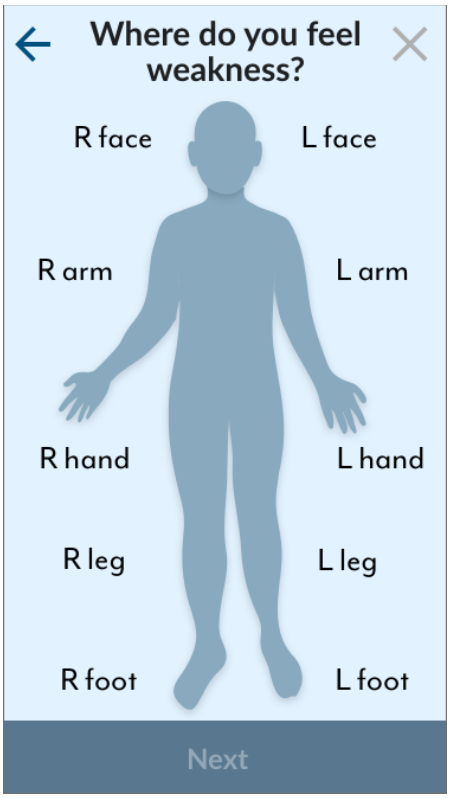


Figure 36. Mark weakness areas.

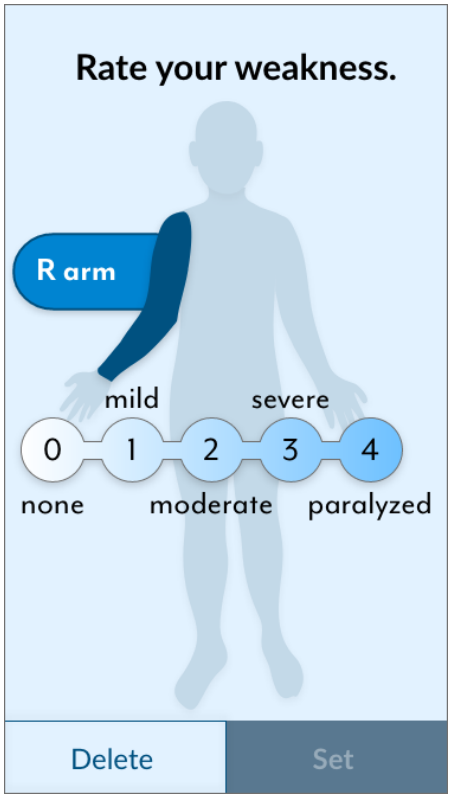


Figure 37. Right arm marked weak.

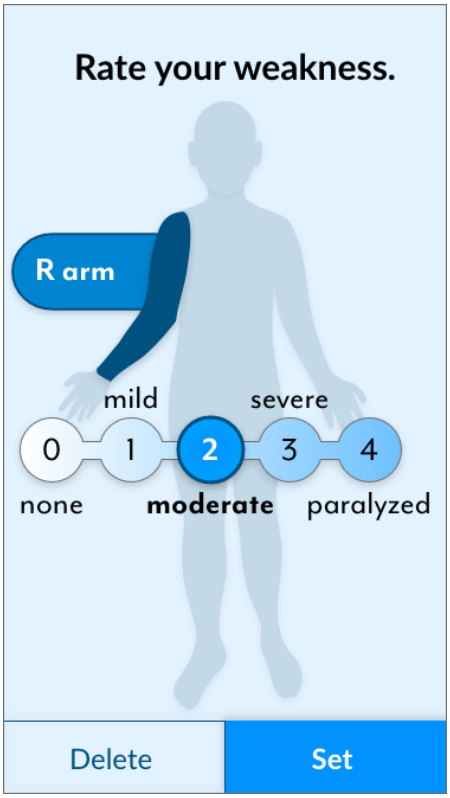


Figure 38. Weakness rated moderate.

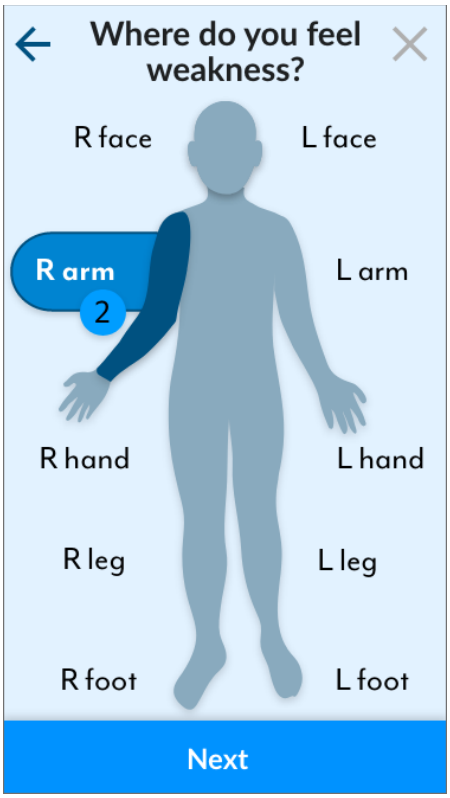


Figure 39. Review weakness areas.

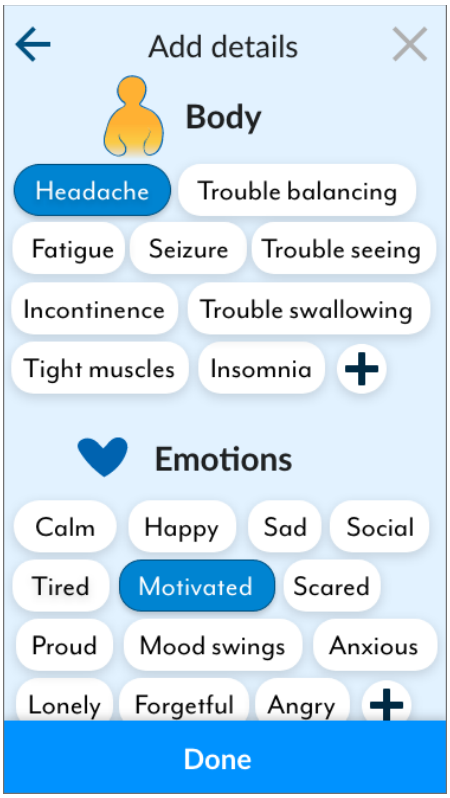


Figure 40. Add additional details.

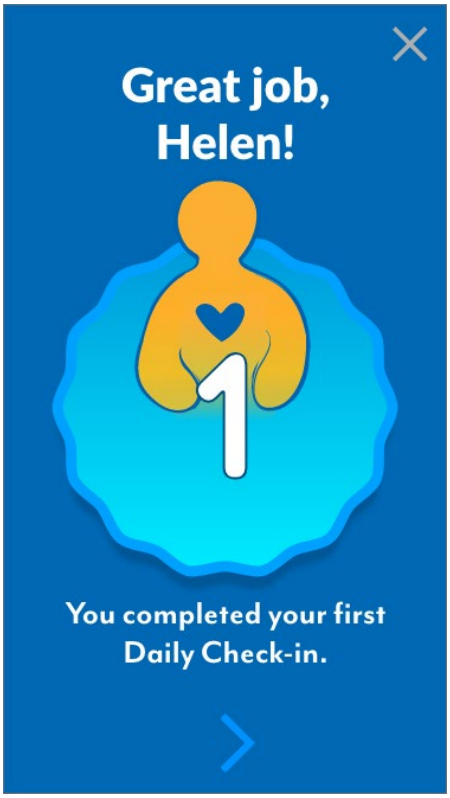


Figure 41. Motivational badge.

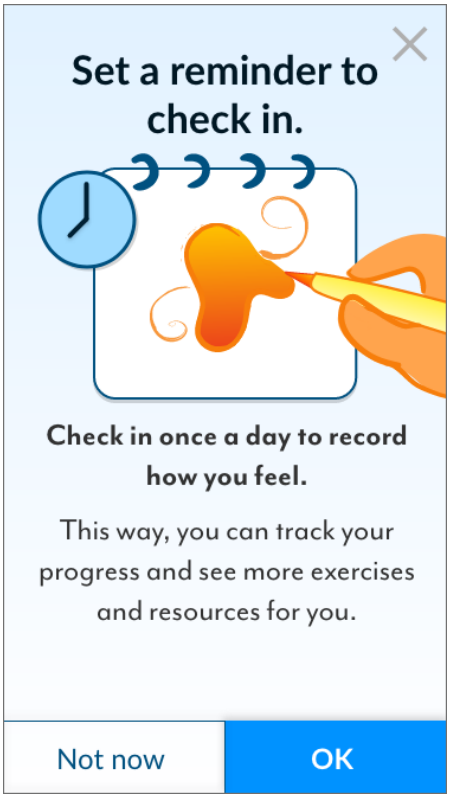
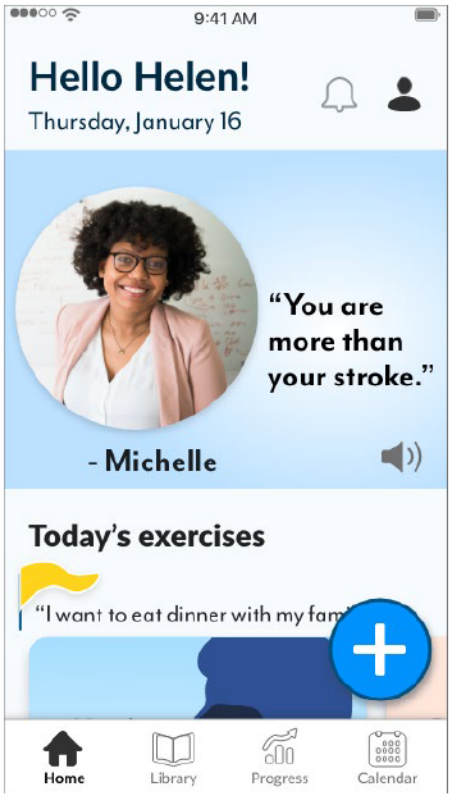


Figure 42. Set check-in reminder.

4. Accessing bite-sized, personalized content: Home

After declining or completing Daily-Check in, the user reaches the *Home* screen (Figures 43-46). *Home* serves as the central hub that provides users bite-sized, personalized information. At the top of the screen, the user is greeted by name and the date is displayed. At the bottom of the screen, the tab bar is a permanent fixture that provides global navigation to all app components: *Home, Library, Progress,* and *Calendar.* The *Home* icon, represented by a house, is filled to indicate current location. The *Log* button, indicated by a blue circle with a white cross inside, remains on the bottom right corner of the *Home* screen, regardless of scrolling by the user. The notification feature, represented by the bell icon in the top right corner, allows easy retrieval of self- reminders, user-saved questions, and information about upcoming appointments. User information including stored Q&A, notes, and privacy and notification settings can be accessed in *Profile*, by tapping on the human icon to the right of the notification bell.

The first block of content displays a motivational quote from a stroke survivor, accompanied by the photo of an individual representing the survivor (Figure 43). The second block of content displays three personalized daily exercises, with a corresponding user-entered "big goal" listed above each exercise, and a counter below, indicating the number of completed daily exercises, or metaphorical "steps taken." (Figure 44). The third block of content displays three personalized learning topics, with a similar counter indicating the number of topics reviewed, or metaphorical "stars read". (Figure 45). The fourth block of content displays completed activities (Figure 46). The purpose of infusing encouraging and positive content throughout the *Home* screen is to motivate the user to engage as much as possible with the provided educational content and self-care activities.



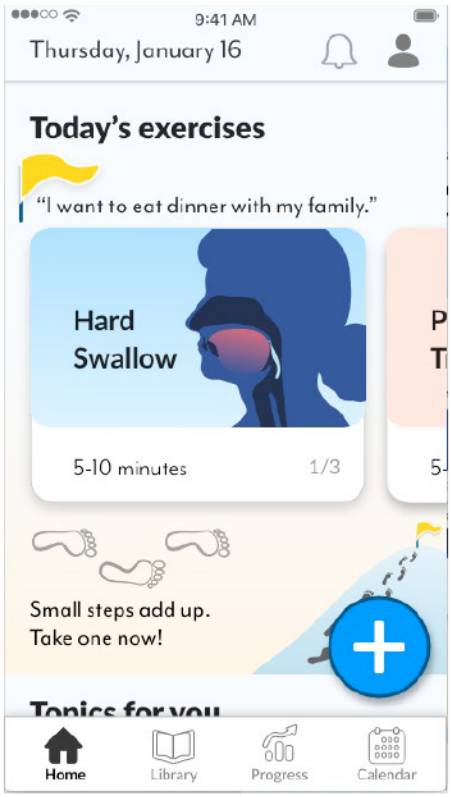
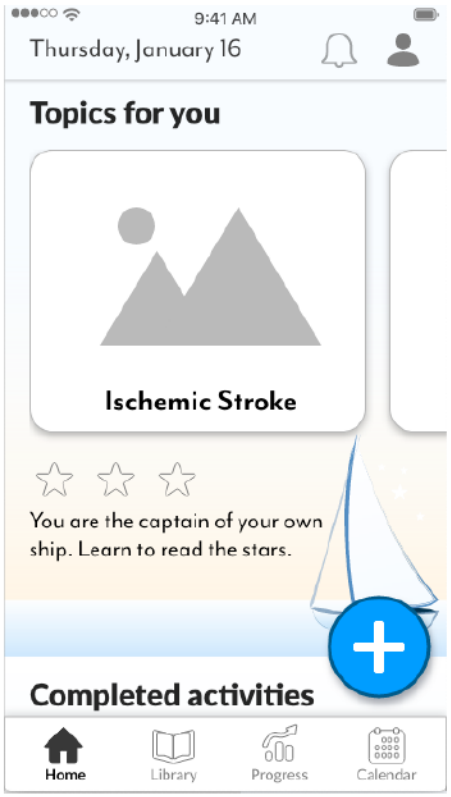


Figure 43. Home: Motivational quote. Figure 44. Home: Daily exercises.



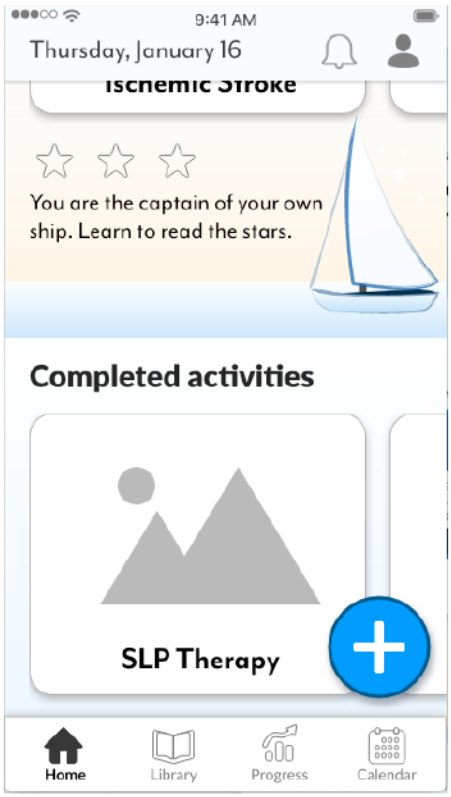


Figure 45. Home: Daily learning. Figure 46. Home: Completed activities.

5. Recording an appointment, note, question, test, or goal: Logging

The log feature is easily accessible from the *Home* for the user to record an appointment, note, question, test, or goal, as shown in Figure 47. If the user has completed Daily Check-in for the day, tapping the large icon for Daily Check-in will display a summary of their previous entry that can be viewed or edited (Figure 48). If the user has not completed Daily Check-in, they will be prompted to do so by tapping the same large icon.

Log is a vital feature of the app that contributes to several enabling objectives. The capability to log questions augments two-way communication between patient and provider. Suggested questions for patients and their carers to ask members of their care team before leaving the hospital can be browsed and saved for convenient retrieval from Notifications on the *Home* screen when the time is right. Patients can choose to dismiss the question when satisfied or append and save answers to questions in text form. Having an organized list of suggested questions cues patients on what information they should obtain from their providers, helps patients make the most of their care team's expertise, and reduces reliance on memory for asking questions and remembering answers.

The capability for patients to set "big goals" may help motivate patients to take charge of their own recovery. Setting a big goal, like "Walk my daughter down the aisle," can fuel a patient's self-initiative to regularly perform small enabling goals, such as toe taps or balancing exercises. Patients can share documented goals with therapists, to enhance shared communication and planning. Recording of appointments, tests, and notes empowers the patients to document and contextualize their early post-stroke experience.

