# An exploration of the barriers and enablers of using electrically assisted bikes (e-bikes) in the development of a stroke intervention for people after stroke.

**by**

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A thesis submitted in partial fulfilment for the requirements for the degree of MSc (by Research) at the University of Central Lancashire

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# ABSTRACT

***Background:*** Recently there has been an increased interest in the development of innovative approaches within stroke rehabilitation interventions to ensure long term maintenance of physical activity levels within the stroke population. Electrically assisted bikes (e-bike) have been shown to be an alternative form of physical activity for sedentary individuals and those with physical limitations. Currently the research into the use of e-bike by stroke survivors is limited and has not been explored within the context of stroke intervention design. This study explored the barriers and enablers to using an e-bike by stroke survivors in the development of a stroke rehabilitation intervention.

***Methods:*** A mixed methods case study approach using semi-structured interviews and e-bike usage data was used. Six stroke survivors with the ability to walk with or without assistance, were recruited from stroke support groups. Subject to approval from their doctor, participants had the opportunity to loan either an e-bike or e-trike for a duration of up to three months. Data collection was carried out over three phases: Pre-loan, during the e-bike loan and post e-bike loan. Semi-structured interviews were conducted pre and post loan to identify barriers and enablers and were analysed within the framework of a behaviour change model (the COM-B model).

***Results:*** Of the six participants, only three went on to loan an e-bike and participate in the post-loan interview. Reasons for withdrawal were because of a lack of storage space, non-approval from their doctor and not feeling comfortable using the e-bike. The analysis using the COM-B model identified that the most common barriers were in relation to the effects of physical impairment, knowledge about the e-bike and fear as a negative emotion. The main enablers were the effect that the e-bike had on fatigue,

social support and the belief that using the e-bike was a mode of physical activity that was enjoyable and good for their health.

***Conclusion:*** The stroke survivors identified several barriers and enablers to using the e-bike. If e-bikes are going to be used as part of a stroke rehabilitation intervention the barriers need to be addressed and build on the enablers to increase physical activity levels post-stroke.

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***'Don't look back, you're not going that way.'***

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***'It's not about being the best, it's about being better than you were yesterday.'***

# PRESENTATIONS

**Conference presentations**:

**Boland, P.**, Connell, L., Thetford, C., Janssen, J., '*Developing a method to explore the barriers and enablers of using e-bikes in the development of a stroke intervention*', Poster presentation, 4th International Health and Wellbeing with Real Impact Conference, Preston, April 2018

**Boland, P.**, Connell, L., Thetford, C., Janssen, J., '*An Investigation into the barriers and enablers of using e-bikes in the development of a stroke rehabilitation intervention.*' Digital poster presentation, National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Career Development Conference: Developing your career in applied health and care research – challenges and opportunities, London, October 2018,

**Competition presentations**

**Boland, P.**, '*An exploration of the barriers and enablers of using electrically assisted bikes in the development of a stroke intervention for stroke survivors.'* Oral presentation, Faculty Round of UCLan Three Minute Thesis competition, Preston, April 2018

**Boland, P**., '*An exploration of the barriers and enablers of using electrically assisted bikes in the development of a stroke intervention for stroke survivors.'* Oral presentation, UCLan final of the Three Minute Thesis competition, Preston, June 2018

**Other presentations**

**Boland, P,** Connell, L., Thetford, C., Janssen, J., *An Investigation into the barriers and enablers of using e-bikes in the development of a stroke rehabilitation intervention.'* Poster presentation, NIHR CLAHRC NWC Research Internship Showcase 2018, Preston, October 2018

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# ABBREVIATIONS

| | |
|---|---|
| BCW | Behaviour Change Wheel |
| E-bike | Electrically assisted bike |
| E-trike | Electrically assisted tricycle |
| FAC | Functional Ambulation Categories |
| GPS | Global Positioning System |
| MRC | Medical Research Council |
| UCLan | University of Central Lancashire |
| UK | United Kingdom |
| WHO | World Health Organisation |
| WHOQOL-BREF | World Health Organisation Quality of Life-Bref |

# CHAPTER 1: INTRODUCTION

## *1.1 Background & Rationale*

In the United Kingdom it is estimated that each year 100,000 strokes occur, equating to one stroke every five minutes (Stroke Association, 2018). However, more people are surviving stroke than ever before with 33 million people surviving stroke worldwide, an 84% increase in people surviving since 1990 (Feigin et al, 2013). It is estimated that 1.2 million people are living in the UK surviving a stroke, most of whom will have some of form of disability (Stroke Association, 2018). This presents new challenges in public health care to ensure that this increased number of stroke survivors live fulfilled lives. This is in addition to the demand of an increased number of people requiring access to rehabilitation services (Stroke Alliance for Europe (SAFE), 2015).

A loss of motor function affecting the movement of the face, arm, and leg of one side of the body is a common impairment which can greatly impact on the individual's walking capacity, ability to carry out daily activities, independence and quality of life (Langhorne et al, 2009). Stroke rehabilitation aims to help stroke survivors regain the skills, physiological function and independence by decreasing the effects of long-term disability with use of aiding devices and exercises or adaptations to their living environment or workplace (Varanasi et al, 2011). For example, rehabilitation may help survivors regain their capacity to walk or a return of speech. Stroke rehabilitation is a complex multidimensional process involving the delivery of individual interventions by a variety of clinicians and specialists which commences at the start of hospital care and may proceed long-term, with some stroke survivors requiring months or possibly years of rehabilitation (Varanasi, 2011). Evidence from systematic reviews and

randomized controlled trials indicates that rehabilitation can help recovery post-stroke especially when utilising physiotherapy that is based on high repetitive task-specific training and aerobic exercise (Langthorne, 2009; Veerbeek et al, 2014; Valkenborghs et al, 2017). Task-specific training involves the use of progressive, meaningful, goal-orientated activities which allow stroke survivors to undertake activities of daily living (Hubbard, 2009). Despite evidence indicating improvements in the quality of stroke rehabilitation research over the past four decades (McIntyre et al, 2015), stroke survivors still face significant barriers to activities and participation in their daily lives. Statistics show that 40% of stroke survivors are living with a moderate to severe disability (Hartman-Maeir et al, 2007; Stroke.org, 2018) and as a result are predisposed to a sedentary lifestyle which can increase their chances of a recurring stroke, risk of cardiovascular diseases and depression (Aaron et al, 2016; Billinger et al, 2014; English et al, 2016).

There is a breadth of evidence that physical activity can improve the effects of stroke such as reduced walking ability and low-fitness levels (Pang et al, 2006; Saunders et al, 2014, 2016; Veekbeck et al, 2011). However, stroke survivors face a variety of barriers to physical activity participation. These include: access to transport, cost, access to activities, lack of knowledge about exercise, health problems, as well as the physical impairments of stroke (Nicholson et al, 2013). The effects of stroke can also severely impact on an individual's participation in activities they took for granted prior to stroke such as: social interactions, family relationships, community engagement and the sense of self-worth that are derived from these activities (Robison et al, 2009). Despite an increased focus on physical activity within the scope of stroke interventions, activity levels remain low as they are not maintained after the intervention has finished (Morris

et al. 2016). This has led to a call for more innovative approaches to improve the design and implementation of stroke rehabilitation interventions and ensure the maintenance of physical activity long term (Brainin et al, 2011; Morris et al, 2016).

Cycling is a task-specific exercise that is widely used in stroke rehabilitation interventions due to its similarities to walking (Brown et al, 2005), its capacity to improve muscle strength and muscle control of the lower limbs as well as incorporating muscle activity of the affected side (Fujiwara et al, 2003; Kim et al, 2015). In addition to being a form of physical activity, cycling could also be seen as a leisure activity for stroke survivors (National Institute for Health and Care Excellence (NICE), 2012). However, to date studies involving cycling within the scope of stroke rehabilitation have been confined to stationary bikes or ergometers which do not represent real life usage (Barbosa et al, 2015; Gaskins et al; 2017).

Over the past decade, there has been an increased interest in the role of technology within stroke rehabilitation. Technologies ranging from mobile phone applications and virtual reality training, to the use of robotic assisted training and devices that provide an objective assessment of physical movements, have been developed to improve stroke rehabilitation interventions at home and within clinical practice (Iosa et al, 2013; Kerr & Baillie, 2016; Levin et al, 2015). These technological advancements have coincided with major developments within cycling and the growth in popularity of electrically assisted bikes (e-bikes) (Fishman & Cherry, 2016). E-bikes provide the user with electrical assistance whilst peddling and are recognised as an alternative form of physical activity for individuals with physical limitations or for those that currently lead sedentary lifestyles (Louis et al, 2012; Dill & Rose, 2012). At the time of writing there

is limited research that has focused on the use of e-bikes and stroke survivors and whether it would be feasible for them to be used as part of a stroke rehabilitation intervention.

This thesis aims to explore the barriers and enablers to using an e-bike in the development of a stroke intervention. Chapter 2 provides an overview of existing literature on stroke and physical activity, the current research surrounding e-bikes, and intervention development within the context of stroke. The mixed methods approach and procedures for data collection and analysis will be outlined in Chapter 3 in addition to the aims and objectives of the study. Chapter 4 reports the results of the study, detailing information about each case study, the barriers and enablers of using an e-bike by stroke survivors in addition to bike usage data. Chapter 5 will discuss the findings of this study in relation to the current research, the implications of the study in relation to intervention design and the strengths and limitations of this study. Finally, Chapter 6 will provide a conclusion to the research.

# CHAPTER 2: LITERATURE REVIEW

This review provides context for the current body of work surrounding the development of stroke interventions, physical activity post stroke and e-bike technology.

## *2.1 Development of a stroke rehabilitation intervention*

Stroke rehabilitation interventions are complex meaning they are multifaceted, with many inter-connected components which have the primary aim of addressing post-stroke problems (Walker et al, 2017). As mentioned in the introduction and discussed in more detail later in this chapter, stroke survivors face a number of barriers to physical activity and therefore the aim of complex interventions that are focused on increasing physical activity levels, are to address these barriers and promote behaviour change (Craig et al, 2013; Morris et al, 2014). Recently, experts within stroke rehabilitation have highlighted the need for complex interventions to be developed within a structured framework in order to improve the effectiveness of how interventions are developed and evaluated (Walker et al, 2017). The Medical Research Council (MRC) Framework for the development and evaluation of complex interventions (Craig et al, 2013) has been widely used within the context of stroke rehabilitation (Walker et al, 2017) and relating to studies involving stroke survivors and their carers (Robinson et al, 2005; Tilling et al, 2005; Krieger et al, 2016).

The MRC Framework is a flexible, non-linear approach consisting of a number of phases and this study is positioned within the developmental phase of the framework as shown in Figure 1 (Craig et al, 2013). Within the development of a complex intervention the MRC recommend that best practice requires that interventions should be developed utilising appropriate theory (Craig et al, 2013). The use of theory allows

for a better understanding of the process required for behaviour change to take place within the population the intervention is targeting (Craig et al, 2008). In a systematic review by Redfern and colleagues (2006) the MRC Framework was used to assess the quality of complex interventions in stroke care and if they are based on relevant theory. In the review, 67 studies, which included 39 randomized control trials were analysed and it was reported that 63% of studies were developed having some form of theoretical basis but only 21% were deemed to have been well developed theoretically. To determine if an intervention was theoretically well-developed the author utilised recommendations from the MRC Framework (Craig et al, 2013) to determine a quality criteria which included the use of an established theoretical framework. It was concluded by the author that the lack of appropriate theory when developing or evaluating complex interventions maybe responsible for the failure of many interventions to demonstrate their effectiveness.

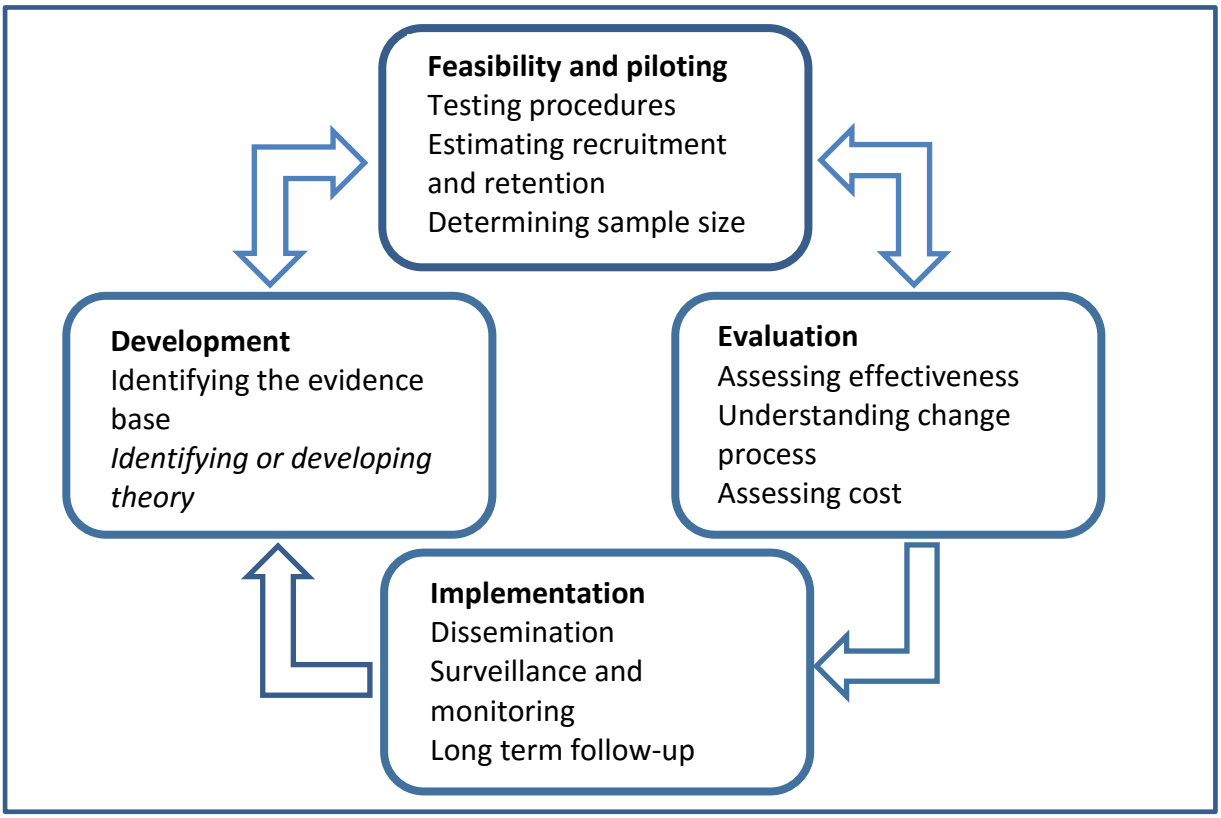


**Figure 1**: **The MRC framework for developing complex interventions (Craig et al, 2013).**

## *2.2 Behaviour Change and the COM-B model*

Despite its importance, there is little guidance on how best to use theory within intervention design (Michie et al, 2011) and there are a variety of theories of behaviour change frequently featuring overlapping constructs (Michie et al, 2014). Together this makes the implementation and evaluation of interventions more difficult (Michie et al, 2011). Michie et al (2014) developed a framework that tackles this problem and assimilates behaviour change theory into the development of complex interventions. The Behaviour Change Wheel (BCW) (see Figure 2) is a theoretical framework based on an amalgamation of various models of behaviour change designed to help guide the thinking behind the factors that affect a change in behaviour (Michie et al, 2014).

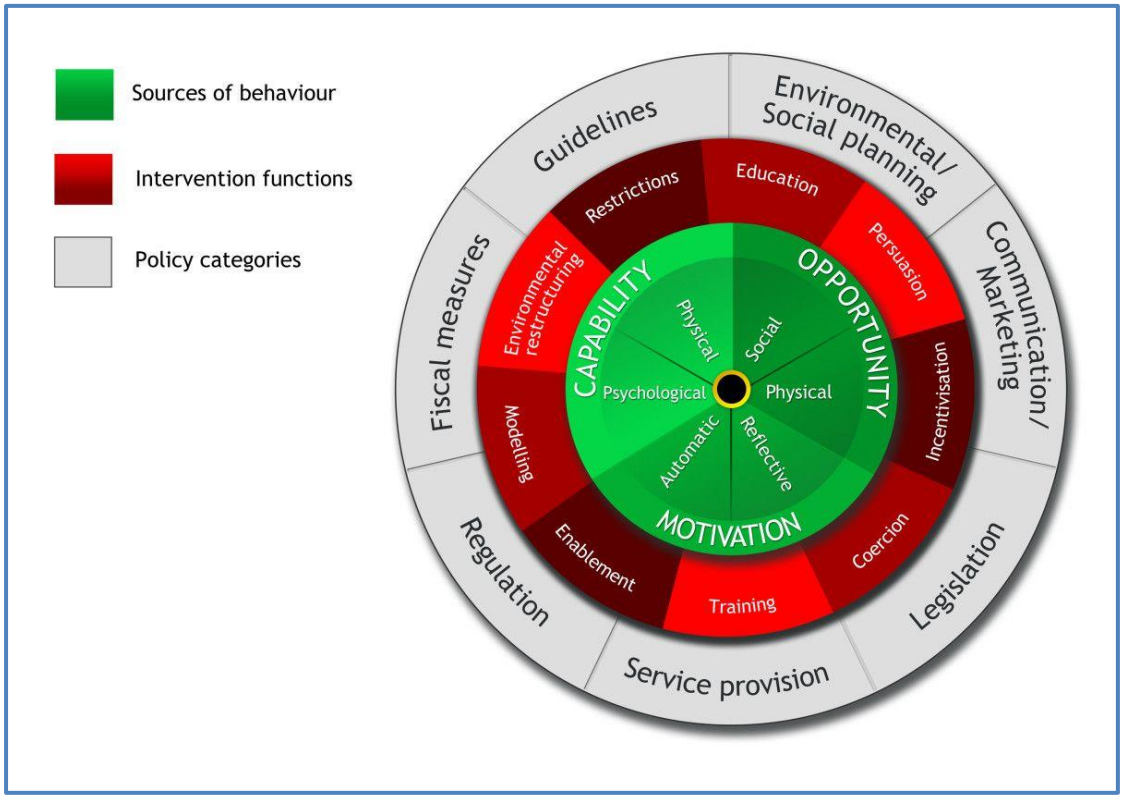


**Figure 2**: **The behaviour change wheel (Michie et al, 2011). Permission to use this image has been provided by Susan Michie and Robert West, two of the journal authors (Appendix 1)**

Figure 2 depicts the BCW as a three-layered system. This study focused primarily on the first two layers. The inner layer represents the components of behaviour also known as the COM-B model (Figure 3). Within this model is it theorised that in order for behaviour change to occur individuals need a combination of capability (C), opportunity (O) and motivation (M) which will explain why a specific behaviour (B) is or is not occurring (Michie et al, 2014). These components can be further expanded: capability can be physical in terms of skills required or the strength or stamina needed to perform a task. Capability can also be psychological: does the person have knowledge or psychological skills to engage in the necessary mental processes? Opportunity can be physical with regards to environmental factors such as resources, time and location. Opportunity can also be social: interpersonal influences, social cues and cultural norms that influence the way people think. Motivation can be reflective involving plans, self-conscious intentions or beliefs. Finally, motivation can be automatic involving emotional reactions, desires, impulses and inhibitions (Michie et al, 2014).

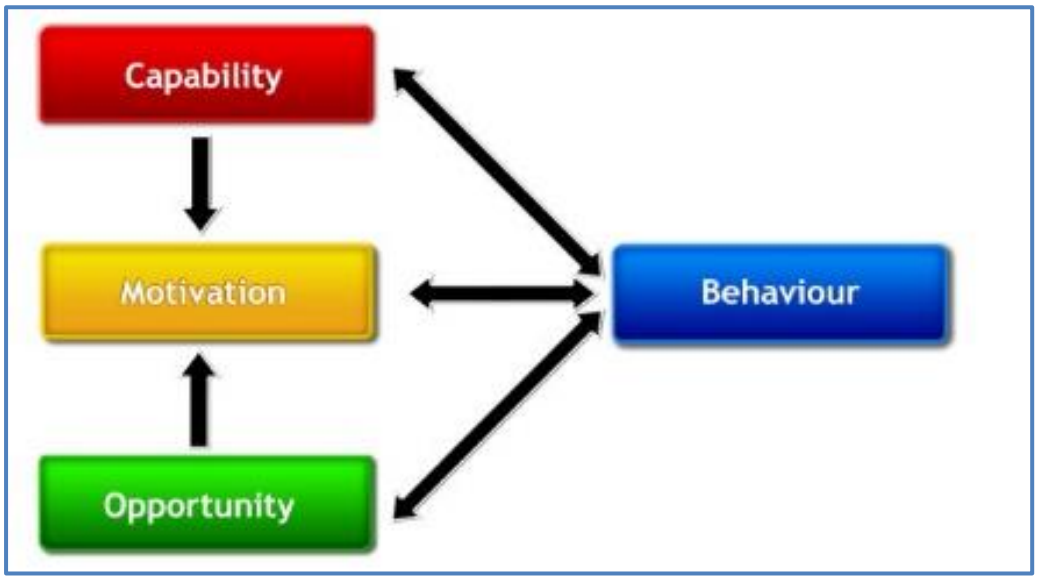


**Figure 3: The COM-B model (Michie et al, 2011). Permission to use this image has been provided by Susan Michie and Robert West, two of the journal authors (Appendix 1)**

As discussed above, the aim of complex interventions is to promote a change of behaviour (Craig et al, 2013) and in order to achieve this we must first understand the factors that influence the uptake of that behaviour i.e. physical activity participation (Morris et al, 2011). In the literature, these factors are described as barrier or enablers and several researchers have looked to investigate how these can impact on physical activity behaviour in stroke survivors (Damush et al, 2015; Morris et al, 2012; 2016; Nicholson et al, 2013; 2017; Resnick et al, 2008; Rimmer et al, 2008; Simpson et al, 2011; Törnbom et al; 2016). The COM-B model has been used to analyse the barriers and enablers in a variety of contexts in healthcare research (Barker et al, 2015; Cassidy et al, 2018; Flannery et al, 2018; McDonagh et al, 2018) and used in the development complex interventions in stroke rehabilitation (Connell et al, 2015; Loft et al, 2017). Recently, Loft et al (2017) used the COM-B model to develop an intervention aimed at strengthening the contribution that nurses play in the inpatient rehabilitation of stroke survivors. Prior to this, the COM-B model was used in a study by Connell et al (2015) to develop an intervention aimed at increasing upper-limb exercise in stroke rehabilitation. The BCW has also been used in research focusing on the behavioural influences in stroke survivors. Nicholson et al (2013) used the Theoretical Domains Framework (Michie et al, 2014): an expansion of the COM-B model to identify the perceived barriers and facilitators to physical activity by stroke survivors. Within this thesis the COM-B model acts as framework for analysis providing the research with a theoretical basis as highlighted within the MRC framework for developing and evaluating complex interventions (Craig et al, 2013).

The second layer of the BCW (Figure 2) shows the intervention functions, a set of broad categories that aim to address the barriers identified from the COM-B model analysis

and bring about a change in behaviour (Michie et al, 2014). Within this thesis, the intervention functions are discussed in Chapter 5 and were used to illustrate what factors would need to change as a result of the analysis using the COM-B model. The third layer of the BCW relates to policy categories which are used to support the execution of intervention functions and these will not be discussed within this thesis.

## *2.3 Stroke & Physical Activity*

There is now good evidence from several randomised controlled trials and systematic reviews that physical activity can positively affect the fitness and wellbeing of stroke survivors (Hill et al, 2012; Pang et al, 2006; Saunders et al, 2013, 2016; Veerbeck et al, 2011). Physical activity is defined as any physical movement that causes energy expenditure because of skeletal muscle contraction (Caspersen et al, 1985). This includes household, occupational and leisure activities. Research has shown that physical activity can improve walking ability (Pang et al, 2006), cardiovascular fitness (Saunders et al, 2013), strength (Hill et al, 2012) and balance (Veerbeek et al, 2014) in addition to improve memory (Cumming et al, 2011), ease depression symptoms (Graven et al, 2011) and post-stroke fatigue (Zedlitz et al, 2012). Moreover, physical activity is considered a method of aiding survivors to adjust to life post-stroke and to the achievement of physical and social goals (Morris et al, 2014). Despite these benefits, stroke survivors report low levels of physical activity even amongst high functioning community-dwelling stroke survivors (Ashe et al, 2009). According to the results of a population-based study by Ashe et al (2009), stroke survivors have the highest proportion of physical inactivity when compared to older adults with diabetes, musculoskeletal, cardiovascular and other chronic diseases.

## *2.4 Stroke & Cycling Post-stroke*

Research has shown that cycling can have a positive impact on the effects of stroke. In individuals with lower limb disorders the primary objective for rehabilitation is the recovery of walking ability (Dickstein, 2008). However, due to a lack of muscle force that provides a support for a secure body weight, some stroke survivors are unable to perform rehabilitation exercises (Barbosa et al, 2015; Dickstein, 2008). Cycling has been shown to share similarities to walking as both are cyclical and repetitive activities (Brown et al, 2005). In addition, cycling has a greater range of motion in the hip and knee joints compared to walking therefore facilitates mobilisation of the lower limb (Lin et al, 2012). For these reasons, cycling is now widely considered an effective method of rehabilitation for stroke survivors (Mazzocchio et al, 2008). To date, cycling in rehabilitation has been used primarily for patients unable to carry out the exercises used in walking rehabilitation and interventions have been limited to indoor activities using stationary ergometers where balance is not a factor and not representative of real life use (Barbosa et al, 2015; Gaskins et al; 2017).

