

# **Co-Design with People Who Have Had a Stroke to Better Understand the Transition from Hospital to Home: A Narrative Account**

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In this paper we report on co-design with people with a lived experience of stroke and their caregivers as part of an ongoing mobile health project to provide better support in the transition from hospital to home. This project was situated in the context of a publicly funded healthcare service in Australia. Our co-design approach involved creating collages and sharing of personal experiences to reflect on support and information received. We focus on the collage and the narrative account of a young woman that illustrates the experiences of living with stroke during this transition and “infrastructuring work” to address gaps in information, services, and support. These gaps did not appear within the healthcare service, but rather in the transition between the healthcare service and home, and also in the transition back to work. Based on these insights, we discuss the design directions for a mobile health prototype to better tailor information and to provide timely support.

CCS CONCEPTS • Human-centered computing~Human computer interaction (HCI)~Empirical studies in HCI

**Additional Keywords and Phrases:** Stroke; transition; experience; patient work; co-design; mobile health

**ACM Reference Format:**

First Author's Name, Initials, and Last Name, Second Author's Name, Initials, and Last Name, and Third Author's Name, Initials, and Last Name. 2018. The Title of the Paper: ACM Conference Proceedings Manuscript Submission Template: This is the subtitle of the paper, this document both explains and embodies the submission format for authors using Word. In Woodstock '18: ACM Symposium on Neural Gaze Detection, June 03–05, 2018, Woodstock, NY. ACM, New York, NY, USA, 10 pages. NOTE: This block will be automatically generated when manuscripts are processed after acceptance.

## 1 INTRODUCTION

The impact of a stroke, defined as a sudden interruption in blood flow to the brain, affects each person in a unique way. Depending on the area of the brain affected, a stroke can impact on a person's ability to move their body, engage with their senses (sight, touch, smell), use language, think, and experience emotions. In Australia, more than 470,000 people live with the effects of stroke, with two thirds of them needing assistance to carry out basic activities of daily living like eating [8]. Therefore, to achieve the best outcomes possible, the pathway to recovery must be tailored to meet the needs of each individual, starting in the hospital and continuing in the home and community [15].

The aim of this research project was to better support the transition from hospital to home for Australians living with stroke and their caregivers through a mobile health application to tailor information to each person's circumstances. A crucial starting point in the transition experience is the discharge planning conducted in the hospital, where clinicians, patients, and caregivers develop a plan for managing recovery at home. Unfortunately, when patients leave the hospital, they not only have to deal with the outcomes of stroke, but they also often experience a lack of medical knowledge, a lack of resources to manage their health, and a lack of confidence in their abilities [17]. Research also shows significant gaps in illness related work at home, i.e., gaps in efforts to manage blood pressure, modify lifestyle factors to reduce the risk of another stroke, and to maintain mental wellness [2]. The outcome of stroke can affect everyday life, from household chores to transportation to managing relationships, as well as biographical work to reconstruct a personal narrative [16]. For some younger people it may also impact on their ability to continue working or require modifications to their work environment to successfully return to work. The COVID-19 pandemic affected the transition, because previously planned procedures and rehabilitation services were reduced to limit the spread of infection or because hospital resources were needed elsewhere [1]. To start to address some of these challenges, this project aimed to design and evaluate a mobile application that provides personally relevant information aligned to the needs and goals determined by people who have had a stroke, caregivers, and the treating clinicians.

In this paper we present initial insights from co-design workshops with people who have had a stroke and their caregivers with a particular focus on "infrastructuring work" during the hospital-to-home transition. While patient work has long been studied in HCI [14, 20], infrastructuring work refers specifically to the often invisible labour by patients to connect and re-configure often fragmented infrastructures, like different healthcare services, physical and digital resources, information, support, etc. [4, 12]. We found this a useful concept to reflect on key challenges experienced in the hospital-to-home transition such as dealing with too much or too little information from various healthcare providers. In this paper we focus on the experiences of one workshop participant, Gloria (pseudonym), who reported positive experiences with the healthcare service infrastructure, but highlighted gaps and challenges with the existing infrastructures in returning home. We close with reflections on the narrative account and the technology prototype.

