



Lessons Learned in Developing a Patient-Centered Website to Support Stroke Patients and Caregivers During Transitions of Care

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Abstract. Stroke is one of the leading causes of adult disability in the United States, affecting almost 800,000 United States citizens annually. Inadequate care during the transition back to home can lead to poor outcomes and delayed recovery. Although the transitional care period is often complex and multifaceted, providing patients and caregivers with timely, relevant education and informational resources remains an important foundation to any transitional care service. Utilizing technology to enhance post-stroke transitional care services and provide unlimited access to information may increase survivors' understanding and ability to manage their stroke recovery during the transition period.

The Michigan Stroke Transitions Trial (MISTT) was a two-phased clinical trial study that engaged stakeholders in developing and refining two patient-centered post-stroke transitional care interventions intended to improve 90-day stroke survivor and caregiver outcomes. This case study describes the Patient-Centered Design approach used to develop the MISTT website intervention, which is a curated, patient-oriented website containing information and resources relevant to lived, post-stroke transitional care experiences.

Lessons Learned: Substantial time, support, and funding is required for a multi-stage approach to creating and building a patient-centered website. Stakeholder engagement was crucial to the final content, design, and functionality of the MISTT website. Stakeholders were instrumental for determining how to apply best practice universal design guidelines to meet needs and preferences for stroke survivors and their caregivers.

Keywords: Aging and UDUX · Stroke · Transitional care · Website development · Health information · Patient education · Patient-centered design

1 Background

Stroke affects close to 800,000 people in the United States every year, and the number is growing, especially as the population ages [1]. Two-thirds of stroke survivors return

home, some after complex transitions between acute hospital, rehabilitation, and nursing care settings [2, 3]. Inadequate care during this critical transition period contributes to hospital readmissions, delayed recovery, and decreased quality of life for patients and caregivers. The cumulative effect of these challenges results in substantial treatment burden [4], which is exacerbated by the poor coordination of existing post-acute care services [2, 3].

Patient and caregiver education remain a cornerstone to increasing engagement and self-management [5, 6]. Similarly, education is an essential, underlying aspect of all transitional care components [5]. Providing access to high quality patient-centered educational information during the transitional care period has the potential to be a cost-effective intervention to improve transitions for both patients and caregivers.

Technology, often labelled as tele-health, tele-medicine, e-health, or m-health for mobile device-related applications and services, offers great potential for improving the medical care and outcomes of patients transitioning across care settings and after returning home [7–11]. However, the implementation of these technologies is complex because they need to ‘fit’ the specifics of the clinical purpose and population; more research is required so that these technologies deliver on their promise. [12, 13]. While studies describing the effectiveness of online tools in support of chronic disease self-management have been undertaken [14, 15], they do not address these online tools’ usability or information quality. O’Reilly et al. [16] found that a potentially useful web-based tool for chronic disease management was poorly adopted by health care providers, in turn making an assessment of its utility and value to patients unattainable.

Access to reliable, accurate, trusted, and easy-to-digest information is consistently identified as a critical need by patients and caregivers recovering from acute stroke and is a critical component of self-management strategies [17]. In the area of stroke, there is limited literature evaluating technology tools, including websites and mobile apps, to promote patient engagement and self-management among stroke patients. For example, a set of reports by Pierce and her colleagues [18, 19] describe a web-based stroke intervention with communication and information resources for family caregivers. Eames et al. [20] found that patients and caregivers were often dissatisfied with the information available. Through interviews Eames et al. [21] learned that patient and caregiver preferences for methods of conveying information after discharge varied, suggesting the need for a variety of formats when offering assistance to this population. Cameron et al. [22] demonstrated the need to have interventions, including information, reflect the changing care environment of stroke patients and caregivers, from the acute stage to long term adaptation to the illness. Thus, information needs will change during the course of the illness and recovery [23] and an adaptable online resource is an ideal.