## *2.5 E-bikes*

Over the past decade there have been major developments in cycling with the growth in popularity of e-bikes (Fishman & Cherry, 2016). E-bike are like conventional cycles except they are equipped with a battery and a motor which provides electrical assistance when the person is pedalling (Johnson & Rose, 2015). By European law, e-bikes have a maximum power output of 250 watts and a maximum speed of 15.5 mph (European Union, 2002). To date, research surrounding e-bikes has primarily focused on healthy individuals, although there are studies focusing on older adults who may experience similar barriers to using the e-bike as stroke survivors such as issues surrounding

physical ability and balance (Johnson & Rose, 2015; Spolander, 2007). In addition, e-bikes are being used as a method of transport for those with disabilities (Blumenstein et al, 2014; Gaskins et al, 2017; Wheels for Wellbeing, 2017a). According to survey data by Wheels for Wellbeing (2017a), a cycling charity based in South London, 18% of disabled cyclists currently use an e-bike. E-bikes have been shown to provide an alternative form of physical activity for those with physical limitations such as low levels of fitness and for sedentary individuals looking to attain a moderate level of physical activity (Gojanovic et al, 2011; Louis et al, 2012; MacArthur et al, 2014; Dill & Rose, 2012). This is due to the minimal amount of effort required to pedal in comparison to conventional cycles (Louis et al, 2012). Simons et al (2009) found that e-bike users are capable of meeting guidelines for moderate physical activity defined by reaching heart rates of 67% of their maximal capacity (%HRmax). According to the American College Association of Sports Medicine, exercise intensities of at least 64-76 of %HRmax are considered to provide health enhancements in healthy adults (Garber et al, 2011). For stroke survivors it is recommended that they participate in three to four, 40-minute sessions of moderate or vigorous activity per week (Kernan et al, 2014). The work of Linder et al (2015) has shown that stroke survivors using motorised bicycles are capable of exercising at moderate intensity for sustained periods. They reported that a 46-year-old male participant who had 11 months prior, experienced an ischemic stroke and was only able to ambulate short distances with the use of a cane was able to exercise at a moderate intensity for the majority of a 45-minute session which was repeated three times a week over the course of eight weeks. However, it should be noted that this was a single participant case study, that took place in a clinical environment and a stationary motor driven bicycle the bike was used and not an e-bike.

## *2.6 Barriers and enablers to using an e-bike and physical activity*

Stroke survivors face a variety of barriers to physical activity and to develop effective interventions is it important to understand the barriers and enablers that prevent or encourage participation in physical activity. Over the past two decades, several qualitative studies and reviews have been published that have explored the barriers and enablers to physical activity for stroke survivors (Damush et al, 2015; Morris et al, 2012; 2016; Nicholson et al, 2013; 2017; Resnick et al, 2008; Rimmer et al, 2008; Simpson et al, 2011; Törnbom et al; 2016). Barriers are identified as perceived obstacles to engaging in behaviour which may help enhance health and prevent disease (Nicholson et al, 2013) and enablers are often referred to in the literature as motivators or facilitators and refer to factors that support, enhance or facilitate participation in physical activity (Rosenkranz et al, 2013). Barriers and enablers are generally categorised as psychological, social, environmental and physical factors (Morris et al, 2012; Nicholson et al, 2013) which also correspond with the core components of the COM-B model (Michie et al, 2014). At the time of writing, the research focusing on the factors effecting e-bike usage and outdoor cycling within the stroke population has been limited to two unpublished studies by Gaskins et al (2017) and McMahon et al (2016).Within this study the COM-B model acted as a framework for analysis and a guide to understanding the barriers and enablers to using an e-bike by stroke survivors which also acts as a starting point in the development of a stroke intervention. The COM-B model was also used as a framework within this literature review to breakdown the current barriers and enablers to physical activity by stroke survivors and explore current e-bike research.

### 2.6.1 Physical Capability

Physical capability relates to having the necessary strength, skill and stamina to carry out a behaviour (Michie et al, 2014). Within the context of stroke this has predominantly been in relation to the effects of physical and cognitive impairment. In a study by Damush et al (2007) using focus group data, stroke survivors felt that their physical impairment prevented them from engaging in physical activity due to problems with their vision and walking abilities. However, the possibility to regain the capacity to walk, improve balance and other physical benefits have been shown to be enablers to physical activity (Resnick et al, 2008).

According to structured interview data by Gaskins et al (2017) 57% of participants reported being unable to hold on to the handlebars and 43% reported having problems keeping their feet on the pedals, although it should be noted that only seven people took part in that portion of the interview and the questions were in relation to normal cycling. McMahon et al (2016) also reported that the stroke survivors had issues concerning balance and that they would require assistance mounting and dismounting a bike, barriers which were also encountered by older e-bike users (Johnson & Rose et al, 2015). It should also be noted from Gaskins' (2017) study that only one of the participants owned an e-bike and only one person tried one on the day of the study and in McMahon's (2016) research none of the participants were e-bike users.

Despite physical impairment featuring as a barrier to cycling in stroke survivors, research has reported that the e-bike has encouraged those with health problems to cycle. According to Jones et al (2016a), the most common reason for individuals purchasing an e-bike was due to a decline in physical ability because of a health

condition with participants citing a lack of strength and stamina as reasons for purchase. Likewise, strength improvement was cited as the main enabler for the stroke survivor who purchased an e-bike in the study by Gaskins et al (2017) and that the electrical assistance provided by the e-bike could also help those stroke survivors who do not have the strength to generate the force required to pedal (McMahon et al, 2016) Some stroke survivors have been shown to encounter a loss of upper body strength as well as grip strength as a result of hemiparesis, a weakness on one side of the body (Renner et al, 2009). Conversely, in a report by Spolander (2007) analysing the needs and requirements of older cyclists, it was highlighted that a lack physical fitness and strength presented safety concerns. Physical strength deteriorates with age and it was noted that older riders may not have the upper body and grip strength to operate brake levers on the bike. This evidence would suggest that using the e-bike to regain strength and stamina post-stroke could be an important factor for stroke survivors and it would be important to consider the adaptations that might be needed to aid those that have reduced strength. Adaptations needed may include moving the brakes to one side, so they can be operated by one hand.

Fatigue is a common symptom of stroke which is described as 'a subjective experience of extreme and persistent tiredness, weakness or exhaustion after stroke, which can present itself mentally, physically or both and to unrelated to previous exertion levels' (Zedlitz et al, 2012, p1046). Therefore, the effects of fatigue have shown to be a barrier to physical activity in stroke survivors (Shaughnessy et al, 2006). In a recent study by Nicholson et al (2017), using the Mutrie Scale (Mutrie et al, 1993) to identify the most influential barriers and motivators to physical activity within a cohort of 50 acute stroke survivors, 48% of participants reported that the most common barrier to physical

activity was ‘feeling too tired’. These findings concur with results from other research (Damush et al, 2007; Törnbom et al; 2016).

In the general population, a common enabler for using an e-bike is to be able to make longer journeys with less exertion especially with regards to hilly areas (Dill & Rose, 2012; Johnson & Rose, 2015; Popovic et al, 2014). Research by Theurel et al (2012) examining the physiological and cognitive responses of e-bike users in comparison to normal cyclists, found that cycling using an e-bike had the effect of reduced muscle fatigue and feelings of exertion. Qualitative research has also shown that the e-bike can positively affect fatigue for those with physical limitations. Semi-structured interview data from 27 e-bike users in Sacramento, California reported that a woman with nerve damage in her legs that prevented her from using a conventional cycle was able to use an e-bike to get around her university campus where she works without getting tired (Popovich et al, 2014). This evidence would suggest that the e-bike could possibly have a similar effect on stroke survivors by allowing them to cycle with minimal effort which may have a positive impact on the effects of fatigue.

### 2.6.2 Psychological Capability

Psychological capability is associated with having the knowledge or psychological skills to carry out a behaviour (Michie et al, 2014). Within research into the barrier and enablers to physical activity in the stroke population, psychological capability primarily relates to having knowledge about physical activity and the importance of physical activity (Nicholson et al, 2013). A qualitative theory analysis using the Theoretical Domains Framework, an extension of the COM-B model by Nicholson and colleagues (2013) reported that knowledge was both a barrier and an enabler to physical activity

with stroke survivors recognising the benefits of physical activity but there was a lack of knowledge of the types of physical activity they could be doing and the intensity to work at.

Despite an increase in the amount of research conducted about e-bikes there are still gaps in the knowledge (Fishman & Cherry, 2016). In a review by Fishman and Cherry (2016) they attribute this to the fact e-bikes are not yet being fully integrated as a travel option in Government established travel and populations surveys, as well as hospital admissions and police crash databases which would help collate data for e-bike usage at a population level (Fishman & Cherry, 2016). In Norway, e-bike usage is low in comparison to conventional cycles and this has been attributed to a lack of knowledge (Fyhri et al, 2017). In a study by Fyhri et al (2017), survey data collected from 4865 participants, showed that only 18% were aware that the motor was activated when pedalling and 33% thought that the battery was recharged by braking. Within studies focusing on stroke survivors, Gaskins et al (2017) reported that stroke survivors were not even sure if they had the physical capability to use the e-bike and indicated a lack of awareness of the adaptations that are available for the e-bike to enable stroke survivors to cycle. This evidence would suggest that there may be a lack of knowledge in general surrounding e-bikes amongst general population which translates to stroke survivors too and could possible act a barrier to use.

### 2.6.3 Physical Opportunity

Physical opportunity relates to environmental factors that are external to the individual, these include having access to resources such as locations, time and the cost to participate in physical activity (Michie et al, 2014). Stroke survivors face a variety of

environmental obstacles which can prevent community engagement and limited access to recreational facilities are a major barrier to physical activity (Rimmer et al, 2008). Survey data collected by Akhtar et al (2013) of 91 stroke survivors living in India reported that the lack of accessible facilities was a key barrier to physical activity, results that coincide with previous research (Rimmer, et al, 2008). A lack of transport and a reliance on friends and family for transportation to physical activity facilities has been shown to be a barrier to physical activity for stroke survivors and has been commented on in several papers (Akhtar et al, 2013; Damush et al, 2007; Nicholson et al, 2013; Rimmer et al, 2008).

The e-bike may be able to mitigate some of these barriers as it can provide a mode of transport and independence for stroke survivors with mobility issues, do not drive or are unable to use conventional cycles. According to a recent survey by Wheels for Wellbeing (2017a) disabled cyclists use their bikes for a variety of reasons: 84% agreed that they cycle for leisure or fun, 76% agreed that they cycled as a mode of exercise, 48% cycle as a means of transport and 29% commute to work by bike, evidence also which concurs with older e-bike users (Jones et al, 2016a). In the same research by Wheels for Wellbeing (2017a) they reported that 69% of disabled cyclists find cycling easier than walking. Due to the speed and assistance of the e-bike, research has shown that users are able to make more journeys over a greater distance, tackle journeys they probably would never have considered making on a conventional cycle and has also shown to replace trips made by foot (Jones et al, 2016a; Langford et al, 2013; Popovic et al, 2014). Given that mobility can be a significant problem for stroke survivors because of impairment (Stroke Association, 2018) the evidence suggests that the e-bike

may be able to provide a mode of transport for stroke survivors and allow them to travel to places that may be difficult to ambulate by foot.

Moreover, whilst there are benefits to using the e-bike as a mode of transport there are number of barriers with regards to the design of the bike. The e-bike is considerably heavier than a conventional cycle due to the added weight of the battery: a standard two-wheel e-bike can weight approximately 25kg compared to the 16kg of conventional cycles (Schepers et al, 2014). This extra weight can affect the manoeuvrability of the e-bike, especially when trying to park, fix to a bike rack, place on public transport and lift over obstacles (Dill & Rose, 2012; Jones et al, 2016a; Popovich et al, 2014). As was already noted, a reduction in strength because of stroke is a problem for some stroke survivors (Renner et al, 2009) therefore the weight of the e-bike maybe a barrier to its use. However, it has also been reported that the additional weight of the e-bike in comparison to conventional cycles has made users feel safer and more stable (Dill & Rose, 2012). With stroke survivors the additional weight may affect issues concerning balance especially when mounting and dismounting the e-bike or riding at low speeds which was reported in research involving older e-bike users (Johnson & Rose, 2015; Spolander, 2007). Within the scope of this research, these issues may affect the choice of e-bike that the stroke survivors chose. Similar research around stroke survivors and outdoor cycling has seen participants opt for a tricycle due to concerns around balance and safety (McMahon et al, 2016).

The additional weight of the e-bike has shown to feed into what has been coined ‘range anxiety’, the fear of not having sufficient battery power to reach your destination (Popovich et al, 2014). The duration of how long the battery lasts for is dependent on

how much assistance is being applied and it can be difficult to predict how long a charge will last (Popovich et al, 2014). Due to this some e-bike users have reported that they have had to take a spare charger with them which increases the weight they are carrying (Jones et al, 2016a; Popovich et al, 2014). This also has the added problem of locating somewhere to charge the e-bike. Charging is usually performed at home or at work as charging points are not readily available which can prevent people from making longer trips (Jones et al, 2016a; Popovich et al, 2014). Taking this into consideration, battery life maybe a barrier to use by stroke survivors depending on the length of journey the stroke survivors intend to make and having a plan in place should they run out of battery on a journey.

Safety has been identified as a barrier to using the e-bike both by stroke survivors and the general public especially with regards to other road users and the speed of the e-bike. Despite the speeds of the e-bike being shown to be a main benefit due to the ability to make more journeys over a greater distance it has also been identified as a barrier (Jones et al, 2016; Popovich et al, 2014). The higher speed of the e-bike in comparison to conventional cycles means the severity of an accident increases and the unexpected speeds of the e-bike puts older or inexperienced e-bike users at risk (Popovich et al, 2014; Schepers et al, 2014). Research by Popovich et al (2014) and Jones et al (2016a) both reported concerns with regards to speed especially the difficulty in distinguishing the e-bike from conventional cycles by pedestrians and other road users when traveling at high speeds. In the study by Gaskins et al (2017) exploring the barriers to using the e-bike by stroke survivors, other road users were cited as a barrier to cycling. However, the speed of the e-bike was not deemed a barrier to the stroke

survivors taking part; this may have been due to the fact that the study was based on speculation rather than experience.

Cycling infrastructure is key to allowing cyclists to ride safely and to navigate from A to B. Recent evidence has identified that disabled cyclists face a variety of barriers to accessing cycling infrastructure and cycling networks (Andrews et al, 2018; Clayton et al, 2017; Wheels for Wellbeing 2017a, 2017b). Interview data from Jones et al (2016a) reported that able bodied e-bike users in the UK and Netherlands experienced problems with infrastructure such as cycle paths not being wide enough, poor surface quality, lack of dedicated space for cycling and parking facilities. These barriers are also shared amongst disabled cyclists, especially the width of cycle paths which could prove difficult for cyclists who are using tricycles or adapted cycles (Clayton et al, 2017). Other barriers caused by poor cycling infrastructure include traversing around obstacles such as bollards, kerbs, and access barriers which require the user to dismount their cycle which is especially difficult if their bike is being used as a walking aid (Clayton et al, 2017; Wheels for Wellbeing 2017b). It is because of these barriers that cycling infrastructure has been cited as the biggest difficulty encountered by cyclists with disabilities (Wheels for Wellbeing, 2017a) and there are calls for policy makers to make cycling infrastructure more inclusive (Andrews et al, 2018; Clayton et al, 2017; Wheels for Wellbeing, 2017a, 2017b). Research focusing on stroke survivors and cycling reported that participants are reluctant to venture on to the roads and would only cycle in areas away from traffic (Gaskins et al, 2017; McMahon et al, 2016). Given the issues that have been identified surrounding cycling infrastructure, stroke survivors may encounter similar barriers whilst using the e-bike and this would not only be an important consideration when developing an intervention but also serve as evidence of

the need for a more improved cycling infrastructure and increase the limited knowledge base around the barriers to disabled cycling.

Cost is a common barrier to using an e-bike (Dill & Rose, 2012; Gaskins et al, 2017; Jones et al, 2016a; Popovich et al, 2014). E-bikes can range in price from £500 to upwards of £2000 and extras such as a spare charger or battery can also increase the cost in addition to any possible adaptations that might be required because of an impairment (The Telegraph, 2018). In the recent study by Gaskins (2017) the price of the e-bike was the main discouraging factor however 60% of the stroke survivors asked also felt an e-bike was affordable. Other research has found that the concerns around cost arise from the possibility of it being stolen and insufficient places to park (Jones et al, 2016a; Popovich et al, 2014). In comparison to some conventional cycles, e-bikes can be considered expensive however depending on the number and length of trips made an e-bike can prove to be cost effective especially in comparison to a car (Dill & Rose; 2012; Jones et al, 2016a; Popovich et al, 2014). In this study the stroke survivors were not expected to purchase the e-bikes and therefore cost may not factor as a barrier, however it could be a barrier if they wish to purchase one after having the experience of using one and when developing an intervention, cost is an important factor to consider (Walker et al, 2017).

Stroke survivors are not a homogeneous group and consequently their needs will vary (Xin Li, 2017). E-bikes can be adapted to meet these needs and enable stroke survivors to cycle (Clayton et al, 2017). The research involving stroke survivors and cycling has reported contrasting views on the role of adaptations. Gaskins et al (2017) found that stroke survivors were receptive to the use of adaptations, citing that the use of the e-

bike would be impractical without them. For participants who were not currently cycling, the use of adaptations could encourage them to cycle. It was also noted in the same study that there was also a lack of awareness of the types of adaptations available. This coincides with recent research into the use of adapted cycles and have found that they have the benefits of increasing confidence and were pleasurable to use, although in this research it was not clear if e-bike were used (Clayton et al, 2017). However, according to McMahon et al (2016) stroke survivors had a different view of the use adaptations, stating that they may inadvertently cause anxiety and increase the risk falling, especially regarding adaptations that involve being strapped to the bike. This evidence would suggest that careful consideration should be made with regards to the adaptations required by the stroke survivors and that additional support may be required to ease any concerns that the participants may have.

### 2.6.4 Social Opportunity

Social opportunity relates to influences from friends, family, healthcare professionals and fellow stroke survivors and has been shown to be a key enabler to physical activity in stroke survivors (Nicholson et al, 2012; Michie et al, 2014; Morris et al, 2012). In a recent study by Morris et al (2017) analysing the barriers and enablers to physical activity of 38 community dwelling stroke survivors reported that not only was social support from friends, family and healthcare professionals required to participate in physical activity but the opportunity to be sociable through physical activity was also an enabler. Research has shown that group exercise, particularly with fellow stroke survivors can have a positive effect on adherence to physical activity and can create a sense of being part of a team (Morris et al, 2012; Resnick et al, 2008). Similarly, research into the barriers and enablers to using an e-bike both in the general population

and stroke survivors has highlighted the importance of social support. According to research by Popovich et al (2014) the influence of family, friends and respected peers was a key factor in the purchase of an e-bike. Survey data from older individuals in Australia (Johnson & Rose; 2015) reported that 27.5% of respondents listed keeping up with friends and family as a reason for purchasing an e-bike and likewise research by Gaskins et al (2016) reported that 30% of stroke survivors gave 'Social' as a reason for wanting to cycle.

Stroke can leave survivors prone to social isolation, increasing the risk of depression and a slow recovery (Stoke Assocation.org, 2015). Research has shown that cycling can have a positive effect on social outcomes. In a recent exploratory study by Hreha et al (2018) investigating the physical, psychological and sociable resilience of stroke survivors taking part in a 16-week cycling program using adapted cycling, reported improvements across all three measures. The study did not indicate whether e-bikes were used, but the author states that adapted bikes could have a positive effect on social outcomes, especially with those who face social isolation, which could be inferred to be the case for e-bikes. Similarly, research exploring the barriers and enablers to outdoor cycling in stroke survivors identified that the desire to be part of a cycling community was a key enabler for stroke survivors (McMahon et al, 2016). This concurs with the research by Clayton et al (2017) which looks at the barriers that disabled people face with regards to cycling in which it recognises the importance of community engagement and social inclusion as a means of improving wellbeing and combating the current inequalities that disabled people encounter because of poor infrastructure.

Is has been reported in research into disabled cycling that the level of support required is dependent on the level of impairment experienced (Clayton et al, 2017). Research focusing on stroke survivors and cycling participation has identified the need for support, especially with regards to transporting, and mounting and dismounting a bike (McMahon et al, 2016). Therefore, taking this into consideration, social support is an important factor in enabling stroke survivors to cycle and as this study was carried out in natural setting and not in a controlled environment then the participants taking part may need assistance from friends, family and caregivers to use the e-bike.

Despite the positive aspects concerning social support and e-bike usage it has also been recognised in some studies that there is a stigma attached to using an e-bike both by the general public and stroke survivors (Dill & Rose, 2012; Gaskins et al, 2017; Jones et al; 2016a; Popovich et al, 2014). It is believed generally between non-e-bike users or those of conventional cycles that the use of an e-bike could be seen as a form cheating because of the assistance provided as well as a perception they are meant for recreational use only and are primarily aimed at lazy, disabled, overweight or older people (Dill & Rose, 2012; Jones et al, 2016a, 2016b; Popovich et al, 2014). Research by Gaskins et al (2016) identified that stroke survivors also shared the perception that the e-bike is cheating with participants claiming they were not interested in using an e-bike because they felt it would not train their weaker side and build up strength. A reaction to this stigma is that people feel self-conscious or apologetic about using an e-bike (Dill & Rose, 2012). This perception could be due a lack of understanding about the use of the e-bike and its benefits and therefore this research may increase the awareness of e-bikes as a mode of transport for stroke survivors.

### 2.6.5 Reflective Motivation

Reflective motivation refers to plans, self-conscious intentions and beliefs (Michie et al, 2014). With regards to physical activity and stroke survivors, reflective motivation has been in relation to beliefs about physical activity, beliefs about capability, self-identity and goal setting.

Research into the motivating factors associated with stroke survivors and cycling has found that the positive effects on health, fitness and wellbeing were key enablers (Gaskins et al, 2017; McMahon et al, 2016). These findings concur with research conducted regarding e-bike usage in the general population (Dill & Rose, 2012; Jones et al, 2016a; Ling et al, 2017; McArthur et al, 2014; Popovich et al, 2014). The belief stroke survivors are going to benefit from using the e-bike in terms of physical activity is an important factor in behaviour change. According to Bandura (2004) knowledge of the health risks and benefits of a behaviour is a prerequisite to change and therefore if the stoke survivors are aware of the benefits of using the e-bike then they are more likely to use it a means of physical activity.

The opportunity to get out of the house and do something independently were also identified as enablers to cycling (McMahon et al, 2016). Research has shown that many stroke survivors do not have the aerobic fitness levels fundamental to independent living (Cress & Meyor, 2003). A meta-analysis by Pang et al (2013) revealed that despite evidence that suggests aerobic exercise can provide improvements in aerobic fitness, walking speed and walking endurance in individuals who have had a mild to moderate stroke, the effects on quality of life such as independence were inconclusive. However, recent survey evidence has shown that many disabled people find cycling

easier than walking due to the fact it is a non-weight bearing activity, reduces the pressure on joints, can aid balance for those using a bicycle as a walking aid and relieve breathing difficulties (Clayton et al, 2017; Wheels for Wellbeing, 2017). Cycling has also been shown to provide the same sense of freedom for disabled cyclists as it does with the general population (Clayton & Musselwhite, 2013; Clayton et al, 2017) Given the assistance that the e-bike provides it may provide the opportunity for stroke survivors to gain increased independence and venture out of the house more often.

Belief about capabilities relates to how confident a person is in their ability to undertake a specific behaviour and can influence the control they believe they have over their own body and social influences (Dixon, 2008; Nicholson et al, 2013). In the literature this is commonly known as self-efficacy and if a person has low beliefs in their ability it can severely impact on their confidence and therefore effect their motivation to carry out a behaviour such as physical activity (Dixon, 2008). Research by Nicholson et al (2013) reported that belief about capability was a common factor with regards to physical activity. Stroke survivors with low capability reported that they felt controlled by people around them preventing them from doing things themselves and felt that their physical impairment also hindered their capabilities to exercise with one participant citing his legs as the "guiding factor" to their capability. Conversely, those with high capability reported they were highly motivated to participate in physical activity. Belief in capability maybe an important factor with regards to how confident stroke survivors are using the e-bike particularly with regards to the effect of impairment. Previous research has shown that stroke survivors have reported lacking the confidence in their physical ability to use an e-bike. (Gaskins et al, 2017).

Goal setting is an important aspect of stroke rehabilitation (Stroke Association, 2012) and research has shown that interventions that include goal setting are more effective for encouraging physical activity (Maes & Karoly, 2005). Research by Resnick et al (2008) identified methods of achieving goals using a treadmill-based intervention. The participants taking part were driven by goals such as regaining walking ability and returning to previous activities they participated in prior to their stroke. To nurture these goals, the exercise was progressive in nature in terms of speed and duration, had positive encouragement and regular feedback from trainers as well as manageable targets. These were cited as important factors in the maintenance of the program and assisted the stroke survivors in achieving their goals. Participants who took part reported improvements in leg strength, endurance, balance and mood. According to Bandura's social cognitive theory (2004), personal goals are a key determinant of behaviour change along with belief in capabilities, knowledge of the health benefits of physical activity and perceived barriers and enablers. Therefore, if the stroke survivors are goal orientated then this may influence how often they use the e-bike and their reasons for using it.

