

# Perspectives of People with Stroke, Caregivers and Healthcare Professionals on an Adaptive mHealth Intervention for Physical Activity in the Prevention of Secondary Stroke: A Qualitative Study

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**Introduction:** Engaging in regular physical activity (PA) is associated with lower mortality following stroke, and PA reduces the chance of recurrent stroke. Despite recent guidelines to optimise PA following stroke, people with stroke are known to be less active than their age-matched counterparts. Given the heterogenous nature of stroke, adaptive PA interventions are recommended for people with stroke. Empirical data is lacking on adaptive PA or behavioural change interventions following stroke. Suggested strategies in the prevention of stroke recommend the use of mobile health (mHealth) interventions in the primary prevention of stroke. A structured stakeholder consultation process is key to successful implementation of complex interventions. This paper reports the findings of our consultation process to inform the development of an adaptive mHealth PA.

**Methods:** We used a qualitative study design to explore the perspectives of key stakeholders on the development of an adaptive PA intervention delivered via mHealth post-stroke. Healthcare workers, carers and people with stroke participated in semi-structured one-to-one or focus group interviews. A reflexive thematic analysis was undertaken on transcribed interviews; key themes and sub-themes were developed using coding and summarised by two researchers, then reviewed by the full research team.

**Results:** Twenty-eight stakeholders were interviewed and three main themes were identified; Key feature of a mHealth intervention, delivering a mHealth intervention, Challenges to development and use. There was widespread agreement across stakeholder groups that an adaptive mHealth PA intervention following stroke would be beneficial to people with stroke, following discharge from acute care.

**Conclusion:** Our consultation supports the development of an adaptive PA programme that addresses specific impairments that can hinder exercise participation after stroke.

**Keywords:** physical activity, stroke, adaptive intervention, intervention design

## Introduction

Globally, in 2019, stroke was the second leading cause of death and the third leading cause of disability-adjusted life years (WHO 2021). Exercise and Physical Activity (PA) are widely promoted during life after stroke; physical fitness

training has been shown to reduce disability during or after usual stroke care.<sup>1</sup> Many stroke survivors display both sedentary behaviour (waking behaviour characterised by an energy expenditure  $\leq 1.5$  metabolic equivalents (METs), while in a sitting, reclining or lying posture<sup>2</sup>) and also physical inactivity (do not meet guidelines for moderate to vigorous physical activity)<sup>3</sup> PA is associated with lower mortality in a dose-dependent manner among community dwelling stroke survivors<sup>4</sup> and greater PA decreases the likelihood of recurrent stroke, myocardial infarction or vascular death.<sup>5</sup> Sedentary Behaviour (SB) and PA are important in relation to all cause and cause specific mortality, and incidence of cardiovascular disease.<sup>6</sup> Despite recommendations, PA levels are known to be low in people with stroke.<sup>3,7,8</sup> High-quality research is lacking around optimal interventions to assess and improve physical activity behaviour following stroke.<sup>9</sup>

Meta-analytic evidence demonstrates that the five-year risk of recurrent stroke is 26.4%,<sup>10</sup> necessitating aggressive interventions to modify PA risk factors for further stroke and disability. Secondary prevention guidelines call for people with stroke to engage in PA at either a moderate intensity, four times per week (minimum of 10 min); or a vigorous intensity twice per week (minimum 20 min) to reduce the risk of recurrent stroke.<sup>11</sup> Given the heterogeneous impact of stroke, adaptive PA interventions, which are personalised to individual preference and performance, are recommended.<sup>12</sup> Adapting PA to individuals' needs, enables person-centred care and increases uptake of such interventions.<sup>13</sup> PA interventions are often delivered in multimodal lifestyle-based interventions; empirical data is lacking on adaptive PA or behavioural change interventions post-stroke, or the optimum sequence of these treatments. The Sequential Multiple Assignment Randomised Trial design (SMART)<sup>14</sup> has been developed for the purpose of designing optimal adaptive interventions. SMARTs are factorial designs in a sequential setting<sup>14,15</sup> and can be described as multi-stage randomised controlled trial designs. Identifying non-responders and allowing for the adaptation of subsequent PA interventions will realise larger benefits and reduce the use of less-effective strategies. Developing the optimal sequence for an adaptive multimodal PA intervention following stroke, has the potential to improve long-term activity and reduce injury burden globally.

In young and middle-aged people, stroke may be increasing due to an increase in metabolic risk factors, including obesity and diabetes mellitus,<sup>16</sup> this represents a large burden on public health resources with implications for long term disability. World Health Organisation guidelines on PA and sedentary behaviour, provide an up to date overview of global recommendations for PA and SB in various populations; current guidelines show that evidence gaps remain in the relationship between volume and/or intensity of PA and health outcomes.<sup>17</sup> The findings of a recent Cochrane review concluded that evidence for reducing SB in people with stroke is still lacking,<sup>9</sup> suggesting that interventions targeting PA could also be used to reduce SB time during the day. Suggested strategies in the prevention of stroke recommend the use of mobile health (mHealth) interventions in the primary prevention of stroke.<sup>18</sup> Mobile Health is defined as the use of mobile and wireless technologies for health, and aims to capitalise on the rapid uptake of information and communication technologies.<sup>19</sup> A recent Cochrane review found that few studies have examined the effect of activity monitors to increase physical activity after stroke; four small RCTs (three studies conducted during inpatient rehabilitation) reporting on 274 stroke survivors.<sup>20</sup> Using mHealth to promote physical activity in people with stroke who are discharged from inpatient rehabilitation has the potential to reduce clinical and cost burden and represents a suitable method of delivering adaptive interventions. Information is lacking about the usability and essential key features of mHealth to increase PA and promote secondary prevention post-stroke.

