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Engaging Stakeholders in Co-Developing the Michigan Stroke Transitions Trial (MISTT) Website Intervention

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ABSTRACT

Background: Complex physical and psychosocial transitional care (TC) challenges occur post-stroke. While technology-based TC interventions promise to increase self-management, user-centered design (UCD) and usability evidence is limited.

Objective: Co-develop online post-stroke patient-centered materials.

Methods: Using community-engaged Rapid Participatory Appraisal (RPA) methods, survivors, caregivers, and healthcare professionals participated in focus groups and usability evaluations to inform the design and usability of a co-developed website addressing post-stroke patient-caregiver TC needs.

Results: A staged iterative website development process evolved: original concept to wireframe prototype, beta website, and final website. Community-engagement informed final content, design, and functionality based on TC experiences. Universal website design guidelines were tailored to stroke survivor-caregiver needs and preferences.

Lessons Learned: Post-stroke TC experiences are diverse; more voices matter. Community-engaged RPA methods align with UCD and usability principles but require dedicated resources and funding for sustainable partnerships.

Conclusions: Community-engaged UCD is critical to creating patient-centered technology-based post-stroke TC interventions.

KEYWORDS: stroke, transitional care, community engaged research, web-based intervention, user-centered design, usability/web accessibility, self-management

INTRODUCTION

As a leading cause of adult long-term disability, stroke affects almost 800,000 Americans annually, resulting in approximately 7.0 million stroke survivors.[1] Following hospitalization, many survivors encounter complex, difficult transitions between different care settings.[2,3] Care transitions result in an array of unmet biopsychosocial post-stroke needs[4,5] that extend beyond the immediate post-discharge transition period[6] and can result in vulnerability and poor outcomes.[2-4,7-9] Given the complexity and variability of stroke effects, needs, and recovery, which change over time,[10] adequately supporting transitional care (TC) remains challenging and current research lacks straightforward solutions.[4,11-13] Introducing self-management skills during the TC period is paramount to improving stroke recovery and quality-of-life. Access to reliable, trusted, and easily digestible information is consistently identified as a critical post-stroke need,[14,15] yet many patients and caregivers are dissatisfied with information received.[15] Furthermore, research shows variation in content and information-seeking needs and preferences that change over time.[10,16,17] Although traditional patient education alone does not adequately address patient-caregiver needs related to problem-solving and psychosocial aspects of care,[18] tailored education and information are critical components of self-management and TC intervention strategies.[14,19-21]

Online tools offer innovative ways to deliver unlimited 24-7 patient-caregiver education[21] for promoting self-efficacy, independence[22] and improving chronic disease self-management.[23-28] However, design guidelines tailored to older adults, who are most likely to be managing chronic illness, are often poorly implemented,[29] resulting in usability challenges.[28,30] Despite a recent surge in the use of these tools, evidence of testing the usability and design of technology implemented within TC is scarce. To date, website usability[31] along with various aspects and needs of TC self-management programs and technologies have been explored among adolescents transitioning from pediatric to adult care within a range of disease contexts and populations.[32-36] Among stroke populations only limited literature has evaluated website and mobile apps to promote patient engagement and self-management during the TC period.[37-41] These studies emphasize the importance of engaging stroke survivors (i.e., patients) and caregivers in the development and usability of technology-based interventions, while highlighting that more research is necessary to advance understanding of technology-based interventions in post-stroke TC. Thus, user-centered design, usability testing, and utilization studies are critical for moving the field forward.

The Michigan Stroke Transitions Trial (MISTT), funded by the Patient Centered Outcomes Research Institute, was a randomized controlled trial that tested the efficacy of two post-stroke TC interventions against usual care for improving stroke survivor and caregiver outcomes.[11,42] MISTT interventions involved a 60-day Social Work Case Management program alone or in combination with access to a patient-centered information website (the MISTT website).

The Chronic Care Model (CCM) provided a conceptual framework for designing interventions that addressed components of TC and chronic disease self-management.[43] CCM reflects the social ecological model, recognizing that health and the impact of health interventions are greatly affected by complicated contexts involving physical, psychosocial, and cultural aspects of health at both the individual and community levels.[44,45] Community engagement is crucial for understanding these contexts and designing appropriate interventions for improving health and community-based outcomes.[44-47] This paper reports the community engaged research (CER) processes involved in co-developing the MISTT website with stakeholders and discusses lessons learned to help inform future technology-based TC intervention development.

METHODS

The MISTT study embraced a rapid participatory appraisal (RPA) CER model, an iterative and adaptive process whereby researchers and community partners collaborate to identify and address community needs through qualitative and quantitative methods.[48] The multidisciplinary MISTT research team included investigators from stroke Epidemiology, Social Work, Communication, and Usability/Accessibility who collaborated with a website design team. Partnerships with local and state health professionals across the stroke continuum were established from coauthors' existing professional networks, thus building on pre-established trust. Partners represented acute care, in-patient rehabilitation, skilled nursing facilities, long-term care facilities, home healthcare, community-based services for the elderly and disabled, and public health organizations. Stroke support groups who had established trust with partner organizations also partnered to share their unique perspectives and priorities based on lived experiences. Working from a shared passion for improving post-stroke transitions, researchers and partners explored TC challenges and brainstormed ideas for incorporating lived experiences into the MISTT research design to ensure maximum benefit to stroke stakeholders. In response to partner recommendations, the website development project involved recruiting and engaging stakeholders from partner institutions. Stroke survivors (i.e., patients), caregivers, and healthcare professionals were engaged through user-centered design (UCD)[49,50] principles to inform the final MISTT website content and format. UCD principles are intrinsically patient-centered and iterative, aligning with RPA goals of co-creating products or interventions with the end-user that reflect/address user needs and preferences.[44,50-53]

Finalized with partners, the MISTT website goals involved 1) meeting stakeholder-identified needs by creating a patient-centered website informed by lived experiences and 2) applying evidence-based guidelines for healthcare website design to ensure usable and accessible website resources for stroke survivors and caregivers.[54] The original proposed concept included eight topic sections (Figure 1). Website development incorporated international standards and universal best practices in content organization, navigation, webpage layout, and accessibility for older adults with disabilities.[49,55,56] The visual and interaction design was intended to make content appealing, easy to read, locate, and navigate.[30,55,57]

The RPA UCD process included partner planning and a series of progressive, iterative stakeholder focus groups (FGs) followed by individual usability evaluation sessions. With partner guidance, researchers were responsible for planning focus group agendas, developing presentations and activities, and facilitating in-person meetings. Healthcare partners were responsible for recruiting stakeholders and collaboratively coordinating stakeholder meetings. Open discussion created a shared learning environment that addressed the continuum of care and resulted in informal yet intentional and collaborative decision making about the website design project. Iterative website modifications were implemented by researchers in response to stakeholder feedback (Figure 2). All engagement activities were approved by IRBs at MSU and each recruitment site.