### 2.6.6 Automatic Motivation

Automatic motivation relates to emotional reactions, desires and impulses (Michie et al, 2014). Fear has been found to be common barrier to physical activity in stroke survivors. Fear of falling, recurrent stroke and a fear of the consequences of physical activity such as bumping into things or feeling fatigued have featured in several studies as barriers to physical activity (Damush et al, 2007; Nicholson et al, 2013; Törnbom et al, 2016). Similarly, fear has also been cited as a barrier to cycling by stoke survivors. Gaskins et al (2017) reported that 50% of participants reported a fear of falling as a

discouraging factor to cycling. In the literature, fear is identified as a negative outcome of physical activity and is closely linked to a lack of confidence (Dixon, 2008; Morris et al, 2012). Therefore, level of confidence maybe an important factor in the effective use of the e-bike by stroke survivors.

In contrast to the negative emotion of fear which is a barrier to physical activity in stroke survivors, using an e-bike is seen as an enjoyable and pleasurable experience. The sense of enjoyment derived from using an e-bike has been highlighted in several studies within the general public (Langford et al, 2017; MacArthur et al, 2014; MacArthur; 2017; Popovich et al; 2014; Sperlich et al, 2012) and research in to the experiences of disabled cyclists using adapted cycles have shown they also experience similar enjoyment (Clayton et al, 2017). Therefore, this may be an important enabler for stroke survivors. A key factor in behaviour change is that for people to identify personal benefits and outcomes and for the activity to be enjoyable (Ryan & Deci, 2000). Therefore, if the e-bike can provide the benefit of being enjoyable for stroke survivors then it is more likely they will increase their usage and thus increase their levels of physical activity.

## *2.7 Aims and Objectives*

### 2.7.1 Aim

The aim of this research was to explore the barriers and enablers of stroke survivors using an e-bike in the development of a stroke intervention using a case study approach.

### 2.7.2 Objectives

1. To use the COM-B model to guide the understanding of the barriers and enablers to using an e-bike in the context of stroke.
2. To explore e-bike usage during a three-month loan period of an e-bike.

## *2.8 Summary*

To date, research into the barriers and enablers of using an e-bike by stroke survivors is limited and no research was found utilising e-bikes within the context of developing a stroke rehabilitation intervention. In this literature review the possible benefits of using an e-bike by stroke survivors were explored as were the barriers and enablers to physical activity and e-bike usage (see Table 1 for a summary). This research will increase the understanding of the barriers and enablers to using an e-bike by stroke survivors and acts as a starting point in the development of a complex intervention.

**Table 1: A summary of the barrier and enablers to physical activity and using the e-bike as identified by the literature**

| | ***Barriers (-) & Enablers (+) to physical activity and using the e-bike*** |
|---|---|
| ***COM-B Model Component*** | ***Literature review*** |
| *Physical Capability* | - Impairment to arms and legs<br>+/- Fatigue<br>- Balance |
| *Psychological Capability* | +/- Knowledge about physical activity<br>- Knowledge about the e-bike/adaptations |
| *Physical Opportunity* | - Accessible facilities<br>- Cost<br>- Transport<br>+/- Infrastructure<br>- Weight of the e-bike<br>- Battery<br>+/- Adaptations |
| *Social Opportunity* | + Social support<br>+ Socialise<br>- Stigma |
| *Reflective Motivation* | + Fitness/health/wellbeing<br>+/- Get out more<br>- Independence<br>+/- Belief about capabilities<br>+ Goal setting |
| *Automatic Motivation* | - Fear of falling<br>- Fear of recurrent stroke<br>- Fear of consequence of physical activity<br>+ Enjoyment |

# CHAPTER 3: METHODS

## *3.1 Introduction*

The previous chapter provided a review of existing literature regarding the use e-bikes within the context of stroke and intervention design. This chapter will describe the method used to fulfil the objectives of the study, the sampling strategy and finally the procedures for data collection and analysis is discussed. Chapter Four reports the main results of the research, followed by a discussion of these findings in Chapter Five.

## *3.2 Methodology*

Within the field of stroke, Walker et al (2017) suggested for interventions to be robust, meaningful and implementable they should be developed within the confines of a framework. The MRC Framework for the development and evaluation of complex interventions (Craig et al, 2013) was selected because it is widely used within the development of stroke rehabilitation interventions and has been used to review complex interventions in stroke care (Redfern et al, 2006; Walker et al, 2017). The MRC framework recommends that intervention development is based on appropriate theory to provide an understanding of the process of the behaviour change that is required for the intervention to be effective (Craig et al, 2013). Therefore, the COM-B model, a subsidiary to the BCW (Michie et al, 2014) was selected as a framework for analysing the barriers and enablers to using an e-bike by stroke survivors because of its capability to analyse behaviour and has also been used within stroke and healthcare research (Loft et al, 2017; Connell et al, 2015).

During the initial planning phase, a variety of different methods were considered for data collection. Individual interviews were chosen over focus groups as discussions

may include issues of a sensitive nature that some may prefer not to discuss in a group setting therefore one-to-one interviews would be more appropriate. Semi-structured interviews were selected over structured and unstructured interviews because they are widely used by health care researchers as they allow for an issue to be explored in great depth and for individuals to share their experiences and perceptions (DiCicco-Bloom & Crabtree, 2006). Semi-structured interviews comprise of pre-planned open-ended questions focused around a specific topic or subject with the interviewer having the flexibility to ask further probing questions to capture more in-depth and rich responses (Bryman, 2016).

A mixed-methods case study design was selected because it allows for the exploration of individual's perceptions and experiences in the development of an intervention utilising data from interviews and quantitative data such as bike usage and questionnaires (Baxter & Jack, 2008). It also allows for direct stakeholder involvement i.e. stroke survivors, which is an important facet of intervention development (Craig et al, 2013). Unlike other qualitative methods, case studies also allow for the integration of quantitative data such as questionnaires to provide a more holistic understanding of the topic being studied (Baxter & Jack, 2008).

Participants had the opportunity to use an e-bike within a natural setting. Very few studies have combined the qualitative method of data collection with this practical element and none of these have focused on stroke survivors. Two qualitative studies were found that utilised a similar approach. A Norwegian study by Fyhri et al (2017) used a combination of surveys and e-bike access to explore the barriers to cycling and Jones et al (2016b) combined an e-bike trial with diaries documenting the experiences

of older e-bike riders. The experience of using the e-bike combined with semi-structured interviews will allow for the stroke survivors to document the barriers and enablers to using an e-bike first hand and not just the perceived barriers.

In addition to the collection demographic data (Appendix 2) and to provide a more holistic overview of each participant this study was supplemented by the World Health Organisation Quality of Life-Bref (WHOQOL-BREF) and the Functional Ambulation Categories. The WHOQOL-BREF is a 26-item instrument designed by the World Health Organisation Quality of Life Group (WHOQOL) (1998) (Appendix 3) to assess perceived quality of life. It provides a self-reported measure of an individual's quality of life covering four domains: physical health, psychological health, social relationships and environment (WHOQOL Group, 1998). It was selected because it has good to excellent psychometric properties of reliability and validity (Skevington et al, 2004). The Functional Ambulation Categories (FAC) provide an indication of the level of walking ability and support required by the participants (Holden et al, 1984). The FAC consists of observation of the participant walking and they are aligned a score between zero and five. Zero means that the participant is totally unable to walk and five means they can ambulate independently. For a breakdown of the FAC categories see Appendix 4. The FAC was selected because it easy to administer and took approximately one to five minutes to complete and has shown to have excellent reliability, good responsiveness and good concurrent and predictive validity in stroke survivors with hemiparesis (Mehrholz et al, 2007).

## *3.3 Ethics & Consent*

This study was approved by the Science, Technology, Engineering, Mathematics and Health Ethics Committee at the University of Central Lancashire (UCLan) (STEMH 844) (Appendix 5). All participants provided written consent (Appendix 6) prior to taking part in the study.

## *3.4 Design*

A mixed methods case study approach using semi-structured interviews, the WHOQOL-BREF, FAC, demographic information and usage data from the e-bikes.

## *3.5 Sampling*

A volunteer sample were recruited from local stroke support groups living within a 20-mile radius of UCLan. Groups were made aware of the study via talks at support group meetings and during exercise classes, newsletter advertisements, and meetings with decision makers. The study was also advertised via posters on the UCLan campus (Appendix 7) and staff and student communication bulletins. Due to a short time frame to conduct the research and the number of e-bikes available a maximum number of eight participants were sought for recruitment.

### 3.5.1 Inclusion criteria

Participants were eligible to take part in the study if they had previously had a stroke, were able to walk (with or without assistance) and must have been able to meet the visual requirements of those relating to mobility scooters/powered wheelchairs which states individuals should be able to read a car's registration number from a distance of 12.3 metres (40 feet) (Gov.uk, 2018). All participants must have been able to speak the

English language to a standard that would allow them to participate in an interview, be over 18 years of age and due to the limitations of the e-bike, they must have weighed less than 20 stone (127 kg).

### 3.5.2 Exclusion criteria

To participate in the study fully, participants were required to get written permission via a letter signed by their doctor (see Appendix 8). Participants were excluded if they were unable to obtain this permission or if the doctor ascertained that the participant had any visual, physical or cognitive impairments that prevented them from safely using an e-bike.

## *3.6 External Collaboration*

The project was conducted with support from a local bike company, that specialises in e-bikes and provided assistance during the project in the form of selecting, fitting, adapting and in training participants to use the e-bike safely.

## *3.7 Procedure*

Participants who expressed an interest via direct contact with the researcher at the stroke support groups were provided with an information sheet (Appendix 9) and a copy of the letter to be signed by their doctor. A copy of the information sheet and consent form was also available in large print for any participants with any visual difficulties. Participants who expressed an interest by other means were sent the same information via email or by post. All participants were then given one week to decide if they wished to take part in the study.

The research was carried out over the course of three phases: before the loan of the e-bike, during the loan and after the loan, as summarised in Figure 4 and described in more detail below.

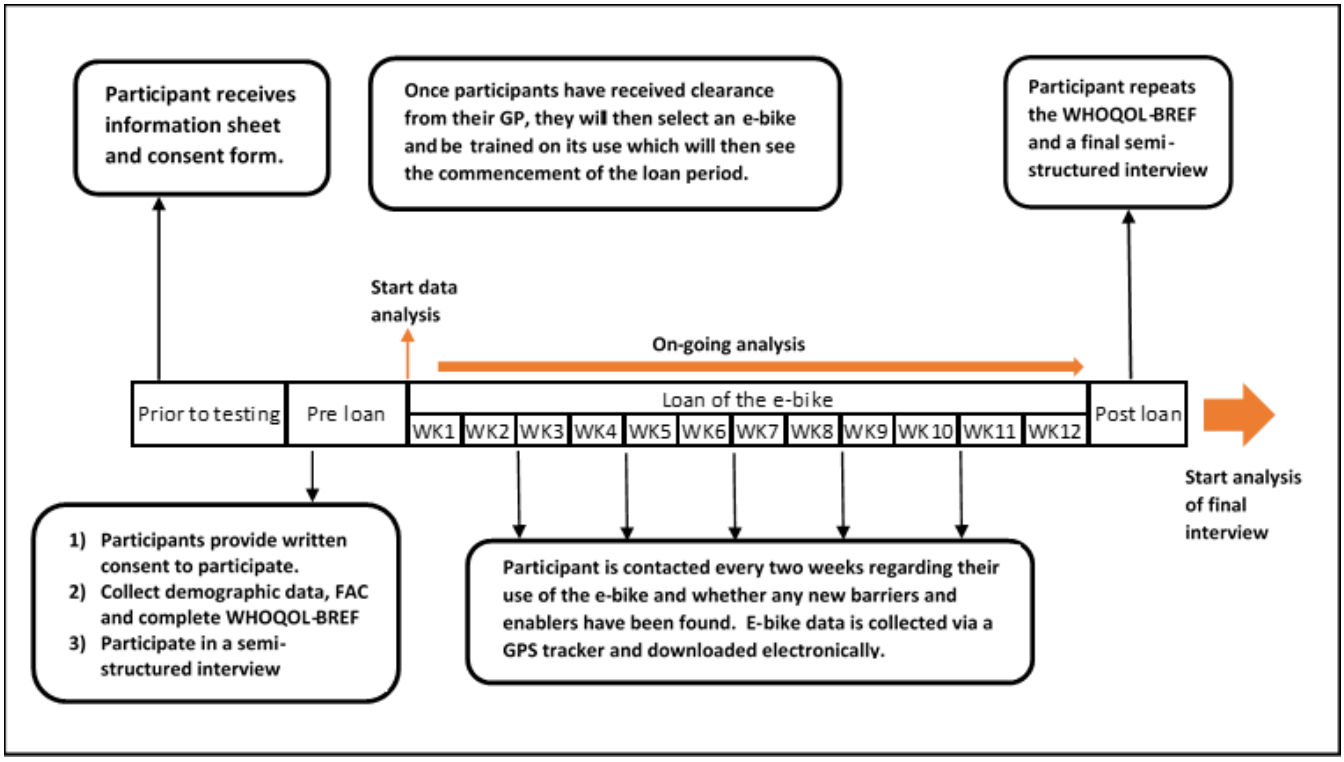


**Figure 4: Data collection and analysis timeline.**

### 3.7.1 Pre-e-bike loan

An appointment was made to meet with the participant at an easily accessible location, such as their home or a location of their choice. The potential participant then provided written informed consent to take part in the study. To describe each case study, demographic information in the form of age, gender, whether it was the participant's first stroke and the length of time since the first stroke occurred was collected as well as completing the WHOQOL-BREF. The WHOQOL-BREF was completed by the participant either with or without assistance from the author or a carer. Due to the sensitive nature of some of the questions, participants had the option to not answer all the questions if they so wished. The participant was then observed walking and their

FAC was recorded. The participant then took part in a semi-structured interview which was digitally recorded using a Dictaphone (Olympus WS-853). The digital recordings were then stored and encrypted on a secure UCLan server ready for transcription.

Semi-structured interviews were used to identify the perceived barriers and enablers to using an e-bike by stroke survivors prior to its use. An interview schedule (Appendix 10) was created based around the COM-B model (Michie et al, 2014), however this was later revised again after the first two interviews were conducts because it was found to be quite restrictive and extra questions and prompts were added (Appendix 11).

The interviews were either conducted with the participant on their own or with their carer or partner present. After an introduction of what the interview entailed and receiving permission to record the interviews, the interview began with a reminder of what an e-bike was and how it functioned. This was then followed by questions surrounding the participant's levels of physical activity before and after their stroke with the purpose of building a rapport and to build a better picture of the case study participant. The next part of the interview focused on why the participant wanted to use an e-bike, what plans they had for using it and if they had any perceived barriers to using one. The interview was concluded with the participant having the opportunity to share any additional information or concerns about using the e-bike.

### 3.7.2 Loaning of the e-bike

Once the participants received clearance from their doctor to confirm that they were safe to use an e-bike, arrangements were made for the participant to be fitted with an e-bike. This involved a representative from the bike company bringing a selection of

e-bikes to the participant for them to choose one that was appropriate for them and highlighting if any adaptations were required to accommodate any disability they may have. Participants were also given the option to be fitted for an e-bike at the bike company premises. Both the author and another member of the research team were present at the fitting of each bike. Once fitted the e-bikes were set up by the bike company for the participant ready for the next visit.

Another visit was arranged for the participant to be trained on how to use the e-bike once the selected e-bike was had been build and adapted. Training was carried out by a representative from the bike company at the participant's home with the author and a member of the research team also present. For participants with severe impairments, the training was supplemented with advice and guidance from the second supervisor, a trained physiotherapist, who was available for additional visits if required. Participants were trained on how to adjust the level of assistance on the e-bike, how to remove the battery for in-door charging and use any of the adaptations that had been made to the e-bike. Participants were monitored cycling up and down their street, ensuring they felt comfortable cycling, allowing them to ask any questions and make any adjustments were made if required. Participants were also provided with a safety helmet, a secure lock, as well as fitted with a LK209C tracker (LK-GPS.com, 2018a). Once training was completed, the loan would commence for a period of up to three months and the participant was contacted every two weeks via telephone to find out if they needed any additional support or if any new barriers had emerged. To record this telephone interaction, a structured interview sheet was designed (Appendix 12) with brief questions on whether the participant had been using the e-bike, if they had encountered any problems and what they had been using the e-bike for e.g. leisure activities,

shopping etc... If the participants encountered any problems in between these calls, they were provided with contact details for both the author and the lead supervisor. Usage data from the e-bike was also downloaded bi-weekly to an Excel (Microsoft 2016) spreadsheet from LK-GPS.net to calculate how long in minutes they were using the e-bike. LK-GPS provides global positioning system (GPS) portable tracking devices that can track in real time the speed and movement of a vehicle and the LK-GPS.net is the interface used to track and download this data (LK-GPS.com, 2018b).

### 3.7.3 The e-bikes


**Figure 5: The e-trike**

As stated above the participants had the opportunity to loan an e-bike for a period of up to three months in which they were provided with an e-bike that is regulated by European law at a maximum power output of 250 W and a maximum speed of up to 15.5 mph per hour (European Union, 2002). Participants had the option of using a standard two-wheel e-bike or a tricycle (e-trike) version (see Figure 5). The choice of e-bike was based on the needs and ability of the participant. All e-bikes were equipped with a low step trough to aid in the ease of mounting and dismounting (Spolander,

2007). Operation of the e-bike is dependent on the user exerting force on the pedals and the battery and motor provide electrical assistance (Peterman et al, 2016). The level of assistance provided can be adjusted using a module on the handlebars. Participants were provided with a safety helmet and a secure bike lock and as part of the informed written consent, they agreed to wear the safety helmet at all times whilst cycling and lock up the bike when it was not in use. The information in Figure 6 indicates the adaptations that were available to meet the participant's needs.

**Arm & Hand**

Glove that straps hand to handlebars
Handle with support for top and bottom of the wrist
Wrist loops that keep the hand in place on handlebars
Brake lever that pulls front and back brake simultaneously

**Leg/Foot**

Pedal with removable magnets to vary magnetic strength to hold foot on the pedal
Pedal to strap foot in place
Pedal with toe clips
Pedal with quick release foot strap

**Balance**

Stabilizer wheels

**Figure 6: Available adaptations to the e-bike**

### 3.7.4 Post e-bike loan

At the end of the loan period, at the participant's home or location of their choosing, participants took part in a final semi-structured interview and repeated the WHOQOL-BREF. Interviews were again digitally recorded using a Dictaphone (Olympus WS-853). These recording were then stored and encrypted on a secure UCLan server ready for transcription. Semi-structured interviews were used to explore the participant's experience of using the e-bike during their loan period. Another interview schedule

was created (Appendix 13) framed around the COM-B model (Michie et al, 2014) in addition to prompts based around information provided during the interview prior to using the e-bike and information gathered during the loan period.

### *3.8 Data Analysis*

Demographic information, e-bike usage data and the results of the WHOQOL-BREF were analysed descriptively in SPSS (IBM Statistics SPSS 24). The results of the WHOQOL-BREF were calculated using the protocol set out by the World Health Organisation for administering and scoring the WHOQOL-BREF (WHO, 1996). The results of the WHOQOL-BREF were divided into four domains: Physical Health, Mental Health, Social Health and Environmental Health. The results for the WHOQOL-BREF completed after the loan of the e-bike were also analysed descriptively. As there appeared to be little advice on applying meaning to the scores from the WHOQOL-BREF, studies that have utilised the WHOQOL-BREF have interpreted the results as such: scores of $\leq 45$ equals low quality of life, scores between 46 to 65 equals moderate quality of life and scores > 65 equal a relatively high quality of life (Ban-Issa, 2011; El Latif et al, 2016).

The data collected from the semi-structured interviews recorded before and after the loan of the e-bike was transcribed, anonymised and coded using NVivo 11 (QSR International). The data collected before the loan of the e-bike was analysed first to identify the perceived barriers and enablers to using the e-bike prior to use. The interview data collected after the loan of the e-bike was analysed later to identify the barriers and enablers experienced whilst using the e-bike. After an interview was transcribed, it was coded using the six components of the COM-B model e.g. physical

capability. This required the author to re-read the data and allocate quotes to the specific components. Quotes were allocated based on the descriptions provided in *The Behaviour Change Wheel: A Guide to Designing Interventions* (Michie et al, 2014 p.63) (see Table 2 for examples). Once it was identified which component the quote applied to these were coded into specific themes relating the component of the COM-B model. For example, if automatic motivation is related to emotions (Michie et al, 2014) and a common emotion that was discussed was fear therefore this was coded under 'Fear' which was a sub-category of automatic motivation. As well as being allocated to a specific component of the COM-B model the quotes were also separated into whether they were a barrier or an enabler.

**Table 2: COM-B model components and examples**

| ***COM-B Model Components*** | ***Example*** |
|---|---|
| *Physical Capability* | Having the strength or ability to cycle |
| *Psychological Capability* | Having the knowledge to be able to cycle |
| *Physical Opportunity* | Having access to places to cycle and the time to cycle |
| *Social Opportunity* | Being influenced to cycle by interpersonal relationships. |
| *Reflective Motivation* | Having the belief that cycling will improve your health |
| *Automatic Motivation* | Feeling excited by being able to cycle. |

**(adapted from Michie et al, 2014)**

# CHAPTER 4: RESULTS

## *4.1 Introduction*

The following chapter documents the results of the study. Firstly, the gender and other characteristics of the sample are described. This is then followed by a summary for each of the participants that took part, for those individuals that were able to loan an e-bike, information collected during that period is included here along information on e-bike usage.

The interview data collected was analysed within the framework of the COM-B model and this chapter describes the barriers and enablers to using the e-bike prior to, during and after using the e-bike. The results are discussed in greater depth in Chapter 5, exploring further the barriers and enablers identified and considered within the context of pre-existing evidence summarised in the introductory chapters.

## *4.2 Case Study Characteristics*

A total of six participants were recruited for the study. However, three participants were unable to loan an e-bike due not being able to store an e-bike in their home, not being able to get doctor's approval and not feeling comfortable using the e-bike. These factors are explained in more detail in the case studies. All the participants names have been changed, they were male with an average age of 63 (SD 6) years. For all except one it was their only incident of stroke with an average time of 31 (SD 26) months since their stroke occurred. The following is an exploration of each of the six case studies pertaining to level of physical activity prior to their stroke and at the time of the study, level of disability including FAC, their perceived quality of life using data from

the WHOQOL-BREF and if they were fitted for an e-bike, a summary can be found in Table 3.

**Table 3: Case study characteristics**.

| ***Participants*** | ***Brian*** | ***Ken*** | ***Jim*** | ***Rob*** | ***Chris*** | ***Tim*** | ***M*** | ***SD*** |
|---|---|---|---|---|---|---|---|---|
| *Age (yrs)* | 72 | 64 | 63 | 56 | 65 | 55 | *63* | *6* |
| *First Stroke* | Yes | No | Yes | Yes | Yes | Yes | | |
| *Time since stroke occurred (months)* | 30 | 72 | 1 | 40 | 36 | 5 | *31* | *26* |
| *Functional Ambulation Category* | 4 | 4 | 5 | 3 | 4 | 5 | | |
| *Living alone or with a partner* | Partner | Alone | Partner | Partner | Alone | Alone | | |
| ***E-bike information*** | | | | | | | | |
| *Able to loan an e-bike (Y/N)* | Y | N | Y | Y | N | N | | |
| *Type of e-bike* | E-trike | - | Two wheeled | E-trike | | | | |
| *Adaptations* | Brakes | | None | Brakes and pedals | | | | |
| ***Quality of life (Pre e-bike loan)*** | | | | | | | | |
| *Physical Health* | 81 | 19 | 81 | 75 | 38 | 44 | *56* | *26* |
| *Psychological* | 88 | 56 | 75 | 81 | 44 | 56 | *67* | *17* |
| *Social* | 94 | 31 | 81 | 75 | 69 | 56 | *68* | *22* |
| *Environmental* | 88 | 31 | 88 | 81 | 75 | 69 | *72* | *21* |
| ***Quality of life (Post e-bike loan)*** | | | | | | | | |
| *Physical Health* | 81 | - | 94 | 63 | - | - | *79* | *16* |
| *Psychological* | 94 | - | 94 | 81 | - | - | *90* | *8* |
| *Social* | ND* | - | 100 | 81 | - | - | *91* | *13* |
| *Environmental* | 81 | - | 100 | 81 | - | - | *87* | *11* |

**Results of the WHOQOL-BREF are scored as ≤ 45= low quality of life, 46-65= moderate quality of life, > 65 = high quality of life. *Brian did not answer all the questions within the Social domain and therefore no score could be calculated.**

## *4. 3 Case Studies*

### 4.3.1 Case Study 1 –Brian

Brian was a 72-year-old man, who lived with his wife and walked with the assistance of a cane. Brian described taking part in a range of activities prior to his stroke these included cycling, golf, swimming and walking. Now Brian maintains activities such as walking, going to the gym and cycling once a week using a specially adapted tricycle at his local running track using provisions set up by the local council. Brian was assessed as having an FAC of five. Based upon the WHOQOL-BREF data recorded prior to loaning the e-bike, Brian reported having a high quality of life across in all four domains. The results of the WHOQOL-BREF taken after the loan of the e-bike were similar however Brian did not answer all the questions within the social domain and therefore no score could be calculated although he did see an increased score in psychological and a drop in the environmental domain.