To address the ongoing need for post-stroke transitional care resources and support, the Michigan Stroke Transitions Trial (MISTT) research team proposed a two-phased clinical trial study – comprised of Development and Trial phases - to develop and test two interventions intended to improve 90-day outcomes for stroke survivors and caregivers [24, 25]. All study-related activities were approved by Biomedical Institutional Review Boards. The MISTT study interventions involved access to a 60-day Social Work Case Management program (SWCM) alone or in combination with access to a patient-centered information website, referred to as the MISTT website. During the Development Phase of

the study, stroke survivors, their caregivers, and stroke-related health professionals were engaged in developing and refining the two study interventions to ensure that they were patient-centered and designed to address a variety of post-stroke patient needs during the transition back to home [26]. In the Trial Phase, efficacy of the two interventions was formally tested in a 3-group randomized controlled trial (see Fig. 1) [24]. Randomized controlled trials are considered as the highest standard study design for determining the efficacy of different interventions on an intended outcome because they compare the intervention groups to a “control” (or unaltered) group, which accounts for additional variables that may also contribute to or influence the outcome of interest [27].

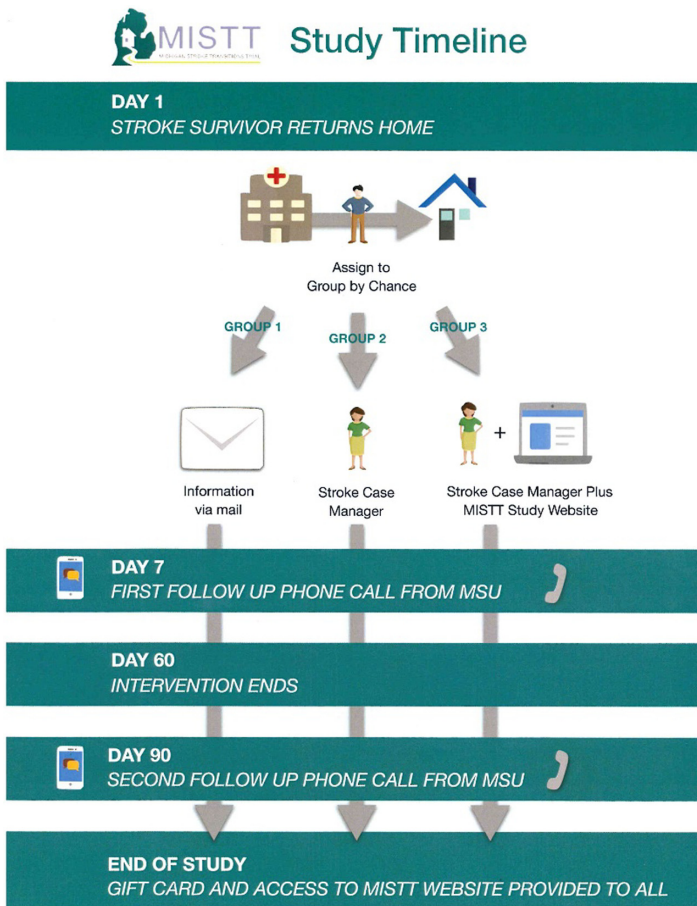


Fig. 1. Michigan Stroke Transitions Trial (MISTT) randomized controlled trial design and timeline.

The aim of this paper is to present a case study describing the development of the MISTT website, a curated patient-centered, mobile-friendly website designed to provide information and support resources for stroke patients and caregivers during their

transitional care period following discharge to home. Decisions about the visual design and interaction design, including embedded functionality, and how these aspects were informed by stakeholder input will be described. Lessons learned about project-related time, complexity, technical support, funding, content, and stakeholder engagement will also be shared. Development of the SWCM intervention [26] and results of the trial are reported elsewhere [24].

2 The MISTT Website Development Process

The MISTT website development process, undertaken during the MISTT study Development Phase, was guided by several key goals, including: 1) meeting stakeholder-identified needs by creating a patient-centered website informed by lived experiences and 2) applying evidence-based guidelines for healthcare web design to ensure usable and accessible informational website resources for stroke survivors and their caregivers. From inception, development of the MISTT website involved an interactive process among the MISTT research team, stakeholder groups, and a creative design team. The technical construction was undertaken by the research team in collaboration with its university’s creative design team. The research team prepared all website content and approved all final decisions regarding visual and interactive design. The originally-proposed concept for the website (see Fig. 2) was based on a broad review of technology-based applications available in medical, health care, and social service fields, together with initial suggestions from stroke patients, caregivers, and health care professionals.