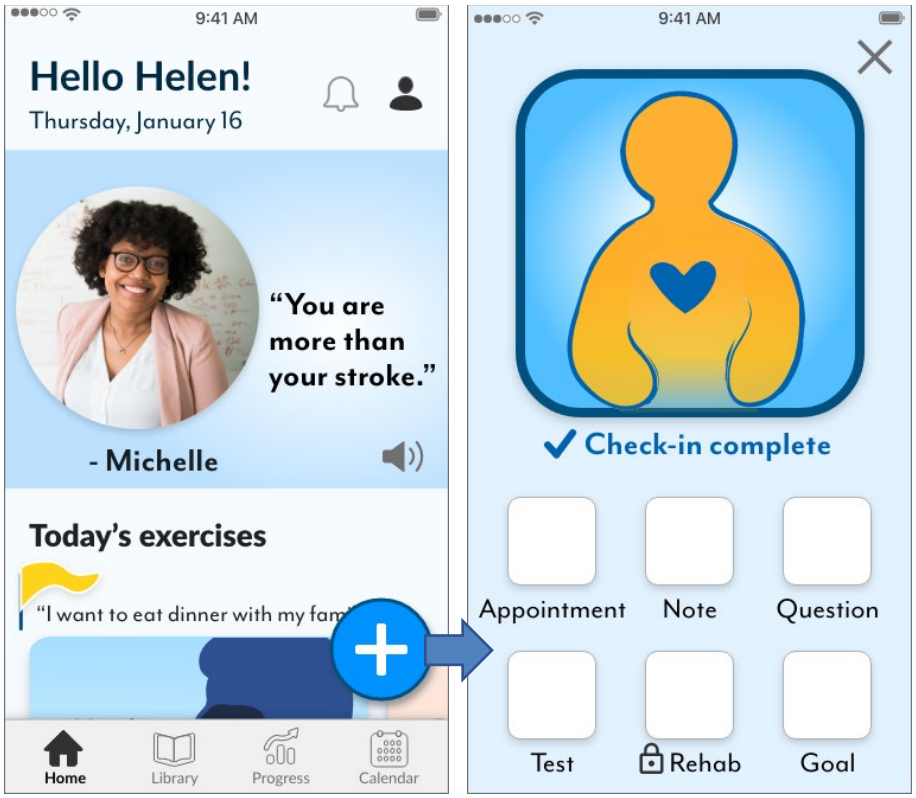


Figure 47. Accessing *Log* from the *Home* screen. Tapping triggers the transition indicated.

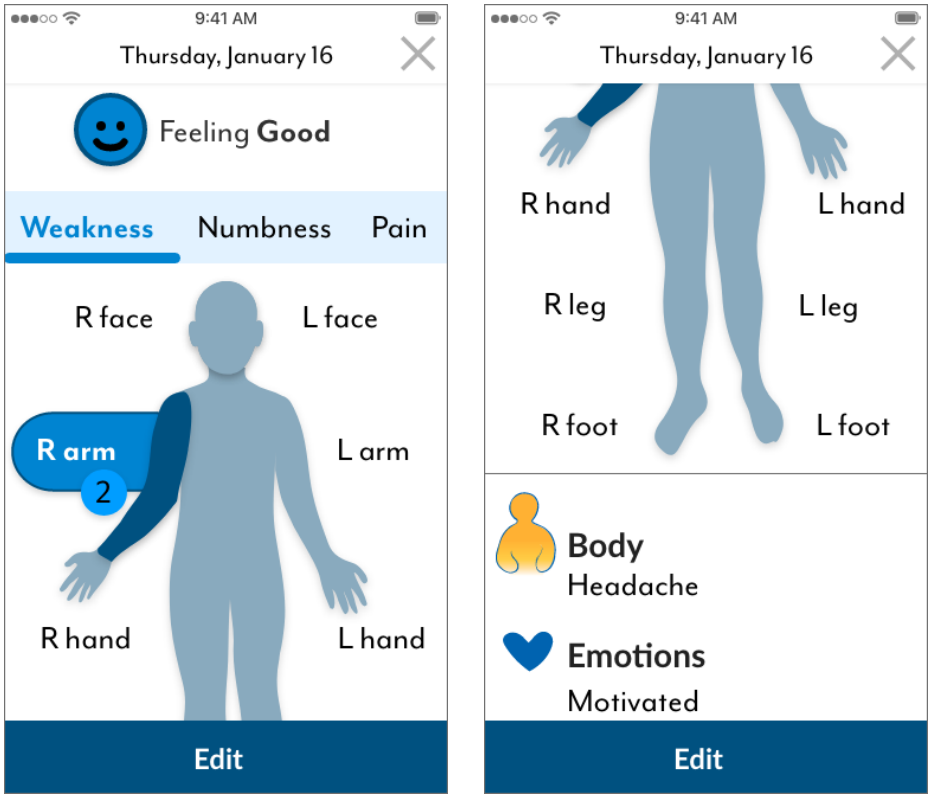


Figure 48. Completed Daily Check-in. Single prototype is split in two for improved viewability.

6. SLP recording current and goal levels for patient with dysphagia: Rehab Session

The logging function "Rehab" was designed specifically for therapist-use, rather than patient-use. This feature allows therapists to securely document session activities and time-based goals for patients in a patient-accessible format; and to schedule daily exercises for patients to perform. In the following prototyped scenario, the therapist is an SLP who records the first session with a patient who has oral dysphagia. "Rehab" is accessed from the log feature, with a lock icon to indicate restricted access for therapists only (Figure 49). This security feature prevents patients from self-documenting inaccurate information. The SLP selects "Speech-Language Therapy" as session type, provides basic contact information, and selects SLP focus areas for that specific patient's therapy (Figures 50-52). In this case, "oral dysphagia" is indicated by the therapist.

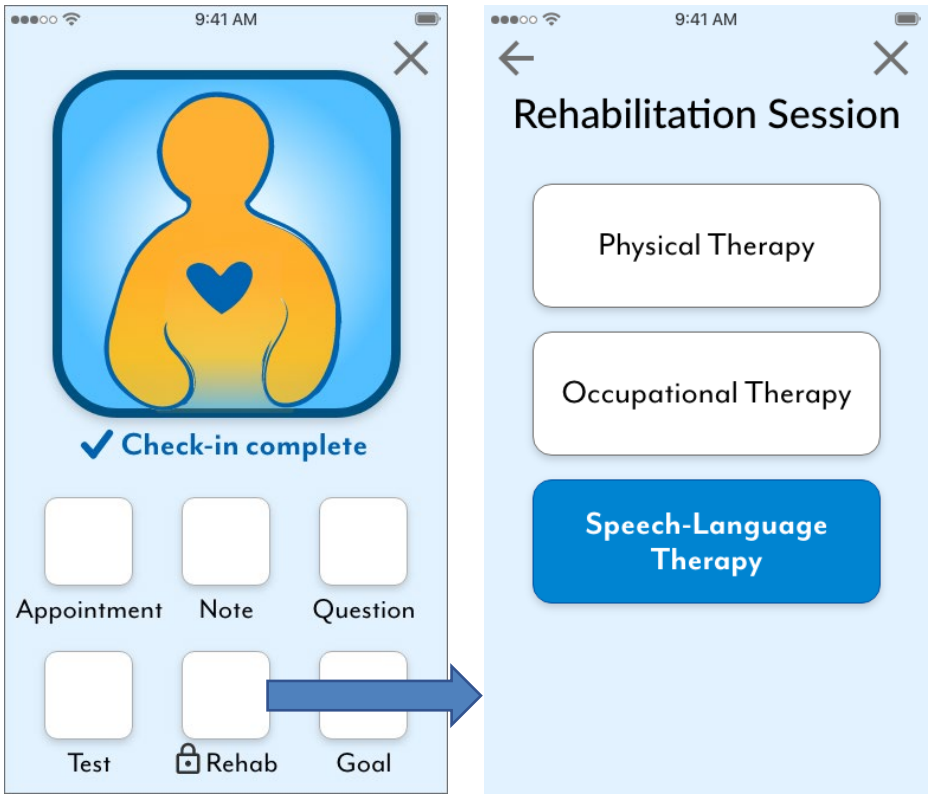


Figure 49. Logging rehabilitation session. Tapping triggers the transition indicated by the blue arrow.

Figure 50. SLP entry of personal info.

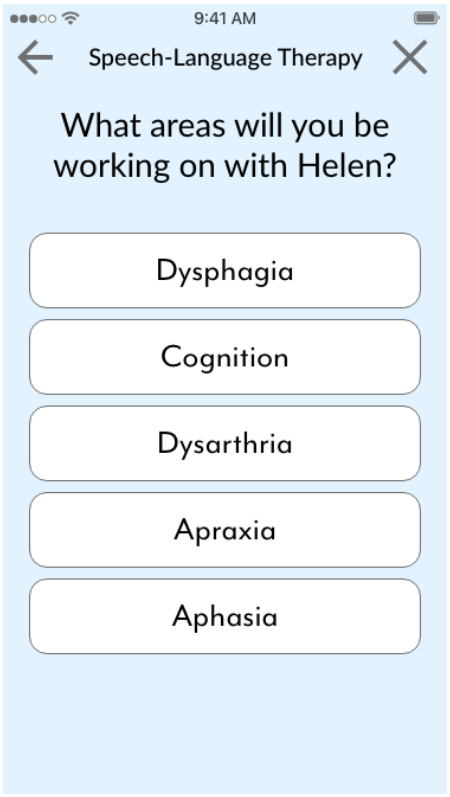


Figure 51. SLP focus area selections.

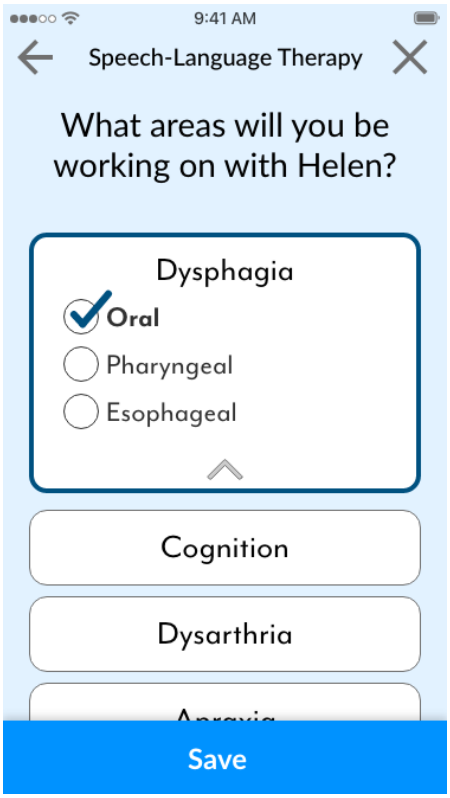


Figure 52. SLP entry of oral dysphagia.

In subsequent screens for documentation of session goals and activities, the therapist-indicated focus areas can be conveniently toggled between using a drop-down menu. Dysphagia was used as the example focus area. The content pertaining to therapy goals and activities for dysphagia was derived from the literature search, inquiry and discussion with an SLP, and analysis of example SLP documentation into patient the Electronic Health Record.

The SLP enters the patient's current and goal levels pertaining to food and drink intake, and performance of swallowing exercises. An example entry for current food intake ability was prototyped (Figure 53). The best possible recovery outcome is for the patient to be able to independently consume regular foods with no signs or symptoms of aspiration. Patients with dysphagia require professional SLP evaluation and guidance to set appropriate incremental goals for improvement. Patients with severe dysphagia who are initially unable to take any food by mouth require a feeding tube. In this case, the SLP would record the current food level as "0- None by mouth." Patients with mild to moderate dysphagia are unable to safely consume regular foods, but may be able to tolerate a narrower, less challenging range of food consistencies. The easiest level is "1- Puree," which includes foods with smooth, uniform consistency, such as apple sauce. For each increasingly challenging food consistency, from levels 1 through 4, the SLP enters the amount of food that is currently tolerated in one sitting, along with the corresponding level of supervision or assistance required during meals. Assistive strategies, such as taking small bites or performing a tongue sweep, may be used while eating to decrease the chance of choking or aspiration. The SLP can add from a preset list, any appropriate assistive strategies that should be used by the patient during consumption of certain foods.

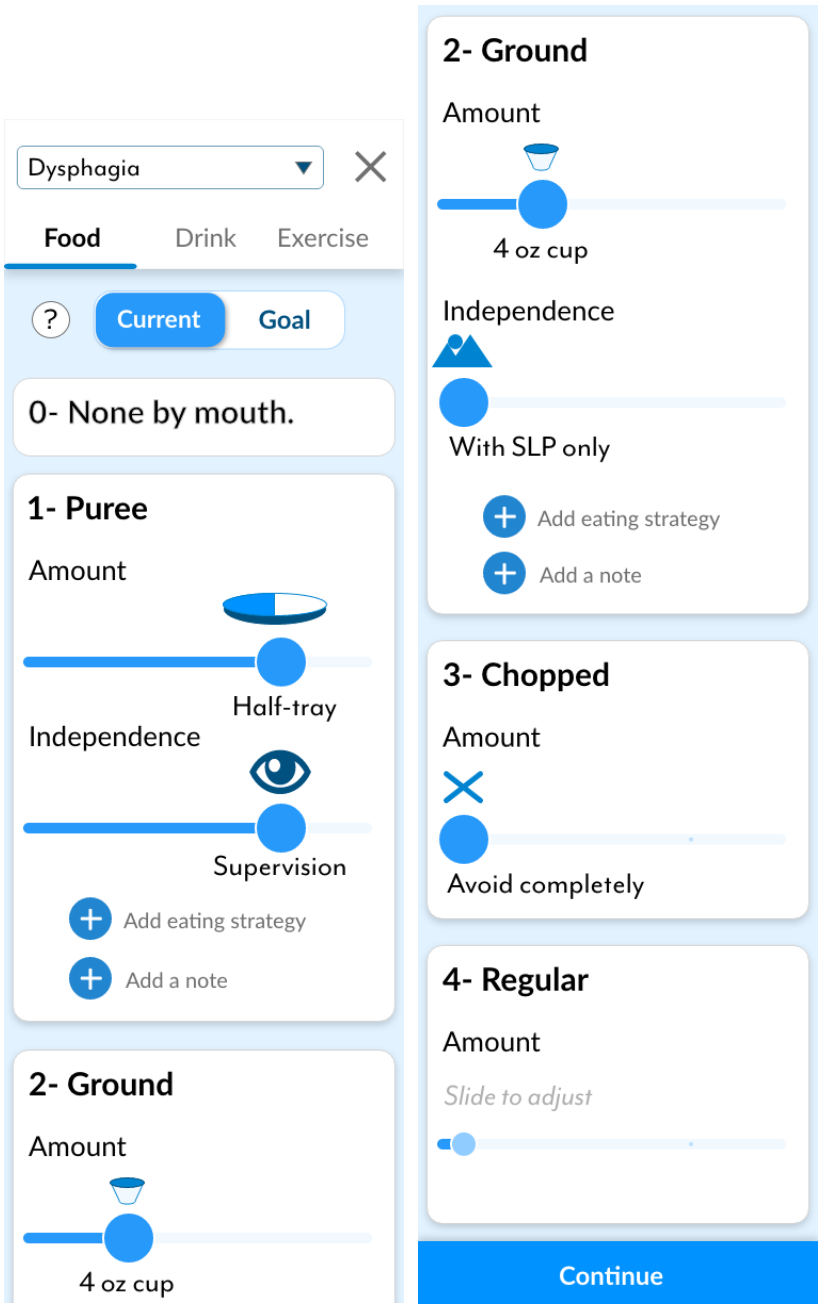


Figure 53. SLP entry for current food intake ability of a patient with dysphagia. Single prototype is split in two for improved viewability.

After documenting current food intake ability, the SLP assigns "Goal" levels for the patient to achieve by specific target dates, using an entry screen paralleling the prototyped "Current" level entry screen. The completed entry is viewable by the patient under "Completed

activities" on the *Home* screen and is securely stored for future retrieval in *Calendar*. Figure 54 shows in lower fidelity prototypes how the information might be presented to patients.