Holding a structured stakeholder consultation exploring all aspects of an intervention as individualised as PA after stroke is key to successful eventual implementation.<sup>21</sup> To this end, the aim of this study is to explore the perspectives of people with stroke, their caregivers and healthcare providers on the design and delivery of an adaptive, personalised mHealth intervention to promote PA after stroke. This qualitative study represents the initial stages of intervention design, informing the development of an adaptive mHealth PA intervention to be investigated using a SMART design.

## Methods

### Study Design

We used a qualitative descriptive study design to explore the perspectives of key stakeholders on the use of mHealth following stroke. This study incorporated reflexive thematic analysis guided by Braun and Clarke's framework.<sup>22,23</sup>

Focus groups and 1-to-1 interviews were performed with people with stroke, carers and healthcare professionals. It was intended to invite participants to focus groups or 1-to-1 interview, allowing for participant preference and acknowledging communication complexity in people with stroke. Due to COVID-19 contingency after two focus groups were completed, data collection was moved to 1-to-1 interview. The focus groups or interviews were moderated and performed by three researchers (SH, MOD, DC) using a prepared semi-structured interview guide ([Supplementary Table 1](#)). Data were collected in-person where possible, and due to the ongoing COVID-19 pandemic; virtually by phone, Skype or Microsoft Teams where applicable. The COREQ standardised reporting guidelines were followed to standardise the conduct and reporting of the research.<sup>24</sup>

## Ethics

Ethical approval was granted by the Faculty of Education and Health Sciences Research Ethics Committee at the University of Limerick [Ref: 2019\_10\_03\_EHS]. The conduct of this study complies with the Declaration of Helsinki.

## Participants

Participants were recruited purposively through hospital and community / professional groups, additional participants were sought through snowball sampling. All participants provided informed consent, including consent for the publication of anonymized responses. All participants were screened for eligibility prior to inclusion by researchers completing the interviews (SH, MOD, DC). People with stroke were recruited through University Hospital Limerick (UHL), and local, community-based stroke support groups. Inclusion criteria for people with stroke were; a confirmed diagnosis of stroke, aged 18 years or more, independently mobile, community-dwelling, without other diagnosed neurological conditions and with sufficient cognitive and communication ability to take part in the study. People with stroke were permitted to attend the interview with a caregiver, if needed for assistance in mobility or communication. Caregivers were recruited from local, community-based support groups for caregivers, eg Headway, Acquired Brain Injury Ireland, and the Irish Heart Foundation. Inclusion criteria for carers were: caregivers, spouses or family members, aged 18 or over who provide care (paid or unpaid), support or assistance to people post-stroke. Recruitment information was provided through a gatekeeper for each organisation and stakeholder group. Healthcare professionals were recruited through professional bodies, eg the Irish Society of Chartered Physiotherapists and the Association of Occupational Therapists of Ireland, and by Twitter, information was provided and distributed through email. Inclusion criteria were membership of their professional body and employment as a physiotherapist, occupational therapist, speech and language therapist, doctor, nurse, social worker or psychologist.

One-to-one interviews lasted 30–45 min and the focus groups lasted 60–70 min. The interview schedule ([Supplementary Tables 1](#) and [2](#)) was developed using the TiDieR framework, as findings will be used to inform the development of a mHealth intervention. The interview schedule allowed for open-ended questioning on key topics across all participants. All interviews were audio recorded, anonymised to ensure confidentiality and transcribed verbatim. Transcripts were double-checked by the research team for accuracy.

## Data Analysis

Qualitative data analysis was coordinated by two members of the research team (AH, NC) who had no prior relationship with any of the study participants. AH is a male Senior Lecturer and experienced qualitative researcher with a particular interest in the application of qualitative research in trials. NC is a male post-doctoral researcher and specialist physiotherapist with 10 years of clinical expertise and a background in mixed methods research. Ongoing analysis was fed back to the larger research team at regular intervals for wider consultation, in keeping with a reflexive thematic analysis.<sup>22</sup> The one-to-one interviews and focus groups were anonymised and transcribed verbatim, to ensure confidentiality. Analysis then followed the six-step procedure:<sup>22,23,25</sup> (1) transcription data were re-read and checked against the audio to ensure accuracy, with researcher notes taken to identify features of interest such as non-verbal sounds, hesitations and humour; (2) pertinent data were coded; (3) codes were ordered into provisional themes; (4) the analysis team compared and discussed themes with a view to consolidating similarities and removing non-applicable data; (5) ongoing focusing and elaboration of the themes was undertaken to explicate the relationships and differences within and

across themes and best narrate the story present within the data; (6) the final results were presented, supported with explanatory transcript excerpts to best describe and explain the meaning captured within the themes. NVivo (version 12.6.1) software was used to store, code and allow rigorous qualitative analysis.

