An Online Self-Assessment Platform for Community-Dwelling Stroke Survivors: Development and Acceptability

Nazemin Gilanliogullari

School of Health and Society,

University of Salford, UK

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ABBREVIATIONS

ADL	Activity of Daily Living
Apps	Applications
ArmA	Arm Activity
BI	Barthel Index
BOSS	Burden of Stroke Scale
CAT	Computerized adaptive testing
CTT	Classic Test Theory
COSMIN	Consensus-based Standards for the selection of health status Measurement Instruments
DASH	The Disability Arm Shoulder Hand Scale
EDAQ	Evaluation of Daily Activity Questionnaire
EDAQ-SS	Evaluation of Daily Activity Questionnaire for Stroke Survivors
eEDAQ-SS	The electronic version of the Evaluation of Daily Activity Questionnaire for Stroke Survivors
digital health	Electronic health
ePROM	Electronic Patient-Reported Outcome Measure
FAI	Frenchay Activities Index
GAD-7	General Anxiety Disorder-7
IADL	Instrumental Activities of Daily Living
ICC	Intraclass Correlation Coefficient
ICF	International Classification Functioning
ICO	Information Commissioner's Office
LHS	London Handicap Scale
MAPHand	The Measure of Activity Performance in the Hand
MRS	Modified Rankin Scale
MSCs	Musculoskeletal conditions
MSKHUB	Musculoskeletal HUB or www.mskhub.com
NEADL	Nottingham Extended Activities of Daily Living Scale
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OA	Osteoarthritis
OM	Outcome Measure
PHE	Public Health England
PHQ-9	Patient Health Questionnaire-9
PHQ-2	Patient Health Questionnaire-2
PIS	Participant Information Sheet
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROM	Patient-Reported Outcome Measures
QoL	Quality of Life
RA	Rheumatoid Arthritis
RMDs	Rheumatic and Musculoskeletal Conditions

RMI	Rivermead Mobility Index
RNLI	Reintegration to Normal Living index
SALT	Speech and Language Therapist
SDM	Shared decision-making
SF-12	Medical Outcome Study Short-Form Health Survey
SIS	Stroke Impact Scale
SIP	Sickness Impact Profile
SIPSO	Subjective Index for Physical and Social Outcome
SSHUB	Stroke Survivors Hub or www.strokesurvivorshub.com
SSQOL-S	Stroke Specific Quality of Life Scale
STRIVE	Stroke Interactive Virtual Therapy
UK	United Kingdom
UoS	University of Salford
Web	Website
WHO	World Health Organisation

ABSTRACT

Background: Activity limitation and participation restriction are common in stroke survivors. Digital health technologies are widely utilised to enable self-management. An online platform, specifically developed for stroke survivors can improve the use of electronic Patient-Reported Outcome Measures (ePROM) to enable self-assessment and empower patients to get involved in their care. The overall aim of this PhD was to develop and test the acceptability of an online self-assessment platform, the Stroke Survivors Hub (SSHUB) to support the long-term self-management of stroke survivors.

Methods: A systematic review was conducted to explore existing disease-specific PROM to assess daily activity limitations in stroke survivors. This informed the development of the Evaluation of Daily Activity Questionnaire for stroke survivors (EDAQ-SS) with the involvement of 10 stroke survivors and 11 experts. Content validity of the EDAQ-SS was evaluated using the International Classification of Functioning (ICF) Core Set for Stroke. Following this, the EDAQ-SS was digitised as an ePROM and the SSHUB was developed. The SSHUB acceptability was tested with stroke survivors (n=57). Additionally, data collected via the eEDAQ-SS were used to explore patterns of activity limitation and participation restriction in British stroke survivors.

Findings: The EDAQ-SS is an appropriate, comprehensive, understandable and relevant PROM to assess the extent of activity limitation and participation restriction in British stroke survivors, and the first stroke specific PROM to differentiate between capacity and performance. The SSHUB is a user-friendly and acceptable online platform to aid self-assessment of stroke survivors' ability to carry our daily activities and aggregated data provide opportunities to examine the frequency and pattern of these difficulties in community-dwelling stroke-survivors.

Conclusion: The EDAQ-SS is an acceptable measure of daily activities for stroke survivors, and freely available on the SSHUB to inform self-management. Future recommendations include the psychometric testing of the EDAQ-SS with a larger sample to establish the measurement validity and reliability, and the strategies to expand the remit of the SSHUB as an online self-management platform.

CHAPTER ONE: INTRODUCTION

1.1 Introduction

1.1.1 Researcher Perspective

I have always found it interesting and challenging to work with stroke survivors as a physiotherapist. Rehabilitation of stroke survivors is a long process and helping stroke survivors to gain their independence back become my life-long passion. During my clinical practice, I come across difficulties in getting a detailed picture of patients' ability to carry out daily activities and being able to quantify these with structured assessments to evaluate interventions. Moreover, I realised that when patients are discharged home, they had limited access to patient information to identify and seek help for their long-term rehabilitation needs. This motivated me to undertake a research degree to explore the evidence-base to develop innovative interventions to empower community-dwelling stroke survivors to support effective self-management. As my primary aim was to create resources that were freely available for all stroke survivors, I have chosen to focus on digital health solutions, as digital tools can also help reach patients located in rural areas or under home care.

This chapter introduces the rationale behind the thesis by exploring the background literature to emphasise the importance of self-management for stroke survivors to improve their rehabilitation outcomes. The aims and objectives of the PhD are introduced and discussed in detail in the following sections.

1.2 Stroke: The Impact on the Individuals

A stroke is a common worldwide problem, and in the United Kingdom (UK), every five minutes someone has a stroke, and it is the fourth single leading cause of mortality (Stroke Association, 2018a). However, from 1990 up to 2010 the mortality rate of a stroke was reduced by 46% (Stroke Association, 2018a), which means there are more and more stroke survivors who need help to support rehabilitation concerning functional limitations. The effect of a stroke depends on several factors, such as the location of the blood interruption in the brain or the amount of the brain tissues affected (Stokes & Stack, 2011). Therefore, the activities of daily living (ADL) limitations of each stroke survivor varies (Stroke Foundation, 2020). However, most common impairments occur in the main bodily functions such as; movement, balance, sensation, speech, coordination, and memory (Stroke Association, 2018; The National Institute for Health and Care Excellence (NICE) guidelines, 2013).

Affected body functioning and structures, such as reduced sensation or poor muscle strength are serious impairments. However, these may not be meaningful for most stroke survivors unless they have an impact on their ADL. The combination of cognitive and physical impairments can result in limitations of daily activities (Kim, Kim, & Kim, 2014). It is argued that the full impact of a stroke on the quality of life (QoL) of an individual and daily living is not recognised until stroke survivors leave the hospital and attempt to return to their daily routines and responsibilities (Ellis-Hill et al., 2009). The impact of losing independence due to a stroke can result in important challenges for stroke survivors. A stroke does not only affect an individual, it affects both stroke survivors and their families (Ramos-Lima, Brasileiro, Lima, Braga-Neto, 2018). Nearly, a quarter of stroke survivors in the UK are of a working-age (Daniel, Wolfe, Busch, & McKevitt, 2009), and reduced physical functioning can result in loss of their job. This is an important factor to consider as the loss of a job can put more pressure on family members and stroke survivors. Moreover, nearly half of the stroke survivors require help from their family members for ADL functioning (Sturm et al., 2002). All of these put more pressure on family members and may affect their relationship with stroke survivors. This can result in a further psychological impact on stroke survivors, reduce their mood and have a negative impact on ADL functioning. Therefore, a stroke is a new and serious challenge for individuals as they need to live with the impact of it and understand how they can manage the limitations in daily activities.

1.3 Activities of Daily Living

Activities of daily living (ADL) are activities that people frequently engage in throughout a normal day; such as work, eating, drinking, shopping and socialising (Legg, Lewis, Schofield-Robinson, Drummond, & Langhorne, 2017). Reduced ADL functioning is associated with comorbidity and leads to poor QoL outcomes (Kim et al., 2014). To give an example; a stroke survivor can have a muscle weakness at the lower limb region that can result in limitations in walking, which might have a negative impact on the ability to go shopping. With stroke mortality having been reduced by 50% in the last two decades, the life expectancy of stroke survivors is increasing (Feigin et al., 2013), and the number of stroke survivors is expected to double in the near future (NHS Long Term Plan, 2019). This will consequently lead to more people in the community living with ADL limitations.

The World Health Organization (WHO) has developed the International Classification of Functioning, Disability and Health (ICF) to provide a standard language and worldwide accepted framework to address the impact of health conditions on human functioning (Stier-Jarner, Cieza, Borchers, & Stucki, 2009; WHO, 2001). It is a globally accepted framework, which not only shows the limitation of a person but also helps to realise what kind of modifications can help to improve a person's QoL. According to the ICF (WHO, 2001), activity limitations are described as difficulties that individual experiences while executing an activity and the severity of the impediment encountered varies between quality and quantity in performing an activity. Participation restriction represents a problem that a person faces while engaging in everyday life situations, i.e., socialisation. It shows the functioning of a person from a social perspective (WHO, 2001). The ICF helps to understand the impact of the environmental modification and conceptual factors on people's functioning and differentiates intrinsic disability (capacity of a person: e.g., difficulty in carrying out a task without using any equipment or having a personal assistant) and extrinsic disability (performance of a person: e.g., difficulty in carrying out a task with equipment or help from someone) (WHO, 2001).

In this manner, increased awareness of the effects of environmental modifications on people's ADL function can help stroke survivors to understand the differences between their capacity and performance. To give an example; if a stroke survivor has difficulty in walking that affects the outside mobility, but if he or she can walk safely and independently with a walking aid, this can show that an adaptation can improve independence in ADL. As a result, this can help to encourage empowerment, improve awareness on ADL limitation and help to do adaptations to have a better QoL. It is important to understand the difference between activity limitation and participation restriction for community-dwelling stroke survivors as it can help to guide their self-management. Understanding the differences in capacity and performance may show stroke survivors how they can adapt their environment or behaviour to increase their independence through self-assessment of their main limitations.

According to the Stroke Association (2018a), 84% of stroke survivors require help with their ADL in the UK (Stroke Association, 2018a). People need to be able to use both their cognitive and physical abilities to complete ADL functioning. Limitations in ADL can persist for a long period of time after a stroke. Inability to complete an ADL can have a negative impact on psychology (i.e., depression or stress) and social living (i.e., loss of responsibility in the family role). Therefore, a stroke can result in depression and reduced social life participation (Legg et al., 2017; Kim et al., 2014). Given the considerable impact of a stroke on individuals' QoL (Kim et al., 2014), it is important to consider ADL limitations from the perspective of a stroke survivor (Kyte et al., 2015; Persson, Danielsson, & Sunnerhagen, 2015) to get a full picture of the wide range of activity and participation restrictions that individuals experience and make this part of self-management.

It can be seen from above that if stroke survivors can have a better understanding of what impact the environmental modifications can have on their performance, they may be able to use them more effectively and understand if they can use these environmental modifications to progress their independence in ADL, which will ultimately have positive impacts on their self-efficacy. Self-efficacy is defined as a person's trust in their capacity, which is positively linked with mobility, ADL and QoL (Korpershoek, van der Bijl, & Hafsteinsdóttir, 2011). As changing self-efficacy promotes self-management after a stroke (National Clinical guideline for stroke, 2016), understanding the daily activities of stroke survivors can provide an insight into stroke survivors' recovery and care that they need (Connolly & Mahoney, 2018; Atler, 2016). Therefore, self-assessment of ADL limitations can help stroke survivors to achieve better self-management.

1.4 Online Self-Assessment of Activities of Daily Living for Better Self-Management

Self-management is a critical part of stroke rehabilitation which helps stroke survivors prevent a future stroke, facilitate rehabilitation and manage their ADL (Kidd, 2018). It is more onerous on people with long-term conditions to take ownership of their health by actively taking part in identifying their health and functional needs to take preventative measures. There are tools that help stroke survivors to actively get involved in their care-pathway and express their limitations in ADL from their perspective. These are known as patient-reported outcome measures (PROM) (Santana & Tomkins, 2021; Meadows, 2011). PROM is a self-completed questionnaire that can be completed by patients independently and used to better understand how patients' health conditions and treatment have impacted their QoL from their perspective (Meadows, 2011).

Most importantly, PROM can be used to improve the self-management of people (Santana & Tomkins, 2021). However, if people cannot access these PROM, they cannot use them for self-assessment. People with long-term health conditions are now using digital health, through applications (apps) and smartphone technologies to conduct self-assessment of their physical and cognitive functioning, mood and health status to support self-management and/or linking their real time data with their healthcare teams to streamline health assessments (WHO: Global strategy on digital health 2020-2025, 2021). Digital health means using information and technologies such as mobile health, wearable technologies and health information to manage illness and promote wellness (Ronquillo, Meyers, & Korvek, 2021). Digital health technologies help people to manage their health by providing more personalised care, increasing access and quality of care, and lowering the cost of healthcare (Ronquillo et al, 2021). Therefore, the use of digital technology, such as an online self-management platform, could widen access to self-assessment via the use of electronic PROM (ePROM) to support community-dwelling stroke survivors' rehabilitation needs.

At the same time, technology is improving and currently, we live in a digital age (The NHS Long Term Plan, 2019). People's lives have changed with technology, and they have started to use smartphones to manage most of their ADL (Davies, Sharp, Homolova, & Bellis, 2019). Improvements in technology have also transformed the way people manage their health. The National Health Services (NHS) has started to move into digital health to widen access to health services and provide better, more timely support to people in the UK. The Department of Health (DoH) (2007b) highlights the important role that the use of technologies can play in improving health outcomes. The Office for National Statistics (ONS, 2020) reported that 96% of households had internet access in the UK in 2020. Moreover, 80% of the households which have at least one adult aged 65 years and over had internet access. Different technologies can be used such as telephones, smartphones, tablets, computers to access different types of health information. Therefore, the administration of PROM by using digital platforms has exponentially increased (Meirte et al., 2020; Streiner, Norman, & Cairney, 2015).

Electronic PROM use may not only result in easy administration or better self-management but also can reduce economic pressure on the healthcare system. Stroke results in a high economic burden on NHS, personal social services and productivity as stroke survivors can lose jobs, result in reduced employment and families can become unpaid carers. It is reported that the societal cost of stroke for a stroke survivor is nearly £49,409 in the first year after the incident (Patel, Berdunov, King, Quayyum, Wittenberg & Knapp, 2020). Therefore, it is important to develop tools that can be cost-effective and efficient as part of stroke rehabilitation and promote self-management. The ePROM administration is cost-effective, acceptable and practical with many advantages (Bonevski, Campbell, & Sanson-Fisher, 2010). Using digital health can help more people to have access to information related to their health by increasing their inclusivity and resulting low-cost impact on the healthcare system (WHO: Global strategy on digital health 2020-2025, 2021), which increases the chance of helping more stroke survivors to express their limitations. It can help to get immediate scores and feedback from ePROM results (Meirte et al., 2020; Cella et al., 2005), which in turn helps to improve the timeline of the assessment periods. It has other advantages, such as people being able to complete questionnaires independently, within their comfortable environment, with more honest answers (Lucas, Gratch, King & Morency, 2014), by taking their time to provide answers without rushing and receiving immediate feedback (Meirte et al., 2020) (Please, refer to Chapter Two for further details on the advantages of ePROM).

For this reason, an online platform for stroke survivors, which can house the ePROM may have the potential to increase inclusivity and improve self-management (Please, refer to Chapter Two for more detail). This is because completing ePROM will increase awareness of the ADL limitations and help to keep stroke survivors' health records. In addition, stroke survivors will have a chance to see the results of their PROM, download their results and share them with their healthcare professionals.

1.5 Thesis Aim and Objectives

The overall aim of this thesis is to develop an online self-assessment platform for community-dwelling stroke survivors to provide access to a valid, reliable, and comprehensive ePROM to assess limitations in ADL and test the acceptability of this platform with stroke survivors to ensure it is fit for purpose. This aim will be met by specific objectives:

(i) A systematic review of the literature to understand if there is a comprehensive PROM that helps to assess ADL limitations of stroke survivors and differentiate capacity from performance.

(ii) To linguistically and culturally adapt an ADL PROM for stroke survivors to make sure that it is comprehensive and shows differences between capacity and performance of stroke survivors.

(iii) To develop an online platform for stroke survivors to house the electronic version of the adapted PROM (ePROM) to increase use of a comprehensive self-assessment tool to inform self-management.

(iv) To use a mixed-methods approach to test the acceptability of both the online self-assessment platform and the ePROM to help stroke survivors capture their ADL limitations in detail.

(v) To analyse the ePROM data collected to explore the frequency and pattern of ADL limitations in British community-dwelling stroke survivors.

1.6 Overview of the Thesis

Chapter One: Introduction

This chapter made an introduction to the rationale of the PhD project by explaining the importance of ADL self-assessment for stroke survivors. Also, it highlights the overall aim of the PhD project followed by the objectives.

Chapter Two: Literature Review

This chapter describes and critiqued the impact of a stroke on daily activities, how the use of an online self-assessment platform can help community-dwelling stroke survivors to take an active part in their care by accessing acceptable, comprehensive, valid and reliable ePROM. Moreover, this chapter critiques the available online platforms for stroke survivors and justifies the need to develop a new online self-assessment platform to house a comprehensive ePROM.

Chapter Three: Systematic Review

This chapter depicted the methods and findings of the systematic review of PROM to assess limitations of ADL in stroke survivors, with an in-depth critical appraisal of the psychometric properties of the measures identified. Findings of this review highlighted the gap in the comprehensive PROM that can be used to assess limitations in ADL for stroke survivors and the rationale behind the decision to develop a new, comprehensive PROM to assess ADL limitations for stroke survivors based on an adaptation of an existing PROM in people with rheumatic and musculoskeletal conditions to assess ADL limitations: Evaluation of the Daily Activity Questionnaire (EDAQ).

Chapter Four: Development and Testing of the EDAQ-SS

This chapter described the development of the EDAQ for stroke survivors (EDAQ-SS) in terms of the linguistic and cultural adaptation of the measure for stroke survivors following the recommended guidelines for PROM development to ensure that the EDAQ-SS is understandable and relevant to the British population of stroke survivors. Moreover, items of the EDAQ-SS were linked with ICF Core Set for Stroke to develop a tool with good content validity. The chapter also expanded upon the digitisation of the EDAQ-SS (eEDAQ-SS) for online administration to widen community-dwelling stroke survivors' use of a stroke-specific digital technology.

Chapter Five: Development and Testing of the Stroke Survivors Hub

This chapter discussed in detail the development and testing of an online self-management platform; the Stroke Survivors Hub (the SSHUB), inspired by the MSKHUB (an existing online self-management platform for people with rheumatic and musculoskeletal conditions), which houses the eEDAQ-SS as the main online assessment. Alongside the eEDAQ-SS, seven other existing stroke-specific measures such as; Stroke Impact Scale, Rivermead Mobility Index were digitised to test the acceptability of their use online and help with the psychometric testing of eEDAQ-SS in the long-term (post-PhD) as sample size calculations revealed the need for a large dataset to establish the psychometric properties of this new measure through Rasch analysis. In addition, usability and acceptability testing of this platform and the eEDAQ-SS were conducted to ensure that it is a user-friendly platform with good inclusivity. Moreover, data collected through the eEDAQ-SS were analysed descriptively and discussed in this chapter to explore distribution of ADL limitations in British community-dwelling stroke survivors.

Chapter Six: Summary of the Results and Conclusion

This chapter provides a summary and discussions of the thesis findings and conclusions to emphasise the novel contribution of the thesis to the wider literature, alongside the implications for future practice and research, and recommendations for the next stages of the SSHUB development and testing.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter describes and critiques the rationale of the aims and objectives of the thesis that were mentioned in the previous chapter. Firstly, the impact of strokes on ADL is discussed followed by a justification of how the use of an online self-assessment platform can help community-dwelling stroke survivors to take an active part in their care by using acceptable, comprehensive, valid and reliable ePROM. Moreover, this chapter shows the available online platforms for stroke survivors and justifies the need to develop a new online self-assessment platform to house a comprehensive ePROM.

2.2 Stroke

2.2.1 Pathophysiology of Stroke

A stroke is also known as a cerebrovascular accident (CVA) and is the most frequent life-threatening neurological disorder (Stokes & Stack, 2011) that is documented as one of the most devastating of all neurological diseases (Mukherjee & Patil, 2011). A stroke is defined by the WHO as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin” (WHO, 1988, p. 1). In other words, a stroke is a brain attack that affects the blood supply in the brain due to the interruption in the blood flow (Stroke Association, 2018a).

It is important to understand the mechanism of the stroke as it can result in better achievement in rehabilitation. Interruption of the blood flow can occur mainly in two different ways; 1) a clot (ischaemic), which is known as the most common type of stroke and forms nearly 80% of the stroke population, or 2) bleeding (haemorrhagic) (Tortora & Derrickson, 2017). Both can deprive brain tissues of oxygen and nutrients causing potential cell death (Tortora & Derrickson, 2017). The brain is an important part of the nervous system that controls and coordinates the motor and sensory function of the body amongst many other functions (Palastanga & Soames, 2012). Therefore, potential cell death in the brain can result in long-term psychological and physical body function impairments (Stroke

Association, 2017). However, each stroke survivor is different, and they exhibit different symptoms. This is why it is crucial to assess each individual separately, provide personalised rehabilitation programmes and help stroke survivors to understand their main limitations to increase their awareness.

2.2.2 Epidemiology

According to WHO, every year 17 million people die from strokes and cardiovascular diseases (WHO, 2019). Nearly 38,000 people out of 100,000 stroke victims die each year in the UK, which makes stroke a leading cause of death and disability (NICE Impact stroke, 2019). The British Heart Foundation (2021) has reported that there are more than 100,000 stroke survivors in the UK each year, and 30% of these stroke survivors have the potential to have another stroke (NICE Impact stroke, 2019; PHE, 2018). The statistics recorded by the British Heart Foundation showed that there were 1.3 million community stroke survivors in the UK in 2021.

Seshadri and Wolf (2007) have documented that with increasing life expectancy, one in six men and one in five women will experience a stroke, and it is common at an older age (Lui & Nguyen, 2018), which includes nearly 59% of stroke survivors (PHE, 2018). However, the average age of having a stroke is decreasing to 40-69 years old (NICE Impact stroke, 2019), and 38% of stroke survivors are facing their first stroke in middle age (between 40 to 69 years old) (PHE, 2018), which is the working age, and it leads to more impact on society. As a stroke is considered the largest cause of complex disability in adults (Adamson, Beswick, & Ebrahim, 2004), currently two-thirds of stroke survivors in the UK are living with a disability, which results in a requirement for help with ADL (NICE Impact stroke, 2019; Stroke Association, 2018a). Unfortunately, due to increasing life expectancy, it is expected that the number of people having a stroke will increase by almost half (NHS Long Term Plan, 2019), which means there might be more people in the community that will lose their independence in ADL, and it will result in more pressure on society.

2.2.3 Economic Burden of Stroke

Stroke lead to an estimated cost of £26 billion a year and put pressure on the healthcare system (NICE Impact Stroke, 2019). The impact of stroke on the economy is not just limited to the healthcare services, it also, widely affects society and has significant long-term physical and psychological impacts on the lives of stroke survivors (Patel et al., 2017; National Audit Office, 2010). This is because deaths, prevention of stroke and managing symptoms of strokes have economic consequences on society (National Audit Office, 2010). To give an example; stroke survivors can lose their jobs due to symptoms of stroke, which can reduce their employment prospects and productivity (Patel et al., 2017b). Being unemployed does not only affect people financially, but also physically and mentally can lead to further problems (Balasooriya-Smeekens, Bateman, Mant & Simoni, 2016). As productivity and income loss results in economic pressure on stroke care, it is important to find strategies to improve the employability of stroke survivors (Balasooriya-Smeekens et al., 2016).

Stroke also have a financial impact on family and friends as they become unpaid carers (Patel et al., 2020; Patel et al., 2017b). It is reported by Patel et al., (2020) that informal care, such as unpaid carers cost £15.8 billion of the total value per year in the UK. It is predicted that the economic burden of stroke cases will increase with the increasing population and cost £43 billion per year in 2025 for those aged 45 years and over (Patel et al., 2020). In addition, the increase in the number of stroke survivors with daily activity limitations will put more pressure on healthcare professionals, as patients will require detailed assessment followed by long-term treatment. It is clear that stroke creates a sizable economic burden in the UK, so it is important to prioritise stroke care in funding and policy support to reduce the impairments that stroke can result on people and result in better prevention (Patel et al., 2017). Therefore, not only for the impact on health care services but for all society, it is crucial to increase coordinated approach, understand the main limitations in ADL from stroke survivors' perspectives, improve rehabilitation outcomes including prevention and self-management to result in improved outcomes in stroke rehabilitation and reduce financial burden. Better treatment outcomes including self-management and prevention are the aim of having better QoL (i.e., return to work), minimising the participation restriction, and enabling the independence of stroke survivors, which will ultimately reduce the pressure on healthcare professionals.

2.2.4 International Classification Functioning Framework

The International Classification Functioning (ICF) is a commonly used internationally recognised conceptual framework in health, which is used in this context to summarise the impact of a stroke (Geyh et al., 2004a, Geyh et al., 2004b). The ICF helps stroke survivors to think holistically about their situation (Tempest, Harries, Kilbride, & De Souza, 2013). It is a classification model that considers not only the effect of a health condition on activities and participation, but also all other surrounding environmental factors, as they can be either a barrier or facilitator to the performance of ADL (Silva, Corrêa, Pereira, & Corrêa, 2017).

It is important to understand that ADL covers a wide range of domains and can be divided into two different categories; basic ADL (also known as personal ADL) and instrumental ADL (IADL) (Legg et al., 2017). Basic ADL are the skills that people need to look after their bodies independently (Foti & Koketsu, 2013). These activities cover bladder and bowel management, washing and dressing, eating and drinking, functional mobility, and care of personal aids, such as splints (Foti & Koketsu, 2013). Instrumental ADL are the functions that help people to be independent in the community (Legg et al., 2017; Foti & Koketsu, 2013). For instance, taking care of others, communication, financial management, shopping or outside mobility that includes driving (Foti & Koketsu, 2013). As a stroke affects both the physical and psychological capability of people, it results in limitations in ADL (Capistrant, Wang, Liu, & Glymour, 2013). Therefore, it is important to understand people's functional level to be able to help them manage their limitations.

As mentioned by the ICF framework, capacity and performance are two qualifiers that help to understand the activity and participation level of a person (WHO, 2001). What an individual can achieve in the current environment is known as performance. On the other hand, capacity is known as the ability of a person to do a task or an action in a standard environment (WHO, 2001). The difference between the capacity and the performance, which can be understood better in a home environment compared to a hospital, can help to understand the impact of the current environment on the activity and participation level. These concepts help to see what kind of contextual factors can help to improve individual performance. Contextual factors show the complete background of a person's life (WHO, 2001). These factors can have negative or positive effects on a person's performance in an activity or participation. If an environmental factor is a barrier to an individual for a specific activity, it can reduce that person's performance. On the other hand, they can also be a facilitator which can lead to an improvement (Silva et al., 2017). So, they always need to be considered in the assessment process to show stroke survivors what they can achieve with the environmental modification and how they can adapt their movements to increase independence in ADL.

In addition to environmental factors, the effect of personal factors needs to be considered during the ADL assessment, which covers age, gender, fitness, psychological situation, etc., (WHO, 2001). These personal factors can also affect an individual's performance. Therefore, they need to be considered when designing a rehabilitation programme. The clear understanding and application of the performance and capacity in real life will help to distinguish intrinsic disability (capacity) from extrinsic disability (performance). It can be concluded that it is important to think holistically as a reduced activity level does not mean that a person will be limited in participation. Understanding the effect of environmental modifications on people's lives can help healthcare professionals to enhance stroke survivors' QoL by providing correct rehabilitation programmes, and help stroke survivors to improve their self-management by knowing how to act on their limitations to improve their independence.

2.2.5 Effect of Stroke

Each stroke survivor will face different effects of a stroke and will have different needs depending on the area of the brain in which damage occurs (Stroke Foundation, 2020; Mendis, 2012). As mentioned in the ICF model (WHO, 2001), there is an interaction between body functions and structure with the activity and participation. Therefore, impairments in body function and structure, e.g., lower limb muscles weakness, can result in activity limitations, e.g., walking, that can affect participation, e.g., walking for shopping. The world statistics have shown that 25-74% of the 50 million stroke survivors require help from caregivers due to ADL limitations (Miller et al., 2010). Experiencing ADL limitations after a stroke can lead to difficulty in participating in leisure activities that take place both at home and in an outside environment.

The reduced ADL functioning is not only linked with physical impairments but also linked with the impact of environmental and personal factors. In addition, it has further effects on people, such as losing confidence. When a stroke affects the body functions, followed by ADL limitations (Legg et al., 2017), it can result in a lack of confidence and reduced social life participation (Kim et al., 2014). Participation in life involves social relationships and experiences in real-life situations (Silva et al., 2017). However, as a result of stroke impairments, some stroke survivors find it difficult to return to their pre-stroke activities and roles. Participation and being involved in social activities have a positive impact on both mental and physical health (Silva et al., 2017). However, there is usually a reduction in social participation post-stroke (Faria-Fortini, Basílio, Scianni, Faria, & Teixeira-Salmela, 2017). Therefore, reduced social participation can result in further psychological impact and can affect the rehabilitation process.

Similarly, mood problems such as anxiety or depression are common to see in stroke survivors (Thomas & Lincoln, 2008), which is known to have a profound effect on the ADL (Hackett, Anderson, House, & Xia, 2008; Chemerinski, Robinson, Arndt, & Kosier, 2001). It is common to have post-stroke fatigue and 50% of stroke survivors experience fatigue shortly after their stroke (Stroke Association, 2012). Suffering from fatigue can result in further depression and mood changes as it affects people's daily life (Stroke Association, 2012). Both the physical and psychological effects, that stroke survivors are faced with, often prevent them from participating in what they want to do or achieve in their daily routine (Wood, Connelly, & Maly, 2010). Therefore, the effect of stroke can result in impairments that affect people in their daily living which makes it important to consider self-assessment of the ADL limitations to increase awareness and improve self-management.

2.3 Assessment of Activities of Daily Living

As the ADL limitation influences confidence, depression, work and social life participation, it correlates with the poorer QoL (Kim et al., 2014), which is a multidimensional construct that covers physical, mental and social domains (Opara & Jaracz, 2010). Health-related QoL is a concept that focuses on the impact of an illness and treatment from the patient's perspective, their satisfaction with life and health status (Jaracz & Kozubski, 2003). Having a stroke can change the way individuals think or behave (Jones, Allerd, Adkins, Hsu, O'Bryant, & Maldonado, 2008). This is why it is important to involve stroke survivors in their care pathway and understand what is important for them to work on in their rehabilitation to improve their QoL.

Van Mierlo (2015) and colleagues have reported that progression on the ADL functioning can improve stroke survivors QoL. Therefore, it is crucial to focus on ADL functioning in rehabilitation and help stroke survivors to gain their independence again (Jeong, Han, Jang, & Lee, 2018) by providing personalised rehabilitation programmes that include self-management, depending on the stroke survivors' limitations and restrictions. To have a holistic understanding of stroke survivors' requirements and to direct the treatment towards improving ADL difficulties, stroke survivors need to have a full ADL assessment including the impact of environmental modifications on their functioning (Ryerson, 2008). The effect of the treatment is positively correlated with the assessment. Therefore, assessment of ADL needs to be continuous to achieve better outcomes in rehabilitation.

Comprehensive ADL assessment is not only important for the acute rehabilitation process but also for self-management. Self-management is one of the key priorities for health in the UK (Naylor et al., 2015; Boger, Demain, & Latter, 2012), and it is known as the active management of people with their symptoms, lifestyle and other consequences that affect their lives due to their chronic condition (Boger et al., 2012; Lorig & Holman, 2003). It is important to understand that assessment of ADL is crucial to increasing the awareness of patients, identifying who needs assistance and providing help to increase their independence, therefore improving their QoL (Edemekong, Bomgaars, Sukumaran, & Levy, 2020). As the ADL limitations are linked with dependency on others, increasing self-awareness in ADL limitations can help stroke survivors to empower themselves and may have a positive impact on self-management. Stroke survivors need to learn how to manage their limitations, but how are they going to self-assess their limitations in ADL to self-manage their condition and improve their QoL, if they have limited self-assessment resources? If the aim is to provide stroke survivors with a chance to self-manage their condition and reduce the risk of hospital admission due to deterioration, which will ultimately reduce the economic burden in NHS, it is important to have tools that people can use independently as part of their self-management.

There has been a growing interest in the use of technology to promote and support self-management. Younger people are more engaged with technology compared to older people. However, the use of new technology by older people has started to increase rapidly (Bhattarai et al., 2019; Pew Research Center Health fact sheet; 2017). The report documented by the Pew Research Center (2014) has shown that 45% of the people who have aged 65 overuse smartphones (Pew Research Center, 2017). More people at an older age have started to use the internet and online health information (Bhattarai et al., 2019; Pew Research Center Health fact sheet; 2017). The rapid increase in the use of this technology shows that there will be more opportunities to use digital health to reach and meet the world's needs with the growing and ageing population.

Expectations of people are changing, and digital health technologies have started to support changes in health services and results in quality improvement. Digital health gives opportunities for more proactive, targeted and coordinated care, improve resources, provide access to specialist expertise, advice, tools for patient engagement and self-management (Imison, Castle-Clarke, Watson, & Edwards, 2016). It is reported that encouragement of using digital health resources have benefits to achieve local priorities including physical and mental wellbeing, prevention, self-care, long-term condition management, shared decision making and appropriate use of urgent and emergency care (WHO: Global Strategy on digital Health 2020 -2025, 2021; Mistry, 2020). The use of digital health technologies has the potential to empower people to be more involved in their care and allow them to take part in their treatment decision (Selvan, Vail, & Anderson, 2020; Affinito, Fontanella, Montano, & Brucato, 2020). On top of these, they have the potential to empower patients to take an active role in their healthcare, deliver the right care at the right time, enable patient-centred care, improve communication between healthcare professionals and patients, improve accessibility, efficiency and equity of healthcare (du Pon et al., 2020; Gee et al., 2015).

For this reason, self-assessment of ADL limitations through digital health technologies is an important part of the self-management process, as it helps to consider stroke survivors' opinions about their situation (Hartford, Lear, & Nimmon, 2019). Patient-centred care is a key for achieving better outcomes and this can only be achieved when the patients' values and preferences about their treatment are considered by healthcare professionals, stroke survivors and their families to make the best decision about the patient, which is known as shared decision-making (SDM) (Armstrong, 2017; Visvanathan et al., 2017). SDM helps stroke survivors to choose the best for their health based on their individual goals. The research showed that SDM helps to improve satisfaction, trust, knowledge and understanding, which is believed that it can result in better outcomes (Voogdt-Pruis et al., 2019; Armstrong, 2017; Shay & Lafata, 2015; Elwyn et al., 2010). As the SDM is a dynamic process that requires every person to share their information, express preferences and agrees on a decision (Visvanathan et al., 2017), it helps to improve the awareness of stroke survivors, which can ultimately help to improve the self-management.

Dwamena et al., (2012) have reported that there is not enough evidence to show which method is more successful to facilitate the SDM. On the other hand, it is known that sensible and successful decisions are made with knowledge about patients' preferences for the future (Creutzfeldt & Holloway, 2012). Therefore, all information about the SDM, awareness and self-management showed that stroke survivors' preferences, limitations from their perspective are key for a successful treatment outcome. In this manner, patient-reported outcome measures (PROM) can be used to help stroke survivors to develop an awareness of the extent of their limitations and help to improve self-awareness (Santana & Tomkins, 2021).

Digital health technologies such as, online platforms provide opportunities to support self-management, help to maintain and improve the quality of management for chronic diseases by engaging patients with their health (WHO: Global Strategy on digital Health 2020 -2025, 2021; du Pon et al., 2020; Gee et al., 2015; Tang et al., 2006). Most importantly an online platform that houses an electronic PROM (ePROM) can help stroke survivors to track their changes over time, get health-related information to educate themselves and use these opportunities to self-manage their condition. Using the benefit of digital health technologies as part of stroke rehabilitation can help stroke survivors to continue managing their symptoms when they discharge from the NHS, keep their gained physical level in rehabilitation and reduce the risk of deterioration.

2.3.1 Patient-Reported Outcome Measures

Patient-centred care is an important part of the healthcare system (Institute of Medicine Committee on the Quality of Health Care in America, 2001), and this can be facilitated by the use of PROM (Santana & Tomkins, 2021) that are completed directly from patients without interruption of their caregivers or care providers (Santana & Tomkins, 2021; Miller et al., 2015; Rathert et al., 2013). Discharging from hospitals to return home after a stroke can be a challenging process for stroke survivors as they struggle to adapt to a new life with their impairments, including physical limitations, stress, depression, cognitive impairment and reduced QoL (Cerniauskaite et al., 2012). Moreover, stroke survivors can deteriorate or require more help for daily activities as they will be more involved in real-life activities and realise what they can or cannot do at their normal living conditions when they are discharged home from the hospital. Few studies have shown the difficulties that stroke survivors faced after they return home (Simeone et al., 2016; Hilton, 2002; Ellis-Hill, Payne, & Ward, 2000). It was documented that stroke survivors need more input to cope better with the limitation of daily activities (Simeone et al., 2016) because they start to return to their normal lives and realise their limitations. This is why the increased awareness in the home environment as opposed to when stroke survivors are in hospital is more important. Self-management is a critical part of stroke management, which starts when people get discharged. It may improve with better development of awareness. However, it might not be possible for stroke survivors to understand their main limitations in daily activities before they are discharged as they do not know what is expecting them in their real life. Therefore, it is important to increase patients' knowledge about their ADL limitations by using PROM that can be completed independently by stroke survivors at their homes to show their limitations from their perspective.

Patient-reported outcome measures help to provide a vehicle for patients' voices and inform clinicians or researchers of patients' views on the impact of their health condition if they have ongoing contact with patients (Hepworth, Rowe, & Burnside, 2019; Fitzpatrick et al., 2006; Bowling, 2005b). Allowing individuals to self-assess their limitations by using a PROM provides an opportunity for limitations to be understood, which with other methods this may not be possible (Deshpande, Sudeepthi, Rajan, & Abdul Nazir, 2011). The use of a PROM helps to provide appropriate treatment (Kingsley & Patel, 2017) by helping people to self-assess their limitations, reflect on limitations to identify what is important for them and increase their awareness, which ultimately improves the self-management (Tai et al., 2020; Santana & Feeny; 2014; Feldman-Stewart & Brundage, 2009). As the wider research shows the effect of PROM use to develop an awareness of ADL limitations, it was important to consider this for stroke survivors because stroke can result in lifelong symptoms that may require self-management.

As a PROM helps to collect information on things that have meaning to people, promote SDM, and monitor patients' progressions in health or treatment to increase awareness (Santana et al., 2015; Wu, Kharrazi, Boulware, & Snyder, 2013), PROM can be used to support patients' self-management (Santana & Tomkins, 2021). To be able to use the PROM efficiently, the definition of the PROM needs to be considered. The National Quality Forum (NQF) defines the PROM as 'any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else' (NQF, 2013). Therefore, questionnaires completed with the involvement of someone else other than a patient has a high risk of including bias as it will not be only the patient's ideas. It is important to provide stroke survivors PROM whenever they need it so they can use them as part of their self-assessment.

2.3.2 Method of Patient-Reported Outcome Measure Administration

Stroke survivors can choose different ways to administer the PROM depending on their preference and limitations; such as mail, face-to-face (paper-and-pencil), or digital (telephone or website) administrations (Kingsley & Patel, 2017) through ePROM. The quality of the collected data can change according to the way of administration (Bowling, 2005). It is reported in 2015 by Cella et al., that due to its advantages paper-and-pencil administration was a commonly used method to administer the PROM. One of the advantages of using paper-and-pencil to administer the PROM is its cost-effectiveness. It can be less cost-effective except for mailings and follow-up costs (Cella et al., 2015). However, the cost-effectiveness needs to be questioned. The amount of money spent on posting or printing the paper-and-pencil administered questionnaires needs to be considered. There are other disadvantages that can be a barrier to use this type of PROM administration. For example, the risk of missing data (Streiner et al., 2015). Participants can miss an item, which can have an impact on the sub-total or total scoring that can result in not understanding all limitations of the people.

Other than the data entry error, there is a more important disadvantage of paper-and-pencil administration that needs to be considered, which is the activity limitations of stroke survivors. Seventy per cent of stroke survivors have upper limb impairment after a stroke (Borschmann & Hayward, 2020; Nakayama, Stig Jørgensen, Otto Raaschou, & Skyhøj Olsen, 1994). Therefore, depending on their dominant hand, stroke survivors with upper limb impairment may struggle to use a pencil to complete the paper versions of the PROM. Body impairments should not be a barrier for stroke survivors to express themselves or their perspective. Comprehensive PROM are the questionnaires that cover most of the items that are relevant to the target population to express their limitations. These PROM help to increase stroke survivors' awareness about their limitations and express what is the main limitation that they want to target in the rehabilitation. Therefore, other methods of administration need to be considered to provide an equal chance to each stroke survivor in their rehabilitation process.

In addition, immediate feedback may help stroke survivors to increase their awareness which can result in better self-management. Use of the paper-and-pencil PROM, require waiting time for the healthcare professionals to score and provide feedback to stroke survivors. Stroke can result in lifelong impairments, which may require long-term self-management. Therefore, waiting for access to the paper version of the PROM and waiting to get feedback from healthcare professionals can affect the self-assessment process. The use of technology can offer an alternative to allow digital administration of ePROM which may overcome these issues.

2.3.3 Electronic Mode of Assessment: Electronic Patient-Reported Outcome Measures (ePROM)

The National Health Service (NHS) has started to use digital platforms as part of the healthcare system to provide easy access to the information that patients need about their health (DoH, 2007). Therefore, the care provided by the NHS is moving towards the digital health area and this needs to be considered when assessing and treating patients (NHS Long Term Plan, 2019; The Topol Review, 2019). With the introduction of technology into our lives, the use of a digital platform for ePROM administration has increased (Streiner et al., 2015). Electronic PROM administration has many advantages over paper administration (Coons et al., 2009), such as, it is cost-effective, acceptable and practical, which increases use; (Bonevski et al., 2010). The use of ePROM can be completed quicker, it does not require manual scoring and it is preferred by patients compared to the paper version (Sabatino et al., 2019). The main benefit of using an ePROM is, it can help a high number of people access a questionnaire at any time and in any place.

Another advantage is ePROM can give a chance to people to get an immediate score and feedback about their PROM results (Meirte et al., 2020; Cella et al., 2005). If a patient uses the paper-and-pen to complete a PROM, they will need to wait to see the healthcare professionals until the next session to see the results, which will then take healthcare professionals' time to score the PROM and decide on the rehabilitation programme or share the results with patients. However, the use of an ePROM can increase the speed of the process. The score of an ePROM can be calculated automatically by the digital platform, and patients can access their score and meaning of the scores immediately, which can help patients to use these results as part of their self-assessment. They can use their results to increase their awareness of their ADL limitations, which may help to self-manage their limitations and share their results with their healthcare professionals before a session. These can help to improve the timeline of the assessment periods, progress SDM and result in better rehabilitation outcomes.

Moreover, when people complete the questionnaires independently through electronic devices, they can be more honest with their answers (Lucas et al., 2014), because sometimes people might feel under pressure when they are asked private questions. This can help to learn more detailed information about the daily activity limitations, including the private questions; (i.e., can you wipe yourself with toilet paper/ clean yourself below). Also, as patients enter their results through an online platform, this reduces the risk of data entry errors to minimal. There is no need to do separate data entry for analysis as in the paper-and-pencil method (Cella et al., 2015). Furthermore, the use of an ePROM can eliminate the missing data problem because people would be prevented from omitting questions (Streiner et al., 2015), as they will not be able to submit their answers unless they answer all of the questions. However, this is a point that needs to be considered carefully, as people should be able to skip any question that they do not want to provide an answer to.

Patient-reported outcome measures are commonly used tools to guide and support patient-centred care (Meirte et al., 2020; CDRH Strategic Priorities 2016-2017), and are traditionally measured by using pen-and-paper version but, use of pen-and-paper versions of the PROM resulted in unreadable, missing or faulty data previously (Allen et al., 2010). The growth of digital health technologies has resulted in opportunities to collect information through ePROM (Meirte et al., 2020). As mentioned by Biesdorf and Biedermann in 2014, people of all ages and sociodemographic backgrounds were comfortable using digital networks and services in the world. Nearly, 78% of adults (aged between 18-65) use smartphones, which shows that optimising the use of apps and web-based interventions are relevant for most of the population (Selvan et al., 2020). It was known that the ePROM help to capture more correct information (Meirte et al., 2020), however, there are people who can find it difficult to use the ePROM due to their disadvantages (Please, refer to section 2.3.4 for detail). People who have characteristics that are protected under the Equality Act2010 are less likely to use the internet. So, it is important to take this into account when moving into digital health. These people have the risk to miss out on the benefits of digital health, which will put more pressure on health services. Therefore, before developing an online platform, it was important to understand if the advantages of ePROM use overcome the disadvantages.

Many studies that were conducted before have shown that the data collected through ePROM are equal to the data collected from a paper version, so there is no difference between paper and electronic versions (White, Maher, Rizio, & Bjorner, 2018; Campbell, Ali, Finlay, & Salek, 2015; Muehlhausen et al., 2015; Gwaltney, Shields, & Shiffman, 2008). Hence, there is a clear shift towards the use of technology that increases the use of ePROM (Meirte et al., 2020; Coons et al. 2015). Patients are motivated to use ePROM as they believe that ePROM provide value and quality to their care (Dolan, 2014). A systematic review conducted by Meirte et al., (2020) compared the disadvantages and advantages of the ePROM. Authors reported that ePROM offer more advantages compared to disadvantages as ePROM help to collect more quality data, facilitate clinical decision making and symptom management, and they have a similar or faster completion time compared to the paper version of PROM. Authors evaluated 14 studies that looked at the preferred modality (electronic or paper version) by participants and in 11 of these papers, ePROM were preferred by participants (Ali et al., 2017; Engan et al., 2016; Smith et al., 2016; Jongen et al., 2016; Shah et al., 2016; Salaffi, Gasparini, Ciapetti, Gutierrez, & Grassi, 2013; Touvier et al., 2010; Salaffi, Gasparini, & Grassi, 2009; Richter et al., 2008; Greenwood, Hakim, Carson, & Doyle, 2006; Bliven, Kaufman, & Spertus, 2001). In addition, out of 16 papers that searched the preference of participants, 13 papers reported that participants preferred ePROM compared to paper version (Engan et al., 2016; Shah et al., 2016; Smith et al., 2016; Wintner et al., 2015; Salaffi et al., 2013; Touvier et al., 2010; Salaffi et al., 2009; Richter et al., 2008; Mangunkusumo et al., 2005). When the completion time of different modes of administration was compared, it was documented that completion times for ePROM were at least similar or faster compared to a paper version (Meirte et al., 2020).

In addition to the above points, the use of ePROM have further advantages than just providing high-quality data, faster completion, patient preferences and low cost. For example, the use of an ePROM provides a real-time data recording, which allows detecting the changes that occur in people and result in immediate action that helps to reduce the symptom burden, complication and readmissions to hospitals (Meirte et al., 2020; Camphell et al., 2015). In addition, the use of ePROM empowers patients and results in better communication (Meirte et al., 2020; Wintner, et al., 2015; Schnall et al., 2014; Richter et al., 2008). Therefore, it can be concluded that the use of an ePROM is linked with better self-management (Santana & Tomkins, 2021).

There are at least 30 PROM available for stroke survivors to assess their ADL limitations (Please, refer to Chapter Three for details). However, as explained before they are still not widely used and this can be because of the limitations of paper-and-pencil and lack of a comprehensive ePROM. The common and correct use of the ePROM can aid healthcare professionals' assessment by providing them information from stroke survivors' perspectives. Most importantly, ePROM can be used as a self-assessment by stroke survivors to aid their self-management by seeking health information on ADL limitations to help themselves and/or help with their rehabilitation through enabling them to take an active part in their care e.g., by telling their therapists what exactly their ADL difficulties are, to what degree.

Stroke survivors need to be able to understand and track changes in their ADL functioning, because these may motivate stroke survivors to realise what they can achieve, understand barriers that they face, set their goals and participate in their rehabilitation, which can help better self-management (Morais et al., 2015). All this awareness of ADL limitations can motivate stroke survivors to make healthy behavioural changes to achieve their targets and have a more independent life. One way of doing this regardless of input from healthcare professionals is to complete comprehensive PROM. The ePROM can solve the accessibility issue by providing easy access to the comprehensive ADL PROM, storing all the data and aiding motivation, behaviour change and goal setting by increasing people awareness (Santana & Tomkins, 2021; Meirte et al., 2020). Despite the literature review (Meirte et al., 2020; Field, Holmes, & Newell, 2019; Faoite, 2018) have shown the benefits of ePROM and NHS advised moving into digital health (NHS Long Term Plan, 2019; DoH, 2007), it is crucial to consider the disadvantages of using ePROM, (Please, refer to section 2.3.4), to provide a balanced argument as there are people who cannot use the digital health technologies.

2.3.4 Disadvantages of Electronic Patient-Reported Outcome Measures

As with any medium to deliver care, there are some disadvantages of using ePROM. These are mainly around the access to technologies, health and digital literacy required to be able to take part in the online self-assessment process and stroke-specific limitations that could impact the use of digital technologies. Firstly, it needs to be considered that some people are not able to use ePROM. People can face some technical issues when they try to complete ePROM, which can be one of the disadvantages (Wintner et al., 2015; Jonassaint, Shah, Jonassaint, & De Castro, 2015; Bliven et al., 2001). People who do not know how to use technical devices, do not have access to the internet or electronic devices, cannot use the ePROM (Meirte et al., 2020; Campbell et al., 2015). Hartkopf et al., (2017) reported that older people who have poor health that has an impact on the QoL, or people who have less technical skills have reported barriers for ePROM use. Most importantly, some patients were worried if there is any privacy barrier that will stop them to use the ePROM (Hartkopf et al., 2017; Liu, Wang, Zhou, & Hong, 2016).

Secondly, it is important to understand that digitalisation can be either a barrier or a facilitator for people. Therefore, it is important to understand people's digital health literacy (Holt, Overgaard, Engel & Kayser, 2020; Kayser et al., 2018). Digital health literacy is known as the ability to use electronic sources to be able to prevent, address and solve a health problem by finding and understanding the health information (Norman & Skinner, 2006). Digital health literacy is shaped by different factors, i.e., environmental, cultural, economic, and societal. It is reported that people with low literacy skills, low digital literacy skills, individuals who speak minority languages, people who have limited access to electronic devices or have conditions that cause them to be concerned about the confidentiality shaped through digital devices are less likely to use digital health platforms (WHO: Recommendations on digital interventions for health system strengthening, 2019).

Thirdly, as a stroke can result in severe limitations, some stroke survivors may lose their jobs, which can lead to difficulty of having internet access at home due to economic problems. Therefore, it was known that not all stroke survivors will have access to the internet to complete ePROM. However, research in 2015, showed that 88% of the adults used the internet (Imison et al., 2016), whereas now, 91% of the population in the UK use the internet (Selvan et al., 2020; The Topol review, 2019). On the other hand, as some people still have the potential not to have internet access, there is a need of using both paper and electronic versions of the PROM to provide every stroke survivor with an equal chance to get the benefit of using PROM.

Fourthly, a stroke can lead to cognition and visual problems (Stokes & O'Neill, 2008). People with cognition or vision problems may struggle to use electronic devices to complete ePROM. However, stroke survivors' carers or family members can help them to complete the ePROM, (that were tested as a proxy report), with stroke survivors' help and permission. Table 1 shows the pros and cons of both digital administration and paper-and-pencil administration. When pros and cons are compared with taking into account the increase in the use of technology in our lives, it is thought that there is a need for considering the use of digital platforms for ePROM administration. This will help stroke survivors to benefit from technology and self-manage their condition.

Table 1: Advantages and disadvantages of different ways of administering PROM

Type of administration	Advantages	Disadvantages
ePROM	• Reduced staff burden • Immediate score and feedback • Interactive • Easy access • Comfortable to answering special questions • More time • Reduce data entry error • Increase self-awareness by helping to track changes over time. • Can be used as part of self-management	• Lack of an internet access • Potential discomfort with technology, as some people might not be happy or eligible to use the technology • Cost • Visual impairments can affect completing PROM from a screen
Paper-and-pencil administration	• Cost-effective • Can be used as part of self-management	• Prone to data entry errors • Data entry and analysing requires more time • Delivering paper-and-pencil copies to patients can be difficult • Requires writing with the affected side (if the affected side is dominant) to complete the questions • Data security • Patients need to contact healthcare professionals to understand the meaning of scores

The disadvantages of the ePROM can make people need assistance to complete them, or have no access to them at all. Therefore, it is important to consider the paper-and-pen version too. Both ways are important as people are different and it is important to provide options to people to improve their accessibility. These disadvantages and concerns can be overcome with the development of an online platform that will be user friendly, easy to use, accepted by the target population, freely available to people, which considers their views and take into account the General Data Protection Regulation (GDPR). Also, the design, user experience, font size and adaptability of user experience need to be considered when developing an ePROM and an online platform that will house it to make it a good self-assessment platform (Meirte et al., 2020; Recinos et al., 2017; Liu et al., 2016; Hochstenbach, Zwakhalen, Courtens, van Kleef, & de Witte, 2016; Shah, et al., 2016, Smith et al., 2016; Wintner et al., 2015; Jonassaint et al., 2015; Schick-Makaroff et al., 2015; McCleary et al., 2013; Keurentjes et al., 2013; Andikyan et al., 2012; Richter et al., 2008).

2.4 Benefits of an Online Self-Management Platform

Digital technologies offer the potential to enhance the quality of health and services by providing opportunities to overcome the health challenges (WHO: Recommendations on digital interventions for health system strengthening, 2019). A lack of accessibility can result in less use of PROM, but an online platform that houses ePROM can solve this problem as they are always available, portable and can be completed across multiple devices (Ali, Johns, Finlay, Salek, & Piguet, 2017; Jongen et al., 2016; Wintner et al., 2015; Campbell, Ali, Finlay, & Salek, 2015; Fanning et al., 2014; Richter et al., 2008). Moreover, they do not result in paper waste (Hochstenbach et al., 2016; Salaffi et al., 2009), makes it easy to store the results of the assessments and provide graphs to show people how they are doing with their ADL limitations. All of these benefits make it easy to use the collected information for research purposes.

Most importantly, ePROM are more accessible than paper versions. However, it is important to differentiate and understand the accessibility, usability, inclusivity and acceptability to create better tools for stroke survivors. Accessibility helps to understand what are the discriminatory aspects for the users with different limitations and everyone with different disabilities can use, understand and interact equally with the website or tools

(W3C Web Accessibility Initiative, 2016). However, accessibility mainly focuses on disability and eliminates the borders. Therefore, it is important to consider other aspects such as inclusivity. Inclusivity is a process where it is closely linked to accessibility, it considers as many people' needs as possible, including their culture, age, education, language, location, economic situation, and it is about diversity to ensure the involvement of everyone (Miller, 2018; W3C Web Accessibility Initiative, 2016). Inclusivity and accessibility are different two things, but accessibility is one of the main outcomes of an effective inclusive design.

It is important to consider that inclusivity design makes sure that it is easy and enjoyable for as many people as possible, where accessibility helps to make special considerations for people with disabilities (Bureau of Internet Accessibility, 2019). Accessibility does not consider the different cultures or perspectives and it tries to support different modes of engagement, but inclusive design tries to find solutions for all users with different needs, behaviour and perspectives (Miller, 2018). For a design to be inclusive, it needs to recognise the exclusion to solve the problems, be patient-centred and involve the people who will use the platform from the beginning of the development process and it needs to be holistic to design a platform for people with different limitations (Miller, 2018). As accessibility is an outcome of inclusivity, the users' limitations need to be considered and people who will use the website need to be involved. Therefore, the images, videos, forms that will be created, the content, access, colour contrast, touch targets, keyboard access need to be considered to make sure that it is user friendly and easy to use. Most importantly, people who will use the website need to be involved in the development process from the beginning and their limitations need to be considered. These will help to make sure that the developed platform is inclusive and covers the accessibility inside it to help for user-centred design.

Moreover, it is important to consider usability as it helps to design tools with users' experience. Usability helps tools to be effective, efficient and satisfying (W3C Web Accessibility Initiative, 2016). However, usability assessment does not help to understand the needs of people with disabilities in detail (W3C Web Accessibility Initiative, 2016). Therefore, it is important to address the accessibility, usability and inclusivity of a tool and website to make it usable, accessible and inclusive design for everyone.

Digital health makes it easier to access health information for people with low health literacy (Mackert, Mabry-Flynn, Champlin, Donovan, & Pounders, 2016). It is important to be aware of the growth of digital health technologies that provide lots of opportunities to people, specifically on collecting information on ePROM. There are many people of different ages and sociodemographic backgrounds around the world, that use the digital network and services (Biesdorf & Biedermann, 2014). Many studies show the role of ePROM in symptom management and decision making (Meirte et al., 2020; Schnall et al., 2014; Andikyan et al., 2012). It allows to detect the complications as soon as possible and act on them, which ultimately helps to reduce symptom burden and deterioration (Meirte et al., 2020). Moreover, ePROM use empower patients and improve their self-awareness of their limitations (Meirte et al., 2020; Hochstenbach et al., 2016; Wintner et al., 2015; Schnall et al., 2014). Online platforms that house ePROM are always available for people to complete, as and when they need to, as they are portable and can be completed using multiple devices (Ali et al., 2017; Jongen et al., 2016; Wintner et al., 2015).

Moreover, research suggests that the use of technology-based interventions for rehabilitation or prevention purposes can help to provide fast and correct treatment and eliminate risks on the healthcare system that can occur due to a high number of stroke cases (Ciccone, Dornonville de la Cour, Forchhammer, & Maier, 2021). Research conducted by Demain et al., in 2013, showed that the use of assistive technology devices, such as electrical devices, which can be used as part of rehabilitation to help recover movement in the upper limb, can help stroke survivors to self-manage their conditions. Research and policies (Ciccone et al., 2021; NHS Long Term Plan, 2019; Demian et al., 2013) showed the importance of moving into digital health and using it as part of stroke rehabilitation, but it is important to understand that not all of the available digital health technologies can solve the problems of self-assessment and progress the self-management. People with low digital health literacy need to be considered to provide equal health for each stroke survivor (Please, refer to section 2.3.4 for details).

Despite the advantages of digital health technologies on self-management, currently, lack of resources, or lack of healthcare professional knowledge about these assistive technologies results in stroke survivors not using these electronic devices (Demain et al., 2013). Currently, there are different platforms available to stroke survivors to help self-manage their condition, and the section 2.5 below will provide a review and critical evaluation of these to examine what they offer, and whether a comprehensive self-assessment is available to users to guide their rehabilitation needs.

2.5 Online Platforms for Stroke Survivors

There are online platforms which were specifically developed for stroke survivors; i.e., My Stroke Guide, which is developed by the Stroke Association, and it is a freely available website that developed specifically for stroke survivors in the UK where they can register to have an account to use it as a self-management tool (Randall, 2017). Stroke Association has mentioned that My Stroke Guide aims to help stroke survivors to communicate with each other, share their experiences, socialise and access up to date research about their condition. However, there was no peer-review published research to support this. As documented in the Stroke Association website, the platform helps stroke survivors to set goals by adding the activity that they want to achieve to a calendar and tracking it. Every time they complete a goal, they earn a symbolic trophy which helps them to recognise their achievement.

The goals set by stroke survivors independently can be broad and involve stroke survivors' hopes and aspirations, which can result in the development of unachievable goals and disappointments for stroke survivors (Plant, Tyson, Kirk & Parsons, 2016). It is reported by research that unrealistic goals can be eliminated by focusing on short-term goals (Conneeley, 2004). Therefore, the involvement of a multidisciplinary team during the goal development process can eliminate this risk and help stroke survivors to understand what they can achieve in short term periods. On the other hand, providing stroke survivors an access to a comprehensive, valid and reliable ePROM to self-assess their limitations can guide their understanding of their ADL limitations and help them to develop more realistic, timely and achievable goals.