MISTT Stakeholder Focus Groups

During FG meetings,[57,58] patients and caregivers shared their lived TC experiences and identified website preferences for content, design, and utilization including potential website utilization facilitators and barriers. In separate FGs, stroke-related healthcare professionals from diverse disciplines and organizations shared their professional experiences spanning various levels and aspects of stroke recovery.

A convenience stakeholder group of stroke survivors (i.e., patients) and their caregivers were recruited within 3-6 months post-discharge from four mid-Michigan (located in 2 cities: Lansing, Ann Arbor) acute care partner hospitals. Adult, acute stroke patients with measurable deficits at the time of stroke discharge (NIH-Stroke Scale [NIHSS] >=2 or modified Rankin Score [mRS] >=2), who broadly represented the hospital's population demographics and clinical features, were recruited via phone, along with their primary caregivers. Interested individuals received an invitation letter and reminder phone call prior to the FG meeting(s). Healthcare professional stakeholders were recruited from a variety of mid-Michigan partner organizations providing stroke care. Organizations shared an e-mail inviting interested persons to contact study personnel about participation.

FG meetings were scheduled at locations with free parking and handicap accessibility. Stakeholder participants signed consent forms, provided demographic information, and were invited to participate in subsequent meetings. They received $50 per meeting to compensate for their time and efforts.

FGs were facilitated by study researchers who encouraged participant confidentiality by asking stakeholders to identify only by first name and creating trust through active listening, empathy, and making space for everyone to share difficult experiences. Data were collected by recording and transcribing discussions and administering written surveys designed to supplement and complement the discussions. Transcriptions were independently coded by two researchers who identified themes related to post-stroke TC using thematic analysis methods;[58,59] written responses were analyzed descriptively.

FG agendas and activities were iterative and built upon previous discussions.[60,61] Although final decisions for meeting agendas, presentations, activities, and facilitation were determined and executed by the research team, all decisions were heavily informed by partners and stakeholders. The iterative FGs were also designed for stakeholders to corroborate and/or correct researchers' conclusions. A total of six patient-caregiver FGs were conducted with three pairs of meetings taking place in each of two locations. Similarly, four FGs were conducted with healthcare professionals, two in each location. Table 1 displays the meetings' primary goals and activities.

MISTT Website Usability Evaluation

Following FGs, a beta website was formally tested for usability (Figure 2, Table 1). Stroke survivors and caregivers were recruited from one partner neurology out-patient clinic in mid-Michigan 2-4 months following their stroke event using the same eligibility criteria as FG recruitment. Usability evaluation sessions were conducted by the MSU Usability/Accessibility Research and Consulting (UARC) team. Standard methods were utilized to test whether the website provided a stakeholder/user-centered experience.[63] Stakeholders performed several tasks using the beta website, which involved typical user situations to identify difficulties, usage patterns, and types of participant errors. To assess their experience and collect feedback, stakeholders were videotaped, asked to think aloud, describe any confusion, rate task difficulty, and complete a post-study questionnaire (Table 1).[64] Usability concerns were summarized and recommendations for improvements were shared with the research team.

RESULTS

The Stakeholder Engagement section highlights information gathered during FGs and Usability Evaluation testing, which informed website content and design. The following Website Evolution section describes the iterative website changes, reporting how results from the RPA UCD process influenced collaborative website development.

Stakeholder Engagement

Patient-Caregiver Focus Groups

Eighteen unique patients and nine caregivers participated in three pairs of patient-caregiver FGs, with many attending multiple meetings (Table 2). Patients averaged 4-months post-stroke, largely discharged directly home without services. Caregivers were all married and mostly female.

Four themes related to post-stroke TC emerged from the first two pairs of FGs: 1) practical and emotional support, 2) preparedness, 3) identifying and addressing unmet needs, and 4) addressing stroke prevention interventions.[65]

Content for the MISTT website was selected by researchers and partners to align with these stakeholder-identified themes, as well as several patient-caregiver-identified TC domains (Figure 3A). Of the eight originally proposed topic sections (Figure 1), patients reported least interest in e-mailing their care team and interacting with caregiving social networking tools, while caregivers expressed interest in all website topics (Figure 3B). Additionally, caregivers reported higher use of all technology tools for accessing online resources (Figure 3C), and fewer caregivers [40% (n=2/5)] reported a change in their technology use after the stroke event compared to patients [67% (n=4/6)]. Comments from patients included, “We have a computer in the house, but I don't use it" and "Using a tablet: At 86, I don't want to start." Most stakeholders had never accessed a healthcare patient portal [60% patients (n=9/15), 71% caregivers (n=5/7)]. One stakeholder shared her lack of awareness, stating, "The doctors didn't say anything to me about it. I didn't know there was any such thing." The eight participants who had previously used a patient portal discussed their experiences with utilization and technical support: "Well, I got an email saying I had an upcoming appointment. It said to log onto your portal. And I couldn't figure out what my password was. I mean I don't know if they ever sent it to me or what—I had no clue what it was or where it was. So I had to call and get it."; expressing frustration with turn-around time for access to records or test results: "When you go in to check some of your records and these reports, I wasn't able to access any of that - the information about what happened right at the time of my stroke, or any of those reports."; and for needing to use different portals for providers associated with different healthcare networks. Stakeholders unanimously suggested that the ideal system would involve a patient-controlled portal where providers would deposit information into one platform, regardless of their network affiliations. As summarized by a stakeholder, "you really want your portal where you can actually electronically talk to the people, talk to your doctors, do all the things, but it's your portal and it doesn't belong to the hospital."

Few stakeholders (n=4/12) had ever used a synchronous online chat room, and 40% (n=4/10) reported they were very unlikely to use one for stroke support. Instead, stakeholders were more likely to engage in asynchronous stroke support discussion forums (58%, n=7/12) stating, "You wouldn't be so shy about things." Although stakeholders discussed concern over security, 74% (n=14/19) expressed interest in participating in an online support group, with some (37%, n=7/19) preferring a local study-specific group, rather than a national or state-wide group.

Healthcare Professional Focus Groups

A total of 34 unique stroke-related healthcare professionals recruited from partner organizations participated in two pairs of FGs. Participants included nurses, discharge planners, stroke neurologists, physiatrists, rehabilitation therapists, social workers, public health officials, and administrators representing diverse clinical settings of hospitals, rehabilitation facilities, nursing homes, and home healthcare agencies. The majority were white females with over half having 10+ years of stroke experience.

Common challenges to stroke TC were identified, including insurance barriers to receiving community-level care (Table 3). Table 4 includes selected comments that illustrate various healthcare, patient, and community-level challenges. Although providers identified inadequate communication as a common TC challenge, they were strongly against creating additional, non-institutional communication systems.

