

Creation of EmpowerMe, a co-designed website to promote self-efficacy in survivors of stroke

Elizabeth A. Lynch, Adrian O'Malley, Zoe Adey-Wakeling, Billie Bonevski, Dominique A. Cadilhac, Saran Chamberlain, Leonid Churilov, Robyn Clark, Richard Cullen, Erin Godecke, Gillian Harvey, Fiona Jones, Jarrad Law, Stacy Larcombe, Natasha A. Lannin, Annette McGrath, Lisa Murphy, Katie Nesbitt, Karly Zacharia, Niranjana Bidargaddi, Coralie English

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Elizabeth A. Lynch¹; Adrian O'Malley²; Zoe Adey-Wakeling^{3,4}; Billie Bonevski⁴; Dominique A. Cadilhac^{5,6}; Saran Chamberlain^{1,7}; Leonid Churilov⁸; Robyn Clark¹; Richard Cullen⁹; Erin Godecke^{10,11}; Gillian Harvey¹; Fiona Jones¹²; Jarrad Law^{13,14}; Stacy Larcombe¹; Natasha A. Lannin^{15,16}; Annette McGrath¹⁷; Lisa Murphy⁹; Katie Nesbitt¹; Karly Zacharia¹⁸; Niranjana Bidargaddi¹³; Coralie English^{18,19,20}

¹Caring Futures Institute, College of Nursing and Health Sciences, Flinders University College of Nursing and Health Sciences Flinders University Adelaide AU

²Lived Experience of Stroke Sydney AU

³Flinders Medical Centre Adelaide AU

⁴Flinders Health and Medical Research Institute College of Medicine and Public Health Flinders University Adelaide AU

⁵Stroke and Ageing Research, Department of Medicine School of Clinical Sciences Monash University Melbourne AU

⁶Public Health and Health Services Research The Florey The University of Melbourne Melbourne AU

⁷Lived Experience of Stroke Adelaide AU

⁸Melbourne Medical School The University of Melbourne Melbourne AU

⁹National Stroke Foundation Melbourne AU

¹⁰Stroke Recovery and Rehabilitation Perron Institute for Neurological and Translational Science Perth AU

¹¹Allied Health Research Sir Charles Gairdner Osborne Park Health Care Group Perth AU

¹²Population Health Research Institute City St George's University of London London GB

¹³Flinders Digital Health Research Centre College of Medicine and Public Health Flinders University Adelaide AU

¹⁴CareMappr Adelaide AU

¹⁵Alfred Health Melbourne AU

¹⁶Department of Neurosciences School of Translational Medicine Monash University Melbourne AU

¹⁷Lived Experience of Stroke Port Elliot AU

¹⁸School of Health Sciences University of Newcastle Australia Newcastle AU

¹⁹Heart and Stroke Program Hunter Medical Research Institute Newcastle AU

²⁰Centre for Research Excellence to Accelerate Stroke Trial Innovation and Translation The University of Sydney Sydney AU

Corresponding Author:

Elizabeth A. Lynch

Caring Futures Institute, College of Nursing and Health Sciences, Flinders University

College of Nursing and Health Sciences

Flinders University

GPO Box 2100

Adelaide

AU

Abstract

Background: Digital health innovations are frequently used to support people to manage chronic health conditions. Stroke is common, and people who have survived a stroke and live in the community must learn to manage their health independently. Digital tools can help, but only if designed to match survivors' specific needs.

In response to a need expressed by people living with chronic health conditions, the Australian government created a funding stream to support the development of a digital resource to support individuals gain confidence in managing their health.

Objective: To co-design a digital resource to promote self-efficacy to manage life after stroke in community-dwelling survivors of stroke.

Methods: Co-design methodology, that emphasized meaningful engagement with intended end-users throughout the design of the website, was used. The project Steering Group comprised health professional researchers, digital designers, people with lived experience of stroke (survivors and carers) and representatives from Stroke Foundation (Australia). A systematic review was conducted to inform core components of the resource. A Lived Experience Workgroup was convened to advise on features

of the digital resource and aspects of its evaluation. Iterative review stages and frequent consultation between the steering group and the Lived Experience workgroup occurred. Online and in-person useability testing was conducted with survivors and carers.

Results: The Lived Experience Workgroup (Workgroup) initially comprised 14 survivors and one carer. One workgroup member was invited to join the Steering Group and co-facilitated all co-design workgroup meetings.