Other online platforms were developed to provide rehabilitative interventions for stroke survivors that are technologically enabled; i.e., the Innovative Stroke Interactive Virtual Therapy (STRIVE) (Johnson, Bird, Muthalib, & Teo, 2018). The STRIVE is developed to offer stroke survivors a personalised rehabilitation programme, repetitive task training and feedback about patients' progression (Johnson et al., 2018). However, stroke rehabilitation includes assessment, goal-setting, treatment and reassessment (Walker, Sunnerhagen & Fisher, 2012; Langhorne, Bernhardt, & Kwakkel, 2011) to see the improvements that stroke survivors have and successfully guide the treatment. On the other hand, the STRIVE does not provide self-assessment by using ePROM. This is not the only platform that provide access to interventions, but not self-assessment for stroke survivors. There are other online platforms or apps that provide only treatment without a self-assessment. For example, Different Strokes is another stroke community service that has an online platform. Different Strokes has developed online exercise classes for stroke survivors who can attend live sessions using social media platforms such as Facebook and improve their stroke recovery when their face-to-face input from a therapist is limited. However, the Different Strokes website does not include an ePROM so stroke survivors cannot use this platform to track their activity limitations over time to evaluate the impact of the intervention to support self-management.

Moreover, My Therappy platform is amongst the digital health technologies which the NHS promote to improve access to apps that are specifically developed for stroke survivors, and endorsed by the NHS. According to My Therappy platform the top five apps include Language Therapy, Dexteria, Peak, Stroke Patient and Headspace. These apps are mainly for stroke survivors to get information about stroke and access available interventions specifically for upper or lower limb, or speech and language problems. However, none of them provide an access to an ePROM for stroke survivors to allow self-assessment and evaluation of the interventions received. Stroke survivors who use these platforms to have rehabilitation input cannot self-assess their physical level and need to get regular input from healthcare professionals. However, one of the opportunities of moving into digital health is to reduce the pressure on the healthcare system by enabling self-management. Stroke survivors can use these platforms as part of their treatment, but they may still require input from healthcare professionals for their assessment to understand what they have achieved. This is because they will not be able to self-assess their limitation in ADL, and get immediate, real-time feedback by completing ePROM. This can affect stroke survivors' self-assessment as they cannot use an online platform to complete ePROM to self-assess their limitations in ADL and increase their awareness. Therefore, there is a gap in digital health sphere for an online platform specifically developed for stroke survivors, and allows completion of an ePROM to facilitate self-assessment.

2.6 Patient-Reported Outcome Measures for Activities of Daily Living

Heterogeneity, mode of administration, time of administration and lack of confidence in using the PROM that assesses ADL function, have been already recognised by researchers as a barrier to synthesise evidence to improve patient-centred care (Verheyden & Meyer, 2016; Boyce, Browne, & Greenhalgh, 2014; Stokes & O'Neill, 2008). The use of ePROM that is available at an online platform can be a solution for most of these problems; such as mode and method of administration, which results in less use of PROM.

However, a lack of comprehensiveness can result in eliminating the use of PROM. It is important to use a PROM that evaluates high numbers of activity and participation components of the ICF. Therefore, a PROM needs to have a systematic link with corresponding categories of the ICF (Cieza et al., 2002). For stroke-specific tools, ICF linking rules can be used to systematically link the ICF Core Sets of Stroke Conditions for post-acute care with the items of the PROM (Geyh et al., 2004a; Geyh et al., 2004b; Cieza et al., 2002). ICF Core Set for Stroke Conditions is the most comprehensive ICF Core Set and covers important and complex impairments, activity limitation or participation restrictions and interactions with environmental factors (Geyh et al., 2004a). The categories included are deemed as the most prominent limitations that stroke survivors face in daily life (Geyh et al., 2004a). Therefore, PROM for ADL limitations must be comprehensive enough to cover these items. Despite research highlighting the importance of involving patients in the development process of PROM, there is still a lack of public involvement (Carlton et al., 2020). As the PROM were predominantly developed by healthcare professionals and researchers, without patient involvement in item generation, it can result in a lack of comprehensiveness.

To give an example, the Barthel Index (BI) is a commonly used PROM to assess ADL limitations (Quinn, Langhorne & Stott, 2011). The BI is an outcome measure originally developed to assess ADL for neuromuscular or musculoskeletal patients (Mahoney and Barthel, 1965). It includes ten items; bowel and bladder control, grooming, toileting, feeding, transferring, bathing, dressing, mobility and stairs. It is a simple scale that takes two-five minutes to complete (Finch, Brooks, Stratford, & Mayo, 2002). On the other hand, the main limitation of the BI is the lack of comprehensiveness and its relative insensitivity (Salter et al., 2013). Therefore, it can only show that stroke survivors are limited, but not detailed enough to explain the main activity limitations.

Another example is the Rivermead Mobility Index (RMI). The RMI can be used to assess disability in mobility and is focused on fundamental aspects of mobility (Collen, Wade, Robb, & Bradshaw, 1991). Its validity initially was assessed on head injury and stroke patients by concurrent measurement of mobility using gait speed and endurance and by standing balance (Collen et al., 1991). It consists of 15 items in total that include 14 self-reported questions and one direct observation (standing unsupported) (Antonucci, Aprile, & Paolucci, 2002). On the other hand, RMI only shows people's ability to move and does not take into consideration achievements by using environmental modifications such as aids (Collen et al., 1991).

In addition to comprehensiveness, PROM need to have good psychometric properties. These criteria are essential to make sure that the PROM assess what they are supposed to assess in the target population (Mokkink et al., 2018; Patchick, Horne, Woodward-Nutt, Vail, & Bowen, 2015). Some of these properties are acceptability, validity, reliability, and responsiveness (Mokkink et al., 2018; Fitzpatrick, Davey, Buxton, & Jones, 1998). The use of outcome measures cannot be recommended unless they have good validity and reliability (Portney & Watkins, 2009) within the target population. Other important psychometric properties that need to be evaluated include three domains; validity, reliability, and responsiveness. Each domain contains different measurement properties (Mokkink et al., 2018; Terwee et al., 2017). Each component is important, and they have a different meaning:

1. **Acceptability** is an important criterion of the PROM because it is the evaluation of how acceptable and relevant the target population finds a PROM (Gibbons & Fitzpatrick, 2012; Fitzpatrick et al., 1998). It is normally assessed by looking at the value of the missing data, response rate, or administration time (Fitzpatrick et al., 1998), and how understandable or relevant participants find the items in the

questionnaire (Menard et al., 2014). Acceptability information is normally assessed by collecting information directly from the target population at the development stage of the questionnaire (Fitzpatrick et al., 1998).

2. **Reliability** is when a PROM does not have a measurement error and provides a similar score when it is repeated under several conditions (Souza, Alexandre, & Guirardello, 2017). Reliability can be assessed in different aspects such as:

   - Test re-test reliability: It is testing the similarity of PROM scores under two different times (Souza et al., 2017). The time interval for the second administration needs to be long enough to reduce the risk of recall bias and short enough to make sure that participants are medically stable (Streiner & Kottner, 2014). Target populations have an impact on the time interval, but it is normally advised to administer the questionnaires again after two weeks. (Streiner & Kottner, 2014). Calculating the interclass correlation coefficient (ICC) is a common method to evaluate test-retest reliability. ICC is expected to be over 0.70 for a PROM to be accepted with a good test re-test reliability (de Vet, Terwee, Knol, & Bouter, 2006; Nunnally & Bernstein, 1994).

   - Internal consistency: It is the degree that all items of a PROM measure the same construct (Terwee et al., 2007; Streiner, 2003). It is commonly assessed by calculating Cronbach's alpha and a score of ≥0.70 is known as an ideal score (Souza et al., 2017; Terwee et al., 2007).

3. **Responsiveness** shows how powerful a PROM is to identify clinically important changes over time (Terwee et al., 2007). A PROM is responsive when the smallest detectable change is smaller than minimal importance change (Mokkink et al., 2010).

4. **Validity** means that a PROM measures what it is supposed to measure (Mokkink et al., 2010; Roberts and Priest, 2006). Validity is divided into two categories; external validity and internal validity:

- **External validity:** It shows whether the results of a study can be generalised to the larger population (Mokkink et al., 2010). External validity cannot be only evaluated by looking at the use of a PROM. The method or sample should also be considered when assessing the external validity (Mokkink et al., 2010).

- **Internal validity:** is the degree to which the relationship between dependent and independent variables is free from the effects of the extraneous factors. Research shows that there are three different kinds of validity, which can assess the internal validity (Mokkink et al., 2010). They are:

  a. **Construct validity:** is when a theoretical construct is measured by an instrument. It has sub-types; convergent validity and discriminant validity (Bolarinwa, 2015).

  b. **Convergent validity:** assesses the degree to which two different instruments or methods can measure the same construct (Bolarinwa, 2015).

  c. **Discriminant validity:** assessing the degree to which a tool provides different results when measuring two different constructs that can discriminate between the construct.

  d. **Criterion validity:** is often known as how well the results of the current outcome measure are enough of a reflection of a previous measure or “gold-standard” that measure a similar construct (Kimberlin & Winterstein, 2008). PROM is ideal when the correlation coefficient is ≥0.70 (Terwee et al., 2007). Criterion validity has two different types; concurrent validity and predictive validity.

  e. **Concurrent validity**: is a form of criterion-related validity. It is a degree to which, the outcome of one-test correlates with outcomes on a criterion test when both tests are given at relatively the same time (Terwee et al., 2007). Concurrent validity is normally assessed by looking at the correlation between the comparison PROM and the main PROM that is tested.

f. **Predictive validity**: is a form of measurement validity in which an instrument is used to predict the same future performance.

g. **Content validity:** is when the content of the measurement tool is the satisfactory reflection of the concept that is supposed to be measured (Polit, 2015). It is the content and clarity of the measurement tool for the target population, and the context that it needs to assess (Terwee et al., 2018a). It is suggested to involve both the target population and the experts of that area in content development (Terwee et al., 2018; Streiner, 2014). After developing the tool, there are different ways to evaluate the content validity. One way of doing this is by linking the items of the PROM to the ICF.

There are a high number of PROM available (Salter et al., 2013; Jenkinson, Gibbons, & Fitzpatrick, 2009), but the evidence to support the psychometric testing of the existing PROM for stroke is inconsistent and their psychometric properties and content needs to be analysed in further detail (Reeves et al., 2018). The use of a PROM by a healthcare professional or a patient with poor validity and reliability can result in erroneous assessments, which can hinder rehabilitation. It is of paramount importance that PROM is tested, and proved to be comprehensive and psychometrically robust to enable effective assessment (Hammond, Prior, Tennant, Tyson, & Nordenskiold, 2015a; Portney & Watkins, 2009).

While there is growing support for using PROM as an outcome measure (Boyce et al., 2014; Devlin & Appleby, 2010), their use in clinical practice remains inconsistent and patchy (Kyte et al., 2015). In general, the literature review showed that the commonly used PROM have relatively fewer items to assess daily activity functioning. However, a detailed systematic search was required to critically analyse the psychometric properties and comprehensiveness of the PROM, which are used to assess ADL limitation for stroke survivors. Therefore, a systematic review is needed to identify and evaluate the existing PROM that are commonly used and specifically developed for stroke survivors to assess ADL limitations. Additionally, the comprehensiveness of the reported PROM must be analysed to determine if they are detailed enough to cover all ADL functions to be sensitive to change. Moreover, their psychometric properties must be analysed critically, to ensure they are valid and reliable. This will help to understand, which PROM are available for use in revealing stroke survivors' daily function and highlight a gap if there is a need for further development of a PROM to specifically assess ADL limitations in stroke survivors. The next chapter detailed the systematic review on PROM of ADL limitations that developed or commonly used for stroke survivors

CHAPTER THREE: SYSTEMATIC REVIEW

Assessment of the Limitations in Activities of Daily Living in Stroke Survivors: A Systematic Review of Patient-Reported Outcome Measures

3.1 Introduction

This review aimed to identify whether any existing PROM with good psychometric properties and detailed content, which aimed to assess ADL limitations for stroke survivors, satisfied the recommendations for a PROM derived from the involvement of both stroke survivors and an expert panel. Firstly, justifications were made for the chosen methodology and used method by following the guidelines to identify papers that include PROM to assess ADL. Secondly, the used method was explained in detail to show how this systematic review identified both PROM and papers that were relevant to analysing the psychometric properties of the identified PROM. Thirdly, the content of each eligible PROM to the inclusion/exclusion criteria was analysed for comprehensiveness. Finally, the method of analysis chosen to understand the finding and complete narrative synthesis was explained in this chapter.

3.2 Rational for the systematic review

3.2.1 Outcome Measures

Outcome measures (OM) are the tools that help to assess the patient's current situation (Fetters & Tilson, 2012), which is crucial for stroke rehabilitation to choose the correct OM as it helps to improve the diagnosis, increase self-awareness and guide the goal setting, also improve the communication between the patient and the healthcare professional (Sullivan et al., 2013). Different types of OM are commonly used in clinical practice:

1. PROM,
2. Observer-reported outcome measures,
3. Clinician-reported outcome measures and
4. Performance-based measure (Velentgas, Dreyer, & Wu, 2013).

Generally, all types of OM are based on a scoring system (Yamamoto & Magalong, 2003) and the obtained score can show the level of limitations that a patient suffers, so it is important to select the correct OM. There is a lot of research available to show the benefit of using the OM for stroke rehabilitation (Sullivan et al., 2013), with good psychometric properties as the psychometric properties provide the intrinsic properties of the OM. The use of the OM with good psychometric properties are recommended by the guidelines (Mokkink et al., 2010) as the use of OM with poor psychometric properties can affect the accuracy of results. Therefore, it is crucial to choose the appropriate OM to understand patients' current situation and progression (Moore et al., 2018).

However, OM are still not used efficiently or often enough, in both research and clinical practice due to different barriers (Sullivan et al., 2013). There are different reasons for not using the OM frequently or efficiently. Clinicians believe that patients may find it hard to complete an OM, there is a lack of knowledge about the OM, lack of skills in how to administer an OM or poor availability of the tools (Sullivan et al., 2013, Jette, Halbert, Iverson, Miceli, & Shah, 2009; Van Peppen, Maissan, Van Genderen, Van Dolder, & Van Meeteren, 2008). Another barrier that results in reduced use of the OM is, the lack of guidelines or recommendations about what the OM includes and which one to use in which situations (Santisteban et al., 2016).

Moreover, there are a high number of OM available for stroke in literature (Salter et al., 2013; Jenkisnon et al., 2009). For example, the research conducted by Santisteban and colleagues (2016) has reported the availability of at least 48 OM, which can only be used to assess the upper limb limitations. Some other OM can be used for lower limb, ADL limitations, fatigue, depression or self-management. There are published papers that show available OM but, when to use them, who to use them for and what are their psychometric properties are additional information that needs to be provided to the healthcare professional who works in the stroke rehabilitation setting.

Due to the high number of OM, there is no consistency to use them as it is difficult to use them all and compare their effect on treatments (Duncan Millar, Van Wijck, Pollock, & Ali, 2019). However, the important thing is to differentiate the performance-based measure and PROM from each other. They are different as PROM are completed by patients and help to collect information from the patient's perspective (Dawson, Doll, Fitzpatrick, Jenkinson, & Carr, 2010), and can be used as part of self-assessment. On the other hand, performance-based OM are completed by healthcare professionals after observing patients function. As both are different, both of them need to be used to achieve better outcomes. Clinicians have reported that outcome measures help to understand the limitation of patients from an objective perspective, but they are not sufficient enough. A stroke is a lifelong condition, and impairments of a stroke can affect different aspects of stroke survivors' various daily activities. Therefore, there is a need to use PROM as part of self-assessment to guide self-management.

3.2.2 Definition of Patient-Reported Outcome Measures

Patient-reported outcome measures help to understand limitations from patients' perspective that they had a chance to observe while they do an activity and can be used to improve the self-management (Santana & Tomkins, 2021; Ashford, Brown, & Turner-Stokes, 2015; Dawson et al., 2010). Also, it helps stroke survivors to realise their limitations and evaluate what they can do by questioning themselves about daily activities in detail (Ashford et al., 2015; Marshall, Haywood, & Fitzpatrick, 2005). PROM show if people can manage adequately in their daily lives, rather than only focusing on what they can do in clinical settings (Ashford, Slade, & Turner-Stokes, 2013; Dawson et al., 2010), which led to increase stroke survivors' awareness of their limitations and ultimately improve their self-management. It is evidenced that successful rehabilitation is linked with patients' confidence, goal-directedness and intimate rehabilitation but, lack of motivation is the main problem that affects rehabilitation (Rapolienė, Endzelytė, Jasevičienė, & Savickas, 2018). Research showed that motivated stroke survivors have better participation in ADL rehabilitation and progress better compared to less motivated people (Rapolienė et al., 2018; Maclean & Pound, 2000). Use of comprehensive PROM that can show people what they can and cannot achieve in ADL limitations and increase their motivation, which can lead to better self-management.

As explained in section 2.2.4, the ICF reported that disability is determined by multiple factors and not just with capacity (WHO, 2001). Comprehensive PROM has the potential to assess differences between the capacity and performance of stroke survivors and show the real effect of limitations on daily activities. The use of PROM may help stroke survivors to understand their main limitations in ADL, increase their awareness followed by motivation and facilitate the goal-setting process to improve treatment outcomes (Kyte et al., 2015).

3.2.3 Why to Conduct a Systematic Review

Despite the advantages of PROM, there are still not enough guidelines to show the available PROM and explain their content and psychometric properties. Systematic reviews can be a guide to select the appropriate OM (Baker, Cano, & Playford, 2011). Different systematic reviews have been previously published about the PROM for stroke survivors and they can be used as a guide by healthcare professionals. However, none of these systematic reviews was specifically evaluated only the PROM that aim to assess ADL limitations for stroke survivors and did not look at the content of the PROM (Reeves et al., 2018; Ashford et al., 2015; Boger et al., 2012; Ashford, Slade, Malaprade, & Turner-Stokes, 2008).

A systematic review published in 2012, aimed to identify the OM that were commonly used to assess self-management (Boger et al., 2012). Forty-three OM were documented in the systematic review, but all of them had limitations. Authors have documented that there is no specific OM to measure self-management specifically (Boger et al., 2012). On the other hand, the systematic review conducted by Boger and colleagues covered all types of OM and was not specific for PROM. It did not help to differentiate the clinician-reported OM from PROM. On top of this, the content of the identified PROM was not analysed to understand the comprehensiveness. Comprehensiveness is important as it helps stroke survivors and healthcare professionals to understand their limitations in most of the daily activities and reduce the risk of eliminating these activities when designing a rehabilitation programme.

Moreover, Ashford et al., (2015) conducted a systematic review of PROM that can be used to assess functional performance in the lower limbs. The authors found eight relevant PROM, however, none of them evaluated the passive function, and only one of them (RMI) had optimal psychometric criteria compared to the rest. On the other hand, the authors documented that RMI had a ceiling effect for high functioning patients (Ashford et al., 2015). This systematic review only evaluated the PROM that were available to assess limitations in the lower limb and did not consider the PROM that assess other limitations. However, ADL limitations are not limited to lower limb activities, therefore, this could eliminate the PROM that are used to assess ADL limitations which cover the upper limb or both of the upper and lower limb.

Finally, Reeves and colleagues (2018) documented a systematic review and aimed to identify the PROM that are currently being used for acute stroke survivors. The authors identified nine PROM in total (five generics and four stroke-specific PROM) (Reeves et al., 2018). The authors concluded that further research is required to evaluate the psychometric properties of these reported PROM (Reeves et al., 2018). Also, not all of the evaluated PROM were specifically developed for stroke survivors. It is important to include patient-generated items to assess the limitations of the target population. Therefore, it is difficult to recommend PROM that are not specifically developed for stroke survivors. A review that evaluated the PROM which are specifically developed for stroke survivors to assess ADL limitations can help healthcare professionals to understand which PROM can be better to choose for stroke survivors, can help stroke survivors to complete correct PROM as part of their self-management and get better results.

There are systematic reviews available that analyse OM or only PROM for stroke survivors. However, there is no review conducted to only evaluate the PROM that are specifically developed or commonly used to assess ADL limitations only for stroke survivors. There is a lack of study to show the psychometric properties and analysis of the content of PROM, which aims to assess the limitations of ADL for stroke survivors. Therefore, conducting a systematic review to find available PROM to assess ADL specifically for stroke survivors and evaluate their psychometric properties and content can be a useful guide to understand if there is a comprehensive, valid and reliable PROM to use for stroke survivors. This can help to see if there is any PROM that can assess the ADL limitations in detail and show limitations from patients' perspectives by actively involving them in their care pathway and can help to guide self-management.

3.3 Aims and Objectives

The systematic review aimed to explore the current literature on available PROM, which assess limitations of ADL for stroke survivors and to critically appraise the evidence for psychometric properties of PROM identified. An additional aim of the study was to evaluate the content of the reported PROM to assess their comprehensiveness and understand if they can help to understand the difference between the capacity and performance of stroke survivors on daily activities.

The objectives of the review were to:

1. Identify PROM that are specifically developed for stroke survivors or commonly used for stroke survivors to assess their ADL limitations,

2. Examine their psychometric properties by evaluating the methods used to develop and test the PROM for the target population,

3. Compare the content of the PROM with ICF Core Set for Stroke (Geyh et al., 2004) to understand if they comprehensively cover all relevant ADL functions and differentiate between capacity and performance.

3.4 Methodology

Before developing a tool, it is important to identify and critically appraise the existing tools that are developed for the same purpose (Streiner & Norman, 2008; Fitzpatrick et al., 1998). As documented by Fitzpatrick and colleagues (1998), reviewing and analysing existing measurement tools is an art as a science. Evaluating the context of measurement is important to understand if a tool is fit to the purpose (Mead & Bower, 2000), so, there was a need to use a method to review the currently available PROM. High-quality systematic reviews help to guide clinical care and they are known as the most reliable evidence (Clarke, 2011). Systematic reviews help to find relevant studies, synthesise information and form a summary of the results by critically analysing the included evidence (Hemingway & Brereton, 2009).

Despite the existing databases, it is difficult to identify all of the existing PROM which aim to assess ADL limitations for stroke survivors, therefore, it was important to be systematic, and reproductive to find relevant publications comprehensively (Jenuwine & Floyd, 2004). Systematic reviews involve a comprehensive plan and search strategies that aim to reduce the bias of recognising, explaining and synthesizing all the relevant articles that are suitable to the topic of the search (Uman, 2011). Conducting a systematic review is difficult and there is a need to understand and follow essential steps (Tawfik et al., 2019):

- Develop a research question and objectives
- Form inclusion and exclusion criteria
- Develop a search strategy to use in every database
- Decide which databases to use for the search
- Apply search strategy to each database, import all results to a library and transfer them to an excel sheet after removing the duplications
- Screen title and abstract to find relevant articles
- Screen full text with the relevant title and abstract
- Conduct a manual search
- Extract data and do a quality test
- Analyse results
- Write your report

Initially, determining a well-defined and precise research question can help to answer it systematically and achieve comprehensive search results (Stern, Jordan, & McArthur, 2014; Riva, Malik, Burnie, Endicott, & Busse, 2012; Thabane, Thomas, Ye, & Paul, 2009). It is important to formulate a feasible, interesting, novel, ethical and relevant question (Tawfik et al., 2019). After formulating the question that needs to be answered, the eligibility criteria need to be developed (Pollock & Berge, 2018), which can help to identify relevant papers that have the potential to answer the question and eliminate the papers that are not linked with the review question. It is not necessary, however, eligibility criteria are normally based on the patient, intervention, comparison, outcome (PICO) approach, study design and date (Tawfik et al., 2019; Bramer, 2015; Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014; Schardt, Adams, Owens, Keitz, & Fontelo, 2007) and it is important to consider both the exclusion and inclusion criteria in detail as they will be used when screening the papers. Therefore, eligibility criteria need to be clear and sufficient.

Understanding and creating key concepts and putting them in a group helps to create elements in a search strategy (Jenuwine & Floyd, 2004) and identifying correct elements help to find the right and relevant research papers to answer the question of the review (Jenuwine & Floyd, 2004). Use of Medical Subject Headings (MeSH) search terms and planning the search strategy carefully help to improve the quality of the search and reduce the risk of errors. Therefore, it is important to choose all necessary terms, including both descriptors and synonyms and combine search techniques (Salvador-Oliván, Marco-Cuenca, & Arquero-Avilés, 2019). However, including too many elements in a search strategy can result in missing relevant references so, it is important to keep the number of elements as low as possible to achieve a high and relevant number of papers (Jenuwine & Floyd, 2004).

The AMSTAR guidelines documented that a systematic review needs to include a search of papers in two databases at least (Shea et al., 2017), but an increasing number of searched databases improves the chance of getting more accurate and comprehensive results (Tawfik et al., 2019). Deciding which database to search depends on the review question. The University of Salford (UoS) has access to more than 350 databases. The Medical Literature Analysis and Retrieval System Online (MEDLINE) is the largest and most widely used database in the world (Jenuwine & Floyd, 2004), but using only MEDLINE might increase the chance of missing relevant papers. Therefore, other systematic reviews which did a similar search were considered to understand which databases were used more often for the stroke field. It was recognised that MEDLINE, Science Direct, Psychological Information Database (PsycINFO), PubMed, ProQuest, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science electronic databases were used very often to find papers for stroke survivors.

Search needs to be conducted at each database and all found papers need to be collected into a library, i.e., Endnote, to delete the duplications and then needs to be reported to an excel sheet. References of the found papers, including their abstract, author name, date of publication, journal, DOI, and URL link need to be recorded on an excel sheet for further analyses (Tawfik et al., 2019). Selecting relevant papers from the found papers at the database depends on the eligibility criteria and non-relevant papers need to be removed with a justification. It is advised by Cochrane guidance that there must be two reviewers who need to work independently to screen the title and abstracts of the found papers by considering the eligibility criteria to document the relevant articles. All excluded records should be given exclusion reasons. If there is a different opinion between two reviewers, a third reviewer can be involved in the decision. The papers with relevant title and abstract need to be reviewed in full for further consideration by each reviewer individually and if there is any disagreement the final decision has to be made by discussing with the third reviewer. It is documented by Moher, Liberati, Tetzlaff and Altman, (2009), that any systematic review needs to follow the Preferred Reporting Items for Systematic Review and Meta-analysis statement (PRISMA checklist, 2009), which is widely accepted. Therefore, use of the PRISMA flow diagram can be used to show how the studies are screened and selected.

Searching only databases for the relevant papers might not be enough as the risk of bias needs to be reduced by doing a hand-search to find if there is any relevant paper that is dropped–off from the initial search (Vassar, Atakpo, & Kash, 2016). Therefore, reference lists of the included studies need to be considered, authors and experts can be contacted and further search can be performed on Google Scholar and PubMed (Tawfik et al., 2019). After deciding the eligible papers, data needs to be extracted by two reviewers independently for analyses. As the systematic review was about the PROM, Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) guideline needs to be considered when analysing the data for psychometric properties of each PROM. The COSMIN was developed to help both clinicians and researchers to improve the selection of the most appropriate measurement tool for a given situation (Mokkink et al., 2018). The COSMIN is an extended protocol to a comprehensive methodological guideline for systematic reviews of PROM (Prinsen et al., 2018) and it includes ten steps, which describes the methods of conducting a systematic review for existing PROM (Prinsen et al., 2018). It has developed in concordance with existing systematic review guidelines, such as PRISMA Statement (2009), or Cochrane handbook for systematic review (Higgins and Green, 2011). It is important to follow each step carefully as it helps to evaluate if the PROM are reliable and valid to use. The ten steps of the COSMIN guidelines are subdivided into three parts (A, B and C).

Part A (perform the literature review) consists of the first four steps, which includes deciding the aim of the study, formulating the eligibility criteria, followed by the search and selecting relevant papers for the systematic review (Prinsen et al., 2018). These steps are standard procedures that need to be covered by all the systematic reviews as mentioned in the previous guidelines (Deeks, Wisniewski, & Davenport, 2013; Higgins & Green, 2011).

Part B (evaluating the measurement properties) covers steps five to seven. These three steps aim to assess the quality of the PROM by evaluating the content validity, internal structure and the rest of the psychometric properties, such as reliability, criterion validity or responsiveness (Prinsen et al., 2018). The final part, C, (Select a PROM) includes the last three steps, eight to ten. These steps include describing the interpretability and feasibility, forming recommendations and finishing the report. It is important to understand each step carefully. This is because the conducted results will show if there is any comprehensive PROM that can be used to self-assess the ADL limitations.

It is advised by the COSMIN guidelines that the methodological quality of the eligible studies and the quality of the PROM need to be evaluated separately (Mokkink et al., 2018). There are guidelines that were developed to follow when aiming to develop and test a PROM (Mokkink et al., 2018; Acquadro, Joyce, Patrick, Ware, & Wu, 2004; Beaton, Bombardier, Guillemin, & Ferraz, 2000). These guidelines help to follow the required and accepted steps when developing and testing the PROM (i.e., required sample size for psychometric testing, suggested timeline for the test re-test assessment, or who needs to be involved in the development process to develop a PROM with good content validity). A research paper can show that a PROM is valid or reliable, but it needs to be checked if the used methodology was done according to the guidelines. This is because if the methodology was not sufficient, the results can be questioned and may require further evaluation. As the quality of the study shows the degree of truthfulness of the results, it is important to assess the quality of the individual studies (Mokkink et al., 2018). COSMIN

Risk of Bias checklist is the tool that is commonly used to assess the methodological quality of single studies on measurement properties for the systematic review of PROM (Mokkink et al., 2018). The Risk of Bias checklist is used to help in completing a separate methodological quality assessment for each psychometric property. So, it is crucial to understand how to apply this checklist as it will provide the correct guide to how PROM are assessed or developed and if the results of the studied ones are truthful.

Quality criteria is a tool that helps to do a meaningful comparison between the measurement qualities (Terwee et al., 2007). The quality criteria are about the method, design and outcomes of the studies on the development or testing of the PROM (Terwee et al., 2007). It covers different measurement tools such as content validity, internal consistency, criterion validity, construct validity, reproducibility, longitudinal validity, responsiveness, floor and ceiling effects, and interpretability (Terwee et al., 2007). As there is no empirical evidence about the criteria for good psychometric properties, the COSMIN quality criteria are opinion based and developed depending on the rule of thumb (Terwee et al., 2007). Each psychometric property is evaluated separately. This is because there is no overall quality score. Guideline authors do not believe that each psychometric property is equally important. They have documented that content validity is the most important psychometric property and people should not use any PROM that has poor content validity (Terwee et al., 2007). On the COSMIN quality criteria, each psychometric property can be rated either (+) sufficient, (-) insufficient, or (?) indeterminate (Mokkink et al., 2018). If all of the results per study are sufficient, the overall rating can be documented as sufficient, however, if there is a difference between the studies, for a measurement property to be rated as sufficient, 75% of the results should meet the criteria (Mokkink et al., 2018). After summarising all the evidence for each PROM and rating the result by using the quality criteria for good measurement properties, the final step is to grade the quality of the evidence by using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach (Mokkink et al., 2018). As these methodologies are used more often when conducting a systematic review to evaluate the psychometric properties of the PROM and report them, these methodologies were agreed to be followed when conducting this systematic review and the methods were explained in the next section.

3.5 Methods

3.5.1 Eligibility Criteria

To answer the aims of the systematic review, the inclusion/exclusion criterion was set using PICO in discussion with the supervisory team. The eligibility criterion was then used to identify eligible PROM and related papers outlining their development and testing.

Inclusion criteria:

- Self-administered PROM, specifically developed or commonly used for stroke survivors.
- Published in English.
- That assess limitations in ADL.
- Had published studies to outline the development and testing, or included details on the psychometric properties in stroke survivors as participants.

Exclusion criteria:

- PROM that requires a structured interview for completion (e.g., clinician-reported outcome measures).
- PROM that was used as an objective assessment (e.g., needs to be completed by a clinician).
- PROM in other languages than English.
- PROM that was developed or tested with aggregated participant groups and data on stroke survivors is not reported separately.
- Case Reports; Editorials; Opinion Papers; Grey Literature that does not provide empirical support for the development and psychometric testing of PROM.

3.5.2 Search Strategy

The search strategy was designed to be comprehensive and detailed to identify all relevant studies that helped to answer the aim of the systematic review. After searching the literature about the PROM, stroke survivors and ADL limitations, the most commonly used keywords were identified by the PhD candidate. To include all the studies that captured PROM which assess ADL limitations for stroke survivors, keywords to represent the same meaning were used, such as questionnaires, PROM or OM. A similar approach has been taken for stroke survivors and ADL. Where necessary, keywords were written in both plural and singular way to cover all the results that included a varied form of words. To give an example, both daily activities and daily activity were used in the search terms. This helped to capture most of the articles that are relevant to answer the aim of the systematic review, but not too many words were included to eliminate the risk of missing relevant and important papers.

To capture all studies published to date, different databases were covered. A systematic search was performed to find articles published between January 1980 to May 2019 in MEDLINE, Science Direct, PsycINFO, PubMed, ProQuest, CINAHL and Web of Science electronic databases. The search was updated in January 2021 to assess if there is an additional paper that was relevant to the question and needs to be added to the review since the last search. Additionally, the reference lists of identified publications containing relevant PROM were then searched to identify further literature on the development and evaluation of these PROM. Keywords with MeSH and text words were used in an order to retrieve the target literature and to find the eligible papers (Table 2). All found papers were downloaded to EndNote and duplications were deleted. The rest of the articles were reported to an excel sheet, including each paper's authors, publication date, title, journal, DOI, URL link and abstract to consider the eligibility by using the inclusion and exclusion criteria.

Table 2: Search Strategy

Stage (1)	
1	(“stroke” OR “CVA” OR “cerebral vascular disease” OR “stroke patients” OR “stroke survivor*)
2	(“activity of daily living” OR “activities of daily living” OR “daily living activity” OR “daily living activities” OR “self-management” OR “self management” OR “personal care” OR “ADL”)
3	(“patient reported outcome measure” OR “outcome measure” OR “questionnaire” OR “questionnaires” OR “self-report” OR “treatment outcome” OR “outcome assessment” OR “patient-reported outcome measure”)
Stage (2)	
4	Combine 1 AND 2
5	Combine 3 AND 4

3.5.3 Selection Criteria

First of all, the titles of the papers were reviewed to identify potentially relevant studies by two reviewers individually (1st reviewer Nazemin Gilanlıoğulları (NG), 2nd reviewer Pornprom Chayasit (PC); a fellow PhD student in a similar field of discipline, who had experience in conducting systematic reviews). The abstract was then considered to see if the title was found to be relevant. Then, the selection criteria were applied to the abstracts of the articles with relevant titles, or full papers when the information provided on the abstract was not sufficient to decide as to the inclusion of the paper in the review. All of the paper selection steps were conducted by two reviewers (NG and PC) individually and discussed later for the final decision.

The full-text paper was read if the abstract indicated relevance, and a final decision was made about the inclusion of the study. The author (NG) did the initial selection of the full papers and was then evaluated by a second reviewer (PC) independently. If there was a disagreement between the two reviewers, they discussed this in a consensus meeting. To solve any further disagreement between the inclusions of any paper, a third reviewer (Lead supervisor; Dr Yeliz Prior) was involved. A further meeting was held by the reviewers to discuss the inclusion of the final studies and the conclusion of the selection process, which helped to be specific in the paper selection by involving the ideas of different researchers.

3.5.4 Quality Assessment and Data Extraction

COSMIN Risk of Bias checklist was used to assess the methodological quality of single studies on measurement properties. After the quality assessment, data were extracted from each included paper about the psychometric characteristics of the PROM. The Risk of Bias checklist is used to help in completing a separate methodological quality assessment for each psychometric property. The COSMIN quality criteria were used by two reviewers (NG and PC), to evaluate the results for each psychometric property. After summarising all the evidence for each PROM and rating the result by using the quality criteria for good measurement properties, the GRADE approach was used to grade the quality of the evidence. The quality of the evidence is graded as high, moderate, low, and very low by using the definition which is explained in the COSMIN Guideline. The GRADE approach considers five different factors to assess the evidence. These factors are risk of bias, inconsistency, indirectness, imprecision and publication bias. The GRADE assessment was done by two reviewers (NG and PC) separately and results are discussed in a meeting. This helped to reduce the risk of bias.

In this systematic review, only eight psychometric properties of the PROM were covered. Each item was rated as sufficient (+), inconsistent (±), insufficient (-), and indeterminate (?) if the item is not evaluated in the included papers. Cross-cultural validity was not evaluated (X) because this study did not aim to assess the psychometric properties of the PROM in other languages or cultures.

3.5.5 Strength of the Evidence

As mentioned previously methodological quality of the eligible studies and the quality of the PROM have been evaluated separately. Therefore, additional quality criteria were agreed upon by the two reviewers (NG and PC) (Table 3), to score the overall quality of each paper. This helped to report a summary of results and show if the results of the papers are trustworthy when they are compared with the strength of the evidence.

Table 3: Overall quality criteria of the studies set by the authors

Criteria	Overall summary of the Quality
In the study, if 75% of the conducted methodological qualities scored adequate and above	Good
In the study, if 50% of the conducted methodological qualities scored adequate and above	Moderate
In the study, if 75% of the conducted methodological qualities scored doubtful or inadequate	Low

3.5.6 Comprehensiveness of Patient-Reported Outcome Measures

A list of ADL items was created after a detailed searching of the literature. This helped to identify the ADL that were most commonly mentioned by stroke survivors and healthcare professionals. The list of daily activities helped to evaluate how comprehensive was each PROM. To eliminate the risk of bias, the items of each included PROM were also linked to the activities and participation categories of the ICF Core Set for Stroke to further evaluate the comprehensiveness of each PROM and understand if they were detailed enough to cover the important activities and participation items.

3.6 Results

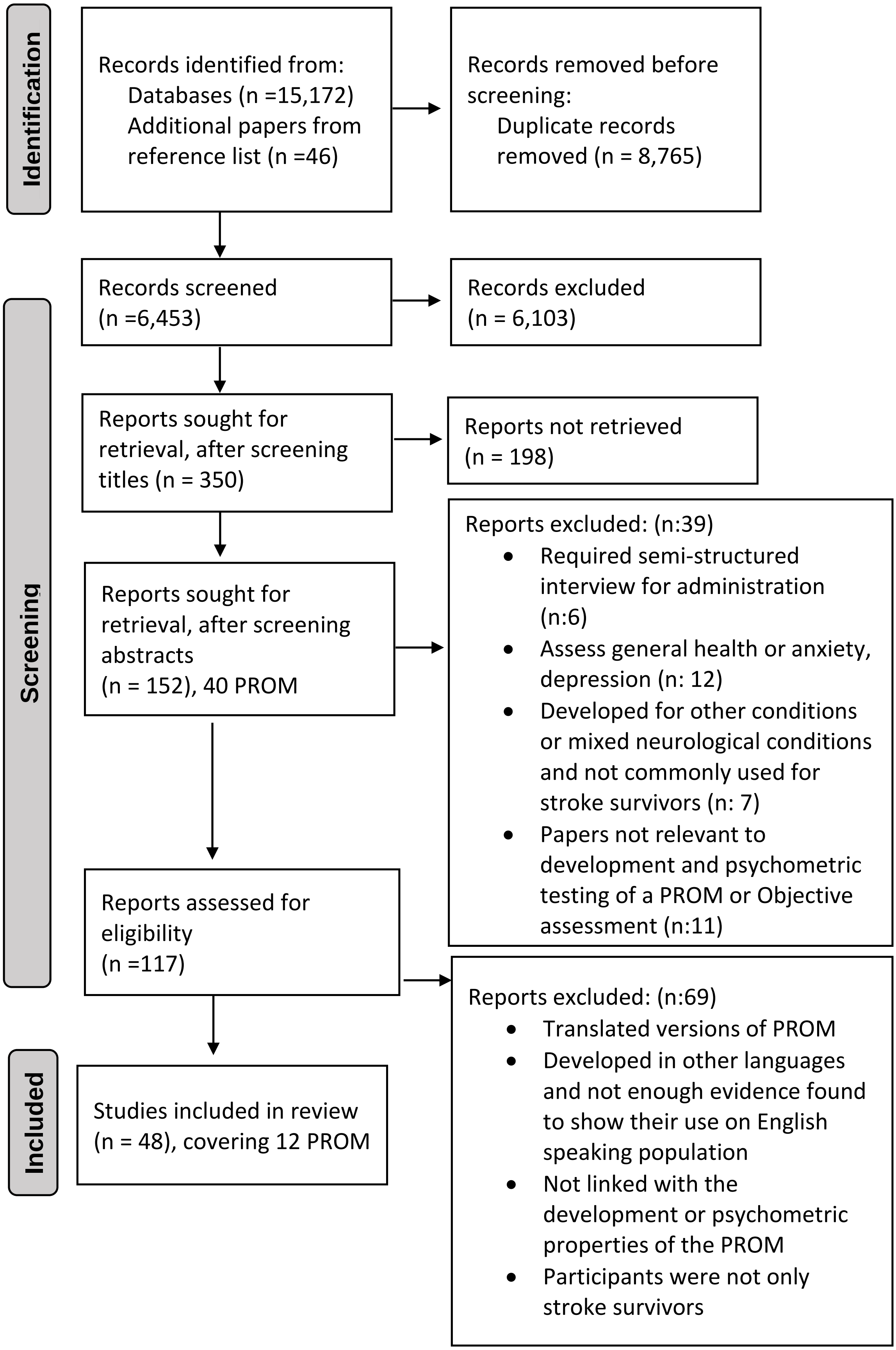
3.6.1 Search Strategy

Initial research identified 15,172 papers in total, which was reduced to 6,453 records after removing the duplications (see Table 4 and Figure 1 for details of the search). After screening the titles, 350 papers were found relevant to the inclusion criteria. The number was reduced to 117 articles to read in full by two reviewers after screening the abstracts. Following the inclusion and exclusion criteria, 48 studies were found eligible for the topic. Sixty-nine articles were excluded either because they were about the development of the OM that requires clinician completion, included a translated version of the PROM or the population involved in the development process was not limited to stroke survivors. In the end, 12 different PROM were identified from these 48 papers, which were specifically developed or commonly used for stroke survivors to assess limitations in ADL. The results of the included papers are summarised in Figure 1, according to the PRISMA guidelines (PRISMA, 2016).

Table 4*:* Number of documents found in each searched database

Date of Search	Database	Years Searched	Number of documents obtained
02/05/19	Medline	All years	299
02/05/19	Science Direct	All years	5,728
03/05/19	PsycINFO	All years	112
04/05/19	PubMed	All years	3,440
05/05/19	ProQuest	All years	398
05/05/19	CINAHL	All years	987
05/05/19	Web of Science	All years	4,208

Figure 1: Flow chart depending on the PRISMA guidelines (Page et al., 2020).



3.6.2. Identified Patient-Reported Outcome Measures

Initially, 40 PROM were identified after reading the 117 abstracts (please, refer to Table 5 for detail). Ten of the PROM were removed because they assess general health, anxiety or depression, such as the Patient Health Questionnaire (PHQ-9 and PHQ-2). As mentioned previously, questionnaires that require an interview for completion are clinical-reported OM and they need to be separated from the PROM. Due to this reason, another six PROM were removed as they required a semi-structured interview for administration, such as the Motor Activity Log (MAL-12, 26, 28).

Each culture is different and translated PROM need to be linguistically and culturally adapted (Please, refer to Chapter Four for detail). Different cultures may have different daily activity interests and not all listed items can be relevant for a culture. Therefore, more attention needs to be spent on linguistic and cultural adaptation before it can be used in a new population (Goggin et al., 2010). After considering the impact of linguistic and cultural adaptation on the use of PROM, three more PROM were excluded as they were developed in different languages, and no evidence was found to show that they were tested on an English-speaking population, such as SATİS-STROKE or the Stroke Adapted Sickness Impact Scale (SA-SIP-30).

Finally, five PROM were excluded either because they were developed for other conditions and there is no evidence to support that they are commonly being used for stroke survivors. To give an example, the Human Activity Profile (HAP) is developed for neurological conditions including stroke but not specifically or not commonly used for stroke survivors, or the Brain Injury Community Rehabilitation Outcome Scales (BICRO) and the Climbing Stair Questionnaire (CSQ). Using patient-generated items are important as it is the main way to understand the meaningful limitations for a target population.

In the end, after strictly applying the eligibility criteria, 12 PROM were included that were self-reported and commonly used for stroke survivors to assess ADL limitations (Figure 1). Table 6 summarises the information about 12 PROM, their domains/items, administrations way/time and the context of development. Table 9 summarises which ADL were covered by the included PROM and shows how comprehensive they were. Also, in Table 10 items of each PROM were further evaluated for comprehensiveness by linking them to the categories of activities and participation included in the comprehensive ICF Core Set for Stroke (Geyh et al., 2004). Interestingly, all PROM were limited in content, which can affect the understanding of the main limitations in detail and provide weak assessment results (Please, refer to section 3.6.4 for detail).

Table 5: 40 PROM identified during the systematic search and if they were or not eligible to the aim of the study

Number of PROM	PROM found after the search	Eligibility	Why
1	Medical Outcome Study Short Form Health Survey (SF-36)	No	Do not assess ADL, generic health status
2	EuroQol Quality of Life Scale (EQ5D)	No	Do not assess ADL, generic health status
3	Rivermead Mobility Scale (RMI)	Yes	Assess ADL limitations and commonly used for stroke survivors
4	Canadian Occupational Performance Measure (COPM)	No	Requires structured interview administration
5	London Handicap Scale (LHS)	Yes	Assess ADL limitations and commonly used for stroke survivors
6	Reintegration to Normal Living Index (RNLI)	Yes	Assess ADL limitations and commonly used for stroke survivors
7	Barthel Index (BI)	Yes	Assess ADL limitations and commonly used for stroke survivors
8	Patient Health Questionnaire (PHQ-9 and PHQ-2)	No	General health questionnaire
9	General Health Questionnaire (GHQ)	No	General health questionnaire
10	Geriatric Depression Scale (GDS)	No	Depression scale
11	Beck Depression Scale (BDI)	No	Depression scale
12	Hospital Anxiety and Depression Scale (HADS)	No	Anxiety and depression scale
13	Activity-specific Balance Scale (ABC)	No	Questions about confidence and not ADL limitations
14	ABILHAND	No	Requires structured interview administration
15	Lower Extremity Functional Scale (LEFS)	No	Not specific for stroke survivors
16	Southampton Stroke Self-Management Questionnaire (SSSMQ)	No	Questions about how people manage rather than ADL questions

Number of PROM	PROM found after the search	Eligibility	Why
17	Stroke Adapted Sickness Impact Scale SA-SIP-30	No	Never validated in an English-speaking population
18	Stroke Specific Quality of Life Scale (SSQLS)	Yes	Assess ADL limitations and specifically developed for stroke survivors
19	Stroke Impact Scale (SIS)	Yes	Assess ADL limitations and specifically developed for stroke survivors
20	Subjective Index of Physical and Social Outcomes (SIPSO)	Yes	Assess ADL limitations and specifically developed for stroke survivors
21	Stroke and Aphasia Quality of Life Scale-39 items (SAQOL-39)	No	Requires structured interview administration
22	Stroke Self Efficacy Scale	No	Assesses only self-efficacy and not ADL limitations
23	Hand Function Survey	No	Requires structured interview administration
24	Motor Activity Log (MAL-12,26,28)	No	Requires structured interview administration
25	Burden of Stroke Scale (BOSS)	Yes	Assess ADL limitations and specifically developed for stroke survivors
26	Nottingham Extended Activities of Daily Living Scale (NEADL)	Yes	Assess ADL limitations and commonly used for stroke survivors
27	Modified Ranking Scale (MRS)	Yes	Assess ADL limitations and commonly used for stroke survivors. However, mainly completed by clinicians through interviews.
28	Frenchay Activities Index (FAI)	Yes	Assess ADL limitations and commonly used for stroke survivors
29	Arm Activity Scale (ArmA)	Yes	Assess upper limb ADL limitations, for neurological conditions
30	Michigan Hand Outcomes Questionnaire (MHQ)	No	No paper found that uses English version on stroke survivors

Number of PROM	PROM found after the search	Eligibility	Why
31	Modified Rivermead Mobility Index	No	The modified version requires the clinician to report and maybe it is observational
32	Climbing Stair Questionnaire (CSQ)	No	Not specific for stroke survivors. Developed with patients with mixed lower limb impairment including stroke
33	Brain Injury Community Rehabilitation Outcome Scales (BICRO)	No	Not specific for stroke survivors. Developed with patients with varied neurological conditions (TBI, Stroke, ABI and MS)
34	Human Activity Profile (HAP)	No	Developed for patients with COPD
35	Sickness Impact Profile (SIP)	No	Not specific to stroke
36	SATİS-STROKE	No	Developed in the French version, no evidence to show its use on the English population
37	Patient-Reported Outcome Measurement Information System (PROMIS)	No	Not specific for stroke, assess general health
38	Neuro-QoL	No	Not specific for stroke, assess QoL
39	Extended Barthel Index	No	Requires clinician administration
40	The Medical Outcomes Study (MOS) short form (SF-36)	No	Not specific for stroke, assess health-related QoL

***Table 6**:* Included PROM, domains/items, administration way/time and content of development.

PROM	Domains	Administration way and time	Context for development
BOSS	Mobility, Self-care, Communication, Cognition, Swallowing, Social Relationships, Energy and Sleep, Negative and Positive Emotions and Summary scale 64 items	Interview or Self-administration Administrations time not reported	Stroke survivors
NEADL	Mobility, Kitchen Tasks, Domestic tasks, Leisure activities 22 items	Interview or Self-administration Administrations time not reported	Stroke survivors
RNLI	11 items to assess Daily Functioning domain and Perception of Self.	Interview or Self-administration 10 minutes to administer as a self-report	Traumatic or incapacitating illness

PROM	Domains	Administration way and time	Context for development
FAI	Meal preparation, washing up, washing clothes, light and heavy housework, local shopping, social occasions, walking outside for more than 15 minutes, hobby, driving/going on bus, travel outing, reading books, household maintenance, gardening, gainful work 15 items	Interview or Self-administration 5 minutes to administer as a self-report	Stroke survivors
SIPSO	Physical function and Social participation 10 items	Self-administration Administrations time not reported	Stroke survivors
LHS	Mobility, Physical independence, Occupation, Social integration, Orientation and Economic self-sufficiency 6 items	Interview or Self-administration 5 minutes to administer as a self-report	Chronic illnesses

PROM	Domains	Administration way and time	Context for development
SS-QOLS	Energy, Family roles, Language, Mobility, Mood, Personality, Self-care, Social roles, Thinking, Upper extremity function, Vision, Work/Productivity 49 items	Interview or Self-administration, but psychometric properties are not tested for self-administration. 10-15 minutes to administer	Stroke survivors
RMI	15 items to assess lower limb mobility	14 self-reported items and 1 direct observation 2-3 minutes to administer as a self-report	Acquired brain injury (Stroke survivors, head injury, neurosurgery)
SIS version 3.0	Strength, Memory/Thinking, Emotions, Communication, ADL/IADL, Mobility, Hand function, Social participation and Stroke recovery 8 domains (59 questions) and 1 domain for stroke recovery	Interview or Self-administration 15-20 minutes to administer	Stroke survivors

PROM	Domains	Administration way and time	Context for development
SIS version 2.0	Strength, Memory/Thinking, Emotions, Communication, ADL/IADL, Mobility, Hand function, Social participation and Stroke recovery 8 domains (64 questions) and 1 domain for stroke recovery	Interview or Self- administration 15-20 minutes to administer as a self-report	Stroke survivors
BI	Feeding, Transferring, Personal hygiene, Toilet transfer, Bathing, Mobility, Stairs, Dressing, Bowels and Bladder. 10 items	Initially developed as an objective assessment but, now can be used as interview or self-administration 2-5 minutes to administer as a self-report	Neuromuscular or musculoskeletal disorders
MRS	6 items to assess the level of independence. Includes options no symptom to severe disability.	Interview or Clinician reported Self-administered 5-15 minutes to administer	Stroke survivors
ArmA	Section A: caring for the affected arm (8 items) Section B: completing activities with the affected arm (13 items)	Self-administered 10 minutes to administer as a self-report	Hemiparetic arm (Stroke survivors involved in the initial development)

3.6.3 Psychometric Properties of the Patient-Reported Outcome Measures

The detailed evaluation of the psychometric properties for the selected PROM was completed by using the COSMIN guideline and summarised in Table 7. All PROM had reasonable information reported about their psychometric properties. However, due to limited information available in the study reporting, not all PROM addressed each psychometric category. The majority of the PROM were scored inconsistently or indeterminately. The RMI, BOSS and the SIPSO were the only three PROM that scored well on most of the categories compared to the others. A majority of the studies evaluated the test-retest reliability, hypothesis testing, criterion validity and responsiveness of the PROM. However, only a few investigated the measurement error or construct validity [dimensionality], also known as structural validity, of the PROM, which had an impact on the internal consistency scoring.

Internal consistency was one of the categories that had an indeterminate score for all 12 PROM even though data were presented in the available papers. This is because, depending on the quality criteria in the COSMIN guideline, PROM need to have enough information about the dimensionality of the construct (structural validity), to be scored for internal consistency (Mokkink et al., 2010). On the other hand, there was not enough data available for the construct validity [dimensionality] of many PROM in the included papers.

In contrast, six PROM (i.e., BOSS, NEADL, FAI, SIPSO, SS-QOLS, ArmA), had good enough evidence to evaluate their content validity. The included PROM were either specifically developed for stroke survivors or commonly used in stroke survivors' assessments (see Table 5 and 6 for details). Four PROM (i.e., RMI, LHS, RNLI, BI), were not developed particularly for stroke survivors, so their content validities have not been evaluated. This showed that items of the PROM may not be representative of stroke survivors and can result in a lack of comprehensiveness.

Interestingly, ArmA scored well for the content validity, but not for the rest of the properties. The ArmA was originally developed involving stroke survivors for hemiparetic upper limbs (Ashford et al., 2013). Other psychometric properties, for example; convergent and divergent validity, unidimensionality, and reliability were assessed on people with hemiparetic upper limbs including stroke survivors, acquired brain injury, multiple sclerosis and other neurological conditions (Ashford, Turner-Stokes, & Siegert, 2013b). Nevertheless, psychometric properties were not specifically tested solely on stroke survivors. Therefore, the remaining articles that evaluated the psychometric properties were not involved in this study.

Table 7: Psychometric evaluation of the included PROM.

PROM	IC	QE	R	QE	ME	QE	CoV	SV	QE	HT	QE	CCV	CV	QE	Re	QE
BOSS	?		+	L	?		+	?		+	M	X	±	H	+	M
NEADL	?		±	M	?		±	?		+	M	X	+	H	?	
RNLI	?		-	L	?		X	?		+	M	X	+	H	+	H
FAI	?		±	L	?		±	?		+	M	X	+	M	+	H
SIPSO	?	H	+	M	?		+	?	H	+	M	X	±	H	+	M
LHS	?		+	VL	?		X	?		+	H	X	+	H	?	
SS-QOLS	?		?		?		±	?		±	L-M	X	±	H	+ for subacute/ - for chronic	L-M
RMI	?		+	VL-M	?		X	?		+	M	X	+	M	+ for acute, – for 90-180 days	M
SIS Version 3.0	?		±	M	?		?	-		+	M	X	±	M	+	M

PROM	IC	QE	R	QE	ME	QE	CoV	SV	QE	HT	QE	CCV	CV	QE	Re	QE
SIS Version 2.0	?		+	VL	?		?	?		+	M	X	±	M	±	L
BI	?		±	M	?		X	?		+	H	X	+	H	+ acute - chronic	H
MRS	?		+ for chronic and - for acute	M-H	?		?	?		+	H	X	+	H	?	
ArmA	?		?		?		+	?		?		X	?		?	

*Quality of the evidence (+) sufficient; (±) inconsistence; (–) insufficient and (?) indeterminate (no data available in the included papers), X: not evaluated in this study. IC: Internal Consistency, QE: Quality of the Evidence, R: Reliability, ME: Measurement error, CoV: Content Validity, SV: Structural validity, HT: Hypothesis testing, CCV: Cross-Cultural validity, CV: Criterion Validity, Re: Responsiveness, L: Low, M: Moderate, VL: Very Low, H: High

3.6.4 Content of the Patient-Reported Outcome Measures

Content validity is the comprehensiveness, relevance, and comprehensibility of the PROM for the construct, target population and the context that it aims to be used (Terwee et al., 2018a). All included items in a questionnaire should be relevant to the purpose of the topic that a PROM aims to measure and to the target population (Patrick et al., 2011; Streiner & Norman, 2008). It is important to involve patients in the development process of the PROM (Meadows, 2011; Fitzpatrick et al., 1998). As the PROM aim to assess situations faced by target populations, the involvement of them in the PROM development can help to improve comprehensiveness and relevance (Trujols, 2013; Staniszewska et al., 2011). Lack of patient involvement in a PROM development can have a negative impact, such as poor sensitivity, validity or response rate (Fossey & Harvey, 2001). Although the importance of patient involvement in PROM development is emphasised in research (Wiering, de Boer, & Delnoji, 2017), the systematic review of PROM for stroke survivors to assess ADL limitations showed that not many of the PROM were developed by considering patients' ideas (Table 8).

Seven of the PROM were specifically developed for stroke survivors. However, the target population was only involved in the development of six PROM (Table 8). The involvement of experts in PROM development is another essential criterion for PROM development (Mokkink et al., 2010). Experts are the people that spend time with the target population, and they have a good idea of patients' limitations and functioning level. It is advised by development guidelines to involve expert panels during the development of a PROM to improve comprehensiveness. The systematic review showed that in only four of the PROM, the ideas of experts were considered. There were only four PROM that included both the target population and experts in development, which were BOSS, SIS, RNLI and ArmA.

On the other hand, this systematic review also aimed to assess the comprehensiveness of the PROM, which has an impact on their content validity. As mentioned previously, a list of the ADL functions was created by doing a detailed search of the literature (Table 9). Unfortunately, none of the evaluated PROM covered all aspects of ADL limitations. To reduce the risk of bias, the items of the 12 PROM were linked with the items of the activities and participation categories of the ICF Core Set for Stroke (Table 10). When the ICF categories were linked with the items of each PROM, it was documented that only the SS-QOLS and the BOSS were the most comprehensive PROM compared to other PROM, but both SS-QOLS (21 categories were covered out of 51) and BOSS (25 categories were covered out of 51) were not comprehensive enough to cover all of the ICF Core Set for Stroke activities and participation categories. Linking items of the PROM to both ICF Core Set and ADL items reported from the literature search showed that the most obvious limitation of all of the 12 PROM was that they were not broad enough to incorporate all the basic and instrumental ADL. They can show if a patient has difficulty with activity but, are not specific enough to determine which part of the action a patient finds challenging.

Importantly, as defined by the ICF (WHO, 2001) disability is not only limited by the capacity of a person but multiply determined by factors influencing performance (e.g., help from others, using aids and adaptations, environmental barriers and facilitators). Therefore, it is important to differentiate the performance from capacity by using a comprehensive PROM. However, this systematic review showed that none of the existing PROM used with stroke survivors demonstrates the influence of personal, contextual and environmental modifications on a person’s capacity. This is an essential part of a PROM, as the environmental factors can result in progression or pose a barrier to patients’ lives (Marcheschi, Von Koch, Pessah-Rasmussen & Elf, 2017). The RMI (Collen et al., 1991) is the only PROM that includes items to assess the mobility with/without using aids and on even/uneven surfaces. These questions help to understand if the environmental factors have an impact on people’s mobility function because people can be limited on mobility without equipment but can walk independently by using an aid. Also, mobility on an uneven or even surface is different and can affect people functioning which is linked with capacity and performance. However, RMI does not provide enough information about the positive or negative impacts of the environmental modifications on stroke survivors. In addition, RMI has an item that needs an observational evaluation from a healthcare professional, which affects to get a total score when completed by stroke survivors independently.

Table 8: Involvement procedure in the PROM development

PROM	Patients involved in the development	Experts involved in the development
SIPSO	✓	X
LHS	X	X
SSQOL	?	X
RMI	?	?
BOSS	✓	✓
NEADL	X	X
RNLI	✓	✓
FAI	✓	X
MRS	?	?
BI	?	?
SIS	✓	✓
ArmA	✓	✓

Table 9: Number of ADL items covered by each PROM.