Stroke signs and symptoms, stroke risk factors, coping strategies, including emotional recovery and behavior, medications, and stroke prevention, were the top five stroke education topics identified by providers, along with 15 reputable resources. The top five medication education topics identified were associated with increasing knowledge and practical skills/resources.

Usability Evaluation

Seven usability evaluation sessions identified significant usability issues with the beta website and provided invaluable information for refining the website to be more user-friendly for post-stroke users. Survivors (n=4) were 2-4-months post-stroke and broadly represented a range of patient characteristics: age 52-70 years, 57% female. Caregivers (n=3) were 52-87 years old, 67% male. Stakeholders self-reported minimal confidence in their ability to use new technology, serving as good representatives of the target population.

MISTT Website Evolution

Development of the MISTT website evolved in stages: moving the original conceptual design into a wireframe prototype, a functional beta website, and the final version (Figure 4). Technical construction was undertaken by MSU's design team in collaboration with the research team who prepared all website content and finalized decisions regarding visual and interactive design.

Stage 1 of website development involved building a prototype wireframe based on the original conceptual design, generated with partners. Informed by partners and FGs, the research team created preliminary content aligned with stakeholder themes for post-stroke TC. Stakeholders emphasized the importance of accessing solid, reputable content from a single location; therefore, content consisted of original material, as well as links to pre-existing authoritative online resources (e.g., American Heart/Stroke Association, National Stroke Association). Applying universal guidelines for older adults,[55,57] the design team then built initial page layouts in a wireframe. Stakeholders provided feedback about the prototype's content and design.

Stage 2 involved converting the prototype wireframe into a stakeholder-informed functional beta website by incorporating patient-caregiver preferences for website design and content into best design practices tailored to post-stroke users. Design changes included larger font size, more space within a page, clear section headings, simple language, creating videos to introduce topics and reinforce important messages, and presenting content in multiple formats (i.e., text, graphics, videos) to accommodate a range of potential post-stroke visual or cognitive deficits. Table 5 outlines the final primary content sections, highlighting how the original proposal evolved in response to stakeholder feedback. Within each topic section, content was organized from summary-level to in-depth information. New content developed by the MISTT team was presented with an active voice of hope focused on introducing a topic, explaining its relevance to stroke TC, and providing an overview of links and materials selected from existing sources. Videos were created to provide helpful hints for navigating the website and for using recommended resources.

Access to the MISTT website required a username/password to track user-specific website utilization data during the trial. Responsive web design practices were used to create a mobile-friendly user interface, and functionality was tested and validated.

Stage 3 of website development involved modifying the beta website into the final MISTT website. Following usability testing, the website underwent a significant redesign to improve ease-of-use and functionality resulting in changes to navigation, site structure, formatting, and content. Navigational structure was improved by dividing content-heavy sections to alleviate information overload; repositioning the search box; re-formatting the primary navigation menu; replicating the navigation menu at the bottom of the page for mobile users; adding a breadcrumb feature at the top of each page; enhancing the prominence of links and buttons by using content-type icons, call-out boxes, and adding descriptions of the linked source; positioning the most useful resources first; adding descriptive headings to provide better context; and using a specific accent color for major section pages to improve orientation. Content was finalized by refining the core stroke and medication content; producing closed-captioned videos for several more topics; using plain language to explain medical terms; shortening sentences to enhance readability; and creating a more personable experience by speaking directly to users with an encouraging tone. Additionally, a log-in page with an introductory video, home page, help/FAQ section, contact section, and improved keyword search were added.

In culmination, the MISTT website was designed as a user-centered resource to provide stroke survivors and caregivers relevant information to manage in-home stroke transitions and recovery. Over a 10-month RPA UCD process, the research team collaboratively developed the MISTT website with community partners and stakeholders, creating a curated, user-oriented website tailored to patient-caregiver preferences that provided information and resources addressing stroke education, prevention, recovery, and community services to promote self-management. The seven primary content sections and supportive features are shown on the homepage (Figure 5).

DISCUSSION & LESSONS LEARNED

RPA are methods inherently aligned with UCD strategies, which allowed stakeholders to co-develop the MISTT website through an iterative design process that embraced cycles of reflection, learning, and actionable feedback. Central to both methodologies are the iterative consultation and involvement of end-users to identify relevant content and preferred functionality, with opportunity for stakeholders to interact and test components throughout the design process. Existing professional networks were critical in identifying partners who advised the research team about needs across the continuum of stroke care, contributed to the overall MISTT study design, recruited FG stakeholder participants for the website development project, and co-organized FGs. These stakeholders were instrumental to our application of website design best practices in supporting stroke survivors and caregivers facing complex biopsychosocial TC experiences. The importance of stakeholder input is evident in the many iterative content and design modifications of this project.

FGs ensured a wide-range of complex patient-caregiver experiences and needs were considered; more voices mattered in understanding variation in post-stroke TC experiences and population-specific website design needs. Stakeholder experiences and needs aligned with components of the CCM framework, validating its conceptual domains for guiding TC intervention development and emphasizing the necessity for tailoring components to the unique needs of post-stroke populations. FG discussions also offered co-learning: survivors and caregivers shared their stories with one another, while acute care health professionals learned how minor post-stroke deficits, often dismissed as insignificant, can have profound psychosocial TC impacts. Additionally, survivors and caregivers learned about system-level challenges that healthcare professionals face during care delivery. These experiences emphasized the critical need for social support and community resources. Although many stakeholder ideas were incorporated into the website, some ideas were either beyond the project's scope or were not feasible within current healthcare system infrastructures. It was important to acknowledge all stakeholder input and then engage in discussions about limitations and feasibility so that stakeholders felt heard but could also realize limitations and engage in discussions about alternative solutions.

Engaging community partners and stakeholders in collaborative development of the MISTT website significantly impacted its content and functionality as an intervention tailored to post-stroke TC needs. RPA requires planning for dedicated funds and staff who can devote effort fostering relationships, planning, executing, and analyzing engagement activities. Funding and time limitations affected this project's ability to conduct additional usability testing and to establish sustainable partnerships with community-based organizations. Although primary stakeholder engagement for website development involved consultation, partners and stakeholders subsequently formed an Advisory Board that provided ongoing feedback and co-developed strategies for unexpected challenges during the MISTT trial. They helped create trial recruitment materials, disseminate information about the FG and trial results, and offered opportunities for the research team to participate in a community collaborative aimed at improving TC. Unfortunately, this partnership dissolved when the grant funding ended. On reflection, partnering with community stakeholders at a deeper level of shared leadership and empowerment may help create opportunities for sustained funding and implementation of collaborative interventions.