Brian was fitted with the e-trike which required both brakes to be repositioned to the right-hand side due to his left-side being his most affected side (Figure 7). Despite spasticity in his left arm Brian was able to steer with both hands and grip the handlebars. Due to the impairment in Brian's left leg, his left foot had the tendency to turn outward slightly and therefore a larger pedal was requested when he was fitted for the e-bike. The e-bike was delivered with standard pedals but when Brian was being trained to use the e-bike this did not prevent Brian from cycling as it was discovered that he was able to position his foot on the pedal and it remained in a fixed position whilst cycling. However, this was monitored and if the pedal had become an issue then it would have been replaced. During the training, Brian appeared confident using the e-bike and was

able to cycle up and down his street and was comfortable using the e-bike at its lowest setting for assistance.

**Figure 7: Repositioned brakes**

Brian loaned the e-bike for 11 weeks and during that time he reported that he primarily cycled with his son around the estate where he lived, approximately once a week for about 15-20 minutes. Brian reported that the e-trike supplemented his other methods of physical activity which included golf, going to the gym and using an adapted tricycle at his local running track. During the loan period Brian encountered a new barrier to using the e-bike: Brian was unable to cycle for a few weeks due to his son going on holiday. During this time Brian did not take the e-bike out as his family did not think he would be safe to cycle on his own. Therefore, there was approximately four weeks where the e-bike was not being used. Brian reported a couple of problems with the e-trike saying that he had to adjust both the seat and the brakes. At the start of the loan period, Brian felt that the level of assistance at level two was too fast and therefore kept it at level one, but he did find the assistance helpful and liked the fact he was actually riding the bike himself. The GPS tracker recorded that Brian made on average of one

journey per week for the six weeks he actually cycled with an average journey time of 12 minutes (SD 14 minutes).

### 4.3.2 Case Study 2 - Ken

Ken was a 64-year-old man and lived on his own. Prior to his stroke Ken played rugby with his grandsons and went hunting with his dogs as a form of physical activity. At the time of the interview Ken described his main hobby as fishing with his local stroke support group. Ken was assessed as having an FAC of five and the results of the WHOQOL-BREF indicate that Ken had a perceived low quality of life physically, socially and environmentally and a moderate quality of life psychologically.

When Ken was fitted for an e-bike he did attempt to cycle using a two-wheeled e-bike. Due to the spasticity in his right arm and fist, his right-hand was strapped to the handlebar using an especially adapted glove. However, when Ken began cycling, his weight shifted to the right-hand side setting him off balance. As a result, he was deemed unsafe for him to use a two-wheeled e-bike. It was suggested that an e-trike would be the best option to use, however Ken did not have the space required to store an e-trike in his home and did not feel that the outdoor garage would have been a safe place to store a e-trike and therefore Ken had to withdraw from the study after the first interview. Ken provided consent for his interview data to be used in this study.

### 4.3.3 Case Study 3 – Jim

Jim was a 63-year-old man who lived with his wife. Jim reported a high quality of life across all four domains of the WHOQOL-BREF prior to the loaning the e-bike. The results of the WHOQOL-BREF taken after the e-bike loan showed that Jim still had a

high quality of life across all four domains, but he also increased his scores after the loan of the e-bike. Jim was fitted with a two-wheeled e-bike which required no adaptations because Jim's stroke led primarily to impairments to his speech and swallowing and therefore was able to ambulate freely with an FAC of five. Prior to his stroke, Jim enjoyed playing crown green bowls and owned a bicycle which he used to sometimes transport his heavy bowling equipment to the nearby bowling green. At the time of the interview Jim said walking his dog was his main form of physical activity. When Jim was trained on the safe use of the e-bike he appeared very confident and stable and was comfortable with the assistance that the e-bike provided.

Jim loaned the e-bike for eight weeks using it for shopping, physical fitness and leisure activities, although unexpected high temperatures experienced during the loan period prevented him cycling at certain times. Jim reported no problems with the e-bike and quite liked the upright riding position of the e-bike. The GPS tracker recorded that Jim made an average of 4 journeys per week with an average journey length of 52 minutes (SD 47 minutes) although it should be noted that for first two weeks of the trial no data was recorded due to technical issues with the GPS trackers.

### 4.3.4 Case Study 4 – Rob

Rob was a 56-year old male who lived with his wife Karen. Rob reported a high quality of life in all four domains of the WHOQOL-BREF. The results of the WHOQOL-BREF taken after the loan of the e-bike were consistent with the results reported prior to loaning the e-bike, however his perception of his physical health dropped slightly to become moderate and the social domain increased.

Rob said he did not participate in any physical activity prior to his stroke, however he did consider himself to be more active now. At the time of the interview Rob described how his physical activity consists of walking and attending exercise classes twice a week at his local cardiac rehabilitation charity where he used the treadmill and stationary cycle to exercise. He also had the same equipment at home.

Rob's left side was the most his affected, particularly his left foot which had a propensity to turn outward and therefore used a leg brace to minimise this. Rob walked with the assistance of a walking aid and has spasticity in his left arm and was assessed as having an FAC of three. Rob was fitted with an e-trike which was overseen by the author, the first supervisor and a representative from the e-bike company. Due to Rob's impairment he was unable to grip using his left hand and the left brake was relocated to the right-hand side and he also had to cycle one-handed with his left arm in a sling. To keep his left foot in position the bike was fitted with a self-levelling foot sandal with ankle support which strapped him in place whilst cycling (Figure 8). A strap was attached to the right pedal to keep his right foot secure and due to Rob's impairment, most of power to start peddling is generated from his right leg. Without a strap in place his foot would slide off the pedal. It was noted that for Rob to be able to mount and dismount safely and secure himself in place he would require assistance which was provided by his wife, Karen. Due to the difficulties faced it was suggested by the author and the first supervisor that, in the first instance Rob should concentrate on getting used to mounting and dismounting the e-trike and cycling in open areas free from hazards such as parked cars.


**Figure 8: The self-levelling foot sandal with ankle support and pedal with a strap attached.**

During the first week of loaning the e-trike, a safety assessment was carried out by the author and the second supervisor, a trained physiotherapist in stroke rehabilitation to ensure that Rob can ride the e-bike safely. Assistance was provided on how to mount the e-trike safely and minimise the effort required both by Rob and for Karen who was assisting him. Rob and Karen described how they had spent time since the last visit practicing mounting and dismounting the e-trike and using a local car park to practice cycling. Rob chose to cycle without the electrical assistance of the e-trike as it was deemed too powerful at this stage, even on the lowest setting. Karen expressed concerns about the effort required to get Rob's right foot in the pedal containing the strap and enquired about having another self-levelling pedal or having the same foot sandal as the left side. However, neither of these options were possible as there was no self-levelling pedal found that would allow for a strap to be attached and it was felt that having another foot sandal would be unsafe as it would mean that Rob would be locked into the e-bike on both sides and if an accident was to occur he would not be able to free himself. Karen also enquired about the possibility of having a larger flatter seat

and a back rest, like that of the recumbent stationary cycle they use at the gym as Rob struggled to maintain an upright position on the e-trike due to Rob's weight shifting slightly to his right side whilst cycling. However, due to the design of the e-trike and where the mechanism for removing the battery was attached to the seat it was not feasible to attach a back-rest and a larger seat in the style that Rob was looking for.

Rob loaned the e-bike for eight weeks and used it to cycle around a local football stadium car park to get used to cycling and improve his physical fitness. Rob reported that he had not used the e-trike as much as he had liked due to experiencing aches and pains in his knees. In addition, because the loan period took place during the football world cup, Rob said that he preferred to watch that than cycle. Rob reported that he was adjusting to getting on and off the e-bike. Due to Rob cycling without the use of the electrical assistance it meant he cycled at such a slow speed the GPS tracker was unable to detect his movements. This combined with Rob's wife cycling the e-trike to cycle to the location where Rob would use it, the GPS data was considered unreliable and was not used.

### 4.3.5 Case Study 5 – Chris

Chris was a 65-year-old male who lived on his own in sheltered accommodation and walked with the assistance of a cane and was assessed as having an FAC of four. Chris reported a low quality of life in physical and psychological domains of the WHOQOL-BREF, though a high quality of life with regards to social relationships and the environment he lives in. Chris described walking as his main form of physical activity prior to his stroke which he also maintained after the stroke in addition to attending exercise sessions at the local cardiac rehabilitation charity. Despite receiving clearance

from his doctor to fully take part in the study, extra caution was taken with Chris as it was observed by the author that during the interview that Chris became easily confused and may have had cognitive issues. Therefore, during the fitting for the e-bike, the author was accompanied by the first supervisor to ensure that Chris was safe to use an e-bike and it was agreed that he would contact the warden of his accommodation and notify them of when he was using the e-bike and where he was going. Chris was fitted for an e-trike which required no adaptations, however when Chris was being trained on how to use the e-bike it was discovered that he found cycling outside frightening and tension on his left side increased, which meant he was inadvertently steering the e-bike to the left and into the curb on the road. Chris did not feel comfortable using the e-bike and he decided it was best if he withdrew from the study as he was unable to ride the e-bike safely. However, he did provide consent to use his interview data in this study.

### 4.3.6 Case Study 6 – Tim

Tim was a 55-year-old man who lived on his own in sheltered accommodation and was able to walk unassisted. The WHOQOL-BREF indicated that Tim had a moderate to high quality of life with regards to his psychological wellbeing, socially and environmentally, however he did perceive himself to have poor physical health. Prior to his stroke, Tim was physically active: going on country walks, circuit training, doing yoga and cycling regularly. At the time of interview Tim described walking as his current form of physical activity which he uses as a "form of therapy and a form of exercise" and was assessed as having an FAC of five. Tim was unable to get approval from his doctor to participate in the loaning of the e-bike and therefore had to withdraw from the study. He did however provide consent to use his interview data in the study.

## *4. 4 Barriers and enablers prior to use of an e-bike.*

The following is an analysis of the results of the semi-structured interviews conducted prior to loaning an e-bike to the six participants. The aim was to identify their perceived barriers and enablers to using an e-bike. The analysis is set within the framework of the COM-B model. For ease of identification, individuals who were provided with an e-bike/e-trike are coded as 'e-bike' or 'e-trike' after their quotes and those that were not given an e-bike are coded as 'no loan' after their quotes.

### 4.4.1 Physical Capability

For the participants, physical capability related to whether a physical or cognitive impairment would affect their use of the e-bike in addition to the effects of fatigue. Physical impairments were perceived as barriers to using the e-bike by all participants with the exception of Jim. The stroke survivors described how impairments to their arms would make it difficult to use the brakes and steer, and impairments to the lower limbs may cause the feet to slip off the pedals:

> *'I've just got the bad arm…I can hold on. I can use the arm to steer and everything, but I won't be able to use the brake.'* – Brian (e-trike)

> *'The only drawback I can see is the length of my arms, they're not as...err...they're not level if you know what I mean?'* – Ken (no loan)

> *'See what happens with this foot [pointing to his left foot] I have a splint it keeps the foot straight. My foot sometimes goes the opposite*

*direction. It sticks out. It's hard to keep it in one position.'* – Rob (e-trike)

Tim also mentioned how he was concerned about using the e-bike on the roads due to possible dizziness or vertigo which can be a side-effect of having a stroke (Stroke.org, 2017b):

*'The only thing I'm worried about, concerned, is if I'm in traffic and I have to look around quickly sometimes I can lose, well not lose my balance but I can sometimes take a fraction of a second to get my bearings again. That's the only thing that does concern me, yeah.'* – Tim (no loan)

The effects of stroke mean that survivors are susceptible to fatigue (Duncan et al, 2012). Participants described the effects of fatigue on energy levels and why they felt the e-bike might help counter these due to the assistance the bike provided. This was described in relation to their reasons for wanting to use an e-bike:

*'But I was thinking, the e-bike might be better because I don't have the same energy levels as normal. The thing about a stroke is you soon get tired... The assistance from the electric will be good.'* – Brian (e-trike)

*'I could in all honesty try cycling on an ordinary bike but what I rather like is the idea if I could be on an electric bicycle at least I could get*

*home again if I ran out of energy. But I don't know because I've never cycled one.'* – Jim (e-bike)

### 4.4.2 Psychological Capability

During the interviews, the participants displayed varying degrees of knowledge about the e-bike. Brian who worked as an engineer prior to retiring appeared very knowledgeable whereas other participants were not fully aware of the e-bikes capabilities:

*'I mean what I did for a living and what I've done I thoroughly understand the workings of the e-bike. I'm well into cycling, my son cycles all time, both my sons do.'* – Brian (e-trike)

In contrast Chris' knowledge of the e-bike and where he could take it was limited:

*'I don't even know if some of these you can drive on the side of the road. It would be ok, but I won't go on them unless told by the police, other police, ambulances and stuff like that.'* – Chris (no loan)

### 4.4.3 Physical Opportunity

The participants related physical opportunity to environmental factors and resources such as locations, the weather, the e-bike as a mode of transport and the adaptations that may need to be made to the e-bike.

The participants had a variety of expectations as to where they would travel to on the e-bike. Many felt that they would use the e-bike for journeys to local amenities and parks or around their estate whereas others felt they could travel longer distances:

> *'[I would use the e-bike] to go fishing. Visit local parks and take my dogs out with me.'* – Ken (no loan)

> *'I'd go around the shops, you know look at them, around town. If [the weather is] really fine, I'd go on the park and drive around the park.'* – Chris (no loan)

> '*Well, I think subject to getting used to it I do rather like the idea of going around because we live fairly countryside here so there's some country lanes that I could go on from there which would appeal to me because I quite like being outside..erm...but in terms of destinations like going into [town] it's 5 miles I haven't really thought about whether I need to do it...so probably I'd just use it for taking the opportunity to go out for the exercise and look around the countryside.'* – Jim (e-bike)

Here Tim encapsulates how the e-bike would allow him to access facilities where he can participate in physical activity but also act as a form of physical activity and increase mobility:

> *'Well I'm hoping to get the benefit from further exercise both on my leg. It will get me more mobile. So mobility, transport and physical*

*exercise is what I'm looking to get from it. I'm also gonna join the gym and I can use the transport to there. Yeah...transport, mobility, physical exercise.'* – Tim (no loan)

Participants also noted that they were aware of the limitations of where they could travel to. Here Brain discusses how he used to cycle with his son on a local cycle track, and despite having plans to return to previous cycling activities, there was an understanding that using the e-bike would be a gradual process and by first staying local it could help build his confidence up.

*'Now we used to do the cycle track on there before because it's so safe. But the [first] thing will be getting from here [is] getting the confidence I'd have to build that up from getting from here to there, you know? I suppose riding around the estate won't be a problem, you notice it's not a really hectic area, but we have to be careful as I'm soon off road, if you know what I mean? You can soon get off road. But even going to the shops for a paper won't be a thing [laughs].'* – Brian (e-trike)

The weather was a factor as to when the stroke survivors would use the e-bike:

*'Obviously depending on the weather but in the summer, I'd quite often use it.'* – Ken (no loan)

However, it was also identified that the participants may not be restricted by certain weather conditions in comparison to conventional cycles and that the e-bike would also help overcome the barriers of travelling in hilly areas:

> *'I think it will be much more convenient, easier to use than a regular push bike particularly in windy conditions and particularly up hill and up hill with a wind.'* – Tim (no loan)

The e-bike was identified as a mode of transport by the stroke survivors enabling them to have a greater sense of independence without having the possible burden of having to rely on others for transport as highlighted by Tim:

> *'There's a friend of mine who I... we've known each other quite a while. I'm going to be visiting his garage quite a lot and possible going to sales with him as well and getting involved in that, so it will actually help me because to ask my friend to come and collect me here it's… I wouldn't say he doesn't mind but it's a bit inconvenient for him. So, if I can make my own way, the better yeah.'* – Tim (no loan)

Furthermore, the e-bike was seen as an alternative form of transport to what some of the stroke survivors currently use such as wheelchairs and mobility scooters:

> *'Because I always wanted something better than that scooter thing, you know. Even though you control it, it only goes 4 miles per hour so you*

*know? That's all. It goes very, very slow though you know?'* – Chris (no loan)

To overcome physical barriers and enable use of the e-bikes by stroke survivors, it is necessary to make modifications and adaptations to the e-bikes, which requires additional resources. From experience in different settings such as the gym, some of the participants were aware of the physical limitations caused by a disability and the way they currently adapt. In this example Brian discusses that he cycled once a week on a running track using a specially adapted tricycle, discussing the adaptations that the tricycle had, how these adaptations enable him to cycle and the adaptations that he thought may be required to ride an e-bike:

*'It's an adult three-wheeler. I use the gears, you know? All he has to do is he straps my bad leg, my left leg foot because if he doesn't my foot twists slightly… When I go to the gym on the exercise bike, I shove my feet in the straps and that's alright. Now the bike [at the running track] doesn't have them so I'll probably need something like that on the pedals just to keep my feet straight, but I get on and off the bike myself.'* – Brian (e-trike)

### 4.4.4 Social Opportunity

The participants related social opportunity to social support from friends and family which was an enabler to using the e-bike, in addition to how the e-bike could be used as a facilitator for meeting new people. They described the support they received in the form of encouragement from friends and family to try the e-bike which acted as an

enabler and positively reinforced the participant's own choice. These statements highlight the support that the participants received:

> *'Well yeah, my son was encouraging me to get a bike. When I went to the cycling [at the running track]. My youngest son. They cycle. They love the bikes. When I told him and showed them, he once came to watch what I was doing, and he said, "Why don't you get one?"'* – Brian (e-trike)

> *'...well obviously my wife knows about it, my daughters know about it and they both thought it was a good idea…. I think people generally know me as a positive person who would try and make the best of what comes along. And this is an opportunity to try something I've never tried and it might just motivate me say, "well there are some things that you can do on this that you can't do without such a bike."'* – Jim (e-bike)

However, it was also noted that not all the participants received the same positive encouragement which could act as a possible barrier to e-bike use. Ken, a stroke survivor who lived on his own stated there was no one encouraging him to use the e-bike and when asked if he had told anyone about his decision to try one he replied:

> *'I've told my sons and my granddaughter, my grandsons. One of them didn't think it won't be a good idea [laughs] to be honest… He said, "I just don't think you'll be able to manage it."'* – Ken (no loan)

The ability to use the e-bike to meet new people and socialise was a common reason for wanting to use the e-bike by the stroke survivors. The participants described how the e-bike would allow them easy access to places where they could socialise. These are some of the responses received:

> *'So I expect there might be some mental stimulation of going somewhere, you know if you say, go to [a near-by village] where there's a coffee bar, you know you think well that would be ok I could go there, get a coffee, you know, come back and I might just meet people.'* – Jim (e-bike)

> *'And also, I shall probably use it in social situations such as visiting the coffee shop and all the rest of it.'* – Tim (no loan)

### 4.4.5 Reflective Motivation

Reflective motivation played a role in why the stroke survivors would want to use an e-bike. Several of the stroke survivors identified that using the e-bike would be good for their health and an enabler to physical activity:

> *'I think I'll get a lot fitter. Burn some weight off which won't go amiss.'* – Rob (e-trike)

> '*I think I would get just an added bit of exercise, wouldn't it really?*' – Brian (e-trike)

The desire to ‘get out and about’ and have more independence following a stroke was also a common enabler for the stroke survivors. Here participants describe how the e-bike could provide them with the opportunity to get out of the home more frequently:

> *‘It gets me out and about a bit more. I can go to the park with the dogs then with my son.’* – Rob (e-trike)

> *‘Well I think when I was aware of the opportunity I think the thought of being able to get out and about and a bit more independent and go places with the combination of some physical exercise because as I understand it you have to pedal as well, or you can pedal as well so the thought of having the physical exercise and if you're getting out of the house struck me as quite an a attractive option.’* – Jim (e-bike)

> ‘*The freedom. The freedom to go wherever I want to go and do what I want and want to do*.’ – Ken (no loan)

Other enablers included the ability to return to an activity the participants enjoyed prior to their stroke i.e. cycling:

> ‘*It wouldn't bother me at all, it would be like being normal. Bikes and cars, I'm just normal.’* – Brian (e-trike)

### 4.4.6 Automatic Motivation

For the participants, automatic motivation related to the anticipated emotions they would get from using an e-bike. Most of the participants reported that they expected to gain some form of satisfaction from using the e-bike or were looking forward to the experience:

> '*I was just in this chair in this room, but I got physio every day in the rehabilitation. Which I looked forward to one hour a day, so I'll probably look forward to riding my bike once a week.'* – Brian (e-trike)

> *'I think a new experience…just hoping that this might be something that's satisfying and rewarding I might actually lead me to say, "You know I quite like this and I might even buy one".'* – Jim (e-bike)

In contrast participants also expressed fear about using even stationary bikes within a gym setting:

> *'I have seen the odd ones there though you know. That's all though. But the trouble is it just frightens me to get on them.'* – Chris (no loan)

During his interview Chris expressed a lack of confidence and knowledge about the e-bike and this fear also manifested when he was being trained to use an e-bike resulting in his withdrawal from the study. Therefore, a lack of confidence and experience of cycling was a major barrier to his use of the e-bike.

### *4. 5 Barriers and enablers after using an e-bike.*

The result section concludes with a breakdown of the final semi-instructed interview within the framework of the COM-B model identifying the actual barriers and enablers identified whilst using the e-bike.

#### 4.5.1 Physical Capability

Prior to loaning the e-bike many of the participants felt that their impairment could be a perceived barrier to using the e-bike. For the three stroke survivors that took part in the loaning of the e-bike it was only Rob's impairment that acted as an actual barrier to using the e-bike. Impairments to his left arm and leg severely hampered his ability to cycle. Due to the increased tone in his foot muscles and a fixed contracture in his toe which caused severe tension in his calf muscle, prevented him from cycling during the loan period despite having Botox injections to relax it, as Rob explains here:

> *'The other day we went on to the park it just wasn't going for it then. I just didn't want to go for it. My calves [have] been giving me a bit of cramp.'* – Rob (e-trike)

As expressed during the initial interview, Tim had shown concerns about using the roads and the possible effect of dizziness from having to quickly look around in traffic. Jim was the only stoke survivor who took the e-bike out on the public roads and despite feeling confident enough to cycle on the roads he also felt that the possible residual effects of stroke could impact on his safety which caused him to be more nervous on the roads and he felt the addition of a bar-end mirror could help:

*'I think if I was going to have my own bike I would probably put a bar-end mirror, you know a rear-view mirror? I think I like that because it saves turning around. I think possible post-stroke that's more difficult than pre-stroke so if you had a rear view mirror, you don't need much of a one but a bar-end one so that you're looking and you can see there is something coming and you can look properly whereas now without a mirror you actually just have to look round and it's fairly easy because the bike's [position is] sit up and beg but you still have to take your eyes off the road to look behind and I think I found that I was more nervous about that than I had been in the past.'* – Jim (e-bike)

As the results of the first set of interviews showed, the stroke survivors perceived that the e-bike would have a positive effect on fatigue, this was shown to be the case for both Jim and Brian who both reported how the assistance offered by the e-bike enabled them to cycle for extended periods without feeling the effects of fatigue:

*'I think what the electric cycle does it gives you the confidence to go further and stay out for longer. I think you just intrinsically feel, "Well there's more assistance if I need it, if I get too tired", and probably although it didn't really recognize it in the early days I probably wasn't more tired and had more general fatigue than what I thought I had and actually the electric cycle works really well in that regard.'* – Jim (e-bike)

*'I feel the way I ride now, I ride it in the first one, number one, there's three [levels of assistance], I ride it in the number one, which is the most effort and if I get a bit tired I could go to number two…And I could sort of get my breath back and then what I do then when I've had a minute, I put it back in number one. But what you can do, you know, you could always get back home with it even if you get tired, you know with you having the three [levels of assistance]. I've not been in three yet [laughs].* – Brian (e-trike)

It was also highlighted that the e-bike had an improved effect on fatigue in comparison to a bike without electrical assistance. Here, Brian was able to compare the level of tiredness that he feels whilst cycling on an adapted cycle and the level of tiredness that he experiences using the e-bike.

'*On the e-bike I don't get tired, on the track one I do. I have a limit and I know my limit so when I get to my limit I pull in. But with the e-bike no matter where I've been…I could feel as though I could carry on and do it again.*' – Brian (e-trike)

The e-bike provided the participants with the capability to travel uphill easily without tiring themselves out, something they felt would not be possible on a conventional cycle:

'*Particularly on the long gradient on [the road] because you've got it there with the assist so you're not wheezing and puffing, you get warm, but you're not killing yourself metabolically like others are so you know,*

*somehow I did that and I thought, 'You know, this is okay, I can complete this.'...You know certainly for me on the gradients number two made life a lot better. Could I cycle some of the gradients with [level] one? Yeah probably. Could I cycle up some of the gradients without any assist? Probably not. So, on that basis for me the electric bike is a bonus.'* – Jim (e-bike)

Another benefit of using the e-bike was a perception that it might have had an impact on mobility. Here Brian discusses how he thinks the e-bike may have helped improve his walking ability:

*'But I don't know it might have helped my legs, you know because I've noticed since I've been on holiday and come back and before I went on holiday I do walk a lot further than I used to do... I do notice it. You know, and I'm a bit more confident on my feet and walking.'* Brian (e-trike)

### 4.5.2 Psychological Capability

During the initial interview, prior to using the e-bike the experienced cyclists such as Brian were said to be quite knowledgeable about how the e-bike worked. However, after having had the opportunity to use an e-bike it transpired that there was a misconception about the e-bike with both Jim and Brian thinking that the e-bike would have worked like a mobility scooter or that you would not have to pedal constantly:

'*I thought it would have been, not harder, I thought it would have been from my background as a motor engineer, I thought it would have been motorized but I realized now with having it a while that you've got to put a certain amount of effort in to in to have it moving. If you don't turn the pedals it doesn't cut in.*' – Brian (e-trike)

'*I realized you could always pedal, but I thought that it was probably like a mobility scooter you could just turn a throttle and it would proceed but it doesn't, and I mean that was made clear when I went to [the bike company] as you know.*' – Jim (e-bike)

### 4.5.3 Physical Opportunity

After using the e-bike, the locations to where the participants thought they could cycle, which was identified as an enabler prior to using the e-bike became a barrier for some of the participants. New barriers and enablers were also reported with regards to the e-bike itself, its design and the adaptations available. As well as being identified as a perceived barrier during the initial interviews, the weather was an important factor that effected when the stroke survivors could cycle.