<table>
<tr><th>ADL Domains</th><th>RNLI</th><th>RMI</th><th>LHS</th><th>BI</th><th>FAI</th><th>SIPSO</th><th>NEADL</th><th>SIS</th><th>BOSS</th><th>SS-QOLS</th><th>MRS</th><th>ArmA</th></tr>
<tr><td>Eating/Drinking</td><td rowspan="5">✓(1)</td><td></td><td></td><td>✓(1)</td><td></td><td></td><td>✓(1)</td><td>✓(1)</td><td></td><td></td><td></td><td>✓(4)</td></tr>
<tr><td>Bathroom/personal care</td><td>✓(1)</td><td></td><td>✓(1)</td><td></td><td></td><td></td><td>✓(2)</td><td>✓(1)</td><td>✓(1)</td><td>✓(2)</td><td>✓(2)</td></tr>
<tr><td>Getting dressed/undressed</td><td></td><td></td><td>✓(1)</td><td></td><td>✓(1)</td><td></td><td>✓(1)</td><td>✓(1)</td><td>✓(1)</td><td></td><td>✓(2)</td></tr>
<tr><td>Bathing/showering</td><td></td><td></td><td>✓(2)</td><td></td><td></td><td></td><td>✓(1)</td><td>✓(1)</td><td>✓(1)</td><td></td><td></td></tr>
<tr><td>Cooking</td><td></td><td></td><td></td><td>✓(2)</td><td></td><td>✓(4)</td><td></td><td>✓(1)</td><td>✓(2)</td><td></td><td></td></tr>
<tr><td>Cleaning the house</td><td></td><td></td><td></td><td></td><td></td><td></td><td>✓(1)</td><td>✓(1)</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Laundry/ Clothes care</td><td></td><td></td><td></td><td></td><td>✓(1)</td><td></td><td>✓(2)</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Moving and transfers</td><td></td><td>✓(9)</td><td>✓(2)</td><td>✓(2)</td><td></td><td></td><td>✓(1)</td><td rowspan="3">✓(8)</td><td>✓(5)</td><td>✓(6)</td><td>✓(2)</td><td>✓(1)</td></tr>
<tr><td>Moving around outdoors/shopping</td><td>✓(2)</td><td>✓(2)</td><td></td><td></td><td>✓(4)</td><td>✓(2)</td><td>✓(7)</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Moving around indoors</td><td>✓(1)</td><td>✓(2)</td><td></td><td>✓(1)</td><td></td><td>✓(1)</td><td></td><td></td><td></td><td></td><td>✓(1)</td></tr>
<tr><td>Communication</td><td></td><td></td><td></td><td></td><td></td><td>✓(1)</td><td>✓(2)</td><td>✓(7)</td><td>✓(7)</td><td>✓(5)</td><td></td><td>✓(2)</td></tr>
<tr><td>Gardening</td><td></td><td></td><td></td><td></td><td>✓(1)</td><td></td><td>✓(1)</td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

ADL Domains	RNLI	RMI	LHS	BI	FAI	SIPSO	NEADL	SIS	BOSS	SS-QOLS	MRS	ArmA
Household maintenance					✓(3)			✓(1)	✓(1)			
Caring												
Hobbies/Leisure/ Social Activities/ Occupation	✓ (4)		✓ (3)		✓(4)	✓(2)	✓(3)	✓(8)	✓(5)	✓(11)		
Bladder/bowel				✓(2)				✓(2)			✓(1)	
Orientation /Cognition			✓ (1)					✓(7)	✓(5)	✓(3)		
Environmental Modifications		✓(1)										
Swallowing									✓(3)			
Pain												
Mood/Emotions								✓(9)	✓(15)	✓(5)		
Stiffness												
Restriction at limbs								✓(9)	✓(8)	✓(5)		✓(9)
Energy									✓(2)	✓(3)		
Sleep problems									✓(2)			

ADL Domains	**RNLI**	**RMI**	**LHS**	**BI**	**FAI**	**SIPSO**	**NEADL**	**SIS**	**BOSS**	**SS-QOLS**	**MRS**	**ArmA**
Satisfaction with life	✓ (2)					✓(2)			✓(7)			
Personality										✓(3)		
Vision										✓(3)		
Achievements with Environmental Modifications												

Table 10: Items of each PROM linked with the activities and participation categories of the ICF Core Set for Stroke

ICF Code and Category titles for activities and participation	RNLI	RMI	LHS	BI	FAI	SIPSO	NEADL	SIS	BOSS	SS-QOLS	MRS	ArmA
d115 Listening												
d155 Acquiring skills					X				X			
d160 Focusing attention									X			
d166 Reading					X		X		X			
d170 Writing							X		X	X		X
d172 Calculating												
d175 Solving problems									X			
d210 Undertaking a single task												
d220 Undertaking multiple tasks												
d230 Carrying out daily routine					X				X	X	X	
d240 Handling stress and other psychological demands						X		X	X	X		
d310 Communicating with – receiving – spoken messages								X	X	X		
d315 Communicating with – receiving – non-verbal messages												
d325 Communicating with – receiving – written messages												
d330 Speaking								X	X	X		
d335 Producing non-verbal messages												
d345 Writing messages												
d350 Conversation								X	X			

ICF Code and Category titles for activities and participation	RNLI	RMI	LHS	BI	FAI	SIPSO	NEADL	SIS	BOSS	SS-QOLS	MRS	ArmA
d360 Using communication devices and techniques							X	X		X		X
d410 Changing basic body position		X						X	X			X
d415 Maintaining a body position		X						X	X	X		X
d420 Transferring oneself		X		X			X	X	X	X		
d430 Lifting and carrying objects		X				X	X					X
d440 Fine hand use								X		X		X
d445 Hand and arm use							X					X
d450 Walking		X	X	X			X	X	X	X	X	
d455 Moving around	X	X		X	X	X			X			
d460 Moving around in different locations	X	X				X	X					
d465 Moving around using equipment												
d470 Using transportation							X					
d475 Driving					X		X					
d510 Washing oneself		X		X					X	X		X
d520 Caring for body parts	X							X				X
d530 Toileting				X				X	X	X		
d540 Dressing						X		X	X	X		X
d550 Eating				X			X		X	X		X
d570 Looking after one's health												
d620 Acquisition of goods and services												
d630 Preparing meals					X		X		X	X		
d640 Doing housework					X		X	X		X		
d710 Basic interpersonal interactions	X					X		X	X	X		
d750 Informal social relationships	X		X		X	X	X		X			

ICF Code and Category titles for activities and participation	RNLI	RMI	LHS	BI	FAI	SIPSO	NEADL	SIS	BOSS	SS-QOLS	MRS	ArmA
d760 Family relationships	X							X	X	X		
d770 Intimate relationships										X		
d845 Acquiring, keeping and terminating a job			X		X			X				
d850 Remunerative employment												
d855 Non-remunerative employment												
d860 Basic economic transactions							X					
d870 Economic self-sufficiency			X									
d910 Community life	X							X	X	X		
d920 Recreation and leisure	X				X			X	X	X		

3.6.5 Quality of Papers

Each PROM scored differently in each psychometric property (Table 7). However, there was a large variance between the quality scores of these studies. The overall quality of 48 papers assessed by using agreed criteria (Table 3) is summarised in Table 11. The results showed that papers that used a low/moderate quality method to test the psychometric properties of a PROM, may suggest that a PROM has a high psychometric characteristic. Therefore, the quality of the evidence needs to be taken into consideration when looking at the score of the psychometric properties.

Table 11: Overall methodological quality of the studies. See Table 3 for the criteria

Included papers	**Overall quality rating**
Doyle, McNeil, Hula, & Mikolic, (2003)	Low
Trigg, Wood, & Hewer, (1999)	Low
Ashford et al., (2013)	Low
Lin et al., (2010)	Good
Duncan et al., (1999)	Moderate
Lin et al., (2010)	Low
Williams, Weinberger, Harris, Clark, & Biller,(1999)	Moderate
Schepers, Ketelaar, Visser-Meily, Dekker, & Lindeman, (2006)	Good
Hsueh, Lee, & Hsieh, (2001)	Good
Doyle et al., (2004)	Good
Doyle et al., (2007)	Moderate
Nouri & Lincoln, (1987)	Low
Gladman, Lincoln, & Adams, (1993)	Good
Harwood, Gompertz, & Ebrahim, (1994)	Low
Green & Young, (2001)	Low
das Nair, Moreton, & Lincoln, (2011)	Moderate

Included papers	Overall quality rating
Sarker, Rudd, Douiri, & Wolfe, (2012)	Good
Trigg & Wood, (2000)	Moderate
Trigg & Wood, (2003)	Moderate
Kersten, Ashburn, George & Low, (2010)	Good
Holbrook & Skilbeck, (1983)	Moderate
Segal & Schall, (1994)	Good
Wilkinson et al., (1997)	Good
Jenkinson, Mant, Carter, Wade, & Winner, (2000)	Good
Piercy, Carter, Mant, & Wade, (2000)	Low
Wu, Chuang, Lin, & Horng, (2011)	Good
Duncan et al.,(2002)	Moderate
Duncan et al.,(2002)	Good
Duncan, Bode, Sue, & Perera, (2003)	Good
Duncan et al.,(2005)	Moderate
Kwon et al.,(2006)	Good
Jenkinson, Fitzpatrick, Crocker, & Peter, (2013)	Moderate
Richardson, Campbell, Allen, Meyer, & Teasell, (2016)	Good
Edward & o'Connel, (2003)	Good
Kwon, Hartzema, Duncan, & Min-Lai, (2004)	Moderate
van Swieten, Koudstaal, Visser Schouten, & van Gijn (1988)	Low
Wilson et al.,(2005)	Good
Banks & Marotta (2007)	Good
Zhao, Collier, Quah, Purvis, & Bernhardt, (2010)	Good
Dennis, Mead, Doubal, & Graham, (2012)	Low

Included papers	Overall quality rating
Gauggel et al., (2002)	Good
Duffy, Gajree, Langhorne, Stott, & Quinn, (2013)	Moderate
Hsieh et al., (2007)	Low
Chen et al., (2007)	Good
Antonucci et al., (2002)	Good
Hsueh, Wang, Sheu, & Hsieh, (2003)	Good
Tooth, Mckenna, Smith, & O'rourke,(2003)	Good
Daneski, Coshall, Tillingand, & Wolfe, (2003)	Low

3.6.6 Summary of the Results

Following a comprehensive systematic search of the literature, through seven electronic databases and including a search through the reference lists of the included papers, only 48 papers were eligible for the review. There were only 12 PROM that were specifically developed and commonly used for stroke survivors to assess ADL limitations. The overall methodological quality of the papers reporting the development and testing of these PROM varied from good to very low quality. Each PROM scored differently for each psychometric property. None of the PROM scored good for all the psychometric properties that were evaluated in this review (Table 7).

The systematic review concluded that currently there is a lack of comprehensive PROM with good psychometric properties that can be used for stroke survivors to assess limitations in ADL. Additionally, none of the PROM helps to consider the effect of the environmental modification on functioning and cannot show differences between capacity and performance of a person.

3.7 Discussion

The systematic review aimed to identify existing PROM used in ADL assessment for stroke survivors, to evaluate their psychometric properties and comprehensiveness. The most important characteristic missing from the existing PROM was comprehensiveness to incorporate all the basic and instrumental ADL that is important to stroke survivors to enable them to lead independent lives. Currently used PROM could help to identify if stroke survivors had difficulties with a given activity, but were not specific enough to determine which part of the activity they struggled with most (e.g., SIS can show that a patient is limited with dressing the top part of the body but, is not detailed enough to show if a patient is limited to do up buttons or fasten clothes at the back). Only the BOSS (Doyle et al., 2003), the SS-QOL (Williams et al., 1999) and the SIS (Trigg et al., 1999), were deemed to have a wide range of activities compared to the other nine PROM, although they were still not comprehensive enough to cover all important activities and participation categories that were reported in the ICF Core Set for Stroke. For a PROM to have good content validity, it needs to have comprehensiveness, comprehensibility and relevant items (Terwee et al., 2018). Therefore, lack of comprehensiveness means that PROM does not have sufficient content validity to be used. This systematic review showed that none of the currently used PROM which assess ADL function could help to complete a comprehensive self-evaluation and enable the provision of a detailed ADL assessment. This may be attributed to the limitations in the development and testing process. Providing stroke survivors with a PROM that have a lack of comprehensiveness eliminates the chance of increasing their awareness of ADL limitations and may result in deterioration. This is because they will not have access to a PROM that can show them how they are doing in each step of ADL to evaluate their activity level and act on their limitations.

In total, 12 PROM were identified to assess ADL limitations specifically for stroke survivors. However, only three of these PROM scored adequately on content validity (BOSS, SIPSO and ArmA) (Ashford et al., 2013; Doyle et al., 2003; Trigg et al., 1999). This revalidates the recommended guidelines for PROM development and testing, as they stipulate that both stroke survivors and healthcare professionals must be involved in the development of the measurements for sufficient content validity. This can help to develop a comprehensive tool that covers all of the ADL needs of a target population to lead independent lives (Terwee et al., 2017). Unfortunately, the remaining PROM scored low on the content validity as only stroke survivors were involved in the development, and not healthcare professionals, or methods to identify items to include in the measures were deemed as low-quality. PROM with a lack of content validity may not reflect all of the problems that patients have due to their conditions (Cook, Wright, Wittstein, Barbero & Tousignant-Laflamme, 2021), which can affect the self-management process.

Despite having high content validity, it is still difficult to recommend the use of BOSS, SIPSO and ArmA due to other considerations such as the lack of evidence to support the use of BOSS in the British stroke survivors (Jenkinson, Gibbons, & Fitzpatrick, 2009). Even though the BOSS was developed and tested in the English language, there might be a culture difference between British and American stroke survivors, which can result in eliminating an important activity for a British stroke survivor in the BOSS. Moreover, the effect of personal, contextual and environmental modifications was omitted by all PROM. This is an essential part of a PROM measuring ADL, as environmental factors can be an enabling or disabling function (Marcheschi et al., 2017). The RMI (Collen et al., 1991) is the only PROM that includes items to assess mobility with and without using aids. However, RMI does not provide enough information about the positive or negative impacts of environmental modifications on stroke survivors because it does not assess the effects of using environmental modifications on ADL functioning other than mobility. This results in people not being able to differentiate the capacity from performance. For example, the use of a PROM can show stroke survivors that they are limited in daily activity, but cannot help them to realise what they can achieve by using an equipment. Helping people to realise their limitations without showing them how they can manage these limitations can result further stress or depression on stroke survivors and not have a positive effect on self-management.

Each psychometric property of a PROM is equally important (Kyte et al., 2015; Mokkink et al., 2010). However, as mentioned above, not enough information was published for the majority of identified PROM to evaluate these in sufficient detail. For ArmA and the SS-QOLS, the psychometric evaluation was limited with a low number of papers. On the other hand, for the SIS, BI and FAI, psychometric properties were evaluated in detail with a large number of studies, but they do not include a comprehensive range of items and do not show any improvements with environmental modifications. Importantly, even with a high number of studies, some PROM scored as inconsistent in some categories. To give an example; RMI (Hsueh et al., 2003), SS-QOLS (Lin et al., 2010) and BI (Schepers et al., 2006; Hsueh et al., 2001) had inconsistent results for responsiveness and due to this, PROM were evaluated twice depending on the stage of the stroke. Results showed that SS-QOLS, BI, and RMI were more responsive to detect changes at the early stages of a stroke, but not at the chronic phase. Psychometric properties are necessary to determine the quality of a PROM's construct, but equally, it is essential that the given PROM is comprehensive to provide a valid and reliable assessment of the target population. Given this, all PROM have failed to fulfil this criterion for a recommendation for future use to ascertain stroke survivors' ADL limitations.

Patient-reported outcome measures included in this review had at least one domain or item to assess the limitations in ADL. However, even those with several items (BOSS and SIS), do not incorporate all parts of the basic and instrumental ADL functions. This can limit the obtainment of detailed information in the assessment period. Not only comprehensiveness but also consideration of the effect of the environmental modifications can help both clinicians and patients to have more realistic goals towards rehabilitation (Marcheschi et al., 2017). It was sought to find at least one PROM that comprehensively assesses all aspects of ADL limitation, also shows the improvements in performance through the use of environmental modifications, but this was found to be another weakness of the PROM. As mentioned in Chapter Two, the use of a PROM can guide self-management. However, limitations documented in this systematic review showed that digitising these PROM for stroke survivors may not help stroke survivors to gain full benefit and affect the self-management process negatively.

3.8 Implications on Rehabilitation and Self-management

The results of this review helped to identify and evaluate the limitations of currently available PROM, which are commonly used to assess restrictions in ADL for stroke survivors. Therefore, there are implications for rehabilitation.

(1) The lack of having a comprehensive measure to assess ADL limitations may affect capturing the main limitations in ADL from the patients' perspective. This can have a negative impact on setting personalised and meaningful goals for stroke survivors, which can be a barrier to providing patient-centred treatment. Also, the lack of a comprehensive PROM can affect improving awareness of ADL limitations and result in a negative impact on self-management.

(2) Due to the inconsistency of the results and the lack of evidence to evaluate the range of psychometric properties of the existing PROM, the review was unable to determine their measurement validity, reliability and responsiveness to detect ADL limitations in stroke survivors.

(3) Mode or time of administration was put forward as a barrier to effective use of the PROM (Weldring & Smith, 2013; Stokes & O'Neil, 2008). However, one of the positive aspects of a PROM is that stroke survivors can complete them in their own time, without requiring the help of healthcare professionals in clinics. This can help to reduce the time constraints placed on clinical appointments, which can be utilised instead to communicate with patients on issues identified as being the most important to them following self-assessment through the use of a PROM. Most importantly, PROM can be used as a self-assessment tool through online platforms and guide self-management.

(4) As none of the existing PROM measured the impact of contextual and environmental factors on ADL, this can limit the ability to distinguish stroke survivors' capacity to undertake ADL from their performance.

(5) There is a need for a comprehensive PROM to assess ADL limitations and show the impact of environmental modification in stroke survivors that is psychometrically robust to ensure validity, reliability and is sensitive to change.

3.9 Limitations

The systematic review searched seven databases (Table 4). However, the search did not include any grey literature or contact with any local experts concerning unpublished studies or thesis. Even the research was renewed (please, refer to section 6.3.1), at the time of this review, there may be other studies being conducted to test the psychometric properties of the PROM that assess ADL limitations for stroke survivors. This may have an impact on the results of the review. However, this systematic review made use of the extensive literature available, as the reference list of the chosen articles were also examined in addition to the database searches.

Also, PROM that requires interview administration was not included in this study as they put time pressure on healthcare professionals and cannot be used by stroke survivors independently through an online self-management platform. This may have resulted in the omittance of other comprehensive and commonly used OM that may be administered via semi-structured/structured interviews. However, this review achieved a comprehensive identification of the existing PROM and robust evaluation of those to support guidance on the use of these in clinical practice and research.

3.10 Conclusion

At the time of the publication of this thesis, to the knowledge of the author, this is the first systematic review that identified and evaluated PROM to assess ADL limitations of stroke survivors. The findings of this review provided an extensive evaluation of the psychometric properties of existing PROM to assess ADL limitations in stroke survivors to inform clinical practice and research. This review concludes that existing PROM to assess ADL limitations in stroke survivors lack psychometric robustness and are not comprehensive enough to provide a thorough self-assessment of their ADL limitations. This can affect stroke survivors' understanding of the extent of their ADL limitations, which can ultimately have a negative impact on their self-management.

Twelve identified PROM scored differently at each psychometric property and they can be used both in the clinic, or research to assess ADL limitations. However, limitations of these PROM can result in identifying important treatment targets or measuring the effects of environmental modifications on performance. These PORM can be used by stroke survivors independently in their home environment to self-assess their limitations in ADL, but a lack of comprehensiveness results in stroke survivors missing to realise their limitations in important ADL functioning and not being able to differentiate at which level of the activity they are limited or how they can adapt their lives to eliminate these limitations. This results in stroke survivors needing more input from healthcare professionals to realise their limited activities and learn how to self-manage them.

Therefore, the development of a comprehensive PROM specific to stroke survivors is required to assess limitations in ADL to achieve valid and reliable outcomes. There is a need to include items to help separate intrinsic disability from extrinsic disability by incorporating the effects of contextual and environmental factors that impact performance. This will not only help to develop a comprehensive ADL PROM but also help stroke survivors to have a tool that can help them to understand how the environmental modifications can improve their QoL. The next section discussed the next step conducted after identifying that there was a need to develop a comprehensive PROM to include in an online self-management platform as a self-assessment tool. Therefore, other PROM that were developed for other long-term conditions were searched.

3.11 Following the Systematic Review: Next Step to Identify a Comprehensive PROM to Assess ADL Limitations

There are other PROM that are currently being used by healthcare professionals in research or clinic to assess ADL limitations for other long-term conditions. However, not all long-term conditions have a longstanding impact on ADL like a stroke. Another disorder that has an impact on ADL functioning for the long-term is musculoskeletal conditions (MSCs) (Banerjee, Jadhav, & Bhawalkar, 2012). MSCs are the most common cause of long-term pain and physical disability for people all around the world (Woolf et al., 2012; European Commission, 2007). MSCs is an umbrella term for different conditions. Osteoarthritis, osteoporosis and back pain are the common types of MSCs. Osteoarthritis (OA) is a highly prevalent condition, which results in limitations of ADL due to the impacts that it has on people (Stamm, Pieber, Crevenna, & Dorner, 2016; Rahman, Kopec, Cibere, Goldsmith & Anis, 2013). Research conducted by Rahman and collages (2013) showed that there is no association between OA and a stroke. However, statistics showed one in five people who are aged 45 and above have an OA in England (Arthritis Research UK, n.d.) and as mentioned previously, the average age of having a stroke is decreasing to 40-69 years old (NICE Impact, 2019). This can help to conclude that stroke survivors who are age 45 and above are likely to have OA.

As OA has a huge impact on ADL limitations and affects people's QoL, like a stroke, PROM that are commonly used to assess ADL limitation for OA were also identified in the initial PROM search, including the Evaluation of Daily Activity Questionnaire (EDAQ). In total, 349 outcome measures were reported in the literature that is currently being used to assess ADL limitations for OA. Some of the identified measures were objective assessments or PROM that assess disease activity or other limitations rather than ADL, such as; depression, pain or mental health. One of the PROM used to assess ADL limitations for OA condition was the EDAQ, which the UK version was developed by the UoS. It was known that the EDAQ for Rheumatic and Musculoskeletal Conditions (RMDs) was a comprehensive tool to assess ADL limitations and it helps to understand the differences between the intrinsic and extrinsic disability (Hammond et al., 2014).

On the other hand, other PROM that aim to assess ADL limitations for OA were evaluated to understand if there is any other PROM that is more comprehensive than the EDAQ. Thirteen of these PROM were specific to a joint, such as; for knee, hip, foot, neck or specific to either upper limb or lower limb (i.e., Shoulder Pain and Disability Index, the Lower Extremity Functional Scale, Measure of Activity Performance of the Hand, and the Disabilities of the Arm, Shoulder and Hand Questionnaire, Hip Dysfunction and Osteoarthritis Outcome Score, Knee Injury and Osteoarthritis Outcome Score, the Copenhagen Hip and Groin Outcome Score, the Oxford Hip Score, Oxford Knee Score, Foot and Ankle Outcome Score, the Foot and Ankle Disability Index Score, Foot and Ankle Ability Measure and Neck Outcome Score). It is important to remember that ADL cover a wide range of domains (Legg et al., 2017), e.g., dressing, eating, drinking, and functional mobility (Foti & Koketsu, 2013). Therefore, PROM specific to a joint may not be enough to evaluate the ADL limitations comprehensively as the daily activities are not linked only with a single joint.

Other PROM that assess ADL limitations were also identified in the research such as the Health Assessment Questionnaire, Bath Ankylosing Spondylitis Functional Index, Sickness Impact Profile, Rheumatoid and Arthritis Outcome Score, Western Ontario and McMaster Universities Osteoarthritis Index, or Roland Morris Disability Questionnaire, but none of these questionnaires was as comprehensive as the EDAQ. When the most commonly used PROM to assess ADL limitations for OA were searched in detail, it was recognised that the EDAQ is the most comprehensive PROM that assesses limitations of ADL and it is the only PROM that helps to understand the effect of environmental modification on ADL functioning to distinguish capacity from performance (Hammond et al., 2015b). Use of the EDAQ was agreed on after evaluating it by following the COSMIN guidelines like the PROM in this systematic review and reviving the items that it includes. The evaluation of the EDAQ items has shown that items could be relevant for stroke survivors.

3.11.1 Evaluation of Daily Activity Questionnaire

The EDAQ is a PROM that overcomes the limitations, such as; lack of comprehensiveness, ability to show differences between capacity and performance. The EDAQ is a self-reported PROM that was developed in Sweden in the 1990s to facilitate a good structured assessment and management in detail for rheumatoid arthritis (RA) (Cederlund, Nordenskiold, & Lundborg, 2001; Nordenskiöld, Grimby, Hedberg, Wright, & Linacre, 1996). The original Swedish EDAQ was published in English. However, it had some limitations and required further development. The Swedish EDAQ was not professionally translated, and not culturally adapted for the British population (Hammond et al., 2014). Therefore, it had some unclear activities. In addition, it did not cover all the problematic functions that are important for the UK RA patients. Moreover, during the development process, only women with RA were involved in the development process (Nordenskiold et al., 1996). Therefore, further development testing of the EDAQ is required for it to be used in the UK RA population.

Following this reason, the EDAQ was developed in British English in 2014, cross-culturally and linguistically validated for use of the UK people with RA by adding new items that are meaningful and relevant to both men and women with RA (Hammond et al., 2015a). Additionally, the EDAQ is systematically linked to the ICF Core Set for RA to evaluate the content of the PROM. The results proved that most of the ICF Core Set activities for RA are covered in the EDAQ. As the ICF is a globally accepted framework, linking the items of the EDAQ to the ICF Core Set for RA showed that this tool is comprehensive and can demonstrate ADL limitations of patients in detail. However, the EDAQ items are only linked with the RA condition and not with other MSCs, so they can be limited. To show the effect of EDAQ on other MSCs, the EDAQ psychometrically tested it on seven other MSCs e.g., OA, Ankylosing Spondyloarthritis, Fibromyalgia and Sjorgen's Syndrome (Hammond, Prior, Horton, Tennant, & Tyson, 2018a). The result proved that the EDAQ has strong psychometric properties and can be used both in clinical and research practice.

The British version of the EDAQ has three parts:

- Part one asks for details about the patients' disease duration, education and working situation. It also covers ten visual analogue scale questions about mood, satisfaction with life, pain, stiffness, limitations and energy (Hammond et al., 2014).

- Part two includes 14 domains with 138 items. It covers the domain of different ADL functions. Self-care inquiries include (Eating/drinking, Dressing, Bathroom/Personal care, Cooking, Cleaning the house, Laundry/Clothes Care and Communication) and Mobility that includes (Moving/transfer, Bathing/Showering, Gardening/Household maintenance, Moving around indoors, and Moving around outdoor/Shopping). Additionally, it has two extra domains, which are Caring and Hobbies/Leisure/Social Activities. Each domain has two sections. Section A assesses a person's ability without any equipment, ergonomic methods or help. Section B assesses how a person can do the same activity with equipment or help (Hammond et al., 2014).

- Part three is a checklist about the equipment that patients use (this section is optional) (Hammond et al., 2014).

One of the most important advantages of the EDAQ is, it includes patient-generated items. Most assessments involve using questionnaires that include pre-determined questions, assumed to be important to the individuals with the closed set (Salter, Hellings, Foley, & Teasell, 2008). However, this does not help to target the main issues. As the EDAQ covers patient-generated items, the included questions are deemed as important and understandable for patients (Hammond et al., 2014). This helped to cover the most important limitations from patients' perspectives and target the main problem in rehabilitation.

The second advantage is that the EDAQ can be completed by patients at home in their own time, which reduces the time burden on healthcare professionals (Hammond et al., 2015b, Hammond et al., 2014). This can help patients to spend time on the questionnaires, stop when they require, rest and continue when they can or want. Thirdly, the EDAQ is a comprehensive tool that covers most of the aspects of the ADL and IADL for MSCs (Hammond et al., 2014). The EDAQ can facilitate detailed self-assessment, which can help to increase the awareness of ADL limitations and may result in better self-management.

The EDAQ is different from other measurement tools because it helps therapists to distinguish an intrinsic disability from an extrinsic disability (by assessing the effect of the environmental modification) (Hammond et al., 2015b). The EDAQ is a questionnaire that helps the participant to engage with the problem identification process, showing them the effect of the current solution they have, and supports a patient to work with the therapist for problem-solving. Moreover, the EDAQ has strong validity and reliability, which is confirmed by the Rasch analysis (Hammond et al., 2018a).

On the other hand, the length of the EDAQ can be seen as a disadvantage, as it can take more than 30 minutes to complete. However, all the items are patient-generated, which shows that they are all considered important for people with that condition. The organisation of the EDAQ as Section A and B can clearly show the differences of a patient in capacity and performance. For example, if a person is unable to get in and out of a bath independently, but can do it easily with a handrail, this can be clearly shown at the EDAQ. This can help healthcare professionals to understand which modifications can be useful to provide to an individual. Most importantly, the EDAQ is easy to access as it is available in both a paper and electronic version. It is housed in www.mskhub.com (MSKHUB), which is sponsored by the UoS and freely available to be used as a self-management tool.

Stroke survivors have similar limitations with people, who have MSCs, such as restrictions in mobility, dressing, washing or shopping. Therefore, the EDAQ has the potential to be a useful tool for stroke survivors. As the EDAQ is not originally developed for stroke survivors, some ADL items that can be considered as an important activity by stroke survivors are not covered by the questionnaire, such as bladder/bowel control or cognition. This is because these may not be important for the people with MSCs. For a PROM to be able to be used in a population and provide efficient results, it needs to be developed by following the accepted guidelines (Mokkink et al., 2018; Patchick et al., 2015; Fitzpatrick et al., 1998). A tool needs to be cross-culturally adapted and psychometrically tested for the target population before it can be used. So, there was a need to further test the use of the EDAQ for stroke survivors (EDAQ-SS) to determine its applicability/strength for use in this population.

However, the EDAQ was not developed for stroke survivors and was not used in this population (Hammond et al., 2015). Even they have similarities, there are still differences between stroke survivors and people with RMDs, i.e., cognitive impairments, visual, sensation or perceptual impairments. A way that can help stroke survivors to access and complete the EDAQ easily and self-manage their condition needs to be considered. As there is a lack of comprehensive PROM to assess ADL limitations for stroke survivors, the development of the EDAQ-SS can help to provide a comprehensive PROM to stroke survivors to self-assess their ADL limitations, increase their awareness and guide their self-management.

When the limitations of the stroke survivors and increased use of digital health were considered, it was important to consider the accessibility of the EDAQ-SS and the ability of the EDAQ-SS to be used as a self-assessment tool. As it was proved before that the ePROM has more advantages than a paper version, and it can overcome barriers that stroke survivors can face (i.e., fatigue, accessibility, easier administration, quicker feedback), it was important to develop an online self-management platform; the Stroke Survivors Hub, to house the electronic EDAQ-SS (eEDAQ-SS) and help stroke survivors to use it as part of their self-assessment to increase their awareness and motivate them for the self-management. The next chapter explained the development of the EDAQ-SS.

CHAPTER FOUR: DEVELOPMENT AND TESTING OF THE EVALUATION OF DAILY ACTIVITY QUESTIONNAIRE FOR STROKE SURVIVORS

4.1 Introduction

One of the aims of this thesis was to develop a paper and an electronic version of a PROM for stroke survivors to self-assess their ADL to help with self-management. Following on from the systematic review in the last chapter it was concluded that there was a need to develop a comprehensive PROM for stroke survivors that will help stroke survivors to self-assess their ADL limitations, show them the difference between their capacity and performance and help them to recognise if the environmental modifications that they use are facilitators or barriers. This chapter outlines the methodology and methods adopted to develop and test the usability of the Evaluation of Daily Activity Questionnaire for Stroke Survivors (EDAQ-SS). Firstly, justifications were made for the chosen mixed methodology, and the research procedures were described and defended with a rationale to support these. Moreover, the method of analysis chosen to understand the findings was outlined and explained.

4.2 Rationale for the Aim of Stage 1

The mixed-method approach, which involved conducting cognitive debriefing interviews, expert panel discussions and the use of ePROM to collect quantitative data, aimed to address the following objectives in this study:

1. To linguistically and culturally adapt the EDAQ (for RMDs) for stroke survivors and develop the EDAQ-SS and eEDAQ-SS to house this PROM on an online self-management platform for stroke survivors (the SSHUB) following the recommended guidelines for PROM development. This involves an iterative process and consist of expert panel meetings and cognitive debriefing interviews with stroke survivors to ensure that the EDAQ-SS was comprehensive, understandable, usable and relevant to the British community-dwelling stroke survivors.

2. To evaluate the content validity of the EDAQ-SS by linking the items to the ICF Core Set for Stroke Conditions.

As discussed in the previous chapter, a valid, reliable and comprehensive PROM to specifically measure ADL limitations in people with RMDs (the EDAQ) which was developed at the UoS and developed successfully into an ePROM within an online self-management platform and research data repository (the MSKHUB) was identified as a suitable PROM to adapt for stroke survivors.

Therefore, the Stroke Survivors Hub (SSHUB) was developed to meet the unmet need for an online self-management platform for stroke survivors to allow self-assessment of their ADL difficulties using an appropriately developed PROM. The platform was made freely available to stroke survivors online via www.strokesurvivorshub.com. The next chapter (Chapter Five) explains the development of the SSHUB and digitisation of the eEDAQ-SS in detail to outline this process. Before the digitisation of the EDAQ-SS, recommended guidelines for the development of a PROM was followed to first linguistically and culturally adapt the EDAQ for stroke survivors. To reduce participant burden, an initial draft of the eEDAQ-SS was designed based on the EDAQ-SS in collaboration with a local IT support company, after the expert panel meeting, prior to the cognitive debriefing interviews taking place to collect information on the usability of both the paper copy of the EDAQ-SS and the eEDAQ-SS housed on the SSHUB from stroke survivors at the same time.

4.3 Research Methodology

4.3.1 Linguistic and cultural adaptation

There are guidelines for linguistic validity and cross-cultural adaptation that need to be followed to develop a PROM by linguistically and culturally adapting it to a new population (Acquadro et al., 2004; Beaton et al., 2000). If a PROM is used in the same language and culture that it was developed for originally, it does not require adaptation (Guillemin, Bombardier, & Beaton, 1993). On the other hand, a PROM needs to be linguistically and culturally adapted by following guidelines before it can be used for another population with a different culture (Mokkink et al., 2019; Acquadro et al., 2004; Beaton et al., 2000). Most of the questionnaires are originally developed in English (Guillemin et al., 1993) but, even in the same country, if the PROM is going to be used for another condition, it needs to be linguistically and culturally adapted (Beaton et al., 2000). Linguistic validity and cross-cultural adaptation is not just translation (European Centre for Disease Prevention and Control (ECDC), 2016; Delgado-Herrera, 2016), it may also include rephrasing the items to make them relevant for the culture of the new population (ECDC, 2016). Cultural adaptation is crucial as it helps in considering important information and culture for the target population (Burke, 2011). Rather than adopting clinical questions developed by researchers, it helps to involve meaningful and relevant questions for the target population in the PROM. The translation is the first step to follow when adapting a PROM to a new language and culture. However, there is no need to translate a PROM if it is already translated into the target language.

At the same time, linguistic and cross-cultural adaptation also takes into account the language and culture of the one with the medical condition, the conceptual equivalence of the items (i.e., the meaning of walking) and item equivalence (i.e., the relevance of using cutlery for the target population) (Delgado-Herrera, 2016; Hewlett et al., 2016), and that how it can make sure that the items of the questionnaire can be used for a new population. Linguistic and cross-cultural adaptation requires iterative rounds of different steps (Hewlett et al., 2016). Step one is the initial translation of the items from the language that it was developed and tested before, into the target language (Delgado-Herrera, 2016). Depending on the guidelines reported by Acquadro et al., (2004) and Beaton et al., (2000), there is a need for two forward translations from the original language to the target language to ensure that items of the PROM are understandable and relevant for the target population when they are translated. Two forward translation processes help to compare the translation and reflect on the wording choice, which then needs to be followed by the second step. Step two is a synthesis of the translation (Beaton et al., 2000), which helps to form one single report after discussing the translated version developed by translator one (T1) and translator two (T2). Step three is the back translation (Beaton et al., 2000). The translated version of the questionnaire needs to be translated back into the original language to make sure that none of the items is incorrect (Leplege & Verdie, 1995).

4.3.2 Expert Panel

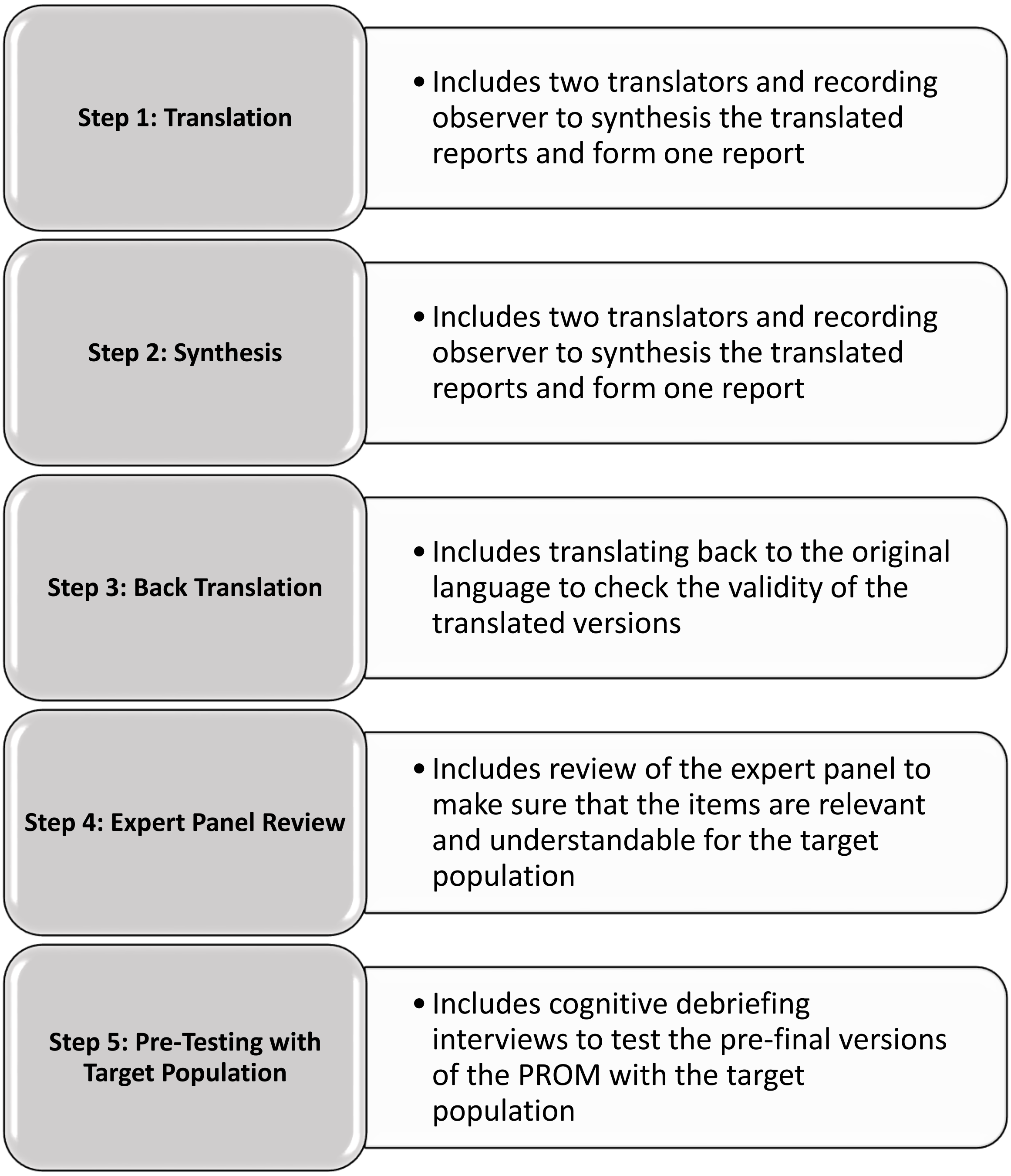
Expert panel members are involved in the development process to ensure there is an idiomatic, semantic, experiential and conceptual equivalence (Hammond, Prior, & Tyson, 2018b; Beaton et al., 2000). Literature suggests that the expert panel needs to involve professionals from different backgrounds who have experience with the target population (Terwee et al., 2018b; Beaton et al., 2000) and knowledge about the development and evaluation of a PROM (Terwee et al., 2018b; Acquadro et al., 2004). The role of the expert panel is to consider the previously translated version of the PROM and make sure that the items of the PROM are understandable and relevant for the target population (Prior, Tennant, Tyson, Kjeken, & Hammond, 2018; Beaton et al., 2000).

It is suggested that the expert panel needs to have a minimum of five experts to provide sufficient information (Terwee et al., 2018a; Lynn, 1986). Involvement of enough experts from different professions is important, as each expert will have ideas on points that they specialise in, and they will look from different perspectives. As an approach to a stroke requires a multidisciplinary team response, which covers different professionals (Clarke, 2013), five members of an expert panel can be inadequate to consider all ideas of different experts. A panel needs to include a healthcare professional, a synthesis recorder, methodologists, native English speakers and translators (Acquadro et al., 2004; Beaton et al., 2000) to achieve a better outcome. The opinions of different professionals on the relevance and comprehensiveness of the PROM are important in assessing symptoms because professionals may have seen many patients with different limitations. Therefore, they help to involve items that are consistent with theory and conditions (Terwee et al., 2018; Mastaglia, Toye, & Kristjanson, 2003).

According to the explanation above, an expert panel is important in achieving cross-cultural equivalence (Beaton et al., 2000), and this aims to replace a culture-specific item into target language items as they may not have the same meaning in another culture. The role of an expert panel is to look at a translated version and make sure that items are translated correctly, and that they are meaningful and understandable by the target population.

However, it might not be enough to only include the knowledge of healthcare professionals. After the first three steps of the linguistic and cultural adaptation, step four helps to develop the pre-final version of the questionnaire and prepare it for the final step; step five: the test of the pre-final version. A target population needs to be involved in this step, which is explained in the next section, to make sure that items are relevant and understandable for their condition (Hewlett et al., 2016; Delgado-Herrera, 2016). Therefore, to be able to develop a PROM these steps, which were reported in the guidelines, need to be followed (Figure 2, summaries the steps of the linguistic and cross-cultural adaptation).

***Figure 2**:* Steps of the linguistic and cross-cultural adaptation



4.3.3 Cognitive Debriefing Interviews and Usability

Stroke survivors live with the day-to-day impact of a stroke, which can significantly differ from one person to another. Therefore, their views on what ADL limitations are most common and how to measure the impact of a stroke on their daily living is paramount. Cultural adaptation is important as it helps to consider the target language and culture rather than trying to make the translated words simple (Delgado-Herrera et al., 2016;

Burke, 2011). Different types of ADL limitations may mean different things to individuals living in different cultural norms (e.g., the ability to operate a kettle to make a cup of tea might be an important ADL to a British stroke survivor, whereas American stroke survivors might consider using a coffee percolator more relevant and important, which requires a different set of motor skills). Therefore, the items of a given PROM must be more relevant, meaningful and understandable for stroke survivors in self-completing such questionnaires.

This is why the recommended guidelines stipulate the importance of conducting cognitive debriefing interviews during the linguistic and cultural adaptation of existing PROM and evaluating its usability with the target population being studied to make sure that the items of the PROM are conceptually equivalence (Delgado-Herrera et al., 2016; Muehlhausen et al., 2016; Burke, 2011). Involvement of the target population in generating the items of the questionnaire helps to develop a comprehensive PROM that includes most of the items which are relevant and important to the target population (Kirwan, Fries, Hewlett, & Osborne, 2011; Staniszewska et al., 2011; Fitzpatrick et al., 1998).

There are different ways to involve patients; such as feedback forms, focus groups or cognitive debriefing interviews (Wiering, Boer, & Delnoij, 2017b). Cognitive debriefing interviews are formal and a recommended methodology that is commonly used in research (Hewlett et al., 2016). Cognitive debriefing interviews help patients to think aloud as they complete or look at the PROM (Hewlett et al., 2016). This process helps a researcher to analyse whether the target population can understand, recall information, judge and respond to options (Drennan, 2003), and consider whether the items of the PROM are relevant to the target population (McColl, 2006). It helps a researcher to consider if there is any problem with the included items and if they need to be rephrased to make them relevant. Cognitive debriefing interviews are techniques that help to realise if the items of the PROM and response format help to detect the problems that are to be assessed. Items of the PROM then need to be modified in light of the responses of the cognitive debriefing interview participants before they can be retested. It helps to evaluate the decision processes made when completing the PROM, which is important as different people can understand and interpret words differently (Tourangeau et al., 2000). It can be summarised that cognitive debriefing interviews can help to evaluate the (Beatty & Willis, 2007):

- Understanding of the questions
- Process people uses to retrieve the relevant information
- Decision processes
- Response processes

The steps mentioned above help to reduce response error and improve the face and content validity of the PROM (Beatty & Willis, 2007) by examining the content, response skills and understanding of the instructions to complete the PROM. Cognitive debriefing interviews is an appropriate methodology to assess which response formats make more sense, which is less challenging and impose less of a burden on stroke survivors (DeMuro, Lewis, DiBenedetti, Price, & Fehnel, 2012). If this stage is not completed, there is a risk of stopping potential users from engaging with the PROM due to the irrelevance of, and dissatisfaction with, items (Lasch et al., 2010, Rat et al., 2007). The cognitive debriefing interviews have been used successfully in the development of PROM for use with other health conditions (Nicklin, Cramp, Kirwan, Urban, & Hewlett, 2010; Christodoulou, Junghaenel, DeWalt, Rothrock, & Stone, 2008; Wu & McSweeney, 2004). If the cognitive debriefing interviews step is eliminated, there is a risk that the developed PROM may not accurately reflect the perspectives of stroke survivors.

There are two ways to administer the cognitive debriefing interviews, either by think-aloud, which helps to collect the information as the participants answer the PROM (DeMuro et al., 2012), or probing, where the interviewer asks specific questions to understand how the participants approached the questions. The first method, think-aloud, requires more work from the participants as they need to answer the questions at that time and comment about each item, which can be a burden on participants (DeMuro et al., 2012). When the probing technique is used it is less of a burden on the participants as the interview is driven by the researcher and not the participants. Cognitive debriefing interviews can be administered either by face-to-face meetings or telephone interviews. Telephone interviews can be challenging for people who have speech and language difficulties, stroke survivors with aphasia might find it difficult to understand the conversation over the phone or people with dysarthria cannot express their ideas from the telephone. However, telephone interviews have more advantages as they help to conduct in-depth interviews in a faster and easier way. In addition, stroke survivors do not need to leave their comfort zone and travel for telephone interviews. Therefore, the probing technique via telephone interview was agreed to be used for the cognitive debriefing interviews, followed by content analyses to analyse the data.

Content analysis is a tool that helps to determine the presence of certain words. Qualitative content analysis is one of the methods to analyse data and interpret the meaning (Schreier, 2012). Common methods to conduct the content analysis were agreed upon, which included reading the comments from participants to understand the concept, dividing sentences into smaller parts, and coding them into smaller parts (Erlingsson & Brysiewicz, 2017; Elo et al., 2014). It is recommended by Acquadro and colleagues (2004) that cognitive debriefing interviews require a small sample size, such as five to ten participants from a target population (Acquadro et al., 2004). Acquadro and colleges (2004) advised that samples need to represent a mixture of demographic details such as gender, age and condition characteristics. The selected sample needs to reflect the particular features of a group within the sample populations to address the research aim (Ritchie & Lewis, 2003).

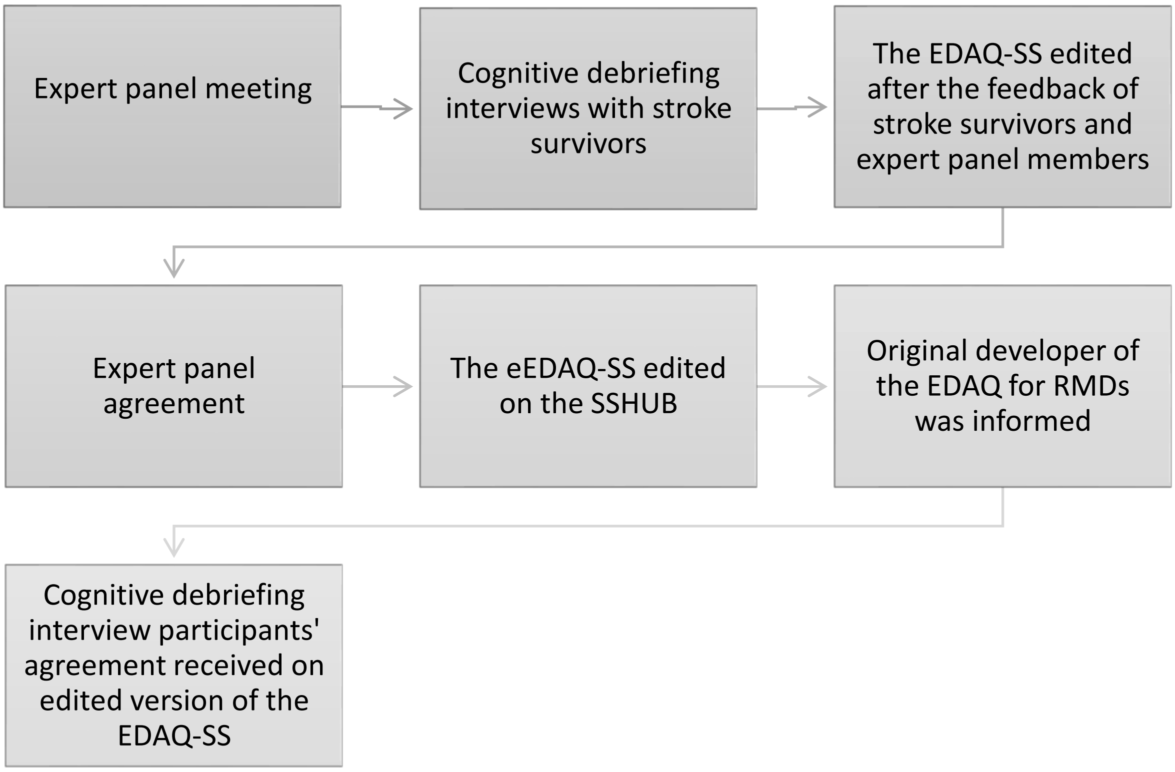
In addition to cognitive debriefing interviews, usability is also needed when developing a PROM and converting it to an ePROM to demonstrate equivalence of the PROM in both versions (Muehlhausen et al., 2016; Coons et al., 2009). Usability is defined as the ability of a product to help achieve goals with efficiency, effectiveness and satisfaction (Krogstad et al., 2018; International Organization for Standardization (ISO)/International Electrotechnical Commission, 1998). It is a formal process that helps the target population to use a product or service effectively, efficiently and with satisfaction (Aiyegbusi, 2020). This helps to develop a PROM that is easy to understand, relevant and meaningful (Acquadro et al., 2004). One of the methods to conduct the usability was asking questions during an interview to get the subjective opinion of the target population on the tool that they use (Aiyegbusi, 2020). This method was used before to conduct usability of ePROM at different conditions (Aiyegbusi, 2020; Muehlhausen et al., 2016) and showed that usability helps to facilitate the improvement of an ePROM development and results more usable, acceptable PROM for the target population (Aiyegbusi, 2020; Muehlhausen et al., 2016).

There is an ongoing debate about the sample size for usability (Macefeld, 2009; Turner, Lewis, & Nielsen, 2006; Spool & Schroeder, 2001). Some studies have shown that five participants can be enough to detect 80% of the issues during usability. On the other hand, another research has shown that up to 15 participants might be needed to conduct more serious participants. However, Aiyegbusi (2020) has reported that usability test is an iterative process and conducting interviews with less sample size to assess usability test can allow the researcher to understand the issues better and correct them after the usability. After searching the prior studies at the literature that conducted usability and based on theories, it was recognised that the commonly used sample size for the usability were ten participants (Landman et al., 2014; Hong et al., 2014; Ehmen et al., 2012; Nielsen, 2000). As the recommended sample size for both the cognitive debriefing interviews and usability were the same and both assessments require interviewing to improve the development of a PROM, evaluation of the usability was conducted during the cognitive debriefing interviews. Therefore, it was agreed to conduct cognitive debriefing interviews and usability during Stage 1 of the research. As a result, Stage 1 included an expert panel consultation (Part-One), and cognitive debriefing interviews with stroke survivors to develop the EDAQ-SS (Part-Two).

4.4 Research Processes

The following sections outline the procedures used to collect and analyse the data. The steps used to develop the EDAQ-SS were summarised in Figure 3.

Figure 3: The summary of Stage 1 Procedure



4.4.1 Ethical Approval

Ethical approval was sought from the UoS Ethics Committee before the commencement of the study. Full approval for Stage 1 was given on the 4th of December 2018 with a REC reference number: HSR1819-023. What follows is an overview of some of the key ethical and governance considerations.

There was no potential physical risk to participants during any part of the data collection. Participants were asked to complete questionnaires about their limitations in daily activities and general health status. These could potentially result in distress, as participants could come to a sudden realisation or reminding of the extent of their limitations, and the impact of stroke on their life, which could result in a sense of loss of identity and distress. Therefore, the following precautions were considered.

Informed consent was obtained prior to the interviews by a registered healthcare professional on the telephone to make sure that the participants were aware of the potential psychological distress taking part in this study could lead to. They were informed that if they found any of the questions upsetting, they could contact a member of the research team to discuss their feelings, as the supervision team included experienced HCPC registered therapists, specifically trained in dealing with such situations. Also, they were reminded that they could stop at any point at the questionnaire completion or the interview stage and have a rest, as well as drop out of the study completely if they wish to without giving any reason.

4.4.2 Stage 1-Part One Expert Panel

The recommended guidelines helped to complete the cultural adaptation and linguistic validation of the EDAQ to make it understandable and relevant for British stroke survivors. The EDAQ had already been translated into British English in 2014 by Hammond and colleagues. Therefore, there was no need to translate the items of the EDAQ into following the first three steps of the guidelines. Yet, the EDAQ was developed for RMDs, which has a different medical culture in relation to a stroke. The adaptation process started with an expert panel review to make sure that items of the EDAQ were understandable and relevant for the target population. Translators were not included in the expert panel, as the EDAQ was already translated into British English (Hammond et al., 2014). The expert panel was designed to allow efficient data presentation, so experts could determine the items that need to be part of a PROM to capture stroke survivors' limitations.

Participants

Inclusion criteria:

- Healthcare professionals and researchers who have experience working with stroke survivors.
- Healthcare professionals and/or researchers who have detailed knowledge about the methodology for PROM development and testing.

Exclusion Criteria:

- Healthcare professionals who do not have experience in working with stroke survivors or understanding of the use of PROM in stroke rehabilitation.

Recruitment

Local networks were used for convenience sampling to ensure that expert panel members could attend face-to-face meetings with minimal costs and spend less time travelling. Most of the expert panel members were healthcare professionals from the NHS. Therefore, contacting local networks helped more healthcare professionals to accept being part of the expert panel as they lost less time from their working environment. Expert panel members were identified from different routes:

1) It is recommended to include the original developer of a PROM in the expert panel when linguistically and cross-culturally adapting an existing PROM to another target population (Wild et al., 2005) as they have the knowledge and expertise about the methodology and developmental stages. Therefore, the methodologist in the expert panel was selected from the team of the EDAQ for RMDs.
1) The Greater Manchester Operational Delivery Network Manager was informed about the research project and notified of the participants required on the expert panel. The network manager kindly agreed to inform the healthcare professionals in the Greater Manchester NHS Trusts meeting these requirements about the project and asked them if they would volunteer to be part of an expert panel for this study.
2) The researcher also identified and contacted academics with a background in healthcare professions and neuro-rehabilitation in local networks (i.e., from UoS, Manchester University and the University of Huddersfield) to kindly consider volunteering in the expert panel.

Contacting both the NHS healthcare professionals and academics from a variety of health professions provided an opportunity to form an expert panel with a broad knowledge and experience in stroke and the methodological expertise to contribute to the development of this new PROM. The panel involved eleven volunteers in total, and their demographic characteristics are described below in Table 12.

Table 12: Demographic characteristics of the expert panel members

Profession	Speciality	Role
Senior Research Fellow	Stroke and Movement Specialist	Researcher
Team Leader	Community Neuro Specialist Physiotherapist	Clinician*
Team Leader	Community Stroke Specialist Physiotherapist	Clinician*
Senior lecturer	Neuro Physiotherapist	Researcher
Social Worker	Specialist in Neurorehabilitation	Clinician*
Clinical Lead Neurorehabilitation, Expertise Commissioning and Service management	Senior Clinical Specialist Therapist	Clinician*
Doctoral student	No expertise in Stroke or the PROM development methodology	Lay member
Senior Research Fellow & Honorary Clinical Academic Lead in the NHS	Advanced Clinical Specialist Occupational Therapist	Methodologist/ Clinician*/ Researcher
PhD candidate	Physiotherapist	Synthesis recorder
Research Fellow	Neurological Psychologist	Researcher
Speech and Language Therapist	Specialist Speech and Language Therapist-Community Stroke Team	Clinician*
*Clinicians were people with knowledge and experience about stroke and its impact on people's lives. They had knowledge about the latest evidence-based practice and could explain what was needed to do a comprehensive ADL assessment in clinical practice.		

Procedure

Once the panel was formed with confirmed membership, all members were briefed about the project and their role within the panel. The expert panellists were sent the paper version of the EDAQ and template of the expert panel report that was going to be used for synthesis recording by email in advance of the face-to-face meeting. They were advised to consider the EDAQ first and identify any items in which they considered that the wording needed to change to be understandable by the average 11 years old in the UK (as this is the average reading age in the UK mentioned by the UK Government in 2019) and to be culturally appropriate activities for the UK stroke survivors. Additionally, members were advised to consider if any of the items needed to be removed or any additional items needed to be added to make them relevant to stroke survivors. The expert panel meeting took place at the University of Salford and last around 90 minutes, including a break. During the meeting, clarity, comprehensiveness and relevance of the domains and items included in each domain were asked of the expert panel by using a structured report to make them relevant for stroke survivors (Terwee et al., 2018a). The meeting was audio-recorded. The audio-recording was transcribed and used alongside the handwritten notes of experts on the paper version of the measure and notes taken by the synthesis recorder were analysed following the meeting to produce a report with the revised version of the PROM. Panel members' comments and feedback was documented and added to the expert panel report to share these with the panel to review and provide further feedback to help produce the pre-final version of the EDAQ-SS, ahead of the cognitive debriefing interviews.

Expert Panel Meeting: Decisions

The Expert Panel members agreed to remove 11 items as they thought they were not relevant to stroke condition. To give an example, the expert panel thought that the 'Wash and dry your feet' question can be removed as there was another item that can cover the same point, 'Take care of your feet'. Also, the expert panel reported that some items can be dangerous for stroke survivors depending on the severity of the stroke, therefore they agreed to remove these kinds of items, such as, 'Climb ladder'. Moreover, the expert panel members decided to add 13 new items to make sure that the EDAQ-SS covers all the relevant items for stroke survivors. To give an example, stroke can result in difficulty in swallowing (Jones, Colletti & Ding, 2020; Daniels et al., 2017), therefore expert panel agreed to add 'Do you have a swallowing problem?' as an additional item (Please, refer to Appx 1 for detail).

Additionally, the expert panel agreed to rephrase the wording of 30 items to make it relevant to stroke survivors. For example, the 'Use shower controls/bath temperature mixers' item was agreed to be separated into two different questions, 'Use shower controls and 'Do you feel the temperature of the water?'. This change was agreed as the ability to use the shower controls requires muscle activation and sensation, while the loss of sensation is a different impairment that can affect the ability to feel hot and cold.

Furthermore, the score options of the eight items were changed to make it easier for stroke survivors with a vision impairment to follow the questionnaire.

Moreover, the panel advise the researcher to consult with a Speech and Language Therapist (SALT), who was not able to attend the expert panel meeting, to consider the need to add extra items under the 'Eating/Drinking' domain to cover 'Swallowing' and have the opportunity to improve the 'Communication' domain, as per their specific expertise in these areas. In addition, the expert panel recognised the need for an additional domain, to address the cognition/perception aspect of ADL limitations, which are deemed as important constructs to affect the daily activities of stroke survivors. To make sure that the pre-final version of the EDAQ-SS covered all the relevant items for stroke survivors, the expert panel also recommended consulting a cognitive psychologist with an experience of the impact of stroke on psychological functioning, as this could also affect the ADL. It was agreed that this would help to inform the items about cognition and perception also (Appx 1: the expert panel report).