Defining features of the digital resource were identified by the Steering Group and the Workgroup, including that the resource would be a website that augmented (not reproduced) existing resources, and it needed to be accessible to survivors of stroke with communication changes. Website specifications were determined by the Workgroup, and included that information needed to be tailored to the individual user, and specific accessibility features were recommended. The Workgroup prioritized what content to be included on the website and recommended the creation of video stories by Australian survivors and carers. A Resource Tailoring Tool was created so information could be individualized to the interests of the website user. Nine webpages containing high priority content were created, comprising text, video stories and a downloadable PDF which summarized key information for that page. Over 150 short video stories were created by 26 survivors of stroke and 10 carers for the website.

Conclusions: Authentic co-design with inclusion of people with lived experience of stroke at all stages of development enabled the successful build of a digital resource (website) to improve self-efficacy. An evaluation of the website is underway. Clinical Trial: ACTRN12624001018505

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Original Manuscript

Creation of EmpowerMe, a co-designed website to promote self-efficacy in survivors of stroke

Elizabeth Lynch	Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia
Adrian O'Malley	Lived Experience of stroke
Zoe Adey-Wakeling	1. Flinders Medical Centre, 2. Flinders Health and Medical Research Institute, College of Medicine and Public Health, Flinders University
Billie Bonevski	Flinders Health and Medical Research Institute, College of Medicine and Public Health, Flinders University
Dominique A. Cadilhac	1. Stroke and Ageing Research, Department of Medicine, School of Clinical Sciences, Monash University 2. Public Health and Health Services Research Group, Stroke Theme, The Florey, University of Melbourne
Saran Chamberlain	1. Lived experience of stroke 2. Caring Futures Institute, College of Nursing and Health Sciences, Flinders University,
Leonid Churilov	Melbourne Medical School, University of Melbourne
Robyn Clark	Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia ORCID City St George's
Richard Cullen	Stroke Foundation, Melbourne, Australia
Erin Godecke	1. Stroke Recovery and Rehabilitation, Perron Institute for Neurological and Translational Science 2. Allied Health Research, Sir Charles Gairdner and Osborne Park Health Care Group
Gillian Harvey	Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia
Fiona Jones	Population Health Research Institute, City St George's University of London
Jarrad Law	1. Flinders Digital Health Research Centre, College of Medicine and Public Health, Flinders University 2. CareMapp, Adelaide, Australia
Stacy Larcombe	Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia
Natasha Lannin	1. Department of Neuroscience, School of Translational Medicine, Monash University. 2. Alfred Health, Melbourne, Australia ORCID: 0000-0002-2066-8345
Annette McGrath	Lived experience of stroke
Lisa Murphy	Stroke Foundation, Melbourne, Australia

Katie Nesbitt	Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia
Karly Zacharia	School of Health Sciences, University of Newcastle
Niranjan Bidargaddi*	Flinders Digital Health Research Centre, College of Medicine and Public Health, Flinders University
Coralie English*	1. School of Health Sciences, University of Newcastle 2. Heart and Stroke Program, Hunter Medical Research Institute 3. Centre of Research Excellence to Accelerate Stroke Trial Innovation and Translation, University of Sydney

- * Joint senior authors

Strategies used to co-design a website (EmpowerMe) to promote self-efficacy in managing a chronic health condition

Abstract (419/450 words)

Background: Digital health innovations are frequently used to support people to manage chronic health conditions. Stroke is common, and people who have survived a stroke and live in the community must learn to manage their health independently. Digital tools can help, but only if designed to match survivors' specific needs.

In response to a need expressed by people living with chronic health conditions, the Australian government created a funding stream to support the development of a digital resource to support individuals gain confidence in managing their health.

Objective: To co-design a digital resource to promote self-efficacy to manage life after stroke in community-dwelling survivors of stroke.

Methods: Co-design methodology, that emphasized meaningful engagement with intended end-users throughout the design of the website, was used. The project Steering Group comprised health professional researchers, digital designers, people with lived experience of stroke (survivors and carers) and representatives from Stroke Foundation (Australia). A systematic review was conducted to inform core components of the resource. A Lived Experience Workgroup was convened to advise on features of the digital resource and aspects of its evaluation. Iterative review stages and frequent consultation between the steering group and the Lived Experience workgroup occurred. Online and in-person useability testing was conducted with survivors and carers.

Results: The Lived Experience Workgroup (Workgroup) initially comprised 14 survivors and one carer. One workgroup member was invited to join the Steering Group and co-facilitated all co-design workgroup meetings.

