Web-based physiotherapy for people undergoing stroke rehabilitation

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Abstract

In the UK, disability is a common consequence of stroke. The improvement of post-stroke arm function is one of the top 10 priority research areas for stroke survivors, carers and healthcare professionals. However, current clinical practice in most of the stroke units within the UK does not meet the recommended dose for rehabilitating stroke patients in the acute stage when functional recovery is at its peak. A higher dose of rehabilitation can result in enhanced functional recovery. Therefore, developing interventions to augment current clinical practice in order to increase the dose of rehabilitation without supervision is becoming a necessity, given the anticipated rise in stroke incidence coupled with the reduction in the number of available physiotherapists worldwide. Telerehabilitation has the potential to provide the stroke population with access to rehabilitation without direct supervision, but stroke-related complications, such as aphasia, may hinder their ability to access these services. This thesis aims to do the following: 1) To evaluate whether an existing web-based physiotherapy platform (www.webbasedphysio.com, now www.giraffehealth.com) can be adapted through a user-centred design to be an acceptable medium to deliver exercise programmes for people after a stroke and 2) To evaluate the acceptability and feasibility, and to explore the possible effectiveness, of an individualised 4-week programme of augmented upper-limb rehabilitation, delivered via the modified web-based physiotherapy platform, for the stroke population in acute stroke rehabilitation.

The first study adopted a user-centred design, which involved modifying an existing web-based physiotherapy platform by gathering views of seven participants, five stroke survivors and two carers, with the aim of customising the platform to be accessible and appropriate for the stroke population. Three consecutive focus groups were conducted for the same participants and data were analysed based on themes. Four themes were identified, which allowed an understanding of participants' needs and preferences in using technology as a medium to deliver rehabilitation and highlighted the required platform modifications using iterative consultation. The data captured different experiences toward disability after stroke from public, clinical staff and stroke survivors. The rehabilitation that stroke survivors received prioritised leg mobility exercises, and family members and carers lacked the needed support. The variation of the kind of rehabilitation provided and the influence of geographical areas were reported as the main barriers to access rehabilitation therefore, stroke survivors reported paying for private physiotherapy and practicing non-prescribed exercises including online resources. The key recommendations included modifications to the web-based physiotherapy platform to improve accessibility (format, information, advice)

and modelling/image (stroke survivor actors filming exercise video recordings) in order to meet their rehabilitation needs. The study concluded with accessible and positively evaluated platform.

The second study was a randomised controlled pilot study to evaluate the feasibility (in terms of recruitment strategy, usage and adherence to the intervention and participants' attrition and safety), acceptability and potential efficacy of delivering a 4-week individualised web-based upper-limb exercise programme using the modified web-based platform compared to usual care in terms of arm function, trunk function and muscle spasticity for stroke survivors in the acute hospital setting. In addition, questionnaires were used to evaluate the feedback of physiotherapists who prescribed and monitored the web-based augmented intervention and to capture views of carers of stroke survivors in the intervention group. Twenty-six stroke survivors were recruited to the study from three acute stroke units and were randomly allocated and equally divided (n=13) into two groups: an intervention group and a control group. Seven participants used the platform and accessed their exercise programmes. Of those, five were adherent to the intervention during the study; these five adherent participants represented half of the patients in the intervention group. Five participants withdrew from the study before the final assessments, of whom three were participants in the intervention group and two were participants in the control group. Although five adverse events were reported during the study, none of these was considered to be related to the intervention. More participants in the intervention group demonstrated clinically important improvements in the Action Research Arm Test (arm function) than in the control group. In addition, among the participants in the intervention group, those who were adherent showed trends towards improvements in the Trunk Impairment Scale (trunk function). In total, seven stroke survivors, five carers and five physiotherapists reported that the delivery of a non-supervised, augmented intervention through the modified web-based physiotherapy platform was acceptable. Among the participants who used the platform, web-based physiotherapy was considered more beneficial to stroke survivors who have carers helping them to access their online exercise programmes.

To summarise, this thesis indicates that web-based physiotherapy is feasible, safe and acceptable for stroke survivors, carers and physiotherapists; furthermore, it is capable of providing unsupervised augmented interventions. More studies that are adequately powered are needed to examine effectiveness of this intervention and provide further insight to the current findings.

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List of Tables

List of Figures

List of text boxes

List of appendices

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Author's Declaration

I hereby declare that explicit reference is made to the contribution of other, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institutions.

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Publication arising from this work

Poster presentations

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List of Abbreviations

UK	The United Kingdom
RCT	Randomised Control Trial
MRC	Medical Research Council
WHO	World Health Organisation
TIA	Transient Ischaemic Attacks
NHS	National health services
ROM	Range of Motion
SLT	Speech language therapy
AVERT	A Very Early Rehabilitation trial
PEDro	Physiotherapy Evidence Database
CHSS	Chest Heart and Stroke Scotland
GDPR	General Data Protection Regulation
OSOP	One Sheet of Paper
GP	General Practitioner
ARAT	Action Research Arm Test
MMSE	Mini Mental State Examination
NIHSS	National Institutes of Health Stroke Scale
TIDieR	Intervention Description and Replication
TIS	Trunk Impairment Scale
MAS	Modified Ashworth scale
ICF	International Classification of Functioning, Disability and Health
MCID	Minimal Clinically Important Difference
AEs	Adverse events
SAEs	Serious adverse events
NIHR	National Institute for Health research
SPSS	Statistical Package for the Social Sciences
SD	Standard deviations
EVERLAP	Early VERsus Later Augmented Arm Physiotherapy
COVID-19	Coronavirus

Chapter 1 : Introduction

This chapter will include an introduction to the PhD topic, the aims of this thesis, an overview of the studies contained within this PhD and the structure of the thesis.

1.1 Background

Stroke is common, affecting 95,000 people per year in the United Kingdom (UK) (Intercollegiate Stroke Working Party, 2016, Scottish Stroke Care Audit, 2019), and it has been found to be a leading cause of disability (Feigin et al., 2014). In the UK, stroke patients, carers and healthcare professionals have listed improving impaired arm functions after to stroke as one of the top ten priorities for research (Pollock et al., 2014a). About 80% of stroke survivors have impaired upper-limb functions early after onset of stroke (Jorgensen et al., 1999). Some studies suggest that increasing the dose of stroke rehabilitation would result in better functional recovery (Pollock et al., 2014b, Lohse et al., 2014, Veerbeek et al., 2014, Kwakkel et al., 2004, Schneider et al., 2016, Langhorne et al., 1996). The first month after stroke was found to be the peak of neuroplasticity (Krakauer et al., 2012) and therefore rehabilitation during this time is important for optimising functional recovery.

However, much of the current practice of stroke rehabilitation in stroke units within the UK does not meet the recommended dose of rehabilitation (Sentinel Stroke National Audit Programme, 2019, Clarke et al., 2018, National Services Scotland Information and Intelligence, 2019). Furthermore stroke incidence is increasing, and the number of physiotherapists is limited (Stewart et al., 2017), therefore delivering adequate stroke rehabilitation can be challenging. Unsupervised augmented interventions increase the time patients are involved in active rehabilitation however research studies are required to investigate their acceptability and effectiveness (Stewart et al., 2017). Using technology supported intervention is one option for stroke survivors. This offers stroke survivors the opportunity to be involved in more active rehabilitation outwith standard therapy times. However, stroke survivors may have difficulties accessing these services and interventions due to particular stroke associated complications such as aphasia (Intercollegiate Stroke Working Party, 2016). This PhD project therefore seeks to achieve two main aims as stated below.

1.2 Aims of PhD project

This PhD has two main aims:

1. To evaluate whether an existing web-based physiotherapy platform (www.webbasedphysio.com, now www.giraffehealth.com) can be adapted through a user-centred design to be an acceptable medium to deliver exercise programmes for people after a stroke.

2. To evaluate the acceptability and feasibility, and to explore the possible effectiveness, of an individualised 4-week programme of augmented upper-limb rehabilitation, delivered via the modified web-based physiotherapy platform, for the stroke population in acute stroke rehabilitation.

1.3 Overview of the PhD studies

At the beginning of this thesis, the literature review includes five main sections covering the key subjects underpinning the thesis, which represent the foundation for this project. Identified gaps in the literature have been flagged up in order to justify the need for telerehabilitation interventions to engage hospitalised stroke survivors in augmented upper-limb exercise programmes. Furthermore, the gaps highlight the importance of customising the web-based physiotherapy platform to the needs of the stroke population in order to overcome rehabilitation barriers and challenges related to developing telerehabilitation tools for exercise delivery. These sections are explained in detail in Chapter two and have informed the thesis aims.

The aims of this PhD thesis were achieved through the following two stages (Figure 1.1):

- Phase 1: User-centred study to make the web-based physiotherapy website an acceptable medium for exercise delivery for the stroke population and to inform Phase 2. Within this stage, three consecutive focus groups were used to elicit the needs and preferences of participants regarding the web-based physiotherapy website, and to modify it using iterative consultation.

- Phase 2: Pilot Randomised Control Trial (RCT) study to evaluate the feasibility and explore potential efficacy of delivering a 4-week personalised upper-limb exercise programme through the modified web-based physiotherapy website for stroke survivors in the acute, hospital setting. This pilot RCT study embedded feedback questionnaires

to explore the views of stroke survivors, carers and physiotherapists on the study intervention.

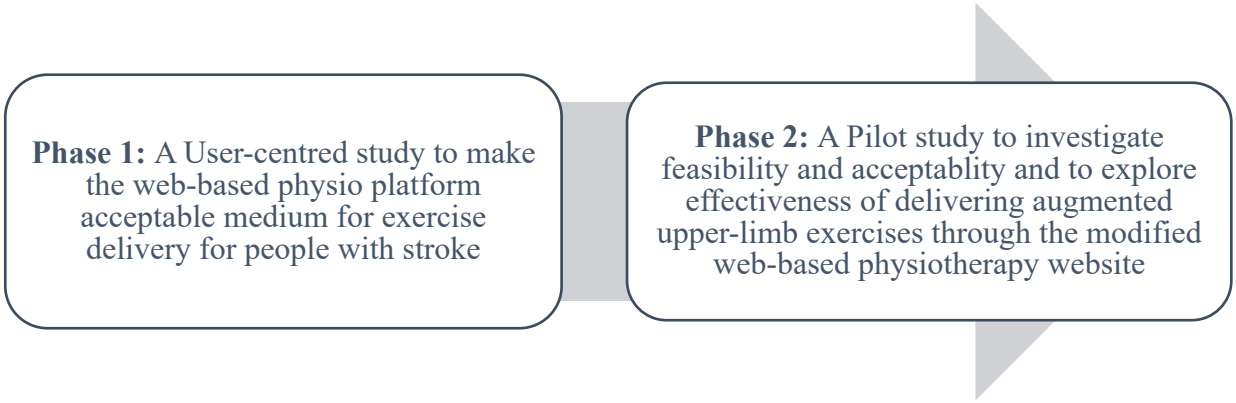


Figure 1.1 Phases of the PhD

This thesis followed the first two stages of the Medical Research Council (MRC) framework, used for the development and evaluation of health interventions (Craig et al., 2013). The four stages are as follows:

1. Development of the intervention
2. Piloting and feasibility
3. Evaluation
4. Implementation

Together, the literature review chapter (Chapter 2) and the user-centre study chapter (Chapter 3) informed stage 1 of the MRC framework, development of the intervention stage. The literature review chapter indicates the chosen type of exercise intervention used in this project, task-specific training, and the user-centre study chapter (Chapter 3) details the customisation and refinement of refining a telerehabilitation tool for exercise delivery, a web-based physio platform (www.webbasedphysio.com, now www.giraffehealth.com) to meet the needs of the stroke population. Chapters 4–6 informed stage 2 of the MRC framework, the piloting and feasibility stage.

1.4 Structure of the thesis

This thesis consists of 7 chapters, outlined as follows:

Chapter 1: An introduction to the topic, the aims of this thesis, the phases of the thesis and an outline of the structure of this thesis.

Chapter 2: A literature review includes five main sections covering the key subjects underpinning the topic of this thesis, namely:

- Stroke disease.
- Stroke management.
- Augmented upper-limb physiotherapy.
- Effect of augmented task-related exercises on the outcomes of upper-limb impairment and upper-limb function within the first 3 months after stroke: Systematic review.
- Telerehabilitation in stroke.

Chapter 3: Presents a user-centred study undertaken in order to modify and customise an existing web-based physiotherapy platform to be acceptable and accessible for people with stroke.

Chapter 4: The aim, objectives and methods of a pilot RCT study, carried out to evaluate the acceptability, feasibility and the likely effect of augmented upper-limb intervention delivered by a web-based physiotherapy platform for people with acute stroke.

Chapter 5: Presents the findings of the pilot RCT.

Chapter 6: Discussion around the results of the pilot RCT in the context of previously published literature.

Chapter 7: Completes the thesis with an overall discussion, recommendations for clinicians and for future studies, the contribution of studies to knowledge, rehabilitation during the coronavirus pandemic and conclusion.

Chapter 2 : Literature review

This chapter reviews the literature about stroke disease. Broadly, the chapter is written in five sections, namely: stroke disease, stroke management, augmented upper-limb rehabilitation, detailed literature review and telerehabilitation in stroke. The sub-sections covered under each main section are detailed by way of an introduction to the section. In addition, the identified gaps in the literature, proposed work within this thesis to address the identified gaps are provided.

2.1 Stroke disease

This section provides brief background information about stroke disease; explores the definition of stroke, its classifications, signs for early recognition, incidence in the UK, as well as its clinical features and symptoms. The significance in relation to the topic of the thesis is also highlighted in the section summary.

2.1.1 Definition and classification

The World Health Organisation (WHO) defines stroke as: "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin" (Aho et al., 1980, p. 114). Transient Ischaemic Attacks (TIA) could be described as 'warning stroke' or 'mini-stroke' and the TIA can be defined as a temporary loss of blood flow to the brain (The American Stroke Association, 2019). At the first onset TIA demonstrates similar symptoms as a full stroke; however, its symptoms last less than 24 hours. Even though the symptoms of TIA are not permanent, they are a warning sign of stroke, as about 50% of all strokes occur in the first 24 hours following a TIA (Chandratheva et al., 2009).

The mechanism of a stroke can be classified into an ischemic or haemorrhagic stroke (Caplan, 2016). From 2000 to 2008 about 81% of all strokes in high income countries were classified as ischemic, which are caused by a blocked cerebral artery, 14% of all strokes were classified as haemorrhagic strokes, which are caused by a ruptured cerebral artery and about 5% of all strokes classified were undefined (Feigin et al., 2009). Ischaemic strokes can be caused by a blood clot that blocks the cerebral artery and is formed by either an atherosclerotic plaque that develops within the artery (thrombotic stroke) or by a blood clot that develops at a point distant from the artery which then navigates to block the blood flow (embolic stroke). Ischaemic

strokes may also be caused by reduced perfusion/blood flow to the brain due to the low perfusion pressure (Caplan, 2016).

Haemorrhagic strokes may occur either on the brain surface, specifically in the area between the arachnoid membranes and the dura matter (subdural/epidural haemorrhages). These are commonly caused by traumatic brain injuries resulting in torn and/or injured veins, or within the brain, specifically within the brain substance (intracerebral haemorrhages), that are usually caused by high blood pressure resulting in damaged arterioles (Caplan, 2016). Haemorrhagic strokes are also considered to be more dangerous than ischemic strokes as they result in a higher rate of early mortality after stroke (within one month), 25-35% mortality for each type of haemorrhagic stroke (subarachnoid and intracerebral haemorrhagic stroke) compared to 10-23% mortality in ischaemic stroke (Feigin et al., 2009).

2.1.2 Early recognition

There are warning signs that can help to identify the presence of a stroke; these are facial weakness, arm weakness, and abnormal speech (Goldstein and Simel, 2005). According to information provided by the UK Stroke Association, the public can recognise the stroke using the acronym "FAST", where the letter "F" stands for 'face' (looking for a facial droop), "A" stands for an 'arm' (check if the arm is drifting), "S" stands for 'speech' (check for slurred or strange speech) and "T" stands for time (time to call emergency) (Stroke Association, 2020).

2.1.3 Incidence

In the UK, there are more than 1.2 million stroke survivors (Stroke.org.uk, 2018) and this number is increasing in England and Wales by 80,000 stroke survivors each year (Intercollegiate Stroke Working Party, 2016) and in Scotland, about 15,000 stroke incidences are estimated annually (Scottish Stroke Care Audit, 2019). Stroke is the fourth most common cause of death in England and Wales (Intercollegiate Stroke Working Party, 2016), is the third most common cause of death in Scotland (National Services Scotland Information and Intelligence, 2019), and is the second cause of death worldwide (World Health Organisation, 2016).

Stroke is also a main cause of disability worldwide (Feigin et al., 2014) and the main cause of disability in Scotland (National Services Scotland Information and Intelligence, 2019). Stroke care consumes a significant proportion of the National Health Service (NHS) budget, roughly

5% (National Services Scotland Information and Intelligence, 2019). Each stroke survivors cost the NHS and social care on average £22,000 in one year and about £45,000 in five years Sentinel Stroke National Audit Programme, 2016). Between 1990 and 2010, stroke death and incidence rates were decreasing worldwide, in part because of increasing awareness of stroke prevention, management and rehabilitation; however, more recently the stroke burden (incidence, death and disability) is projected to double due to anticipated increase in population size and aging in the coming decades (Feigin et al., 2014).

2.1.4 Risk factors of stroke

2.1.4.1 Non-modifiable risk factors

There are many non-modifiable risk factors for stroke including: age, gender, ethnicity and genetics (Boehme et al., 2017). Generally, people over the age of 55 are more likely to have a stroke, doubling every decade thereafter (Roger et al., 2012). The incidence of stroke is generally higher in women compared to men, which is attributed to their longer lifespan as the risk of having a stroke increases with age (Reeves et al., 2009, Roger et al., 2012) however men are at a higher risk of stroke than women with increasing age (Kapral et al., 2005). People with South Asian and African ethnicity are more likely to have a stroke 10 years earlier than those with a white ethnicity (Banerjee et al., 2012). Even though these are factors that are not subject to change, it is important to identify people who are at risk of having a stroke so they can benefit from prevention programmes.

2.1.4.2 Modifiable risk factors

Individuals' lifestyle plays an important role in increasing or decreasing the risk of stroke by manipulating the controllable factors. These factors are hypertension, dyslipidaemia, diabetes mellitus, atrial cardiopathy, atrial fibrillation, obesity, sedentary behaviour and lifestyle, alcohol intake and smoking (Boehme et al., 2017).

2.1.5 Clinical features and symptoms of stroke

2.1.5.1 Arm function

Some people with stroke experience long-term motor deficiency, impaired functional activities and decreased participation in activities of daily living (Langhorne et al., 2009). A stroke may affect the arm function in the form of a loss of active movement, decreased sensation, dexterity,

and coordination which may prevent stroke survivors from undertaking normal everyday activities, such as eating, dressing, drinking and washing (Geyh et al., 2004).

About 50% of stroke survivors still have limited arm function six months post-stroke (Kwah et al., 2013). Improving arm function after stroke was therefore identified by health professionals, stroke survivors and carers as one of the top 10 research priorities in the UK (Pollock et al., 2014a). The effect of treatment approaches for the upper-limb after stroke will be discussed in section 2.3.1.

This is especially so given that stroke survivors do not get enough rehabilitation for their upper-limbs (section 2.2.2) especial at a crucial stage of their rehabilitation journeys, which is within the first 2 months onset of stroke where their neuroplasticity is at its peak (section 2.3.2). These were major considerations in the choice of, 'improving arm function after stroke' as a topic for this thesis.

2.1.5.2 Trunk function

The level of trunk function plays a crucial role in the process of arm rehabilitation as there is a positive relationship between the trunk and upper-limb functions. Wee et al. (2015), for example, has suggested that the stabilisation of the lower-limbs and the lumber spine facilitates arm function. Approximately 83% of stroke survivors demonstrate impaired balance after stroke; of those, 27% might be able to sit but couldn't stand, 40% might be able to stand but couldn't take a single step and 33% might be able to walk but they still demonstrate impaired balance (Tyson et al., 2006). Impaired balance can be caused by weakness of the trunk muscles (Dickstein et al., 2004) and abnormal sensory integration (Oliveira et al., 2011). Loss of proprioception and weakness of trunk muscles on one side of the body reduces patients postural control ability (Geiger et al., 2001), functional abilities (Karatas et al., 2004) and increases the risk of falling towards the affected side (Eng et al., 2008).

Impaired trunk function i.e. limited trunk function including poor dynamic and static sitting balance, is common among stroke survivors (Karatas et al., 2004). Trunk control forms an essential component of balance (Jijimol et al., 2013) and is associated with gait and functional abilities (Verheyden et al., 2006). Furthermore, impaired trunk function can be used as a predictor of walking ability and balance (Duarte et al., 2009), and moreover, predicts the ability to undertake activity of daily living (Di Monaco et al., 2010, Franchignoni et al., 1997, Hsieh et al., 2002, Verheyden et al., 2007). Trunk training approaches aimed at improving functional

sitting balance and trunk performance have been found to be effective in improving trunk performance and dynamic sitting balance in a systematic review of 11 trials (317 participants) (Cabanas-Valdes et al., 2013). This systematic review provided moderate quality evidence as the mean PEDro score of the included studies was 6.3 out of 10 (range 3 to 8).

2.1.5.3 Spasticity

Spasticity is a recognised complication after stroke which may affect levels of functional activities of stroke survivors, including arm and trunk functions. Spasticity is defined as "disordered sensory-motor control, resulting from an upper motor neuron lesion" (Burridge et al., 2005, p. 72). It can lead to limited motor performance by changing the mechanical and physiological feature of muscles (i.e. increased muscle tone) as well as by exaggerated reflexes (Cacho et al., 2017). As such, spasticity can limit stroke survivors' ability to practice their previous level of ADLs due to overactive muscles around the joints such as shoulder and elbow joints (Zorowitz et al., 2013).

Spasticity as a result of stroke in the developed countries fluctuates based on the time of the assessment, with a range of projected prevalence from 4% to 42% (Wissel et al., 2013). Spasticity can be a main cause of pain and disability for stroke survivors due to increased muscle tone and exaggerated tendon jerk reflexes. Furthermore, if spasticity is not treated, it may cause contractures (Bhalla and Birns, 2015). In addition to the previously mentioned consequences of spasticity, spasticity may also affect ADLs (Bhalla and Birns, 2015), cause issues with sleep which may lead to depression and fatigue. Spasticity may also affect sexual activities and result in issues with positioning (Bhalla and Birns, 2015).

One of the aims of stroke management is decreasing the negative impact of spasticity and in addition preventing secondary complications. Spasticity can be treated using pharmacological and non-pharmacological interventions; however, the evidence to support this is not robust and more high-quality trials are needed (Bhalla and Birns, 2015). Therefore, clinical guidelines are generally based on recommendations made by experts. Non-pharmacological interventions include stretching, splinting, postural management, standing and exercises. Pharmacological interventions are recommended at the lowest effective dosage and these interventions include oral drugs (i.e. baclofen, tizanidine, dantrolene and gabapentin), cannabinoids, botulinum toxin, intrathecal baclofen and chemical neurolysis. Interventions targeting spasticity are used to treat and/or prevent increased muscle tone and to increase the Range of Motion (ROM),

which in turn contributes towards improving function and relieving pain (Nair and Marsden, 2014).

Shaw et al. (2010) conducted an RCT to investigate the clinical effectiveness of treating spasticity of the upper-limb for stroke survivors one month after their stroke by adding botulinum toxin type A to an upper-limb exercise programme. The primary outcome measure was ARAT at 1 month and the secondary outcome measures involved measuring upper-limb impairment/function, activity limitation, stroke-related quality of life, participation restriction and pain at 1, 3 and 12 months. They did not find botulinum toxin type A effective in facilitating the improvement of upper-limb functions, but it provided some stroke survivors with the opportunity to perform some basic upper-limb functional activities such as putting the arm in a sleeve while dressing and opening the hand to cut fingernails at 1, 3 and 12 months. It also lead to improved upper-limb strength at 3 months, decreased muscle tone at 1 month and decreased pain at 12 months. A more recent RCT conducted by Lindsay et al. (2021) investigated the efficacy of botulinum toxin compared to a placebo injection for hospitalised stroke survivors with no arm function. Spasticity, contractures, the use of splints and upper-limb function were assessed. Although the botulinum toxin injections were not found to be effective in improving upper-limb function, they were effective in reducing spasticity and contractures for up to 3 months. The findings from the studies by Lindsay et al. (2021) and Shaw et al. (2010) imply some type of relationship between spasticity and upper-limb function. The management of spasticity should be individualised and planned by a multidisciplinary team, considering the intervention options available to individuals who have had a stroke, and based on their goals and needs. Spasticity is subject to change over time; therefore, it is crucial to amend individuals' treatment plans through regular assessments in order to successfully manage his/her spasticity (Bhalla and Birns, 2015).

2.1.5.4 Aphasia

Aphasia is a loss of the ability to process of produce and compresence language as a result of a brain injury (National Aphasia Association, 2018). This brain damage can be caused by head trauma, brain tumours or infection, but the most common cause is stroke (National Aphasia Association, 2018). The prevalence of aphasia among stroke survivors in UK is approximately 50% (Intercollegiate Stroke Working Party, 2016). For the diagnosis of aphasia, at least one of five communication modalities is affected: verbal expression, auditory comprehension, writing, reading, and gestures. Aphasia may result in different levels of language impairment

depending on the degree of involvement by the above identified communication modalities, which also influences the severity of the aphasia (Code and Herrmann, 2003, Parr et al., 1997). There are different types of aphasia, and each type can be recognised by identifying whether the person with aphasia is able to speak fluently, understand spoken words and repeat phrases or words (National Aphasia Association, 2018) (Figure 2.1).

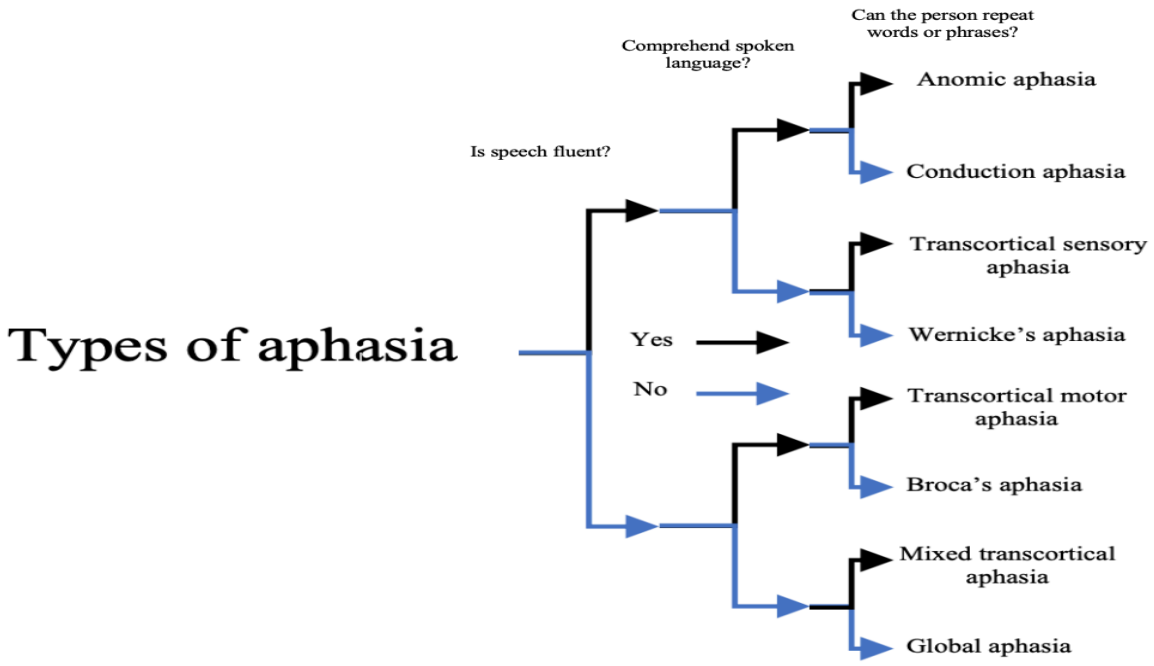


Figure 2.1 The different types of aphasia (National Aphasia Association, 2018)

Aphasia after stroke does not only affect the person's language, but it may also significantly affect his/her social life, mood, employment, and self-image as well as his/her family/carers (Intercollegiate Stroke Working Party, 2016). Intervention approaches for aphasia include constraint-induced aphasia therapy, cognitive-linguistic therapy, communication therapy, drug therapy, Speech and Language Therapy (SLT), and computerised SLT. However, the literature supporting these interventions is still limited (Intercollegiate Stroke Working Party, 2016). A Cochrane review showed that some studies (27 studies and 1620 participants) found SLT interventions beneficial compared to no therapy but the length of time these benefits could last was unknown. In addition, a limited number of studies (9 studies and 447 participants) demonstrated a small effect of SLT interventions compared with social support. Finally, studies investigated SLT interventions in different doses, durations, intensities, administration and approaches (38 studies and 1242 participants) concluded that high-intensity SLT interventions

carried out for up to 15 hours per week were beneficial in terms of minimising the severity of aphasia. However, attending high-intensity SLT interventions is challenging for people with aphasia (Brady et al., 2016).

People with aphasia and difficulties in producing and comprehending language may also have impaired arm function after stroke this may need to be taken into account when designing interventions to improve upper-limb function.

2.1.5.5 Other clinical features and symptoms of stroke:

Stroke may also affect survivors in the following: cognitive ability, the ability to control the bowel and bladder (continence), fatigue, mental ability, mobility, psychological problems (i.e. anxiety and depression), pain, loss of sensation, lack of interest in sex, swallowing problems (dysphagia), and limited vision (Intercollegiate Stroke Working Party, 2016). These impairments may prevent stroke survivors from engaging in functional activities and social events (Geyh et al., 2004).

2.1.6 Section summary

Stroke has been identified as the main cause of disability in Scotland and globally and the incidence of stroke the UK is increasing. The risk of getting stroke is related to non-modifiable reasons such as age, gender and ethnic background and by modifiable reasons which can be determined by an individual's lifestyle, such as high cholesterol, smoking and physical inactivity. Stroke may negatively affect stroke survivors in a number of ways, including balance, arm function, communication ability and muscle tone. Addressing the consequences of stroke is important to optimise patients' social participation and their performance of functional activities and in addition prevent stroke complications such as muscle contracture.

2.2 Stroke management

The stroke management section provides an explanation about the care that patients with stroke currently receive in the UK. In particular, the management processes at stroke units and stroke rehabilitation centres are explored. The significance of stroke management will be highlighted in the section summary.

2.2.1 Stroke unit

Different care methods and modalities are provided for people with stroke once they are admitted to hospital and there is a push to ensure global consistency of care. In the UK, the care that stroke survivors receive in the acute stage is provided by a multidisciplinary team within one unit, referred to as the "stroke unit" (Trialists'Collaboration, 2013). Stroke units now form a crucial part of stroke services in high-income countries (based on World Bank definitions) while their application is unclear in low-income countries. The studies undertaken in low-income countries were conducted in large cities; therefore, the situation in rural areas might not be the same. These studies found stroke units beneficial, particularly in terms of the number of survivals after a stroke, but they were ambiguous in terms of overcoming disabilities and discharge from hospitals following stroke (Langhorne et al., 2012).

The stroke unit should provide an encouraging environment for stroke survivors and the care provided should mainly come from consultant physicians, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, rehabilitation assistants and social workers, all of whom should be expert in the management of stroke in terms of the skills and knowledge related to interacting with stroke survivors and their carers (Trialists'Collaboration, 2013). In addition, stroke units should involve carers in the rehabilitation of stroke survivors and provide patients, carers and staff with education and training programmes (Trialists'Collaboration, 2013). Stroke unit may also provide access for stroke survivors to other services, if required, like orthotics and wheelchair services (National Institute for Health and Clinical Excellence, 2012).

It has been established that stroke units have demonstrated promising results for patients with stroke by increasing their chance of surviving and overcoming their disabilities (Langhorne and Dennis, 2004, Trialists'Collaboration, 1997). Further, stroke units have also shown a reduction in odds of death and/or dependency compared to general medical wards one year after stroke ($p=0.0007$) in a systematic review conducted by Trialists'Collaboration (2013).

2.2.2 Rehabilitation of stroke survivors

Once stroke survivors are admitted to hospital, they should be screened for their orientation, swallowing, transfers, positioning, moving, handling, continence, pressure area risk, nutritional status and communication to ensure their safety and comfort (National Institute for Health and Clinical Excellence, 2012). Besides, stroke survivors should be medically assessed of their

cognition, hearing, strength, vision, tone, balance and sensations, taking into consideration their previous level of functional abilities and other potential impairments (such as pain and depression), activity level and participation level. The impact of stroke on stroke survivors' family members and/or carers should also be considered (National Institute for Health and Clinical Excellence, 2013). A study was conducted by Mackenzie et al. (2007) to investigate the needs of 42 stroke carers in the UK through a survey. The survey included questions about their needs, satisfaction and knowledge at two time points: before discharge and 4–6 weeks after discharge. The participants highlighted that they needed support before and after discharge, to overcome emotional, psychological and behavioural changes. They also needed local support services and reported that the burden of caring for a stroke survivor rose after discharge, and they felt lonely. A more recent survey conducted by The Stroke Association (2018) explored the needs of stroke survivors and carers and also explored the challenges they faced after stroke. More than 11,000 stroke survivors and carers across the UK completed the survey, either online or paper based. The survey included questions related to how their lives changed after a stroke, the time since their stroke, the challenges they faced with coping with the stroke and the kind of support provided, as well as any areas where they would have liked to have been better supported. The responses were provided by both genders (55% by men), and the majority of the participants were white (94%) and over the age of 65 years (73%). The findings indicated that the stroke affected their lives in more than one aspect, including the physical, cognitive and emotional aspects, and that this could negatively affect their relationships. These aspects could also discourage stroke survivors from working and, in addition, cause their social lives to be hampered. The stroke survivors needed emotional support as well as encouragement and support to seek help in order to overcome their barriers, as only about 33% of the participants accessed relationship support services. The participants also needed financial support and/or advice as the stroke affected their work and finances, but only 10% of the participants sought financial support. Over one quarter (26%) were not aware of these services or reported that these services were not available. Twenty-five per cent of the participants graded the financial support provided as poor (The Stroke Association, 2018).

Further, before and during the process of the rehabilitation, stroke survivors should have regular meetings with the healthcare professionals to set meaningful and achievable goals that include both short-term and long-term elements, and these goals should be updated regularly based on their progress. A tailored plan of rehabilitation should then be set for each stroke

survivor based on his/her needs and targeted goals and these plans should be regularly checked by the multidisciplinary team (National Institute for Health and Clinical Excellence, 2013).

Exercise, for example, plays an important role in rehabilitation programmes for people with stroke to minimise their residual level of disability (Brogardh and Lexell, 2012). Exercise is defined by Caspersen et al. (1985, p. 128) as "a subcategory of physical activity that is planned, structured, repetitive, and purposeful in the sense that the improvement or maintenance of one or more components of physical fitness is the objective". According to NICE guidelines, the rehabilitation (physiotherapy, occupational therapy and SLT) of stroke survivors who are able to follow the recommended dose starts with a minimum of 45 minutes session over 5 days per week and the intensity can be increased based on the ability of the stroke survivors and his/her functional recovery (National Institute for Health and Clinical Excellence, 2012). However, the amount of rehabilitation is frequently reported as lower than the amount of the recommended therapy (which is 45 minutes of each physiotherapy and occupational therapy) in most of the stroke units within the UK, particularly in England and Wales, accounting for a median of 35 minutes for physiotherapy and 40 minutes for occupational therapy (Sentinel Stroke National Audit Programme, 2019). To increase the amount of rehabilitation through physiotherapy and occupational therapy, a few stroke units now offer seven-day services (Sentinel Stroke National Audit Programme, 2019). In Scotland, the amount and duration of delivered rehabilitation were not clearly mentioned in the National Services Scotland Information and Intelligence (2019) report and also, they did not indicate whether or not the provided rehabilitation meets the recommended. However, there is a recent trend to increase rehabilitation levels in the homes of stroke survivors. Although stroke survivors receive their sessions on a daily basis in the UK, throughout the working week, during their hospitalisation period, rehabilitation staff face difficulties with providing the recommended rehabilitation interventions for stroke survivors due to: time spent in information exchange among therapists (daily handovers about patients) and non-patient contact activity (e.g. documentations), staffing levels and deployment (availability of rehabilitation team), factors related to patients (e.g. medical condition and willingness), therapists' limited knowledge of the evidence that increased frequency and intensity of therapy improves outcomes within the first six months after stroke, influence of external audit of stroke services and limited use of a planned therapy timetable (Clarke et al., 2018). A systematic review aimed to investigate the amount of therapy in rehabilitation sessions during the hospitalisation (Serrada et al., 2016). The review included studies conducted in Australia, United States, New Zealand and Norway but not the UK and

found that approximately 79 percent of stroke survivors' exercise sessions are focused on their lower limbs, devoting only 21 percent of the sessions to the upper-limbs, highlighting the need for stroke survivors to have extra upper-limb exercises (Serrada et al., 2016). All of the participants agreed that only a small amount of time was devoted to stroke survivors' upper-limbs. This implies that there is a focus among the developed countries on stroke survivors' lower-limb exercises, in preference to upper-limb exercises. A cross-sectional study conducted by Stockley et al. (2019) aimed to record the time and content of upper-limb exercises provided by physiotherapists and occupational therapists for stroke survivors in the UK during their hospital stay. Data were collected using online surveys to UK-based therapists. The study recruited 156 respondents, and the findings indicated that the reported time and content of upper-limb therapy were markedly less than the recommended therapy, and the therapy received by those with severe upper-limb impairment was even less still, as well as being inconsistent (Stockley et al., 2019). Therefore, it could argue that most of the stroke rehabilitation sessions provided in the UK are not providing enough upper-limb exercises as stroke survivors receive rehabilitation sessions by both physiotherapists and occupational therapists five days per week and that is still less than recommended thereby for upper-limb, with the result that improving upper-limb function was identified as one of the top ten research priorities for stroke research in the UK (Pollock et al., 2014a).

NICE guidelines also recommend providing stroke survivors and their carers with information about useful resources that meet their needs. However, a survey in the UK through the Medical Research Council, General Practice Research Framework and population-based stroke registers showed that both stroke survivors (799 participants) and carers believed that current practice does not provide enough support to meet their needs (McKevitt et al., 2011). The stroke survivors required support for their physical issues (i.e. pain, falls and incontinence), stroke-related issues (i.e. emotional changes, fatigue, memory and concentration) and social participation (i.e. work activities, loss of income, increase in expenses, employment issues, financial advice and relationships). In addition, they required more information about stroke. These needs were varied among stroke survivors depending on geographical area (England, Wales or Scotland), the ability to communicate and ethnic background (McKevitt et al., 2011). Recent reports about the care in the UK showed that there is a variation between different sites across the UK in terms of delivering consistent care and in supporting stroke survivors and carers (Sentinel Stroke National Audit Programme, 2019, National Services Scotland Information and Intelligence, 2019). Improvement plans are made on a regular basis to ensure

the delivery of consistent and adequate care and support (Sentinel Stroke National Audit Programme, 2019, National Services Scotland Information and Intelligence, 2019). In addition there is variation across sites in informing stroke survivors and carers about useful resources (Care Quality Commission, 2011, Mold et al., 2006).

The optimum time to begin their rehabilitation post stroke is not clear. In a Cochrane review to determine if very early mobilisation (starting within 24 hours of stroke) is safe and beneficial to stroke survivors revealed that very early mobilisation did not increase the chances of stroke patients surviving and did not facilitate their recovery (Langhorne et al., 2018). Langhorne et al. (2018) explained that low quality evidence suggested very early mobilisation decreased stroke survivors' hospitalisation period by around one day. However, findings from a recent large RCT (A Very Early Rehabilitation trial [AVERT]) suggested that very early mobilisation could increase risks of mortality (Langhorne et al., 2018).

2.2.3 Section summary

Stroke survivors in the UK receive their care in specialised stroke units from multidisciplinary teams. Current stroke rehabilitation care is more beneficial for stroke survivors in terms of dependency and/or incidence of death than previous, where patients with different diseases received their care in one unit. Furthermore, current stroke units consider the needs of carers/family members for support. They also involve them in education programmes. However, the rehabilitation that patients with stroke and carers/family members received is negatively hindered by the following facts:

- The dose of stroke rehabilitation is lower than the recommended dose suggested by NICE guidelines
- Patients with stroke and carers/family members are not receiving enough support after discharged from hospitals

2.3 Augmented upper-limb physiotherapy

This section explores the literature on the following areas of augmented upper-limb physiotherapy: rehabilitation interventions for upper-limb, neuroplasticity and upper-limb rehabilitation after stroke as well as dose-response relationships in stroke rehabilitation. Further, the limitations related to the evidence on dose-response in relation to upper-limb function are flagged.

2.3.1 Rehabilitation interventions for the upper-limb

A Cochrane overview is a study of systematic reviews while Cochrane review is a review of studies (Pollock et al., 2018). A Cochrane overview identified many rehabilitation intervention methods for rehabilitation of the upper-limbs (Pollock et al., 2014b). These include the following:

- Bilateral arm training
- Biofeedback
- Bobath therapy
- Brain stimulation (tDCS and rTMS)
- Constraint-induced movement therapy
- Electrical stimulation
- Hand-on therapy (manual therapy)
- Mental practice
- Mirror therapy
- Music therapy
- Pharmacological interventions
- Robotics
- Sensory interventions
- Strength training
- Stretching and positioning
- Positioning of the shoulder
- Hand splinting
- Shoulder supports
- Task-specific/repetitive task training
- Virtual reality

Pollock et al. (2014b) overview included 40 systematic reviews of 503 clinical trials (18,078 participants). The outcome measures used to investigate efficacy of these intervention in relation to arm function included the following: Upper Extremity Function Test or Action Research Arm Test, Box and Block Test, Wolf Motor Function Test, Frenchay Arm Test, Functional Test of the Hemiparetic Upper Extremity, Upper Extremity Performance Test for the Elderly, Sodring Motor Evaluation of Stroke Patients-arm section, Chedoke Arm and Hand

Activity Inventory and Motor Assessment Scale-hand movement or advanced hand movement scores. In addition, outcome measures used in this overview to assess hand function include the following: ABILHAND, Jebsen Hand Function Test, Nine-Hole Peg Test, Purdue Peg Test and Stroke Impact Scale. The following rehabilitation interventions were considered effective to improve post-stroke upper-limb function: mirror therapy, mental practice, and constraint-induced movement therapy, a relatively high dose (more than 20 hours) of repetitive task practice, virtual reality and interventions for sensory impairment (Pollock, Farmer, et al., 2014). Furthermore, higher dose of these interventions was preferable; however, the optimal dosage was not known, and more studies are required in order to identify the optimum dose for different interventions (Pollock et al., 2014b). The evidence to support these findings was of moderate quality, which indicates a need for further studies to confirm or dispute these findings. The Cochrane review group judged the quality of evidence as moderate for the following reasons: limited number of trials and participants, heterogeneous findings between the trials, low-quality reviews or poor reporting of methods, or poor reporting of trials (Pollock et al., 2014b).

A more recent systematic review and meta-analysis, that included 104 clinical trials (5225 participants) investigated upper-limb interventions for stroke survivors during their first 4 weeks from the onset of stroke (Wattchow et al., 2017). Upper-limb interventions were not limited to the previously mentioned, but they also included other interventions, including kinesio taping. Wattchow et al. (2017) did not use the same structure as Pollock et al. (2014b) in categorising the upper-limb interventions so a greater number of interventions was found. A total of 21 upper-limb interventions were investigated in this review. These interventions were: task specific training, constraint-induced movement therapy, biofeedback, electrical stimulation, air splint, bilateral arm training, circuit class therapy, interventions for somatosensory functions, kinesio tape, mechanical arm trainer, medication, mirror box therapy, music therapy, passive movement, reflex inhibiting/immobilisation, robotics, shoulder strapping/orthosis, static positional stretch, strength training, virtual reality training/video gaming and Bobath therapy. In addition, Wattchow et al. (2017) did not identify specific outcome measures to detect changes in upper-limb functions as they included studies using any measures of upper-limb impairment and activity such as the Barthel Index. Wattchow et al. (2017) summarised findings of this systematic review for clinicians: four upper-limb interventions were found to be effective interventions, two of them were recommended to be used as part of usual rehabilitation care (constraint-induced movement therapy and task-

specific training), the two other interventions were recommended to use as supplementary interventions in addition to usual rehabilitation care (biofeedback and electrical stimulation) and one intervention was not found to be effective (Bobath therapy) in improving upper-limb function in the first 4 weeks of stroke. There was not enough evidence to support or refute the other interventions.

Overall, the number of clinical trials to support or refute the efficacy of each upper-limb intervention varies between the two systematic reviews as Pollock et al. (2014b) included more clinical trials than Wattchow et al. (2017). In Wattchow et al. (2017), each of the 7 included upper-limb interventions were evaluated in only one clinical trial and the six other interventions were investigated two to three trials each. On the other hand, Pollock et al. (2014b) included systematic reviews of upper-limb interventions accounting for at least three clinical trials for two interventions (Bobath therapy, music therapy and positioning of the shoulder) and at least 13 clinical trials for the rest of the interventions. Even though there was overlap in terms of the studies included within each study, the quality of the included studies in Pollock et al. (2014b) was higher as they included only RCTs unlike Wattchow et al. (2017) who included other study designs (pre/post-test design and control trials). Therefore, the systematic overview conducted by Pollock et al. (2014b) provided more robust findings for upper-limb interventions. Overall, the efficacy of two upper-limb interventions (task related exercise and constraint-induced movement therapy) were supported by both Pollock et al. (2014b) and Wattchow et al. (2017).

Dejong et al. (2004) demonstrated a taxonomy that aims to capture the diversity and complexity of rehabilitation interventions by providing a model that describes essential categories of rehabilitation interventions. Based on that, musculoskeletal (such as strength exercises) and neuromuscular (such as constraint-induced movement therapy) interventions are generally provided to facilitate functional practice, while other interventions that use perceptual and sensory attributes as well as cognitive ones (such as mental practice and repetitive task training) are provided to facilitate skill acquisition. In addition, healthcare professionals may deliver such interventions with or without additional modalities (such as electrical stimulation) or devices (such as robotics). These interventions can be delivered in different settings (such as a hospital or home) and they are essential to improve upper-limb function, which is a key element of stroke rehabilitation, which in turn is required to reduce patient disability and also to maximise patient outcomes (Pollock et al., 2014b). Rehabilitation interventions can be used individually or combined, and these interventions aim to address specific impairments, such as

muscle shortness, or to facilitate function, such as arm reaching (Pollock et al., 2014b). Healthcare professionals deliver the appropriate rehabilitation approach based on the upper-limb assessment, stroke survivors' goals and participation (Langhorne et al., 2011).

2.3.1.1 Repetitive task-specific training:

Task-specific training or functional task training involves individuals practising activities related to daily life as a whole or part of the activity – for example, reach-to-grasp (Turton et al., 2017). This kind of exercise could be provided as a form of repetitive task training where these activities are repeated within a single session (French et al., 2016). Evidence suggests that functional upper-limb interventions (those containing direct practice of different upper-limb functions) are superior to impairment-based interventions in promoting functional recovery (Kwakkel et al., 2004, Langhorne et al., 2009, van der Lee et al., 2001).

Repetitive task-specific training has been theoretically underpinned by studies associated with motor learning (Butefisch et al., 1995, Magill and Anderson, 2010) and stroke rehabilitation (Veerbeek et al., 2014). Motor learning can be described as a process of gaining a new skill as a result of practising a new task or through experience (Schmidt et al., 2018).

Repetitive task-specific training optimises motor learning by practising selected functionally relevant and meaningful tasks, which in turn encourages active cognitive involvement of stroke survivors in rehabilitation and is seen as a primary motivational factor (French et al., 2016, Schmidt and Lee, 2019). It is hypothesised that the direct involvement of stroke survivors in task-specific training improves the quality and consistence of their motor performance, thereby enhancing the process of task learning (Schmidt and Lee, 2019). Other components of repetitive task-specific training in order to optimise motor learning include knowledge of performance (either intrinsic or extrinsic feedback on performance), intensity of practice (discussed in section 2.3.3) and type of practice (Schmidt and Lee, 2019). Types of practice for the repetitive task-specific training are varied and are scheduled based on the stroke survivor's stage of task learning. Types of scheduled practice include individuals performing part or whole task practice, massed or distributed practice and random or blocked practice (Schmidt and Lee, 2019).

2.3.2 Neuroplasticity and early upper-limb rehabilitation after stroke

Neuroplasticity can be defined as the process of re-organising the function of the cerebral cortex through experience to acquire a new skill (Nudo, 2006). The evidence suggests that a

lesion to the motor cortices, as a result of a stroke, triggers cortical neuroplasticity in the residual cortical tissue, which in turn undergoes changes in function and structure to provide the base for rehabilitation (Nudo, 2006). These changes can be either adaptive or maladaptive based on the quality as well as the quantity of the practised task (Buma et al., 2013, Nudo, 2013). Hundreds of repetitions of task-specific training are a fundamental part of guiding neuroplasticity for stroke survivors in order to improve their functional recovery, as suggested by animal studies (Birkenmeier et al., 2010). Dedicated neural networks – an information processing system within the brain – represent particular functions or behaviour (Da Silva et al., 2017). This implies that an intervention targeting a particular neural network would better improve that specific function, thereby supporting interventions targeting specific tasks. The dose-response relationship is expanded further in the following section 2.3.3.

A study conducted by Krakauer et al. (2012) showed that three levels of changes were observed in the peri-infarct cortex for animal models, namely, cellular, molecular and physiological. The results showed that the ideal time for rehabilitation is unknown, but the authors indicated that the peak for neural plasticity occurs from the first week (particularly, 5 days after brain injury) to the first month following stroke (Krakauer et al., 2012). This implies that the first month after stroke is a crucial time for recovery. A study conducted by Nakayama et al. (1994) indicates that early upper-limb rehabilitation, up to two months after stroke, could improve upper-limb function. A Cochrane overview confirmed the relationship between the timing of upper-limb rehabilitation intervention and its effectiveness was supported with low quality evidence, so more studies are required (Pollock et al., 2014b).

2.3.3 Dose-response relationships in stroke rehabilitation

The dose of the exercise programme is defined using the FITT Principle, where the letter ‘F’ stands for frequency, ‘I’ stands for intensity, ‘T’ stands for time, and the final ‘T’ stands for the type of exercise programme (American College of Sports Medicine, 2013). The literature implies that high levels of exercise or general practice (tasks associated with ADLs) promote better skills, assuming that these exercises or practices are challenging and carried out in a progressive and skilful manner (Taub et al., 2013, Boyd et al., 2010). The process of neuroplasticity after a stroke relies not only on the quality of the practised exercise but also on the dose of the performed exercises, which implies that there is a positive relationship between the dose of the practised exercises and functional recovery (Nudo, 2013). More details about

how the dose of rehabilitation guides the process of neuroplasticity is discussed above in section 2.3.2.

Many systematic reviews suggest that there is a positive relationship between an augmented intervention (that is intervention provided in addition to usual care) and functional benefit after stroke (Pollock et al., 2014b, Lohse et al., 2014, Veerbeek et al., 2014, Kwakkel et al., 2004, Cooke et al., 2010, French et al., 2016, Galvin et al., 2008, Schneider et al., 2016, Langhorne et al., 1996). However, some of these systematic reviews do not support this positive relationship between augmented intervention and upper-limb functional benefits after stroke in particular; instead, they report a correlation between augmentation and ADLs (Galvin et al., 2008, Cooke et al., 2010, Kwakkel et al., 2004). Different explanations were provided by these studies for the ineffectiveness of upper-limb augmented interventions for improvements in upper-limb functions. Galvin et al. (2008) stated that many of the included studies were of interventions that did not aim to improve upper-limb function so explaining the non-significant findings in the meta-analysis. On the other hand, Cooke et al. (2010) explained that the heterogeneous use of different upper-limb outcome measures in the included studies could be the reason for the non-significant findings. Kwakkel et al. (2004), included 32 studies (n=32) of which only five investigated the effect of different augmented interventions on the upper-limb functions and within these, no significant difference was reported. The dose relationship of augmented interventions to improve upper-limb functions is still ambiguous and requires further investigation.

Kwakkel et al. (2004) indicated that more than 16 hours of augmented intervention is required to ensure functional benefits in activities of daily living within the first 6 months and they noted that outcomes measuring activity of daily livings such as the Barthel index are more sensitive to improvements of lower-limb function than upper-limb. Furthermore, Veerbeek et al. (2014) indicate that for the augmented intervention to achieve a significant beneficial effect in body function levels including upper-limb function and activity of daily living, a minimum of 17 hours is required over 10 weeks. However, only two studies out of the included 80 investigated the effect of the augmented upper-limb interventions. Pollock et al. (2014b) suggested that a minimum of 20 hours of task training is required to achieve a beneficial effect in upper-limb function; however, this was based on moderate- quality evidence. Schneider et al. (2016) indicated that usual rehabilitation needs to be more than double what it is currently to guarantee functional benefits but increasing rehabilitation periods to this extent is challenging as stroke

units in the UK, for example, are facing difficulties with delivering the recommended dose of rehabilitation, not to mention augmented interventions. See section 2.2.2 for more details about delivered doses in the UK.

Even though these systematic reviews were different in terms of the quantity of the recommended augmented interventions and in terms of the evidence for the effectiveness of an augmented intervention in maximising upper-limb functions, they all agreed that more studies are required that investigate the effect of augmented interventions on upper-limb function.

2.3.4 Limitations in the current evidence on dose-response relationships in improving upper-limb function following stroke

After reviewing the systematic reviews presented above in section 2.3.3, the researcher decided to conduct his own systematic review and this decision was made for the following reasons. First, this research was targeting the stroke population in the first 3 months after a stroke. None of these systematic reviews included solely participants in this period. Second, the researcher wished to include only studies that investigated augmented interventions with the aim of improving upper-limb function. Finally, the researcher used a broader definition of upper-limb augmented interventions to include any upper-limb intervention that aimed to improve upper-limb function in order to better understand their effectiveness and to avoid investigating the effect of single intervention approach. The definition used by the researcher is "performing any upper-limb task-related exercise in addition to usual care that aims to improve upper-limb function or decrease upper-limb impairment". Based on the identified limitations provided in this section, a detailed review was carried out systematically reviewing the existing literature under the specific conditions. The findings from this systematic review helped to investigate the effectiveness of upper-limb augmented interventions and to identify the gap in the literature in this regard. The feasibility of augmented interventions, the level of supervision and method of intervention delivery were also explored in order to provide justification for the intended outcome of the research project.

2.3.5 Section summary

A wide variety of upper-limb interventions have been considered effective in improving upper-limb function for the stroke population. These interventions can be used as appropriate based on the judgment of healthcare professionals (physiotherapists and/or occupational therapists), provided they are in relation to stroke survivors agreed goals. It has also been suggested that

patients with stroke benefit the most in improving their upper-limb functions in the first 2 months of the onset of stroke. The current literature regarding the relationship between the dose and upper-limb function after stroke is not sufficient and more trials are required.

2.4 Effect of augmented task-related exercises on the outcomes of upper-limb function and upper-limb impairment within the first 3 months after stroke: A systematic review

This systematic review was carried out to address the gap outlined in section 2.3.4 related to evidence of the effects of augmented interventions on upper-limb function.

2.4.1 Aim and research question

The aim of this systematic literature review was to investigate the efficacy of augmented upper-limb rehabilitation, in addition to usual care, for stroke survivors in the first three months after stroke. Therefore using the PICO strategy, where the letter "P" stand for population, letter "I" stand for intervention, letter "C" stand for comparison and letter "O" stand for outcome (Schardt et al., 2007) the research question is: "What is the effect of augmented upper-limb training on adults within 3 months of any type of stroke compared to usual care and/or lesser doses than the augmented intervention in addition to usual care in measures of upper-limb function or impairment".

2.4.2 Search strategy

The search was conducted in January 2019 and was updated in December 2020 after the PhD viva with restriction on publications to be published in English language, relating to humans. The available evidence using the following electronic databases: the Cochrane Library, CINAHL, Physiotherapy Evidence Database (PEDro), Web of Science Core Collections, Medline and Embase were utilised. In addition, reference lists of relevant articles were searched. Keywords and Medical Subject Headings for the search strategy demonstrated in Table 2.1 and search strategy used for each database presented in detail in Appendix 1. Keywords were generated based on synonyms and free-text terms of medical subject headings related to different databases.