## 2 CO-DESIGN APPROACH

This research took place in Brisbane, Australia, as part of a research project called "Better Individualised Stroke Care Using Technology (BISCUT)". The aim of BISCUT was to design and evaluate mobile technology to better connect different healthcare services and to tailor support for people who have had a stroke and their caregivers in their transition from hospital to home. The target cohort for this project were people who are discharged within a few days following acute treatment of their stroke and who do not require in-patient rehabilitation but are usually referred for community-based rehabilitation which they are required to self-manage at home. This research project was conducted in collaboration between Metro North Hospital and Health Service and Queensland University of Technology. The

healthcare service is part of a publicly funded universal healthcare system in Australia, which covers hospital inpatient care and limited, medically necessary, home health care for Australian citizens and permanent residents.

The BISCUT project was based on a co-design approach that brings together people living with stroke, caregivers, health professionals, health management, and researchers. This approach is based on a number of propositions: (1) that all people are creative and have ideas to improve their lives (creative proposition)[18]; that all end users have a right to be included in the design process (moral proposition) [3]; and (3) that collective creativity (co-creation) across the whole span of the design process produces better outcomes (pragmatic proposition) [3, 19]. Hence, all project efforts, from the conception of the project, to the ethics approval, to co-design workshops were developed and conducted, including this paper, in collaboration with a person living with stroke, researchers and professionals in health and HCI.

We conducted four co-design workshops to examine the work and the experiences of their transition from hospital to home in an Australian context. Workshop 1 involved joining a stroke support group to listen to their stories and to discuss the project aims (approximately 20 participants). Workshop 2 involved five people who have had a stroke and one caregiver recruited through personal contacts. Workshop 3 was conducted with participants recruited through the health service (three participants). In workshop 4 we re-visited the stroke support group from the initial workshop during their regular meeting (20 participants). All workshops were conducted in person.

The workshop structure varied between the workshops. Workshops 1 was informal and simply involved getting to know group members, listening to their stories and informally presenting the project aims. Workshops 2 to 4 followed a similar structure to learn about the transition experience and discuss ideas for a mobile health application. After an introduction of the workshop participants and the project, we conducted a drawing exercise to highlight that everyone is creative and can contribute ideas [10]. The main workshop activity was to create a personal collage of the transition from the hospital to home and to share the story with other workshop participants. Each participant received a collage kit that included a large piece of paper, pens, post-it notes, photos and drawings related to recovery from a stroke, sentence prompts (e.g., when I have a question, I speak to...), and emotion words (e.g., anxious, supported) [9]. Participants spent between 30 and 40 minutes to create their own collages, followed by a 30-minute show and tell session where participants shared their stories with each other. In workshop 2, the collage was followed by a brief discussion of ideas and information that would have made a difference in each person's transition journey. In workshop 3 we created collages and we discussed an early prototype with participants. Workshop 4 focused solely on discussing a digital prototype with the workshop participants to develop ideas and to refine the information, functionality, and the look and feel of the application. All group discussions were audio-recorded for later analysis.

The findings presented in this paper are based on a narrative analysis [5] to make meaning of the experience of transitioning home after a stroke and the work involved in dealing with gaps in infrastructure. Instead of breaking up the data from many participants into codes and themes (e.g., through a ground theory approach), narrative studies are typically only focused on one or two participants to provide an in-depth account of their experience [7]. In our analysis, we focused on the experience of Gloria, a woman in her early thirties, whose life had been disrupted by a stroke three years prior to the workshop. We chose Gloria, because her account was rich in examples of infrastructure gaps and work. The analysis was based on her collage of the transition from hospital to home (see Figure 1) and a transcript of her verbal account. The first author transcribed the audio-recording and re-told the story of Gloria's transition and the gaps in infrastructure she experienced. The re-told story has been reviewed with all co-authors to ensure that both the details and the story as a whole are truthful and in line with the way the story has been told during the workshop.



Figure 1: The collage was used in the workshop to illustrate and talk about personal experiences in the transition from hospital to home after a stroke. Gloria's collage shows her transition from hospital (column A) to home (B), including the first few months of being at home (C) to the present day (D). The text on the bottom lists information that would have made a difference in her transition.