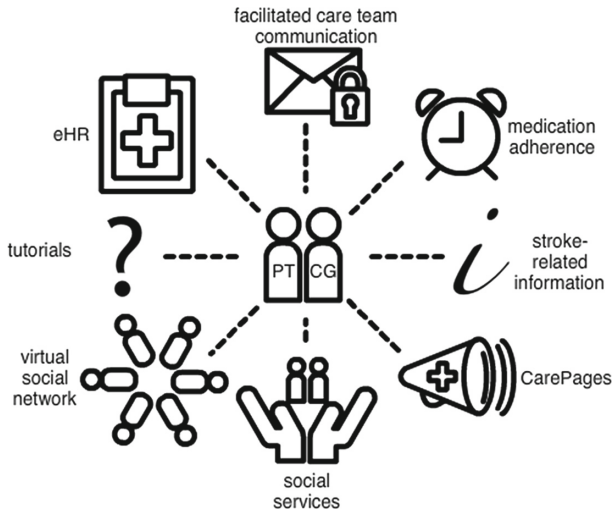


Fig. 2. Originally-proposed conceptual design of the MISTT website.

The development process involved a 10-month, 3-staged approach where, in Stage 1, the original conceptual design was fashioned into a non-functional prototype website. In Stage 2, the prototype website was converted into a stakeholder-informed, functional

beta website, and in Stage 3, the beta version was iteratively modified into the final production version of the MISTT website. Each stage involved modifications in response to input from patient, caregiver, and healthcare professional stakeholders (see Fig. 3). The prototype was a wireframe design (consisting of preliminary content and initial page layouts) of the original website concept, while the beta version was a functional website implementation. The efficacy of the final MISTT website was subsequently tested in the randomized controlled trial [24].

2.1 Stakeholder Engagement

Stakeholder engagement during the MISTT Development Phase involved stroke survivors (i.e., patients) and their caregivers, as well as stroke-related healthcare professionals. Focus groups were chosen as the primary method to gain a better understanding about the ‘lived experience’ of stroke survivors and caregivers during the transitional care period and to generate ideas for refining the MISTT website content and design preferences. Stroke survivors and their caregivers were the intended end users for the MISTT website. Three different pairs of patient-caregiver focus groups were conducted throughout Stage 1 and Stage 2 in each of two geographic locations, resulting in six total patient-caregiver focus group sessions (see Fig. 3). Eighteen patients and nine caregivers participated, with many attending more than one session. Participants in the first two sessions identified major themes related to the post-stroke transition to home [26], while participants in the third and fourth sessions reported their likelihood of using various potential online resources to address needs associated with these major themes. In the last two focus group sessions, patients and caregivers interacted with a prototype of the MISTT website where they participated in a series of exercises to identify their preferences in relation to the website’s information architecture and visual design including style, fonts, and graphics.

In addition to the patient-caregiver focus groups, two pairs of focus groups were also conducted with 34 different stroke-related healthcare professionals. The professionals represented a diverse set of clinical professions and clinical settings, including social workers, nurses, neurologists, psychiatrists, rehabilitation therapists, hospitals, and administrators from rehabilitation facilities, nursing homes, and home healthcare agencies. At these sessions, common challenges to achieving successful stroke transitions were discussed, and important stroke education and medication education topics for patients and caregivers were identified.

2.2 User-Centered Website Design

User-centered design (UCD) is a formal approach to the product (i.e., website) design and development process that prioritizes conducting user experience research from end users throughout an iterative product lifecycle. Incorporating end user input throughout the website’s design and development is critical to the UCD approach [28]. UCD considers user characteristics, tasks, user interface features/functionality, and the environmental context during the user-driven design process. The process typically includes context of use, user requirements analysis, design, user experience evaluations (and then iterating

back to design), followed by implementation, launch and maintenance [29]. Patient-centered design is a specific type of UCD where the end user is the patient (rather than the provider or clinician), and patients have a voice in the design and development process, helping to design the website or care intervention collaboratively with healthcare providers, medical staff, and design teams [30, 31]. The MISTT study approached website design and development with a patient-centered design process where the end users were stroke survivors and their caregivers.