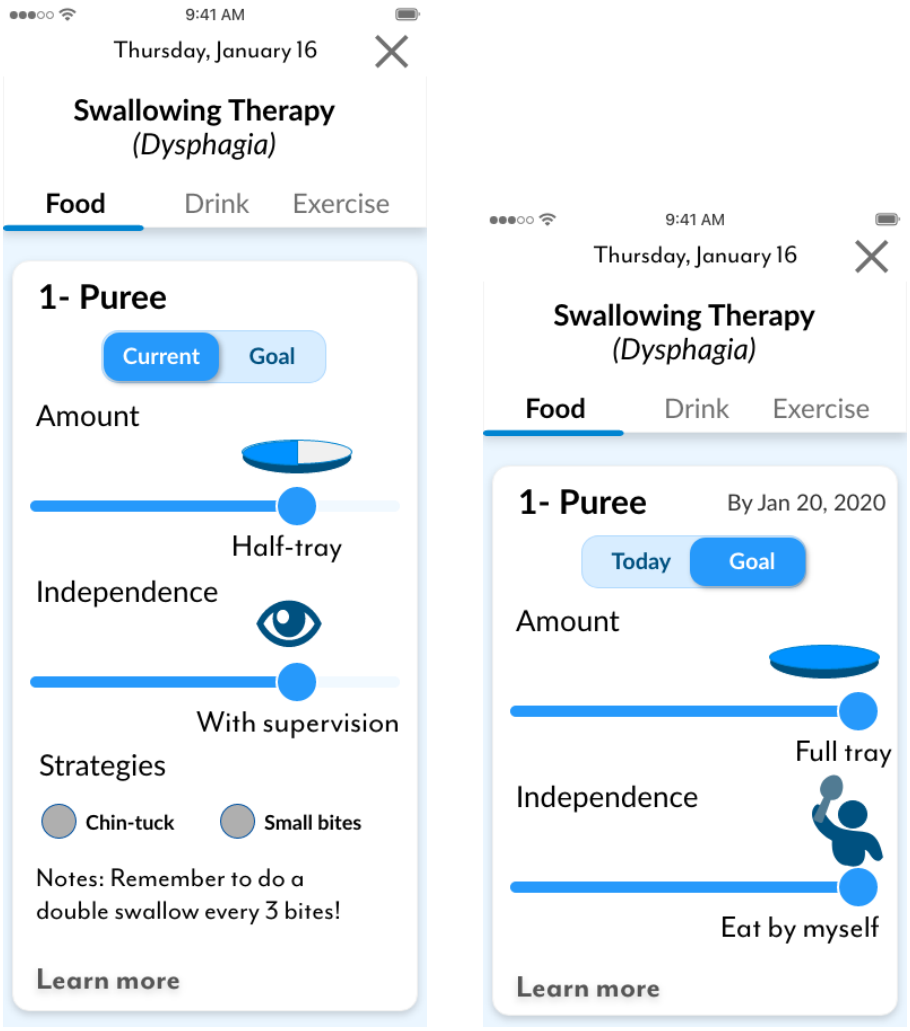


Figure 54. Patient view of recorded swallowing therapy session. Current (left) and goal (right) food levels are shown, set for Level 1 consistency- Puree.

7. Looking for more information and recovery activities: Library

Library is the central storage location for all learning modules. The process of personalization pulls learning modules most relevant to the user into their daily feed in *Home*. Patients looking for more information about topics not displayed in *Home* can visit the *Library*. *Library* was designed for patients to locate desired information as quickly and conveniently as possible. The user can choose to find information by searching, filtering by category, or simply

scrolling through “All” available content (Figure 55). Content navigation is optimized by using tiered organization (Figure 56). Content is organized most broadly under three areas: “Essential,” “Rehabilitation,” and “Prevention.” Under the broad area of “Rehabilitation,” modules are grouped into more specific groups: “Your Focus Areas,” “Strength & Mobility,” “Thinking & Language,” “Emotions,” and “Sensations.”

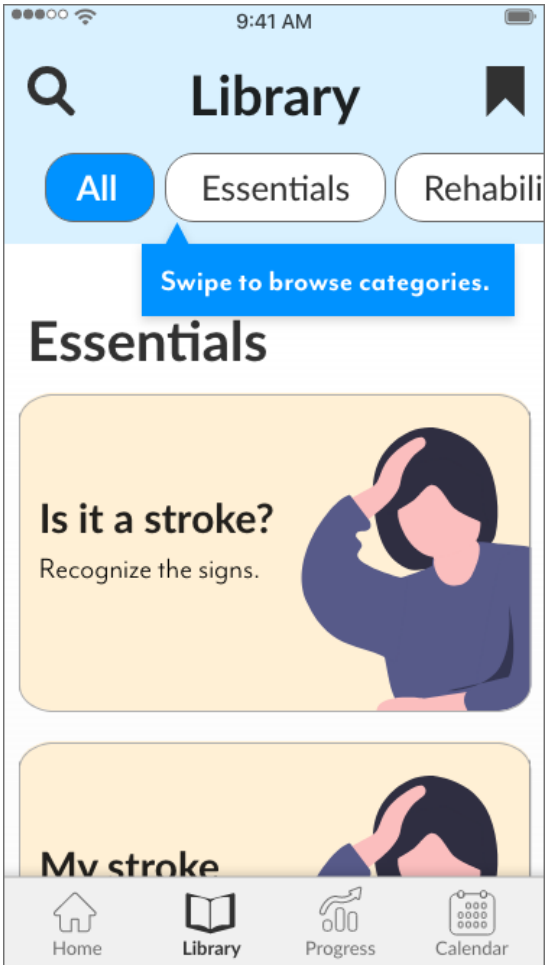


Figure 55. Multiple navigation options in Library. Default setting on “All” enables users to see all modules by scrolling. Note search icon in top left corner and swipe-able categories at the top of the screen.

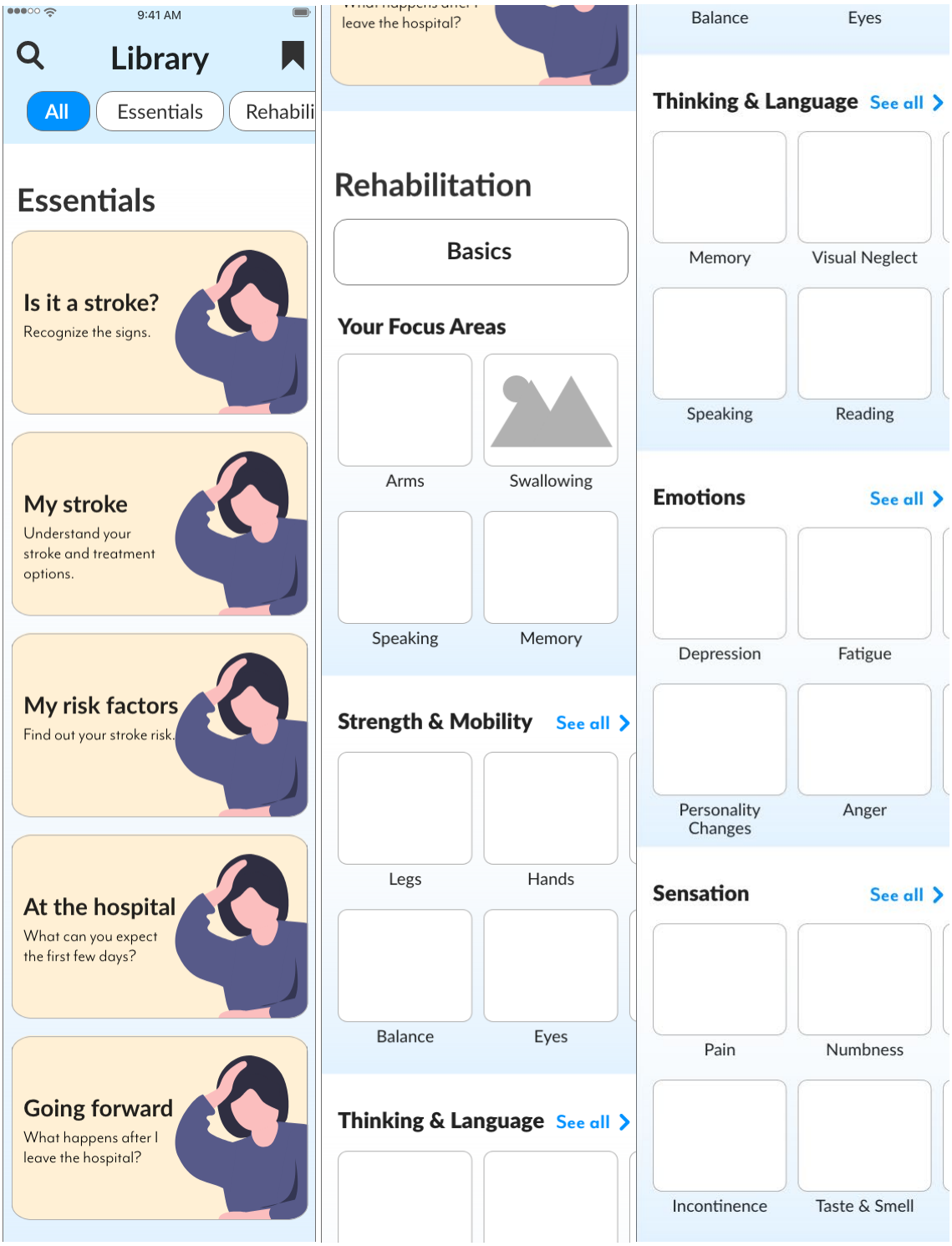


Figure 56. Tiered organization of content within *Library*. Default setting on "All" enables users to see all modules by scrolling. Information hierarchy is applied to organize modules from a broad to narrow focus. Single prototype is split into thirds for improved viewability in this figure.

Within “Rehabilitation,” an introductory trailer “Basics” explains to patients how rehabilitation works, as suggested by the low-fidelity prototype in Figure 57. Modules within “Your Focus Areas” are personalized based on patient and therapist-entered information.

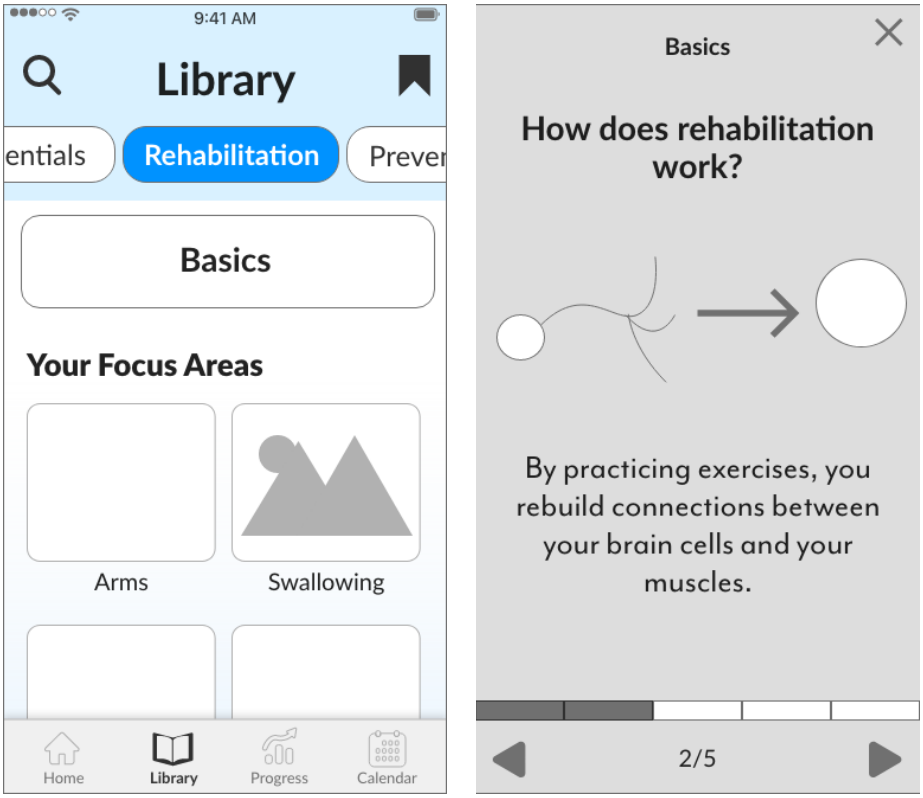


Figure 57. “Rehabilitation Basics” introductory trailer. Tapping the module “Basics” in the left screen opens an introductory trailer that explains broadly what rehabilitation is and how it works.

Seen in Figure 58, the swallowing module was prototyped as an example learning module opened for the first time within “Rehabilitation: Your Focus Areas.” The swallowing module organizes content into three blocks that address the following sequence of questions a patient in rehabilitation therapy might find themselves asking:

1) **Essential information:** “Where do I stand currently?”
2) **Big goal:** “Where do I want to go?”
3) **Small goals:** “How do I get there?”

At the top of the screen is **essential information** that defines dysphagia and emphasizes the importance of swallowing rehabilitation. Below essential information is a prompt to **set a big goal,** which functions to bridge small goals and nuanced care instructions to a personal, tangible motivator. Below the big goal prompt, a library of exercises and learning topics, representing **small goals** are provided in a swipe card at the bottom of the screen. Learning topics may include dysphagia diets, importance of oral hygiene, and safe eating and drinking strategies.

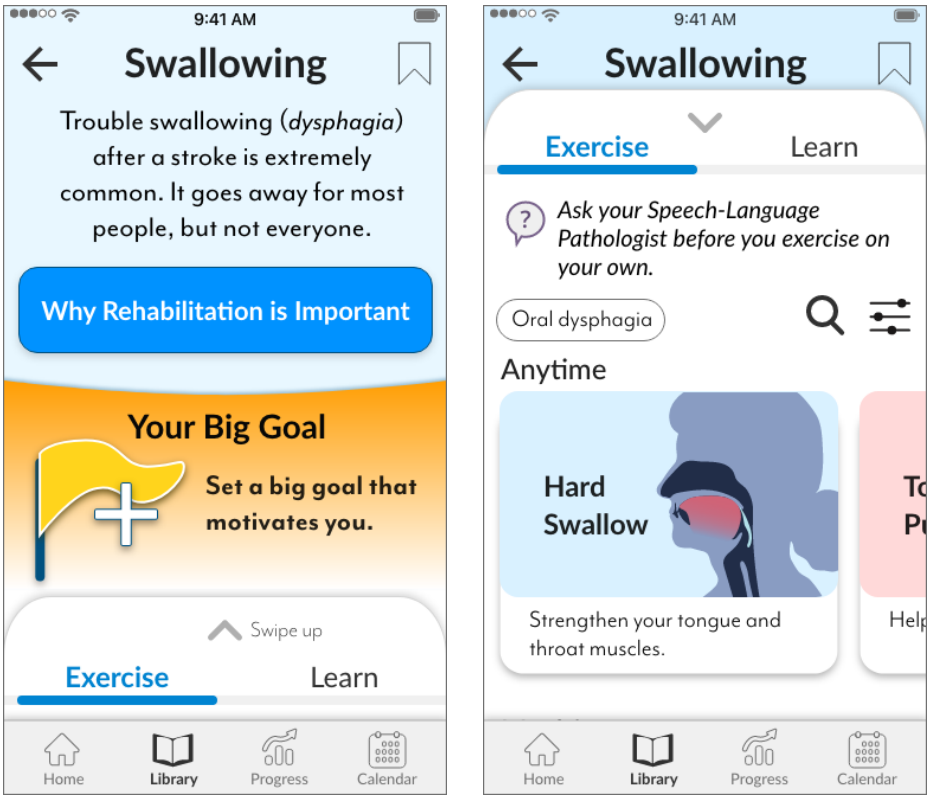
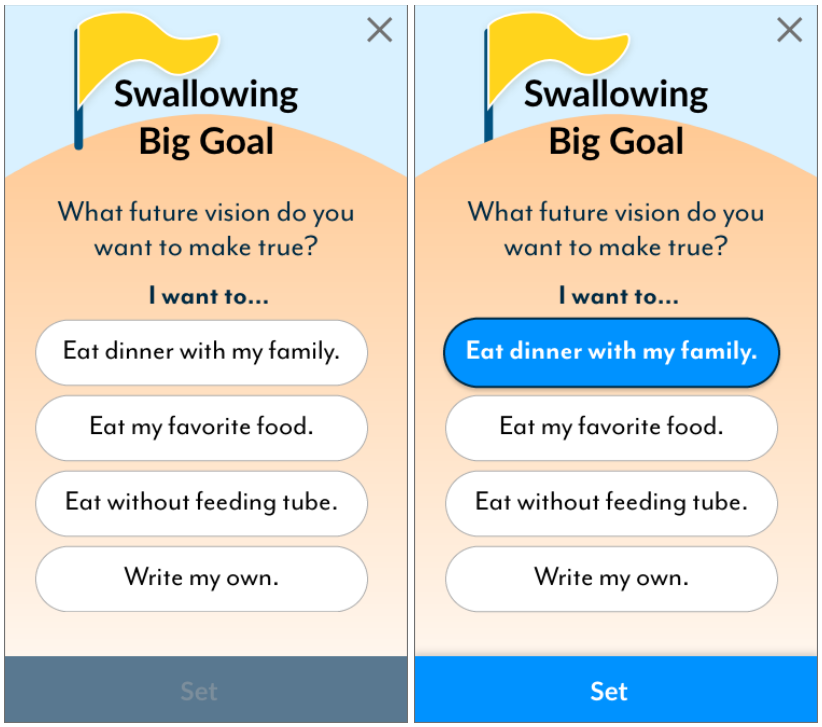
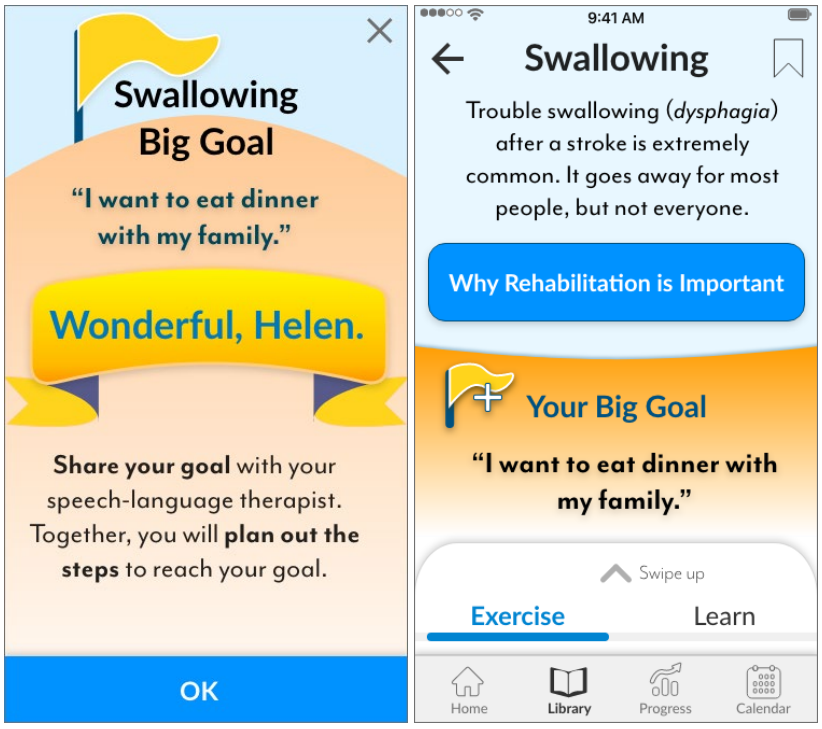


Figure 58. Example "Swallowing" learning module for first-time use. Left screen shows use of information hierarchy, with essential information about dysphagia and swallowing rehab at the top, prompt to set a big goal in the middle, and exercises and learning content in a tucked card at the bottom. Right screen shows card swiped open.