This advice was followed and further discussions took place with a clinical specialist SALT identified via local networks through emails and telephone discussions. The SALT has provided additional written feedback on the PROM via email, notably commenting that '*SALT will love to have this level of detail about a patient. It could generate discussion and problem-solving opportunities*.' Her comments were added to the expert panel report following a discussion with the supervision team. This included an addition of 30 new items under five different domains (Conversation, Eating/Drinking, Reading, Writing, and Money/Numbers) (Appx 1).

At the same time, similar discussions took place with a Neurological Psychologist (NP) identified through local networks by emails and a telephone conversation. The NP was also previously involved in the development of a cognition PROM for stroke survivors (i.e., Patient Reported Evaluation of Cognitive Status (PRECİS) (Patchick, Vail, Wood, & Bowen, 2016) thus, had expert knowledge of this area of research. She has suggested that the expert panel should consider including the first 12 items of the PRECIS in the Cognition/Perception domain of the EDAQ-SS. As some of these items were already covered within the other domains of the EDAQ-SS, seven items were included in the Cognition/Perception domain following a consultation with the expert panel.

Apart from the points above, additional comments were added by the NP and SALT about the EDAQ. It was advised to change the answer option from horizontal to vertical for stroke survivors with neglect. In addition, further comments were mentioned about the instructions, additional items and redundancy. Answer options of the paper version of the EDAQ-SS agreed to a change to vertical and on the eEDAQ-SS to be kept horizontal. This provided both options to stroke survivors to get their opinions in the cognitive debriefing interviews.

In general, the feedback of the expert panel demonstrated that most of the EDAQ items are relevant for stroke survivors (Please, refer to Appx 1 for a summary of the expert panel report). This showed that people with RMDs have similar ADL limitations to stroke survivors. A few additional items and a domain needed to be included to cover all the ADL aspects for stroke survivors. After using the expert panel feedback, and editing the EDAQ-SS, both paper and eEDAQ-SS were ready for Stage 1 cognitive debriefing interviews and usability evaluation.

4.4.3 Stage 1-Part Two Cognitive Debriefing Interviews and Understanding the Usability

Conducting cognitive debriefing interviews and evaluating usability helped to make the EDAQ-SS domains and items more relevant and understandable to stroke survivors. Moreover, it resulted in developing an effective, efficient eEDAQ-SS that resulted in stroke survivors being satisfied with it.

Participants

A convenience sampling frame (i.e., stroke survivors with a variety of ages, gender, socio-economic and health status) was used at the cognitive debriefing interviews and usability evaluation to ensure that a lot of information was collected from different people.

Inclusion criteria

- People who experienced at least one stroke (of any aetiology, e.g., ischaemic or acquired/traumatic haemorrhagic)

Community-dwelling stroke survivors who;

- Are aged over 18 (no upper age limit)
- Can understand, speak and write English (as we are validating the English version of EDAQ-SS) either independently or through the assistance of a family/friend or carer
- Have no **other long-term chronic health condition that impacts their daily activities***
- Have access to the internet and a personal e-email account
- Can provide informed consent
- Live in the UK
- Can use the internet either independently or through the assistance of a family/friend or carer
- At the sub-acute or chronic stage of the stroke (≥1 week).

***They may have other long-term chronic health conditions such as arthritis or diabetes, but as long as this does not impact their daily activities as much as the stroke, they will still be eligible. Therefore, participants were asked to complete the EDAQ-SS by considering the impacts that happened after they had a stroke and not before.

Exclusion criteria

Stroke survivors who;

- Cannot give informed consent
- At the acute stage (<1 week)

Recruitment strategy

Stroke survivors were recruited by utilising the stroke volunteer database of the Clinical Rehabilitation Research Group at the UoS. Stroke survivors who had participated in previous studies at the Centre for Health Sciences Research, who agreed to be contacted for future research, were contacted by the PhD candidate. Stroke survivors from the volunteer database who met the inclusion criteria were sent a participant invitation letter by email or telephone (depending on the stated preference of the participants on the volunteer list) and kindly asked to contact the research team to express an interest in taking part in the study if they were willing to participate. When potentially eligible participants contacted the researcher, they were telephoned by the researcher at a mutually convenient date and time to discuss the study further to give them a chance to ask any questions they may have, and go through the screening to confirm their eligibility. The inclusion/ exclusion criteria stated above were used to ascertain eligibility.

Following this, participants were posted/e-mailed the participant information sheet (PIS), describing the study in further detail and a consent form with FREEPOST envelope to return. Participants have asked to consider providing consent for a minimum of 24 hours. If participants were happy to take part, they returned the signed consent form using the FREEPOST envelope. Once written consent was received, the researcher countersigned the consent form and returned a copy of the form to the participant for their records. The original consent forms were stored in a locked filing cabinet in a secure location at the UoS. Given the complex and broad effect of a stroke on participants, ten participants were desirable, and this helped to include a mixture of participants.

Procedure

Part two of Stage 1 included two steps. Firstly, participants were asked to complete the eEDAQ-SS, which was edited after the expert panel meeting, and this was followed by cognitive debriefing interviews. These interviews were aimed at helping the research team determine if there were any items in the EDAQ-SS, which needed to be added, removed or altered to be relevant for stroke survivors.

Step One-Completing the Questionnaire

After providing informed consent, participants were directed to a URL link of the SSHUB. Additionally, they received through the post an interview information letter that included a paper copy of the questionnaire (this was required to assess the paper version of the questionnaire as it can be used in paper form in the future), a consent form and FREEPOST envelopes to send the relevant paperwork back to the researcher. Alternatively, an electronic consent form was available for the participants. If participants couldn't post the consent form for any reason, they had a chance to complete an electronic version and email it back to the researcher by using their personal email address.

In addition to EDAQ-SS, the questionnaire booklet included two other PROM, the Measure of Activity Performance in the Hand (MAPHand) and the Disability Arm Shoulder Hand Scale (DASH). The data for the MAPHand and DASH questionnaires were also collected as these instruments had not been tested for use on British stroke survivors before. They have the potential to be a useful and relevant PROM to assess upper limb daily activity limitations. The data collected will be used to linguistically and cross-culturally adapt these instruments after this PhD is completed as a postdoctoral project. This decision was taken by the PhD supervision team to reduce the future burden of data collection in the same sample for PROM specific development

The researcher asked participants to complete the ePROM through SSHUB in their own time within one week of receiving it (Please, refer to Chapter Five for the SSHUB registration process). If they had any difficulties in completing the questionnaire independently (e.g., to type, read or understand), they were informed that they could get help from their family members, friends or carers. Stroke survivors informed the researcher if they required any help to complete the questionnaire during the interview. The first part of the EDAQ-SS included questions about themselves and their health (demographic details). The second part of the questionnaire included questions about limitations in daily activities.

Step Two-Cognitive Debriefing Interviews and Understanding the Usability

During the first telephone call, the researcher also arranged a time suitable for the stroke survivors who participated in the research, to take part in a cognitive debriefing interview within one week of completing the questionnaire. Stroke survivors were at their home during the cognitive debriefing interviews and the discussion happened through a telephone call with the PhD candidate at a mutually convenient date and time. It was easier to schedule telephone interviews than face-to-face meetings due to contextual factors such as being able to travel long distances, as participants were recruited from wide regions of the UK. Despite the advantages of the telephone interviews, there were some points to consider. Stroke survivors could have impairments that could be a barrier for them to conduct a telephone interview, i.e., problems with speech. There is no potential to use visual aids in a telephone interview. Therefore, participants were informed that they could choose either face-to-face interviews or telephone interviews. However, participants who agreed to participate in the project preferred the telephone interviews. The interview times were arranged depending on a participant’s preference, and they lasted for approximately one hour. Participants received the paper copy of the questionnaire to look at the format and to use it as a reference during the interview. This was because they needed the questionnaire in front of them to take part in the telephone interview to enable them to talk about each item on the questionnaire in detail with the researcher.

During the interview, the researcher had a paper version of the EDAQ-SS and a cognitive debriefing interview structured form. There was a structured form for each participant, and these forms were used to document each feedback item and comments of the participants next to relevant items and domains (Please, refer to Appx 2 for detail on cognitive debriefing interview structured form). After doing a comprehensive literature search to understand how to conduct a cognitive debriefing interview to develop a PROM, and following the guidelines, structured interview questions were agreed upon with the supervision team. The structured interview was used to understand the:

1. Clarity of the instructions, layout and length
1. How easy or difficult it was to understand the EDAQ-SS on a numeric scale of 1 to 5
2. How important it is to include or remove each item, and if there is any important activity missing (i.e., if they would like additional items to be added to given domains).

Additionally, the time participants spent completing the eEDAQ-SS and what technical problems they have faced during the submission of it for usability were considered (Hong et al., 2014). Moreover, after searching the literature, critically reviewing, linking papers, aligning with sample needs and discussing with the supervision team, additional questions (detailed below) were documented at the end of the cognitive debriefing interview questions to obtain a thorough understanding of the stroke survivors’ views of the EDAQ-

SS and evaluate if both the paper EDAQ-SS and eEDAQ-SS housed on the SSHUB are easily understandable, comprehensive and usable for stroke survivors. These questions were:

1. If the EDAQ-SS provide sufficient information to them and their healthcare professionals about the difficulties that stroke survivors face?
2. If they are satisfied with the items and domains of the EDAQ-SS and would consider using it again as a self-assessment tool?
3. How long did it take for them to complete the eEDAQ-SS and if they had any technical issues while completing it?

After the interviews, the notes and cognitive debriefing form results from the interviews were analysed with content analysis to improve the EDAQ-SS. The revised version of the EDAQ-SS was forwarded to the expert panel. In addition to the EDAQ-SS, the expert panel received the cognitive debriefing report which included the highlighted changes compared to the expert panel report. The expert panel was asked to provide feedback about the changes that occurred at the cognitive debriefing and inform the researcher if they had any further advice regards to improving the EDAQ-SS. Participants of the cognitive debriefing interview and original developer were emailed concerning the revised version of the EDAQ-SS before acceptability testing with wider participants.

Data analysis

Development of the EDAQ-SS items

During the cognitive debriefing interviews, categorical responses of the closed questions were documented, and any comments were recorded. From the responses to the cognitive debriefing interviews, the median score for the importance of items was calculated to get the spread of the middle half of the data. A decision was made for a cut-off score based on the literature for the PROM development (Hammond et al., 2014). This was, if 30% of the participants preferred to remove a question or found a question difficult to understand, the question would either be removed or rephrased if appropriate. Also, stroke survivors' comments were analysed through content analysis to decide upon the removal or addition of new items. Common methods of conducting the content analysis were used (Erlingsson

& Brysiewicz, 2017; Elo et al., 2014) and after reading the interview notes, again and again, the comments of the participants were divided into the smaller parts into meaning units. These small parts were grouped into categories and in this way, it was decided which items identified by the participants were to be added to the EDAQ-SS. The researcher finalised the British EDAQ-SS using these patient-generated items under the guidance of the supervision team before sharing the finalised questionnaire with the expert panel and participants in the cognitive debriefing interview for feedback.

Usability

During the cognitive debriefing interviews, additional questions were asked to assess the usability of the EDAQ-SS and the eEDAQ-SS (Please, refer to Table 13 for detail). The researcher recorded stroke survivors' comments by taking detailed notes to aid with the content analyses. Sentences were divided into smaller parts and coded. The percentage for the optional responses for each question were calculated.

Table 13: Questions asked to stroke survivors to evaluate the usability of the EDAQ-SS

Usability of the EDAQ
Do you think EDAQ was easy to complete?
Do you think it will provide sufficient information to your healthcare professionals about the difficulties that you face?
Do you think items of the EDAQ-SS are easy to understand?
Do you think the length of the questionnaire is good?
Would you like to add any extra or remove any items from the questionnaire? If yes, can you give detail, please?
Are you satisfied with the items and domains of the EDAQ-SS?
How long did it take for you to complete the EDAQ-SS?

Content validity

Following the completion of the cognitive debriefing interviews, the contents of the latest version of the EDAQ-SS was evaluated against the ICF linking rules (Cieza et al., 2004) to systematically link the individual items with the ICF Core Set for Stroke Conditions (Geyh et al., 2004a) to ensure that the EDAQ-SS was comprehensive (Please, refer to Table 16 and Table 17 for further details).

4.4.4 Stage 1-Findings

Participants

Cognitive debriefing interviews were conducted between December 2018 and March 2019. All volunteers from the UoS volunteer database who had agreed to be conducted again for future research were invited to take part. Thirteen people responded to the invitation, three of whom subsequently withdrew interest. One person did not want to do an interview (including both face to face and telephone interviews), and another two did not want to complete a questionnaire (both paper and electronic versions) at this time. Ten people were recruited to participate. The interview time ranged from 45 to 50 minutes. Only one interview took 120 minutes (please, refer to section 4.5.1 for detail), with rests in between as required by the participants. Participants' demographic characteristics were reported in Table 14.

***Table 14**: Stage 1: Participants' demographic characteristics*

Stroke Survivors (n: 10)	**Number**
Range of age (years)	49-81
Gender M:F (n)	7:3
Type of stroke (n)	Ischemic: 7 Haemorrhagic: 3
Injury side at the brain (n)	Brainstem: 1 Cerebellum: 1 Left: 5 Right: 3
Effects of the Stroke (n)	Hemiplegia: 7 Aphasia: 3 Vision: 3 Reduced balance: 1 Neglect: 2 Dysarthria: 1 Memory issues: 2
Accommodation (n)	House: 7 Bungalow: 1 Flat: 2
Have internal steps Y: N	7: 3
Problem using stairs Y: N	4: 6
Stair lift Y: N	1:9
Lives with family: Alone	6:4
Affected side of body Left: Right: N/A	4:5:1
Any other health condition impacting health (e.g., Arthritis) Yes: No	4: 6
Required help to complete questionnaires Yes: No	1: 9

Findings of the Cultural adaptation, Item Generation and Usability

Backwards translation of the EDAQ-SS was not needed as the items were already developed for the British English population, but rephrasing was done to ensure that they were appropriate for the target population. Participants rated Part-One of the EDAQ-SS as very important and relevant (scales of importance and relevance; 1=relevant/important: 5=not relevant/ important). For items in Part-Two, the median scores for the importance of activities were calculated as data that was not normally distributed and shown in Table 15. Eight items were preferred by 30% of the participants to be removed, also 11 additional items and two assistive devices were suggested by participants (please, refer to Appx 2 for details), and these additional items were added to the EDAQ-SS.

In addition, all participants including participants with visual impairments (two participants with neglect, a participant with blurry vision and a participant with sensitivity to light) preferred horizontal answer options as opposed to the vertical ones. Besides number scales, they preferred additional visual cues such as emoji faces, to make it clear for every stroke survivor. Moreover, participants preferred clear instructions, which explain to them that they needed to complete both sections A and B in Part-Two of the EDAQ-SS. Submitting the answers without completing both sections were not possible, as the submit button would only appear when all the questions were answered. This decision was thought before Stage 1 to avoid missing data. However, all of the participants preferred more guidance, such as highlighting the missing questions so it would be clearer for them to follow.

After collecting the quantitative data, open-ended questions were asked to identify participants' views about activities in the EDAQ-SS, whether the EDAQ-SS would be helpful in a discussion concerning their limitations with healthcare professionals and if participants were satisfied with both the EDAQ-SS and eEDAQ-SS to assess the usability. The first version of the EDAQ-SS, which was edited by the expert panel, was used at the cognitive debriefing interviews. The first version of the eEDAQ-SS took 40 minutes to complete (SD: 18.6; range 15 to 60 minutes), but some participants took longer to complete it and reported that they had taken breaks, as they were too tired to complete all the questionnaires at once. In addition, two participants had technical issues with the SSHUB which resulted in them taking a long time to complete the ePROM (Please, see Chapter Five about details of technical issues reported and how these were addressed).

Despite this, all participants reported that they found the EDAQ-SS easy to understand, detailed and relevant. Participants thought that the EDAQ-SS would provide sufficient information for their self-assessment of the ADL limitations, which will help them to discuss with their healthcare professionals. A participant mentioned that: "***EDAQ-SS underlines and shows that people can improve. I am pleased that so much work is done for stroke survivors. I think it is necessary.***" Most importantly, nine out of ten participants reported that completing the EDAQ-SS helped them to **increase their awareness** of their ADL limitations, which was an important part of the self-assessment. Only one participant out of ten reported that the EDAQ-SS was long. However, she thought that all the items were relevant and no question made her think why they were asked. Another comment from another participant was: "***This questionnaire addresses things that you avoid. It made me realise that I can do better***."

Furthermore, nine out of ten participants found it **easy** to use eEDAQ-SS at the SSHUB and they would be happy to use it in future. Seven participants out of ten reported that compared to the paper version they **prefer** to use the eEDAQ-SS. This is because they can only use one hand, so they cannot write. They found it easy to use tick boxes to answer the questionnaire. One participant mentioned that he was happy to use an electronic version if this was the only option. Two participants mentioned that they preferred the paper version (one does not use the internet and another one mentioned that people may have limited internet access, so the paper version could be useful for more people). All of the participants provided feedback to improve the SSHUB for the future (Please, refer to Chapter Five for detail).

Table 15: Summary of the Cognitive Debriefing Interview Findings

Domain and item	**Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)**	**Number of people who wanted to remove or rephrase the item**	**Rewording of the items**
EATING/DRINKING			
1.Drinking from glass	1:0	0	
2.Drinking from cup/mug	1:0	0	
3.Use a knife and fork	5:2	10	Use a cutlery
4.Slice food (e.g., bread, cheese)	1:1	0	
5.Get the milk out of the fridge	1:0	0	
6.Open a milk carton/ plastic bottle and pour out	1:0	0	
7.Open a bottle top (e.g., lager)	2: 4	3	Removed
8.Open a screw top jar or bottle	1:0	0	
9.Open a tin or a ring pull can	1:0	0	
10.Open a packet/pouch	1:0	0	
11. Enjoy a normal diet	2:1	0	
12. Enjoy a normal drink	2:1	0	
13. Keep well nourished	5:2	6	Removed
14. Enjoy meals with family/friends	1:1	0	
15. Swallow tablets	1:0	1	
IN THE BATHROOM/PERSONAL CARE			
1.Get on and off the toilet	1:0	0	
2.Wipe yourself with toilet paper /clean self below	1:0	0	
3.Using sanitary or/and incontinence products	1:0	0	
4.Flush the toilet	1:0	1	
5. Arrange your clothes before and after going to toilet	1:0	0	
6.Wash your hands	1:0	1	
7.Brush and comb your hair	1:0	0	
8. Use a tube of toothpaste	1:1	2	
9. Brush your teeth	1:0	4	Brush your teeth/dentures
10.Open a medicine bottle/ blister pack	1:0	1	

Domain and item	**Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)**	**Number of people who wanted to remove or rephrase the item**	**Rewording of the items**
11.Do your make up or shave	1:0	0	
12.Put on jewellery/watch	2:1	2	Put on standard or elasticated jewellery/watch
13. Control your bladder	1:0	0	
14. Control your bowel	1:0	0	
GETTING DRESSED/UNDRESSED			
1.Put on / take off a coat	1:0	0	
2.Pull clothes over your head	1:0	0	
3.Put on front-opening clothes	1:0	0	
4.Do up/undo buttons	1:0	0	
5. Pull clothes over your feet (e.g., trousers or skirts)	1:0	0	
6.Do up /undo zips	1:0	0	
7.Put on tights/ socks	1:0	0	
8.Take shoes/ boots on and off	1:0	0	
9.Tie shoelaces	1:0	0	
10.Put on/take off gloves	1:0	0	
11.Fasten clothes at the back	3:3	4	Fasten clothes/ undergarments at the back
BATHING/ SHOWERING			
1.Get in and out of the bath	1:0	0	
2.Shower whilst standing	1:0	0	
3.Use shower controls	1:0	0	
4.Feel the temperature of the water?	1:0	0	
5.Turn taps (any in home)	1:0	0	
6. Wash all your body parts	1:0	0	
7. Dry all your body parts	1:0	0	
8.Wash your hair	1:0	0	
9.Style/ blow-dry your hair	1:0	1	
10. Take care of your hands and feet including cutting/filing your nails	1:0	1	
COOKING			
1.Stand while working in the kitchen	1:0	0	
2.Set the table/ carry plates, cups etc	1:0	0	

Domain and item	Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)	Number of people who wanted to remove or rephrase the item	Rewording of the items
3.Peel and chop vegetables	1:0	0	
4.Carry a full pan to/ from the cooker	1:0	0	
5.Drain water from a saucepan (e.g., vegetables, pasta)	1:0	0	
6.Remove heavy items (e.g., bag of sugar) from top cupboards	1:0	0	
7.Baking (e.g., cakes, bread, pastry)	1:0	0	
8.Take things in/out of oven	1:0	0	
9.Wash up	1:0	0	
10.Put crockery/pans etc., into kitchen cupboards	1:0	0	
11.Use a kettle (e.g., fill, pour)	1:0	0	
12. Use your cooker/microwave	1:0	0	
13.Open fridge door	3:2	7	Removed
14.Prepare and cook a snack and/or a meal	1:0	1	
MOVING AROUND IN DOORS			
1.Walk indoors (e.g., get to toilet/ bathroom; round kitchen)	1:0	0	
2.Open the front/ back door	1:0	0	
3.Lock and unlock doors	1:0	0	
4.Get to the front door in time to answer	1:0	0	
5.Get to the phone in time to answer	1:0	0	
6.Stand for longer periods	1:0	0	
7.Get up and down steps/ stairs	4:3	8	Separated into two different questions: -Get up and down steps -Get up and down stairs
8.Bend to floor/pick up items	1:0	0	
9.Reach up	2:1	2	
10. Get on /off floor	1:0	0	

Domain and item	**Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)**	**Number of people who wanted to remove or rephrase the item**	**Rewording of the items**
11. Carry items around the house	1:0	0	
12.Manage heating (e.g., controls, woodburner, multifuel stove, open fire)	1:0	0	
CLEANING THE HOUSE			
1.Make the bed	1:0	0	
2.Dust and wipe surfaces	1:0	0	
3.Sweep up/ mop floor	1:0	2	
4.Wring out a cloth	1:0	0	
5.Vacuum clean	1:0	2	
6.Open a window	1:0	0	
7.Clean windows	1:0	0	
8.Clean the bath and/or shower	1:0	0	
9.Heavy housework (e.g., move furniture, take down curtains)	2:1	2	
LAUNDRY/ CLOTHES CARE			
1.Do the hand washing	3:3	3	Removed
2.Use a washing machine (e.g., load and unload)		0	
3. Hang out and folding washing	1:0	0	
4.Plug in and pull out a plug (any in home)	1:0	1	
5.Put up an ironing board	1:0	0	
6.Iron	1:0	0	
7.Do small repairs e.g., hemming, buttons	1:0	2	
8.Cut cloth and/ or use scissors	1:0	3	Use scissors
9.Pick up pins/needles	4:1	4	Removed
MOVING AND TRANSFERS			
1.Get into and out of bed	1:0	0	
2.Turn over and sit up in bed	1:0	1	
3. Stand up from a chair	1:0	0	
4.Pull up bedclothes/duvet	1:0	0	
5.Getting a comfortable sleeping position	1:0	1	
6. Sit independently (e.g., in a car, train)	1:0	0	
7. Move from bed to chair	1:0	0	
COMMUNICATION			

Domain and item	**Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)**	**Number of people who wanted to remove or rephrase the item**	**Rewording of the items**
1.Use a phone / mobile (call/ text/ any functions)	1:0	1	
2.Read directions on food packets	1:0	0	
3. Follow instructions on a microwave	1:0	0	
4.Read and choose from a menu	1:0	2	
5. Read newspapers/magazine/books	1:0	2	
6. Read street names and road signs	1:0	0	
7. Read maps	1:0	0	
8. Use a computer and a mouse	1:0	0	
9. Use remote controls and/ or environmental control	3:1	3	Removed
10. Write a shopping list	1:0	0	
11. Write a letter	1:0	10	Write a letter/card
12. Fill out a from	1:0	0	
13. Write a card	1:0	10	Removed
14. Chat in social situations	1:0	0	
15. Talk with the doctor	1:0	0	
16. Order in a café, pub or restaurant	1:0	0	
17. Ask and/or give directions	1:0	0	
18. Tell bus/taxi driver your destination	1:0	0	
19. Ask for something in a local shop	1:0	0	
20. Exchange something	1:0	0	
21. Complain in a shop	1:0	0	
22. Give money and count change	1:0	0	
23. Use a pin pad in cash machine	1:0	0	
MOVING AROUND OUTSIDE/ SHOPPING			
1.Walk on level ground	1:0	0	
2.Go for a long walk (e.g., a mile)	1:0	0	
3.Go upstairs without a handrail	4:1	10	Removed
4.Travel by public transport	1:0	2	Separated into two different questions:

Domain and item	**Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)**	**Number of people who wanted to remove or rephrase the item**	**Rewording of the items**
			- Get on and off a bus -Get on and off a train
5.Get in and out of a car and open car door	1:0	0	
6.Drive a car (e.g., hold steering wheel, turn car key, change gear)	1:0	2	
7.Fill the car with petrol	1:0	0	
8.Open a heavy (e.g., shop) door	1:0	0	
9.Walk around the shops	1:0	0	
10.Carry shopping	1:0	0	
11.Do the weekly shopping	1:0	0	
12.Safely cross the road in time for the light	1:0	0	
13. Walking on uneven floor	1:0	0	
14. Walking in slopes	1:0	0	
GARDENING/ HOUSEHOLD MAINTENANCE			
1.Light gardening (e.g., weed, prune, plant)	1:0	0	
2. Heavy gardening (e.g., dig, mow)	1:0	2	
3.Clean the car (inside and out)	1:0	2	
4.Do household repairs	1:0	1	
5.Car maintenance (e.g., oil, water)	1:4	4	Removed
CARING			
1. Feed another person, prepare bottles	1:0	0	
2. Bathe another person/ change nappies	1:0	0	
3. Dress another person	1:0	0	
4. Do another person's hair	1:0	0	
5. Use equipment for another person (e.g., high chair, push wheelchair, car seat)	1:0	0	
6. Put another person in/ out of high chair, push chair, high seat, wheelchair	1:0	0	
7. Help move another person	1:0	0	

Domain and item	Participants' relevance rating (Median: IQR) (1 =relevant, 5 =not relevant)	Number of people who wanted to remove or rephrase the item	Rewording of the items
8. Engage or occupy with another person	1:0	0	
HOBBIES, LEISURE AND SOCIAL ACTIVITIES			
1.Crafts (e.g., knitting, crochet, sewing, embroidery, model making)	1:0	0	
2.Do-It-Yourself (e.g., using tools, decorating)	1:0	2	
3.Visit friends/ socialising(e.g., pub, cinema, theatre)	1:0	0	
4.Attend community / religious groups or classes	1:0	0	
5.Physical activities (e.g., dance, active sports, swimming, bicycling, fishing)	1:0	0	
6.Quiet recreation (e.g., painting, cards)	1:0	0	
7.Performing arts (e.g., music, choir, dramatics)	1:0	0	
8. Pet care (e.g., feed, groom, walk)	1:0	0	
COGNITION/PERCEPTION			
1. Think quickly	1:0	0	
2. Concentrate	1:0	1	Concentrate (e.g., when driving, talking, reading)
3. Remember new things	1:0	0	
4. Discuss news/current issues	1:0	0	
5. Make decisions	1:0	1	Separated into two questions: - Make a decision about daily choices (e.g., what to eat) -Make decisions about financial issues (e.g., manage money)
6. Do things in the right order	1:0	1	Do things in an order

After the completion of the cognitive debriefing interviews with stroke survivors, the EDAQ-SS was revised in accordance with the comments from stroke survivors, which helped to make the EDAQ-SS relevant and understandable to the target population. As recommended by the linguistic validity and cultural adaptation guidelines, the edited version of the EDAQ-SS was reviewed by the expert panel members following the cognitive debriefing interviews. The expert panel agreed with the changes in the report that had occurred after the cognitive debriefing interviews, which were highlighted and justified. The researcher contacted expert panel members individually to acquire their views on the changes. Feedback was collated, analysed and the EDAQ-SS was edited further to meet both the expert panel's recommendations and stroke survivors' needs. Following the approval of the final version of the questionnaire by the expert panel, the EDAQ-SS was shared with the original developers and participants of the cognitive debriefing interviews for further comments. Linguistic and cultural adaptation of the EDAQ-SS was completed as no further changes were required by the stroke survivors or the original developer. The EDAQ-SS was deemed to be understandable, relevant and comprehensive. The next stage in the development of the EDAQ-SS was to examine its' content validity.

The International Classification of Functioning Linking

The ICF has provided a needed international standard in functioning, disability and health (WHO, 2001). The ICF model reports that people's disability functioning is linked with their health conditions and contextual factors. Therefore, it is important to understand the effect of environmental and personal factors on an individuals' activities and participation to be able to differentiate their capacity to do these from their performance. For example, an individual might have a limitation in bathing independently, which is a capacity issue, but this limitation could be supported by environmental facilitators e.g., a bath seat and hand rails, enabling them to function independently in performing this task. However, to be able to understand the full picture of a person's functioning, it was necessary to include the ICF domains in a questionnaire (Raggi et al., 2013). ICF linking rules were used by researchers across the globe and it helps to create the language for describing a person's health and lived experience of health. A PROM needs to have a systematic link with corresponding categories of the ICF (Cieza et al., 2002). It is reported by MacDermid (2021), that ICF linking rules and cognitive debriefing interview procedures are necessary for a PROM to have good content validity. For the stroke-specific tools, ICF linking rules can be used to systematically link the ICF Core Sets of Stroke for post-acute care with the items of the PROM (Geyh et al., 2004a; Geyh et al., 2004b; Cieza et al., 2002).

Due to this reason, each item of the EDAQ-SS was systematically linked with the ICF code, within the ICF Core Sets of Stroke. Initial linking was done by the PhD candidate, which then was checked and validated by the lead supervisor. Results showed that the EDAQ-SS has good content validity as most of the ICF Stroke Core Set Activities and Participation items (44/51 categories) were included (Please, see Table 16 and 17 for details). Seven items of the ICF Stroke Core Set Activities and Participation (d465- Moving around using equipment, d172-Calculating, d240-Handling stress and other psychological demands, d845-Acquiring, keeping and terminating a job, d770-Intimate relationships, d855-Non-remunerative employment and d850-Remunerative employment) were not covered by the EDAQ-SS. However, these items were not seen as problematic during the expert panel meeting and cognitive debriefing interviews by stroke survivors.

Table 16: ICF linking with items of the EDAQ-SS

Domain and items	ICF Code/ICF Category
EATING/DRINKING	
1. Drink from a glass	D445- Hand and arm use
2. Drink from a cup/mug	D445- Hand and arm use
3. Use cutlery	D550- Eating
4. Slice food (e.g., bread, cheese)	D440- Fine hand use
5. Get the milk out of the fridge	D440 (inclusion: picking up, grasping, manipulation and releasing)- Fine hand use
6. Open a milk carton/ plastic bottle and pour out	D440- Fine hand use
7. Open a screw top jar or bottle	D440- Fine hand use
8. Open a tin or a ring pull can	D445- Hand and arm use
9. Open a packet/pouch	D440- Fine hand use
10. Enjoy a normal diet	D550- Eating
11. Enjoy a normal drink	D550- Eating
12. Enjoy meals with family/ friends	D710- Basic interpersonal interactions
13. Swallow tablets	D550- Eating
IN THE BATHROOM/ PERSONAL CARE	
1. Get on and off the toilet	D410- Changing basic body position
2. Wipe yourself with toilet paper /clean self below	D530- Toileting
3. Using sanitary or/and incontinence products	D530- Toileting
4. Flush the toilet	D445- Hand and arm use
5. Arrange your clothes before and after going to toilet	D540- Dressing
6. Wash your hands	D510- Washing oneself
7. Brush and comb your hair	D520- Caring for body parts-
8. Use a tube of toothpaste	D520- Caring for body parts
9. Brush your teeth/dentures	D440- Fine hand use
10. Open a medicine bottle/ blister pack	d445- Hand and arm use
11. Do your make up or shave	D520- Caring for body parts
12. Put on standard or elasticated jewellery/watch	D440- Fine hand use
13. Control your bladder	D530- Toileting
14. Control your bowel	D530- Toileting

Domain and items	ICF Code/ICF Category
GETTING DRESSED/ UNDRESSED	
1. Put on / take off a coat	D540- Dressing
2. Pull clothes over your head	D540- Dressing
3. Put on front-opening clothes	D540- Dressing
4. Do up/undo buttons	D440- Fine hand use
5. Pull clothes over your feet (e.g., trousers or skirts)	D540- Dressing
6. Do up /undo zips	D440- Fine hand use
7. Put on tights/ socks	D540- Dressing
8. Take shoes/ boots on and off	D540- Dressing
9. Tie shoelaces	D440- Fine hand use
10. Put on/take off gloves	D540- Dressing
11. Fasten clothes/ undergarments at the back	D445- Hand and arm use
BATHING/ SHOWERING	
1. Get in and out of the bath	D420- Transferring oneself
2. Shower whilst standing	D510- Washing oneself
3. Use shower controls	D440- Fine hand use
4. Feel the temperature of the water	D510- Washing oneself
5. Turn taps (any in home)	D440- Fine hand use
6. Wash your all body parts	D510- Washing oneself
7. Dry your all body parts	D510- Washing oneself
8. Wash your hair	D510- Washing oneself
9. Style/ blow-dry your hair	D520- Caring for body parts
10. Take care of your hands and feet including cutting/filing your nails	D520- Caring for body parts
COOKING	
1. Stand while working in the kitchen	D415- Maintaining a body position
2. Set the table/ carry plates, cups etc.	D430- Lifting and carrying objects
3. Peel and chop vegetables	D630- Preparing meals
4. Carry a full pan to/ from the cooker	D630- Preparing meals
5. Drain water from a saucepan (e.g., vegetables, pasta)	D430- Lifting and carrying objects
6. Remove heavy items (e.g., bag of sugar) from top cupboards	D430- Lifting and carrying objects
7. Baking (e.g., cakes, bread, pastry)	D630- Preparing meals

Domain and items	ICF Code/ICF Category
8. Take things in/out of oven	D430- Lifting and carrying objects
9. Wash up	D640- Doing housework
10. Put crockery/pans etc., into kitchen cupboards	D430- Lifting and carrying objects
11. Use a kettle (e.g., fill, pour)	D430- Lifting and carrying objects
12. Use your cooker/ microwave	D430- Lifting and carrying objects
13. Prepare and cook a snack and/or a meal	D630- Preparing meals
MOVING AROUND IN DOORS	
1. Walk indoors (e.g., get to toilet/ bathroom; round kitchen)	D460- Moving around in different locations
2. Open the front/ back door	D445- Hand and arm use
3. Lock and unlock doors	D445- Hand and arm use
4. Get to the front door in time to answer	D460- Moving around in different locations
5. Get to the phone in time to answer	D460- Moving around in different locations
6. Stand for longer periods	D415- Maintaining a body position
7. Get up and down steps	D460- Moving around in different locations
8. Get up and down stairs	D460- Moving around in different locations
9. Bend to floor/pick up items	D410- Changing basic body position
10. Reach up	D445- Hand and arm use
11. Get on/off floor	D410- Changing basic body position
12. Carry items around the house	D430- Lifting and carrying objects
13. Manage heating (e.g., controls, wood burner, multifuel stove, open fire)	D440- Fine hand use
CLEANING THE HOUSE	
1. Make the bed	D640- Doing housework
2. Dust and wipe surfaces	D640- Doing housework
3. Sweep up/ mop floor	D640- Doing housework
4. Wring out a cloth	D445- Hand and arm use
5. Vacuum clean	D640- Doing housework
6. Open a window	D445- Hand and arm use
7. Clean windows	D640- Doing housework
8. Clean the bath and/or shower	D640- Doing housework
9. Heavy housework (e.g., move furniture, take down curtains)	D640- Doing housework
LAUNDRY/ CLOTHES CARE	

Domain and items	ICF Code/ICF Category
1. Use a washing machine (e.g., load and unload)	D640- Doing housework
2. Hang out and folding washing	D640- Doing housework
3. Plug in and pull out a plug (any in home)	D440- Fine hand use
4. Put up an ironing board	D445- Hand and arm use
5. Iron	D640- Doing housework
6.Do small repairs e.g., hemming, buttons	D440- Fine hand use
7. Use scissors	D440- Fine hand use
MOVING AND TRANSFERS	
1. Get into and out of bed	D420- Transferring oneself
2. Turnover and sit up in bed	D410- Changing basic body position
3. Stand up from a chair	D410- Changing basic body position
4. Pull up bedclothes/duvet	D440- Fine hand use
5. Getting a comfortable sleeping position	D415- Maintaining a body position
6. Sit independently (e.g., in a car, train)	D415- Maintaining a body position
7. Move from bed to chair	D420- Transferring oneself
COMMUNICATION	
1. Use a landline phone / mobile (call/ text/ any functions)	D360- Using communication devices and techniques
2. Read directions on food packets	D166- Reading
3. Follow instructions on microwave	D155- Acquiring skills
4. Read and choose from a menu	D166/ d315- Reading/ Communicating with receiving non-verbal messages
5. Read newspapers/ magazine/books	D166- Reading
6. Read street names and road signs	D166- Reading
7. Read maps	D166- Reading
8. Use a computer and a mouse	D360- Using communication devices and techniques
9. Write a shopping list	D170/ d335- Writing / Producing non-verbal messages
10. Write a letter/card	D345/ d315- Writing messages/ Communicating with receiving non-verbal messages
11. Fill out a form	D155/d315- Acquiring skills/ Communicating with receiving non-verbal messages
12. Chat in social situations	D350/d750- Conversation/ Informal social relationships

Domain and items	ICF Code/ICF Category
13. Talk with the doctor	D330- Speaking
14.Order in a café, pub or restaurant	D155- Acquiring skills
15. Ask and/or give directions	D230- Carrying out daily routine
16. Tell bus/taxi driver your destination	D210- Undertaking a single task
17. Ask for something in a local shop	D310- Communicating with – receiving – spoken messages
18. Exchange something	D175- Solving problems
19. Complain in a shop	D175- Solving problems
20. Give money and count change	D860- Basic economic transactions
21. Use a pin pad in cash machine	D440- Fine hand use
MOVING AROUND OUTSIDE/ SHOPPING	
1. Walk on level ground	D450- Walking
2. Go for a long walk (e.g., a mile)	D450- Walking
3. Get on and off a bus	D470- Using transportation
4. Get on and off a train	D470- Using transportation
5. Get in and out of a car and open car door	D420- Transferring oneself
6. Drive a standard or adapted car	D475- Driving
7. Fill the car with petrol	D620- Acquisition of goods and services
8. Open a heavy (e.g., shop) door	D445- Hand and arm use
9. Walk around the shops	D460- Moving around in different locations
10. Carry shopping	D430- Lifting and carrying objects
11. Do the weekly shopping	D620- Acquisition of goods and services
12. Safely cross the road in time for the light	D460- Moving around in different locations
13. Walking on uneven floor	D455- Moving around
14. Walking in slopes	D455- Moving around
GARDENING/ HOUSEHOLD MAINTENANCE	
1. Light gardening (e.g., weed, prune, plant)	D155- Acquiring skills
2. Heavy gardening (e.g., dig, mow)	D155- Acquiring skills
3. Clean the car (inside and out)	D210- Undertaking a single task
4. Do household repairs	D210- Undertaking a single task
CARING	
1. Feed another person, prepare bottles	D570- Looking after one’s health

Domain and items	ICF Code/ICF Category
2. Bathe another person/ change nappies	D570- Looking after one's health
3. Dress another person	D570- Looking after one's health
4. Do another person's hair	D570- Looking after one's health
5. Use equipment for another person (e.g., high chair, push wheelchair, car seat)	D570- Looking after one's health
6. Put another person in/ out of high chair, push chair, high seat, wheelchair	D570- Looking after one's health
7. Help move another person	D570- Looking after one's health
8. Engage or occupy with another person	D570- Looking after one's health
14. HOBBIES, LEISURE AND SOCIAL ACTIVITIES	
1. Crafts (e.g., knitting, crochet, sewing, embroidery, model making)	D920- Recreation and leisure
2. Do-It-Yourself (e.g., using tools, decorating)	D920- Recreation and leisure
3. Visit friends/ socialising (e.g., pub, cinema, theatre)	D760- Family relationships
4. Attend community / religious groups or classes	D910- Community life
5. Physical activities (e.g., dance, active sports, swimming, bicycling, fishing)	D920- Recreation and leisure
6. Quiet recreation (e.g., painting, cards)	D920- Recreation and leisure
7. Performing arts (e.g., music, choir, dramatics)	D920- Recreation and leisure
8. Pet care (e.g., feed, groom, walk)	D570- Looking after one's health
15. COGNITION/ PERCEPTION	
1.Think quickly	D160/230- Focusing attention/ Carrying out daily routine
2.Concentrate (e.g., when driving, talking, reading)	D160- Focusing attention
3.Remember new things	D210- Undertaking a single task
4.Discuss news/current issues	d325/d115- Communicating with – receiving – written messages/ Listening
5. Make a decision about daily choices (e.g., what to eat)	D230- Carrying out daily routine
6. Make decisions about finances (e.g., manage money)	D870- Economic self-sufficiency
7. Do things in order	D220- Undertaking multiple tasks
8. Notice things on both side of you	D160- Focusing attention

Table 17: ICF linking for Part 1 (About You and Your Health) items of the EDAQ-SS

Part one items	**ICF Code/ICF Category**
Mood	B152- Emotional functions
Pain when resting	B280- Sensation of pain
Pain when moving	B280- Sensation of pain
Stiffness	B735- Muscle tone functions
Fatigue	B130- Energy and drive functions
Worry	B152- Emotional functions
Sleep problems	B134- Sleep functions
Satisfaction with life	-

4.5 Discussion

Linguistic and cross-cultural adaptation is a long process that requires an iterative approach from multiple stakeholders (van Alphen et al., 2015). However, to achieve the most accurate results, the EDAQ-SS was linguistically and cross-culturally adapted for British stroke survivors by following the guidelines (steps 3-5) and considering the recommendations of the expert panel and stroke survivors. Therefore, the Stage 1-Part One process of the EDAQ-SS development meets the requirements for PROM development, as it was developed with stroke survivors' perspectives in mind. In addition to the paper version, the eEDAQ-SS was developed to help stroke survivors to use it as a self-assessment tool to improve their self-management. The EDAQ-SS's content validity was established for the first time by using the ICF linking strategy. However, there is still much work to be done to assess the methodological qualities and psychometric properties of the EDAQ-SS using a larger, more representative sample to ensure that the EDAQ-SS is a valid and reliable PROM and can be recommended for use in assessing ADL limitations for stroke survivors. However, this could not be done within the PhD timeline due to recruitment challenges. Please, refer to section 6.7.1 for more detail.

4.5.1 The EDAQ-SS Linguistic and Cultural validity

Linguistic and cultural adaptation was an important process to make sure that EDAQ-SS was developed by following the required guidelines and adapted for stroke survivors by considering their culture and limitations. Initially, after the expert panel meetings, 11 items were removed from the EDAQ, and eight more items were removed after the cognitive debriefing interviews by stroke survivors. After completing the cognitive debriefing interviews and expert panel meetings, it was recognised that stroke survivors' perspectives can differ from healthcare professionals, which is why it is important to incorporate target populations' views when developing a PROM. Therefore, considering both the ideas of stroke survivors, who are experts on how stroke affects them and the knowledge and experience of healthcare professionals, who see stroke survivors with different impacts each day, helped to develop a comprehensive PROM that helps to show differences between capacity and performance for stroke survivors. This helped to develop a tool with good content validity, which makes the EDAQ-SS different from other available PROM.

Generic PROM, such as BI, are often used as part of stroke management. However, generic tools are not clinically contextualised and they are not developed with the involvement of the target population, which results in a lack of content validity due to poor comprehensiveness (van Alphen et al., 2018). As mentioned in Chapter Three, lack of comprehensiveness was the main limitation of other PROM that aim to assess limitation in ADL of stroke survivors. After developing the EDAQ-SS, the ICF linking helped to recognise that the EDAQ-SS is the most comprehensive PROM to assess ADL limitations for stroke survivors when compared to other PROM that was found at systematic review (SIS, BI, RMI, MRS, SIPSO, LHS, SSQOL, BOSS, NEADL, RNLI, FAI, ArmA). Following the guidelines and conducting an expert panel meeting followed by a cognitive debriefing meeting helped to achieve this comprehensiveness.

Cognitive debriefing interviews took 45 to 50 minutes for nine participants as they were happy with the content and thought that the EDAQ-SS is easy to understand. Only one participant required 120 minutes to complete the cognitive debriefing interview as he provided detailed comments about each item of the EDAQ-SS. The participant was asked if he would like to continue another day, but he preferred to finish the interview and mentioned that time was not an issue for him. At the end of the cognitive debriefing interview, it was realised that all the 160 items in 15 domains at the EDAQ-SS were relevant to stroke survivors, which showed that other PROM content was not enough to cover all the ADL limitations from stroke survivors' perspective.

The linguistic validity and cultural adaptation of the EDAQ-SS have shown that even a PROM is developed in the target population language, it still needs to be linguistically and culturally adapted for a new population as each health condition may result in different impairment. The changes in the EDAQ for RMDs showed that stroke survivors need more detailed PROM to assess ADL limitations as they might have additional limitations and require rephrasing of words to make the activities relevant to their impairments. On the other hand, linguistic and cross-cultural adaptation is not enough for a PROM to be used or recommended to be used by patients. The validity, reliability, responsiveness, acceptability and usability of a PROM need to be considered before it can be used efficiently (Weldring & Smith, 2013).

4.5.2 Usability

A stroke has a different impact on different people, therefore time needed to complete the eEDAQ-SS can change depending on people. However, in general, it took 40 minutes to complete, and this can put time pressure on people. To eliminate this time pressure, stroke survivors were able to complete the eEDAQ-SS (including all 15 domains) within a week. They could save their answers and continue whenever they felt comfortable.

On top of this, stroke survivors who completed the eEDAQ-SS reported that they realised the differences between the eEDAQ-SS and other PROM which were available on the SSHUB. Nearly, 80% of stroke survivors reported limitations of other ePROM, i.e., not having the 'Not Applicable' option and forcing stroke survivors to provide an answer to an item that is not relevant to them or having general questions on ADL. Researchers might eliminate including the 'Not Applicable' option as it can be a challenging process to score this option and can have an impact on the total score (Kelly et al., 2018; Holman, Glas, Lindeboom, Zwinderman, & de Haan, 2004). However, it is important to consider that not every single item that is included in a PROM will be relevant for each stroke survivor. Therefore, forcing them to provide a negative or positive answer to an item without giving them the opportunity of the 'Not Applicable' option might result in them having a wrong total score or increase the chance of not using the PROM. One participant has reported that she did not want to complete other PROM than the EDAQ-SS that were available on the SSHUB, as they did not have a 'Not Applicable' option. She felt that other PROM were forcing her to answer an activity that was not part of her life before the stroke. This showed that EDAQ-SS has advantages compared to other PROM and nine out of ten stroke survivors were happy with the content of the EDAQ-SS. They have reported that eEDAQ-SS helps them to increase their awareness and motivate them.

On the other hand, most of the stroke survivors found it difficult to understand how to complete both sections A and B of the EDAQ-SS. Therefore, a few adaptations were carried out to the SSHUB to make the instructions easier and submission simple (Please, refer to Chapter Five for details). The evaluation of the usability helped to understand the technical issues that stroke survivors can have when completing the eEDAQ-SS, which helped to improve the inclusivity of the eEDAQ-SS from the SSHUB. Usability assessment was an important process, as it helps to develop tools that are effective, efficient and satisfying (W3C Web Accessibility Initiative, 2016). Lack of usability can result in unsatisfaction of the target people, which will make them not use the tool as part of rehabilitation. Therefore, it was an important part to consider the usability assessment of the EDAQ-SS and make it a user-friendly, easy to use tool for stroke survivors before further evaluating its psychometric properties.

4.5.3 Content Validity

Content validity is an important part of the PROM development process as it helps the PROM to have relevant items that are representative of the target population' conditions (MacDermid, 2021; Mokkink et al., 2010). The EDAQ-SS had good content validity based on the ICF Core Set for Stroke as almost all of the categories of the activities and participation were covered, except seven out of 51 categories. This is because the ICF linking process, which focuses on the content, and cognitive debriefing interviews, which focuses on how patients interpret responses to the content, are complementary methods to develop a PROM with a good content validity (MacDermid, 2021). Both methods were involved in the development process of the EDAQ-SS. Therefore, the EDAQ-SS is more comprehensive compared to the rest of the PROM, which aims to assess ADL limitations for stroke survivors (such as; SIS and BOSS) (Doyle et al., 2003; Duncan et al., 1999). Unfortunately, during the systematic review, it was recognised that not all of the previously developed PROM included the cognitive debriefing interviews or ICF linking methods as part of their development process, which resulted in developing PROM with a lack of comprehensiveness.

Forty-four categories of the ICF Core Set for Stroke out of 51 (82.4%) were covered by the EDAQ-SS. The rest of the categories, which were not included in the EDAQ-SS were not seen as problematic by stroke survivors as they did not ask to involve these as an item, even after discussing these categories with stroke survivors. They thought that these categories were covered as part of other questions. The category, which questions the use of equipment, was covered in section B of the questionnaire and not specifically covered by an item. However, this is not an issue because the use of equipment was not an item in the EDAQ-SS either as it was relevant for all of the items. After searching other PROM for ADL limitations, it was realised that the EDAQ-SS is the only PROM that aims to show the effect of the equipment on activity level for stroke survivors, which can show stroke survivors if they can improve or affect their independence in an ADL by using help or equipment and help them to increase their awareness. For example, SIS helps to show that stroke survivors can have limitations with cutting food by using a fork and knife. However, the limitation in this activity does not make that person limited. It is important to consider if that person can achieve this activity with an adaptation, i.e., adapted cutlery. Therefore, having a PROM that can show stroke survivors what activity they can achieve with an adaptation can increase their self-awareness and help them to have better QoL. However, none of the other PROM that helps to assess ADL limitations for stroke survivors can do this, except the EDAQ-SS. For that reason, the eEDAQ-SS may have a good potential to be used as part of self-management as it will help to increase stroke survivors' awareness of their capacity.

In addition, the items which were missing from the EDAQ-SS, such as; the personal and intimate relationships and information about employment, were not identified as problematic in the cognitive debriefing interviews. However, the information about the employment situation was covered in the registration part of the SSHUB. The EDAQ-SS may have been too focused on everyday activities for stroke survivors, which resulted in the elimination of consideration of relationships as appropriate. Personal and intimate relationships and employability were documented under the ICF Stroke Core Set Activities and Participation categories but, they were not reported as an important item by stroke survivors in the development stage of the EDAQ-SS.

To summarise, the EDAQ-SS is developed to be used as a self-assessment tool to help stroke survivors to increase their limitations in ADL comprehensively, and including more items would increase time to complete it, which may result in stroke survivors not being willing to complete it. Content validity assessment showed the comprehensiveness of the EDAQ-SS and the difference of it from other PROM. As the EDAQ-SS has good content validity, it could be considered to be used as a self-assessment tool to assess ADL limitations in detail and increase stroke survivors' awareness by helping them to realise their limitations and not to ignore them in their self-management.

4.5.4 Comparing EDAQ-SS with other PROM

To date, the EDAQ-SS is the only comprehensive PROM in ADL to show the impact of environmental modifications on ADL function. Thus, differentiate capacity from performance when considering potential disabilities. Additionally, the eEDAQ-SS was deemed by stroke survivors as having the potential to be a good self-assessment tool to evaluate their ADL limitations. Also, unlike other PROM, the eEDAQ-SS is freely available via an online platform specifically developed for stroke survivors, with their preferences as to the design to increase usability. The eEDAQ-SS provides potential to stroke survivors to evaluate their ADL limitations in different domains and track their changes over time, as and when they require to do so to monitor their progress. This is not possible for stroke survivors to do with any other stroke PROM, as they are either not comprehensive, or consider environmental factors, and most importantly not easily available through a self-assessment platform to track their progress over time.

Digital interventions are commonly and effectively used as part of self-management for other chronic conditions, such as RA, diabetes, hypertension, asthma, and heart disease. The aim of self-management is not to replace professional care received by healthcare professionals, but to help people to manage their condition, improve their independence and achieve better healthcare (Taylor et al., 2014). It was reported by Morton et al. (2017) that the use of digital interventions helps people to monitor their health and results in greater self-awareness to motivate them and improve themselves. The EDAQ-SS is based on the EDAQ for RMDs, and as explained before, the EDAQ was successfully embedded within a self-management/data repository platform; the MSKHUB, of which the UoS is the sponsor and data custodian (Please, refer to section 5.3.1 for detail). Therefore, the development of the SSHUB that will be based on the EDAQ-SS has the opportunity to provide easy use of the EDAQ-SS, which will improve the self-assessment. It will also help to collect data from stroke survivors by completing the comprehensive EDAQ-SS which has the potential to conduct further research and help stroke rehabilitation and assessment process. The ePROM use has become more popular with the development of digital health as they have more potential to provide easier access and improve the self-assessment by developing awareness of limitations.

Another research done by Tai et al., (2020) showed that the use of the EQ-5D-5L, which is a PROM used to measure QoL, helped people to improve their self-awareness and support their adherence. So, literature shows that the use of a PROM and ePROM has the potential to work for other conditions. The development of the eEDAQ-SS helped to develop a comprehensive tool that can show the impact of environmental modifications on ADL functioning and can be used easily as a self-assessment tool. As stroke can lead to life-long limitations, the use of the eEDAQ-SS via the SSHUB may result in improvements in self-management and help for prevention. However, before the use of the eEDAQ-SS as a self-assessment tool can be advised, its acceptability needs to be evaluated, which is Stage 2 of the EDAQ-SS development process (Please, refer to Chapter 5, section 5.3.3). This is because if a tool is acceptable by the target population it can ensure that the tool can be used. The next chapter explained the development process and acceptability testing of the eEDAQ-SS and the SSHUB.

CHAPTER FIVE: DEVELOPMENT AND TESTING OF THE STROKE SURVIVORS HUB (SSHUB)

5.1 Introduction

This chapter aims to provide further information and the rationale behind the development of the Stroke Survivors HUB (SSHUB) available online via www.strokesurvivorshub.com. Firstly, justifications were made for the chosen steps to develop the SSHUB. Secondly, methods that guide the design of an online self-management platform for British adults with stroke was explained. Thirdly, the usability and acceptability of this platform by stroke survivors were evaluated and reported in this chapter. Finally, the data collected during the development and testing stage of the eEDAQ-SS was also used to conduct a descriptive analysis to estimate the pattern and distribution of ADL limitations in British stroke survivors, as there is no detailed data on this in the literature.

5.2 Rationale for the aim

The impairment of stroke results in burdens on stroke survivors' QoL and healthcare system (Steven, Emmett, Wang, McKevitt, & Wolfe, 2017; Béjot, Daubail, & Giroud, 2016). Research has shown that stroke survivors feel unprepared during the transition period from home to the community (Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015). Self-management become an important part of stroke rehabilitation to facilitate the interventions related to transitional care and support the long-term impact of stroke (Fugazzaro et al., 2021; Eng et al., 2019; Fryer, Luker, McDonnell, & Hillier, 2016). It is reported that the use of digital health technologies helps to provide more effective self-management (Morton et al., 2016). Worldwide, people of all ages and from different sociodemographic backgrounds are more comfortable using digital technologies (Biesdorf & Biedermann, 2014). Moreover, ePROM administration has more benefits than the pen-and-paper version (Meirte et al., 2020) and it improves self-management (Santana & Tomkins, 2021). As mentioned in Chapter Two, there is a lack of an online platform that houses ePROM for stroke survivors to use as part of their self-assessment, which can result in the positive effect that stroke survivors can gain. Therefore, it was important to develop an online platform that houses the eEDAQ-SS to help stroke survivors use it as part of their self-assessment to guide their self-management.

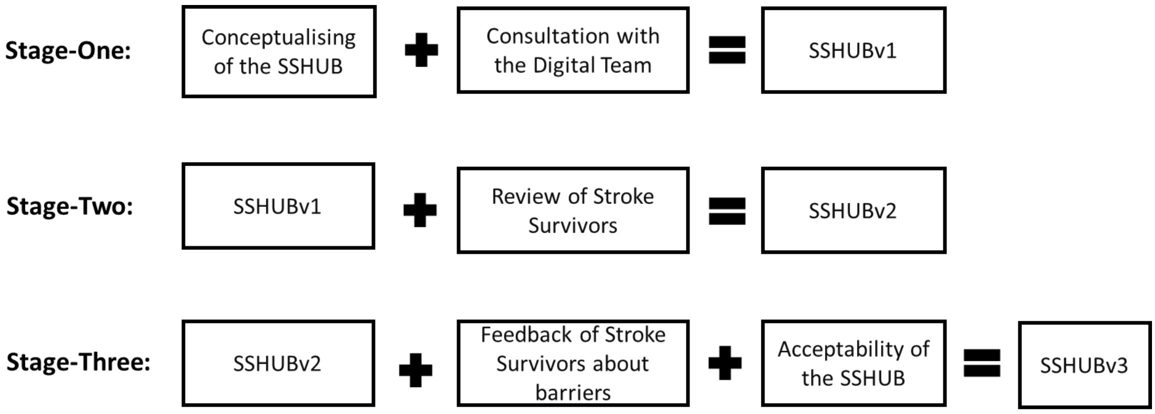
The technical development of the online self-management platform; the SSHUB, was undertaken by the PhD candidate with guidance and training from the lead supervisor (Dr Y Prior), the founder and lead of the online self-management platform for people with RMDs, the MSKHUB (www.mskhub.com). Dr Prior worked closely with the original developer of the EDAQ for over a decade and led the digitisation of the EDAQ to eEDAQ to house it on the MSKHUB to aid self-management of people with MSCs. The MSKHUB was developed with extensive Patient and Public Involvement (PPI) as the active participation of patients in research, rather than for patients, is now acknowledged as the most important ingredient of effective outcomes (Smits, van Meeteren, Klem, Alsem, & Ketelaar, 2020). Patient involvement in research helps to achieve better research with greater impact (Smits et al., 2020), but insufficient attention has been given to user-centred design when developing a system that aims to provide information for patients (Cresswell, Bates, & Sheikh, 2013). Systems need to solve the issues and provide the needs of people who will use them (Imison et al., 2016). Therefore, modelled on the MSKHUB approach for development, stroke survivors' involvement in the development of the SSHUB was paramount from the start of this project.

The literature shows that it is important to evaluate the usability of a system when aiming to develop a platform that has human-computer interaction (Hong et al., 2014; Kushniruk & Patel; 2004). Usable systems help people to use the system effectively, efficiently, safely and enjoyably (Kushniruk & Patel; 2004; Preece, Sharp, & Rogers, 2002). Usability also helps to assess the technical effectiveness by recording if the website users can complete the given task without an error or not, and the technical efficiency by controlling how long it takes to complete a task (Hong et al., 2014; Shneiderman & Plaisant 2009; Kushniruk, Patel, & Cimino, 1997). Assessment of the acceptability helps to collect more information from website users on their general experiences about the website, how easy to use it, if it is user-friendly, and if they are satisfied with it (O'Malley et al., 2014; Grindrod, Li, & Gates, 2014; Hong et al., 2014). As the aim was to develop an online self-assessment platform with stroke survivors for stroke survivors, it was essential to assess the usability and acceptability of the SSHUB and eEDAQ-SS with the target population to guide the iterative development process of the SSHUB. Thus, the SSHUB was set out on the assumption that the involvement of system users in the testing process to improve the usability and assessment of their satisfaction with the system is a crucial part of the development process (Vasilica, 2015; Norman, 1998).