During the initial interview, the locations that the participants could cycle was not seen as a barrier although after loaning the e-bike it appeared that there were issues regarding the participants having access to locations and road safety. Rob who had originally identified areas such as the parks and the local shops as places he would like to cycle was restricted to cycling on a local car park. He deemed his own street unsafe

to cycle on due the hazards in that area which was apparent even before he got the e-bike, as this statement shows:

> '*It used to be the same when I was in my chair going down the street. You'd still get the idiots come flying around the bend*.' – Rob (e-trike)

In contrast, Brian who cycled predominantly on a route around his estate which was considerably less busy than where Rob lived had a more positive experience with motorists:

> '*I have found that cars let me go <laughs>. Yeah, I've noticed there's been a time or two there's been a car behind me, whether they're curious about the bike. You know, but they've let me get around something before they've come past.'* – Brian (e-trike)

On the occasion that Rob was able to venture onto his local park, which had recently provided a venue for a concert, the terrain proved problematic for Rob to ride the e-bike:

> '*When you get on the path, of course with that concert being on, every where's a bit bumpy*.' – Rob (e-trike)

As discussed by the participants prior to loan of the e-bike the weather was a factor to using the e-bike. During the loan of the e-bike the UK experienced hot temperatures which hindered the participant's motivation to cycle. Despite attempts to cycle, the

hot weather was said to affect the participant's concentration and make them feel uncomfortable, as these statements illustrate:

> '*I was frustrated at first because I sort of, if you like [I'm] waiting for the bike to come there's good weather and then the good weather continued but actually it's just too hot. You know, but for me, I don't really like it when he gets really hot… You just got bit too clammy, too sweaty and you know, it's just less pleasant*.' – Jim (e-bike)

> *'Just can't win. It's catch 22, sometimes it rains, I've not been up to it if it rains and it would be too bloody hot!'* – Rob (e-trike)

As noted by one of the stroke survivors prior to loaning the e-bike, the e-bike was also able to counter the effects of certain weather conditions and thus enabling the participants to continue to cycle. This was shown to be the case for Brian:

> *'Yeah, but that's another thing with that bike – wind. See, you get the wind with you and wind against you its hard work. You get the wind against you with this bike and it's not there [laughs]…it disappears you know the bike just takes it. Whatever condition it goes at the same, so you can't grumble at that.'* – Brian (e-trike)

The e-bike presented various barriers and enablers to the stroke survivors with the electrical assistance featuring prominently as did the components of the e-bike in general in addition to the adaptations made to the e-bike. Barriers to using the e-bike

included the assistance being too powerful, the battery running out, the weight of the bike and seat causing discomfort:

> '*[The battery running out] didn't cause me any problems other than the bike is quite heavy to cycle compared with an ordinary bike without any electrical assist... It cuts out pretty acutely because you've got the gauge thing saying you've got 60, 40, 20, or 10 or whatever it goes to. I thought, "oh, I'm alright I've got about four miles to go", and it just stops. That's a pain.*' – Jim (e-bike)

> *'I just feel that the assistance could be a bit too fast, especially when I hit a hill [or] slope. I just get nervous then.'* – Rob (e-trike)

> '*Sometimes you can slip off [the seat] but sometimes at the front as well cos you get a sore backside sometimes*.' – Rob (e-trike)

The adaptations made to the e-bike were both a barrier and enabler to usage and one of the stroke survivors found they were able to adapt themselves without the use of a specific adaptation. The e-trikes used by Rob and Brian had adaptations to the brakes which enabled both to be operated from their non-effected side:

> '*When the brakes have been adjusted, yeah that's been good for me, so I can get my hand around the brakes.*' – Rob (e-trike)

However, the adaptations made to the pedals were both a barrier and enabler. The e-trike used by Rob was fitted with two different pedals: a self-levelling foot sandal with ankle support and a pedal with a strap attached. Despite enabling Rob to cycle once he was fitted into the e-bike, he did require the assistance of his wife in mounting and dismounting from the e-bike which was a difficult process. During the final interview Rob demonstrated how he got on and off the e-trike and in the process, he stood on his wife's hand causing a moment of frustration:

> '*I couldn't see that foot because Karen was saying "you're on my hands!" but I just couldn't see it to get into the strap.*' – Rob (e-trike)

This contrasts with Brian who whilst being fitted for the e-bike had requested a larger pedal to keep the foot on his paretic side in place but when the bike was delivered it still had the standard pedal fitted. However, Brian, was able to successfully adapt to the e-bike with the aid of his son:

> '*The only problem I had was with the pedal, but I've sorted that. It's probably a good thing I didn't use an adapter because I've adapted myself to do it, so it's been good... my son helped me, we found that when we got the seat in the right position when my leg was stretched it didn't come off. What happened was the seat was too low and when I was pedalling my foot would come off but I've raised the seat and [by] raising the seat and putting a bit more effort into this leg [his right leg], pedalling it's come natural so now I very rarely, occasionally it will*

*slide and I'll stop and I'll reposition it back to normal and off we go.*'

– Brian (e-trike)

Despite the aim of adaptations being to reduce the impact of a stroke related impairment it was reported that the prospect of being strapped in could be a cause of fear for stroke survivors. In the final interview, Brian was able to compare his experience of cycling using the adapted tricycle in which he is strapped in to that of the e-bike without adapted pedals and how it makes him feel and the independence he has using the e-bike:

*'When I arrived at the [running track] he straps my foot on, but I don't like that, I don't like being strapped on. At least with this bike on my own I can manage, I can get on and get off, no problem. But you're strapped, you know, you need somebody to undo the strap although I do undo it myself…Subconsciously you think about it, you think if anything would happen. I think when I'm on the track I get right at the other end and something gets trapped… I just have to stop and wait for help. Where on this bike. I would just get off and probably the distances I'm going and we're going around in a circle, I would probably walk home.'* – Brian (e-trike)

For one participant having the experience of being able to try an e-bike provided them with the impetus to purchase one because it was something they enjoyed doing, despite the cost of the e-bike:

*'I think now having used one I think yeah, you know, I like this. And I think I'd use it enough to justify the expense or spend on an e-bike. It's not exactly a fortune, you know but it is something I would enjoy doing.'*

– Jim (e-bike)

### 4.5.4 Social Opportunity

The influence of social support from friends and family featured prominently as an enabler for most of the stroke survivors interviewed prior to using the e-bike. Social support was an important factor during the loan of the e-bike, however opinions on how the e-bike could be used as a method to socialise and meet people differed for one stroke survivor after the loan period.

Family members played a significant role in enabling stroke survivors to use an e-bike acting as someone to cycle with and help mount and dismount the e-bike and it also had the positive effect of creating a routine for them:

'*Well my son has [made it part of a routine], every week. I mean like he says he was back [from holiday] Wednesday and I mean he said, "Are you alright for Saturday?" It's something he's going to do now.'*

– Brian (e-trike)

During the initial interviews, several of the participants felt that using the e-bike would be an opportunity to socialise and meet new people and during the interview one of the stroke survivors did indicate that they had met someone they knew whilst out on

the e-bike. However, Jim felt that cycling for him was primarily a solo experience and he also felt there was a stigma attached to the e-bike by cyclists of more conventional cycles:

> '*I think compared with those people who are avid cyclists on road bikes they're seen as something outside of their circle. You know it's a bit like, I don't know, having a van when everyone else has got a sports car, you know, they're all vehicles but you know, I think the people on the road bikes they want to wear the colourful Lycra and go around in pairs and you know cycle particular routes and distances, but I didn't particularly envisage joining any of them or competing with any of them. I think they probably don't see it as serious cycling. You know, like, "Why would you do that? I might as well have an ordinary bike while my legs work." I think there's a lot of ignorance, in fact you do have to pedal it's not like a mobility scooter that you can just twist and go, you know.*' – Jim (e-bike)

### 4.5.5 Reflective Motivation

The participants reported that reflective motivation played a role in their use of the e-bike. Beliefs about capabilities, having goals and a belief that using the e-bike would benefit them were all discussed by the stroke survivors.

Beliefs about capabilities were discussed in relation to the participant's feelings of their own ability to use the e-bike and the control they were afforded by their families and their impairment. Here Brian discusses that despite having the support from family (as

shown by comments regarding Social Opportunity) and feeling confident to use the e-bike, Brian's family did not believe he was safe enough to ride the e-bike on his own:

> '*My son comes with me. He's a keen cyclist. So, he's really been a godsend because I would have gone on my own, but you know people don't seem to think I'm safe [laughs] ... I let them have their way but I'm totally sound in mind and body. I mean I can ride a bike. If I was to go out on it now I could go anywhere on it, it wouldn't be a problem. You know, but like I say if it makes him feel better if he's with me.*' – Brian (e-trike)

As discussed previously Rob's impairment effected his ability to use the e-bike, this also had a negative impact on his confidence and belief in his capabilities:

> *'I feel totally 100% safe using the bike. It's just me, myself. It's me, really having one hand to steer and one to pull to the right all the time.'* – Rob (e-trike)

Later in the interview Rob also indicated a lack of motivation to use the e-bike which could be linked to his lack of confidence on the e-bike:

> *'I think it's just me, myself with the bike. The bike's ok. Sometimes you don't feel up to going out on the bike like most people.*' – Rob (e-trike)

The participants indicated that they were motivated by goals and ambitions and the use of the e-bike showed the stroke survivors what they were capable of post-stroke and the progress they had made:

> *'And it's a goal, you know, all these things are goals, the bike's been a good one though from day one getting back to that. You know, you wonder, see you're always wondering if you should be doing it. I don't know if you understand? You get on it and you do it and should I be doing it? Should I not be going back? Should I not be...? Where in your normal life you wouldn't be thinking like that, you'd get on and go for a ride well I'm at the stage now where I get on and go for a ride. When I'm out I'm not thinking, "Oh, I should be getting back". That's gone now.'* –Brian (e-trike)

> *'Come home, feeling very upbeat, very positive. Not exhausted but almost first in a sense, a sense of accomplishment that you know that, "Yeah, you can do this." Could I do it without the assisted bike? Well I said to [my wife] probably not. I don't think I could do it at the moment without some assistance. If I did I'd have to do it a lot slower. You know, whereas this way you can just keep going because you know providing you keep turning the pedals the motor offers you that level of assistance. So yeah, a positive outlook, this is what I was going to do, an accomplishment when I'd done it and it inspired me then to say, "well right next time I do it I'm going to do from [home]".'* – Jim (e-bike)

During the initial interviews the e-bike was identified as an enabler to physical activity and a motivator to "get out and about" and this was a notion confirmed by the stroke survivors in the final interview:

> *'It's a brilliant idea because you're getting the exercise as well. Which is what you want it for isn't it really? You don't just sit on the seat and steer it, it's not much use to you.'* – Brian (e-trike)

> *'Would I have gone out and cycled on my own bike during this time? Probably not. Because I had access to the e-bike the answer, "Yes I did cycle and cycled more." ...did it motivate me to want to get out? I think the answer to the question is, "yes". You know, I think it was a positive thing.'* –Jim (e-bike)

### 4.5.6 Automatic Motivation

The participants described contrasting emotions when detailing their experiences of using the e-bike. Both Brian and Jim were positive about their experience and enjoyed using the e-bike and Jim was even considering purchasing one because of having the opportunity to use one during the study:

> '*I've just gone out to enjoy riding and I've done that. You know, I've just enjoyed it. We've come back, and we've put it back in the garage and I'm not tired and I'm not out of breath and I don't want to lie down.*'
> – Brian (e-trike)

*'Really glad I've had the chance to use it. I think it's given me the confidence to say, "Yeah, I can do this," and probably I'll, you know when [the representative from the bike company] collects it in due course I'll arrange to see him or his colleague at the [bike company], the one at the retail outlet.'* – Jim (e-bike)

This contrasts with Rob who throughout his interview spoke of being nervous using the e-bike and a fear of bumping into things:

*'I tend to stay off the street because my confidence isn't brilliant on the street. It's down to my own confidence, yeah being out on the street cos I don't want to bump into cars… It's just bumping into anything. I don't want to bump into anybody or anything.'* – Rob (e-trike)

When the e-bikes were being fitted, the e-trike versions were not available for all participants to try and it was noted by one of the stroke survivors that this could be a barrier to future use and that better preparation could manage the emotional response to not being able to use the two-wheeled version:

*'Well it's something you do gradually. You don't write it off. When you came and [the representatives from the bike company] came with the van with the two wheelers on and all that, you can get down, low and think, "Well I can't do that!" But I knew very well that I could do the three wheelers. See that was out but as soon as they brought the three-wheeler it was so easy.'* – Brian (e-trike)

## *4.6 Summary*

A number of barriers and enablers were identified prior to using the e-bike, during and after the loaning of the e-bike. These are summarised in Table 4 below and are discussed in more detail in the next chapter.

**Table 4: A summary of the barriers and enablers reported by the stroke survivors before, during and after the loaning of the e-bike.**

| | ***Barriers (-) & Enablers (+) to using the e-bike*** | | |
|---|---|---|---|
| ***COM-B Model Component*** | ***Prior to loaning the e-bike*** | ***During the loan of the e-bike*** | ***After the loan of the e-bike*** |
| *Physical Capability* | - Impairment to arms and legs<br>- Dizziness<br>+ Fatigue | - Aches and pains<br>+ Fitness | - Impairment to arms and legs<br>- Residual effects of stroke<br>+ Fatigue<br>+ Physiological improvements |
| *Psychological Capability* | +/- Knowledge about the e-bike | | - Understanding about what an e-bike does |
| *Physical Opportunity* | + Location<br>+/- Weather<br>+ The e-bike as a mode of transport<br>+ Adaptations<br>- Storage | - Weather<br>+ The e-bike as mode of transport and for leisure | +/- Locations<br>+/- Road safety<br>+/- Weather<br>+/- The e-bike<br>+/- Adaptations<br>+ First-hand experience |
| *Social Opportunity* | +/- Encouragement<br>+ Socialise | +/- Family | + Social support<br>+ Routine<br>- Stigma |
| *Reflective Motivation* | + Fitness/health<br>+ Get out and about<br>+ Return to normal | | + Goals<br>- Belief about capability<br>+/- Confidence<br>+ Fitness/health |
| *Automatic Motivation* | + Satisfaction | | + Enjoyment<br>- Fear |

# CHAPTER 5: DISCUSSION

## *5.1 Introduction*

The aim of this research was to explore the barriers and enablers when using an e-bike in the development of a stroke intervention using a case series approach with two objectives: (1) to use the COM-B model to guide the understanding of the barriers and enablers to using an e-bike in the context of stroke and (2) to explore e-bike usage during a three-month loan period of an e-bike. This chapter discusses the findings of this research, exploring the barriers and enablers identified within the context of current research. The next chapter address the strengths and limitations of the study in addition to areas of future research and it concludes by looking at the implications of this study within the development of future stroke interventions using e-bikes.

## *5.2 Main Findings*

All the participants that took part in this study were male, three of the six participants who took part in the interview prior to using the e-bike withdrew because they did not have a place to store the e-bike, could not get approval from their doctor or did not feel comfortable using the e-bike. This study identified several barriers and enablers to using the e-bike by stroke survivors. The COM-B model provided a framework for analysis in addition to data captured from structured interviews via telephone and from bike usage data. The stroke survivors reported barriers and enablers to using the e-bike that were common to the general public (Jones et al, 2016a; 2016b, Popovich et al, 2014) as well as factors that were specific to stroke survivors (Gaskins et al, 2017; McMahon et al, 2016). Prior to using the e-bike the stroke survivors perceived that physical impairment could be a barrier to using the e-bike and physical impairment hindered the use for one of the participants. There was a belief prior to loaning the e-

bike that it would have a positive effect on fatigue and this was reported to be the case for some of the stroke survivors who loaned the e-bike. After the loan period it was discovered there was a misconception about the workings of the e-bike which would indicate a lack of knowledge. The participants also identified barriers to using the e-bike with regards to the type of e-bike and design especially with regards to the weight and battery life. The weather was a recurring barrier although it was also felt the e-bike could handle certain weather conditions. All the participants that used an e-bike lived with a partner and those that withdrew lived on their own. Social support from friends and family was a key enabler to the stroke survivor's use of the e-bike both as a voice of encouragement, a companion to cycle with and for someone to help mount and dismount the e-bike. Although one participant thought there was a stigma attached to using the e-bike. The participants exhibited a variety of motivating factors for using the e-bike such as personal goals and being aware that using the e-bike would be a form of physical activity that would improve their health and be an enjoyable activity. Belief in capability was a motivational barrier and one of the participants had a fear of bumping into things. The bike usage data could only be obtained from two of the participants and indicated that the participant with less severe physical impairment using a standard e-bike cycled for longer and made more journeys than the participant who had the e-trike who made approximately one journey per week for an average time of 12 minutes. Therefore, the second objective for this study was not successfully completed.

### *5.3 Gender*

The participants within this study were all male, even though both men and women were approached to take part. There are several factors to consider as to why this may have occurred such as current physical activity levels and the impact of stroke.

Research into the influence of gender and physical activity levels in stroke survivors is limited but according to the Active Lives Adult Survey carried out by Sport England (2018) they report that woman (aged 16 or above) are more likely to be more physically inactive than men, with 27% of women achieving less than 30 minutes of physical activity per week compared to 24% of men. In addition to being predominantly less active female stroke survivors are also likely to be associated with certain common barriers to physical activity. Vahlberg et al (2018) examined the factors influencing physical activity levels in 187 community dwelling stroke survivors. They found that balance was associated with physical activity in women and that woman demonstrated a greater fear of falling than men. Poor balance and the fear of falling have been closely linked and shown to have a negative effect on physical activity (Morris et al, 2017). Fear of falling due to poor balance was cited as a significant barrier to cycling in a recent unpublished study (Gaskins et al, 2017) and therefore this may have been a decisive factor as to why woman did not wish to take part in this study. In addition, the extra weight of the e-bike has been reported as an inconvenience to women (Popovich et al; 2014). However, a recent Belgian study by Van Cauwenberg et al (2018) analysing the characteristics of older e-bike users, reported that women were more likely to be e-bike users and it was suggested that the electrical assistance provided by the e-bike may appeal to women due to them having a lower muscle mass in comparison to men and that cycling using an e-bike would be easier in comparison to a conventional cycle (Brady et al, 2014). In another study, sedentary women reported higher levels of enjoyment when riding an e-bike in comparison to a conventional cycle (Sperlich et al, 2012). Taking these factors into consideration and the health implications of physical inactivity, future research may wish to look at the gender differences and factors that affect e-bike usage in stroke survivors.

### *5.4 The e-bike and adaptations*

From the interviews prior to using the e-bike the participants were aware of the adaptations available for the e-bike and how they could enable them to cycle. A previous study by Gaskins et al (2017) highlighted that the lack of awareness of the types of adaptations available for the e-bike and how having adaptations would encourage the stroke survivors to use one. Within this study, awareness could be attributed partly to the fact that the participants either already used an adapted cycle or adapted the equipment they used at the gym such as using elastic straps to secure feet to a stationary bike. The participants within McMahon's study (2016) were also aware of the adaptations available however this could be because the study involved them trialling adapted bikes.

Of the three stroke survivors that took part in the loan of an e-bike, two of them required the bike to have adaptations made to the brakes and pedals. This was both a barrier and enabler to using the e-bike. The adaptations enabled the participants to cycle and having the brakes positioned on the least effected side was a benefit to the participants allowing them to stop the bike easily with one hand. However, adaptations to the pedals proved more problematic. One of the participants had adaptations made to both pedals which meant that he required assistance from his wife both mounting and dismounting the e-bike which was shown to be a struggle for the participant and their partner. Adaptations that involve being strapped into the cycle have been identified as causes of anxiety and fear of falling for stroke survivors both within this study and in previous research (McMahon et al, 2016).

Conversely, another participant who had originally requested a larger pedal to keep his foot in place whilst cycling was able to adapt himself easily by just placing his foot on the pedal in the desired place and it remained there. Similarly, previous research has shown that some people with disabilities can cycle without the aid of adaptations. A study by Hickman (2015) reported how he cycles with the use of a prosthetic leg and explained how the free mobility of cycling was able to hide his disability allowing disabled individuals to fit into a cycling community. The research into adaptations on e-bikes is currently limited to one study by Blumenstein et al (2014) which involved trialling an adapted e-bike for youths with cerebral palsy. Therefore, despite the apparent benefit of encouraging stroke survivors to use an e-bike, from a practical perspective further research is required on the use of adaptations by stroke survivors in the use of e-bike to enable them to cycle independently.

The e-bike itself also provided barriers and enablers to its use. One participant reported issues with the battery and the weight of the e-bike after the battery ran out when he was out on a long journey and had to pedal home without assistance which makes the additional weight of the e-bike more apparent. This finding concurs with previous research which has also identified the weight of the bike and battery life as negative aspects of using the e-bike (Dill & Rose; 2012; Jones et al, 2016a; Popovich et al, 2014). For some stroke survivors this can be extra problematic because stroke can impact on strength, fitness and energy levels (Renner et al, 2009), extra consideration would be required with regards to the length of journey and to what would happen if the battery did run out unexpectedly.

The design of the e-bike was also a barrier to its use, with regards to the e-trike in particular. One of the participants found the seat uncomfortable but due to the design of the e-trike he was using, a larger seat with a back-rest was not available. Of the five participants who were fitted for an e-bike, all but one opted for an e-trike which mitigates the issue of balance (Spolander, 2007). As reported in the literature review this was also found to be the case in previous research whereby stroke survivors have had the opportunity to trial different types of cycles (McMahon et al, 2016). Despite the benefits in terms of balance and safety, the extra weight, size and issues with manoeuvrability in tight spaces meant that e-trikes are difficult to store (Spolander; 2007). This was observed with one of the stroke survivors who had to withdraw from the study because he did not have enough room to store an e-trike in his home. E-trikes also have a high centre of gravity meaning that care must be taken when turning corners for fear of the bike toppling over (Spolander; 2007) which would be a concern for stroke survivors who are using an adaptation that involves them being strapped in to the bike. For the participants that loaned an e-trike they were either travelling at low speeds, had support with them in the form of family members or were cycling in wide open spaces to reduce the risk of accidents. Therefore, despite the advantages of opting for an e-trike over the two-wheeled version of the e-bike, other factors would need to be considered when developing an intervention using the e-trike with stroke survivors.

Within this study the different types of e-bike were not explored. Recent studies into disability cycling has highlighted the variety of bicycles used by people with disabilities such as tandems and recumbent cycles which are available as an e-bike or can be retrofitted to incorporate electrical assistance (Wheels for Wellbeing, 2017b). Within the scope of this research, for the participant who had problems with the seat and lack

of back support, a recumbent cycle may have been a better alternative. Research has shown that due to the reclined riding position, recumbents improve comfort and manoeuvrability whilst cycling (Spolander et al, 2007), are a popular choice for disabled cyclists (Green Bay Press Gazette, 2016; Stroke Association.org, 2011) and are available with electrical assistance or can be retrofitted with a motor (Get Cycling, 2011).

### *5.5 Physical Capability*

Prior to loaning of the e-bike most of the participants perceived that their physical impairment would be a barrier to using the e-bike. Disability to their arms and legs were identified as factors which would affect their ability to cycle. This concurs with the previous research into the barriers to cycling by stroke survivors. Gaskins et al (2017) reported that not being able to hold onto the handlebars and feet falling off the pedals were reasons that discouraged stroke survivors from cycling. During the loan of the e-bike the effects of impairment effected the use of the e-bike in one participant in particular (Rob). Aches and pains in his knees and feet prevented him from cycling at certain points during the loan period. Also because of the impairment in both his left arm and left leg he struggled to both mount and dismount the cycle and because he had to cycle one handed he cycles without the aid of electrical assistance as it was deemed too powerful. Participants also spoke of feeling uneasy on the roads reporting concerns about having to look quickly from side to side which could possibly be because of the residual effects of stroke i.e. dizziness or vertigo. There were no studies found that have looked in to the residual effects of stroke and cycling in stroke survivors although research has found that dizziness is related to issues around balance and is a barrier to physical activity (Robison et al, 2009). A study by Winkens et al (2006) also reported

that dizziness was associated with a loss of cognitive function. This evidence would suggest that the level and type of impairment are an important factor to consider when developing an intervention for stroke survivors using e-bikes. In this study the participants with less severe impairments required less support and required fewer adaptations. Previous research that has explored the barriers to using an e-bike by stroke survivors (Gaskins et al, 2017; McMahon et al; 2016) was not explicit as to the level of impairment of its participants, although McMahon (2016) did mention that one of the limitations of their research was that despite being able to walk independently with, or without the use of a walking aid, that the participants were not severely impaired which could increase the barriers encountered. The effects of impairment on the use of an e-bike by stroke survivors could be an area of interest for future research and because some stroke survivors may wish to travel on roads research into the residual effects of stroke and cycling may be warranted.

In the final interview one of the stroke survivors felt that confidence in their walking ability had improved during the loaning of the e-bike. Previous research has shown that cycling can improve walking ability in stroke survivors when included in an aerobic training program (Barbosa et al, 2015). Currently there has been no research found that has tested whether e-bikes can help improve walking ability in stroke survivors but given the similarities that cycling has to walking (Brown et al, 2005) and the addition of the electrical assistance future research may wish to explore this further.