An example of a patient setting a big goal for swallowing was prototyped (Figure 59). The patient is encouraged to share their goal with their SLP to facilitate communication. The redundancy of this goal-setting feature in *Log* and *Library* increases the probability of user engagement.



A B



C D

Figure 59. Patient sets a big goal for swallowing. User selects from preset options or writes their own goal (A-B). The user receives positive feedback after goal-setting (C) and the new goal is added to the swallowing module screen (D).

The design goal of *Library* is to make the patient or carer's experience of finding specific, relevant resources (eg. More swallowing exercises) as smooth and efficient as possible. An organized directory for existing stroke survivor resources within *Library* may be a valuable addition. The swallowing module prototype was designed with the patient perspective in mind, to improve patient engagement with learning modules and recovery activities. Together, the *Library* prototypes provide a design template that can be evaluated by patients for usability and teaching efficacy.

Information Architecture and Progressive Personalization

The initial *information architectur*e was revised and refined to contextualize the numerous individual prototypes and key tasks in relation to each other and illustrate their universal connectivity. This second iteration of the flowchart (Figure 60) serves as a map that demonstrates how the app functions as a unified, multi-functional stroke recovery resource. Because personalization was a central feature of the app, a supplemental diagram showing progressive personalization was constructed to expound upon the concept. This diagram has been appended to the top of the flowchart to synthesize, summarize, and highlight key processes that contribute to personalization.

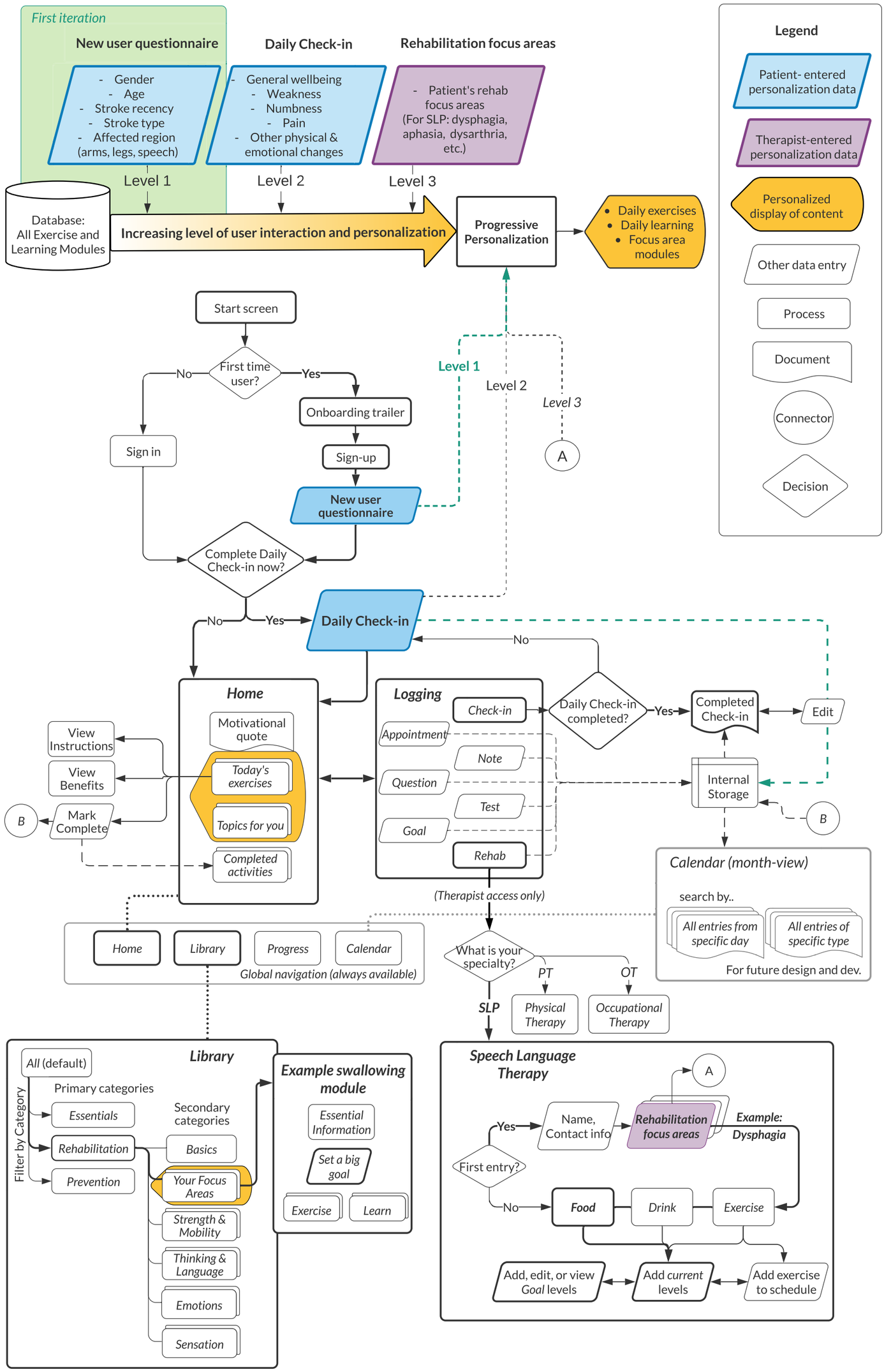


Figure 60. Second iteration of information architecture flowchart with progressive personalization diagram.

The database of "all learning and exercise modules" represents a vast repository of all educational content that is potentially stored in the app. Personalization is the process of sorting and prioritizing information from this database to match patients with information most relevant to their currently experienced needs. Three successive entry points of information are indicated: New user questionnaire, Daily Check-in, and Rehabilitation session. At each entry point, increasingly patient-specific information is entered, providing the substance for curating increasingly patient-specific content. Personalized content is displayed in prominent locations within the app, including daily exercises and learning modules in the *Home* screen (Figures 44-45) and focus area modules within *Library: Rehabilitation* (Figure 55). This progressive model is user-centered, as it empowers the patient to drive the level of personalization experienced. It also incentivizes patients to regularly interact with the app, by updating displayed content in response to changing need. For example, if a patient reports a new symptom in Daily Check-in, a module about pain management may be displayed on their *Home* screen, and included in "Your focus areas" within the *Library: Rehabilitation.*

The larger information architecture flowchart can be read as a map that shows how a user can navigate the app and use its various functions and features. Prototyped tasks and paths are outlined in bold. Beginning from the start screen, the first-time user's path through onboarding trailers, sign-up, and the new user questionnaire (level 1 personalization) is shown. (See Figures 18-23.) Both first-time and returning users are then presented with the option to complete Daily Check-in (level 2 personalization) prior to arriving at the *Home* scree. The path for a user who agrees to do so was digitally prototyped. (See Figures 31-40.) Information from the completed Check-in is moved into the app's internal storage. Once the user is in the *Home* screen, navigation is fully directed by user choice. The user can immediately interact with personalized modules within *Home; Log* a question, note, test, appointment, or goal; complete, view, or edit Daily Check-in; or visit *Library, Progress,* or *Calendar,* which are globally navigable. Within *Library,*

the tiered organization of content designed in prototypes is notated by “categories.” (See Figure 56). The hierarchy guides the user to the specific learning module they seek; the *Swallowing* module for dysphagia was prototyped as an example (Figure 58). The path taken by a Speech Language Pathologist for entry of a patient’s rehabilitation focus areas (level 3 personalization), and recording of session goals and activities is detailed, using dysphagia as an example. (See Figures 50-53.)

The inclusion of “internal storage" indicates that all entered information is designed to be stored within the app rather than cloud-based. It also highlights the flow of information to communicate that stored data must be retrievable and displayed back to patients and providers in a meaningful way. *Progress* and *Calendar* features were included during early design stages to serve this output function. Concept design for these two features was initiated, but were deprioritized for prototyping during identification of key tasks. The purpose of *Calendar* is to provide users access to view and share previously entered activities, with no additional data processing. The purpose of *Progress* is to provide users with meaningful analyses of previously entered information, such as symptom trending or goal progression. Motivational elements such as accumulated streaks and badges are also located here.

The information architecture flowchart and progressive personalization diagram were used by the team to define a minimum viable product (MVP) for the first iteration of the app development, highlighted in green. The MVP will include the first level of personalization, generated from patient data entered through the first user questionnaire. Daily Check-in will be developed to collect measurable recovery data stored in the app internally but will not be used for personalization at this time. These assets provide guidance and foresight for future app development.

Asset Referral Information

The assets from this thesis can be viewed through the website for the Department of Art as Applied to Medicine at Johns Hopkins University School of Medicine: https://medicalart.johnshopkins.edu. The author can be contacted through the departmental website or at htangbioviz.com.

DISCUSSION

Project Objectives and Scope

Stroke is a culmination of numerous comorbid health conditions that leads to an immediate change in neurological function. The purpose of the project was to design a digital health platform that improves upon current hospital-based stroke education to better prepare patients for their transition from hospital to home after stroke. Because full design and development of the ideal, personalized app requires substantial time and funding, the predefined scope of this thesis project was to (i) design the overall structure and organization of the app and (ii) prototype specific paths that would demonstrate its key components and functionalities. To this end, flowcharts of information architecture and digital prototypes of key app functions and components were created. Additionally, a conceptual diagram conveying a strategy for progressive personalization was constructed.

These results are not a finalized solution, but rather a set of intermediary assets that were founded and iteratively evolved based on principles of user-centered design. Together, these assets provided the app developer with a concrete blueprint for building the first iteration of a minimum viable product (MVP). In addition to directly contributing to the development phase, the assets function as visual communication tools for stakeholders to continue collaborating, ideating, and establishing a shared future vision for the app.

Progressive Personalization in the App

Personalization was identified as the key strategy for providing patients with specific, relevant information regarding their condition and recovery plan. The process of personalization requires input of patient-specific information in order to generate the patient-relevant output. Receiving information that the patient perceives as most relevant to their self-care may yield

better results in the education process. A conceptual model for progressive personalization was designed to propose that increasing levels of user interaction with the app should lead to an increasingly personalized experience. In this model, a baseline level of personalization is provided to all users, who must complete the initial questionnaire to sign up. Above this baseline, the degree of personalization is driven by user actions that reflect their self-determined needs and interests. This patient-centered approach empowers patients to take an active learning role and respects their learning preferences and expressed needs.

The diagram for this progressive personalization informed discussions for immediate and future development plans for the app. Implementation of progressive personalization will begin in phase two of this project, beyond the scope of this thesis. However, prototypes were developed that visually demonstrate key screens for patient information input to communicate this concept of personalization during that phase of development. This model puts forth a strategy for personalization that will help to structure and direct future design and expansion of the app, as additional content is incorporated.

Role of Collaboration, Testing, and Iteration for User-Centered Design

Designing a patient-centered app that successfully achieves its objectives necessitates regular input from all involved stakeholders throughout the process. In this project, I had the opportunity to observe the care team, interact with the multidisciplinary specialists, and interview patients about their perceived needs in real time within the hospital setting. Defining the initial scope required an understanding of the needs and goals of both the primary users (patients and their carers) and secondary users (healthcare providers). Inquiry and collaboration with providers involved in the continuum of stroke care supplied crucial context for narrowing and refining the scope of this project. Initial research, derived primarily from literature, revealed the broad array of challenges faced by stroke patients and their carers and potential impact of an app used at the

time of hospital discharge. From this broad, overarching perspective of the problem, a generalized, all-encompassing solution emerged as the first draft of information architecture. This version served as an excellent tool for inquiry and collaboration with stakeholders.

Active, ongoing communication with content experts drew out key details needed to sharpen understanding of the problem. For example, an initially identified problem was that patients with dysphagia were not performing swallowing exercises, either due to lack of understanding or lack of motivation. An initial solution was to create a visual tool for guided swallowing exercises that emphasized the benefits of performing them and provided integrated education. From additional inquiry, significant new insights were gained. Detailed care instructions for patients' dysphagia treatment plans are often lost after discharge. Care team therapists document patient-specific instructions, progress notes, and goals into the Electronic Health Record (EHR); but the information is sometimes not transferred to the patient's primary care provider or to their out-patient rehabilitation center. This knowledge gap was identified as a crucial problem for which a solution could be designed within a personalized recovery app.

As design refinement progressed, usability testing was essential for maintaining user-centeredness and exposing flawed assumptions. Consider the following case study, shown in Figure 61:

A common scenario after stroke includes patients experiencing dysphagia (difficulty swallowing), who are at heightened risk for the development of pneumonia, a life-threatening complication after stroke. The patient was envisioned to identify their swallowing difficulty and record specific details about their dysphagia using the app. However, the details of dysphagia are described in clinical terms ("oral," "pharyngeal," "esophageal"), and patients would likely need to rely on their SLP for this information. An action button "Import latest SLP findings" was designed as a shortcut to import detailed information previously logged by an SLP during therapy sessions. But regardless how prominent the button, in usability testing, it seemed invisible to

users, who proceeded to answer the question with their own best guess, using the "oral," "pharyngeal," or esophageal" options. This was evidence of illogical design. Because the information had all been previously imported, it would already be stored. In addition, users should not be asked questions they are not expected to know the answer to.

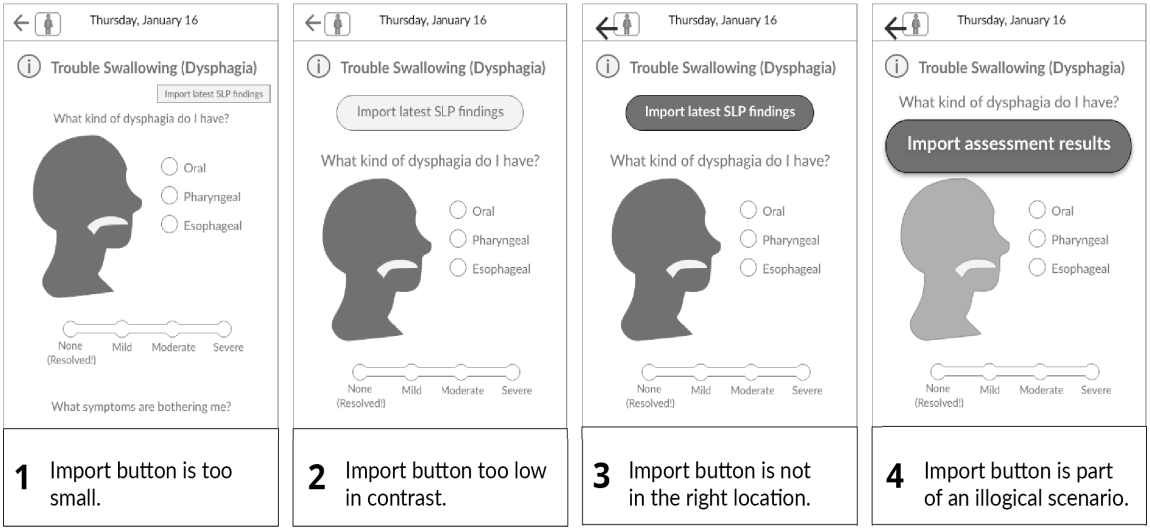


Figure 61. Usability testing revealing flawed design. Over four rounds of testing, the button to import the answer to the question, "What kind of dysphagia do I have?" was ignored. After many alterations in UI failed to elicit a change in user behavior, it became clear the underlying scenario was flawed. Some text not intended to be read.