This narrative account provided in this paper is subject to several limitations: we did not discuss or rewrite our findings with Gloria, which would have enhanced the truthfulness and may have created further insight into her experience. We also do not imply that the findings from a single participant are applicable to other people living with stroke in Australia. Each person is uniquely affected by a stroke, depending on the impact on their brain, personal

history, care received, etc. This account is based on the experiences with a publicly funded healthcare system in an Australian metropolitan area, and other healthcare systems in Australia, e.g., in a rural area, may work differently. Hence, comparisons with other narrative accounts would be useful to enhance the applicability of the findings.

### 3 FINDINGS

Gloria was a young adult in her early thirties, whose life was disrupted by a stroke three years ago. Gloria's collage (see Figure 1) and her verbal account provided rich insights into the impacts to her personal life and marriage, the disruption to her professional work as a fitness instructor, and the emotional journey of recovering from a stroke. Below we re-tell her story of transitioning from the hospital to home and of the work performed by Gloria and her husband.

#### 3.1 Transition Experiences

Gloria's account of transitioning from hospital to her home, up to today's situation, was structured into four phases (as illustrated through the four columns of her collage in Figure 1). Firstly, the experience of the immediate aftermath of the stroke in the hospital was characterised by feelings of losing control and frustration. Gloria was young and living a very healthy lifestyle, and hence the stroke was a surprise and shock to her: "*I was a fitness instructor, and I was into eating healthy and everything. So it was really out of the blue when it happened. It felt really like out of control, like in the picture, like a storm, without understanding it.*" Gloria felt upset that it happened to her and also frustrated with the loss of her abilities, i.e., her inability to speak and the slow recovery process: "*I felt really frustrated, because I had very strong aphasia. I couldn't say anything really. Then I could just say one word. There was a lot of time, I couldn't say much. I felt very frustrated, and then I felt angry.*"

Secondly, the experience of transitioning from hospital to home could be summarised as intimidating. Gloria explained that "*it's been really hard in the recovery [in hospital], but I think the hard work started at home. So I felt really intimidated and nervous thinking that, how is it going to happen [at home]?*" Gloria's husband provided crucial support throughout this time to continue rehabilitation, manage everyday life, and to offer emotional support.

Thirdly, Gloria described that it took several months to even begin to come to terms with the effects of stroke, both for Gloria and her husband. Looking back, Gloria stated that "*I have to admit that I was fortunate. I lost a bit of balance, but I could get back into exercise and I was hopeful. My family of in-laws supported me. It's not the same as family. But my husband was a really big support.*" Whilst feeling fortunate, Gloria also highlighted that she struggled with her situation, in particular, with the effects of stroke on her emotions: "*I've always been a very optimistic person, but it's tough. It's taking a toll on you.*"

Finally, looking at the present time, Gloria had achieved a lot that she was proud of. She was able to get back to paid work, move into her own home, and start a family. There have also been other achievements, like being able to enjoy listening to music and being able to dance again, which have been important for Gloria's wellbeing and sense of progress: "*I've always been enjoying music. Although I find it very overwhelming, having it in the background and doing a thing at the same time is still a bit much. But it's a good exercise.*" None of these achievements came without challenges and work, which are described next.

#### 3.2 Transition Challenges and Infrastructuring Work

For Gloria, the primary concern was not the health service infrastructure per se. Like other workshop participants, Gloria praised the healthcare infrastructure: "*The medical system was really good in terms of health. I've been checked very well*

*and looked after.*" Instead, the challenges emerged in managing the transitions from the hospital and rehabilitation services back home and returning to work.

### 3.2.1 Transitioning Back Home

Transitioning back home brings multiple challenges: independent rehabilitation efforts and other efforts to manage the impacts of stroke (e.g., medication); managing everyday life from household chores to personal relationships; and work to reconstruct a personal narrative and identity. Importantly, this transition also starts in hospital, to prepare the person living with stroke and their caregivers for life at home through information about the stroke and how to manage its effects independently at home.