### *5.6 Fatigue*

Despite the literature review identifying fatigue as a barrier to physical activity by stroke survivors (Damush et al, 2007; Shaughnessy et al, 2006; Tőrnbom et al, 2016;

Nicholson et al, 2017), participants in this study who were able to utilise the electrical assistance of the e-bike identified that it had a positive effect on fatigue and prior to using the e-bike some of the participants discussed how the e-bike would have a positive effect on energy levels. During the final interviews the participants explained about how the e-bike gave them the confidence to cycle further for longer and tackle hilly areas without feeling tired. One participant was even able to make the comparison to how they were more tired using an adapted bike without assistance compared with the e-bike. These findings concur with previous research in the general public (Dill & Rose, 2012; Popovich; 2014) and older e-bike users (Johnson & Rose, 2015). However, it should be noted that only two participants were able to cycle with the electrical assistance on and their average length of journey varied drastically between the two participants. One participant had an average journey time of 12 minutes whereas the other participants made much longer journeys with an average journey time of 52 minutes. It should also be noted that the second participant was also less impaired of the two with only an impairment to his speech. Despite this, the apparent positive effect should not be discounted as a perceived outcome of increased energy and endurance could be a key enabler for stroke survivors to use the e-bike and justifies further study possibly using qualitative research techniques.

### *5.7 Psychological Capability*

The interviews prior to and post using the e-bike demonstrated there are misconceptions and a lack of knowledge about how the e-bike functions, even by experienced cyclists, with participants citing that they thought that it was going to be like a mobility scooter or were unaware that you must pedal continuously, a misconception that has also been reported in other research (Jones et al, 2016b).Similar misconceptions have also been

reported in the literature and have been attributed to a lack of available information and lack of experience of using e-bikes (Fyhri et al, 2017). It is understood that experience and knowledge are positively associated to attitudes, level of usage and a reduction in fear about the disadvantages of new modes of transport (Donaghy, 2011). A Norwegian study by Fyhri et al (2017) found that there was a severe lack of knowledge surrounding e-bikes with only 18% of participants who took part in a survey being aware that the motor was activated when pedalling. They also reported that knowledge was the strongest predictor of purchasing an e-bike. Similar to this study, people were offered the opportunity to try an e-bike although with a focus on exploring whether the experience would impact on the amount they were willing to pay for an e-bike. In Fyhri's (2017) research, a random selection of 66 participants were given the opportunity to loan an e-bike for a period of between two and four weeks. Questionnaire data captured after the loan was completed indicated that people were willing to pay a significantly higher price for an e-bike in comparison to a control group that had not had the opportunity to loan an e-bike and that authors reported they had seen real changes in people's willingness to purchase an e-bike because of having the opportunity to try one. Within this study one of the participants stated that they were intending to purchase an e-bike and that their misconceptions around the e-bike changed because of the experience provided by this study. Therefore, this evidence would suggest that knowledge and experience are key in enabling stroke survivors to use an e-bike and ways of gaining these need to be considered when developing an intervention.

### *5.7 Social Opportunity*

The results of the interviews indicate that the stroke survivors required a variety of support to enable them to use the e-bike. However, participants also required approval from their doctor to participate in the loaning of the e-bike. For one participant this proved a barrier as he could not get the required approval and had to withdraw from the study. Research has shown that the support from health care professionals is viewed as an important influence with regards to physical activity (Morris et al, 2017), however if e-bikes were to be used in an intervention requiring support from clinical services then the factors influencing why they would not prescribe the use of e-bikes needs to be investigated.

The results of this study illustrated the importance of having social support from caregivers and family members in the use of the e-bike. The three participants who loaned an e-bike all lived with a partner or had a family member to provide support for them in the form of accompanying them out to ensure they were safe, provide them with a routine and to help them mount and dismount the e-bike. In addition, prior to loaning the e-bike most of the stroke survivors indicated that friends and family were a positive influence in encouraging them to use the e-bike. This supports previous research that has shown that the support of friends and family to be an important enabler to physical activity engagement (Morris et al, 2012; 2016; 2017). Moreover, whilst most of the participants received positive encouragement one participant was told by a family member that they did not feel they would be able to use an e-bike and that it was not a good idea. This participant withdrew from the study because of issues around storage; however, this lack of encouragement could have a negative effect on his participation in physical activity in the future. Recent research into stroke survivors'

perspectives on aerobic exercise early after stroke identified that a lack of support from a partner or family was a common barrier to participation (Prout et al, 2016).

From the interviews it was discovered that the level of support required was also dependent on the level of impairment experienced by the participant which concurs with current research regarding cycling with a disability (Clayton et al, 2017). Within this study, the participants that used the e-trike required social support to help mount and dismount the bike and required someone to cycle with to ensure they were safe. Compared to the participant that used the standard two-wheel e-bike who only had an impairment to his speech, they required no social support to cycle. These findings align with previous research into cycling and stroke survivors which identified that social support was an important factor in enabling them to cycle, reporting needs such as requiring help mounting and dismounting, and support for transporting a bike (McMahon et al, 2016). Although social support from friends and family allowed the stroke survivors to use the e-bike, it also highlighted a possible problem for those without social support within the context of developing an intervention. For example, if Rob had not had his wife there to help him mount and dismount the e-bike, he would not have been able to use the e-bike as it required someone to secure his feet in the peddles. Due to the adaptations used and the area Rob lived in not being deemed safe to cycle, he also required social support to help get him to the local car park they used as a safe area to cycle. This had the impact of limiting where Rob could cycle but it also meant that he was unable to cycle without his wife being present. Therefore, social support could be a limiting factor in the use of the e-bike by individuals with severe impairments and consequently alternative options would need to be considered when developing an intervention.

Of the three stroke survivors who loaned an e-bike, two rode with either a family member or partner accompanying them, either cycling on their own bike alongside them or taking the e-bike to a location to cycle with the stroke survivor following behind in their wheelchair. The other stroke survivor chose to cycle on his own. Previous research has shown that having company is a common enabler to physical activity in stroke survivors (Damush et al; 2007; Resnick et al; 2008; Tőrnbom et al, 2016). Similarly, some of the stroke survivors in this study also reported the e-bike would provide an opportunity to socialise and meet new people. This agrees with previous research both in older adults and stroke survivors where socialising was identified as an enabler to using an e-bike and that physical activity such as cycling is a means to socialise (Gaskins et al, 2017; Johnson & Rose, 2015; Morris et al, 2017).

Studies into the barriers and enablers to physical activity in stroke survivors have shown that exercising with other stroke survivors can have an important influence on motivation to participate in physical activity (Morris et al, 2012, Resnick et al; 2008). In this study, none of the participants used their e-bikes to cycle with other stroke survivors. However, they did take part in physical activity where other stroke survivors participate such as at a local cardiac rehabilitation charity or using adapted cycles on a running track. Future research may wish to investigate e-bike use within a group setting and whether they encourage stroke survivors to increase their levels of physical activity and it could prove valuable for those stroke survivors who do not have enough storage space for an e-bike or lack social support.

The participant who cycled on his own felt there was a stigma attached to the use of the e-bike by those who rode racing bikes and that the e-bike might be perceived as cheating

or seen as not being serious cycling. This was cited as a reason for not seeking out the opportunity to cycle in a group. This aligns with other research involving both stroke survivors and the general public who has also felt there is a stigma attached to using the e-bike (Dill & Rose, 2012; Gaskins et al, 2017; Jones et al; 2016a, 2016b; Popovich et al, 2014). According to Gaskins et al, (2017), it was reported that stroke survivors felt that using the e-bike was cheating and would prevent an increase in strength by not exercising the weaker side. It is not clear whether this stigma deterred other stroke survivors from taking part in the study, but it could be a factor worth exploring in future research.

### *5.8 Physical Opportunity*

Prior to loaning the e-bike, the stroke survivors identified the e-bike as a mode of transport that would give them the independence to travel to locally, visit the countryside and relieve the burden placed on friends to supply a mode of transport. A lack of transport is a common barrier to physical activity by stroke survivors (Damush et al, 2007; Nicholson et al, 2013) and the participants within this study encountered a variety of barriers with regards to locations they were unable to access. The participant who had the least impairment was able to travel more freely and make longer journeys, whereas stroke survivors with more severe impairment were restricted to where they took the e-bike. The main reason for this was to build up confidence and to try and progress further each ride. The need for starting slowly and gradual was cited as a way of overcoming challenges to cycling by McMahon et al (2016). The participants in the McMahon (2016) study thought this might be made possible with the aid of training devices to get used to being on a bike as well as having access to help. This evidence

highlights the need of training and education to build the confidence of stroke survivors using e-bikes.

Whilst using the e-bike, the stroke survivors did report concerns around road safety. Due to living on a busy street or because roads are considered too busy to cycle on, in addition to problems with infrastructure particularly cycling paths in local parks which were described as problematic by one of the stroke survivors. Road safety and infrastructure are concerns for general e-bike users, cyclists with disabilities and the cycle community in general (Popovich et al, 2014; Jones et al, 2016a; Clayton et al, 2017). Studies involving stroke survivors have reported that they would be reluctant to travel on the roads due to concerns around other road users and traffic (Gaskins et al, 2017; McMahon et al, 2016). Recently there has been a call for further research into the issues that cyclists with disabilities face with regards accessing cycling infrastructure and the obstacles that disabled cyclists face such as poorly designed gates, kerbs and narrow cycle paths (Clayton et al, 2017).

The weather was identified as a barrier and enabler to using the e-bike by the stroke survivors before and after using it. The perception amongst the stroke survivors that the weather could dictate when they could cycle depending on the conditions. During the loan of the e-bikes, the UK experienced unexpectedly hot weather (Met Office, 2018) which affected when the participants could cycle, the length of journey and their motivation to cycle. However, stroke survivors also felt that the e-bike would allow them to cycle in adverse conditions with wind being a prime example. These findings agree with previous research that suggest the weather is a factor in cycling. Interview data by e-bike owners in Sacramento, California reported e-bike owners felt that hot

weather was not a barrier to using the e-bike due to the minimal amount of effort required to cycle (Popovich et al; 2014) which conflicts with the findings of our research. However, this could be due to the UK being a temperate climate and hot weather is considered unusual and requiring a lot adaptation (BBC, 2013). Despite this, the reports from the stroke survivors that the e-bike can handle windy conditions does concur with previous research by Popovich et al (2014) who also noted that wet and cold weathers can decrease battery life and cause rust to the e-bike's electrical components. Given its fluctuating and unpredictable manner, weather is an important factor to consider when developing an intervention especially with regards to storage, and the time of year to cycle. Additionally, concerns around safety especially rainy conditions which can impact on travelling on cycle paths which can become slippery or muddy (Jones et al, 2016a).

### *5.9 Reflective and Automatic Motivation*

The stroke survivors identified a variety of reflective and automatic motivation factors that acted as enablers and barriers to using the e-bike. Prior to using the e-bike most of the stroke survivors identified that the e-bike would act as a form of physical activity that could improve their fitness and health. This corresponds with previous research into the barriers and enablers to using an e-bike by stroke survivors (Gaskins et al, 2017; McMahon et al, 2016) in which participants listed improved fitness and health as reasons for cycling. Similarly, participants also perceived that they would get some form of satisfaction from using the e-bike and after using it described how much they enjoyed the experience. This agrees with previous results from e-bike studies within the general population who have also reported how much enjoyment they derive from using the e-bike (Langford et al, 2013; MacArthur et al, 2014; MacArthur; 2017;

Popovich et al; 2014; Sperlich et al, 2012). The results of this study would support the theory that identifying personal benefits and outcomes, combined with enjoyment have a positive effect on behaviour change (Ryan & Deci, 2000). It would also suggest that the e-bike could encourage stroke survivors to cycle due to the health benefits it provides and because it is an enjoyable activity they may be more likely to increase their usage and thus increase physical activity levels.

However, for some of the stroke survivor's negative emotions were connected to the use of the e-bike. They exhibited a fear of bumping into things whilst cycling and during the first set of interviews one participant indicated a fear of trying to cycle within a gym setting using a stationary bike. Fear of bumping into things was not reported in the previous literature focusing on e-bike and stroke survivors (Gaskins et al, 2017; McMahon et al, 2016) in which fear of falling and fear of being judged featured as barriers to cycling. However, it was reported as a barrier to physical activity in a study by Damush et al (2007) who reported that 23% of participants claimed that a fear of running into things prevented stroke survivors from engaging in physical activity. Within the literature regarding e-bike usage and the general population fear of bumping into things has been in relation to the speed of the e-bike and a fear of accidents involving other road users (Popovich et al, 2014). The participant that reported the fear of bumping into things did not utilise the electrical assistance on the e-bike and therefore speed was not a factor, but it was more due to his ability to cycle as his impairment meant he was cycling one-handed and therefore had limited control of the e-bike. Nonetheless, this fear and the effects of his impairment had an impact on his confidence and belief in his capability to use the e-bike which also impacted on his motivation to cycle. Motivation and belief in capabilities are closely connected (Dixon,

2008). Motivation is the factor that causes someone to act and to sustain this they must have a belief in their capabilities to maintain the desired behaviour. Therefore, building confidence is integral if a person is to stay motivated leading to a possible change in behaviour (Dixon. 2008).

Belief in capability was also discussed by one of the stroke survivors in relation to their family members having the belief that they were not safe to cycle on their own, despite the participant being confident on the e-bike. The participant did have his son to accompany him on the e-bike which eased these concerns however it did prevent him from cycling when his son went on holiday during the loan period. Within this study, it has been identified that social support is an important factor in enabling stroke survivors to use an e-bike depending on their level of impairment and therefore concerns around safety from family members does not necessarily have to be a barrier to using the e-bike. An article in Stoke Connection magazine (Stoke Association.org, 2011) highlighted that despite concerns about safety from his wife, David, an American stroke survivor was able to cycle using a recumbent bike on bike paths with an assistant accompanying him. Despite reporting that it sometimes proved difficult finding a partner to cycle with, he was also able to highlight the positives such as being able to bond with someone and share a healthy and enjoyable experience. This evidence highlights the need for social support for stroke survivors with their use of the e-bike and within the development of an intervention attention should be paid to those individuals who do not have support readily available to enable them to also use the e-bike.

## *5.10 Implications*

As discussed in the literature review, the barriers and enablers identified by the COM-B model can be used in the development of a complex intervention and elicit behaviour change (Michie et al, 2014). Table 5 illustrates the intervention functions and their links to the COM-B model. The intervention functions are a set of broad categories which aim to enhance the enablers and address the barriers identified from the COM-B model that are likely to facilitate behaviour change (Michie et al, 2014). To provide an insight in to how the barriers and enablers could be used as a starting point in the development of a stroke rehabilitation intervention, this thesis will now provide examples using the COM-B model elements, the intervention functions and the main barriers and enablers reported by the stroke survivors. Not all of the intervention functions are covered but examples are provided for how specific intervention functions could address the factors reported within this study. A more thorough breakdown of the intervention functions is available in *The Behaviour Change Wheel: A Guide to Designing Interventions* (Michie et al, 2014).

**Table 5: Matrix of links between COM-B and intervention functions**

| | Intervention functions | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| COM-B components | Education | Persuasion | Incentivisation | Coercion | Training | Restriction | Environmental restructuring | Modelling | Enablement |
| *Physical capability* | | | | | ■ | | | | ■ |
| *Psychological capability* | ■ | | | | ■ | | | | ■ |
| *Social opportunity* | | | | | | ■ | ■ | ■ | ■ |
| *Automatic motivation* | | ■ | ■ | ■ | ■ | | ■ | ■ | ■ |

**Adapted from Mitchie et al (2014)**

### 5.10.1 Physical Capability

Within the framework of the COM-B model the main barriers identified within physical capability were in relation to the effects of impairment. The main intervention function that could affect this barrier involve training and enablement (Table 5). Training may be provided with the aid of a combination of e-bike experts, cycling instructors and physiotherapists to identify the specific needs of the individual. This may work in a similar fashion to what has recently been proposed by Krops et al (2018). They developed a community based physical activity intervention for disabled individuals and suggested that participants have a pre-intervention assessment by a physiotherapist to discuss personal barriers and enablers, then partake in a physical assessment. With regards to stroke survivors and e-bikes this could be used to assess their needs concerning level of impairment and support requirements. In Krop's (2018) research this information is then used by an 'Activity Coach' to help decide which activities the person can participate in but in this case the 'Activity Coach' could be used to identify the appropriate adaptations or style of e-bike. Research by Klein et al, (2005) also proposes training techniques for inexperienced cyclists with disabilities to help overcome issues with balance and stability, which could be used in the development of an e-bike intervention.

### 5.10.2 Psychological Capability

A major barrier within psychological capability was the lack of knowledge or misconception that the participants held around e-bikes. As identified in Table 5 the intervention functions that may have an effect in overcoming this barrier are once again training and enablement as well as education. Education could come in the form of

online materials, videos, visits to stroke support groups which could also provide stroke survivors the experience of trying an e-bike. It should also detail the various types of e-bikes available as well as their adaptations. Information should be inclusive and free from the stereotypes that e-bikes are primarily for disabled, lazy or elderly people or that e-bikes are a form of cheating (Dill & Rose, 2012; Jones et al, 2016a; Popovich et al, 2014; Wheels for Wellbeing, 2017b).

### 5.10.3 Automatic Motivation

The main barrier encountered with regards to automatic motivation was in relation to fear of bumping into things and within the literature it has also featured in relation to a fear of falling (McMahon et al, 2016). The intervention functions in Table 5 propose a variety of categories that could address this issue. In addition to training, it proposes that persuasion, incentivisation and environmental restructuring as functions as well as modelling and coercion. With regards to environmental restructuring, improvements to cycling infrastructure such as the removal of obstacles such badly designed kerbs and wider cycles paths may help reduce the fear of falling and bumping into things. Incentives such as rewards could also play a role in overcoming fear. As fear is closely linked to a lack of confidence (Dixon, 2008) is has been hypothesised that for those whose physical activity levels are low, having an incentive may help boost confidence and belief in capability (Mitchell et al, 2016), which was another barrier to using the e-bike identified within this study. Rewards could come via the use of smartphone technology and GPS data. Developments in smartphone technology applications has shown to be an innovative method of tracking physical activity levels in stroke survivors (Dobkin & Dorsch et al, 2014) and combined with GPS data could allow

stroke survivors to track their e-bike activity and be rewarded when they reach specific milestones.

### 5.10.4 Social Opportunity

Although social support was primarily an enabler to using the e-bike, there were restrictions placed upon the stroke survivors when using the e-bike such as being reliant on the availability family members because of the support the participants needed to allow them to cycle such as helping them to mounting and dismounting the e-bike. In addition to easing these restrictions attention must be paid to those that do not have social support in place which would allow them to use an e-bike. Michie et al (2014) recommend that the intervention functions that could help address barriers associated with social opportunity are environmental restructuring, modelling, restrictions and enablement. Environmental restructuring could include cycling infrastructure and making the environment more inclusive for stroke survivors to cycle. In a recent report by Jones et al (2016b) they recommended the development of a dedicated cycling infrastructure separate from the busy roads and pedestrians which would allow ease of movement and allow people to cycle socially. Wheels for Wellbeing (2017b) also advocates the use of cycling hubs as a means of cycling socially and develop social networks which could provide an opportunity for volunteers or fellow cyclists to act as assistants for those individuals who need help using their e-bike. Enablement could include providing the partners or caregivers with an e-bike or possibly a tandem e-bike (Van Raam.com, 2018) which would enable them to cycle together. This could have effect of increasing the time spent doing physical activity, ease concerns around safety, and although stroke survivors would be cycling with a companion it could

also increase their independence as they would be able to go on trips they would probably have not made by themselves.

## 5.11 Strengths and Limitations

### 5.11.1 Strengths

The strengths of this study are that it was conducted in a natural setting allowing stroke survivors to experience the use of an e-bike something that has not been done before. It enabled the stroke survivors to identify the barriers and enablers to using the e-bike first hand via pre and post interviews rather than just providing a perception of these barrier and enablers. Data was also collected whilst participants were using the e-bike which allowed for enablers and barriers to be documented around the time they occurred which reduced the chances of recall bias.

The study was conducted within a framework using behavioural theory for analysis something that is encouraged within the development of complex interventions by the MRC (Craig et al, 2013) and something researchers of recently published randomised controlled trials have come under scrutiny for lacking (Walker et al, 2017). This study also added to the limited body of research focusing on stroke survivors and the barriers and enablers to using an e-bike as well as adding to the research surrounding barriers and enables to cycling in the disabled population which is also limited (Clayton et al, 2017).

### 5.11.2 Limitations

Limitations of the study include a restriction on time. As this was a Masters by research project it was conducted within the space of one year. This was the first time this type

of research had been conducted with stroke survivors and encountered issues around public liability insurance and ethics particularly with regards the safety of the participants and exclusion criteria. This impacted on the original scheduled length of time for recruitment and the length of time that the stroke survivors could loan the e-bikes for.

The sample of participants was restricted due to the number of e-bikes available and the time scale of the study and due to various factors, the number of participants who loaned an e-bike were reduced to three people. However, despite the limited number of participants, the interview data was still able to uncover several barriers and enablers to using the e-bike by the stroke survivors.

As stated above, the project involved collaborating with several stakeholders which included a local bike company who faced challenges in terms of having to order the various types of e-bikes and adaptations used by the stroke survivors which effected the time constraints of the study.

The author was relatively inexperienced at interviewing at the start of the study, more probing questions might have been asked during the earlier interviews after more training or exposure to interviews. Also, observational field notes may have added some extra richness to the data

The GPS trackers used for this study proved to be problematic when collecting usage data from the e-bikes due to technical issues surrounding the logging of their SIM cards which meant that data was not recorded for the first two weeks of the loan period for

two of the participants. The trackers were also not able to track the slow movements of the participant who did not use the electrical assistance. This meant that the second objective of the study was not achieved due to the small quantity of data retrieved from the e-bikes. Future research may wish to look at different types of GPS trackers or other means of tracking e-bike usage i.e. heart rate monitors, fitness watches or mobile technology.

Although some of the stroke survivors' partners were present for the interviews and contributed, their data could not be used as consent from partners to participate was not part of the ethics application. Future research may wish to seek the views of partners and caregivers with regards to the use of the e-bike by stroke survivors.

Prior to the loan of the e-bike, participants were not assessed to identify their needs, a thorough assessment by a trained physiotherapist may have impacted on the barriers faced by the stroke survivors and the adaptations required.

### 5.11.2 Areas for future research

Future research could use the results of this study to develop a pilot intervention for stroke survivors. As was noted in the discussion section all the participants that took part in the study were male, further research may clarify why women did not want to take part and provide information on the barriers and enablers they encounter when using an e-bike. Further research could investigate the physiological changes of stroke survivors whilst using an e-bike, especially with regards to fatigue, strength and effect of disability. Other types of e-bikes and adaptations could also be explored. One of the participants who withdrew from the study because he could not get approval from his

doctor to take part, therefore further study could investigate how clinicians and other health care professionals feel about e-bikes as a possible tool for rehabilitation. Another avenue of research could be to look at whether e-bike encourages stroke survivors to cycle if they are used within a group setting. Research has shown peer support from fellow stroke survivors is a key enabler to physical activity (Damush et al; 2007; Resnick et al; 2008; Tőrnbom et al, 2016) but in this study none of the participants chose to cycle with other stroke survivors. Conversely, it was reported there was a perceived stigma attached to using the e-bike which concurs with previous research into the barriers of using an e-bike by stroke survivors (Gaskins et al, 2017), therefore future research could explore the reasons behind this and if it is a possible deterrent to e-bike use by stroke survivors.

In addition to interviews, future research could encompass an observational element which document the barriers and enablers whilst the participants are using the e-bikes. A recent study by Jones et al (2016b) investigating how the built environment and technology could be improved to support and promote cycling in older adults used a mixture of trials (including the use of e-bikes), biographical interviews and video observation in which a cyclist navigated around a predefined route whilst being shadowed by a researcher. Both participant and researcher's bikes were fitted with video cameras, a GPS device and a Galvin Skin Response Device to monitor stress levels. Afterwards the footage was played back the cyclists and used as a prompt to gain an insight in their experience of cycling on that route. This innovative approach could lend itself to this type of research. Research using a larger sample size and letting the users have the e-bike for longer period may also yield different results as would exploring the experiences of e-bike users who have owned an e-bike for some time.

# CHAPTER 6: CONCLUSION

## *6.1 Conclusion*

The aim of this thesis was to explore the barriers and enablers of stroke survivors using an e-bike in the development of a stroke intervention using a case study approach with the objectives of firstly using the COM-B model behaviour change model to guide the understanding of the barriers and enablers to using an e-bike in the context of stroke and secondly explore e-bike usage during a three-month loan period of an e-bike.

The stroke survivors identified several barriers and enablers to using the e-bike. The main barriers were in relation to the level of physical impairment and the effect that it had on the stroke survivors' ability to use the e-bike, as well as the impact it had on reflective and automatic motivation with regards to belief about capability and fear of bumping into things. There were also misconceptions about what the e-bike does which suggests a lack of knowledge (psychological capability). Key enablers included the positive effect that the e-bike had on fatigue, the belief that using the e-bike was a mode of physical activity that was good for their health and was enjoyable. Social support (social opportunity) from family members was a key enabler providing stroke survivors with someone to cycle with as well as providing assistance mounting and dismounting the e-bike. The COM-B provided an effective method of analysing the barriers and enablers to using the e-bike and the results of this study can be used as a starting point in the development of rehabilitation intervention with a focus on building on the enablers and addressing the barriers identified. Due to the limited amount of GPS data that was collected from the e-bikes it was not possible to fulfil the second study objective.

