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Developing and applying a usability testing methodology for a website with survivors of stroke and caregivers: a tutorial

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Abstract

Survivors of stroke, particularly those with communication difficulties, are often excluded from usability testing of digital health tools. This exclusion limits the accessibility and relevance of digital interventions. This tutorial presents a tailored methodology for usability testing of a co-designed website, EmpowerMe, developed to enhance self-efficacy in survivors of stroke and caregivers. A multidisciplinary team created a usability conceptual framework that included survivors with and without communication difficulties. Testing procedures were adapted to accommodate cognitive, motor and communication needs. Outcome measures included usability scores, task completion rates, knowledge acquisition, and user experience feedback. The tutorial offers a replicable framework for inclusive usability testing in digital health, especially for populations with neurological and communication impairments.

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Developing and applying a usability testing methodology for a website with survivors of stroke and caregivers: a tutorial

Abstract

Survivors of stroke, particularly those with communication difficulties, are often excluded from usability testing of digital health tools. This exclusion limits the accessibility and relevance of digital interventions. This tutorial presents a tailored methodology for usability testing of a co-designed website, EmpowerMe, developed to enhance self-efficacy in survivors of stroke and caregivers. A multidisciplinary team created a usability conceptual framework that included survivors with and without communication difficulties. Testing procedures were adapted to accommodate cognitive, motor and communication needs. Outcome measures included usability scores, task completion rates, knowledge acquisition, and user experience feedback. The tutorial offers a replicable framework for inclusive usability testing in digital health, especially for populations with neurological and communication impairments.

Introduction

Usability testing is a critical component of digital design, encompassing learnability, efficiency, memorability, error prevention and user satisfaction.[1, 2] Despite its importance, survivors of stroke, particularly those with communication difficulties, are frequently excluded from formal usability testing, creating inequitable and inaccessible digital health designs and limiting applicability.[3-6] This exclusion of survivors of stroke with communication difficulties such as aphasia (a communication disability affecting participation and access to information) and apraxia of speech (difficulty accessing motor pathways required for speech), has created an inequitable evidence base in stroke research often necessitating repeated studies with survivors of stroke with communication difficulties.[7, 8]

Stroke is a leading cause of disability worldwide, often resulting in cognitive, physical, and communication impairments. [9] The diverse range of post-stroke disability highlights the importance of rigorous usability testing to ensure interventions are both accessible and effective to survivors of stroke.

Background

Globally, stroke is the second leading cause of death, accounting for 11.6% of all deaths.[10] Stroke can be devastating to survivors and their families when they suddenly acquire a permanent disability for which they are completely unprepared. Successful management of long-term health conditions relies on self-efficacy, a person’s confidence in their ability to carry out a certain behaviour.[11] Self-efficacy, the belief in one’s ability to perform behaviours necessary for achieving specific goals, is a critical factor in stroke recovery.[11] It supports engagement in rehabilitation, fosters independence, and helps individuals navigate the complex emotional and physical challenges following a stroke. Higher self-efficacy is associated with less depression and better quality of life, activities of daily living and physical function after stroke.[11] However, survivors of stroke are rarely given advice about programs that could enhance their self-efficacy,[12] suggesting that self-efficacy is poorly addressed in this population. Our team developed a website, EmpowerMe, through collaboration with people with lived experience of stroke (a working group) and Stroke Foundation Australia, to build self-efficacy in survivors (Trial ID: Australian New Zealand Clinical Trials Registry [ACTR] number 12624001018505).

During website co-design workgroup meetings, the lived experience working group comprising survivors of stroke and carers emphasised the importance of being able to find and understand information that was relevant to them. This underpinned the ongoing design sessions, which focused on workshopping features such as intuitive navigation, tailored content, and presentation formats that optimise learning and retention. Survivors and carers prioritised the need to enhance self-efficacy for individuals coping with communication or cognitive changes, fatigue, or physical disability. Their insights not only shaped the design of the EmpowerMe website and but also the development of a

usability testing methodology that could accommodate diverse needs.