### Rigour

In this study rigour was ensured by utilising triangulation whereby initially two researchers (NC, AH) completed initial thematic analysis of one transcript from each participant group independently, before comparing, discussing and agreeing initial themes.<sup>26</sup> Coding of transcripts was then completed by one researcher (AH). At the conclusion of each interview, the researcher summarised the discussion and received confirmation / clarification from the stakeholders to ensure accuracy. Reflexivity is a key component of Braun and Clarke’s approach to thematic analysis.<sup>22</sup> These initial themes were discussed by members of the research team (NC, AH, MOD, DC, MC, PB, SH), which allowed reflexivity in undertaking subsequent interviews and analysis. Triangulation was also achieved by ensuring ongoing comparison of the data from all three participant groups adding to the complexity and completeness of the data.<sup>27</sup> NVivo allows integration of researcher notes and memos with the stored data and developing themes. This facilitated continuous discussion of themes and sub-themes between the research team, reducing bias and provided an audit trail supporting the results.<sup>27</sup> Finally, steps four and five of the analysis were repeated after consultation with the interviewees and whole research team.

### Findings

Twenty-eight participants were recruited from all stakeholder groups and completed the interviews (12 people with stroke, six caregivers (paid or unpaid) and 10 healthcare workers (HCWs); seven Physiotherapists and three Occupational Therapists). Characteristics of participants are outlined in Table 1. Two face-to-face focus groups (three people with stroke and four people with stroke, respectively) were completed and all other interviews were subsequently completed virtually one-to-one with individuals, due to Covid-19 pandemic restrictions. One person with stroke attended a focus group with their carer who assisted in communication due to aphasia. A purposeful and snowball sampling approach was taken, to recruit a representative sample of participants of varying age, occupation and experience (Carers / HCWs). Initially a target of 10 participants per group were targeted, additional people with stroke were recruited in order to

**Table 1** Characteristics of Participants

Healthcare Workers	Mean Age (Range)	Years in Stroke Service	Occupation (n=)		
(n = 10)	34 years (30–54)	4 (2–25)	Physiotherapist	7	
			Occupational Therapist	3	
Carers	Mean Age (range)	Years as a Carer	Occupational status (n=)		
(n = 6)	66.5 years (31–72)	5.5 (3–10)	Retired	3	
			Business Owner	1	
			Teacher	1	
			Farmer	1	
People With Stroke	Mean Age (range)	Years Since Stroke	Occupational Status (n=)	Location (n=)	
(n = 12)	54.5 years (21–67)	7 (0.6–12)	Working part-time:	2	Rural: 6
			Working full-time:	1	Urban: 6
			Student:	1	
			Retired:	3	
			Unemployed:	5	

increase diversity of age and physical abilities. Data collection ended in the three participant groups when analysis indicated that the interviews were no longer providing new insights into the questions of interest.

The findings outlined below present themes and sub-themes related to the perspectives of key stakeholders on the design of a mHealth intervention following stroke. The themes and sub-themes are presented in [Table 2](#) and are discussed in detail below with illustrative supporting quotes.

## Theme 1: Key Features of a mHealth Intervention

This theme has four sub themes (goal setting for motivation, variation in PA programs, positive monitoring and feedback and adaptive interventions). It describes participants' views on the qualities of a mHealth intervention in terms of how a mHealth intervention should be delivered. This theme identifies that participants believe that a mHealth intervention would support enhanced PA, as long as the device and format met their needs. Analysis of the data also notes that participants identified recent changes in behaviour during COVID 19 lockdowns; some technologies have been adopted to maintain contact between HCWs and people with stroke to monitor progress, utilising greater device ownership in response to the pandemic.

Like since COVID I've been doing online sessions. So like for some people, it's worked really well because, you know, they're often the ones that just need the coaching or you know, the direction (HCW7, 30 years, female, senior physiotherapist)

All of the participant groups were clear that an important quality of any mHealth intervention is goal-setting. Adaptable goal-setting was seen as a means of increasing the motivation of stroke survivors to engage in PA ... making it competitive against themselves (HCW1, 31 years, female, senior physiotherapist)

Appropriate goals were described by participants as needing to be realistic, as well as being adjusted to the people with strokes' physical abilities, open to context change such as the daily weather conditions and modifiable by the progress made by individuals. There was a consensus that the goals should be agreed between people with stroke and HCWs initially, and then reviewed, based on their progress.

We will decide on the goals at the start ... and then maybe allows us to work with that goal for maybe six weeks (HCW6, 38 years, female, physiotherapist)

Participants also noted that variation would support mHealth use by maintaining interest in an intervention:

... even if you change it (PA intervention) every, not even if you change the whole thing, but like, say, the first, first week, you have all normal and then the following week just one of them exercises is different, then the next week two of them exercises are different. (Person with stroke 10, 40 years, female)

There was considerable agreement amongst the participants regarding the need to make any mHealth intervention adaptable and personalised to the needs of the individual people with stroke supported by ongoing monitoring and