Table 2.1 Topic groups and keywords used in the searches

Topic group	Keywords
Stroke disease	Cerebrovascular Disorders/, stroke* cva*, cerebral vascular*, post stroke*, brain*, ischemia*, infarction*, thrombosis*, emboli*, occlusion*, haemorrhage*, haematoma*, bleed*, ischemia*, cerebral*, cerebellar*, intracerebral*, intracranial*, vertebrobasilar*, subarachnoid*, hemiplegia/, paresis/, hemiplegia*, hemi impairment*, paresis*, paretic*
Physiotherapy/occupational therapy	Physical Therapy Modalities/, physical therapy*, occupational therapy*, Rehabilitation/, Recovery of Function/, Exercise Movement Techniques/, functional task*, functional movement*, motor*, schedule*, intervention*, therapy*, programme*, regime*, protocol*, movement*, task*, skill*, performance*
Augmented intervention	Intensity*, frequency*, duration*, dose*, total units*, amount*, quantity*, how much*, repetition*
Upper limbs	Upper extremity/, upper limbs*, arm*, shoulder*, hand*, elbows*, forearm*, finger*, wrist*

Note. "/" means Mesh headings and "*" means free text

2.4.3 Inclusion and exclusion criteria:

2.4.3.1 Inclusion criteria

Articles were included where they:

- Included adults over 18 years old
- Included participants with stroke receiving UL rehabilitation within 3 months of their diagnosis of any type of stroke
- Investigated the effects of augmented upper-limb training. The augmented upper-limb intervention for the purpose of conducting this review was defined as "performing any upper-limb task-related exercise in addition to usual care or at a higher dose than usual care that aims to improve upper-limb function or decrease upper-limb impairment"
- Compared the effect of augmented intervention with usual care

- Used at least one outcome measure of upper-limb function or upper-limb impairment
- RCT
- Included mixed population only if the data for stroke participants can be extracted

2.4.3.2 Exclusion criteria

Articles were excluded if they were:

- Conference abstracts or posters
- Comparing the effect of dose-matched interventions only

There were no restrictions placed on publication date. Results of the search were exported to Endnote reference manager software to remove duplication and then exported to Rayyan QCRI software to organise the screening and selection process. The researcher screened articles by titles and abstracts against the eligibility criteria and then retrieved full papers as appropriate (Figure 2.2). Three studies were included from reference lists of the relevant articles. The researcher consulted the three academic supervisors (LP, EC and AD) for an independent view if there were papers whose inclusion was in doubt.

The included studies were independently assessed for their quality in terms of external validity, internal validity and the reporting of the statistics by PEDro group. The PEDro scale is a valid and reliable scale to assess methodological quality of trials (Maher et al., 2003, de Morton, 2009). This scale contains 11 items where each item scores one point except the initial item in the scale (for stating the inclusion/exclusion criteria) as per the scale guidelines. The rest of scale items covers domains of randomisation, characteristics of recruited participants, blinding of participants/assessors, completeness of assessments and statistical analysis. The scale gives a score out of ten where higher score indicates trial of higher quality.

Data extraction was carried out by the researcher into three evidence tables (Appendices 2-4). The first table is an introductory table showing PEDro rating, setting and baseline patients' characteristics. The second table provides an overview of the nature of augmented intervention in terms of method of delivery, level of supervision and description of the type of provided intervention. For the third table, the following data were extracted: author and study design, study population, augmented dose of the augmented intervention (in terms of number of

repetitions /times spent in practice), control intervention, outcome measures and main findings. Augmented practice was defined as the active time spent in practice or as the number of repetitions (Woldag et al., 2003, Kwakkel et al., 1997). The scheduled dose for the augmented intervention was recorded (Table 2.2). The dose was defined in this systematic review as the scheduled quantity of the augmented active involvement of stroke survivors in rehabilitation, in addition to usual care in terms of the duration or number of repetitions (Woldag et al., 2003, Kwakkel et al., 1997).

2.4.4 Results

Table 2.2 provides PEDro rating, setting and baseline patients' characteristics in the studies included in this review (19 studies). It should be noted that one of the included studies was reported in two articles, Lincoln et al. (1999) and Parry et al. (1999). The difference between these two articles is in stratifying the participants into two groups based on their RMA-arm movement scores for the analysis in Parry et al. (1999).

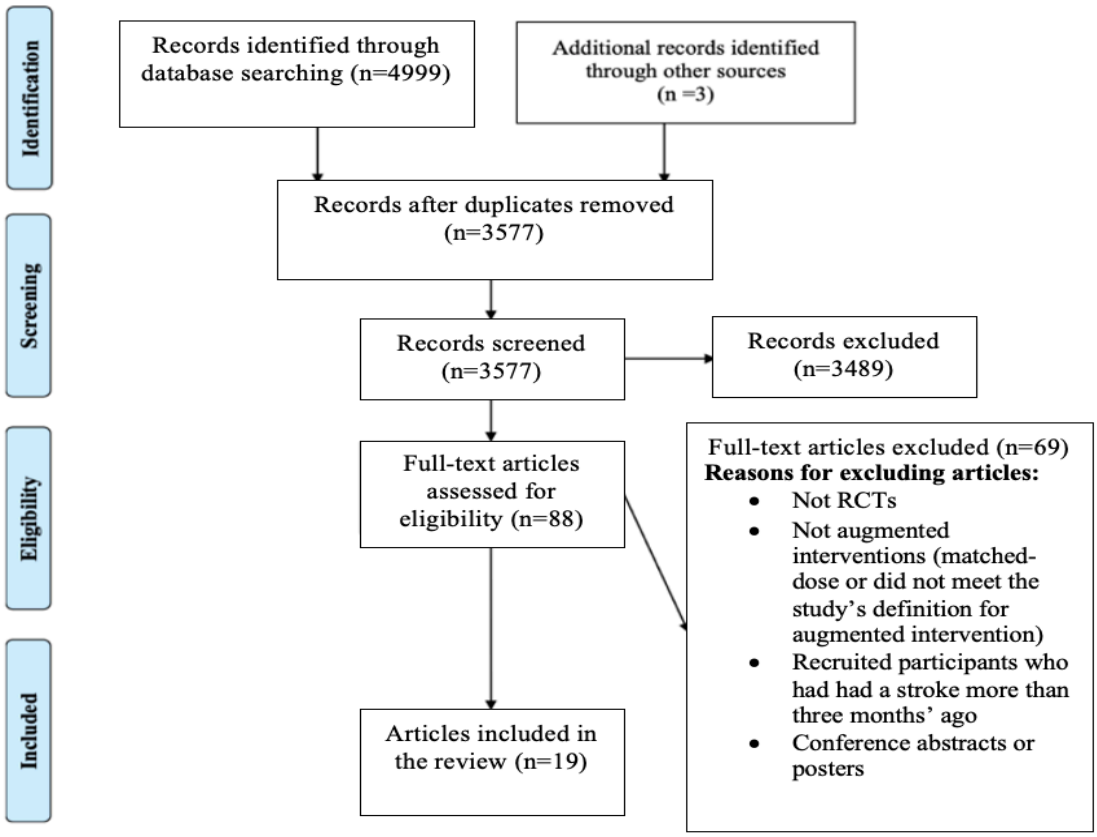


Figure 2.2 Prisma diagram of the detailed review (Moher, Liberati, Tetzlaff, Altman, & Grp, 2009)

All the 19 included studies were RCTs and included 1535 stroke survivors. The included studies were based in different countries, most commonly the UK (5 studies each) and Australia (4 studies). The rest of studies were based in the United States (3 studies), Singapore (2 studies) and Canada, Germany, Korea, Netherlands and China (one study each). In addition, these studies were assessed for their quality by PEDro and their scores ranged from 5 to 8 with a mean of 6.6 score suggesting good quality evidence (Cashin and McAuley, 2020) (Table 2.4).

Table 2.2 PEDro rating, setting and baseline patients' characteristics in the studies included in this review

Author and Pedro rating	**Setting**	**Age (years)**	**ARAT/ FMA-UE**	**NIHSS**	**FIM**
Sunderland et al. (1992), 132 stroke survivors, Pedro rating (6/10)	UK	For severe group (who couldn't perform any part of the FAT), median =65 for the intervention group and 68 for the control group, for mild group (who were able to perform any part of the FAT), median=67 for the intervention group and 70 for the control group.	NR	NR	NR
Lincoln et al. (1999) and Parry et al. (1999), 282 stroke survivors, Pedro rating (6/10) for Lincoln et al. (1999) and (5/10) for Parry et al. (1999).	UK	Median=73	**ARAT:** median=0	NR	NR

Author and Pedro rating	Setting	Age (years)	ARAT/ FMA-UE	NIHSS	FIM
Rodgers et al. (2003), 105 stroke survivors, Pedro rating (8/10)	UK	Median=74	**ARAT:** median= 6 for the intervention group and 0 for the control group	NR	NR
Winstein et al. (2004), 64 stroke survivors, Pedro rating (6/10)	US	Range 35–75	**FMA-UE:** mean= 18.70 for the functional task group, 23.55 for the strength training group and 19.85 for the control group)	NR	Mean= 59.55 for the functional task group, 61.35 for the strength training group and 62.5 for the control group
Platz et al. (2005a), 62 stroke survivors, Pedro rating (8/10)	Germany	Mean= 62 for the arm impairment-oriented training group and 60 for the Bobath and the control groups	**ARAT:** mean= 8 for the arm impairment-oriented training group, 9.6 for the Bobath group and 6.4 for the control group	NR	NR
Donaldson et al. (2009a), 20 stroke survivors, Pedro rating (8/10)	UK	Mean=72.8	**ARAT:** mean=31	NR	NR

Author and Pedro rating	Setting	Age (years)	ARAT/ FMA-UE	NIHSS	FIM
Harris et al. (2009), 103 stroke survivors, Pedro rating (8/10)	Canada	Median=71	**ARAT:** mean=71	NR	NR
Dromerick et al. (2009), 52 Stroke survivors, Pedro rating (7/10)	US	Mean = 63.9	**ARAT:** mean = 22.5	Mean = 5.3	Mean = 57.8
Burgar et al. (2011), 54 stroke survivors, Pedro rating (6/10)	US	Mean=62.5 for the low-dose group, 58.6 for the high-dose group and 68.1 for the usual care group)	**FMA-UE:** mean=26.7 for the low-dose group, 19 for the high-dose group and 24.2 for the usual care group	NR	Reported only for upper limb items-max 63, mean= 17.7 for the low-dose group, 21.5 for the high-dose group and 15.9 for the usual care group
Kwon et al. (2012), 26 stroke survivors, Pedro rating (5/10)	Korea	Mean=57.5	**FMA-UE:** mean= 60.31 for the intervention group and 56.38 for the control group	NR	NR
Hayward et al. (2013), 28 stroke survivors, Pedro rating (7/10)	Australia	Mean=63 for the experimental groups and 62 for the control group	NR	NR	Range 30–82 for the experimental groups and not reported for the control group

Author and Pedro rating	Setting	Age (years)	ARAT/ FMA-UE	NIHSS	FIM
Han et al. (2013), 32 stroke survivors, Pedro rating (8/10)	China	Mean=52.40 for the group A, 53.70 for the group B and 44.60 for the group C	**ARAT:** 0.80 for the group A, 1.5 for the group B and 1.1 for the group C	NR	NR
Yin et al. (2014), 26 stroke survivors, Pedro rating (6/10)	Singapore	Mean= 58.35	**ARAT:** mean=11 for the intervention group and 17.5 for the control group	NR	Median=90 for the intervention group and 88 for the control group
English et al. (2015), 190 stroke survivors, Pedro rating (7/10)	Australia	Mean= 69·9	NR	NR	Median=40
Kong et al. (2016), 105 stroke survivors, Pedro rating (6/10)	Singapore	Mean= 57.5	**ARAT:** mean= 7.2	Mean= 6	Mean=70 for Nintendo Wii group, 72.4 for CT group and 76.4 for control group
Brkic et al. (2016), 24 stroke survivors, Pedro rating (5/10)	UK	Median=71 for the intervention group and 65 for the control group	**ARAT:** median=32 for the intervention group and 8 for the control group	Median=3 for the intervention group and 6 for the control group	NR
Kwakkel et al. (2016), 159 stroke	Netherlands	For favourable prognosis participants mean=58.97 for the CIMT group and 65.34 for	**ARAT:** for favourable prognosis participants mean=23.93 for the CIMT	For favourable prognosis participants mean=4.17 for the CIMT group and 4.75	**NR**

Author and Pedro rating	Setting	Age (years)	ARAT/ FMA-UE	NIHSS	FIM
survivors, Pedro rating (7/10)		the control group, for unfavourable prognosis participants mean=58.94 for the EMG-NMS group and 58.53 for the control group.	group and 20.97 for the control group, for unfavourable prognosis participants mean=0.62 for the EMG-NMS group and 0.80 for the control group.	for the control group, for unfavourable prognosis participants mean=9.06 for the EMG-NMS group and 8.73 for the control group.	
Horsley et al. (2019), 50 stroke survivors, Pedro rating (8/10)	Australia	Mean=68.5 for the intervention group and 68.5 for the control group	**NR**	**NR**	53.6 for the intervention group and 44.7 for the control group
Rogers et al. (2019) 21 stroke survivors, Pedro rating (6/10)	Australia	Mean= 64	**NR**	Mean= 3 for the intervention group and 2.3 for the control group	**NR**

United Kingdom (UK), Frenchay Arm Test (FAT), National Institutes of Health Stroke Scale (NIHSS), Not Reported (NR), Functional Independence Measure (FIM) and United States (US)

* Level of arm impairment was measured by either Action Research Arm Test (ARAT) or Fugl-Meyer Assessment-Upper extremity (FMA-UE),

* Stroke severity was measured by National Institutes of Health Stroke Scale (NIHSS)

* Level of disability was measured by Functional Independence Measure (FIM)

Table 2.3 below provides a summary of the nature of the augmented interventions in the studies included in this review (19 studies).

Table 2.3 Descriptions of upper-limb augmented interventions

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
Handbook of a printed exercise programme	Harris et al. (2009), inpatients and home setting (unsupervised intervention)	Exercises were listed in an exercise book and aimed to improve the performance of the affected upper-limb. Three exercise books were developed (for mild, moderate, severe impairment) and the participants received the appropriate version based on their performance in the Fugl-Meyer Motor Impairment Scale. Each book included a variety of graded exercises (functional oriented, range of motion, strengthening and fine and gross motor skills) along with demonstrative pictures and the required equipment (for example, ball and towel). A maximum of 24 hours of augmented exercise was scheduled over one month.
	Brkic et al. (2016), inpatients and home setting (unsupervised intervention)	This unsupervised augmented intervention was provided to participants by an individualised handbook where they could find guidance about their selected tasks along with advice section on about stroke care and recovery. They also recorded their performed exercises in the handbook. The dose of the augmented exercise programme was measured in repetition as the participants were asked to perform two selected upper-limb tasks, 20 times each session, 2 sessions a day over one month.
Robotic	Burgar et al. (2011), inpatients setting (fully supervised intervention)	This augmented intervention was provided either as usual rehabilitation (up to 15 hours) or in the form of robotic exercises either up to 15 (low-dose group) or 30 (high-dose group) hours, which were upper-limb exercises mediated by a robotic device, and aimed to improve upper-limb function by asking the participants to perform movements (passive, active assisted and active resisted) and/or a task (2 or 3 dimensional reaching at table or eye level) based on their level of upper-limb function and their functional range of motion.

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
One to one intervention (provided by rehabilitation staff)	Sunderland et al. (1992), inpatients and home/ outpatients setting (fully supervised intervention)	Usual rehabilitation sessions but provided with more upper-limb exercises to the arms. Participants in the intervention group received usual care sessions but with more arm exercises during their sessions
	Lincoln et al. (1999) and Parry et al. (1999), inpatients and home/ outpatients setting (fully supervised intervention)	There were two experimental groups, led by a qualified physiotherapist or an assistant physiotherapist per week for 5 weeks (maximum of 10 hours) • The sessions led by a qualified physiotherapist were provided based on the Bobath approach and the participants were asked to perform functional and/or movement tasks between these sessions, if appropriate. • The sessions led by an assistant physiotherapist included the participants performing functional activities, receiving instruction to improve body positioning and performing a range of arm movements (active, assisted and passive). A maximum of 10 hours of augmented exercise was scheduled for each group over five weeks.
	Rodgers et al. (2003), inpatients and home/ outpatients setting (fully supervised intervention)	Participants in the intervention group received extra fully supervised upper-limb sessions that were led by a physiotherapist and occupational therapist. A maximum of 15 hours of augmented exercise was scheduled over six weeks.

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
Continue - one to one intervention (provided by rehabilitation staff)	Winstein et al. (2004), inpatients and outpatients setting (fully supervised intervention)	There were two experimental groups, functional task and strength training: • Functional task sessions included progressive functional task-oriented exercises provided to improve upper-limb function. • Strength training sessions included a variety of strengthening exercises to increase muscle strength. A maximum of 20 hours of augmented exercises were scheduled for each group over 4-6 weeks.
	Platz et al. (2005a), inpatients setting (fully supervised intervention)	There were two experimental groups, Bobath and impairment-oriented: • The Bobath intervention aimed to improve arm muscle control and function. • The impairment-oriented intervention aimed to restore arm movement coordination. A maximum of 15 hours of augmented exercise was scheduled for each group over four weeks.
	Donaldson et al. (2009a), inpatients setting (fully supervised intervention)	There were two experimental groups, conventional physical therapy and functional strength training: • Patients in the conventional physical therapy group received extra sessions to perform some tasks, such as practising reaching, with the focus of sensory input to guide the movements (hands-on therapy approach). • Patients in the functional strength training group received extra sessions that aimed to improve upper- limb function (hands-off therapy approach). A maximum of 24 hours of augmented exercise was scheduled for each group over 6 weeks.

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
Continue - one to one intervention (provided by rehabilitation staff)	Dromerick et al. (2009), inpatients setting (fully supervised intervention)	There were two experimental groups, standard CIMT group (dose-matched treatment to the control treatment) and high-intensity CIMT group (augmented intervention): • Participants in the standard CIMT group performed two hours of shaping daily and they were required to wear a padded constraint mitten for six hours daily. • Participants in the high-intensity CIMT group performed three hours of shaping daily and they were required to wear a padded constraint mitten for most of the day (90% of their awake time). The shaping therapy comprised basic activities such as daily living tasks and skilled functional tasks. The occupational therapist graded these functional activities according to the study protocol in order to align them with the motor skills of the patient. A maximum of 10 hours of augmented exercise was scheduled over 2 weeks.
	Han et al. (2013), inpatients setting (fully supervised intervention)	There were three experimental groups, group A (a maximum of 30 hours of augmented intervention); group B (maximum of 60 hours of augmented intervention); and group C (maximum of 90 hours of augmented intervention), of the same intervention but different doses over a period of six weeks: The augmented intervention was tailored to the participants based on their level of functional arm impairment. These augmented sessions included strengthening exercises, range of motion exercises and positioning and functional task exercises.

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
Continue - one to one intervention (provided by rehabilitation staff)	English et al. (2015), inpatients setting (fully/partially supervised intervention)	There were two experimental groups, seven-day treatment and circuit class: • The participants in the seven-day treatment group received their usual therapy on seven days a week, including a total of 3 rehabilitation hours in addition to their usual care (fully supervised augmented intervention). • Participants in the circuit class group received two 90 min sessions a day with 22 hours of rehabilitation in total in addition to their usual care (partially supervised augmented intervention).
	Kwakkel et al. (2016), inpatients setting (fully supervised intervention)	There were two experimental groups, CIMT and EMG-NMS: • Participants within the CIMT group participated in one hour per day of supervised graded therapy. This aimed to improve the affected arm and hand's ability to perform task-based activities, including finger extension. These augmented sessions were administered in either single sessions (60 minutes) or two sessions (30 minutes each), based on the tolerance level of the patient and the time available on the day. Patients were advised to wear a padded safety mitt for a total of three hours of their workday for five weeks after the stroke incident. • With the participants within the EMG-NMS group, the Stiwell-Med4 system was employed to administer finger extensor stimulation to the participants for two 30-minute sessions. This was performed on each workday for three weeks. A maximum of 7.5 hours of augmented exercise was scheduled over three weeks.

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
Virtual reality	Kwon et al. (2012), inpatients setting (fully supervised intervention)	Sessions were provided in a virtual environment. One occupational therapist supervised all the sessions, which employed five different games to practice lifting and reaching. A maximum of 10 hours of augmented exercise was scheduled over four weeks.
	Yin et al. (2014), inpatients setting (fully supervised intervention)	Sessions were provided in a virtual reality environment, which simulated a grocery store setting. Within each session, the participants performed 15 sets of a reaching activity while standing, based on their active range of movement in the affected hand. Extrinsic feedback was incorporated such as a cheering sound to motivate the patients. A maximum of 4.5 hours of augmented exercise was scheduled over two weeks.
	Rogers et al. (2019) inpatients setting (fully supervised intervention)	Patients in the intervention group received exploratory and goal directed tasks; these tasks ranged from patients performing simple arm movements in different directions to them making different sounds and shapes through movement in a virtual reality environment based on their level of arm impairment. A maximum of 4.8 hours of augmented exercise was scheduled over four weeks.
Virtual reality and one to one intervention (provided by rehabilitation staff)	Kong et al. (2016), inpatients setting (fully supervised intervention)	There were two experimental groups, conventional therapy and Nintendo Wii: • The extra sessions received by participants in the conventional therapy group were in the form of tailored exercise that aimed to improve upper-limb function. • Participants in the Nintendo Wii group were provided with a virtual reality environment using game software delivered by Wii. The occupational therapists selected the games based on the participants' level of functional abilities. A maximum of 12 hours of augmented exercise was scheduled for each group over three weeks.

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s
Dynamic splint	Hayward et al. (2013), inpatients setting (fully supervised intervention)	There were two experimental groups where the participants performed exercises with a dynamic splint, the SMART arm, to facilitate reaching practice for patients with severe arm impairment. Both groups received visual feedback on the movement. One group also received electrical stimulation. Assistance from the researchers was provided where required. A maximum of 20 hours of augmented exercise was scheduled for each group over four weeks.
	Horsley et al. (2019), inpatients setting (fully supervised intervention)	Sessions were provided using a dynamic splint, the SMART arm, accompanied with electrical stimulation (the device is explained above in Hayward et al. (2013) study). A maximum of 25 hours of augmented exercise was scheduled over five weeks.

The majority of the studies investigated fully supervised augmented interventions. Augmented upper-limb rehabilitation, in addition to usual physiotherapy, for stroke survivors has been delivered through unsupervised self-administered upper-limb exercises (written sheet of exercises) (Harris et al., 2009, Brkic et al., 2016), partially supervised (intervention provided to a group of stroke patients) by physiotherapist staff (English et al., 2015) or fully supervised (one to one intervention) by rehabilitation staff (Han et al., 2013, Lincoln et al., 1999, Rodgers et al., 2003, Donaldson et al., 2009a, Parry et al., 1999, Winstein et al., 2004, Platz et al., 2005a, Burgar et al., 2011, Kwon et al., 2012, Hayward et al., 2013, Yin et al., 2014, Kong et al., 2016, Rogers et al., 2019, Horsley et al., 2019, Dromerick et al., 2009, Sunderland et al., 1992, Kwakkel et al., 2016). Table 2.4 provides a summary of the studies included in this review.

Table 2.4 Upper-limb augmented interventions in people following stroke

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
Sunderland et al. (1992), RCT, 132 stroke survivors	Participants in the intervention group (n=65) received similar dose to usual care with more arm exercises during their sessions the intervention lasted up to 18 weeks (4 to 7 weeks in an inpatient setting and 6 to 11 weeks in an outpatient setting.	Usual care (n=67)	FAT and NHPT (Baseline and 6 months)	Enhanced upper-limb interventions facilitated arm functional recovery for the stroke population. Participants were stratified into two groups according to their scores on the FAT. These were mild group (who were able to perform any part of the FAT) and severe group (who couldn't perform any part of the FAT). At 6 months participants with mild arm impairment had significant changes in favour of the intervention group for only the NHPT ($p < 0.05$). For participants with severe arm impairment there was a trend in favour of the participants in the control group; however, this was not significant ($p > 0.1$).
Lincoln et al. (1999) and Parry et al. (1999),	Patients in two experimental groups received fully supervised extra rehabilitation sessions that lasted for	Usual care (n=95)	ARAT, RMA-arm movement and NHPT (5 weeks, 3	The findings from this study confirmed the effectiveness of augmented interventions for patients with less arm impairment and

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
RCT, 282 stroke survivors	approximately 2 hours per week for 5 weeks (maximum of 10 hours) in addition to usual care. These sessions were led by either a qualified physiotherapist (n=94), or an assistant physiotherapist (n=93). Experimental groups, participants and interventions were the same in both articles Lincoln (1999) and Parry et al. (1999).		months (RMA-arm movement only) and 6 months)	suggested that an augmented intervention with more emphasis on repetitive functional tasks was the most beneficial treatment approach. In a Lincoln et al. (1999) article, no statistically significant changes between the groups in ARAT p=0.62 at 5 weeks and p=0.55 at 6 months; RMA-arm movement p=0.73 at 5 weeks, p=0.65 at 3 months and p=0.69 at 6 months; and NHPT p=0.53 at 5 weeks and p=0.75 at 6 months. In the other article conducted by Parry et al. (1999), the participants were divided into two groups for the analysis. These groups were: more severely impaired participants (scored 0 or 1 in RMA-arm movement) and less severely impaired (scored 2 or more in RMA-arm movement). For the more severely affected participants, no statistically significant differences were found between the groups in any of the

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
				outcome measures for all of the assessment points: p > 0.99 at 5 weeks and p=0.79 at 6 months for RMA-arm movement and p=0.86 at 5 weeks and p=0.59 at 6 months for ARAT. For the less severely affected participants, the group comparison for both ARAT and RMA-arm movement approached significance (p=0. 07) at the post-intervention assessment, while no statistically significant differences were observed at 6 months in MRA (p=0.37) and ARAT (p=0.12). For the less severely affected participants who had completed the augmented interventions significant differences were seen for ARAT p=0.009 at 5 weeks and p=0.02 at 6 months and RMA-arm movement p=0.006 at 5 weeks and p=0.04 at 6 months.
Rodgers et al. (2003), RCT,	Participants in the experimental group (n=51) received extra rehabilitation sessions their upper-limbs and that were led	Usual care (n=54)	ARAT and FAT (baseline, 3 months and 6 months)	The augmented intervention did not improve arm function in any of the identified outcome measures at 3 and 6 months:

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
105 stroke survivors	by a physiotherapist and occupational therapist, 30 minutes each, 5 days per week for up to 6 weeks in addition to their usual care (a max of 15 hours).			p=0.968 at 3 months and p=0.736 at 6 months for ARAT, and p=0.715 at 3 months and p=0.679 at 6 months for FAT.
Winstein et al. (2004), RCT, 64 stroke survivors	Participants in two experimental groups received fully supervised upper-limb sessions; 5 sessions per week, each lasting for 1 hour for a period of 4-6 weeks (a maximum of 20 hours) in addition to usual care. These two groups were: functional task (FT, n=22) and strength training (ST, n=21).	Usual care (n=21)	FMA-UE and FTHUE (baseline, post-intervention and 9 months)	For augmented upper-limb interventions, the severity of arm impairment played an important role in gaining benefits. In the subgroup analysis at the post-intervention assessment, the augmented intervention groups showed a statistically significant improvement in FMA-UE (p=0.04) and in FTHUE (p=0.34). Higher scores in favour of the augmented intervention group were mainly demonstrated in patients who were less affected by the stroke. Non-significant changes were recorded at 9 months in both FMA-UE (p=0.24) and FTHUE (p=0.91). For further analyses, the participants were divided into two groups: more (scores between 4.2 and 6.8 in OPS) and less

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
				(between 1.6 and 4.1 in OPS) severely impaired. Statistically significant between-group differences were only found for the less severely affected participants in FMA-UE post-intervention (p=0.005), and at 9 months (p=0.24). No statistically significant differences were reported in FTHUE p=0.05 at post-intervention and p=0.91at 9 months. No statistically significant between-group differences were recorded for the more severely affected participants in any of the outcome measures.
Platz et al. (2005a), RCT, 62 stroke survivors	Participants in the experimental groups received 20 additional sessions, each lasting for 45 minutes over a period of one month (a maximum of 15 hours). That augmented time was provided based on the Bobath approach (Bobath group, n= 21) or arm impairment-oriented training (BASIS group, n=21).	Usual care (n=20)	FMA-UE and ARAT (baseline and post-intervention)	Only the participants in the BASIS group demonstrated that the augmented intervention had a favourable effect in FMA-UL (p=0.04), while the effect of both augmented interventions (Bobath and BASIS groups) compared to usual care did not reach statistically significant results in FMA-UL (p=0.26) and in ARAT (p=0.83).

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
				The effect of functional recovery was more influenced by the type of intervention than the dose of the intervention.
Donaldson et al. (2009a), RCT, 20 stroke survivors	Participants in two experimental groups received fully supervised upper-limb rehabilitation sessions for up to 1 hour each session, 4 sessions per week for 6 weeks in addition to usual care (a maximum of 24 hours). These two experimental groups were: conventional physical therapy (CPT, n=10) and functional strength training (FST, n=10).	Usual care (n=10)	ARAT and NHPT (baseline and 6 weeks)	No statistically significant differences were found between the three groups in the identified outcome measures at 6 weeks in ARAT (p=0.232) and NHPT (p=0.928) however, participants in the FST group demonstrated the largest change in both ARAT and NHPT while participants in the CPT group showed the smallest change in these measures.
Harris et al. (2009), RCT, 103 stroke survivors	Participants in the experimental group (n=53) were asked to perform a series of upper-limb exercises 6 times per week; each session lasted 60 minutes for 4 weeks without supervision (a maximum of 24 hours).	Usual care and education book with general information about stroke (n=50)	CAHAI, ARAT and MAL- the quality of movement scale (baseline and 4 weeks)	The use of a handbook to deliver unsupervised augmented upper- limb exercises was effective in terms of cost and treatment. It was time efficient and safe with a high level of satisfaction. The participants in the intervention group achieved significant improvements compared to the control group in CAHAI (p

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
				< 0.001), ARAT (p=0.025) and MAL-quality of movement scale (p=0.007).
Dromerick et al. (2009), RCT, 52 stroke survivors	Participants in the experimental groups received fully supervised intervention for two weeks for either dose-matched to usual care group (standard CIMT group, n=19) or up to 10 hours (high-intensity CIMT group, n= 16)	Usual care (n=17)	ARAT (baseline, 2 weeks and 3 months)	Generally, there was no significant impact for the treatment groups (p<0.61). For all groups, the total ARAT scores were better at 3 months than at the baseline (p< 0.001). There were no significant differences between the standard CIMT and control groups from baseline to 2 weeks and from baseline to 3 months. During comparison of all three groups, a significant group x time interaction (p < 0.01) was noted for the total ARAT for the high-intensity CIMT group. Moreover, the ARAT scores from baseline to 3 months were significantly lower for high-intensity CIMT patients than for those in both the control group and the standard CIMT group (p<0.006 and p<0.01, respectively).

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
Burgar et al. (2011), RCT, 54 stroke survivors	Participants in the experimental groups received fully supervised upper-limb sessions mediated by robotic devices, for either up to 15 (low-dose group, n=19) or 30 (high-dose group, n= 17) hours, or while receiving usual rehabilitation sessions of up to 15 hours (n=18) in addition to their usual care. The planned augmented intervention was terminated either when participants completed their scheduled number of sessions or when they were discharged from hospital.	N/A	FMA-UE, WMFT (baseline, post-intervention and 6 months)	No significant group differences were observed for both FMA-UE and WMFT at post-intervention and 6 months p=0.47 at post-intervention and p=0.26 at 6 months for FMA-UE, p=0.75 at post-intervention and p=0.05 at 6 months for WMFT-functional ability; and p=0.65 at post-intervention and p=0.08 at 6 months for WMFT- time. A significant dose correlation was found for robotic exercises on FMA-UE scores at the post-intervention assessment (p=0.04).
Kwon et al. (2012), RCT, 26 stroke survivors	Participants in the experimental group (n=13) practised extra upper-limb sessions. Each session lasted for 30 minutes, 5 days a week for 4 weeks in addition to usual care (a max of 10 hours).	Usual care (n=13)	FMA-UE and MFT (baseline and post-intervention)	Both groups scored significant improvements in FMA ($p < 0.05$), but only the experimental group reached a significant score in MFT ($p < 0.05$). The study did not compare the results of the two groups.

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
Hayward et al. (2013), RCT, 28 stroke survivors	Participants in the experimental groups performed exercises with a dynamic splint either with (intervention group 1, n=4) or without electrical stimulation (intervention group 2, n=4) in addition to usual care. These sessions were provided 5 days per week, with each lasting for 60 minutes over 4 weeks (a max of 20 hours).	Usual care (n=20)	MAS - Item 6 (Upper Arm Function (MAS6)) (baseline and 4 weeks)	The authors demonstrated that augmented upper-limb interventions using the SMART arm could benefit stroke survivors with severe arm impairments to gain more functional recovery as there was statistically significant difference between the SMART groups compared to usual care in MAS6 (p=0.024).
Han et al. (2013), RCT, 32 stroke survivors	All the participants in this study received an arm-augmented intervention in addition to their usual care. The participants were allocated to one of three different groups; group A (1 hour, n=11, a max of 30 hours), group B (2 hours, n=10, a max of 60 hours) and group C (3 hours, n=11, a max of 90 hours). All of these augmented interventions were fully supervised and provided 5 times per week for 6 weeks.	N/A	FMA-UE and ARAT (baseline, 2 weeks, 4 weeks and 6 weeks)	This study suggested that increasing arm rehabilitation could improve arm function. At 2 weeks, there were no significant differences between the groups in both FMA-UE (p=0.098) and ARAT (p=0.160). At 4 weeks, the participants in group C showed significantly greater improvement than the participants in groups A and B in FMA-UE (p=0.025). In ARAT, the participants in group C showed significantly greater improvement than group A only and relatively greater improvement than group B (p=0.023).

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
				At the 6 weeks assessment, participants in groups B and C improved more than group A in both ARAT (p=0.008) and FMA-UE (p=0.005). No statistical difference was detected between groups B and C.
Yin et al. (2014), RCT, 26 stroke survivors	Participants in the intervention group (n=13) received an extra nine sessions, each lasting for 30 minutes, over two weeks in addition to usual care (a maximum of 4.5 hours).	Usual care (n=13)	FMA-UE, ARAT and MAL- quality of movement scale (baseline, 2 weeks and 1 month)	No significant differences between the groups were identified in all of the outcome measures p=0.65 at 2 weeks and p=0.97 at 1 month for FMA-UE, p=0.65 at 2 weeks and p=0.25 at 1 month for ARAT, and p=0.83 at 2 weeks and p=0.097 at 1 month for MAL- the quality of movement scale.
English et al. (2015), RCT, 190 stroke survivors	Participants in the experimental groups received augmented sessions for both upper and lower extremities for a period of 4 weeks. These groups were: seven-day treatment (SDT) n=96, max of 3 hours group and circuit class (CC), n= 93, max of 22 hours).	Usual care (n=94)	WMFT- time, (baseline and 4 weeks)	The result did not show a statistically significant difference between the groups (p=0.45).

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
Kong et al. (2016), RCT, 105 stroke survivors	Two experimental groups, Nintendo Wii (NW, n=35) and conventional therapy (CT, n=35) received usual care in addition to 12 extra upper-limb sessions, each lasting for 60 minutes, for the period of 3 weeks (a maximum of 12 hours) with full supervision from the occupational therapist.	Usual care (n=35)	FMA-UE and ARAT (baseline, 3 weeks, 7 weeks and 15 weeks)	There were no statistically significant differences between the groups at the different points of the assessment p=0.15 at 3 weeks, p=0.31 at 7 weeks and p=0.30 at 15 weeks for FMA-UE and p=0.21 at 3 weeks, p=0.26 at 7 weeks, and p=0.41 at 15 weeks for ARAT. The researchers attributed the non-significant differences between the groups to the number of participants who had severe arm impairment as most of the participants recruited in this study had severe arm impairment.
Brkic et al. (2016), RCT, 24 stroke survivors	Participants performing unsupervised two selected upper-limb tasks (or part of tasks if participants couldn't complete tasks), 20 times each session, 2 sessions a day for one month in addition to their usual care (n=13).	Usual care and education book with general information about stroke (n=11)	ARAT (baseline, one month/3 months)	Group comparison was not performed. This study suggested that delivering an unsupervised intervention using an individualised handbook was feasible and acceptable for the participants.

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
Kwakkel et al. (2016), RCT, 159 stroke survivors	Participants were stratified into two groups according to their ability to extend their fingers to receive fully supervised interventions. These were participants with a favourable prognosis (n=29) (>10° of finger extension) and an unfavourable prognosis (n=50). The first group received one hour per day of CIMT over three weeks or usual care (a max of 7.5 hours), while the second group were assigned to one hour per day of EMG-NMS over three weeks or usual care (a max of 7.5 hours).	Participants were stratified to two groups of usual care, participants with a favourable prognosis (n=29) and an unfavourable prognosis (n=51)	ARAT, FMA-UE, NHPT, FAT, WMFT (Baseline, 5 weeks, 8 weeks, 12 weeks, 26 weeks)	The results presented clinically significant differences in ARAT only in favour of CIMT at 5 (p=0.011), 8 (p=0.002), and 12 (p=0.023) weeks post-stroke. However, there were no clinically significant differences at 26 weeks post-stroke. No clinically significant differences were found in favour of EMG-NMS in any of the assessed measures. Although significant improvements in upper-limb function were observed, there was no evidence that either CIMT or EMG-NMS had an impact on neurological improvements in the period immediately following a stroke.

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings
Horsley et al. (2019), RCT, 50 stroke survivors	Participants in the intervention group were encouraged to perform reaching exercises with a dynamic splint in addition to usual care (n=25). This augmented intervention was provided 5 days per week, with each lasting for one hour over five weeks (a max of 25 hours).	Usual care (n=25)	MAS - Item 6, 7 and 8 (baseline, 5 weeks and 7 weeks)	There were no statistically significant differences between the intervention and control groups at both 5 and 7 weeks.
Rogers et al. (2019) RCT, 21 stroke survivors	Participants in the intervention group (n=10) received upper-limb sessions, each lasting for 30 - 40 minutes, over four weeks in addition to usual care (a max of 4.8 hours).	Usual care (n=11)	Box and Blocks Task (baseline, post-intervention and two months.	Participants in the intervention group achieved significant improvements compared to the participants in the control group in Box and Blocks Task (p =0.008) post- intervention.

Abbreviations:

Randomised Control Trial (RCT), Action Research Arm Test (ARAT), Frenchay Arm Test (FAT), Nine Hole Peg Test (NHPT), Rivermead Motor Assessment (RMA), Fugl-Meyer Assessment-Upper extremity (FMA-UE), Functional Test of the Hemiparetic Upper Extremity [FTHUE], Orpington Prognostic Scale (OPS), Chedoke Arm and Hand Activity Inventory (CAHAI), Motor Activity Log (MAL), Wolf Motor Function Test (WMFT), Manual function Test (MFT) and Motor Assessment Scale (MAS)

Table 2.5 PEDro scores for the studies included in this review

Author	C1	C2	C3	C4	C5C	C6	C7	C8	C9	C10	C11	**Total (max 10)**
Sunderland et al. (1992)	1	1	0	1	0	0	1	1	0	1	1	(6/10)
Lincoln et al. (1999)	1	1	1	1	0	0	1	0	0	1	1	(6/10)
Parry et al. (1999)	0	1	0	0	0	0	1	1	0	1	1	(5/10)
Rodgers et al. (2003)	1	1	1	1	0	0	1	1	1	1	1	(8/10)
Winstein et al. (2004)	1	1	1	1	0	0	0	1	0	1	1	(6/10)
Platz et al. (2005a)	1	1	1	1	0	0	1	1	1	1	1	(8/10)
Donaldson et al. (2009a)	0	1	1	1	0	0	1	1	1	1	1	(8/10)
Harris et al. (2009)	1	1	1	1	0	0	1	1	1	1	1	(8/10)
Dromerick et al. (2009)	1	1	0	1	0	0	1	1	1	1	1	(7/10)
Burgar et al. (2011)	1	1	0	1	0	0	1	1	0	1	1	(6/10)
Kwon et al. (2012)	1	1	0	1	0	0	1	0	0	1	1	(5/10)
Hayward et al. (2013)	1	1	1	1	0	0	1	0	1	1	1	(7/10)
Han et al. (2013)	1	1	1	1	0	0	1	1	1	1	1	(8/10)
Yin et al. (2014)	1	1	1	1	0	0	0	1	0	1	1	(6/10)
English et al. (2015)	1	1	1	1	0	0	1	1	0	1	1	(7/10)
Kong et al. (2016)	1	1	0	1	0	0	0	1	0	1	1	(6/10)
Brkic et al. (2016)	1	1	0	1	0	0	0	1	0	1	1	(5/10)
Kwakkel et al. (2016)	1	1	0	1	0	0	1	1	1	1	1	(7/10)
Horsley et al. (2019)	1	1	1	1	0	0	1	1	1	1	1	(8/10)
Rogers et al. (2019)	1	1	1	1	0	0	0	1	0	1	1	(6/10)

C1=Eligibility Criteria (do not count for overall score); C2: Random Allocation; C3: Concealed Allocation; C4: Baseline Comparability; C5: Participant Blinding; C6: Blinding Therapist; C7: Assessor Blinding; C8: < 15% Dropout; C9: Intention to Treat; C10: Between-Group Difference, C10: Point Estimate and Variability.

The included studies operationalised the term 'augmented' differently, as the augmented dose was performed by increasing time of rehabilitation, increasing the number of sessions or the number of repetitions, combined or separately. In these studies, different outcome measures were used to assess arm function; the most commonly used were ARAT (11 studies) and FMA-UE (8 studies). Eleven of these studies had two experimental groups while eight had only one group in addition to the control groups (Rodgers et al., 2003, Harris et al., 2009, Kwon et al., 2012, Yin et al., 2014, Brkic et al., 2016, Sunderland et al., 1992, Horsley et al., 2019, Rogers et al., 2019). The majority of these studies compared augmented interventions with usual care alone, except for 4 studies, two of which provided participants in the control group with generic information about stroke (Harris et al., 2009, Brkic et al., 2016), while the other two provided lower doses of the augmented intervention in addition to usual care (Burgar et al., 2011, Han et al., 2013).

The effects of these augmented interventions varied, as seven studies demonstrated significant benefits in favour of the augmented intervention (Parry et al., 1999, Winstein et al., 2004, Harris et al., 2009, Han et al., 2013, Hayward et al., 2013, Lincoln et al., 1999, Rogers et al., 2019, Sunderland et al., 1992, Kwakkel et al., 2016) while the remaining eight studies did not (Rodgers et al., 2003, Burgar et al., 2011, Donaldson et al., 2009a, English et al., 2015, Kong et al., 2016, Yin et al., 2014, Horsley et al., 2019, Dromerick et al., 2009). One study showed favourable effect in one of their two augmented groups while the effect of both intervention groups was not statistically significant compared to usual care (Platz et al., 2005a). In addition, two studies did not perform a group comparison (Brkic et al., 2016, Kwon et al., 2012).

2.4.5 Discussion

The effectiveness of augmented intervention was not confirmed; however, based on this review, three main factors were found to influence the effectiveness of augmented interventions. These were type of the augmented intervention, the population (severity of stroke survivors' arm impairment) and the dose of the augmented intervention. For the type of intervention, Parry et al. (1999), Platz et al. (2005a), Donaldson et al. (2009a), Lincoln et al. (1999) and Winstein et al. (2004) compared different augmented interventions and indicated that augmented functional task-oriented exercises were the most effective type of intervention. In relation to the dose, 10 hours of additional rehabilitation over 5 weeks are required to be effective in improving arm function and only in participants who do not have severe arm impairment (Parry et al., 1999, Lincoln et al., 1999) or 15 hours a month of augmented

intervention is required to improve arm function if the intervention is targeting functional tasks (Platz et al., 2005a). Other studies that demonstrated a positive effect investigated at least 20 hours of augmented interventions over a period of 4-6 weeks (Winstein et al., 2004, Harris et al., 2009, Han et al., 2013) and furthermore, Han et al. (2013) found that a higher dose of the same content resulted in greater improvements. With regard to the population, participants with less severe arm impairment were found to benefit from the augmented intervention the most (Parry et al., 1999, Winstein et al., 2004, Kong et al., 2016, Lincoln et al., 1999). Winstein et al. (2004) and Parry et al. (1999) stratified their participants into two groups based on their level of arm impairment and reported that people with less arm impairment benefited more from upper-limb augmented interventions compared to those with sever arm impairment.

Conducting a meta-analysis was not considered as it was difficult to rationalize the data (the included studies investigated different doses of augmented intervention). In addition, limited number of studies stratified the participants based on their arm impairment.

Seven studies showed statistically significant differences, favouring the augmented interventions due to the population (stratifying the participants into less impaired and more severely impaired participants, the favourable effect occurs on the less impaired participants only) and the high doses of functional augmented intervention (Parry et al., 1999, Harris et al., 2009, Han et al., 2013, Lincoln et al., 1999, Winstein et al., 2004, Hayward et al., 2013, Rogers et al., 2019, Kwakkel et al., 2016). Nine studies reported non-statistically significant changes, this lack of significant effect may be due to the low-dose augmented intervention and the lack of investigation into the effect of augmented intervention for solely participants with less severe arm impairment (Donaldson et al., 2009a, English et al., 2016, Yin et al., 2014, Kong et al., 2016, Horsley et al., 2019, Rodgers et al., 2003, Burgar et al., 2011, Dromerick et al., 2009, Platz et al., 2005a). Donaldson et al. (2009a) delivered a relatively high dose of augmented intervention (up to 24 hours in total); however, was underpowered. In addition, English et al. (2015) delivered a relatively high dose of augmented intervention (up to 22 hours); however, this augmented intervention was not focused on improving upper-limb function as it was focus on restoring general function and independency such as ability to walk.

The majority of these studies required supervision from healthcare providers to deliver the augmented upper-limb intervention; however, healthcare providers find it difficult to deliver the recommended dose of 45 minutes each session and to provide five sessions per week for stroke survivors, not to mention the need to deliver augmented interventions (National Institute

for Health and Clinical Excellence, 2013, Clarke et al., 2018). In addition, there is an inconsistency in the delivery of rehabilitation in different areas across the UK (more details about how rehabilitation is provided in the UK is provided in section 2.2.2) (Sentinel Stroke National Audit Programme, 2019, National Services Scotland Information and Intelligence, 2019). It is therefore necessary to explore new approaches to delivering augmented interventions without supervision from healthcare providers. Telerehabilitation interventions have a huge potential to deliver such interventions (more details about telerehabilitation interventions are provided in section 2.5) (Laver et al., 2020). It should be noted that none of the studies included in the review used technology to deliver their intervention; therefore, future studies in this area should investigate the feasibility and efficacy of delivering unsupervised augmented rehabilitation using technology, in order to lower the load placed on healthcare providers and to facilitate the rehabilitation provided to stroke survivors.

The augmented interventions in the included studies were varied in terms of their type and dose, making rationalising their findings difficult. The validity of findings about the efficacy of the augmented interventions is therefore limited. Particularly, it was not possible to confirm which aspect of the augmented intervention (dose or type) had more of an influence on participant outcomes. However, the presented systematic review provided preliminary findings about the efficacy of the augmented intervention and it can be used as a basis for future research, which should investigate the dose-response of the augmented intervention in order to better judge its efficacy.

In summary, three main factors could influence the efficacy of these interventions: type and dose of augmented intervention, and the level of participant's arm impairment. It is significant to note that despite the need of developing new tools to deliver unsupervised upper-limb interventions, most of the studies investigated fully or partially supervised augmented interventions, and only two studies explored feasibility and potential efficacy of unsupervised augmented interventions, and none used technology to administer the interventions. Even though this systematic review has some methodological issues as it compared different interventions that are not dose-matched which might limit the validity of the findings, it helped to justify the intended outcome of the feasibility study and also to highlight the contribution of the feasibility study to the available literature.

2.5 Telerehabilitation in stroke

As the incidence of stroke is expected to increase along with the projected increase in population in developed countries (Truelsen et al., 2006), developing new useful and cost-effective intervention approaches is required. Interest in using technology in rehabilitation is increasing (Brochard et al., 2010, Johansson and Wild, 2011, Tchero et al., 2018, Laver et al., 2020). Telerehabilitation can be defined as the use of information and communication technology to deliver rehabilitation services over a distance (Brennan et al., 2009).

Different technology tools can be used in stroke rehabilitation for patients to communicate with the rehabilitation team, including videophone (Forducey et al., 2012) and telephones (Boter and Hestia Study Group, 2004, Mayo et al., 2007, Chumbler et al., 2012). Furthermore, technology has also been used as a tool to deliver therapy for stroke survivors, for example the use of virtual reality (Rogante et al., 2010), robotics (Wolf et al., 2015), online website (van den Berg et al., 2016) and videodisk that include recorded exercises (Redzuan et al., 2012). Electronic databases including Pedro, Medline and Embase were examined in December 2020 to identify the available literature related to telerehabilitation for stroke population using the following keywords “Telerehabilitation AND Stroke”.

A previous systematic review investigated the effectiveness of telerehabilitation interventions for people with stroke (Johansson and Wild, 2011). The review included nine studies and within these studies different telerehabilitation tools were used and that included telephone (Boter and Hestia Study Group, 2004, Grant et al., 2002), videophone (Buckley et al., 2004), videoconferencing hardware and software (Huijgen et al., 2008, Piron et al., 2009, Holden et al., 2007, Piron et al., 2004, Lai et al., 2004), and online website (education and support for caregivers) (Pierce et al., 2004). The quality of the included studies was weak, with only small sample size and only four studies were RCTs; therefore, it was difficult to determine the efficacy of telerehabilitation interventions. However, these interventions provided promising results but more research studies with better quality were needed (Johansson and Wild, 2011).

A more recent and more robust systematic review and meta-analysis was conducted by Tchero et al. (2018) to establish whether telerehabilitation interventions were effective for the stroke population. Unlike the systematic review conducted by Johansson and Wild (2011), Tchero et al. (2018) included RCTs only. Fifteen studies were included in the systematic review and of those, twelve were included in the meta-analysis. The interventions in the included studies were

delivered in participants' homes except one intervention which was delivered in an in-patient setting (van den Berg et al., 2016). In addition, the aims of the interventions in the included studies were varied. Four studies aimed at improving upper-limb function (Piron et al., 2009, Piron et al., 2008, Huijgen et al., 2008, Wolf et al., 2015), four studies aimed at improving lower limb function and balance (Chumbler et al., 2012, van den Berg et al., 2016, Lin et al., 2014, Llorens et al., 2015), five studies aimed at improving quality of life and depression (Boter and Hestia Study Group, 2004, Mayo et al., 2007, Linder et al., 2015, Forducey et al., 2012, Smith et al., 2012) and two studies aimed at improving ADLs (Chen et al., 2017, Redzuan et al., 2012). Furthermore, the telerehabilitation tools used also varied. These tools were: telephone (Boter and Hestia Study Group, 2004, Mayo et al., 2007, Chumbler et al., 2012), videophones (Forducey et al., 2012), online website (chat programme and stroke resources) (Smith et al., 2012), videoconferencing hardware and software (Chen et al., 2017, Huijgen et al., 2008, Piron et al., 2009, Piron et al., 2008, Lin et al., 2014, Linder et al., 2015, Llorens et al., 2015, Wolf et al., 2015), online application (rehabilitation exercises and stroke resources) (van den Berg et al., 2016) and videodisks (Redzuan et al., 2012). Tchero et al. (2018) demonstrated that telerehabilitation interventions were feasible and could be used as an alternative to face to face interventions, as telerehabilitation interventions showed similar effects to usual care interventions with no statistically significant differences between the groups in the Barthel Index, the Berg Balance Scale, the Fugl-Meyer Assessment for upper extremity, and the Stroke Impact Scale. However, more studies are required to confirm these findings. Some limitations were highlighted by the researchers, such as small sample sizes and an inability to analyse some of the data as a result of heterogeneity.

Another recent review conducted by Laver et al. (2020) aimed to determine the effect of telerehabilitation interventions compared to interventions delivered face to face or when there is no intervention or usual care. This review provided more robust evidence and included more RCTs than Tchero et al. (2018) systematic review. Twenty-two studies were included in this review; of these, fourteen studies were included in the meta-analysis. Similar to the systematic review conducted by Tchero et al. (2018), all of the included studies were RCTs and were heterogenous in terms of the aims of the interventions and how they were delivered (Laver et al., 2020). All the included studies investigated telerehabilitation interventions in out-patient settings (participants' homes or a long-term care facility). The aims of the interventions varied, as eight targeted enhancing health and well-being (Boter and Hestia Study Group, 2004, Smith et al., 2012, Mayo et al., 2007, Bishop et al., 2014, Kirkness et al., 2017, Saal et al., 2015,

Rochette et al., 2013, Wan et al., 2016), six targeted enhancing upper-limb function (Huijgen et al., 2008, Piron et al., 2008, Piron et al., 2009, Bizovičar et al., 2016, Carey et al., 2007, Cramer et al., 2018), six targeted enhancing lower-limb functions, mobility and balance (Llorens et al., 2015, Chumbler et al., 2012, Lin et al., 2014, Deng et al., 2012, Chen et al., 2017, Forducey et al., 2012) and two targeted enhancing speech and language (Meltzer et al., 2018, Vauth et al., 2016). The tools used to deliver the intervention include telephone, videophones, an online website and videoconferencing hardware and software. Low- or moderate-level evidence explained that telerehabilitation interventions are feasible and associated with outcomes for ADLs that are equivalent to face-to-face interventions and no therapy or usual care (Laver et al., 2020).

Even though the effectiveness of these different telerehabilitation tools is not yet confirmed previous research studies found using technology tools for rehabilitation feasible with high satisfaction (Johansson and Wild, 2011, Tchero et al., 2018, Laver et al., 2020).

Our research group has developed a website, www.webbasedphysio.com (now www.giraffehealth.com), to deliver and monitor physiotherapy rehabilitation. The website contains three main sections: exercise, home page, and advice. The exercise section consists of an extensive library of exercise pages, each with a video showing a specific exercise with written and audio explanation of each exercise. The feasibility and acceptability of this web-based physiotherapy have been tested for people with multiple sclerosis and demonstrated improvements in symptoms and physical function with high satisfaction rates among both patients and therapists (Paul et al., 2014, Paul et al., 2019). It was not clear whether web-based physiotherapy is accessible for those with cognitive impairment as these patients were excluded in Paul et al. (2019), while cognitive functions were not measured for the participants in Paul et al. (2014) study. The website has been tested and modified to suit people with chronic obstructive pulmonary disease, axial spondyloarthritis and spinal cord injury populations (Coulter et al., 2016, Coulter et al., 2015a, Coulter et al., 2015b) and also for those with diabetes from South Asian communities in the UK (Paper at review). Only a few participants in all the studies conducted using web-based physiotherapy encountered difficulties in reading the content of the website and navigating the website, while the majority did not experience any difficulties. Although the current web-based physio platform has shown positive results, the website has not been tested for people with poor cognitive function and it has also not been modified for people who have experienced a stroke. Future studies aiming to use the website

for the stroke population need to consider modifying the website to meet the needs of the stroke population in advance.

For the stroke population, web-based platforms have been developed for different purposes such as educational goals and support (Kim et al., 2013, Steiner and Pierce, 2002), but studies that deliver both rehabilitation exercises and provide stroke resources are very limited. In terms of using the internet for therapeutic purposes, different tools of telerehabilitation have been found to be feasible and satisfactory for people after stroke (Johansson and Wild, 2011, Tchero et al., 2018, Laver et al., 2020). However, these tools differ to the web-based physio platform as they need either a direct connection with a professional (such as telephone (Boter and Hestia Study Group, 2004, Mayo et al., 2007, Chumbler et al., 2012) or videophones (Forducey et al., 2012)) or software to produce a virtual environment (like virtual reality) (Rogante et al., 2010). Only one study conducted by (van den Berg et al., 2016) used a telerehabilitation tool to deliver rehabilitation programmes along with stroke resources; however, it was conducted in the Netherlands while the web-based physiotherapy platform used in this PhD work has been used in the UK for different long-term conditions and showed positive effects with high satisfaction rates (Paul et al., 2014, Paul et al., 2019, Coulter et al., 2016, Coulter et al., 2015a, Coulter et al., 2015b), but not yet used for stroke population.

2.5.1 Advantages and challenges of telerehabilitation in stroke

Telerehabilitation provides an opportunity to overcome barriers that inhibit stroke survivors from participating in rehabilitation programmes, including cost, transportation and access to rehabilitation; furthermore, it promises to provide unsupervised augmented interventions (Laver et al., 2013). Despite the advantages that are associated with telerehabilitation interventions, there also a key challenge that is delivering professional hands-on therapy which includes techniques in assessing and treating stroke survivors (Russell, 2009). There are many challenges that inhibit patients from engaging in and/or adhering to telerehabilitation interventions and these include the complexity of the interventions and poor knowledge sharing about telehealth innovations (Standing et al., 2018). The available evidence is limited, and the methods used in these studies are frequently reported as heterogeneous (Kumar et al., 2013). Furthermore, there are a lack of frameworks, polices and funds to support this area of research (Johnston et al., 2015). A noteworthy point is the growing interest in telerehabilitation interventions as the number of RCTs included in systematic reviews in telerehabilitation for stroke patients is increasing over time (Laver et al., 2020, Tchero et al., 2018, Johansson and

Wild, 2011). Another challenge for patient engagement is the resistance of healthcare providers and patients to technology (Standing et al., 2018). The risk of experiencing a stroke is increased when people get older (Roger et al., 2012), and older people are generally thought to be less confident in using new technology and would rather prefer to continue face-to-face therapy instead (Laver et al., 2020). Healthcare providers are reported as being more resistant to using new technology than patients (Burke et al., 2015). It is essential for healthcare providers to support the use of technology in rehabilitation in order to maximise patients' engagement in rehabilitation (Hamilton et al., 2018). The ongoing development in communication technology is also challenging patients' engagement in telerehabilitation as they need to use a reliable and easy-to-use tool or piece of equipment (Standing et al., 2018). The lack of user-centred approach in health approaches may also limit patients' engagement in telerehabilitation interventions (Standing et al., 2018) as a user-centred approach would enhance patients' engagement with telerehabilitation. The engagement of the target population in the development of a telerehabilitation intervention is fundamental as it maximises the quality of the intervention and ensures that it is accessible to the target population (Jankowski et al., 2017). Consideration of all of the above listed challenges is essential to ensure a proper implementation of telerehabilitation interventions and also to ensure patient involvement in active rehabilitation

It is important to address rehabilitation barriers and minimise challenges as lack of physical activity and exercise among stroke survivors, which can lead to an increased incidence of recurrent stroke and a decrease in physical function and cardiovascular fitness (Billinger et al., 2014). Therefore, studies investigating telerehabilitation in stroke are essentials as telerehabilitation could be an effective way to deliver rehabilitation to people following stroke.