To address the gap in inclusive usability testing, this tutorial describes the development and application of a tailored methodology that we used with survivors of stroke and with communication difficulties, and caregivers. Our goal is to provide a practical framework for researchers and designers working with neurologically diverse populations.

Conceptual Framework

The conceptual framework guiding this usability methodology outlines the full cycle of testing activities, from initial preparation through to final analysis. It was designed to ensure that each stage of the process could be adapted to meet the needs of survivors of stroke, including those with communication challenges.This framework comprises a series of steps to follow for inclusive usability testing (see Figure 1). The framework was generated through discussions with the multidisciplinary research team, which included digital designers, health professionals, survivors of stroke and carers. Usability testing strategies were informed by discussions with the lived experience workgroup. Central to our framework was the integration of lived experience. Survivors and caregivers from the lived experience working group helped identify barriers to digital access and shaped the testing procedures so that the intended users, (individuals with varying consequences of stroke) could be recruited and appropriately supported as usability testing participants.

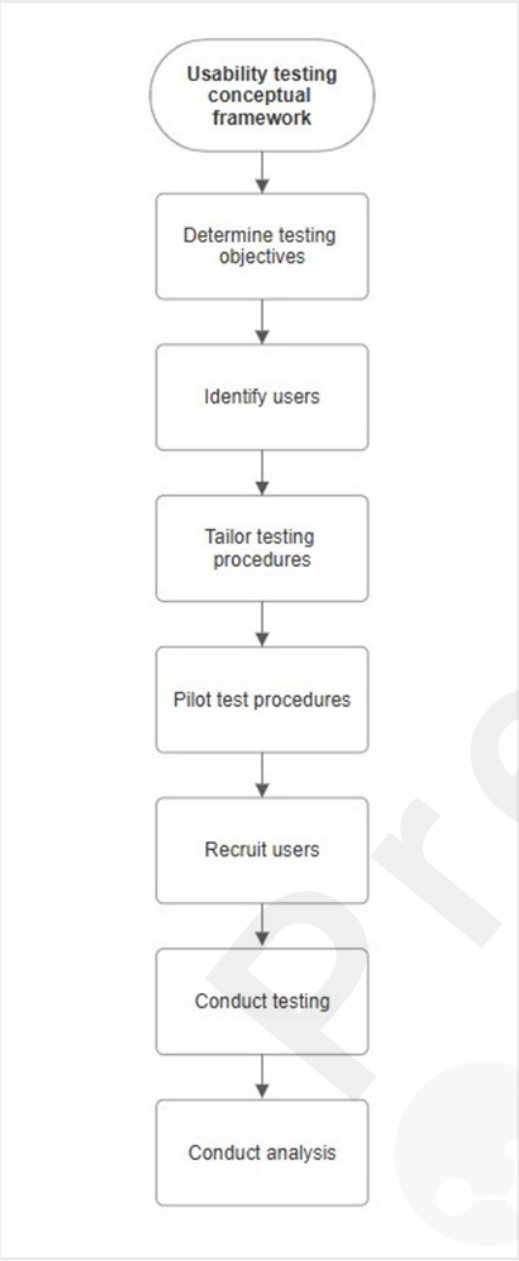


Figure 1 Usability Conceptual framework

and the includes defining the testing procedures to establish clear objectives, formulate hypotheses and assumptions, and determine the types of tasks users will complete. In addition, it identifies the intended users, specifically, user groups who face barriers, such as survivors with communication difficulties. Building on this, the standard usability testing approach should be tailored to accommodate the identified user group by adapting testing materials, session formats, and communication strategies as needed. Inclusive recruitment strategies should be applied, and informed consent must be made accessible. Before recruiting users, refine the approach and conduct a pilot test to identify any technical or procedural issues. Once ready to begin testing, use the developed scripts for moderator introductions, user instructions, and tasks. Finally, analyse user performance and feedback using usability scores, task outcomes, and qualitative user input

Throughout each phase, specific adaptations were made to support participation by individuals with communication difficulties. These included the use of aphasia-friendly language, teach-back techniques, and personalised technology setup support. The framework served not only as a planning tool but also as a guide for responsive, inclusive testing practice.