Throughout the development phase, the MISTT team relied extensively on user interface design guidelines and best practices, along with the Web Content Accessibility Guidelines (international standard for designing inclusive websites) [32], to inform each step of the MISTT website design and development. The website design was intended to make content easy to locate and to consume, with simple navigation, multiple options for users, and an appropriate reading level [33]. The core design goals were organization and navigation (information architecture and flow of the pages), page layout, and content. Stakeholder feedback was imperative to understanding how to feasibly and practically implement each element to meet post-stroke capabilities and preferences. The following sections will outline the three stages employed for developing the MISTT website using a patient-centered design process (see Fig. 3), as well as discuss the impacts and contribution of stakeholder feedback on iterative content and design creation.

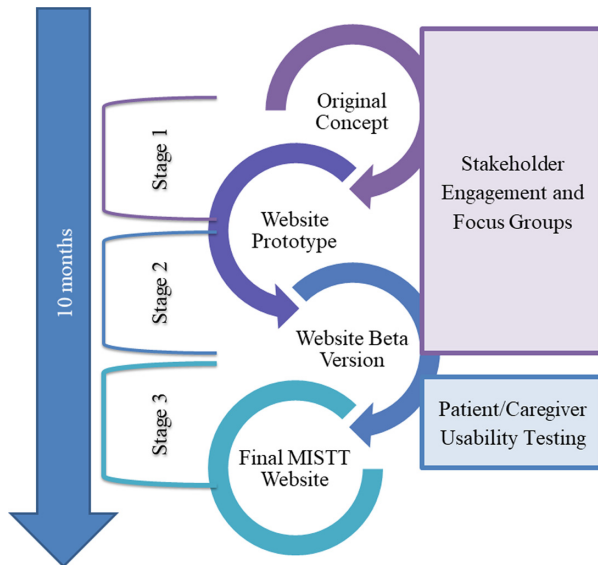


Fig. 3. The MISTT website development phase: a staged, patient-centered design approach.

2.3 Stage 1: Original Concept to Prototype Website

The primary focus in Stage 1 was to develop a prototype website from the original design concept. This involved identifying patient-centered content topics relevant to

the in-home transitional care period, gathering feedback on the original content topics compiled by the research team, and then creating a prototype website consisting of wireframes with preliminary content and initial page layouts. Discussions during the first two pairs of patient-caregiver focus groups revealed common post-stroke informational and transitional care needs, which were summarized into four core themes: 1) practical and emotional support, 2) preparedness, 3) identifying and addressing unmet needs, and 4) addressing actions and interventions related to stroke prevention [26]. MISTT website content was subsequently written to align with these themes, addressing several care domains that participants indicated were important to them during their transition, including physical and mental function, stress, quality of life (QOL), quality of care, stroke knowledge and prevention strategies, and integration back into community roles.

Patient and caregiver focus group participants also emphasized the importance of solid, reputable content that could be easily accessed from a single location. The creative design team implemented the MISTT website content by obtaining content from existing authoritative sources and linking to existing websites, where possible, to avoid re-creating already available authoritative information. Linking to established online resources minimized the need for ongoing content revisions, as revisions would generally be managed by the original authors and institutions. Discussions during the second pair of patient-caregiver focus groups revealed priority topics that patients and caregivers reported they were most likely to access online, including information about medications, joining stroke support groups, and other stroke-related information (i.e., how to prevent another stroke, returning to work or driving, etc.).

Participants in the stroke-related health professionals focus groups emphasized the importance of patients and caregivers having access to information about stroke signs and symptoms, stroke risk factors, coping strategies, medications, medication management strategies, and stroke prevention. They suggested a variety of reputable resources including the Mayo Clinic, American Heart Association, National Stroke Association, and also shared stroke-related resources from their institutions.