2.6 Identified gaps in the literature

Despite the evidence suggesting the need for a higher dose of rehabilitation to facilitate neuroplasticity and functional recovery in stroke survivors, especially in the early stages after stroke (sections 2.3.2 - 2.3.3), current practice in most stroke unites within the UK do not meet the recommended dose of rehabilitation (section 2.2.2). Stroke survivors, carers and healthcare professionals identified improving arm function as a research priority (Pollock et al., 2014a). The majority of the research studies that investigated upper-limb augmented interventions were fully supervised and none of them used technology as a medium to deliver rehabilitation programmes. Many telerehabilitation tools have been investigated for the stroke population,

but a limited number of these tools have delivered exercises and resources for the stroke population (section 2.5). Most of the telerehabilitation studies are home based studies while the technology could also be used to augment in patient therapy to help reach the recommended guidelines. Further studies on the implementation of non-supervised augmented intervention are required due to the limited number of therapists and the increasing number of stroke survivors worldwide (Stewart et al., 2017).

2.7 Telerehabilitation interventions to engage hospitalised stroke survivors in augmented upper-limb exercise programmes

One possible way to provide non-supervised rehabilitation is to develop a telerehabilitation tool that enables stroke survivors to perform their rehabilitation programme independently or with the support of non-clinical staff. Upper-limb rehabilitation programmes are mainly delivered by physiotherapists and occupational therapists, but these programmes have been delivered by other health professionals or even by a family member or carer with similar improvements in terms of arm function and activities of daily living measures; however, evidence to support these interventions has been limited (Harris et al., 2009, Coupar et al., 2012a). However, a recent systematic review suggested that some self-directed arm therapy programmes can be effective in improving arm function and activity of daily living measures, but this effect may vary based upon the type of the interventions and timing of the rehabilitation (Da-Silva et al., 2018). Indeed, based on the review (section 2.4), no studies have investigated the effectiveness of telerehabilitation methods in providing unsupervised upper-limb-augmented interventions in an inpatient setting and only two studies have investigated unsupervised augmented interventions during the hospitalisation period using other methods (Harris et al., 2009, Brkic et al., 2016). Therefore, it is important to examine the effectiveness of these approaches for hospitalised stroke survivors as telerehabilitation approaches have been found to be promising in the delivery of augmented interventions during the first month after the stroke onset – a crucial period in patients' rehabilitation journeys, when neuroplasticity is at its peak (Krakauer et al., 2012, Nakayama et al., 1994).

2.7.1 Web-based physiotherapy platform as a mode to deliver augmented interventions

Web-based physiotherapy website used in this PhD work is a novel mode of rehabilitation delivery; it can address some of the barriers that prevent hospitalised stroke survivors from participating in augmented upper-limb rehabilitation programmes. The website can provide

upper-limb exercises without the supervision of a rehabilitation team as the exercises are initiated by professionals and the instructions on how to perform each exercise are tailored to each stroke survivor. This can overcome the inability to meet the recommended time of rehabilitation sessions for each stroke survivor demonstrated by Clarke et al. (2018) and discussed in section 2.2.2. The website offers on-demand physiotherapy sessions that are available 24/7 and thus can be accessed by stroke survivors at times convenient to them. The availability of these sessions is important as patients spend most of their time being inactive as reported by West and Bernhardt (2012). Thus, the web-based physiotherapy may be a potential tool to deliver augmented upper-limb physiotherapy for stroke survivors in an inpatient setting.

Until now, no studies have assessed the feasibility of using the web-based physiotherapy platform to deliver augmented upper-limb physiotherapy for hospitalised stroke survivors. Therefore, prior to using this platform in the clinical setting, it was important to explore the views of stroke survivors and their carers about the website in order to modify it based on their needs and preferences. Modifying the website to suit this population would make it acceptable and fit for purpose, promote patient-centred care and lay a solid foundation for future research studies in this area of rehabilitation delivery.

Chapter 3 Customization & Modification of a Web-based Physiotherapy Website through User-Centred Design

Chapter Two discussed the identified gap in the literature, which showed the need to customise and refine an existing website, a web-based physio platform (www.webbasedphysio.com, now www.giraffehealth.com), as this website had never been used for a stroke population.

The study presented in this chapter followed stage one of the MRC framework, which includes the following four stages (Craig et al., 2013):

1. Development of the intervention
2. Piloting and feasibility
3. Evaluation
4. Implementation

This Chapter focussed on development of the intervention (stage 1) of the MRC framework. This study relied on a User-Centred Design (UCD) to explore the views of stroke survivors and their carers about an existing web-based physiotherapy website with the aim to modify it to suit the stroke population (Janamian et al., 2014, Mao et al., 2005) (see section 3.6). This informed the next stage of this thesis and the MRC framework (Chapters 4–6). This chapter presents the specific aims of the study, research questions, methodological underpinnings, research design, participant recruitment, data collection process, data analysis, as well as the discussion and conclusion.

3.1 The web-based physiotherapy platform

The web-based physiotherapy platform (www.webbasedphysio.com, now www.giraffehealth.com), enables physiotherapists and other healthcare professionals to create individually tailored exercise programmes for their patients and to monitor patient progress. The platform includes an advice and education section, a library of exercise videos and an exercise diary section. The physiotherapist can enter the platform using their unique username and password. Physiotherapists have admin account privileges enabling them to create named accounts for their patients. The physiotherapist can then draw upon the resources available on the platform to create an exercise programme based on the individual patient's needs and capabilities. The video library is diverse, including clips of exercises that range in their difficulty and nature. To tailor the exercise programme, the physiotherapist selects the

appropriate exercise videos for the patient and adds accompanying written instructions against each video. The general advice section may also be modified by the physiotherapist as required.

To activate a patient's account after it has been created by the physiotherapist, the patient receives an email with a confirmation link and the opportunity to set a password. Having successfully logged into the platform, patients will be able to view the exercise programme that the physiotherapist has created for them, the specifically selected videos and the accompanying written instructions and the general advice section. The platform also provides the patients with the opportunity to write notes for the physiotherapists in the diary section, to provide their feedback about the personalised exercise programme.

The feasibility and effectiveness of using web-based physiotherapy were examined for people with different long-term conditions (discussed in more details in section 2.5). Even though the web-based physiotherapy platform was developed for people with different long-term conditions, the website needed to be customized according to the needs and preferences of the stroke population since strokes may cause different levels of impairment, including physical and cognitive abilities (Intercollegiate Stroke Working Party, 2016). As such, the design and content (advice section and exercise video clips) of the original version of the platform might not be suitable and/or acceptable for the stroke population (Mao et al., 2005, Janamian et al., 2014). In order to avoid this issue, which may lead to a lack of use, it was critical to modify the website so that it met the needs and preferences of the stroke population. The main purpose of customizing the web-based physiotherapy platform for the stroke population was to create a tool for exercise delivery, either for hospitalized patients (as augmented exercises) or discharged stroke patients; it was not intended to be used as an alternative to usual stroke care.

3.2 Aim of the study

The main aim of this study was to explore the views of stroke survivors and their carers about the web-based physiotherapy website with the aim to modify it using a user-centred approach. Specifically, the researcher sought to use the views, feedback and recommendations of the participants to modify or reconstruct an existing web-based physiotherapy website through the user-centred approach. Data collection and analysis methods commonly associated with qualitative research, namely focus groups and thematic data analysis, are often used in user-centred studies (Hawkins et al., 2017) and hence were adopted in this study.

3.3 Research questions

- What are the views of stroke survivors and their carers on using web-based physiotherapy to deliver their rehabilitation programme?
- What are the strengths and weaknesses of the current version of the current web-based physiotherapy website for people after stroke?
- What modifications are required for the current web-based physiotherapy website in order to make it acceptable and suitable for people with stroke and their carers?

Carers are defined as anyone such as a family member, a friend, or even a child who is responsible for providing care on a regular basis for a person who has a disability (Nantional Health Service, 2020). The care provision comprises assisting patients in basic daily activities and tasks including help with feeding, food preparation, cleaning, washing, dressing and mobility, which could not be done independently by the patient (Nantional Health Service, 2020).

Given the above set of research aims and questions, the methodological underpinnings of the research are presented below in section 3.5.

3.4 Ethical approval

Ethical approval was obtained from the Research Ethics Committee of the College of Medicine, Veterinary and Life Science, University of Glasgow, UK with the project number: 200160126 (Appendix 5).

3.5 Methodological underpinnings

Polit and Beck (2017) have argued that the plan designed and used to carry out a study can be simply referred to as its approach. The research approach used is significant for a number of reasons, not least for supporting the credibility of the research findings. Creswell and Creswell (2017) identify three core components that should influence the choice and selection of a research approach to ensure that it addresses any particular research question. These are the philosophical worldview (paradigm); the research design; and the research methods. These factors interact to guide researchers' decisions over structuring and organising the research approach and the methods employed to answer the research questions (Creswell and Creswell, 2017). It is also suggested that the research paradigm informs and guides the design and

methods (Mertens, 2008). This section provides a brief narrative of the research approach employed in this study, seeking to provide justification for the choices made during the research.

Philosophical paradigms: Understandably, every research has a philosophical underpinning and no research takes place within a philosophical vacuum. Popular philosophical positions in research include positivism, interpretivism or constructivism, and pragmatism (that is, the worldview that there may be various or multiple (subjective and/or objective) ways at arriving at reality) (Onwuegbuzie et al., 2009). Briefly, positivism is a philosophical position that seeks to abide by what is considered to be 'factual' knowledge gained through measurements and observation – that is, all knowledge should be tied to observational forms of verification and methodologically founded on scientific experiments (Knight and Ruddock, 2009). Epistemologically, positivism is seen as a position that advocates the application of the methods of the natural sciences to the study of social reality and beyond (Bryman, 2016). Furthermore, positivism posits that scientific knowledge is derived from the accumulation of data obtained theory-free and value-free from observation. This suggests that anything that cannot be observed and thus in some way measured (quantified) is of little or no importance (Creswell, 2011). Positivism is seen as a direct opposite of interpretivism and it is associated with other terms including 'postpositivist', 'empirical science' and 'postpositivism' (Creswell, 2011).

Interpretivism, also sometimes refers to as constructivism, is an approach that considers the dynamic and changing nature of society and it understands that there could be multiple interpretations of an event, shaped by the individuals' historical or social perspective (Cohen et al., 2011). This philosophical position suggests that research outcomes need to be examined through the eyes of the participants rather than through those of the researcher. Furthermore, the paradigm argues that reality is constructed through interpretations affected by culture, personal experience and worldviews (Neuman, 2014). Given that the purpose of this research was to explore the experiences of patients and carers undergoing stroke rehabilitation using web-based physiotherapy, the interpretivist paradigm was considered appropriate to help achieve the aims and objectives of this study. This study was therefore sited within an interpretive paradigm and it acknowledges that truth is subjective and value laden.

Traditionally there are two schools of thought: quantitative and qualitative approaches. In brief, qualitative research seeks to provide an understanding of social or human reality from

multiple perspectives (Denzin and Lincoln, 2011). It is usually conducted in a natural setting and involves a process of constructing a detailed and comprehensive picture of the area of interest (Neuman, 2014). The underlying assumptions in qualitative research include: the existence of multiple realities in any given situation; the fact that the research is context bound; its forms are primarily inductive; and it recognises and acknowledges the value-laden nature of research (Denzin and Lincoln, 2011, Neuman, 2014). Qualitative research conforms to interpretivism. By contrast, quantitative research involves testing theory, measuring with numbers, and analysing with statistical techniques (Tavakol and Sandars, 2014). The fundamental assumptions that underpin quantitative research include: an objective reality independent of the researcher; a primarily deductive form; and a goal of generalising and contributing to theory (Yilmaz, 2013). Quantitative research conforms to positivism. Given that this study sought to explore what would best meet the needs of stroke survivors and their carers, in relation to web-based physiotherapy, it was particularly important to give due regard to their feedback and to use it to make any necessary changes (Knobel, 2002). This study was therefore based on the qualitative approach using a UCD design and focus groups.

In terms of the research design, the researcher adopted User centred design (UCD). It has been described as “a philosophy based on the needs and interests of the user, with an emphasis on making products usable and understandable” (Norman, 1988, p.188). User centred design is often viewed as key to ensuring that a website meets the needs of its users (Mao et al., 2005, Janamian et al., 2014). It is therefore essential that this study investigates what would best fulfil the needs of stroke survivors and their carers, in relation to web-based physiotherapy, by using their feedback to make the necessary changes to the website based on the practice of UCD (Knobel, 2002). A UCD approach lies at the heart of this study, whose aim is to maximise the quality of healthcare tools and ensure that they are accessible to individuals who have had a stroke (Jankowski et al., 2017). Further explanation about how the UCD design was adopted in this study is provided below in section 3.6. Finally, the methodology of a research study describes the process and how the researcher gains the desirable knowledge and understanding (Denzin and Lincoln, 2011, Neuman, 2014).

Focus groups have traditionally been used to discover people's attitudes and beliefs and to determine their needs in user-centred studies; in this study they are used to improve web-based health interventions (Ferney and Marshall, 2006, De Vito Dabbs et al., 2009). This study brought together three consecutive focus groups of stroke survivors. Liamputtong (2010)

defines focus groups as organised discussion groups, led by one or more moderators, who come together in a safe setting to discuss their views, outlook, emotions and ideas about a particular subject, or a product (more details about focus groups are provided in section 3.10). The overarching goal was to ensure that the final website meets the needs of its target users.

3.6 User-Centred Research Design

Patient and public involvement in health and social care changes/improvements can fall into five categories: undefined involvement; targeted consultation; embedded consultation; co-production and user-led research (Hughes and Duffy, 2018). Coupe and Mathieson (2020) point out that each of these definitions describes different levels of public involvement and can be used to determine and steer the appropriate kinds of involvement in this area – while also concurrently bearing in mind resource availability. The UCD adopted in this study is a philosophy and a process that places the person at the centre and focuses on cognitive factors as they come into play during people's interactions. Although this definition does not directly suggest the necessity of user involvement in the process, it nonetheless suggests that their involvement in the process ensures that their needs and interests are being met. It is an evaluative process that uses various methods and tools within organizations to improve the understanding of user and task requirements, supporting the iteration of design and evaluation (Mao et al., 2005, Janamian et al., 2014). User-centred research has to overcome many obstacles, including: ensuring there is a shared understanding of goals; spelling out and managing the multi-faceted nature of participants' roles; elucidating the terminology linked to system development; explaining the rationale for various features; collaborating and agreeing features; converting ideas into practical features; and making sure that all of the participants are in full agreement with the goal and the undertaking (Nordgren, 2009, Revenas et al., 2015).

UCD methods can be extremely valuable, although using them in the right way, for the right reasons and at the right time is critical. The UCD expert is focused on usefulness, ease of use and ease of learning for the user (Mao et al., 2005). This approach comprises a set of steps, methods and tools.

3.6.1 Characteristics of the User-Centred Design

Fundamentality, all definitions of UCD are characterized by a focus on the user, and on incorporating the user's perspective into all the stages of the design process (Bazzano et al.,

2017). UCD puts the intended users at the centre of its development. Benyon (2014) identified the following as the salient features of the UCD approach:

- It involves the stakeholders directly during the whole of the development process.
- The processes are carried out in an iterative fashion, with the cycle being repeated until the project's usability objectives have been attained. This makes it critical that the participants in these methods accurately reflect the profile of the actual users.
- It requires the active involvement of users and a clear understanding of the user and task requirements.
- It requires an appropriate allocation of functions between the users and the research.

3.6.2 Principles of the User-Centred Design

According to INVOLVE (2019), the following key principles underpin research designs that places the service-user at the centre of the research process. The principles include the following:

- Power sharing – that is, jointly owing the research and working together to achieve a common understanding.
- Inclusiveness – that is, making sure the research team (the researchers and the participants) includes all those who can contribute meaningfully and including all perspectives and skills of the team.
- Respect and equal opportunity – that is, respecting and valuing the contribution of all the participants and the researchers and demonstrating that everyone is of equal worth.
- Reciprocity – that is, ensuring that everyone benefits as a member of the team and that no one is taking undue advantage of the team.
- Building and maintaining relationships – that is, the need for joint understanding and consensus building in order to unlock the full potential of the entire research team (the researchers and the participants and always make the team feel valued).

The researcher thought that there were good reasons for settling on the UCD. For instance, it was thought that the inclusion of stroke survivors and their carers in the design and modification of the web-based physiotherapy website would greatly enhance the quality of the targeted services. It could be argued that the three-stage framework used in this study and the involvement of stroke survivors and their carers in the UCD process provided a mechanism for

tailoring intervention(s) to the context and target population in order to maximise their acceptability and reduce the likelihood of problems with implementation.

3.6.3 Benefits and weaknesses of the User-Centred Design

Hawkins et al. (2017) highlighted that user-centred studies are associated with benefits and weaknesses aspects in a research, these are presented below:

Benefits

- It provides the needed opportunity for research participants who have the required knowledge and experience of the subject matter to be involved directly in the research right from the start to the finish of the research.

- The inclusion of the intended beneficiaries of the research outcomes during UCD process means that interventions can be tailored to meet their needs and boost credibility and acceptability.

Weaknesses

- The process of UCD at some point in time needs consolidation and validity regardless of the fact that the process appears both iterative and fluid.

- The UCD process can involve competing priorities and goals, as well as inherent interdisciplinary tensions regarding the conduct of research.

- The process of UCD can also be time-consuming requiring active engagement from those involved over an indeterminate amount of time.

3.6.4 The actual process of User-Centred Design

In terms of the actual process, a user-centred framework for interventions, presented by Hawkins et al. (2017), was adopted in this study, see Figure 3.1 below. In a recent systematic review conducted by Greenhalgh et al. (2019) that aimed to identify frameworks that could be used for involving public and patients in research, 65 frameworks were identified; however, the majority of these frameworks were used by their developers only, which implies that the transferability of these frameworks is limited. Hawkins et al. (2017) framework was considered appropriate for this study primary because it was considered simple, pragmatic, holistic and fitted with meeting the research objectives.

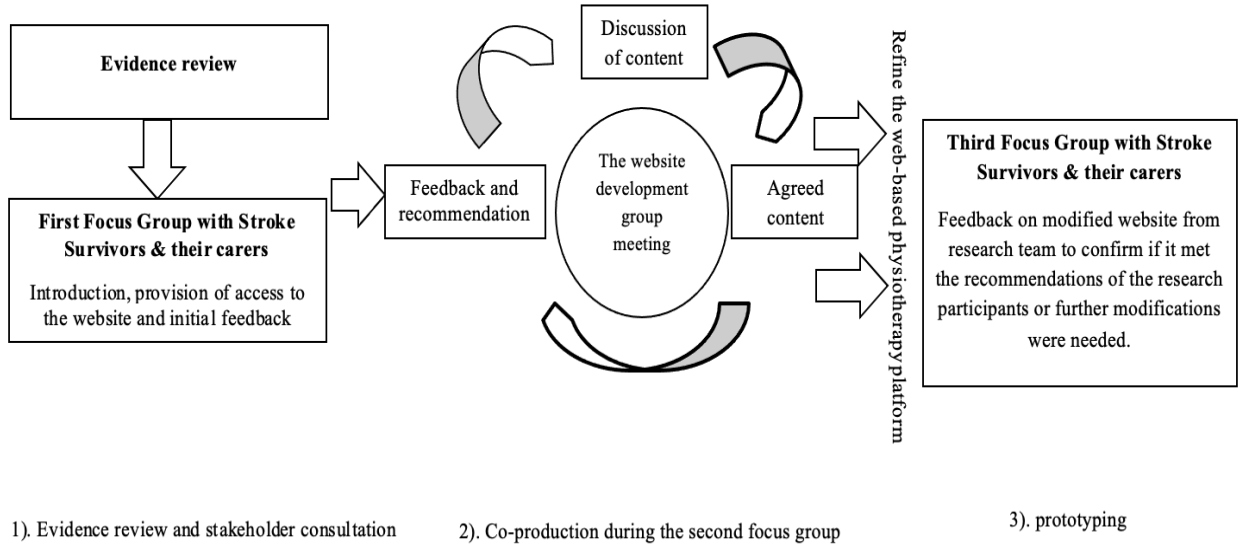


Figure 3.1 Process of User-Centred Design (Hawkins et al., 2017)

Stage one: Evidence review and stakeholder consultation

During this stage, the existing literature on the use of web-based physiotherapy to provide access to resources and for rehabilitation was reviewed in the area of telerehabilitation (Tchero et al., 2018, Johansson and Wild, 2011) and web-based physiotherapy in particular (Paul et al., 2014, Coulter et al., 2016, Paul et al., 2019, Paul et al., 2016, Coulter et al., 2015b, Coulter et al., 2015a). This stage also required the input of key stakeholders including stroke survivors and their carers with the aim of gathering vital information that would be vital to modifying the web-based platform to meet the needs of the target context and population in order to maximize acceptability and reduce problems with implementation. Inviting carers of stroke survivors was important not only because they are stakeholders in their own right, but also to ensure that stroke survivors with a higher level of disability (that is, those with limited mobility and require support from their carers) were given the opportunity to participate. This provided the researcher with a robust view about the accessibility of web-based physiotherapy. These key stakeholders were identified as people with direct experience of stroke or experience of looking after a stroke survivor. The input of the stroke survivors and their carers are reported in section 3.17.3 below.

Stage two: Co-production

The term 'co-production' is the original term used in the model of Hawkins et al. (2017), but this study did not adopt the co-production approach, instead adopting the UCD approach. Tew et al. (2004) presented a tool that can be used to detect the level of involvement of research participants in a trial, called the 'ladder of involvement'. Based on that, the level of involvement of stroke survivors and their carers was meaningfully progressed to level 4 (collaboration) in this study. The co-production phase used by Hawkins et al. (2017) is meant to be a phase for negotiation and recommendation-making in this study.

This phase of the project provided the researcher, stroke survivors and their carers the opportunity to reflect on the findings from stage one. Overall, the process was participatory and collaborative, and all members were provided with opportunities to make their voices heard (explored further under section 3.17.3).

Stage three: prototype stage

The aims of the prototype phase of the project were to refine the outcome of the first two stages of the framework (the refined web-based physiotherapy platform) and address any issues with the acceptability and feasibility of the website before conducting a formal feasibility study. A panel of experts was therefore consulted about the final modified web-based physiotherapy website (explored further under section 3.17.3). This panel comprised stroke survivors, their carers participated in this study and researchers. The participants were asked to access the website and navigate it before and after the agreed modifications to the website were implemented. This helped to detect issues with the website's accessibility and acceptability, and the feasibility of using it to deliver exercise interventions to the stroke population. The four steps used by the researcher during the UCD process to cover stages 1, 2 and 3 included the following:

1. Explore views of the participants on the original web-based physiotherapy website
2. List recommendations made by the participants for modification of the original web-based physiotherapy website
3. Negotiate with the participants on the changes that can be made using shared decision-making
4. Explore views of participants on the final, modified web-based physiotherapy website.

Although the original framework includes three stages to adapt interventions based on views of the service users; the web-based physiotherapy platform used in this study is a tool of intervention delivery and it is not an intervention by itself. The three stages of the framework offered pragmatic guidance to the participants on the UCD process and were considered most relevant to achieving the objective of the study. However, its implication has been negligible since the objective was mainly to successfully negotiate with the participants and to produce a revised platform that was more conducive for their use. In addition, this thesis presents a pilot study (chapters 4-6) that evaluated the feasibility and acceptability of the revised web-based physiotherapy to deliver exercises programmes to stroke population.

Even though the benefits of user-centred studies are well documented, it should be acknowledged that this study was negatively affected by the competing priorities and goals of the research participants (more details is provided under 'Features of meaningful UCD' heading). A further limitation was the time constraints placed on the project due to it being part of a PhD study. It was hoped that using a UCD to modify the website with the participants would give them a heightened sense of ownership and responsibility. The cumulative effect of the four steps was to give the research participants a sense of ownership/responsibility in the entire research process and a sense of pride in its outcomes. The participants were empowered to a degree when they were asked to make recommendations as to what features they liked and/or did not like about the web-based physiotherapy platform. The objective was to ensure that their recommendations were used in redesigning and tailoring it to meet their needs - hence, giving them a sense of ownership.

The involvement of healthcare professionals in the UCD process would have added to the quality of the outcomes of this study (Still and Crane, 2017). However, it was difficult for this study to invite healthcare professionals to three consecutive focus groups as their time was limited (Clarke et al., 2018). It is important to note that the supervisors in this study comprised two physiotherapists and one nurse so the views of HCPs were considered but future studies should consider more active involvement of clinicians implementing the intervention.

3.6.5 Features of meaningful User-Centred Design

It is to be noted that all of the above key principles were observed at various stages of this study alongside other established features that guide a meaningful UCD process in research (INVOLVE, 2019). These features are:

- Establishing ground rules
- Joint ownership of key decisions
- Ongoing dialogue
- A commitment to relationship building
- Flexibility
- Opportunities for personal growth and development
- Continuous reflection
- Valuing and evaluating the impact of user-led research

Establishing ground rules and a commitment to relationship building: While some of these features needed to be done from the start, for example establishing ground rules and a commitment to relationship building; other features such as ongoing dialogue and joint ownership of key decisions, valuing and evaluating the impact of user-led research, as well as creation of opportunities for continuous reflection permeated throughout the research process. The following discussion demonstrates how these features were embedded in this study.

Ongoing dialogue and joint ownership of key decisions: In this study, there was ongoing communication between the researcher and the research participants right from the onset. Further, the researcher ensured that the participant took part in key decision-making throughout the research process. For example, prior to amending the web-based physiotherapy website, the research participants were offered the opportunity to make recommendations which were considered during the amendments. The outcome showed that the modifications made to the web-based physiotherapy website would address some of the challenges they were facing with the existing website and make it patient-centred.

Valuing and evaluating the impact of user-led research and continuous reflection: The diversity of patients' preferences and experience and having them taking part in the decision-making between the researcher and participants were the main challenges and these have been confirmed in the literature (Revenas et al., 2015, Nordgren, 2009).

Although everyone's feedback about the website was given due consideration in order to make the website more acceptable to the stroke population, some suggestions were simply not feasible and had to be negotiated. Negotiations between the researcher and the research participants led to making some necessary amendments. For example, one of the participants' suggestions was to provide the web-based physiotherapy website with a description of which

muscles are they working on during exercises. This was discussed extensively between the researcher and the research participants with the aim of getting to know the best way to get it done on the platform. Eventually, a consensus was agreed that it would be best to only state the goal of each exercise on the website instead of a comprehensive description.

Opportunities for personal growth and development: Yet other features such as the creation of opportunities for personal growth and development were not met because of the short lifespan and time limitation of this study. Therefore, the researcher had no opportunity to evaluate the personal growth and development of the research participants. Besides, the number of research participants had decreased from seven in the first focus group to only three in the final focus group which made the opportunity to evaluate the personal growth and development of the research participants harder.

Flexibility: Flexibility in terms of meeting times and dates were also not met due to the logistics of organizing the group in an accessible location.

Based on the demonstrated features of the user-centred process, explained above, and the fact that the views of the participants after they had explored the final version of the website were positive, the researcher can conclude that a meaningful UCD process was achieved in this research.

3.7 Research settings and access

The study took place in an accessible room for people with special needs such as physical disability in the School of Medicine at the University of Glasgow. The participants were recruited from a Chest Heart and Stroke Scotland (CHSS) stroke support group. The researcher and an academic supervisor contacted CHSS for permission to contact the group. CHSS is a health charity in Scotland (https://www.chss.org.uk/) that offers a variety of services for stroke survivors and families who are affected by stroke to enhance their confidence and overcome any difficulties in communication or performing daily activities after a stroke. These services enhance the chances of surviving a stroke, living longer and more independently. The services are also aimed at supporting people with any physical or psychosocial challenges as a result of a stroke and other cardiovascular and respiratory conditions.

3.8 Sampling method

Both qualitative and quantitative researchers are faced with sampling choices that are supposed to facilitate a deep understanding of the phenomenon under research. Broadly speaking, the choice is between probability and non-probability sampling techniques. Probability sampling refers to random sampling techniques that predict the likelihood of individuals being selected from a population (Blackstone, 2018). In other words, probability sampling provides everyone within a population the same chance of being chosen, because of the random selection process (Gerrish and Lacey, 2014). The identified merits of probability sampling include less bias and more representativeness (Polit and Beck, 2017). However, probability sampling has also been noted to be time consuming because of the numbers involved, and it is difficult to identify an entire study population (Gerrish and Lacey, 2014). The different types of probability sampling techniques include simple random sampling, stratified sampling, systematic sampling and cluster sampling.

Non-probability sampling is a sampling technique with an unknown likelihood of individuals being selected from a study population (Neuman, 2014). Non-probability sampling is not usually carried out arbitrarily, but often follows a set procedure and research protocols. The key features of non-probability sampling include non-representativeness and not wishing to generalise to a larger population (Ritchie et al., 2013). Qualitative studies often use non-probability sampling techniques, where the research objective is about depth and idiographic understanding, rather than breadth and nomothetic understanding (Kogan et al., 2011). The different types of non-probability sampling techniques include convenience sampling, purposive sampling, and snowball sampling. Given that this research focused on a specific group of people, stroke survivors and their carers, the convenience sampling technique was used for the selection of the participants for this study.

Convenience sampling refers to a non-probability sampling technique through which potential participants are recruited to take part in the study based on their proximity and accessibility (Polit and Beck, 2017). The convenience sampling technique is often criticised for not being able to produce rich data, being subject to bias and failing to provide a wide perspective (Parahoo, 2014). Despite this, it remains a common approach in healthcare studies (Polit and Beck, 2017, Parahoo, 2014). In convenience sampling, although researchers choose the most readily accessible subjects, they nonetheless must still meet the required set criteria for inclusion and exclusion (Fusch and Ness, 2015). Furthermore, convenience sampling is

considered suitable for small studies as well as studies where data have to be gathered over a short period of time (Silverman, 2013). Convenience sampling is also less expensive and quicker to implement (Griffiths and Bridges, 2010).

In this study, the researcher recruited the participants from a stroke organisation, focusing on individuals who had a stroke and their carers. Participation was based on set criteria for inclusion and exclusion, agreed with the academic supervisors (Polit and Beck, 2017). Given the nature of the target participants and the potential challenges they could bring, including possible multi-faceted clinical disorders and/or cognitive problems, careful planning and consultation were necessary at this stage of the research (Intercollegiate Stroke Working Party, 2016).

There is no ideal number of participants for a single focus group, but typical focus group range from 4 to 12 people who share a similar problem or experience. Krueger and Casey (2014) have argued that fewer than 4 participants in a focus group could limit ideas and more than 12 participants could provide trivial data as some participants might not have the chance to express their point of view. Therefore, this study aimed to recruit a total of 4-12 participants, both stroke survivors and their carers. The same participants were re-invited to the subsequent groups.

In qualitative studies, the number of participants identified is based on the required information and that is guided by the concept of data saturation, which can be defined as continuous data collection to reach a point where no new data emerge (Polit and Beck, 2017). This was not applied as this study followed a user-centred framework where the same participants were invited to attend all the focus groups during the process of data collection.

3.9 Recruitment of research participants

The actual recruitment process involved contacting stroke survivors who were members of the CHSS support group in Glasgow and inviting them to participate in this study. In order to do this, the researcher and another member of the research team visited CHSS support groups to explain the purpose of the study and invite them to participate. Below are the inclusion and exclusion criteria used.

3.9.1 Inclusion criteria

There were different inclusion criteria for stroke survivors and their carers.

Stroke survivors were included if they fulfilled the following criteria.

- Over 18 years old
- Had had a stroke
- Resided within the Greater Glasgow area, UK
- English speakers
- Discharged from hospital
- Able to use computer, tablet, or smart television either with or without support from their carers in their own home with internet access
- Had an email address
- Willing to participate in the study and to attend all focus group meetings

Carers were included if they fulfilled the following criteria:

- Over 18 years old
- Resided within the Greater Glasgow area, UK
- Able to speak and understand English
- Willing to participate in the study and to attend all focus group meetings
- Able to use computer, tablet, or smart television in their own home with internet access
- Had an email address
- Identified as a carer to someone who has had a stroke

3.9.2 Exclusion criteria:

Participants were excluded if they were unable to provide written, informed consent (this was assessed based on the judgment of the researcher following a formal assessment by the clinical team).

CHSS support group members who were interested were given a participant information sheet (Appendix 6) and were asked to contact the research team either by email or telephone if they decided to take part in the study. Only stroke survivors and carers who fulfilled the inclusion and exclusion criteria and agreed to participate in the study were recruited to participate in the study. Written informed consent (Appendix 7) was obtained from all participants immediately prior to the first focus group. For those with higher disability, their carers helped the researcher to communicate in order to explain the consent form to them to ensure that they were happy to participate. The researcher was also available to address any concerns and questions about the

study from the participants prior to the start of the study. Participants were informed prior to the commencement of the study, and at the start of every focus group that they had the right to refuse to answer a question(s) and/or even withdraw from the study without giving a reason.

3.10 Data collection method

Qualitative research methods allow a better understanding of the experiences and views of stroke survivors and carers. They allow an exploration of the decision-making process as well as providing insights into how interventions may alter care provisions (Barrett and Twycross, 2018). In order to achieve the above, the researcher must obtain data that are holistic, rich and nuanced – that is, data that allow themes and findings to emerge through careful analysis. This section explores the data collection strategy for this study, acknowledging the options that were available to the researcher and providing justifications for the chosen strategy.

In theory, the core approaches to qualitative data collection are observations and interviews (in-depth interviews and focus groups) (Creswell and Creswell, 2017, Cohen et al., 2015, Merriam and Tisdell, 2015). These methods provide opportunities for the gathering of data that are rich and provide good insights. For instance, participant and non-participant observations represent a powerful approach for the gathering of qualitative data (Cohen et al., 2015). Observations provide opportunities to capture a wide range of information – that is, verbal and non-verbal – as well as data about environmental factors (Twycross and Shorten, 2016). According to Merriam and Grenier (2019), observations are mostly used when requiring a fresh perspective, or when it is not possible for participants to discuss the researched phenomenon. The limitations of observations, however, primarily include addressing ethical dilemmas, depending mainly on researchers' perspectives, and being less reliable, as they are influenced by researchers' views, biases and subjective interpretations (Cohen et al., 2015, Bell and Waters, 2018). Although the use of observations was initially considered at the outset of this research, the issues identified in the methodological literature regarding the validity and reliability of observations made this a less desirable form of data collection for this study (Bryman, 2016, Bell and Waters, 2018, Cohen et al., 2015). More importantly, the use of observations, which depend on the researcher's perspectives, was considered insufficient to achieve the aims of this research. Therefore, when considering the most appropriate approach to carry out this study, the use of focus group discussions was adopted in order to generate data which would provide answers to the research questions.

Interviews, which can be conducted individually or in focus groups, offer the most direct and straightforward approach to the gathering of qualitative data related to a particular phenomenon (Bryman, 2016). They can be tailored to the research questions, the characteristics of the participants and the preferred approach of the researcher, which can be open/unstructured interviews or structured ones (Barrett and Twycross, 2018).

Over the years, focus groups have gained popularity as a research instrument in social research, especially in the healthcare sector (Krueger and Casey, 2014). By definition, a focus group is an organised interview with a specific group of people to express their understanding about particular topic (Holloway and Galvin, 2016)– details on how this was facilitated are provided in section 3.10.1 - 3.10.2 below. Although often criticised as potentially inhibiting the disclosure of sensitive information, that data can be affected by the influence of dominant individuals and that some individuals may make up answers if they do not want to be seen by other group members to be inefficient (Krueger and Casey, 2014); it was considered most suitable for the needs of this study. Focus groups provide opportunities for in-depth discussion and interaction between the researcher and participants; therefore, these discussions may enhance the understanding and perception of participants on the topic (Bryman, 2016, Neuman, 2014). Furthermore, focus groups may encourage people to show different responses rather than reaching a consensus on discussed areas to enable deeper understanding of participants' perspectives on the research questions (Holloway and Galvin, 2016). Another comparative advantage of focus groups over individual one-to-one interviews is that the former provides richer pools of data because of the involvement of more than one individual in the discussion (Holloway and Galvin, 2016, Cohen et al., 2015).

Some practical steps taken to mitigate the above identified limitations of focus groups as a research tool were that the research was carefully planned, and a written strategy provided guidance on how to best gather the views of the focus groups based on Holloway and Galvin (2016) and Krueger and Casey (2014) recommendations (see section 3.10.1 - 3.10.2). It was also envisaged that no sensitive information was to be discussed during the focus group sessions but participants who did not feel comfortable discussing particular topics and/or sharing their opinion about a particular topic were excused – that is, such participants were at liberty to leave the session if they needed to do so. The data collection process involved the following: preparation for the focus groups, facilitating the focus groups, data management and data analysis. These processes are presented in detail below.

3.10.1 Preparation for the focus groups

The researcher read and followed practical guidelines on how to conduct a qualitative focus group (Krueger and Casey, 2014, Holloway and Galvin, 2016). These guidelines were to help the researcher to be well prepared to conduct the focus group interviews and to gather as much data as possible from the participants. The planning and preparation involved the following:

- Choosing a date and time that was convenient for the participants and the researcher. Individual participants were then contacted through phone calls and text messages. Those with email addresses were also emailed to remind them about the agreed dates and times of the focus group interviews.

- An appropriate and convenient room environment for the participants, -The room where the focus groups took place was a room with access to toilets, and accessible to those using a wheelchair. Arrangements were also made for parking spaces for those who used their own cars and those who came via public transport were reimbursed. Some refreshments were also provided.

- Record the focus groups using a high-quality voice recording.

- Providing a structured agenda for each focus group (Appendices 8, 9, 10). This was to facilitate meaningful discussions and to ensure a two-way conversation. In addition, having a structured agenda helped with time management and ensured that key aspects were allocated sufficient to be discussed.

- A list of probe questions that the researcher might use in the focus groups to encourage the people to participate or to give more details about a subject (Appendix 11).

- An identification badge with the first names of participants was provided for each participant to help the participants recognise each other and therefore facilitate discussions.

- Providing participants with reminders at the start and finish of each focus group discussion on the importance of confidentiality.

3.10.2 Facilitating focus groups

The researcher contacted all participants by email or phone to confirm the location, date and time of the focus group. The same participants were invited to attend three consecutive focus groups. The consent process was completed with each participant in the first focus group and the consent was re-affirmed at each focus group.

The moderating team for each focus group session consisted of two members of the research team, one of whom was an observer (AD – PhD supervisor) and the other was a discussion facilitator, the researcher (AA). The observer and facilitator were the same for all the focus groups. In each focus group the moderating team introduced themselves and explained the purpose of the focus group. The facilitator used a projector to display the website to participants and each focus group session lasted approximately 60 minutes. Only first names of participants were used during the focus groups and these were anonymised during typing of the transcripts. Throughout the process, the researcher focused on leading the discussion and prompting the participants to participate and express their views. The observer was taking notes on the general impression about the focus group, and on observed nonverbal cues.

Demographic information of participants was gathered in the beginning of the first focus group on a form which was completed for each participant. Demographic information was recorded in relation to age, gender, time since stroke (stroke survivors only), relationship to stroke survivor (carers only), occupation, ethnicity, education level, level of familiarity with using the internet, and general health status

The researcher developed a topic guide to be used in the focus groups. This guide was based on the aims of this study, previous research on telerehabilitation and the creation and/or adaptation of digital health platforms and interventions, in order to meet the needs of different populations (Domenech Rodriguez et al., 2011, Demiris et al., 2004, Ferney and Marshall, 2006). Then, the researcher discussed these topic guides with the academic supervisors (LP, EC and AD), prior to amending them appropriately. The topic guide considered a number of topics, namely: the participants' views on the internet as a source of medical information and rehabilitation; the previous version of the web-based physiotherapy platform; how it could be improved to allow more members of the stroke population to access it; and measures that could make the platform more fit for purpose (Appendices 12-14). In order to make sure that the focus group discussions were directed to meet the objective of this study, the researcher

reminded the participants at the beginning of each focus group about the aim of this study. The researcher also confirmed the intended future use of the modified web-based physiotherapy platform, which is to make web-based physiotherapy an appropriate tool with which to deliver exercise programmes for the stroke population. Overall, three focus group sessions were held at three different stages during the research as part of the UCD process:

The first focus group explored the participants' experiences of living with stroke (Appendix 12). In addition, this focus group was for the participants to get to know each other, to demonstrate the website and to provide the participants with access to the website. To facilitate this the researchers distributed a description of how to access the web-based physiotherapy website (Appendix 15) and the list of questions that were going to be discussed in the second focus group (Appendix 13). After the first focus group, two examples of simple shoulder stretching exercises were posted on the exercise section, and information related to stroke disease was posted on the advice section within the website. The participants were asked not to perform these exercises, but only to access them the following week.

The second focus group was planned to be conducted one week after the first focus group. The moderator team in this focus group asked the participants about their specific impressions of the web-based physiotherapy website (Appendix 13). This focus group was conducted to explore the views of the participants regarding the exercises and education sections of the current website, and modifications to the website were planned based on their suggestions. At that time, the education section was not ready on the web-based physiotherapy site; however, their preferences regarding what to include in the advice section were obtained.

The timeline for the third focus group was not known as it was dependent on implementing the agreed modifications to the original version of the website but was expected to be conducted two months after the second focus group. In this focus group, the modified website was shown to the participants, to obtain their feedback and confirm if this revised platform was acceptable to people from the stroke population and their carers. In order to obtain the participants' feedback, they were asked questions about the modified website (Appendix 14).

Following the third focus group, any final modifications were made to the web-based physiotherapy site, based on the findings from this focus group.

3.11 Number of participants in each focus group, timing and timetable

Seven, five and three participants attended the three consecutive focus groups respectively. The time lapse between the first and second focus groups was one week for the participants to access the web-based physiotherapy website. However, the time lapse between the second and third focus groups was approximately 4 months, - allowing time for modifications to the web-based physiotherapy website (see Figure 3.2).

Recruitment took three weeks and data were collected between 13th June 2017 and 23rd October 2017

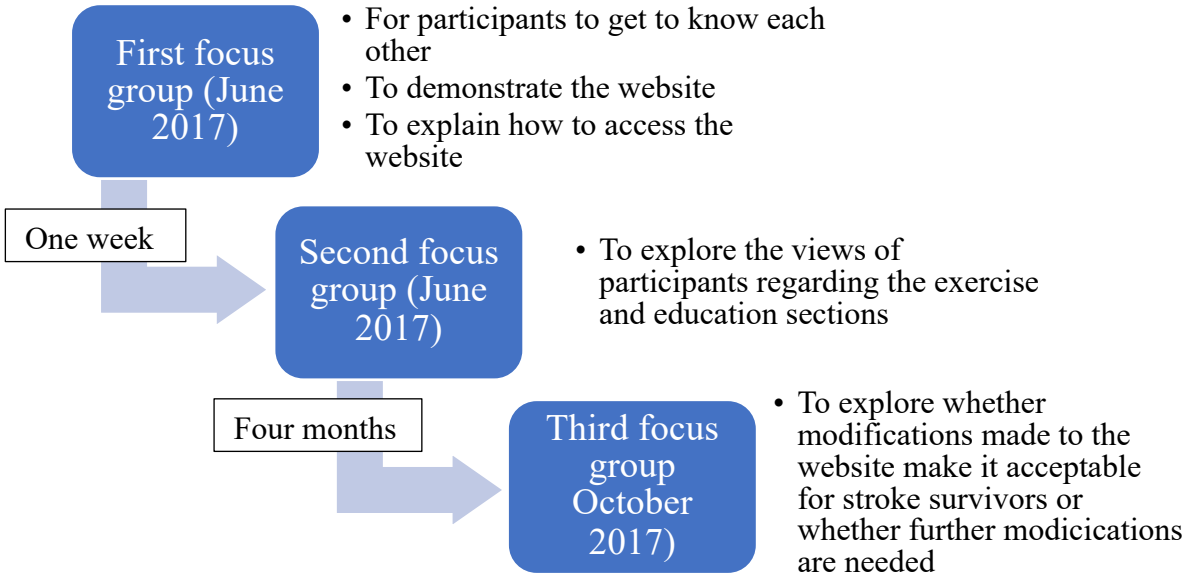


Figure 3.2 Timing of the focus groups

3.12 Ethical considerations

All the participants remained anonymous, and the data were managed in a way which ensured total confidentiality, and protected their human rights, autonomy and privacy. The General Data Protection Regulation (GDPR) legislation of 2018 was followed. Participants were given a unique ID number and data were anonymised for storage. The recorded interviews were destroyed as soon as transcribed. All data were saved on a secure server within the University of Glasgow. At the end of the study, these anonymous data were saved on a storage device and stored in a filing cabinet in a locked room in the Nursing & Health Care School at the University of Glasgow for up to 10 years as per the University of Glasgow regulations.

Stroke survivors who were interested in participating in the study, had read the participants information sheet, fulfilled the inclusion/exclusion criteria, and decided to take part in the study were contacted by the researcher for the first focus group. Written informed consent was obtained at the first focus group. Clear and simple sentences were used in the consent form and in the participants information sheet and further, the research team were available to provide extra explanations if needed. All participants' concerns and questions they might have about the study were answered prior to the start of the study. In order to ensure meaningful information was obtained from the participants to modify the website as appropriate, they were able to use the website for one week before the focus group. The researcher also aimed to be inclusive and recruit as diverse a group of stroke survivors as possible but were aware that this may raise some issues such as accessibility of stroke survivors with different level of functional disabilities to the room where focus group were taking place. The researcher therefore considered strategies to maximise inclusion. For example, the focus groups were conducted in an accessible venue and travelling expenses were covered. The three focus groups took place in convenient place at the University of Glasgow with disabled access room for stroke survivors. Additionally, as carers are often well-placed to support their relative with communication and both stroke survivors and their relatives/carer were invited to take part.

The patients were informed that being a part of the study was entirely voluntary and were free to withdraw from the study at any time, without giving any reason, without their legal rights or their care being affected. Furthermore, the patients were informed that there were no direct benefits from taking part, however some people enjoy meeting and talking to others who have had similar experiences. It was explained that the study may benefit other stroke survivors who use the web-based physiotherapy website in the future. The patients were also informed that there were no foreseeable risks in taking part in this study. However, the study took up some of their time.

3.13 Data management

Data were handled and stored in line with the General Data Protection Regulation (GDPR) principles enshrined in the Data Protection Act 2018 (Carey, 2018). Participants were given a unique ID number and data were anonymised for storage. The recorded interviews were destroyed as soon as transcribed, within three months of the data collection period. All data were saved on a secure server within the University of Glasgow. The server files were password-protected and accessible only by the researcher. The ethics committee approval

allowed the researcher to retain consent forms and transcripts until successful completion of the project, to enable reporting of results, including publication in peer reviewed journals, and completion of the researcher's PhD. According to the University of Glasgow regulations, the anonymised data will be stored in a filing cabinet in a locked room in the Nursing & Health Care School at the University of Glasgow for up to 10 years.

3.14 Data analysis

Recorded interviews, interview transcripts and field notes taken by the moderating team during the focus groups for this research study were later analysed and a record of all the decisions taken in the analysis were kept.

The data analysis phase of any research plays a significant bridging role in translating the conceptual plan of the research to a meaningful and actionable one through elaborate and succinct interpretation. However, data analysis in qualitative research does not follow a fixed plan or rule, as the processes of data collection, analysis and interpretation are merged throughout the research process (Coe et al., 2021). This means that there is usually an overlap across data collection, analysis and interpretation in qualitative research, which is a distinguishing feature of qualitative data analysis (Cohen et al., 2015).

There are many available approaches to the analysis of qualitative data, the most common of which are grounded theory, content analysis, conversation analysis, discourse analysis, hermeneutist analysis and thematic analysis (Pope et al., 2000, Ritchie et al., 2003). When deciding the type of analysis to perform, Cohen et al. (2015) advised researchers to abide by the principle of *fitness for purpose*. Therefore, in this study, the researcher analysed the data using thematic analysis, which is commonly used in qualitative studies, as this type is considered to be the most appropriate analysis to provide comprehensive answers to research questions (Burnard et al., 2008). The various advantages of using thematic analysis encouraged its choice. For example, thematic analysis is highly flexible and can be applied in a range of studies, since it offers a full and detailed, yet still multi-layered, description of data (Braun and Clarke, 2006, Castleberry and Nolen, 2018). Thematic analysis also requires less comprehensive theoretical and technological knowledge, while still providing the researcher with a straightforward means of analysing data, which is extremely useful for novice researchers (Braun and Clarke, 2006). Researchers who are not experienced with qualitative analysis will find thematic analysis easy to understand and put into practice, since its

prescriptions and procedures are limited (Braun and Clarke, 2006, Castleberry and Nolen, 2018). Furthermore, Braun and Clarke (2006) and Castleberry and Nolen (2018) argue that thematic analysis is an effective tool for investigating the various viewpoints of participants in research studies. It also yields unexpected insights and draws attention to similarities and differences. This makes thematic analysis the most appropriate choice in this study. Nevertheless, as with any method, thematic analysis also has some limitations including the likelihood of some degree of inconsistency and the potential for incoherence if the researcher does not ensure rigour during the process of developing themes (Holloway and Todres, 2003). To address this limitation, the researcher ensured following the guidelines set by Burnard et al. (2008) throughout the data analysis process. Although there are many available approaches to analysing qualitative data, thematic analysis is most commonly used in qualitative studies (Pope et al., 2000, Ritchie et al., 2003). In fact, the process of thematic content analysis is quite similar to that involved in other types of qualitative analysis such as ground theory analysis as the process itself involves analysing transcripts, developing themes found in the data and collecting examples from the text that are allocated to each theme (Burnard et al., 2008).

One academic supervisor reviewed the analysis and met with the researcher to reach a consensus in all identified themes. In addition, all academic supervisors reviewed and agreed on the overall analysis and findings. The data analysis process included the following steps.

3.14.1 Transcript preparation

The focus groups were audio-recorded using a digital Dictaphone (Sony ICD-PX370). Recordings were later transcribed for analysis. In the first instance, the researcher produced a verbatim transcript of each focus group which included laugher, cross talking, unusual events and any other event that distracted from, or halted, the discussion. Verbatim transcription was carried out in order to increase the chance that the transcript would reflect more accurately the views of participants in the focus group Holloway and Galvin (2016). In addition, the transcripts were reviewed by a member of the research team who is a native English speaker and from the same geographical area as the participants to ensure the accuracy of the text. Transcripts also included field notes taken by one member of the research team (observer AD). The field notes recorded nonverbal clues and facial expressions for the purpose of capturing general impression about the focus group and in addition to record any unusual events as explained by Holloway and Galvin (2016).

3.14.2 Thematic analysis

Thematic content analysis was undertaken using Burnard's approach of analysing and presenting qualitative data. An iterative process of data analysis was followed to put the data into relevant categories – that is, related codes were condensed into categories and later into themes (Burnard et al., 2008). Burnard's approach to analysing the data comprises five stages:

Stage 1: Open coding : The researcher carried out a reading of each document (focus group transcript, and field notes) and assigned a code for each piece of information be it a single sentence, paragraph or section based on their relevance to single issue (Burnard et al., 2008). The codes were always summarised word labels noted in the margins of the transcripts next to the related sections with assigned meanings and/or definitions. These were then printed and kept in a filing cabinet in a locked room in the Nursing & Health Care School at the University of Glasgow for reference. The coded data were cross checked with the transcripts to identify similarities and/or difference in the codes. An example of an open coding is given in Table 3.1.

Table 3.1 Examples of open (initial) coding in the transcripts

Transcript excerpt	Open (initial) coding
Participant 3 (carer): "I would say the hemianopia never really troubled you … it's just accepting that as it was you know and once you can't see with your other eye, are you quite happy with that?" Participant 4 (stroke survivor): "As long as I see my grandchildren growing up, I'm happy with that." Participant 3 (carer): "Certainly, doesn't stop you from watching television" [FG2*]	Living with eye problems after stroke
Participant 6 (stroke survivor): "See I struggle with the walk" Participant 7 (stroke survivor): "Oh yes, but it can sometimes feel something isn't right the first moments you put your foot down to walk again…?" Participant 6 (stroke survivor): "I know it's not right when I walk …." FG2	Struggling with walking after stroke

*FG2: Second focus group.

An academic supervisor (EC) independently reviewed the codes that the researcher had created in the first stage of the analysis (open coding). She agreed with almost all the codes and suggested the addition of further codes. The researcher and the academic supervisor (EC) then met and reached a consensus on a list of identified codes. The open coding process was carried out manually – that is, without the use of a software package.

Stage 2: Aggregation and re-grouping of the initial codes: On completion of the initial open coded stage (Burnard et al., 2008), the researcher listed all of the agreed codes on several clean sheets of paper and then refined the codes by removing any similar or duplicated codes. This strategy had the effect of reducing the number of codes, which facilitated the process of data categorisation. At the end of this stage, the researcher had collected a list of non-duplicated codes and anonymised ID for the associated respondents, compiled on a clean sheet of paper.

Stage 3: Identifying the themes: This involved the categorisation of the identified codes into bigger and more meaningful units (Burnard et al., 2008) The researcher used the One Sheet of Paper (OSOP) method for those lists to rationalise and condense the codes into different categories (Ziebland and McPherson, 2006). The researcher mind-mapped the codes for all focus groups onto a large sheet of paper in a way that grouped similar codes together. Thus, one large sheet of paper was established for each focus group that contained all the relevant codes arranged into categories (see Appendix 16). Each OSOP sheet provided a summary of the data gathered from each focus group and how they were connected to form all the categories and themes. An academic supervisor (EC) independently reviewed the process of categorisation, and how the themes were formed. An example of how themes were identified is provided in Table 3.2:

Table 3.2 Examples of theme and relevant categories

Transcript excerpt	Open (initial) coding	Categories	Theme
Participant 3 (carer): "I would say the hemianopia never really troubled you … it's just accepting that as it was you know and once you can't see with your other eye, are you quite happy with that?" Participant 4 (stroke	Living with eye problems after stroke	Patient attitude to disability	

Transcript excerpt	Open (initial) coding	Categories	Theme
survivor):" As long as I see my grandchildren growing up, I'm happy with that" FG2			Attitude to disability
Participant 5 (stroke survivor): "I did get referred back to the physiotherapy by a consultant, … when we got there, another person was running off their feet. The physiotherapist only asked me what was it that I was there for and added that she thought that I would have improved a lot more when I explained to her why I was there and that it was the consultant who made the referral…her reception was really cold and unwelcoming to say the least…" FG1	Stroke team giving discouraging information	staff attitude to disability	
Participant 6 (stroke survivor): "I think if you travel on public transport, it's terrible and it's absolutely shocking, you're on the bus and the bus is away, you know, and if you've got a bad arm, there's just no respect for you whatsoever, another thing I find when you're say Morrison's or Tesco's, and someone's behind you and you're parking, they're huffing and huffing you know, "Hurry up," you know, and I feel, you know, they can-- that just bothering, I'm just disabled, so just wait" FG1	Public attitude to disability	Public attitude to disability	

FG1: First focus group and FG2: Second focus group.

Stage 4: Coding to Themes: This stage involved assigning each identified theme and all of the relevant data with a specific colour (Burnard et al., 2008). Highlighting the data in the transcript provided an opportunity for the researcher to ensure that all the data had been coded and allocated to the relevant themes.

Stage 5: Themes filing: In the fifth and the final stage of the thematic data analysis, the colour-coded data that belonged to each theme were extracted into separate Microsoft Word files (Burnard et al., 2008). After highlighting each theme with a specific colour in all of the transcripts during stage four of the analysis, the researcher prepared one file per theme, then extracted the data from all of the transcripts and posted them in the relevant theme file.

Once the themes were established, the researcher looked at connections between themes, comparing and contrasting within the themes, and identifying deviant cases. Therefore, further analysis was carried out and a record of all the decisions made in the data analysis were kept.

3.14.3 Peer review

This process allowed the data, processed by the researcher, to be reviewed independently by an academic supervisor (EC). This independent review process offered the needed insights and perspectives to the identified themes and contributed to minimising potential personal bias by the researcher Burnard et al. (2008). Through the peer review process, the academic supervisor (EC) met with the researcher on several occasions and they reached a consensus on all identified labels and themes. At the end of each stage, the researcher sent a draft copy for the results of that stage to the academic supervisor (EC).

3.15 Research quality and trustworthiness

Quality of the research was an integral part of the research process to help clarify the processes used and to ensure the rigour, trustworthiness and integrity of the research as explained by Lincoln and Guba (1985). To ensure the quality of the research, the four criteria of trustworthiness suggested by Lincoln and Guba (1985) were applied. These are: credibility, transferability, dependability and confirmability. Table 3.3 below provides a summary of the techniques followed in this study to ensure trustworthiness and rigour.