Design of Usability Testing Procedures

One methodology available to conduct usability testing is a test series approach, which involves multiple structured sessions designed to evaluate the usability of a product or service across key domains, such as ease of use, efficacy, efficiency, accessibility, and user satisfaction. [13] This approach was selected for testing the EmpowerMe website, as it allowed for iterative refinement and in-depth observation of user interactions.

Usability tests are research activities that rely on the direct involvement of a product's intended users. In this methodology, survivors of stroke and caregivers were central to the evaluation process. Their interactions with the website were observed synchronously (session and data collection were conducted in real time), either online or in person, and their feedback was collected through post-task interview questions. This dual approach enabled the research team to identify usability barriers and opportunities for improvement. Based on the conceptual framework Appendix 1 highlights corresponding specific modifications and actions for usability testing with survivors of stroke.

Determine testing objectives

In any usability testing, the design team should consider how they anticipate users will interact with the digital resource and test these assumptions. Typically, usability testing will evaluate navigation and technical features of the resource, along with appropriateness of content for the intended user group. Our usability testing focused on four core areas, website functionality, navigation and ease of use, relevance and clarity of information and overall user experience.

During the website build, features were incorporated into the website to enhance tailoring of content to the individual's needs and interests. The design team created assumptions about how users would interact with the website, and how they would find information (Figure 2).