At this stage, the creative design team built a prototype website based on the proposed components of the original concept design. They applied their interpretation of universal guidelines intended for older adults in the absence of stakeholder input. The prototype user interface design was intended to make content easy to locate and consume. Best practices and design guidelines included simple organization and navigation (information architecture and page flow), consistent page layout, larger font sizes and color contrast, and plain language content [34, 35]. The prototype version was a wireframe with preliminary content and initial page layouts that allowed the study team to share with stakeholders for initial feedback. This stage was an important aspect of the iterative patient-centered design process that would inform subsequent revisions of the website's design and development.

2.4 Stage 2: Prototype to Beta Version

Stage 2 of the development phase was focused on understanding patient and caregiver preferences for website design and content, and on building a functional beta version of the website based on their preferences and best design practices. A preliminary website

prototype design and set of content topics were presented in the third pair of patient-caregiver focus groups, using the original conceptual design outlined in Fig. 1. These focus group discussions assisted the team's understanding of end user preferences and influenced the tone used in identifying, preparing, and refining content. The prototype was then converted into a beta version, which was an early functional website with substantial stakeholder-informed content. The beta version presented content in multiple formats (i.e., text, graphics, videos) to respond to different learning and access styles. Videos were identified as an essential feature, specifically for survivors with post-stroke deficits impacting their ability to read text. Content organization was improved to move from elementary or summary-level information to more in-depth details for each topic.

Content developed by the MISTT research team focused on introducing the topic at hand, explaining its importance to the context of stroke and stroke recovery, providing an overview of the selected links and materials, and providing videos with helpful hints for navigating the website. A short introduction to each external link/resource was provided, acknowledging its original source. Based on stakeholder suggestions, messages were presented with an active voice of hope, and the content was intended to provide a comprehensive scope of material to address physical/functional health, mental/emotional health, social, lifestyle, and environmental aspects of stroke.

Ultimately, stakeholder feedback informed which content topics of the original website concept to retain and which to discard in the beta website. Table 1 summarizes modifications made to the original concept topics based on this feedback, along with the subsequent content topics used to develop the beta version and ultimately retained in the final MISTT website. To determine the most relevant content topics, patients and caregivers were asked during the second pair of focus groups how likely they were to interact with each of the eight originally proposed content components. Patients were least interested in e-mailing their care team and interacting with a caregiving social networking tool, while caregivers were more likely overall to interact with various aspects of the website. Both stakeholder groups identified a significant need for caregiver-related resources, which resulted in creating a separate section dedicated to caregiver needs.

The stroke information section was expanded and a separate section for stroke recovery and prevention information was created based on evidence that stakeholders view stroke, stroke recovery, and stroke prevention as related but distinct topics. Thus, "stroke information" was revised to focus on the disease pathology, symptomatology, and treatment of stroke, while the "stroke recovery and prevention" section was focused on post-acute deficits, care, recovery, and rehabilitation, as well as risk factors and ways of preventing stroke recurrence. The medication information section was expanded beyond the original concept of medication adherence to include information about common post-stroke medications and how they work, how to talk with their doctors and pharmacist about medications, drug interactions, medication-related financial resources, and other medication-related resources.

Post-stroke support is crucial to successful transitions of care and the website intervention addressed support at two levels – social support and social services. Due to minimal interest by patients and caregivers in utilizing a social networking tool, the research team dropped the original concept of building a project-supported networking tool and the social networking section was eliminated. Instead, established resources for

Table 1. Results of stakeholder feedback on the initial website concept and how these influenced the final MISTT website components.