One of the challenges highlighted by Gloria was the overwhelming amount of information received in hospital: "*All of the information I was given at the hospital – it was just too much reading.*" This was particularly problematic, because Gloria experienced both impairments to express and comprehend language as well as fatigue. In Gloria's situation, her husband performed the work of filtering the large amount of information on how to manage the effects of stroke. However, her husband's time was limited due to paid work and household work: "*It took me months to read something and understand so I didn't feel like looking. So my husband would have to, but he didn't have time.*"

On the issue of emotional wellbeing, Gloria reported that she received too little information and too late. Feeling strong and uncontrollable emotions, feelings of anxiety, and having depression are common after having a stroke. These impacts of stroke are not always experienced immediately but rather emerge over time. Gloria commented that she wished that she had personally received information about the impacts of a stroke on your emotions whilst still in hospital. Furthermore, she wished she had received information about peer support groups which provide an important infrastructure for people to discuss and normalise their experiences. "*When I was in the rehabilitation, nobody gave too much information. Nobody said to me about depression really. They told my husband, but nobody told me to explain to me the possible outcome. So anyways, it's good with all these groups to get this connection to be able to share and to understand you are not alone, which is really good.*"

### 3.2.2 Transitioning Back to Work

Gloria described that she felt "*let down and ignored*" by the medical system when she had to return to work. However, Gloria also stated that "*the medical system was really good in terms of health*" and that "*there is nothing else you could do much more*", acknowledging that the responsibilities of the medical system are obviously concerned with her health, which may at times clash with other needs, like the ability to return to work.

The first challenge was that Gloria could not go back to her previous work because of the need to drive a car and the lack of public transport in her area. "*Basically I was told that I can't drive, because it was too far. So I had to either move somewhere else, but we had a contract for a rental. So we couldn't just move out like this. Or change my job, but my job was on a contract, and I didn't want to leave my job like that. So I just been left like that and I had to deal with it.*"

Hence, a second challenge was to find suitable work. Finding a new position can be stressful for anyone. However, living with the effects of stroke made it particularly challenging for Gloria due to fatigue, speech impairments, and the impact of stroke on her self-confidence: "*I still had to apply for a job and nobody gave me any support. And my interview – this was very stressful at the time, because you don't feel confident.*"

As a form of personal infrastructuring, Gloria included a personal diary in her collage which she used to manage information during phone calls. The stroke impacted on Gloria's ability to speak and remember information. Hence the

diary was useful to prepare for phone calls with health services and prospective employers: “*making phone calls was a very challenging thing. I had to write down to say this, explain why – you feel a bit stupid to express yourself normally.*”

Gloria was able to resolve these challenges and find suitable work. She found a sympathetic doctor who offered support for getting back to driving. Going back to work also enabled her to afford to move house, which reduced the length of the commute. “*I went back to work in May. And then we bought a house and moved to a lovely place – in the mountains. We wanted some space in the nature. We can't complain – we worked really hard, but it worked out.*”

#### 4 DISCUSSION

The main contribution of this paper is a narrative account of a person with a lived experience of stroke originating from a co-design process to build better healthcare infrastructure. The account suggested that the healthcare services in an Australian metropolitan context provided excellent treatment and rehabilitation services, but it also highlighted challenges in the transition from the health service to the home and back to work, which involved various types of work: emotional work to come to terms with the impact of a stroke, support work by the spouse, and informational work by family members to cope with the wealth of information offered in hospital. In terms of infrastructuring work [12], the narrative account highlighted infrastructure breakdowns and infrastructuring work at the boundaries between health services, home, and work. We presented evidence of personal infrastructuring by the person living with stroke to: work through diaries to scaffold telephone conversations, deal with gaps in transport infrastructure that adversely affected the person’s ability to return to work and, gaps in conveying information about access to peer support group infrastructures to cope with strong emotions and depression after stroke.