Regular usability testing allowed mistakes to be exposed before they become incorporated into higher fidelity prototypes, saving valuable time and effort. The usability case study also clearly supports Garrett's (2010) arguments for using a bottom-to-top design approach (26). He explains how a bi-directional ripple effect constrains higher level decisions (like button design) to lower level decisions (like functionality). Decisions made at a higher level sometimes forces reevaluation of the decisions made at a lower level (Figure 62). This ripple effect keeps design solutions anchored to the foundational "strategy plane" at the bottom, which are defined by the goals and expectations of the user.

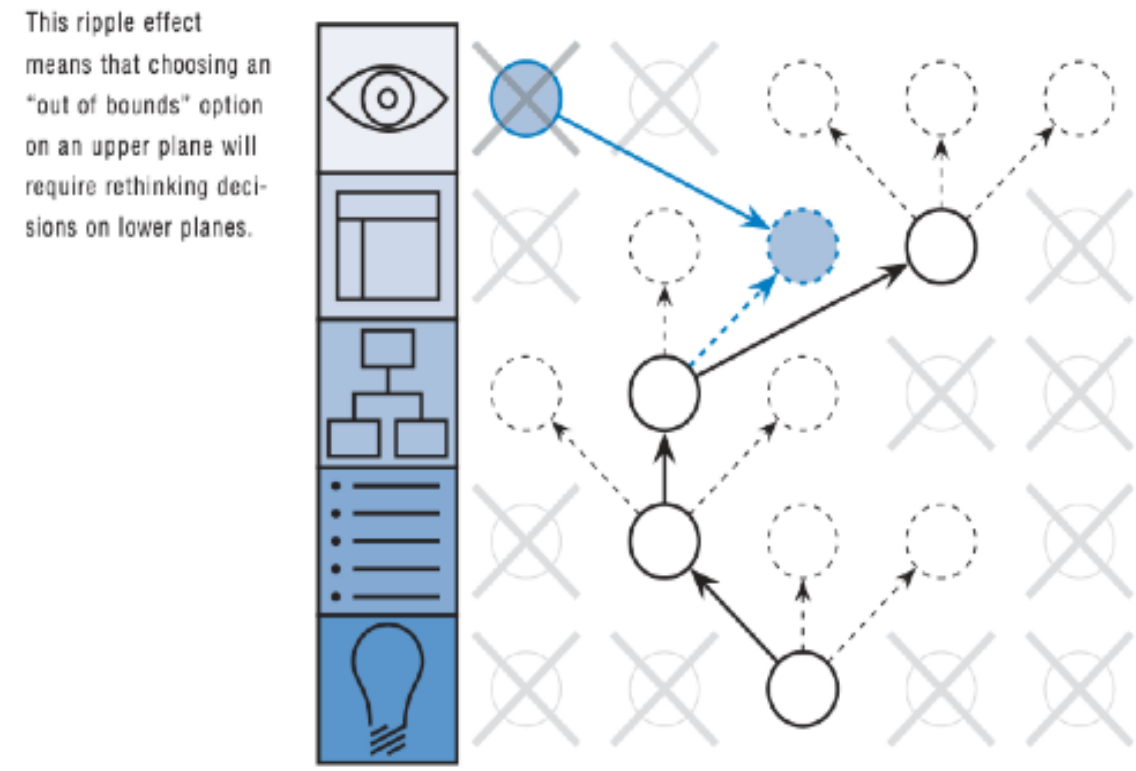


Figure 62. Bidirectional ripple effect of user-centered design. Figure from *Elements of User Experience* (Garrett 2010, 26).

Limitations

All primary goals of the thesis project were achieved. The thesis results provided the information architecture for the developer to code the minimal viable product. Additional time, funding, and human resources are required for additional iterations and implementation of the final designs. All prototypes are in active development and iteration processes; some identified key functions are not yet prototyped. Ideally, all end users of the app - patients and members of the multidisciplinary healthcare team - are involved throughout the design process. To date, usability testing has been conducted with volunteers who are serving as proxies for the patients until formal usability testing can be conducted with patients. Therapists actively working in the stroke center at JHH could not be extensively involved in stakeholder feedback due to the

demanding nature of their work schedules; thus, the majority of content was reviewed by select representatives of the multidisciplinary clinical team (neurologist, nurse, SLP, and student). Legal consideration such as HIPAA and copyright prevent immediate incorporation for some proposed design elements. For example, the suggestion for audio documentation of physicians' spoken answers to patient questions may require consideration of a consent process before proceeding. Usage of motivational quotes and photos from actual stroke survivors will require permission. The developed app will require review with the legal department to assure patient understanding that the app does not replace the recommendation of their health care provider.

Future Directions and Recommendations for the App

While there are limitations noted, this thesis work will serve as the foundation for the development of a patient centered app that has the potential to change the landscape of post-stroke education. The assets from this project are being used to move the app from design into development phase. The app developer's scope is found in Appendix G. The minimum viable product will be refined in its own iterative cycle of coding, evaluation, and revision, with the participation of the extended multidisciplinary team, which consists of therapists, nursing, social work, pharmacist and neurologists. Prior to official release, it will be tested by a small group of patient volunteers and then released as a beta version. Upon release, the app will then be beta-tested by a larger subset of stroke patients at the JHH stroke center.

To implement the principles of user-centered design, members of the multidisciplinary team, who hold specialized expertise within the stroke care system and also represent the app's secondary users, should be involved early in the continuing stages of design refinement and development. During the early, abstract stage, it is easier to expose fundamental design flaws and generate novel solutions. At a later stage, when designs look more concrete, it is easy for thinking

to be pigeon-holed within the proposed structure of the app, with only surface level issues being examined.

The features of the app should be prioritized and pared down through usability testing and inquiry conducted with patients. Trying to address multiple needs with a single mobile app can make it unwieldy and disorienting to the user. Therefore, the team plans to incorporate a small sampling of each feature in the first iteration of the app. This initial version will include the Daily Check-in (logging and tracking symptoms), self-reminders for asking questions (documented patient-provider communication), a few basic exercises (personalized, actionable goals), and a few learning modules (personalized learning). User engagement with respective features could be measured quantitatively based on screen flow analysis, as well as qualitatively based on surveys results.

Patient inquiry will also be useful for detecting any patterns (demographics, stroke severity) that distinguish patients and carers who are more likely to use a personalized recovery app from those who are less likely. Regardless of how well the design is executed, some patients may simply not be interested in using an app as a learning platform. These individuals' learning preference should be respected and alternate educational resources should be offered. User personas should be revisited and revised to more accurately reflect the identified subset of prospective users for whom the app is primarily designed.

Regarding design of information, a user-centered approach should continue to be applied, with a focus on helping providers build a common language with patients across written, auditory, and visual formats. Based on research and observation, a balance must be struck between optimistic and realistic communication to prevent either discouragement or misinformation. Content design choices should be made based on desired learning outcomes, and principles of instructional design. When the rehabilitation-documenting platform is pursued in the future, the team should consider building out a separate, secure app for therapists to use.

Involvement of medical illustrator(s), who have dual skillsets in both visual communication and the biomedical field, may help provide a valuable "translation" service between medical professionals and patients throughout design. The medical illustrator's unique interdisciplinary background allows them to first process information from both the provider's and patient's viewpoints, and then bridge the two by building a common language with their visual, content, and instructional design skills.

Future Directions for Improving Stroke Education

Research during this project revealed an abundance of existing resources and products designed for stroke survivors and their carers. One immediate solution for improving current stroke education is to leverage currently existing resources and organize them for optimal usage. The major barrier to learning from these resources is not poor quality, but rather the overwhelming quantity that must be synthesized by the patient and their carer. Development of a personalized app would augment but not replace the currently used written resources. The quality of written handouts currently being given to patients should be periodically assessed and tested against other handouts, to measure usability and learning outcomes. Equally the content within the app deserves such ongoing scrutiny.

JHH stroke unit rooms are currently each equipped with an iPad. The iPads in patient rooms could be used to consolidate existing electronic resources for stroke survivors, in addition to housing the personalized recovery app. Podcast and YouTube video playlists could be curated and labeled. Stroke-specific and relevant apps for recovery could be downloaded and organized into folders with appropriate labels, such as "Hand games" and "Brain training games." Members of the stroke care team could orient the patient/ carer to resources on the iPad and incorporate them into therapy as they see fit.

Healthcare providers are the ultimate source of personalized knowledge for patients. Finding strategies to improve patient-provider communication and knowledge transfer through transitions of care would likely have a significant positive impact on patient and carer preparedness. A strategy to automate or at least highly streamline conversion of EHR clinical documentation into personalized patient instruction and progress reporting would be immensely useful. Patient-relevant clinical information, such as therapy goals and progress notes, could be translated into patient-friendly language and conveyed using multimedia format (writing, illustrations, animations, audio) to accommodate various learning preferences. By building upon aspects of the existing stroke care system (eg. EHR documentation, available services and products), change can be effected in a systematic, widespread way that conserves valuable time and resources while improving patient outcomes. While the current app design does not allow for such integration between the EHR and the app, the potential for expansion in future iterations would be a worthwhile endeavor.

CONCLUSION

Current methods for hospital-based stroke education are not well-suited for meeting the highly variable and individualized learning needs experienced by stroke patients and their carers. To address this shortcoming, user-centered methodology was adopted for the design of a recovery app that is fundamentally centered around the goals and expectations of stroke patients and providers. The resulting information architecture, conceptual diagram for progressive personalization, and digital prototypes demonstrating key features and functionalities provided both a concrete foundation for app development and a visual means for communication and collaboration between stakeholders.

Frequent input by stakeholders and content experts was essential to guiding the direction and refinement of design, while keeping the app grounded in its user-centered foundation. As the app moves into the first iteration of development, continued collaboration and beta testing with patients and the multidisciplinary care team should be conducted to evaluate usability and to correct design flaws as early in the development process as possible. This iterative workflow that is organized and systematic, yet characterized by fluidity and openness allows for accommodation to changing constraints and new insights. Upon release for patient use at Johns Hopkins Hospital, the recovery app will augment existing verbal and written education resources. The addition of this personalized digital health resource expands available learning modalities to better accommodate diverse patient learning preferences.

From app design to handout selection, user-centered design provides a framework for innovating educational solutions that directly address the specific learning needs of each stroke patient. Implemented on a broader scale, the principle of user-centered design can improve access to and usability of existing educational resources for stroke patients and their carers. While the user-centered methodology was employed specifically for the design of a stroke recovery app, it

is potentially generalizable to app design for other chronic diseases, including heart failure and diabetes. The recovery app resulting from this intrinsically patient- centered approach to early stroke education has the potential to improve patient knowledge, motivate the patient in their recovery plan, and improve overall outcomes. In an era of personalized health care, such technology is essential to the patient's success.

APPENDICES

Appendix A: Enabling Objectives and Features

Text copied below from original working Word document:

The overall goal: "Increase patient knowledge about their unique condition in order to improve self-management, motivation, and recovery outcomes," will be **enabled through the following features:**

1. INDIVIDUALIZED EDUCATION

To contextualize patient's stroke experience in a securely stored, modifiable location

A. Understandable clinical documentation
   i. Diagnosis (What happened to me? Eg. Ischemic stroke in left temoral lobe)
   ii. Treatment (What are doctors doing to treat you? Eg. Clot buster)
   iii. Test results
B. Risk factors (eg. High blood pressure)
C. Disabilities (eg. Right side weakness, Dysarthria)
   i. Can be a reference baseline for setting rehab goals.
D. Glossary

2. GOAL-SETTING (ACTIONABLE)

To involve the patient in setting and working toward realistic, achievable goals for recovery

A. Involve patient in setting realistic, achievable goals for recovery.
B. Road map showing journey from hospital to home (and possibilities in between)
   i. Orient the patient with milestones and what to expect.
   ii. Educate what "recovery from stroke" might mean. (Could be partial or full)
C. Rehabilitation goals (PT/OT/SLP)
   i. Overarching goal(s) (I want to play the guitar- OT)
   ii. Suggested categories: mobility, cognitive, self-care, social skills, communication
   iii. Stepwise goals (eg. Daily exercise- Fingertap 3x20- or suggest an iPad game!)
   *requires easy, efficient input

iv. Modifiable and celebrated achievements

D. Prevention goals
   i. Lifestyle changes (diet, exercise)

E. Daily suggestions and reminders

F. Encouragement

3. PROGRESS JOURNALING AND TRACKING

To enables incremental progress to be tracked and referenced.

A. Day log facilitates incremental progress
   i. Tasks and goals to work on today
   ii. Daily tips and reminders
   iii. Notes, mood, questions, symptoms for the day

B. See progress over time for different categories
   i. Symptoms, mood, goal milestones

C. Camera feature and gallery
   i. Special assistance devices, miscellaneous.

4. EFFECTIVE COMMUNICATION WITH HEALTHCARE PROVIDERS

To document 2-way communication between patient/ carer and stroke care team.

A. Introduction to members of the care team and their unique roles
   i. Record name, contact info

B. Recording questions and answers and notes
   i. Suggested questions- prompts in appropriate locations of the app
   ii. Stored questions to ask at appropriate time

C. Allow sharing of patient-logged data with clinician

Reluctant **Richard**

"I thought people my age didn't get strokes. I'm a healthy guy. I never take medication. Why should I start now? I just want to go back to work as soon as possible."

Demographics

Age: 32
Gender: Male
Ethnicity: Black
Family: Married, 1 child
Education: High school graduate
Occupation: Roofer

Background

Richard had a TIA (transient ischemic attack.) He woke up one morning with what he thought was just a headache, and proceeded to go to work. A coworker noticed that his speech was garbled and his face was drooping, so she called an ambulance. At the hospital, doctors prescribed him blood-thinning medication to take daily. Richard is reluctant to comply, as being on medication conflicts with his self-perception as a healthy, active individual. Richard will be able to leave the hospital in a few days with no serious disabilities.

Recovery Motivators

- Return to work
- Live a normal life
- Provide for the family

Recovery Barriers

- Denies health problems
- Distrustful of doctors' recommendations
- Does not like being told what to do
- Fearful of being perceived as sick or disabled

Medical History

Hypertension (hereditary)
Former smoker

Stroke Effects

None
(Transient headache and weakness)

Key Traits

Tech Proficiency

Provider Relationship

Attitude Toward Change

Core Needs

- Teach him his risk factors and treatment rationale
- Give him time and space to process information and reach conclusions independently
- Match his learning preference(s)
- Reframe his perspective by showing him others like him

Determined **Diana**

Demographics

Age: 46
Gender: Female
Ethnicity: White
Family: Divorced, 2 children
Education: College graduate
Occupation: Financial Advisor

"I have a young daughter, who I plan to be there for. I want to know everything I can do to recover quickly and prevent another stroke. If it's about diet and exercise, I will make those changes.

Background

Diana had an ischemic stroke after a series of mini strokes (TIAs) that she had previously dismissed as bad migraines. She was cleaning her car when her left arm and leg went numb. Realizing she was having a stroke, she immediately dialed 911. Due to her quick response, doctors were able to administor medication that dissolved the clot. Diana wants to be well-informed and highly involved in discussion of her treatment plan. She looks forward to rehabilitation sessions and is eager to learn activities she can do on her own to recover her daily functioning.

Recovery Motivators

- Sets goals and finds joy in achievement
- Refuse to give into limitations
- Provide for her daughter
- Seeks information

Recovery Barriers

- Does not like waiting around in bed
- Unclear about what she can do on her own
- Cannot keep track of advice given verbally
- Worried she isn't asking all the right questions

Medical History

Overweight
Hypertension
Hypercholesterolemia

Stroke Effects

Weakness of left arm and leg
Impaired short-term memory

Key Traits

Tech Proficiency

Provider Relationship

Attitude Toward Change

Core Needs

- Help her create incremental goals to reach her longterm goals
- Provide her with tools to monitor and communicate her progress
- Enable her to take notes
- Refer her to additional learning resources

Discouraged **Dylan**

"Why did this happen to me? I feel overwhelmed and ashamed about my disabilities. I'm broken. I don't want my grandchildren to see me."

Demographics

Age: 69
Gender: Male
Ethnicity: White
Family: Married, 3 adult children
Education: Some college
Occupation: Retired

Background

Dylan had a hemorrhagic stroke. He collapsed while in the kitchen one morning. His wife was home and called 911. Doctors performed decompression surgery to remove blood from the brain and repair the ruptured vessel. At the hospital, Dylan is emotionally distressed by the extent of his disabilities and feels hopeless, which prevents him from getting the most from his therapy sessions. Dylan's family is supportive and assists with his supervision in the hospital.

Recovery Motivators

- Feel less anxious about his health
- Being there for his grandchildren
- Feel connected to his family

Recovery Barriers

- Focuses on his limitations and losses
- Experiences shame and sadness
- Highly dependent on family support

Medical History

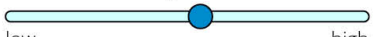
Atrial fibrilation
Coronary artery disease
Obesity
Smoking

Stroke Effects

Paralysis of left arm and leg
Visual neglect (left-side)
Dysphagia
Dysarthria

Key Traits

Tech Proficiency



Social Support

Attitude Toward Change

Core Needs

- Reassure him and be positive
- Involve family in supporting and tracking his progress
- Transition from fixed to growth mindset
- Provide small, achievable goals

Independent **Isabel**

"I've always taken care of myself, and I hate having to depend on other people. I'm the one who took care of the kids growing up and now my husband when his health deteriorated."