Defining features of the digital resource were identified by the Steering Group and the Workgroup, including that the resource would be a website that augmented (not reproduced) existing resources, and it needed to be accessible to survivors of stroke with communication changes. Website specifications were determined by the Workgroup, and included that information needed to be tailored to the individual user, and specific accessibility features were recommended. The Workgroup prioritized what content to be included on the website and recommended the creation of video stories by Australian survivors and carers. A Resource Tailoring Tool was created so information could be individualized to the interests of the website user. Nine webpages containing high priority content were created, comprising text, video stories and a downloadable PDF which summarized key information for that page. Over 150 short video stories were created by 26 survivors of stroke and 10 carers for the website.

Conclusions: Authentic co-design with inclusion of people with lived experience of stroke at all stages of development enabled the successful build of a digital resource (website) to improve self-efficacy. An evaluation of the website is underway.

Trial Registration: Trial Id: ACTRN12624001018505

Keywords: stroke; website; self-efficacy; co-design; digital health.

Introduction

Digital health innovations are commonly used to support people to manage their chronic health conditions.[1, 2] For any digital innovation, it is recommended that designers work with intended users during the development phase to optimize acceptability and uptake.[3]

A common chronic condition is stroke, which affects more than 100 million people worldwide.[4] Despite reductions in the incidence of stroke in high income countries, prevalence of people living with stroke is increasing because of ageing populations and better survival rates.[5] Stroke can affect an individual's physical ability, energy levels, mood as well as their ability to communicate, concentrate and understand.[6] Changes to cognition, communication and stroke-related fatigue can present difficulties for some survivors in accessing digital health technologies. Further, survivors of stroke with communication difficulties and people with cognitive changes are frequently excluded from participating in research, [7, 8] and little guidance exists in the published literature on how to work with survivors of stroke when designing a digital health innovation.

People living with chronic health conditions were consulted about research priorities to address in Australia, and prioritized the development of digital resources to promote health self-efficacy.[9] Self-efficacy is an individual's confidence in their abilities[10], and when teamed with health, relates to an individual's confidence in their abilities to manage their health effectively. A research team was convened, and sought to develop a digital resource to build health self-efficacy in survivors of stroke.

A co-design approach was chosen so survivors of stroke and other key stakeholders could be meaningfully involved and engaged throughout the entire research process,[11] from conceptualizing and building the digital resource, through to its subsequent evaluation. This paper describes how the team co-designed an accessible digital resource to promote self-efficacy in survivors of stroke.

Methods

The principles of design science in information systems research were used to guide the development of an innovative, purposeful digital resource.[12] The design process was planned to systematically incorporate the needs and preferences of survivors of stroke and carers through each planning and design stage of the digital resource.[11] Four steps were followed: Determining what was required from the resource, determining specifications of the resource, building the resource to the specifications, and testing the resource to

Defining requirements

- Build self-efficacy
- Augment existing resources
- Accessible to survivors of stroke
- Incorporate hope and acceptance



Website specifications

- Individually tailored content
- Accessibility features



Content specifications

- Include priority content
- Include real survivor stories
- Include variety of media



Building website

- Accessibility plugin
- Resource Tailoring Tool built and refined
- 9 webpages created
- Content tagged to topic areas



Creating content

- Website name selected
- Self-efficacy definition finalised
- Videos recorded and edited
- Text resources prepared - overviews and detailed information



determine if it met requirements. These are presented in Figure 1.

The team coordinating the study (hereafter referred to as the Steering Group) comprised 20 members (16 women) and included 14 academic researchers from health, bioinformatics and biostatistics disciplines, two survivors of stroke, one carer, health professionals and representatives from Stroke Foundation (Australia), the national stroke advocacy body. The Steering Group determined the features of the digital resource that were essential, and the adaptable features that should be determined by people with lived experience of stroke (See Figure 2). The Steering Group met online monthly.

A Lived Experience Workgroup (hereafter referred to as the Workgroup) was convened, comprising survivors of stroke and carers to advise on the adaptable features of the digital resource. Fourteen survivors and one carer (10 women) were recruited to the Workgroup, representing community-dwelling people of different ages (ranged from 43-76 years), stroke-related changes and time since stroke (6 months to 17 years). Workgroup members were from 6 Australian states/territories. Some had extensive experience in research and co-design, whereas three had no prior research experience.