In this manner, by following the similar usability and acceptability studies published in the literature (LeLaurin et al., 2021; Moore, Avery, Price, & Flynn, 2020; Sanchez et al., 2019; Arjadi, Nauta, & Bockting, 2018; Prior et al., 2018; Sureshkumar et al., 2016; Jones, Dear, Hush, Titov, & Dean, 2016; Hong et al., 2014; Kushniruk & Patel, 2004) and adapting them according to the needs of the target population, the SSHUB that based on the eEDAQ-SS was developed in three stages as follow (Please, refer to Figure 4 for the summary of SSHUB development stages):

- ***Stage 1:*** To develop a self-management platform for stroke survivors (www.strokesurvivorshub.com [SSHUB]) initially modelled on the MSKHUB website template by working together with a digital team, which originally designed the MSKHUB.
- ***Stage 2:*** To test the usability of the alpha and beta versions of the SSHUB before sharing the online link to the SSHUBv1 with participants at the cognitive debriefing interviews to gather their views and recommendations to make further improvements prior to the wider testing at Stage 3 to produce SSHUBv2.
- ***Stage 3:*** To test the acceptability of the SSHUBv2 and eEDAQ-SS with a larger group of participants to further develop the SSHUB to finalise the online platform for a wider audience in the UK (SSHUBv3).

Figure 4: Summary of the SSHUB development stages



The overall goal of the SSHUB is to provide integrated self-management solutions for stroke survivors, although this is a long-term goal for the platform and not addressed within this PhD due to time and resource constraints. This PhD established the very foundation of this self-management platform by conducting the initial development stage by working together with stroke survivors and an IT Company and assessing its acceptability. Stroke survivors can find the latest evidence-based practice research and complete ePROM to express their limitations in ADL from their perspective and see their changes over time by actively getting involved in their care pathway via the SSHUB. This will have a long-term impact on stroke rehabilitation as it will help stroke survivors to realise their limitations that occurred after stroke and eliminated by stroke survivors until they are discharged to home and could have a positive impact on self-management. However, apps and web-based interventions have risks and challenges for healthcare delivery. Therefore, there are key important points that need to be considered when developing an online web-based platform, such as data privacy, clinical assurance, acceptability of the platform by the target population. Section 5.3 expands on the important points that need to be considered when developing an online platform.

In addition to the above aims for the development of the SSHUB, another aim was to conduct an analysis of the data collected from completion of the eEDAQ-SS to explore the pattern and distribution of ADL limitations in British stroke survivors to describe the most common ADL difficulties reported by the study participants. Although this was a relatively small sample, and the results, therefore, are not representative of the target population, the level of data collected was rich enough to justify this analysis to provide a snapshot of the most common ADL difficulties reported by the study participants to set the context. The procedures and findings of this analysis were also explained in the later part of this chapter as an additional, and useful insight into the stroke survivors' perceptions on their ADL limitations, measured by the eEDAQ-SS.

5.3. Development of the Stroke Survivors Hub

A good website design means that website users with all abilities and backgrounds should have a good site experience, which means providing language support, making a clean and simple user interface or adding images and videos (Bureau of Internet Accessibility, 2019). Digital health can be more effective, reduce costs and provide better outcomes (Mistry, 2020) and online self-management platforms can provide more opportunities for patients to have greater control of their health. However, it is important to differentiate the accessibility and the inclusivity to make sure that people with different symptoms can use the SSHUB easily.

Due to this, it was crucial to consider the points that were covered by digital inclusion (NHS, Digital: Digital inclusion guide for health and social care, 2019). Firstly, for people to be able to use the developed online platform, they will need to have connectivity, which means having access to the internet through broadband, Wi-Fi and mobile. As the recent statistics showed, 91% of the population in the UK use the internet (Selvan et al., 2020; The Topol review, 2019), therefore most of the population have access to the internet through different platforms. Secondly, people need to have accessibility so the online platform needs to be designed in a way that it can meet stroke survivors' needs. Thirdly, online platforms need to be easily accessible through computers, laptops, phones and be user friendly to be used effectively. Research showed that the use of online platforms has been improved and people are more willing to use digital health (The Topol Review, 2019; NHS Long Term Plan; 2019). Nearly 54% of adults in the UK looked up health information online within three months in 2019, 40 million visits a month to the NHS.uk website was done through smartphones, computers and tablets (Ofcom: Communication Market Report, 2018), which shows that optimising the use of apps and web-based interventions for mobile technologies is important.

Following these requirements, barriers to digital inclusion were considered when developing the SSHUB. The SSHUB development was designed in a way to optimize the engagement of stroke survivors, make sure that different stroke survivors with different symptoms can use the SSHUB to assess their ADL limitations. To ensure the online platform development meets the needs of the target population, there are NHS design principles (2018) that need to be considered when developing a digital service. These include:

1. '***Putting people at the heart of everything you do'*** (NHS design principles, 2018, p.1): When developing an online platform, the ideas of the healthcare professionals or stroke survivors needed to be considered.

2. '***Design for the outcome'*** (NHS design principles, 2018, p.2): The SSHUB was developed to help stroke survivors to increase their awareness of ADL limitations, see their progression over time and increase their self-management by involving stroke survivors more actively in their care pathway.

3. '***Be inclusive'*** (NHS design principles, 2018, p.3): The SSHUB needed to be easy to use and accessible for stroke survivors with different limitations.

4. ***'Design for context'*** (NHS design principles, 2018, p.4): Other people's ideas and experiences who had experience developing a similar online platform needed to be considered when developing the SSHUB.

5. ***'Design for trust'*** (NHS design principles, 2018, p.5): The SSHUB needed to be reliable and secure. Especially, the SSHUB aimed to store the data of stroke survivors to be used in further research. Therefore, the GDPR policy needed to be considered.

6. ***'Test your assumption*** (NHS design principles, 2018, p.6)***':*** The SSHUB needed to be tested with stroke survivors to get their feedback, and gather evidence on people's opinions to further improve it.

7. ***'Make, learn, iterate'*** (NHS design principles, 2018, p.7)***:*** The SSHUB needed to be improved after the initial testing to make it easier to use and more useful for the target population.

8. ***'Do the hard for to make it simple'*** (NHS design principles, 2018, p.8)***:*** Time needed to understand what is the aim of the SSHUB, what stroke survivors need and how the SSHUB could be simplified and be away from complexity.

9. '***Make thing open-it makes things better'*** (NHS design principles, 2018, p.9): The results of the SSHUB needed to be shared to make sure that other people can be aware of this platform and see its benefits.

The National Institute for Health and Care Excellence (NICE) developed an evidence standards framework for digital health technologies in 2019 that updated in 2021 which shows what a digital health technology needs to add value to the UK healthcare system. It is reported by the NICE that a newly developed digital health technology needs to have evidence of effectiveness that is relevant for the target population, who will use the online platform and evidence on economic impact. The NICE (2021) classifies the developed digital health technology under three different tiers, depending on its functional classification. As the aim of the SSHUB was to provide access to ePROM to help stroke survivors to track their changes over time, improve their awareness and use this information as part of their self-assessment to guide the self-management, it was categorised under tier C. For a digital health technology that goes under the tier C category and to be able to have a value on the UK healthcare system, it needs to cover and show evidence on the effectiveness and meet standards for tier C. Some of these values are as follow (NICE, 2021, pp. 10-14):

- The developed digital health technology reflects current standards or best practices in the UK healthcare system.
- It needs to be evidenced that the target population used and tested the digital health technology for usability.
- It demonstrates evidence that the developed digital health technology reduces the inequalities within the healthcare system, so improve inclusivity.
- The developed platform covers correct and relevant information.
- To have evidence that the developed digital health technology is value for money, the target population used the platform and got a benefit from it.

- Digital health technology provides an opportunity for the users to communicate with others who are diagnosed with the same condition or can find useful links that can be used as guidance to get support when needed.
- In addition, a digital health technology under tier C needs to demonstrate its effect on it for the representative users (NICE, 2021, pp. 10-14).

The use of technology helps to empower patients to be more actively involved in their care pathway, but for this to be successful, patients, careers and the public need to be involved as partners in their care and education (NICE: evidence standards framework for digital health technologies, 2021; The HEE Topol Review, 2019). Therefore, developed digital health tools should not result in inequalities (The HEE Topol Review, 2019). On the other hand, it is crucial to consider the ethical issues. The developed digital health tool should not result in any harm and remain faithful to the core ethical principles. The collected data need to be transparent, resilient, robust and legally enforceable (Duggal, Brindle, & Bagenal, 2018), and used safely and effectively (The HEE Topol Review, 2019).

After reading and understanding the need to develop a good, inclusive digital platform it was decided to include ideas of stroke survivors as part of the SSHUB development. This included working with an IT company, searching other platforms, testing the SSHUB with and without the target population and finally assessing the acceptability of the SSHUB and eEDAQ-SS to understand the developed website is easy to use and accepted for stroke survivors. The following section explained how the SSHUB was developed.

5.3.1 STAGE ONE: Development of the SSHUB-Version 1

The SSHUB was not developed to replicate existing platforms of stroke survivors, but to create a platform that stroke survivors can use to complete ePROM to track their changes on ADL limitations and improve their self-management with personalised advice on their limitations in the future. Stage One of the development process included two steps; Step-1 other platforms were searched to guide the conceptualisation of the SSHUB and Step-2 worked with an IT company to develop the alpha and beta version one of the SSHUB (SSHUBv1).

Step One-Conceptualising of the Stroke Survivors Hub

There was a model of the website at the UoS, the Musculoskeletal Hub (MSKHUB; www.MSKHUB.com). The MSKHUB was sponsored by the UoS, which houses the eEDAQ for RMDs. It is an online self-management platform that is available for people with RMDs and facilitates access to valid, reliable health information, advice on self-management, assistive technology, and peer support through an online community via social networks and other evidence-based ePROM to support the self-assessment needs of those with RMDs. The MSKHUB is different from other online self-management platforms which were developed specifically for stroke survivors, as it facilitates easy use of the evidence-based ePROM and provides tailored assessment for individuals.

The MSKHUB

The MSKHUB was co-produced for people with RMDs by people with RMDs and a clinical reference group consisting of experts in this field to serve as a self-management platform to aid care in the community (Prior et al., 2018b). It aims to assist the self-management of RMDs by enabling self-assessment through the use of evidence-based, valid and reliable ePROM, commonly used in practice by rheumatology rehabilitation teams (mainly occupational therapy and physiotherapy) in the NHS (Prior et al., 2018b).

The ePROM hosted in the MSKHUB includes the EDAQ as the main ADL assessment (Hammond et al., 2014), in addition to other upper-limb PROM MAP-HAND (Prior et al., 2018), and DASH (Solway, Beaton, McConnell, Bombardier, 2002), a work participation PROM and psychological assessments (The Patient Health Questionnaire-9 (PHQ-9) (Spitzer, Kroenke, and Williams, 1999) and General Anxiety Disorder-7 (GAD-7) (Spitzer, Kroenke, Williams, & Löwe, 2006), as well as a generic health status questionnaire to allow a holistic self-assessment of difficulties in daily activities, overall wellbeing, and participation in work and leisure. The MSKHUB enable individuals with musculoskeletal pain or complaint to have free access to online self-assessment (ePROM), to create a secure, personalised health record, which can then be used to inform them whether they should seek medical help and/or advice, and/or simply signpost them to useful patient information sources available online and it is also used as a large data repository for rehabilitation outcomes in people with RMDs to further facilitate empirical research.

Through the MSKHUB, users create personal health records and can download their assessment results to share these with their healthcare professionals if needed to aid a structured rehabilitation process, or simply bring it along to a Primary Care consultation to highlight functional difficulties they are experiencing to seek the opportunity to be referred to a specialist, secondary care services such as physiotherapy, podiatry and occupational therapy. They can build on their assessments over a long period to assess the trajectory of their difficulties or improvement through automatically generated charts on their progress for each assessment. Another aim of the MSKHUB is to provide a data repository for future research to investigate the range of functional limitations in daily activities for people with RMDs and evaluate the range of aids and adaptations individuals utilise to reduce the impact of RMDs on their QoL (Prior et al., 2018).

Therefore, the MSKHUB was used as a conceptual model and technical template for the design of the SSHUB, as the UoS sponsored both platforms to increase the use of reliable self-assessment platforms as part of self-management. However, the SSHUB aimed to be a self-assessment platform and further developed to be a self-management platform for stroke survivors, not RMDs. As both websites were aimed to meet the needs of different target populations, the SSHUB needed to be developed and tested independently for stroke survivors. The MSKHUB helped to conceptualise the model of the SSHUB but, further work was needed on the design, information and ePROM that were going to be included at the SSHUB and this was done in a collaboration with an IT company to ensure a high-quality platform with sufficient data protection mechanisms are in place.

Step Two: Consultation with the Digital Team

As advised by the NHS design principles (Digital inclusion guide for health and social care, 2019), NICE: an evidence standards framework for digital health technologies (2021) and HEE Topol Review (2019), people who know about the development of a digital platform need to be involved in the development process of a new digital platform. Pixel Kicks Ltd. is an award-winning digital agency based in Manchester sand easy reach of the UoS. They were specialised in WordPress and digital marketing. They were involved in designing and developing at least 34 different websites, but most importantly, led the design/development of the MSKHUB as the digital partner. Therefore, Pixel Kicks Ltd was invited as commercial partners to assist the design and iterative development of the SSHUB, as complex web-design skills and knowledge is not the remit of this PhD and development of a large online platform to house ePROM requires access to a specialist team with a track record in the design and management of secure, large and interactive databases.

Data management and security

There are fundamental requirements for any web-based repository system to be successful (Kim, 2018). These include the system structure for the type of data is stored, and the mechanism for storing data to ensure its security. The SSHUB also has the potential to be a data repository platform to evaluate stroke survivors' difficulties in ADL, which requires a multistage process to design to ensure the data collected over time is securely maintained and protected. Designing a platform, which will keep the participants' data, needs an in-depth examination of the cloud environment, available hardware, and network technology (Kim, 2018; Horvath, Ecklund, Hunt, Nelson, & Toomey, 2015). This is because as reported by the Information Commissioner's Office (ICO) in 2018, data security and confidentiality are key ethical processes within research, which need to be considered very carefully. The SSHUB aimed to collect some personal information to create a tailored health profile for users and build a longitudinal record of stroke survivors' self-assessment trajectory to help them with self-management. Therefore, it was important to make sure that the SSHUB is in line with guidance issued by the ICO, the Legal and Information Governance team. When designing an online health platform, which collects sensitive personal data, it is important to consider the rights to safeguard personal data and protect unlawful processing of personal data.

The SSHUB used the information collected from participants to provide them with a personal health profile to enable them to build a record of their self-assessments. The data collected on participants' health status was kept in a secure, anonymised, confidential database to help researchers inform future interventions for people with stroke conditions. The collected dataset did not identify participants in any way and the aggregated data was accessed by the research team. Upon registration to the SSHUB, participants provided an online consent (Appx 4-Picture 1), to maintain a dialogue with them until they choose to leave the study.

They consented to take part in this study by understanding that their participation was voluntary, they were free to withdraw at any time, agreed to complete ePROM, and provide personal details that were kept confidential to be accessed by the UoS research team only. Also, by providing an online consent, they agreed that the information collected about them will be used to support other research in the future and the aggregated and anonymised data may be shared with other research teams to utilise for secondary data analysis, subject to obtaining an ethical approval from the School of Health and Society Research Ethics Panel. Data custodian for future data requests would be the PhD lead supervisor (Dr Yeliz Prior).

In future, as part of the SSHUB registration process, the SSHUB users will be asked to read and agree to the online data protection and privacy notice to provide an informed consent to the SSHUB to process their data for the purposes outlined above. They will be informed that they can withdraw consent at any time by completing the online GDPR Checklist form or by phoning, writing to the people who are responsible from the SSHUB. The SSHUB does not pass on information gained from the participant's engagement with the website without their consent. However, the SSHUB may disclose participants' personal information to meet legal obligations, regulations or valid governmental requests. The SSHUB may also enforce its terms and conditions, including investigating potential violations of its terms and conditions to detect, prevent, mitigate fraud, security or technical issues; or to protect against imminent harm to the rights, property or safety of the SSHUB, its clients and/or the wider community.

The UoS was the data controller and legally responsible for the transparent, lawful, secure and fair collection of participants' personal information. It was made sure that:

- Data was accurate,
- Data was collected for legitimate purposes that were clearly stated,
- Provided ability for amends/ deletion of data,
- Not kept data without reason or if consent was withdrawn,

- Not to re-use data for a different purpose other than that for which it was obtained, and permission was given.

Personal data were collected about participants from the forms that they completed online, from records of correspondence and details of their visits to the website, including but not limited to personally-identifying information like Internet Protocol addresses. The SSHUB from time to time used such information to identify participants and collect statistics about the behaviour of participants. The SSHUB processed personal data during the duration of any registration and will continue to store only the personal data needed for six years after the registration has expired to meet any legal obligations. After six years any personal data not needed will be deleted. At any point whilst the SSHUB was in possession of or processing participants' personal data, all data subjects had rights of access, rectification, to be forgotten, to restriction of processing, right of portability, and to object to automated processing, including profiling. After proofing the identification, the SSHUB at participants' request can confirm what information hold about them and how it was processed. Participants had and will continue to have the chance to request the following information:

- Identity and the contact details of the person or organisation that has determined how and why to process their data.
- Contact details of the data protection officer, where applicable.
- The purpose of the processing as well as the legal basis for processing.
- If the processing is based on the legitimate interests of the SSHUB or a third party such as one of its clients, information about those interests.
- The categories of personal data are collected, stored and processed.
- Recipient(s) or categories of recipients that the data is/will be disclosed.
- How long the data will be stored?
- Details of their rights to correct, erase, restrict or object to such processing.
- Information about their right to withdraw consent at any time.
- How to lodge a complaint with the supervisory authority (ICO)?
- Whether the provision of personal data is a statutory or contractual requirement, or a requirement necessary to enter into a contract, as well as whether they are

obliged to provide the personal data and the possible consequences of failing to provide such data.

- The source of personal data if it wasn't collected directly from stroke survivors.
- Any details and information of automated decision making, such as profiling, and any meaningful information about the logic involved, as well as the significance and expected consequences of such processing.

Participants were provided with contact details of the UoS and ICO, so they had the chance to complain about the SSHUB if they wanted to. The SSHUB uses cookies, which is a string of information that a website stores on a visitor's computer, and that the visitor's browser provides to the website each time the visitor returns. The used software helped the SSHUB to identify and track visitors and their website access preferences. The SSHUB website visitors who do not wish to have cookies placed on their computers should set their browsers to refuse cookies before using the SSHUB website.

In future, the UoS and their research partners will continue to access and control the data collected from the SSHUB, following the completion of appropriate ethical review and research governance checks by the UoS. Any findings arising from the research conducted by using data collated through the SSHUB will be submitted for publication in Scientific Journals to help stroke researchers and health services to learn from this research, but participants will not be identified in any report or publication. The SSHUB will continue to acts on behalf of the UoS in the capacity of a data processor. When working exclusively as a data processor, the SSHUB will be acting on the instruction of the UoS and will work hard to ensure that the data collection processes are fully GDPR compliant. As well as determining the means by and purposes for which that data is processed.

During the development of the SSHUB, the GDPR policy, UoS GDPR policy, Data Protection Act and Privacy and Electronic Communications Regulations were followed to protect and enhance the rights of the data subjects. Initially, a GDPR privacy policy was developed for the SSHUB, which covered all topics mentioned above, to inform the participants about their rights and how their data will be used in the research. The written GDPR policy for the SSHUB was agreed with the supervision team and given to Pixel Kicks Ltd. to include on the SSHUB.

A GDPR policy was not enough to protect the data. To be able to maintain the confidentiality and security of the data, a participant identification (ID) was provided to all the participants as soon as they have registered to the SSHUB, and this ID was only known by the researcher to maintain confidentiality. The participant ID was linked to identifiable data on a separate file, which was stored on a secure UoS server. All data were anonymised for confidentiality.

By considering all the point mentioned above, all online consent forms, personally identifiable information was stored in the UoS servers and secured by passwords only accessible by the research team. An info@ email address was created for the website and all the relevant information was linked to this email address which was protected by a username and password that was only known by the researcher. The completed online consent forms and the registrations to the SSHUB were automatically sent to the admin email account of the researcher. All data that were sent to and from the SSHUB, including in the back-end and the front-end, which was encrypted using an SSL (secure sockets layer) certificate. Data analysis (Statistical Package for the Social Sciences [SPSS]) files can only identify participants by nominated participant IDs.

SSHUB Content

As this platform was specifically for stroke survivors and the name of the website should make a direct inference to this population, this online platform was named the Stroke Survivors HUB (SSHUB) through consensus of the supervision team and the copyrights of www.strokesurvivorshub.com and www.strokesurvivorshub.co.uk URLs were obtained for the UoS. The Pixel Kicks Ltd. was employed to design the SSHUB based on the database template used for the MSKHUB, as both platforms used the same PROM, which albeit differed in content had the same layout. As both websites were developed for different populations with very different cognitive and physical functioning needs, adaptations were needed for the SSHUB to make it useful and user-friendly for the target population.

The SSHUB was developed using WordPress (2021), which is an open-source Content Management System integrated with other social components (WordPress, 2021). The SSHUB development process was managed by the PhD candidate. Initially, a timeline was created to make sure that the development process occurs within the PhD timeline. A series of actions were planned (e.g., reviewing other online platforms, understanding the fundamental security requirements and then deciding on the template of the SSHUB). After the initial decision, the regular meetings (included having face-to-face and virtual meetings, utilisation of the Basecamp platform to have interactive communication through assigned tasks and responsibilities to manage the project), took place with the IT company to make sure that they understand the requirements, and reach the project schedule, cost and technical performance.

Initial meetings with the IT company were useful to initiate interactive and good communication but were not enough. The project manager (PhD candidate) had to monitor the development and testing process closely by using both a participant account and admin account to identify the potential issues that have been missed by Pixel Kicks Ltd. It was important to make sure that the SSHUB was designed in a way that can be used by stroke survivors easily. Tracking the issues regularly and finding solutions to them helped to maintain a team working to aid the development of the SSHUB within the project timelines.

The initial development of the SSHUB was a challenging process and required close working relationship with the developers. Each stage of the SSHUB development was followed and controlled by the PhD candidate to ensure that the platform was inclusive, easy to use, and secure for stroke survivors. The usability of the SSHUB was paramount in this process to avoid stroke survivors having to deal with potential technical problems. It was recognised that verbal explanation could result in misunderstanding, therefore, other methods e.g., visual representation of the information, were used to ensure that the SSHUB was user friendly. All of the pages and information that were agreed to be included on SSHUB was decided by the PhD candidate and a template was created before each meeting for each page to be discussed with the developers, which required regular testing and iterative developmental stages after the initial prototype development (Please, refer to Appx 4 for pictures of the SSHUB content).

To be able to test the psychometric properties of the EDAQ-SS after this PhD, participants needed to complete other PROM used in the measurement of ADL alongside the EDAQ-SS to compare whether the response to the EDAQ-SS correlates with the response to similar scales, to ensure they have similar psychometric properties. Therefore, after completing a comprehensive search, it was decided to include eight different PROM, including the EDAQ-SS at the SSHUB. As part of this thesis, the following ePROM were digitised with the licence holder's agreement and tested for usability as a digital tool to be available on the SSHUB for psychometric testing:

- EDAQ-SS
- SIS version 3 (a self-reported questionnaire with 59 items that assesses health-related quality of life) (Duncan, Bode, Sue, & Perera, 2003).
- SF-12v2 (a self-reported questionnaire with 12 items that assesses generic health) (Ware, Kosinski, Turner-Bowker, & Gandek, 2005).
- RMI (a self-reported questionnaire with 15 items that assesses mobility disability) (Collen et al., 1991).
- PHQ-9 (a self-reported questionnaire with nine items that assesses depression) (Spitzer, Kroenke, & Williams, 1999)
- GAD-7 (a self-reported questionnaire with seven items that assesses anxiety) (Spitzer et al., 2006).
- MAP-HAND (a self-reported questionnaire with 18 items to assess limitations of hand-on activities) (Prior et al., 2018).
- DASH (a self-reported questionnaire with 38 items to assess limitations of the arm, shoulder and hand-on activities) (Solway et al., 2002).

Using the SSHUB to house different questionnaires was hopped to allow comparison of the EDAQ-SS with other measures of the same and related constructs and widely used general health status measures. After discussion with the NHS healthcare professionals, it was revealed that the SIS and RMI are commonly used PROM for stroke survivors. As mentioned in the systematic review (Chapter Three), RMI is a PROM with strong psychometric properties compared to most of the PROM (Chen et al., 2007; Hsueh et al., 2003; Antonucci, et al., 2002; Green & Young, 2001). Additionally, PHQ-9 and GAD-7 are the self-reported questionnaires that would help to collect information about depression and anxiety of the participants (Spitzer et al., 2006; Spitzer et al., 1999), which will be used for psychometric testing. The SF-12 is a regularly used generic health questionnaire (Ware, Kosinski, Turner-Bowker, & Gandek, 2005) and the results of the SF-12 will help to compare the generic health items of the EDAQ-SS. The MAPHand and DASH were included at the SSHUB, but not for the psychometric testing. The data for the MAPHand and DASH questionnaires would also be collected as these PROM were not tested for use in British stroke survivors and the data collected will be used to test the psychometric properties of these instruments as hand and upper limb functional issues are also common amongst stroke survivors, and having target PROM to aid the assessment of such specific ADL difficulties would be beneficial for stroke rehabilitation.

After deciding which PROM to digitise, the license of each PROM was obtained from the copyright holders before they were converted to ePROM. The main point during the development of the ePROM was to keep the PROM in their original format, but at the same time to make them easy to use in a digital environment. Therefore, much attention was paid to the presentation of the PROM. A template was created for each PROM by the PhD candidate to show how each PROM should look like electronically at the SSHUB. This helped to show Pixel Kicks Ltd. how each PROM needs to appear and what instructions need to be included on each page. Development of the ePROM was conducted in a way to avoid changing the original appearance of the PROM, as agreed with the copyright holders. Following the appearance of the PROM, another template was created in an excel format for the data export.

The data export templates were created in a way that can be useful to analyse the data in the SPSS. These templates helped to explain to Pixel Kicks Ltd. how the data should be presented when it is exported from the SSHUB in a CVS format. The data export was crucial for data analysis. Even a small mistake from the data export can affect the results. Therefore, this section required detailed testing. Additionally, information for how to score each PROM was provided to Pixel Kicks Ltd. to include the total scores in the data export files. The complex total scoring, such as for the SIS will be conducted manually, or for SF12v2, the calculating software will be used that was provided by the copyright holders.

After developing the presentation of the PROM, the preview of the SSHUB was created for the alpha testing process, which was not visible to the public and conducted by the PhD candidate. Both a participant account and an admin account were used by the PhD candidate to alpha test the SSHUB. All of the pages on the SSHUB were checked individually to make sure that they are easy to access and they include correct information, then each PROM was completed and submitted through a participant account and the received data was checked from the admin account. Correct submissions of the PROM were crucial to avoid the missing data, to make it easy for participants to follow and get the data in the correct timeline. Therefore, submissions of the PROM were tested in detail to avoid any mistakes.

Unfortunately, after the alpha internal testing process, areas that needed development were found that could have an impact on the data collection. It was recognised from the participants' account that after completing each questionnaire people need to return to the dashboard to submit their results. This could cause confusion and result in missing data, as participants would not understand that data need to be submitted manually by returning to the dashboard. For all the ePROM, except the eEDAQ-SS, a submit button appeared at the end of the PROM page under the items when all the questions were completed. As the EDAQ-SS has 15 domains, the submission button was different. "Save" or "save and continue" buttons were appeared after completing each domain (Appx 4-Picture 9). When people chose 'Save' they were redirected to the dashboard. If they choose the "save and continue" button, they continued with the next domain and the "Submit" button was available at the end of the 15th domain. Participants needed to complete both sections A and B at the EDAQ-SS to be able to submit their results. They only were able to pass section B if they choose "Not applicable" as an answer in section A.

Additional to the previous points, the SSHUB required further improvements to make it user-friendly for each stroke survivor. For example, the researcher realised that the size and colour of the tick boxes (that will be used to answer each question) were too small and light coloured. About two-thirds of stroke survivors have visual problems after stroke (Stroke Association, 2017). Literature review showed that stroke survivors can have a sensitivity to bright colours, lights or patterns (Tosta & Johnson, 2009). Therefore, to meet the requirements of each person, the tick boxes for the ePROM were made bigger and darker. Other than font and size changes, the format of the SSHUB was checked from different devices. The SSHUB can be used through both desktop and mobile devices such as tablets or phones. Stroke survivors can sign in from any device, needing no software other than a standard web browser. Therefore, further updates were done to make the

SSHUB mobile friendly (i.e., to be able to scroll the screen from left to right to see all the answer options of each question).

As the SSHUB was going to be used by stroke survivors independently to track their changes in ADL limitations and share their results of ePROM with their healthcare professionals if they want to, advice of healthcare professionals was obtained during the expert panel meeting. The preview of the initial SSHUBv1 was shown to the expert panel during the meeting to discuss the platform and the content that would be available on the website. The registration questions were created with the help of an expert panel team to make sure that questions could help to collect useful information to create a health record for stroke survivors. Registration questions were developed in a way to provide an easy registration and login process for stroke survivors (i.e., to be able to create memorable passwords and usernames). After creating the registration question with the expert panel, these questions were provided to Pixel Kicks Ltd. to be applied on the SSHUB.

However, during the alpha testing process mistakes were recognised that could result in confusion and be a barrier to stroke survivors. For example, it was realised that website users were receiving automatically created passwords after registration, which was not the aim as it was better for stroke survivors to create memorable passwords or usernames. The registration or sign up page was the first page that stroke survivors completed on the SSHUB (Appx4-Picture 2). Therefore, it had to be easy without any submission issues. These problems that were recognised and documented during the testing process guided the PhD candidate to have another meeting with Pixel Kicks Ltd. to solve issues with the registration. In the end, the registration page was made simple which guided stroke survivors to provide their demographic information and create a memorable username and a password.

Finally, for the development of the linguistic and cross-cultural adaptation, stroke survivors were only required to complete the EDAQ-SS, in addition, MAPHand and DASH questionnaires. Therefore, for the initial testing process other five PROM were hidden by the Pixel Kicks Ltd. to avoid confusion of the participants during the linguistic and cultural adaptation process of the EDAQ-SS. These PROM were made accessible to the stroke survivors before the acceptability assessment.

In total, the development and the alpha testing process of the SSHUB took nine months, and SSHUBv1 was ready to go on-live for the next stage, beta testing, which was the process that stroke survivors will use the website to test and provide feedback. Testing by healthcare professionals was not enough to develop a user-friendly and acceptable platform. Therefore, feedback of the stroke survivors was needed to assess the usability of the SSHUB.

5.3.2 STAGE TWO: Development of the SSHUB Version-2

Design principles for digital inclusion (2019), NHS design principles (2018), and NICE: an evidence standards framework for digital health technologies (2021) suggest including target population when designing a digital platform to make sure that the digital platform will be useful and user-friendly. User involvement in the development process is important to ensure the usability, acceptability and usefulness for future engagement from the target population (Bernhard et al., 2018). The overall long-term aim of the SSHUB is to be an online self-management platform for stroke survivors to access patient education and tailored self-assessment using ePROM when needed. This PhD aimed to initiate the first stage of this long-term vision by digitising the EDAQ-SS and other PROM that can help to assess the limitations in ADL, creating the online platform to house these self-assessments and to test the usability and acceptability of both the SSHUB and the eEDAQ-SS.

The second part of the usability evaluation included conducting an interview during the Cognitive Debriefing Interview part of the EDAQ-SS development to answer questions on the usability of the SSHUBv1. A list of questions was developed to assess the usability by searching the literature, evaluating questionnaires that were used in the usability evaluation of the online platforms (Prior et al., 2018; Hong et al., 2014) and adapting these according to the stroke survivors' specific needs. For example; if they were happy to use the ePROM, what problems the SSHUB had that could limit their use if stroke survivors would like to continue to use the SSHUB in the future, and what further development is required to ensure it is user-friendly. In addition, during the interview, participants were encouraged to further comment on the design and usage of the SSHUBv1 and the researcher recorded these by taking detailed field notes.

The same ten participants who were involved in the development process of the EDAQ-SS were involved in the usability test of the SSHUBv1. They were age ranged 49-81, with different characteristics (Please, refer to Table 14 in Chapter Four, for demographic characteristics of the participants). Each stroke survivor, who was involved in the cognitive debriefing interviews had a different range of impairments (e.g., there were participants with aphasia, hemiplegia, memory issues, reduced balance, neglect and dysarthria). This helped to have opinions of stroke survivors with different ADL limitations, which means they needed different adaptations on the SSHUB to be able to use it. Out of ten participants, only a participant required an explanation before he completed the online questionnaire. Eight participants used either their laptops/computers to complete the questionnaires, one used a mobile phone and one used a tablet. Broad participant characteristics, different use of electronic devices helped to get different feedback about the SSHUB.

After searching the literature and comparing similar studies, different questions were documented to understand the ideas of the target population on the SSHUB. Therefore, a series of questions were asked to the participants to understand if it is easy to use the SSHUB. Descriptive statistics were used to explore the mean usability scores. All comments from the participants were written in detail and the most frequently used phrases or keywords were identified and delineated a range of responses for each section on the SSHUB and their overall experience.

- **How did you find the SSHUB?**

In general, participants liked to use the SSHUB and they said it is user-friendly. Each participant provided different feedback, depending on which electronic device they have used and what impairments they had as a result of a stroke. For example; a participant who used an iPad mentioned that there was a technical issue that stopped the participant to scroll the page from side to side. Another participant with neglect, who used a computer to complete the eEDAQ-SS mentioned that the list of equipment is not in an alphabetic order, which made it difficult to follow, the font size of questions needed to be bigger and the colour need to be darker so she can complete the ePROM easier.

- **Do you think it was easy to register to the SSHUB?**

Participants critiqued the registration process to the SSHUB. All participants thought that it was easy to follow the instructions and register to the SSHUB.

- **What questions do you think we can add or remove from the registration?**

Nine of the participants said that there is no additional question that they think needs to be added to the registration questions. However, a participant has reported an issue with the registration:

'I had only a balance issue after my stroke, but there was no option to show that I have a balance problem under the question 'Have you been diagnosed with any of the following conditions or impairments following stroke?'. As this is a common problem for stroke survivors, the researcher agreed to include this in the registration questions.

- **What would you like to change about the SSHUB to make it easier?**

As mentioned previously, two members from the expert panel for the EDAQ-SS development have mentioned that they prefer answer options of the ePROM to be vertical, as this could be easy to follow for stroke survivors. Stroke survivors had both the electronic and paper version of the PROM, which included different answer options, one vertical and one horizontal. During the cognitive debriefing interviews, stroke survivors were specifically asked about the answer option format to elicit participants' preferences. Incidentally, all participants preferred a horizontal version. The same question was asked to participants with visual problems (two participants with neglect, a participant with blurry vision and a participant with sensitivity to light). They also said that they would prefer horizontal answer options, but it would help them if the letters were bigger and the lines between questions were more pronounced.

Two participants who used a tablet and phone to complete the online questionnaires have mentioned that 'There is no option to scroll from side to side to see all the answer options, which made it hard to use the SSHUB'. A participant with a tablet reported '*I have tried to use my phone to complete the questionnaires, but couldn't as there were no options to zoom in and out the screen, so I have decided to use my tablet but there was no option to scroll screen from side to side. I had to rotate my tablet screen to horizontal to see all the* *answer options. To be honest, this was the most challenging part and I was at a point to give up and not to complete it'*. Another participant with a phone had to use a computer to complete the questions. This problem has been reported to Pixel Kicks Ltd. immediately during the Stage 1 data collection and corrected for other participants.

Moreover, three of the participants have mentioned that the SSHUB needs to have a 'Not Applicable' option for the domains of the EDAQ-SS. Stroke survivors thought that they should not complete the questions of an EDAQ-SS domain if they do not have an impairment at that daily activity. Participants were informed by the researcher that to be able to do this, all the EDAQ-SS domains need to be tested for validity and reliability. In addition, after assessing the psychometric properties of the EDAQ-SS the items will further be analysed by using Computerized Adaptive Testing (CAT).

One participant advised changing the 'Caring domain' picture for the EDAQ-SS due to its colour. The rest of the participants were happy with the colour of the website and its design. Another participant who used a phone to complete the questionnaire mentioned that it is difficult to find the questions from the SSHUB when using a mobile phone. This was because when you click on a questionnaire, a picture appears, and it was difficult to understand that they need to click on the picture to access the questions. This was another point that required discussion with Pixel Kicks Ltd.

- **Was it easy to complete the online questionnaires?**

When participants logged in to the SSHUB and had access to the dashboard, questionnaires were available on the left-hand side. However, it was realised from the admin account that a couple of the participants missed the final questionnaire to complete as they had to scroll down the page to see it. Also, the researcher asked this during the interview and participants mentioned that they did not realise they had to scroll down to find another questionnaire. This showed that this needs further work to make it clear.

Furthermore, another point that was recognised from the admin account was that some participants submitted an answer for the same questionnaire couple of times. A participant has mentioned in the interview *'I completed some of the questionnaires twice because when I logged in to the SSHUB for the second time, there was no notification to inform me* *that I had completed the questionnaire before. So, I thought that I forgot to complete the questionnaires the first time and had to complete all questionnaires again'*. This problem was reported by other stroke survivors too and it put time pressure on stroke survivors, which needed to be considered carefully.

Finally, the researcher recognised that two participants have chosen higher scores for the About You and Your Health (AYYH) questionnaire (part one of the EDAQ-SS), which indicates that they are not happy, have pain and are not satisfied with their lives. However, they have mentioned the opposite during the interview. This showed that the participant was confused with the answering option and thought that number '10' indicates a positive answer and the '0' negative answer. Participants have mentioned that using visual cues (e.g., emoji faces) with explanations could help to understand the answer options better for the AYYH.

- **Was it easy to submit your responses?**

Participants mentioned that when they submit questions, they wanted the system to highlight the missing questions in red. Therefore, they could understand which question they have missed rather than looking for it.

- **Did you require any help to complete the online questionnaires?**

Out of ten participants, only a participant required help to complete the online questionnaires. The rest of the participants found it easy to register and follow instructions to use the SSHUB.

- **Would you like to use the SSHUB in future?**

Nine out of ten participants found it **easy** to use the SSHUB and they said they will be happy to use it in future. A participant reported *'I am so happy to see that you are trying to improve stoke survivors' lives. It can be challenging to live with the symptoms of the stroke. I was completely independent before but now I need some help with my cooking, dressing or washing and this can be challenging. I spend time using the website and I can see the potential that this website can help me to understand my struggles and guide me to find a solution for them.'*

Additionally, seven participants out of ten reported that they **prefer** to complete the ePROM rather than the paper version. This was because seven of the participants could only use the unaffected hand, which affected their writing ability. They found easy to use tick box options to answer the questionnaires. A participant, which has the affected dominant hand, mentioned that *'I cannot complete a paper questionnaire, as I cannot write. If it was a paper questionnaire I had to ask my carer to complete it for me, and I prefer to pay for the care to help me in another function during this hour rather than wasting time completing a paper questionnaire. So, I preferred to complete the electronic version of the questionnaires.*'

Another participant has reported that *'I am happy to use an electronic version if this is the only option that I have'.* On the other hand, two participants have preferred the paper version (one does not use the internet very often and the other one mentioned that people may have limited internet access, so the paper version can be useful for more people). To summarise, eight out of ten participants were happy to use the SSHUB to complete ePROM. All these critical feedbacks were documented during Stage Two and a list of the changes was made. After discussing and agreeing with the supervisor team, a meeting with Pixel Kicks Ltd. was arranged to discuss the improvements required to develop SSHUB version two (v2).

SSHUB v2

During the evaluation of the SSHUBv1 usability, it was understood that it required further adaptations and improvements to make it more usable and user-friendly for stroke survivors. After creating a further improvement list for the SSHUB and meeting with Pixel Kicks Ltd. to discuss how to implement these changes, the SSHUBv2 was created. The list of the changes that were discussed with Pixel Kicks Ltd. was summarised in Table18

.

Table 18: Summary of the changes discussed with Pixel Kicks Ltd.

Proposed changes	Decision taken
• The font size of the questions was changed to make them more readable	• Implemented
• The format to submit the ePROM were changed	• Implemented
• Missed items (i.e., not answered) were highlighted with red after pressing the submit or save button to make it clear	• Implemented
• The lines between questions were made more prominent to differentiate between them	• Implemented
• Visual cues such as emoji faces were added next to the AYYH questionnaire answer options to make them understandable and easy to follow for stroke survivors	• Implemented
• The written text was changed to a darker colour (from dark grey to black) to make it more visible	• Implemented
• The size of the tick boxes was made larger and the colour was made darker	• Implemented
• The dashboard was edited to fit all the available questions to one page	• The website developer from Pixel Kicks Ltd has mentioned that they can remove the profile picture, which was located on the dashboard and create more scape for the list of the questionnaires. Additionally, they made the scroll down line thicker and darker to make it more prominent

Proposed changes	Decision taken
• The EDAQ-SS was edited so the answers that were completed but, not submitted within a week can be reset. This is because the EDAQ-SS questions ask about the daily activity level within the last two weeks	• Implemented
• Resubmission was edited and participants cannot resubmit their answers immediately. There is a two-week timeline for all questionnaires	• Implemented
• The last two sections of the DASH are optional. Participants can submit the questionnaire without providing an answer to q31-38 of the DASH. Therefore, the submission of the DASH was edited to allow this, and it was made clear to the participants that these sections are optional	• Implemented
• All ePROM made visible to the participants	• Implemented
• The alignment of the answer options was edited for each ePROM	• Implemented
• Zoom in and out option added to the SSHUB pages when using a phone	• Implemented
• Registration questions were updated, and name-surname options added	• Implemented
• The available ePROM were numbered, and the colour was made darker to make them more prominent	• Implemented

Additional changes were done by the researcher such as changing the content of the research page and the welcome page, changing the picture of the questionnaires, items of the EDAQ-SS followed by the development process, and editing the FAQ page to make it easy to use (Appx 4-Picture 10). Additional questions were added to the FAQ page to explain how to register, provide a consent form, login, find the list of the questionnaires and complete the questions. A stroke can impact the reading, writing and speaking ability of stroke survivors (Stroke Association, 2012). Therefore, the use of pictures helps stroke survivors to understand the information better. Pictures were attached to the FAQ page to provide visual cues to the participants. These guided stroke survivors much better to understand how to use the SSHUB. It took five months to complete these initial changes and make the SSHUB live again. After these changes, the SSHUBv2 was developed and was ready to be tested further for acceptability with a wider population.

5.3.3 STAGE THREE: Development of the SSHUB Version-3

As the aim was to provide stroke survivors with a self-assessment tool to help them develop an awareness of their ADL limitations by using the advantages of digital health, it was important to concentrate on the eEDAQ-SS and SSHUB to understand their acceptability and create version 3 of the SSHUB (SSHUBv3). This helped to develop the SSHUB and the eEDAQ-SS further, prepare it for the evaluation of stroke survivors' engagement with it and improve the SSHUB development.

Acceptability is defined as the perception that helps to understand if the provided treatment, service or practice is agreeable, or satisfactory (Proctor et al., 2011). Before using the PROM, it is important to understand its acceptability (Ng et al., 2019). The acceptability is a critical part of a PROM development as it is the key concept in implementation science because if a tool is not acceptable, it will never be widely used (Menard et al., 2014; Parsons, Fairclough, Wang, & Hinds, 2012; Ji et al., 2011). The acceptability with other properties like appropriateness, feasibility, penetration, cost and sustainability processes are preconditions to providing good service delivery and clinical outcomes as they help to develop a tool that is relevant to the target population and includes items that are accepted by the people who will use it (Proctor et al., 2011). The criterion for acceptability is personal. Therefore, different people can have different opinions about the acceptability of a tool depending on their needs and preferences. For this reason, the target population is involved in evaluating the acceptability of the measure's items. The target population's reaction to the item's understanding ability is considered in assessing the acceptability (Menard et al., 2014). Therefore, involving stroke survivors with different demographic details can provide a wider opinion on the acceptability of the tools. This could provide a wider perspective and help to make these tools useful for different people. In addition, missing answers to the items of the PROM needs to be considered when assessing acceptability, i.e., how often participants skip an item. Moreover, qualitatively the comments of participants about the items need to be analysed to assess the acceptability of a PROM (Menard et al., 2014). As the acceptability is important to evaluate the acceptance of the developed tool by the target population, it was agreed to assess the acceptability of the eEDAQ-SS after developing it with the acceptability of the SSHUB. Therefore, this section aims to explore stroke survivors' experience in terms of the acceptability of the eEDAQ-SS and the SSHUB and to demonstrate their potential to support stroke survivors in self-assessing their ADL limitations. This section explains the procedure that took place to assess the acceptability and findings that were collected.

Participants

A convenient sample was needed (i.e., stroke survivors with a variety of ages, gender, socio-economic and health status), and the same inclusion and exclusion criteria were used as the earlier sample. Please refer to section 4.4.3 for detail.

Recruitment

Participants were recruited via variety of mediums to achieve a larger sample to test the acceptability. Initially, participants who were recruited for Stage 1 were contacted again by the PhD candidate through telephone or email based on the participants' preference to ask if they would like to also participate in the Stage 2. As these participants were involved in the development process of the EDAQ-SS, it was going to be useful to include their ideas for the acceptability of the SSHUB. In order to reach a large and more varied sample, an additional number of recruitment strategies were employed as below:

- **Community Groups**: Leaders of the community stroke support groups (i.e., Brain and Spinal Injury Clinic (BASIC), Different Strokes, Chest Heart & Stroke Scotland) were contacted and participant invitation sheet/recruitment flyers were provided them to share these with their members and displaying information on their websites to reach potential participants. The research team did not contact potentially eligible participants themselves; initial contacts were made by the community group leader already known to them and any people who were interested in taking part were asked to contact the research team directly via the contact details included on the recruitment flyer/invitation letter. A recruitment advert form was completed for Different Strokes and Chest Heart & Stroke Scotland that were sent to them after receiving the UoS Ethics Approval to advertise the project on their website.
- **Volunteers database:** Participants from the UoS volunteer database who did not involve in Stage 1 due to reaching target numbers or any other unforeseen reasons were also contacted. Those who agreed to be contacted for other research were sent a participant invitation letter by email and asked to contact the research team via the contact details included in the letter.
- **Social Media platforms:** Social Media platforms such as Twitter and Facebook were used to advertise and recruit participants for this study using the study-specific Twitter handle (@SSHUBSocial) and Facebook Pages (Strokesurvivorshub). Interested potential participants were either ‘replied’ to the tweet or ‘direct message’ the researcher on the appropriate social media platforms, or contacted the researcher directly by telephone or e-mail advertised on the study e-poster advertised.

People who were interested in participating but had further questions were able to contact the research team by using the contact details on the recruitment flyer/letter of invitation. Potential participants were able to follow the URL link to the SSHUB on the PIS to provide online consent and register with the SSHUB.

Sample Size

There is a lack of consistency in the information about the sample size requirement for the acceptability assessment of the online self-management platforms or the ePROM. Research conducted by other researchers to assess the acceptability of interventions for other conditions has reported that the sample size needs to be a minimum of 20 participants (Kane et al., 2017; Hong et al., 2014). Some studies assessed the acceptability of a PROM by using a randomised control trial method and recruited more than 200 participants (Sierakowski et al., 2020; Smith et al., 2018). On the other hand, the most recent study conducted by Porter et al., (2021) used mixed methods approach and recruited 68 participants to assess the acceptability of a PROM. As the mixed methods approach was used to conduct the acceptability assessment with stroke survivors, who can have different symptoms, and after considering the time for recruitment available and the likely potential recruitment rates estimated at an earlier stage, it was agreed to set the sample size for 50 participants and stop recruitment when recruitment targets were reached.

Procedure

In the acceptability assessment, 57 stroke survivors were recruited in total to provide both qualitative and quantitative data to test the eEDAQ-SS and the SSHUB by using mixed methods approach. Due to the slow recruitment and drop-out, it included two different steps. Initial 14 participants were contacted to understand the barriers of the eEDAQ-SS and SSHUB. After improving them, 43 more participants were recruited to conduct the acceptability evaluation.

At the beginning of the acceptability assessment, eight ePROM were available on the SSHUB (Please, refer to Section: SSHUB Content for details of these ePROM), because this platform was going to be a self-assessment platform and it was aiming to provide different tools for stroke survivors to increase their awareness. Also, the data of these different ePROM were going to be used after the PhD to conduct the psychometric properties of the EDAQ-SS. Initially, it was recognised that recruitment was challenging (please, refer to section 6.5 for details on recruitment challenges), and it took nearly four months to recruit

20 participants. However, some participants dropped out (n:6) and the rest of the participants did not complete all of the ePROM (n:14). Therefore, it was important to understand the barriers of completing the eEDAQ-SS on the SSHUB before further continuing to recruit for acceptability. This was an important part as the barriers that stopped people to complete the ePROM via the SSHUB was going to have a negative impact on the acceptability assessment.

Due to this reason, the first 14 participants who did not complete all of the ePROM were contacted by email to ask about the barriers and get feedback. It was recognised that main problem was to complete different ePROM within a week that aim to assess the same content. After realising the reasons for not participating in the study, seven ePROM were hidden from the SSHUB, and only the eEDAQ-SS were left to evaluate its acceptability. After this change, 43 additional participants were recruited and in total, 57 stroke survivors participated in the acceptability assessment.

Both qualitative and quantitative methods were used to evaluate the acceptability. Quantitative data were collected to investigate how (i) understandable, (ii) helpful were the eEDAQ-SS and SSHUB, (iii) if stroke survivors would consider using the eEDAQ-SS and SSHUB in future as part of their assessment process to evaluate their progress over time. Qualitative data were used to obtain participants' views on (i) barriers and (ii) facilitators to use the eEDAQ-SS and SSHUB, (iii) whether the eEDAQ-SS helped them to recognise the limitations in ADL.

Initially, participants who were recruited from different platforms for the acceptability assessment were provided with the URL link of the online consent form and registration page of the SSHUB. If they were happy to participate and did not have a further question to ask, they were asked to use the URL link, which was available on the PIS to provide online consent, followed by registering with the website. Registration questions helped to collect demographic details about the participants. Followed by registration, participants were directed to the Dashboard, which included the eEDAQ-SS. Participants had a week to complete the eEDAQ-SS and submit their answers. They could save their answers to the domains of the eEDAQ-SS and continue later (within a week) and submit their answers after finishing the whole domains of the eEDAQ-SS. From the admin account, the researcher could see when the answers were submitted. Therefore, participants who completed the eEDAQ-SS within a week were contacted via their email addresses, which they had provided during registration, to assess the acceptability of the eEDAQ-SS and SSHUB. Participants were emailed the acceptability questionnaire through an email that included ten closed questions with a five scale rating option, and three open-ended questions to collect both qualitative and quantitative data for the acceptability of the eEDAQ-SS and SSHUB. Participants who completed this questionnaire were asked to email their responses back to the researcher. If participants did not email their responses within a week after receiving the email, a reminder email was sent to kindly ask their opinions and complete the acceptability questionnaire.

Acceptability questions were developed after searching and critically reviewing the literature on acceptability assessment, (Prior, Sammut, & Vasilica, 2018b; O'Malley, Dowdall, Burls, Perry, & Curran, 2014; Hong et al., 2014; Landman et al., 2014), and considering the needs of the stroke survivors to adapt questions depending on the needs of participants. Participants were asked to answer these questions by choosing one of the answers from the five scale rating option and emailing them back to the researcher. These questions were:

- How understandable were the questions of the eEDAQ-SS?

  1—difficult to understand
  2
  3
  4
  5—easy to understand
- How helpful was the eEDAQ-SS in describing their limitations in daily activities?
  1—very unhelpful
  2
  3
  4
  5—very helpful

- Was the amount of time it took to complete the eEDAQ-SS to create their personalised health record acceptable?

  1—very unacceptable

  2

  3

  4

  5—very acceptable

- How would they rate their overall satisfaction with the self-assessment processes used in this online platform?

  1—very dissatisfied

  2

  3

  4

  5—very satisfied

- Would they consider keep using the eEDAQ-SS to assess their daily activity limitations in future?

  1—not at all

  2

  3

  4

  5—very much

- How easy was the SSHUB for them to use?

  1—very difficult

  2

  3

  4

  5—very easy

- How easy was it to register online to create their personal health record?

  1—very difficult

  2

  3

  4

  5—very easy

- How much did they enjoy using this online platform?

  1—not at all

  2

  3

  4

  5—very much

- Would they consider keep using the SSHUB in the future to help with the self-management of their stroke?

  1—not at all

  2

  3

  4

  5—very much

There were additional open-ended questions at the end of the questionnaire:

a. What were the main limitations and advantages of the eEDAQ-SS and the SSHUB platform?
b. Did the eEDAQ-SS help you to realise your limitations in daily activities and act on them to improve your self-management?
c. Other comments

Data Analysis

Feedback of stroke survivors on barriers to complete the eEDAQ-SS and use the SSHUB

Within the emails sent to the first 14 participants, thoughts were captured through transcribing the written feedback received. Comments of participants were used as a reference throughout the interpretative process. Collected demographic information summarised to report a description of the characteristics of stroke survivors.

Quantitative data for the acceptability

Within the acceptability questionnaires, closed questions that generated categorical data were asked to identify participants' views and whether it was easy to use and understand the information. The percentage for the optional responses for each question were calculated. Collected demographic information was summarised to report a description of the characteristics of stroke survivors.

Qualitative data for the acceptability

In addition to the close questions, participants' feedback was collected within a written comment box by asking their positive and negative thoughts, how this ePROM and digital platform helped stroke survivors to realise their daily activity limitations and act on these limitations to self-manage their conditions. Any comments provided by the participants were recorded verbatim. Data was analysed through content analysis as highlighted in the earlier section. These comments were utilised in informing the further development of the eEDAQ-SS and SSHUB.

Findings

Feedback of stroke survivors on barriers to complete the eEDAQ-SS and use the SSHUB

As mentioned earlier, initial 14 participants (Male:5, Female:9) who stopped completing the eEDAQ-SS were conducted via email to get their feedback on barriers to completing the eEDAQ-SS or the SSHUB before conducting further acceptability assessment. Participants' age ranged from 37-70 years old and ten had an ischemic stroke while four had haemorrhagic. Participants did not differ in their socio-demographic details and stroke status from those who completed the questionnaire and left it. All participants including those who completed the questionnaire or not, sent an email to explain the barriers that affected them to complete ePROM. These barriers including the solutions advised by stroke survivors were summarised in Table 19. Both participants who completed or leave the questionnaire provided similar comments.

***Table 19**:* Barriers that stopped participants from completing the eEDAQ-SS and solutions advised by participants

List of barriers	A number of participants found this as a barrier	Solutions advised by participants
Time	13	-Reduce the number of the eEDAQ-SS items -To complete only relevant domains
Too many PROM to complete	14	-Reduce the number of PROM -Give a longer time to complete the PROM
Length of the eEDAQ-SS	7	-Reduce the number of PROM -To be able to submit a single domain
Some PROM are repeating the same questions	10	-Cancel the questions that ask the same thing -Automatically answer similar questions when one question is answered
Design of the EDAQ-SS	2	-Make it clear that both Section A and B need to be submitted -List the equipment in alphabetic order (for the EDAQ-SS) -To be able to skip a domain, if it is not applicable -More pictures
Not mobile-friendly	3	-Make it easy to complete the PROM through mobile phones
PROM other than the EDAQ-SS do not give 'Not Applicable' answer option and counts as you either can or cannot do the activity	7	-Put a not applicable answer option -Remove other PROM

Acceptability of the eEDAQ-SS

After getting feedback on barriers to completing the eEDAQ-SS, it was clear that the main problem was the number of the ePROM on the SSHUB. Therefore, seven ePROM, except the eEDAQ-SS, were hidden to view from the SSHUB to increase the completion of the eEDAQ-SS to recruit more participants. The goal of the eEDAQ-SS was to provide a comprehensive self-assessment of ADL limitations for stroke survivors. Therefore, it was important to understand what needed to improve to increase adherence and make it more useable and acceptable for the target population. Assessment of the acceptability helped to analyse the problems, find a solution for them and further develop the eEDAQ-SS.

In total, 57 participants were successfully recruited via different platforms following the removal of the other PROM of the SSHUB; eight people from the UoS volunteer list (participants of Stage 1-Development of the EDAQ-SS), 42 stroke survivors from the Twitter account, and seven people from the community services. The participants were asked to complete the acceptability questionnaire via email and provide comments on the eEDAQ-SS. All the participants responded. In total, the study sample included 31 males and 26 females, and their demographic and stroke characteristics are described below in Table 20.

Table 20: Demographic details of participants who provided feedback for acceptability of the eEDAQ-SS

Stroke Survivors (n=57)	Number
Age (years)	31-90 years old
Gender M: F (n)	31:26
Type of stroke	Ischemic: 47 Haemorrhagic: 8 I do not know: 2
Injury side at the brain	Brainstem: 1 Cerebellum: 6 Right: 26 Left: 16 Both Sides: 4 I do not know: 4
Effects of the stroke	Hemiplegia: 37 Aphasia: 16 Reduced balance: 22 Dysarthria: 15 Memory issues: 16 Depression or Anxiety: 17 Stress: 16 Hearing loss: 13 Visual problem: 13
Accommodation	House: 28 Bungalow: 15 Flat: 14

After reducing the number of the repetitive ePROM measuring similar outcomes at the SSHUB, the recruitment number increased to 57 participants in total over nine months. The sample size was agreed to be 50, but 57 participants were recruited in total as new information was continued to be received until the last five participants. The recruitment for the acceptability assessment was ended after the data saturation reached. Eighty-three responders registered on the website, and 57 (68.7%) participants completed the eEDAQ-SS. This further supported the assumption that a high number of ePROM was the main barrier to using the SSHUB to complete the eEDAQ-SS, as participants found this too burdensome. All participants were contacted for the acceptability of the eEDAQ-SS disseminated via the SSHUB and all responded. Figure 5 depicts the responses of the participants on the acceptability of the eEDAQ-SS in a stacked bar chart. In addition, responders also provided additional comments on the eEDAQ-SS, which was summarised in Table 21.