| Original components of the initial concept | Final MISTT website components informed by stakeholder feedback |
|--|--|
| Stroke-related information (e.g., disease pathology, symptomatology, and treatment of stroke; stroke recovery and prevention) | Very strong interest, especially from caregivers; retained, expanded, and reorganized into two separate topic sections: 1) Stroke Education and 2) Stroke Prevention and Recovery |
| Medication information to prevent another stroke (e.g., medication management, health literacy, complexity of dosing, patient-physician communication, etc.) | Very strong interest, especially from caregivers; retained and expanded as the Medication Information section |
| Electronic health record (provides access to patients records through hospital portals) | Some interest, especially from caregivers; modified content and renamed section to My Providers to encourage portal benefits and use |
| E-mail your care team (a ‘facilitated care team communication tool’ that supports direct patient-caregiver contact with providers) | Very little interest; discarded initial concept of creating a study-specific communication tool. Content within the My Providers section encouraged patients to organize a list of their provider contact information and communicate through their patient portal |
| Link to social services in your area (e.g., meals, transportation, respite care, access to durable medical equipment, etc.) | Some interest; retained as Community Resources section focused on Michigan 2-1-1, a free 24/7 confidential resource to provide information about local services to help with transportation, medical supplies, respite care, etc. |
| Social networking (project-supported networking tool) | Some interest; revised and expanded as Stroke Support Groups section to include caregiver social support resources; discarded project-supported tool |
| Family support websites (free websites pages that help family and friends communicate when a loved one is receiving care) | Very little interest; support-related resources moved to social support section. Original section replaced with the Caregiver Resources section to provide a variety of resources relevant to post-stroke caregiving roles |

social networking tools were identified and combined with other support resources into the Stroke Support Group section. The Stroke Support Group section included information for several local, regional, and national face-to-face support groups, as well as telephone and e-mail-based support groups or networks. In response to focus group discussions, support resources relevant to stroke survivors under the age of 50 were added. The social services section was renamed Community Resources to help stakeholders

better understand its content. Community-based social services vary across communities and often shift in availability or range of services due to funding and competing priorities. To decrease the efforts required in maintaining an up-to-date list of local community services, the website referred users to Michigan 2-1-1. Michigan 2-1-1 is a free confidential state-wide resource, available 24 hours a day, seven days a week, that provides information about a broad range of local services, including services addressing needs associated with transportation, medical supplies, housing or housing repairs, respite care, etc.

Healthcare providers deemed the idea of a facilitated care team communication tool impractical; thus, the originally proposed concepts for the facilitated care team communication tool and electronic health record sections were significantly modified and merged into a new section entitled My Providers. This modified section focused on encouraging and supporting patients to use their hospital-based patient portal to communicate with their providers. Simple, introductory information was created to help patients understand how to access and navigate their hospital-specific patient portals along with the associated benefits of utilizing their portal. In addition, the creative design team developed a structure within the MISTT website for documenting a contact list of the patient's providers/services, thereby creating a single repository for organizing this information.

Overall, the feedback from both the patient-caregiver and healthcare professional focus groups directly informed the scope and depth of content as well as the visual and interaction design of the beta version of the website.

2.5 Stage 3: Beta Version of the MISTT Website

In Stage 3, a usability evaluation was undertaken on the beta version of the website. Usability was evaluated quantitatively and qualitatively in terms of its core components: Effectiveness, efficiency, and satisfaction [36]. To obtain feedback on how well the website met user expectations for content, visual design, and interaction design, four stroke survivors and three caregivers completed 60 to 75-min individual sessions that involved a series of information-seeking tasks. Results indicated that the website needed significant improvement to meet the needs of stroke survivors and caregivers. While the participants were able to find basic information, e.g., types of strokes (100% task success) and local face-to-face support groups (100%), finding more detailed information on other websites that the MISTT website linked out to was much more difficult. For example, only one out of seven participants was able to find information on drug interactions, and none were able to locate transportation resources. The System Usability Scale (SUS) score for the MISTT website was 51.8 for the combined patient-caregiver participant group, which is below average and considered only marginally acceptable [37].

Recommendations from the usability evaluation were incorporated into the final stage of website development to prepare the MISTT website for the randomized controlled trial during the Trial Phase of this research project (which is outside of the scope of this paper and will not be discussed here). Modifications were undertaken to simplify the website's structure, content, and navigation to make it more user-friendly and appropriate for post-stroke users based on guidelines for designing websites for older adults [34, 35, 38]. Specific changes included adding a Home option on the far-left side of each page,

as participants often tried to click the Main Menu header (flat text) to get back to Home. Each major section of the website was also given a specific accent color to help orient users. Also, the primary navigation menu was re-formatted, a table of contents was added at the top of webpages containing four or more headings, and the navigation menu was replicated at the bottom of the page for mobile users.