**Table 2** Themes and Sub Themes

Themes	Sub Themes
1) Key Features of a mHealth Intervention	<ul style="list-style-type: none"> <li>● Goal setting for motivation</li> <li>● Variation in PA programs</li> <li>● Positive monitoring and feedback</li> <li>● Adaptive Interventions</li> </ul>
2) Delivering a mHealth Intervention	<ul style="list-style-type: none"> <li>● Trusted professional support and education</li> <li>● Addressing carer burden</li> <li>● Timing of mHealth interventions</li> </ul>
3) Challenges to Development and Use	<ul style="list-style-type: none"> <li>● Familiarity with technology</li> <li>● Physical and cognitive limitations</li> <li>● Not an alternative to professional contact</li> </ul>

feedback. For people with stroke, being aware of their levels of PA and the knowledge that this was being monitored by a professional was viewed as both motivational and providing security around undertaking physical activity. People with stroke also indicated they would like to receive feedback based on their levels of PA, both positive and negative. Positive and simple feedback, such as: well done or you are doing really well (PWS1, 57 years, male)

Such feedback was perceived by people with stroke as a positive reinforcement or a reward to maintain or increase the levels of PA:

The other things that would be great I know there isn't such a thing as a fatigue monitor or a balance monitor but it would be fantastic if you had something in the app that would say, well, you have done enough for the day (Person with stroke 1, 57 years, male)

HCWs in common with people with stroke also emphasised the importance of delivering daily prompts and reminders for both physical activity, and rest. These prompts and reminders being perceived by HCWs and people with stroke as important to increase the motivation to engage in physical activity and contribute to physical activity becoming a habit.

Both HCWs and carers agreed that monitoring and feedback should be provided on an ongoing basis, suggesting that the feedback should be delivered individually and in-real time if possible:

Personalised feedback online over Zoom? Ehm, yes. Probably, it depends on how you'd, how you structure the whole thing. But I mean, there will be ways of providing the feedback in real time to people, you know, because obviously, you do it verbally, if you wanted to get into a breakout room and do it (HCW2, 54 years, female, occupational therapist)

HCWs also noted the lack of current mHealth interventions and the need for adaptable individualised approaches to support people with stroke on discharge from hospital care:

They (mHealth interventions) would be tailored to each, each patient ... I guess as long as you could tailor it from, virtually, as long as you're getting the correct information from them on how they're maybe achieving the exercises. So ... you'd need a, nearly a subjective marker or an outcome measure on how they feel they're doing on the exercises to tailor it a bit more, or to know what kind of difficulty they found in the exercises. (HCW1, 31 years, female, Senior Physiotherapist)

To get more understanding of the kind of adaptive mHealth that participants would like; people with stroke and their carers were specifically asked about their experiences of and expectations of adaptive interventions. Participants were asked how interventions should be progressed or changed if a people with stroke felt that they were not responding to the intervention. Both people with stroke and carers reported that they had not been given modifications to exercise programs following discharge. When considering app adaptability, participants suggested that adaptability in app-based PA programmes would be positive:

Something different to do. And, you know, that's why I'm saying, you know, to do it every day of the week I think would be for them a bit monotonous ... whereas the once a week, and it was something different every week, it didn't feel like a penance. You know, they were quite happy to do it. (CA3, 63 years, female, carer for 3 years)

This carer also directly linked adaptability with individualising PA to meet the needs of the people with stroke:

I think for the individual, it's better if it's over, if it's adapted for the person, you know, because, you know ... Then I think it has to be individual, an individual program for the actual person. (CA3, 63 years, female, carer for 3 years)

Similarly this people with stroke suggested that any mobile app technology be reactive, showing adaptability to allow progression and improvement:

How quickly should it be before the program or the app says, "OK [Participant's name] is not enjoying this or is having difficulty with it? I'm going to try a different approach with her". Maybe, you know, increasing the number of steps each week. What do you think would show me that you're getting on well with the program? (people with stroke 8, 50 years, female)

The *Key Feature of a mHealth Intervention* theme indicates that while there are some variations between HCWs, people with stroke and carers perception of how PA can be facilitated through mHealth, there is a common view that positive

motivation and goal setting with feedback, along with ongoing monitoring and app adaptability can enhance activity by providing attainable adaptable programmes, security and encouragement.

## Theme 2: Delivering a mHealth Intervention

The theme *delivering a mHealth intervention* has three sub-themes (trusted professional support and education, addressing carer burden and timing of mHealth interventions). People with stroke and carers indicated the need for clear support for usage from HCWs, specifically to ensure safe application of any exercise focused intervention. Carers particularly felt under resourced to facilitate an exercise intervention following hospital discharge.