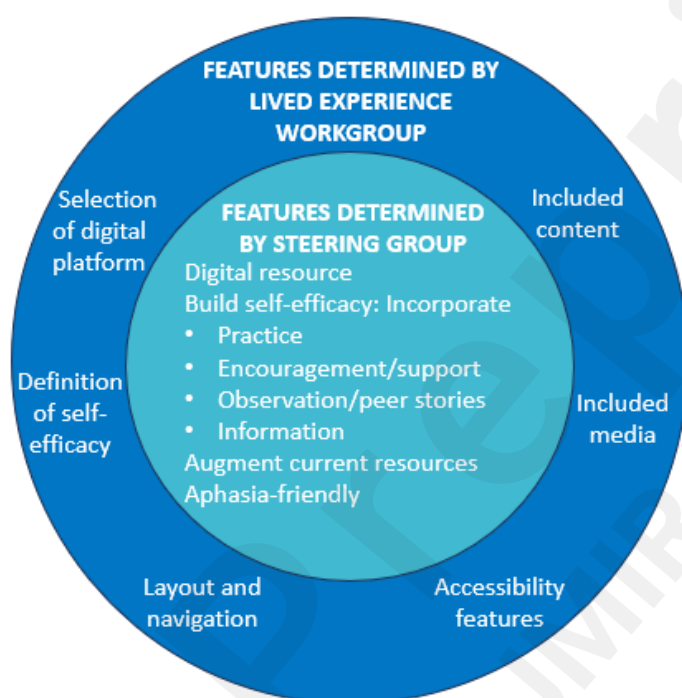


Figure 2. Core and adaptable features of the digital resource

Workgroup meetings were run online via Microsoft Teams. All Workgroup members were offered support to familiarize themselves with Microsoft Teams at the start of the project. Meetings were co-facilitated by an academic researcher (author EAL) and a survivor of stroke (authors SC or AO'M). Each meeting was attended by a maximum of five Workgroup members to allow time for contributions from each attendee, so three meetings (attended by

different Workgroup members) were held to discuss each topic. Discussion points were sent to attendees prior to each meeting, and collated notes from all the Workgroup meetings were distributed to all attendees within a week of the final meeting. Workgroup members were reimbursed for their time at rates recommended by New South Wales Consumer Alliance.

Six rounds of Workgroup co-design meetings were conducted between June-December 2023, interspersed with 3 online surveys between meetings. A further three rounds of co-design meetings were co-facilitated by a digital designer and a survivor of stroke (author SC) to determine the technological features of the digital resource. The Workgroup reconvened between March-April 2024 to review the digital prototype. The topics discussed at the meetings are presented in Table 1.

Useability testing of the digital resource was conducted with four carers, four survivors of stroke with no self-reported language changes, and with four survivors with moderately severe aphasia, a language disorder that affects communication. None of the people involved in useability testing had been involved in the design or development stages. Tasks were designed to test navigation around the website, and comprehension of the content. This methodology has been described elsewhere. (Manuscript submitted to JMIR concurrently).

Table 1. Focus of Workgroup meetings

Meeting number	Main agenda item
1	Introduction to project Discuss ways of working Definition of self-efficacy Personal experience of building self-efficacy after stroke
2	Terms of reference Definition of self-efficacy Do different groups of people have different self-efficacy needs? Resources to support self-efficacy Selection of digital platform
3	Measuring self-efficacy Content to include on website
4	Content to include on website - Existing resources that should be included - Preferred format Previous (good and bad) learning experiences using digital technology
5	Recap of progress to date Format of resources Features to include on website
6	Experiences using websites for information about health or wellbeing Features of websites that make them harder/easier to use, more/less enjoyable Opinions on - Interactive features on websites - Sharing personal information on websites - Receiving “push” emails or text messages Any changes to the way information is processed since stroke
7	Identifying individual’s information-seeking behaviors and digital

	preferences
8	Reviewing prototype of quiz to tailor content
9	Reviewing and refining prototype of quiz
10	Reviewing website prototype Feedback on layout, color palette Name of website

Results

Defining requirements of the digital resource

The Lived Experience Workgroup recommended that a website would be the most acceptable digital resource to support survivors of stroke develop their self-efficacy. Essential requirements determined prior to project commencement was that the website would be free to access and needed to augment, not reproduce, information and other supports already available (such as available through Stroke Foundation and its website EnableMe[13]). The website needed to be accessible to non-experts in stroke, with low or medium levels of health literacy, and accessible to people with stroke related changes, including changes to cognition, communication or reading ability. The Workgroup highlighted the importance of including representation of people of different ages, genders and cultural backgrounds.