Demographics

Age: 74
Gender: Female
Ethnicity: Black
Family: Married, 1 adult child
Education: College graduate
Occupation: Part-time librarian

Background

Isabel had an ischemic stroke. She was walking her dog at the park when she fell. A passerby called 911 and she was taken to the hospital, where doctors performed a thrombectomy. Isabel feels like her body has let her down. She is highly uncomfortable with relying on others' help to meet her needs, and she has a history of hiding her health problems from friends and family. She is highly motivated to keep her independence.

Recovery Motivators

- Maintain her independence
- Have her dignity
- Return to caring for her husband and dog
- Have control of her health

Recovery Barriers

- Refuses to accept help
- Loneliness and depression
- Does not let on when she doesn't understand something

Medical History

Atrial fibrilation
Former smoker
Hypertension

Stroke Effects

Left-sided weakness
Dysphagia
Dysarthria
Anxiety

Key Traits

Tech Proficiency

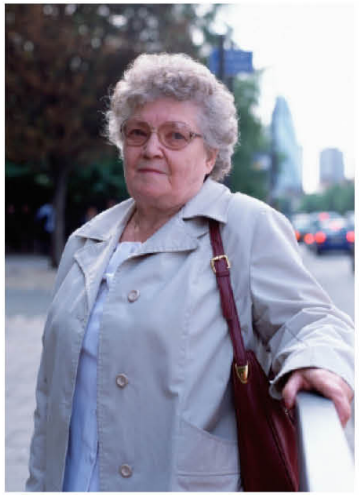
Social Support

Coping Style

Core Needs

- Give her options
- Help her set goals that allow independent living
- Help her gain practical skills
- Make education available to her

Acquiescant
Alice



"I just do what the doctors and nurses tell me to do. They're taking good care of me here in the hospital. I don't decide how life goes, but I trust the professionals to do what's good for me."

Demographics

Age: 70
Gender: Female
Ethnicity: White
Family: Married, no children
Education: High school graduate
Occupation: Retired

Background

Alice had an ischemic stroke two years after her first. She woke up from a nap with extreme dizziness and blurred vision. She tells her husband who calls 911. At the hospital, doctors performed a thrombectomy. Alice takes medication as directed and is cooperative during her rehabilitation sessions. She does not ask many questions aside from those addressing her immediate needs. She listens to doctors but is forgetful.

Recovery Motivators

- Be as comfortable as possible
- Have access to caregivers and doctors
- Brace for the what's around the corner
- Focus on here and now

Recovery Barriers

- No concrete strategy for prevention
- Tries not to think about what might happen in the future
- Sets big goals without knowing how to reach them
- Cannot keep track of advice given verbally

Medical History

Previous stroke
Smoking
Obesity
Hypertension

Stroke Effects

Paralysis of right arm and leg
Right side vision loss
Fatigue
Left-sided weakness (previous stroke)

Key Traits

Tech Proficiency

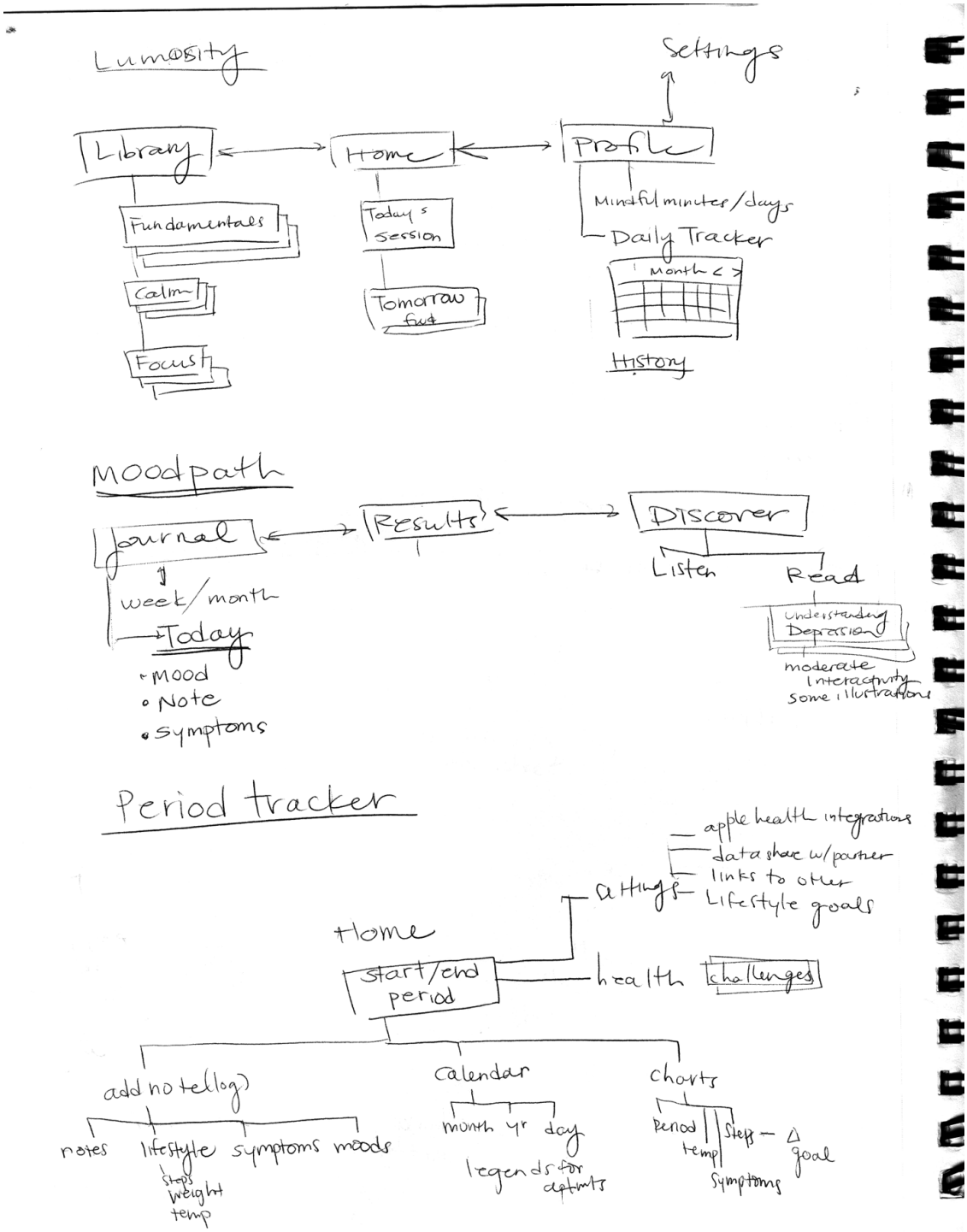
Provider Relationship

Coping Style

Core Needs

- Engage her in her treatment plan
- Teach her how to set incremental goals
- Encourage her to ask questions
- Simplify instructions

Appendix C: Analysis of Information Architecture of Existing Apps



Appendix D: Synthesis of Existing Resources for Stroke Survivors

Table 4. Currently available products and services for stroke survivors.

Category	**Resource/ Product Name**	**Description**
Rehabilitation devices	Saebo: Multiple products including SaeboGlove, SaeboFlex, SaeboVR, and SaeboMind FlintRehab: FitMi, MusicGlove	Functional rehabilitation from home (primarily upper and lower extremities). FlintRehab manufactures FitMi rehabilitation system for clinic as well. (focus: arms, legs, core)
	ACP: Synchrony	Dysphagia treatment system designed for SLP practice, Clinical protocols, training, and support available
Stroke-specific apps	Stroke Active	Rehabilitation platform connecting patients and therapists: Form team with multiple therapists, patient-appointed representatives; communicate using secure message board; complete tasks assigned by therapists; video recorded tasks (UK)
	Constant Therapy	Personalized speech, language, and cognitive therapy for people recovering from stroke and other brain injury, and those living with dementia
	Stroke Rehab (9zest.com)	Personalized therapy plans, with exercises in realms strength and mobility, speech, dexterity, orofacial, anxiety and sleep, pain management (FDA classified medical device)

	Stroke Awareness Foundation Stroke Scales for EMS StrokeRiskAnalyzer	Stroke identification, risk analysis
General apps	Candy Crush Angry Birds Balloon Frenzy Solitaire	Gamified practice for hand-eye coordination, finger dexterity
	Lumosity Mind Elevate Peak BrainHQ	Personalized brain training games for memory, attention, processing speed, problem solving, math, reading comprehension
	Medisafe Google Calendar Petual	Adding and tracking medications, appointments, goals and reminders
	Wellpepper Calm Headspace Moodpath	Self-care and wellness apps
Web Resources	Stroke.org (American Stroke Association)	Primary US national voluntary health agency providing all-encompassing resources and information
	Stroke Connection Magazine	Social support for stroke survivors and carers (published by ASA)
	Healthtalk.org	Personal stories of stroke survivors shared in filmed home interviews (73 people living in the UK)
	Flintrehab.org	Neurorehabilitation devices for sale, recovery blog, free eBook

	Recoveryafterstroke.com	Free eBook and podcast episodes, webinar, coaching (website created by stroke survivor Bill Gasiamis)
	Tedysteam.org	Informational blog, financial assistance program, general info (stroke signs and prevention)
Written resources	American Stroke Association: *Life After Stroke, Let's talk about stroke* series, *Stroke Rehabilitation Planning List, Making Rehabilitation Decisions* Canadian Heart & Stroke: *Your Stroke Journey* Dartmouth-Hitchcock Medical Center: *About Stroke: A guide for Patients and Families*	Guides for patients and carers providing overview of all stroke care, or specific aspects (eg. Rehabilitation) Links to additional resources
YouTube videos	"What is a Stroke?" -HealthSketch "Stroke Education- Causes and Effects" -Mackenzie Health "Stroke Patient Education- Dysphagia" -Royal Victoria Regional Health Centre "7 Steps to Stroke Recovery" - Stroke Recovery Association of BC	Free educational videos designed for stroke survivors and their carers can be found on YouTube (whiteboard animations, PowerPoint lectures, video).
Podcasts	*StrokeCast* *Recovery After Stroke* *Stroke Stories*	Social support from stroke survivors; topics include rehabilitation, recovery, prevention; guest speakers include neurologists, OT, PT

Appendix E: "My Recovery Journey" Interactive Paper Binder

"My Recovery Journey" page 1/9

_____'s

Recovery Journey

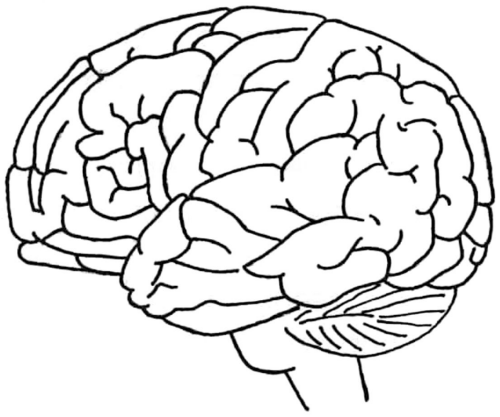
"My Recovery Journey" page 2/9

Patient Addressograph label

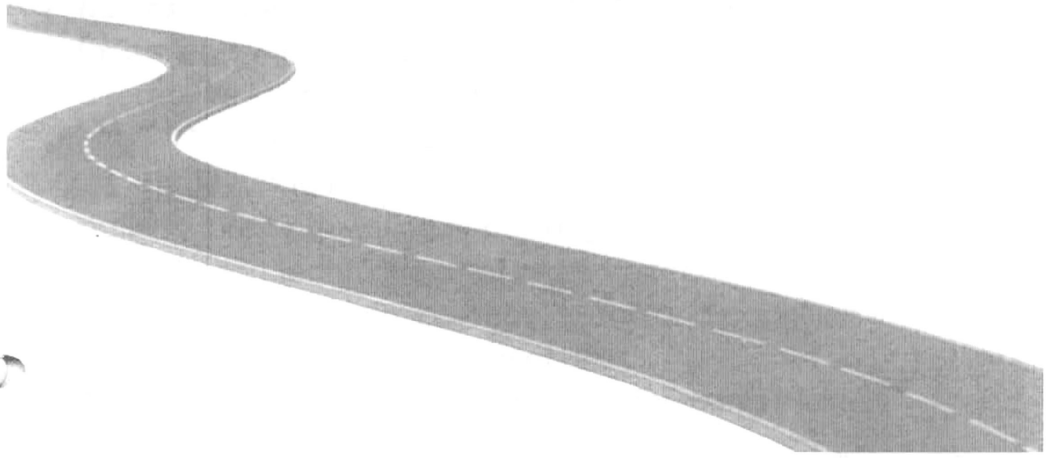
You had a(n)_____ stroke

In the _____ lobe of the brain.

You may expect/experience the following:



large text



My Team

- **Brain Recovery Unit (BRU).** A specialized inpatient unit for patients with new stroke.
  - **BRU Clinical Technician.** A technician specialized in monitoring and assisting with daily activities for a patient with new stroke.
  - **BRU Nurse.** A nurse specialized in assessing, educating, and managing care for a patient with new stroke.
- **Case Manager.** Helps coordinate care from multiple providers, and connect to community resources.
- **Dietician.** Teaches about healthy eating and specialized diets.
- **Health Buddy.** A friend or family member who will be your partner in health and can provide extra support after you leave the hospital.
- **Neurologist.** Specializes in the prevention, diagnosis and treatment of stroke and other diseases of the brain and spinal cord.
- **Neuroscience Critical Care Unit (NCCU).** Intensive care unit for patients with serious, challenging and life-threatening diseases which require continuous monitoring.
  - **Occupational Therapist (OT).** Helps patients learn strategies to manage daily activities such as eating, bathing, dressing, writing or cooking. Specializes in rehabilitation techniques that promote recovery of coordination, strength, balance, vision, and cognition to maximize function and quality of life.
- **Physiatrist.** Specializes in rehabilitation following injuries, accidents or illness.

continue

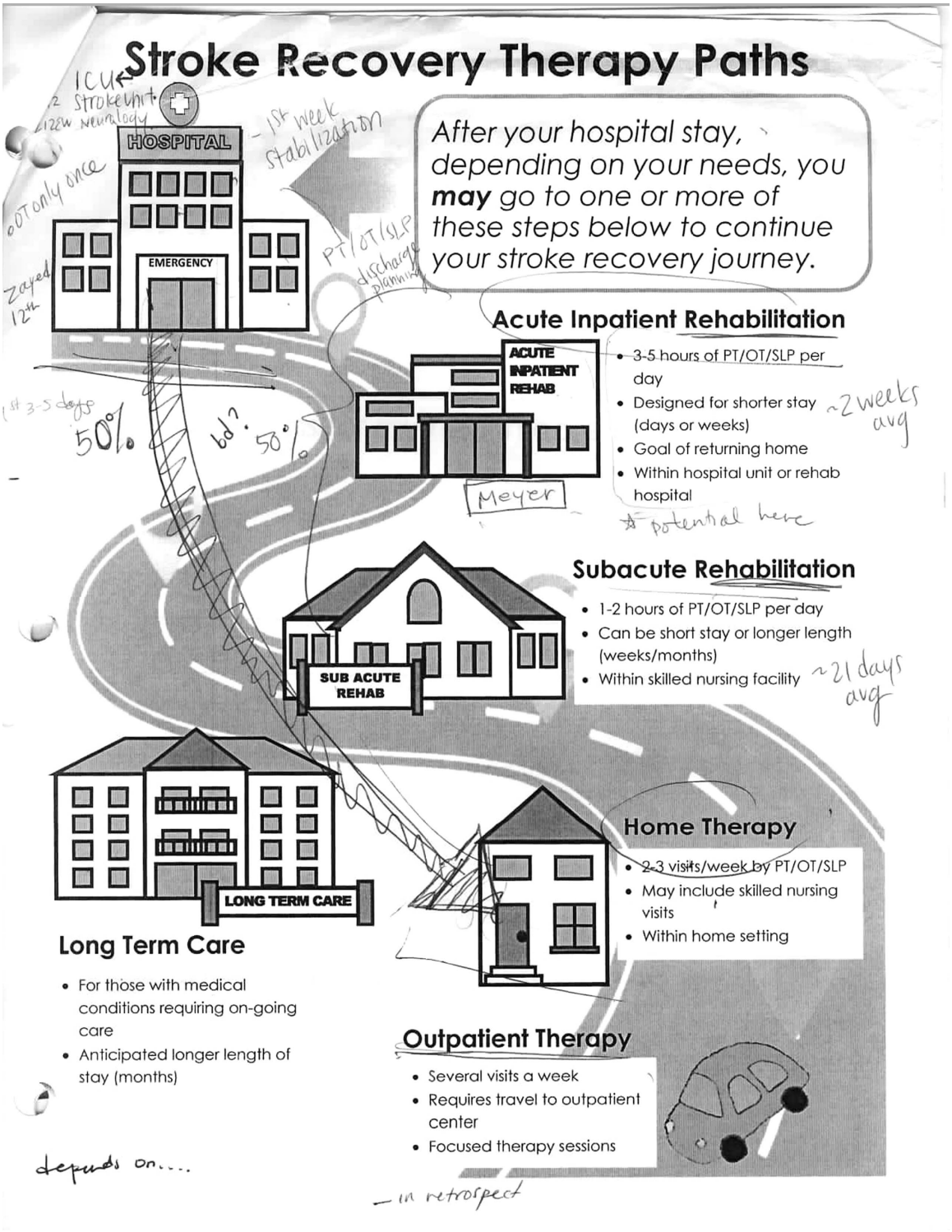
App use begins when

My Hospital Stay

Below is a generalized checklist for a patient with new stroke.