Summary and Future Directions

Engagement activities with partners and stakeholders were critical for ensuring the MISTT website was tailored to post-stroke survivors and caregivers. Technology-based TC interventions is an emerging field that can deeply benefit from RPA and UCD methodologies. Particularly within the community-based stroke population, there is much to learn about the context and application of technology, including its goals as an educational, organizational, service, support, and communications resource, its usability, and its actual utilization given the complexities of post-stroke TC. Engaging patients-caregivers must remain a priority in advancing our understanding and application of health technology within post-stroke communities.

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FIGURES

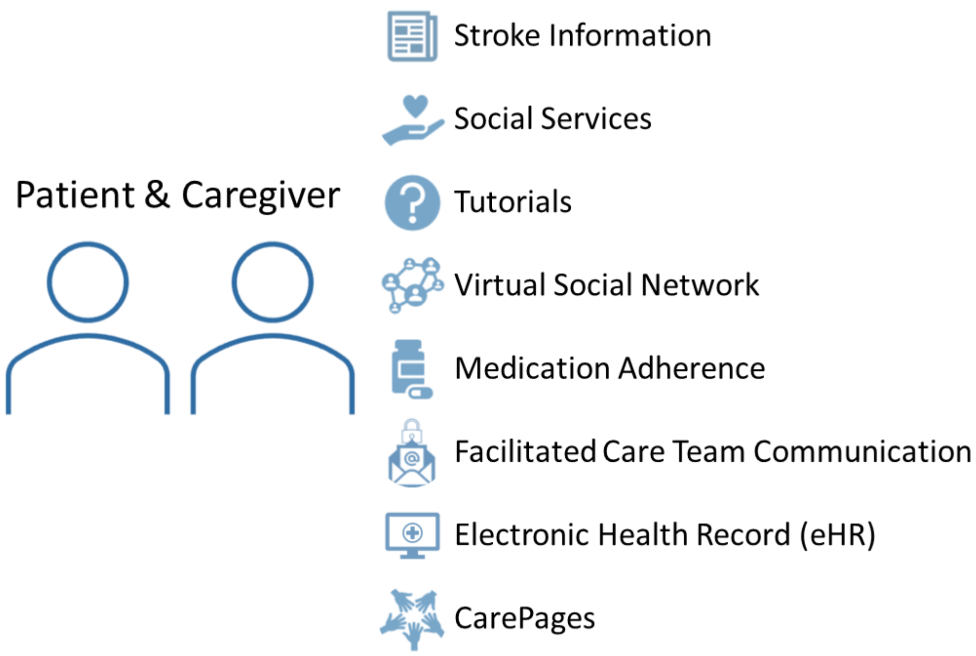


Figure 1: Original 8-topic conceptual proposal for the MISTT website, modified from Fritz MC, Swierenga SJ, Freddolino PP, Coursaris CK, Woodward AT, Reeves MJ. Lessons learned in developing a patient-centered website to support stroke patients and caregivers during transitions of care. In: Lecture Notes in Computer Science. *Springer International Publishing; 2021:450-466.*

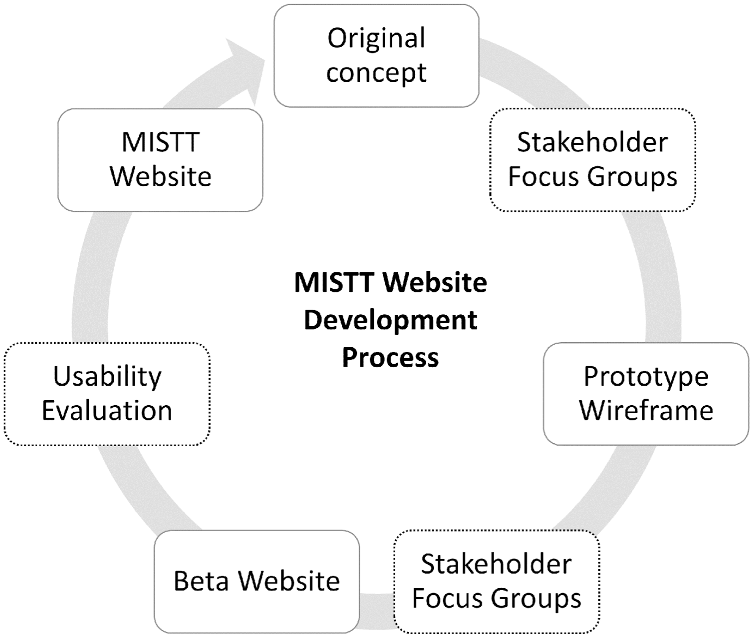
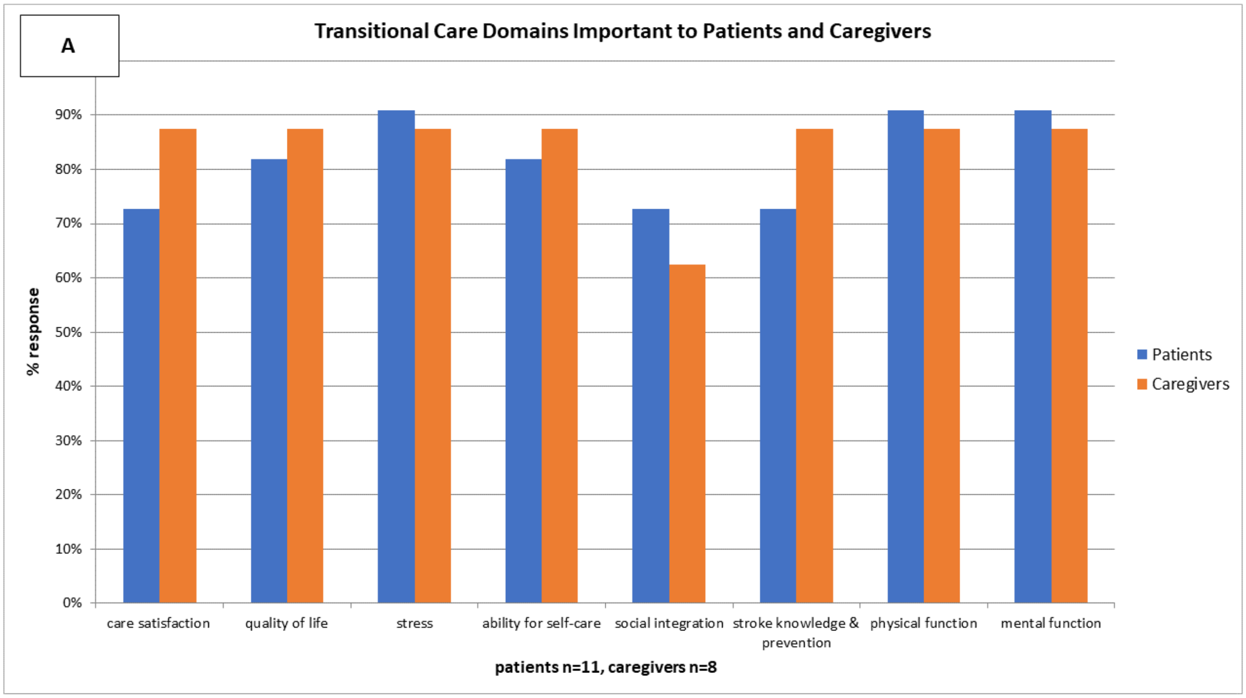
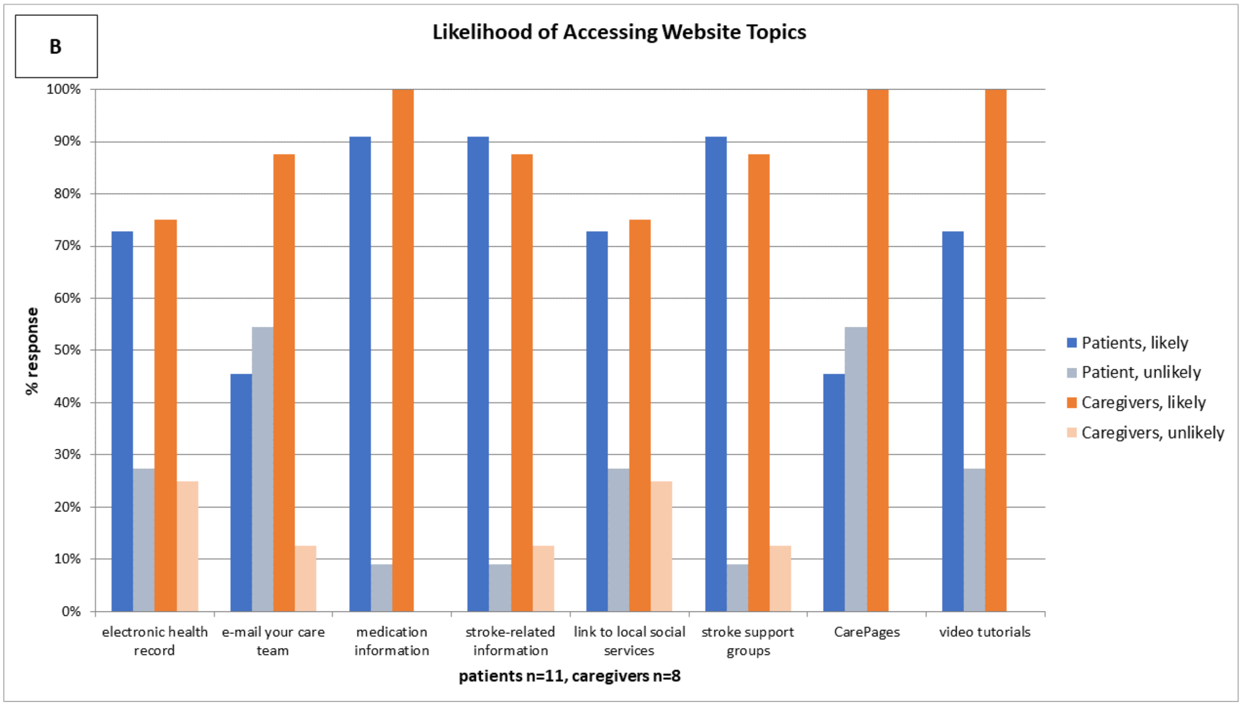