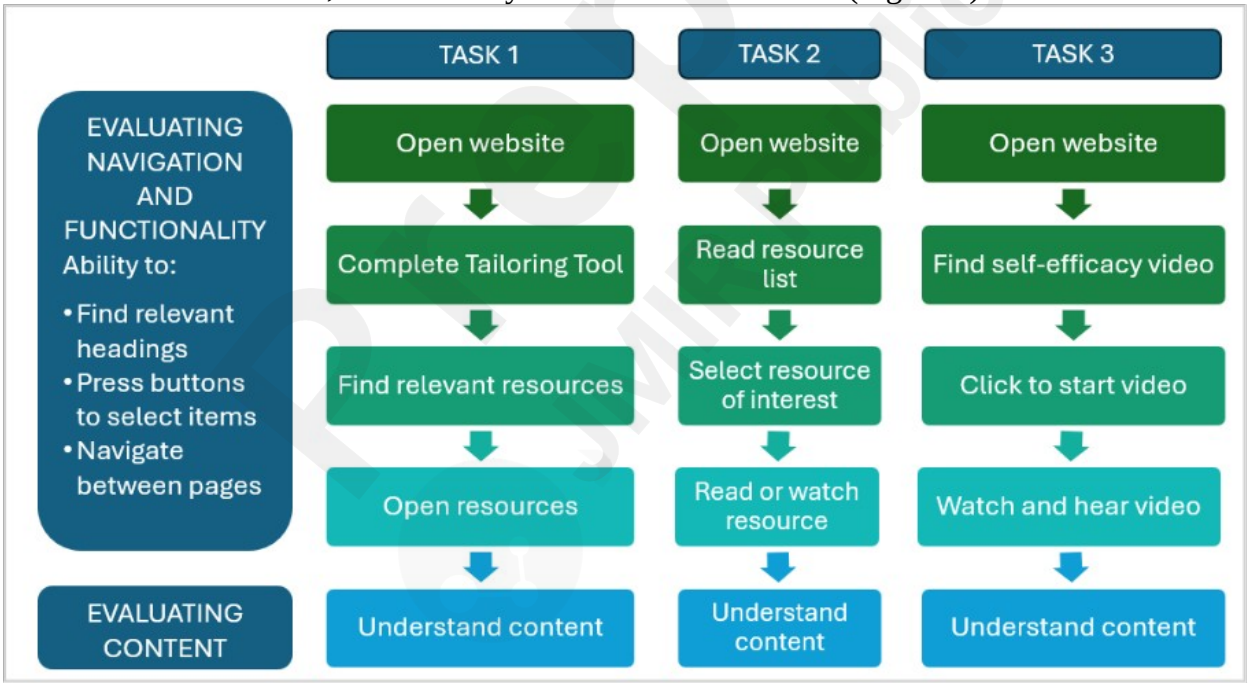


Figure 2 Usability testing tasks

Subsequently, the team defined anticipated actions of website use; watch the landing video, navigate to and complete the tailoring tool (a questionnaire that centralises content within the website that is relevant to the user), navigate to tailored resources, navigate to, and proceed to watch self-efficacy videos (practice, encouragement from others, skill development, learning from others, information), navigate between website pages and tasks and navigate back to the website from resource opening on a separate tab.

In line with intended objectives, usability outcomes included website usability scores using the standardised System Usability Scale (SUS). The SUS was developed to provide a measure of

people's subjective perceptions of the usability of a website in a short period of time.[2] It is a valid instrument with 10 questions and a reliable Likert scale. [14, 15] Other outcomes were task completion time and rates based on screen recordings, knowledge acquisition through teach-back, and user experience feedback via a customised questionnaire.

Identify intended users

Digital health interventions should be tested by users who reflect the target group. It is important to identify any subgroups who might interact with the resource differently or face challenges using it, and ensure they are included in the usability testing. The intended users of the EmpowerMe website were survivors of stroke and their caregivers. Three discrete groups of users were identified to include in usability testing:

a) Survivors of stroke with communication difficulties: The team considered that if the website was accessible to people with communication difficulties, it would also meet the accessibility needs of people with mild cognitive changes.
b) Survivors of stroke without communication difficulties: We also wanted to include survivors of stroke without communication difficulties, to see whether the structures and content were pitched at the right level for people without communication impairments but potentially living with other challenges such as visual changes or fatigue.
c) Caregivers: We sought to include caregivers, because more than 50% of survivors of stroke living in the community require family caregiver assistance.[16, 17] Carers of survivors of stroke frequently have an important role in finding relevant information and making healthcare decisions after the stroke, as well as supporting the survivor of stroke to build their self-efficacy.

Tailor testing procedures to the needs of the intended users

When planning usability testing, it is important to consider potential barriers the intended users may face when accessing the digital resource. Testing procedures should evaluate whether the barriers have been suitably addressed during the design, and strategies should be used that account for these barriers during testing (e.g. simple instructions for people with cognitive changes). Factors to consider in all usability testing include digital literacy, vision, dexterity, and how concentration levels could impede person's ability to interact with the features of the digital resource. Other factors such as age of intended users, literacy and education levels, and language related factors which affect how users engage with the content should also be considered. Finally consider the space in which testing will be conducted, how long the procedures will take, the complexity of the testing activities and how these influence the needs of the intended users.

For this project, we also considered common challenges arising from strokes, such as communication difficulties which result in individuals having difficulty understanding verbal instructions or communicating their responses, cognitive or attention changes, visual field loss and neurological fatigue, which is often exacerbated by looking at screens and when concentrating.

To avoid distraction and sensory overload, usability testing for all participants was conducted in a one-to-one moderated format rather than in a group. To meet the needs of people with communication difficulties, in-person usability testing was planned. An aphasia-friendly consent form (using simple language, short sentences, and visual aids) was prepared, along with an aphasia-friendly script for the testing procedures. Usability testing sessions were co-moderated by a speech pathologist with expertise in working with people with communication difficulties. For survivors of stroke without communication difficulties and caregivers testing sessions were limited to 75 minutes to avoid fatigue, which allowed for 15 minutes for set-up of technology and equipment and 60 minutes for usability tasks. For survivors of stroke with communication difficulties, sessions were allocated 3 hours, to allow for regular breaks and extended time to complete tasks to avoid undue fatigue within sessions.