To kind of give him some support like, from someone who knew what they were doing – for a bit of exercise, from someone who would be qualified... I'm not qualified (CA1, 66 years, female, carer for >10 years)

When asked about who should facilitate a mHealth PA intervention, the data shows mixed views regarding the most appropriate background of any individual, with consensus that it should be a HCW:

They would need to be someone with a cardiac rehabilitation background (HCW5, 32 years, female, senior physiotherapist)

The OTS [Occupational therapists] and physios [Physiotherapists] (person with stroke 4, 58 years, male)

My doctor, or a GP [General Practitioner] (perons with stroke 8, 50 years, female)

Carers also responded to questions of who should deliver mHealth in terms of their own role. Taking a view of the potential qualities of people “behind” any app, relative to their own caring role:

I as a caregiver could definitely look into providing, but I think a more qualified healthcare worker could be, they could be trained up in the use the app as well. Probably they'd have a better knowledge of what exactly the participant is trying to achieve out of this. And, tailor the particular challenges to the person's needs as well. So I think it could definitely be rolled out for both caregiver and professional carer (CA6, 31 years, male, carer for 6 years)

The importance of the role of the carer was referred to regularly by people with stroke, carers and HCWs as a key enabler to physical activity and as such, an enabler of mHealth. Carers were seen as:

Key to encourage and drive patients to do what they need and to ensure the intensity that is needed for recovery for patients. (HCW1, 31 years, female, senior physiotherapist)

Although the social support from carers is recognised as a key enabler to physical activity, HCWs did not identify the level of burden faced by carers, while carers were clear they were not qualified to support mHealth interventions without HCW input and education from HCWs:

I'm not qualified, or, I can take him for a walk or I can do this and that and the other, but you know (CA 1, 66 years, female, carer for 10 years)

The potential for added pressure on carers relates to the carer's perception that some people with stroke would need support to handle the mHealth intervention due to their physical or cognitive limitations.

Wouldn't be able to manage it himself, you'd have to have somebody with him to turn it on for him and to set it up for him, you know (CA4, 72 years, female, carer for 5 years)

It was also clear from people with stroke that carers play an important role as supporters and motivators.

But sometimes there's not always someone there to support you when you want to do physical activities. So sometimes it's not that you can't do it, it's that you need supervision. (Person with Stroke 7, 21 years, female)

While broadly positive about the introduction of a mHealth intervention, carers were acutely aware of their burden and relationships with people with stroke and the potential for mHealth to add to that burden. The data illustrated that people

with stroke as well as carers perceive the need to be educated in the use of a mHealth intervention in order to enable effective use.

Participants had views on the timing of the introduction of mHealth and for some stakeholders, pre-discharge rehabilitation was seen as a good time to introduce a mHealth intervention. HCWs and people with stroke felt that there would be benefit to people with stroke becoming familiar with and using an app before hospital discharge:

There's a role definitely in the acute setting or the rehab setting, to mention it (mHealth) and even get them set up and trying it before they go again, I think that buy-in is there, rather than saying, Oh, yeah, there is this, when you get home and they forget about it. Because, there is that adjustment piece of when they get home. But if this is something that they've been trained on and there is a bit of a routine already, or they're familiar and happy with it. I think there's a lot to be said for that (HCW8, 30 years, female, senior physiotherapist)

I spent nine months (in hospital rehab settings). So if over the nine month period I started using the app you know it became part of my life if it became very familiar it became second nature when I come out of hospital I wouldn't need as much support unless the app is showing I was doing something wrong. You know? (person with stroke 3, 57 years, male)

Carers also favoured introducing the app at the beginning of physical rehabilitation to provide a structure and increase the motivation of the stroke survivors:

Once they're gone to a physical rehab centre, maybe just to integrate it slowly there, because it will probably give them a bit of a structure and challenge as they come out of there. They begin their recovery process, something to motivate them to achieve smaller goals, smaller goals each and every day and kind of building on them day by day until the level they aspire to (CA6, 31 years, male, carer for 6 years)

Participants were in agreement that a mHealth intervention should be delivered on a planned regular basis. However, there were some divergent views regarding the frequency and duration of any intervention. People with stroke and carers were often cautious:

It has to be short. It has to be short. If it's too long they won't engage, they will just switch off. If you are doing exercises, to vary them every day so that there will be something new for them (CA4, 72 years, female, carer for 5 years)

The theme *delivering a mHealth intervention* describes how participants had a range of views on mHealth delivery. All of the participants recognise the importance of people with stroke, carers and HCWs buying into and supporting its use to enhance physical activity, but carers in particular have concerns about their role as motivators and facilitators. People with stroke and carers also indicated the need for clear education and support for usage from HCWs, specifically, around ensuring safe application of any exercise focused intervention. There was agreement that timing the mHealth intervention to allow education on its subsequent use would be optimal. Overall, this theme represents a consensus between the participant groups on the importance of having professional support to moderate and direct adaptive, individualised mHealth use.

### Theme 3: Challenges to Development and Use

The theme *Challenges to Development and Use* has three sub-themes (familiarity with technology, the potential impact of stroke-specific deficits on the use of mHealth and the wariness of a mHealth intervention not to be introduced as an alternative to professional contact). The findings describe a number of possible challenges to the introduction and use of mHealth interventions. These include concerns that the use of a mHealth intervention could be challenging for some people with stroke based upon their understanding of the technology and preferences for traditional health intervention delivery. Participants noted concerns around technology use, including connectivity issues, data protection and concerns regarding the safety of this mode of delivery:

#### How Private Would That Be Kept? (Person with Stroke 2, 63 Years, Male)

There were also concerns raised regarding being monitored by technology:



Big Brother is looking at you, you know you pick it up and you say Christ I only have that much done not having a good day or I'm too tired. So it's kind of constantly there (Person with stroke 1, 57 years, male)

An essential feature for mHealth noted by participants, particularly carers, was that the nature of the interface should account for the health consequences of a stroke. Participants noted these were a significant issue, with both physical and cognitive limitations post-stroke cited as factors impacting their capacity to use a mobile app:

They don't have tablets, so the screen is too small maybe on their relative's phone they're trying to use. You know, there are certain factors that, you know, visually, are they impaired after the stroke anyway, so you're not going to know are they seeing the full screen? (HCW10, 36 years, female, senior occupational therapist)

Participants also noted how negative affective states, associated with stroke and emotional / mental health could impact on mHealth use, referring specifically to:

Low Mood, Fatigue, Apathy, Depression (HCW5, 32 Years, Female, Senior Physiotherapist)

and

Fear, Worry, Anxiety (HCW7, 30 Years, Female, Senior Physiotherapist)

## Low Mood, Fatigue, Apathy, Depression (HCW5, 32 Years, Female, Senior Physiotherapist)

and

## Fear, Worry, Anxiety (HCW7, 30 Years, Female, Senior Physiotherapist)

These HCWs saw these as significant barriers to mHealth use by people with stroke as well as impacting on carers' ability to encourage use. Similarly, one carer noted:

I suppose, especially with men, I think they dwell back on what they were able to do... whereas now they can't do it and even though they might try, they fail. Do, do you know, so, that in itself is a bit, I suppose, not degrading but, do you know what I mean?. (CA3, 67 years, female, carer for 3 years)

There was also an underlying concern among carers about mHealth becoming an alternative to HCP input rather than an adjunct:

Maybe younger people who are more in tune with technology and is more part of their lives, they might take to it. But my own belief is this, technology does not replace personal contact. And it's essential to have human contact, motivate people, and to just make people feel connected. (CA5, 62 years, female, carer for 5 years)

In summary, *Challenges to Development and Use* describes how mHealth, while largely viewed as a positive innovation and adjunct to current means of increasing physical activity, is not viewed entirely positively. While the analysis of this theme does raise a number of concerns, it should be seen in the light of the broadly positive view of mHealth innovations in the data. These sub-themes highlight some cautionary principles, which future research and interventions should address.

## Discussion

We aimed to establish the perspectives of key stakeholders, on the use of mHealth to deliver an adaptive PA intervention for people with stroke. We established that carers, HCWs and People with stroke are receptive to mHealth interventions targeting increased PA, and that certain considerations should be incorporated into the development of an adaptive intervention in this population. Stakeholders agreed that goal setting and regular prompts with feedback to encourage PA would be necessary in order to achieve a regular exercise program using mHealth. It was clear that the nature of the interface is critical to adoption of mHealth interventions in this population, taking account of factors which can limit smartphone use. There was agreement across stakeholder groups, that the optimal time to deliver a mHealth intervention, is after discharge from formal inpatient care, and that it could be introduced to patients prior to discharge. It was clear

that both people with stroke and their carers struggle to cope with the decreased input from HCWs after discharge from hospital and that an mHealth intervention could provide both guidance on appropriate exercise and a link to the healthcare team. This was seen as beneficial by HCWs who saw an opportunity to track PA objectively as an adjunct to being reviewed in outpatient or community settings. Specific consideration of disability following stroke, was highlighted across themes, and mHealth interventions need to be tailored to the needs of people with stroke who may not always feel comfortable or safe with mainstream technology options such as fitness trackers or online training programs. In support of mHealth adoption, many people with stroke reported using teleconferencing for communicating with family and community support groups during the COVID 19 pandemic. There was widespread agreement that ease of use is key and support is needed from HCWs or carers in the setup and establishment of a PA routine using mHealth.

In response to the COVID 19 pandemic, healthcare globally adapted rapidly to increase telehealth while ensuring quality of care and safety for vulnerable patients.<sup>28</sup> Technologies have been rapidly adapted by healthcare organisations and patients, this was confirmed by the findings of this study and places mHealth for people with stroke at a key turning point, particularly in relation to community care. Key stakeholders, most importantly people with stroke in this study reported that they were using technology for both social connectivity and connecting with support groups. Previous studies have found a general lack of stroke support services for carers and people with stroke after discharge from hospital care, both in Ireland and globally.<sup>29,30</sup> The use of mHealth in the promotion of PA and secondary stroke reduction is an emerging field, the current study presented an encouraging outlook on this possibility from the perspective of key stakeholders.

This study specifically explored the perspectives of stakeholders on an adaptive intervention to increase PA, which to our knowledge has not been reported in this population. The capability of an adaptive study design to examine optimal treatment and facilitate decision making was explored. Stakeholders agreed that interventions should be tailored to the capacity of individual people with stroke, rather than a “one size fits all” approach, however it was reported by HCWs that stroke services are often limited on discharge from hospital care, and both people with stroke and carers confirmed that their PA advice and exercise interventions were not adapted or tailored over time following discharge. People with stroke reported that they were unsure of what exercise parameters they should be following, and in the absence of tailored programs, carers reported concern about guiding or facilitating an appropriate exercise program at home. Adaptive interventions / multi-stage randomised controlled trial designs are underway in other patient populations, examining treatment for musculoskeletal disorders,<sup>31,32</sup> this study design could optimise the adaptation of PA interventions in this population. Changes in the intensity or variety of exercise prescribed in response to fatigue or participation rate, could be an example to help progress physical training throughout an intervention. Exercise prescription and PA is just one component in secondary stroke prevention.<sup>11</sup> It is clear from the key stakeholders included in this study that adaptive interventions are lacking and needed in this population. In order to establish how PA behavioural change interventions can be best integrated into an adaptive program to increase lifestyle PA, further research examining the optimal sequencing of complimentary lifestyle interventions is needed.