Figure 2: MISTT website development: a staged, stakeholder/user-centered collaborative design process. Community partners were involved in generating the original concept while stakeholders informed iterative modifications of the original website concept, resulting in a prototype wireframe and functional beta website prior to finalizing the MISTT website.

MISTT=Michigan Stroke Transition Trial


A
Transitional Care Domains Important to Patients and Caregivers
% response
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
care satisfaction
quality of life
stress
ability for self-care
social integration
stroke knowledge & prevention
physical function
mental function
patients n=11, caregivers n=8
Patients
Caregivers


B
Likelihood of Accessing Website Topics
% response
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
electronic health record
e-mail your care team
medication information
stroke-related information
link to local social services
stroke support groups
CarePages
video tutorials
patients n=11, caregivers n=8
Patients, likely
Patient, unlikely
Caregivers, likely
Caregivers, unlikely

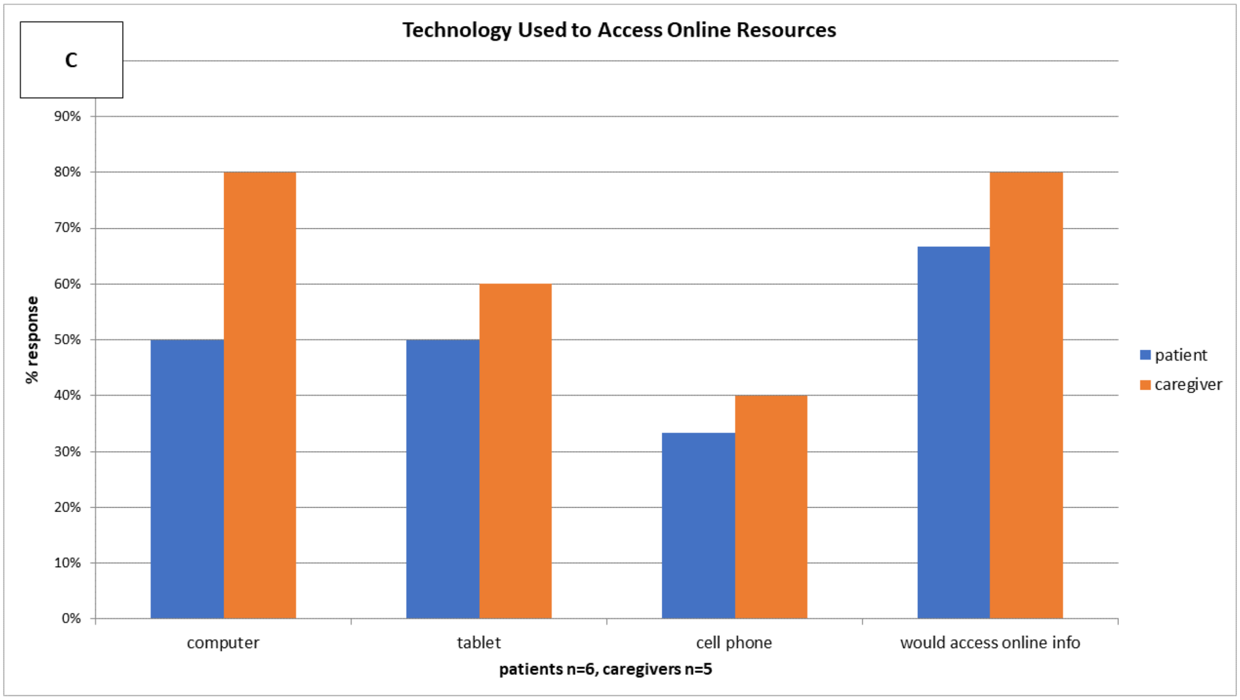


Figure 3: A. Transitional care (TC) domains important to stroke patients and caregivers; B. Likelihood of stroke patients and caregivers accessing proposed website topics; C. Technology used by stroke patients and caregivers to access online resources.