The Lived Experience Working Group recommended online usability testing for carers and for

survivors of stroke without communication difficulties, so they could participate without the need to travel, which can contribute to fatigue and stress when finding the venue at an unfamiliar location. Further, participating in usability testing from a survivor's home would allow them to use adaptive equipment if required. After a stroke adaptive equipment can support users through both hardware and software solutions. Some examples of these are sticky keys, voice recognition help with typing and keyboard shortcuts, large key or one-handed keyboards, and eye tracking systems. These adaptations could not be accommodated for in-person testing as they are often hardware aids, fitted to personal devices. We needed to record the session on our software systems.

Having the option to participate in-person was also suggested if the survivor of stroke or carer preferred not to participate online.

Pilot testing procedures

Pilot testing runs through a planned usability session in advance of the planned testing. This usually involves one to two sessions and is important to validate the wording of the script, determine how long the session will take and highlight any other issues that could compromise the effectiveness of the session.[18] It can help find problems including whether the participants understand the instructions and tasks, whether the tasks elicit the required information to address the assumption, whether the tasks can be completed and the time required to complete the tasks.[18]

The online usability testing procedures for this project were pilot tested with two test users to identify any human or system issues. Sessions required additional time to allow for user's technology skills and aptitude. There were system delays at the start in the form of Zoom pop up messages. We addressed this with a Zoom instructions guide tailored for users (Appendix 2). It covered how to join the meeting, how to start and stop screen sharing, how to use optional features (share computer sound, optimise for full-screen video) and how to leave the meeting.

Recruit users

Users were recruited through advertising on the Stroke Foundation (Australia) EnableMe website and EnableMe newsletters, and through invitation emails sent to distribution lists associated with the project. An online booking page was linked to the project team's calendar, and prospective users could book their own session, or book directly through the project manager if preferred. When the booking was confirmed, prospective users were emailed an information sheet, consent form for signing and an instructional list about what to expect. Users completing an online usability testing session and were sent the Zoom instructional list. The research speech pathologist explained the information sheet to each user with communication difficulties, using aphasia-friendly language and allowing time for processing of information. She checked participant's understanding of the information as part of the consent process.

Formal synchronous usability testing typically requires a sample size of 10-12 users and less formal, asynchronous testing 4 to 5 users.[16, 17] This number is sufficient to uncover around 80% of usability issues.[17] Beyond this it is unlikely that more users will illicit new information, with the most severe usability issues consistently detected with those first few users.[17] We recruited 11 users, 8 survivors (4 with communication difficulties) and 3 carers.

Conduct testing

Usability scripts were developed to guide participants through the required navigation tasks and assess knowledge acquisition (Appendix 3). All participants were given a set of tasks designed to promote specific interactions within the website of particular interest.

Online and in-person sessions with survivors of stroke without communication difficulties and caregivers were moderated by author KN. In-person sessions with survivors of stroke with communication difficulties were moderated by author EG (research speech pathologist with expertise in aphasia-friendly practices), with support from KN for task instructions.

Usability testers followed a prepared script, to ensure there was consistency across all sessions and between moderators (Appendix 4). All sessions (including those conducted in-person) were video-recorded using the record function on Zoom for remote session and screen recorded for in-person

session. Sessions commenced with introductions; a description of the project and an outline of how the session would flow. The moderator guided participants through each session by asking usability testing questions which were either task-based or knowledge-based and observing participant behaviour. Moderators checked in regularly with users, to see whether they wanted to take a rest break.

Conduct analysis

The SUS Calculator Software Package was used to analyse mean and standard deviations for overall, individual and sub-group SUS scores.[19] The raw mean score was normalised by establishing a benchmark percentile of the website's position when compared to other websites (Appendix 5). To determine whether differences in SUS scores in the different groups of users were significant sub-group mean scores for survivors of stroke with communication difficulties were compared to those of survivors without communication difficulties, using a between-subject 2-sample t-test, with statistical significance set at $p \leq 0.05$ (Appendix 6). Knowledge acquisition was analysed using the 'chunk and check' technique, where one task is given at a time (chunk) then followed by 'Teach Back' (check), ensuring repetition if needed, checking reception and maximising recall.[20] These responses are presented narratively, and include users quotes and responses. Data from the user experience survey were tabled against the data from task-time and task-completions. This allowed the team to examine usability from different perspectives, providing an opportunity to make targeted website changes when issues were identified.