Content-heavy categories were broken up into separate categories or shorter sections to alleviate how much information users needed to process within each overall category, and the overall number of pages was reduced to ensure the fewest possible clicks to get to information [33, 34, 38]. The team also spent considerable time working with the content applying best practices and design guidelines, such as using plain language to aid users in comprehending text, use, and simplifying and shortening sentences to their main points [33, 34]. Also, speaking to stroke survivors directly with an encouraging tone instead of talking about them (e.g., directly state the actions patients should take, instead of what not to do) was a key takeaway from the user tests.

Changes to the page layout included moving the search box closer to the main content to help users notice it; ensuring the search box (and other main-level navigation) was located in the same place on every page of the website [34]; and simplifying the format of the results page. Related content was visually grouped together, descriptive headings were added to provide better context [34], and the most useful resources were placed first on the page [33, 34].

Other page-level enhancements included increasing the prominence and visibility of links and buttons within the pages (e.g., creating specific content type icons/colors and created callout boxes), revising the link text to match the page title of the landing page, and having all external links open a new browser tab. Font sizes were enlarged, spacing was increased, and color contrasts were increased to support accessibility (using darker, heavier weight fonts) [34, 35, 38]. Meaningful text descriptions were added to images (via alt text), so that screen reader assistive technology could read it out for users with visual disabilities [33, 34]. Finally, during this final stage the core stroke and medication content was revised and finalized, a Caregiver Resources section was added, and videos, with closed captions, were produced for several content sections.

2.6 Final Version of MISTT Website Intervention

The final MISTT Website was a curated, patient-centered website that provided information and resources addressing stroke education, prevention, recovery, and community services (see Fig. 4). It was designed to encourage patient activation and self-management. The final seven main sections of the MISTT website (mistt.org) included: 1) Stroke Education, 2) Stroke Prevention and Recovery, 3) Medication Information, 4) My Providers – including a section that allowed patients to organize a contact list of their various providers and information promoting and encouraging use of the patient’s hospital patient portal, 5) Community Resources – access to community resources for social services, 6) Stroke Support Groups, and 7) Caregiver Resources – to assist caregivers with their role. Additionally, the MISTT website included a welcome video, account details page, search function, help/FAQ page, and a contact form. To allow data collection of website utilization during the randomized controlled trial, access to the MISTT website required a username and password.



Fig. 4. Screenshot example of the MISTT Stroke Information landing page, which showcases the navigation structure, page layout, and plain language content.

3 Lessons Learned

The experience of designing and developing the MISTT website as an intervention to be tested in a randomized controlled trial provided several lessons learned. These lessons, which may be valuable to website development efforts in other transitional care studies, healthcare contexts, or populations, can be categorized under the headings of time, complexity, technical support, funding, content, and stakeholder engagement.

3.1 Time

It quickly became apparent that everything related to website design and development required more time than expected. From participant recruitment and organizing the stakeholder focus groups used to guide content creation, to the actual process of creating and editing text and video content, time was a constant challenge. Despite having planned a

discreet phased approach to the overall MISTT project, the initial Development Phase timeline was insufficient for conducting a formal accessibility audit and limited the amount of video production and usability testing sessions that were conducted. Fortunately, videos were produced along with a high-level accessibility review and usability testing with seven stakeholders. Research funders and investigator teams should plan substantial time (>10 months) when developing and testing a technology-related intervention, even when planning to utilize existing content and resources.

3.2 Complexity

The process of designing and developing the MISTT website was more complicated than originally envisioned. For example, locating and/or creating content at the appropriate reading level, packaged in a way that met best practices for user interface design and was appropriate for a post-stroke population, was quite challenging. The design process was more complex and required more time than initially anticipated due to the extent of team interaction needed to create and revise user interface requirements, design the website structure (information architecture), integrate the content into appropriately-sized pages, and incorporate media including graphics, videos, and links to external websites. It is critical to recognize the number of moving pieces and the complexity that each piece assumes in planning and executing the development of a website intervention using a patient-centered approach. Consideration and anticipation of alternative plans are recommended for each aspect of the development process to accommodate flexibility in achieving project goals.