Table 3.3 Summary of the performed strategies to ensure trustworthiness and rigour

Criteria of the trustworthiness	Action taken in this study to
Credibility	• Exploration of negative cases • The use of verbatim quotes • Member checking • Peer review
Transferability	• Thick description
Dependability	• Peer review • Coding journal
Confirmability	• Coding journal • Reflexivity (reflective fieldnotes by the observer)

3.15.1 Credibility

Polit and Beck (2017) explain that credibility refers to how reliable the study is in terms of presenting the truth of the data and their interpretations according to the participants. To increase the credibility of the data, the researcher should explore negative cases such as the individual experiences of participants that deviate from most of the other participants (Ziebland and McPherson, 2006). In addition, the study findings should be reported using verbatim quotes from the participants that capture their views, as suggested by Hannes (2011).

Credible data that captured the participants' views of web-based physiotherapy were targeted in this study. Thus, the researcher used verbatim quotes from the participants in the reported findings in order to enhance the credibility of the findings. Furthermore, the researcher explored and presented negative cases in the analysis. This expanded the understanding of issues related to the use of the web-based physiotherapy platform for the stroke population, such as the need for one-to-one physiotherapy sessions besides the web-based physiotherapy programme.

In addition to those listed above, the researcher used other techniques to improve credibility. The researcher presented the information to the participants and used member checking. This can be defined as a process of asking the participants to assess the research findings in order to confirm that they accurately represent their expressed views (Thomas, 2006). Thomas (2006)

indicated several ways of carrying out member checking with the participants and these included giving them a summary of the discussed issues at the end of the interview; checking the interpretation of the discussed issues at a subsequent interview; having an informal conversation with the participants; and providing them with a preliminary and/or final report of the analysis.

A noteworthy point was made by Sandelowski (1998) that the present clarity of voice recording devices may limit the importance of the participants verifying the analysis. In this research study, a voice recording device was used and in addition, member checking was used at the third phase of the research when the research participants were asked to review and comment on the summaries of the transcripts of the first and second focus groups. In addition, the participants were asked about the researcher's interpretation of their words and asked for alternatives if something was not clear. This helped the researcher to avoid misinterpreting the data. All stroke survivors agreed that their transcripts were an accurate record of previous focus groups. The researcher ensured that the data analysis reflected the participants' views, which limited the researcher's influence on the analysis.

Another technique used by the researcher to improve credibility was ensuring that all of the supervisors were involved at each stage of the research (details in section 3.14.3). Peer review to enhance credibility can have a negative effect as external analysts such as student supervisors might not be immersed enough in the data to analyse and judge the study findings (Sandelowski, 1998). However, the academic supervisor (EC) looked at the early stages of the analysis and independently analysed the data. In addition, EC was familiar with the topic of this study, stroke rehabilitation. Furthermore, Ziebland and McPherson (2006) supported peer review to improve credibility as discussions of the data could provide opportunities to better understand the data and become immersed in it. As such, the peer review technique was adopted from the initial coding to the final findings.

Lastly, the researcher used measures in order to improve the credibility, reliability and confirmability of the data. Although the researcher was familiar with stroke and its complications theoretically and in practice, the use of web-based physiotherapy websites for rehabilitation purposes was new to the researcher. Furthermore, the research involved more than just the researcher throughout the data collection processes – from participant identification through to the facilitation of the focus groups. The presence of two academic supervisors, one to oversee the analysis from stage 1 (see section 3.14.3) and the other to attend

all three focus groups, take fieldnotes, reflective fieldnotes and engage in all the due diligence processes that followed during data processing and analysis, reduced researcher bias.

A number of techniques to enhance credibility were adopted as planned. According to Korstjens and Moser (2018), prolonged engagement in the research field enhances a deeper understanding of the research undertaken. To achieve this aim, the same participants were invited to the focus groups. The study followed a user-centred method, which means that all the participants shared decisions with the researcher, and the researcher spent sufficient time in the research field to better understand the focus of this research. Finally, using the process of triangulation, as demonstrated by Noble and Heale (2019), to compare emerging themes helped to ensure the validation of data throughout the research process.

3.15.2 Transferability

According to Polit and Beck (2017), the transferability (refer to external validity) of a qualitative study can be defined as the extent to which the findings of the research can be applied in another context. The transferability of the research is generally judged by the reader; therefore, a detailed description of the study methods for collecting, analysing and presenting the data is essential (Ryle, 2009, Polit and Beck, 2017). It was important to ensure that the research findings were transferrable to similar situations or groups. Therefore, a thick description was given to the reader of the background of the study settings, the participants' demographic information and the methods used for data collection and analysis.

Since the transferability of the study is judged by the reader, a thick description about how the UCD was implemented in this study (see section 3.6), research settings and access (see section 3.7), the characteristics of participants (see section 3.17.1) and methods used to analyse the data (see section 3.14) were presented and explained for the reader in this chapter.

3.15.3 Dependability and Confirmability

Dependability (refer to reliability) of qualitative data is achieved when the data are consistently, accurately and logically analysed (Polit and Beck, 2017). Hannes (2011) clarified that dependability could be enhanced by peer review and keeping records of coding journal. In this study peer review of coding was facilitated and the researcher kept records of coding journal.

It has been argued that confirmability (also referred to as objectivity) of the data is achieved when the researcher handles the data based on input from the participants, not his/her own perspective (Polit and Beck, 2017). It is common in qualitative research that the objectivity is affected by the inherited bias (Bryman, 2012). In order to minimise the likelihood of any unintended bias in this research, the researcher relied on being reflexive and the use of coding journal (Bryman, 2012). Holloway and Galvin (2016) defined reflexivity as critical self-reflection of researchers to their own prejudice. Ramacciati (2013) has also described the concept as the key criterion to ensure rigour of qualitative studies. Therefore, the researcher was conscious of his own views, opinions and perceptions and allowed the observer, an academic supervisor (AD), to take reflective fieldnotes about his actions to help in his reflections. The research team met each time after the focus group sessions and the researcher enquired from AD if there were any notes to take onboard going forward. There was nothing substantial in the reflective fieldnotes that bordered on the lack of criticality of the researcher. The other concept relied on was the use of coding journals in order to further improve the dependability and confirmability of the research findings for this study. In this instance, a clear and verifiable record of all decisions made was kept on file as an audit trial of coding decisions – coding journal. The attached extract in Box 3-1, provides an example of how a focused coding made by one participant created a new category in the theme *staff attitude to disability* and how the creation of this category triggered the researcher to check the transcripts of the focus groups looking for similar data to be added to this new category.

Both dependability and confirmability were enhanced by the researcher following strategies to limit his potential inherited source of bias, as planned. He used fieldnotes and coding journals to show that the themes were synthesised based on the views of the participants. An audit trial was also considered to enhance the dependability and confirmability of this study as planned, through the use of a coding journal. Peer review by an academic supervisor was another strategy used in this study to maximise confirmability (see section 3.14.3).

Box 3.1 Extract from the coding journal on the theme "Staff attitude to disability"

participant 5 (stroke survivor) "I did get referred back to the physiotherapy by a consultant, … when we got there, another person was running off their feet. The physiotherapist only asked me what was it that I was there for and added that she thought that I would have improved a lot more when I explained to her why I was there and that it was the consultant who made the referral…her reception was really cold and unwelcoming to say the least… " Participant 5 (stroke survivor) FG1.

This focused coding was analysed and therefore, created new category of the theme 'Staff attitude to disability'. The researcher added couple of quotes made by the participants to this category when he checked the transcripts of the focus groups (in MS Word)

3.16 Extending ethical approval

Extending the ethical coverage was requested from the Research Ethics Committee and was approved in October 2017 (Appendix 17). This was requested because implementing the agreed modifications to the original version of the website took longer than expected.

3.17 Findings

This section comprises the following: characteristics of the participants, as well as the identified themes which were, attitudes to disability, quality of care and support provided for stroke survivors, lack of access to rehabilitation services, and user centred design of the web-based physiotherapy website.

3.17.1 Characteristics of the participants

In terms of numbers, five stroke survivors and two carers participated in the study, the majority of whom were female. On average, the five stroke survivors had lived 5 years and 5 months after stroke. The two carers who attended the focus groups were spouses of two stroke survivors. Generally, the participants did not have restricted mobility, but two stroke survivor participants had difficulties walking long distances and one had difficulties climbing stairs. All the participants declared that they were in a good health. They were completely literate, retirees and ethnically white British. Most of the participants also had access to the internet and used it on a daily basis for a variety of purposes such as shopping and booking tickets, events or holidays. Details of the participants' demographic information are provided in Table 3.4.

Table 3.4 The participants' demographic information

Demographic information	Participants (n=7)
Gender:	
Male	2 (29%)
Female	5 (71%)
Age:	
54-59 years	2 (29%)
60-64 years	5 (71%)
Participants:	
Stroke survivors	5 (71%)
Carers	2 (29%)
Time since stroke (stroke survivors only):	
3-4 years since stroke	2 (40%)
6-8 years since stroke	3 (60%)
Educational level:	
Secondary school	2 (29%)
College	4 (57%)
Postgraduate	1 (14%)
General health status (informal self-reported):	
Good	2 (29%)
Fair	5 (71%)
Internet Use:	
Daily	4 (57%)
Weekly	1 (14%)
Never	2 (29%)

3.17.2 Number of participants in each focus group

The number of research participants decreased across the three focus groups. Seven participants attended the first focus group (five stroke survivors and two carers), and five participants attended the second focus group (four stroke survivors and one carer). Finally, only three participants attended the third focus group (two stroke survivors and one carer).

3.17.3 Identification of themes

In relation to the identification of themes across all three focus groups, four main themes were identified with each theme containing other categories. These categories contained codes that were considered sufficiently distinct to stand alone. The themes and relevant categories are summarised in Table 3.5.

Table 3.5 Summary of the themes and relevant categories

Themes	Relevant categories
Attitudes to disability	• Public attitude to disability • Staff attitude to disability • Patient attitude to disability
Quality of care and support	• Prioritising leg mobility exercises • Lack of support for family members & carers
Lack of access to rehabilitation services	• Geographical influence on access • Age and access to rehabilitation services • Disparity in the kind of rehabilitation services provided by hospitals • Reliance on alternative rehabilitation services
User centred design of the web-based physiotherapy website	• Views of participants on the existing web-based physiotherapy website • Recommendations for the modification of the existing web-based physiotherapy website • Negotiating with participants on achievable changes • Views of participants on the final web-based physiotherapy website

From the above table, three themes (attitudes to disability, quality of care and support, and lack of access to rehabilitation) emerged mainly from the first focus group but the last theme (User centred design of the web-based physiotherapy website) emerged mainly from the second and

third focus groups and marginally from the first focus group. Each theme is now explored in greater detail.

3.17.3.1 Attitudes to disability

This was a major theme from the first focus group. The data revealed that attitudes to/towards disability was an important factor in the rehabilitation journey of stroke survivors. The participants suggested that attitudes to/towards disability can either facilitate or hinder the rehabilitation journey. They identified three types of attitudes to/towards disability – public attitude, staff attitude and patients' attitude.

***Public attitude to disability*:** There was an agreement among all the participants about the negative attitudes of the general public towards stroke survivors. It was highlighted that the public attitude to stroke survivors' disability, either in shops or on public transport, could be negative. The group particularly commented about drivers of public transport. For instance:

> *"It's simply disgusting to hear drivers of public transport talk about us as if we are not worthy to use their services…" Participant 6 (stroke survivor).*

> *Participant 1 (carer) agreed with participant 6 and added that: "It's absolutely awful, and a terrible experience. For example, I had an argument with a driver one day when he was being rude to us because we were struggling to get off the bus. But this wasn't our fault, but the mobile chair's battery was playing up… you know what I mean… some of them are awful and inconsiderate…" FG1.*

***Staff attitude to disability*:** The participants who were stroke survivors also explained the importance of the attitude of doctors and how it may contribute to their rehabilitation. The majority of participants appeared unhappy with the lack of positivity from clinical staff including their unwelcoming demeanour, diction and sometimes verbal aggressiveness towards them. Some examples are as follows:

> *"I did get referred back to the physiotherapy by a consultant, … when we got there, another person was running off their feet. The physiotherapist only asked me what was it that I was there for and added that she thought that I would have improved a lot more when I explained to her why I was there and that it was the consultant who made the referral…her reception was really*

cold and unwelcoming to say the least…" Participant 5 (stroke survivor) FG1.

"sometimes the choice of words by health professionals and their approach to the concerns of the patients can help make or break a stroke survivor undergoing rehabilitation… But some staff are simply disrespectful towards us people with disability …that's my experience anyway" Participant 7 (stroke survivor) FG1.

Patients attitude to disability: Stroke can cause different levels of disabilities and people respond to its symptoms differently. Thus, diverse attitudes to disability were reported by the participants based on their lived experiences highlighting how their lives have changed after their stroke.

"…I must say I have my dark moments, but I found that I've met so many nice people through it. I have changed, but for the better… Before (before the stroke) I wasn't sociable, I was one dimensional, but now I'm two dimensional" Participant 7 (stroke survivor) FG1.

Even though there were personal differences among the stroke survivor participants in response to disability, they appeared optimistic and positive in returning to their previous level of functioning because their minds were still productive:

"Nothing's impossible… We are able to return to our previous activities and have the opportunity to speak with other participants. This is keeping us active, physically and mentally…" Participant 5 (stroke survivor) FG1.

Another attitudinal challenge identified by stroke survivor participants was their relationship with family members and/or carers. It was noted that some avoided speaking about stroke-related issues with their family members or carers and excluded them when they attended stroke support groups. It appeared the stroke survivors felt they were being a burden on their carers and were trying their hardest to lessen such burden. The following quotation buttress this sentiment:

"The work we do in that group (stroke survivors support group) wouldn't lend itself to a carer coming in because you're trying to encourage the

person...to take some responsibility for themselves. We (stroke survivors) say a lot of things that we wouldn't say if a carer was there" Participant 5 (stroke survivor) FG3.

3.17.3.2 Quality of care and support

The rehabilitation programmes that the participants received were focused mainly on their mobility, without considering movement of their upper-limbs or support for their family members and carers. The following are examples under each category.

Prioritising leg mobility exercise: Participants in this study indicated that the rehabilitation programmes provided for them by NHS hospitals were focused on their walking ability and nothing was provided for their arms. For instance:

"... well, he's doing really well with his mobility and with his leg, but yet to start anything with his arms. The physiotherapists had kind of said, 'oh, but we can only concentrate one thing at a time" Participant 3 (carer) FG1.

Lack of support for family members & carers: Participants suggested that providing support to carers and family members of stroke survivors was as crucial as the provision of rehabilitation services for the stroke survivors because they played an important role in the rehabilitation process. Both carer participants alluded to this sentiment but noted that the reality was different. They indicated that, like many family members and/or carers, they often felt ignored during the rehabilitation process because such support services focused solely on the stroke survivors both during their hospitalisation period and following discharge. In the words of Participant 1 (carer):

"I don't want to sound selfish because I do recognise that this person (stroke survivor) should be given priority and the needed attention. But the point is, I still think they (healthcare professionals) need to recognize how carers and family members feel and that we also need some help…" Participant 1 (carer) FG3.

3.17.3.3 Lack of access to rehabilitation services

The lack of access to rehabilitation services was described in the following ways: geographical influence on access, disparity in the kind of rehabilitation services provided by hospitals and reliance on alternative rehabilitation services.

Geographical influence on access: `The participants indicated that it was not always convenient in terms of distance between the location of hospitals that provide stroke support group services and the residence of stroke survivors. For example:

> *"… we need such services regularly, but it is not always accessible to everyone. I just get really frustrated" Participant 5 (stroke survivor) FG1.*

> *"when I look and I see what's offered in Lanarkshire, compared to what's offered in Glasgow, the comparison is not there. You can't…. compare but you'll get a poor result if you look at Glasgow, there's a track team, and everybody is linked up and they talk to each other…" Participant 5 (stroke survivor) FG1.*

Another stroke survivor mentioned that they had to move houses in order to live closer to the stroke services:

> *"we used to live in *** [names town], but we've moved closer to the city for *** (stroke survivor) to have access to hospitals and things like this (take part in research studies) …" Participant 3 (carer) FG1*

It was further suggested that the geographical location of a stroke survivor affects when they get their initial physiotherapy referrals. For instance:

> *"… there is an awful amount of time to wait before you manage to get a physiotherapy referral in this country [Scotland], … Mine was 18 weeks and my condition was deteriorating everyday" Participant 6 (Stroke Survivor) FG1.*

Age and access to rehabilitation services: A stroke survivor indicated that the age of the stroke survivor also has an influence on their access to rehabilitation services. The participant explained that, during her hospitalisation period, she received extra rehabilitation hours because of her age, as she was the youngest stroke survivor on the ward:

"…. because I was the youngest person in the ward the rest were all old people, I got more physio time with the medical team. That was something that kept me going (doing more therapy) … Sometimes it was an hour and a half Monday-Friday. I would hate to have lost that" Participant 5 (stroke survivor) FG3.

Disparity in the kind of rehabilitation services provided by hospitals: Participants reported differences between the hospitals regarding the kind of rehabilitation services they provide for stroke survivors including information and GP services. The participants suggested that information which could be helpful for stroke survivors like support groups should be shared with stroke survivors and their carers, as they faced a lack of resources following discharge. For example:

*"Can I just say that *** (stroke survivor) never had anything like that, no phone calls since…" Participant 5 (stroke survivor) adding to what was said: "The day we were at the vision thing (stroke support group), one of the stroke nurses was there with one of the guys who's currently doing the mindfulness group (stroke support groups), and she phoned him (stroke survivor) and she said, "there's this vision thing on, she brought him, she brought him in!" FG1.*

The participants also identified that the insufficient provision of General Practitioners (GPs) was one of the reasons for this disparity in referrals to rehabilitation services provided by hospitals.

"I don't think there's enough that goes on in our surgeries (GPs) to let us know about the groups and things that you could go to… this is due to the shortage of GPs in the country" Participant 3 (carer) FG1.

Reliance on alternative rehabilitation services: The participants explained that once stroke survivors had been discharged from hospital they needed to continue their rehabilitation, which led them to look for alternatives to the NHS services, as they did not receive sufficient advice and guidance from the NHS rehabilitation staff. These alternative rehabilitation services include the use of the internet, private rehabilitation centres, and other available resources. For example:

*"I have to rely on the internet to look for things like this (this study) like what we're doing just now, just to go through, because there was no advice given to us about what groups or rehabilitation would be available, I had to actually go and research on that myself, you know, to see what was on and what *** (stroke survivor)'s capabilities would be" Participant 3 (carer) FG1.*

Other stroke survivor participants sought help from a private rehabilitation provider in order to continue their rehabilitation.

"Uh my experience was very frustrating for the first 10 months, and I was trying to look for things to do, there was nothing available, when your NHS and physiotherapy came to end, it was just go on with it, or pay for it, which I did" Participant 5 (stroke survivor) FG1.

Further, some stroke survivor participants admitted that they have sought help from other sources like buying exercise books or watching exercises on YouTube in order to continue their rehabilitation. For instance:

*"We got the Stroke Survivor Book, I bought it for *** (stroke survivor), and it's quite good, there are quite a lot of exercises, and different things in it" Participant 1 (carer) FG1.*

"When you look at physio on YouTube [channel "physicaltherapyvideo" on the YouTube], they seem to come up straight off, yeah, yeah, they're great, they're really good" Participant 5 (stroke survivor)

Researcher (AA) asked a question: "Okay when you found these exercises, are you sure this is the exercise that fits you? Or do you just think that this one is good for me?"

Participant 5 (stroke survivor) answered: "... because I've been doing so many, I do know if they're credible or not, I know, and they [channel "physicaltherapyvideo" on the YouTube] seem to be very credible, because the language they use is exactly what my physio would use too, you know" FG1.

This stroke survivor believed that that particular YouTube channel was a credible source because of its professional presentation.

3.17.3.4 User centred design of the web-based physiotherapy website

Under the concept of UCD, this section seeks to highlight the contribution of the research participants to the evaluation and revision of the web-based physiotherapy website as explained in section 3.6. The UCD process involved the following four steps: exploring views of participants on the original web-based physiotherapy website, recommendations by participants for revision of the web-based physiotherapy website, negotiating with participants on the changes that can be made, and allowing participants to have a voice on what and how the final web-based physiotherapy website should look and finally explore their views on the final version of the web-based physiotherapy website. The four steps used during the user-centred process is presented below.

Views of the participants on the existing web-based physiotherapy website: The participants provided feedback on the existing web-based physiotherapy website at two different stages of the research: when they saw the website for the first time (1st focus group) and after they had accessed and observed the website for one week (2nd focus group). Overall, their initial feedback on the web-based physiotherapy website was that it was clear and looked good.

> *"I think it's [web-based physio] good… it seems basic and seems straightforward for everyone, I think" Participant 6 (stroke survivor):*
>
> *Participant 3 (carer) added: "it is user friendly" FG1*

Further, the participants were asked for an evaluation of the web-based physiotherapy website after they accessed it for a week. In this instance, the consensus was that the website would be helpful in enabling stroke survivors to continue their rehabilitation journey because it was considered easy to access and use. All participants were unanimous in their responses that they thought the website would help to with their health needs. They provided various reasons including:

> *"it provides clear instructions on what to do… I quite like (web-based physio) because of its accuracy and professionalism. … something is tailored to you, and you know this is going to work for you… so, it enhances self-confidence" Participant 7 (stroke survivor):*

Participant 6 (stroke survivor) added "it is easy to follow" FG2.

However, one stroke survivor participant with hemianopia faced difficulties with using the website as the participant did not recognise the existence of some of the website's content because of his vision problem. His carer commented that:

> *"The only slight problem is that *** (stroke survivor) had difficulty with his vision today (when accessing the web-based physio). He's got hemianopia but that actually has nothing to with the website" Participant 3 (carer) FG2.*

Even though this was considered a limitation of the original website, this issue is common among stroke survivors with hemianopia as they face similar experiences with other stroke resources such as the exercise leaflet provided to stroke survivors when they are discharged from hospital. Relative to other stroke resources such as the exercise leaflet provided by the NHS, the research participants spoke favourably about the website in terms of clarity and structure. It was suggested that the website was clearer and well-structured compared to the NHS exercise leaflets which they suggested were difficult to read. However, the participants made some recommendations for the modification of the original web-based physiotherapy website – explored below.

Recommendations for the modification of the existing web-based physiotherapy website: The participants in the first and second focus groups requested access to wider information, and suggested ways that such information could be presented. They also made suggestions as to how to maximise engagement with the website. Specifically, the following three main recommendations were made:

- A feature that will send reminders to users of the web-based physiotherapy website either by email or text message
- A feature that sends a weekly summary of what the website users have done in the previous week
- A feature that sends pop-up messages that encourages the website users to keep exercising

Their expressed views were captured in the following quotes:

"we need an alert to your phone or an email (suggestions for a reminder to exercise), just anything daily….., exercise time yet or something" Participant 5 (stroke survivor) FG2.

The participants thought that stroke survivors with eyesight problems could face difficulties reading due to the size of the font on the website. The recommendation was that users should be given the option to enlarge the font size to a desired size.

"…, providing a device that will allow users to adjust the font size will help immensely" Participant 5 (stroke survivor) FG2.

Further, the participants made recommendations for the creation of additional features to the website including an advice section (Figure 3.3). Their recommendations included:

- Links to external resources.
- Stroke support groups.
- Information about stroke.
- Encouragement and motivational pictures and text.
- Tips on exercises.
- An introduction that demonstrates the differences between stroke survivors in terms of how stroke can affect them.
- A brief description of human anatomy and body kinematics.

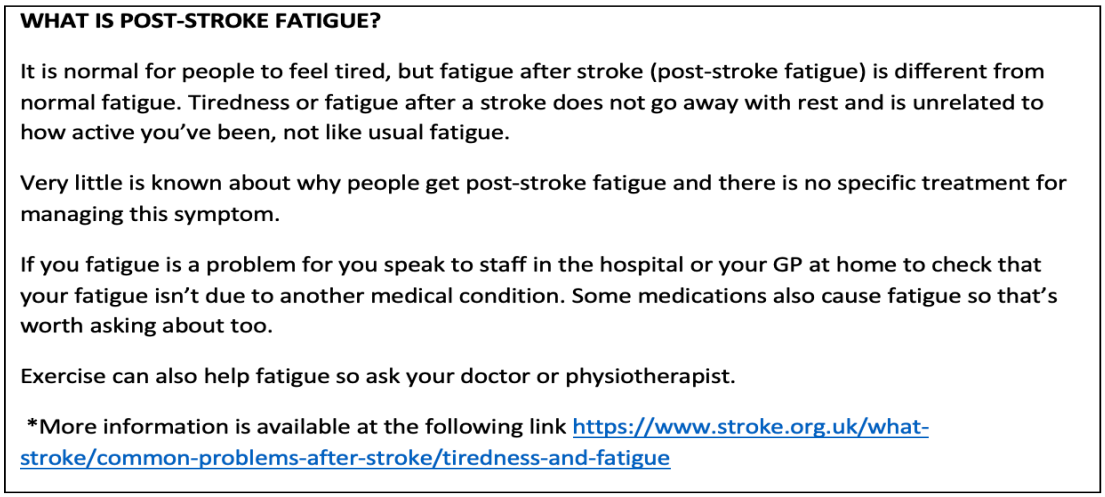
The following were the expressed views under the above listed points:

"basically, tips for exercises that would be pretty easy to understand" Participant 6 (stroke survivor) FG1.

"I think this will be helpful in conjunction with thinking about other websites that have proven to be quite good over the years, like self-help for stroke and maybe the NHS I can't remember…… a mindfulness one, I think things like that are quite good" Participant 5 (stroke survivor) FG2.

"Some encouragement, you know, these exercises are there to help you, will not everybody get on as well as everybody else so keep trying and eventually you will get what you need" Participant 4 (stroke survivor) FG2.

"A welcome to the website you know saying we know the strokes are so different and we know everyone is different, maybe just a wee introduction of a stroke and understanding that we can't cover everything in the website" Participant 5 (stroke survivor) FG2.



WHAT IS POST-STROKE FATIGUE?

It is normal for people to feel tired, but fatigue after stroke (post-stroke fatigue) is different from normal fatigue. Tiredness or fatigue after a stroke does not go away with rest and is unrelated to how active you've been, not like usual fatigue.

Very little is known about why people get post-stroke fatigue and there is no specific treatment for managing this symptom.

If you fatigue is a problem for you speak to staff in the hospital or your GP at home to check that your fatigue isn't due to another medical condition. Some medications also cause fatigue so that's worth asking about too.

Exercise can also help fatigue so ask your doctor or physiotherapist.

*More information is available at the following link https://www.stroke.org.uk/what-stroke/common-problems-after-stroke/tiredness-and-fatigue

Figure 3.3 Example of the new advice section in the web-based physio platform

When the participants observed the exercise section which is where the videos, explanation and guidance on the therapeutic exercises are presented on the website, they proposed having a stroke survivor, rather someone with other chronic diseases, demonstrate the exercises using one side of the body rather than both sides (Figure 3.4). Moreover, they suggested that each exercise video should illustrate the goal of the filmed exercise, identify which muscle is working and use a cartoon character for illustration:

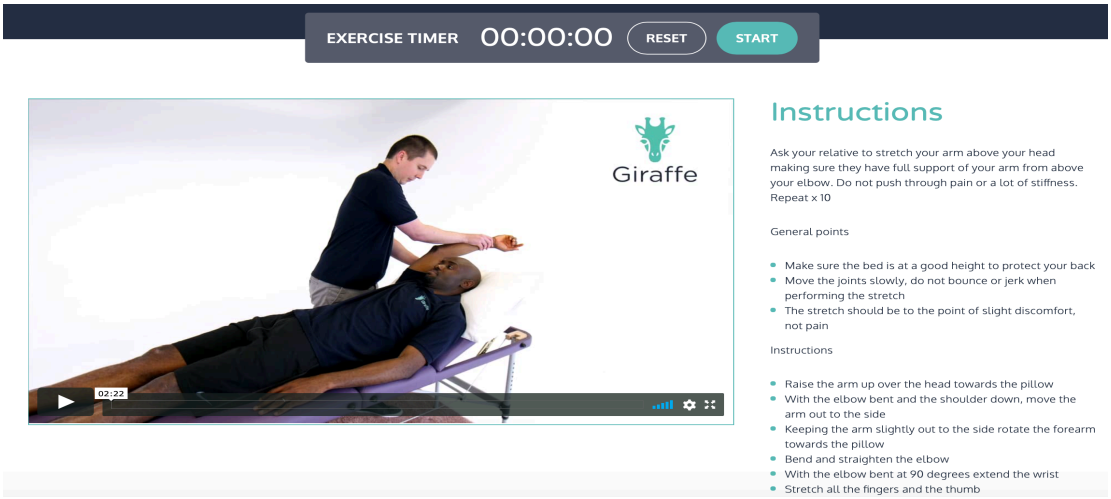


Figure 3.4 Example of new exercise videos

Negotiating with participants on achievable changes: The "negotiation" phase provided another platform for shared decision-making both amongst the research participants as well as between them and researcher regarding the required modifications to the website. This phase was necessary mainly because it was costly and sometimes impracticable to accommodate all the recommendations made by the research participants in revising the website. The two main steps followed at the 'negotiation' phase were:

- Participants were asked to agree a set of recommendations from those originally made by them based on their actual needs and in order of preferences.
- The researcher then entered into further negotiations with the participants by proposing alternative recommendations and highlighting the practical challenges associated with some of the recommendations made by the research participants.
- Consensus was built in a shared decision-making manner by both the researcher and the research participants.

For instance: One key suggestion made by participants was to embed into the website a discussion forum that would enable website users to share their personal journeys as well as share useful information encountered by most of the participants. This recommendation was negotiated because the researcher had concerns over confidentiality and privacy of users. It was therefore brought to the attention of the research participants who then understood the concerns expressed by the researcher. The researcher further suggested that some of the content and interactions might be harmful to users if there is no competent monitoring mechanism in

place. The researcher further argued that there might be too much information that might be overburdening to users. This point was there negotiated successfully, and the decision was to drop that recommendation.

> *"I know we talked last week about social networking, but I just think that can't work, and somebody would have to monitor this site…" Participant 5 (stroke survivor) FG2.*

Another point negotiated was whether the website should provide help for people with hemianopia. This point was negotiated mainly among the research participants with some guidance from the researcher. They concluded that sticking to the original objective of the website is more important, since those with hemianopia could seek further help for their visual problems from other websites:

> *"I think the limb exercise is more important because he (stroke survivor with hemianopia) knows where to get help for hemianopia if they really need it…" Participant 3 (carer) FG2.*

When one stroke survivor participant suggested the need to have direct interaction with a physiotherapist to monitor the website, the rest of the research participants disagreed with the suggestion. Instead, they argued that the web-based physiotherapy videos and instructions showed people how to perform the exercises, the website users will be trained to do the exercises and their rehabilitation programmes will be recommended by physiotherapists based on their clinical assessments. In addition, the participants and the researchers concluded by repeating the importance of keeping the regular one to one physiotherapy sessions and clarified that the web-based physiotherapy platform was not an alternative to normal one to one physiotherapy:

> *"I know exactly where this participant (stroke survivor) is coming from… but I still think that maintaining such one-to-one support sessions with a physiotherapist is super important. It appears some of us are taking it for granted but I won't underestimate the benefits of such one-to-one contacts…." Participant 5 (stroke survivor) FG2.*

Another feature negotiated successfully between the researcher and the research participants was that of the inclusion of an exercise diary. Through this feature, each exercise on the website

has an exercise diary which is a box that the website users can tick when they have completed the exercise. As an alternative to providing them with encouragement and feedback about their performance the researcher explained that website users complete the exercise diary when they perform each exercise and he also posted a reminder to use it in the advice section. The researcher also explained that website users can find a summary of their performance in the diary section. The participants commented that the diary section was an acceptable alternative:

> *"..... Well, that's better than nothing because you want to see something that helps you to track your progress. You need something, really and this one is good" Participant 7 (stroke survivor) FG3.*

Further, the researcher stated that they could not embed the website with reminders for the website users but would ask the physiotherapists to contact the website users if the physiotherapist noticed people had not been doing their exercise. This was also successfully negotiated between the researcher and the research participants who thought it was a good, alternative to what they originally wanted:

> *"Very good. Personal touch, but that is good because I mean you feel as though somebody cares" Participant 7 (stroke survivor): FG3.*

Finally, the participants suggested posting a brief description of human anatomy and body kinematics in the advice section, but the researcher thought that it would be easier for the website users if they replaced this suggestion by clarifying the goal of each exercise on the web-based physiotherapy. The participants agreed that stating the goal of each exercise would be enough and added that posting information about human anatomy and body kinematics might dilute the main message.

All the above negotiated recommendations were then fed into the original website and the revised website was presented to the research participants for their final comments. For those recommendation that could not be applied due to practical reasons, alternative solutions were negotiated and agreed on as demonstrated above. Further, the researcher conferred with the research participants and sought their final approval of the negotiated recommendations and alternative solutions during the third focus group. For instance, the researcher uploaded an aphasia-friendly version of the advice section to the web-based physiotherapy website (example is provided below in figure 3.5) and also provided instructions of how to zoom in and

out of the website pages as an alternative to embedding the web-based physiotherapy with a font adjustment tool, and the participants were happy with the alternative amendment.

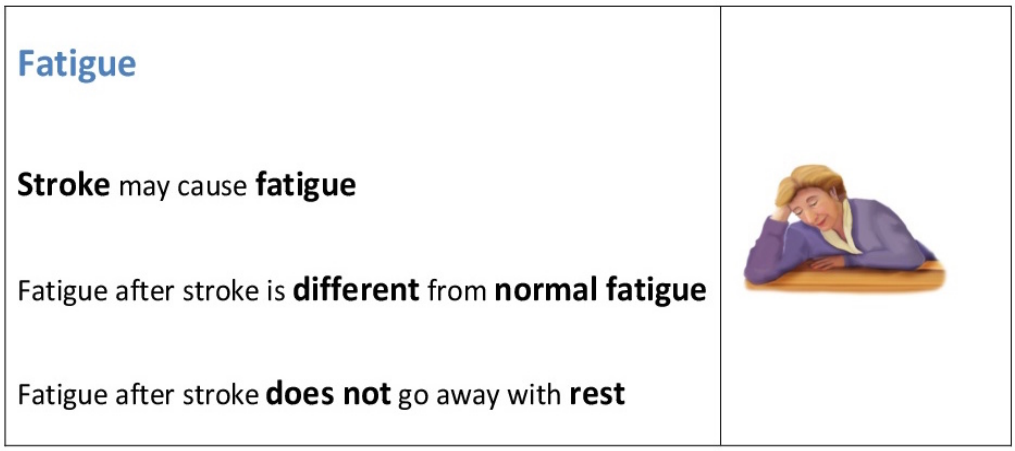


Figure 3.5 Example of aphasia version of the advice section in the web-based physiotherapy platform

Throughout this phase, the researcher was mindful of the potential of social desirability response bias and its undesirable impact. Latkin et al. (2017) have argued that social desirability response biases are likely to lead to inaccurate and erroneous conclusions in health research. Therefore, the researcher encouraged the research participants to express their views independently and without recourse to what other participants had to say. The researcher also provided continuous assurances, probed for more information from individual participants and asked for personal stories/experiences to substantiate their contributions. The table below (Table 3.6) provides examples:

Table 3.6 Summary of the negotiated and agreed amendments to the web-based physiotherapy platform

No	**The group's list of initial recommendations**	**The negotiated issues**	**The final agreed amendments to the website**
Negotiation for the web-based physio platform in general			
1-	Embed the website with an advice section that includes the following: • Links to external resources (i.e., stroke support groups) • Motivational text and pictures • Generic information about stroke and how they affect people at different levels • Description about human anatomy • Discussion forum for the website users	There were no issues with the advice section except for the points of adding information about human anatomy and embedding the website with a discussion forum. For the information about human anatomy, it was decided that this was too complicated for the website users. For the discussion forum, the confidentiality and privacy of the website users and the possibility of them posting harmful information were discussed. In addition, if we added everything, we would have a huge advice section.	A stroke specific advice section was added to the website without information about human anatomy or a discussion forum (Figure 3.3) (Appendix 18)

No	**The group's list of initial recommendations**	**The negotiated issues**	**The final agreed amendments to the website**
2-	The website should target helping people with hemianopia	It was preferred to stick with the original aim of the website as there are other websites to help people with hemianopia.	No amendments were made
3-	Having direct contact with physiotherapists	It was thought that the website is not an alternative for regular one-to-one therapy and the videos and explanation on the website make this clear.	No amendments were made
4-	Reminders sent to the website users to do their exercises	The required costs and time plus the fact that this is part of a PhD project.	This was not applicable. However, it was agreed that if physiotherapists contacted website users if they were missing on the system, adding reminders was not necessary
5-	Provide the website users with a weekly summary of their performance and embed the website with a pop-up cartoon character to encourage the users to exercise		These suggestions were not possible, and it was agreed that the diary section in the website would be enough. In addition, a reminder for the website users to use the website was provided in the advice section.

No	**The group's list of initial recommendations**	**The negotiated issues**	**The final agreed amendments to the website**
6-	Embed the website with an option to enlarge the font size of the text		The website was embedded with an aphasia version of the advice section (Figure 3.5) (Appendix 19) and it was agreed that instructions would be provided in the advice section for zooming in and out the pages.
Negotiation for the exercise section within the web-based physio platform			
7-	Stroke survivors filmed performing the exercises	No issues were discussed.	Agreed and new exercises were filmed (Figure 3.4).
8-	Exercise one side of the body at a time		
9-	Explain the goal of each exercise and identify which muscle is working, illustrated by a cartoon character	Specifying which muscle is working was discussed as being too complicated.	The goal of each exercise is illustrated in both written and audio without identifying the muscles that are working.

Views of participants on the final web-based physiotherapy website: In the third focus group, the participants provided evaluation about the advice section which is where to find information on how to get the most out of the web-based physiotherapy, useful information about stroke and tips for helping stroke survivors and their carers to cope with stroke. All the participants thought that this section was informative and easy to read and understand. The overall feedback regarding the modified website was positive and the research participants appeared happy with the new videos and the advice section. No further suggestions were made for consideration.

3.18 Discussion

The focus of this study was to identify areas that require modifications to an existing web-based physiotherapy platform based on the UCD involving the researcher, stroke survivors as well as their carers. The website had previously been evaluated by people with different long-term conditions, including multiple sclerosis (Paul et al., 2014, Paul et al., 2019) and spinal cord injury populations (Coulter et al., 2016, Coulter et al., 2015b, Coulter et al., 2015a). However, this was its first evaluation in stroke survivors and their carers. Modifying the website to meet the needs of stroke survivors lays a useful foundation for future research studies using this platform hence enriching the available evidence in the area of rehabilitation delivery. The key findings of the research include the following:

- Stroke survivors and their carers reported that rehabilitation available through the NHS was often focused on mobility and the lower limb, while upper-limb rehabilitation was not a priority. This was reported in the "quality of care and support" theme under the "prioritising leg mobility exercises" category.
- Access to rehabilitation was reported as time-limited, inconsistent or with geographical variation in access to services. Consequently, some stroke survivors reported accessing unregulated, non-prescribed exercise resources that they found online. This was reported in the "lack of access to rehabilitation services" theme.
- The final version of the web-based physiotherapy site was preferred, acceptable and meets the needs of stroke population. This was reported in the "user centred design of the web-based physiotherapy website" theme under the "views of participants on the final web-based physiotherapy website" category

This section discusses the findings of this research in terms of addressing the specified research questions critically.

- **What are the views of stroke survivors and their carers on using web-based physiotherapy to deliver their rehabilitation programme?**

The views of stroke survivors and their carers on using web-based physiotherapy suggested that web-based physiotherapy has the potential to overcome existing rehabilitation barriers and to provide stroke survivors and carers with stroke support resources. The findings confirm rehabilitation barriers that have been demonstrated in other studies for stroke survivors in the

United Kingdom including delays in accessing rehabilitation facilities after discharge (Mellor et al., 2015); and insufficient amount of rehabilitation in hospital (Clarke et al., 2018); the differences in the availability and quality of care and stroke support resources across different sites (Sentinel Stroke National Audit Programme, 2019, National Services Scotland Information and Intelligence, 2019); variations in informing stroke survivors and carers about available resources (Care Quality Commission, 2011, Mold et al., 2006); and a lack of support and unmet physical and stroke-related needs (McKevitt et al., 2011). These barriers were also identified in this study leaving research participants disillusioned about existing rehabilitation options available to them. The participants did indicate that they did not rely on the rehabilitation exercises prescribed by the NHS; rather they pursued alternative rehabilitation options available either through private rehabilitation centres or online, for example, using YouTube. This finding demonstrates that the stroke survivors and their carers appeared to have difficulty in following the rehabilitation offered by the NHS and were exploring alternative options.

The participants explained how they had faced rehabilitation barriers since they had been diagnosed with a stroke and therefore, they were constantly exploring alternatives to the care provided by the NHS, including the use of the internet. They were positive about this web-based physiotherapy website and appreciated the opportunity to use it, especially as this platform was customised to their views and preferences. The final version of the website was modified to meet their rehabilitation needs. Therefore, this research question was considered as fully answered.

- **What are the strengths and weaknesses of the current version of the web-based physiotherapy website for people after stroke;** and **What modifications were required, if any, in order to make the website acceptable and suitable for people with stroke and their carers?**

This study followed a UCD in order to identify the strengths and weaknesses of the existing and final version of the web-based physiotherapy platform and engaged patients in decision-making to identify the required modifications (details about the use of UCD is discussed above in section 3.6). As evidenced in Table 3.6 the weaknesses and required modifications to the current version of the web-based physiotherapy website were highlighted. The need for having an advice section accompanied with regular updated resources in the web-based physiotherapy platform was agreed. As such, the participants and the researchers found that providing the

web-based physiotherapy platform with generic information and external links to continuously updated resources (for example, Stroke Associations and support websites) (Figure 3.3) would address this gap. Another weakness identified was associated with people who demonstrate some symptoms of stroke such as aphasia. Aphasia could affect the ability of stroke survivors to comprehend the language used on the platform (see section 2.1.5.4). Therefore, an aphasia-friendly version of the platform was developed using the National Institute for Health Research resources based on the stroke association guidelines (Figure 3.5) (Stroke Association, 2012, National Institute for Health research, 2014). Finally, it was agreed that acting roles in the exercise videos on the platform should be played by stroke survivors, performing the exercises using one limb at a time and that each exercise should state the goal of the exercise at the beginning. Therefore, new exercise videos with the above agreed features were added to the website (Figure 3.4).

It was crucial for this study to present findings about the process of UCD at different stages (before and after implementing the agreed modifications to the website), not only to show how this study adopted the UCD but also to check if there were any other uncovered weaknesses in the final version. However, the participants' feedback about the final version of the website was totally positive and no suggestions were provided.

In terms of strengths, the final version was considered user friendly and helpful in providing access to information and resources as well as easier to use. Similar feedback was provided by people with spinal cord injury in another study aimed at evaluating the same website for this population using patient-centred approach (Coulter et al., 2015b).

The telerehabilitation provides people with long-term conditions, like stroke, with a more efficient and accessible mode of rehabilitation as well as support resources for stroke survivors and carers (Kairy et al., 2009, Brennan and Barker, 2008). In addition, the use of telerehabilitation is not restricted to difficult-to-reach groups or those who do not have access to rehabilitation services; rather it can be used to increase the dose of the prescribed intervention (Laver et al., 2013). In this study, the researcher did not include any difficult-to-reach participants for practical reasons (Rockliffe et al., 2018). All of the participants were residing within the Greater Glasgow area, were able to use computers (either stroke survivors or their carers), had access to the internet and did not have restricted mobility. In addition, the participants were recruited from CHSS stroke support groups. Using a telerehabilitation tool like web-based physiotherapy could also address some of the stroke survivor rehabilitation

barriers as it offers educational and support resources and on-demand physiotherapy sessions that are available at times convenient to stroke patients, in cases where conventional therapy might not be accessible or sufficient. Telerehabilitation interventions have the potential to tighten the gap between stroke survivors' and carers' needs and current practices (Laver et al., 2013).

3.18.1 Study limitations and implications for future research

The study has some limitations that need to be considered. First of all, the study findings could have been affected by the adopted sampling method – convenience sampling (Bornstein et al., 2013). The convenience sampling method has been criticised for not being able to provide an in-depth understanding of the topic. Wider perspectives on the topic could have been obtained if, for example, purposive sampling had been adopted (Parahoo, 2014). In addition, there are no specific procedures in convenience sampling as it aims to recruit participants based on their proximity and accessibility; therefore, selection bias cannot be ruled out (Polit and Beck, 2017). The fact that some participants used the internet either on a daily or weekly basis while some had never used it strengthened the findings of the study as this was useful to capture a wider range of views.

This study aimed to recruit 4–12 participants, therefore recruiting 7 participants was acceptable. However, the number of participants attending the three consecutive focus groups decreased as 7 participants attended the first focus group, 5 attended the second and only 3 participants attended the third. This may negatively affect the implementation of the user-centred approach in this study. In addition, this study invited the same participants to all the focus groups, therefore, the concept of data saturation was not relevant to this study.

Furthermore, the researchers considered the required costs and time, and the users' preferences, when implementing the suggested amendments. Therefore, some of the suggested amendments were not implemented, such as equipping the web-based physiotherapy platform with a font adjustment tool and sending reminders to users to use web-based physiotherapy. However, alternative solutions were provided and agreed with the participants to address the unmet suggestions. Moreover, while the participants accessed the website and viewed all of its content, in order to better judge the feasibility of the web-based physiotherapy platform, richer feedback may have been possible if the participants had followed a personalised rehabilitation programme, not just viewed it. Therefore, further studies are required to investigate how the

web-based physiotherapy can deliver a rehabilitation programme for the stroke population and provide stroke resources.

3.18.2 Implications for the study and recommendations for future research

This study established that the web-based physiotherapy platform was accessible and acceptable to a group of stroke survivors and carers by giving them access to an appropriate source of stroke resources and rehabilitation without the need for direct supervision. However, studies are essential to examine the implementation of the final version of the website in clinical practice. Chapters 4-6 in this thesis present a pilot RCT study evaluating the feasibility of the final version of the web-based physiotherapy platform in exercise delivery for stroke population.

More studies with a large sample size that explore the views of stroke survivors, carers and professionals regarding the use of telerehabilitation tools are also required to better understand the needs and preferences of these populations. This study indicates the significance of adopting a user-centred approach to develop tools to deliver rehabilitation such as the web-based physiotherapy platform for the stroke population.

3.19 Conclusion

This study appeared to have delivered on its objective to provide deliverable rehabilitation programmes and providing stroke resources via the web-based physiotherapy platform. In practical terms, the research participants found the modified web-based physiotherapy website acceptable and recognised the platform as a potential option to overcome rehabilitation barriers based on their needs and preferences. The findings from this study can be applied to the area of telerehabilitation delivery.

Chapter 4 : Augmented Upper-limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a pilot study: Aim, objectives and methods

The gaps identified in the existing literature justifying further research on current practice in stroke units in the UK have been discussed in chapter two of this thesis. In summary, the identified gaps are as follows:

- Often stroke patients have less rehabilitation than recommended during their hospital stay in the UK
- Physiotherapists in the UK face difficulties in providing the recommended dose of rehabilitation
- There is contradictory evidence from studies investigating the effect of delivering upper-limb augmented interventions for the stroke population in in-patient settings
- Very few studies have investigated unsupervised upper-limb augmented interventions and none of them used the internet as a medium for rehabilitation delivery

This study followed the MRC framework for the development and evaluation of health interventions (Craig et al., 2013). This framework recommends following four stages:

5. Development of the intervention
6. Piloting and feasibility
7. Evaluation
8. Implementation

Chapter 3 in this thesis focussed on development and refinement of the intervention (Stage 1) and the study presented in this chapter is guided by the processes stipulated under Stage 2 of the MRC framework. This study aimed to evaluate the acceptability and feasibility, and to explore the possible effectiveness, of an individualised 4-week programme of augmented upper-limb rehabilitation, delivered via the modified web-based physiotherapy platform, for the stroke population in acute stroke rehabilitation. The study is presented over three chapters:

- Chapter 4: Aims, objectives and methods used in the study
- Chapter 5: Presentation of the study results
- Chapter 6: Discussion of the results in relation to the existing literature

The study used the CONSORT reporting guidelines by Schulz et al. (2010), which includes a list of 25 item that need to be checked, in order to facilitate reporting accuracy and completeness, as well as interpretation and assessment.

4.1 Study aim and objectives

The aim of this study was to evaluate the acceptability and feasibility, and to explore the possible effectiveness, of an individualised 4-week programme of augmented upper-limb rehabilitation, delivered via the modified web-based physiotherapy platform, for the stroke population in acute stroke rehabilitation. A feasibility study is defined by as 'a piece of research done before the main study in order to answer the question 'Can this study be done?' (National Institute for Health Research, 2016). In this study, the feasibility was carried out to evaluate the following parameters (Lancaster et al., 2004, National Institute for Health Research, 2016):

- Assess the study's protocol and intervention.
- Estimate the recruitment rate of a future study.
- Assess the suitability of inclusion/exclusion criteria of a future study.
- Report adherence of stroke survivors to an augmented upper-limb physiotherapy intervention.
- Explore feedback of stroke survivors, carers and physiotherapists to the study intervention.
- Evaluate data collection methods.
- Record attrition rates.
- Record participant safety.
- Identify the strengths and limitations of the study.

The primary research objectives of the study were:

- To evaluate the adherence of participants to an augmented upper-limb physiotherapy intervention.
- To identify the feasibility of augmented physiotherapy, delivered through a web-based platform, for people after stroke in terms of recruitment and attrition rates, and participant safety.

The secondary research objectives of the study were:

- To explore the extent to which the augmented intervention affected upper-limb function, trunk impairment and muscle spasticity compared to usual care.
- To evaluate the feedback of stroke survivors, carers and physiotherapy staff on the platform.

4.2 Study design and ethical approval

The study design was a pilot RCT in order to address the study objectives. A pilot RCT is defined as a small study that is carried out to further educate a larger study (Arnold et al., 2009). The pilot study was necessary in this research because it was not clear if a technology tool like the web-based physiotherapy platform could be a suitable medium to deliver augmented upper-limb exercises for inpatient stroke survivors. In addition, the web-based physiotherapy platform had not been used before with a stroke population; therefore, providing further justification for the need for a pilot study that could guide a future definitive RCT. In terms of ethics, the study was approved by the West of Scotland Research Ethics Committee in September 2018 (Appendix 20) and Research and Development approval was given by NHS Lanarkshire in September 2018 (Appendix 21). The study lasted just over 13 months, commencing on 17/09/2018 and ending on 26/8/2019.

4.3 Sampling method

Recruitment of participants was performed via convenience sampling (details about convenience sampling and why this was considered the most suitable approach for sampling is provided in section 3.8). Participants were recruited to the study from three stroke units within NHS Lanarkshire; University Hospital Hairmyres, University Hospital Wishaw and University Hospital Monklands. The study recruited stroke survivors, carers and members of the physiotherapy team who had been involved in setting up stroke survivors on the platform.

Targeted sample size for each group of participants (stroke survivors, carers and physiotherapy team) is justified as follows. For stroke survivor participants, initially the sample size and recruitment period were calculated for recruitment only at one site, which was the stroke unit at Hairmyres Hospital. This unit offers 19 beds, and the average number of stroke survivors admitted to the unit per month is 34. Based on the number of people potentially available during the study period (the recruitment period is 1 year), it was expected that a total of 30 stroke survivor participants would be recruited. As recruitment was slower than expected we extended

recruitment to other stroke units in NHS Lanarkshire. These were: the stroke unit at the University Hospital Monklands and the stroke unit at the University Hospital Wishaw, see section 4.9 for more details.

As the expected number of stroke survivors to be allocated to the intervention group was 15, a maximum of 15 carers were expected to be recruited from the three sites. Each physiotherapist should deliver and monitor rehabilitation programmes for at least 2 stroke survivors to be recruited to the study; therefore, a maximum of 8 physiotherapists were expected to be recruited as there were 15 stroke survivors expected to be recruited to the intervention group.

4.4 Inclusion/exclusion criteria, screening measures and recruitment

The recruitment process was guided by inclusion and exclusion criteria specific to each participant group. These are provided below.

4.4.1 Inclusion Criteria

Stroke survivors were invited to take part if they fulfilled the following criteria:

- Over 18 years old
- Had moderate to severe upper-limb functional limitation due to stroke (score 0-39 in the Action Research Arm Test (ARAT)) (discussed in section 4.8.1)
- Diagnosed with first stroke and admitted to the rehabilitation unit
- Able to sit in a chair or a bed
- Able to use a computer or tablet with or without help from carers
- Able to understand English language
- Able to provide informed written consent (this was assessed based on the judgment of the researcher following a formal assessment by the clinical team).

Carers were invited to participate in the study if they fulfilled the following criteria:

- Over 18 years old
- Able to support the patient in the augmented physiotherapy programme (intervention group)
- Able to understand and speak English language

This study invited a carer/family member of someone who had had a stroke, had agreed to take part in the study and had been allocated to the intervention group. It was important to gather their views as the person may need some support from his/her partner, relative or carer to use the website and/or do their arm exercises. Therefore, obtaining feedback from these support partners provided the researcher with greater insight into the study intervention.

The physiotherapy staff who delivered and monitored the augmented physiotherapy programmes were invited to take part in the study. As the physiotherapists delivered and monitored the study intervention, it was important for this study to obtain their feedback about their experience with the intervention in order to better judge its feasibility. To be included each physiotherapist would have delivered and monitored rehabilitation programmes for at least 2 stroke survivors.

4.4.2 Exclusion Criteria

Stroke survivors were excluded if:

- They had significant cardiorespiratory, orthopaedic, neurological or other condition which would preclude them from taking part in an exercise programme.
- They had moderate to severe cognitive impairment (score less than 25 in the Mini Mental State Examination (MMSE) (discussed below).
- They had a shoulder subluxation (a substantial amendment was requested from the Ethics committee to this exclusion criteria and this was approved on the 14 November 2018 (substantial: change of inclusion/exclusion criteria) (REC Ref AM01, appendix 22), more detail is provided in section 4.9.
- They were participating in another research study.

There were no exclusion criteria for carers and physiotherapists.

The Mini–Mental State Examination (MMSE) is a valid, reliable measure for identifying cognitive impairment (Folstein et al., 1975, Grace et al., 1995). The MMSE assesses cognitive ability by asking the participants to perform functions related to orientation, concentration, language, and the ability to follow commands. The maximum score is 30 and the lowest is 0, higher scores demonstrate lower cognitive impairment. The time to complete the MMSE is up to 10 minutes (Folstein et al., 1975) (Appendix 23).

4.4.3 Recruitment, screening, consent and demographic information of stroke survivors

The researcher and an academic supervisor attended each stroke unit to explain the purpose of the study to the physiotherapy team and outline the inclusion/exclusion criteria. In terms of the stroke survivors, potential participants were informed of the study by the physiotherapists in the stroke unit. Potential participants received a participant information sheet (Appendix 24), and in addition, a participant information sheet for their carers (Appendix 25) if appropriate (see below). Potential participants were advised to contact the research team or physiotherapists in the ward if they would like to take part in the study.

Aphasia-friendly versions of the stroke survivor's participant information sheet (Appendix 26) and consent form (Appendix 27) were available if required based on guidelines provided by National Institute for Health research (2014) and Stroke Association (2012). This participant information sheet included a tear off sheet with 'I am interested in taking part' written on it. Aphasic patients and/or their relatives/carers were advised to hand this sheet to the physiotherapist when they were receiving treatment, or they could directly approach the research team or the physiotherapists on the ward.

If the potential participant agreed to take part, the researcher attended the stroke unit to assess them for their eligibility to participate in the study. Potential participants and/or their carers could ask questions about the study, and they were also informed that they were free to withdraw from the study at any time. Informed written consent was obtained (Appendix 28) and all the stroke survivor participants were given the "Just move" leaflet from Chest Heart & Stroke Scotland (Appendix 29) before allocating them to their treatment group. This leaflet, which contains information about the importance of exercise and physical activity was given to all the participants to allow valid comparisons to be made between the groups regarding secondary research objectives.

Demographic information as recommended by Kwakkel et al. (2017) were collected for this study. The following demographic information were recorded by the researcher either by getting information directly from the stroke survivor or from his/her medical records (with their consent): age, sex, time since stroke, ethnicity, level of education, stroke severity (National Institutes of Health Stroke Scale [NIHSS]), living arrangement and walking status before stroke (by a question), previous use of computers (by a question) and general health status were

collected directly from the stroke survivor. Medical history (stroke risk factor, co-morbid conditions and previous TIA); stroke type (haemorrhage or ischaemic), stroke sub-type (lacunar, large artery or undetermined), stroke location (cortical, subcortical, midbrain or brainstem), imaging (if stroke confirmed by imaging, CT or MRI) and thrombolysis therapy were collected from his/her medical records.

The NIHSS is a valid and reliable tool to assess the severity of stroke (Hinkle, 2014). Different domains are assessed in the NIHSS: the level of consciousness, vision, language, arm and leg motor abilities, facial palsy and sensory responses to pinprick. The NIHSS scale is scored from 0 to 42, with higher scores indicating higher stroke severity. The assessment takes five minutes to complete (Brott et al., 1989).

4.4.4 Recruitment, screening, consent and demographic information of carers

It was not mandatory that all stroke participants had a career/relatives/family member (from now referred to collectively as carers) participating. However, carers were invited to take part. The physiotherapists in the stroke unit informed the carers about the study. Once the stroke survivors were allocated to the intervention group, the researcher provided their carer with a participant information sheet.