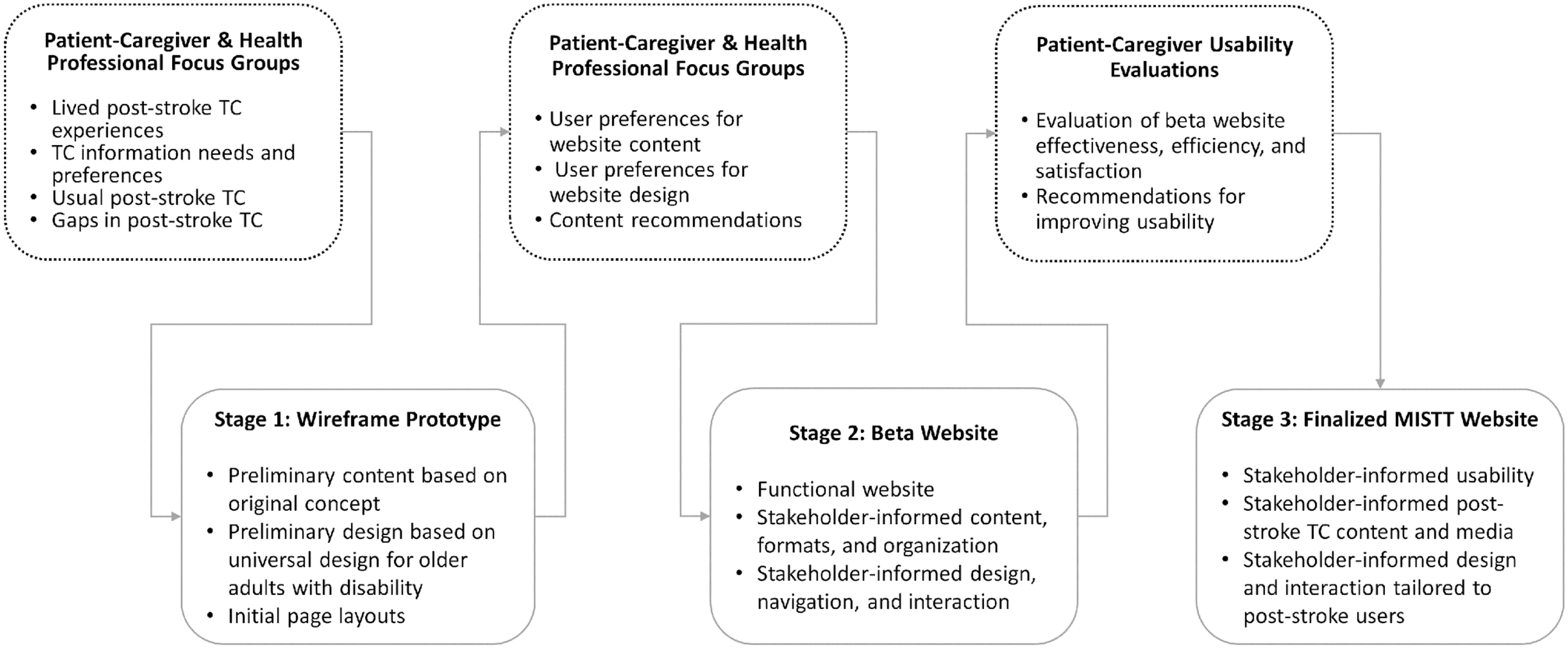
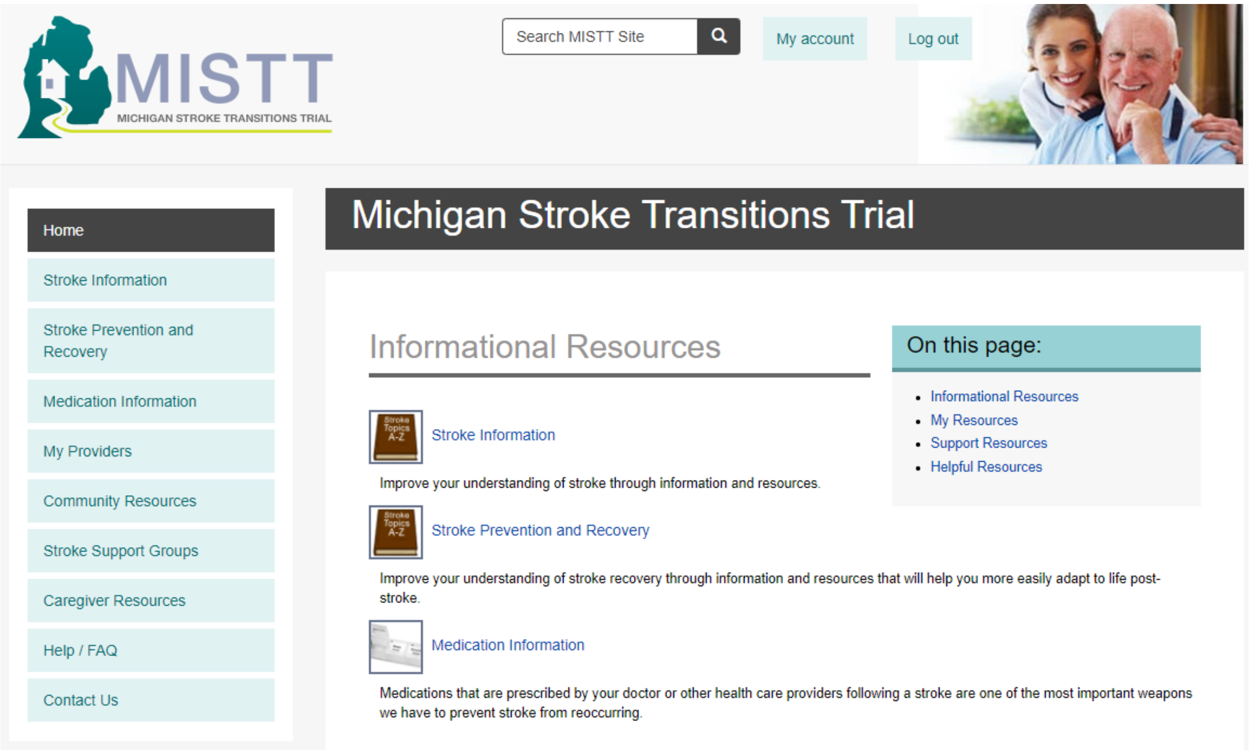