# CHAPTER 7: REFERENCES

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# CHAPTER 8: APPENDICES

## Appendix 1: Email correspondence from Robert West and Susan Michie providing permission to use diagrams of the COM-B model and Behaviour Change Wheel

**From:** Robert West [redacted]
**Sent:** 06 March 2019 09:10
**To:** Paul Boland <Research Support Team>
**Subject:** Re: Permission to use Behaviour Change Wheel and COM-B model

I am happy to give permission but do make sure it is properly attributed

Best wishes

Robert

Professor Robert West
Department of Behavioural Science and Health
University College London
Website: www.rjwest.co.uk
Email: [redacted]
Telephone: [redacted]
Twitter: robertjwest

** SAVE THE DATE: 'Behaviour Change for Health: Digital & other Innovative Methods' Conference 9-10 April 2019 **

**Abstract submission ends:** 16th November

**For more information:** https://www.ucl.ac.uk/behaviour-change/events

On Wed, 6 Mar 2019 at 09:00, Paul Boland <PBoland2@uclan.ac.uk> wrote:

Hello Professor West,

I am a Masters student at the University of Central Lancashire and I have recently completed a project investigating the barriers and enablers to using electrically assisted bikes (e-bikes) by stroke survivors. For this study I utilised the COM-B model as a framework for analysis. The reason I am contacting you is to seek permission to use the diagram of the COM-B model and the Behaviour Change Wheel in my thesis or if you could advise me on how to go about getting this permission.

Kind regards

Paul S Boland

**From:** Michie, Susan <[redacted]>
**Sent:** 06 March 2019 09:11
**To:** Paul Boland <Research Support Team>
**Subject:** Re: Permission to use Behaviour Change Wheel and COM-B model

Dear Paul

You have my permission for this

Best wishes

Susan Michie

Sent from my iPad

On 6 Mar 2019, at 08:57, Paul Boland <PBoland2@uclan.ac.uk> wrote:

> Hello Professor Michie,
>
> I am a Masters student at the University of Central Lancashire and I have recently completed a project investigating the barriers and enablers to using electrically assisted bikes (e-bikes) by stroke survivors. For this study I utilised the COM-B model as a framework for analysis. The reason I am contacting you is to seek permission to use the diagram of the COM-B model and the Behaviour Change Wheel in my thesis or if you could advise me on how to go about getting this permission.
>
> Kind regards
>
> Paul S Boland

**Appendix 2: Demographic information sheet**


Interview Schedule 2

**Participant No.** ☐

## Exploring the perceptions and experiences of using an electric bike after stroke

## DEMOGRAPHIC INFORMATION (Version 2, 15/03/18)

1. Age ____ years

2. Gender Male Female Prefer not to say

3. Is this your first stroke? Y / N Prefer not to say

4. How long has it been since your stroke occurred? ___ years ___ months

**Appendix 3: WHOQOL-BREF**

# WHOQOL-BREF

# INTRODUCTION, ADMINISTRATION, SCORING

# AND GENERIC VERSION OF THE ASSESSMENT

**Field Trial Version**

**December 1996**

**PROGRAMME ON MENTAL HEALTH**

**WORLD HEALTH ORGANIZATION**
**GENEVA**

This manual was drafted by Alison Harper on behalf of the WHOQOL group. The WHOQOL group comprises a coordinating group, collaborating investigators in each of the field centres and a panel of consultants. Dr J. Orley directs the project. He has been assisted in this by Professor M. Power, Dr W. Kuyken, Professor N. Sartorius, Dr M. Bullinger and Dr A. Harper. The field centres involved in initial piloting of the WHOQOL were: Professor H. Herrman, Dr H. Schofield and Ms B. Murphy, University of Melbourne, Australia; Professor Z. Metelko, Professor S. Szabo and Mrs M. Pibernik-Okanovic, Institute of Diabetes, Endocrinology and Metabolic Diseases and Department of Psychology, Faculty of Philosophy, University of Zagreb, Croatia; Dr N. Quemada and Dr A. Caria, INSERM, Paris, France; Dr S. Rajkumar and Mrs Shuba Kumar, Madras Medical College, India; Dr S. Saxena and Dr K. Chandiramani, All India Institute of Medical Sciences, New Delhi, India; Dr M. Amir and Dr D. Bar-On, Ben-Gurion University of the Negev, Beer-Sheeva, Israel; Dr Miyako Tazaki, Department of Science, Science University of Tokyo, Japan and Dr Ariko Noji, Department of Community Health Nursing, St Luke's College of Nursing, Japan; Dr G. van Heck and Mrs J. De Vries, Tilburg University, The Netherlands; Professor J. Arroyo Sucre and Professor L. Picard-Ami, University of Panama, Panama; Professor M. Kabanov, Dr A. Lomachenkov and Dr G. Burkovsky, Bekhterev Psychoneurological Research Institute, St. Petersburg, Russia; Dr R. Lucas Carrasco, University of Barcelona, Spain; Dr Yooth Bodharamik and Mr Kitikorn Meesapya, Institute of Mental Health, Bangkok, Thailand; Dr S. Skevington, University of Bath, United Kingdom; Professor D. Patrick, Ms M. Martinand, Ms D. Wild, University of Washington, Seattle, USA and; Professor W. Acuda and Dr J. Mutambirwa, University of Zimbabwe, Harare, Zimbabwe.

New centres using the field version of the WHOQOL-100 are: Dr S. Bonicato, FUNDONAR, Fundacion Oncologica Argentina, Argentina; Dr A.E. Molzahn, University of Victoria, Canada; Dr G. Yongping, St Vincent s Hospital, Victoria, Australia; Dr G. Page, University of Quebec at Rimouski, Canada; Professor J. Fang, Sun Yat-Sen University of Medical Sciences, People s Republic of China; Dr M. Fleck, University of the State of Rio Grande do Sul, Brazil; Professor M.C. Angermeyer, Dr R. Kilian, Universitätsklinikum Klinik und Poliklinik für Psychiatrie, Leipzig, Germany; Mr Kwok Fai Leung, Hospital Authority, Hong Kong; Dr B.R. Hanestad, University of Bergen, Norway; Dr M.H. Mubbashar, Rawalpindi General Hospital, Pakistan; Dr J. Harangozo, Semelweis University of Medicine, Budapest & Dr L. Kullman, National Institute of Mental Rehabilitation, Budapest, Hungary; Professor I. Wiklund, Health Economics & Quality of Life, Astra Hässle AB, Sweden; Dr C. Fidaner, Dr Behçet Uz Paediatric Hospital, Balçova/Izmir, Turkey; Dr G. de Girolamo, Servizio Salute Mentale USL 27, Italy; Professor P. Bech, Frederiksborg General Hospital, Denmark; Dr R.S. Pippalla, Howard University, College of Pharmacy and Pharmaceutical Sciences, Washington, DC, USA and Dr H. Che Ismail, School of Medical Sciences, Kelantan, Malaysia.

**Further information can be obtained from:**
Dr John Orley
Programme on Mental Health
World Health Organization
CH-1211 Geneva 27, Switzerland

# WHOQOL-BREF
# Introduction, Administration, Scoring and Generic Version of the Assessment

## Introduction

The WHOQOL-100 quality of life assessment was developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality of life assessment that would be applicable cross-culturally. The development of the WHOQOL-100, has been detailed elsewhere (i.e. Orley & Kuyken, 1994; Szabo, 1996; WHOQOL Group 1994a, 1994b, 1995). This document gives a conceptual background to the WHOQOL definition of quality of life and describes the development of the WHOQOL-BREF, an abbreviated version of the WHOQOL-100. It also includes a generic English language version of the WHOQOL-BREF, instructions for administering and scoring, and proposed uses for this short form of the WHOQOL.

## Rationale for the development of the WHOQOL-100

WHO's initiative to develop a quality of life assessment arose for a number of reasons. In recent years there has been a broadening in focus in the measurement of health, beyond traditional health indicators such as mortality and morbidity (e.g. World Bank, 1993; WHO, 1991), to include measures of the impact of disease and impairment on daily activities and behaviour (e.g. Sickness Impact Profile; Bergner, Bobbitt, Carter et al, 1981), perceived health measures (e.g. Nottingham Health Profile; Hunt, McKenna and McEwan, 1989) and disability / functional status measures (e.g. the MOS SF-36, Ware et al, 1993). These measures, whilst beginning to provide a measure of the impact of disease, do not assess quality of life *per se*, which has been aptly described as "the missing measurement in health" (Fallowfield, 1990). Second, most measures of health status have been developed in North America and the UK, and the translation of these measures for use in other settings is time-consuming, and unsatisfactory for a number of reasons (Sartorius and Kuyken, 1994; Kuyken, Orley, Hudelson and Sartorius, 1994). Third, the increasingly mechanistic model of medicine, concerned only with the eradication of disease and symptoms, reinforces the need for the introduction of a humanistic element into health care. By calling for quality of life assessments in health care, attention is focused on this aspect of health, and resulting interventions will pay increased attention to this aspect of patients' well-being. WHO's initiative to develop a quality of life assessment arises from a need for a genuinely international measure of quality of life and a commitment to the continued promotion of an holistic approach to health and health care.

## Steps in the development of the WHOQOL-100

The WHOQOL-100 development process consisted of several stages. These are explained in brief within this document. For a detailed description, the reader is referred to the WHOQOL Group (1994a, 1994b, in preparation). In the first stage, concept clarification involved establishing an agreed upon definition of quality of life and an approach to international quality of life assessment.

*Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.*

This definition reflects the view that quality of life refers to a subjective evaluation which is embedded in a cultural, social and environmental context. Because this definition of quality of life focuses upon respondents' "perceived" quality of life, it is not expected to provide a means of measuring in any

detailed fashion symptoms, diseases or conditions, but rather the effects of disease and health interventions on quality of life. As such, quality of life cannot be equated simply with the terms "health status", "life style", "life satisfaction", "mental state" or "well-being". The recognition of the multi-dimensional nature of quality of life is reflected in the WHOQOL-100 structure.

In the second stage of development, exploration of the quality of life construct within 15 culturally diverse field centres was carried out to establish a list of areas/facets that participating centres considered relevant to the assessment of quality of life. This involved a series in meetings of focus groups which included health professionals, patients and well subjects. A maximum of six specific items for exploring each proposed facet were generated by each centre's focus group. To enable the collaboration to be genuinely international the 15 field centres were selected world-wide to provide differences in level of industrialisation, available health services, and other markers relevant to the measurement of quality of life (e.g. role of the family, perception of time, perception of self, dominant religion).

In the third stage of development, questions from each centre were assembled into a global pool. After clustering semantically equivalent questions, 236 items covering 29 facets were included in a final assessment. Pilot work involved administration of this standardised assessment to at least 300 respondents within each centre.

Following field testing in these 15 centres, 100 items were selected for inclusion in the WHOQOL-100 Field Trial Version. These included four items for each of 24 facets of quality of life, and four items relating to the 'overall quality of life and general health' facet (see Table 1). The method by which these 100 items were selected is fully documented elsewhere (The WHOQOL Group, in preparation). The WHOQOL-100 Field Trial Version is currently being tested in new centres world-wide (these centres are outlined on page 6 of this document). The initial conceptual framework for the WHOQOL-100 proposed that the 24 facets relating to quality of life should be grouped into 6 domains. Recent analysis of available data, using structural equation modelling, has shown a four domain solution to be more appropriate. For a more detailed explanation of this, the reader is referred to The WHOQOL Group (in preparation). The WHOQOL-BREF is therefore based on a four domain structure (see Table 1).

## Table 1 - WHOQOL-BREF domains

| Domain | Facets incorporated within domains |
|---|---|
| 1. Physical health | Activities of daily living<br>Dependence on medicinal substances and medical aids<br>Energy and fatigue<br>Mobility<br>Pain and discomfort<br>Sleep and rest<br>Work Capacity |
| 2. Psychological | Bodily image and appearance<br>Negative feelings<br>Positive feelings<br>Self-esteem<br>Spirituality / Religion / Personal beliefs<br>Thinking, learning, memory and concentration |
| 3. Social relationships | Personal relationships<br>Social support<br>Sexual activity |
| 4. Environment | Financial resources<br>Freedom, physical safety and security<br>Health and social care: accessibility and quality<br>Home environment<br>Opportunities for acquiring new information and skills<br>Participation in and opportunities for recreation / leisure activities<br>Physical environment (pollution / noise / traffic / climate)<br>Transport |

## Development of the WHOQOL-BREF

The WHOQOL-100 allows detailed assessment of each individual facet relating to quality of life. In certain instances however, the WHOQOL-100 may be too lengthy for practical use. The WHOQOL-BREF Field Trial Version has therefore been developed to provide a short form quality of life assessment that looks at Domain level profiles, using data from the pilot WHOQOL assessment and all available data from the Field Trial Version of the WHOQOL-100. Twenty field centres situated within eighteen countries have included data for these purposes (see Table 2). The WHOQOL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included.

## Table 2 - Centres included in development of the WHOQOL-BREF

| Centres in the pilot version of the WHOQOL | Centres in the field trial of the WHOQOL-100 |
|---|---|
| Bangkok, Thailand | Bangkok, Thailand |
| Beer Sheva, Israel | Beer Sheva, Israel |
| Madras, India | Madras, India |
| Melbourne, Australia | Melbourne, Australia |
| New Delhi, India | New Delhi, India |
| Panama City, Panama | Panama City, Panama |
| Seattle, USA | Seattle, USA |
| Tilburg, The Netherlands | Tilburg, The Netherlands |
| Zagreb, Croatia | Zagreb, Croatia |
| Tokyo, Japan | Tokyo, Japan |
| Harare, Zimbabwe | Harare, Zimbabwe |
| Barcelona, Spain | Barcelona, Spain |
| Bath, UK | Bath, UK |
| St Petersburg, Russia | Hong Kong |
| Paris, France | Leipzig, Germany |
| | Mannheim, Germany |
| | La Plata, Argentina |
| | Port Alegre, Brazil |

The WHOQOL-BREF is available in 19 different languages. The appropriate language version, and permission for using it, can be obtained from The WHOQOL Group, Programme on Mental Health, World Health Organisation, CH-1211 Geneva 27, Switzerland. Under no circumstances should the WHOQOL-BREF be used without consultation with The WHOQOL Group. A methodology has been developed for new centres wishing to develop a further language version of the WHOQOL-100 or the WHOQOL-BREF. This can be obtained from The WHOQOL Group, Programme on Mental Health, World Health Organisation, CH-1211, Geneva 27, Switzerland.

Questions should appear in the order in which they appear in the example WHOQOL-BREF provided within this document, with instructions and headers unchanged. Questions are grouped by response format. The equivalent numbering of questions between the WHOQOL-BREF and the WHOQOL-100 is given in the example version of the WHOQOL-BREF to enable easy comparison between responses to items on the two versions. The WHOQOL-100 field test permitted centres to include national items or facets that were thought to be important in assessing quality of life. Where centres wish to include additional national items or modules to the WHOQOL-BREF, these should be included on a separate sheet of paper and not scattered amongst the existing 26 items. There are three reasons for this:

1) To control for item order effects which could occur and change item meaning.
2) The WHOQOL-BREF represents an agreed upon core set of international items.
3) The WHOQOL-BREF is likely to be used where quality of life is amongst one of several parameters being assessed. Therefore additional national information can be obtained by including additional modules and measures

## Administration of the WHOQOL-BREF

For any new centre not previously involved in either the development or field testing of the WHOQOL-100, the procedure being followed to field test the WHOQOL-BREF should be identical to that used to field test the WHOQOL-100. The instrument should be piloted on at least 300 people. This figure is based on the required numbers of respondents needed for analysis of pilot data. The sample of respondents to whom the assessment should be administered ought to be adults, with 'adult' being culturally defined. While stratified samples are not essential, a sampling quota should apply with regard to:

- Age (50% = <45 years, 50% = 45+ years)
- Sex (50% = male, 50% = female)
- Health status (250 persons with disease or impairment; 50 well persons)

With respect to persons with disease or impairment, this group should contain a cross-section of people with varied levels of quality of life. One way of attempting this would be to include some people with quite severe and disabling chronic diseases, some people in contact with health facilities for more transient conditions, possibly some attending a family practitioner, and others who are in contact with the health service for reasons that are not likely to impinge upon their quality of life to any great extent. By sampling patients from a cross-section of primary care settings, hospitals and community care settings this could most likely be achieved.

The WHOQOL-BREF should be self-administered if respondents have sufficient ability: otherwise, interviewer-assisted or interview-administered forms should be used. Standardised instructions, given on the second page of the WHOQOL-BREF example assessment, should be read out to respondents in instances where the assessment is interviewer-administered.

For centres who have already participated in the development and field testing of the WHOQOL-100, the above option of testing the WHOQOL-BREF is preferred, but not imperative where specific studies of patient groups are planned.

## Frame of reference and time frame

A time frame of two weeks is indicated in the assessment. It is recognised that different time frames may be necessary for particular uses of the instrument in subsequent stages of work. For example, in the assessment of quality of life in chronic conditions, such as arthritis, a longer time frame such as four weeks may be preferable. Furthermore, the perception of time is different within different cultural settings and therefore changing the time scale may be appropriate.

## Proposed uses of the WHOQOL-100 and the WHOQOL-BREF

It is anticipated that the WHOQOL assessments will be used in broad-ranging ways. They will be of considerable use in clinical trials, in establishing baseline scores in a range of areas, and looking at changes in quality of life over the course of interventions. It is expected that the WHOQOL assessments will also be of value where disease prognosis is likely to involve only partial recovery or remission, and in which treatment may be more palliative than curative.

For epidemiological research, the WHOQOL assessments will allow detailed quality of life data to be gathered on a particular population, facilitating the understanding of diseases, and the development

of treatment methods. The international epidemiological studies that would be enabled by instruments such as the WHOQOL-100 and the WHOQOL-BREF will make it possible to carry out multi-centre quality of life research, and to compare results obtained in different centres. Such research has important benefits, permitting questions to be addressed which would not be possible in single site studies (Sartorius and Helmchen, 1981). For example, a comparative study in two or more countries on the relationship between health care delivery and quality of life requires an assessment yielding cross-culturally comparable scores. Sometimes accumulation of cases in quality of life studies, particularly when studying rare disorders, is helped by gathering data in several settings. Multi-centre collaborative studies can also provide simultaneous multiple replications of a finding, adding considerably to the confidence with which findings can be accepted.

In clinical practice the WHOQOL assessments will assist clinicians in making judgements about the areas in which a patient is most affected by disease, and in making treatment decisions. In some developing countries, where resources for health care may be limited, treatments aimed at improving quality of life through palliation, for example, can be both effective and inexpensive (Olweny, 1992). Together with other measures, the WHOQOL-BREF will enable health professionals to assess changes in quality of life over the course of treatment.

It is anticipated that in the future the WHOQOL-100 and the WHOQOL-BREF will prove useful in health policy research and will make up an important aspect of the routine auditing of health and social services. Because the instrument was developed cross-culturally, health care providers, administrators and legislators in countries where no validated quality of life measures currently exist can be confident that data yielded by work involving the WHOQOL assessments will be genuinely sensitive to their setting.

## Scoring the WHOQOL-BREF

The WHOQOL-BREF (Field Trial Version) produces a quality of life profile. It is possible to derive four domain scores. There are also two items that are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100. Explicit instructions for checking and cleaning data, and for computing domain scores, are given in Table 3. A method for the manual calculation of individual scores is given on page 1 of the WHOQOL-BREF assessment form. The method for converting raw scores to transformed scores when using this method is given in Table 4, on page 11 of these instructions. The first transformation method converts scores to range between 4-20, comparable with the WHOQOL-100. The second transformation method converts domain scores to a 0-100 scale.

Where more than 20% of data is missing from a assessment, the assessment should be discarded (see Step 4 in Table 3). Where an item is missing, the mean of other items in the domain is substituted. Where more than two items are missing from the domain, the domain score should not be calculated (with the exception of domain 3, where the domain should only be calculated if $\leq$ 1 item is missing).

Any national items should be scored separately from the core 26 item of the BREF. During the analysis the performance of any national items will be examined for possible use in alter national studies. At this stage of field testing national and core items must not be mixed in administration or scoring of the BREF.

An SPSS syntax file that automatically checks, recodes data and computes domain scores may be obtained from Professor Mick Power, Department of Psychiatry, Royal Edinburgh Hospital, Morningside Park, Edinburgh, EH10 5HF (email: mj@srv2.med.ed.ac.uk; fax: + 131 447 6860)

## Table 3 - Steps for checking and cleaning data and computing domain scores

| | Steps | SPSS syntax for carrying out data checking, cleaning and computing total scores |
|---|---|---|
| 1. | Check all 26 items from assessment have a range of 1-5 | RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS).<br>(This recodes all data outwith the range 1-5 to system missing). |
| 2. | Reverse 3 negatively phrased items | RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1).<br>(This transforms negatively framed questions to positively framed questions) |
| 3. | Compute domain scores | COMPUTE DOM1=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4.<br>COMPUTE DOM2=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4.<br>COMPUTE DOM3=MEAN.2(Q20,Q21,Q22)*4.<br>COMPUTE DOM4=MEAN.6(Q8,Q9,Q12,Q13,Q14,Q23,Q24,Q25)*4.<br>(These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated). |
| 4. | Delete cases with >20% missing data | COUNT TOTAL=Q1 TO Q26 (1 THRU 5).<br>(This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-100 items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment).<br>FILTER OFF.<br>USE ALL.<br>SELECT IF (TOTAL>=21).<br>EXECUTE.<br>(This second command selects only those cases where 'total', the total number of items completed, is greater or equal to 80%. It deletes the remaining cases from the data set). |
| 5. | Check domain scores | DESCRIPTIVES<br>VARIABLES=DOM1 DOM2 DOM3 DOM4<br>/STATISTICS=MEAN STDDEV MIN MAX.<br>(Running descriptives should display values of all domain scores within the range 4-20). |
| 6. | Save data set | Save data set with a new file name so that the original remains intact. |

## Table 4 - Method for converting raw scores to transformed scores

| DOMAIN 1 | | |
|---|---|---|
| Raw Score | Trasnformed scores | |
| | 4-20 | 0-100 |
| 7 | 4 | 0 |
| 8 | 5 | 6 |
| 9 | 5 | 6 |
| 10 | 6 | 13 |
| 11 | 6 | 13 |
| 12 | 7 | 19 |
| 13 | 7 | 19 |
| 14 | 8 | 25 |
| 15 | 9 | 31 |
| 16 | 9 | 31 |
| 17 | 10 | 38 |
| 18 | 10 | 38 |
| 19 | 11 | 44 |
| 20 | 11 | 44 |
| 21 | 12 | 50 |
| 22 | 13 | 56 |
| 23 | 13 | 56 |
| 24 | 14 | 63 |
| 25 | 14 | 63 |
| 26 | 15 | 69 |
| 27 | 15 | 69 |
| 28 | 16 | 75 |
| 29 | 17 | 81 |
| 30 | 17 | 81 |
| 31 | 18 | 88 |
| 32 | 18 | 88 |
| 33 | 19 | 94 |
| 34 | 19 | 94 |
| 35 | 20 | 100 |

| DOMAIN 2 | | |
|---|---|---|
| Raw score | Trasnformed scores | |
| | 4-20 | 0-100 |
| 6 | 4 | 0 |
| 7 | 5 | 6 |
| 8 | 5 | 6 |
| 9 | 6 | 13 |
| 10 | 7 | 19 |
| 11 | 7 | 19 |
| 12 | 8 | 25 |
| 13 | 9 | 31 |
| 14 | 9 | 31 |
| 15 | 10 | 38 |
| 16 | 11 | 44 |
| 17 | 11 | 44 |
| 18 | 12 | 50 |
| 19 | 13 | 56 |
| 20 | 13 | 56 |
| 21 | 14 | 63 |
| 22 | 15 | 69 |
| 23 | 15 | 69 |
| 24 | 16 | 75 |
| 25 | 17 | 81 |
| 26 | 17 | 81 |
| 27 | 18 | 88 |
| 28 | 19 | 94 |
| 29 | 19 | 94 |
| 30 | 20 | 100 |

| DOMAIN 3 | | |
|---|---|---|
| Raw score | Transformed scores | |
| | 4-20 | 0-100 |
| 3 | 4 | 0 |
| 4 | 5 | 6 |
| 5 | 7 | 19 |
| 6 | 8 | 25 |
| 7 | 9 | 31 |
| 8 | 11 | 44 |
| 9 | 12 | 50 |
| 10 | 13 | 56 |
| 11 | 15 | 69 |
| 12 | 16 | 75 |
| 13 | 17 | 81 |
| 14 | 19 | 94 |
| 15 | 20 | 100 |

| DOMAIN 4 | | |
|---|---|---|
| Raw score | Transformed scores | |
| | 4-20 | 0-100 |
| 8 | 4 | 0 |
| 9 | 5 | 6 |
| 10 | 5 | 6 |
| 11 | 6 | 13 |
| 12 | 6 | 13 |
| 13 | 7 | 19 |
| 14 | 7 | 19 |
| 15 | 8 | 25 |
| 16 | 8 | 25 |
| 17 | 9 | 31 |
| 18 | 9 | 31 |
| 19 | 10 | 38 |
| 20 | 10 | 38 |
| 21 | 11 | 44 |
| 22 | 11 | 44 |
| 23 | 12 | 50 |
| 24 | 12 | 50 |
| 25 | 13 | 56 |
| 26 | 13 | 56 |
| 27 | 14 | 63 |
| 28 | 14 | 63 |
| 29 | 15 | 69 |
| 30 | 15 | 69 |
| 31 | 16 | 75 |
| 32 | 16 | 75 |
| 33 | 17 | 81 |
| 34 | 17 | 81 |
| 35 | 18 | 88 |
| 36 | 18 | 88 |
| 37 | 19 | 94 |
| 38 | 19 | 94 |
| 39 | 20 | 100 |
| 40 | 20 | 100 |

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WHO/MSA/MNH/PSF/97.4
English only
Distr.: Limited

# WHOQOL-BREF

## PROGRAMME ON MENTAL HEALTH
## WORLD HEALTH ORGANIZATION
## GENEVA

**For office use only**

| | Equations for computing domain scores | Raw score | Transformed scores* | |
|---|---|---|---|---|
| **Domain 1** | (6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18<br>☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ | = | **4-20** | **0-100** |
| **Domain 2** | Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)<br>☐ + ☐ + ☐ + ☐ + ☐ + ☐ | = | | |
| **Domain 3** | Q20 + Q21 + Q22<br>☐ + ☐ + ☐ | = | | |
| **Domain 4** | Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25<br>☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ | = | | |

* Please see Table 4 on page 10 of the manual, for converting raw scores to transformed scores.