Figure 5: Stacked bar chart of the participants' responses to five closed questions asked to assess the acceptability of the eEDAQ-SS

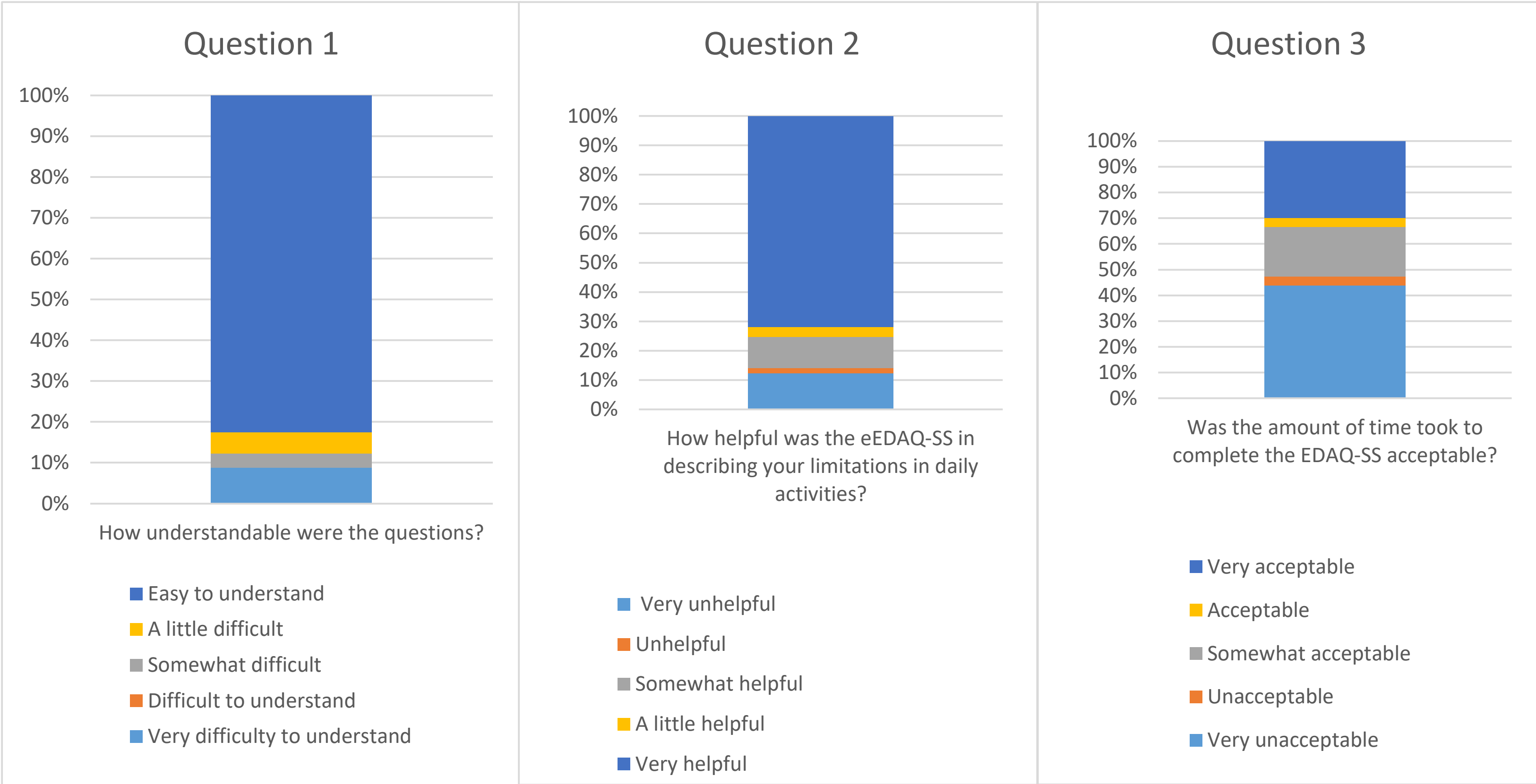


Figure 5: Stacked bar chart of the participants' responses to five closed questions asked to assess the acceptability of the eEDAQ-SS

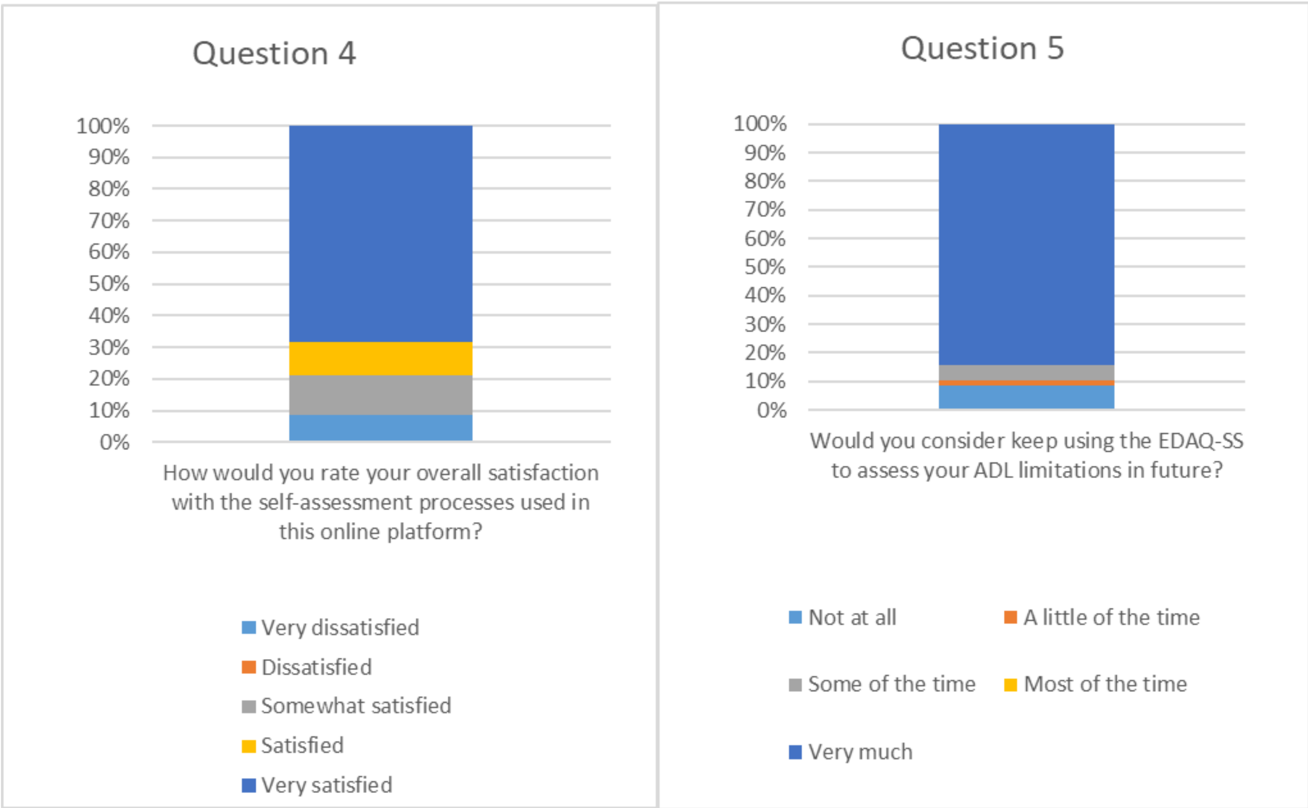


Table 21: Summary of comments provided by stroke survivors (n: 57) on the eEDAQ-SS

Question	% of people who agreed with these statements	General Comments Received
Barriers to completing the eEDAQ-SS	49.2%	Length of the questionnaire.
	62.7%	Prefer to skip a domain if it does not apply to their condition.
	16.9%	Difficult to find aids that they use from the list of equipment.
Facilitators to use the eEDAQ-SS	86.0%	It is a comprehensive questionnaire and covers most of the daily activity limitations.
	88.1%	All of the items were relevant for stroke survivors.
	89.3%	A comprehensive PROM that can be used to increase self-awareness.
	100%	Not Applicable option is useful as this is not available at other PROM for stroke survivors. Therefore, when completing a PROM, which does not have not applicable option stroke survivors either skip the question or complete it which affects their total score.
	96.6%	Helped them to realise what they can and cannot do.
	88.1%	Helped them to contact their therapist and discuss their limitations.
	78.0%	Helped them to realise the effect of aids they use on their daily activity.

Impact of eEDAQ-SS on realising the limitations of daily activities	42.4%	They realised which equipment does not help them to improve their activity level and discussed this with their therapists
	64.4%	They think that number of items is long, but all of the items are relevant to their condition and helped them to actively get involved in their treatments.
Additional comments	89.5%	They will be happy to use it in future.
	86.0%	They prefer to see their total score of the ePROM and be able to share these with their healthcare professionals.
	29.8%	They prefer to have a short form of the eEDAQ-SS.

Acceptability of the SSHUB

Once initial technical problems, which prevented people to register to the SSHUB and completing the ePROM, have been overcome, the consensus was that the SSHUBv2 itself was straightforward to use. A few minor problems were identified. In total 57 participants were contacted for the acceptability of the SSHUB. Figure 6 represents the responses of the participants on the acceptability of the SSHUB in a stacked bar chart. In addition, 57 of the participants provided additional comments on the SSHUB. Table 22 summarises the comments on the SSHUB that stroke survivors provided during the acceptability assessment.

Figure 6: Stacked bar chart of the participants' responses to five closed questions to assess the acceptability of the SSHUB

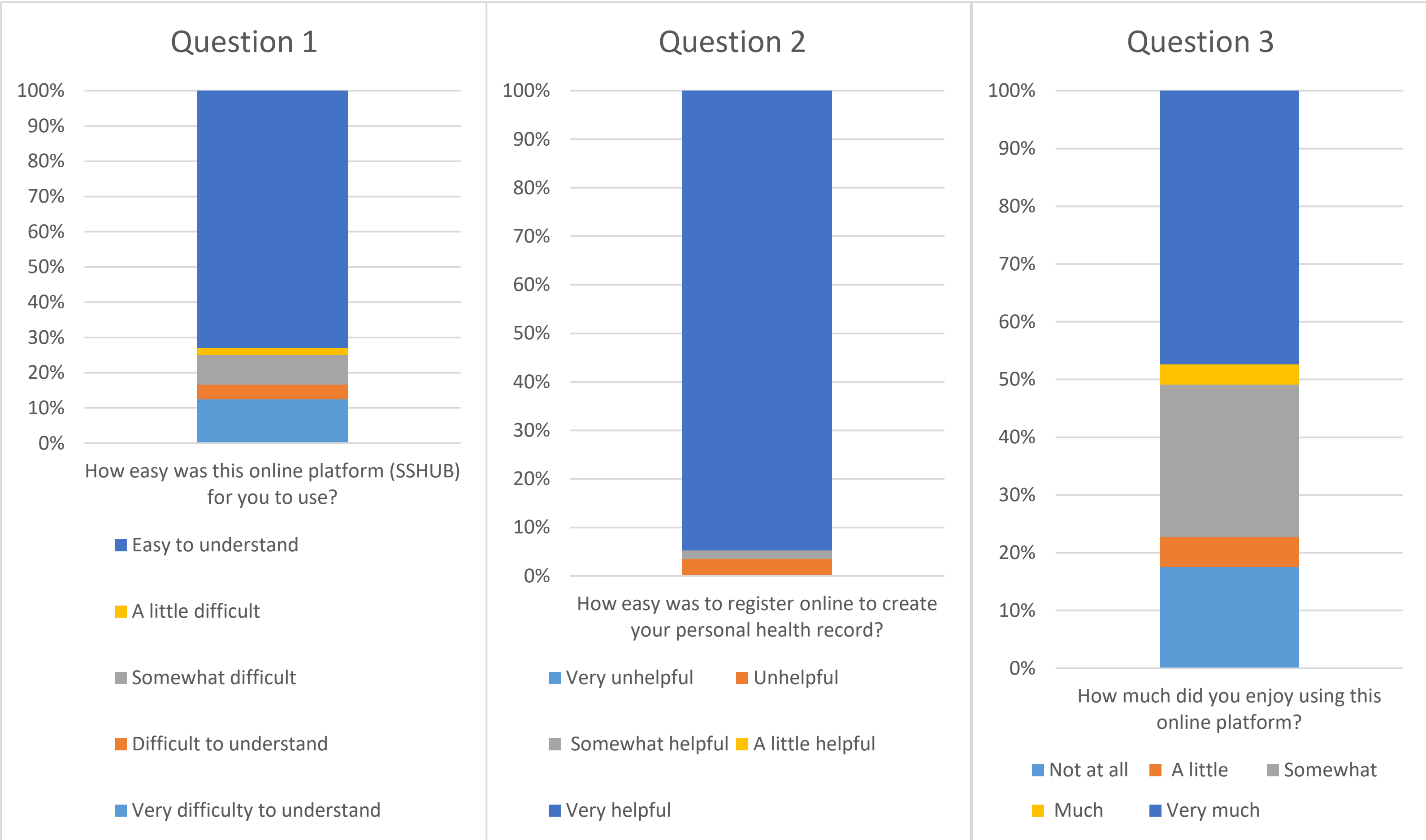


Figure 6: Stacked bar chart of the participants' responses to five closed questions to assess the acceptability of the SSHUB

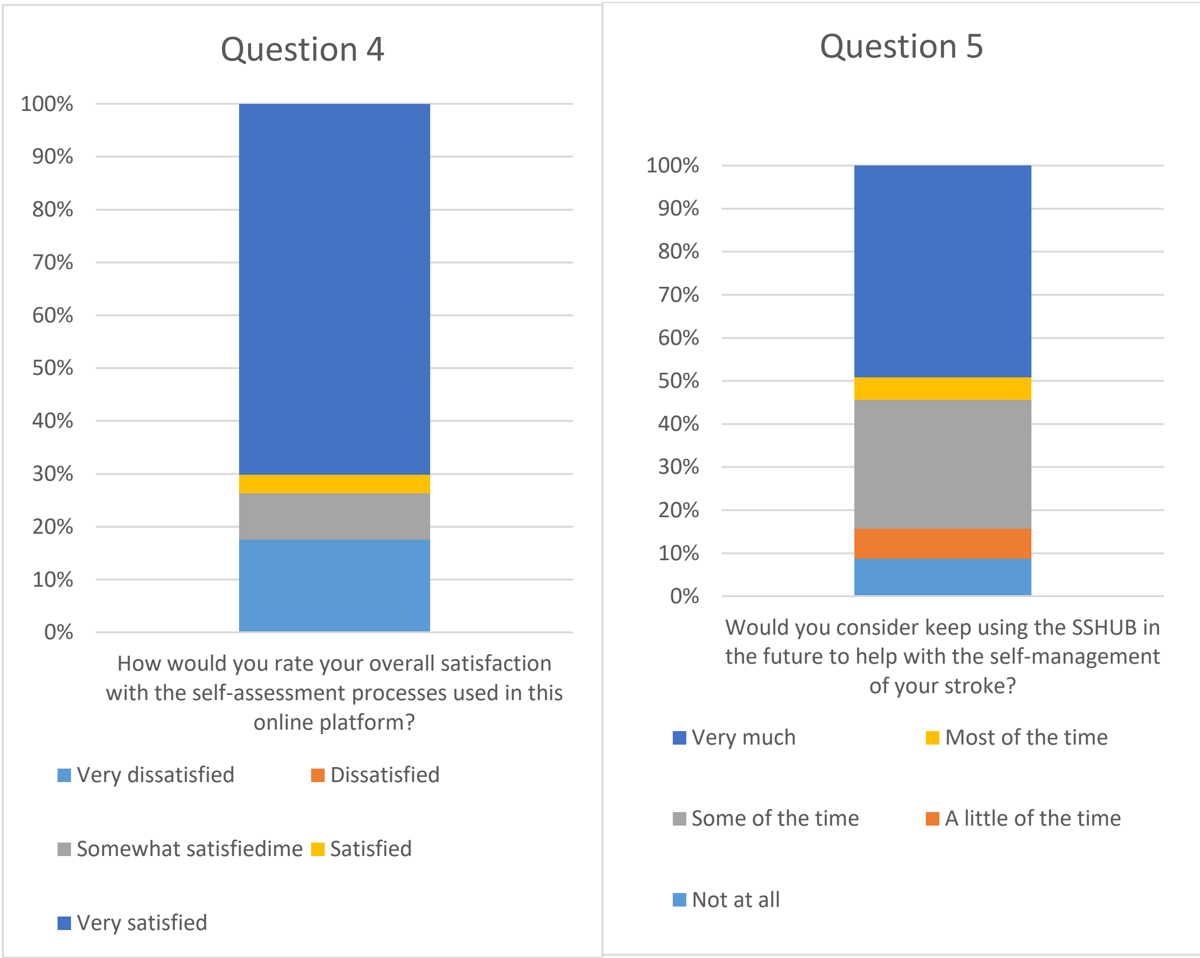


Table 22: Summary of comments provided by stroke survivors (n: 57) on the SSHUB

Question	**% of people who agreed with these statements**	**General Comments Received:**
Limitations to using the SSHUB	5.3%	Many questions to answer during the registration.
	96.5%	Prefer to see the score of the questionnaires.
	47.4%	Prefer to access more information on the website.
	7.0%	Difficult to complete the SSHUB via mobile.
Advantages of the SSHUB	100%	Easy to login
	94.7%	Provide easy access to the ePROM at anytime
	87.7%	Easy to follow and use the SSHUB
	85.9%	Good font, size and colour
Additional comments	91.2%	During the COVID-19 there was limited access to face-to-face self-assessment platforms. This platform helped to realise that there is something they can still use to assess their limitation and self-manage their conditions at home by discussing their results with their healthcare professionals by telephone.
	77.2%	They will be happy to use it in future
	84.2%	They prefer to have an application for the phone

To summarise, mixed methods approach was used to assess the acceptability of the eEDAQ-SS. The quantitative data helped to understand that participants did not have any big issue with completing the eEDAQ-SS as they highlighted it was easy to complete. Participants reported that they will prefer to use the eEDAQ-SS as a self-assessment tool in future as it helps them to develop their awareness of ADL limitations and discuss their issues with their healthcare professionals. The qualitative data helped to understand that eEDAQ-SS increased the accessibility and made it easy to complete it for stroke survivors and they enjoyed using the eEDAQ-SS. However, while most of the participants provided positive feedback on the acceptability of the eEDAQ-SS, there was some negative feedback to consider too. Nearly 44% of the participants thought that eEDAQ-SS is long and there is a need to make it shorter. However, this is a point that needs to be considered after conducting the psychometric testing of the EDAQ-SS. Please refer to section 6.7.1 for detail.

Acceptability of the SSHUB showed that it is a user-friendly platform that helps stroke survivors to complete the eEDAQ-SS anytime to self-assessment their ADL limitations. There are still important parts that need further development (please, refer to section 6.7.2 for detail), but the findings of the acceptability assessment indicated that SSHUB has a good potential to be a good self-management platform in future and help stroke survivors to use it as part of their self-assessment tools as it increases the inclusivity. The SSHUB is the only platform that house the eEDAQ-SS, which helps to collect detailed information, therefore, has the potential to be a data repository platform for the UoS and guide further research for stroke rehabilitation. To give an example, detailed data on ADL limitations of participants were collected during the acceptability assessment, which was used to conduct an analysis and understand the frequency and pattern of ADL limitations of British community-dwelling stroke survivors. The next section explained the rationale and findings of this analysis.

5.4 Distribution of ADL Limitations in British Community-Dwelling Stroke Survivors

There is a lack of research to show the pattern and distribution of stroke on daily activity limitations for British community-dwelling stroke survivors, therefore, data collected via the eEDAQ-SS during the acceptability assessment was analysed descriptively to explore the frequency and pattern of ADL limitations in British stroke survivors.

Post-stroke people suffer from different neurological deficits depending on the location and size of the lesion (Whitiana et al., 2017). Different stroke survivors might suffer from different symptoms after the stroke. However, motor deficits are more common than any other lesions (Brewer, Horgan, Hickey, & Williams, 2013). Motor deficits can affect people's ability to perform daily activities, which might result in dependence on other people. This further disability linked with the limitations in daily activities result in handicap (i.e., decreased social participation). The effects of a stroke might be felt in different aspects of stroke survivors' lives. Their limitations might affect their family members, have negative impacts on their economic and social situations (Whitiana et al., 2017; Di Carlo; 2009).

All limitations that are linked with each other create a cycle in which the patient can get worse (Haghgoo, Pazuki, Hosseini, & Rassafiani, 2013). Effective management is crucial in reducing disability and providing independence for patients (Whitiana et al., 2017; Staines, Mccoy, & Brooks, 2009). Assessment of the ADL limitations is one of the indicators used to understand stroke survivors' current situation. It is recorded in research that about 50 million stroke survivors in the world have physical, cognitive and emotional problems, and 25%-74% of these people are dependent on daily activities (Pei et al., 2016; Miller et al., 2010). On the other hand, there is no research to show which ADL limitations British stroke survivors are affected in detail (i.e., drinking from a cup, using showering controls, washing hair or standing up from a chair). Understanding the pattern of ADL limitations for British stroke survivors can help to understand what percentage of stroke survivors are affected in what daily activity limitation in general. This information can help to develop further assessment and rehabilitation tools that can be linked to patterns and prevalence of stroke survivors. As the data collected in this study is from a limited sample, it just described the data distribution to identify patterns in these limitations to provide some insight into the difficulties experienced by the study participants. However, as the SSHUB will develop further into a research data repository for stroke survivors, it will be possible to obtain more meaningful prevalence and patterns data on this population.

5.4.1 Data collection and scoring

The total score for each domain for sections A and B can be calculated separately by summing item scores within that domain. This indicates the stroke survivors' overall ability in that domain both without ergonomic solutions (Section A) and with ergonomic solutions (Section B). For Part 2 Section A, each answer response has a different score, (Not applicable: 0; No difficulty: 0; Some difficulty: 1; Much difficulty: 2; Unable to do: 3). For the total score of Section A of a single domain, the score of each item is added. For Section B, if an item is ticked as 'Yes' to question 'Do you use an aid or other method?' and then an answer needs to be provided to Section B. Each answer has a different score as mentioned above. If a person chooses to answer 'No' to the question 'Do you use an aid or other method?'; or 'Yes' but item in Section B is not completed, the score of the item will be the same as in Section A. Finally, if a person chooses the last option, 'Has help/someone else does it', they are asked NOT to complete Section B and the score for that section will be the same as in Section A. For a total score of a single domain of Section B, the scores of Section B plus scores of Section A (if none used/has helped) is added as the ability is unchanged when someone helps or they use no equipment. This method was applied to the SSHUB, which helped to calculate the score of each participant automatically.

Participants (n:57) were asked to complete the eEDAQ-SS within a week of registration. Participants were provided with an ID as soon as they have registered to the SSHUB and responses were anonymised by making sure that the exported data has only participant ID and not any personal identification information. Individual answers to each item could be seen through an admin account on SSHUB. Data was downloaded directly from the SSHUB as a CSV file and then uploaded to the SPSS software to conduct the analysis.

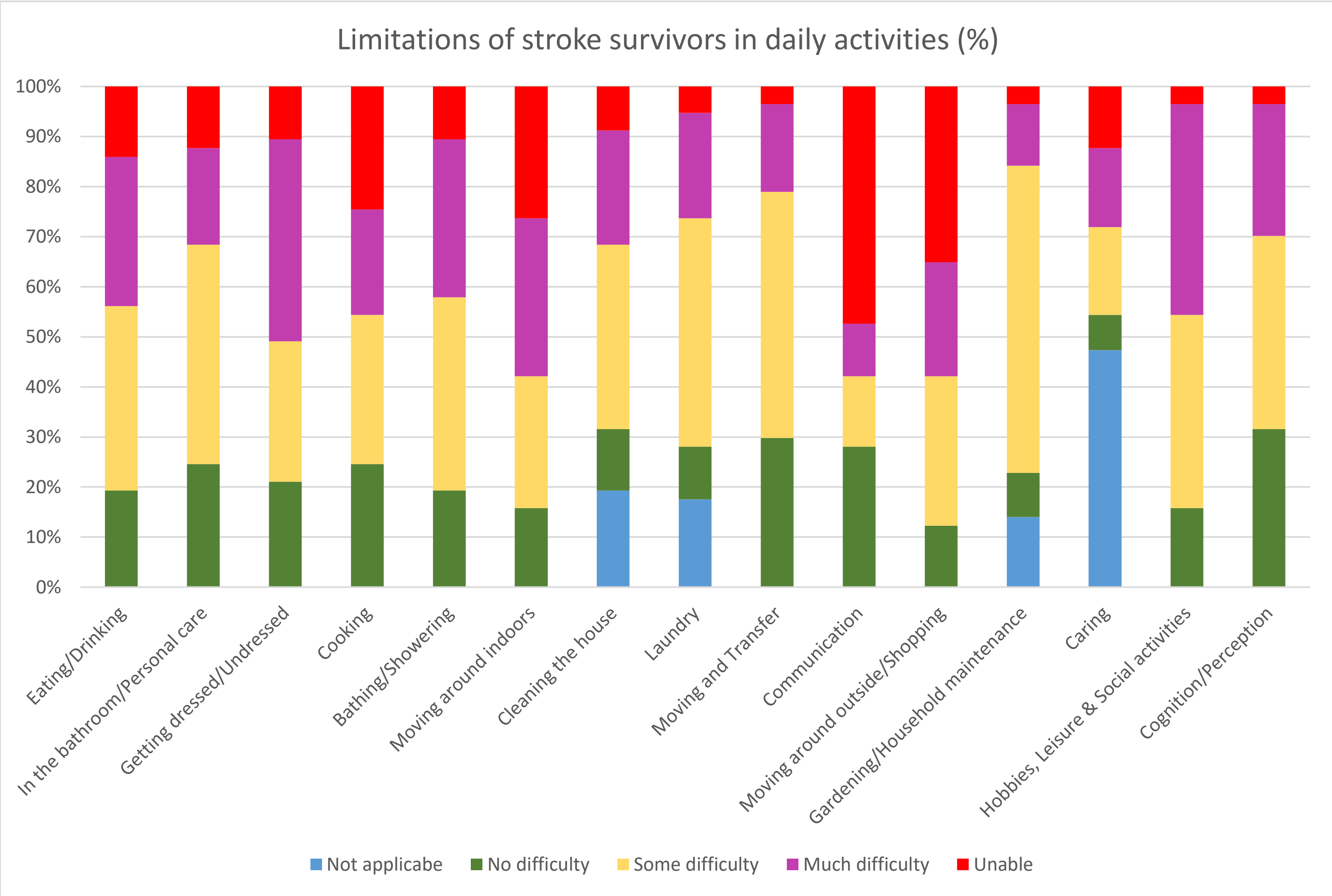
5.4.2 Data analysis

The data were analysed descriptively, in which the percentages for individual items were calculated to understand which limitations were commonly reported and/or more severely impacted the stroke survivors' ADL. To aid visual representation of the findings, data were presented in a stacked bar chart for each domain (Figure 7).

5.4.3 Findings

Participants selected the 'Not applicable' option only for the 'Caring', 'Gardening', 'Cleaning the house' and 'Laundry domains' (4/15). The 'Caring' domain was answered with the highest 'Not applicable' option as 47.4% of the participants. The 'Communication' domain (47.4%) followed by the 'Moving around outside/shopping' (35.1%) domain were the two domains that got the highest response for the unable to answer option. This showed that most of the participants have limitations with outside mobility rather than indoor mobility, as only 26.3% of the participants were limited with indoor mobility. On the other hand, 29.8% of the participants had no difficulty with transfers. This analysis showed that most of the participants had some difficulties in most of the domains; 'Eating/Drinking' (36.8%), 'Personal care' (43.9%), 'Cooking' (29.8%), 'Bathing/Showering' (38.6%), 'Cleaning the house' (36.8%), 'Laundry' (45.6%), 'Moving and transfer' (29.8%), 'Gardening' (61.4%), 'Hobbies', 'Leisure & Social activities' (38.6%), and 'Cognition/Perception (38.6%)'. However, these stroke survivors were able to do their daily activities with the help of environmental modifications. Therefore, this analysis helped to understand that participants' performance improved with the use of environmental and personal modification, which showed there is a difference between capacity and performance.

***Figure 7*: Pattern and distribution of ADL limitations across 15 domains of the eEDAQ-SS**



5.5 Discussion

The design and development process of the SSHUB and eEDAQ-SS were discussed in this chapter. During the initial search, no other online platform was found which provides stroke survivors access to the comprehensive ePROM to assess their ADL limitations to provide personalised self-management advice based on ePROM. The SSHUB and eEDAQ-SS were specifically developed for stroke survivors with the involvement of stroke survivors and healthcare professionals, which helped to make it user-friendly, understandable and easy to use. Activity limitations after a stroke can change over time. Therefore, stroke survivors need to realise their progression or deterioration to understand their main limitations and keep a record of their changes in ADL function to be able to self-manage their condition. The SSHUB has the potential to provide feedback to stroke survivors about their current progression on ADL immediately and help to support their self-management by increasing their self-awareness.

5.5.1 Acceptability of the eEDAQ-SS

The acceptability assessment of the eEDAQ-SS showed that it is a PROM that has benefits but also needs some improvements that need to be considered after the PhD to further improve it. First of all, stroke survivors found the eEDAQ-SS readable and understandable, which helps stroke survivors to empower themselves. This is because, the EDAQ-SS is a disease-specific and not a generic PROM, and was designed for stroke survivors to assess their daily activity limitations with stroke survivors. This made the EDAQ-SS cover meaningful activities for the target population, which was the main limitation of the other PROM that were commonly being used for stroke survivors to assess ADL limitations (please refer to Chapter Three). Participants (71,9%) thought that the eEDAQ-SS helped to describe their symptoms. This shows that the use of the eEDAQ-SS has the potential to empower them by increasing their awareness of limitations and the impact of limitations on their independence, which may help to improve their self-management.

Completing ePROM by an older population with comorbidities including visual impairments, memory problems or arthritis, can make ePROM filling more challenging (Kane et al., 2017). However, this issue was not reported by the participants as most of the participants were older (>70) and did not require assistance to complete ePROM via the SSHUB. More than half of the participants (68,4%) were satisfied with the eEDAQ-SS and did not find it burdensome, which showed that the development process was successful and helped to develop tools with high acceptability. Poor literacy is an important barrier to PROM accessibility (Kane et al., 2017; Jahagirdar, Kroll, Ritchie, & Wyke, 2012). The accessibility of the eEDAQ-SS was not assessed in this PhD project, but poor literacy can affect the acceptability of the PROM by the target population and eliminate its use. However, this was not an issue reported by the participants as the results showed that most of the participants (82.5%) found the items of the EDAQ-SS understandable.

Evidence in the literature on other health conditions showed that patients are willing to use ePROM regularly as it helps them to detect their changes, improve their communications with healthcare professionals, results in better QoL and less admission to hospitals (Kyte et al., 2020; Denis et al., 2019; McCann, Maguire, Miller, & Kearney, 2009; Velikova et al., 2004). The results of this PhD project was in line with these results as nearly, all of the participants (84.2%) were happy to use the eEDAQ-SS again in the future to evaluate their progress and discuss their situation with their healthcare professionals. Therefore, it showed that the use of the eEDAQ-SS has the potential to improve their self-assessment and eliminate the risk of hospital admissions.

On the other hand, it was important to understand why the rest of the participants did not consider using the eEDAQ-SS, to be able to progress it for stroke survivors with different needs and improve its inclusivity. Less than half of the participants (43.9%) thought that it took a long time to complete the eEDAQ-SS and some of the participants mentioned that they would prefer to skip the domains that were not relevant to them or would prefer to have fewer items. On the other hand, they could not find any item which was not relevant to their condition, and they thought that one week was good enough to complete it. This showed that the expectation of each stroke survivor is different and evaluating psychometric properties with a wider population after this PhD project can help to understand the thought of more stroke survivors on the EDAQ-SS and further develop it. However, current results indicated that most of the stroke survivors are happy to use the current version of the eEDAQ-SS as part of their self-assessment process to increase their self-awareness of ADL limitations. Therefore, cognitive debriefing interviews were successful in revealing possible pitfalls related to item acceptability and reducing the ambiguity of wording for maximum clarity and validity of the PROM. It can be concluded that the evaluation of acceptability has proved that the eEDAQ-SS was acceptable and user friendly to be used by the target population. The final stage in the development of the PROM is to examine its psychometric properties to ensure it is a valid and reliable measure and can be recommended to be used with this population.

5.5.2 Acceptability of the SSHUB

As explained through this chapter, three stages were followed to develop the SSHUB, and assess its usability and acceptability. Stages One (development process) and Two (usability evaluation) have demonstrated that community-dwelling stroke survivors thought that the SSHUB was useful, but required few improvements to increase its usability. Ninety per cent of the participants were happy to use the SSHUB in future as a self-management platform. Participants were new to the SSHUB, but they did not report any issue with the registration process. They were happy that they had a chance to create their personalised username and password as this increased their chance to remember registration details and use the SSHUB later.

During the usability, the main challenge for the users was the submission technique of the eEDAQ-SS because it was not clear to participants how to submit Section A and B. If they missed a question they were not allowed to submit the questionnaire and it was not obvious to them which question they have missed. In addition to submission, participants wanted minor changes to the font size and colour of the ePROM. Usability is critical to produce an effective digital health technology and a digital technology with poor usability is unlikely to be accepted by the target population (Sousa & Lopez, 2017; Sun, Zhu, Hsiao, 2015). More importantly, digital technologies with limited usability can be harmful for the target population (Sousa & Lopez, 2017). Therefore, to eliminate the risk of developing a platform with poor usability, the challenges and other technical errors that were identified during the usability evaluation were corrected by working together with Pixel Kicks Ltd. and the SSHUB to further improve the platform by following stroke survivors' suggestions.

The method used to assess the acceptability of the SSHUB was successful as all of the recruited participants used the SSHUB and completed the eEDAQ-SS, followed by the acceptability questionnaire via email. Study implementation strategies were effective, such as reminding emails to ensure recruited participants read the PIS and complete the eEDAQ-SS before completing the acceptability questionnaire. The design of the SSHUB had advantages during the data collection. Participants had to complete the online consent form before registering to the SSHUB, which made sure to receive all of the consent forms before collecting the data. In addition, the design of the SSHUB helped to eliminate the risk of missing data as participants were not able to skip a question and they were supposed to provide an answer to be able to submit their responses. The acceptability assessment revealed a high level of ease of use and usefulness of the SSHUB. It showed that the SSHUB provided a comprehensive approach taking the needs of wider stroke survivors into account to ensure this platform can engage a larger population of adults who live with the impact of stroke.

In addition, most of the participants felt the benefit of using the SSHUB. Despite being an older age group with limited experience of using online self-management platforms or technology, participants generally found the SSHUB easy to use and appreciated the benefit of using it. Almost, all of the participants (94,74%) thought that it was easy to register to the website. However, they have mentioned that there were many questions to answer during the registration and they preferred to eliminate some of the questions to reduce the length of the registration to one page. All of the participants (100%) managed to use the SSHUB independently and they have reported that it is easy to complete the eEDAQ-SS. They preferred electronic version rather than paper version, as electronic version provided them more advantages. This showed that the use of digital health is more preferred by stroke survivors and it was a correct decision to develop the SSHUB to increase the use of the eEDAQ-SS and encourage self-assessment. The SSHUB has provided them with a platform that they can use in their home and at their comfort. NICE: evidence standards framework for digital health technologies, 2021; The HEE Topol Review, 2019 and NHS Long Term Plan (2019) have advised the use of digital technologies as part of health and self-management as they have lots of advantages, but it is important to consider the issues that they can result, such as lack of face-to-face interactions with healthcare professionals (Villalobos et al., 2020). It is important to understand that the SSHUB is not developed to overcome face-to-face interventions, but to guide the self-assessment and help stroke survivors to actively get involved in their care pathway. However, the acceptability assessment showed that the SSHUB needs further improvements after the PhD to make it a self-management platform.

Some participants have recommended providing more information in the SSHUB, i.e., access to other ePROM for the assessment of QoL and other conditions, such as depression and anxiety. This made to critically analyse the findings obtained from the initial 14 participants of the acceptability assessment that provided feedback about the limitations of the SSHUB and eEDAQ-SS, as it was an opposite comment. Eight different ePROM were developed for the SSHUB to be used for the psychometric testing of the EDAQ-SS. They were hidden from participants because they were found limited by the participants and resulted in less use of the SSHUB. However, the SSHUB aims to be a self-management platform in future. Stroke is a condition that results in more problems than physical impairments, such as depression (Towfighi et al., 2017), which can affect the QoL. Therefore, including PROM that aims to assess different impairments can help to provide stroke survivors more opportunities.

Participants have reported that in future they would like to see their total score of the eEDAQ-SS, as this will help them to use the SSHUB as a self-management platform and increase users' awareness of their levels of ADL limitations. This can encourage them to alter their behaviour on their ADL limitations. Some of the participants have reported that their self-monitoring behaviour has changed and they have realised some of the limitations in their daily activities, which they have avoided before. Completing the eEDAQ-SS through the SSHUB helped them to realise their limitations and discuss these with their healthcare professionals to act on these.

Despite the limitations of this study (please, refer to Chapter Six for detail), it was one of the first to report testing usability and acceptability of a website that house ePROM to guide self-management by evaluating the ADL limitations. This study has shown that the SSHUB was acceptable and user-friendly to use by stroke survivors. However, further development of the SSHUB, i.e., providing the meaning of scores to the users of the website and making more PROM to be available on the SSHUB will make the platform more useful. The SSHUB is an online self-assessment platform, which aimed to provide stroke survivors with easy completion of the ePROM and useful information, such as links to community stroke services or articles that they can read to improve their knowledge about their condition. The SSHUB needs to progress further after the PhD to help stroke survivors to access the results of the ePROM, download their results, record their results and see their changes over time. The results of the ePROM will help stroke survivors to self-assess themselves, see their progressions or deteriorations and act on their limitations by discussing their results with their healthcare professionals.

5.5.3 Future of the SSHUB

As discussed, this PhD aimed to build the foundations of the SSHUB and there is a wider vision for the use of the SSHUB, which requires further research in the near future, following the completion of this PhD. Most importantly a collection of data will continue to test the psychometric properties of the eEDAQ-SS across a larger, representative sample to meet the power calculation requirements to undertake psychometric testing. As justified in Chapter Two, psychometric testing is an important part of PROM development, which needs to be tested before a PROM can be used efficiently in clinical and research contexts (Mokkink et al., 2018). However, due to the improvement that took a long time, the PhD timeline was not long enough to recruit enough participants to analyse the psychometric properties of the EDAQ-SS.

In addition, other ePROM will be added and reinstated at the SSHUB with licencing permission, to provide more opportunities to stroke survivors to access ePROM that can help them to get immediate feedback about their limitations and use these results as part of their self-management. There were other features developed by the researcher during the SSHUB development, but not discussed in this thesis as they are not part of the revised aims of this PhD. Therefore, they were hidden from view for the duration of the PhD and will be made available to stroke survivors in future, when wider data collection starts. For example, in the future participants will have opportunities to see their total scores of the ePROM as soon as they complete and submit them, as well as an explanation of these scores in lay language to summarise what these means for their functional status.

Most importantly, stroke survivors will be able to download a PDF of their completed assessments to be able to store this personally or share it with their healthcare team to seek further support for rehabilitation. This platform will help them to track their changes over time and improve their awareness, so they will be able to use the SSHUB as a self-management platform, which was identified as an unmet need during this PhD. Additionally, the SSHUB will keep a record of stroke survivors ePROM scores and will present the changes of scores on a diagram to show participants if they got better or worse over time. This will guide stroke survivors to understand where they need more input to improve their independence in ADL. Thus, this PhD has built the foundations to make these features available following the completion of the thesis.

5.5.4 Distribution of ADL Limitations in British Community-Dwelling Stroke Survivors

It is important to understand the challenges stroke survivors face as it helps to identify the long-term problems that healthcare services need to concentrate on to help stroke survivors (Ch'ng, French, & McLean, 2008). The results of the analysis showed that the 'Caring' domain was the main domain that 47.4% of the participants did not find relevant. This could be because of the age of the participants as 33.3% of the participants were aged 65 and over or the ability as if the participants are not independent themselves, they may not care for others. These findings showed that the EDAQ-SS has similarities with the EDAQ for RMDs, as in the concurrent validity of the English, Dutch and German versions of the EDAQ the 'Caring' domain had a weak correlation with other measures as few participants had caring responsibilities (Hammond et al., 2020). Therefore, there is a need to test the EDAQ-SS further with people who have caring responsibilities to test its validity. The 'Communication' domain (47.4%) and 'Moving around outside/shopping' (35.1%) domain were the two domains that got the highest response for the unable to do answer option. This showed that most of the participants have limitations with outside mobility rather than indoor mobility, which was a different result than the previous studies.

Previous studies showed that stroke survivors are mainly limited with independent walking, bathing, eating/drinking, dressing and housework (van de Port, Kwakkel, van Wijk, Lindeman, 2006; Pajalic, Karlsson, Westergren, 2006). However, analysis conducted as part of this PhD project showed that the main restriction that participants had was outside mobility. A study conducted in South Africa by Rouillard, De Weerdt, De Wit and Jelsma (2012) reported that community-dwelling stroke survivors who had an intensive post-stroke rehabilitation for six months were not independent in housework, food preparation, shopping and use of public transport. However, none of these studies reported the limitation in communication which was one of the main limitations that participants had in this study. Limitations in communication might have a negative impact on people's psychology and result in poor QoL.

On top of these, the analysis conducted as part of this PhD to understand the frequency and patterns of ADL limitations showed that stroke survivors ADL functioning improved with the use of aids and adaptations. Therefore, people's independence followed by QoL can improve with an adaptation, but stroke survivors need to be aware of this so they can incorporate these strategies into their long-term self-management to improve functional outcomes. Improvement on awareness on the effect of equipment use, or realising main limitations in ADL can help stroke survivors to understand what is the main issue that affects their QoL and what is the next step that they need to take in their self-management.

CHAPTER SIX: SUMMARY OF THE RESULTS AND CONCLUSION

6.1 Introduction

The rationale for this thesis was born from the need to help stroke survivors access online technologies based on evidence-based practice to assist them with self-managing their conditions through a self-assessment of their limitations in daily activities. The underlying assumption was that helping stroke survivors to increase their understanding of the extent to which ADL limitations affect their independent living would enable them to take an active role in their long-term care, as informed patients make better treatment choices. The number of stroke survivors is expected to increase as a result of the ageing population in the UK and with this increase, there will be more stroke survivors who will need help with ADL in the future. As the pressures on health services increase, self-management using online technologies will become an important part of the UK health landscape. This chapter brought together the concluding remarks, provided a discussion to synthesise the results of the studies undertaken in this thesis and made suggestions for future research.

6.2 Summary of Thesis Aim and Objectives

The overall aim of this PhD project was to contribute to stroke assessment and treatment to help stroke survivors' self-management by taking the advantage of digital health technologies to ensure this was freely for all. This aim was achieved by:

(i) Conducting a systematic review of the literature to understand if there is a comprehensive PROM that can help to assess the ADL limitations of stroke survivors and differentiate capacity from performance.

(ii) Developing a stroke-specific self-assessment questionnaire to measure activity limitation and participation restriction that is comprehensive, understandable and easy to use for stroke survivors.

(iii) Creating an ePROM to improve and widen use of it as part of self-assessment of daily activities for stroke survivors.

(iv) Developing and testing the acceptability of the SSHUB and use of the eEDAQ-SS by using a mixed methods approach to ensure these are appropriate for stroke survivors.

(v) Providing a detailed picture of the frequency of pattern on activity limitations and participation restrictions in stroke survivors to further determine the extent to which stroke impacts their life.

A broad literature review was conducted within the first three months of the PhD research to better understand the impact of self-management on improving the ADL limitations, the benefits of ePROM use and how this ePROM can be used as a self-assessment tool by stroke survivors to guide their self-management in order to inform the background of the thesis. Questions identified through this broad literature review were further examined with a comprehensive systematic review of the PROM to assess ADL limitations in stroke survivors to identify gaps for research and practice.

Following the systematic review, it was acknowledged that although there were existing PROM to assess ADL limitations in stroke survivors, these were limited in content and none of them measured the effect of environmental modifications on ADL functioning. Thus, the systematic review concluded that there is an unmet need for a comprehensive PROM to assess ADL limitations in stroke survivors, which is also capable of differentiating between intrinsic and extrinsic disabilities to provide target for interventions. In order to make this PROM widely available to stroke survivors to enable self-assessment and support self-management in the future, the PhD aims included the development and digitisation of this PROM to make it freely available to all stroke survivors through an online self-management platform, developed for and with stroke survivors to ensure its usability and acceptability.

As a good model of such a platform had already been developed at the UoS for people with RMDs (the MSKHUB) based on a valid and reliable ADL assessment EDAQ for RMDs, the Stroke Survivors Hub (SSHUB) was developed based on this model, firstly following the recommended guidelines for PROM development to ensure that the adaptation of the EDAQ to EDAQ-SS was completed appropriately using evidence-based practice, and then by digitising this PROM to eEDAQ-SS to house it on the SSHUB platform. This process followed iterative developmental stages to ensure that both the paper version of the

EDAQ-SS as well as the eEDAQ-SS and the SSHUB platform were usable and acceptable by the target population.

Following a successful usability assessment, both the EDAQ-SS and the SSHUB were further developed and evaluated for their acceptability. This indicated that both the eEDAQ-SS and the SSHUB were acceptable and stroke survivors were happy to use both of these tools in the future to self-assess their ADL limitations. Additionally, participants reported that with some progression, the SSHUB could become a beneficial self-management platform in the future. Stroke survivors from different age groups and backgrounds could benefit from the use of the paper version of the EDAQ-SS, which is also available now to meet this need, following the completion of the psychometric testing after the PhD to ensure its validity and reliability in this population.

To conclude, this PhD project has shown that the use of a comprehensive ePROM helps to conduct a self-assessment that is linked with increased awareness, which may lead to better self-management and help stroke survivors take more active roles in their care, as they will be better informed about their needs to help with planning their rehabilitation priorities. More developmental work needs to be done to further improve the SSHUB for it to become a fully-fledged self-management platform for stroke survivors, but this requires further testing of the platform with a wider population at a national level in order to collect a sufficiently large dataset measured at two-time points to allow testing of the psychometric properties of the eEDAQ-SS to establish its validity and reliability. However, this PhD thesis has successfully laid the foundations for this wider testing to take place at a national level through the development of the ePROM as well as the design and testing of the usability and acceptability of the online platform to bring this to a satisfactory level and quality to ensure that the next stage could be realised.

6.3 General Discussion

This section discussed the key findings of the thesis to consider its original contribution to the stroke rehabilitation field, the strengths and limitations of the research undertaken and the wider implications of the findings on practice and research to recommend future directions.

6.3.1 The Systematic Review

The systematic review was originally undertaken at the beginning of this PhD project during 2018-2019 to identify existing PROM to measure ADL in stroke survivors as well as their content and psychometric properties to assess whether a PROM already exists that can sufficiently assess all required ADL with valid and reliable rigour. In order to identify keywords, a broad literature review was carried out to find other terms to define ADL, PROM and stroke survivors. This helped to identify a large number of studies that were relevant to the aim of the systematic review. The systematic review was conducted using seven different electronic databases covering the period from the time of their inception to 2019, and a reference list of the included papers was included in the search. However, this search did not cover grey literature, such as unpublished papers or non-commercial publications, and no contact was made with any experts with regard to unpublished studies or theses. There could potentially be relevant working papers that were unknown to the author at the time.

The search for the systematic review was revisited in May 2021 to identify any papers that had been published after the review had been completed. In total, 11 new papers were considered to be relevant after reading the titles of the studies. However, after evaluating the abstracts and full papers, the decision was made not to include them in the review as they did not meet the inclusion criteria. Thus, to the best of the researcher's knowledge, by the time of the submission of this thesis, no other additional PROM were identified that met the inclusion criteria.

The systematic review was an important part of this PhD thesis as it helped to develop the baseline of the research. Initially, a literature review was conducted, but a literature review is a less systematic way of collecting and synthesizing information about a topic (Snyder, 2019; Tranfield, Denyer, & Smart, 2003) and it gives an overview of what is known about a specific topic. On the other hand, a systematic review is an important process for decision-makers as this process helps to make a decision based on the totality of evidence rather than a single study (Bunn, Trivedi, Alderson, Hamilton, Martin & Iliffe, 2014; Sheldon, 2005). Therefore, it was important to conduct a systematic review and find an answer to the question that was developed during the literature review. This systematic review was the first to compare existing stroke-specific ADL PROM to be compared and then analysed by linking their items with the ICF Core Set for Stroke. The systematic review formed the base of this PhD project as it showed that there is a need to conduct a study and adapt a comprehensive PROM for stroke survivors to guide their self-assessment. Therefore, the systematic review resulted in a search for other PROM for long-term conditions to understand if there is any other comprehensive PROM that can be used to assess ADL limitations that shows the effect of environmental modification. The systematic review was published as an abstract (Appx 5) to increase awareness of the importance of comprehensive ADL PROM for stroke survivors.

6.3.2 The Evaluation of Daily Activity Questionnaire for Stroke Survivors

Linking the items of the EDAQ-SS with the ICF Core Set for Stroke (Geyh et al., 2004a) helped to demonstrate that the EDAQ-SS covers most of the activities reported by the ICF and has good content validity, which means that the EDAQ-SS included items that have meaning for stroke survivors. It is documented by Terwee et al., (2018) that content validity is the most important psychometric property of a PROM and the most challenging component to assess. Content validity depends on items being rich, diverse and relevant to the construct (MacDermid, 2021). It is important to optimize the content validity of a PROM, which can be done by conducting cognitive-debriefing interviews and the ICF linking process (MacDermid, 2021). By following the correct methodologies to develop the EDAQ-SS it helped to develop a PROM with good content validity. The EDAQ-SS provides stroke survivors with the opportunity to evaluate their daily activity functioning from different perspectives. To give an example, stroke survivors could be asked whether they can use cutlery or if they can carry a plate, rather than general questions such as whether they have problems with eating and drinking. This detailed evaluation can help stroke survivors to understand which step of the eating and drinking activity is challenging for them. Understanding the main limitation in an activity can help to concentrate on and manage a specific problem, rather than thinking that all eating activities are problematic. Therefore, the EDAQ-SS has the potential to show stroke survivors what are their main issues rather than indicating them a general problem, so they can take appropriate steps and self-manage their condition. However, a good content validity is not enough for a PROM to be recommended. A PROM needs to have good validity, reliability and responsiveness before it can be recommended (Mokkink et al., 2018; Terwee et al., 2017; Portney & Watkins, 2009). Therefore, other psychometric properties of the EDAQ-SS need to be evaluated after the PhD.

Moreover, asking detailed questions on different ADL can help stroke survivors to realise the solutions that they have ignored until that time to improve their QoL. For example, one participant mentioned that completing the EDAQ-SS helped her to understand her limitations in gardening activities that she ignored after suffering a stroke. She reported that increasing her awareness enabled her to find a solution and manage these limitations to improve herself in gardening activities by resting between activities, prioritising the activities or using a stool to sit while tending flowers. This helped her to do something that she had enjoyed before having a stroke, thus increasing her ability to participate in a meaningful activity. This is an important goal in physiotherapy and occupational therapy as it helps to motivate and encourage patients by showing them how they can adapt their lifestyle to increase their independence.

Occupation-based interventions may be more beneficial than exercise alone because they promote motivation, engagement and show differences in motor performance compared to non-purposive exercise (Collis, Signal, Mayland & Clair, 2020; Dy & Yancosek, 2017). It is reported that participating in meaningful activities (i.e., slicing vegetables) helps to promote health and improve QoL (Patil et al., 2018; Wilcock & Hocking, 2015). A study conducted by Weinstock-Zlotnick & Mehta (2018) reported that using meaningful activities had beneficial effects on functioning for people with upper extremity disorders. A systematic review conducted by Collis et al., (2020) showed that purposeful activities have the potential to enhance movement and show impairments in motor activities. Therefore, understanding the main limitations and participating in meaningful activities have greater potential to improve motivation and lead to better activity for stroke survivors. The comprehensiveness of the EDAQ-SS has the potential to show people the activities in which they are limited, which can guide their rehabilitation by incorporating that activity into their rehabilitation programme and making it meaningful for them.

Furthermore, the usability assessment of the EDAQ-SS indicated that it helped stroke survivors to self-assess their ADL functioning and understand how aids and adaptations can enable them to participate in meaningful activities independently. This is because compared to the other PROM, the EDAQ-SS helps stroke survivors to differentiate their intrinsic capacity from their ability to perform with environmental enablers. It is crucial to identify the difference between capacity and performance as it can help to improve independence in daily activities, not only for rehabilitation but also to increase the motivation of stroke survivors and show them what they can achieve. Research conducted by Holsbeeke et al., (2009) attempted to understand the differences between the capacity, capability and performance of children with cerebral palsy. The research showed that motor capacity and capability only partially reflect performance. Environmental and personal factors have an impact on capacity, capability and performance. As a result, it is important to understand the differences between performance and capacity to make decisions about the focus of the therapy to maximise the independence in ADL and improve QoL. Therefore, by using the EDAQ-SS, stroke survivors can increase their awareness, motivate themselves and guide their decisions to increase their independence in ADL.

Due to the rapid development in digital health, ePROM have more advantages than paper-and-pen versions of the PROM. However, it is important to remember that people with low digital inclusivity may struggle to get the full benefit of digital technologies as they may not be able to access the internet or will struggle to use electronic devices. Therefore, both versions of the EDAQ-SS are available for stroke survivors. The usability assessment showed that the eEDAQ-SS helped stroke survivors to complete ePROM more easily, and also provided them with an electronic health record to form a bigger picture of their functional limitations and progress with these over time with repeated assessments.

Furthermore, the acceptability assessment of the eEDAQ-SS provided a rich insight into the perspectives of stroke survivors regarding the comprehensiveness of the eEDAQ-SS. However, the acceptability of the eEDAQ-SS also showed that some people will still prefer to use its paper-and-pen version. This could affect their ability to obtain immediate feedback, but can still help stroke survivors to self-assess their situation, improve their communication with their healthcare professionals and guide their self-management. Even though there are people who prefer the paper version of the EDAQ-SS, others will prefer the eEDAQ-SS. The use of an online self-assessment platform can help to provide more opportunities for self-assessment to people. Therefore, it is important to understand the benefit of the SSHUB that houses the eEDAQ-SS and provide people with the opportunity to self-assess their ADL limitations and track their changes.

6.3.3 The Stroke Survivors Hub Results

The SSHUB was developed as an online self-assessment platform that houses the eEDAQ-SS as the main self-assessment tool, which was tested for usability and acceptability by stroke survivors and further developed with their feedback and suggestions to ensure it is fit for purpose. The vision of this online platform is to further develop it into a fully functioning self-management platform with personalised advice based on the eEDAQ-SS outcomes, and also to use it as a research data repository to facilitate additional stroke rehabilitation research. Although the SSHUB has some similarities with other online platforms (e.g., stroke survivors can use the SSHUB to access research about their condition or health-related information, similar to My Stroke Guide), there are important differences that differentiate the SSHUB from other online platforms that were developed for stroke survivors. This is because the SSHUB is the only online platform specifically developed for stroke survivors through evidence-based research studies to provide personalised advice on ADL limitations following the completion of an ePROM specifically developed for this purpose.

The acceptability assessment demonstrated the advantages of the SSHUB and the areas in which it requires further development. Most importantly, stroke survivors expressed the opinion that the SSHUB can be considered for use in the future. However, stroke survivors were not able to see the scores of the eEDAQ-SS during the testing process and were also unable to see the charts that could help to track their changes over time. This was because, during the PhD project, the SSHUB was still in the development stage. However, these options were being developed and hidden from stroke survivors. All of these options will be available for stroke survivors to use after the PhD project is completed, which will make the SSHUB more useful and part of the self-management process. The usability and acceptability assessments of the SSHUB showed that the development of the SSHUB in collaboration with stroke survivors and an IT Company was successful. Furthermore, the participants agreed that the content of the SSHUB was supportive for the self-assessment and it has the potential to be further developed as a self-management platform.

Digital health is now commonly used by people and it has the potential to improve care and provide new opportunities to people with multimorbidity (Barbabella, Melchiorre, Quattrini, Papa, & Lamura, 2016). As mentioned in previous chapters, digital health helps to improve access to healthcare services, assists with self-management, enables monitoring, supports decision-making and enhances care coordination and integration (Barbabella et al., 2016). Digital health is frequently used around the world, as people can track their changes over time and self-manage their conditions. For example, the My Arthritis App is an arthritis management application that supports people with arthritis via engaging and effective learning and communication tools (AMPERSAND, 2021). People can monitor their physical and mental wellbeing, stress level or sleep on a daily basis by completing ePROM. They can also share their data with their GP if they prefer. The My Arthritis App provides access to different courses and a library to give people the opportunity to balance their lifestyles and manage their symptoms. The application does not aim to replace the appointments with the medical team but is intended to help people to self-manage their conditions, prioritise their management and improve their overall health and wellbeing, which will ultimately improve their confidence and control of their lives (AMPERSAND, 2021). This application helps people to engage with and increase their knowledge of their condition so that they feel more empowered and in control of their lives, which increases the chance of having better outcomes. It is being frequently used by people with arthritis with positive effects. As this example shows, digital health is commonly and successfully being used for people with other long-term conditions and it has a benefit on people's health. Therefore, SSHUB has the potential to be successful as a digital health platform and help stroke survivors manage their conditions.

Moreover, many people with different conditions use health applications or websites to manage their symptoms. For example, health applications are commonly being used for oncology patients (Böhme, von Osthoff, Frey, & Hübner, 2018). Lu et al. (2021) reported that there are 41 apps that can be used to track symptoms for oncology patients. These apps can be used to track patient-reported outcomes and understand changes from the patient's perspective over time (Lu et al., 2021). The use of health apps can help patients with cancer to self-manage their conditions by tracking their treatments, recording their medications, and monitoring side effects (Charbonneau et al., 2020). The research showed that the use of health applications increases the empowerment and self-efficacy of patients with cancer and helps them with self-management (Groen et al., 2015).

Another example is Remote Monitoring of Rheumatoid Arthritis (REMORA), which is a smartphone app that helps to monitor the symptoms of people with RA. Research has shown that REMORA highlights information that could be missed such as shorter-lived flares. It empowers people by increasing their self-awareness and improving their understanding of their condition. It is an acceptable and feasible platform that has generated a temporally rich research dataset for RA (Sharp et al., 2018). After searching the wider literature on digital health, it was recognised that many online platforms exist that were developed for different health conditions, which house PROM to help people to monitor their level, motivate them and increase their awareness to guide their self-management. This was also needed for stroke survivors. As the online platforms that house PROM have a positive impact on people with other conditions, the SSHUB has significant potential to help stroke survivors self-manage their conditions further.

Other than providing stroke survivors with the opportunity to complete ePROM easily and increase their awareness by tracking their changes over time, the SSHUB will also have more benefits. To give an example, it will help to collect data via a comprehensive ePROM and will act as a data repository platform that will provide endless opportunities for primary and secondary research studies. Please refer to Section 6.7.2 for detailed information about the future of the SSHUB.

6.3.4 Distribution of ADL Limitations in British Community-Dwelling Stroke Survivors

As each stroke survivor is different, they all require a detailed assessment and personalised rehabilitation process to achieve better outcomes and increase their independence in ADL. As explained in Section 5.4.1, previous studies have investigated the main limitations of stroke survivors in ADL. A study conducted by Cawood, Visagie and Mji in 2016 aimed to evaluate the connection between impairments, participation restrictions and activity limitations after stroke. A total of 267 participants were involved and the researchers used the Modified Barthel Index and SIS version 3 to assess their limitations in ADL. The research showed the limitations of stroke survivors in terms of personal hygiene, washing and dressing, transferring from bed to chair, walking, climbing stairs, eating and drinking, and using a wheelchair. The results demonstrated that the main problems that the participants faced were climbing stairs and propelling a wheelchair. However, as explained in the systematic review (Chapter Three), BI and SIS are not comprehensive enough to show all the limitations in ADL. They can show that stroke survivors are limited but not detailed enough to understand at which step of the activity they are limited or if they can improve with an adaptation. Therefore, conducting a study to show the pattern of activity limitations and participation restrictions for stroke survivors with a non-comprehensive PROM does not give detailed data.

However, as the EDAQ-SS is a comprehensive PROM, specifically adapted and tested for acceptability for stroke survivors, it was important to understand the pattern of activity limitations and participation restrictions that British stroke survivors are faced with by using the EDAQ-SS. The data collected through the eEDAQ-SS provided a very detailed window into specific ADL limitations including eating, drinking, washing, gardening, cooking, walking, cognition and communication. Therefore, there was value in examining the distribution and pattern of these ADL limitations in British stroke survivors through an analysis of the data collected in this study.

Following this decision, the analysis of the data collected from 57 stroke survivors showed that the caring domain was the least relevant to stroke survivors compared to the rest of the 14 domains, as 47.4% of the participants choose the ‘not applicable’ option for the items that were included in this domain. It was clearly recorded that daily activities reported under the communication and moving around outside domains were the main domains that stroke survivors perceived themselves as being limited. The findings of the analysis showed that each participant was limited with a different ADL and therefore required different input (please refer to Section 5.4 for details). However, this analysis was only conducted with 57 participants, which is a small sample for a condition with such variability and results cannot be generalised. The SSHUB aims to be a data repository platform; therefore, collecting data by using the EDAQ-SS via the SSHUB will help to conduct further analyses on the pattern and prevalence of the ADL limitations and understand how the pattern will change with a wider population compared to smaller sample size.

This analysis demonstrated the importance of self-management because, as each person needs different input to increase their independence in their daily living, increasing their awareness of their daily activity limitations can guide them to find a solution to manage them. Furthermore, the results indicated that the use of equipment had a positive impact on people's functioning as the scores of Section B (activity level with a piece of equipment) decreased compared to Section A (activity level without equipment) for all of the participants. Therefore, the results showed that stroke survivors' ADL functioning improved with the use of correct equipment and there was a difference between capacity and performance. It is important to remember that helping people to understand this can help them to increase their motivation and can also have a positive impact on self-management (Holsbeeke et al., 2009). As the EDAQ-SS is the only PROM that helps to differentiate capacity from performance when assessing ADL limitations for stroke survivors, conducting an analyses to evaluate the frequency and pattern of ADL limitations on stroke survivors will provide important information for stroke rehabilitation.

6.4 Strengths of the Studies

This PhD project was conducted in a specific order. After a wider literature review, a systematic review was conducted to support the rationale of the project for the development of the EDAQ-SS and SSHUB. The EDAQ-SS was developed using a systematic approach and by following the guidelines (Mokking et al., 2010; Acquadro et al., 2004; Beaton et al., 2000). These guidelines guided the development of the EDAQ-SS and helped to initiate the development of a tool with good content validity, usability and acceptability.