Discussion

This paper describes the development and application of a methodological approach for the usability testing of a novel website to build self-efficacy for survivors of stroke. Our methodological approach was designed to assess how users navigate through the website, whether they could find relevant information, and whether the information was easy to understand. We also evaluated satisfaction with the website, to support changes to the website and/or confirm its readiness for release. This work advances the field of digital design in health by promoting explicit reporting of methodological approaches for accessible usability testing.

We specifically sought to include survivors of stroke with and without communication difficulties in our usability testing, to ensure the website was accessible to these groups. However, published evaluation and usability testing processes of health interventions frequently lack clear, detailed descriptions.[21] Additionally, there is no standardised framework for planning these evaluations with people with disabilities, such as survivors of stroke.[21] Involving survivors of stroke with communication difficulties is even more difficult due to the complex language requirements of many evaluation procedures.[22] Given the lack of guidance available on how to conduct usability testing with survivors of stroke with and without communication difficulties, we have developed and published our methods in this tutorial. We anticipate this tutorial will be of benefit to future designers and researchers who seek to create digital resources for people with neurological conditions, communication impairments or other barriers to participating in usability testing of a digital resource. Bringing together experts in the field of digital design, health care and lived experience was important to facilitate both digital design and usability testing. In the current project, we have demonstrated how people with high needs (survivors of stroke with communication difficulties, who tend to have worse outcomes than survivors without communication difficulties), who are frequently excluded from participating in research can actively contribute to decisions about whether a digital resource is suitable to meet their needs and whether any adaptations are required.[8, 23, 24] We consider that more research needs to be done that focuses on, rather than excludes, people with communication difficulties. Further, it is important to recognise that there are strategies and processes that can enable full participation of people with communication difficulties in research activities.[8] It was imperative that we adapted our usability testing procedures to meet the needs of this group. Our rigorous planning processes, where digital designers provided input about usability testing processes, and health professionals and people with lived experience of communication

difficulties advised on adaptions required to these testing processes, resulted in a successful usability testing process. Our template can be used and adapted to meet the needs of other under-served, yet high needs groups who may face more barriers to both accessing digital resources and participating in usability testing and other forms of research.

Future implications

The inclusive framework outlined in this tutorial highlights for digital health interventions developers and researchers the importance of prioritising accessibility from the outset in project planning. Furthermore, it can be adapted for other populations with neurological or cognitive impairments, such as traumatic brain injury, dementia or developmental disorders. By demonstrating that survivors of stroke, including those with communication difficulties, can meaningfully participate in usability testing, this approach challenges existing norms and promotes equity in digital health design. Policymakers and funding bodies may be influenced to support inclusive design practices as a standard requirement for digital health design.

Limitations

We were unable to recruit survivors of stroke or carers with significant vision impairment, as the website's read-aloud functionality was not available during the testing period. In addition, the study did not incorporate a targeted strategy to engage users from culturally or linguistically diverse backgrounds; all participants spoke English as their first language. These limitations highlight challenges in achieving inclusive usability testing and reinforce the importance of adopting more adaptive and accessible research approaches. As a result, the usability outcomes for the EmpowerMe website may have limited generalisability, particularly in relation to populations not represented in the users.

Conclusion

This tutorial highlights the importance of inclusive formal usability testing in the development of digital health tools. By involving survivors of stroke, including those with communication difficulties and caregivers we improved the EmpoweMe website relevance and accessibility, resulting in a replicable framework for others to use. The adapted testing procedures and team collaboration demonstrate that meaningful inclusion is feasible and beneficial.

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