Another essential requirement of the website was that it needed to support self-efficacy in Australian survivors of stroke and people in their support network (family members, friends, carers), so should incorporate features such as learning from/observing other survivors and carers, and information. Elements that were identified by Workgroup members as being important to building self-efficacy and a sense of wellbeing after stroke were having a purpose in life, having self-compassion, having goals to work towards, being realistic while also having hope. Acceptance that things have changed and having resilience to bounce back if experiencing a setback were also recognized as intertwined with a person's confidence in their abilities. These elements guided the development of resources hosted on the website.

Setting specifications

Specifications of website

Workgroup members expressed that the website needed to incorporate a feature so that information could be tailored to each user, who could then “choose their own adventure” to find information or other resources relevant to them. Interactivity in the form of a chatbot was universally rejected by Workgroup members. However, a feature where users were asked a series of questions about areas of interest or information need that would then guide the user to a curated list of relevant resources was deemed to be of benefit. The Workgroup also recommended that the tailoring feature be optional, so users who preferred not to provide information about themselves, or people who prefer to “browse” could look through all the available resources.

In terms of accessibility features for survivors of stroke, use of consistent layout and spacing was suggested to improve the accessibility of information for people with visual field loss. Use of sans serif font, having aphasia-friendly text options and availability of captions for videos and adjustable playing speed were recommended to meet the needs of people with communication impairments. The Workgroup recommended having a text-to-voice option so users could choose to listen to rather than read the written information. Use of large boxes for clickable links (rather than underlined text) was recommended to improve functionality for people with motor control difficulties. Avoiding any

spontaneous animations, background music and moderating the tone of voice and volume on videos was important for people who experience sensory overload.

Other recommended features were not specific to the needs of survivors of stroke, included having options to adjust the website colors and having clear navigation pathways.

Specifications of content to include

Priority content to include on the website was determined by the Workgroup. Members reviewed a list of common health-related needs after stroke from a validated Stroke Needs Assessment Survey[14], and were invited to nominate other topic areas that were not listed that they considered important to address. Two topics that were nominated were *Defining self-efficacy and its importance* and *Seeking relevant information*.

Following these discussions, a “long-list” of 18 topics to include on the website was created. The Workgroup completed a survey to identify the top 10 topics to include and ranked them in order of importance. Data from ranking exercises were analysed using a graph theory-based voting system. [15]. The list of priority content topics is presented in Table 2. The most important topics to address were “What is self-efficacy and why is it important” and “How to be involved in healthcare decisions”. Due to substantial overlap in content, two topics (“Managing concentration problems” and “managing cognitive changes”) were grouped together, leaving nine priority topics to address.

Table 2. Priority content to include and number of videos created

	Topics, prioritized by Lived Experience Workgroup	Number of videos	
		Survivors	Carers
1	Defining self-efficacy and its importance	50	9
2	Being involved in decisions	7	4
3	Seeking information you need	10	6
4	Advocating for yourself	12	2
5	Managing fatigue	11	2
6	Emotional problems	10	3
7	Managing cognitive changes*	6	3
8	Managing mobility changes	11	2
9	Managing speaking difficulties	10	9
10	Managing concentration problems*	-	-

*Due to substantial overlap in content, “managing cognitive changes” and “managing concentration problems” were combined into one topic

Results from a systematic review conducted by the research team about self-management interventions to improve self-efficacy in stroke survivors[16] did not highlight any further components that needed to be incorporated into the website.

Specifications of content format

To meet different users’ learning styles, the website needed to host content in a variety of media, inclusive of video, text (including downloadable information sheets) and audio resources. For written information, having both “bite-size” information chunks and “deep-dive” detailed information for topics was preferred, so a user could browse headlines of topics, and then go into detail on topics of interest to them.

To enhance self-efficacy via vicarious learning from peers, the Steering Group and Workgroup

planned to include content delivered via testimonials from survivors of stroke and carers. There was a strong preference from Workgroup members for these to be real, unscripted video-stories of Australian survivors and carers who shared their struggles and how these were managed as well as their experiences of recovery. Specifically, Workgroup members recommended using home recordings (e.g. via smart phone camera or Zoom videoconferencing) rather than professional videographers to prepare the video stories, as they felt this improved the relatability of the person sharing their story and made the stories and messages more credible. Preferred length of videos was less than 3 minutes.

For the delivery of information prepared by health professionals, Workgroup members preferred to have real people in any videos rather than using graphics or animations, and use of Australian-specific information when available.