Subsequently, the SSHUB development and digitisation of the EDAQ-SS occurred, which took nearly three years in total and further work is still required. However, the involvement of both stroke survivors and an IT Company, in addition to understanding the barriers to the use of these tools, helped to improve both of them and develop an online self-assessment platform that was accepted by stroke survivors.

Most importantly, the main strength of the study was that both the EDAQ-SS and the SSHUB were developed for stroke survivors with the contribution of stroke survivors. The involvement of users at each step of the development and testing process helped to achieve a good outcome with the development of two useful tools that include items and sections that have meaning to the target population and contribute to the stroke assessment and self-management process. Digital health is commonly used for other health conditions to manage people's symptoms. Therefore, the development of the SSHUB to house the eEDAQ-SS helped to develop the opportunity for stroke survivors to take advantage of these benefits. On the other hand, there were some limitations and challenges that were faced during this PhD project. The next section explained these in detail.

6.5 Limitations

Although this research achieved its overriding aim of developing an appropriate ePROM for stroke survivors to assess daily activity limitations and an online platform for stroke survivors' self-assessment, there were some unavoidable limitations. In addition to those already highlighted with regard to each study within this thesis, the following points are necessary to consider.

Firstly, recruitment was the main limitation of the study. Recruitment for projects is a dynamic process that requires continuous improvements and evaluation (Howard, de Salis, Tomlin, Thornicroft, & Donovan, 2009). Recruitment challenges were expected in this population, as it was initially difficult to recruit participants because of the limited recruitment channels. For example, the voluntary database for stroke survivors of the UoS only had 15 people. Furthermore, the PhD project was self-funded and did not receive NIHR CRN support, which affected the input from the NHS. However, the recruitment period lasted nearly nine months and managed to recruit enough participants to represent the mixed and general demographic information for the usability and acceptability assessment. From the initial recruitment day, the sample size was improved until the end of the PhD.

On the other hand, the sample size for both the usability (n:10) and acceptability (n:57) was small. Therefore, it was not possible to make a comparison between subgroups, i.e., differences in user satisfaction stratified by age, gender, internet use, computer skills, and type of stroke. Future research should include larger sample size and longer testing time to maximize users' inputs in both the eEDAQ-SS and SSHUB acceptability assessment. The small sample size also resulted in the psychometric testing of the EDAQ-SS being postponed until after the PhD project. There is a lack of consistency in the information about the sample size requirement for psychometric testing. Different characteristics can have an impact on sample size calculation, such as the aim of the research, target population or complexity of the item being tested (Cappelleri, Jason, Lundy & Hays, 2014). For the Classic Test Theory (CTT), the sample size should be large enough to be descriptive and provide meaningful data (Cappelleri et al., 2014). In addition, recommendations on sample size calculation differ according to different sources. Hambleton and Jones (1993) suggested that having 200-500 participants for CTT and over 500 participants for the item response theory (IRT) should be sufficient. The rule of thumb suggested traditionally for the sample size calculation of similar scales is to have five participants per item for explanatory factors (Tabachnick & Fidell, 1996).

The current version of the EDAQ-SS consists of 160 items in 15 domains. This research was focused upon stroke survivors, who can have a high degree of variability in clinical and demographic presentation, so the sample size needs to be sufficiently wide to cover different types of stroke (i.e., ischemic and haemorrhagic stroke), gender and age variabilities to ensure it is representative of the target population. Therefore, using the rule of thumb, i.e., five participants for 160 items, would suggest that 800 stroke survivors would need to take part in psychometric testing of the EDAQ-SS, which was outside of this PhD timeline and will be conducted after the PhD. However, it was important to discuss the barriers with the existing participants to understand the methods that need to be used to improve recruitment for postdoctoral research.

Due to the above reasons, the method of recruitment administered was evaluated to understand which method of recruitment was more successful. The findings indicated that advertising on social media platforms and community services provided better potential to recruit participants. Online advertisements provided the opportunity to reach broader populations from anywhere around the country. People can access the advertisements easier from an online platform than a poster. Therefore, the recruitment strategy focused more on online recruitment, and more time was spent on informing people about the project via community services, which used their online platforms for this purpose. The research was advertised on different platforms to increase the likelihood that more people would be informed about it. The percentage of people who were recruited from each platform was calculated, and it was recorded that 87% of the participants heard about the project from an online advertisement, either from the official Twitter account, Facebook or from the tweets shared by the community services. Community-dwelling stroke survivors were the target population for this PhD project and not stroke survivors in the acute phase. Therefore, recruitment from the NHS was not included. However, after finishing the development of the final version of the SSHUB, it could be used by any stroke survivors, including during the acute phase. Therefore, the ethics application can be submitted to the NHS. Based on these recruitment results, it was concluded that recruitment from social media was the best option.

Secondly, some people initially consented to participate but either dropped-out of the study or did not complete all of the ePROM. Any problem with recruitment can delay the timeline of a research project and reduce the ability to achieve the aim of the research (Patel et al., 2003). Therefore, it is important to understand the challenges of recruitment and try to find a solution to these in order to achieve better outcomes in the research. After collecting information about the barriers to completing the EDAQ-SS via the SSHUB from the participants, the decision was made to ask the participants to complete the eEDAQ-SS and not other ePROM because they had limitations that were challenging for stroke survivors (please refer to Chapter Four and Five for details). It was realised that the number of volunteers increased after hiding the rest of the ePROM from the SSHUB. Initially, it was possible to only recruit an average of ten participants per month, but as soon as the seven other ePROM were hidden and participants were only asked to complete the eEDAQ-SS, ten participants were recruited within a week. This proved that participants found it difficult to complete all the ePROM.

However, it was important to consider that sample size was good and sufficient for the development process, usability and acceptability testing. The sample size for both the usability and acceptability assessment has been frequently used in similar research. As the recruitment period lasted nearly nine months, enough participants were ultimately recruited to represent the mixed and general demographic information for the usability and acceptability assessments. Furthermore, recruitment was terminated because no additional information was obtained from the final five participants, which showed that data saturation was reached.

6.6 Implications

6.6.1 Implications for Stroke Survivors

A better understanding of daily activity functioning level is important to (i) increase stroke survivors' awareness about their ADL limitations, (ii) identify whether their capacity is different to their performance, and (iii) help to guide their self-management. Self-management is an important concept in stroke rehabilitation (Satink, Cup, de Swart & Nijhuis-van der Sanden, 2015), and it helps to result in better health outcomes, which ultimately result in improved QoL (Nott, Wiseman, Seymour, Pike, Cuming & Wall, 2019; Warner, Packer, Villeneuve, Audulv & Versnel, 2015). For patients to make decisions about their self-management, they need to keep a record of their health data (Villalobos, Vela & Hernandez, 2020). This study helped to identify that stroke survivors can avoid what they can or cannot do unless they are asked about it. Stroke survivors can increase their awareness of their ADL limitations by self-assessing their ADL with a comprehensive ePROM that can be easily completed on an online platform to track their changes over time.

The research evidence suggested that patients are at the centre of care and the care provided by healthcare professionals needs to be adapted depending on the patient's need, value and preference (Hartzler & Pratt, 2011). As personalised care is one of the main goals of the healthcare system, this can be facilitated with the use of a PROM (Santana & Tomkins, 2021; Institute of Medicine Committee on the Quality of Health Care in America, 2001). Each person is different and they are motivated to engage in self-management in different ways (Santana & Tomkins, 2021). Increasing stroke survivors' awareness by using ePROM to evaluate their limitations in ADL can help stroke survivors to understand what the main problem that affects their life is and empower them to self-manage.

This research showed that eEDAQ-SS is an acceptable ePROM that can be used for the self-assessment of ADL limitations. Moreover, due to its comprehensiveness, it can increase awareness and also empower self-management in the future. The EDAQ-SS was developed in a way that it can be completed by stroke survivors without the need for input from healthcare professionals. The development of the eEDAQ-SS was the right decision as it is a usable and acceptable ePROM that can be easily and regularly completed via the SSHUB by stroke survivors. This provides the potential for stroke survivors to comprehensively self-evaluate their daily activity limitations, and have a better understanding of the main issues that affect their independence. As the EDAQ-SS has two sections that help to understand the impact of environmental modifications on ADL functioning, stroke survivors can understand which environmental modifications have positive or negative impacts on their activity level and differentiate their intrinsic disability from their extrinsic disability. This project has the potential to help stroke survivors become more actively involved in their functional assessment and service provision because the use of the eEDAQ-SS has the potential to improve the goal setting process. This is because regular use of the eEDAQ-SS via the SSHUB can help stroke survivors to understand their activity level and engage in more constructive discussions with their healthcare professionals. This can facilitate better goal setting, and therefore, better rehabilitation outcomes.

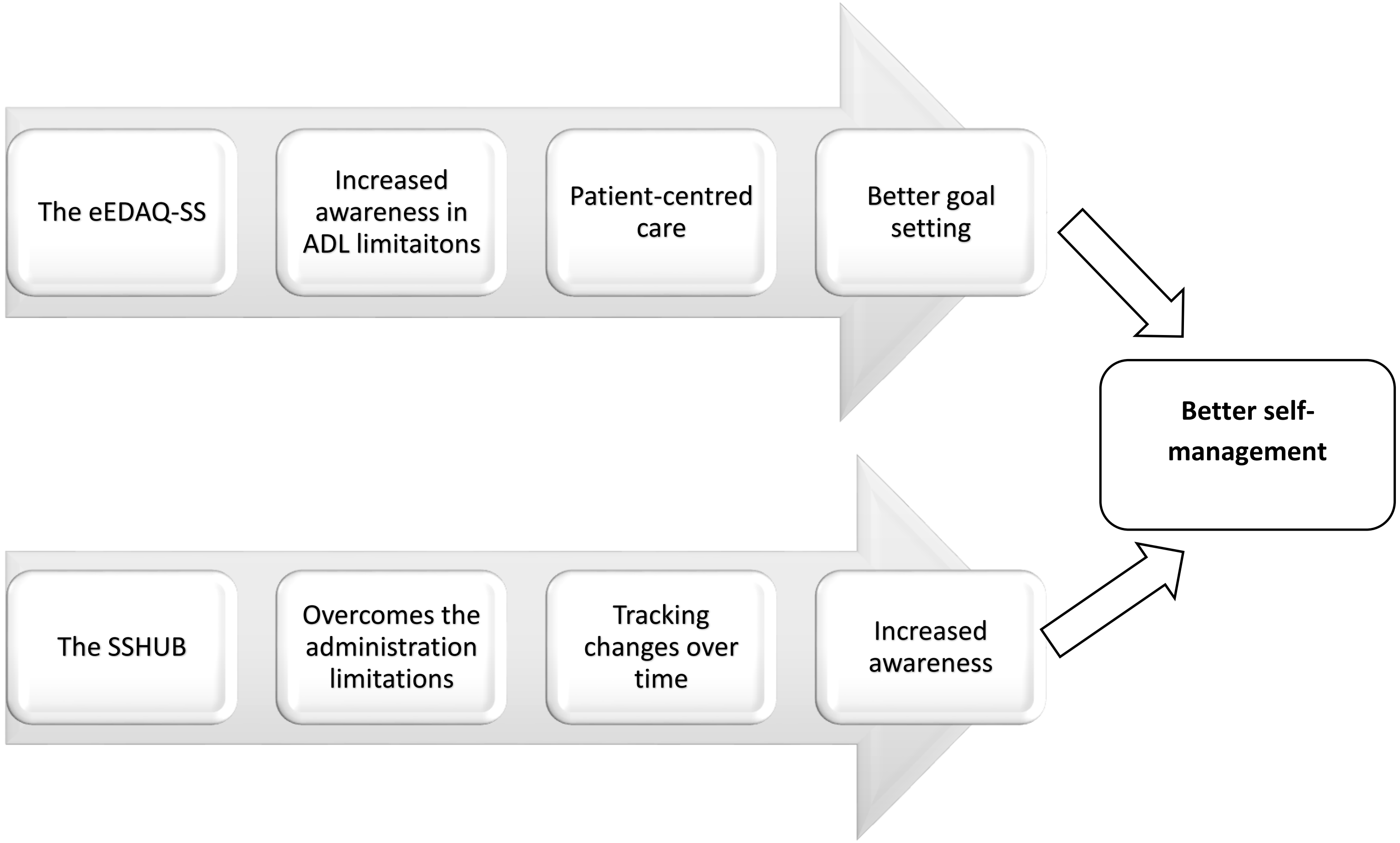
The use of digital health technologies as part of self-management help people to increase their awareness, track their health data, acquire their self-care needs with the help of healthcare professionals and family member (Villalobos et at., 2020). This benefit of digital health technologies was supported in this PhD project. The acceptability and usability evaluation of the SSHUB showed that using the SSHUB for the administration of the ePROM helped stroke survivors to overcome the limitations of the paper-and-pencil versions of the PROM. Stroke survivors with affected upper limbs or impaired vision can benefit from the advantages of the SSHUB, such as easy submission techniques, colour, font size, and tick boxes that make the items of the questions easy to follow and read. Most importantly, the SSHUB increased the potential to complete the eEDAQ-SS easily and provided the opportunity for stroke survivors to complete it whenever they want.

On the other hand, there are many barriers that can affect the use of digital health technologies, such as lack of motivation or engagement to use the technology, and lack of understanding the health literacy (Villalobos et al., 2020). Lack of usability or age factor can result in difficulty in adapting to new technology. If a digital health technology has lots of technical errors, long processes to produce an action it can be time-consuming for people and result in loss of interest (Lie, Karlsen, Oord, Grau, Oftedal, 2017; Nelson, Mulvaney, Gebretsadik, Ho, Johnson & Osborn, 2015). Therefore, it was important to search the needs required to improve the user experience to avoid the identified barriers that stroke survivors can face when using the SSHUB. This made the SSHUB different as it is assessed for usability and feedback was obtained from the participants to evaluate the barriers and find solutions for them. Feedback obtained from the participants showed that the SSHUB was a good self-assessment platform and has good potential to become a self-management platform in the future with further improvement.

6.6.2 Implications for Practice

Routine use of the PROM in clinical practice can help to increase patient management by enhancing patient-healthcare professional communication, helping to understand what is important to them, guiding shared-decision making and tracking the patient's progression before, during and after the rehabilitation (Basch, 2017; Santana & Feeny, 2013; Snyder et al., 2012; Santana & Feeny, 2009; Velikova et al., 2004). The eEDAQ-SS can be completed by stroke survivors independently through the SSHUB, and in the future, stroke survivors will be able to save their results and print them in a PDF format from the SSHUB. This will help stroke survivors to share their results with their healthcare professionals. Healthcare professionals can use the results of the eEDAQ-SS to identify the main restrictions in stroke survivors' daily activity functioning and target the main problems in rehabilitation from the stroke survivors' perspective. A completed version of the eEDAQ-SS with calculated scores will help healthcare professionals to save time and spend more time on discussing results, observational assessments and designing rehabilitation programmes. Combining the results of both the objective assessments and the EDAQ-SS will help healthcare professionals to think holistically, increase their awareness about the effect of environmental modifications on stroke survivors' ADL functioning, and understand the key areas of focus during the rehabilitation to improve stroke survivors' independence. Figure 8 shows the effects that the eEDAQ-SS and SSHUB may have on the stroke survivors' rehabilitation.

Figure 8: Potential impact of the eEDAQ-SS and SSHUB on self-management



6.6.3 Contribution to Healthcare Challenges

The main impact of the stroke on the NHS is the cost. As mentioned before average cost spent on stroke cases per year in the UK is nearly £26 billion and it is believed that this cost will rise to between £61 to £91 billion in 2035 as the impact of stroke on the health and care system is increasing with an increasing population (Patel et al., 2021; NICE Impact stroke 2019). It is important to consider rehabilitation tools that can reduce the overall cost of stroke both on society and economically. There are lots of considerations by the NHS to reduce the impact of stroke on the healthcare system and provide better treatment to the stroke survivors, such as the NHS Long Term Plan (NHS Long Term Plan, 2019).

It is documented in the NHS Long Term Plan that the involvement of digital health will be the mainstream across the NHS for stroke care (NHS Long Term Plan, 2019). This is the point where this PhD project can help the healthcare system in the UK. The SSHUB is a digital platform that can help stroke survivors to use different self-assessment tools to self-assess their ADL limitations and understand their current state of functional ability. It provides guidance around effective self-management and prevention of the risk of deterioration following discharge. Regular use of the SSHUB can provide personalised health assessment to guide effective self-management, and ultimately improve their QoL, whilst potentially reducing the burden on healthcare providers.

However, the use of digital health technology is not without problems. The use of digital health technologies as part of self-management will help to reduce the economic burden on the NHS, however, it will result in a lack of face-to-face interactions with healthcare professionals (Villalobos et al., 2020). The communication between the healthcare professionals and patients results in increased motivation to achieve previously set goals. Also, a lack of face-to-face interaction with healthcare professionals can result in patients avoiding the recommendations provided by digital health technologies (Villalobos et al., 2020; Lie et al, 2017). It is important to be aware of the benefit of digital health technologies on stroke rehabilitation but stroke survivors also need to have the opportunity to have face-to-face interaction with healthcare professionals whenever required to control the advantage that they can achieve from the online self-management tools.

6.7 Further research

6.7.1 Further testing of the EDAQ-SS

A further evaluation for the psychometric properties of the EDAQ-SS with a larger population will need to be conducted before the EDAQ-SS can be used efficiently. For the psychometric testing, the involvement of a more diverse sample is warranted to enable ongoing investigation of the scale structure and validity of the EDAQ-SS. Currently, the extent to which scores from the EDAQ-SS relate to clinically desirable outcomes is unknown. Further investigation is required to examine the meaning and relevance of normative, low, mid-range and high scores to practice. Therefore, there is a need to conduct longitudinal studies to enable the scores from the EDAQ-SS and the clinical significance of any change scores to be interpreted.

Moreover, a pertinent question for healthcare professionals working with people affected by stroke is the appropriateness of using the EDAQ-SS for clinical decision-making regarding the type and provision of rehabilitation to improve independence in daily activities. Such decisions will be subject to an ongoing investigation of the validity of the EDAQ-SS including responsiveness and the testing of hypothesised changes. In addition, the ability of patients to complete the eEDAQ-SS in their own time will reduce the time spent on completing the PROM at clinics and provide more time for healthcare professionals to spend with stroke survivors for the objective assessment in interventions. However, the EDAQ-SS validity and reliability need to be assessed before it can be further used in clinical practice.

Different people with different symptoms due to stroke were involved in this PhD project and used the eEDAQ-SS during the development stage. Although stroke survivors with communication or cognitive impairments were included in the development stages of the EDAQ-SS, one of the limitations of PROM remains that many people with cognition and communication problems following a stroke would be discouraged from completing a questionnaire. The development and investigation of a version of the EDAQ-SS that could be completed by a nominated proxy, which would enable those people whose impairment is sufficient to prevent self-report use of the EDAQ-SS, is therefore advocated. The relationship between proxy and patient self-reports of the EDAQ-SS needs to be assessed in terms of reliability and validity. An alternative could be validation of the EDAQ-SS for carer-assisted completion. In addition, a linguistic and cross-cultural adaptation of the EDAQ-SS, for example for people from differing ethnic backgrounds, can be investigated. The EDAQ-SS can be validated for use in multi-country studies and can be translated and tested for use in other languages, such as Turkish.

A final recommendation is that the EDAQ-SS should be investigated with computerized adaptive testing (CAT). The research has shown that the score of an outcome measure can be accurately predicted from fewer questions by asking the correct questions (Kane et al., 2020; Harrison et al., 2019). To be able to do this, there is a need to develop a predictive model through CAT. CAT aims to identify the correct subset of questions selected from the full questionnaire that can be asked to the patient on the basis of their previous responses (Kane et al., 2020; Gibbons et al., 2016). CAT helps to analyse how the response pattern affects the overall outcome scores, then uses this information to minimise question burden in an accurate manner by using its own recognition of these patterns to self-improve its efficiency (Kane et al., 2020; Harrison et al., 2019). However, to be able to develop the CAT version of a PROM, PROM needs to be validated. Therefore, a CAT version of the EDAQ-SS can be developed after testing the psychometric properties of the EDAQ-SS to reduce the time burden on stroke survivors.

6.7.2 Further Development of the Stroke Survivors Hub

The arguments presented in this thesis highlight the need for the online stroke self-management platform, which stroke survivors can use to access and complete a comprehensive ePROM to assess their daily activity limitations and become actively involved in their care pathway. Although there are online platforms that stroke survivors can use to access information and communicate with other stroke survivors to self-manage their condition, the development of a platform to access comprehensive ePROM to view their progression or deterioration in ADL over time has not been elicited before. The development of the SSHUB as part of this PhD has shown that the SSHUB will be a useful platform for stroke survivors. It will provide easy access to the eEDAQ-SS and help stroke survivors to obtain more information. Access to ePROM, health-related information and research will help stroke survivors to use the SSHUB as a self-management platform.

However, the SSHUB currently needs further work:

1. To display the meaning of the ePROM scores,
2. To record the results of the ePROM on a chart, so stroke survivors can see if they are progressing or deteriorating over time,
3. To provide stroke survivors with the opportunity to download their results and share them with their healthcare professionals,
4. To create a registration page for healthcare professionals, so they can have access to the eEDAQ-SS,
5. Make other ePROM visible on the SSHUB.

All of these options were already developed and available on the SSHUB, but they were hidden from stroke survivors as it was still under development. These options will be made visible to stroke survivors after the PhD project. This PhD work marks the foundation of the creation of this hub as well the testing of its acceptability and usability. The Centre for Health Sciences Research at the UoS will be involved in the further development of the SSHUB.

6.7.3 Informing Healthcare Professionals and Stroke Survivors about the SSHUB and the EDAQ-SS

To be able to help stroke survivors to benefit from the EDAQ-SS and SSHUB, they need to be informed about these tools so they can start to use them as part of their assessment and rehabilitation process and become involved in the future testing process. Several steps were taken before informing both healthcare professionals and stroke survivors about the EDAQ-SS and SSHUB, but more opportunities will be used in the future to continue to inform stroke survivors and healthcare professionals. The steps that were completed during the PhD project to inform people about the eEDAQ-SS and SSHUB are mentioned below:

- Presentations were given to the healthcare professionals at the Greater Manchester Neuro-Rehabilitation Operational Delivery Network to inform healthcare professionals about the SSHUB and eEDAQ-SS and the rationale behind the development of these tools.

- The PhD project was presented at a patient carer meeting of community service to inform stroke survivors and their carers about the SSHUB and eEDAQ-SS.
- Poster and oral presentations were presented at the Upper Limb Stroke Rehabilitation Summer School, the SPARC 2018, 2019 and the UK Stroke Form 2019 to both healthcare professionals and stroke survivors to obtain their feedback.

- In the future, manuscripts will be written about the development of the SSHUB and the eEDAQ-SS that will be submitted as peer-reviewed articles for publication. Therefore, people can read about these tools and understand their benefits. In addition, other community groups such as BASIC and Different Strokes will be contacted to inquire about opportunities to present the results of the study at community groups and abstracts will be submitted to conferences to inform people about this PhD project and its outcomes.

6.8 Summary of Key Findings

- Stroke results in impairments that affect ADL functioning.

- Limitations in ADL are linked with poor QoL, which affects stroke survivors mainly when they are discharged from the hospital to the community.

- Self-management is an important part of stroke rehabilitation, which has the potential to reduce the pressure on the healthcare system.

- PROM helps to improve self-management.

- There is a lack of a comprehensive PROM to assess ADL limitations. This may affect the ability to capture the main limitations in ADL from the perspective of stroke survivors. This can have a negative impact on setting personalised and meaningful goals for stroke survivors, which can be a barrier to providing patient-centred care and future self-management.

- The EDAQ-SS addressed this by providing a comprehensive self-assessment tool that has good content validity. Moreover, it helps stroke survivors to comprehensively self-assess their intrinsic limitations in ADL and increases their awareness of strategies to promote self-management using aids and adaptations.

- The paper version of the EDAQ-SS is freely available to utilise in clinical settings to inform clinical assessment and shared decision-making process during goal-setting and evaluation of interventions.
- Electronic PROM has more advantages than the paper-and-pen version.
- Digital health technologies have lots of recognised benefits and can help to improve self-management.
- However, digital health technologies are not accessible and/or usable by all stroke survivors. Therefore, the EDAQ-SS is available in both paper-and-pen and electronic versions to help increase accessibility and usability.
- The SSHUB is a user friendly, easy-to-use online platform that enables self-assessment of daily activity limitations via a comprehensive and easy to use ePROM to aid self-management and have capacity to house other stroke-specific ePROM in the future.
- The SSHUB will provide future opportunities for research into the ADL limitations in stroke survivors by providing a large, longitudinal data repository to further stroke rehabilitation research.
- Future opportunities for the SSHUB includes expanding on self-management tools that links with tailored assessments, and potential linguistic and cultural adaptation to other languages to increase access to stroke self-management tools worldwide.

6.9 Conclusion

This PhD project has achieved the intended outcomes of the development and acceptability testing of the stroke specific ePROM, the EDAQ-SS following the recommended guidelines, and the design and acceptability testing of an online self-assessment platform, the SSHUB for stroke survivors, which houses this ePROM to help stroke survivors to assess their difficulties in daily activities. The thesis has made several critical contributions to the existing knowledge regarding stroke assessment and self-management. Prior to this, there was no comprehensive PROM that could help with assessing the ADL limitations and participation restrictions for stroke survivors to help to differentiate their capacity from their performance. The development and testing of the EDAQ-SS has helped to provide a comprehensive PROM in both paper and electronic format to the stroke field, which has the potential to empower self-management.

The SSHUB, can be considered as a starting point to guide stroke self-management and the use of the eEDAQ-SS can help to guide the rehabilitation of stroke survivors in performing daily activities from the patient's perspective. The SSHUB and EDAQ-SS can be used to inform the development of future interventions that can support self-management following stroke, which target areas that are most important and relevant to stroke survivors. Interventions aimed at improving patients' independence in daily activities can be evaluated with a comprehensive instrument from stroke survivors' perspective. Finally, completing the eEDAQ-SS on a regular basis can help stroke survivors to increase their awareness and will have a positive impact on their self-management. There is a need for further research to develop these tools, which will involve the wider testing of the psychometric validity and reliability of the ePROM, development of the SSHUB to a self-management platform and to assess the impact of using these within healthcare settings to establish whether they could be implemented as a clinical tool to assist healthcare professionals.

To conclude, this research provided the opportunity to obtain real-time feedback from stroke survivors and understand their perceptions of difficulties in daily activities using the EDAQ-SS via the SSHUB. The use of digital health systems such as the SSHUB are more widespread following the Covid-19 pandemic, with increased use of remote consultations in primary and secondary care. People with long-term conditions are encouraged to partake in self-assessment using digital tools to inform their self-management and assist health professionals involved in their care to plan appropriate treatments. To this end, this thesis provides future opportunities that are in line with the NHS Long Term Plan, as the use of SSHUB can help to provide more timely and efficient care for stroke survivors. This PhD project has generated evidence that the SSHUB has the potential to become a self-management platform to support stroke survivors to actively engage in their rehabilitation. Active self-management can lead to fewer hospital admissions due to deterioration, reduce the burden on healthcare professionals, and regular self-monitoring could help to save costs associated with frequent healthcare consultations, which can ultimately lead to improving care pathways for community-dwelling stroke survivors in the UK.

APPENDICES

Appx 1: Expert panel report

The clinical and contextual relevance will be assessed to make the EDAQ relevant and understandable for stroke survivors.

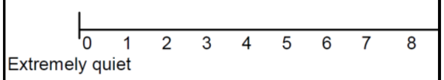
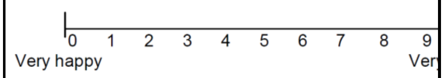
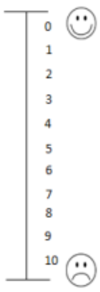
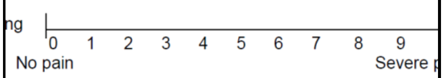
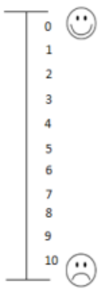
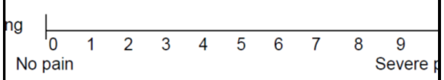
Synthesis recorder: Miss Nazemin Gilanliogullari (PT)

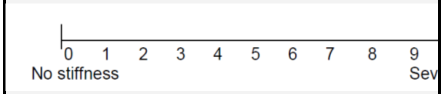
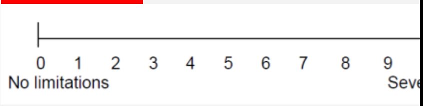
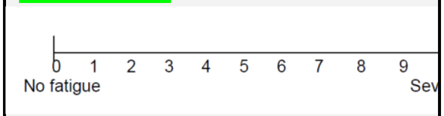
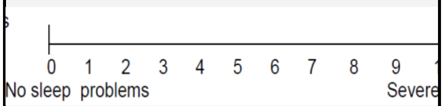
Date of meeting: 19/11/18

Additional items suggested by expert panel members
Removed items
Rephrased items

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
Evaluation of Daily Activity Questionnaire [EDAQ] for MSC and Rheumatic Conditions (A Hammond, A Tennant, S Tyson, U Nordenskiold, 2014)		**Evaluation of Daily Activity Questionnaire [EDAQ] for Stroke Survivors (EDAQ-SS)**	**Agreed**
Part 1: Please x the boxes below where relevant.	x		
1. How long have you had your condition? __________ (years)		**How long have you had your neurological condition? (weeks) (months) (years)** • **Stroke** • **MS** • **PD** • **SCI** • **GBS** • **Other (text box)**	*Agreed*
Additional item		**Have you been diagnosed with any of**	*Agreed*

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
		the following conditions or impairments following stroke? • Weakness (weak arm or/and leg) • Aphasia (difficulty with language or speech e.g., reading, listening, writing, speaking). • Dysarthria (difficulty of speaking, unclear speech) • Hearing loss • Visual problem (e.g., eye movement problem) • Depression or Anxiety • Stress • Memory or cognition problem • Sensory Problem	
2. Are you working (paid/ unpaid), in education or planning to return to/start these? Yes (tick box) / No (tick box)		To have two questions: 1. Are you working (paid or unpaid) or in education? 2. Are you planning to return to work or education?	*Agreed*
3. Have you taken part in a patient education programme to help you manage your arthritis?		Have you been given advice and information about self-management of your neurological condition?	*Agreed*

Original Version Items:	**EDAQ for RMDs Version Items: Tick (x) if agreed not to change**	**EDAQ for Stroke Survivors [EDAQ-SS] Version Items:**	**The consensus of the Expert Panel**
Yes (tick box) / No (tick box)			
4. If yes, how long was it for (in hours)? ________		**N/A**	*N/A*
For the following questions, we ask you to CIRCLE the number below the line which best reflects your situation at the moment.	**x**		
1.1. It is said that arthritis can be in an active or quiet phase. In which are you at the  moment?		**N/A**	*N/A*
Describe your: 1.2. Mood: 		**Answer option to be vertical with happy/sad faces option** 	*Agreed*
1.3. Pain when resting 		**Answer option to be vertical with happy/sad faces option** 	*Agreed*
1.4. Pain when moving 		**Answer option to be vertical with happy/sad faces option**	*Agreed*

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
1.5. Stiffness 		**Answer option to be vertical with happy/sad faces option**	*Agreed*
1.6. Limitations in joint movement 		**N/A**	*N/A*
1.7. Fatigue 		**Answer option to be vertical with happy/sad faces option**	*Agreed*
1.8. Worry 		**Answer option to be vertical with happy/sad faces option**	*Agreed*
1.9. Sleep problems 		**Answer option to be vertical with happy/sad faces option**	*Agreed*
1.10. Satisfaction with life 		**Answer option to be vertical with happy/sad faces option**	*Agreed*
Part Two: Your ability to do everyday activities	**x**		
Please tick (x) to indicate your ability carrying out the activities listed below **during the last two weeks.** Please fill in both sections:	**x**		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
A: 'How do you do it without using an aid/gadget, alternate method or help?'	x		
If you do not normally do the activity, tick "not applicable".	x		
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns.	x		
Leave B blank if you tick "no" or "have help."	x		
1. EATING/DRINKING	x		
1.Lift a glass		**Drinking from glass**	**Agreed**
2.Lift a cup/mug		**Drinking from cup/mug**	**Agreed**
3.Use a knife and fork	x		
4.Slice food (e.g., bread, cheese)	x		
5.Get the milk out of the fridge	x		
6.Open a milk carton/ plastic bottle and pour out	x		**The expert panel prefers to remove this item as it is covered in the "cook" domain but we will get the ideas of stroke survivors.**
7.Open a bottle top (e.g., lager)	x		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
8.Open a screw top jar or bottle	x		
9.Open a tin or a ring pull can	x		
10.Open a packet/pouch	x		
Additional item		Do you have a problem with swallowing?	**Agreed**
Additional item		Do you have a problem with chewing?	**Agreed**
Additional item		Do you have a problem with stirring (e.g., when making a cup of tea)?	**Agreed**
2. IN THE BATHROOM/PERSONAL CARE	x		
1.Get on and off the toilet	x		
2.Wipe yourself with toilet paper /clean self below	x		
3.Use suppositories/tampons		**Using sanitary or/and incontinence products**	**Agreed**
4.Flush the toilet	x		
5.Arrange your clothes after going to the toilet		**Arrange your clothes before and after going to the toilet**	**Agreed**
6.Wash your hands	x		
7.Brush and comb your hair	x		
8.Brush your teeth	x	**Reorder: question 9**	**Agreed, but the expert panel offered to join these questions into one question. So, need to**
9.Use a tube of toothpaste	x	**Reorder: question 8**	

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
			get ideas of stroke survivors.
10.Open a medicine bottle/ blister pack	**x**		
11.Do your make up or shave	**x**		
12.Put on jewellery/watch	**x**		
Additional Item		**Do you have an incontinence problem?**	**Agreed**
3. GETTING DRESSED/UNDRESSED			
1.Put on / take off a coat	**x**		
2.Pull clothes over your head	**x**		
3.Put on front-opening clothes	**x**		
4.Do up/undo buttons	**x**		
5.Pull clothes over your feet		**Pull clothes over your feet (e.g., trousers or skirts)**	**Agreed**
6.Do up /undo zips	**x**		
7.Put on tights/ socks	**x**		
8.Take shoes/ boots on and off	**x**		
9.Tie shoelaces	**x**		
10.Put on/take off gloves	**x**		
11.Fasten clothes at the back	**x**		**Check with stroke survivors to make sure that this item covers**

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
			wearing a bra.
4. BATHING/ SHOWERING			
1.Get in and out of the bath	x		
2.Shower whilst standing	x		
3.Use shower controls /bath temperature mixers		**Have two items:** **1. Use shower controls** **2. Do you feel the temperature of the water?**	**Agreed**
4.Turn taps *(any in home)*	x		
5.Wash your back and neck		**Can you wash all body parts**	**Agreed**
6.Dry your back and neck		**Can you dry all body parts**	**Agreed**
7.Wash and dry your feet		**N/A**	**Agreed**
8.Wash your hair	x		
9.Style/ blow-dry your hair	x		
10.Cut/file your finger nails	x	**Can you take care of your hands and feet including cutting/filing your nails**	**Agreed as one item**
11.Take care of your feet	**One item**		
5. COOKING			
1.Stand while working in the kitchen	x		
2.Set the table/ carry plates, cups etc	x		
3.Peel and chop vegetables	x		
4.Carry a full pan to/ from the cooker	x		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
5.Drain water from a saucepan (e.g., vegetables, pasta)	x		
6.Remove heavy items (e.g., bag of sugar) from top cupboards	x		
7.Baking (e.g., cakes, bread, pastry)	x		
8.Take things in/out of oven	x		
9.Wash up	x		
10.Put crockery/pans etc., into kitchen cupboards	x		
11.Use a kettle (e.g., fill, pour)	x		
12.Turn cooker knobs		**Can you use your cooker/microwave**	**Agreed**
13.Open fridge door	x		
14.Prepare and cook a snack and/or a meal	x		
6. MOVING AROUND INDOORS			
1.Walk indoors (e.g., get to toilet/ bathroom; round kitchen)	x		
2.Open the front/ back door	x		
3.Lock and unlock doors	x		
4.Get to the front door in time to answer	x		
5.Get to the phone in time to answer	x		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
6.Stand for longer periods	x		
7.Get up and down steps/ stairs	x		
8.Bend to floor/pick up items	x		
9.Reach up	x		
10.Kneel		**Get on /off the floor**	**Agreed**
11.Carry heavy items around the house		**Carry items around the house**	**Agreed**
12.Manage heating (e.g., controls, woodburner, multifuel stove, open fire)	X		
7. CLEANING THE HOUSE			
1.Make the bed	X		
2.Dust and wipe surfaces	X		
3.Sweep up/ mop floor	X		
4.Wring out a cloth	X		
5.Vacuum clean	X		
6.Open a window	X		
7.Clean windows	X		
8.Clean the bath and/or shower	X		
9.Heavy housework (e.g., move furniture, take down curtains)	X		
8. LAUNDRY/ CLOTHES CARE			
1.Do the hand washing	X		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
2.Use a washing machine (e.g., load and unload)	X		
3.Hang out washing		**Hang out and folding washing**	**Agreed**
4.Plug in and pull out a plug (any in home)	X		
5.Put up an ironing board	X		
6.Iron	X		
7.Do small repairs e.g., hemming, buttons	X		
8.Cut cloth and/ or use scissors	X		
9.Pick up pins/needles	X		
9. MOVING AND TRANSFERS			
1.Get into and out of bed	X		
2.Turn over and sit up in bed	X		
3.Stand up from a chair without armrests		**Stand up from a chair**	**Agreed**
4.Pull up bedclothes/duvet	X		
5.Getting a comfortable sleeping position	X		
6.Sit for longer periods (e.g., in a car, train)		**Can you sit independently**	**Agreed**
Additional item		**Move from bed to chair**	**Agreed**
10. COMMUNICATION			
1.Use a phone / mobile (call/ text/ any functions)	X		
2.Hold a book		**N/A**	**Agreed**

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
3.Write	X		
4.Handle money/ cards; use cash machine/pay by card	X		
5.Use a computer and a mouse	X		
6.Use remote controls (e.g., TV)		**Use remote control and/or environmental control**	**Agreed**
Additional item		**Do you have speech and language problems?**	**Get the opinion of a SLT**
Additional item		**Can you express yourself in spoken or written language?**	
Additional item		**Can you understand what is being said to you?**	
11. MOVING AROUND OUTSIDE/ SHOPPING	x		
1.Walk on level ground	x		
2.Go for a long walk (e.g., a mile)	x		
3.Go upstairs without a handrail	x		
4.Travel by public transport	x		
5.Get in and out of a car and open car door	x		
6.Drive a car (e.g., hold steering wheel, turn car key, change gear)	x		
7.Fill the car with petrol	x		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
8.Open a heavy (e.g., shop) door	x		
9.Walk around the shops	x		
10.Carry shopping	x		
11.Do the weekly shopping	x		
12.Hold a walking stick		N/A	Agreed
13.Use a mobility scooter		N/A	Agreed
Additional item		Are you able to safely cross the road in time for the light	Agreed
Additional item		Walking on uneven floor	Agreed
Additional item		Walking in slopes	Agreed
12. GARDENING/ HOUSEHOLD MAINTENANCE			
1.Change a light bulb		The expert panel prefers to remove this item	Get the opinion of stroke survivors
2.Light gardening (e.g., weed, prune, plant)	x		
3. Heavy gardening (e.g., dig, mow)	x		
4.Climb ladders		The expert panel prefers to remove this item	Get the opinion of stroke survivors
5.Clean the car (inside and out)	x		
6.Do household repairs	x		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
7.Car maintenance (e.g., oil, water)	x		
13. CARING			
1.Feed a child, prepare bottles		**Feed another person, prepare bottles**	**Agreed**
2.Bathe a child/ change nappies		**Bathe another person/ change nappies**	**Agreed**
3.Dress a child		**Dress another person**	**Agreed**
4.Do a child's hair		**Do another person's hair**	**Agreed**
5.Use children's equipment (e.g., high chair, push chair, car seat)		**Use equipment for another person (e.g., high chair, push a wheelchair, car seat)**	**Agreed**
6.Put a child in/ out of high chair, push chair, high seat		**Put another person in/ out of high chair, push chair, high seat, wheelchair**	**Agreed**
7.Lift and carry a child		**Help move another person**	**Agreed**
8.Play with children		**Engage or occupy with another person**	**Agreed**
9.Care for others (e.g., elderly relatives)		**N/A**	**Agreed**
14. HOBBIES, LEISURE AND SOCAIL ACTIVITIES			
1.Crafts (e.g., knitting, crochet, sewing, embroidery, model making)	x		
2.Do-It-Yourself (e.g., using tools, decorating)	x		

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
3.Visit friends/ socialising(e.g., pub, cinema, theatre)	x		
4.Attend community / religious groups or classes	x		
5.Physical activities (e.g., dance, active sports, swimming, bicycling, fishing)	x		
6.Quiet recreation (e.g., painting, cards)	x		
7.Performing arts (e.g., music, choir, dramatics)	x		
8.Pet care (e.g., feed, groom)		**Pet care (e.g., feed, groom, walk)**	**Agreed**
9.Take dog for a walk (e.g., hold leash)		**N/A**	**Agreed**
Understanding of response categories	x		
• Not applicable • Without difficulty • Some difficulty • Much difficulty • Unable to do • Do you use an aid or other method? Yes/ No • Have help/Someone does it for me			
Please describe below which aid/s or other method/s you use		**Additional suggestions:** • **Using unaffected side** • **Using verbal or physical cues,**	**Get the ideas of the Stroke Survivors for further**

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
		prompts, strategies • Do you do activities in a specific order • Orthotics	methods that they use
1. Do you use/wear (please tick if applicable): Wrist splint/s (tick box) Walking aid (tick box) Shoe insole/s (tick box) Knee brace (tick box) Any other splint/s: please state			
2. Overall, which aids/gadgets you own do you value the most?			
0 1 2 3 4 5 6 7 Not at all bothered 3. How do you feel about using aids/gadgets? (please circle the number)			
4. What do you do yourself to help self-manage your symptoms/ condition?			
5. What is the most important thing you want to continue to do in life or to manage?			

Original Version Items:	EDAQ for RMDs Version Items: Tick (x) if agreed not to change	EDAQ for Stroke Survivors [EDAQ-SS] Version Items:	The consensus of the Expert Panel
If there is anything else you would like to tell us, or if you have any other comments, please write below:			

Do you think any additional item(s) needs to be included or excluded for the UK Stroke Survivors? If yes, please give detail:

Suggested items for inclusion	The consensus of the Expert Panel
1. Cognition and perception domain	Consult with a cognitive psychologist to get ideas.
2. Communication domain and Eating/Drinking domain (needs additional items for the swallowing)	Consult with a Speech and Language Therapist

Any additional comments:

In section B: have another column to ask:

-What is your alternative method: Are you using your dominand side to complete the activities?

APPX 2: Cognitive Debriefing Interview Report

The EDAQ-SS Stage 1: Cognitive Debriefing (CD) interview summary

Stage 1 participant number: 10 stroke survivors (six male, four female) identified through our research volunteers database, aged between 49-81.

Overall, the CD interviews showed that the EDAQ-SS items tested in this study are both understandable and relevant to the sample population in the UK.

It was agreed before the CD interviews that if 30% of the participants prefer to remove a question or find a question difficult to understand, that question will be either removed or rephrased.

Part 1:

Instructions: Response options: 100% of the participants commented that it would be better to have the answer options horizontal with emoji faces. They believe that for people who have neglect or cognition problems, it can be easier to understand the answer options with emojis for Part 1. Therefore, it can be good to make the answer options horizontal and include both verbal and emoji options. This may help different stroke survivors to understand the response options better.

Q1.6- Worry: One participant has mentioned that it can be good to rephrase this question to Anxiety. She believes that stroke survivors have more anxiety problems than worry. However, this additional item was not mentioned by other participants.

Part 2:

Instructions: Participants (n=10) have mentioned that they think instructions need to be clearer that they need to complete both sections A and B. Therefore, it can be good to make the sentence 'Please, fill in both sections' bold. In addition, all of the participants that completed the eEDAQ-SS have mentioned that the online submission version guided them to complete both sections, as they were not allowed to submit their answers without completing both sections.

Instructions: Participants prefer to make it clear if it is asked about their limitations that occurred due to stroke and not due to other conditions, such as arthritis. Therefore, it can be a good idea to mention in the Part-2 title that we are asking their abilities to do everyday activities after a stroke.

Domain Eating/Drinking:

Q3. Use a knife and fork: Participants (n=10) have mentioned that they can only use a fork to eat, but not both at the same time as they are one-handed. Participants reported that the question is asking if they can use both knife and fork at the same time. Four participants preferred this question to be two separate questions. Six participants wanted to rephrase it, to make it clear that it was tried to understand if they can use cutlery to eat. As it was tried to assess their ability to use cutlery to eat, the question was rephrased to "Use cutlery".

Q4. Slice food (e.g., bread, cheese): One participant has mentioned that he prefers this question to be removed. However, this is not mentioned by the rest of the participants. In general, participants have mentioned that they do not slice food, due to their upper limb impairment. They said that they ask someone to slice it for them or use a device to help them. They also reported that they get sliced bread. However, when the PhD candidate has mentioned that this question aims to understand their ability to do this activity, they agreed to keep the question.

Q5. Get the milk out of the fridge: Participants have mentioned that this question is repeating the "Open a fridge door" question from the Cooking domain. However, they also mentioned that this question covers more tasks than the other question. Therefore, they prefer to keep this question and remove the other one.

Q7. Open a bottle top (e.g., lager)
Q8. Open a screw-top jar or bottle
Q9. Open a tin or a ring pull can

Participants (n=three) have mentioned that these questions are repeating each other. They documented that Q7 can be removed as it is cover by Q8. On the other hand, seven participants have mentioned that each question is covering different action and needs to be included.

Q11. Enjoy a normal diet
Q12. Enjoy a normal drink
Q13. Keep well-nourished

Six participants mentioned that Q11 and Q13 are repeating each other. Three participants preferred to keep Q11 and other three preferred to keep Q13. Four participants reported that Q13 is asking a bit more then Q11 and both need to be included. One participant has mentioned that she struggled to understand what we are asking in Q11-13. She prefers Q11 to be rephrased "Are you eating a well balance diet" and Q13 to be rephrased 'Are you having five meals a day". In addition, same participant has mentioned that it can be better to ask if they have difficulty in swallowing, before Q11-13. It can be concluded that Q11 and 13 were the most problematic items for stroke survivors.

Q14. Enjoy meals with family/friends: Participants have mentioned that this question is relevant and easy to understand. Especially, one participant documented that this is a good point and need to be covered for stroke survivors. Another participant has mentioned that this question is important as stroke survivors may feel embarrassed eating with friends if they cannot use a knife. Most of the participants reported that they choose food that does not require cutting to eat near their friends. On the other hand, it is documented by two participants that "Q3. Visit friends/socialising (e.g., pub, cinema, theatre" at the 'Hobbies' domain may cover this question, and Q14 can be removed from the 'Eating/Drinking' domain. However, this question is measuring the ability of participation rather than activity and it is specific for the 'Eating/Drinking' domain.

Q15. Swallow tablets: One participant has mentioned that this question can be rephrased as "Swallow tablets with fluids" because this is the usual way of completing this action. The rest of the participants found this question relevant and understandable.

Domain Bathroom/Personal Care:

Q4. Flush the toilet: A participant has mentioned that toilets can be adapted at stroke survivors' own houses. So, flushing a toilet can be different at home and in other places. She has mentioned that she prefers this to be two separate questions. 1. Flush the toilet at home 2. Flush the toilet outside. However, other participants found this question easy to understand and did not require any adaptation to the question.

Q6. Wash your hands: One participant has mentioned that he can only wash one hand, so the question can be rephrased as "Wash your hand". It is also suggested by one participant that it can be asked if people can wash one or two hands. On the other hand, PhD candidate has mentioned that the question aims to understand if they have limitations in washing both hands. Therefore, they were happy to keep the question as it is.

Q8. Use a tube of toothpaste
Q9. Brush your teeth

Four participants have mentioned that they prefer these two questions to be one question. On the other hand, other six participants have mentioned that these are two different actions and they need to be separate questions. PhD candidate has agreed that these are two different actions and some people maybe only limited with one of them. So, it will be useful to keep these questions separate.

Q10. Open a medicine bottle/ blister pack: It is reported by one of the participants that these are two different actions and need to be asked in two separate questions. She reported that as a stroke survivor, she can do one of them (open a medicine bottle), but not the other one (blister pack). However, other participants did not find this problematic.

Q12. Put on jewellery/watch: It is mentioned by one participant that jewellery is a broad term. She can wear a bracelet, but not a necklace as it requires the use of two hands. In addition, she has mentioned that it can be good to ask if they can wear standard or elasticated jewellery. This can be a good idea to cover, as stroke survivors use adaptations. So, the question can be rephrased: “Put on standard or elasticated jewellery/watch.

Domain Getting Dressed/undressed:

Q11. Fasten clothes at the back: There were four female participants and two participants have mentioned that they do not think this question covers wearing a bra. They preferred to rephrase this and ask “Fasten clothes/undergarments at the back’. This can help to cover both clothes that require fasting at the back and the bra.

Domain Bathing/Showering:

Q9. Style/ blow-dry your hair Q10. Take care of your hands and feet including cutting/filing your nails	One participant reported that these questions are personal care and they should be placed under the “Bathroom/Personal Care domain”.

Domain Cooking:

Q13. Open fridge door: Participants thought that this is repeating Q5. Get the milk out of the fridge from the ‘Eating/Drinking’ Domain. They have mentioned that it can be good to remove one of the questions. Participants believe that question in the ‘Eating /Drinking’ domain includes more tasks than this question. Therefore, this question can be removed.

Q14. Prepare and cook a snack and/or a meal: One participant reported that preparing a snack can be different action than preparing a meal, and he prefers them to be separate questions. On the other hand, other participants mentioned that they are the same actions.

Domain Moving around Indoors:

Q7. Get up and down steps/stairs: Half of the participants have mentioned that this question needs to be two separate questions. Some stroke survivors can only manage steps but cannot go up and downstairs due to the balance problem. Also, some people only need to use internal steps and do not have stairs at home. Therefore, it is important to understand if people struggle with each task separately.

Q9. Reach up: Participants (n=three) have mentioned that this question is repeating Q6. Remove heavy items (e.g., bag of sugar) from top cupboards at the 'Cooking' domain, as both require reaching action. On the other hand, the rest of the participants (n=seven) have mentioned that reaching up is a different action than reaching with heavy items. Therefore, they both should be included.

<u>Domain Cleaning the House:</u>

Q3. Sweep up/ mop floor
Q5. Vacuum clean

Three participants have advised to include these items as one question. It was reported by another participant to remove Q5 and only keep Q3. On the other hand, rest of the participants were happy to keep these as two separate questions. They have mentioned that they think they require two different skills, because a vacuum cleaner is heavier than the rest.

Q9. Heavy housework (e.g., move furniture, take down curtains): Two stroke survivors have mentioned that after having a stroke, heavy housework may not be relevant anymore. So, they prefer to remove this question.

<u>Domain Laundry/Clothes care:</u>

Q1. Do the handwashing: Three stroke survivors reported that hand washing is not relevant for them anymore, as they are limited with one hand and they use a washing matching even if it requires hand wash.

Q4. Plug in and pull out a plug (any in the home): Advised by a participant to rephrase this question to Pull in and out an electrical plug. He has mentioned that this will be better to understand the question. However, the rest of the participants were happy about the wording of the question.

Q7. Do small repairs e.g., hemming, buttons: Two participants advised to remove this question, as they think it is not applicable for stroke survivors. However, the rest of the participants were happy to keep it as it was relevant for them.

Q8. Cut cloth and/ or use scissors: Participants (n: three) have mentioned that “Cut cloth” is not relevant for them anymore. However, they use scissors, even for cutting their food. So, they preferred this question to be rephrased as “Use scissors”.

Q9. Pick up pins/needles: Four participants have mentioned that this question is not relevant for stroke survivors. One participant has stated that it can be rephrased to pick up tablets and another participant has mentioned rephrasing it to pick up coins. She pointed out that they only pick up coins during the rehabilitation, but are not relevant in daily activities.

<u>Domain Moving and Transferring:</u>

Q2. Turnover and sit up in bed: Advised by one participant that this question includes two different activities that are important to know separately. Some people are only able to turn over, but cannot sit up in bed. So, preferred to separate this into 1. Turnover in bed 2. Sit up in bed. The rest of the participants were happy to keep it as one question.

Q5. Getting a comfortable sleeping position: One participant advised to rephrase this to “Q5. Getting a comfortable sleeping position with pillows”.

<u>Domain Communication:</u>

Q1. Use a phone/mobile (call/ text/ any functions): Advised by participants to add landline word in front of the phone, to make it clear that it covers both mobile and landline phone.

Q4. Read and choose from a menu

Q5. Read newspapers/magazine/ books

Two participants reported that these questions are same, and they can be written as one question. However, rest of the participants preferred to keep them separate, as they believe they are different.

Q9. Use remote controls and/ or environmental control: Two participants reported that this question is not clear, and it is repeated in other questions, so it can be removed. Another two participants have mentioned that it is difficult to understand what this question asks. One participant said that it can be rephrased to: "Use TV remote control + heating control". However, if it was rephrased like this, it will repeat Q12 at the "Moving around indoors" domain. This question was problematic for the participants.

Q11. Write a letter

Q13. Write a card

In generally, participants thought that these two questions may be repetition of each other and one of them can be removed. It is recommended by one of the participants not to remove any of the questions and combine them. 'Write a letter/card'.

<u>Domain Moving around outside/shopping:</u>

Q3. Go upstairs without a handrail: In general, stroke survivors were not happy with this question as it asks doing the action WITHOUT a handrail. They were worried that this is not safe and asking the question can encourage people to do it. They have also mentioned that after having a stroke they were always advised to use a handrail. Therefore, they do not think this can be applicable to them. Three participants have advised to rephrase it WITH a handrail. Two participants preferred to remove it. They have also mentioned that this is repeating the Q7 at the 'Moving Around Indoor' domain. They reported that people, who can go up and down stairs indoors with a handrail, could do it outside as well. This question was problematic.

Q4. Travel by public transport: Two participants told that this question needs to be rephrased. One of them suggested asking, “Travel alone by public transport”. She has mentioned that when they travel alone, they need to think about more things such as safety, balance, speed, steps etc. However, when they go out with someone, they can get support. Another participant documented that travelling on a bus and train are different tasks due to the step height difference. He reported that buses have a higher step to get on /off, but it is easier to get on/off a train. He prefers to ask these as two separate questions “Q1. Get on/off a bus” “Q2. Get on/off a train”.

Q6. Drive a car (e.g., hold steering wheel, turn car key, change gear): Participants (n= two) have documented that it can be better to remove the brackets as you need to do these if you can drive a car. Another stroke survivor has mentioned that most of the stroke survivors can drive an adapted car. Therefore, it can be better to ask if they drive standard or adapted cars.

Domain Gardening/Household maintenance:

Q2. Heavy gardening (e.g., dig, mow): It is reported by three participants that heavy gardening is not easy for stroke survivors and most of them avoid doing it. Therefore, they preferred to remove this question. However, when the PhD candidate has mentioned that each stroke survivor is different and the question aims to understand if they can do it or if they are limited due to a stroke, they have agreed to keep it.

Q3. Clean the car (inside and out): Two participants documented that this question can be removed as it is not applicable to them. On the other hand, other participants have mentioned that even if it is not relevant for them, stroke may affect different age groups and younger people may still do this.

Q4. Do household repairs: One participant reported that this question covers a lot of tasks. Therefore, it can be difficult to provide an answer, as he can do some repairs, but not all. Another participant mentioned that he prefers this question to be removed, as it can be a difficult task for highly impaired stroke survivors. This question was challenging for these two participants. However, the rest of the participants found it easy to understand.

Q5. Car maintenance (e.g., oil, water): Four participants have mentioned that this is not relevant for them anymore. They have mentioned that even if they drive, there are services that check these for them and they do not need to do it.

Domain Hobbies, Leisure and Social Activities:

Q1. Crafts (e.g., knitting, crochet, sewing, embroidery, model making): One participant has mentioned that they know the meaning of Crafts, so it can be better to remove the brackets. However, it can be good to provide examples and make it clear for other people. The rest of the participants were happy about the wording.

Q2. Do-It-Yourself (e.g., using tools, decorating): Participants (n= two) have mentioned that they prefer to remove this question as it is not relevant for them. However, the rest of the participants found it relevant for their condition.

Domain Cognition/Perception:

In general, most of the participants found this domain relevant and easy to understand. However, one participant has mentioned that it is too general, and it needs to ask few details. Her suggestions were:

Q2. Concentrate: She reported that concentration on different activities are different and it can be important to understand if stroke survivors can concentrate when doing different activities. She advised mentioning; 1. Concentrate on driving, 2. Concentrate on talking, 3. Concentrate on reading. Therefore, it can be good to give examples in brackets.

Q5. Make decisions: She has mentioned that making decisions about simple daily tasks and difficult tasks is different. She prefers to divide this and ask about: 1. make decisions about daily choices (e.g., what to eat) 2. Make decisions about finance.

Q6. Do things in the right order: She reported that the word “Right” is wrong to use. This is because everyone has their own order and it is correct for them. Therefore, she prefers to rephrase this question as “Do things in an order”.

Expert panel member advised to rephrased this to ‘Do things in order’.

Four participants advised that Domains **“Caring”, “Gardening” ‘Hobbies’ and Cleaning**” needs to be optional for people. They have mentioned that these domains are related to the age, living conditions or severity of the condition. Three of the participants preferred to remove the “Caring” domain. On the other hand, the other three participants have mentioned that they look after their grandchildren. Also, they said that it is important to include this domain for the young stroke survivors who have a responsibility to look after someone.

Stroke survivors are different, and these domains can be relevant for other people. Some participants advised to have “Not Applicable” option next to the domain name, so if they do not think that it is applicable for them, they can skip the domain without answering the questions. This can be an option to consider in the future, after testing the psychometric properties of the EDAQ-SS.

The list of the items that some participants recommended to remove (these questions were not problematic for most of the participants, so they are not removed):

1.2 Pain when resting (About You and Your Health)

1.7 Sleep problems (About You and Your Health)

Q5. Get the milk out of the fridge (Eating/Drinking domain)

Q4. Carry a full pan to/ from the cooker (Cooking domain)

Q6. Remove heavy items (e.g., bag of sugar) from top cupboards (Cooking domain)

Q10.Put crockery/pans etc., into kitchen cupboards (Cooking Domain)

Q10. Get on /off floor: One Stroke Survivors has (Moving Around Indoors)

Q12.Manage heating (e.g., controls, wood burner, multifuel stove, open fire) (Moving Around Indoors)

Q2. Dust and wipe surfaces (Cleaning domain)

Q6. Open a window (Cleaning domain)

Q7. Clean windows (Cleaning domain)

Q8. Clean the bath and/or shower (Cleaning domain)

Q7. Read maps (Communication domain)

Q16. Order in a café, pub or restaurant (Communication domain)

Q19. Ask for something in a local shop (Communication domain)

Q20. Exchange something (Communication domain)

Q21. Complain in a shop (Communication domain)

Q9. Walk around the shops (Moving around outside/Shopping domain)

Additional Questions advised by participants in general (the same question is not mentioned by more than one participant. Each participant has mentioned a different additional question):

1. Get on/off buss (included)
2. Get on/off train (included)
3. pick up tablets
4. Do you see PT/Dr currently?
5. Fasten a bra
6. Drive a standard car (included)
7. Drive an adapted car (included)
8. Ask the age of the person that needs care
9. Open a lower-case window
10. Open an upper care window
11. Pick up coins
12. Getting a comfortable sleeping position with pillows
13. Turnover in a bed
14. Sit up in a bed
15. Use a food processor (it is added to the equipment section at the SSHUB)
16. Add grabber to gadgets/aids section (it is added to the equipment section at the SSHUB)
17. Fastening clothes domain

18. Get milk out of eye level fridge
19. Get milk out of the low-level fridge
20. Flush the toilet at home
21. Flush the toilet outside
22. Wear elasticated jewellery/watch (included)
23. Wear standard jewellery/watch (included)
24. Concentrate on driving (included)
25. Concentrate on reading (included)
26. Concentrate on talking (included)
27. Recognise new things
28. Make decisions about daily choices (e.g., what to eat) (included)
29. Make decisions about finances (included)
30. Have a separate domain for fastening clothes
31. Add at home to the 'Moving indoor' domain and have a separate section for unfamiliar homes.