Carers were given an opportunity to ask questions about the study. If they agreed to participate in the study, they were asked to sign the consent form (Appendix 30). The following demographic information were recorded for carers: age, gender, relationship to stroke survivor, occupation, ethnicity, level of education, previous use of computers and general health status.

4.4.5 Recruitment, screening, consent and demographic information of physiotherapy staff

In terms of recruitment, the researcher invited all physiotherapists who delivered and monitored the augmented physiotherapy programme to take part in this study. The physiotherapy staff from the stroke units were informed of the study by the researcher and were given a participant information sheet (Appendix 31). Physiotherapy staff were also given an opportunity to ask questions about the study. If they agreed to participate in the study, they were asked to sign a consent form (Appendix 32). The following demographic information were recorded: age,

gender, occupation (physiotherapist or assistant physiotherapist), level of education, previous use of computers and time working in the stroke unit.

4.4.6 Randomisation

Following consent, baseline (initial) assessments of stroke survivors were performed by the researcher and participants were then randomised into the augmented physiotherapy group or control group using 30 opaque sealed envelopes, each containing a piece of paper with a number written on it (numbers were from 1-30). Simple randomisation was used by the researcher to allocate the participants into the study groups.

Prior to randomisation, a set of sequent numbers (1-30) was generated by the researcher. Each number was placed in a separate envelope, and then these envelopes were systematically shuffled in order to avoid compromising the randomisation. Subsequently, these envelopes were randomly placed on top of each other in one pile.

Participants were randomised by choosing one of the envelopes, each containing a unique number that allocated the participants to either the intervention or control group. Envelopes with odd numbers allocated participants to the intervention group and those with even numbers allocated participants to control group. The researcher then assigned participants either to the intervention group or control group, based on their chosen envelopes. The researcher was also the assessor and therefore was not blinded to participants' group allocation.

4.5 Control group

During the study, the stroke survivors in the control group received usual physiotherapy care only. Normally in NHS Lanarkshire usual physiotherapy care is provided by physiotherapists and assistant physiotherapists, if needed, for an average of 4 to 5 sessions per week, each lasting approximately 45 minutes. Physiotherapists provide one to one rehabilitation sessions based on the Bobath approach and the sessions are focused more on the lower limb.

The number, duration and content of all standard physiotherapy sessions, including any upper-limb exercises, were recorded by clinical physiotherapists and occupational therapists for both groups, using developed forms. The forms available for recording standard physiotherapy sessions are limited and the researcher avoided using the form presented by Donaldson et al. (2009b) as it required a detailed description of each session, which would impose on the

workload of the physiotherapists. Therefore, the researcher relied on a simple form to record these sessions (Appendix 33).

4.6 Intervention group

Stroke survivors in the intervention group undertook a progressive, individualised 4 week upper-limb physiotherapy intervention delivered via web-based physiotherapy (www.webbasedphysio.com, now www.giraffehealth.com) in addition to usual care. The individualised exercise programme was provided/prescribed by the participant's physiotherapist and was based on clinical assessment, their goals and level of upper-limb function. The augmented programme comprised upper-limb and trunk exercises (example of an exercises programme is provided in Figure 4.1).

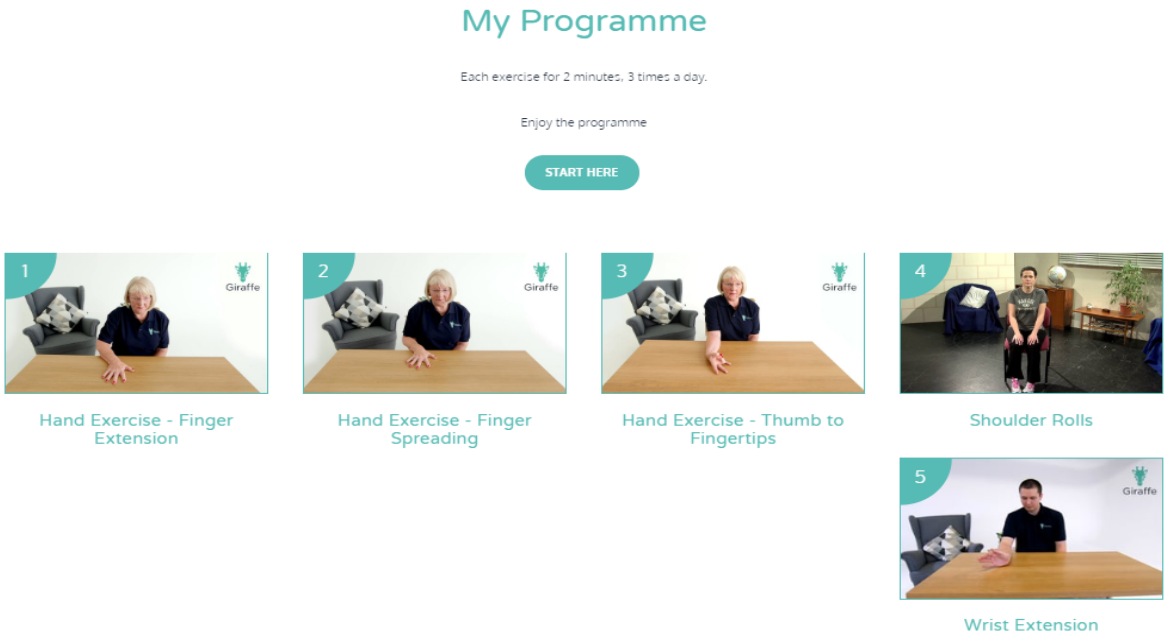


Figure 4.1 Example of an exercise programme in the web-based physio

The web-based physiotherapy platform (www.webbasedphysio.com, now www.giraffehealth.com) includes a library of exercise videos that is diverse, including clips of exercises that range in their difficulty and nature. Each of these exercises is demonstrated on the website with basic instructions to website users. Physiotherapists can add more individualised instructions to the users' programme based on the physiotherapist's judgment in relation to stroke survivors agreed goals. An example of the available exercises is provided in Table 4.1 and an example of how these exercises are presented in the website to the website

users is provided in Figure 3.4. Further examples of these exercises may be found at the web-based physiotherapy platform (www.giraffehealth.com).

Table 4-1 An example of the available exercises within the web-based physiotherapy platform

Body part	Name and goal of the exercises	Instruction provided in the website to users
Hand and wrist	Active/assisted forearm pronation/supination - this exercise is generally to improve movement of arm, to increase range of motion and to prevent/minimise hand/wrist flexion deformity after stroke.	• Sit well supported in a chair or stand if confident to do so. • You may wish to rest your forearm on a pillow on your lap. • Use your unaffected hand to assist rotating the wrist on your affected arm, so your palm alternates between facing up and down. • Repeat as instructed.
	Finger extension - this exercise is generally to improve the movement of fingers, to increase range of motion, to facilitate isolated finger movements and avoid mass movement patterns after stroke, to decrease pain and stiffness (by moving muscles and improving blood circulation) and to prevent/minimise hand/wrist flexion deformity after stroke.	• Sit well supported on a chair with a table in front of you • Rest your hand on the table with your palm facing downwards • Raise your thumb keeping your other fingers on the table, hold for 3-5 seconds and rest it back on the table • Repeat the movement with the other fingers one at a time • Make sure the movement is slow and controlled
	Finger spreading - the goal of this exercise is generally to improve mobility and control of fingers.	• Sit well supported on a chair with a table in front of you. • Rest your hand on the table with your palm facing downwards. • Spread your fingers as far apart as you can, hold for a few seconds and bring them back together • Repeat as instructed. Make sure the movement is slow and controlled.
	Picking up small object - the main goal of this exercise is to improve fine finger	• Sit well supported on a chair with a table in front of you. • Have some small objects on the table such as pens, buttons or cotton reels.

Body part	Name and goal of the exercises	Instruction provided in the website to users
	function (grasp and release function).	• Pick up each small object in turn, lift it to the other side of the table and carefully place it down. • Return the objects, in turn, to their original position.
Arm and trunk	Object passing - this exercise is generally to improve grasping, releasing and reaching function, to improve balance and to improve control of trunk.	• Sit on a sturdy chair with both feet flat on the floor and your weight evenly distributed on your bottom, keep looking straight ahead throughout the exercise • Hold a plastic toy, cup or similar object. • In a slow and controlled manner, bend forward to have more space behind your back. • Pass the object behind you using your affected hand and use your other hand to retrieve it. • Maintain a good posture throughout.
	Reaching - this exercise is generally to improve grasping, releasing and reaching function, to improve balance and to improve control of trunk.	• Sit well supported on a chair with a table in front of you. • Place 3 objects on the table, one to your right, one to your left and one front. • Touch each object in turn returning to the front each time. • If instructed repeat with your other hand.
Pelvis	Knee raise - the main goals of this exercise are to strengthen core muscles and to improve control of trunk.	• Sit well supported on a chair • Lift your knee up and down • Repeat with your other leg • Make sure the movement is slow and controlled • To make this more difficult do the exercise faster
	Pelvic tilt - the main goals of this exercise are to strengthen core muscles and to improve control of trunk.	• Sit forward on a chair or in your wheelchair. • Tilt your pelvis by pulling in your tummy muscles and extending your spine • Sit back slowly • Repeat this exercise as instructed • Make sure the movement is slow and controlled

The duration and intensity of the programme was based on participant's level of functional ability. For stroke survivors with low exercise capacity the overall time of the exercise was less to begin with and built up over time to 30 minutes, five sessions per week (including weekends) in addition to their usual physiotherapy care. The dose and frequency of the intervention study were tailored to the participants in order to judge the feasibility of using the web-based physiotherapy platform in delivering augmented intervention.

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All stroke survivors in this group received an explanation of their upper-limb programme and how to use the website, and each participant was given individual log in detail to access his/her exercises and educational section. Physiotherapists reviewed and revised the progress of each participant once a week and made any necessary changes to their programme. Participants were able to contact the research team at any time during the study to ask any question related to the website or to contact physiotherapists to request a change in their programme. If participants had communication difficulties, where appropriate, an explanation of the participant's upper-limb programme and how to access the web-based physiotherapy site was provided to their carers who then supported the stroke survivors to undertake their exercise programme. In addition, an aphasia-friendly version of the advice section on the website was available to them.

Stroke survivors used their own tablets/laptop to access their programme however if they did not have an internet enabled device they were provided with a tablet and/or internet access (if the Wi-Fi at the ward was poor) for the duration of the study.

An intervention description template introduced by Hoffmann et al. (2014), the Template for Intervention Description and Replication (TIDieR), was completed for this study. This ensured the completeness of the intervention reporting, and it improved the quality of the description of the augmented intervention investigated in this study (Table 4.2).

Table 4-2 Completed Template for Intervention Description and Replication (TIDieR) checklist for the augmented web-based physiotherapy programme

1.	Name of the intervention	Augmented upper-limb task-specific exercises for stroke survivors during their hospital stay
2.	Why (rationale and essential elements of the intervention)	**Rationale** • Stroke survivors undergo less rehabilitation than is recommended during their hospital stay; therefore, stroke survivors need to practise augmented rehabilitation. • The available literature on rehabilitation, neuroscience and skill acquisition suggests that a high dose of task-specific practice is needed to facilitate functional recovery after stroke. • It is recommended that stroke survivors practise a high dose of task-specific exercises early after stroke, when neuroplasticity is at its peak, in order to facilitate their functional recovery. • The augmented exercises need to include activities that are functionally relevant and meaningful to stroke survivors in order to facilitate skill acquisition. • The available research on delivering unsupervised upper-limb intervention to stroke survivors during their hospital stay is limited and needs to be strengthened. • In additional, none of the available research used the internet as a tool to deliver unsupervised upper-limb intervention to hospitalised stroke survivors; therefore, studies in this area are required. **Essential elements:** • Progressive task-specific exercises that are prescribed based on stroke survivors' functional capabilities as judged by physiotherapists. • Functionally relevant tasks that are meaningful to each stroke patient.
3.	What (materials)	• The web-based physiotherapy website includes three main sections: the home page, a video library of exercises and an advice section that includes generic information about strokes. • The video library includes over 270 diverse exercises, including clips of pre-defined task-specific exercises (such as picking up small objects, lifting a cup and reaching) as well as stretching and passive exercises. The included exercises range in their difficulty.

		• Within each video clip, there is a box that is used to record the website users' performed exercises, the diary section. The diary section is where the website users can find the exercises that they have done and where the website users are able to leave a note about each exercise they attempt.
4.	What (procedures)	• The participant's physiotherapist prescribes/provides an individualised upper-limb exercise programme based on clinical assessment, their goals and level of upper-limb function. • The duration and intensity of the augmented programme are based on the participant's level of upper-limb functional abilities, and this is judged by their physiotherapists. • Each participant is provided with individualised log in details and also provided with explanations of how to use the website in order to access his/her exercises and educational section. • Where appropriate, an explanation of the participant's rehabilitation programme and how to access the website is also provided to carers to support participants with communication difficulties to undertake their rehabilitation programme. • Review the rehabilitation programme once a week (or more if the participants find the programme too easy or too difficult) for four weeks (or before discharge, if earlier). • Final assessments. • Amendments to exercise programme can take place when appropriate based on the participant's response to the exercise programme. • Participants are provided with a tablet and internet access for the duration of the study if they are unable to use their own tablet/laptop to access the website.
5.	Who provided	NHS Physiotherapists.
6.	How (mode of delivery)	• Participants practise their exercise programme independently. • If the participants experience any difficulties, they can contact the researcher (to ask any questions related to the website) and the physiotherapists (to request a change in their programme). • The exercise programme is reviewed once a week by physiotherapists.
7.	Where (location)	The augmented intervention was delivered in the acute stroke unit.
8.	When and how much	**When:** • Once the participant is stable after stroke onset.

		Dose: • Five sessions per week, each lasting 30 minutes, for a period of 4 weeks in addition to usual rehabilitation care. • Participants with low exercise capacity may begin with a smaller number of sessions and/or shorter overall time of each session and vice versa. • Each exercise programme is prescribed by physiotherapists based on participants' level of functional ability.
9.	Tailoring	• Physiotherapists prescribed the augmented upper-limb exercise programmes to individuals by assessing their upper-limb functional level as well as considering their goals. • Physiotherapists progress the level of exercise difficulty considering individuals' response to the augmented intervention.
10.	How well	**Planned:** Participants were asked to use the diary section (by ticking the box) each time they completed an exercise to record their practised exercises. For participants who required support to use the website, carers were asked to use the diary section every time the participant completed an exercise. **Adherence to the augmented intervention was recorded by participants and/or carers using the diary section.** The number of completed exercise diaries each week and over the intervention period (up to four weeks) is used to measure adherence. Adherence was presented as a percentage of completed exercise diaries based on the participant's prescribed rehabilitation programme.

4.7 Primary outcome measures

4.7.1 Recruitment strategy

The recruitment strategy was assessed by the number of stroke survivors who:

- Met the inclusion criteria and were invited to take part in the study
- Agreed to take part in the study
- Participated in the study

4.7.2 Usage of the web-based physiotherapy platform and adherence to the augmented intervention

The usage of the of the web-based physiotherapy website was measured as the number of participants who logged in to their augmented programmes and completed at least one exercise or left a comment. Adherence to the augmented intervention was measured by the number of completed exercise diaries per week and over the intervention period. This was expressed as a percentage of the participant's prescribed programme. It should be noted that the web-based physiotherapy website records the number of completed exercise diaries only; thus, the researcher was not able to check the actual number of exercises undertaken. This may negatively affect the reliability and validity of the findings, which is a common issue with self-reported approaches (Nicolson et al., 2018). Participants who completed all their prescribed exercises for at least two third (66.6%) of their prescribed sessions (maximum of 20 sessions, 5 sessions a week) were considered adherent (Hawley-Hague et al., 2016). Usually in this study, the physiotherapists prescribed one or a maximum of two challenging exercises for the participants in addition to their main programme in order to facilitate their functional recovery. These challenging exercises were not provided to all the participants but provided to those who had the potential to perform them as based on the judgement of the physiotherapists. On these occasions, the participants were considered to have fully completed their sessions, even if they had left out the most challenging exercises without even attempting to complete them because they thought them to be too difficult (this information was obtained from the comments provided by the participants on each exercise in their prescribed programmes).

4.7.3 Participant attrition

The attrition of participants was assessed by the number of participants who dropped out.

4.7.4 Participants' safety

Safety of the participants (stroke survivors) in the augmented intervention was measured by the number of adverse events and serious adverse events (explained in more details in section 4.10).

4.8 Secondary outcome measures

Stroke survivors in the intervention and control groups were assessed at baseline (week 0) and post-intervention (week 5). Demographic information was collected, and the following outcome measures were taken: ARAT, Trunk Impairment Scale (TIS) and Modified Ashworth scale (MAS) (detailed below. In addition, stroke survivors in the intervention group and their carers completed a questionnaire following the intervention, providing feedback on the augmented intervention, including the use of the web-based physiotherapy platform. Kwakkel et al. (2017) established a consensus recommendation for the measurements to be employed in sensorimotor stroke rehabilitation studies, including the use of ARAT to measure changes in upper-limb activity limitation. As muscle spasticity and trunk function may interfere with changes in upper-limb activity limitation, the decision was made to use MAS (Cacho et al., 2017) and TIS (Wee et al., 2015). In addition, the choice of outcome measures was also made to better understand the potential effect of the upper-limb augmented intervention based on the International Classification of Functioning, Disability and Health (ICF) framework (Geyh et al., 2004). One chosen outcome measure (MAS) captures body function and the structural impairment domain, while the other chosen outcome measures (ARAT and TIS) capture the activity limitation domain (Santisteban et al., 2016). The combination of these chosen outcome measures can be used to assess impairments that affect stroke survivors' ability to perform functional activities and participate in society (Santisteban et al., 2016, Geyh et al., 2004).

If stroke survivors, in either the intervention or control groups, were discharged from the hospital before the end of the 4-week intervention period, the post-intervention assessment took place before their discharge.

Physiotherapists completed a questionnaire after the final patient had completed the week 5 assessment. This questionnaire provided feedback on the setting up and delivery of the augmented intervention via the web-based physiotherapy platform.

4.8.1 The Action Research Arm Test (ARAT)

The Action Research Arm Test (ARAT) assesses the function and dexterity of the arm in people with upper-limb limitation and was both a screening and outcome measure. The ARAT tool is a valid and reliable tool for stroke survivors and measures arm function in 19 items grouped into the following subscales: grasp (6 items), pinch (6 items), grip (4 items) and gross motor (3 items) (Hsieh et al., 1998, Platz et al., 2005b). Scores range from 0 to 57, where a score of 57 would indicate normal arm performance and a score of 0 would indicate an inability to perform any part of the test. Total time to administer the ARAT is approximately 10 minutes (Lyle, 1981) (Appendix 34). The Minimal Clinically Important Difference (MCID) for the ARAT in stroke survivors is an increase of 5.7 points in scores (van der Lee et al., 1999).

Standardised guidelines are available for administering the test (Yozbatiran et al., 2008, Platz, 1999). This study followed Platz (1999) guideline to administer the ARAT test with some modifications to standardise test administration among participants. These modifications include adding a maximum time limit to each task of the test. Furthermore, the study used an ARAT kit equipment that precisely placed items used in the test such as balls and blocks in specific starting and destination positions. Lastly, the same cup and the same amount of water (150 ml) was used for all participants to assess grip function within ARAT.

The ARAT is a straightforward for measuring upper-limb functional abilities across a number of tasks, with different levels of complexity. The test looks at a range of arm functions, including simple and gross tasks as well as dexterity. Li et al. (2012) noted that ARAT scores, given their focus on functional tasks, are useful predictors of improvements in activity daily living outcomes. The test can be administered without formal training and can be completed quickly when dealing with higher functioning patients, since scoring is based on the ordered grading system of the Guttman scale. Assessments have shown high levels of test, retest and interrater reliability.

Although the above could be seen as advantages of the ARAT, it has some limitations. For patients with a high level of functional abilities, ARAT can take up to 20 minutes or even longer to carry out. The administration of the test requires quite a long list of materials, and

major floor and ceiling effects have been noted (Lin et al., 2009, Thompson-Butel et al., 2015). Patients with severe impairments or those with close to normal function may not be ideal candidates for the test, since van der Lee et al. (2002) determined that in these patients the scale is not sufficiently sensitive to reveal changes in performance levels. As a result, some critics argue that ARAT should only be used for assessing patients with moderate to severe hemiparesis (Chanubol et al., 2012). Based on that, and considering the ceiling effect, it was necessary for this study to exclude patients with scores of 39 or higher at baseline, in order to ensure that a clinically significant difference can be observed at four weeks. This is because the test gives points for arm and hand movements, in spite of the fact that the patient may be unable to pick up objects in the testing setting (Chanubol et al., 2012). Fundamentally, the 39 or higher scores baseline was informed by evidence in the existing literature. For instance, the work of Gratten et al (2019), which solely interprets ARAT scores suggest that patients with ARAT score of 39-57 are considered as patients with high upper limb function and were excluded in their study. Further, Van der Lee at al (2002) suggest that patients with high functional abilities (arguably 39 or higher) may not be ideal candidates for the test because the scale is not sufficiently sensitive to reveal changes in performance levels. These provided justification to exclude patients with scores of 39 or higher at baseline.

4.8.2 Trunk Impairment Scale (TIS)

The intervention in this study included trunk exercises to help the participants to improve their trunk function and balance and, thus, facilitate their upper-limb function. Therefore, identifying the level of trunk impairment was important. The Trunk Impairment Scale (TIS) (Appendix 35) is a 17-item measure for assessing the level of motor impairment of the trunk (Verheyden et al., 2004) e.g. coordination and sitting balance (static and dynamic). The scores range from 0 to 23 with lower scores indicating high levels of motor deficit in the trunk. The time required to complete this valid and reliable scale for stroke (Collin and Wade, 1990) is up to 20 minutes. This study followed Verheyden et al. (2004) guideline to administer the TIS test. There was no published MCID for the TIS.

According to Verheyden et al. (2004), the TIS is sufficiently reliable, internally consistent and valid to be used in stroke research and clinical practice. However, the patient must be able both to sit upright for the test and to obey simple commands. Therefore, the ability of stroke survivors to sit in a chair or on a bed was added to the inclusion criteria of this study. In the stroke population, it has been determined that the TIS has a large ceiling effect in two of the

three test subscales (Verheyden and Kersten, 2010). TIS was considered appropriate for this study, as it is one of a few scales of the trunk function; however, more research is required to evaluate the reliability, validity and responsiveness of TIS.

4.8.3 Modified Ashworth scale (MAS)

The Modified Ashworth scale (MAS) is a scale used to measure the level of spasticity in people with neurological conditions (Ashworth, 1964) (Appendix 36). The MAS is a valid and reliable tool to use with the stroke population (Ghotbi et al., 2011). The MAS scores range from 0 to 4, with higher scores indicating an increase in muscle tone. The time required to administer the MAS varies depending on which muscles are tested; however, the expected time to measure the spasticity of shoulder adductor, elbow flexor, wrist flexor and finger flexor muscle groups in this study is up to 5 minutes. This study followed Bohannon and Smith (1987) guideline to administer the MAS test. The intervention in this study aimed at improving arm function; however, spasticity of these muscle groups is common in stroke survivors and could hinder the improvement of arm function. Therefore, identifying the level of spasticity in these muscle groups is important.

The MAS is very common and routinely used in clinical sittings to evaluate spasticity (van Wijck et al., 2001). However, Pandyan et al. (2005) explained that there are different definitions of spasticity, but none of them provide a precise definition. Therefore, it is important for clinicians to identify precisely which particular aspects of this phenomenon are being evaluated and also to ensure that valid outcome measures are used. A number of experts have queried whether the Ashworth scale is a suitable or trustworthy measure of spasticity. It has been argued that the scale simply describes resistance to passive movement, and therefore focusses on one element of spasticity, instead of offering a general measurement (Pandyan et al., 1999, Pandyan et al., 2001). Damiano et al. (2002) concluded that the Ashworth scores measure stiffness rather than the magnitude of resistance.

According to a systematic review undertaken by Pandyan et al. (1999), the drop in the MAS's reliability is due to the differences of opinion on the 1 and 1+ rating. Ansari et al. (2006) stated that the MAS could be modified and the 1+ rating could be eliminated, to overcome this issue. Assessments of the modified scale, when applied to small samples of patients to evaluate wrist and elbow flexors reveal satisfactory (adequate to excellent) interobserver reliability ($k = 0.63$-0.89) (Ansari et al., 2009, Kaya et al., 2011).

Gregson et al. (2000) point out that the lack of clarity in the wording within the scale and its subjective rating indicate the need to develop standard procedures for assessing spasticity using the Ashworth scale, which may in turn improve reliability.

The reliability of the MAS depends on which muscle is being assessed, and, overall, the MAS is most useful for assessing the elbow and wrist; therefore, it is considered appropriate for assessing upper-limb spasticity in this study (Pandyan et al., 1999, Gregson et al., 2000).

4.8.4 Participant feedback

The feedback of the physiotherapy staff, stroke survivors in the intervention group and their carer (if relevant), including the use of the web-based physiotherapy platform was evaluated using a questionnaire.

Exploring the views of participants through questionnaires can be criticised mainly for the lack of depth of the feedback compared to qualitative research (focus group and individual interviews) (Parahoo, 2014, Polit and Beck, 2017). For example, in questionnaires, the researcher cannot probe for more illustration and/or justification about the provided responses and the respondents may not understand some items of the questionnaires differently from the researcher. In addition, in questionnaires, the researcher cannot observe non-verbal cues (Parahoo, 2014, Polit and Beck, 2017). However, questionnaires are an economical and time-efficient way to collect data compared to qualitative research (Parahoo, 2014). In this study, the questionnaire was administered on a one-to-one basis in order to answer any questions that the participants might have about any item in the questionnaire. In addition, the instrument included a free-text space so that the participants could further justify their responses, giving the researcher deeper understanding of the phenomenon. More importantly, questionnaires might be a more comfortable choice for participants who need flexibility in time, and speed in answering questions (Bryman, 2016). The presence of the researcher may also influence what participants say in interviews (Cohen et al., 2015). Therefore, the decision was made to collect the views of participants using self-reported questionnaires, rather than alternative techniques such as individual interviews.

Overall, three versions of the questionnaire were developed, each tailored for stroke survivors, carers and physiotherapy staff (Appendix 37- 39). The questionnaires were piloted to ensure the following: the instructions and questions were clear, there were no objections towards any of the questions, and important topics were covered fully. It was conducted in two phases

Phase 1: A recommendation to develop more items than were ultimately required in the final version of the questionnaire was followed: there were 23 items for the stroke survivor version, 19 items for the carer version, and 18 items for the physiotherapist version, as some of these items were to be revised or deleted (Gehlbach and Brinkworth, 2011). The developed questionnaires were sent by email to three experts, all of whom were academics with a doctorate in the healthcare field. These experts were asked to determine the relevance of the statements in terms of context, sections, and their alignment with the research aims. In addition, the experts were asked to provide feedback about the items of the questionnaires which were helpful in learning which aspects of the construct were not well reflected by the developed items. The experts suggested merging and/or deleting some items, making changes to the order of the items within the questionnaires, simplifying the questionnaires' language in order to make it easier for lay people to understand, and adding more items to the questionnaires so that they would fully cover the construct. Their feedback was considered, and the questionnaires were modified accordingly. The modifications include the following: simpler language for items, re-arranged order of items, merging/deleting some items, and addition of items to the questionnaires, such as asking participants how they were trained/instructed in the use of the website. The final item numbers for the updated questionnaires were as follows: 18 items for the stroke survivor version, 8 items for the carer version and 9 items for the physiotherapist version. These modifications have strengthened the validity of the questionnaires.

Phase 2: The updated questionnaires were then shared via email with two physiotherapists with a master's degree or doctorate in physiotherapy via email. The physiotherapists were requested to provide feedback on the questionnaires, including the clarity of question wording and the instructions. Both physiotherapists were of the opinion that that the questionnaires were clear. They also considered the questionnaire to be an effective tool to assess what it was intended to measure. Therefore, no further changes were made.

4.9 Protocol amendment

As pilot studies are conducted for exploratory purposes, it is recommended to change the protocol to resolve limitations (Eldridge et al., 2016). At the start of the study, one of the exclusion criteria was shoulder subluxation. It was noticed that in the stroke units shoulder subluxation was a common complication in people with post-stroke hemiplegia and was

adversely affecting recruitment rates. Therefore, the researcher checked the literature and consulted with physiotherapists working in the stroke units, and they established that stroke patients with mild to moderate shoulder subluxation (less than 1½ fingerbreadth gap) could safely be included in the study. Based on that, the inclusion criteria were amended to include stroke survivors with shoulder subluxation who scored less than grade 3 (less than 1½ fingerbreadth gap) (Hall et al., 1995).

The use of fingerbreadth palpation to measure shoulder subluxation is a valid and reliable method that is commonly used in clinical practice (Hall et al., 1995, Boyd et al., 1993, Prevost et al., 1987). This method identifies the space between the acromion (the inferior aspect) and the humeral head (the superior aspect) and then classifies the shoulder subluxation into one of the following: grade 0 (no subluxation), grade 1 (½ fingerbreadth gap), grade 2 (1 fingerbreadth gap), grade 3 (1½ fingerbreadth gap), grade 4 (2 fingerbreadth gap), or grade 5 (2½ fingerbreadth gap) (Hall et al., 1995) (Appendix 40).

A substantial amendment to the protocol was requested from the Ethics Committee and this was approved on the 14 November 2018 (substantial: change of inclusion/exclusion criteria) (REC Ref AM01, Appendix 22). Participants with shoulder subluxation started their augmented programme with hand and trunk exercises, arm exercises were gradually introduced as judged appropriate by the physiotherapist. In addition to the applied substantial amendment to the protocol, permission was sought to open up recruitment from other stroke units in NHS Lanarkshire as the recruitment was slower than the expected rate and only one site was initially planned for recruitment. The requests were approved (Appendix 41-42). The added sites to recruitment were the stroke units at the University Hospital Monklands and at the University Hospital Wishaw.

4.10 Safety, risk assessment & Adverse Serious Events

Exercise is generally safe, but participants were informed that they may experience some discomfort following exercise which should be mild and last no longer than 48 hours and that this is a normal reaction to beginning a new exercise regime. Moreover, the controlled environment in the hospital would minimise the risk greatly by providing the appropriate medication or intervention, when necessary.

Adverse events (AEs) included the following, whether attributed to the intervention or not:

- Falls
- Musculoskeletal injury
- New shoulder pain and subluxation
- Any other symptom or injury

Serious adverse events (SAEs) included:

- Death
- Incidence of life-threatening illness
- Require extra care at hospital for any reason
- Any occurrence that results in significant impairment or disability
- Any medical event that could be describe as significant by the Principal Investigator

SAEs and AEs related to the study were dealt with as appropriate by the Principal Investigator and reported to the sponsor using the standard reporting procedures (Health Research Authority, 2020).

4.11 Ethical considerations

Prior to assessing each participant against the study eligibility criteria and obtaining his/her written informed consent, the researcher answered all concerns and questions that the participant might have about the study. He also confirmed that taking part in the study was entirely voluntary and that he/she was free to withdraw from the study at any time, without giving any reason

For stroke survivor participants: People with communication problems, including aphasia, are often excluded from studies, but the researchers wished to include them. Therefore, they followed guidelines published by the Stroke Association to create an aphasia version of the advice section and they used the National Institute for Health research (NIHR) resources to improve the website's acceptability to stroke survivors with aphasia (National Institute for Health and Clinical Excellence, 2012, Stroke Association, 2012). As a stroke may result in aphasia, aphasia versions of the consent form and participant information sheet were provided for stroke survivor participants (Appendices 26-27). Moreover, the researcher was present on a one-to-one basis to help the participants fill in all the study documents (demographic forms, consent forms and questionnaires) and to clarify any points in each document.

Falls are common in people with stroke; however, the augmented programme comprised upper-limb and trunk exercises, therefore from a safety perspective it did not require the participants to walk or stand. The exercise was generally safe, but the participants were informed that they may experience some discomfort afterwards that should be mild and last no longer than 48 hours. This is a normal reaction to beginning a new exercise regime. However, the controlled environment in the hospital minimised the risk greatly by providing the appropriate medication or intervention, if necessary. In addition, the exercise programme started gently, based on the stroke survivors' level of ability, and gradually progressed. The web-based physiotherapy contains an advice section where participants may find useful information and resources about how to avoid falls and how to deal with other effects of stroke (e.g., fatigue and body neglect).

The participants were informed that prescribed augmented upper-limb exercises delivered through the web-based website could help stroke survivors to improve the function of their arms and trunk as well as decrease any muscle spasticity in their arms; however, this was not guaranteed. The participants were also informed that their feedback about the intervention would help the researchers to develop interventions for other stroke survivors who use web-based physiotherapy in the future.

For physiotherapist and carer participants: The participants were informed that there were no foreseeable risks in taking part in this study. However, the study might take up some of their time. The participants were also informed that there were no direct benefits from taking part, although their feedback about the intervention would help the researchers to develop interventions for other stroke survivors who use the web-based physiotherapy in the future.

4.12 Data management

The data were held in accordance with the GDPR principles enshrined in the Data Protection Act 2018(Carey, 2018). Participant data were anonymous; a unique ID number was used for each participant (physiotherapy staff, stroke survivors and carers) during the study. The data were held on a secure server at the University of Glasgow and the server files were accessible only by the researcher. Upon completion of the study, participants' personal data was destroyed. As per the University of Glasgow Data Management Protocol, the anonymised data were stored in a filing cabinet in a locked room in the Nursing & Health Care School at the University of Glasgow for up to 10 years.

4.13 Statistical analysis

Quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS) version 25. The Shapiro-Wilk test was used to assess normality for the distribution of continuous variables as demonstrated by Laerd (2018) and SPSS Tutorials (2021).

2021). For participants' demographic data, stroke characteristics for stroke survivor participants and primary outcome measures (measures for feasibility), means with standard deviations (SD), or medians with ranges (where appropriate) for continuous variables and numbers with percentages were used for ordinal and categorical variables in order to provide an overview of the data.

For the secondary outcome measures (ARAT, TIS and MAS), the score differences between baseline assessment and post intervention assessments were calculated for each participant and for each outcome measure (ARAT, TIS and MAS). In addition, non-parametric statistics were calculated for each outcome measure (ARAT, TIS and MAS).

To enter the scores of MAS into the SPSS spreadsheet and measure the differences, the MAS scores were revised demonstrated in the following Table 4.3.

Table 4-3 Modifies Ashworth Scale scoring

MAS original scoring	**MAS scoring in this study (**Ashworth, 1964)	**Score interpretation** (Bohannon and Smith, 1987)
0	0	No increase in muscle tone
1	1	Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension
1+	2	Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM
2	3	More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved
3	4	Considerable increase in muscle tone, passive movement difficult
4	5	Affected part(s) rigid in flexion or extension

For the feedback questionnaires, frequencies and percentage were calculated to summarise findings of ordinal and categorical variables and in addition, content analysis was used with the free text comments on the evaluation questionnaires. Content analysis is a systematic and reliable method of quantifying and describing phenomena (Sandelowski, 1995). Content analysis of data often involves two major steps - that is, data preparation and data organisation (Elo and Kyngas, 2008). The former step requires the researcher to be immersed in the research process in order to facilitate understanding of the data. The latter step involves the process of coding the data by the researcher by putting them into categories (Elo and Kyngas, 2008).

In this study, the content analysis process was inductive, and the process of analysis consisted of five steps:

- First, analysis began with the reading and scrutiny of participant answers. This enabled the researcher to gain a comprehensive understanding of the key issues reported by participants.
- Second, the text was broken down into smaller segments, which were referred to as meaning units.
- Third, the text of the meaning units was condensed further, without changing its essential meaning.
- Fourth, codes were assigned to the condensed meaning units and those codes were subsequently grouped into categories.
- Finally, the researcher selected categories for reporting results or analysed the data further and formulated themes, according to the quality of the gathered data.

The results of this study are presented in Chapter Five.

Chapter 5 : Augmented Upper-limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a pilot study: Results

This chapter shows the findings of the pilot study described in Chapter 4.

5.1 Demographics and stroke characteristics

5.1.1 Demographics for stroke survivor participants

The cohort comprised of 11 males (42.3%) and 15 females (57.7%), with equal numbers in both the control and intervention groups. The mean age was 69 years (SD 12) and 67 years (SD 11) for the control and intervention groups respectively (Table 5.1). All the participants were allocated to either control or intervention group within 5 weeks of stroke. Across the two groups, 24 participants (92.3%) were white British and had a secondary school education. Twelve participants (46.1%) previously used computers on a daily basis.

Table 5-1 Stroke survivor participants' demography

Categories	Control group (n=13)	Intervention group (n=13)
Age: Mean ± SD	69 ±12	66.85 ± 11
Gender:		
Male	5 (38.5%)	6 (46.2%)
Female	8 (61.5%)	7 (53.8%)
Time from stroke to randomisation: Mean ± SD	3.23 ± 1.7 weeks	2.8 ± 1.7 weeks
Ethnicity:		
White British	12 (92.3%)	12 (92.3%)
Another ethnicity	1 (7.7%)	1 (7.7%)
Educational level (highest degree):		
Secondary school	7 (53.8%)	9 (69.2%)
Primary school	1 (7.7%)	0 (0%)
College	5 (38.5%)	3 (23.1%)
University (Postgraduate)	0 (0%)	1 (7.7%)
Computer use:		
Daily	5 (38.5%)	7 (53.8%)
Occasionally	1 (7.7%)	1 (7.7%)
Never	7 (53.8%)	4 (30.8%)
Only when relative helps	0 (0%)	1 (7.7%)

5.1.2 Stroke characteristics

Stroke characteristics for all participants are shown in Table 5.2. Twenty three participants (88.4%), in both intervention and control groups, were able to walk independently before the stroke, and only one participant from each group (7.7%) was able to walk independently after the stroke. In terms of living arrangement, eight participants (61.5%) in the intervention group and three participants (23.1%) in the control group indicated that they lived alone. Further, 18 participants in both groups (69.2%) indicated that they lived in their own homes pre-stroke. The scores of the severity of strokes (NIHSS) were slightly higher for participants in the control group than for those in the intervention group, indicating that participants in the control group

were more affected by the stroke. Scores of arm functions after stroke (ARAT) were similar for both groups with a slightly higher range for those in the intervention group.

Overall, the information collated from the participants indicated several stroke risk factors, most commonly, smoking, hypertension and alcohol consumption. Twenty one participants (80.7%) across both groups did not indicate having any previous TIA. In terms of stroke type, 17 participants (65.3%) across both groups indicated that they had an ischaemic stroke, and all had their stokes confirmed by imaging (most commonly CT scan). Finally, five participants (38.5%) from each group received thrombolysis/reperfusion therapy.

Table 5-2 Baseline stroke survivor participants' stroke characteristics

Categories	**Control group (n=13)**	**Intervention group (n=13)**
Able to walk independently before stroke with or without walking aid	13 (100.0%)	10 (76.9%)
Able to walk independently after stroke	1 (7.7%)	1 (7.7%)
Living alone	8 (61.5%)	3 (23.1%)
Living in own home	10 (76.9%)	8 (61.5%)
Able to move hands after stroke (e.g. minor movements of fingers/hand or wrist)	5 (38.5%)	9 (69.2%)
General health status after stroke:		
Excellent	3 (23.1%)	2 (15.4%)
Fair	9 (69.2%)	6 (46.2%)
Poor	1 (7.7%)	5 (38.5%)
National Institutes of Health Stroke Scale (0 = no symptoms, 42 = severe stroke): Mean ± Standard deviation	9.6 ± 6.3	6 ± 2
Action Research Arm Test–affected side only (total scores, 0 – 57): Median (range)	0 (0-21)	0 (0-36)

Categories	Control group (n=13)	Intervention group (n=13)
Stroke risk factors:		
Diabetes	2 (15.4%)	2 (15.4%)
Hypertension	4 (30.8%)	8 (61.5%)
Smoking	5 (38.5%)	3 (23.1%)
Alcohol consumption	5 (38.5%)	4 (30.8%)
Coronary artery disease	4 (30.8%)	2 (15.4%)
Atrial Fibrillation	2 (15.4%)	1 (7.7%)
Hyperlipidaemia	0 (0%)	3 (23.1%)
Previous transient ischaemic attack (TIA)	2 (15.4%)	3 (23.1%)
Stroke type:		
Ischaemic	8 (61.5%)	9 (69.2%)
Haemorrhage	5 (38.5%)	4 (30.8%)
Stroke sub-type:		
Lacunar	1 (7.7%)	4 (30.8%)
Large artery	5 (38.5%)	3 (23.1%)
Undetermined	6 (46.2%)	6 (46.2%)
Missing data	1 (7.7%)	0 (0%)
Stroke location:		
Cortical (Internal Capsule)	2 (15.4%)	4 (30.8%)
Cortical (Middle cerebral artery)	5 (38.5%)	0 (0%)
Cortical (Frontal lobe)	1 (7.7%)	3 (23.1%)
Subcortical (Thalamus)	1 (7.7%)	0 (0%)
Subcortical (Basal Ganglia)	1 (7.7%)	3 (23.1%)
Midbrain (Medulla)	1 (7.7%)	0 (0%)
Brainstem	0 (0%)	1 (7.7%)
Missing data	2 (15.4%)	2 (15.4%)

5.1.3 Demographics for carer participants'

The below table (Table 5.3) provides the demographic information for the carers who participated in this research. All considered themselves to be in excellent health and were aged from 26-55 years. They were two males (sons) and three females (two daughters and one wife), and majority of participants were British. Three had a college degree, one had a postgraduate degree and the other had another qualification. All indicated they use the computer on a daily basis and the mean length of using computers was 22.5 (SD 6.4) years.

Table 5-3 Carer participants' demographic information

Categories	**Carers (n=5)**
Age: (years) Mean ± SD	36.8 ±11
Occupation:	
Information Technology	1 (20%)
Personal trainer (works at gym)	1 (20%)
Delivery driver	1 (20%)
Housewife	1 (20%)
Home support	1 (20%)
Length of computer use in years: Mean ± SD	22.5 ± 6.4
Frequency of computer use:	
Daily	5 (100%)
Occasionally	0 (0%)
Never	0 (0%)
Educational level:	
College	3 (60%)
University (Postgraduate)	1 (20%)
Secondary school	1 (20%)

5.1.4 Demographics for physiotherapy participants

In terms of the physiotherapists who participated (n=5), the gender distribution was one male to four females and the mean age was 35.4 (SD 7.7) years. All participants identified as computer literate. The average length of computer use was 18.8 (SD 2.16) years. In addition, physiotherapy participants had been working in the stroke unit for 4.4 (SD 3.6) years.

5.2 Primary outcome measure

Primary outcome measures were recruitment rates, usage and adherence to the web-based physiotherapy programme, participant' attrition, as well as participant safety.

5.2.1 Recruitment strategy

Recruitment for the stroke survivor participants took place from 17/09/2018 to 20/08/2019, within this period, a total of 26 stroke survivor participants were recruited. Initially there was only one site open for recruitment, but the recruitment of the study was slower than expected; therefore, we extended our study to other stroke units from NHS Lanarkshire, University Hospital Wishaw and University Hospital Monklands, see section 4.9 for more details. The overall recruitment rate across all the study sites was 2.4 participants per month.

The CONSORT flow diagram in Figure 5.1 provides more detail about number of participants who were assessed, randomised and completed the study assessments, the reasons for excluding participants and participant dropouts.

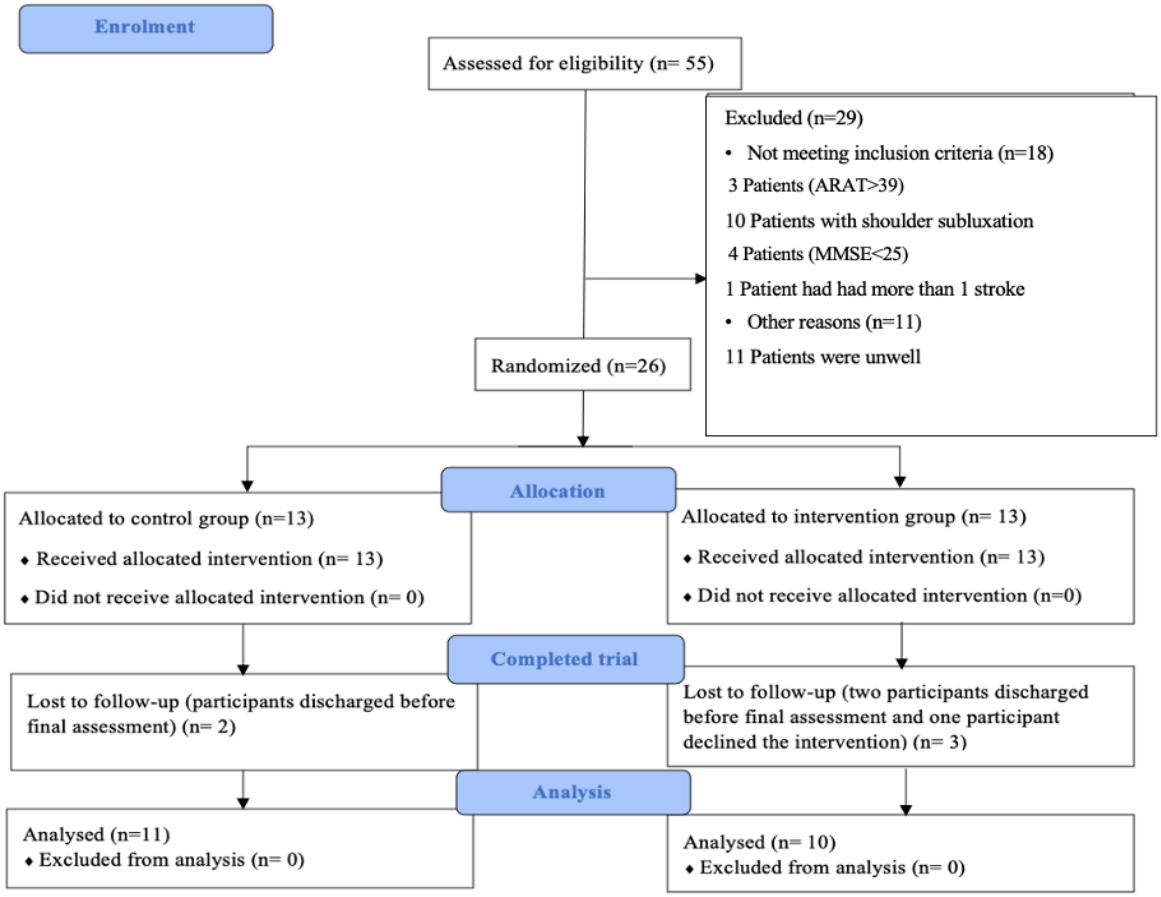

Figure 5.1 CONSORT flow diagram for recruitment of the participants

5.2.2 Usage and adherence of the web-based physiotherapy platform

Data from Table 5.4 demonstrates that seven out of the ten participants (70%) logged in to the web-based physiotherapy website and completed at least one complete exercise session. Of the remaining three participants (representing 30%), two participants did not log in to the platform at all and one participant logged in to the platform and performed some exercises but did not complete a full exercise session.

The adherence to the augmented intervention was measured using the completed exercises sessions which was self-reported by the participants completing the online exercise diary on the web-based physiotherapy website. The recorded data only captured the number of exercises per session; the duration of each exercise was not calculated. The types of exercises were not fully recorded as these were subject to continuous change by the participating physiotherapist based on the needs of stroke survivors; therefore, only the type of exercise in the final exercise programmes were recorded. Participants who had severely impaired arm functions were not

asked to perform task specific exercises; instead, they were instructed to perform stretching and passive exercises based on judgment of physiotherapists. Although some studies suggest that augmented upper-limb stretching and passive exercises are not superior to usual care in terms of preventing upper-limb mobility and decreasing spasticity (Salazar et al., 2019, Katalinic et al., 2011), these exercises were prescribed by the patients physiotherapist to minimise the pathological changes that occur in the muscles and tendons of the upper extremities as a result of stroke (You et al., 2014, Page, 2012). Out of the seven participants who were considered web-based physiotherapy website users, five participants (71.4%) were adherent to the augmented intervention as they performed more than two-thirds of their prescribed augmented intervention; while the remaining two participants (28.6%) were not adherent to the intervention as they performed lower than the required two-thirds of the augmented intervention. The five adherent participants account for 50% of all participants in the intervention group. The mean number of completed sessions for all the participants in the intervention group was 3.7 sessions per week while the mean number of completed sessions for those who were considered adherent to the intervention was 5.3 sessions per week. Among the participants who were adherent to the intervention, four of the five participants practiced more exercises without logging in to the platform because they memorised them. The participants reported doing their exercises from memory in their feedback questionnaires. Therefore, the exercise diary provided an underestimation of completed exercise sessions for those participants.

A further analysis was performed to investigate if the number of prescribed exercises for each participant could be a factor to facilitate or impediment adherence of the participants. The number of prescribed exercises for the participants was not found to be an impediment for the adherence as the number of prescribed exercises was almost similar or even higher for the adherent participants. The number of prescribed exercises for the non-adherent participants ranged between 3-5 exercises per session and for the adherent participants the range was between 3-10 exercises per session. In general, there were no preferred days and/or specific days of the week (weekdays or weekends) that the participants chose to undertake their prescribed exercises.

Table 5-4 Usage of the web-based physiotherapy platform and adherence to augmented web-based physiotherapy programme

P	Duration of participation in weeks	No of prescribed exercises	No of completed programmes (sessions)	Days of practice the programmes	Practiced exercises without logging to the website	Percentage of completed exercise diaries	Completed programmes per week
5	4.28	6-10 exercises	60	Every day	No	280%	14
10	2.57	4-5 exercises	19	Consecutive days- not specific days	Yes	158.3%	7.4
17	4.28	3 exercises	20	Consecutive days- not specific days	Yes	93.4%	4.67
11	4.28	3 exercises	18	Consecutive days- not specific days	Yes	84%	4.2
13	2.43	4 exercises	9	Consecutive days- not specific days	Yes	74%	3.71
28	2.43	3 exercises	4	Random days	No	32%	1.65
30	2.43	5 exercises	3	Weekdays	No	24%	1.23

P	Duration of participation in weeks	No of prescribed exercises	No of completed programmes (sessions)	Days of practice the programmes	Practiced exercises without logging to the website	Percentage of completed exercise diaries	Completed programmes per week
35	2.3	6 exercises	0	Friday	No	0%	0
27	4.28	5 exercises	Never used the website	N/A	N/A	0%	0
3	4	5 exercises	Never used the website	N/A	N/A	0%	0

*Abbreviations: P: participant identification code, No: Number. * Completed programmes per week was calculated using the following formula: (No. of completed programmes ÷ duration of participation in weeks). *Percentage of completed exercise diaries was calculated using the following formula: (No. of completed programmes ÷ prescribed exercise programmes (5 sessions a week). *Participants 5 and 10 practiced more than their prescribed exercises programmes; therefore, their percentage of completed exercise diaries exceeded 100%. * The target for each participant was to perform the augmented exercises in five sessions per week (including weekends) in addition to their usual physiotherapy care. However, as exercise programmes were individualised, this was presented as number of prescribed exercises in the table, and that was subject to continuous change by the participating physiotherapist based on the needs of stroke survivors, and therefore presented as ranged numbers. *Participants who performed at least two third (14 sessions) of their prescribed exercises (maximum of 20 sessions) were considered to be adherent to the intervention (Hawley-Hague et al., 2016).

5.2.3 Participants' attrition

Five participants two from the control group, and three from the intervention group did not complete the study assessments due to dropping out of the study. The two participants from the control group and two from the intervention group dropped out because of discharge before final assessment, which meant that the researcher was unable to complete their final assessment. In the intervention group one participant dropped out because he declined the prescribed intervention which meant that the participant decided to withdraw from the study. The baseline data for these participants was included in the descriptive analysis.

5.2.4 Participants' health & safety

The health and safety of participants was a paramount consideration throughout the research process. There were recorded adverse events, particularly shoulder pain (n=2), fatigue (n=1) and fall (n=2). None of these adverse events was related to the study intervention. The study did not record any serious adverse events (n=0).

5.3 Secondary outcome measures

These include ARAT, TIS, MAS and feedback questionnaire.

5.3.1 The Action Research Arm Test (ARAT)

In the intervention group 8 out of 10 participants improved by more than the MCID (5.7 points in scores) in their ARAT measurements while in the control group 6 out of 11 participants showed clinically significant improvements in their ARAT measurements (Table 5.5). The ARAT score was available for all participants at baseline (100%), but it was not available for 5/26 participants post intervention (19%). The median difference between the two groups in ARAT score was similar. The Shapiro-Wilk test was used to assess normality, ARAT scores $W(26) = 0.593$, $p = 0.000$ at baseline and $W(21) = 0.800$, $p = 0.001$ post intervention. As the p-values were less than 0.05 the ARAT data were not normally distributed.

Table 5-5 Baseline, post-intervention and difference between the measurements of ARAT for each participant

Participant		ARAT scale		
		Baseline	**Post intervention**	**Differences**
3	Intervention	0	48	48
5	Intervention	0	7	7
10	Intervention	32	51	19
11	Intervention	3	14	11
13	Intervention	36	57	21
17	Intervention	12	51	39
24	Intervention	11		
26	Intervention	7		
27	Intervention	0	0	0
28	Intervention	0	8	8
30	Intervention	0	8	8
33	Intervention	0		
35	Intervention	0	0	0
Median (range)		0 (0-36)	11 (0-57)	8.5 (0-48)
2	Control	2	15	13
4	Control	0		
9	Control	21	44	21
14	Control	0	0	0
15	Control	0	1	1
18	Control	0	0	0
19	Control	1		
20	Control	0	15	15
21	Control	3	11	8
25	Control	0	43	43
31	Control	5	18	13
39	Control	0	0	0
40	Control	0	0	0
Median (range)		0 (0-21)	11 (0-44)	8 (0-43)

*No post intervention measurements for participants 4,19,24,26 or 33 as all dropped out.

5.3.2 Trunk Impairment Scale (TIS)

There was an overall trend for both intervention and control groups toward an increase in TIS. All participants in the intervention group increased their TIS (range 2-7) score except one who stayed the same. Similarly, all except two of the participants in the control group increased their TIS (range 1-10) score (Table 5.6). The TIS score was available for all participants at baseline (100%), but it was not available for 5/26 participants post intervention (19%). The Shapiro-Wilk test was used to assess normality, TIS scores were $W(26) = 0.935$, $p = 0.102$ at baseline and $W(21) = 0.942$, $p = 0.234$ post intervention. As these p-values were greater than 0.05 the data were for the TIS were normally distributed.

Table 5-6 Baseline, post-intervention and difference between the measurements of TIS for each participant

Participant		Trunk impairment scale		
		Baseline	**Post intervention**	**Differences**
3	Intervention	13	18	5
5	Intervention	11	13	2
10	Intervention	17	23	6
11	Intervention	10	10	0
13	Intervention	4	11	7
17	Intervention	16	20	4
24	Intervention	18		
26	Intervention	21		
27	Intervention	19	21	2
28	Intervention	16	21	5
30	Intervention	13	16	3
33	Intervention	16		
35	Intervention	8	10	2
Median (range)		16 (4-21)	17 (10-23)	3.5 (0-7)
2	Control	16	16	0
4	Control	8		
9	Control	16	17	1
14	Control	13	17	4
15	Control	4	10	6
18	Control	7	7	0
19	Control	16		
20	Control	8	18	10
21	Control	19	21	2
25	Control	0	8	8
31	Control	15	17	2
39	Control	17	18	1
40	Control	7	14	7
Median (range)		13 (0-19)	17 (7-21)	2 (0-10)

*No post intervention measurements for participants 4,19,24,26 or 33 as all dropped out.

5.3.3 Modified Ashworth Scale (MAS)

Assessment of muscle spasticity in this study was performed for four muscle groups, these were: shoulder adductor, elbow flexor, wrist flexor and finger flexor muscle groups. There were no notable trends for either intervention or control groups of all the assessed muscle groups (Table 5.7). The MAS score for the four muscle groups was available for all participants at baseline (100%) but it was not available for 5/26 participants post intervention (19%). The mean difference between the two groups was similar for all the assessed muscle groups. The Shapiro-Wilk test was used to assess normality for all the assessed muscle groups, all MAS scores were not normally distributed. The Shapiro-Wilk test result for shoulder adductor muscle group was $W(26) = 0.879$, $p = 0.006$ at baseline and $W(21) = 0.875$, $p = 0.012$ post intervention, elbow flexors p $W(26) = 0.849$, $p = 0.001$ at baseline and $W(21) = 0.859$, $p = 0.006$ post intervention, in wrist flexors $W(26) = 0.849$, $p = 0.001$ at baseline and $W(21) = 0.808$, $p = 0.001$ post intervention and in fingers flexors $W(26) = 0.829$, $p = 0.001$ at baseline and $W(21) = 0.867$, $p = 0.008$ post intervention. As the p-values were all less than 0.05 the MAS scores were not normally distributed.