3.3 Technical Support

Reflecting a typical approach within an academic setting, the MISTT creative design team included an internal university-based website development group. They were tasked with developing a website from content provided by the MISTT research team and implementing evidence-based guidelines for healthcare web design. Although the team had expertise in instructional website design and development within learning management systems, they were not as familiar with designing public-facing websites for general, non-academic or patient audiences. Unfortunately, this misalignment of expertise became clear only after website construction was well underway. As an example of how this impacted the development timeline, the navigation structure within each of the content topic sections had to be reorganized several times because there were too many sub-sections or the individual pages were too long without adequate navigation aids and longer text management (e.g., 'back to top' links). Additional personnel were hired to fulfil visual design, videography, and video production needs because the web developers lacked these skills and expertise. Partnering with an internal or external vendor who has the capacity and expertise to respond to a full range of technological needs is extremely important. In addition, having a technology project manager is recommended for ensuring process efficiency and effectiveness of deliverables that meet project objectives.

3.4 Funding

The budget allocation for website design and development was insufficient for the total scope of activities related to website design and development and the production of materials. As an example, funding for video creation was not included in the original budget; however, videos turned out to be an essential aspect of the website based on stakeholder feedback. As a result, re-budgeting required identifying low-cost or “free” resource solutions, even if the final solutions were not the most effective or preferred options. Fortunately, the University environment provided access to students with relevant skills. The MISTT project offered an opportunity for interested students to participate in research while gaining experience in their field of study, which included media and information studies. Careful planning, including realistic budgeting, is crucial for conducting a successful website design and development project because available funds may impact the scope, timeline, and quality of the finished product.

3.5 Content

The MISTT website was ultimately designed to complement social work case management services and to encourage patient activation and self-management. One constant challenge during content development was to resist the temptation of providing material that was too in-depth and comprehensive, rather than summarizing critical facts. It was also important to use authoritative resources that would not require constant updating by the project team.

Reducing the content available from multiple authoritative sources into manageable and accessible web pages was a much greater challenge than finding relevant material. The amount of information potentially useful to patients and caregivers was immense and required careful selection, followed by careful editing to simplify language and reduce total volume. Dedicating time and resources to gathering stakeholder feedback on content topics, scope and depth of information, and preferences for the way content is formatted and presented are essential in ensuring a patient-centered development process. Substantial modifications were made to content topics and concepts in response to stakeholder feedback.

3.6 Stakeholder Engagement

Although the original concept for the MISTT website reflected limited stakeholder input at the time the original proposal was written, these discussions merely provided a starting point for what information and resources stroke patients and caregivers might need after returning home. Engaging a larger group of patients, caregivers, and healthcare professionals, especially patients and caregivers who recently experienced their post-stroke transition of care, expanded the scope of ideas related to gaps in post-stroke healthcare services and post-stroke needs. The emerging lesson revealed the importance of engaging a larger group of stakeholders. Focus group discussions highlighted the lesson that because stroke and stroke recovery are complex and variable, individual post-stroke experiences and needs are even more complex and diverse. In order to create a comprehensive intervention targeted to the broader stroke population, it is crucial to ensure it

addresses the wide-ranging scope of patient-caregiver experiences and needs. Regarding patient-centered website design, patients and caregivers were crucial in understanding how to implement universal design principles relevant to post-stroke capabilities and preferences. In addition to content, stakeholder input critically impacted decisions about organization, navigation, and page layout.

In summary, substantial time, support, and funding is required for a multi-staged approach to creating and building a patient-centered website. Stakeholder engagement was crucial to the final content, design, and functionality of the MISTT website. Stakeholders were instrumental for determining how to apply best practice universal design guidelines to meet needs and preferences for stroke survivors and their caregivers. The methodologies and lessons learned in the MISTT study Development Phase may be valuable for planning the design and development of websites or digital tools more broadly in other transitional care populations and in other healthcare contexts.

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