Building the website and developing content

Incorporating accessibility features

An accessibility plugin (UserWay) was used to allow users to customize the site to their needs. This included options like increasing contrast, enlarging the text, increasing the text spacing, highlighting links so clickable elements are more prominent, and other options. (See supplementary File 1)

Building the Resource Tailoring Tool

The Workgroup members met with a digital designer and shared their post-stroke information experiences, device usage patterns, content preferences, and strategies for validating health information. Following this session, the designer developed distinct user personas (see Table 3) and used this information to develop a quiz-based tailoring prototype to accommodate all identified personas. The subsequent two sessions were used to refine the prototype through iterative feedback, emphasizing content relevance and quiz structure. Workgroup members provided critical input on optimal questionnaire length, preferred response formats, and content delivery mechanisms.

Table 3: Personas of stroke survivors accessing digital information emerging from the design sessions

Characteristics	Tech savvy (n=4)	Traditional learner (n=3)	Supported learner (n=3)
Digital skills	High confidence with multiple devices	Prefers structured content	Confident but needs accessibility features
Learning style	Self-directed research, critical evaluation	Relies on medical professionals	Institution-guided learning
Information sources	Multiple sources, fact-checking, research background	Printed materials from traditional health channels	Verified institutional sources
Preferred content format	Short videos, blogs, interactive content	Academic content, structured text	Short videos (<15 min), articles
Device usage	Multiple devices (phone, tablet, laptop)	Preference for larger screens	Phone and laptop primarily
Support needs	Independent	Guided learning	Accessibility

	learners	approach	adaptations
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Following development and feedback, the Resource Tailoring Tool was trialed and finalized. It comprised 2-3 (depending on responses) multiple choice questions that subsequently became more precise to identify topics of interest to each user. Additional questions were added to the start of the tool to collect demographic data of users for research purposes. See Table 4.

Table 4. Questions to guide content curation

What topics would you like to explore today?		
How to build my confidence after stroke		Finding information I need
		Learning from survivors or carers
		Practice
		Support from others
		Skill development
How to speak up for what I want or need		Self-advocacy
		Involvement in decisions about my care
How to manage effects from the stroke	Managing physical changes	Using my arm
		Bladder and bowel problems
		Falls prevention
		Mobility changes
		Swallowing
	Managing changes that are hard to see	Vision
		Cognitive (thinking and memory) changes
		Speaking difficulties
		Pain and sensation changes
		Emotional changes
		Fatigue

The Resource Tailoring Tool was a plugin to the website built using Flutter Web, which sat on top of the website to add the quiz-based tailoring information. The structure of the Tailoring Tool and the content provided was stored in a Webiny Content Management System.

Preferred language, definitions

Terminology was considered and workshopped in both Workgroup and Steering Group meetings. Most Workgroup members (except for individuals with occupational therapy or education backgrounds) were unfamiliar with the word “self-efficacy” at the start of the project, and some found it hard to pronounce. Many Steering Group members and Workgroup members felt that the

word “self-efficacy” was not part of general day-to-day language and were concerned use of it might be off-putting. However, some Workgroup members felt that it was important to educate survivors and carers about self-efficacy, and familiarization with the word “self-efficacy” was an important educational component that could empower survivors and carers. The Steering Group then decided to use lay language (avoiding the word “self-efficacy”) in headings and titles and include the word “self-efficacy” in second-tier text designed to inform and educate users.

After several iterations, the preferred definition of self-efficacy, determined by the Workgroup, was “*Belief in my abilities to achieve the things that matter to me*”.

Naming the website

Initially, the Steering group anticipated naming the website ASSET-Stroke according to the project name (derived from codesigning digitAl Solution for Self-Efficacy afTer stroke). However, both the Steering Group and Workgroup agreed that this name did not encapsulate the philosophy and purpose of the website and was unlikely to attract the attention of survivors of stroke unfamiliar with the project. Accordingly, discussions were facilitated, and voting was conducted with the Workgroup, and the domain name EmpowerMe was selected. This name aligns with others curated by Stroke Foundation, such as EnableMe[13] for survivors of stroke and carers and InformMe[17] for health professionals working with survivors of stroke.

Creating website content

Project team members created content and accompanying downloadable PDFs to address each priority topic area. All text was edited until it was deemed to be understandable by people who had completed grade 7 at school by Microsoft Copilot. Text resources for “Managing speaking difficulties” was edited by a speech pathologist with expertise in aphasia (author EG) and then checked and further edited with a survivor of stroke with moderate aphasia.