Table 5-7 Baseline, post-intervention and difference between the measurements of MAS for each participant

Participant		MAS (shoulder adductor muscle group)			MAS (elbow flexor muscle group)			MAS (wrist flexor muscle group)			MAS (fingers flexor muscle group)		
		Baseline	Post intervention	Differences	Baseline	Post intervention	Differences	Baseline	Post intervention	Differences	Baseline	Post intervention	Differences
3	Intervention	0	0	0	1	0	-1	2	0	-2	1	0	-1
5	Intervention	1	1	0	2	2	0	2	2	0	1	1	0
10	Intervention	1	1	0	1	1	0	1	0	-1	0	0	0
11	Intervention	1	2	-1	0	1	1	1	1	0	2	1	-1
13	Intervention	1	1	0	1	1	0	1	0	-1	0	0	0
17	Intervention	2	2	0	2	3	1	1	1	0	1	1	0
24	Intervention	2			1			1			1		
26	Intervention	1			1			1			1		
27	Intervention	1	1	0	0	0	0	0	0	0	0	0	0
28	Intervention	1	1	0	2	2	0	2	2	0	1	1	0
30	Intervention	2	2	0	0	1	1	1	1	0	1	1	0
33	Intervention	2			0			0			0		
35	Intervention	1	2	-1	1	2	1	2	1	-1	3	2	-1

Median (range)		1 (0-2)	1 (0-2)	0 (-1-0)	0 (0-2)	1 (0-3)	0 (-1-1)	1 (0-2)	1 (0-2)	0 (-2-0)	1 (0-3)	1 (0-2)	0 (-1-0)
2	Control	0	2	2	1	2	1	0	1	1	0	2	2
4	Control	1			2			3			3		
9	Control	3	1	-2	2	1	-1	1	0	-1	1	0	-1
14	Control	3	1	-2	3	2	-1	2	1	-1	3	3	0
15	Control	2	3	1	1	2	1	1	2	1	3	4	1
18	Control	3	3	0	2	1	-1	1	1	0	1	1	0
19	Control	0			0			1			1		
20	Control	2	2	0	2	2	0	2	1	-1	1	1	0
21	Control	3	2	-1	2	1	-1	1	1	0	1	1	0
25	Control	0	0	0	0	0	0	0	0	0	0	0	0
31	Control	3	2	-1	2	2	0	1	1	0	1	2	1
39	Control	1	1	0	0	0	0	3	2	-1	4	2	-2
40	Control	2	1	-1	2	2	0	1	1	0	2	2	0
Median (range)		2 (0-3)	2 (0-3)	0 (-2-2)	2 (0-3)	2 (0-2)	0 (-1-1)	1 (0-3)	1 (0-2)	0 (-1-1)	1 (0-4)	2 (0-4)	0 (-2-2)

*No post intervention measurements for participants 4,19,24,26 or 33 as all dropped out.

5.3.4 Participants feedback questionnaires

5.3.4.1 Questionnaire for Stroke Survivors

Participants' access and practice of augmented interventions:

All the stroke survivor participants in the intervention group responded to the questionnaire (n=10). Out of the ten stroke survivors who participated in the questionnaire, seven undertook at least one exercise of their programmes via the web-based physiotherapy website while three did not do any of their exercise programmes. One main reason was provided by those who did not undertake any exercise, namely: *"no signal at the ward" Stroke survivors 27 and 3*.

It should be noted that the participants who did not perform any exercises did not provide feedback on the study intervention but were asked to provide the reasons for not performing and logging in to their exercise programmes only.

The following section reports the feedback of the seven stroke survivor participants who undertook at least one exercise via the web-based physiotherapy website:

Section 1: Evaluation of the augmented exercise programme:

Data from Table 5.8 reveals the feedback of the stroke survivor participants of the intervention. In general, the participants found the augmented exercise programme easy to understand, beneficial, and did not increase their level of fatigue. In addition, even though some of the participants reported difficulty in contacting the physiotherapy team in order to make changes to their exercise programmes, most indicated that they would be happy to use the platform again in the future.

Table 5-8 Frequencies and Percentages for answers respondents about the evaluation of the augmented exercise programme

Statement		Strongly agree	Moderately agree	Neither agree or disagree	Moderately disagree	Strongly disagree
I feel I benefited from the exercise programme.	Freq.	5	2			
	%	71.4	28.6			
The exercises were clear and understandable.	Freq.	5	2			
	%	71.4	28.6			
The exercise programme did not increase my fatigue (tiredness).	Freq.	5		2		
	%	71.4		28.6		
It was easy to contact the physios to make changes to my exercise programme.	Freq.	3		3		1
	%	42.9		42.9		14.3
I was happy with the length of time it took for the study assessments.	Freq.	3	2	2		
	%	42.9	28.6	28.6		
I would be happy to do exercises using this website again in the future.	Freq.	6	1			
	%	85.7	14.3			

Section 2: Evaluation of the website

Overall, the participants expressed positive views with using the website to perform exercises and the majority of the participants did not find any difficulties in learning how to use it (Table 5.9).

Table 5-9 Frequencies and Percentages for answers respondents about the evaluation of the website

Statement		Strongly agree	Moderately agree	Neither agree or disagree	Moderately disagree	Strongly disagree
Doing my exercises through the website gave me the chance to choose when to exercise.	Freq.	6		1		
	%	85.7		14.3		
Doing my exercises through the website gave me the feeling of being independent in exercising.	Freq.	6	1			
	%	85.7	14.3			
Learning to use the website for my exercises was easy for me.	Freq.	5		2		
	%	71.4		28.6		

Section 3: Evaluation of the augmented intervention in practice:

The weekly frequency of exercise, three participants (42.9%) reporting 3-5-times per week, one participant (14.3%) reporting 7-times per week; and three participants (42.9%) reporting 14-times per week. This means that the percentage of participating stroke survivors met and even exceeded the targeted average of exercises per week which was 7 times per week and was set by the physiotherapist.

The majority of participants (71.4%, n=5) reported spending less than 30 minutes per session and 28.6% (n=2) spent up to an hour per session. It was not possible to calculate how much time participants spent exercising; however, just over half participants indicated performing these exercises on a daily basis (reported above).

Six (85.7%) out of seven participants reported requesting help from partners/relatives to do their exercise programmes. For those participants, two participants (33.3%) indicated they did their programme 3-5 times per week, one participant (16.7%) indicated 7-times per week,

two participants (33.3%) indicated 14-times per week and one participant (16.7%) did not report the average. Moreover, none of the stroke survivor participants indicated asking the staff for help. In the comments four stroke survivors explained that they needed help from their partner/relative to practise their exercise programmes in three main ways – provide motivation and physically supporting the weaker part of the body. Below are the views expressed by the participants in terms of the support needed from their partner/carer:

"To do the exercises in the beginning" Stroke survivor 28.

"Encourage me to do my exercise" Stroke survivor 17.

"Help me with my weak hand and the shoulder" Stroke survivor 5.

Six participants (85.7%) indicated that the exercises using the website without supervision was easy and one participant (14.3%) indicated neither easy nor difficult. The participants were asked to provide more details about their answers, and five participants indicated that practising the exercises was easy for them because the website was easy to use. The main features reported as making the website easy to use were its clarity and self-explanatory nature. Below are the examples from the data:

"It was easy" Stroke survivors 5, 35 and 28

"It was clear" Stroke survivor 30.

"It was self-explanatory, you just watch and listen, it was simple'" Stroke survivor 10.

No difficulties were reported with using the website without supervision, although this was prompted for.

To determine if there had been any contamination between participants in the different groups participants were asked if they discuss their exercises with other patients. Two participants (28.6%) indicated that they discussed their exercise programmes with other patients and five participants (71.4%) indicated that they did not. In addition, one participant

(14.3%) indicated that other patients asked his/her about his/her augmented exercises and six participants (85.5%) indicated no other patients asked about their exercise programmes.

5.3.4.2 Questionnaire for Carers

All the carers who helped their partner/family and had been allocated in the intervention group responded to the questionnaire (n=5).

Section 1: Evaluation of the augmented exercise programme:

All participating carers strongly agreed that it was easy to help their partners/relative to do the exercises, that the exercises were clear and understandable and that they would be happy to use the website to help their partner/relative in their future rehabilitation exercises.

Section 2: Evaluation of the website

All participating carers strongly agreed that learning to use the website for a partner/relative's exercise was easy.

Section 3: Evaluation of the augmented intervention in practice:

For the weekly frequency of how often each carer helped their partner/relative to do his/her exercise programme, three participants (60%) indicated 7-times per week and two participants (40%) indicated 3-5 times per week. All the carers stated they helped the patients to access and practice their exercise programmes. Expressed views from the data in terms of the provided support to their partner/carer are as follows:

> *"To do exercises" Carers 2,4 and 6.*

> *"To access exercise programme and show the videos" Carers 4, 6 and 8.*

> *"To bring some tools demonstrated in the videos to exercise'" carer 4.*

The responses of carer participants came in line with responses of the stroke survivor participants as both reported stroke survivors had required help in accessing and performing the rehabilitation exercises. It should be highlighted that two of the stroke survivors had two carers helping them with the exercises at the same time and both carers responded to the questionnaires separately. The maximum number of occasions where help

was reported by carers was 7-times per week. Similar to stroke survivor participants, none of the carers who participated asked the staff for help

Four (80%) of the participating carers considered it easy to help a partner/relative to exercise using the website without supervision. Only 1 (20%) of the participating carers indicated that it was neither easy nor difficult. The following is further details provided by the participants when asked if they had concerns about helping their partner/relative to exercise – this ranged from simply indicating that it was easy for them to nothing was difficult. The following are the reported data:

"It was easy to use" Carers 1, 2, 4 and 8.

"Nothing was difficult" Carer 6.

5.3.4.3 Questionnaire for physiotherapists

All the physiotherapists who helped in delivering and monitoring exercise programmes stroke survivors responded to the questionnaire (n=5).

Section 1: Evaluation of the augmented exercise programme:

The responses of physiotherapy participants show that few were concerned about the benefits of the study intervention (Table 5.10). In addition, the majority of the participants found the exercises clear and well explained so they thought that stroke survivors would understand them, and they would be happy to use the website again in the future. The participants showed some concerns about monitoring the augmented intervention as it imposed to their workload. Overall, the responses about the augmented exercises were positive.

Table 5-10 Frequencies and Percentages for answers respondents about the Evaluation of the augmented exercise programme

Statement		Strongly agree	Moderately agree	Neither agree or disagree	Moderately disagree	Strongly disagree
I think the stroke survivors benefited from the exercise programme.	Freq.	2	2			1
	%	40.0	40.0			20.0
Monitoring the augmented programme did not impose on my day-to-day care of the patients.	Freq.	1	1	1	2	
	%	20.0	20.0	20.0	40.0	
The exercises were clear and understandable to the stroke patients.	Freq.	1	3		1	
	%	20.0	60.0		20.0	
I would be happy to provide exercises using this website again in the future.	Freq.	3	1	1		
	%	60.0	20.0	20.0		

Section 2: Evaluation of the website

In Table 5.11, it can be seen that one (20%) out of five physiotherapists provided a concerned response about learning how to use the website and the process of setting the exercises programmes, while the responses of 4 participants (80%) were positive about the website.

Table 5-11 Frequencies and Percentages for answers respondents about The Evaluation of the website

Statement		Strongly agree	Moderately agree	Neither agree or disagree	Moderately disagree	Strongly disagree
Learning to provide exercises using the website was easy for me.	Freq.	1	1	2	1	
	%	20.0	20.0	40.0	20.0	
The procedure of signing the stroke survivors up to the website was straight forward.	Freq.	1	3	1		
	%	20.0	60.0	20.0		
The procedure of setting the treatment plan up was straight forward.	Freq.	1	3		1	
	%	20.0	60.0		20.0	

Section 3: Evaluation of the augmented intervention in practice:

The physiotherapist participants provided details about the advantages/disadvantages of providing the exercise programme using the website from a physiotherapist's perspective. Notable advantages highlighted were: The website gave stroke survivors a sense of control thereby boosting their physical and mental health status:

> *"Help patients to feel involved and control of their rehabilitation and influence in their mental health" Physiotherapist 2.*

The website also provides opportunity for carers and/or family members to support stroke survivors in their rehabilitation journeys:

> *"Good idea to have such a website for families to assist with the exercise" Physiotherapist 9.*

> *"Help relatives or family members to be involved in the rehabilitation" Physiotherapist 2.*

Another advantaged identified was that the website provided extra exercises and instructional materials each time a patient chooses to engage with the website which promotes recovery:

> *"Extra exercise for patients to do to aid recovery" Physiotherapist 7.*

> *"Patients use their spare time to do more exercise beneficially for recovery" Physiotherapist 2.*

Finally, the simplicity of the website and the way it was administered made things easier for stroke survivors and physiotherapists:

> *"Easy to administer" "No overload impact to rehab" Physiotherapist 6.*

> *"Exercise very well described and useful to have videos of the specific exercise" Physiotherapist 9.*

In terms of disadvantages, these were broadly structural, technology or practical related. The structural disadvantage was associated with the limited exercises for upper-limb:

> *"Felt there were a very limited range of upper-limb exercises" Physiotherapist 9.*

> *"Poor choice of exercise and selection" Physiotherapist 6.*

Technological disadvantages were related to the poor internet connection in hospitals, the difficulty of older people to use technology and the compatibility of computers in NHS hospitals to the website:

> *"Wi-Fi in hospital not always good" Physiotherapist 9.*

> *"Not all patients managed to use tablet themselves' 'some patients remembered to exercise and then did not log in to do them each time" Physiotherapist 7.*

"Sometime setting up exercise through hospital computer systems difficult" Physiotherapists 1.

"Difficult when it comes to elderly as they don't use technology" Physiotherapist 2.

"Website not compatible with NHS software [internet explorer]" Physiotherapist 6.

Practical disadvantage was acknowledged that the augmented intervention delivered by the web-based physiotherapy platform might not be suitable for all stroke survivors:

"Limited for patients with cognitive deficient" Physiotherapist 2.

"Not suitable for all elderly people" Physiotherapist 6.

"Many patients found it difficult to use and felt too tired to do as additional therapy work aside daytime therapy" Physiotherapist 9.

Four (80%) of the physiotherapists who participated indicated that they monitored stroke survivors' exercise programmes once per week and one participant (20 %) indicated that she/he monitored these programmes twice per week.

5.4 Summary

- The use of the web-based physio website to provide augmented intervention without supervision is a safe, feasible, and acceptable approach for stroke patients, carers, and physiotherapists alike.
- The web-based physio website may be more helpful to patients who have carers to aid in accessing their exercise programmes.
- Recruitment of participants with severely impaired arm function (ARAT=0) allowed physiotherapists to prescribe passive and stretching exercises to a large number of patients, instead of the intended functional task-specific exercises.
- The participants in the intervention group had more clinically important differences in ARAT compared to the participants in the control group.

- Higher scores on the Trunk Impairment scale were achieved by patients compliant with the augmented intervention compared to the patients who were not. There was no difference in other outcomes.

Chapter 6 : Augmented Upper-limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a pilot study: Discussion, study limitations and conclusion

This chapter presents discussions of the findings of the pilot study in relation to the outcome measures that are presented in chapter 5 and with respect to the current literature. The study's limitations, lessons learnt from this pilot study to inform future research and a conclusion are also addressed in this chapter.

6.1 Primary outcome measures

6.1.1 Recruitment

The recruitment strategy for this study was based on a set of inclusion and exclusion criteria. Overall, 55 stroke survivors met the inclusion/exclusion criteria. Of the 55 potential participants, 29 patients were excluded mainly due to deterioration of their medical health (n=11, 37.9%) and had shoulder subluxation as per the initial inclusion/exclusion criteria (n=10, 34.5%). The remaining patients were excluded for other reasons. The initial inclusion and exclusion criteria were identified as a barrier to recruitment as, in the first two months of recruitment, they meant ten participants with shoulder subluxation were excluded. Therefore, there was an amendment made to ethics that only those with significant subluxation were excluded and this improved the recruitment rate (section 4.9).

The study originally planned to recruit 30 participants. However, this target could not be met due to the initial inclusion and exclusion criteria and the number of sites for recruitment. The study started with only one study site (14 participants recruited from Hairmyres Hospital) before other sites were opened for recruitment which enabled the study to recruit 12 more participants: eight participants from the University Hospital Monklands and four participants from the University Hospital Wishaw. Therefore, it is recommended for future studies to start with more than one site for recruitment.

Due to time constraints, it was not possible to extend the recruitment period. Even though the targeted number of 30 participants was not met, 26 participants were recruited. Kieser and Wassmer (1996) suggested that the recommended sample size for pilot research studies with two experimental arms can range between 20 and 40 participants. Therefore, the recruitment strategy followed in the study was feasible and the study recruited sufficient number of participants for a pilot study.

6.1.2 Usage and adherence of the web-based physiotherapy platform

For the use of the web-based physiotherapy in this study, seven (70%) out of ten participants in the intervention group logged onto their exercise programme and completed at least one exercise and/or left a comment. These findings are comparable with the findings from previous studies of different populations in the area of web-based health interventions (Pierce and Steiner, 2013, Akinci et al., 2018). Pierce and Steiner (2013) evaluated the design and use of a website designed to provide support and education resources to stroke carers in the United States and they reported that 19% of participants never posted to the website. Akinci et al. (2018) investigated the effect of exercises delivered via a website in the management of type 2 diabetes in Turkey and found that 28% of participants never used the website. It should be noted that this pilot study was conducted in hospital settings while studies conducted by Pierce and Steiner (2013), Akinci et al. (2018) were home based.

The main reason for participants not using the website in this pilot study was poor Wi-Fi signal in the ward. This problem was taken under consideration and participants were provided with a tablet computer with internet access for the duration of the study and also provided with a full explanation of how to use and access the website. However, connection to the internet varied in different rooms within the wards. It is therefore recommended for future studies to ensure that there is stable internet connection at the study site.

For adherence to the augmented intervention in this study, of the participants who used the website (n=7), five were adherent to the intervention (71.4%) as they completed at least two third (66.6%) of their prescribed sessions (Hawley-Hague et al., 2016) and the mean of completed sessions per week for those participants was 5.3. This figure is comparable with a previous study that investigated the efficacy of providing unsupervised upper-limb exercise programmes for hospitalised stroke patients to maximise arm function (Harris et al., 2009). Harris et al. (2009) reported that the participants adhered to the intended sessions of augmented intervention of 1 hour a day, 6 days a week for 4 weeks on average 3 hours and 4.8 days per week. In addition, the adherence rate in this study was comparable with another study that explored efficacy of the same platform used in this study for people with multiple sclerosis (Paul et al., 2019). Paul et al. (2019) reported that during the first four weeks of the study 63% of participants completed at least 75% of their exercise programme. Furthermore, adherence to exercise diaries in these studies used self-report by the participants recording completion of the exercises in their online exercise diary within the web-based

physiotherapy website and this approach has limited reliability and validity (Nicolson et al., 2018). For instance, the completed exercise sessions for four participants in the current study was underestimated as they completed their exercise programme without logging in as reported in their evaluation questionnaires (see section 6.2.2) and thus these sessions were not recorded. Therefore, the results of this pilot study were in line with previous research. The results also indicated that participants using the platform in future studies should be reminded to record their exercises to better judge their adherence to the intervention.

It was found from the evaluation questionnaires for stroke survivors and carer participants that exercising without supervision was acceptable and not difficult (section 6.2.4). However, many stroke survivor participants sought help from their carers to access the website and/or perform their exercises. Therefore, this pilot study identified that having a carer who can assist is a facilitator for participation and adherence to their exercise programmes as all participants with carers helping them were adherent to the study intervention.

The findings from this study suggest that neither the number of prescribed exercises nor number of times per week the participant was asked to complete their programme affected adherence. Therefore, the augmented exercise programmes were not found to be a burden for participants while practicing their usual daily physiotherapy and/or occupational therapy sessions.

6.1.3 Participants' attrition

The level of participant attrition was 19% in both control and intervention groups. This figure is lower than the 20% rate of attrition or more which according to Dumville et al. (2006) increases the possibility of bias. This attrition rate is slightly higher than those in other studies that investigated unsupervised augmented intervention in acute stroke (Harris et al., 2009, Brkic et al., 2016). Brkic et al. (2016) reported an attrition rate of 8% at the four-week point, due to the participants' emotional status caused by their illness. Harris et al. (2009) reported an attrition rate of 9% at the four-week point due to the following: the participants declining to join the control group, experiencing pain or being in acute care. However, the two studies cited above did not use technology to deliver the augmented intervention to stroke survivors. In the current study, the main reason for the lower level of attrition was that the participants were discharged before their final assessments.

6.1.4 Participants' health & safety

Unsupervised intervention via the web-based physiotherapy programme for the in-patient stroke population in this study was deemed to be safe. Five adverse events were recorded in this study: falls (n=2), shoulder pain (n=2) and fatigue (n=1), and none of these were considered as being serious. The recorded adverse events of falls were not related to the study intervention because the intervention comprised upper-limb exercises only and none of these exercises required the participants to stand. Conversely, the recorded adverse events of shoulder pain and fatigue were anticipated among participants as these are recognised as stroke-related symptoms and are common among stroke survivors (Duncan et al., 2005). Due to these adverse events amendments were made to the specific participants exercise programmes as well as any other prescribed exercises programme when necessary. These amendments were made by their physiotherapists by adding/removing a specific exercise and/or number of the prescribed upper-limb exercises to meet the participants' current capability to practice the augmented intervention. This improved their adherence to the intervention as well as ensuring that the upper-limb exercises were safe and appropriate. These findings support previous work in studies delivering unsupervised augmented intervention for stroke patients in hospital setting which used other forms of exercise delivery that is a printed exercise programme (Harris et al., 2009, Brkic et al., 2016). Brkic et al. (2016), for example, did not record any injuries related to the intervention study while Harris et al. (2009) recorded some adverse events such as shoulder pain, but these were not considered as being serious.

6.2 Secondary outcome measures

6.2.1 The Action Research Arm Test (ARAT)

Improving arm function was the main goal of the augmented intervention in this study since it was identified as a research priority (Pollock et al., 2014a). A systematic review of the literature about the efficacy of augmented intervention can be found in section 2.4. Three main factors were outlined that could facilitate or hinder the efficacy of augmented intervention:

- The type of augmented intervention; task- oriented or functional task were most beneficial.

- Level of arm impairments, stroke survivors who have high levels of arm impairment are less likely to gain improvements.
- The dose of augmented intervention; at least 10 hours over 5 weeks is reported to be enough to achieve a meaningful beneficial effect, but this occur only when the other conditions as above (type of intervention and patients with less severe arm impairment) are met otherwise more time is needed to achieve a meaningful effect.

The inclusion/ exclusion criteria in this study were changed during the study in terms of the level of arm impairment to include participants with severe arm impairment (ARAT score=0) as outlined in section 6.2.1 and subsequently more passive and stretch exercises were included within participants' augmented interventions as appropriate. Of the participants who completed the study assessments (n=21), 13 participants from both groups had severe arm impairment (ARAT score=0), six participants from the intervention group and seven participants from the control group. The ARAT scores for 6 out of those 13 participants did not change (two participants from the intervention group and four participants from the control group) while the scores for the remaining participants (n= 8, four participants from each group) who started with a score of 1 or more showed an increase in their ARAT scale following the completion of the programme. Therefore, including participants with severe arm impairment (ARAT score=0) might have been contributed to the lack of improvement of arm function in the study. Based on the above future studies that explore the efficacy of augmented upper-limb intervention on upper-limb function should consider recruiting stroke survivors with mild to moderate arm impairment only (ARAT score > 0).

The overall changes in ARAT scores in this pilot study were in favour of participants in the intervention group, as more participants in this group (8 out of 10) had improvement exceeding the MCID (5.7 points in scores) whereas in the control group only 6 out of 11 participants. Although this provides some indication of the likely effect of the augmented intervention on upper-limb function, the potential effect of the augmented intervention is unclear as this study was not fully powered to detect variation between the two study groups. Most previous work in the field of upper-limb augmented interventions for hospitalised stroke patients demonstrated non-statistically significant differences between the study groups in terms of the ARAT scale (Rodgers et al., 2003, Donaldson et al., 2009a, Yin et al., 2014, Kong et al., 2016, Platz et al., 2005a). However, that was due for different reasons and that include: studies were unpowered to detect changes among the study groups

(Donaldson et al., 2009a) and low-dose augmented interventions (Yin et al., 2014, Kong et al., 2016, Rodgers et al., 2003, Platz et al., 2005a).

6.2.2 Trunk Impairment Scale (TIS)

The TIS was assessed in this study because having a good trunk function is essential to be able to control upper-limb function (Wee et al., 2015). The TIS mean scores at baseline and post intervention for both groups indicated that the participants were able to perform trunk function activities in terms of static and dynamic sitting balance and co-ordinated movements while sitting unsupported. Therefore, the level of trunk impairment did not explain the lack of improvement of arm function observed. It has been suggested that there is lack of evidence to associate trunk exercises with improvements in the upper-limb functions (Alhwoaimel et al., 2018). However, Wee et al. (2015) established that the stabilisation of the lower-limbs and the lumber spine facilitates arm function thus justifying the assessment of trunk function in this study.

Even though the augmented intervention in this study was not aimed at improving trunk function, the physiotherapists prescribed some trunk exercises as part of the participants' augmented intervention, as a means to facilitate upper-limb function. In the TIS, participants in the intervention group achieved lower scores than those in the control group. Conversely, participants who were adherent to their intervention gained higher scores than participants in both the control group and those in the intervention group who were non-adherent. Even though the findings from this study showed higher changes in TIS scores favouring participants who were adherent to their intervention, there is no available MCID for the TIS measurement that could be used to better judge this research outcome. Therefore, the likely effect of the augmented intervention on trunk impairment is unclear. To date, none of the studies that examined the effect of augmented upper-limb intervention for stroke survivors in hospital setting assessed trunk function. A recent systematic review and meta-analysis conducted by Alhwoaimel et al. (2018) showed that trunk exercises can positively affect trunk functional abilities and that this effect is at its peak for stroke survivors at their acute stage.

6.2.3 Modified Ashworth scale (MAS)

The measurements of muscle spasticity were assessed because spasticity can hinder improvements in arm function (Bhalla and Birns, 2015). The overall mean scores for all the participants in the control and intervention groups for all the assessed muscle groups did not indicate an increase in muscle tone. Therefore, muscle spasticity for the assessed muscle groups was not found to impede the improvement of function of the upper limbs in this study as the mean scores of all the assessed muscles were generally low and the highest recorded mean score was 1.8 (SD 12) for the shoulder adductor muscle group which indicates a slight increase in muscle tone with minimal resistance for less than half of the ROM.

The augmented intervention in this study was not aimed at improving muscle spasticity, but stretching and passive exercises were delivered to participants to facilitate upper-limb function, as 13 participants in this study had severely impaired arm function (ARAT=0). Studies suggest that stretching and passive exercises are not effective in decreasing muscle spasticity; however, they help to reduce the pathological change at the muscles and tendons as a result of stroke (You et al., 2014, Page, 2012, Salazar et al., 2019, Katalinic et al., 2011).

Changes of MAS scores for this study were generally similar between the two groups. In the existing literature that investigated the effect of augmented upper-limb exercises for hospitalised stroke patients, one study (one study reported in two articles) assessed muscle spasticity in the elbow and wrist flexors (Lincoln et al., 1999, Parry et al., 1999) and one in the wrist flexors (Platz et al., 2005a). These two studies did not find any statistically significant changes across their respective groups. Unlike this pilot study, Lincoln et al. (1999), Parry et al. (1999) and Platz et al. (2005a) provided augmented intervention sessions that were fully supervised by clinicians without using technology to deliver interventions.

It should be noted that these findings should be interpreted with caution, specially that the participants were not asked if they had received any intervention for their spasticity, such as anti-spasticity medications, during their hospital stay.

6.2.4 Participants feedback questionnaires

The participating stroke survivors, carers and physiotherapists reported that the augmented exercise programme delivered through the web-based physiotherapy website was clear, easy to use and helpful, and that they would be keen to use the web-based physiotherapy website as a tool for rehabilitation again in the future. The findings of this study confirmed the

previous conclusion from Phase 1 in this thesis (the user-centred study, Chapter 3) on the accessibility and acceptability of the web-based physiotherapy website for the stroke population, but in clinical practice this was identified as a gap in the literature. This was consistent with another study conducted by Coulter et al. (2016) aimed at evaluating the satisfaction and efficacy of the web-based physiotherapy platform but for people with spinal cord injuries.

Further, the data suggest that stroke survivors were satisfied with the augmented intervention indicating that the intervention has not increased their level of fatigue. Even though one physiotherapist reported that many stroke survivors felt too tired to practice the augmented intervention, the overall responses from the stroke survivors suggested the opposite.

The physiotherapists who participated in the study clarified that the process of signing up new patients and setting up their exercise programmes was easy and was not considered an imposition on their daily workload. However, some physiotherapist participants criticised the website programme for not being compatible with some web browsers on the computers at hospitals, internet explorer in particular. The physiotherapists also noted that the package included a limited number of upper-limb exercises. These are points that would need to be considered when designing further research studies using this website.

There was agreement among the stroke survivor and carer participants on the ease with which they could practice their exercises using the web-based physiotherapy website without direct supervision by health professionals. This finding was concluded in a qualitative study that aimed to customise the web-based physiotherapy for stroke population, Phase 1 in this thesis (the user-centred study, Chapter 3), and was confirmed in this study, when neither the stroke survivors nor carers asked staff for any assistance with the exercises. This finding is in line with another study which delivered unsupervised upper-limb augmented intervention using handbook exercises for hospitalised stroke patients (Brkic et al., 2016). However, the findings indicated that out of the participants who used the web-based physiotherapy website (n=7), six patients required help from their partners/carers in accessing and practicing using the web-based programmes. This confirm the previous conclusion that patients with carers helping them to access their exercise programmes are more likely to benefit from the website.

In a recent study, Schnabel et al. (2020) explored the experiences of stroke survivors and carers who practiced high dose of upper-limb augmented intervention, up to 27 hours over

six weeks. The intervention was delivered through both fully supervised sessions, led by physiotherapists, and unsupervised rehabilitation sessions, performed according to a handbook exercise. This study was part of the Early Versus Later Augmented Arm Physiotherapy (EVERLAP) after stroke trial and participants underwent usual care in addition to augmented upper-limb physiotherapy either early, within three weeks of stroke, or late, at nine weeks after stroke, compared to usual care alone. In the end, the participants reported positive feedback about the high dose of augmented intervention delivered through fully supervised and unsupervised rehabilitation sessions. Many also indicated that they had coped well with the intervention, although some participants needed support to practice the unsupervised rehabilitation sessions (Schnabel et al., 2020). Similar patient experience was demonstrated in this pilot study as the participants reported positive experiences with the augmented web-based physiotherapy intervention. The presence of carers to support stroke survivors also facilitated their engagement with the unsupervised rehabilitation sessions. However, the two research projects, the study conducted by Schnabel et al. (2020) and this pilot study, differed in their methods of delivery of the intervention: face-to-face and printed exercises in the case of the former, and web-based exercises in the case of the latter.

Another recent study conducted by Vloothuis et al. (2018) as the qualitative part for the CARE4STROKE trial (Vloothuis et al., 2019) looked at how stroke survivors experienced augmented task specific exercises delivered via an e-health application by their carers. While the aim of the whole trial was to increase stroke survivors' functional abilities and promote early supported discharge plans, this study clarified that stroke survivors benefitted from exercises delivered through the internet as they were more independent in their rehabilitation and therefore more ready to be discharged (Vloothuis et al., 2018). Similar patient experience was observed in this study as most of the stroke survivors found the web-based physiotherapy website an appropriate medium for rehabilitation that helped them to be involved in the process of rehabilitation. The web-based physiotherapy platform was found to be capable of narrowing the distance between the needs of stroke survivors (Mackenzie et al., 2007) and the insufficient rehabilitation provisions for their upper-limbs (National Services Scotland Information and Intelligence, 2019, Sentinel Stroke National Audit Programme (SSNAP), 2019) by providing them with access to rehabilitation as most of the stroke survivor participants indicated exercising 3-5 times per week or more.

Contamination between the stroke survivor participants in both groups was considered in this study by asking if patients were discussing the exercises with other patients. A few

patients mentioned that they discussed their exercise programmes with other patients, but none were taking part in this study.

6.3 Study limitations

This study had some limitations. The assessor and the participants (physiotherapists, stroke survivors and carers) in this study were unblinded to group allocation, which may represent a source of bias, such as competitive therapy bias, where physiotherapists increase the dose of usual rehabilitation sessions for patients in the control group, as they feel those patients are disadvantaged in the study (Rodgers et al., 2003). Furthermore, the web-based physiotherapy does not calculate the duration of the performed exercises; therefore, this was not calculated in this pilot. Measuring the time of practiced augmented intervention would have provided more insight about the efficacy of intervention. It should be noted that the augmented intervention investigated in this study was delivered via the web-based physiotherapy website which is created and managed by the lead academic supervisor. This may have potentially led to bias of the study findings. However, the lead academic supervisor was not directly involved in any data collection and the other two academic supervisors - had no conflict of interest with the web-based physiotherapy programme.

Another limitation in this study was the small sample size and the lack of statistical power to detect significant differences between the study groups. Furthermore, this pilot study could not investigate the variation in usual care among the participants; the researcher did consider measuring this variation, and therefore developed a form for physiotherapists to complete for each participant at discharge, to record which upper-limb exercises were included in normal physiotherapy sessions, and the duration of these exercises. However, the majority of these forms were not completed by the physiotherapists.

The use of feedback questionnaires to capture the participants' experiences is generally criticised for not providing enough depth in the provided feedback (Parahoo, 2014, Polit and Beck, 2017). Although the feedback questionnaires in this study included free text to give the participants an opportunity to further justify their responses, the obtained feedback was generally superficial. Furthermore, the self-reporting nature of these questionnaires limited the reliability and validity of the provided feedback, as participants may have deviated from the truth by choosing the more socially acceptable responses, or participants may not have been capable of accurately assessing their experiences (Nicolson et al., 2018). This implies that the experiences of participants have not been explored fully in this study due to the use

of questionnaires instead of other forms of qualitative research such as individual interviews to explore participants' experiences. Lastly, there were two issues regarding the participants' feedback questionnaires that were completed by stroke survivors, carers and physiotherapists in this study, despite the academic supervisors and physiotherapists' judgement of their validity (explained in section 4.8.4). Using agreement statements instead of questions in some questionnaire items may have influenced the responses of the participants (to be positive) (Artino et al., 2011), and failing to pilot the questionnaires to be judge by the target populations (stroke survivors and carers) may result in some items being unclear (Gehlbach and Brinkworth, 2011). These two steps are essential in the development of questionnaires to ensure that none of the items is problematic. However, the questionnaires contained free text comments for the participants to provide unbiased and accurate responses and in addition, the researcher was available to help the participants with completing the questionnaires when required (Parahoo, 2014, Polit and Beck, 2017).

6.4 Study outcome, lessons learnt from this pilot study to inform future research

6.4.1 Augmented Upper-limb Physiotherapy pilot study outcome

Thabane et al. (2010) indicate that pilot studies are concluded with one of the following options:

'(i) Stop - main study not feasible; (ii) Continue, but modify protocol - feasible with modifications; (iii) Continue without modifications, but monitor closely - feasible with close monitoring and (iv) Continue with- out modifications - feasible as is' (Thabane et al., 2010, p. 5).

The study on augmented upper-limb physiotherapy for hospitalised stroke survivors showed that a randomised control trial to assess the clinical effectiveness of the augmented web-based upper-limb physiotherapy programmes is feasible with modifications to the study protocol. Details about the lessons learnt from this study that can inform future studies are provided below.

6.4.2 Lessons learnt from this pilot study to inform future research

6.4.2.1 Recruitment

There was variation among the study sites in the number of recruited participants per month with 1.3 participants per month for Hairmyres Hospital, 0.9 participants per month for the University Hospital Monklands and 0.7 participants per month for the University Hospital Wishaw. Three possible reasons were identified that could explain the variation among the study sites: the relationship between the researcher and the physiotherapists; the capacity of the physiotherapists in the stroke units; and a lack of financial support (McGill et al., 2020). The relationship between the researcher and physiotherapists was good overall at all the study sites, but it was strongest with clinicians at Hairmyres Hospital as they were involved in all the stages of the study such as setting up and amending the study's inclusion and exclusion criteria. In contrast, the other two sites were involved in the study at later stages. Other reasons for this variation were the personal holidays and sick leave of the physiotherapists, which in turn increased their workload in stroke units as the number of available physiotherapists to support the study decreased. The physiotherapists were not financially compensated for their time while participating in this study, which may have adversely affected the overall recruitment at all three sites but does not explain the variation among the study sites.

The number of physiotherapists involved in the study and therefore able to recruit participants was another factor in the variation between sites. There were three physiotherapists at Hairmyres Hospital compared to two physiotherapists at the other two hospitals. The recruitment rates were higher at Hairmyres as there were more physiotherapists available for the task of recruiting.

Based on the above, it is important for future studies to:

- Build a solid relationship with all the study sites and involve them from the early stages of the study.
- Ensure financial support for the physiotherapists to show appreciation for their time and to facilitate recruitment.
- Consider the additional workload placed on the physiotherapists
- Set a target number of participants to be recruited at each site.
- Ensure that there are sufficient physiotherapists at each site

- Set a contingency plan for recruitment in case they encounter delays in their intended recruitment plan.

6.4.2.2 Inclusion/exclusion criteria

The stroke survivors who participated in this study were willing to take part in the study during their hospital stay and they were happy to access the internet to perform their upper-limb exercise programme. The web-based physiotherapy programme was designed to meet the needs of stroke survivors with different levels of upper-limb impairments. The eligibility criteria applied in this study required amendments to enhance the recruitment rate and to deliver the intended functional task-specific/oriented exercises. Therefore, future studies should use the amended eligibility criteria, and consider other suggested amendments to the protocol presented in this section to enhance the recruitment rate.

Considerations of common complications after stroke such as shoulder subluxation should be taken into consideration when designing the upper-limb augmented programme as this adversely affected recruitment rates. In addition, including participants with severely limited arm functions (ARAT=0) resulted in the delivery of passive exercises rather than functional task-specific/oriented exercises. Therefore, future studies should exclude those patients. In addition, more studies should be developed specifically to explore interventions for patients with severely limited arm functions (ARAT=0) that meet their rehabilitation goals as all participants with ARAT score above 0 progressed as a result of the exercises, which was not the case with those with ARAT score 0 at baseline. It is therefore instructive to highlight that in this study half of participants with ARAT score 0 (7 out of 13) progressed after practicing the prescribed exercise sessions which indicates that they may still recover to some extent. The recovery of upper-limb function can be predicted by the stroke survivors' age and gender, the site of the stroke lesion, the level of upper-limb impairment and the presence of evoked motor and somatosensory potential (Coupar et al., 2012b). Nijland et al. (2010) suggest that the early presence of voluntary movement in shoulder abduction and finger extensions (within three days of stroke) can be used as a predictor for full recovery of upper-limb function for up to sixty percent of stroke survivors. Another study conducted by Stinear et al. (2017) presented an algorithm that sequentially merged the variables of age, the level of upper-limb impairment, the presence/absence of motor-evoked potentials and the site of the stroke lesion or stroke severity (NIHSS) to predict the recovery of upper-limb function for seventy-five percent of stroke survivors. Therefore, future studies should stratify stroke survivors based on their NIHS score at randomisation into either favourable prognosis

participants or unfavourable prognosis participants, in order to better understand the potential effect of the study intervention on stroke survivors with different levels of functional impairment.

6.4.2.3 Randomisation

The randomisation procedure followed in this study was easy to follow and worked well. However, the level of upper-limb function (ARAT score) varied between the two study groups. Therefore, future studies should consider stratifying participants based on their ARAT score at randomisation to ensure groups are balanced at baseline in terms of the level of upper-limb function. This will provide a clearer insight into the efficacy of the study intervention.

6.4.2.4 The web-based physiotherapy programme (augmented intervention)

A general description of the web-based physiotherapy website and how it worked was provided earlier in the beginning of Chapter 3. In addition, the TIDieR template was used to describe the study intervention, see Table 4-2 (Hoffmann et al., 2014). The website user manual (Appendix 15) worked well as it provided clear instructions on how to access and use the website. It could be used for futures studies that use web-based physiotherapy to deliver exercise programmes. However, the user manual requires minor modification to reflect these instructions on the new interface of the website.

The use of the physiotherapy website to deliver the augmented intervention was criticised in this study by physiotherapists (see section 6.2.4) for the limited number of upper-limb exercises and because the website was not compatible with browsers available in NHS computers. Therefore, future studies using the website to deliver upper-limb exercises to hospitalised patients need to consult clinical physiotherapists to check and expand on the library of upper-limb exercises within the website, based on their preferences. A consultation with an information technologist is also required to ensure the compatibility of the website with different browsers including those available in NHS computers. Future studies using the website also need to remind the participants regularly to record their practised exercises as four participants in this study used their memory to practise their augmented exercises, without logging in to the platform.

Although the participants in this study were provided with tablets and internet access when required, some participants did not access their exercise programme due to the poor Wi-Fi

signal on the ward. The internet connection varied at different study sites, and it also varied in different rooms within each site. Therefore, future studies using the website should ensure a stable internet connection for all the participants to facilitate their adherence to the study intervention.

The dose and frequency of the study intervention was set to judge its feasibility not its efficacy; therefore, future studies aiming to assess the efficacy of the upper-limb augmented intervention for stroke survivors during their hospital stay need to deliver at least 10 hours of task-oriented or functional-task augmented intervention if the participants have less severe arm impairment (Parry et al., 1999, Lincoln et al., 1999). Otherwise, the duration of the augmented intervention needs to be increased (Platz et al., 2005a, Winstein et al., 2004, Harris et al., 2009, Han et al., 2013).

6.4.2.5 Control group and usual rehabilitation care

The control group received usual rehabilitation care along with the "Just move" leaflet from Chest Heart & Stroke Scotland, which provides generic information about the importance of physical activity and exercises (Appendix 25). This study aimed to record the usual rehabilitation sessions for each participant with a form developed for this purpose (Appendix 33). Although the developed form was simple and easy to complete, the form did not meet its goal as the majority of these forms were not completed. Therefore, future research studies that aim to investigate augmented interventions should develop a strategy to monitor data completeness including the record of usual care for people with stroke. Researchers should also consider whether the participants are receiving any medication such as anti-spasticity drugs, in order to obtain a clearer conclusion about the efficacy of the intervention if fully powered to detect variation among study groups.

6.4.2.6 Study attrition

The level of participant attrition in this study could have been reduced (Dumville et al., 2006). The main reason for attrition in this pilot study was discharge before final assessment; therefore, it is recommended for future studies to ensure regular checks of participants' discharge plans.

6.4.2.7 Outcome measures

This study would suggest that the ARAT is an appropriate primary outcome measure for studies aiming to investigate efficacy of augmented upper-limb intervention for hospitalised stroke survivors. ARAT is also widely used and provide a valid and reliable measure of upper-limb function (Platz et al., 2005b, Hsieh et al., 1998). In addition, selection of ARAT to measure upper-limb function is recommended by Kwakkel et al. (2017) who generated a consensus of outcome measures to be used in stroke rehabilitation studies. The overall completeness of ARAT scores in this study was good with only five missing scores for 26 participants (three from the intervention group and two from control group) and the main reasons for missing these scores was discharge before final assessment indicating that ARAT measure can be used in future studies.

Assessing muscle spasticity measure and trunk function was decided in this study because they may facilitate/hinder recovery in upper-limb activity limitation (Wee et al., 2015, Cacho et al., 2017). However, outcome measures used in this study require amendments. Future studies need to give more consideration to the clinical importance of the outcome measures as well as to comparability with relevant studies. The MAS and TIS outcome measures are not common in studies delivered augmented upper-limb interventions to stroke survivors during their hospital stay. Future studies may consider a measure of upper-limb impairment such as the Fugl-Meyer as it is more clinically relevant, widely used and recommended by Kwakkel et al. (2017) to be used in stroke rehabilitation studies.

Exploring the views of the participants in this study using developed questionnaires provided superficial responses and did not provide deep information on how to develop the intervention and/or understand participants' adherence. Although the questionnaires contained free text comments for the participants to provide unbiased and accurate responses and in addition, the researcher was available to help the participants with completing the questionnaires when required, obtaining feedback of participants using individual interviews would have provided a deeper understanding about the experiences of the participants. Individual interviews or focus groups would provide the researcher the opportunity to probe for more information from the participants and to observe non-verbal cues; thereby interviews are recommended to be used for future studies (Parahoo, 2014, Polit and Beck, 2017).

Future studies should consider selection measure of pain in the affected upper-limb and fatigue as they may occur as a result of practising high dose of augmented upper-limb intervention. For example, assessment of fatigue would have added more insight to this study as there was a conflicting finding between the feedback of stroke survivors and that of the physiotherapist participants. One physiotherapist claimed that some stroke survivors felt too tired as a result of practising their augmented exercises, while none of the stroke survivors indicated an increase in their level of fatigue due to the augmented intervention.

6.4.2.8 Study blinding

The assessor, stroke survivors, carers and physiotherapists should have been blinded to group allocation to avoid representing a source of bias such as competitive therapy bias (Rodgers et al., 2003). This point has been considered but due to the nature of the study the assessor who also provided technical support to participants in the intervention group to access their exercises programme when required, could not be blinded, nor could participating physiotherapists as they were required to set up participants' programmes and also provided usual rehabilitation care to participants at intervention and control groups). Although blinding clinical physiotherapists and participants to group allocation is not possible due to the nature of the study, employing an outcome assessor is recommended for future studies.

6.5 Recommendations for clinicians

- Using the web-based physiotherapy platform to deliver an unsupervised upper-limb augmented intervention appears to be safe, acceptable and feasible for the stroke population as this study did not record injuries related to the study intervention (section 6.1.4). In addition, the participants reported a positive feedback about the study intervention in their feedback questionnaires (section 6.2.4).

- Stroke survivors' level of arm impairment and the presence of helpful carers should be taken into consideration when designing unsupervised upper-limb augmented interventions through the web-based physiotherapy website.

- Stroke survivors with severe arm impairments are less likely to gain benefits and those with carers helping them are more likely to practise their web-based exercise programmes. In their evaluation questionnaires many stroke survivors in this study reported that they sought help from their carers to access the website and/or perform

their exercises (section 6.2.4). In addition, all the participants who started with scores higher than 1 in ARAT at baseline assessment showed clinically significant improvements while those who started with a score of 0 at baseline showed less clinically significant improvements (section 6.2.1).

6.6 Conclusion

Delivering an upper-limb non-supervised augmented exercise intervention using a web-based physiotherapy website for stroke patients in the inpatient setting is feasible, safe and acceptable to patients, carers and physiotherapists. Stroke patients allocated to the intervention group gained more clinically important improvements than those in the control group in the ARAT measure, and, in addition, patients who adhered to the intervention gained higher scores than those who were not in TIS measure. A fully powered RCT is required to investigate the efficacy of unsupervised augmented upper-limb interventions for this patient group to strengthen the study findings.

Chapter 7 : General discussion, conclusion and recommendations

7.1 Summary of the PhD studies

This thesis aimed to make an existing web-based physiotherapy platform (www.webbasedphysio.com now www.giraffehealth.com) accessible and suitable for use for people who had had a stroke. It also investigated the feasibility of using the modified platform as part of rehabilitation delivery of upper-limb augmented intervention for the stroke population during their hospitalised period. After a comprehensive literature review, these aims were proposed to address crucial literature gaps.

In order to meet these aims, two studies were conducted. Within the first phase, a study was conducted to modify the web-based physiotherapy platform and to inform the second phase. A user-centred design was followed to capture the needs and preferences of stroke survivors and carers, with whom three focus groups were conducted consecutively. As a result of this study, the needs and preferences of this population were recognised in terms of using technology to deliver exercises and therefore the web-based physiotherapy platform was modified to meet these preferences and needs. Even though the findings of this study were based on observations, the overall findings could be of interest to other researchers and clinicians.

In the second phase, a pilot RCT study was conducted to evaluate the acceptability and feasibility, and to explore the possible effectiveness, of an individualised 4-week programme of augmented upper-limb rehabilitation, delivered via the modified web-based physiotherapy platform, for the stroke population in acute stroke rehabilitation. This study measured and explored recruitment, attrition, adherence, safety and the effect of this intervention on arm function, trunk function and spasticity of the shoulder (elbow flexor shoulder adductor, wrist flexor and fingers flexor muscle groups). In addition, it collected feedback from the participants (stroke survivors, carers and physiotherapists) about the study intervention. The study findings indicated that using the web-based physiotherapy platform to deliver unsupervised augmented upper-limb interventions for stroke survivors during their hospital stay is acceptable, safe and feasible. Furthermore, the web-based physiotherapy platform has the potential to provide effective interventions. However, a fully powered RCT study is essential to confirm, extend or refute these findings.

7.2 Contribution of work to knowledge

The two studies conducted in this thesis have contributed knowledge to the current evidence of rehabilitation delivery for people with stroke. They have also addressed important gaps in the literature. The user-centred study was the first to include stroke survivors and carers using a UCD to modify a technology-based rehabilitation delivery website to suit the needs of the stroke population. The pilot RCT study was the first to explore the feasibility and efficacy of an upper-limb augmented intervention for hospitalised stroke population delivered by a web-based physiotherapy platform (www.webbasedphysio.com now www.giraffehealth.com).

The work undertaken in this thesis is in line with the current development in communication technology as it considered challenges that inhibit stroke survivors from engaging in remote telerehabilitation interventions (Laver et al., 2020, Standing et al., 2018). It adopted a UCD approach in order to demonstrate the appropriate implementation of telerehabilitation as well as to facilitate patient engagement with this intervention. The interest in telerehabilitation has grown in recent years, but there has been limited consideration of the challenges to telerehabilitation implementation (see section 2.5.1) (Laver et al., 2020, Tchero et al., 2018, Johansson and Wild, 2011, Standing et al., 2018). UCD is a shift from making assumptions about what is best for the participants by giving them the opportunity to take ownership of the research. They are directly involved in decisions over what needs to be done and how they want it done (Batalden et al., 2016, Rix and Marrin, 2015, Osborne et al., 2016, Alford, 2014). It has been evident that incorporating the views of the users leads to a 'better' designed intervention (see section 3.6) (Standing et al., 2018, INVOLVE, 2019). This approach was considered appropriate for this study because it is an ethical, just and pragmatic way of producing resources. It was also thought that the inclusion of stroke survivors and their carers in the design and modification of the web-based physiotherapy website would greatly enhance the quality of the targeted services. The service user feedback led to changes being made to the platform that facilitated navigation and the content was made more acceptable to a stroke population. Partnership between researchers and the target population is at the heart of health care and needs to be situated also at heart of its research (Hardwick and Worsley, 2010).

This thesis is in line with current developments in the area of stroke rehabilitation (Bernhardt et al., 2019). Bernhardt et al. (2019) explained that in the development of stroke trials, the

following needs to be considered: the dose and type of the intervention, who the participants are and when to enrol participants in the intervention. Different types of upper-limb interventions were demonstrated in section 2.3.1 and the repetitive task-specific training was identified as the most appropriate type of intervention. The hospitalisation period for stroke survivors was targeted in this thesis as it is where the peak of neuroplasticity takes place (see section 2.3.2 for more details). It is suggested that stroke survivors with mild/moderate upper-limb function (ARAT>0) who receive at least 10 hours of upper-limb functional exercises are more likely to benefit from the augmented intervention investigated in this thesis (see section 2.3.3 and section 2.4.4 for more details). However, the recommended dose and participants with ARAT>0 were not targeted in this thesis as it aimed to evaluate the acceptability and feasibility of augmented upper-limb exercise delivery for hospitalised stroke survivors, not to assess the efficacy of the study intervention. It must be acknowledged that this study should have targeted the recommended dose of augmented upper-limb intervention and included participants with ARAT>0, in order to gain more insight about the potential effect of the study intervention.

Combining the above provides researchers and/or clinicians with an opportunity to overcome stroke rehabilitation barriers, respond to criticism from researchers of stroke units' inability to meet the recommended dose of rehabilitation (National Services Scotland Information and Intelligence, 2019, Sentinel Stroke National Audit Programme (SSNAP), 2019, Clarke et al., 2018) or to provide the appropriate support for stroke survivors (The Stroke Association, 2018). This was achieved by modifying a technology-based tool, a physiotherapy website, to meet the needs of the stroke population using the platform as a medium for exercise delivery. This filled a gap in the literature as there are very few studies explaining the need for similar tools (see section 2.6 for more details) (Stewart et al., 2017, Laver et al., 2020).

7.2.1 Rehabilitation and the coronavirus pandemic

SARS-CoV-2 is a virus that has spread all over the world and new cases are still occurring (World Health Organization, 2020). The mortality rate ranges from three to nine percent (World Health Organization, 2020). Intensive care unit admission rates are approximately five percent, and roughly forty-two percent of patients who are hospitalised will need oxygen therapy (Guan et al., 2020). The available data suggests that certain people are at higher risk of developing severe forms of Coronavirus (COVID-19), and they will need admission to

hospital and/or ICU support. These people include male older individuals who have one or more co-morbidities (Chen et al., 2020, Zhou et al., 2020, World Health Organization, 2020).

Rehabilitation is a critical component of treatment for non-COVID-19 patients with particular conditions, and its delay can have a significantly negative impact on health outcomes (Robison et al., 2009, Billinger et al., 2014). Rehabilitation is provided by a multidisciplinary team, with physiotherapy and occupational therapy forming an integral part of the process (Pan American Health Organization, 2020). Throughout the coronavirus pandemic, physiotherapy has been crucial in the acute and post-acute rehabilitation of patients with COVID-19, and in the continued delivery of rehabilitation services to elderly and disabled patients, with necessary pandemic-related adjustments to ensure the safety of patients (Bearne et al., 2021). Due to their position at the frontline of healthcare, physiotherapists have been at a heightened risk of contracting COVID-19 (Pan American Health Organization, 2020). Hence, several aspects require consideration and modification, such as the restrictions imposed on direct contact in patient consultations (face-to-face sessions) (Minghelli et al., 2020); greater adherence to infection, prevention and control guidelines; and the use of personal protective equipment (Pan American Health Organization, 2020).

In response to the COVID-19 pandemic, physiotherapists have implemented remote consultations (National Health Service England, 2020), so as to ensure that non-COVID patients can continue to receive their treatment. A key aspect of this is preventing the long-term negative impacts of stopping physiotherapy services, which include future heightened demand and increased disability (Chartered Society of Physiotherapy, 2020). Consequently, despite the pandemic, physiotherapist services remain an expectation. Physiotherapy can be delivered remotely to ensure that there is no face-to-face contact between the practitioner and the patient. This has been achieved using a number of delivery methods, including telephone, video, email, SMS, apps or online platforms – and there is a published guide available which details how to effectively implement remote physiotherapy (Barts Health NHS Trust, 2021)

Traditionally, when a patient requires physiotherapy, a face-to-face appointment is scheduled. However, technological progress has made huge strides in bringing locations, service providers and patients together (Laver et al., 2020). Advancements in communication technology have been implemented in the provision of remote healthcare

services, which is the basis of telerehabilitation (Galea, 2019). With regard to the significant progress represented by current technology, numerous studies have advocated for telerehabilitation to be implemented into physiotherapy services (Galea, 2019, Brochard et al., 2010). In fact, it has become fundamental to many physiotherapy services throughout the world during the pandemic (Chartered Society of Physiotherapy, 2020). Telerehabilitation has been extremely useful for populations requiring physiotherapy who are at high risk in regard to COVID-19, particularly the elderly population and those with a range of disabilities or pre-existing conditions (Pan American Health Organization, 2020). Telerehabilitation offers advantages to patients with different conditions, as it provides them with access to rehabilitation from distance, and could save their time and money, despite the imposed restrictions of social distancing or self-isolating, due to the highly contagious nature of the SARS-CoV-2 virus (Chartered Society of Physiotherapy, 2020, Laver et al., 2020). However, telerehabilitation cannot facilitate the physical touch element of physiotherapy, or 'hands-on physiotherapy'; therefore, face-to-face appointments remain essential in certain cases. Furthermore, telerehabilitation is not appropriate for all patients, as they represent many different conditions, and it is not expected to entirely replace face-to-face appointments in the future (National Health Service England, 2020). Section 2.5.1 in this thesis provides more details of the advantages and challenges associated with telerehabilitation interventions.

The use of telerehabilitation tools, such as the web-based physiotherapy platform used in this thesis, to deliver rehabilitation exercises has been called for, for people with different conditions including stroke (Bearne et al., 2021). This indicates the great importance of developing such a tool to facilitate the functional recovery of those patients as well as to facilitate usual care practices and to protect society from the spread of the SARS-CoV-2 virus.

7.3 Overall conclusion and recommendations for future studies

The thesis findings suggest that a web-based physiotherapy platform could be a feasible and acceptable way to deliver exercise programmes to the stroke population. It has the potential to close the gap between the current practice in the UK of not meeting the recommended dose of rehabilitation, especially for upper-limb function (Sentinel Stroke National Audit Programme, 2019, National Services Scotland Information and Intelligence, 2019) by providing them with access to rehabilitation. However, this thesis should be considered as a

foundation to build on for future studies, as more robust research studies to confirm or refute these findings are required. Recommendations for future studies are presented from each study in section 3.18.2 and section 6.4, and to keep follow-up of stages 3 and 4 of the MRC framework from the thesis, more fully powered studies are required.