I.D. number

| | | | |
|---|---|---|---|
| | | | |

**ABOUT YOU**

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**? Male Female

What is you **date of birth**? _____ / _____ / _____
Day / Month / Year

What is the highest **education** you received?
None at all
Primary school
Secondary school
Tertiary

What is your **marital status**?
Single Separated
Married Divorced
Living as married Widowed

Are you currently **ill**? Yes No

If something is wrong with your health what do you think it is?_____illness/ problem

## Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

| | | Not at all | Not much | Moderately | A great deal | Completely |
|---|---|---|---|---|---|---|
| | Do you get the kind of support from others that you need? | 1 | 2 | 3 | 4 | 5 |

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

| | | Not at all | Not much | Moderately | A great deal | Completely |
|---|---|---|---|---|---|---|
| | Do you get the kind of support from others that you need? | 1 | 2 | 3 | 4 | 5 |

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

**Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.**

| | | Very poor | Poor | Neither poor nor good | Good | Very good |
|---|---|---|---|---|---|---|
| 1(G1) | How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|---|---|---|---|---|---|---|
| 2 (G4) | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about **how much** you have experienced certain things in the last two weeks.

| | | Not at all | A little | A moderate amount | Very much | An extreme amount |
|---|---|---|---|---|---|---|
| 3 (F1.4) | To what extent do you feel that physical pain prevents you from doing what you need to do? | 1 | 2 | 3 | 4 | 5 |
| 4(F11.3) | How much do you need any medical treatment to function in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 5(F4.1) | How much do you enjoy life? | 1 | 2 | 3 | 4 | 5 |
| 6(F24.2) | To what extent do you feel your life to be meaningful? | 1 | 2 | 3 | 4 | 5 |

| | | Not at all | A little | A moderate amount | Very much | Extremely |
|---|---|---|---|---|---|---|
| 7(F5.3) | How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |
| 8 (F16.1) | How safe do you feel in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 9 (F22.1) | How healthy is your physical environment? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

| | | Not at all | A little | Moderately | Mostly | Completely |
|---|---|---|---|---|---|---|
| 10 (F2.1) | Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| 11 (F7.1) | Are you able to accept your bodily appearance? | 1 | 2 | 3 | 4 | 5 |
| 12 (F18.1) | Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 13 (F20.1) | How available to you is the information that you need in your day-to-day life? | 1 | 2 | 3 | 4 | 5 |
| 14 (F21.1) | To what extent do you have the opportunity for leisure activities? | 1 | 2 | 3 | 4 | 5 |

| | | Very poor | Poor | Neither | Good | Very good |
|---|---|---|---|---|---|---|

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | poor nor good | | |
| 15 (F9.1) | How well are you able to get around? | 1 | 2 | 3 | 4 | 5 |

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|---|---|---|---|---|---|---|
| 16 (F3.3) | How satisfied are you with your sleep? | 1 | 2 | 3 | 4 | 5 |
| 17 (F10.3) | How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 18(F12.4) | How satisfied are you with your capacity for work? | 1 | 2 | 3 | 4 | 5 |
| 19 (F6.3) | How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 20(F13.3) | How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 21(F15.3) | How satisfied are you with your sex life? | 1 | 2 | 3 | 4 | 5 |
| 22(F14.4) | How satisfied are you with the support you get from your friends? | 1 | 2 | 3 | 4 | 5 |
| 23(F17.3) | How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |
| 24(F19.3) | How satisfied are you with your access to health services? | 1 | 2 | 3 | 4 | 5 |
| 25(F23.3) | How satisfied are you with your transport? | 1 | 2 | 3 | 4 | 5 |

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

| | | Never | Seldom | Quite often | Very often | Always |
|---|---|---|---|---|---|---|
| 26 (F8.1) | How often do you have negative feelings such as blue mood, despair, anxiety, depression? | 1 | 2 | 3 | 4 | 5 |

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

**Do you have any comments about the assessment?**

.....

.....

**THANK YOU FOR YOUR HELP**

**Appendix 4: Functional Ambulation Categories**

| FAC | Ambulation Description | Definition |
|---|---|---|
| 0 | Nonfunctional ambulation | Subject cannot ambulate, ambulates in parallel bars only, or requires supervision or physical assistance from more than one person to ambulate safely outside of parallel bars |
| 1 | Ambulator-Dependent for Physical Assistance Level II | Subject requires manual contacts of no more than one person during ambulation on level surfaces to prevent falling. Manual contacts are continuous and necessary to support body weight as well as maintain balance and/or assist coordination |
| 2 | Ambulator-Dependent for Physical Assistance Level I | Subject requires manual contact of no more than one person during ambulation on level surfaces to prevent falling. Manual contact consists of continuous or intermittent light touch to assist balance or coordination |
| 3 | Ambulator-Dependent for Supervision | Subject can physically ambulate on level surfaces without manual contact of another person but for safety requires standby guarding on no more than one person because of poor judgment, questionable cardiac status, or the need for verbal cuing to complete the task. |
| 4 | Ambulator-Independent Level Surfaces only | Subject can ambulate independently on level surfaces but requires supervision or physical assistance to negotiate any of the following: stairs, inclines, or non-level surfaces. |
| 5 | Ambulator-Independent | Subject can ambulate independently on nonlevel and level surfaces, stairs, and inclines. |

**(Holden et al, 1984)**

**Appendix 5: Letter of approval from the BAHSS Ethics Committee**

05 April 2018

Jessica Janssen / Paul
Boland School of
Health Sciences
University of Central
Lancashire

Dear Jessica / Paul

Re: BAHSS Ethics Committee Application
Unique Reference Number: STEMH 844 FR Amendment 04_04_18

The BAHSS Ethics Committee has approved your proposed amendment to your application 'An exploration of the barriers and enablers of using electrically assisted bikes (e-bikes) in the development of a stroke intervention'.

Yours sincerely

Alison Naylor

pp STEMH Ethics Committee

**Appendix 6: Participant consent form**

University of Central Lancashire

**Participant No.** ☐

## Exploring the perceptions and experiences of using an electric bike after stroke

**CONSENT FORM (Version 2, 22/03/2018)**

Please initial box

1. I confirm that I have read and understood the information sheet (Version 2, Date 22/03/2018) for the above study "Exploring the perceptions and experiences of using an electric bike after stroke". I have had the opportunity to consider the information and ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason but that data collected already at the point of withdrawal may not be removed from the study. ☐
3. I agree:
   - For personal data to be collected and anonymised ☐
   - To participate in an individual interview with a Masters student from UCLan and complete a quality of life questionnaire at the beginning and at the end of the research. ☐
   - To allow the interviews to be audio-recorded, transcribed and anonymised. ☐
   - For anonymised information to be used in reports and publications. ☐
   - That my participation in the second part of the study is subject to having received clearance from my GP ☐

to take part in the loan and safe use of an electric bike. And that I understand there may be a fee involved for obtaining this clearance which I will be reimbursed.

- To loan an electric bike for a duration of up to 3-months. Wear the safety helmet provided at all times when using the bicycle as well as store it in a secure location when it is not in use, using the lock provided. ☐

- To be contacted every two weeks during the loan period via telephone to monitor if I require any support using the electric bike. ☐

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |
| _____ | _____ | _____ |
| Name of researcher | Date | Signature |

Optional consent:

Please indicate if you agree to the following:

- I am happy to be contacted for other research studies in the future by the UClan stroke team (please provide address details below). ☐

- I would like to receive a summary of the findings of this study (please provide address details below). ☐

**Appendix 7: Campus poster advertisement**

**Poster removal date: 18/05/2018**

uclan
University of Central Lancashire

# HAVE YOU OR DO YOU KNOW SOMEONE WHO HAS HAD A STROKE?

To help develop future stroke rehabilitation interventions we are looking for volunteers to take part in a **MSc student project** to explore their thoughts of using an e-bike post stroke and then explore their experiences of using an electric bike after a loan period.

**AM I ELIGIBLE?** If you have previously had a stroke but are able to walk (with or without assistance) then you might be eligible to participate (confirmation from your GP is required).

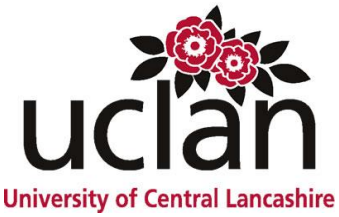
**WHAT WOULD BE INVOLVED?** If you agree to participate :

1. At a convenient location you will take part in an individual interview and complete a quality of life questionnaire at the start and at the end of the research.
2. You will have the opportunity to loan an electric bike for a maximum duration of **3-months** and you will be contacted every two weeks via telephone to monitor your progress.

**FOR MORE INFORMATION:** Please contact **Paul Boland**: pboland1@uclan.ac.uk or my supervisor **Dr. Jessie Janssen**: jjanssen@uclan.ac.uk, 01772 894560

**This project has been approved by the UCLan STEMH Ethics Committee. Ethics No: 844**

**Appendix 8: Letter of approval from a participant's doctor**




## Exploring the perceptions and experiences of using an electric bike after stroke

Dear Sir or Madam,

_____[Insert participant name] is requesting to take part in the above study (see attached information sheet for further details). The study is specifically aimed at stroke survivors and because of this all participants are legally obliged to seek doctor's approval to enable them to take part.

Could you please confirm that the participant is safe to take part in this research and although they have previously had stroke they have no other condition which will be exacerbated and/or impairment that will influence their safety or jeopardise the safety of others.

Conditions/Impairments include, but not limited to, any of the following:

**Physical:** - upper or lower limb, comorbidities

**Cognitive:** – neglect, spatial awareness, apraxia

**Visual:** – neglect, visual field defects and other deficits

### Participant Involvement

During this research the participant will be asked to:

1) Take part in an individual interview and complete the WHOQOL-BREF quality of life questionnaire at the start of the study and

repeated again at the end of the study. The WHOQOL-BREF is a widely used quality of life assessment tool which some mental health questions that some people may find upsetting. For example, one of the questions asks: “How often do you have negative feelings such as blue mood, despair, anxiety, depression?” The participant is not obliged to answer these questions and the researcher will be on hand to answer any questions they may have regarding the questionnaire.

2) They will be loaned an electrically assisted bike (e-bike) for a maximum duration of 3-months which they can use for any leisure or outdoor activities. E-bikes provide the user with electrical assistance whilst pedalling and are regulated at 250 W maximum continuous rated power output and have a maximum speed of up to 25 km per hour (15.5 mph) (as regulated by the European Union). The user can select the level of assistance required using a module on the handlebars and it can also be used a conventional cycle. The e-bikes can also be fitted with a range of adaptations to facilitate any disability that the participant may have as a result of their stroke. These include:

***Arm & Hand***

Glove that straps hand to handlebars
Handle with support for top and bottom of the wrist
Wrist loops that keep the hand in place on handlebars
Brake lever that pulls front and back brakes simultaneously

**Leg/Foot**

Pedal with removable magnets to vary magnetic strength
Pedal to strap foot in place
Pedal with toe clips
Pedal with quick release foot strap

**Balance**

Stabilizer wheels

This study is run with support from Ian Gibbs from I Cycle Ltd, a retailer that specialises in E-bikes and all adaptations and training will be carried out with Ian's assistance. Participants will also be supplied with a safety helmet which they will be asked to wear at all times whilst using the e-bike.

To confirm that the participant is safe to take part in this study please complete the section below:

---

Participant's Name_____

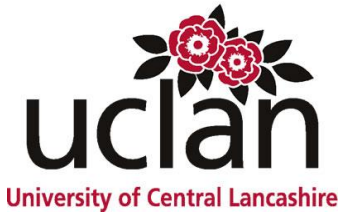
I can confirm that in my opinion this patient is safe to participate in this research and although they have previously had a stroke they have no other condition which will be exacerbated by using an e-bike and/or any impairment that will jeopardise their safety or the safety of others.

| _____ | _____ | _____ |
|---|---|---|
| Print name | Date | Signature |

If you have any questions regarding the study, please contact:

Dr Jessica Janssen,
School of Health Sciences,
University of Central Lancashire,
Preston,
PR1 2HE
Email address: jjanssen@uclan.ac.uk
☎ 01772 894560

**Appendix 9: Participant information sheet**




## Exploring the perceptions and experiences of using an electric bike after stroke

## PARTICIPANT INFORMATION SHEET (Version 3, 26/03/2018)

### What is the purpose of the study?

This is Masters Research project conducted by Paul Boland from the University of Central Lancashire and a supervisory team of Dr. Jessica Janssen, Dr. Louise Connell and Dr. Clare Thetford. The research is also supported by I Cycle Ltd, an electric bike retailer. The purpose of the study is to find out what you think about using an electric bike after stroke and to discuss your experiences after a 3-month loan period.

### What is an electric bike?

Electric bikes provide the user with electrical assistance whilst pedalling and have a maximum speed of up to 25 km per hour (15.5 mph) (as regulated by the European Union). The user can select the level of assistance required using a module on the handlebars and it can also be used a conventional cycle. Electric bikes can also be fitted with a range of adaptations to facilitate any disability that the participant may have as a result of their stroke.

### Do I have to take part?

It is up to you to decide whether to participate. Places are limited and therefore recruitment will be on a first come, first served basis.

If you decide not to take part, this will in no way affect the way you are treated in any way. The research is divided into three parts:

Part 1: You will provide some personal details, complete a quality of life questionnaire and take part in an individual interview.

Part 2: You will be loaned an e-bike for three months and be contacted regularly to monitor your progress.

Part 3: Once the loan period has finished you will complete the same quality of life questionnaire from Part 1 and take part in a final interview.

In order to take part in Part 2 of the study, you must get approval from your GP who you must get to sign the attached letter to confirm that you are safe to use an electric bike. If any fee is accrued in obtaining permission from your GP, you will be fully reimbursed by the university for any costs involved. Whilst you are seeking approval you can take part in the first part of the study. At the start of the research, we will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

**Am I eligible to take part?**

To take part you must have previously had a stroke and are able to walk (with or without assistance). As stated above, approval from your GP is required to confirm that you are safe to use an electric bike. You must be over 18 years old, be able to read car's registration number from a distance of 12.3 meters (40 feet), able to speak English to a standard that will allow you to participate in the interview and weigh less than 20 stone (127kg).

**What will happen to me if I take part?**

If you agree to take part you will be asked to take part in the first part of the research which consists of participating in an individual

interview with a member of our research team, completing a quality of life questionnaire and providing some personal information about yourself. The quality of life questionnaire contains personal questions that you may find upsetting, if this is the case you can leave them blank. In the interview you will be asked about your thoughts on using an electric bike and the questionnaire will be used to gather information on your current quality of life. The interview will last no longer than 45 minutes to an hour and will be audio-recorded. The interviews will be carried out at your home or a convenient location of your choosing. You may withdraw from the interview at any time without giving a reason. This concludes the first part of the research. After the completion of part one of the study you will have a week to withdraw from the study.

Subject to having received permission from your GP you may then participate in the second part of the study. This involves a member of our research team coming back to see you, along with a member of the I Cycle Ltd team. You will then select an electric bike which you will be fully trained on the safe use of and will be fitted with any adaptations you require. You will also be provided with a safety helmet and a secure bike lock. Once you have been trained on the use of the e-bike you will then be able to loan the bike for a maximum period of up to 3-months. Whilst loaning the bike, a member of our research team will contact you every two weeks to find out how you are getting on and if you require any support. Data from the electric bike will also be collected electronically during the 3-months and used to calculate how much the bike is being used. During the 3-month loan period, you may withdraw from the research project at any time without giving a reason.

After the loan period has finished you will be interviewed again to discuss your experiences of using the electric bike and complete a second quality of life questionnaire. You can still withdraw at any point during the interview without giving a reason.

**What are the possible benefits of taking part?**

You will have the opportunity to try out different styles of an electric bike which can be adapted to suit your needs. You can then loan your selected electric bike which you can use for leisure and daily activities or any other activity of your choosing. The study team will be on hand to answer any questions or concerns you may have. Your participation may help in the development of future rehabilitation interventions for stroke survivors.

**What are the possible risks of taking part?**

Receiving approval from your GP will ensure that you are fit enough to take part in in this study and can use an electric bike safely. However, as you will be loaned an electric bike which has a maximum speed of 25 km per hour (15.5 mph) there is a possible risk of injury whilst cycling. To minimise this risk, you will be provided with a safety helmet and trained on how to use the electric bike by a member of the I Cycle Ltd team. The bike will also be adapted to facilitate any disability you may have.

As stated, the quality of life questionnaire you will be completing, contains personal questions that some people may consider upsetting, if this is the case you can leave these questions blank. The researcher will be on hand to answer any questions you may have, and you will be provided with the contact details for the Stroke Association Helpline if you require additional support.

**Will my taking part in the study be kept confidential?**

Your confidentiality will be respected. No study data that shows your identity will be released or published e.g. all quotes will be anonymised or pseudonyms used. All records that identify you by name or initials will be kept in locked filing cabinets at the University of Central Lancashire separate from the data collected.

**Is there any costs involved in taking part?**

There is no cost to take part in the study, however your GP may ask for a fee to sign the letter confirming you are safe to take part and for this you will be reimbursed by the university, providing you have a receipt.

**What will happen to the results of the research study?**

Findings will be shared widely using a range of methods including peer-reviewed publications, written feedback to participants and conference presentations.

**What will happen if I don't want to carry on with the study?**

You are free to withdraw from the study at any time. If you withdraw from the study, we will not collect any further data. However, data that has already been collected up until the point of withdrawal, and that has been anonymised cannot be removed from the study.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Paul Boland – pboland1@uclan.ac.uk or Jessica Janssen ☎ 01772 894560). If you remain unhappy and wish to complain formally, you can do this by contacting University Officer for Ethics at OfficerForEthics@uclan.ac.uk.

**Who is organising the research?**

The research is sponsored by the University of Central Lancashire and is being conducted by research staff from the University of Central Lancashire.

**Who has reviewed the study?**

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the STEMH Ethics Committee at the University of Central Lancashire.

**Contact for further information**

**Specific information about this research project, please contact:**

The Principal Investigator:

Dr. Jessica Janssen,

School of Health Sciences,

University of Central Lancashire,

Preston,

PR1 2HE

Email address: jjanssen@uclan.ac.uk

☎ 01772 894560

You may keep this information sheet and you will also be given a copy of the signed consent form to keep.

**Appendix 10: Interview schedule (Pre-e-bike loan)**

University of Central Lancashire

**Participant No.**

☐

## Exploring the perceptions and experiences of using an electric bike after stroke

## INTERVIEW SCHEDULE (Phase 1) (Version 1, 21/02/2018)

Can you tell me about your activities before your stroke?
(Did you cycle before your stroke?)

What activities are you doing now?

What are your reasons for wanting to use an e-bike?

What are your plans for using the e-bike? (Where will you go?)

| | |
|---|---|
| Physical Capability | Are there any physical factors that could affect your e-bike use? (arm, leg, other condition, balance) |
| Psychological Capability | Are there any mental factors that could affect your use of the e-bike? (neglect, fear, confidence) |
| Physical Opportunity | Do you have access to the right resources to use the e-bike? (time, location) |
| Social Opportunity | Would there be anyone influencing you to use the e-bike? (GP, family and friends) |
| Reflective Motivation | How do you think you will benefit from using the e-bike? |
| Automatic Motivation | What are you looking forward to most about using the e-bike? |

**Appendix 11: Amended interview schedule (Pre-e-bike loan)**

University of Central Lancashire

**Participant No.**

☐

# Exploring the perceptions and experiences of using an electric bike after stroke

## INTERVIEW SCHEDULE (Phase 1) (Version 4, 10/05/2018)

This is the first part of the project and we're going to discuss your thoughts and feeling about using an e-bike and we can then start the second part once you have received clearance from your GP. Is that all clear?

I am OK to record this interview?

Just a reminder of what an e-bike is, it's a bicycle that has a motor which can provide you with power assistance when pedalling so not much effort is required to pedal, particularly in hilly conditions. The maximum speed the bike can reach is 15.5 mph and you can change the amount of assistance you receive using a control on the bike.

---

Before your stroke did you take part in any form of physical activity or exercise? (Walking, dancing, jogging, aerobics)
(Did you cycle before your stroke?)

How did you feel about that?

What did you like about it?

What was the main reason for doing this type of activity?

What physical activities do you do now?

How do you feel about your current levels of physical activity?

What are your reasons for wanting to use an e-bike?

What are your plans for using the e-bike? Where do you plan you to go? How long for?

Can you envision how you will use the e-bike?

Can you describe how you would use the e-bike?

Can you think of any reason why you might not be able to use the e-bike?

Is there anything preventing/hindering you from using the e-bike?

How do you think you would overcome those?

If you were given an e-bike right now is there anything you would struggle with?

| | |
|---|---|
| Physical Capability | Are there any physical factors that could affect your e-bike use?<br>(arm, leg, other condition, balance) |
| Psychological Capability | Are there any psychological factors that could affect your use of the e-bike?<br>(neglect, fear, confidence) |
| Physical Opportunity | Do you have the right resources to use the e-bike such as location or time? |
| Social Opportunity | Would there be anyone encouraging you to use the e-bike?<br>(GP, family and friends) |
| Reflective Motivation | How do you think you will benefit from using the e-bike? |
| Automatic Motivation | What are you looking forward to most about using the e-bike? |

Is there anything else you would like to tell me?

**Appendix 12: Bi-weekly contact sheet**

**Participant No.** ☐

## Exploring the perceptions and experiences of using an electric bike after stroke

## Bi-weekly Contact Sheet (Phase 2) (Version 1, 21/02/2018)

Date: ___/___/___

Have you been using the e-bike? Y / N

How often would you say you were using it?_____

If they answer no, find out why:

_____

Have you encountered any problems whilst using the e-bike, or issues which have prevented you from using it?

_____
_____
_____
_____

What have you been using the e-bike for?

| | | | |
|---|---|---|---|
| Leisure activities | ☐ | Visiting friends/family | ☐ |
| Going to the park | ☐ | Cycling with friends/family | ☐ |
| Shopping | ☐ | Commuting to work | ☐ |
| Physical fitness | ☐ | Cycling with a group | ☐ |

Other_____

Is there anything else you would like to briefly tell us about how you feel about using the e-bike?

_____
_____
_____

**Appendix 13: Interview schedule (Post e-bike loan)**

University of Central Lancashire

**Participant No.** ☐

## Exploring the perceptions and experiences of using an electric bike after stroke

## FINAL INTERVIEW SCHEDULE (Phase 3) (Version 3, 30/07/2018)

## Think "what, how, why?"

## Think of opposites e.g. if they think of a positive experience ask them if there can think of a time when it didn't go smoothly…or vice versa.

What was it like using the e-bike? What have you used it for? Was it what you expected?

Can you talk me through a time you used the e-bike (from start to finish)? (Think positive and negative experiences)

Did anyone have to help you get on and off the e-bike? How did that make you feel?

What sort of things helped you to cycle? (Adaptations, people, locations, the assistance)

| | |
|---|---|
| Automatic Motivation | How did you feel when you first started using the e-bike? (Nervous, excited, apprehensive)<br><br>If negative, how did they overcome these? |
| Physical Capability | Have you encountered any physical problems using the e-bike? |

| | |
|---|---|
| | (Strength, fatigue, problems with the adaptations)<br><br>How did you overcome these?<br><br>How did you feel physically using the e-bike? (was it tough, easier) |
| Psychological Capability | How did using the e-bike make you feel? (fear, confident)<br>If negative, did they overcome?<br>If it improved their confidence, how did it improve? |
| Physical Opportunity | Did you use the e-bike more or less than you expected? If so, why is this?<br>Were there any factors that prevented or hindered you from using the e-bike? (time, location, safety concerns)<br><br>How did you feel about the electrical assistance provided by the e-bike? |
| Social Opportunity | Did anyone encourage you to use the e-bike? (Friends, family)<br>Did you get into a routine of using the e-bike and can you describe that routine? (Think factors that may hindered that routine e.g. time, weather, people.) |
| Reflective Motivation | Has using the e-bike had an impact on your life? (Positive, negative) |

If you had the opportunity would you continue to use the e-bike in the future? (Find out why).

If you were to take part in something like this again do you have any tips or advice for how it could be improved? (Suggestions, what could help others?)

Was there anything that you know now about using the e-bike that you'd wished you known at the start?

Is there anything else you would like to tell me?