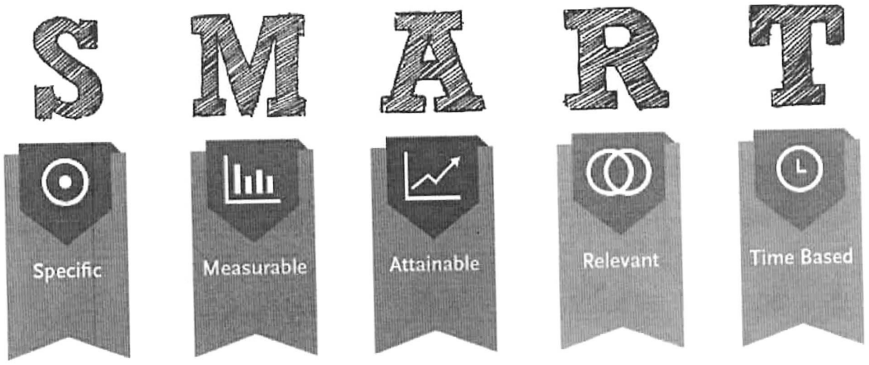
Emergency Room	
	CT scan
	Meet with Neurologist
Day 1-2: Inpatient Unit	
	Admission with inpatient Neurologist
	Admission with inpatient nurse
	Swallow screen
	Orthostatic Vital Signs
	Background questionnaires
	Blood sugar check
	Blood clot prevention
	Cardiac telemetry
	Fasting initial bloodwork for lipid panel
	Daily bloodwork
	Daily morning visit by Stroke Team ?
	MRI
	Echocardiogram
	Evaluation for rehabilitation therapy
	Stroke prevention medications
	Stroke recovery medications
Day 2-3: Inpatient Unit	
	Daily bloodwork
	Daily morning visit by Stroke Team
→	Daily rehabilitation therapy (if needed)
	Social Worker or Case Manager visit
	Discharge Planning

"My Recovery Journey" page 5/9



My Recovery Goals

Big Goals:



Action Plan — SMART goals

Daily log

Date:

My goal today:

Questions for my health care team:

My notes:

Notes from my team:

"My Recovery Journey" page 8/9

Daily log

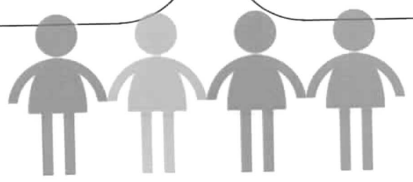
Date:

Physical Therapy

Occupational Therapy

Speech Language Therapy

Nursing



Helpful Information

Family Medical Leave Act

If you are working, first contact your Human Resources department for FMLA paperwork.

FMLA provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. During this period of leave, health benefits are also to continue without disruption.

Fact sheet: https://www.dol.gov/whd/regs/compliance/whdfs28.htm

Application forms: https://www.dol.gov/whd/fmla/forms.htm

Available for both individual and/or family member that may be providing care.

Social Security Disability

A paid disability benefit for individuals that are not able to work for at least one year, related to a medical condition.

An application can be submitted online or at your local Social Security Administration Office

Online application: https://secure.ssa.gov/iClaim/dib

To find your local office: https://secure.ssa.gov/ICON/main.jsp

Maryland Department of Human Services / Department of Social Services

Offices are located in each county within the state of Maryland with separate offices in Baltimore City.

DSS assists with evaluation and connection to Temporary Cash Assistance, The Food Supplement Program, Energy Assistance and Medical Assistance.

To Find Your Local Office: http://dhs.maryland.gov/local-offices

Appendix F: Example Therapist Documentation in the Electronic Health Record

Screenshots of an SLP's documentation into Epic Systems EHR (page 1/2)

SLP Treatment Section:

Neuromuscular facilitation/re-training
Neuromuscular facilitation/re-training: Increased frequency of swallows;Expiratory Muscle Strength Training (EMST)
(increase freq)Bolus type/volume comments: dipped tsp w/ honey thick liquid orange juice and 1/2 tsp volumes x30
(increase freq)Incidence of post swallow cough or throat clearing: none
(increase freq)Level of cueing: mod cues for 1-2-3 swallow fast throughout, continues w/ inconsistent coordination and swallow initiation 5 seconds - absent initiation despite oral motor movements attempting to initiate swallow
(EMST)Assessed peak expiratory flow: 5 cmH20
(EMST)Unit set at % of peak expiratory flow: 5 cmH20 (lowest setting)
(EMST)Repetitions: 5 reps
(EMST)Number of Repetitions: 5 sets
(EMST)Level of cueing: min cues fading to supervision
(EMST)Comments: pt motivated, required cues for rest breaks as he wanted to continue w/ task, left EMST within reach per request

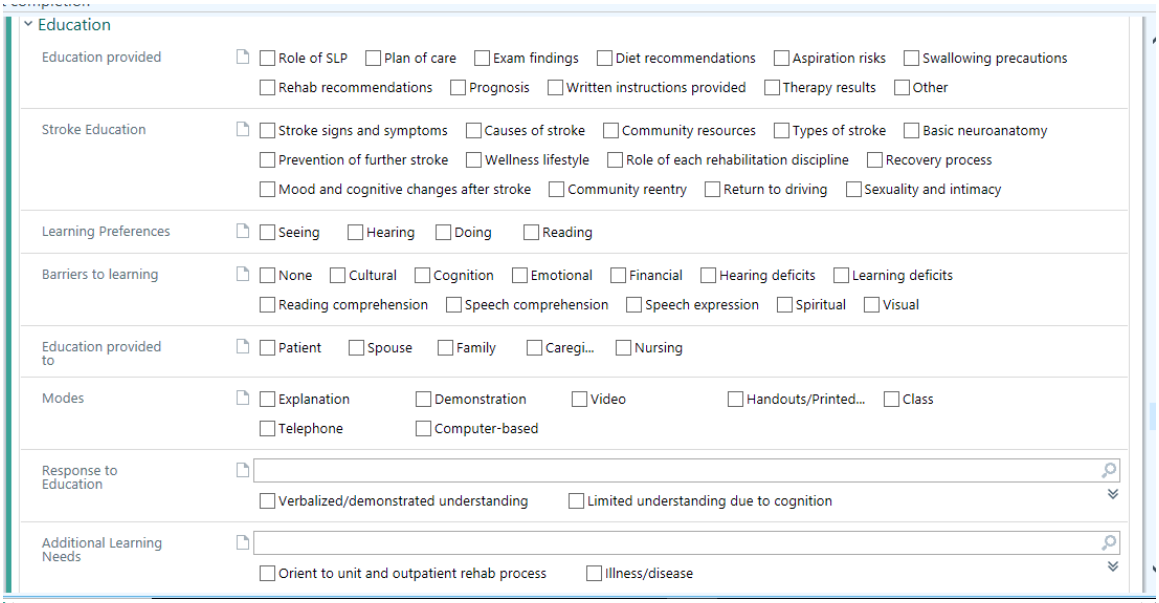
Neuromuscular facilitation/re-training
Neuromuscular facilitation/re-training: Hard and fast swallows
(Hard, Fast) Number of swallows performed : X40, 5-15mL of thin liquid ginger ale; cough x2 w/ larger volumes and endorsing aspiration; mod cues initially faded to supervision to initiate drinking, pt distracted by sEMG machine and was relying on that to cue him to swallow

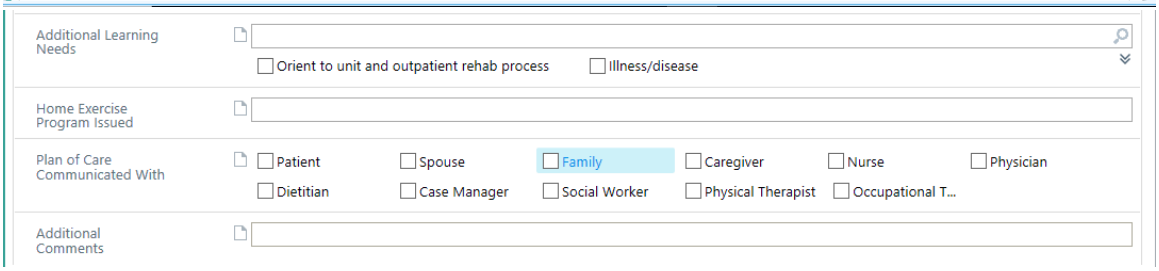
sEMG
Purpose : EMG to enhance motor learning
Preparation/Baseline Evaluation: established resting baseline of muscle activity to ascertain the resting point;established swallow baseline using average amplitude measures of 5 swallows
Electrode Placement: Suprahyoid placement (midline location)
Treatment task: (tongue pull backs)
Treatment task comments: +59/119 (49% accuracy) w/ diver tongue pull backs, w/ improving completion of task and achieving some high targets this date, more compared to previous date
Progress Measures: Percent success surpassing threshold

SLP Assessment Section:

Assessment:
Assessment Summary: Pt seen for ongoing treatment, session targeting lingual strengthening exercises and orientation, introduced EMST this date. Pt continues to require mod-max multimodal cues throughout session to maintain arousal and attention to task. Pt with poor task persistance, will benefit from ongoing SLP treatment. Pt's son present at bedside and updated.
Referral Diagnosis: Large R MCA stroke with hemorrhagic conversion
Treatment Diagnosis: Oropharyngeal Dysphagia, Severe Cognitive Impairment
Rehab Potential: Good
Response to Therapy: Fair
Goals
Goal 1: Patient will tolerate puree solids without s/s of penetration/aspiration by 1/30/20.
Goal 2: Patient will complete lingual resistance exercises to improve oral bolus control with min cues by 1/30/20.
Goal 3: Patient will complete EMST to improve cough strength at 75% of max (once cleared by MD team) with min cues by 1/30/20.
Goal 4: Patient will complete PO trials with SLP with varying viscosities and volumes to improve timing of swallow by 1/30/20
Goal 5: Pt will complete simple sustained attention tasks w/ 60% accuracy and max cues by 1/30/20
Goal 6: Pt will complete simple problem solving/ executive function taks w/ 50% accuracy and max cues by 1/30/20
Goal 7: Pt will complete simple short term memory recall tasks w/ 80% accuracy and max cues by 1/30/20
Goal 8: Pt will be oriented x4 w/ mod cues by 1/30/20

SLP Education Section:





Education:
Education
Education provided: Role of SLP;Plan of care;Exam findings;Diet recommendations;Aspiration risks;Swallowing precautions
Stroke Education: Recovery process;Role of each rehabilitation discipline
Learning Preferences: Seeing;Hearing;Doing
Barriers to learning: Cognition
Education provided to: Family;Patient;Nursing
Modes: Explanation;Demonstration
Response to Education: Verbalized/demonstrated understanding
Additional Learning Needs: Treatment plan
Plan of Care Communicated With: Patient;Family;Nurse

Appendix G: Draft of Development Scope for First Iteration of App

Scope of work shared by app developer (page 1/2)

"StepWise" - Version 1 - Scope of Work
Revised March 17, 2020 Michael
Hamilton

- User Registration/Login
    - Login UI
        - Pin code
        - Forgot pin code (tbd)
    - New user app walkthrough
    - Account setup
        - Name
        - Email Address
        - Pin code (optional)
    - Patient questionnaire
        - Gender
        - Age
        - Date of stroke
        - Type of stroke
        - Affected areas
- Daily Check In
    - Splash UI
    - General wellness
    - Symptom selection
    - Symptom location
    - Misc wellness tags
    - Check in complete UI
    - Reminder Opt-In
        - Locally scheduled
- Home Page
    - Welcome Header
        - User's name
        - Today's Date
        - Reminders
            - Launches a modal list
        - Note Taking
            - Launches modal note taking interface

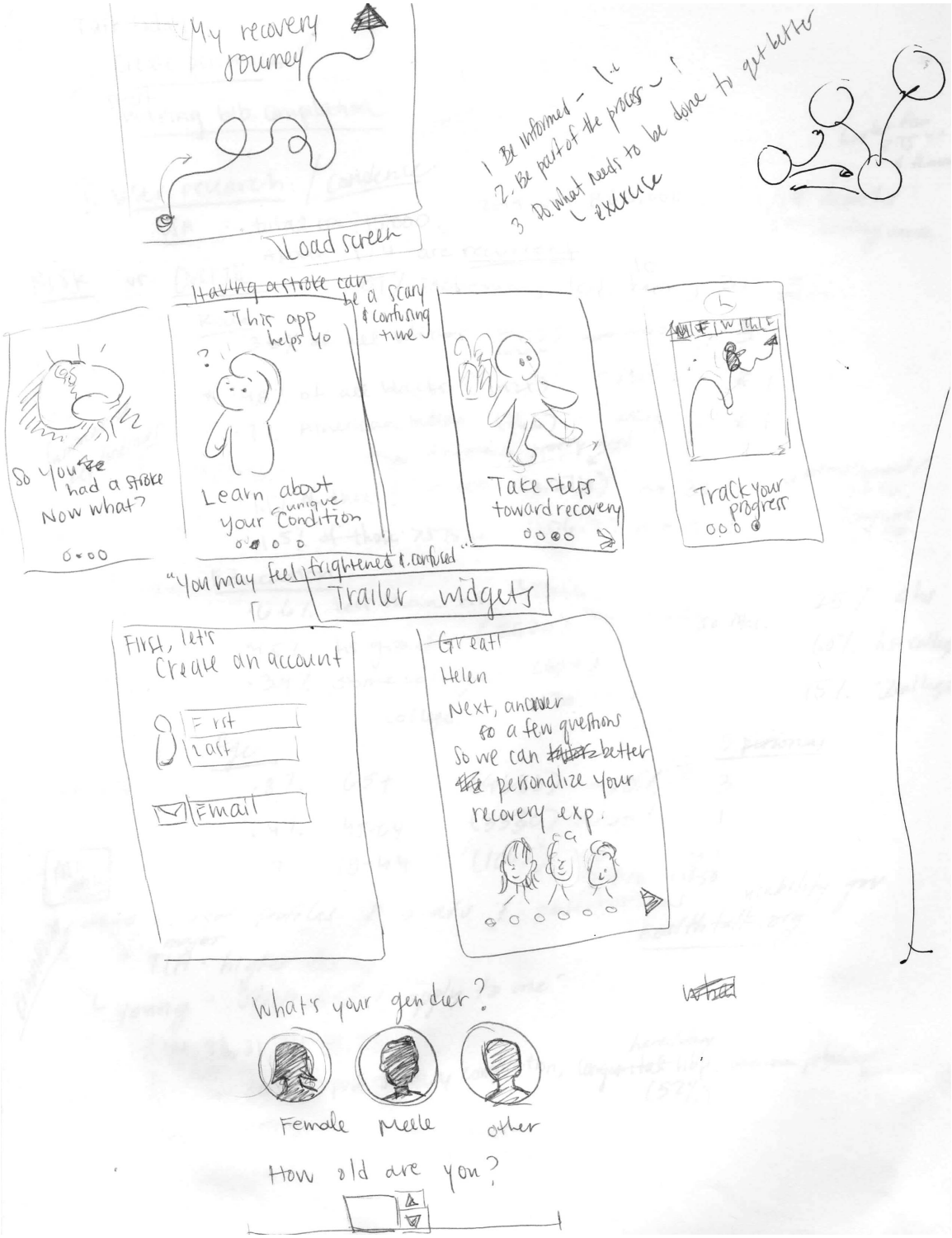
Scope of work shared by Michael Hamilton (page 2/2)

- Inspirational quotes (TBD?)
    - Collection of quotes
        - Source from stroke association
    - Images or avatars
- Targeted Exercises
    - Cards link directly to exercises
    - Cards show exercise image and duration
- Curated Resources
    - Based on user registration questionnaire
- Tabbed Navigation
    - Home
        - Navigates to main UI (quotes, exercises, and resources)
    - Resources
        - Navigates to resources UI (educational content)
    - Progress
        - Navigates to progress UI (calendar of progress, filterable by type)