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Appendices

Appendix 1 Search strategy

Database	Search Strategy
Cochrane library	MeSH descriptor: [Cerebrovascular Disorders] explode all trees OR (stroke$):kw OR (cva$) OR (cerebrovascular$) OR (cerebral vascular$) OR ((poststroke or post-stroke or cerebrovasc$ or brain vasc$or cerebral vasc$ or apoplex$ or SAH)) OR (((brain$ or cerebr$ or cerebell$ or intracran$ orintracerebral or vertebrobasilar) near/5 (isch?emi$ or infarct$or thrombo$ or emboli$ or occlus$))) OR (((brain$ or cerebr$ or cerebell$ or intracerebral orintracranial or subarachnoid) near/5 (haemorrhage$ orhemorrhage$ or haematoma$ or hematoma$ or bleed$))) OR MeSH descriptor: [Hemiplegia] explode all trees OR MeSH descriptor: [Paresis] explode all trees OR ((hemipleg$ or hemipar$ or paresis or paretic)) AND MeSH descriptor: [Physical Therapy Modalities] explode all trees OR (physical therapy) OR (physiotherapy) OR (occupational therapy) OR (rehabilitat$) OR MeSH descriptor: [Recovery of Function] explode all trees OR MeSH descriptor: [Rehabilitation] explode all trees OR MeSH descriptor: [Exercise Movement Techniques] explode all trees OR ((functional near/5 (task$ or movement))) OR (((motor or movement$ or task$ or skill$ or performance) near/5 (schedule$ or intervention or therap$ or program$ or regim$ orprotocol$))) AND (intensit$) OR (frequen$) OR (duration$) OR (dos$) OR (total units$) OR (amount$) OR (quantit$) OR (how much$) OR (repetit$) AND MeSH descriptor: [Upper Extremity] explode all trees OR ((upper near/2 limb*)):ti,ab OR (upper near/2 extremit*):ti,ab OR arm:ti,ab OR shoulder:ti,ab OR hand:ti,ab OR elbow:ti,ab OR forearm:ti,ab OR wrist:ti,ab OR finger$:ti,ab
Web of Science Core Collections	TS=(Cerebrovascular Disorders)) OR TS=(stroke$)) OR TS=(cva$)) OR TS=(cerebrovascular$)) OR TS=(cerebral vascular$)) OR TS=((poststroke or post-stroke or cerebrovasc$ or brain vasc$ or cerebral vasc$ or apoplex$ or SAH))) OR TS = (Hemiplegia)) OR TS= (Paresis)) OR TS = (hemipleg$ or hemipar$ or paresis or paretic) AND TS=(functional near/5 (task$ or movement)) OR TS= (physiotherapy* OR "physical therapy" OR "occupational therapy") OR TS= ("Recovery of Function" OR "Rehabilitation" OR "rehabilitat$") AND TS= ("intensit$" OR "frequen$" OR "duration$" OR "dos$" OR "total units$" OR "amount$" OR "quantit$" OR "how much$" OR "repetit$")) OR TS= (Upper Extremity) OR TS= (upper near/2 limb*) OR TS=(upper near/2 extremit*) OR TS= ("arm" OR "shoulder" OR "hand" OR "elbow" OR "finger$" OR "forearm" OR "wrist")
Medline and Embase via Ovid	exp Cerebrovascular Disorders/ OR stroke$.tw. OR cva$.tw. OR cerebrovascular$.tw. OR cerebral vascular$.tw. OR (poststroke or post-stroke or cerebrovasc$ or brain vasc$or cerebral vasc$ or apoplex$ or SAH).tw. OR ((brain$ or cerebr$ or cerebell$ or intracran$ orintracerebral or vertebrobasilar) adj5 (isch?emi$ or infarct$or thrombo$ or emboli$ or occlus$)).tw. OR ((brain$ or cerebr$ or cerebell$ or intracerebral orintracranial or subarachnoid) adj5 (haemorrhage$ orhemorrhage$ or haematoma$ or hematoma$ or bleed$)).tw. OR hemiplegia/ or exp paresis/ OR (hemipleg$ or hemipar$ or paresis or paretic).tw. AND exp Physical Therapy Modalities/ OR physical therapy.tw. OR physiotherapy.tw. OR occupational therapy.tw. OR rehabilitat$.tw. OR Rehabilitation/ OR Recovery of Function/ OR Exercise Movement Techniques/ OR (functional adj5 (task$ or movement)).tw. OR ((motor or movement$ or task$ or skill$ or performance) adj5 (schedule$ or intervention or therap$ or program$ or regim$ orprotocol$)).tw. AND intensit$.tw. OR frequen$.tw. OR duration$.tw. OR dos$.tw. OR total units$.tw. OR amount$.tw. OR quantit$.tw. OR how much$.tw. OR repetit$.tw. AND upper extremity/ OR (upper adj2 limb*).tw. OR (upper adj2 extremit*).tw. OR arm.tw. OR shoulder.tw. OR hand.tw. OR elbow.tw. OR forearm.tw. OR finger$.tw. OR wrist.tw.
Pedro	Stroke AND upper limb
CINAHL	(MH "Cerebrovascular Disorders+") OR TX stroke$ OR TX cva$ OR TX cerebrovascular$ OR TX cerebral vascular$ OR TX (poststroke or post-stroke or cerebrovasc$ or brain vasc$ or cerebral vasc$ or apoplex$ or SAH) OR TX ((brain$ or cerebr$ or cerebell$ or intracran$ orintracerebral or vertebrobasilar) N5 (isch?emi$ or infarct$or thrombo$ or emboli$ or occlus$)) OR TX ((brain$ or cerebr$ or cerebell$ or intracerebral orintracranial or subarachnoid) N5 (haemorrhage$ orhemorrhage$ or haematoma$ or hematoma$ or bleed$)) OR (MH "hemiplegia+") OR (MH "paresis+") OR TX (hemipleg$ or hemipar$ or paresis or paretic) AND (MH "Physical Therapy Modalities+") OR TX physical therapy OR TX physiotherapy OR TX occupational therapy OR TX rehabilitat$ OR "Rehabilitation/" OR "Recovery of Function/" OR "Exercise Movement Techniques/" OR TX (functional N5 (task$ or movement)) OR TX ((motor or movement$ or task$ or skill$ or performance) N5 (schedule$ or intervention or therap$ or program$ or regim$ orprotocol$)) AND AB intensit$ OR TI intensit$ OR AB frequen$ OR TI frequen$ OR AB duration$ OR TI duration$ OR AB dos$ OR TI dos$ OR AB total units$ OR TI total units$ OR AB amount$ OR TI amount$ OR AB quantit$ OR TI quantit$ OR AB how much$ OR TI how much$ OR AB repetit$ OR TI repetit$ AND upper extremity OR AB (upper N2 extremit*) OR TI (upper N2 extremit*) OR AB (upper N2 limb*) OR TI (upper N2 limb*) OR AB (upper N2 limb*) OR TI (upper N2 limb*) OR AB arm OR TI arm OR AB shoulder OR TI shoulder OR AB hand OR TI hand OR AB elbow OR TI elbow OR AB forearm OR TI forearm OR AB finger$ OR TI finger$ OR AB wrist OR TI wrist

Appendix 2 The first data extraction template

Author and Pedro rating	Setting	Age (years)	ARAT/ FMA-UE	NIHSS	FIM

Appendix 3 The second data extraction template

Method of delivery	Author, setting and level of supervision of the intervention	Description of the augmented intervention/s

Appendix 4 The third data extraction template

Author and design	Dose of the augmented intervention	Control intervention	Outcome measures	Main findings

Appendix 5 College of Medicine, Veterinary and Life Science Research Ethics Committee approval

University of Glasgow

19/5/17

MVLS College Ethics Committee

Project Title: Acceptability of Web-based Physiotherapy for People Undergoing Stroke Rehabilitation and Their Carers
Project No: 200160126

Dear Dr Cowey,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End August 2017
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Clinical Reader / Honorary Consultant
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

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Appendix 6 Participant information sheet

Participant Information Sheet

Acceptability of Web-based Physiotherapy for People Undergoing Stroke Rehabilitation and Their Carers

This is an invitation to take part in a research study. The study is being carried out by a PhD candidate and academic staff in the School of Medicine, Dentistry and Nursing at the University of Glasgow.

Before you decide whether or not to take part it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Thank you in advance for taking the time to read this and to decide whether or not you wish to take part.

Why have I been chosen?

We have developed and evaluated a website (www.webbasedphysio.com) for the remote delivery and monitoring of physiotherapy exercise programmes. To date we have not evaluated its effectiveness in people who have had a stroke. The first step in doing so is to get the views of people who have had stroke and/or their carer/significant other so we can develop the current site to ensure it is appropriate for people after stroke. You have been chosen to take part as you have had a stroke and/or live/care for a person who has had a stroke and who are happy to share their opinions about our website.

What is the aim of the study?

The aim of this study is to adapt the web-based physiotherapy website for use by people with stroke and their family/carers, based on their opinions about the website.

Do I have to take part?

Being a part of the study is entirely voluntary, so it is your decision. The research team will demonstrate the website to you, after that, they will ask you questions related to the website. Remember that you will be able to withdraw from the study at any time, without giving any reason.

What will happen to me if I take part?

If you decide to take part in the study, the chief investigator will contact you by telephone or email to arrange for you to participate in three different focus groups. The researcher will ask you to give your written consent to take part before the start of the first focus group, and you will be asked to give details about your age, gender, time since stroke (stroke survivors only), relationship to stroke survivor (carers only), occupation, ethnicity, education level, level of familiarity with using the internet , and general health status

The focus group will include up to six people with stroke and their carers to discuss the acceptability of our web-based physiotherapy website, https://www.webbasedphysio.com/. The research team will show you the website and how to use it. These focus groups will be informal and will last approximately 60 minutes for each. The focus groups will be held at an accessible room in the University of Glasgow.

In each focus group the researcher will start by introducing themselves and will explain the topic for discussion. A second person from the research team will be present to take some notes and the focus group will be audio-recorded. The researcher will ask some questions to encourage discussion about the web-based physiotherapy website. In the first focus group meeting, a full demonstration of the website and how to use it will be given. You will then be given log-in information so you can access some exercises on the website over the following one week.

One week after the first focus group, the second focus group will be arranged. In the second focus group, we will ask about your views and opinions on the website and what changes we should make to the website to make it better.

We will then aim to make those changes which might take up to two months, after that the third focus group will be arranged. In the third meeting, the modified website will be demonstrated to get your feedback and to check whether this revised version is acceptable for people with stroke.

What are the possible risks of taking part?

There are no foreseeable risks in taking part in this study. However, the study will take up some of your time.

What are the possible benefits of taking part?

There are no direct benefits from taking part, however some people enjoy meeting and talking to others who have had similar experiences. The study may benefit other stroke survivors who use the web-based physiotherapy website in the future.

Expenses and payment

A £30 M&S gift voucher will be provided to you at the end of the third focus group. In addition, we will cover reasonable local travel expenses. Refreshments will be provided in each focus group.

Will my taking part in this study be kept confidential?

Yes, all data collected throughout the study will be kept strictly confidential. You will be given a unique identification number, so data will be anonymised for storage and only the research team will be able to access your information. In addition, all the audio-recordings from focus groups will be destroyed.

What will happen if I don't want to continue in the study?

You are free to withdraw at any time, without giving any reason, without your legal rights or your care being affected.

What if there is a problem?

We do not expect problems to be caused by this study. But, if you have any concern about any aspect of this study, you can contact any member of the research team (see contact details below).

What happens to the results of the research study?

The study findings may be published in an academic journal or presented at scientific meetings. The findings will also be presented as part of a PhD thesis. Moreover, a summary of findings will be sent to all participants who wish to see them.

Who has reviewed this study?

The study has been approved by the University of Glasgow, College of Medicine, Veterinary and Life Science Research Ethics Committee.

Contact details

If you are interested in participating, please contact:

Abdullah Alhusayni, PT, MSRS
Research physiotherapist and PhD Candidate
University of Glasgow
0141 330 3568
a.alhusayni.1@research.gla.ac.uk

If you have questions or concerns about the study, please contact:

Abdullah Alhusayni, PT, MSRS
Research physiotherapist and PhD Candidate
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Thank you for your time

Appendix 7 Consent form

University of Glasgow College of Medical, Veterinary & Life Sciences

Patient Identification Number for this study:

CONSENT FORM

Title of Project: Acceptability of Web-based Physiotherapy for People Undergoing Stroke Rehabilitation and Their Carers

Name of Researchers: Abdullah Alhusayni, Professor Lorna Paul, Dr Aleksandra Dybus and Dr Eileen Cowey

Please initial box

I confirm that I have read and understand the participants information sheet dated _____ (version _____) for the above study and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I understand that the researchers may publish my views anonymously in journals, in the PhD thesis and for the teaching and training of health and social care staff	☐
I agree to take part in the above study.	☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

Consent form
Version 1. 20/04/2017

Appendix 8 First focus group plan

2:00 – 2:30 → we will collect consent forms and demographic information and distribute badges with their first names

We will start recording and run the focus group from 2:30 (or 2:45 if required)

Introduction → 5 min

- Welcoming and thanking them for taking part in the study

- explaining the purpose of the study

Overview of the focus group → 5 min

- will get to know each other
- ask about their attitude toward using the internet
- what do we expect from them
- demonstrating the WBP

Start with opening question of what are their names and where they came from → 5 min

Ask questions related to their attitude of using the internet → 10 min

- What do they feel about using the internet?
- What do they use the internet for?

Explain to them what do we expect from them in this study and distribute the question list → 5 min

Presenting WBP and how to access it → 15 min

- Answer their questions

- View their initial impression about the WBP

- Ask them what do prefer to find in the advice section? (Tips about the exercises, link to other websites, or advises of how to set goals and target it)

- Distribute steps of how to access it

Thanking them for their time and remind them about the purpose of the study → 5 min

Appendix 9 Second focus group plan

11:00 – 12:00 → we will give people who haven't had a chance to access the website to look at it

(People who haven't access the WBP will come at 11:30, while other people will come at 12:00)

We will start recording and run the focus group from 11:45 (or 12:00 if required)

Introduction → 2-3 min

- Welcoming and thanking them for taking part in the study
- remind them about the purpose of the study

Overview of the focus group → 2-3 min

- We will discuss the list of questions
- Answer their questions
- Talk about what we will did with their views

Start with list of questions (some may take 10 minutes and some may take less than 5 minutes)→ 60min

Thanking them for their time and remind them about the purpose of the study → 2 min

11:00 – 12:00 → we will give people who haven't had a chance to access the website to look at it

(People who haven't access the WBP will come at 11:30, while other people will come at 11:45)

We will start recording and run the focus group from 11:45 (or 12:00 if required)

Introduction → 2-3 min

- Welcoming and thanking them for taking part in the study

- remind them about the purpose of the study

Overview of the focus group → 2-3 min

- We will discuss the list of questions
- Answer their questions
- Talk about what we did with their views

Start with list of questions (some may take 10 minutes and some may take less than 5 minutes)→ 30 -45 min

Thanking them for their time → 1-2 min

Appendix 11 Prepared probes to use in the focus groups

Probes that I might use:

Speake about myself or my assistance

Would you explain further?

Would you say more?

Tell us more

Say more

Is there anything else?

Please describe what you mean

I don't understand

I agree → what experience have you had that make you feel that way?

To remind them to facilitate more than one point of view:

Does anyone see it differently?

Has anyone has different experience?

Are there other points of views?

Expert participant's → opinions of each one of you about the website is important for us

Dominant talkers (avoid eye contact):

Thank you Tom, Does anyone feel differently?

That's one point of view; let's hear what others have to say

Tom you look like you want to say something

Shy participants (increase eye contact) :

Tom, I don't want to leave you out of the conversation, what do you think ?

Tom, you haven't had a chance what do you think?

Question:

I would love to answer this question at the end of the conversation, please remind me and we will talk about it

Appendix 12 Questions for the 1st focus group

Questions for the internet as a source for medical information and rehabilitation

- What do you know about stroke disease?
- How does stroke affect your life?
- How would you describe your experiences of the stroke care that you received?
- Do you face any difficulties that prevent you from exercising?
- Have you ever used the Internet to get information about a disease, medication, treatment or exercise? If yes, can you describe this experience? If no, is there any reason that prevents you from doing so?

Appendix 13 Questions for the 2nd focus group

- What do you think about this website?
  - How do you think this website might help you to take care of your health? (Why? Why not?)
  - What is your impression about logging into the website?
  - What is your impression about completing the diary?
  - What is your impression about navigating around the website?
  - What is your impression about the exercise section of the website?
  - What is your impression about the advice section in the website? How easy or difficult this section was to understand?
  - What is your impression about font? Colours? Videos?
  - Explain to us how easy or difficult this website was to use?
  - What features of the website did you like? What features did you not like?
  - What features do you think should be added/changes on the website? (Why?)

    (E.g. change font size or colour manually, multi-quality videos and reminder notification to access the website)
  - Was there anything you didn't like or didn't understand in the website?

Appendix 14 Questions for the 3rd focus group

- What is your impression about the modifications made to the website?

(E.g. logging into the website, the exercise section, the advice section, completing the diary and navigating around the website)

- Explain to us how easy or difficult this modified website was to use?
- Is there anything else we could do to improve the site further? Why?
- What other features would you like to add to this website? (what/ why, why not)
- Are there any other topics you would like to discuss regarding this website?

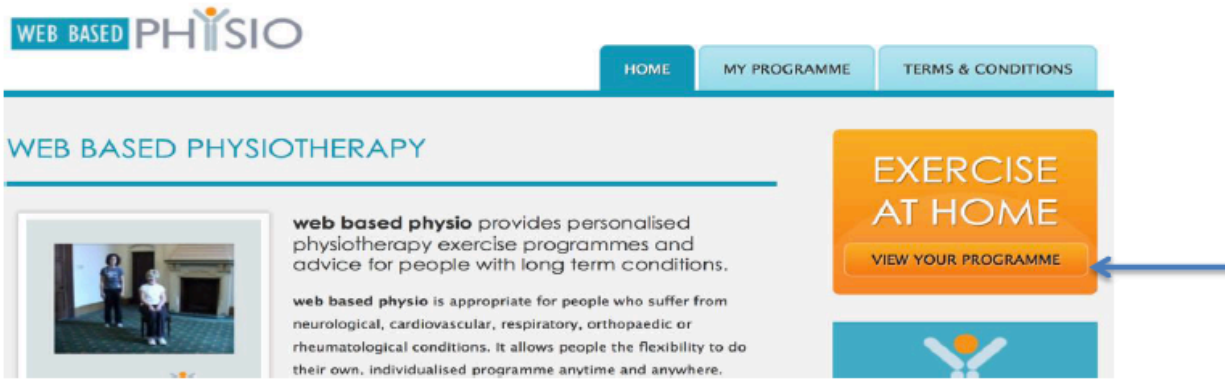
Appendix 15 Instructions of how to access the web-based physio

How to use your online exercise programme

1. You will receive an email from mvls-web-basedphysio@glasgow.ac.uk

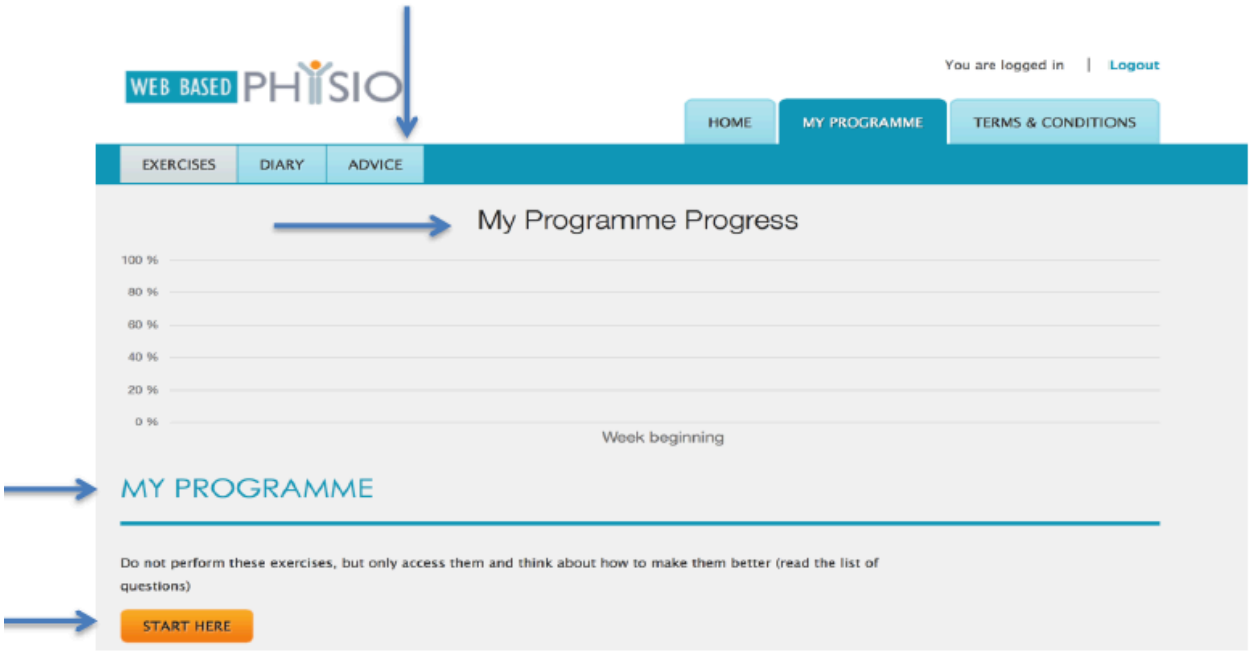
2. Follow the link in the email, you will be asked to create and confirm a password for your account

3. Then, you can log in using your email address and the password you have set to get to the exercise programme website.



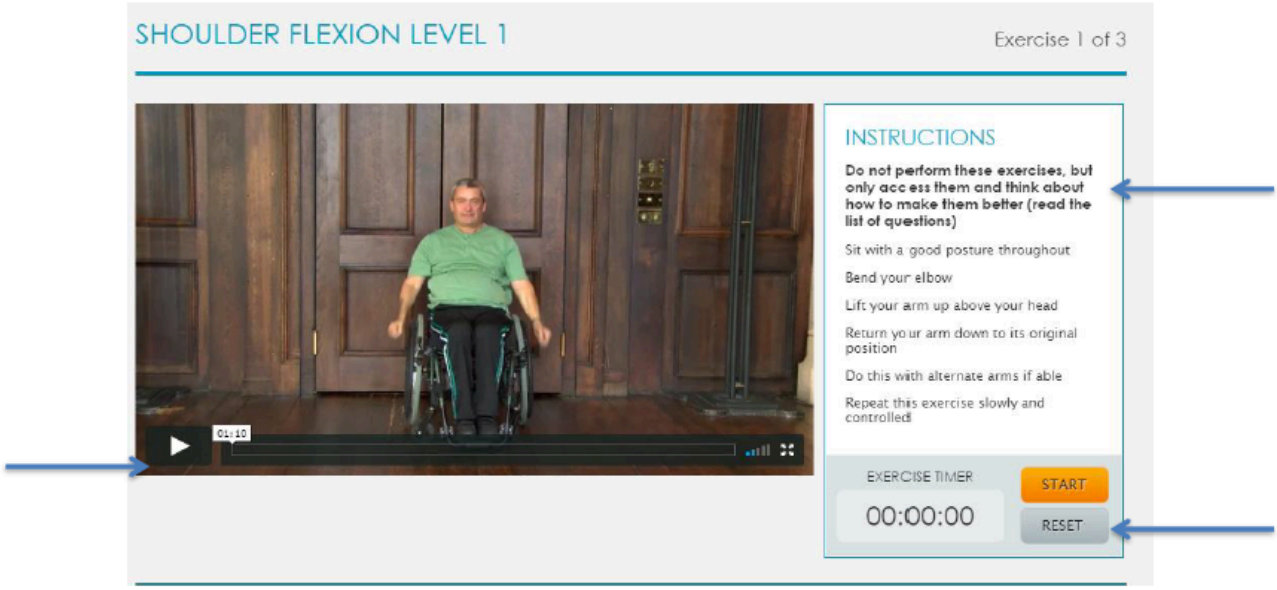
4. You will see your home page- which includes:
    a. 'My programme progress'- this will show you each time you have logged in
    b. 'My programme'- this is where you will find the instructions for each exercise in your plan.

5. To access the exercises staring from the first one, click 'start here', or you can click 'view exercise' under any individual exercise to get stratight to that one.
6. To access the advice section, click 'ADVICE' in the top left of the page



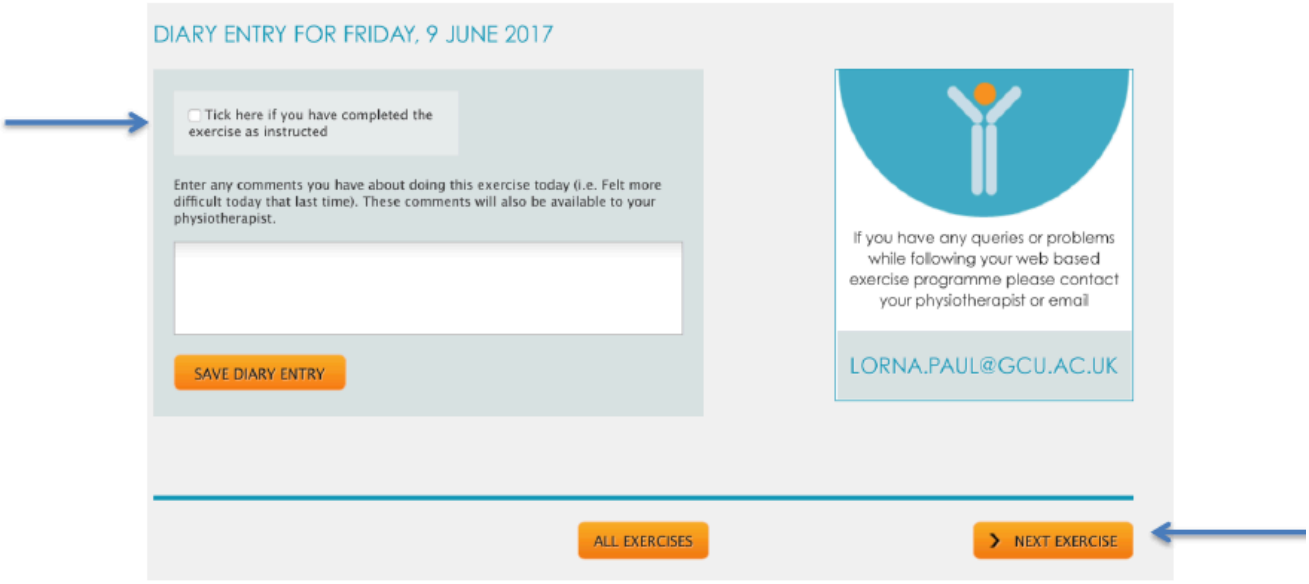
On the page for each exercise you will see-

1. A video which takes you through the basic exercise- simply click the 'play' button to play it.
2. A list of instructions- these will include specific instructions your physiotherapist has added which are tailored for you, so make sure to check these
3. An exercise timer- click 'start' to begin timing your exercise. You need to click 'stop' when you finish, as this will transfer the time you have practiced into your exercise bank.

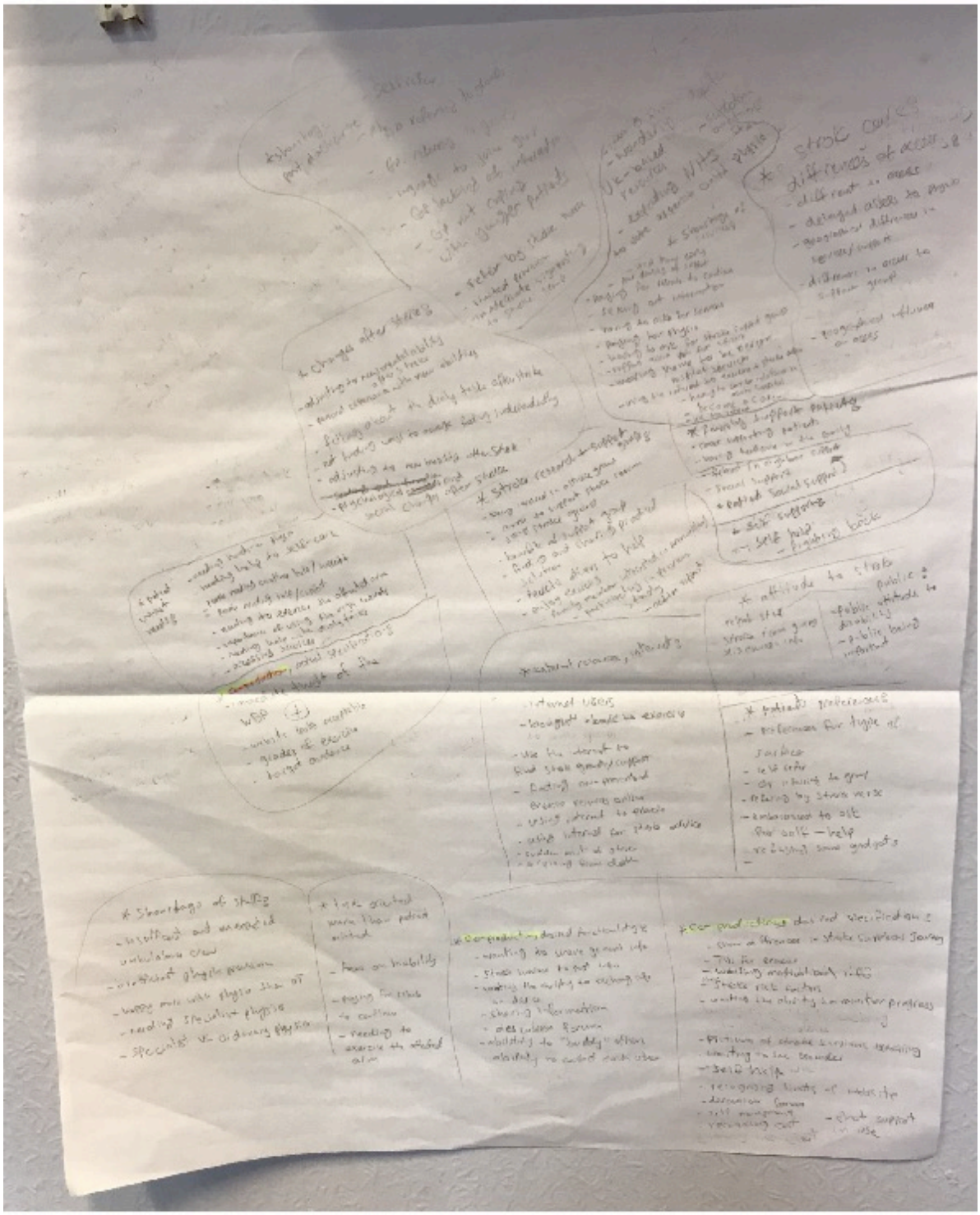


4. An exercise diary- you can log any practice you have done when you were not using the timer here (this will update the exercise bank to make sure it counts to your weekly total), plus any notes about the exercise for your physiotherapist.

You can navigate onto the next exercise, or the full list of exercises using the tabs at the bottom of the page.



Appendix 16 Photo of an OSOP (One Sheet of Paper) analysis



Appendix 17 Approval of extended ethical coverage

RE: Postpone Estimated Project End Date (200160126)

ME

MVLS Ethics Admin <mvls-ethics-admin@glasgow.ac.uk>

Monday, October 2, 2017 at 6:37 PM

To: Eileen Cowey; MVLS Ethics Admin

Cc: Abdullah Ibrahim S Alhusayni; Paul, Lorna; Aleksandra Dybus

This message is flagged for follow up. Start on Wednesday, October 18, 2017. Due by Wednesday, October 18, 2017.

Hi Eileen and Abdullah

Your amendment request to extend the end date of project 200160126 to end of October 2017has been approved. Please treat this email as evidence of said approval. We will keep a copy of it on file for reference

Regards
Neil

Neil Allan
MVLS Ethics Administrator

Direct line: 0141 330 5206

Institute of Infection, Immunity & Inflammation
College of Medical, Veterinary & Life Sciences
Glasgow Biomedical Research Centre
Room 314, Sir Graeme Davies Building
University of Glasgow
120 University Place
Glasgow G12 8TA
The University of Glasgow, charity number SC004401

Appendix 18 The New advice section in the web-based physio platform

Section 1: INTRODUCTION:

Welcome to the Web-based physiotherapy.

If you have visual problems, you need to make sure you are able to read all the text in each page.

If you can't read the text, you should zoom in on a webpage to help you read it.

Here are some tips on how to do this:

To zoom in on web pages, click (Command)-(+) multiple times to continue zooming in (for Mac users) and click (Ctrl) – (+) multiple times to continue zooming in (for Windows users).

If you have any problems with your programme you should contact your physiotherapist.

WHILE DOING THE EXERCISES WITHIN THIS PROGRAMME AS ADVISED BY YOUR PHYSIOTHERAPIST IT IS IMPORTANT TO:

- Ensure you are safe while you are exercising. Do the exercises as instructed. Have a chair or something steady to keep your balance if required.
- Pace yourself. Have short breaks between exercises, or spread your exercise programme out throughout the day.
- Complete your exercise diary each time you complete your exercises and remember to leave comments for your physiotherapist.
- If you have any queries or problems while following your web-based exercise programme please contact your physiotherapist.

HOW TO GET THE MOST OUT OF WEB-BASED PHYSIO?

We hope that you enjoy using web-based physio. We would like to help you get the most out of web-based physio and to benefit from using the system. Below is some advice!

- Make sure you use a password that you will easily remember.
- If you have any problems using the website ask a member of the family to help or contact your physiotherapist.
- Follow the exercises that you have been given, discuss any issues or problems with your physiotherapist.
- Complete your exercises as instructed.
- Get into a routine with your exercise programme. Regularly completing your exercises is the best way to reach the goals you discussed with your physiotherapist.
- Contact your physiotherapist if you want a change made to your exercise programme. You might want your exercises to be harder, easier or simply want a change.
- Don't complete your programme when you feel unwell. Seek advice from your physiotherapist or the staff in the hospital.
- You can contact the research team at any time about the project by email (alhusayni.1@research.gla.ac.uk) or phone (0141 330 3568).

Do not forget to complete your exercise diary each time you complete your exercises and remember to leave comments for your physiotherapist! This is the best way that we can tell how you are doing and using these we can progress your exercises. If you don't tell us how you are doing, we won't know!

Section 2: STROKE

What is stroke?

A stroke is a medical condition that occurs when the blood supply to part of the brain is interrupted, causing some problems with brain function.

What are the main types of stroke?

There are two main types of stroke:

a) Ischaemic stroke, caused by a blocked blood vessel in the brain (this happens in 85% of all strokes).
b) Haemorrhagic stroke, caused by bleeding in the brain (15% of all strokes).

What are the effects of stroke?

Strokes affect different people in very different ways. Often people have different levels of disability depending on where the stroke takes place in the brain, and how much the brain is affected. In general, a stroke which affects one side of the brain leads to symptoms in the opposite side of the body.

A stroke may result in:

• Weakness in the arms and legs.

• Changes in arm and leg muscles to be spasm muscles (known as spasticity) or to be floppy muscles (known as flaccidity).

• Balance problems.

• Problems with speaking, understanding, reading and writing.

• Swallowing problems.

• Problems with bowel and bladder control.

• Pain and headaches.

• Fatigue – tiredness that does not go away.

• Problems with memory and thinking (sometimes this is called aphasia).

• Eyesight problems.

• Numbness and/or pins and needles.

• Neglect of one side of the body.

*More information is available at the following link, https://www.stroke.org.uk/what-stroke, https://www.chss.org.uk/stroke-information-and-support/

WHAT IS NEGLECT?

Neglect of one-side of the body affects some (but not all) stroke survivors. We can define people who have body neglect after their stroke as people who have difficulties to recognize one side of their body. If you have neglect, you need to improve your attention and awareness of your affected side.

HOW TO INCREASE THE AWARENESS OF YOUR NEGLECTED SIDE?

There are many things that you can do to improve the awareness of your neglected side.

• Place any commonly used items such as the phone or TV remote control on a table beside your affected side to encourage you to look and reach for them on that side.

• While seated, ensure that your back is straight and your shoulders level.

• If you can try and use your affected hand during daily activities.

WHAT IS POST-STROKE FATIGUE?

It is normal for people to feel tired, but fatigue after stroke (post-stroke fatigue) is different from normal fatigue. Tiredness or fatigue after a stroke does not go away with rest and is unrelated to how active you've been, not like usual fatigue.

Very little is known about why people get post-stroke fatigue and there is no specific treatment for managing this symptom.

If you fatigue is a problem for you speak to staff in the hospital or your GP at home to check that your fatigue isn't due to another medical condition. Some medications also cause fatigue so that's worth asking about too.

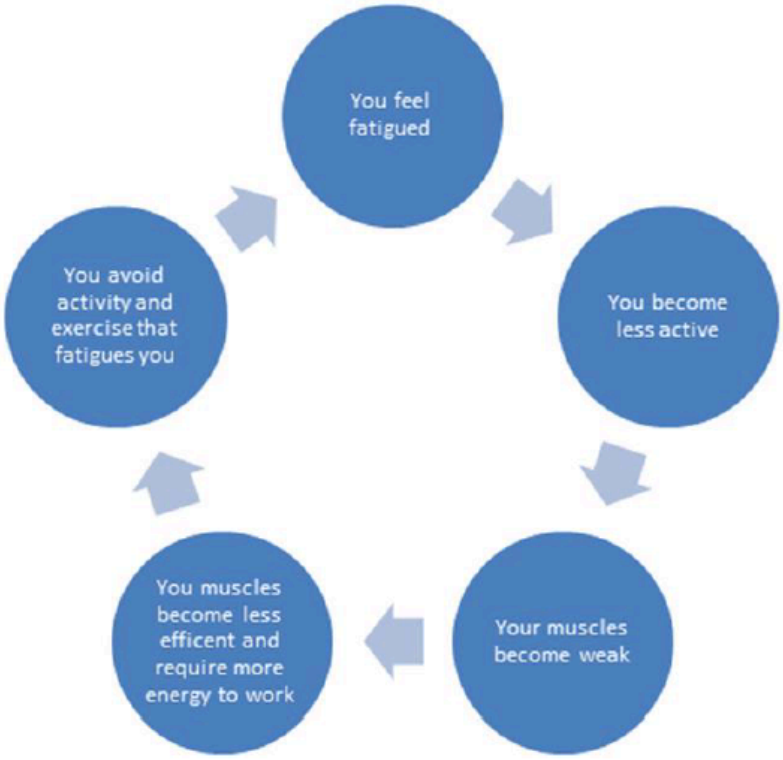
Exercise can also help fatigue so ask your doctor or physiotherapist.

*More information is available at the following link https://www.stroke.org.uk/what-stroke/common-problems-after-stroke/tiredness-and-fatigue

SHOULD I EXERCISE IF I FEEL TIRED (FATIGUE)?

It is important to recognise your fatigue, both when exercising and in everyday life. It is best not to 'work through' your fatigue as you may feel worse, often for a few days afterwards.

However, avoiding exercise and activity is not the answer. Doing so can lead to a cycle of inactivity, where already weak muscles that aren't used become weaker. These muscles become less efficient and require more energy to carry out tasks. This makes exercise and participating in general activity even more difficult and tiring.



The good news is that exercise can help your fatigue. It allows you to build your muscle endurance and strength to help you remain as fit and active as possible.

WILL YOUR BALANCE BE AFFECTED AFTER STROKE?

Balance problems occur in some people after stroke. People with affected balance are a bit lopsided when they are sitting and might feel unsteady or dizzy when they walk. Balance problems can also results in falls, which, as well as potentially causing injury and affect people's confidence. Balance can be a problem after stroke due to one or more reasons:

- Weakness in the arms and legs.
- Changes in arm and leg muscles to be spasm muscles (known as spasticity) or to be floppy muscles (known as flaccidity).
- Loss of sensation/feeling.
- Neglect of one side of the body.
- Loss of concentration when walking
- Eyesight problems.
- Another medical condition or as a side effect of medication.

*More information is available at the following link,
https://www.stroke.org.uk/sites/default/files/balance_problems_after_stroke.pdf

WHAT TO DO TO AVOID A FALL?

There are many things that you can do to avoid a fall. There are some examples:

- Use any walking aids or splints, if you have been given one by your physiotherapist or other health care professional.
- Avoid walking on a wet surface.
- Change your home arrangements, lift loose rugs and carpets.
- Avoid talking when walking to not distract your attention.
- You may need some adaptation in your home; often occupational therapists can help you with this.
- Wear good supporting footwear.
- Ensure you do any balance exercises you have been given by the physiotherapist.

*More information is available at the following link,
https://www.stroke.org.uk/sites/default/files/balance_problems_after_stroke.pdf

DOES EXERCISE HELP PEOPLE WITH STROKE?

Yes, exercise plays an important role in rehabilitation programmes for people with stroke to improve their physical and mental ability. In addition, exercises can benefit people with stroke:

- Improve the efficiency and strength of muscles.
- Improve circulation and fitness.
- Improve bone density.
- Improve appetite.
- Improve social life.
- Improve general well-being, and feel good factor!
- Improve your mental ability.
- Reduce the chance of having another stroke.
- Lower blood pressure and cholesterol level.
- Improve sleep.
- Help with weight control.
- Improve the immune system.
- Improve body image and self-esteem.

*More information is available at the following link,
https://www.stroke.org.uk/sites/default/files/exercise_and_stroke.pdf , http://selfhelp4stroke.org/

WHAT OTHER THINGS HELP AS WELL AS EXERCISE?

In order to reduce your risk of stroke and keep healthy, it is important to:

- Stop smoking.
- Eat healthily.
- Be active.
- Watch your weight.
- Drink less alcohol.
- Remember to take your prescribed medicines.

Section 3: FAQ:

HOW CAN I FIT EXERCISE INTO MY LIFE?

To be effective, exercise needs to be a regular part of your life so that it becomes part of your routine. To help you get the best out of your exercise programme think about the best time of day for you to exercise. Fatigue may vary through the day so some times in the day will be better than others. Set aside a time to do your exercises.

HOW CAN I MAKE EXERCISE ENJOYABLE?

There are many ways that help you to enjoy your exercise:

- Get an exercise partner.
- Exercise to music.
- Reward yourself when you reach your goals.
- Track your progress using the web-based physio website.

Keep going – it might be hard at first, but it does get easier.

WHAT IF I CAN'T DO MY EXERCISE PROGRAMME FOR A WHILE?

There may be times when you do not feel able to exercise, or when it would be wise to do less than usual, for example, if you catch a cold or a urinary tract infection. It is often a good idea to rest and recover from an illness rather than push yourself too hard. Whatever your reasons for taking a break from exercise, remember to start again and build up slowly. If you need to, set yourself lower targets to begin with, pace yourself and build up gradually to a level you can manage. If you have stopped your exercise programme for any reason it is important to contact your physiotherapist to let them know and to plan your return to your programme.

SECTION 4: CARER SECTION

WHAT WILL I EXPECTED TO DO IF I BECOME THE PATIENT'S CARER?

After a stroke, people often have different levels of disability depending on where the stroke takes place in the brain and how much the brain is affected. The patient might need help with any task no matter how easy it is, for example, eating with a spoon.

Stroke survivors might need help with the following aspects:

- Personal care, for example, bathing and dressing.
- Healthcare needs, for example, medication and appointments.
- Transferring, for example, from bed to chair.
- Emotions – be prepared for behavior or mood changes and be on the lookout for depression.
- If the patient has body neglect, you need to try to 'tune up' that side, let the patient know about different things on his/her right and left sides, and remind the patient to use that side.

WHAT ELSE DO WE WANT YOU TO DO?

We wanted to add a few things to the list, including:

- Help the patient to read the advice section and use the WBP (if needed).
- Help the patient to perform stretching exercises as instructed in the WBP.
- Encourage the patient to follow his/her rehabilitation programme.

HOW CAN YOU PROTECT YOUR BACK?

As a carer for a stroke patient who will help the patient to perform stretching exercises, you might cause pain in your back, so here are some tips to protect your back:

- Listen to the instructions in the videos carefully. You need to know exactly how you are going to move the patient.
- Communicate with the patient before you start moving him/her and don't rush. The patient needs to know how you plan to move him/her.
- The patient's bed should be at the same height as your waist.
- Ensure that your feet are stable before you move the patient.
- Do not lean over to move or lift the patient; bend your knees (squat) instead.
- Always keep your back straight.
- Use the strength of your arm muscles to move the patient, not your back.

When you transfer the patient from bed to wheelchair or from wheelchair to bed:

- Inspect the surface you are planning to move the patient to and make sure it's safe and clear. For example, if you are moving the patient to wheelchair, make sure you lock the wheels and remove the armrest and the footplate.
- Make sure the wheelchair is close to the patient's stronger side (if you are transferring the patient from the bed to the wheelchair).
- Make sure the bed is close to the patient's stronger side (if you are transferring the patient from the wheelchair to the bed).
- Adjust the height of the bed properly so the patient can get his/her feet flat on the floor (when sitting on the edge of the bed) before you transfer the patient.
- Transfer the patient to his/her stronger side.
- Ask the patient for help.
- If the patient is too heavy, uncooperative or in an awkward position, ask for help.

Section 5: Other resources:

- Stroke support group in any area, Stroke association, https://www.stroke.org.uk/clubs%20?field_support_service_type_tid=10356
- Community Stroke Services, chest heart and stroke Scotland, https://www.chss.org.uk/community-stroke-services/
- Link to self-management website, http://selfhelp4stroke.org/
- Link to mindfulness resources http://www.nhs.uk/conditions/stress-anxiety-depression/pages/mindfulness.aspx

Appendix 19 Aphasia version of the new advice section in the web-based physio platform

Section 1: INTRODUCTION:

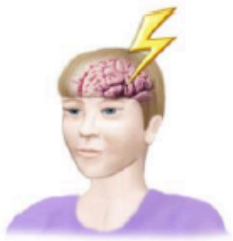
Visual problem Make sure you are able to **read all the text** on **each page**

Zoom in on a webpage to **help** you read the text **Click (Command) and (+)** on the keyboard to **Zoom in (Mac)**	
Click (Ctrl) and (+) on the keyboard to **Zoom in (Windows)**	

Web based physio **Ensure you are safe** while you are exercising	
Do the **exercises as instructed**	
Have breaks between exercises or repetitions	
Complete your **exercise diary** each time you complete your exercises	

Leave comments about your **exercise** for your physiotherapist	
Contact your **physiotherapist** if you have any **problems** or **questions** about your **exercises**	 
Contact Abdullah if you have any questions about **the project**: Email (alhusayni.1@research.gla.ac.uk) or phone (0141 330 3568)	 

Section 2: STROKE:

## Stroke disease **Stroke** is caused by a problem with the **blood supply** to the brain	

## Two main types of stroke: **A blocked blood vessel** in the brain causes **ischaemic stroke**	

Bleeding in the brain causes **haemorrhagic stroke**	
Ischaemic stroke happens **more than** haemorrhagic stroke	

Effects of stroke Stroke may result in **different levels** of **disability**	
Stroke may affect **balance**	
Stroke may result in problems with **memory** and **thinking** (**aphasia**)	
Stroke may result in **eyesight problems**	
Stroke may result in **numbness**	
Stroke may affect **swallowing**	
Stroke may affect **bowel and bladder control**	

Stroke to the **right side** of the brain **affects** the **left side** of the body Stroke to the **left side** of the brain **affects** the **right side** of the body Stroke may result in **spasms or floppy muscles**	 
Stroke may result in **pain** and **headaches**	 

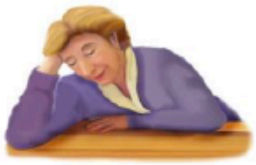
## Neglect Stroke may result in **neglect of one side** of the body **So you may only see one half of your surroundings** Try to **use** your **affected side** during **daily activities**	

Fatigue

Stroke may cause **fatigue**

Fatigue after stroke is **different** from **normal fatigue**

Fatigue after stroke **does not** go away with **rest**



If you have fatigue

There is **no specific treatment** for **fatigue**

Exercise is **good** to help improve fatigue

Balance and falls

Stroke may affect **balance**

Poor balance may result in a **fall**

Falls may result in **loss of confidence**

How to avoid fall

Make changes to your **home** so you have **space to walk**

Walk only on **dry surfaces**

Concentrate on your movement when you walk

Use your **walking aid**

Perform your **exercises**

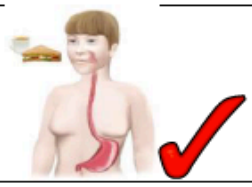
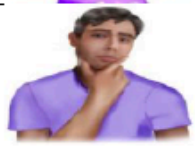
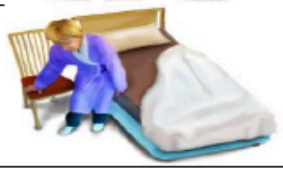
Contact your **physiotherapist** for advice

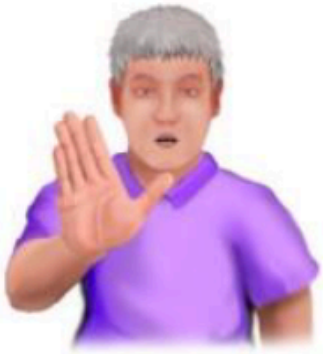
Contact your **occupational therapist** for home adaptation/aids

Exercise

Exercise will **improve** your **muscle power**

Exercise will **improve** your **blood circulation**

Exercise will **improve** your **bone health**	
Exercise will **improve** your **appetite**	
Exercise will **improve** your **social life**	
Exercise will **improve** your general **health**	
Exercise will **improve** your **thinking/concentration**	
Exercise will **reduce** your chance of you **having another stroke**	
Exercise will **reduce** your **blood pressure** and **cholesterol level**	
Exercise will help you to **sleep better**	
Exercise will help you to **control your weight** Exercise will **improve** your **immune system** Exercise will **improve** your **self-esteem**	

Keep in good health **Stop smoking** Watch your **weight** **Drink** less **alcohol**	
Eat healthily	
Be **active**	
Remember to **take** your **medicine**	

Section 3: FREQUENTLY ASKED QUESTION:

Tips to enjoy your exercise Get an exercise **partner** Exercise to **music**	

Reward yourself when you reach your goals **Track** your **progress**	
Keep going	

## Stop exercising **Do not exercise** if you feel **unwell** **Rest** until you **recover**	
Do not push yourself too hard	
Contact your **physiotherapist for advice**	

Section 4: OTHER RESOURCES:

Other recourses

Link to Stroke support group in any area, Stroke association, https://www.stroke.org.uk/clubs%20?field_support_service_type_tid=10356

Link to Community Stroke Services, chest heart and stroke Scotland, https://www.chss.org.uk/community-stroke-services/

Link to mindfulness resources http://www.nhs.uk/conditions/stress-anxiety-depression/pages/mindfulness.aspx

Link to self-management website, http://selfhelp4stroke.org/

Appendix 20 The West of Scotland Research Ethics Committee approval

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Dr Eileen Cowey
Lecturer
University of Glasgow
59 Oakfield Avenue
School of Medicine, Dentistry and Nursing
Nursing & Health Care School
G12 8LL

West of Scotland REC 1
West of Scotland Research Ethics Service
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow G3 8SJ
www.nhsggc.org.uk
Date 04 September 2018
Direct line 0141-232-1806
e-mail WosRec1@ggc.scot.nhs.uk

Dear Dr Cowey

Study title:	**There are two titles for this proposed study: Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study**
REC reference:	**18/WS/0101**
Protocol number:	**GN18PY228**
IRAS project ID:	**245931**

Thank you for your letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a Sub-Committee of the REC at a meeting held on 04 September 2018. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		27 July 2017
IRAS Application Form [IRAS_Form_17052018]		17 May 2018
Letter from statistician [Statistical Plan]	1	03 May 2018
Non-validated questionnaire [Stroke survivors demographic information questionnaire]	2	06 August 2018
Non-validated questionnaire [Carer demographic information questionnaire]	2	06 August 2018
Non-validated questionnaire [Physiotherapy staff demographic information questionnaire]	2	06 August 2018
Other [WBP User Manual]	1	03 July 2018
Other [leaflet about the importance of exercises and physical activity]	F30 Oct 2016	
Other [Record of UL exercises]	2	06 August 2018
Participant consent form [Consent for Stroke Survivors, Aphasia version]	3	06 August 2018
Participant consent form [Consent for stroke survivors]	3	06 August 2018
Participant consent form [Consent for Carers]	3	06 August 2018
Participant consent form [Consent for Physiotherapy Staff]	3	06 August 2018
Participant information sheet (PIS) [PIS for stroke survivors, Aphasia version]	3	06 August 2018
Participant information sheet (PIS) [PIS Stroke survivor]	3	06 August 2018
Participant information sheet (PIS) [PIS Carer]	3	06 August 2018
Participant information sheet (PIS) [PIS Physiotherapy Staff]	3	06 August 2018
Research protocol or project proposal [Study Protocol]	3	06 August 2018
Response to Request for Further Information [Response to Ethics]		
Response to Request for Further Information [Response to Ethics 2]		
Summary CV for Chief Investigator (CI) [CI and SUpervisors CV]		27 April 2018
Summary CV for student [Student CV]		03 May 2018
Summary CV for supervisor (student research) [Professor Lorna Paul CV]		
Summary CV for supervisor (student research) [Dr. Aleksandra Dybus CV]		27 April 2018

Document	*Version*	*Date*
Validated questionnaire [Action_Research_Arm_Test]		
Validated questionnaire [Mini Mental State Examination]		
Validated questionnaire [Modified Ashworth Scale]		
Validated questionnaire [Modified_Rankin_Scale]		
Validated questionnaire [NIH_Stroke_Scale]		
Validated questionnaire [Tardieu_Scale]		
Validated questionnaire [The Trunk Impairment Scale]		
Validated questionnaire [Evaluation Questionnaire for Stroke Survivors]	3	06 August 2018
Validated questionnaire [Evaluation Questionnaire for Carers]	2	06 August 2018
Validated questionnaire [Evaluation Questionnaire for physiotherapy staff]	2	06 August 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

18/WS/0101	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Dr Malcolm Booth
Chair

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Mrs Emma-Jane Gault , University of Glasgow*
Ms Cynthia Dolier, NHS Lanarkshire
Lead Nation Scotland: nhsg.NRSPCC@nhs.net

West of Scotland REC 1

Attendance at Sub-Committee of the REC meeting on 04 September 2018

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Peter Hutchison	GP (Vice Chair)	Yes	Chair of Meeting
Dr John D McClure	Statistician	Yes	
Mr James Timmons	IT Manager (Retired)	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Kirsty Burt	Senior Co-ordinator

Appendix 21 The Research and Development approval for Hairmyres hospital

NHS Lanarkshire

Dr Eileen Cowey
Lecturer
University of Glasgow
59 Oakfield Avenue
School of Medicine, Dentistry and Nursing,
Nursing & Health Care Schoo
GLASGOW
G12 8LL

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 10 September 2018
Enquiries to Cynthia Dolier, R&D Facilitator
Direct Line 01236 712460
Email cynthia.dolier@lanarkshire.scot.nhs.uk

Dear Dr Cowey

Project title: Augmented Upper Limb Physiotherapy using a Web-Based Physio Platform for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

R&D ID: L18047

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Fiona MacDonald	Post Advanced Practitioner Physiotherapist	Principal Investigator	University Hospital Hairmyres

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK and EU Data Protection legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.cso.scot.nhs.uk/ or the Research & Development Intranet site: http://firstport2/staff-support/research-and-development/default.aspx
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely

Raymond Hamill – Senior R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Miss Fiona MacDonald	Post Advanced Practitioner Physiotherapist	fiona.macdonald@lanarkshire.scot.nhs.uk	Principal Investigator
Miss Emma-Jane Gault	Clinical Research & Development	emmajane.gault@glasgow.ac.uk	Sponsor Contact
Mr Abdullah Alhusayni	PhD in Nursing and Health Care	a.alhusayni.1@research.gla.ac.uk	Named Contact
Dr Mark Barber	Consultant Physician in Geriatric Medicine	mark.barber@lanarkshire.scot.nhs.uk	Named Contact

Appendix 22 The West of Scotland Research Ethics Committee approval of the amendment on the protocol

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Dr Eileen Cowey
University of Glasgow
59 Oakfield Avenue
Glasgow
G12 8LP

West of Scotland REC 1
West of Scotland Research Ethics Service
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow G3 8SJ
www.nhsggc.org.uk
Date 13 November 2018
Direct line 0141-232-1806
e-mail WosRec1@ggc.scot.nhs.uk

Dear Dr Cowey

Study title:	**There are two titles for this proposed study: Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study**
REC reference:	**18/WS/0101**
Protocol number:	**GN18PY228**
Amendment number:	**AM01 (substantial: change of inclusion/exclusion criteria) (REC Ref AM01)**
Amendment date:	**02 November 2018**
IRAS project ID:	**245931**

The above amendment was reviewed on 12 November 2018 by the Sub-Committee in correspondence. The amendment is a change in inclusion and exclusion criteria to include those with shoulder subluxation less than grade 3.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP)	AM01 (substantial: change of inclusion/exclusion criteria) (REC Ref AM01)	02 November 2018
Research protocol or project proposal	4	22 October 2018

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/WS/0101:	Please quote this number on all correspondence

Yours sincerely

On behalf of
Dr Malcolm Booth
Chair

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Cynthia Dolier, NHS Lanarkshire*
Mr Abdullah Alhusayni, University of Glasgow

West of Scotland REC 1

Attendance at Sub-Committee of the REC meeting on 12 November 2018

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Peter Hutchison	GP (Vice Chair)	Yes	Chair of Meeting
Dr John D McClure	Statistician	Yes	

Also in attendance:

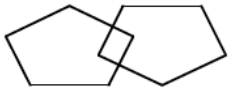
Name	*Position (or reason for attending)*
Mrs Kirsty Burt	Senior Co-ordinator

Appendix 23 Mini-Mental State Examination (MMSE) (Folstein et al., 1975)

Mini-Mental State Examination (MMSE)

Participant ID: _____ Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, …) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

Appendix 24 The participant information leaflet for stroke survivors

Participant (Stroke Survivor) Information Sheet

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

This is an invitation to take part in a research study. The study is being carried out by Abdullah Alhusayni, PhD candidate, and academic staff in the School of Medicine, Dentistry and Nursing at the University of Glasgow.