Figure 4: Staged evolution of the MISTT website using a community-engaged rapid participatory appraisal (RPA) user-centered design (UCD) process resulting in the Final MISTT website, an informational website for post-stroke transitional care (TC) users. TC=transitional care; MISTT=Michigan Stroke Transition Trial



Michigan Stroke Transitions Trial

Informational Resources

Stroke Information

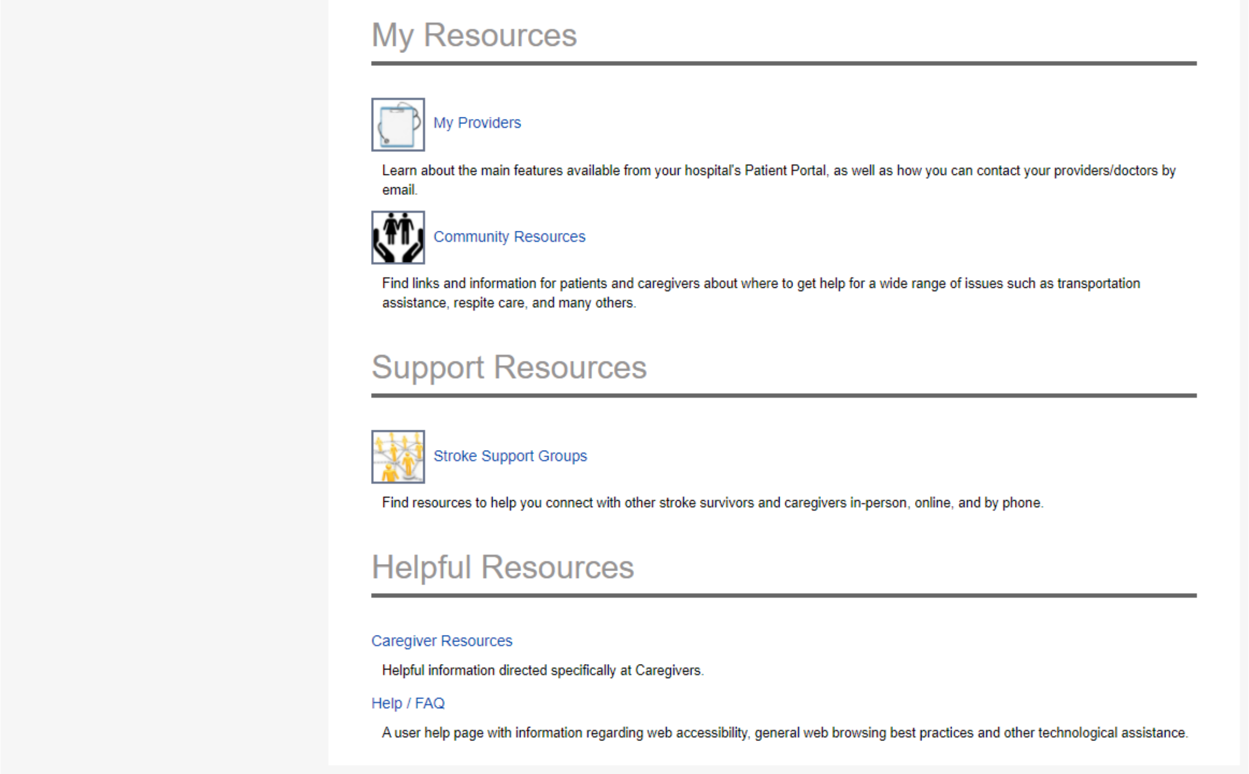
Improve your understanding of stroke through information and resources.

Stroke Prevention and Recovery

Improve your understanding of stroke recovery through information and resources that will help you more easily adapt to life post-stroke.

Medication Information

Medications that are prescribed by your doctor or other health care providers following a stroke are one of the most important weapons we have to prevent stroke from reoccurring.



My Resources

My Providers

Learn about the main features available from your hospital's Patient Portal, as well as how you can contact your providers/doctors by email.

Community Resources

Find links and information for patients and caregivers about where to get help for a wide range of issues such as transportation assistance, respite care, and many others.

Support Resources

Stroke Support Groups

Find resources to help you connect with other stroke survivors and caregivers in-person, online, and by phone.

Helpful Resources

Caregiver Resources

Helpful information directed specifically at Caregivers.

Help / FAQ

A user help page with information regarding web accessibility, general web browsing best practices and other technological assistance.

Figure 5: Screenshot of the final MISTT website homepage, featuring the seven primary content topic sections and supportive features (search box, account details, Help/FAQ, contact us).

TABLES

Table 1: Stakeholder engagement in developing the MISTT website: goals and activities of each focus group (FG) meeting

Stakeholder Engagement	**Location(s) (City/ies)**	**Month**	**Engagement Goals**	**Engagement Activities**
Patient-Caregiver FG #1	Lansing, Ann Arbor	February	1) understand lived in-home, post-stroke patient-caregiver TC experiences 2) determine patient-caregiver TC information needs and preferences.	● consent, demographics form ● group discussion about stroke and TC, information needs, and ongoing post-stroke concerns
Healthcare Professional FG #1	Lansing, Ann Arbor	March	1) understand usual care practices 2) identify post-stroke TC gaps	● consent, demographics form ● group discussion about usual TC practices, in-home post-stroke

Stakeholder Engagement	**Location(s) (City/ies)**	**Month**	**Engagement Goals**	**Engagement Activities**
				challenges, and post-discharge follow-up
Patient-Caregiver FG#2	Lansing, Ann Arbor	March	1) corroborate post-stroke TC themes that emerged from the first FGs 2) identify outcome domains most important to patients-caregivers 3) understand patient-caregiver preferences for online information content and formatting	● consent, demographics form ● group discussion about post-stroke TC themes, measuring outcomes that matter, and accessing reliable stroke information ● surveys addressing post-stroke TC themes, measurement themes, interest in using the proposed website components, and technology access and use

Stakeholder Engagement	**Location(s) (City/ies)**	**Month**	**Engagement Goals**	**Engagement Activities**
Patient-Caregiver FG#3	Lansing, Ann Arbor	April	1) understand patient-caregiver preferences for scope, depth, and different presentations/ formats of stroke information 2) seek ideas for helping stroke patients-caregivers access and utilize the MISTT website	● consent, demographics form ● interact with a prototype of the MISTT website by completing 5 exercises using a laptop and mouse ● surveys addressing preferences for the content and format of online stroke information, medication information, social services, social support, patient portal familiarity/use, and navigating the prototype wireframe