Conceptually, we found that transitions and infrastructuring work offer useful perspectives for HCI research to better understand the experiences of patients and caregivers and to design digital technologies that provide support to address gaps in information and the work required to coordinate different healthcare and support services. Transitions are a central concept in nursing research [21]. Particularly transitions in and out of the health system are critical for the overall wellbeing and recovery of people with stroke, and more work is needed to address gaps and breakdowns during transitional periods. As highlighted by others [6], a narrow focus on managing the effects of illness in hospital and at home is not sufficient, because chronic conditions like stroke also affect everyday life work and relationships as well as a person’s sense of self. Hence, looking at the transitions and work performed at home opens up several opportunities for HCI researchers: instead of narrowly focusing the design of digital technology on supporting rehabilitation and other illness work, it highlights opportunities to support people who have had a stroke in everyday life work to recognise fatigue, to promote relationships with peers, or to provide opportunities for reflection and forming a personal narrative [16, 22]. We hope that the perspectives of transitions and infrastructuring work are also useful for HCI researchers working with people with other chronic conditions, such as heart disease, cancer, and diabetes, which require ongoing coordination with different healthcare and support services.

Reflecting on the co-design process, we found that the collage activities in workshops 2 and 3 were particularly helpful to engage participants in the design process. In other words, collages were effective in terms of the moral proposition of co-design to include users in the design process [3] and also in terms of the creative proposition [18], showing that all participants are creative. Creating the collage gave the participants time to engage with the materials, to reflect on their personal experience, and to form a narrative, before sharing it with other participants. The group setting and the shared task also helped to facilitate trust, so that participants felt that they could share personal and emotional experiences and provide comfort to one another [11]. However, looking back the design process, we are yet unsure how effective our co-design process was in terms of the pragmatic proposition [3] that it leads to better design

outcomes. There was little engagement with other co-design activities that we had prepared to generate ideas and mock-ups to better tailor information. Some ideas from participants, like simple access to information without requiring a long password, stood in conflict with the technical and legal infrastructure in which the healthcare service operates. The relatively short time frame of the project also made it difficult to continue our collaboration with participants to translate experiences and ideas into a prototype.

These challenges notwithstanding, the project delivered on its aim to create a mobile health prototype that tailors information to each person living with a stroke and their caregivers to provide personalised information at the time when it is needed. We hope that this will mitigate challenges highlighted by Gloria about feeling overwhelmed with the need to read through large amounts of information as well as gaps in access to information. Figure 2 shows a mobile application prototype, which is currently evaluated through a trial study. We are particularly interested how information can be provided to people living with stroke and caregivers in a meaningful way to learn about the stroke and its effects, to support them in achieving their goals, and to provide resources to connect with peer groups and health services. We are aware that standalone information from a mobile application will not be sufficient to address all the gaps identified in this paper. However, like a technology probe [13], it will prompt further discussion of the issues experienced during the transition and the value of the technology design.

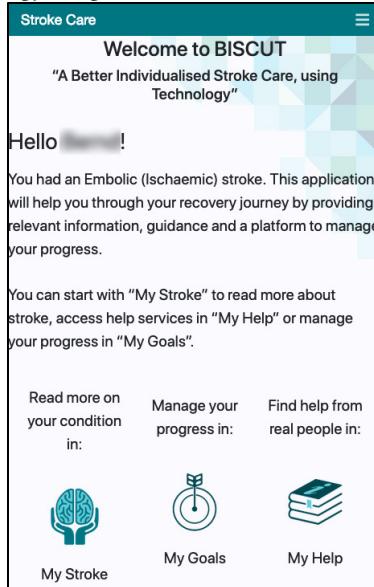


Figure 2. BISCUT prototype used in co-design workshops to discuss how to tailor information for people living with stroke. The prototype offers personalized information about the stroke, goal setting, and access to help through support groups and services.

## 5 CONCLUSIONS

This paper highlighted gaps and infrastructuring work in the transition from hospital to home and in returning to the workplace, such as gaps in information about the effects of stroke and access to infrastructure like support groups. To address such gaps, this research project is currently trialling a mobile health application that tailors information to each person living with stroke and their caregivers. This will also provide an opportunity to continue to refine how people living with stroke, caregivers, and health professionals can collaborate to achieve a better transition to home and a successful pathway to the best recovery possible for each individual including returning to work.

## ACKNOWLEDGMENTS

We would like to thank all participants in our workshops for sharing their stories and ideas for the BISCUT prototype. We are grateful for the support of all BISCUT team members for making this project a reality. This research has been supported through LINK Innovation funding by Metro North Hospital and Health Service.

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