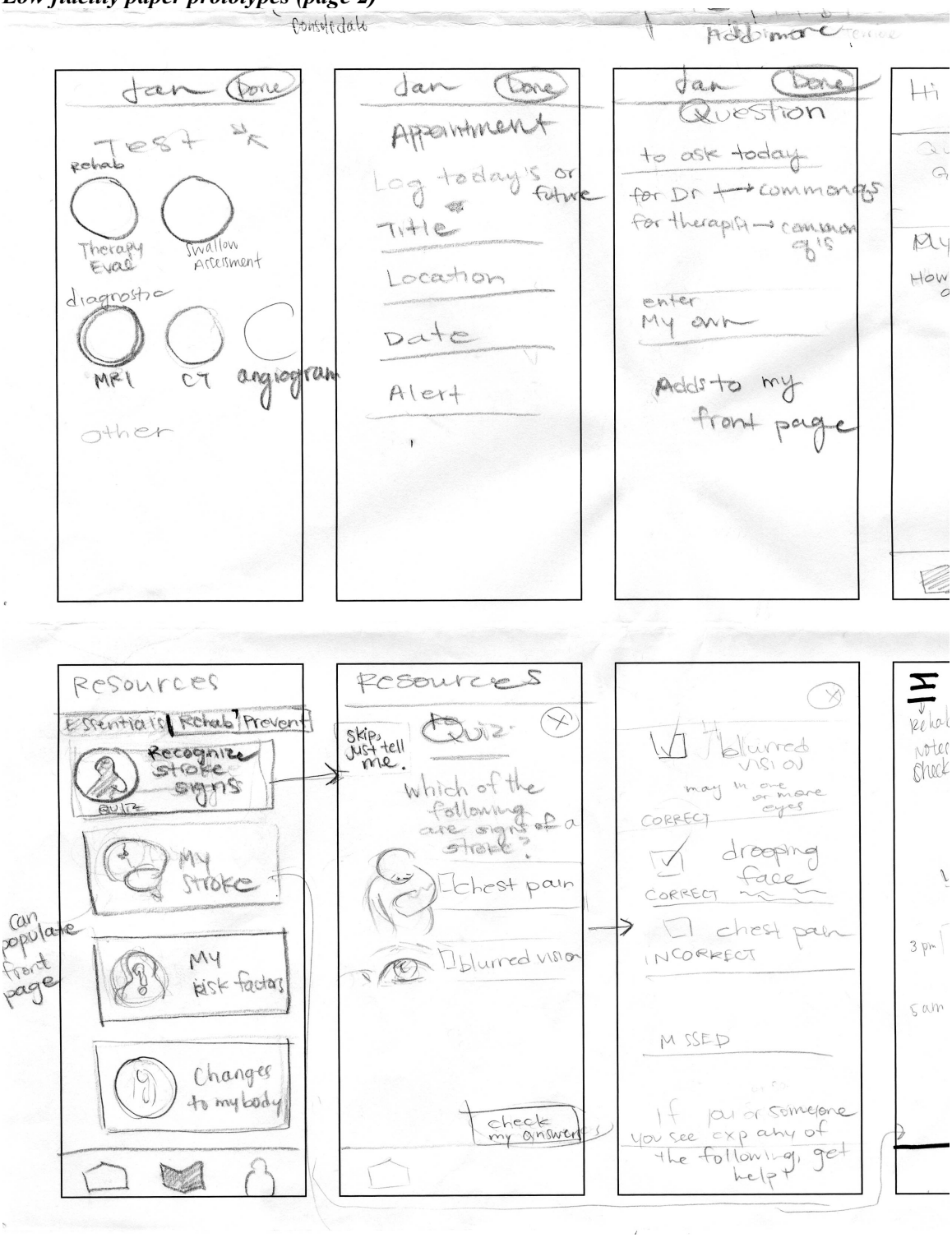
- Exercises (specifics TBD)
    - Hand/finger
        - Timed taps over a set duration
    - Swallowing
        - Guided hard swallow over a set duration
    - Walking/gait
        - Time to walk a set number of paces
- Resources
    - Categorized by type/relevance
    - Text reader
    - In-app video player
    - Show resources as read
    - Content TBD (provided by Mona & team)
- Progress
    - Calendar overview
        - Individual dates selectable to show daily progress, notes, etc.
        - Add notes to an individual day
    - Filter to show progress by exercise, daily checkin, notes, etc.
    - Charts where applicable (exercise progress over time)
    - Clinician View
        - Aggregate applicable data (TBD) for a general overview of progress

Appendix H: Additional Intermediary Prototypes and Concept Design

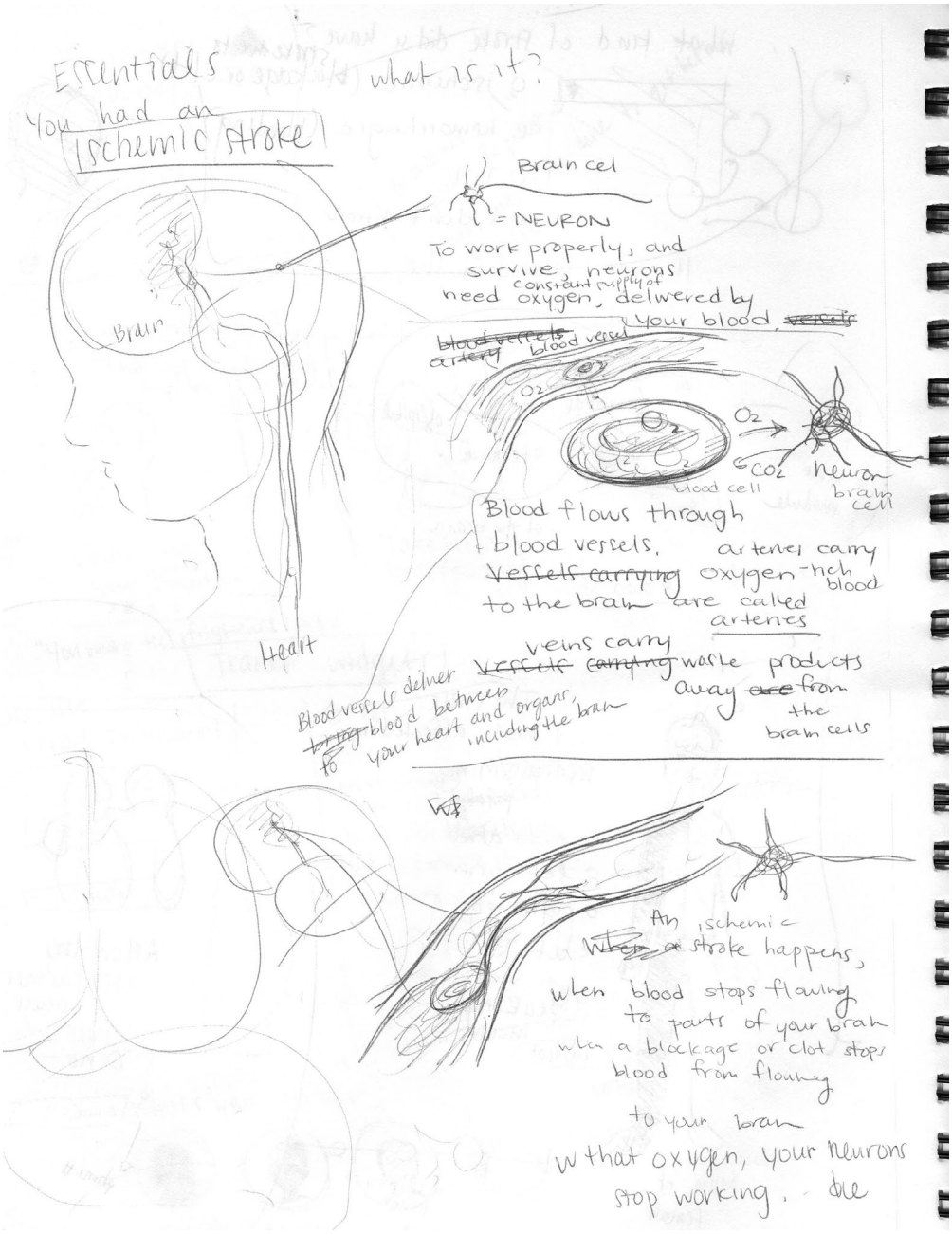
Low fidelity paper prototypes (page 1)



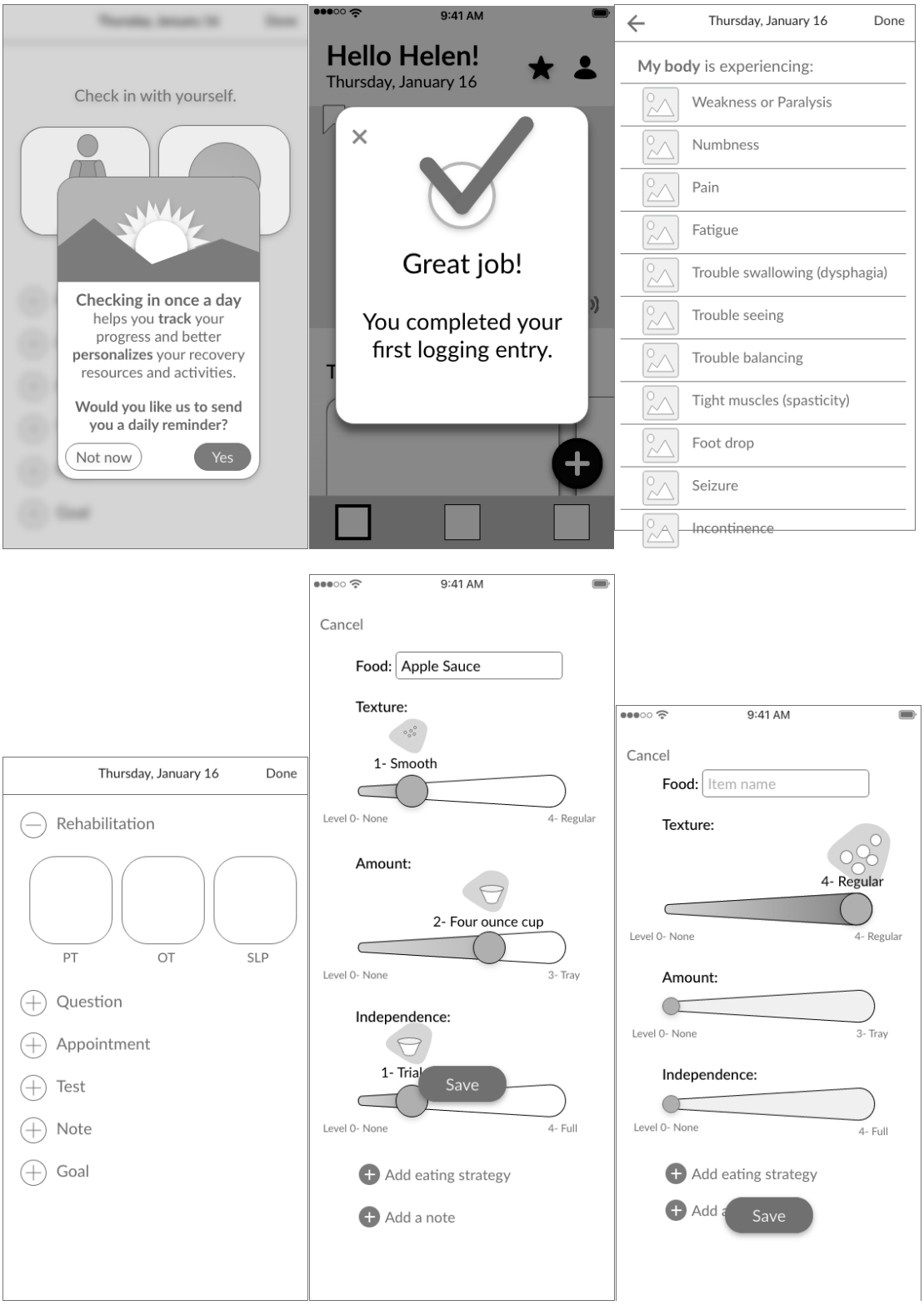
Low fidelity paper prototypes (page 2)



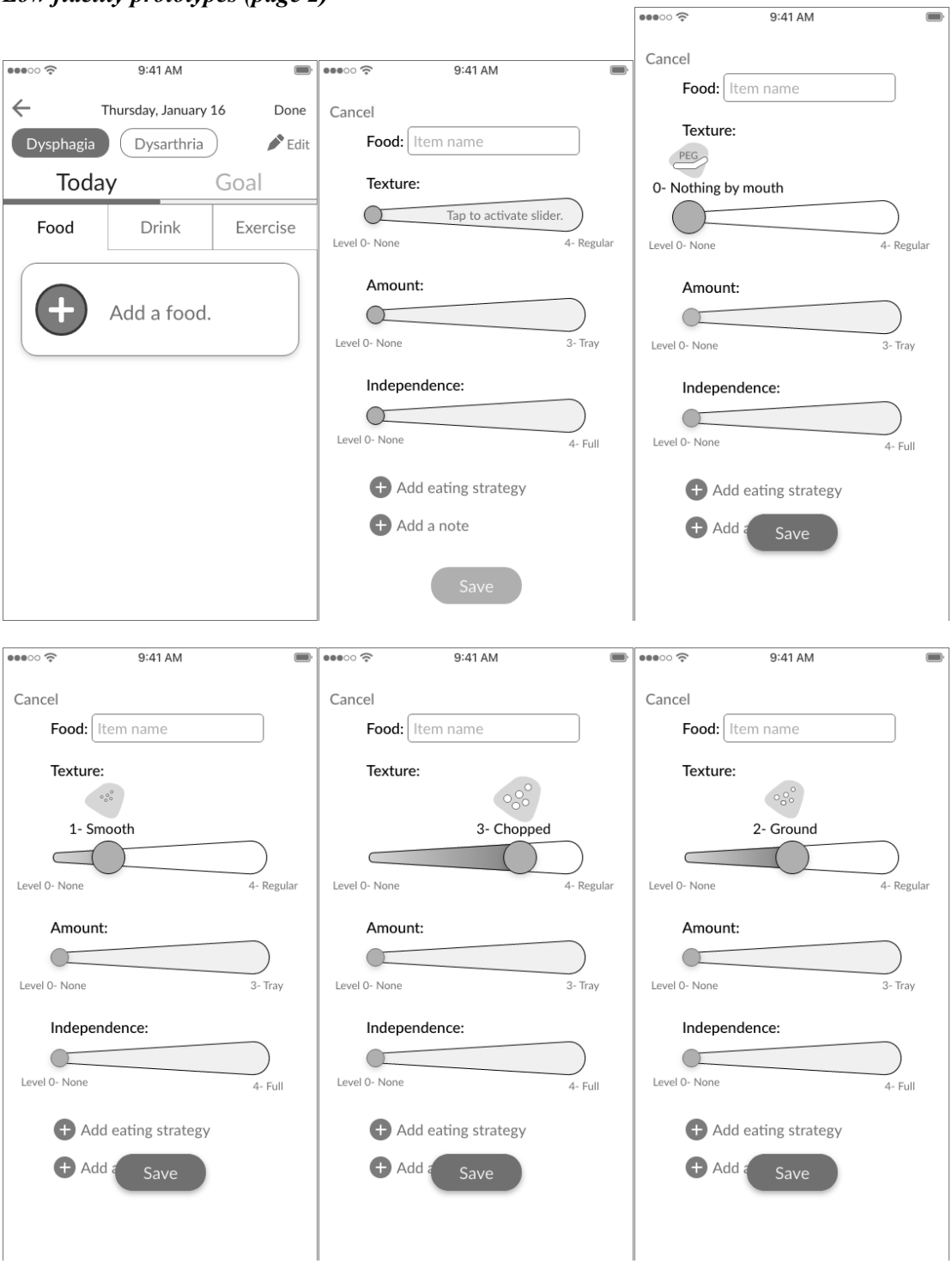
Concept design for "My Stroke" learning module



Low fidelity digital prototypes (page 1)



Low fidelity prototypes (page 2)



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VITA

Helen Tang was born in San Jose, California, and grew up drawing animals and swimming outside under year-round sunshine. Ms. Nanda, Helen's favorite elementary school teacher, taught both science and art classes, nurturing in Helen's early life a blended love for the two subjects. In 2016, she received her Bachelor of Arts in Biology at Brown University in Providence, Rhode Island. While at Brown, she explored various topics within biology, as well as across other disciplines, including visual arts, public health, and anthropology. She became increasingly cognizant of the important role interdisciplinarity plays in solving complex real, world problems. After graduation, she worked at the biotechnology company Intrexon for two years. During this time, she discovered the field of scientific and medical illustration. She was immediately captivated by the prospect of having a career steeped in both art and science, that existed for the purpose of promoting scientific and medical understanding. She applied to and was thrilled to be accepted into the Medical and Biological Illustration graduate program at Johns Hopkins University. During her studies, she was supported by the William P. Didusch Scholarship and earned a Research Grant Scholarship from the Vesalius Trust for her thesis work. Helen will graduate with a Master of Arts degree in May 2020, and looks forward to putting her blossoming creative communication skillset to use for translating scientific and medical knowledge, both within the scientific community and to the broader public.