Stakeholder Engagement	**Location(s) (City/ies)**	**Month**	**Engagement Goals**	**Engagement Activities**
Healthcare Professional FG#2	Lansing, Ann Arbor	May	1) understand usual care practices 2) identify post-stroke TC gaps 3) recommend stroke education and medication management content topics and resources 4) gather feedback for the content and format of a prototype of the MISTT website	● consent, demographics form ● group discussion about post-stroke measures used in acute and post-acute care, usual discharge practices, post-discharge follow-up, patient portals, patient-family communication, and screenshots of the prototype wireframe ● surveys addressing stroke education and medical management topics and resources

Stakeholder Engagement	**Location(s) (City/ies)**	**Month**	**Engagement Goals**	**Engagement Activities**
Patient and Caregiver Website Usability Evaluation Testing	Lansing	October	1) evaluate website effectiveness, efficiency, and satisfaction* 2) summarize usability concerns 3) suggest recommendations for improving website usability	● consent ● interact with a beta version of the MISTT website through a series of 6 task scenarios during individual, 1-hr usability sessions ● surveys addressing task difficulty, the System Usability Scale, and website content, organization, and formatting

**In usability evaluation, effectiveness measures how well a given usability goal is met, efficiency measures how much energy it takes to achieve the goal, and satisfaction measures how happy a user is with the experience*[62]

FG=focus group; TC=transitional care

Table 2: Characteristics of stroke patient and caregiver stakeholders for MISTT focus groups

Variable/Characteristic	**Patient Stakeholders n (%)**	**Caregiver Stakeholders n (%)**
Number of unique participants	18	9
Focus Group Site		
-Lansing	7 (39%)	4 (44%)
-Ann Arbor	11 (61%)	5 (56%)
Number of focus groups attended		
-One	7 (39%)	2 (22%)
-Two	5 (28%)	3 (33%)
-Three	6 (33%)	4 (44%)
Age (Mean years, range)	64 (33-86)	69 (59-87)
Sex		
-Female	7 (39%)	6 (67%)
Race		
-White	14 (78%)	7 (78%)
-Non-white	4 (22%)	2 (22%)
Ethnicity		
-Hispanic/Latino	0 (0%)	0 (0%)
-Non-Hispanic	18 (100%)	9 (100%)
Marital status	13 (72%)	9 (100%)

Variable/Characteristic	**Patient Stakeholders n (%)**	**Caregiver Stakeholders n (%)**
-Married	5 (28%)	0 (0%)
-Not married		
Education level		
-High school or less	2 (11%)	3 (33%)
-Some college	8 (44%)	4 (44%)
-College degree	8 (44%)	2 (22%)
Annual household income		
-<$30,000	4 (22%)	0 (0%)
-$30,000-$49,999	5 (28%)	4 (44%)
-$50,000-$69,999	4 (22%)	2 (22%)
-$70,000-$89,999	3 (17%)	2 (22%)
-≥$90,000	2 (11%)	1 (11%)
Post-stroke (Mean months, range)	4 (1-7)	Not applicable
Initial discharge destination		Not applicable
-Home without services	13 (72%)	
-Home with services	1 (6%)	
-Acute rehabilitation	4 (22%)	
-Subacute rehabilitation	0 (0%)	

MISTT=Michigan Stroke Transition Trial

Table 3: Frequency of specific healthcare, patient- and community-level challenges to successful stroke transitions identified by health care professionals

Healthcare-level Challenges	**n**
Post-stroke medical follow-up, appointment availability	16
Consistency of care planning across settings; insufficient resources/staff	13
Communication between providers	9
Communication between providers and patients	8
Ability to address psychosocial, environmental, socioeconomic issues; non-patient centered	7
Access to in-home assessment	3
Limited eMR access	2
Patient-level Challenges	**n**
Ability to retain information, lack of understanding about stroke and stroke care	13
Denial, unrealistic expectations for recovery and transitional stroke care	11
Caregiver burden	9
Financial burden	8
Navigating the healthcare system	7
Disability - physical or cognitive	6
Understanding differences between providers and unrealistic expectation of services	5
Ability to refuse in-home services	4
Ability/availability to communicate with providers	1
Community-level Challenges	**n**
Insurance regulation requirements and limitations	16

Awareness/access to community resources	8
Support group awareness and participation	2

Table 4: Healthcare professional comments that illustrate major challenges in post-stroke transitional care (TC)

Healthcare Professional Comment	**Challenge**
"The problem is there are mixed messages with what the primary care doc recommends; they'll recommend one thing and then say, 'Follow up with your neurologist' and then we recommend something different"	Healthcare-level
"They've seen many, many new physicians that they don't necessarily trust. And you would be surprised about how many people … have done all the things that they have been told to do while they have been institutionalized. But now they're home and things have changed"	Health-care level
"Not understanding the trajectory of their illness or their prognosis can be a barrier to services or to treatment goals because they don't foresee having problems or don't want to talk about long-term care"	Patient-level
"Sometimes patients/families are in denial, and they think, 'When I get home it's going to be the same as it was before my stroke'"	Patient-level
"There is a lot more regulation regarding ability to get in the home and get reimbursed"	Community-level

"Patients need help looking for programs that will pay for other services, whether it be like building a ramp on a home or securing assistance with paying for medication"	Community-level

eMR=electronic medical records

Table 5: Co-developing the primary MISTT website content sections with stakeholders

Final MISTT Website: Primary Content Sections	**Originally Proposed Themes**	**Outcome of surveys and focus groups**	**Final Status of Proposed Themes**
1) Stroke Information 2) Stroke Recovery and Prevention	Stroke-related information	Strong interest	Retained and expanded; reorganized Stroke Recovery and Prevention into a separate topic section
3) Medication Information	Medication adherence information	Strong interest	Retained and expanded to educate about common post-stroke medications, mechanisms of action, how to talk to your doctor/pharmacist, drug

			interactions, financial resources
4) My Providers	Electronic health record, i.e., direct access to patient portals	Some interest	Retained; focused on assisting and encouraging utilization of existing hospital patient portals for accessing medical information and communicating with clinicians
	E-mail your care team (the ‘facilitated care team communication tool’ to provide direct communication with your healthcare team)	Little interest and unfeasible to implement	Excluded the facilitated care team communication tool; replaced with a structure for creating an organized contact list of the patient’s providers and services
5) Community Resources	Link to social services in your area	Some interest	Retained

6) Stroke Support Groups	Stroke support groups	Some interest, especially in local support groups	Retained
	CarePages online social network	Strong interest	Retained
7) Caregiver Resources		Strong interest	Added in response to significant stakeholder interest/need
Additional Resources: Log-in page, Home page, help/FAQ section, keyword search function	Video tutorials	Some interest	Retained and expanded

MISTT=Michigan Stroke Transition Trial; FAQ=frequently asked questions