Completion time: In generally, it took **45 to 50 minutes** in total to complete three questionnaires for the participants. Some participants have mentioned that **15-20 minutes** were enough for them to complete only the EDAQ-SS.

Comments about the EDAQ-SS: All participants found the EDAQ-SS easy, detailed and good. They thought that the EDAQ-SS will provide sufficient information to the healthcare professionals about their limitations.

One participant mentioned that: "*The EDAQ-SS underlines and shows that people can improve. I am pleased that so much work is done. I think it is necessary.*"

One participant reported that the EDAQ-SS was long. However, she thinks that all the items were relevant and no question made her think why it has been asked.

Another comment from another participant was: "*This questionnaire addresses things that you have avoid. It made me realise that I can do better*."

Comments about the SSHUB: Nine out of 10 participants found **Easy** to use the SSHUB and they said they will be happy to use it in future.

Seven participants out of 10 reported that they **prefer** to use eEDAQ-SS. This is because they can only use one hand, so they cannot write. They found easy to use tick boxes to answer the questionnaire. One participant has mentioned that he is happy to use an electronic version if this is the only option that he has. Two participants have mentioned that they prefer the paper version (one does not use the internet and the other one mentioned that people may have limited internet access, so the paper version can be useful for more people). All of the participants have provided feedback to improve the SSHUB for the future.

Note: After discussing with the expert panel grammar mistakes were corrected. In general, the expert panel were happy with the current changes.

APPX 3: Final Version of the EDAQ-SS

University of Salford MANCHESTER	EDAQ-**SS**	Office Use Only:

EDAQ-SS

Evaluation of Daily Activity Questionnaire for Stroke Survivors

Optional:______________________________

NAME: ______________________________ HOSPITAL:______________________________

Date of Birth: (dd/mm/yyyy) NHS Number: ______________________________

EDAQ-**SS**

The Evaluation of Daily Activity Questionnaire for Stroke Survivors (EDAQ-SS): Part 1 and 2 are modified by Gilanliogullari N, Hollands K, Hammond A and Prior Y, from the British version of EDAQ, which adapted by Hammond A et al., 2014, from the Swedish EDAQ developed by Ulla Nordenskiold PhD et al., Sweden.

The EDAQ-SS development and testing are a PhD project at the University of Salford.

No part of the EDAQ-SS can be modified without prior permission. If you have any question, please contact to Nazemin Gilanliogullari:

n.gilanliogullari@edu.salford.ac.uk

The EDAQ-SS (Evaluation of Daily Activity Questionnaire for Stroke Survivors) helps us understand your abilities and problems when doing your daily activities after having a stroke. You may have noticed that using aids, everyday gadgets/ equipment or even different ways of doing things (e.g., using an unaffected hand) reduces some of these problems. Sharing your problems and solutions with us helps us to help you.

What to do:

There are **two parts**. Part One asks about how stroke is affecting you now. Part Two asks about your ability to do your daily activities in the last two weeks. Please answer **all** questions.

In Part Two:

Think about your ability in the last **two weeks**. There is an example of how to complete this on page 7. **Please read these instructions and the example before filling in**.

Each page is divided into two sections. Each question should be answered **twice.**

Section A (left side of the page):

How you do the activity **without** using aids/ gadgets, alternate methods (e.g., two-handed grip) or help?

- If you do not normally do the activity, tick "**Not Applicable**" (e.g., if you do not drive; or someone else always normally does that activity).
- If you no longer do the activity due to stroke (i.e., Someone else now has to do it for you), please tick "**Unable to do**."

Section B (right side of the page):

For **each** activity, please **tick** (✓) in the middle column either**:**

- **Yes:** if you use an aid/gadget or alternate method, then **always** complete Section B on the right side. Describe how you do it **with** an aid/gadget or an alternate method. Then **tick** (✓) how easy/difficult this is.
- **No**: if you do **not** use an aid or alternate method. Do **not** complete the rest of section B.

- **If you have help/ someone else does it for you** because of your health condition, please tick (✓) this column. Do **not** complete the rest of section B.

You can also contact us if you need further help.

Please leave the “score” column blank.

Part One: About You and Your Present Health

Please (✓) the boxes below where relevant.

1. How long have you had your neurological condition? ____(weeks)(months)(years)

- Stroke ☐
- Multiple Sclerosis ☐
- Parkinson's Disease ☐
- Spinal Cord Injury ☐
- Gullian Barré Syndrome ☐
- Other ________________

2. Have you been diagnosed with any of the following conditions or impairments following stroke?

- Weakness (weak arm or/and leg) ☐
- Aphasia (difficulty with language or speech e.g., reading, listening, writing, speaking) ☐
- Dysarthria (difficulty of speaking, unclear speech) ☐
- Hearing loss ☐
- Visual problem (e.g., eye movement problem) ☐
- Depression or Anxiety ☐
- Stress ☐
- Memory or cognition problem ☐
- Balance problem ☐
- Sensory problem ☐
- Other ________________

3. Are you working (paid/ unpaid), or in education?

Yes ☐ No ☐

4. Are you planning to return work or education?

Yes ☐ No ☐

5. Have you been given advice and information about self-management of your neurological condition?

Yes ☐ No ☐

For the following questions, we ask you to CIRCLE the number below the line which best reflects your situation at the moment.

<u>Describe your:</u>

1.1 Mood:

0 1 2 3 4 5 6 7 8 9 10

Very happy — Very unhappy

1.2 Pain when resting:

0 1 2 3 4 5 6 7 8 9 10

No pain — Severe pain

1.3 Pain when moving:

0 1 2 3 4 5 6 7 8 9 10

No pain — Severe pain

1.4 Stiffness:

0 1 2 3 4 5 6 7 8 9 10

No stiffness — Severe stiffness

1.5 Fatigue:

0 1 2 3 4 5 6 7 8 9 10

No fatigue — Severe fatigue

1.6 Worry:

0 1 2 3 4 5 6 7 8 9 10

Not worried — Severely worried

1.7 Sleep problems:

0 1 2 3 4 5 6 7 8 9 10

No sleep problems — Severe sleep problems

1.8 Satisfaction with life:

0 1 2 3 4 5 6 7 8 9 10

Very satisfied — Very dissatisfied

Instructions: Example of how to fill in the EDAQ-SS

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

EXAMPLES:	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Drink from a cup/mug		✓						✓							
2.Turn taps				✓			✓			**Use tap turner/lever taps**	✓				
3.Pull out a plug			✓					✓							
4.Open a jar				✓			✓			**Jar opener**	✓				
5.Vacuum clean				✓			✓			**Take breaks, use two hands**		✓			
6. Put on/take off a coat				✓				✓							
7. Get in/out of bath					✓		✓			**Use a bath seat**		✓			
8. Climb ladder					✓			✓							
9. Drive a car	✓														
10. Clean windows				✓					✓						
Total Score: Section A =										**Total Score: Section B =**					

Part Two: Your ability to do everyday activities after stroke

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: ‘How do you do it without using an aid/gadget, alternate method or help?’ If you do not normally do the activity, tick “not applicable”.
B: ‘How else do you do it with an aid/gadget or alternate method?” Fill in the middle columns. Leave B blank if you tick “no” or “have help.”

1.Eating / Drinking	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Drink from a glass															
2. Drink from a cup/mug															
3. Use cutlery															
4. Slice food (e.g. bread, cheese)															
5. Get the milk out of the fridge															
6. Open a milk carton/ plastic bottle and pour out															
7. Open a screw top jar or bottle															
8. Open a tin or a ring pull can															
9. Open a packet/pouch															
10. Enjoy a normal diet															
11. Enjoy a normal drink															
12. Enjoy meals with family/ friends															
13. Swallow tablets															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: ‘How do you do it without using an aid/gadget, alternate method or help?’ If you do not normally do the activity, tick “not applicable”.
B: ‘How else do you do it with an aid/gadget or alternate method?” Fill in the middle columns. Leave B blank if you tick “no” or “have help.”

2. IN THE BATHROOM/ PERSONAL CARE	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Get on and off the toilet															
2. Wipe yourself with toilet paper /clean self below															
3. Using sanitary or/and incontinence products															
4. Flush the toilet															
5. Arrange your clothes before and after going to toilet															
6. Wash your hands															
7. Brush and comb your hair															
8. Use a tube of toothpaste															
9. Brush your teeth/dentures															
10. Open a medicine bottle/ blister pack															
11. Do your make up or shave															
12. Put on standard or elasticated jewellery/watch															
13. Control your bladder															
14. Control your bowel															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

3. GETTING DRESSED/ UNDRESSED	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Put on / take off a coat															
2. Pull clothes over your head															
3. Put on front-opening clothes															
4. Do up/undo buttons															
5. Pull clothes over your feet (e.g trousers or skirts)															
6. Do up /undo zips															
7. Put on tights/ socks															
8. Take shoes/ boots on and off															
9. Tie shoelaces															
10. Put on/take off gloves															
11. Fasten clothes/ undergarments at the back															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

4. BATHING/ SHOWERING	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Get in and out of the bath															
2. Shower whilst standing															
3. Use shower controls															
4. Feel the temperature of the water															
5. Turn taps (any in home)															
6. Wash your all body parts															
7. Dry your all body parts															
8. Wash your hair															
9. Style/ blow-dry your hair															
10. Take care of your hands and feet including cutting/filing your nails															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

5. COOKING	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Stand while working in the kitchen															
2. Set the table/ carry plates, cups etc															
3. Peel and chop vegetables															
4. Carry a full pan to/ from the cooker															
5. Drain water from a saucepan (e.g. vegetables, pasta)															
6. Remove heavy items (e.g. bag of sugar) from top cupboards															
7. Baking (e.g. cakes, bread, pastry)															
8. Take things in/out of oven															
9. Wash up															
10. Put crockery/pans etc into kitchen cupboards															
11. Use a kettle (e.g. fill, pour)															
12. Use your cooker/ microwave															
13. Prepare and cook a snack and/or a meal															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

6. MOVING AROUND IN DOORS	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Walk indoors (e.g. get to toilet/ bathroom; round kitchen)															
2. Open the front/ back door															
3. Lock and unlock doors															
4. Get to the front door in time to answer															
5. Get to the phone in time to answer															
6. Stand for longer periods															
7. Get up and down steps															
8. Get up and down stairs															
9. Bend to floor/pick up items															
10. Reach up															
11. Get on/off floor															
12. Carry items around the house															
13. Manage heating (e.g. controls, woodburner, multifuel stove, open fire)															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

7. CLEANING THE HOUSE	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Make the bed															
2. Dust and wipe surfaces															
3. Sweep up/ mop floor															
4. Wring out a cloth															
5. Vacuum clean															
6. Open a window															
7. Clean windows															
8. Clean the bath and/or shower															
9. Heavy housework (e.g. move furniture, take down curtains)															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

8. LAUNDRY/ CLOTHES CARE	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Use a washing machine (e.g. load and unload)															
2. Hang out and folding washing															
3. Plug in and pull out a plug (any in home)															
4. Put up an ironing board															
5. Iron															
6.Do small repairs e.g. hemming, buttons															
7. Use scissors															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

9. MOVING AND TRANSFERS	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Get into and out of bed															
2. Turn over and sit up in bed															
3. Stand up from a chair															
4. Pull up bedclothes/duvet															
5. Getting a comfortable sleeping position															
6. Sit independently (e.g. in a car, train)															
7. Move from bed to chair															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: ‘How do you do it without using an aid/gadget, alternate method or help?’ If you do not normally do the activity, tick “not applicable”.
B: ‘How else do you do it with an aid/gadget or alternate method?” Fill in the middle columns. Leave B blank if you tick “no” or “have help.”

10. COMMUNICATION	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Use a landline phone / mobile (call/ text/ any functions)															
2. Read directions on food packets															
3. Follow instructions on microwave															
4. Read and choose from a menu															
5. Read newspapers/ magazine/books															
6. Read street names and road signs															
7. Read maps															
8. Use a computer and a mouse															
9. Write a shopping list															
10. Write a letter/card															
11. Fill out a form															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

10. COMMUNICATION (continued)	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
12. Chat in social situations															
13. Talk with the doctor															
14.Order in a café, pub or restaurant															
15. Ask and/or give directions															
16. Tell bus/taxi driver your destination															
17. Ask for something in a local shop															
18. Exchange something															
19. Complain in a shop															
20. Give money and count change															
21. Use a pin pad in cash machine															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

11. MOVING AROUND OUTSIDE/ SHOPPING	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Walk on level ground															
2. Go for a long walk (e.g. a mile)															
3. Get on and off a bus															
4. Get on and off a train															
5. Get in and out of a car and open car door															
6. Drive a standard or adapted car															
7. Fill the car with petrol															
8. Open a heavy (e.g. shop) door															
9. Walk around the shops															
10. Carry shopping															
11. Do the weekly shopping															
12. Safely cross the road in time for the light															
13. Walking on uneven floor															
14. Walking in slopes															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

12. GARDENING/ HOUSEHOLD MAINTENANCE	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Light gardening (e.g. weed, prune, plant)															
2. Heavy gardening (e.g. dig, mow)															
3. Clean the car (inside and out)															
4. Do household repairs															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

13. CARING	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Feed another person, prepare bottles															
2. Bathe another person/ change nappies															
3. Dress another person															
4. Do another person's hair															
5. Use equipment for another person (e.g. high chair, push wheelchair, car seat)															
6. Put another person in/ out of high chair, push chair, high seat, wheelchair															
7. Help move another person															
8. Engage or occupy with another person															
Total Score: Section A =										**Total Score: Section B =**					

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: 'How do you do it without using an aid/gadget, alternate method or help?' If you do not normally do the activity, tick "not applicable".
B: 'How else do you do it with an aid/gadget or alternate method?" Fill in the middle columns. Leave B blank if you tick "no" or "have help."

14. HOBBIES, LEISURE AND SOCAIL ACTIVITIES	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some=one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1. Crafts (e.g. knitting, crochet, sewing, embroidery, model making)															
2. Do-It-Yourself (e.g. using tools, decorating)															
3. Visit friends/ socialising(eg pub, cinema, theatre)															
4. Attend community / religious groups or classes															
5. Physical activities (e.g. dance, active sports, swimming, bicycling, fishing)															
6. Quiet recreation (e.g. painting, cards)															
7. Performing arts (e.g. music, choir, dramatics)															
8. Pet care (eg feed, groom, walk)															
					Total Score: Section A =									**Total Score: Section B =**	

Please tick (✓) to indicate your ability carrying out the activities listed below during the last two weeks. **Please fill in both sections:**
A: ‘How do you do it without using an aid/gadget, alternate method or help?’ If you do not normally do the activity, tick “not applicable”.
B: ‘How else do you do it with an aid/gadget or alternate method?” Fill in the middle columns. Leave B blank if you tick “no” or “have help.”

15. Cognition/ Perception	**A.** How do you do it **without** an aid/gadget, alternate method or help?						Do you use an aid or other method?		Have help/ Some-one does it for me	**B.** If yes, how else do you do it **with** an aid/gadget or alternate method?					
	Not Applicable	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score	**Yes**	**No**		Please describe below which aid/s or other method/s you use?	Without difficulty	Some difficulty	Much difficulty	Unable to do	Score
1.Think quickly															
2.Concentrate (e.g. when driving, talking, reading)															
3.Remember new things															
4.Discuss news/current issues															
5. Make decision about daily choices (e.g. what to eat)															
6. Make decisions about finances (e.g. manage money)															
7. Do things in order															
8. Notice things on both side of you															
Total Score: Section A =										**Total Score: Section B =**					

Finally:

1. Do you use / wear (*please tick if applicable*):

Wrist splint/s ☐ Walking aid ☐ Shoe insole/s ☐

Any other splint/s ☐ Please state: ____________ Knee brace ☐

2. Overall, which aids/gadgets you own do you value the most?

____

____

3. How do you feel about using aids/gadgets? *(please circle the number)*

0 1 2 3 4 5 6 7 8 9 10

Not at all bothered Very bothered

4. What do you do yourself to help self-manage your symptoms/ condition?

____

____

____

5. What is the most important thing you want to continue to do in life or to manage?

____

____

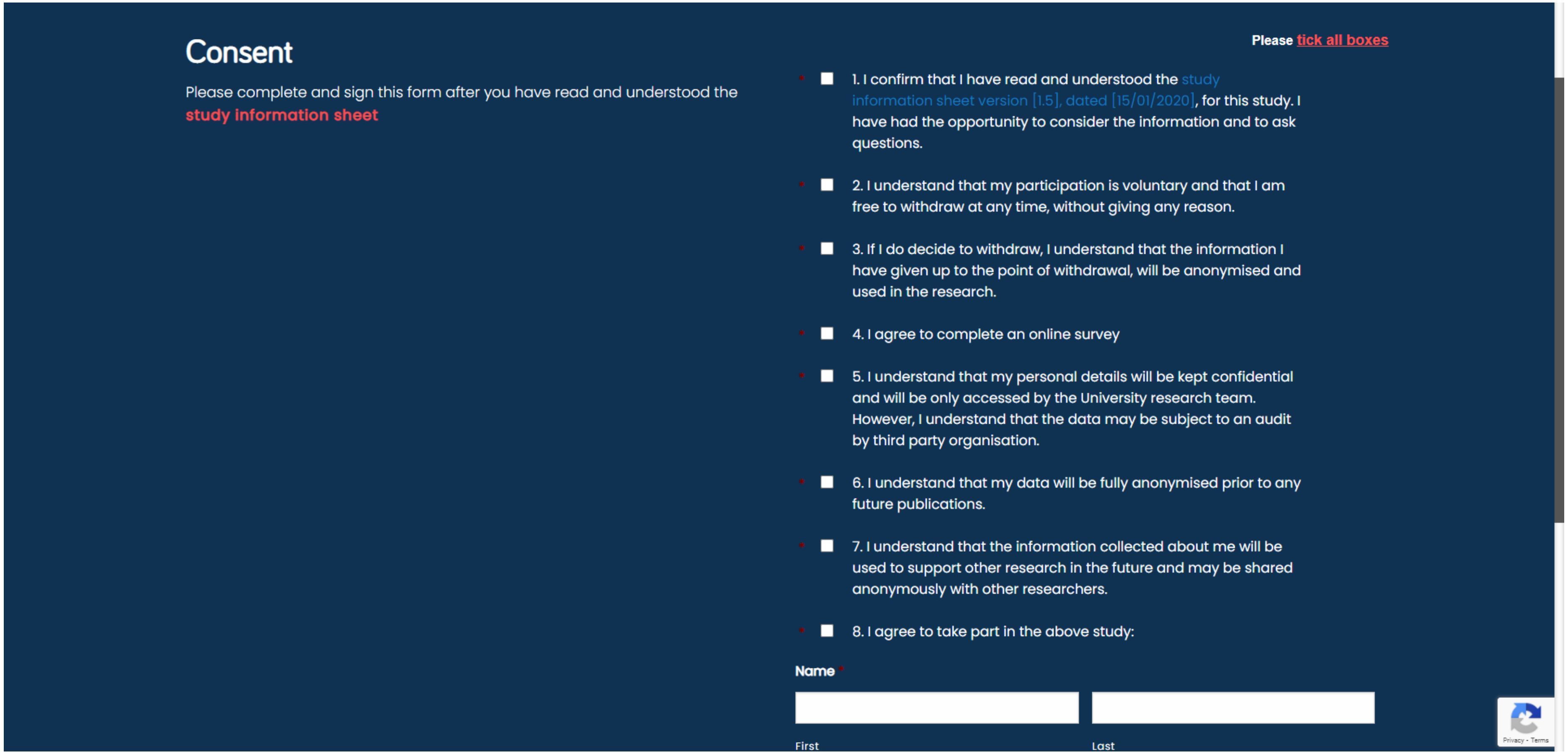
____

If there is anything else you would like to tell us, or if you have any other comments, please write below:

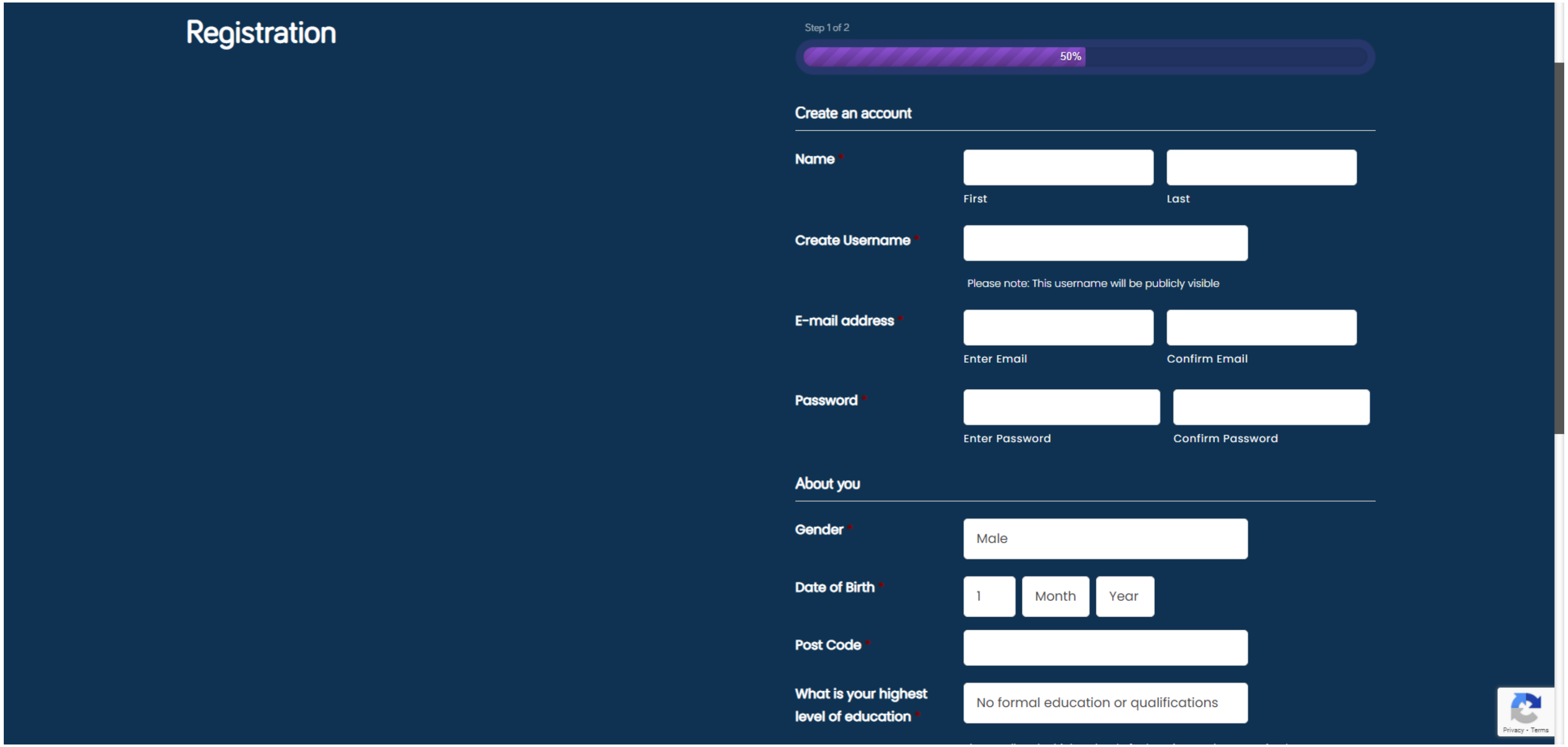
Thank you for completing the EDAQ-SS. Please check you have not missed any questions or pages.

APPX 4: Pictures of the SSHUB

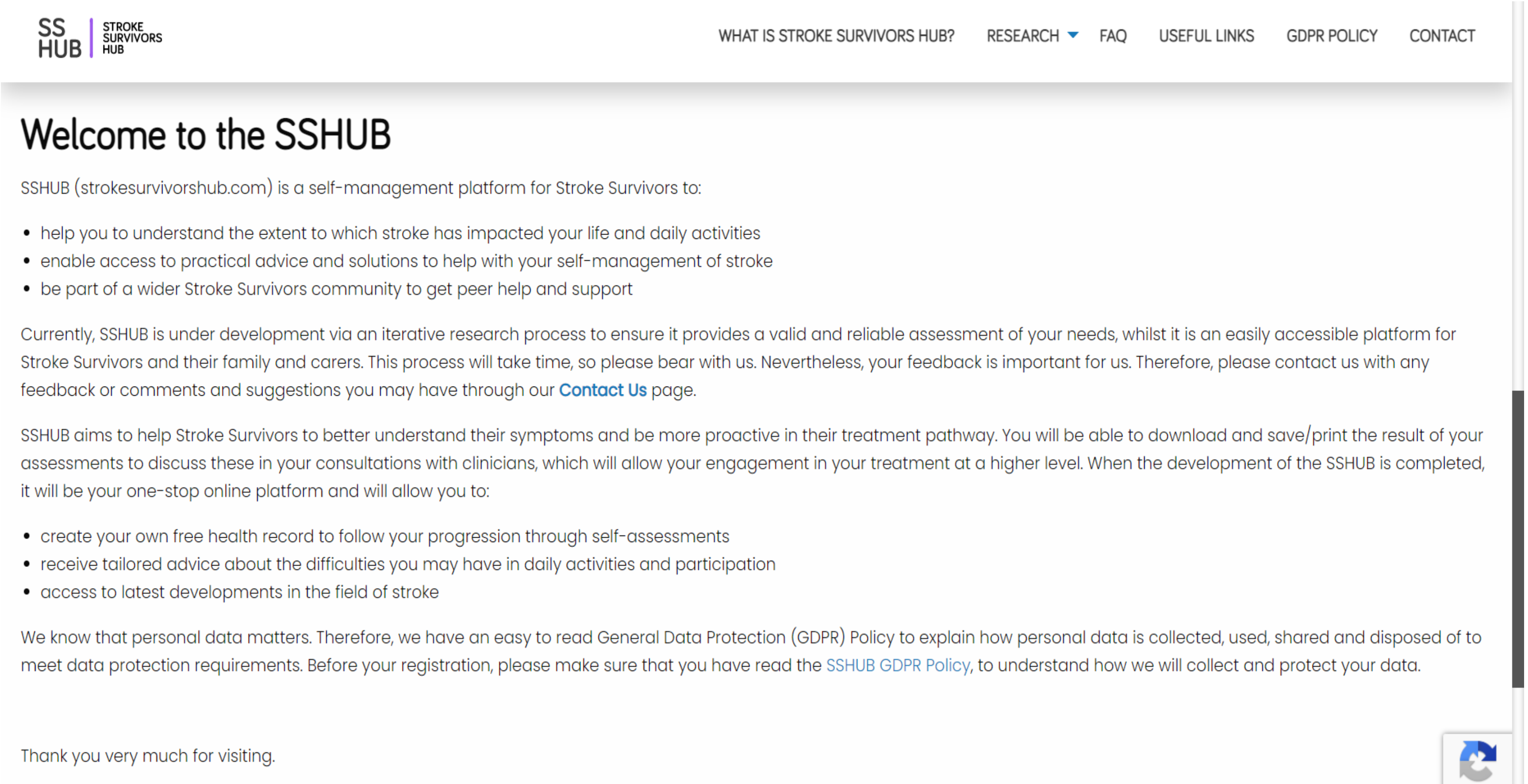
Picture 1: Screenshot of the ‘Consent form’ page which is part of the registration at the SSHUB



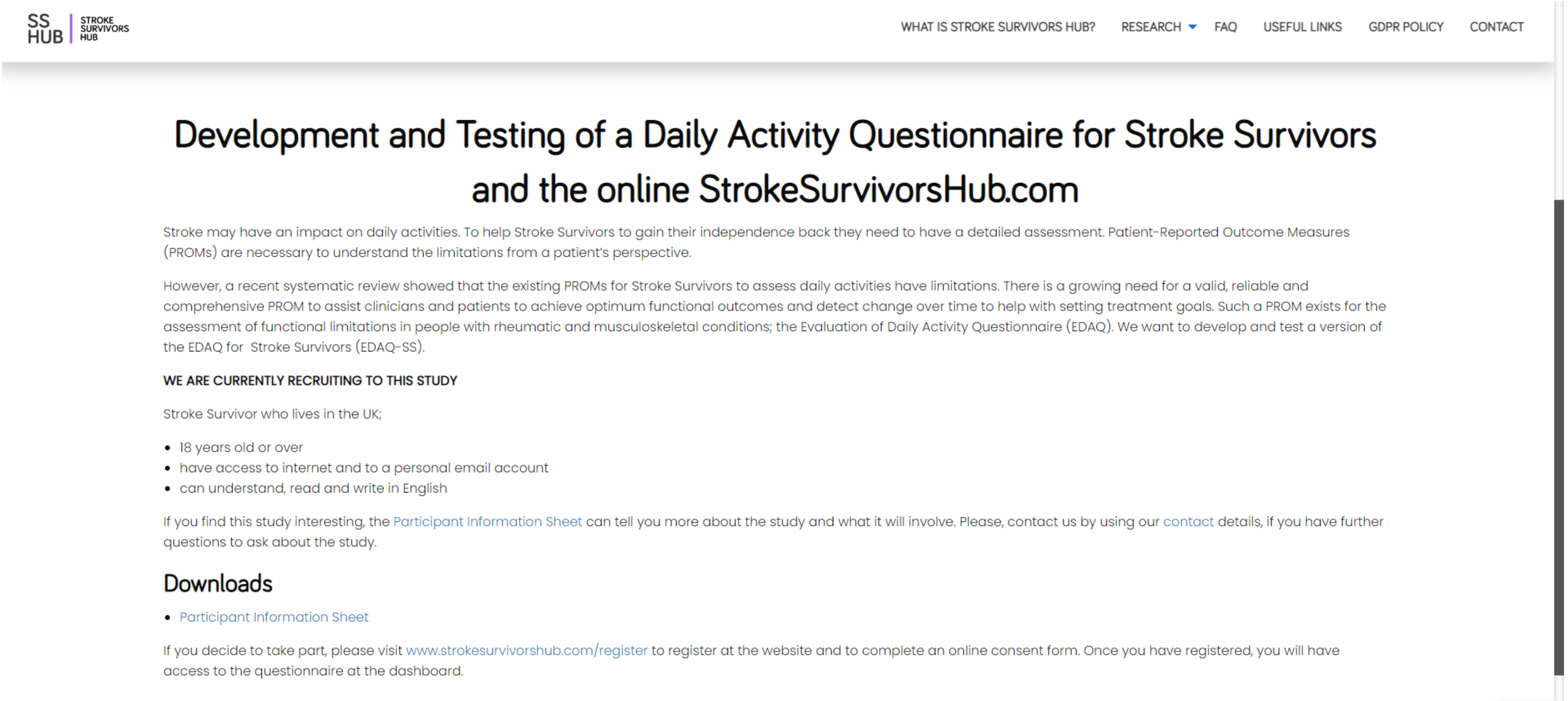
Picture 2: Screenshot of ‘Registration’ page at the SSHUB



Picture 3: Screenshot of 'What is the Stroke Survivors Hub' page on the SSHUB



Picture 4: Screenshot of 'Research' page on the SSHUB


SS HUB | STROKE SURVIVORS HUB

WHAT IS STROKE SURVIVORS HUB? RESEARCH FAQ USEFUL LINKS GDPR POLICY CONTACT

Development and Testing of a Daily Activity Questionnaire for Stroke Survivors and the online StrokeSurvivorsHub.com

Stroke may have an impact on daily activities. To help Stroke Survivors to gain their independence back they need to have a detailed assessment. Patient-Reported Outcome Measures (PROMs) are necessary to understand the limitations from a patient's perspective.

However, a recent systematic review showed that the existing PROMs for Stroke Survivors to assess daily activities have limitations. There is a growing need for a valid, reliable and comprehensive PROM to assist clinicians and patients to achieve optimum functional outcomes and detect change over time to help with setting treatment goals. Such a PROM exists for the assessment of functional limitations in people with rheumatic and musculoskeletal conditions; the Evaluation of Daily Activity Questionnaire (EDAQ). We want to develop and test a version of the EDAQ for Stroke Survivors (EDAQ-SS).

WE ARE CURRENTLY RECRUITING TO THIS STUDY

Stroke Survivor who lives in the UK;

- 18 years old or over
- have access to internet and to a personal email account
- can understand, read and write in English

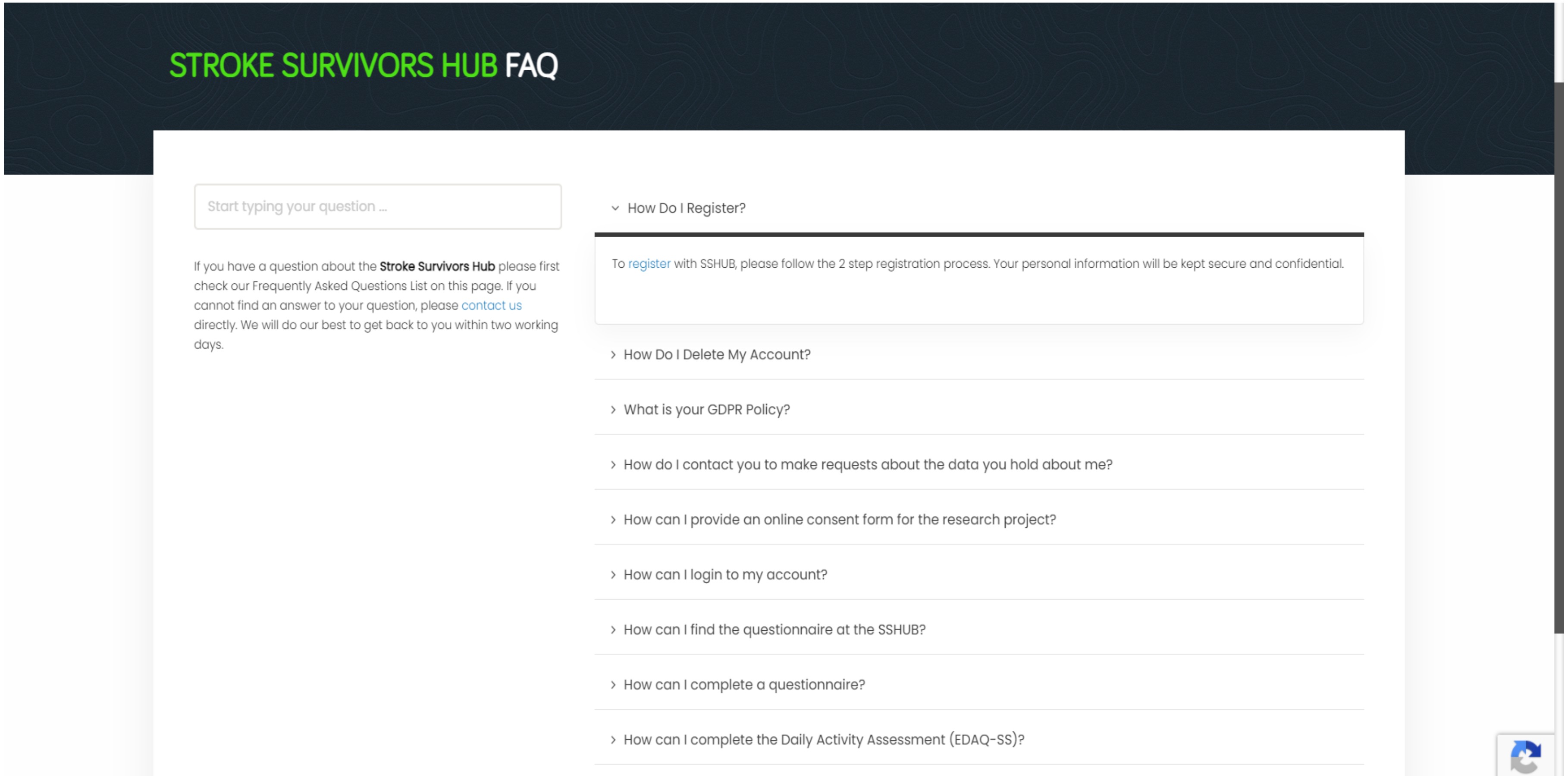
If you find this study interesting, the Participant Information Sheet can tell you more about the study and what it will involve. Please, contact us by using our contact details, if you have further questions to ask about the study.

Downloads

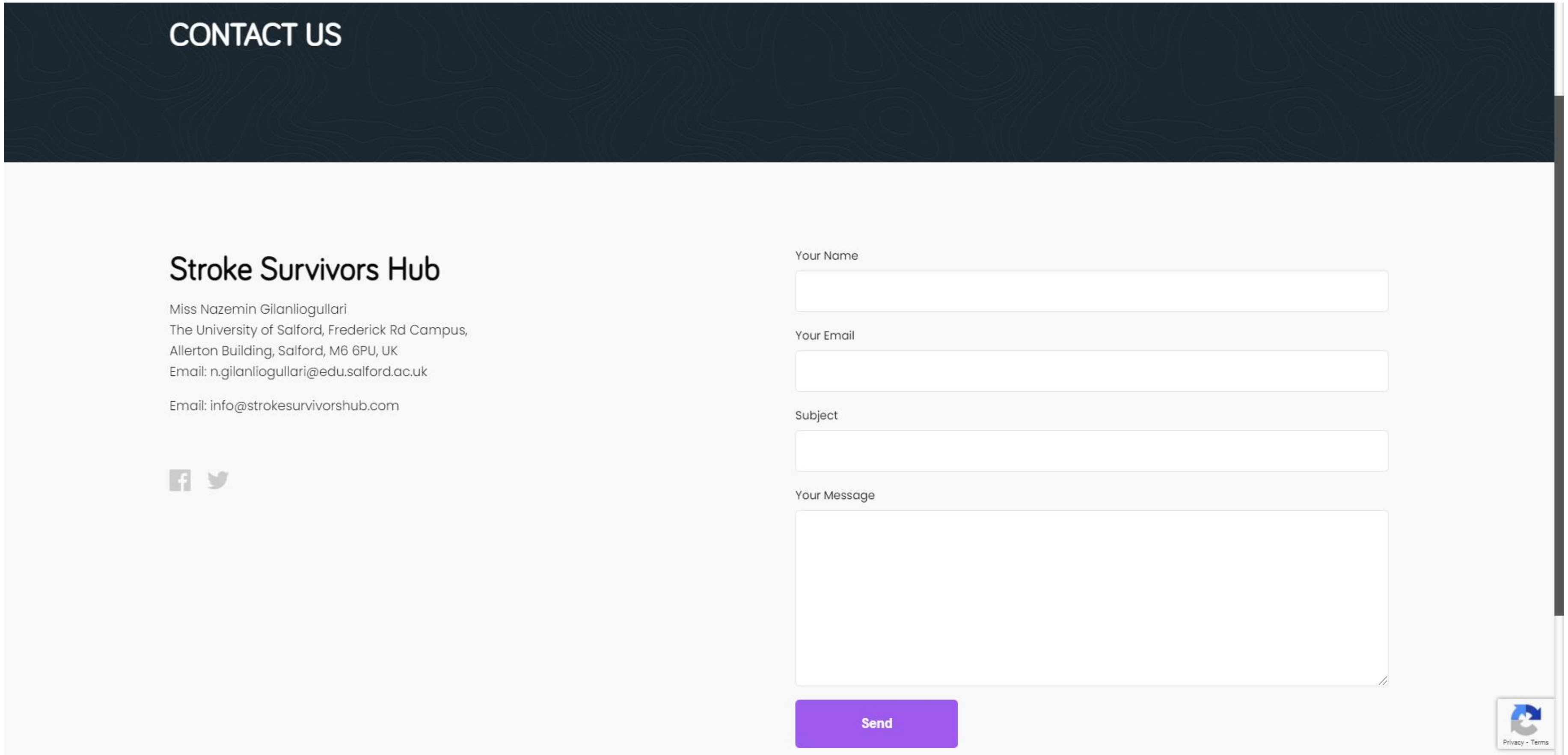
- Participant Information Sheet

If you decide to take part, please visit www.strokesurvivorshub.com/register to register at the website and to complete an online consent form. Once you have registered, you will have access to the questionnaire at the dashboard.

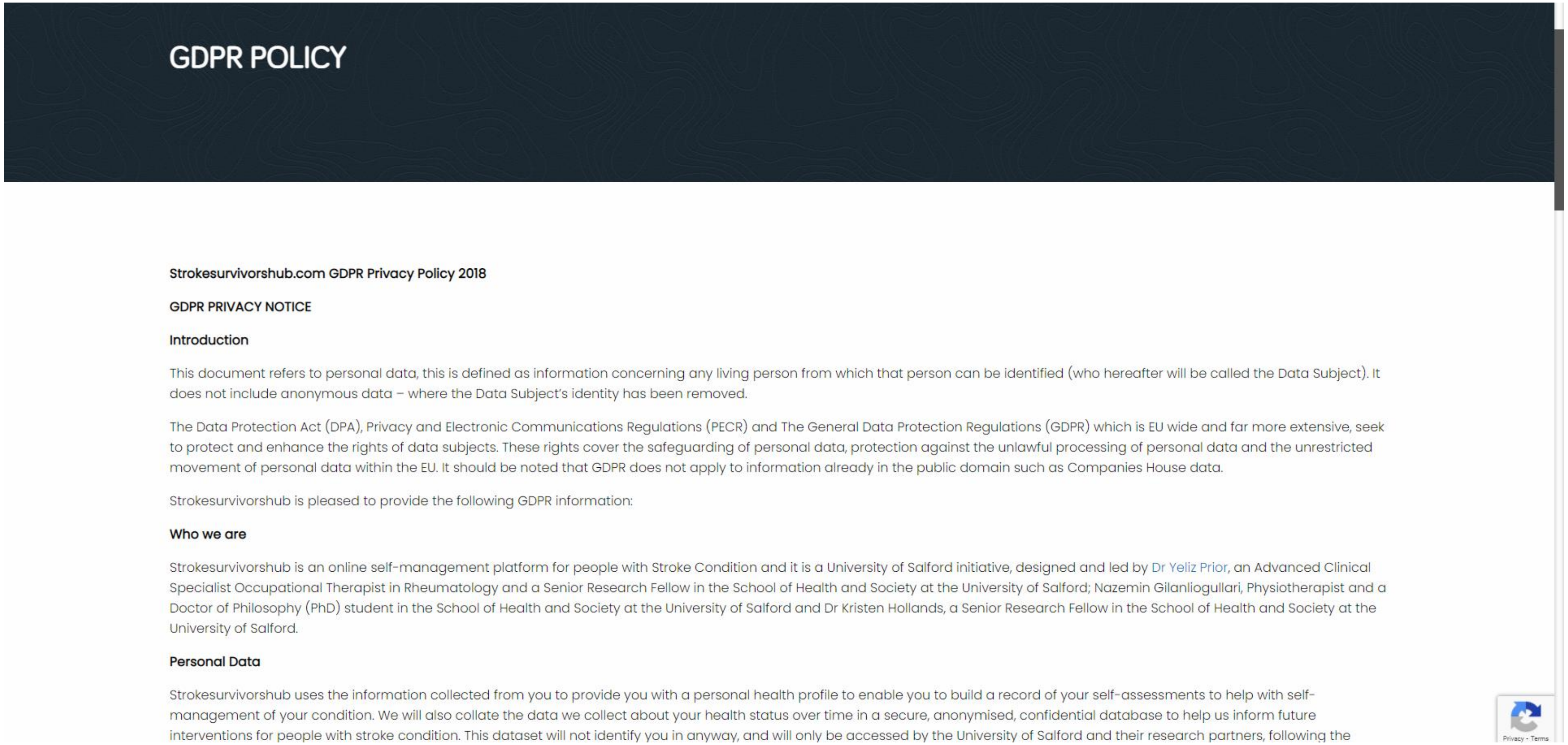
Picture 5: Screenshot of ‘Frequently Asked Questions (FAQ)’ page on the SSHUB



Picture 6: Screenshot of 'Contact' page on the SSHUB



Picture 7*:* Screenshot of ‘GDPR policy’ page on the SSHUB



GDPR POLICY

Strokesurvivorshub.com GDPR Privacy Policy 2018

GDPR PRIVACY NOTICE

Introduction

This document refers to personal data, this is defined as information concerning any living person from which that person can be identified (who hereafter will be called the Data Subject). It does not include anonymous data – where the Data Subject’s identity has been removed.

The Data Protection Act (DPA), Privacy and Electronic Communications Regulations (PECR) and The General Data Protection Regulations (GDPR) which is EU wide and far more extensive, seek to protect and enhance the rights of data subjects. These rights cover the safeguarding of personal data, protection against the unlawful processing of personal data and the unrestricted movement of personal data within the EU. It should be noted that GDPR does not apply to information already in the public domain such as Companies House data.

Strokesurvivorshub is pleased to provide the following GDPR information:

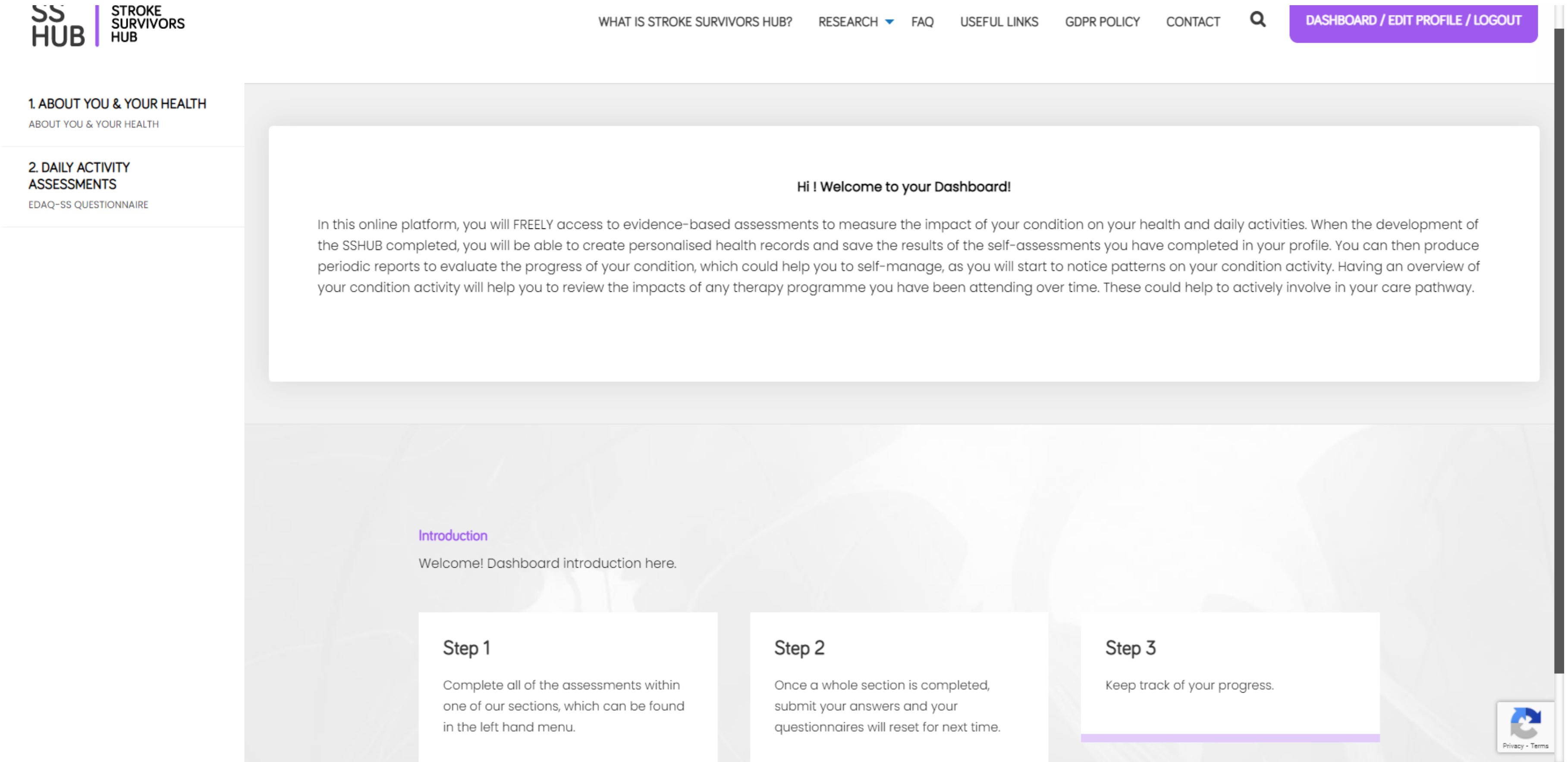
Who we are

Strokesurvivorshub is an online self-management platform for people with Stroke Condition and it is a University of Salford initiative, designed and led by Dr Yeliz Prior, an Advanced Clinical Specialist Occupational Therapist in Rheumatology and a Senior Research Fellow in the School of Health and Society at the University of Salford; Nazemin Gilanliogullari, Physiotherapist and a Doctor of Philosophy (PhD) student in the School of Health and Society at the University of Salford and Dr Kristen Hollands, a Senior Research Fellow in the School of Health and Society at the University of Salford.

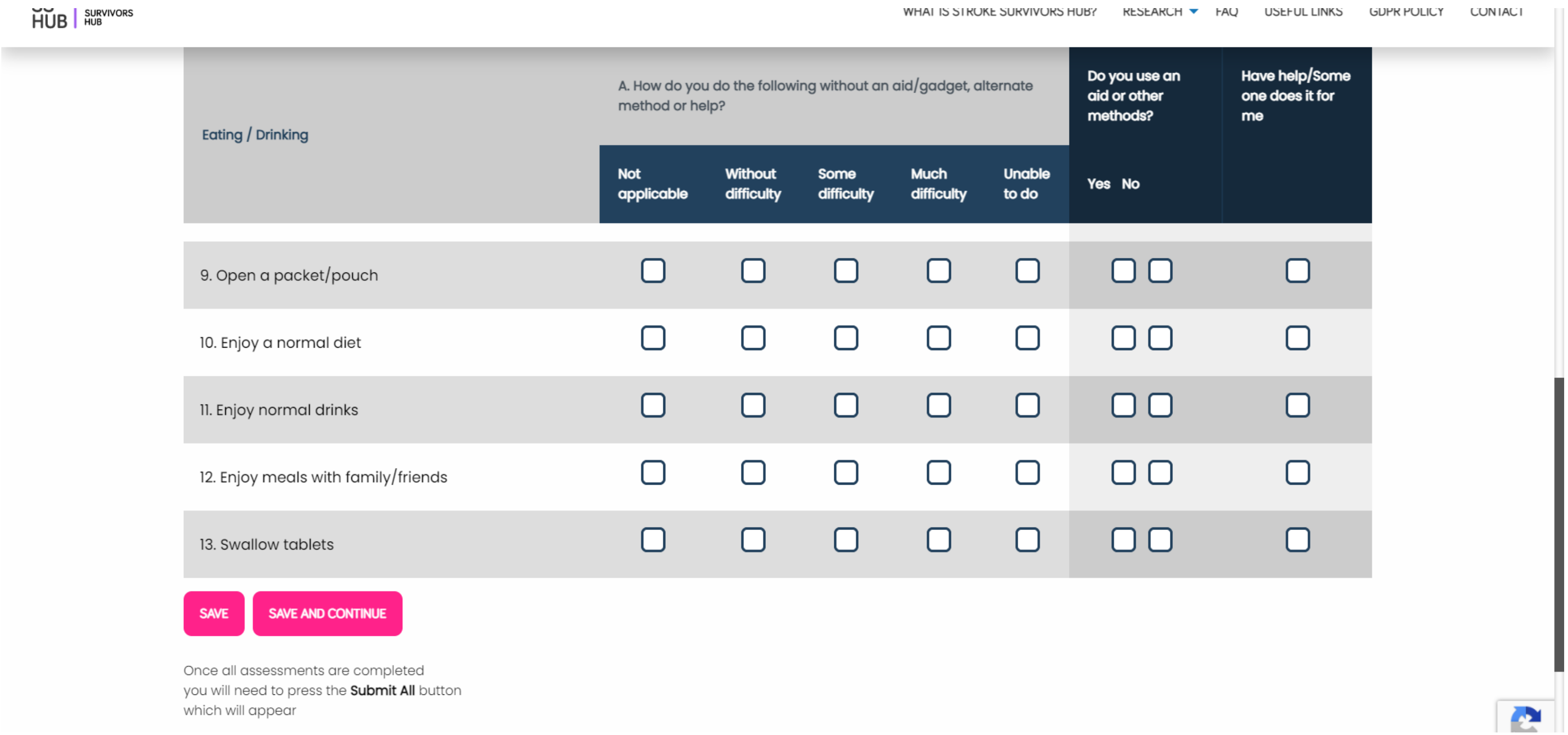
Personal Data

Strokesurvivorshub uses the information collected from you to provide you with a personal health profile to enable you to build a record of your self-assessments to help with self-management of your condition. We will also collate the data we collect about your health status over time in a secure, anonymised, confidential database to help us inform future interventions for people with stroke condition. This dataset will not identify you in anyway, and will only be accessed by the University of Salford and their research partners, following the

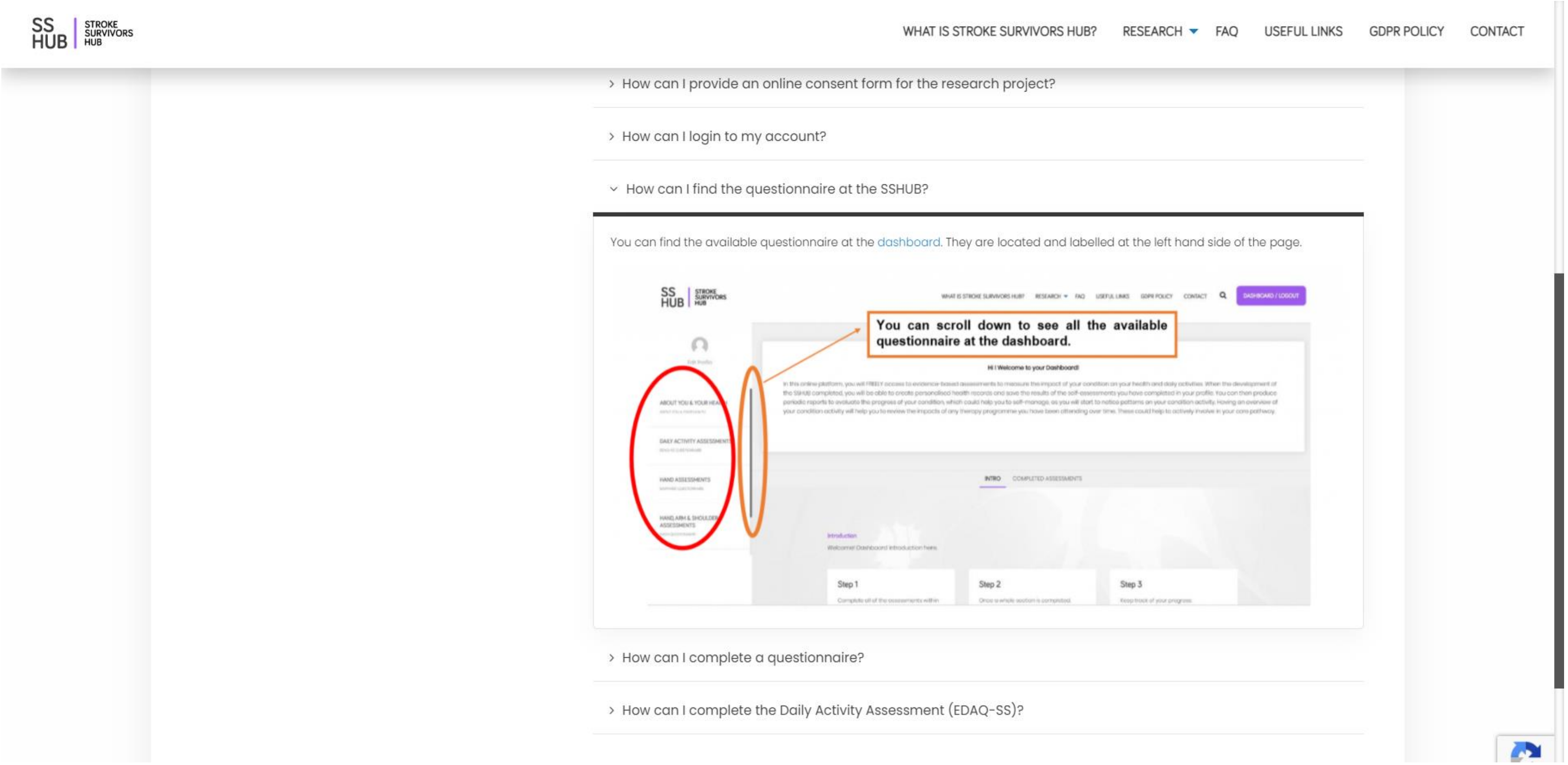
Picture 8: Screenshot of ‘Dashboard’ page on the SSHUB



Picture 9: Screenshot of Eating/Drinking domain of the EDAQ-SS on the SSHUB



Picture 10: Screenshot of FAQ page at the SSHUBv2



APPX 5: Published Conference Abstracts

Development and Psychometric Testing of a Daily Activity Questionnaire for Stroke Survivors and the Online StrokeSurvivorsHub.com

Nazemin Gilanliogullari

School of Health & Society
Email: n.gilanliogullari@edu.salford.ac.uk

Supervisor
Dr Yeliz Prior – y.prior@salford.ac.uk
Dr Kristen Hollands – k.hollands@salford.ac.uk

Abstract

Around 84% of the Stroke Survivors (SS) need help with daily activities; such as eating and walking. To help SS to gain their independence back, they need to have a detailed assessment. Patient-Reported Outcome Measures (PROMs) are necessary to understand the limitations from a patient's perspective. However, a recent systematic review showed that the existing PROMs for SS to assess daily activities have limitations.

My PhD aims to address this problem. A PROM, which overcomes these limitations exists for rheumatic and musculoskeletal conditions; the Evaluation of the Daily Activity Questionnaire (EDAQ). The aim of this PhD project is to develop and test the EDAQ for SS (EDAQ-SS). Additionally; an online platform developed for SS (www.strokesurvivorshub.com), to include the digitised version of the EDAQ-SS.

Initially, the EDAQ was reviewed by an expert panel and cognitive debriefing interviews conducted with SS to identify whether the EDAQ-SS is understandable and relevant for SS. The validity and reliability of the EDAQ-SS will be tested by asking SS to complete an online questionnaire two-three weeks apart.

Development of the EDAQ-SS will help SS to have an active involvement in their functional assessment and set personalised goals. The use of a valid and reliable PROM will help healthcare professionals to deliver patient-centred care. The EDAQ-SS will also be available online at the www.strokesurvivorshub.com, as a self-assessment tool. This will make it easy to complete an electronic assessment to help both SS and the healthcare professionals to have improved access to assessment tools.

Keywords

Daily activities, patient-reported outcome measure, stroke

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Assessment of the limitations in activities of daily living in stroke survivors: a systematic review of patient-reported outcome measures

Gilanliogullari N[1], Hollands K[1], Prior Y[1] and Chayasit P[2]
[1]University of Salford, UK; [2]Srinakharinwirot University, Thailand

Introduction: Heterogeneity in outcome measures to evaluate independence in activities of daily living (ADL) after stroke has been recognised as a barrier to synthesise evidence to inform patient-centred care. This systematic review aimed to identify patient-reported outcome measures (PROMs) used to assess ADL limitations in Stroke Survivors and evaluate their psychometric properties in this population to make recommendations for use of outcomes in future research and clinical assessment.
Method: The search included articles published by May 2019. Search criterion was applied to the seven different electronic databases. Only papers published in English, conducted to develop or evaluate PROMs assessing ADL in Stroke Survivors were included. The quality assessment was conducted using the COSMIN checklist by two assessors.
Results: Following the inclusion criteria, 48 papers examining 12 self-administered PROMs were included in the review. Most studies evaluated test-retest reliability and responsiveness; only a few investigated construct validity [unidimensionality] or measurement error. There was large variance in quality of studies. None of the identified PROMs covered both basic and instrumental ADL. The effect of personal, contextual and environmental modifications was also overlooked.

Conclusion: There were no PROMs, which were deemed to be fully comprehensive to provide detailed ADL assessment of Stroke Survivors' difficulties. Some existing PROMs lacked psychometric validity. Further development of a PROM, which includes both basic and instrumental ADL, considering the impact of environmental modifications specific to Stroke Survivors is needed. This will help to understand the main limitations of Stroke Survivors from their perspective and improve health outcomes.

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