There are a number of key considerations for the use of technology following stroke. Frequent input and caregiver guidance appear to be required to ensure that people with stroke engage with the use of mobile devices. A randomised study of 41 chronic stroke survivors previously reported that changes in lifestyle PA improved with mHealth use, but people with stroke required support from caregivers in use of the mHealth intervention,<sup>33</sup> this was echoed by the current study. Few studies to date have examined mHealth use to increase PA in this population,<sup>20</sup> highlighting the physical and cognitive challenges which people with stroke face and the complexity required to ensure usability in delivery. Additionally, carers reported that the lack of outpatient and community support for people with stroke following discharge was creating stress and burden. The lack of adaptable interventions over time following discharge highlights the opportunity for an adaptable mHealth intervention to respond to an individuals’ PA and functional ability following discharge. Carers described burgeoning burden with the need to attend and prepare for medical appointments. Burden has been associated with the duration of provided care, while carers in good health perceive significantly lower burden.<sup>34</sup> Providing a simple and easy to use PA intervention through mHealth has the potential to improve quality of life for both people with stroke and their carers.

## Strengths and Limitations

The primary strength of the current study is that, to our knowledge, it is the first to explore the perspectives of key stakeholders on the design and delivery of an adaptive PA intervention, using mHealth for people with stroke. Another strength, relating to the novelty of this research relates to the fact that these key stakeholder perspectives will be used in a future, first-in-class SMART trial, wherein we will use this novel trial design to develop an adaptive, personalised intervention post-stroke. The study benefits from the application of the COREQ standardised reporting guidelines throughout. In addition, as this work will inform the development of an intervention, it benefits from the use of the TIDier framework in the development of the interview schedule. One limitation is the participants' relative inexperience with the use of PA apps. There is potential for this to have hindered the discussion among participants, as they were providing input based upon limited experience. However, the aim of this piece of work was to examine perspectives on the design and delivery of an intervention that aims to promote PA, which is personalised to individual preference and performance and adapts to individuals' needs, which is delivered using mHealth. Therefore, participants were invited to offer views on a possible future app based upon their existing experience and views.

## Implications for Future Research

The complexity of prescribing PA interventions following stroke and the need for multi-modal approaches to increasing PA highlight the need for further research in the optimal use of mHealth in this population. PA is known to reduce secondary stroke risk and future studies should determine the appropriate timing of and sequencing of behavioural change and structured PA interventions; evaluating the use of mHealth in an adaptive intervention to increase PA and reduce SB following stroke.

## Conclusion

Key stakeholders agreed that the use of mHealth to deliver a PA program would be most beneficial following discharge from inpatient care, and that programs to increase PA and reduce SB should be adaptive to the individual needs of people with stroke, taking into account the specific impairments that can hinder PA participation following stroke. Future mHealth interventions to increase PA in this population need to address physical and cognitive limitations following stroke while being adaptive to individual needs and responses to treatment.

## Disclosure

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## References

1. Saunders DH, Sanderson M, Hayes S, et al. Physical fitness training for stroke patients. *Cochrane Database Syst Rev.* 2020;3(3). doi:10.1002/14651858.CD003316.pub7.
2. Tremblay MS, Aubert S, Barnes JD, et al. Sedentary Behavior Research Network (SBRN) – terminology Consensus Project process and outcome. *Int J Behav Nutr Phys Act.* 2017;14(1):75. doi:10.1186/s12966-017-0525-8
3. Fini NA, Holland AE, Keating J, Simek J, Bernhardt J. How Physically Active Are People Following Stroke? Systematic Review and Quantitative Synthesis. *Physical Therapy.* 2017;97(7):707–717. doi:10.1093/ptj/pzx038
4. Joundi R, Patten S, Williams J, Lukmanji A, Smith E. The Association between Physical Activity and Mortality among Community-dwelling Stroke Survivors (1683). *Neurology.* 2021;96(15 Supplement):1683. doi:10.1212/WNL.96.15\_supplement.1683
5. Turan TN, Nizam A, Lynn MJ, et al. Relationship between risk factor control and vascular events in the SAMMPRIS trial. *Neurology.* 2017;88(4):379–385. doi:10.1212/WNL.0000000000003534
6. WHO. *WHO Guidelines on Physical Activity and Sedentary Behaviour for Children and Adolescents, Adults and Older Adults.* World Health Organization. 2020.
7. English C, Manns PJ, Tucak C, Bernhardt J. Physical activity and sedentary behaviors in people with stroke living in the community: a systematic review. *Physical Therapy.* 2014;94(2):185–196. doi:10.2522/ptj.20130175
8. English C, Healy GN, Coates A, Lewis L, Olds T, Bernhardt J. Sitting and Activity Time in People With Stroke. *Physical Therapy.* 2016;96(2):193–201. doi:10.2522/ptj.20140522
9. Saunders DH, Mead GE, Fitzsimons C, et al. Interventions for reducing sedentary behaviour in people with stroke. *Cochrane Database Syst Rev.* 2021;6(6). doi:10.1002/14651858.CD012996.pub2.