Expressions of interest were advertised for survivors of stroke and carers to create video-stories to be hosted on the website about building self-efficacy after stroke, with a focus on the prioritized topic areas. Twenty-six survivors of stroke and ten carers recorded video-stories, usually over Zoom with a project team member, lasting up to 30 minutes. The project team edited the recordings into numerous short (30s to 3-minute) videos, creating more than 150 videos (See Table 2). Each edited video was sent to the individual for approval or further editing, before uploading to Stroke Foundation YouTube channel, and being allocated to a topic area (one of the nine priority topics when appropriate). A thumbnail with brief title was provided for each video. Video contributors were reimbursed for their time.

Creating webpages

The main website was developed on Wordpress, which allowed content to be easily updated by non-technical team members, if needed, and was compatible with Stroke Foundation’s systems to allow Stroke Foundation to manage the website on project completion. The nine priority topics were organized into nine webpages. The website home page presented information from the highest priority topic, “Defining self-efficacy and its importance”. The Resource Tailoring Tool was presented at the top of the page, presented as a prominent click box to “Find resources relevant to you”.

The subsequent eight topic webpages were created using a standard template, use of icons and formatting to ensure consistent layout. Each page had a lay description of the topic, a video about the topic, text about how to build self-efficacy in the topic, written content for carers about the importance of self-efficacy for carers or the carer’s role in supporting self-efficacy of survivors, and

thumbnails and titles of relevant videos created by survivors and carers relevant to the topic.

Organizing resources within the website

Resources created as part of the project, and existing resources relevant to the priority content areas were tagged by project team members regarding topic, format and weighting in Webiny Content Management System. Resources developed as part of the project were weighted higher than pre-existing resources, and Australian resources were weighted higher than internationally produced resources. The tags and weightings were used to curate a list of relevant resources for individuals when the Resource Tailoring Tool was used.

Evaluating the website

Results of usability testing have been reported elsewhere (Manuscript submitted to JMIR concurrently). In brief, issues identified included problems with visibility of resources after use of the Resource Tailoring Tool; layouts that were difficult for people with inattention; and layouts that were problematic (text heavy) for people with aphasia. These were subsequently addressed by the design team.

The potential of the digital resource “EmpowerMe” to influence self-efficacy, health-related quality of life, participation and anxiety and depression in different cohorts of survivors (stratified by age and time since stroke) is currently being evaluated using as part of a Phase II trial. (Trial registration ID: ACTRN12624001018505)

Discussion

We have presented how a digital resource in the form of a website can be built specifically to meet the needs of a client group with heterogeneous challenges, including cognitive, language and motor changes. Rather than retrofit an existing website to the needs of people with post-stroke visual, motor, cognitive or sensory changes, we designed the website pro-actively to meet the diverse needs of the intended user group. People with lived experience of stroke were included at all stages, from preparation and submission of the grant, being members of the Steering Group, to facilitating and contributing in Lived Experience Workgroup meetings and contributing to this manuscript.

The Steering Group actively sought to balance the power dynamic between the academic researchers and people with lived experience. Following project commencement, the team recognized the need for more Lived Experience leadership to facilitate the Lived Experience Workgroup meetings. One workgroup member (survivor of stroke) with experience in both research and in facilitating online peer groups accepted an invitation to join the Steering Group, co-facilitate workgroup meetings and was employed as a research assistant for the life of the project to assist in data analysis.

Principal Results

Within a research framework, we were successfully able to embed systems to support people with lived experience of stroke to contribute meaningfully alongside a team of multi-disciplinary experts to co-design a digital resource to address self-efficacy after stroke. Recognizing the different expertise of each party allowed the team to determine who decided each feature of the digital resource, to simultaneously address the needs and preferences of survivors of stroke and carers and maintain the rigor and aims of the research process.

Survivors of stroke and carers, who comprised the Lived Experience Workgroup determined the digital platform (website with feature to direct the user to individually relevant information), the priority content to include, and the priority format of resources (home-made video stories) to be

developed by the project team. In contrast, the project Steering Group, (which included two survivors of stroke and one carer) made fewer decisions but worked consistently to incorporate feedback and suggestions from the Lived Experience Workgroup, positioning these within best-practice frameworks of adult learning, self-efficacy, self-management and digital design.

Limitations

By nature of engagement, wherein meetings were conducted online via Microsoft Teams, the Lived Experience Workgroup members who contributed over the duration of the project tended to have high levels of digital literacy. This was a proof-of-concept project and there was not a specific strategy to recruit people from linguistically or culturally diverse backgrounds. Several team members (on Steering group and Lived Experience Workgroup) were born in countries other than Australia, but most team members spoke English as a first language. Should the website indicate promise at improving outcomes for survivors of stroke, future work will be undertaken to engage with culturally and linguistically diverse groups of survivors and carers.