Before you decide whether or not to take part it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Thank you in advance for taking the time to read this and to decide whether or not you wish to take part.

Why have I been chosen?

We are looking for stroke survivors over the age of 18 years who have been diagnosed with their first stroke and admitted to the rehabilitation unit. To take part you need to have limited arm function, able to sit on a chair or a bed, to use a computer or tablet with or without help from carers and to understand English.

What is the purpose of the study?

Weakness in the arm is common after stroke and can affect your ability to perform some tasks. Studies show that extra sessions of arm exercise can help stroke survivors to improve their arm function and that the first 3 months is the best time to gain these benefits.

We have developed and evaluated a website (www.webbasedphysio.com) for delivering and monitoring physiotherapy exercise programmes. This website has been modified for people after stroke. The purpose of this study is to assess if doing extra physiotherapy for the arm through our web-based physio website gives any extra benefits to the usual physiotherapy received on the ward. Moreover, we would like to get feedback in terms of the experience of doing the exercise programme, including the use of the web-based physiotherapy website.

Do I have to take part?

No, being part of the study is entirely voluntary, so it is your decision. You should read this information leaflet and, if you are interested in taking part, you should contact the research team (see contact details below) or physiotherapists in the ward. Remember that you will be able to withdraw from the study at any time, without giving any reason.

What will happen to me if I take part?

If you decide to take part in the study, you will be given an opportunity to ask questions about the study. It is fine if you would like to take part but have never used a computer or tablet before, because we will provide a full explanation of your upper limb programme and how to use and access the website and we can also provide you with a tablet computer with internet access for the duration of the study, if necessary.

The researcher will ask you to give your written consent to take part. The initial assessment will involve providing some background details about yourself, such as your age, sex, time since diagnosis with stroke, ethnicity, level of education, previous use of computers, living arrangements and ability to walk before stroke, your ability to walk and move your hands after your stroke and general health status. After that, you will be asked to complete three questionnaires about how stroke affects your daily living, your level of general function before stroke and your current mental ability. The researcher will help you to complete these questionnaires, if required. The researcher will then assess the function and muscle tension in your affected arm and your trunk function. You will then be given the “Just move” leaflet about the

importance of exercises and physical activity. The first session will take approximately 60 minutes to complete. You will then be allocated to either the intervention or control group described below. After the assessment, the researcher will access your medical records where it is relevant to this research.

Whether you are allocated to the intervention or the control group, the researcher will see you again in the ward after four weeks, or just before you are discharged, to repeat the assessments. At this time, if you are in the intervention group, you will also be asked to complete a short questionnaire related to your experience of doing the exercise programme, including the use of the web-based physiotherapy website. The researcher will help you to complete these questionnaires, if required. The expected time to complete this assessment is approximately 50 minutes.

What happens if I am in the control group?

If you are allocated to the control group, you will have standard physiotherapy care on the ward, which may include a leaflet with arm exercises. At the end of the study if you wish, we will develop a personalised exercise programme based on your assessment and provide you with access to the website; however, your personalised exercise programme will not be followed up.

What happens if I am in the intervention group?

If you are allocated to the intervention group, you will be asked to follow an extra exercise programme that focuses on your affected arm. The programme will be delivered via the web-based physio website. You will be assessed by the physiotherapist at the hospital and an individualised arm exercise programme will be set up for you by the physiotherapist. You will be asked to do these exercise 5 times per week for 4 weeks (or for the duration of your hospital stay if that is less than four weeks) in addition to the physiotherapy care that you receive on the ward. This programme will be reviewed and revised by the physiotherapists once a week, and changes will be made to your programme, if necessary. Your exercise programme will be based on your current level of functional ability and will gradually and gently increased to the point where you are able to perform these exercises for 30 minutes

each session. You may also contact the physiotherapist to make changes to your programme, if you feel that these are necessary.

The physiotherapists will give you an explanation of your upper limb programme and how to access and use the website. The researcher will ask you to provide your e-mail address for the web-site access and you will then be given log-in information so you can access your exercises on the website over the following four weeks. If you have any communication difficulties, the physiotherapist will provide your family member/carer with a full explanation of your upper limb programme and how to access and use the website and ask him/her to support you to undertake your exercise programme. In addition, an aphasia-friendly version of the website will be available to you, which was developed to make the website more understandable to people with communication difficulties. You, or your family member/carer, can contact the researcher at any time during the study to ask any questions related to the website (see contact details below).

You will have to return the tablet at the end of the study if we gave you one, however you will still be able to access the website even when the study is completed, although the physiotherapist will no longer be reviewing your programme.

What are the possible risks of taking part?

Arm exercises can be associated with some discomfort however we will ensure that, if you are in the intervention group, your exercise programme is started gently, based on your level of ability, and gradually progressed, but otherwise there are no foreseeable risks in taking part in this study.

What are the possible benefits of taking part?

We hope that this exercise programme will help improve function of the arm and trunk as well as decrease any muscle tension in the arm, however, this cannot be guaranteed. Moreover, feedback about the intervention should help us develop interventions for other stroke survivors who use web-based physiotherapy in the future.

Will my taking part in this study be kept confidential?

Yes, all data collected throughout the study will be kept strictly confidential. You will be given a unique identification number, so data will be anonymised for storage and only the research team will be able to access your information. Representatives of the study sponsor, The NHS Greater Glasgow and Clyde, may audit the study to check that the study is being conducted properly. If that happens, they might have access to your study information, but they would also keep your information strictly confidential.

What will happen if I don't want to continue in the study?

You are free to withdraw at any time, without giving any reason, without your legal rights or your care being affected. Any data collected prior to your withdrawing from the study will still be used.

What if there is a problem?

We do not expect problems to be caused by this study. But, if you have any concern about any aspect of this study, you can contact any member of the research team (see contact details below). The usual NHS complaints procedure is also available to you.

What happens to the results of the research study?

The study findings may be published in an academic journal or presented at scientific meetings. The findings will also be presented as part of a PhD thesis. Your personal data will be destroyed upon completion of the study. Moreover, a summary of findings will be sent to all participants who wish to see them.

Who has reviewed this study?

The study has been reviewed and approved by the West of Scotland Research Ethics Committee.

Contact details

If you are interested in participating, please contact:

The researcher:

Abdullah Alhusayni, PT, MSRS

PhD Candidate

University of Glasgow

0141 330 3568

a.alhusayni.1@research.gla.ac.uk

If you have questions or concerns about the study, please contact:

Dr Eileen Cowey

Lecturer

University of Glasgow

0141 330 2069

Eileen.Cowey@glasgow.ac.uk

Thank you for your time

Appendix 25 The participant information leaflet for carers

University of Glasgow

NHS Lanarkshire

Participant (Carer) Information Sheet

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

This is an invitation to take part in a research study. The study is being carried out by Abdullah Alhusayni, PhD candidate, and academic staff in the School of Medicine, Dentistry and Nursing at the University of Glasgow.

Before you decide whether or not to take part it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Thank you in advance for taking the time to read this and to decide whether or not you wish to take part.

Why have I been chosen?

You have been chosen as you are the carer/family member of someone who has had a stroke who has agreed to take part in a study. This study involves the person who has had a stroke following an extra exercise programme that focuses on his/her affected arm, delivered via the website 5 times a week for 4 weeks. This person may need some support from you to use the website and/or do their arm exercises.

What is the purpose of the study?

Weakness in the arm is common after stroke and can affect stroke survivors' ability to perform some tasks. Studies show that extra sessions of arm exercise can help stroke survivors to improve their arm function and that the first 3 months is the best time to gain these benefits.

We have developed and evaluated a website (www.webbasedphysio.com) for delivering and monitoring physiotherapy exercise programmes. This website has been modified for people after stroke. The purpose of this study is to examine if doing extra physiotherapy for the arm through our website gives any extra benefits to the usual physiotherapy received on the ward. Moreover, we would like to get your feedback in terms of your experience supporting the stroke survivors doing their exercise programme, including the use of the web-based physiotherapy website.

Do I have to take part?

No, being part of the study is entirely voluntary, so it is your decision. You should read this information leaflet before your participation. Remember that you will be able to withdraw from the study at any time, without giving any reason. It is not mandatory that all stroke survivors have carers, however, those who do will be invited to take part.

What will happen to me if I take part?

If you decide to take part in the study, contact the researcher (see contact details below) or the physiotherapists in the ward. You will be given an opportunity to ask questions about the study.

The researcher will ask you to give your written consent to take part. You will then be asked to give some background details about yourself, such as your age, gender, relationship to stroke survivor, occupation, experience of using computers, ethnicity, education level, and general health status.

The physiotherapists will give you and your partner/family an explanation of his/her upper limb programme and how to access and use the website. You or your partner/family member can contact the researcher at any time during the study to ask any questions related to the website (see contact details below). You may also contact the physiotherapist if you feel that changes are needed to the programme.

At the end of the study, the researcher will ask you to complete a short questionnaire related to your experience of supporting your partner/family member in doing their

exercises, including the use of the web-based physiotherapy website. The expected time to complete the questionnaire is approximately 5 - 10 minutes.

Please note, you may not be eligible to take part in the study and your eligibility is dependent on the outcome of the randomisation of your partner or family member who had a stroke, as we will invite carers/family members of stroke survivors who allocated in the intervention group only.

What are the possible risks of taking part?

There are no foreseeable risks in taking part in this study. However, the study will take up some of your time.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part, although we hope that this exercise programme will help the stroke survivors improve their arm and trunk functions, as well as decrease any muscle tension in their arms, however, this cannot be guaranteed. Moreover, feedback about the intervention should help us develop interventions for other stroke survivors who use the web-based physiotherapy in the future.

Will my taking part in this study be kept confidential?

Yes, all data collected throughout the study will be kept strictly confidential. You will be given a unique identification number that linked to the stroke survivor, so data will be anonymised for storage and only the research team will be able to access your information. Representatives of the study sponsor, The NHS Greater Glasgow and Clyde, may audit the study to check that the study is being conducted properly. If that happens, they might have access to your study information, but they would also keep your information strictly confidential.

What will happen if I don't want to continue in the study?

You are free to withdraw at any time, without giving any reason, without your legal rights or your care being affected.

What if there is a problem?

We do not expect problems to be caused by this study. But, if you have any concern about any aspect of this study, you can contact any member of the research team (see contact details below). The usual NHS complaints procedure will also be available to you.

What happens to the results of the research study?

The study findings may be published in an academic journal or presented at scientific meetings. The findings will also be presented as part of a PhD thesis. Your personal data will be destroyed upon completion of the study. Moreover, a summary of findings will be sent to all participants who wish to see them.

Who has reviewed this study?

The study has been reviewed and approved by the West of Scotland Research Ethics Committee.

Contact details

If you are interested in participating, please contact:

The researcher:
Abdullah Alhusayni, PT, MSRS
PhD Candidate
University of Glasgow
0141 330 3568
a.alhusayni.1@research.gla.ac.uk

If you have questions or concerns about the study, please contact:

Dr Eileen Cowey
Lecturer
University of Glasgow
0141 330 2069
Eileen.Cowey@glasgow.ac.uk

Thank you for your time

Appendix 26 The Aphasia-friendly version of the stroke survivor's participant information leaflet

University of Glasgow

Participant (Stroke survivor) Information Sheet

Aphasia version

NHS Lanarkshire

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

What is the research?

We are doing some **research**

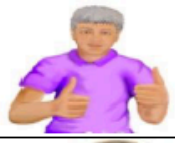
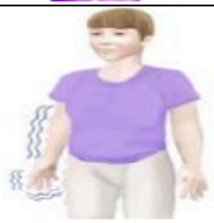
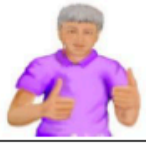
It is about **stroke and extra arm exercises**

Who is doing the research?

The **main researcher** is **Abdullah Alhusayni**

He is studying for a PhD

The research is done by staff at **University of Glasgow**

Why me? You have had **a first stroke**	
You are over the age of **18 years**	
The stroke affected your **arm** You find it **hard to use your arm**	
You are having **treatment** for your stroke in hospital	
You are able to sit on a **chair** **Or** You are able to sit on a **bed**	 
You are able to use a **computer** or **tablet** Your **carer** can **help** you to use the **computer**	
You are able to understand **English**	

Why are we doing the research?

After a stroke……

Some people **can't use** their **arms**

Arm exercises can **help**

People **usually** exercise **4-5 times a day**

We **want to know**…

Is it **better** to **do more arm exercises**?

The arm exercises will be **shown** to you

on a website (www.webbasedphysio.com)

Do I have to take part?

No, you can **choose** whether to take part

You **don't** have to **do this research**

If you **don't take part** you will still get your **normal**

care/help

Do I have to take part (continue)? You can **take your time to decide** You can **read** the **information again** You can **talk** to your **family** to **help you decide**	
Let us know if you want to **take part** You can contact **physiotherapists in the ward** **Or** You can contact **Abdullah** **Email** alhusayni.1@research.gla.ac.uk or **phone** 0141 330 3568	  
If you **change** your **mind**, you **can stop** at **any time** You **don't** have to **give** a **reason** If you **stop** you will **still get** your **normal help/care**	 

What will happen to me if I take part?

If you decide to **take part**

Abdullah will **answer** your **questions**

Abdullah will then ask you to **sign a consent form**

This says that **you understand** the research and **you agree** to **take part**

Abdullah will then ask you **questions about yourself**

This will **include**:

Your **age** your **sex** your **ethnicity**

Time since your **diagnosis** with **stroke**

Your **level of education**

Your **previous use of computers**

Your **life before stroke**

Your **ability to walk before stroke**

Your **ability to move your hand** and **walk now**

Your general **health status**

What will happen to me if I take part (continue)? **Abdullah** will then ask you to **complete three questionnaires about**.... **How stroke affects your daily life** **Your abilities before stroke** **Your current mental ability** **Abdullah** will **help** you to **fill** in the **questionnaires**	
Abdullah will **assess** your **affected arm function** **Abdullah** will **assess** the **muscles** in your **affected arm** **Abdullah** will **assess** your **trunk function** The **assessments** should last **60 minutes**	
Abdullah will **access** your **medical records** to obtain more **information** related **to this research**	

What next?

Abdullah will then ask you **questions about yourself**

You will be **given the "Just move" leaflet** about the **importance of exercises and physical activity**

You will be **allocated** to **one** of **two groups by choosing an envelope**

Treatment **A** - **the intervention group or**

Treatment **B** - **the control group**

The study will last **for one month**

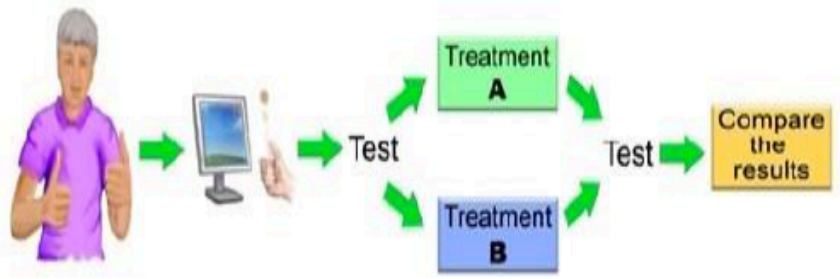
Or

Just **until** you are **discharged**

Then you will **see Abdullah again** in the ward

Abdullah will **repeat the assessments for you**

The **assessments** should last **50 minutes**



What next (continue)?

If you had treatment A.....

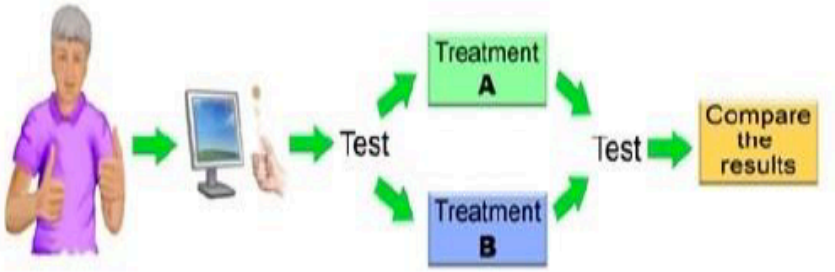
Abdullah will then ask you to **complete a questionnaire**

The **questionnaire** is related to ....

Your experience of **doing extra exercise, including the use of the web-based physiotherapy website**

Abdullah will **help** you to **fill** in the **questionnaire**

This will help us **learn** about the **treatment**



What happens if I am in the treatment A group? As well as the standard physiotherapy, the physiotherapist will assess your **arm** The physiotherapist will set up your **exercise programme** You will be asked to **do extra exercises** for your **affected arm 5 times a week** The physiotherapist will check your **exercises** **programme** every week You can **see/find the exercises** on the **website**	
The exercise programme will **start** at **your level** of ability It should last **30 minutes each time** Some **people find** this **too tiring** **If so, start** by doing as **much as you can**	

What happens if I am in the treatment A group (continue)?

The physiotherapist will explain to you **your upper limb programme and how to use the website**

The physiotherapist will need to get your e-mail for web-site access.

The physiotherapist will then give you a **log-in information**

You will **access your exercises** on the website.

You **can continue to access** your **exercises** when the **study is completed**

The physiotherapist will ask your **relative** to **help you if you need it**

Contact Abdullah if you have any **questions** about **the study**:

Email alhusayni.1@research.gla.ac.uk or phone 0141 330 3568

What happens if I am in the treatment B group?

You will have **standard physiotherapy** care on the **ward**

The physiotherapists may provide you with a leaflet with **arm exercises**

At the **end of the study** if you wish …

You **can use web-based physiotherapy**

What might be difficult about taking part?

You may find the exercise **tiring**

and **makes your arm a bit sore**

However…

Your **exercise programme** will start gently

What might be good about taking part? Your **exercise programme may help**.. **Improve** your **arm function** **Improve** your **trunk function** **Decrease** any **muscle tension** in your arm However… the **therapy may not help** you	 
You might **help** us to give **better service** to people in the **future**	

Who will see the information about me? We will keep the information about you **safe** **Only** the **researchers** will see the **information about you** We will **take out your name** and **personal details**	
People from NHS Greater Glasgow & Clyde may **check** our **records** to **make sure we** are **working correctly** **If** that **happens**... They will keep the **information about** you **safe**	

What will happen if I don't want to continue in the study? If you **change** your **mind**, you **can stop** at **any time** You **don't** have to **give** a **reason** If you **stop** you will **still get** your **normal help/care** If you **stop information already collected** about **you** will still be used	 

What if something goes wrong?

This is very **unlikely**

However,

If you have any concern about **this study**.

There are **people to talk to**

You can contact: Abdullah Alhusayni:

Email alhusayni.1@research.gla.ac.uk or **phone** 0141 330 3568

Or

Dr Eileen Cowey:

Email Eileen.Cowey@glasgow.ac.uk or **phone** 0141 330 2069

The **usual NHS complaints** procedure will be **available** to you

What will happen to the results? We will **give you the results** of the research	
We will share the **results** with **other researchers** and with **other people** who have a **stroke** at **conferences** and **meetings** and through **publications**	
The results will **not use your name**	

Who has reviewed this study? The study has been **reviewed** and approved by **the West of Scotland Research Ethics Committee**.	 

How to tell us you want to take part?

If you want to take part

remove this page and hand it to

the physiotherapists or **Abdullah** or your **relatives/carer**

or

other **patients could hand** it to the **physiotherapists or Abdullah**

I am interested in taking part

Thank you for your time

Appendix 27 The Aphasia-friendly version of the stroke survivor's consent form

University of Glasgow

Participant Identification Number for this study:

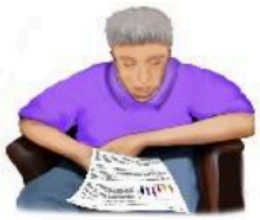
NHS Lanarkshire

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

Name of Researchers: Abdullah Alhusayni, Professor Lorna Paul, Dr Aleksandra Dybus and Dr Eileen Cowey

Please mark  yes no

1. I have **read** the **information** about the **research** (dated _26/11/2018__ (version __4__)) yes no	
2. I have had the **chance** to **ask questions** about the research yes no	

3. I understand that **I can stop being in the research** at any time	
4. **I understand that If I stop I do not** have to **give a reason** ...and I will **still get my normal care**	
5. I understand that I will be **allocated** to **one** of **two groups** Treatment **A - the intervention group or** Treatment **B - the control group**	

6. I **consent** to giving the researcher **my email address** in order for me to access the web-based physio website yes ☐ no ☐	
7. I understand that **information** about me will be **kept safe** yes ☐ no ☐	
8. I understand that when **results** are shared the researcher will **not use my name** yes ☐ no ☐	

9. I understand that researchers may **share** **my experiences of taking part in the study** with **other researchers** and with **other people** who have a **stroke** at **conferences** and **meetings** and through **publications** 	
10.I understand that **NHS Greater Glasgow & Clyde staff** may **check my information** 	
11. I understand that **researchers** will **access** **my medical records** to obtain **information** **related** to **this** **research** 	

University of Glasgow

Participant Identification Number for this study:

NHS Lanarkshire

12. If I stop being in the Research, **information already collected** about me will still be used  yes no	
13. I agree to take part in this research  yes no	

Name of participant _____

 **Signature**

_____  **Date** _____

Name of researcher _____

 **Signature**

_____  **Date** _____

(1 copy for subject; 1 copy for researcher)

Appendix 28 The consent form for stroke survivor

University of Glasgow

Consent form for Stroke Survivors

NHS Lanarkshire

Participant Identification Number for this study: ……..

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

Name of Researchers: Abdullah Alhusayni, Professor Lorna Paul, Dr Aleksandra Dybus and Dr Eileen Cowey

Please initial box

1. I confirm that I have read and understand the participant (stroke survivor) information sheet dated *26/11/2018* (version *4*_) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. All data (personalised and study data) collected up to the point of withdrawal from the study will be retained until the end of the study. ☐
3. I understand that I will be randomised to one of two groups (usual care or usual care plus a 4 week augmented upper limb exercise programme). ☐
4. I consent to giving the researcher my email address in order for me to access the web-based physiotherapy website. ☐
5. I understand that information collected about me may be looked at by authorised individuals from the study sponsor NHS Greater Glasgow & Clyde, the research team, or from the regulatory authorities where it is relevant to my taking part in this research. ☐
6. I understand that the research team will require access to my medical records where it is relevant to this research and I agree to this. ☐
7. I understand that the researchers may use my experiences of taking part in the study for the teaching and training of health and social care staff or publish it with data being anonymous in scientific journals, or the PhD thesis. ☐
8. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

Consent form for Stroke Survivors
Version 4. 14/12/2018

Appendix 29 Just move leaflet

JUST MOVE

Chest Heart & Stroke Scotland

Being active can help you live a healthier, longer life. There are lots of different ways you can be more active, even if you find it difficult to move around. This factsheet explains why physical activity is so important and suggests activities and resources that can help you to get moving.

FACTSHEET

Physical activity is any movement of the body that uses energy and can be as simple as walking, housework or gardening. Regular physical activity can help reduce your risk of serious health conditions such as heart disease, stroke, respiratory illness and early death.

You can benefit from being more active whatever your age, size or physical condition. You may feel that being active is difficult because of an existing health condition but any activity is better than none.

Why is physical activity important?

Being active every day can help improve your physical and mental health.
Regular physical activity can help to:

- Reduce the risk of diseases including heart disease, stroke and type 2 diabetes
- Manage existing health conditions such as heart disease, type 2 diabetes, chronic obstructive pulmonary disease (COPD) and stroke
- Lower your blood pressure and cholesterol levels
- Maintain a healthy weight or help you to lose weight if you need to
- Strengthen your heart and improve your breathing
- Increase your energy levels
- Improve concentration, mood and self esteem
- Improve balance and co-ordination
- Maintain your independence

'There's no doubt that exercising will make you healthier and increasing your activity even by a small amount can improve your sense of well-being and help you live better with a long-term condition. Also, getting fit can be fun!'

Gordon, Cardiac Group Member

CHEST HEART & STROKE SCOTLAND
Rosebery House • 9 Haymarket Terrace • Edinburgh EH12 5EZ
Tel: 0131 225 6963 • Fax: 0131 220 6313 • Advice Line Nurses: 0808 801 0899
Email: adviceline@chss.org.uk • Website: www.chss.org.uk
Scottish Charity No. SC018761

F30
OCTOBER 2016

FACTSHEET

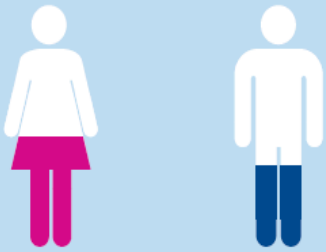
How much physical activity should I do?

Current guidelines recommend that adults should try to be active every day to stay healthy. Over the course of a week, you should aim to do 150 minutes (2 and a half hours) of **moderate** activity. This can be broken down in to manageable amounts of time to suit you. Just ten minutes at a time on a regular basis can provide physical and health benefits. It is important to start gradually and slowly build up the amount of activity you do.

'Moderate' activity means being slightly breathless but still able to hold a conversation; for example, a brisk walk would normally be classed as 'moderate' activity.

IN SCOTLAND

Nearly half of all women



Nearly a third of all men

DON'T do the recommended amount of physical activity

Where do I start?

It's never too late to start becoming more active.

When deciding what type of exercise you choose make sure you pick something that you are interested in and will enjoy doing. You will then be much more likely to stick to it. Think about how you will find the time to do it and how you can build it into your routine. You may also want to think about whether you would prefer to exercise with others or do it alone.

How to stay safe while being active

- Warm up before you start as this can help prevent injury
- Build the pace up gradually and slow down gradually rather than just stopping suddenly
- Wear comfortable clothes and shoes
- Stay hydrated by drinking water before, during and after activity
- Do some stretching exercises before and after your activity

What sort of activity should I do?

Choose an activity that makes you move enough to make you feel warm and a little out of breath but you are still able to have a conversation. This is called moderate activity and includes things like walking, gardening, cycling or swimming.

Vigorous activity includes things like running, aerobics, and sports such as tennis or football. It can also include hiking uphill or riding a bike fast or uphill. During activities like this, it will be harder to keep up a conversation. For most people, to do an activity like this would require some training and may not be appropriate if you already have a chest or heart condition.

Your weekly activity should also include muscle strengthening activity at least two days a week to keep your muscles, bones and joints strong. This would include activity such as exercising with weights, yoga or tai chi, gardening or simply carrying your shopping.

People at risk of falls can also benefit from activity that helps improve balance such as dancing, bowling or tai chi.

If your mobility has been affected and you use a wheelchair, there are chair-based exercises that you can do. These involve a series of seated stretches and movements to increase your heart rate and exercise your muscles and joints. Wiggling your feet or making circles with your ankles regularly can be a good way of seated exercise and can help your lower-body circulation. There may also be chair-based exercise classes held at local leisure centres or community centres in your area that you could join.

Call the CHSS Advice Line nurses on 0808 801 0899 for details of organisations and resources for chair-based exercises or other local classes that can help you increase your physical activity.

Reduce your sitting time

If you have a long-term health condition, you might find being active difficult. However, there are still things you can do to help yourself. One of the things that all of us should do is to reduce the amount of time spent sitting for a long time. This can be done by reducing time spent watching TV or using a computer, or by breaking up time spent sitting down by standing up and walking every so often. For example, stand up during the advert breaks on TV, get off the bus a stop earlier than you usually would, or park a couple of streets further away.

FACTSHEET

What can help me to stay motivated?

The most important thing is to do something you enjoy which you can fit in to your daily routine.

Tips for staying motivated

- Try something new
- Exercise with a friend or find out about a local group in your area
- Try using a pedometer or an app that counts the number of steps you take and the distance you've walked
- Keep a personal diary so that you can stay focused and see your progress more clearly
- Set yourself goals

Setting goals

Setting goals will help keep you focused and motivated by giving you something to aim for. Set yourself realistic goals and give yourself a timescale in which to achieve these goals. For example, set a goal to walk 20-30 minutes three times a week. Once you have reached that goal you can think about the next one. A longer term goal might be to take part in an event such as a charity walk.

Be realistic about what you can and can't do. Make sure you have a back-up plan. For example, think about what you will do if it is raining and you were planning to walk. Is there an indoor activity you could do instead or do you need to make sure you have wet-weather clothes with you?

Reward yourself for all your hard work by recognising when you have achieved your goals. Think of things that you could reward yourself with such as a massage, a new pair of trainers, a trip to the cinema or day trip out.

FACTSHEET

FACTSHEET

Is there any exercise I shouldn't do?

You shouldn't do physical activity if you feel unwell or have a high temperature. Also if you have a long-term health condition, speak to your doctor before you start any form of exercise so that they can ensure that it is safe for you to do and it won't affect any ongoing treatment. Some forms of physical activity may not be appropriate for people with certain conditions; for example, contact sports for people with an implanted device. Often the solution is to choose another form of activity.

Exercising with a long-term chest condition

It can be tempting to avoid exercise if you have a long-term chest condition because you may think it will make you breathless or make your chest worse. However, it has been shown that regular exercise will give you better control of your breathing as well as help your general fitness levels. If you use a reliever inhaler always have it with you when exercising. It is important not to be more than moderately breathless.

Exercising if you have heart condition

If you have an existing heart condition or have experienced a heart attack, you should avoid activity that requires you to hold your breath or requires sudden bursts of energy such as push-ups or sit-ups. It is also important to take time to warm up before exercise and cool down afterwards to allow your heart rate to build up gradually and return to normal gradually.

Exercise after stroke

Regular exercise can reduce your risk of stroke by a quarter. If you have recently had a stroke, you may not be able to be more active straight away but when you feel ready, talk to your doctor or therapist about what is right for you. Depending how your stroke has affected you, you may need to adapt your activities or try new ones. Exercise can help with your overall recovery and is an important part of your rehabilitation after a stroke.

It is important to pace yourself and not overdo it. You should always stop if you experience pain or severe discomfort.

FACTSHEET

Where can I find help?

Below are some organisations and resources that can help you find ways to get more active. Find out about exercise-based support groups near you such as the CHSS affiliated support groups by visiting www.chss.org.uk/groups or call the CHSS Advice Line nurses on 0808 801 0899. Your local leisure centre and council will also have details of activity programmes and classes for all ages and fitness levels.

If exercise classes are not for you, you might find that individualised exercise programmes taught by appropriate professionals might work better. There are also plenty of exercise DVDs available which include all levels of ability as well as chair-based programmes.

Other organisations and resources that can help:

- **Paths for all (Scotland)** www.pathsforall.gov.uk
- **Ramblers** www.ramblers.org.uk/scotland
- **Extend** www.extend.org.uk
- **NHS Choices** www.nhs.uk/livewell
- **Scottish Disability Sport** www.scottishdisabilitysport.com
- **Active Scotland** www.activescotland.org.uk
- **ALISS** www.aliss.org
- **Take Life On** www.takelifeon.co.uk
- **Jog Scotland** www.jogscotland.co.uk
- **Age UK** www.ageuk.org.uk/scotland
- **World Walking** www.worldwalking.org

Useful fitness apps

There are a number of smart phone apps available, many of which are free, that can help you achieve your fitness goals. Below are some of the more popular options.


- **My Fitness Pal** www.myfitnesspal.com


- **Fitness Tracker** www.fitness-tracker.com


- **Fitocracy** www.fitocracy.com

NHS Choices (www.nhs.uk) has a range of suggestions, including getting-started videos, strength and flex videos, exercises for older people and fitness apps.

If you would like to speak to one of our nurses in confidence, please call the Chest Heart & Stroke Scotland Advice Line nurses

0808 801 0899

free to call from landlines and mobiles.

Published October 2016
Next review due October 2019

Appendix 30 The consent form for carers

University of Glasgow

NHS Lanarkshire

Consent form for Carer

Participant Identification Number for this study: ……..

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

Name of Researchers: Abdullah Alhusayni, Professor Lorna Paul, Dr Aleksandra Dybus and Dr Eileen Cowey

Please initial box

1. I confirm that I have read and understand the participant (carer) information sheet dated __*06/08/2018*__ (version _*3*__) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. All data (personalised and study data) collected up to the point of withdrawal from the study will be retained until the end of the study. ☐
3. I understand that information collected about me may be looked at by authorised individuals from the study sponsor NHS Greater Glasgow & Clyde, the research team, or from the regulatory authorities where it is relevant to my taking part in this research. ☐
4. I understand that the researchers may use my experiences of taking part in the study for the teaching and training of health and social care staff or publish it with data being anonymous in scientific journals, or the PhD thesis. ☐
5. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

Consent form for Carer
Version 3. 06/08/2018

Appendix 31 The participant information leaflet for physiotherapists

Participant (Physiotherapy staff) Information Sheet

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

This is an invitation to take part in a research study. The study is being carried out by Abdullah Alhusayni, PhD candidate, and academic staff in the School of Medicine, Dentistry and Nursing at the University of Glasgow.

Before you decide whether or not to take part it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Thank you in advance for taking the time to read this and to decide whether or not you wish to take part.

Why have I been chosen?

You have been chosen to take part as you are one of the physiotherapists who has been involved in prescribing and monitoring the augmented physiotherapy programmes for this study and we wish to evaluate your feedback on this intervention, including the use of the web-based physiotherapy platform.

What is the purpose of the study?

Weakness in the arm is common after stroke and can affect stroke survivors' ability to perform some tasks. Studies show that extra sessions of arm exercise can help stroke survivors to improve their arm function and that the first 3 months is the best time to gain these benefits.

We have developed and evaluated a website (www.webbasedphysio.com) for delivering and monitoring physiotherapy exercise programmes. This website has been modified for people after stroke. The purpose of this study is to examine if doing extra physiotherapy for the arm through our web-based physio website gives any extra benefits to the usual physiotherapy received on the ward. Moreover, we would like to get your feedback in terms of your experience managing the exercise programme, including the use of the web-based physiotherapy website.

Do I have to take part?

No, being part of the study is entirely voluntary, so it is your decision. You should read this information leaflet before your participation. Remember that you will be able to withdraw from the study at any time, without giving any reason.

What will happen to me if I take part?

If you decide to take part in the study, there are few things that you will be asked to do, before, during and at the end of the study.

Before the start of the study, the research team will attend to the stroke unit to explain the study and demonstrate the web-based physiotherapy website (www.webbasedphysio.com), and you will be given an opportunity to ask questions about the study.

The researcher will ask you to give your written consent to take part. You will then be asked to give some background details about yourself, such as your age, gender, occupation, education level, experience of using computers and time since working in stroke unit. After that, you will receive training in the use of the website.

When the study starts, the physiotherapists will be asked to do the following:

- Approaching potential participants (stroke survivors and carers) from the stroke ward by contacting the researcher and distributing the participant information sheet.
- Assess the stroke survivors who have been allocated to the intervention group and set up an individualised arm exercise programme for each participant.

The rehabilitation programme needs to build up in a gradual manner to reach a point where the stroke survivors are able to perform these exercises for 30 minutes each session, 5 times a week in addition to the physiotherapy care that they receive while on the ward.

- Review the stroke survivor participants' rehabilitation programmes once a week and revise as appropriate.
- Respond, as appropriate to any requests from participants to change to their programme.

At the end of the study, the researcher will ask you to complete a short questionnaire related to your experience of monitoring the exercise programme, including the use of the web-based physiotherapy website. The expected time to complete the questionnaire is approximately 5 - 10 minutes.

Remember, you can contact the researcher at any time during the study to ask any questions related to the website and/or the study (see contact details below).

What are the possible risks of taking part?

There are no foreseeable risks in taking part in this study. However, the study will take up some of your time.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part, although we hope that this exercise programme will help the participants (stroke survivors) by improving their arm and trunk functions and decreasing any muscle tension (spasticity) in their arms, even though this cannot be guaranteed. Moreover, feedback about the intervention should help us develop interventions for other stroke survivors who use the web-based physiotherapy in the future.

Will my taking part in this study be kept confidential?

Yes, all data collected throughout the study will be kept strictly confidential. You will be given a unique identification number, so data will be anonymised for storage and only the research team will be able to access your information. Representatives of the study sponsor, The NHS Greater Glasgow and Clyde, may audit the study to

check that the study is being conducted properly. If that happens, they might have access to your study information, but they would also keep your information strictly confidential.

What will happen if I don't want to continue in the study?

You are free to withdraw at any time, without giving any reason, without your legal rights being affected.

What if there is a problem?

We do not expect problems to be caused by this study. But, if you have any concern about any aspect of this study, you can contact any member of the research team (see contact details below). The usual NHS complaints procedure will also be available to you.

What happens to the results of the research study?

The study findings may be published in an academic journal or presented at scientific meetings. The findings will also be presented as part of a PhD thesis. Your personal data will be destroyed upon completion of the study. Moreover, a summary of findings will be sent to all participants who wish to see them.

Who has reviewed this study?

The study has been reviewed and approved by the West of Scotland Research Ethics Committee.

Contact details

If you are interested in participating, please contact:

The researcher:

Abdullah Alhusayni, PT, MSRS

PhD Candidate

University of Glasgow

0141 330 3568

a.alhusayni.1@research.gla.ac.uk

If you have questions or concerns about the study, please contact:

Dr Eileen Cowey

Lecturer

University of Glasgow

0141 330 2069

Eileen.Cowey@glasgow.ac.uk

Thank you for your time

Appendix 32 The consent form for physiotherapists

University of Glasgow

NHS Lanarkshire

Consent form for Physiotherapy staff

Participant Identification Number for this study: ……..

Official title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Lay title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

Name of Researchers: Abdullah Alhusayni, Professor Lorna Paul, Dr Aleksandra Dybus and Dr Eileen Cowey

Please initial box

1. I confirm that I have read and understand the participant (physiotherapy staff) information sheet dated __26/11/2018__ (version _4__) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. All data (personalised and study data) collected up to the point of withdrawal from the study will be retained until the end of the study. ☐
3. I understand that information collected about me may be looked at by authorised individuals from the study sponsor NHS Greater Glasgow & Clyde, the research team, or from the regulatory authorities where it is relevant to my taking part in this research. ☐
4. I understand that the researchers may use my experiences of taking part in the study for the teaching and training of health and social care staff or publish it with data being anonymous in scientific journals, or the PhD thesis. ☐
5. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

Consent form for Physiotherapy staff
Version 4. 14/12/2018

Appendix 33 Form to record of upper-limb exercises

Record of upper limb exercises

Study title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Participant ID number: ..... Date this form completed: ...../...../.....

Please circle or tick the appropriate option:

During the participant hospitalisation period, did the participant get upper limb exercises during his/her normal physio?

Yes ◯ No ◯

If yes, please complete the following table by circling or ticking the appropriate option, and filling the blanks:

Type of exercise	Please circle or tick all the appropriate options	Duration
Flexibility exercises	◯	.....
Strengthening exercises	◯	.....
Functional exercises	◯	.....
Other, please indicate:	◯	.....

Thank you for taking the time to complete this questionnaire

Record of upper limb exercises
Version 2
06/08/2018

Appendix 34 Action Research Arm Test (ARAT) (Platz, 1999)

ACTION RESEARCH ARM TEST

Patient ID: **Centre:**

Examiner: **Date :**

Scoring: 0 = can perform no part of test
1 = performs test partially
2 = completes test, but takes abnormally long time or has great difficulty
3 = performs test normally
(for scoring insructions, see also Carroll, 1965, p.484)

A. Subtest Grasp

In this test the patient has to pick up wooden blocks and a stone from a table and put in on a platform, situates approximately 30cm above the table.

		Evaluation	
		Left	**Right**
1	Woodblock 10 cm (If score = 3, total = 18 and go to Grip)		
2	Woodblock 2.5 cm (If score = 0, total = 0 and go to Grip)		
3	Woodblock 5 cm		
4	Woodblock 7.5 cm		
5	Cricketball 7.5 cm diameter		
6	Stone 10 x 2.5 x 1 cm		
SUBTOTAL *Grasp*		/18	/18

B. Subtest Grip

The patient has to pour water from one glas to another and lift aluminium tubes. He has to move them from one side of the table to the other, 30 cm further. He also has to pick up an iron washer and let it slide over a bolt.

		Evaluation	
		Left	**Right**
1	Pour water from glass to glass (pronation) (If score = 3, total = 12 and go to Pinch)		
2	Tube 2.25 cm (If score = 0, total = 0 and go to Pinch)		
3	Tube 1 cm		
4	Washer over bolt		
SUBTOTAL *Grip*		/12	/12

C. Subtest Pinch

The patients has to pick up small ball-bearings or marbles from the table and put them on a platform, approximately 30 cm above the table.

		Evaluation	
		Left	**Right**
1	Ball bearing, 6 mm, 3rd finger and thumb (If score = 3, total = 18 and go to Grossmovement)		
2	Marble, 1.5 cm, index finger and thumb (If score = 0, total = 0 and go to Grossmt)		
3	Ball bearing 2nd finger and thumb		
4	Ball bearing 1st finger and thumb		
5	Marble 3rd finger and thumb		
6	Marble 2nd finger and thumb		
SUBTOTAL *Pinch*		/18	/18

D. Gross movement

	Evaluation	
	Left	**Right**
1 Place hand behind head (If score = 3, total = 9 and finish)		
2 (If score = 0, total = 0 and finish)		
3 Place hand on top of head		
4 Hand to mouth		
SUBTOTAL *Gross movement*	/9	/9

ACTION RESEARCH ARM TEST TOTAL SCORE

TOTAL SCORE	/57	/57

Appendix 35 Trunk Impairment Scale (TIS) (Verheyden et al., 2004)

The starting position for each item is the same. The patient is sitting on the edge of a bed or treatment table without back and arm support. The thighs make full contact with the bed or table, the feet are hip width apart and placed flat on the floor. The knee angle is 90°. The arms rest on the legs. If hypertonia is present the position of the hemiplegic arm is taken as the starting position. The head and trunk are in a midline position.
If the patient scores 0 on the first item, the total score for the TIS is 0.
Each item of the test can be performed three times. The highest score counts. No practice session is allowed.
The patient can be corrected between the attempts.
The tests are verbally explained to the patient and can be demonstrated if needed.

Item			
	Static sitting balance		
1	Starting position	Patient falls or cannot maintain starting position for 10 seconds without arm support	☐ 0
		Patient can maintain starting position for 10 seconds If score = 0, then TIS total score = 0	☐ 2
2	Starting position Therapist crosses the unaffected leg over the hemiplegic leg	Patient falls or cannot maintain sitting position for 10 seconds without arm support	☐ 0
		Patient can maintain sitting position for 10 seconds	☐ 2
3	Starting position Patient crosses the unaffected leg over the hemiplegic leg	Patient falls	☐ 0
		Patient cannot cross the legs without arm support on bed or table	☐ 1
		Patient crosses the legs but displaces the trunk more than 10 cm backwards or assists crossing with the hand	☐ 2
		Patient crosses the legs without trunk displacement or assistance	☐ 3
		Total static sitting balance	/7
	Dynamic sitting balance		
1	Starting position Patient is instructed to touch the bed or table with the hemiplegic elbow (by shortening the hemiplegic side and lengthening the unaffected side) and return to the starting position	Patient falls, needs support from an upper extremity or the elbow does not touch the bed or table	☐ 0
		Patient moves actively without help, elbow touches bed or table If score = 0, then items 2 and 3 score 0	☐ 1
2	Repeat item 1	Patient demonstrates no or opposite shortening/lengthening	☐ 0
		Patient demonstrates appropriate shortening/lengthening If score = 0, then item 3 scores 0	☐ 1
3	Repeat item 1	Patient compensates. Possible compensations are: (1) use of upper extremity, (2) contralateral hip abduction, (3) hip flexion (if elbow touches bed or table further then proximal half of femur), (4) knee flexion, (5) sliding of the feet	☐ 0
		Patient moves without compensation	☐ 1
4	Starting position Patient is instructed to touch the bed or table with the unaffected elbow (by shortening the unaffected side and lengthening the hemiplegic side) and return to the starting position	Patient falls, needs support from an upper extremity or the elbow does not touch the bed or table	☐ 0
		Patient moves actively without help, elbow touches bed or table If score = 0, then items 5 and 6 score 0	☐ 1
5	Repeat item 4	Patient demonstrates no or opposite shortening/lengthening	☐ 0
		Patient demonstrates appropriate shortening/lengthening If score = 0, then item 6 scores 0	☐ 1

Item			
6	Repeat item 4	Patient compensates. Possible compensations are: (1) use of upper extremity, (2) contralateral hip abduction, (3) hip flexion (if elbow touches bed or table further then proximal half of femur), (4) knee flexion, (5) sliding of the feet	☐ 0
		Patient moves without compensation	☐ 1
7	Starting position Patient is instructed to lift pelvis from bed or table at the hemiplegic side (by shortening the hemiplegic side and lengthening the unaffected side) and return to the starting position	Patient demonstrates no or opposite shortening/lengthening	☐ 0
		Patient demonstrates appropriate shortening/lengthening If score = 0, then item 8 scores 0	☐ 1
8	Repeat item 7	Patient compensates. Possible compensations are: (1) use of upper extremity, (2) pushing off with the ipsilateral foot (heel loses contact with the floor)	☐ 0
		Patient moves without compensation	☐ 1
9	Starting position Patient is instructed to lift pelvis from bed or table at the unaffected side (by shortening the unaffected side and lengthening the hemiplegic side) and return to the starting position	Patient demonstrates no or opposite shortening/lengthening	☐ 0
		Patient demonstrates appropriate shortening/lengthening If score = 0, then item 10 scores 0	☐ 1
10	Repeat item 9	Patient compensates. Possible compensations are: (1) use of upper extremities, (2) pushing off with the ipsilateral foot (heel loses contact with the floor)	☐ 0
		Patient moves without compensation	☐ 1
		Total dynamic sitting balance	/10
	Co-ordination		
1	Starting position Patient is instructed to rotate upper trunk 6 times (every shoulder should be moved forward 3 times), first side that moves must be hemiplegic side, head should be fixated in starting position	Hemiplegic side is not moved three times	☐ 0
		Rotation is asymmetrical	☐ 1
		Rotation is symmetrical If score = 0, then item 2 scores 0	☐ 2
2	Repeat item 1 within 6 seconds	Rotation is asymmetrical	☐ 0
		Rotation is symmetrical	☐ 1
3	Starting position Patient is instructed to rotate lower trunk 6 times (every knee should be moved forward 3 times), first side that moves must be hemiplegic side, upper trunk should be fixated in starting position	Hemiplegic side is not moved three times	☐ 0
		Rotation is asymmetrical	☐ 1
		Rotation is symmetrical If score = 0, then item 4 scores 0	☐ 2
4	Repeat item 3 within 6 seconds	Rotation is asymmetrical	☐ 0
		Rotation is symmetrical	☐ 1
		Total co-ordination	/6
		Total Trunk Impairment Scale	/23

Appendix 36 Modified Ashworth Scale (MAS) (Bohannon and Smith, 1987)

General Information:

- Place the patient in a supine position
- If testing a muscle that primarily flexes a joint, place the joint in a maximally flexed position and move to a position of maximal extension over one second (count "one thousand one")
- If testing a muscle that primarily extends a joint, place the joint in a maximally extended position and move to a position of maximal flexion over one second (count "one thousand one")
- Score based on the classification below

Scoring:	
0	No increase in muscle tone
1	Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension
1+	Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM
2	More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved
3	Considerable increase in muscle tone, passive movement difficult
4	Affected part(s) rigid in flexion or extension-

Patient Instructions:

The patient should be instructed to relax.

Muscle Tested	**Left/right**	**Score**
Arm adductor muscle group		
Elbow flexor muscle group		
Wrist flexor muscle group		
Finger flexor muscle group		

Appendix 37 Questionnaire for Stroke Survivors

Participant Identification Number for this study:

Study title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

1. Did you do any of the exercises in your programme? Yes ◯ No ◯	
If you answered 'Yes', please go straight to Question 2. **If you answered 'No', could you please let us know why that was?** Enter your comments here: **(Thanks for your feedback – there is no need to answer further questions)**	

Participant Identification Number for this study:

Section 1: Evaluation of the augmented exercise programme:

Question number	Question	Please circle one answer				
2.	I feel I benefited from the exercise programme.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
3.	The exercises were clear and understandable.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
4.	The exercise programme did not increase my fatigue (tiredness).	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
5.	It was easy to contact the physios to make changes to my exercise programme.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
6.	I was happy with the length of time it took for the study assessments.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
7.	I would be happy to do exercises using this website again in the future.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree

Section 2: Evaluation of the website

Question number	Question	Please circle one answer				
8.	Doing my exercises through the website gave me the chance to choose when to exercise.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
9.	Doing my exercises through the website gave me the feeling of being independent in exercising.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
10.	Learning to use the website for my exercises was easy for me.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree

Section 3: Please answer the following questions and add your comments, if appropriate:

11. On average, how many times each week did you do your exercise?

Once per week ◯ Twice per week ◯ 3-5 times per week ◯ Other, please specify:.....

12. On average, how long did you spend doing the exercises each exercise session?

Less than 30 minutes ◯ Up to 1 hour ◯ 1-2 hours ◯ Other, please specify:.....

University of Glasgow

Participant Identification Number for this study:

NHS Lanarkshire

13. Did your partner/relative help you do your exercise programme? Yes ◯ No ◯ **If yes, please answer the following questions:**

How often? Once per week ◯ Twice per week ◯ 3-5 times per week ◯ Other, please specify:.....

What did you need your partner/relative to help you with?

14. Did you ask staff to help you do your exercise programme? Yes ◯ No ◯ **If yes, please answer the following questions:**

How often? Once per week ◯ Twice per week ◯ 3-5 times per week ◯ Other , please specify:.....

Who did you ask? Nursing staff ◯ Physiotherapy staff ◯ Other, please specify:.....

What did you need the staff to help you with?

15. How difficult/easy was exercising using the website without supervision?	Easy ◯	Neither easy nor difficult ◯	Difficult ◯	
Please provide details. For example, did you worry about not exercising properly or knowing how many exercises you needed to do? **Please tell us about things that went well? What was difficult (if anything)?**				
16. Only for participants who have problems with speech, memory and thinking (aphasia) Was the website aphasia version helpful?				
Certainly yes ◯	To a large extent ◯	To some extent ◯	No ◯	I didn't use it ◯
17. Did you discuss your exercises with other patients?	Yes ◯	No ◯		
18. Did other patients ask you about your exercises?	Yes ◯	No ◯		

Thank you for completing this questionnaire

Appendix 38 Questionnaire for carers

Participant Identification Number for this study:

Study title: Additional physiotherapy sessions focussing on arm rehabilitation for people after stroke during the early inpatient period? A feasibility study

Please answer the following questions and add your comments, if appropriate:

1. Did you help your partner/relative to do any of his/her exercise programme? Yes ◯ No ◯	
If you answered 'Yes', please go straight to Question 2. **If you answered 'No', could you please let us know why that was?** Enter your comments here: **(Thanks for your feedback – there is no need to answer further questions)**	

Participant Identification Number for this study:

Section 1: Evaluation of the augmented exercise programme:

Question number	Question	Please circle one answer				
2.	It was easy for me to help my partner/relative to do the exercises.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
3.	The exercises were clear and understandable.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
4.	I would be happy to use this website to help my relative/partner exercising again in the future.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree

Section 2: Evaluation of the website:

Question number	Question	Please circle one answer				
5.	Learning to use the website for my partner/relative's exercises was easy for me.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree

Participant Identification Number for this study:

Section 3: please answer the following questions and add your comments, if appropriate:

6. How often did you help your partner/relative to do his/her exercise programme?

Once per week ◯ Twice per week ◯ 3-5 times per week ◯ Other, please specify:.....

What did you help him/her with?

7. Did you ask staff to help your partner/relative doing his/her exercise programme? Yes ◯ No ◯ **If yes, please answer the following questions:**

How often? Once per week ◯ Twice per week ◯ 3-5 times per week ◯ Other, please specify:.....

Who did you ask? Nursing staff ◯ Physiotherapy staff ◯ Other, please specify:.....

What did you need the staff to help your partner/relative with?

Participant Identification Number for this study:

8. How difficult/easy was helping your partner/relative to exercise using the website without supervision?

Easy ◯ Neither easy nor difficult ◯ Difficult ◯

Please provide details. For example, did you worry about helping your partner/relative to exercise properly or knowing how many exercises your partner/relative needed to do?

Please tell us about things that went well? What was difficult (if anything)?

Thank you for completing this questionnaire

Appendix 39 Questionnaire for physiotherapists

Participant Identification Number for this study:

Study title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

Section 1: Evaluation of the augmented exercise programme:

Question number	Question	Please circle one answer				
1.	I think the stroke survivors benefited from the exercise programme.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
2.	Monitoring the augmented programme did not impose on my day to day care of the patients.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
3.	The exercises were clear and understandable to the stroke patients.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
4.	I would be happy to provide exercises using this website again in the future.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree

Participant Identification Number for this study:

Section 2: Evaluation of the website

Question number	Question	Please circle one answer				
5.	Learning to provide exercises using the website was easy for me.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
6.	The procedure of signing the stroke survivors up to the website was straight forward.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree
7.	The procedure of setting the treatment plan up was straight forward.	Strongly disagree	Moderately disagree	Neither agree or disagree	Moderately agree	Strongly agree

Section 3: Please answer the following questions and add your comments, if appropriate:

8. From a physiotherapist's perspective what do you think are the advantages/disadvantages of providing the exercise programme using the website?
Advantages: **Disadvantages:**
9. On average, how many times each week did you monitor the exercise programmes?
Once per week ◯ Twice per week ◯ 3-5 times per week ◯ Other, please specify:.....

Thank you for completing this questionnaire

Appendix 40 The fingerbreadth palpation to measure shoulder subluxation (Hall et al., 1995)

Glenohumeral subluxation was defined as a palpable gap between the inferior aspect of the acromion and the superior aspect of the humeral head that is ½ fingerbreadth or more. A 0–5 grading scheme was used:

0= no subluxation

1=½ fingerbreadth gap

2=1 fingerbreadth gap

3=1½ fingerbreadth gap

4=2 fingerbreadth gap

5=2½ fingerbreadth gap

Appendix 41 The Research and Development approval for Monkland hospital

Re-issued – addition of University Hospital Monklands

Dr Eileen Cowey
Lecturer
University of Glasgow
59 Oakfield Avenue
School of Medicine, Dentistry and Nursing,
Nursing & Health Care School
GLASGOW
G12 8LL

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 04/12/2018
Enquiries to Cynthia Dolier, R&D Facilitator
Direct Line 01236 712460
Email cynthia.dolier@lanarkshire.scot.nhs.uk

Dear Dr Cowey

Project title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

R&D ID: L18047

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Fiona MacDonald	Post Advanced Practitioner Physiotherapist	Principal Investigator	University Hospital Hairmyres
Julie MacDonald	Advanced Practitioner Physiotherapist	Principal Investigator	University Hospital Monklands

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK and EU Data Protection legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.cso.scot.nhs.uk/ or the Research & Development Intranet site: http://firstport2/staff-support/research-and-development/default.aspx
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely

Raymond Hamill – Senior R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Miss Julie MacDonald	Advanced Practitioner Physiotherapist	Julie.Macdonald3@lanarkshire.scot.nhs.uk	Principal Investigator
Miss Emma-Jane Gault	Clinical Research & Development	emmajane.gault@glasgow.ac.uk	Sponsor Contact
Mr Abdullah Alhusayni	PhD in Nursing and Health Care	a.alhusayni.1@research.gla.ac.uk	Named Contact
Dr Mark Barber	Consultant Physician in Geriatric Medicine	mark.barber@lanarkshire.scot.nhs.uk	Named Contact

Appendix 42 The Research and Development approval for Wishaw hospital

Dr Eileen Cowey
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R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
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ML6 0JS

Date 28 January 2019
Enquiries to Cynthia Dolier, R&D Facilitator
Direct Line 01236 712460
Email cynthia.dolier@lanarkshire.scot.nhs.uk

Dear Dr Cowey

Project title: Augmented Upper Limb Physiotherapy for Acute Stroke Survivors undergoing Inpatient Stroke Rehabilitation; a feasibility study

R&D ID: L18047

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NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Fiona MacDonald	Post Advanced Practitioner Physiotherapist	Local Collaborator	University Hospital Hairmyres
Julie MacDonald	Advanced Physiotherapy Practitioner	Local Collaborator	University Hospital Monklands
Jaclyn Robertson	Highly Specialist Physiotherapist	Local Collaborator	University Hospital Wishaw

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK and EU Data Protection legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.cso.scot.nhs.uk/ or the Research & Development Intranet site: http://firstport2/staff-support/research-and-development/default.aspx
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely

Raymond Hamill – Senior R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Miss Fiona MacDonald	Post Advanced Practitioner Physiotherapist	fiona.macdonald@lanarkshire.scot.nhs.uk	Local Collaborator
Miss Julie MacDonald	Advanced Physiotherapy Practitioner	julie.macdonald3@lanarkshire.scot.nhs.uk	Local Collaborator
Miss Jaclyn Robertson	Highly Specialist Physiotherapist	jaclyn.robertson@lanarkshire.scot.nhs.uk	Local Collaborator
Miss Emma-Jane Gault	Clinical Research & Development	emmajane.gault@glasgow.ac.uk	Sponsor Contact
Mr Abdullah Alhusayni	PhD in Nursing and Health Care	a.alhusayni.1@research.gla.ac.uk	Named Contact
Dr Mark Barber	Consultant Physician in Geriatric Medicine	mark.barber@lanarkshire.scot.nhs.uk	Named Contact