10. Mohan KM, Wolfe CD, Rudd AG, Heuschmann PU, Kolominsky-Rabas PL, Grieve AP. Risk and cumulative risk of stroke recurrence: a systematic review and meta-analysis. *Stroke*. 2011;42(5):1489–1494. doi:10.1161/STROKEAHA.110.602615
11. Kleindorfer DO, Towfighi A, Chaturvedi S, et al. 2021 Guideline for the Prevention of Stroke in Patients With Stroke and Transient Ischemic Attack: a Guideline From the American Heart Association/American Stroke Association. *Stroke*. 2021;52(7):e364–e467. doi:10.1161/STR.0000000000000375
12. Billinger SA, Arena R, Bernhardt J, et al. Physical activity and exercise recommendations for stroke survivors: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2014;45(8):2532–2553. doi:10.1161/STR.0000000000000022
13. Jones F, Gombert-Waldron K, Honey S, et al. Using co-production to increase activity in acute stroke units: the CREATE mixed-methods study. *Health Services Delivery Res*. 2020;8:35.
14. Murphy SA. An experimental design for the development of adaptive treatment strategies. *Stat Med*. 2005;24(10):1455–1481. doi:10.1002/sim.2022
15. Almirall D, Nahum-Shani I, Sherwood NE, Murphy SA. Introduction to SMART designs for the development of adaptive interventions: with application to weight loss research. *Translational Behav Med*. 2014;4(3):260–274. doi:10.1007/s13142-014-0265-0
16. Feigin VL, Abajobir AA, Abate KH, et al. Global, regional, and national burden of neurological disorders during 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet Neurol*. 2017;16(11):877–897. doi:10.1016/S1474-4422(17)30299-5
17. Bull FC, Al-Ansari SS, Biddle S, et al. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. *Br J Sports Med*. 2020;54(24):1451. doi:10.1136/bjsports-2020-102955
18. Pandian JD, Gall SL, Kate MP, et al. Prevention of stroke: a global perspective. *Lancet*. 2018;392(10154):1269–1278. doi:10.1016/S0140-6736(18)31269-8
19. Agarwal S, LeFevre AE, Lee J, et al. Guidelines for reporting of health interventions using mobile phones: mobile health (mHealth) evidence reporting and assessment (mERA) checklist. *BMJ*. 2016;352:i1174. doi:10.1136/bmj.i1174
20. Lynch EA, Jones TM, Simpson DB, et al. Activity monitors for increasing physical activity in adult stroke survivors. *Cochrane Database Syst Rev*. 2018; 7. doi:10.1002/14651858.CD012543.pub2
21. Hamilton AB, Finley EP. Qualitative methods in implementation research: an introduction. *Psychiatry Res*. 2019;280(112516):112516. doi:10.1016/j.psychres.2019.112516
22. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589–597. doi:10.1080/2159676X.2019.1628806
23. Braun V, Clarke VCIUTA?. Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling Psychother Res*. 2021;21(1):37–47. doi:10.1002/capr.12360
24. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042
25. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. doi:10.1191/1478088706qp063oa
26. Bazeley P. *Qualitative Data Analysis Practical Strategies*. Los Angeles, CA: SAGE Publications; 2013.
27. Casey D, Murphy K. Issues in using methodological triangulation in research. *Nurse Researcher*. 2009;16(1351–5578):40–55. doi:10.7748/nr2009.07.16.4.40.c7160
28. Fisk M, Livingstone A, Pit SW. Telehealth in the Context of COVID-19: changing Perspectives in Australia, the United Kingdom, and the United States. *J Med Internet Res*. 2020;22(6):e19264. doi:10.2196/19264
29. Mj MP, Harbison J. *National Stroke Audit Rehabilitation Units 2016*. Irish Heart Foundation / HSE. 2016.
30. Pindus DM, Mullis R, Lim L, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. *PLoS One*. 2018;13(2):656.
31. Skolasky RL, Wegener ST, Aaron RV, et al. The OPTIMIZE study: protocol of a pragmatic sequential multiple assessment randomized trial of nonpharmacologic treatment for chronic, nonspecific low back pain. *BMC Musculoskelet Disord*. 2020;21(1):293. doi:10.1186/s12891-020-03324-z
32. Fritz JM, Sharpe JA, Lane E, Santillo D, Greene T, Kawchuk G. Optimizing treatment protocols for spinal manipulative therapy: study protocol for a randomized trial. *Trials*. 2018;19(1):306. doi:10.1186/s13063-018-2692-6
33. Grau-Pellicer M, Lalanza JF, Jovell-Fernández E, Capdevila L. Impact of mHealth technology on adherence to healthy PA after stroke: a randomized study. *Topic Stroke Rehabil*. 2020;27(5):354–368. doi:10.1080/10749357.2019.1691816
34. Kavga A, Kalemikerakis I, Faros A, et al. The Effects of Patients' and Caregivers' Characteristics on the Burden of Families Caring for Stroke Survivors. *Int J Environ Res Public Health*. 2021;18(14):7298. doi:10.3390/ijerph18147298