Comparison with Prior Work

There is a growing body of literature documenting how to facilitate co-design and interactive workshops online, particularly since the COVID-19 pandemic.[18-21] Now that social distancing measures have lifted, online methods of co-designing have remained popular, with obvious benefits of reducing travel time, costs and increasing accessibility for people who live in regional and remote areas.[21, 22] While some researchers in previous work have described using interactive features of online platforms to enhance activity within online co-design meetings,[19, 23] interactions with the Lived Experience Working Group in the current project were mostly dialogue-based, which was sufficient to achieve the outcomes required for each meeting.

The project reported in this manuscript is far from the first website to have involved intended users in the design. Supporters of collaborative design methods argue that involving target users when designing a digital resource will improve the resource impact through better user engagement and satisfaction.[22, 24-26] However, the level of involvement of the intended users can vary greatly between studies that report using co-design methods. While co-design has been described as “meaningful end-user engagement in research design and includes instances of engagement that occur across all stages of the research process”[11]^{p2-3}, it is also acknowledged that the engagement activities “range in intensity from relatively passive to highly active and involved.[11]^{p.3} In a systematic review which tabled the most common co-design activities in studies reporting co-design of digital health solutions, two of the most common activities reported were interviews and surveys.[27] Implicit in these activities are the research team setting the agenda and seeking “data” from participants. Other common activities were workshops[27] which are more collaborative and allow for a two-way exchange of information, having been described as occasions in which a group of people can acquire new knowledge or perform creative problem-solving.[28]

Intended users have been variably involved in determining whether a website would be of benefit, ranging from not being involved in the decision, (for instance when the rationale of developing a website is based on disease incidence and rates of technology use[25]), to contributing data supporting the idea (e.g. rationale is underpinned by interviews of participants living with the condition under investigation[29]) to sharing responsibility for the decision to develop the website (for example when people with lived experience are members of the research team and help shape the research proposal.[30, 31])

Similarly, the level of input and decision-making responsibility of representatives of the intended

user group about features of the co-designed websites varies. Intended users could contribute data to be used by the design team to make decisions (such as people being recruited as participants in interviews, focus groups or co-design sessions)[24, 29], they could advise on features (for example via Lived Experience Advisory Groups)[24, 29, 31] or be decision-making partners (for example via being members of the research or design team).[30, 31] Different groups of people from the intended user group were frequently involved at multiple levels within studies (for instance as participants and others as advisors).

Compared to prior work, the current project used more active and involved methods of working with people with lived experience of stroke throughout the design of the website than has been reported in most other publications reporting on co-design of websites to support health or wellbeing. Unique to this project was the need to develop a website that was accessible to people with language, visual, motor, cognitive or sensory changes from their stroke. We identified one published work presenting co-design of a website to support physical activity and diet to reduce secondary stroke.[31] This was also conducted in Australia, with four academic researchers and one team member from Stroke Foundation also involved in the current project. These two Australian projects involved contributions from people with lived experience of stroke and included survivors of stroke in the authorship team; the current project convened a Lived Experience workgroup, and Pogrebnoy and colleagues [31] consulted people with lived experience via a Consumer Advisory Group (one survivor of stroke advised on both projects). Differences include that the website developed by Pogrebnoy was an adaptation of a newly created telehealth service, whereas in the current study, the program and content were co-designed and integrated as part of the website build. Together the projects demonstrate that collaborative ways of working are feasible, even when working with people who experience communication, cognitive or physical challenges after their stroke. These ways of working are transferable to other clinical fields, and the methods reported in this paper could be used by other research and design teams.

Conclusions

We have demonstrated how a multidisciplinary team of academic researchers, people with lived experience of stroke and Stroke Foundation representatives can work collaboratively from inception of a project to co-design a digital resource known as the “EmpowerMe” website which hosts content to meet the needs of survivors with stroke to support self-efficacy.

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Author contributions: Developed study proposal and shaped research design (EAL, AO'M, BB, DC, LC, EG, NL, LM, NB, CE, ZA-W, RC, RC, GH, FJ, AMcG), led data collection (EAL, SC, AO'M), led website build and design (NB, JL), led video-story development (SL, KN, EAL, KZ, SC), led manuscript writing (EAL, NB, KN). All authors have contributed to the shaping of the website through Steering group and project group discussions. All authors have reviewed and commented on the final version of the manuscript.

Conflicts of Interest

None declared

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Supplementary Files

Figures

Steps followed to design the EmpowerMe website and content.



Core and adaptable features of the digital resource.

